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## LIST OF KEY WORDS

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- ⌘ Asset-based approach
- ⌘ Asset-based coping
- ⌘ Community-based coping
- ⌘ Community development
- ⌘ Coping with HIV&AIDS
- ⌘ Empowerment
- ⌘ Informal settlement community
- ⌘ Interpretivism
- ⌘ Interventionist research approach
- ⌘ Participatory Reflection and Action / Participatory Rural Appraisal (PRA)

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\* Included as hard copy

\* Included as hard copy (selected items) and on compact disc

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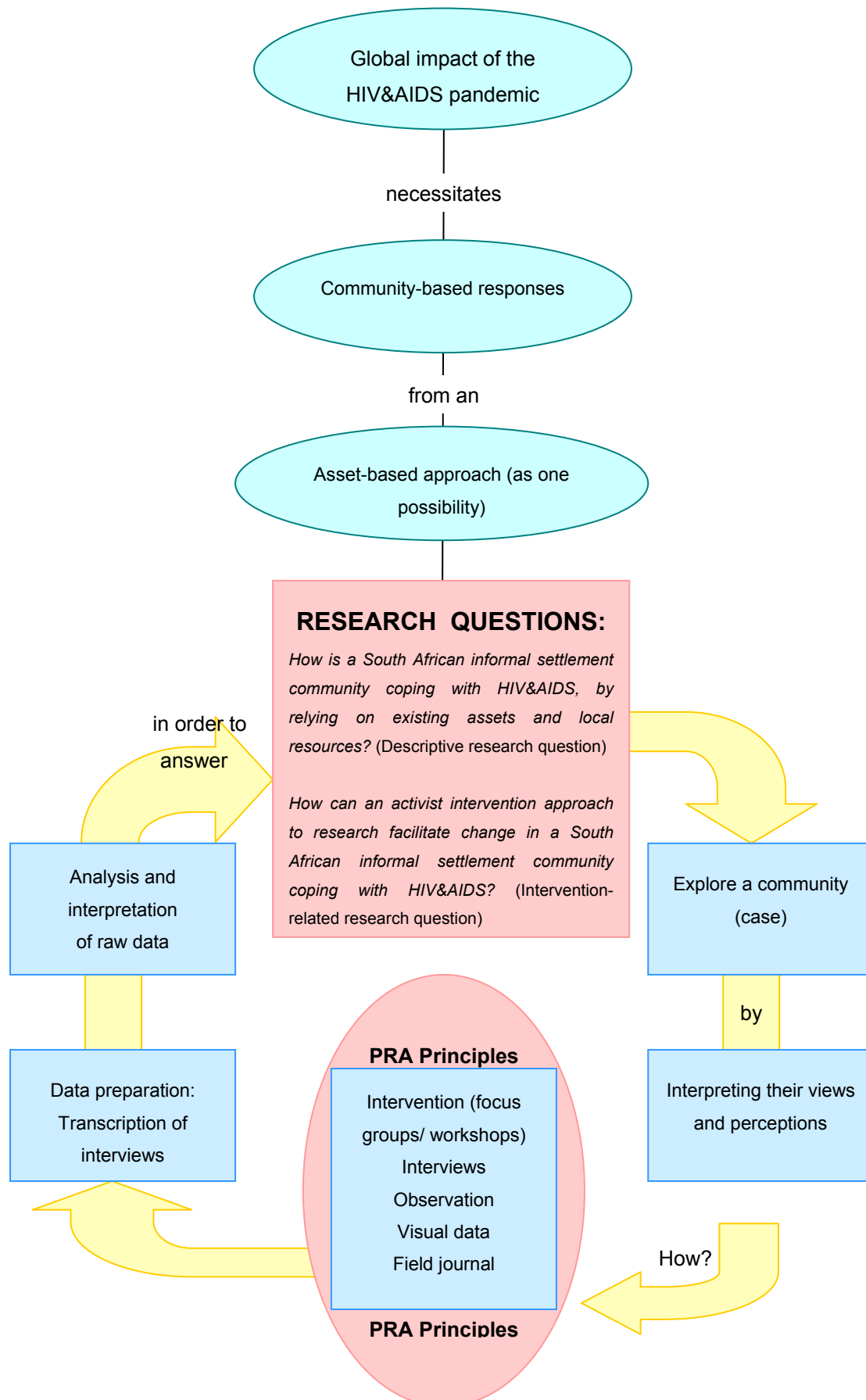
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## CHAPTER 1 AT A GLANCE





## 1.1 INTRODUCTION AND RATIONALE

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Both scientific and non-scientific literature indicates the vast and escalating impact of HIV&AIDS on communities, with reference to the people that are infected with HIV, as well as those affected directly or indirectly, by the growing number of people dying or debilitated by the disease. Given that the South African government regards dealing with the pandemic as a community-based matter (Gow & Desmond, 2002), it seems important to determine how South African communities are responding to HIV&AIDS at present. In poverty-stricken parts of South Africa, communities are coping with HIV&AIDS, relying on the resources and knowledge at hand, with mixed results. Enhanced knowledge and reflection are, however, required to promote a better understanding of the coping strategies that are currently being employed.

Thus, the primary purpose of my study is to *explore and describe the manner in which a South African informal settlement community is currently coping with HIV&AIDS, within the theoretical framework of the asset-based approach* (descriptive purpose). As such, I firstly focused on exploring the experiences and lives of a South African informal settlement community infected with and affected by HIV&AIDS. I frame coping with HIV&AIDS-related challenges within an approach not only acknowledging barriers to coping, but also relying on existing assets and available resources in the local community and without introducing additional resources. Secondly, I aimed at *exploring and describing the way in which an activist intervention approach to research (anchored in the above mentioned theory of the asset-based approach, might facilitate change in the patterns of coping employed by the selected community* (intervention-related purpose). Research in this area could provide critical insight into aspects such as vulnerabilities, strengths, aspirations, expertise and future prospects of people whose lives are often painfully affected by HIV&AIDS. In addition, the way in which I relied on (and aspired to contribute to) existing theory to develop and implement an integrated intervention research approach, adds to the potentially unique contribution of my study.

Africa is the most affected region by HIV&AIDS in the world, with 70% of the global total of HIV positive people located in Sub-Saharan Africa. South Africa has one of

the fastest growing rates of HIV infection and is regarded as experiencing one of the most powerful and probably the largest HIV&AIDS pandemic worldwide. As adult HIV prevalence is reported to have already been 20% in South Africa by the end of 2001, our country is one of only five countries in which the adult HIV prevalence has either reached or gone beyond 20%. It is estimated that 13% of South African children between the ages two and fourteen years have lost their mothers, fathers or both their parents due to HIV&AIDS, whilst 25% of South African children aged fifteen to eighteen have lost at least one caregiver. It is further predicted that these statistics will peak in 2015, when 3 million South African children would have lost their mothers and a total of 5.7 million one or both of their parents (Marais, 2005; Brookes, Sishana & Richter, 2004; Connolly, Colvin, Shisana & Stoker, 2004; Townsend & Dawes, 2004; Mugabe, Stirling & Whiteside, 2002; Stanecki, 2002; UNAIDS, 2002).

Statistics like these emphasise the powerful impact of HIV&AIDS. The social and economic effects of this pandemic are complex and potentially devastating to families, communities and economies. The vast impact of HIV&AIDS urges people to work together and collaboratively address the challenge – on international, national, regional and local levels (Department of Economic and Social Affairs of the United Nations, 2005a; Barolsky, 2003; Smart, 2003b; International HIV/AIDS Alliance, 2001).

Due to the urgency and nature of the pandemic, many discussions are held concerning policies and strategies for managing the effects of HIV&AIDS. Given that African societies are predominantly characterised by subsistence economies, the question of *how* rural and informal settlement communities and households are coping with HIV&AIDS is often raised and has been the focus of many research projects (see for example Donahue, 2002; Germann, 2002; Fox, 2001; Kilmer, Cowen & Wyman, 2001; Ndethiu, 2001; Emmett, 2000; Foster & Williamson, 2000). Yet, despite countless conferences, workshops and statistical models, the problems remain: millions of people are still dying of AIDS and the challenges of supporting people infected with and affected by HIV&AIDS seem to be growing. Perhaps now, more than ever, it is necessary to listen more carefully to and learn from the very people who are coping with HIV&AIDS on a daily basis.

In an attempt to address this need for research on ground level, I undertook this study. For the purpose of my study, I assumed that South African communities (including poverty-stricken and informal settlement communities) **are** currently coping with the challenges related to HIV&AIDS, by relying on local resources and existing assets. As such, I presumed a possible connection between community members' embedded knowledge of coping and the theory of the asset-based approach. Therefore, I decided to explore the manner in which the asset-based approach relates to coping with HIV&AIDS, by employing activist intervention research within a South African informal settlement community.

Existing literature on HIV&AIDS often focuses on supporting orphaned and vulnerable children. Smart (2003a; 2001), as well as Kelly (2000c), emphasise the generally agreed upon idea that any intervention to assist vulnerable children might be based in and managed by the affected communities themselves. In my opinion, this approach might not be limited to supporting children, but may also be applied to other community members infected with and affected by HIV&AIDS. I regard community members as being in the best position to know which households are severely affected, what kind of help is needed, who is dying of AIDS, who is taken care of by relatives or other community members, and who is living on their own. Although volunteers within communities might be motivated to assist wherever they can, the role of outside resources mostly focuses on empowerment or capacity building of community members. With regard to outside resources, the following questions remain: *Should outside support merely be provided? Could agency in South African communities be facilitated in terms of using existing assets and best practices to address the challenge at hand? How might intervention research facilitate change and empowerment within the context of coping with HIV&AIDS?*

I support the view that communities ought to not merely focus on their concerns, but that they might also focus on existing internal resources, knowledge, skills and assets that could assist them in coping with the challenges posed by HIV&AIDS. *Outside* resources and capacity may contribute after *inside* possibilities have been identified; and then only as a supplement to capacity building, assisting community members to reach the identified goals and proposed activities. However, I

acknowledge the potential of outside intervention initiatives serving as catalysts of change (Smart, 2003a; Hunter & Williamson, 2001; Kelly, 2000c). I now discuss the relevance and rationale of my study in terms of the questions that guided my focus.

### **1.1.1 WHY HIV&AIDS?**

Extensive media coverage on the impact of HIV&AIDS over the past few decades raised my interest in this field of research. Being a scholar in the field of Educational Psychology, as well as a practising educational psychologist by profession, my initial concern focused on children whose lives are touched by the pandemic. I developed a specific interest in the challenge of accommodating and taking care of orphaned and vulnerable children after the death of a parent, and started contemplating the manner in which rural communities might be supported in coping with this challenge.

Based on my initial interest, I conducted a pilot study in March 2001, exploring the *ways in which rural communities accommodate orphaned and vulnerable children after the death of a parent*. At the time I was involved as a lecturer in a distance education programme, lecturing educators of the Eastern Cape Province. I involved these students as participants in my pilot study, conducting two focus groups with them. Based on the findings of the pilot study (baseline data for this study), I realised that South African rural communities were – at that stage – indeed coping with the HIV&AIDS challenge, in their own unique way and by relying on the limited resources available to them. As South African rural communities are often characterised by a lack of resources such as children's homes, clinics, hospitals and sufficient health care services, other community members (mostly family members) were left with no choice but to take orphaned children into their care, thereby addressing the challenge by relying on themselves and their own skills as primary resources.

Despite the participants' concern, that South African rural communities were not satisfactorily equipped to cope with the challenge effectively, and their indication that more outside assistance should be provided, it was still evident to me that these communities were coping in their own unique ways without external resources. Based on such preliminary conclusions, and being convinced that outside help and facilities were not bound to be provided to all South African rural and economically

disadvantaged communities within the near future, I refined my interest in terms of the *asset-based approach*. I also decided not only to focus on rural communities, but on poverty-stricken communities of a wider scope. I shifted my focus to *informal settlement communities in urban areas*, due to the vast increase of such communities in South Africa, and based on the fact that these communities are typically characterised by poverty and limited outside help. I further decided not to limit my study to children, but to extend it to other community members who have to *cope with the challenge of being infected with and affected by HIV&AIDS*. I based this decision on the possibility of covering a broader scope of interest, as the challenge of coping with HIV&AIDS is not limited to coping with orphaned children.

Various projects and programmes have been initiated in South Africa to provide for the needs of people infected with and affected by HIV&AIDS. To date, such initiatives have focused on strengthening and supporting the capacity of families to care for children; mobilising and supporting community-based responses; building up the capacity of children and young people to meet their own needs; ensuring that government develops appropriate policies, grants and services for vulnerable children; and raising awareness to create an environment that enables support for communities infected with and affected by HIV&AIDS (Smart, 2003a; Gow & Desmond, 2002; Mugabe *et al.*, 2002).

Early government responses to the pandemic and its related needs include health responses, such as the *HIV&AIDS/STD Strategic Plan for South Africa 2000-2005* and the *National Integrated Plan for Children Infected and Affected by HIV&AIDS*. These plans focused on, amongst other things, reducing the number of new HIV infections as well as the impact of HIV&AIDS on individuals, families and communities; providing treatment, care and support services at health facilities as well as in communities; expanding the provision of care to orphaned and vulnerable children; strengthening voluntary counselling and testing; and promoting Life Skills and HIV&AIDS education in schools. Recently, state responses have often centred on social development, education and welfare, in an attempt to deal with the HIV&AIDS pandemic in an effective and integrated manner (Birdsall & Kelly, 2005; Gow & Desmond, 2002; South Africa Department of Social Development, 2002).

However well-intended, such policy-orientated responses have not yet engendered adequate results (Smart, 2003a; Gow & Desmond, 2002), begging the question as to whether or not the general public, and, more particularly, people who are poverty-stricken, are indeed benefiting, and whether agency to cope with HIV&AIDS is indeed facilitated by outside providers or resources. Another concern is the availability of such initiatives in the wide-spread areas of our country. My concern specifically relates to rural areas and informal settlement communities, where such barriers as language and illiteracy, location, time and cost implications tend to inhibit target groups' abilities to access programmes, and *vice versa*.

The focus of my study stemmed from concerns like these, as well as from continued emphasis on the need to research and address possible ways of coping with the pandemic more effectively. Furthermore, research on care and support often tends to focus on communities being trained and guided by outsiders, thereby not acknowledging communities' capacities to '*teach*' outsiders about their ways of coping. As a result, I decided to focus on and learn from a South African informal settlement community facing the HIV&AIDS challenge – a community that is typically characterised by poverty and limited resources. Completing a study on the manner in which South African communities are currently coping with the challenge in terms of what they have (using existing knowledge and local resources as an entry point) might provide a practical tool for policy- and decision-makers. Findings might be relied upon to design and implement cost-effective and appropriate interventions that could strengthen the current and future livelihoods of households and communities that are affected directly or indirectly by HIV&AIDS. Such interventions might also not be limited to South Africa, but be employed in other African countries that are similarly affected by the pandemic. In addition, the outcome of my study could add to existing theory on the asset-based approach. On a methodological level, my study might serve as an example of one way in which intervention research and participatory methods might be merged.

### **1.1.2 WHY COPING?**

The reality of HIV&AIDS signals the fact that the pandemic is affecting communities on a world-wide level and that its impact will continue in future. Therefore, individuals

and communities are required to cope with the pandemic, for the sake of their own health and general well-being. Facing and addressing a challenge implies a reaction, whether it entails avoiding the difficult situation or employing strategies to deal with it in a manner acceptable to the individual involved. In my opinion, it is important for communities to deal with the contemporary challenge of HIV&AIDS, thereby employing coping strategies (Nnko, Chiduo, Wilson, Msuya & Mwaluko, 2000; Child Protection Society of Zimbabwe, 1999).

As a scholar and practitioner in the field of Educational Psychology, I believe in supporting people to address and overcome the challenges that they face. I view coping as a prerequisite for mental health, and support Ebersöhn and Eloff (2006) who regard people as capable of addressing life challenges and finding solutions to their problems, thereby coping. I also regard individuals as able to enhance their own coping skills and to identify and mobilise resources that might assist them when addressing challenges, such as those related to HIV&AIDS. Therefore, I firstly believe that people who are able to cope with challenges can live a content and meaningful life. Secondly, I regard the answers to challenges as being present and situated within individuals (and their contexts) themselves. However, they might benefit from external facilitators to act as catalysts to initiate the process of coping.

### **1.1.3 WHY THE ASSET-BASED APPROACH?**

Kretzmann and McKnight (1993) initially introduced the asset-based framework, propagating the development and empowerment of communities from the inside out. The asset-based approach contrasts with the so-called deficit approach (medical model), which isolates the causes of a particular problem and recommends action based on resources, knowledge or conditions that are found to be lacking. As such, an asset-based approach focuses on the strengths, abilities, resources and possibilities that already exist, but may not yet have been (adequately) mobilised (although not negating the existence of barriers and challenges). The asset-based approach correlates with the basic principles of Positive Psychology (Seligman, 2002), according to which I approach my work as a scholar in Educational Psychology – both during intervention (as clinician) and during research (as academic).



Applying the asset-based approach to the challenge of coping with HIV&AIDS in contemporary South Africa implies that the focus shifts from inventorying the shortfalls of households and communities (in this case, those located in informal settlements and economically disadvantaged parts of the country), to mobilising and putting to work the natural, cultural and physical resources, skills, abilities, networks and support systems – in short, the assets – that already exist and are locally available for everyday use. Instead of following a corrective approach, which essentially posits people infected with and affected by HIV&AIDS as victims in need of external intervention (as apparent in most previously cited literature on coping and intervention), I regard ground level community members as agents and experts who hold the key to developing appropriate coping strategies in their communities. I regard the asset-based approach to be appropriate for exploring possible manners of coping with HIV&AIDS, given that communities have historically been able to cope with a wide range of challenges, often with inspiring and informative results.

## 1.2 PURPOSE OF THE STUDY

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Being both a descriptive and an intervention-related study, the purpose of my study is twofold. The *descriptive purpose* is to explore and describe the manner in which a South African informal settlement community (Eastern Cape region) is coping with HIV&AIDS, by relying on existing assets and local resources. In an attempt to elucidate this first part of my purpose, I utilise the asset-based approach as a theoretical lens to interpret the coping strategies currently employed by community members. In this manner, I attempt to relate coping (or not) by the particular community to existing assets within the community (aspects such as knowledge base, skills, local systems, resources, infrastructure and available services).

The *intervention-related purpose* is to explore how an activist intervention research approach might facilitate change and empower an informal settlement community in relation to community members' ways of coping with HIV&AIDS. By relying on my descriptive understanding of existing theory *as well as* emerging knowledge, I aim at describing how the process of being actively involved and intervening in a research field might facilitate change (or not). I relate such change (or the absence thereof) to



the selected community's increased (or not) awareness of local resources that they can rely on in coping with HIV&AIDS, thereby implying empowerment.

Therefore, I explored an informal settlement community's ways of coping, which ultimately culminate in patterns of coping, in order to determine the possibility of using the asset-based approach to address the challenge of HIV&AIDS. As such, the anticipated theoretical contribution of my study lies in the possibility of elaborating on available literature on the asset-based approach and on coping, whilst the anticipated practical value lies in presenting a documented example that may inform other communities during future capacity building initiatives, with regard to possible ways of coping with HIV&AIDS. Furthermore, knowledge might be created concerning the potential value of employing an intervention and participatory approach to research within the context of coping with HIV&AIDS.

### 1.3 RESEARCH QUESTIONS

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This study is directed by the following central research questions:

- ⌘ ***How is a South African informal settlement community coping with HIV&AIDS, by relying on existing assets and local resources?*** [Descriptive research question]
- ⌘ ***How can an activist intervention approach to research facilitate change in a South African informal settlement community coping with HIV&AIDS?*** [Intervention-related research question]

These central research questions imply a **relationship** between the **descriptive part of my study** (descriptive research question) and the **intervention approach that I employed** (intervention-related research question). The potential way in which intervention might impact on coping entails both a theoretical relationship between the theory that I relied upon and the methodological approach that I developed and employed; and secondly a relationship between research and intervention. In order to address my central research questions I therefore situated research within intervention, but also intervention within research, doing intervention *via* research

and research *via* intervention. As such, my research questions do not revolve around the relationship between different communities' ways of coping with HIV&AIDS, but rather imply a relationship between theory and practice (methodology).

In order to explore my primary research questions, the following secondary questions are addressed:

- ⌘ What are the perceptions of a South African informal settlement community with relation to coping with HIV&AIDS?
- ⌘ With which challenges does a South African informal settlement community have to cope, with specific reference to the HIV&AIDS pandemic?
- ⌘ How does a South African informal settlement community currently cope with HIV&AIDS?
- ⌘ Which asset-based trends exist in current ways of coping with HIV&AIDS?
- ⌘ Which changes in coping patterns might be facilitated by employing intervention research?
- ⌘ How can participants' implementation of the asset-based approach inform coping with HIV&AIDS?

#### 1.4 UNIQUE CONTRIBUTION OF THE STUDY

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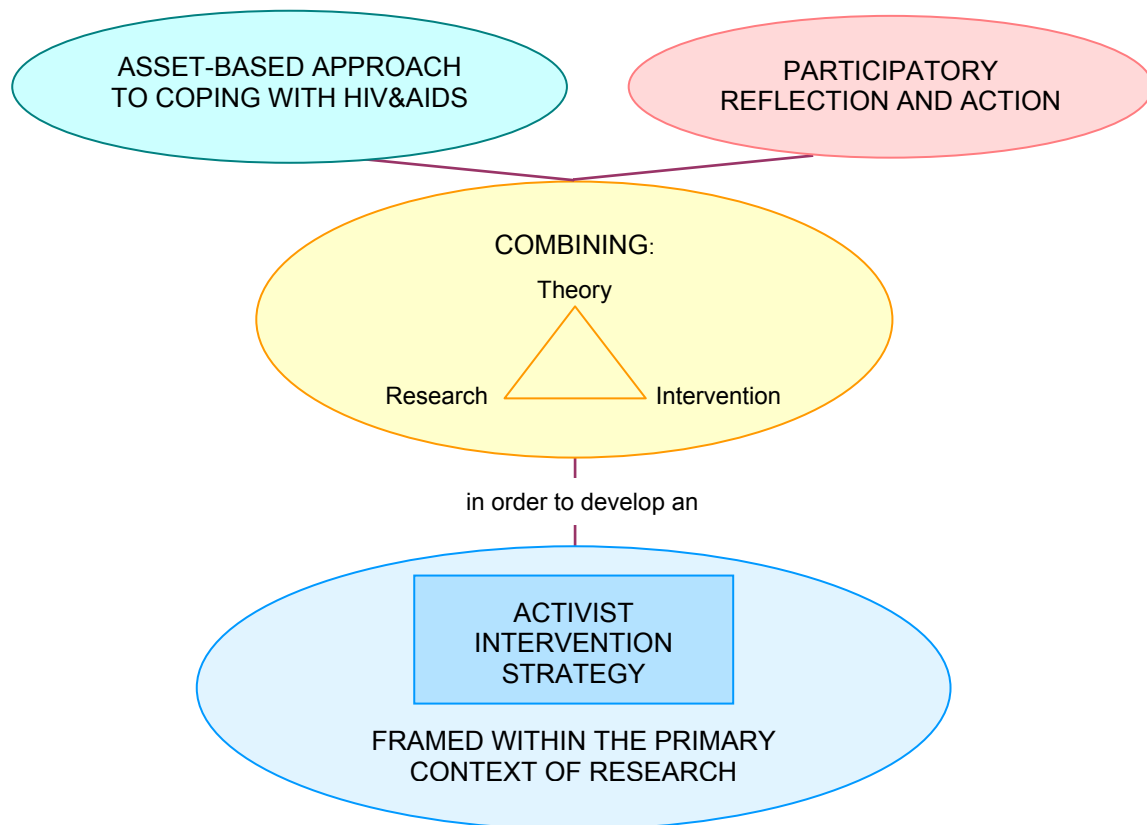
I relate the unique contribution of my study to its innovative nature, in terms of the manner in which I integrated existing theory, research and intervention. In planning and conducting my study I firstly relied on existing theory relating to the asset-based approach to coping. I focused this existing body of knowledge in terms of coping with HIV&AIDS, as well as doing intervention. I combined the theory of the asset-based approach with that of Participatory Reflection and Action<sup>1</sup> (PRA), in order to develop and facilitate an activist intervention strategy<sup>2</sup> in a South African informal settlement community. This was done with the primary goal researching the selected

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<sup>1</sup> I prefer the use of **Participatory Reflection and Action**, as opposed to **Participatory Rural Appraisal**, as proposed by Chambers (2004). Refer to section 3.3.1.2.1 for clarification in this regard.

<sup>2</sup> I selected an activist approach (PRA principles) in order to actively promote agency and empowerment within the selected community.

community's way of coping with HIV&AIDS, by relying on existing assets and local resources. Based on the outcomes of my study, the activist intervention strategy that I developed is currently in the process of being replicated in three other South African research settings<sup>3</sup>. Figure 1.1 provides a summary of the innovative contribution of my study, in terms of the intervention that I developed.



**FIGURE 1.1: CONTRIBUTION IN TERMS OF DEVELOPED INTERVENTION**

The intervention research approach that I selected therefore provided me with a mechanism to facilitate a research process, which ultimately resulted in change within an informal settlement community. By involving the selected community in planning and conducting the intervention, participants fulfilled an active role during the process of knowledge generation. Based on their relationships with the research process and findings, community members could take coping agency. As such, participants experienced certain changes within the context of their own ways of coping with HIV&AIDS, as the study progressed. These changes resulted in the participants being empowered to develop new approaches in helping the community

<sup>3</sup> Two urban communities in Gauteng, one rural community in Mpumalanga.

cope with HIV&AIDS, thereby doing even more towards the end of the study than what they were doing at the outset of the study. A direct outcome was the development and implementation of three school-based projects which might enhance the community's coping with HIV&AIDS. In addition to the participants' involvement, my own prolonged and active involvement and constant facilitation of the research and intervention process added to the positive changes that occurred.

## 1.5 ASSUMPTIONS

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I approached this study with the following assumptions:

- ⌘ I assumed that the selected community is currently coping with community members infected with and affected by HIV&AIDS, by relying on available knowledge, skills and resources.
- ⌘ I assumed that asset-based trends exist in communities' coping repertoires.
- ⌘ I assumed that the selected community is a good example of typical informal settlement communities in the Eastern Cape Province, concerning its way of coping with HIV&AIDS.
- ⌘ I assumed that the participants would be open and willing to respond and discuss their community's way of coping with the HIV&AIDS challenge.
- ⌘ I assumed that PRA could successfully be applied within (and together with) the particular community in the context of coping with HIV&AIDS.

## 1.6 CLARIFICATION OF KEY CONCEPTS

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In order to ensure a clear understanding, I henceforth conceptualise the key concepts. I operationalise the concepts within the context of my study.

### 1.6.1 ASSET-BASED APPROACH

As opposed to the needs-based approach, where emphasis is placed on problems, needs and deficiencies, the *asset-based approach* regards problem solving in terms

of creating and rebuilding relationships between individuals, associations and institutions, emphasising enablement and empowerment. The focus is on assets, possibilities, abilities, capacities and resources that already exist, but might not have been mobilised yet. Working with that which exists in a given family or community, and focusing on the available assets (although not negating problems), inevitably result in individuals, families and communities feeling empowered and valuable (Ebersöhn & Eloff, 2006; Kretzmann & McKnight, 1993).

The *asset-based approach* has been referred to as the *half-full-glass* approach to intervention (as opposed to the *half-empty-glass* approach) (McDonald, 1997), and as the *capacity focused alternative* (McKnight & Kretzmann, in Ammerman & Parks, 1998). This strengths-based approach represents the idea that communities (regardless of ethnic culture, race or economic conditions) are able to cope with challenges by focusing on what they have, instead of what they do not possess. In this manner, so-called successful communities rely on their own assets instead of outside help in addressing challenges (Eloff, 2006a; Kretzmann & McKnight, 1993).

### 1.6.2 COPING

*Coping* refers to efforts by individuals to survive in the short term, by implementing the necessary strategies to deal with existing or emerging problems and challenges, as well as any related negative emotions (Aldwin, 1994). Mugabe *et al.* (2002) distinguish between *psychological coping* and *economic coping*, where the former refers to dealing with trauma emotionally, and the latter to the management of resources to deal with a prolonged life event of, for example, orphanhood.

An individual's way of *coping* with challenges is influenced by time and context, as well as subjective experiences of the challenge faced. *Coping* can thus not be regarded as a static concept, but as dynamic by nature. Concerning external influences, coping is continuously influenced by social and cultural factors. For the purpose of my study, I focused on *community-based coping*, implying that communities possess the ability to effectively address the challenges they face. In this manner, *community-based coping* involves community members sharing responsibilities, thereby addressing challenges within a dynamic and multi-functional

social system (Loots, 2005; Donnelly, 2002; Aldwin, 1994). Within the context of my study, *coping* therefore refers to the strategies employed by the members of an informal settlement community, in order to address the challenges implied by HIV&AIDS, both psychologically and economically.

### 1.6.3 SOUTH AFRICAN INFORMAL SETTLEMENT COMMUNITIES

By definition, the concept *community* refers to a group of people or families living in the same geographic area under common laws, having certain things in common and being made up of individuals who rely on one another to help satisfy their needs and live according to certain norms, rules or common policies. The group is characterised by fellowship, friendly associations, mutual sharing and common interests. Individuals are usually united by shared services, attitudes, interests, aims, needs, cultural beliefs, values, heritage and religion (Bender, 2004; Sims, 2002; Berns, 2001; Pearsall, 1999; Random House Webster's unabridged Dictionary, 1998; Plug, Louw, Gouws & Meyer, 1997; Longman Dictionary of English Language and Culture, 1992; Barker, 1991).

Jary and Jary (1995:100-101) provide a comprehensive description of the concept *community*, and state that the term refers to '*any set of social relationships operating within certain boundaries, locations or territories*', and that these relationships can take the form of social relationships which are actualised within specific geographical areas, or of relationships that are not locally operative, but exist on a more abstract, ideological level. Sociologists therefore focus on the nature and quality of the social relationships within a community, rather than on the categorisation and identification of the physical and geographical characteristics of the community. In summary, sociologists define the concept *community* in terms of geographical meaning or settlement within a fixed and bounded territory (*community as locality*), in terms of a network of interrelationships, characterised by both conflict and mutuality, and thirdly in terms of a particular type of social relationship, characterised by certain qualities (so-called *community spirit* or *community feeling*) (Bender, 2004; Jary & Jary, 1995).

The *Encyclopaedia of Social and Cultural Anthropology* (Barnard & Spencer, 1996) supports this description by identifying the following four key qualities in

communities: a smallness of social scale, homogeneity of activities and states of mind of the members of the community, a consciousness of distinctiveness and self-sufficiency across a range of needs and through time. Various attempts have been made over the years to define the concept *community* within the field of Anthropology, which led to the conclusion that people regard the concept *community* as the milieu which most essentially belong to them and that they are prepared to assert their ownership and membership, whether the community they belong to is defined in terms of locality, ethnicity, religion, occupation, interest or even humanity.

Wagner, Swenson and Henggeler (2000) describe the concept *community* from a community-based intervention perspective, which I also focus on in my study. From this perspective, *community* is regarded as a concept involving firstly a *who* and secondly a *where*, the former referring to a group of people residing in the same region and under the same government, whilst the *where* refers to the place or region where the specific group of people are residing. It follows that community-based intervention implies the identification and targeting of a specific group of people (the *who*), taking place somewhere in the community (the *where*), with the aim of addressing certain problems of a community by working with that community.

Refining the concept *community* in terms of the basic principles of PRA results in a definition in terms of the outsider-insider perspective, where the purpose is to enable local community members to conduct their own analysis of the community, followed by the development of an action plan and putting strategies into action (Webber & Ison, 1995; Chambers, 1992). This implies a process of learning from one another, creating a *learning community*, which in my study mainly consisted of educators, sharing their perspectives on the community within which they found themselves present on a daily basis. The team members who are involved bring their knowledge, skills, experiences and interpretations to the field and are respected for their contributions.

For the purpose of my study, the concept *South African informal settlement communities* refers to societies or groups of people living in informal settlements in the Republic of South Africa, where the members are united by shared ideas, attitudes, interests, aims and needs. These social groups are characterised by



poverty and a lack of extended facilities that are mostly present in towns or city areas, such as running water, electricity and other basic community services. Concerning the selected case in my study, the concept a *South African informal settlement community* refers to a group of people living in an informal settlement in the Eastern Cape (Nelson Mandela Metropole), being characterised by high levels of unemployment, poverty and HIV infection, as well as a lack of sufficient infrastructure and basic services in the community. Although I regard the participants in my study as forming part of the selected informal settlement community, I acknowledge the fact that a substantial number of participants do not reside in that particular community, thereby making them *outsiders* in the true sense of the word. However, I assumed that working in the selected community and spending the biggest part of their daily lives there enabled the participants to provide perspectives in line with that of *insider* community members.

#### **1.6.4 COMMUNITY MEMBERS INFECTED WITH AND AFFECTED BY HIV&AIDS**

HIV is the abbreviation for *Human Immunodeficiency Virus*, a variable retrovirus that can cause AIDS by invading and inactivating helper T cells of the immune system, thereby leaving the person vulnerable to fatal infections and other illnesses that people with healthy immune systems will usually be able to fight. HIV infection and infectiousness is presumed to be lifelong. HIV is transmitted by blood, semen, vaginal fluid and breast milk. Transmission may therefore occur by means of any activity during which these fluids are exchanged between a person who is HIV infected and someone who is not (Benner & Hill, 1999; Pearsall, 1999; McDonald, 1998; Random House Webster's unabridged Dictionary, 1998; Barker, 1991).

AIDS is the international abbreviation for *Acquired Immune Deficiency Syndrome*, a fatal disease caused by infection with HIV. The progress of HIV infection can be divided into five stages, the first being an asymptomatic incubation period of several weeks during which the virus replicates. During this period, before the development of antibody responses, symptoms such as fever, night sweats, rash, arthralgias and lymphadenopathy can occur. Stage two (a few months to many years) is characterised by the infected person being asymptomatic, but infectious. Stage three is characterised by symptoms such as mild infections, weight loss and fatigue; stage



four by symptoms such as episodic occurrences of pulmonary tuberculosis, pneumonia, persistent fever, excessive weight loss and other symptoms; whilst stage five is characterised by the immune system being so severely suppressed that the body cannot defend itself against infection. The diagnosis of AIDS is only made in this last stage (Page, Louw & Pakkiri, 2006; Benner & Hill, 1999; McDonald, 1998; Thomas, 1997; Barker, 1991).

For the purpose of my study, the concept *community members infected with HIV* refers to people of the community who are living with the HI virus being active and alive in their bodily systems. They may have been infected (or contaminated) sexually, vertically or as a result of unsafe health practices, where *unsafe health practices* refers to practices such as traditional health practices (for example scarification), cultural practices (for example circumcision), unscreened blood products and contaminated medical instruments. In South Africa most HIV infected children below the age of 13 are infected due to transmission from an infected mother to her child during pregnancy, at birth or from breastfeeding (by an infected mother or somebody else than the mother who is infected). It is estimated that approximately one in three babies born to infected mothers will themselves be infected (23% prenatal, 65% intrapartum or from early breastfeeding and 12% post-natal). The additional risk of HIV transmission from an infected mother to her child via breastfeeding is estimated at 14% (one in seven) on a worldwide level (Shisana, Mehtar, Mosala, Zungu-Dirwayi, Rehle, Dana, Colvin, Parker, Connolly, Dunbar & Gxamza, 2005; Smart, 2001; Pearsall, 1999; McDonald, 1998).

McDonald (1998:5) defines *people affected by HIV&AIDS* as people '*who live in close association with a person(s) who is living with HIV/AIDS and whose lives are significantly 'affected' by this reality*'. Concerning *children affected by HIV&AIDS*, the following definition of Smart (2001:19) applies: '*children who may be abandoned or orphaned as a result of HIV/AIDS, may be from an HIV infected family, may be vulnerable to becoming HIV infected or may be from an uninfected family in an affected community*'. People affected by HIV&AIDS have thus been influenced negatively and in a harmful way by HIV&AIDS (Random House Webster's unabridged Dictionary, 1998).

South African individuals/communities may be affected by HIV&AIDS on a direct level by means of daily contact with HIV infected people, by sharing their homes with orphaned children or by means of participation in community programmes in order to address the needs of those infected with and affected by HIV&AIDS. On an indirect level, South African citizens are affected by the socio-economic effect of the pandemic, such as weakening levels of education, health care and social services (Smart, 2001). As a result, people from uninfected households in affected communities are inevitably also affected by the HIV&AIDS pandemic, whether directly or indirectly.

## 1.7 PARADIGMATIC PERSPECTIVE

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In order to provide the reader with a general orientation and the necessary background in conjunction with which the rest of this thesis should be read, I henceforth provide a brief discussion of my selected paradigm, methodological choices and process. More detailed discussions of these aspects are included in chapter three.

I support Mouton's (2001) theory that researchers function in various *worlds* in order to gain knowledge (also refer to Babbie & Mouton, 2001). Within the context of my study, *everyday life (world 1)* refers to the contemporary problem of effectively and sustainably coping with HIV&AIDS in informal settlement communities in South Africa (refer to section 1.1.1). Applying the *world of science (world 2)* to my study provides the background and progress of my research, in terms of the conceptual framework consisting of the HIV&AIDS pandemic, the theory of coping and the asset-based approach (refer to sections 1.1.2 and 1.1.3, which are explored in more detail in chapter two). With regard to the *world of meta-science (world 3)*, my qualitative study is anchored in and guided by the interpretivist paradigm.

Conducting my research from an interpretivist paradigm enabled me to conduct the study amongst participants in an informal settlement community in their natural environments, in order to gain information and insight regarding their ways of coping with HIV&AIDS, by relying on existing assets, resources, support systems, facilities,

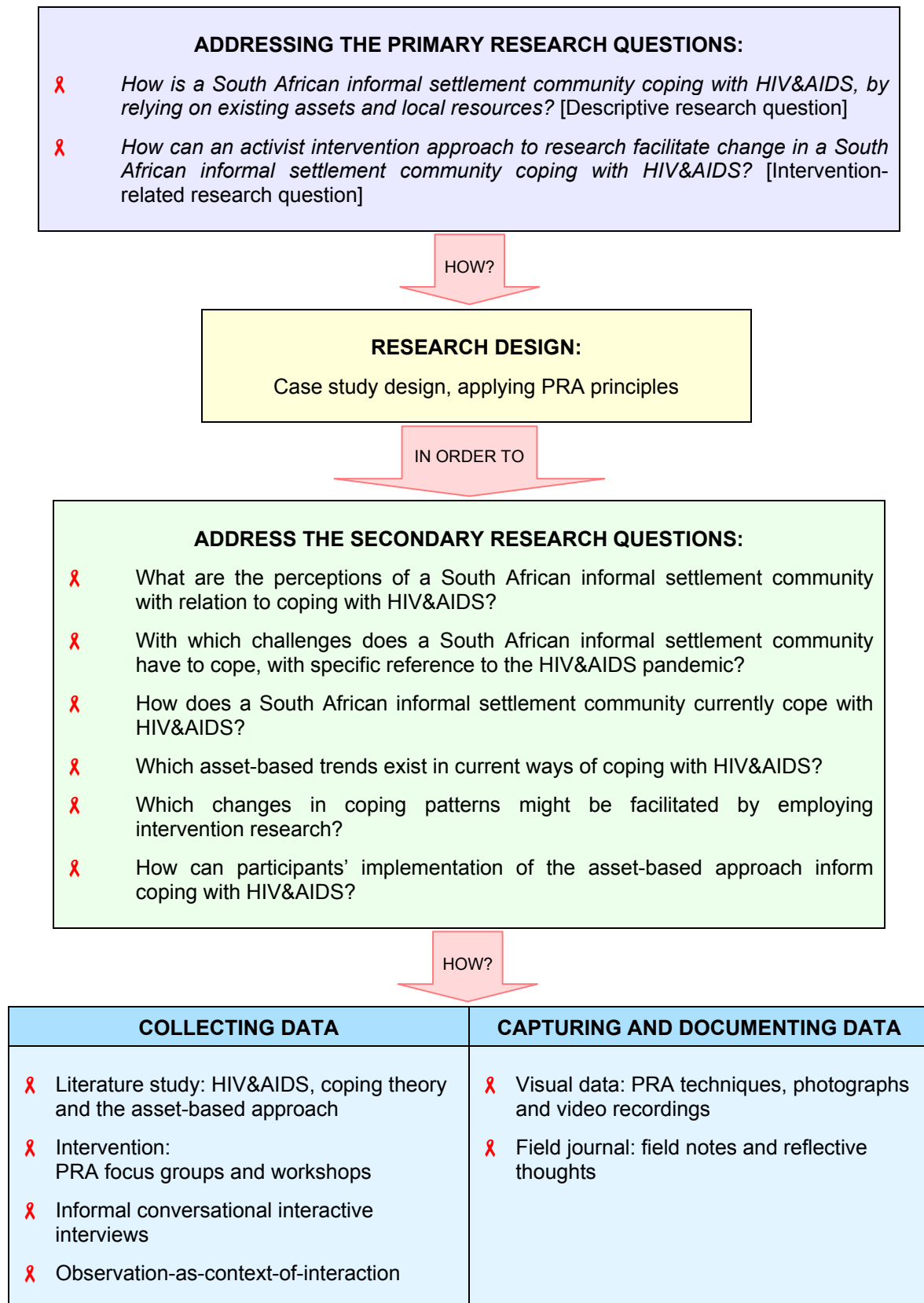
knowledge base and skills. I aimed at understanding the participants in terms of their own definitions, meanings and perceptions of their life-worlds. The manner in which a South African informal settlement community is coping with HIV&AIDS was explored, based on the subjective perspectives of the individuals involved, including their experiences and views on their everyday lives, their contexts and frames of reference (Terre Blanche & Durrheim, 2002).

## 1.8 RESEARCH METHODOLOGY AND STRATEGIES

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I undertook in-depth field research, in combination with *intervention* (research *via* intervention and *intervention via* research), in a South African informal settlement community, in order to explore and describe the manner in which residents cope (or not) with HIV&AIDS and its impact on families, households and livelihoods. The selected research design and methods enabled me to obtain rich descriptions of the various ways in which participants were able to mobilise existing assets and implement the asset-based approach in coping with HIV&AIDS. In addition, I was able to explore the coping strategies of HIV infected community members themselves. Both these aspects improved my understanding of the status and prospects of South African communities coping with HIV&AIDS, in relation to the asset-based approach. As my study progressed, I was further able to explore the changes that had been facilitated within the selected community, based on the research approach that I had selected.

As an introduction to this section, I relate my research questions to the selected research design and data collection strategies in Figure 1.2. This is followed by a discussion of my research design and justification of my decision to follow a community-based intervention research approach, applying PRA principles. Thereafter, I briefly explain my data collection, analysis and interpretation, ethical considerations and quality criteria.



**FIGURE 1.2: LINKING RESEARCH QUESTIONS TO RESEARCH DESIGN AND DATA COLLECTION ACTIVITIES**

### 1.8.1 RESEARCH DESIGN

I selected an *in-depth case study* design applying *PRA principles*, in order to explore and understand the manner in which informal settlement communities implement the asset-based approach (or not) to cope with HIV&AIDS, by understanding the context in which the participants form their views and responses. One South African informal settlement community was selected and studied in order to deal with the purpose of the study by addressing the research questions. The study focuses on the said rich and thick descriptions of the manner in which a South African informal settlement community is currently coping with people infected with and affected by HIV&AIDS, by relying on existing assets and local resources (Merriam, 1998).

In line with the basic principles of the PRA approach, the mode of living of the selected community was taken as the starting point of my study and the wealth of social indigenous knowledge that community members possess was recognised throughout the process (Archer & Cottingham, 1996). I kept in mind that this community had been coping with HIV&AIDS in its own unique way thus far, making use of whatever limited resources exist and are accessible.

I regard an in-depth case study design, in combination with the principles of PRA, as suitable for my study, as I view the participants as the experts who hold the key to any understanding and insight into their ways of coping with HIV&AIDS – being embedded knowledge. Furthermore, PRA stems from a consideration of practical issues rather than being theoretically driven, emphasising the empowerment of people during the research process. This shift in power, resulting in me (the researcher) merely acting as facilitator, and the participants as experts in the research process, supports both the interpretivist paradigm and the asset-based approach, as well as community-based intervention. Implementing visual techniques, as suggested by the PRA approach, is regarded as suitable for undertaking research in communities characterised by poverty (such as informal settlement communities), where participants might not possess a high level of literacy and might probably be addressed more effectively on a concrete, visual level than on an abstract level (Archer & Cottingham, 1996; Nelson & Wright, 1995).

#### **1.8.1.1 Why a community-based intervention approach to research?**

According to a community-based intervention approach, individuals and children are regarded as part of and the products of the communities they live in, resulting in the idea that communities have a social obligation to provide access to resources that would promote the health of community members. Even more importantly, community-based intervention implies some degree of community ownership of the intervention. As most individuals usually regard themselves as members of their specific communities, they might support any efforts to improve the communities in which they live (Mugabe *et al.*, 2002; Wagner *et al.*, 2000).

Gibson, Swartz and Sandenbergh (2002) state that communities spontaneously develop ways of coping with trauma and life's difficulties. Communities often have systems in place whereby neighbours will assist people who have been bereaved emotionally and economically, with the understanding that assistance will be reciprocated when necessary. In South Africa, this tendency towards self-help is manifested in social and religious institutions, and prevalent in poverty-stricken and informal settlement communities (Mugabe *et al.*, 2002).

At present, extended family members, neighbours and friends, for example, tend to deal instinctively with the challenges presented when children are orphaned due to HIV&AIDS. Despite initial concerns that community members would not be able to care for children infected with and affected by HIV&AIDS, the past couple of years have demonstrated that relatives, foster parents, adoptive parents and other caregivers are indeed able to assist others in need (Mugabe *et al.*, 2002; Anderson, Ryan, Taylor-Brown & White-Gray, 1999; Geballe, Gruendel & Andiman, 1995). This tendency of extended family members supporting others and taking children into their care was also highlighted during my pilot study, conducted in 2001.

I support the view that coping with a challenge lies in the hands of community members (if not family members). To my mind, the questions remain as to how communities are coping with the HIV&AIDS challenge at present, and who is indeed supporting the vulnerable members of the community? Although emphasis is often placed on aspects such as material needs and capacity building as part of the

preparation of community members, I posit that other areas need to be explored. Concerns such as the following come to mind: *Do communities have enough resources to support community members infected with and affected by HIV&AIDS? Are community members informed about the HIV&AIDS pandemic and its impact? What knowledge and skills do community members possess to cope with people infected with and affected by HIV&AIDS? Are community members emotionally prepared to cope with the impact of HIV&AIDS? Do community members feel competent enough to cope with the daily challenges implied by HIV&AIDS?*

Against this background and questions like these, I decided to employ a community-based intervention approach during my research. I selected this approach in order to scrutinise my assumption that the answer to effective coping with the HIV&AIDS challenge is situated within communities themselves, and furthermore that (from an asset-based approach) communities cope by relying on the resources and skills that already exist, some of which they might still be unaware of.

#### **1.8.1.2 Why Participatory Rural Appraisal (PRA)?**

##### **Linking theoretical constructs to methodological choices**

During my study, I wanted to explore the application value of this seemingly appropriate, yet still emerging, approach (PRA), especially in terms of a sensitive issue such as HIV&AIDS, where I assume the community members to be the experts on their own perceptions and ways of dealing with the challenge. As I regard community-based coping as one accountable response to coping with HIV&AIDS, applying PRA (being a community-based participatory approach) seemed to be best-fit for my study. I view PRA as an activist approach, during which the involvement of people who are directly affected by a certain phenomenon or challenge (HIV&AIDS within the context of my study) is encouraged. As such, I continually encouraged participants to think for themselves, contribute to their own learning rather than receive information from me and my co-researchers (my supervisor and four Masters students, jointly supervised by us), share their knowledge and work together in order to face the challenges implied by HIV&AIDS. I aimed at stimulating community awareness amongst participants, in turn encouraging their enthusiasm to take action when issues arise during discussions and inevitably resulting in change. This implies



a shift from viewing myself (and my co-researchers) as *outsider* professionals who can provide information and our own advice (so-called *etic* approach) to a focus on *insider* participation and understanding from an insider's perspective (*emic* approach) (Chambers, 2004; Binns, Hill & Nel, 1997; Webber & Ison, 1995; Chambers, 1994a).

Consequently, applying PRA principles enabled me to replace the historical focus on finding and solving problems with facilitating change, by means of empowering the role players (participants) during the process of intervention (research). In shifting my focus, I emphasise transformation and the *creation of power* from the inside out, as opposed to merely *receiving power* from people who already possess it (thereby *giving power* to people seemingly being *without power*). Christians (2000:148) summarises this idea: '*Therefore, research is not the transmission of specialized data but, in style and content, a catalyst for critical consciousness*'. By being involved and contributing to the process, community members (participants) fulfilled the role of active partners during the entire intervention research process – in the various aspects and development procedures. In this manner, participants were able to experience a high level of ownership and develop other appropriate strategies to cope with the challenges implied by HIV&AIDS, against the background of their specific contexts (Chambers, 2004; International HIV/AIDS Alliance, 2001; Webber & Ison, 1995). The application of these underlying principles of PRA appeal to me as a scholar in Educational Psychology, as I support the idea of facilitating change and am experienced in applying such principles within the field of Educational Psychology, during intervention with single clients or families.

By applying PRA principles during my field work, I could gain from the various advantages implied by the approach. Firstly, I relied on the advantage of the information provided usually being accurate, as it is based on local people's personal knowledge. In addition, participants often tend to cross-check one another when participating in activities. Secondly, plans that are made by local people usually have a higher propensity of being successful than those planned by outsiders, as local people have first-hand knowledge of their situation and take into account local conditions when planning activities to address challenges. This idea correlates with my assumption that communities are presently coping with HIV&AIDS by relying on their own knowledge and the local resources available to them. This further implies



yet another advantage of PRA, namely that community members could be empowered during the research process and activities, firstly by an increase in their understanding of the challenges and opportunities they face, and secondly by the community participation that was initiated. The result of applying these advantages to my study was that I could continuously appeal to participants (community members) to participate in the analysis of the community, enabling them to express their views and share their perceptions of (their) reality, thereby providing insight into the selected community's challenges, priorities, strengths and values, and being motivated to become involved in participatory action (Chambers, 2003; Heaver, 1992).

Apart from participatory approaches being regarded as particularly effective when exploring sensitive issues such as the experiences of people concerning HIV&AIDS-related aspects (International HIV/AIDS Alliance, 2001), applying PRA principles during my research enabled me to best address my research questions. In addition, the basic principles of PRA correlate well with the underlying principles of the asset-based approach, which forms the basis of the conceptual framework against which I undertook my study. This correlation is illustrated in the following words of Robert Chambers, founder of PRA, which directly apply to the asset-based approach: '*PRA has often astonished facilitators and surprised local people who have found themselves doing things they did not know they could*' (Chambers, 2003:103). In addition, the PRA saying '*they can do it*' also directly applies to the asset-based approach and could be observed during my study.

According to the asset-based approach, the focus falls on the utilisation of existing resources, assets, skills and abilities, as a way of addressing and coping with the challenges implied by HIV&AIDS. By choosing to apply PRA principles, my research process did indeed focus on the skills and competencies already present in the community. It required of me to facilitate agency amongst community members to analyse the information they had generated during PRA activities. The analysis was directed by the main issues and challenges affecting the lives of the community, the available resources and services in the community (whether they had been utilised or not), as well as any other potential resources – also those outside the community. In addition, community members (participants) were guided to prioritise the challenges

they face, select a few to work on and formulate action steps to address them in terms of three new projects they initiated, by putting their plans into action and by mainly relying on their own knowledge and the resources available to them within the local community. Having the roles reversed (basic PRA principle) implied that I regarded the participants (insiders) as the experts. This once again correlates with my training as educational psychologist, according to which the client is viewed as the expert (Chambers, 2003; Cornwall, Musyoki & Pratt, 2001; Absalom & Mwayaya, 1997).

In addition to PRA supporting the basic principles of the asset-based approach, and due to the fact that the application of PRA principles enabled me to address my research questions, I based my methodological choice of applying PRA principles on the fact that the PRA approach is relatively new and still emerging. Applying a research approach on which limited research has been done to date, enabled me to explore the application value of the approach in a South African community. Although a study by Binns *et al.* (1997) indicates that PRA can indeed be successfully implemented in rural South Africa to facilitate social and economic improvement, limited research findings exist concerning the application of the approach in other contexts in South Africa, more specifically within the field of Educational Psychology. In addition, very little research and writing on the use of PRA in South Africa has been done, as existing literature mainly reports on international studies – leaving the field for research in South Africa wide open.

During my study, I (as the researcher and supported by my co-researchers) acted as facilitator, in order to learn from those who understand from an emic perspective. Binns *et al.* (1997) categorise PRA as a bottom-up approach and a *sensitive rural research methodology* that can be used effectively to conduct research on sensitive topics, as it might enable the researcher to interpret people-environment relationships. This approach is in contrast with the so-called top-down rural developmental strategies that often do not appreciate the whole picture, especially by not acknowledging the complete context and local people's knowledge, skills, aspirations, needs, perceptions and understandings. Respecting community members as key role-players during the process of research addresses the challenge of power and politics within research, as described by Christians (2000).

By respecting community members as research partners during my study, collaboration, mutuality and equal communication could be enhanced, whilst power and domination by outsiders were discouraged.

### **1.8.2 SELECTION OF CASE AND PARTICIPANTS**

I used purposive sampling to select one South African informal settlement community (the case) (Patton, 2002; Babbie & Mouton, 2001; Mayan, 2001). The selected community is located near the Nelson Mandela Metropole in the Eastern Cape Province – a province that incorporates the former homelands of Transkei and Ciskei, and is characterised by poverty, a high rate of unemployment, small-scale and often marginal agriculture, as well as a history of labour migration designed to service the mining industry. In identifying the community, I adhered to the criteria that the selected community had to be an informal settlement community, located in the Eastern Cape and characterised by poverty and limited resources.

I gained entry into the selected community *via* an educator in the Eastern Cape Province, whom I know from my work as a distance education lecturer at the University of Pretoria's Faculty of Education. Apart from this community, I have been networking continuously with educators, researchers and community leaders in other parts of South Africa, providing me with the possibility to later elaborate on the project or to select alternative research sites if it seemed to become necessary.

After identifying the community (the case), I relied on the principal of a primary school in the particular community to select ten educators as primary participants (*educator-participants* hereafter) for initial intervention sessions (focus groups/workshops). In turn, I relied on my own networking abilities as well as a few of the educator-participants in identifying other (secondary) participants – to be involved during individual interviews. Thus, key informants guided me to once again employ purposive sampling. These key informants also acted as local fieldworkers and interpreters, in order to build rapport and facilitate communication in the indigenous languages spoken by participants.

### 1.8.3 DATA COLLECTION

As apparent from Figure 1.2, I employed both an *intervention (focus groups combined with workshops that relied on PRA informed techniques)*, and *informal conversational interactive interviews* as primary data collection strategies (Wilkinson, 2004; Leach, 2003b; Patton, 2002; Morgan, 1997). These strategies were supported by *observation-as-context-of-interaction* (Angrosino & Mays de Pérez, 2000) and captured in the form of *visual data* (Creswell, 1998; Archer & Cottingham, 1996). Raw data were documented in the form of a *field journal* (Patton, 2002; Mayan, 2001) – consisting of field notes and reflective thoughts, which focused on general observations, non-verbal information and descriptions of the existing asset and knowledge base, as experienced and observed by me and my co-researchers and/or perceived and communicated to us by participants. As I am not of the same background and culture as the participants, I relied on field workers and other stakeholders in the community with regard to the interpretation of non-verbal communication. Detailed discussions of the various data collection strategies that I employed follow in section 3.3.3.

The initial phases of my study involved several intervention sessions (focus groups/workshops) with ten selected educator-participants. These sessions were followed by more intervention sessions and individual interviews with the same participants, as well as other community members (such as educators, church leaders and representatives of non-governmental organisations [NGOs hereafter]), over a period of two years. Amongst other participants, interviews were conducted with individual members of the community who have in the past or are at present supporting people infected with and affected by HIV&AIDS, as well as with community members who are HIV positive themselves. Interviews were conducted in the community, for example at the school, a church in the community or at the homes of participants. Intervention sessions and interviews were audio-taped and transcribed verbatim.

Data collection activities focused on exploring the views and opinions of participants regarding the manner in which their community is coping with HIV&AIDS, by relying on existing assets and local resources. As my study progressed, I further focused on

exploring possible changes that might have been facilitated by the activist intervention research approach I employed. Throughout, I did not aim at drawing conclusions from the views and opinions expressed by individuals, but rather at providing coherent descriptions of their discussions for further analysis. This supports a basic principle of PRA, according to which the participants should be regarded as partners throughout the research process. I relied on multiple methods, as a strategy to add rigour, richness and depth to the study. By employing crystallisation, different methods could add and reflect different nuances to the data collected, resulting in a richer, more refined view of the reality being researched (Janesick, 2000).

#### **1.8.4 DATA ANALYSIS AND INTERPRETATION**

Data analysis commenced while the intervention sessions and individual interviews were taking place. Based on preliminary analysis, I redesigned questions when necessary. A more detailed thematic analysis of the transcribed intervention sessions and interviews followed after all interviews had been completed, during which I identified and explored themes and concepts, followed by a final analysis. The final analysis focused on a comparison of different categories of themes and concepts, the identification of variations and connections between them, and, ultimately, the integration of the various themes and concepts, to result in an interpretation of the research area (Rubin & Rubin, 1995). Interpretations were linked to existing theory, with the aim of understanding how a South African informal settlement community is coping with HIV&AIDS, interpreted from an asset-based approach.

I was personally responsible for the initial data analysis and interpretation activities. After having studied and annotated raw data in terms of topics, themes and issues, I was supported by my supervisor, who fulfilled the role of secondary data analyst. In addition, I consulted with the participants, regarding the authenticity of emerged themes throughout the study, in an attempt to enhance the dependability of the findings and to facilitate participants' ownership of the process (Terre Blanche & Durrheim, 2002). Although I initially (after my first field visit) employed the software data analysis programme Atlas.Ti with the aid of an external coder, I decided to rely on my own analysis without the assistance of the software programme from the

second field visit onwards. My decision was mainly based on my comparison of the analysis of the initial intervention sessions (using Atlas.Ti) with my independent analysis of the raw data obtained during the pilot study (not relying on a software programme), and concluding that I feel more comfortable with doing the data analysis manually and independently (Mouton, 2001; Berg, 1998).

#### **1.8.5 ETHICAL CONSIDERATIONS**

I respected the human nature of participants throughout the research process. I followed the necessary ethical guidelines to ensure that participants were not deceived, did not experience any form of distress, knew what was going on during the research process and knew that they were entitled to withdraw from the study at any time (Babbie & Mouton, 2001; Hayes, 2000).

With regard to interacting with human participants, I obtained informed consent before intervention sessions or interviews were conducted, audio-taped or photographed. Participants were assured of the confidentiality, privacy and anonymity of any information shared. Participants were also requested to respect the confidentiality, privacy and anonymity of any information shared by others during the research process. I took the necessary steps to protect the confidentiality of my sources, for instance by disguising or altering identifying information on photographs and when interviews were transcribed, and by ensuring that my field journal, audio-tapes, transcripts and other data were kept in a secure environment. Representation ethics were addressed by consulting with the participants after themes had emerged from the data, in order to ensure that the findings indeed reflect their voices and not only mine (Oliver, 2003; Cohen, Manion & Morrison, 2001; Hayes, 2000). A more detailed discussion of the various ethical guidelines adhered to in working with human participants is included in chapter three.

#### **1.8.6 QUALITY CRITERIA**

Throughout the research process, I aimed at sufficiently addressing methodological challenges, thereby adding rigour to my study and improving on the quality and trustworthiness of the final product. I adhered to the belief that a firm qualitative



research design and methodological choices imply an approach that is rigorous by nature, but also flexible enough to encapsulate the various nuances, complexities and multi-facetness of the social situation that is being researched (Sterk & Elifson, 2004; Patton, 2002).

I entered the research field with my own personality and history, being a white South African graduate female. This implies the possibility of subjectivity and prejudices, which are often present in interpretivist studies. Ample opportunity was provided to clarify issues with the participants where there seemed to be uncertainty, as multiple meanings were bound to be ascribed to the reality that the study focused on. In this way, and by being aware of the possibility of researcher bias, I aimed to obtain *confirmable* findings and conclusions (Patton, 2002; Seale, 2000).

Due to the fact that meanings vary across different contexts of human interaction, I did not seek generalisable findings. By producing rich and detailed descriptions of the structures of meanings that developed during the research process I did, however, strive for *transferability* of my findings. I strived to produce findings that are convincing and believable, in an attempt to meet the criterion of *credibility*. In addition, I attempted to produce rich and credible findings by making use of crystallisation. Furthermore, I aimed at obtaining findings that will convince the reader that the findings did indeed occur as reported, meeting the criterion of *dependability*. Finally, I aimed at obtaining *authentic* findings, by providing a balanced perspective of the various views, perceptions and beliefs of the participants (Terre Blanche & Durrheim, 2002; Seale, 2000). A more detailed discussion of the strategies that I employed to meet these criteria follows in chapter three.

In addition to addressing the criteria for trustworthiness, I strived to meet the core criteria for rigorous qualitative research, as formulated by Steinke (2004). The criterion of *inter-subject comprehensibility* can be met by firstly documenting the research process, secondly by relying on interpretations in groups and peer debriefing, and thirdly by employing codified procedures<sup>4</sup>. In my study, I aimed to

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<sup>4</sup> To illustrate the manner in which I reflected on my application of theory into practice, I henceforth rely on a blue font colour.

document the process in such a way that any external reader will be able to follow my study step by step and assess the process and results. In addition, I continually discussed my project with colleagues. I also include detailed descriptions of the steps of data analysis in this thesis. Concerning the criterion of *providing a thorough indication and appropriateness of the research process*, I regard the qualitative procedures that I selected as suitable for my study and research questions, in terms of the selected data collection strategies, ways of selecting participants, as well as methodological decisions within the context of the wider investigation. In adhering to *empirical foundation*, the development of new theory relied on the data obtained during my study, namely on the perceptions and views of the participants. I *identified the challenges and potential limitations* of my study (formulated in chapters three and six), indicating the conditions that need to be fulfilled for the results to be transferable and applicable to other contexts. With regard to the criterion of *coherence*, the theory that developed during the process of my study can be regarded as internally consistent. Furthermore, I processed and reported on any contradictions in the data and interpretations. Concerning *relevance*, I regard my research questions as relevant and my study as meaningfully contributing to existing theory, implying application value in future. Finally, I aimed to meet the criterion of *reflected subjectivity* (referring to the extent to which the researcher as part of the social world is incorporated in the study and theory making), *by constantly relying on self-observation and reflections to stay aware of my personal preferences and background*. Furthermore, I continuously used relationships of trust between the participants and myself to my benefit.

## 1.9 OUTLINE OF CHAPTERS

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The outline of chapters in this thesis is as follows:

### **CHAPTER 1 : SETTING THE STAGE**

Chapter one serves as a background chapter to the thesis, by providing an introductory orientation, general overview of the study and a discussion of the reasons for selecting the particular phenomenon as research area. The rationale, relevance and contribution of the study, statement of the research purpose and



questions and clarification of key concepts are provided, followed by a brief overview of the selected paradigm, research design and methodological choices. Ethical considerations and ways of addressing quality criteria are briefly introduced.

## **CHAPTER 2 : EXPLORING EXISTING LITERATURE AS BACKGROUND TO THE STUDY**

Chapter two provides the conceptual framework for the study by exploring authoritative literature on the topic that is being researched. The HIV&AIDS pandemic is reviewed and discussed. In addition, this chapter includes a discussion of coping theory, with specific reference to community-based coping and coping strategies typically employed within the context of HIV&AIDS. The chapter concludes with a discussion of the asset-based approach and a presentation of my conceptual framework.

## **CHAPTER 3 : DESIGNING AND CONDUCTING RESEARCH IN THE FIELD**

In chapter three the research process is described in detail in terms of the selected research design and methodology followed during the empirical part of the study, in order to investigate the research problems as formulated in chapter one. The methods of data collection, data analysis and interpretation are outlined and justified, followed by discussions of the strengths and challenges implied by my methodological choices. The chapter concludes with discussions on ethical considerations and quality criteria.

## **CHAPTER 4 : REPORTING ON THE RESULTS OF THE STUDY**

Chapter four consists of the presentation and discussion of the data and information obtained and analysed during my study. Results are provided in terms of the themes and sub-themes that emerged during data analysis. Verbatim responses are included where appropriate, in order to further elucidate the results that are presented.

## **CHAPTER 5 : RELATING RESEARCH FINDINGS TO EXISTING LITERATURE**

In chapter five the research findings are viewed against existing literature (as presented in chapter two), with the aim of relating them to existing theoretical frameworks and models, in order to reach conclusions regarding the research problem. Explanations, correlations and discrepancies between my findings and relevant literature findings are highlighted and interpreted.

## **CHAPTER 6 : CONCLUDING THE JOURNEY AND RECOMMENDING FOR THE FUTURE**

Chapter six includes a summary of the main findings of the study, in terms of the research questions and purpose of the study, as formulated in chapter one. The main conclusions of the study are presented and discussed, followed by reflections in terms of the contributions and strengths of the study, as well as the challenges faced during the study. The chapter concludes with recommendations for further research and practice.

### **1.10 CONCLUSION**

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In this chapter I provided an introduction and general orientation to the study, in order to serve as a background against which the rest of the thesis can be read. I discussed the rationale and relevance of the study in terms of several choices that I had to make when planning my study. I formulated my central research questions against the background of these choices and considerations, as follows: *How is a South African informal settlement community coping with HIV&AIDS, by relying on existing assets and local resources?*; and, secondly: *How can an activist intervention approach to research facilitate change in a South African informal settlement community coping with HIV&AIDS?*

After introducing the contribution of my study, stating the assumptions with which I approached the study and clarifying the key concepts within the framework of my study, I provided a brief overview of my selected paradigm, methodological choices and process of the empirical part of the study. In addition, I briefly explained how I addressed ethical issues and quality criteria during my study. These aspects are explained in more detail in chapter three.

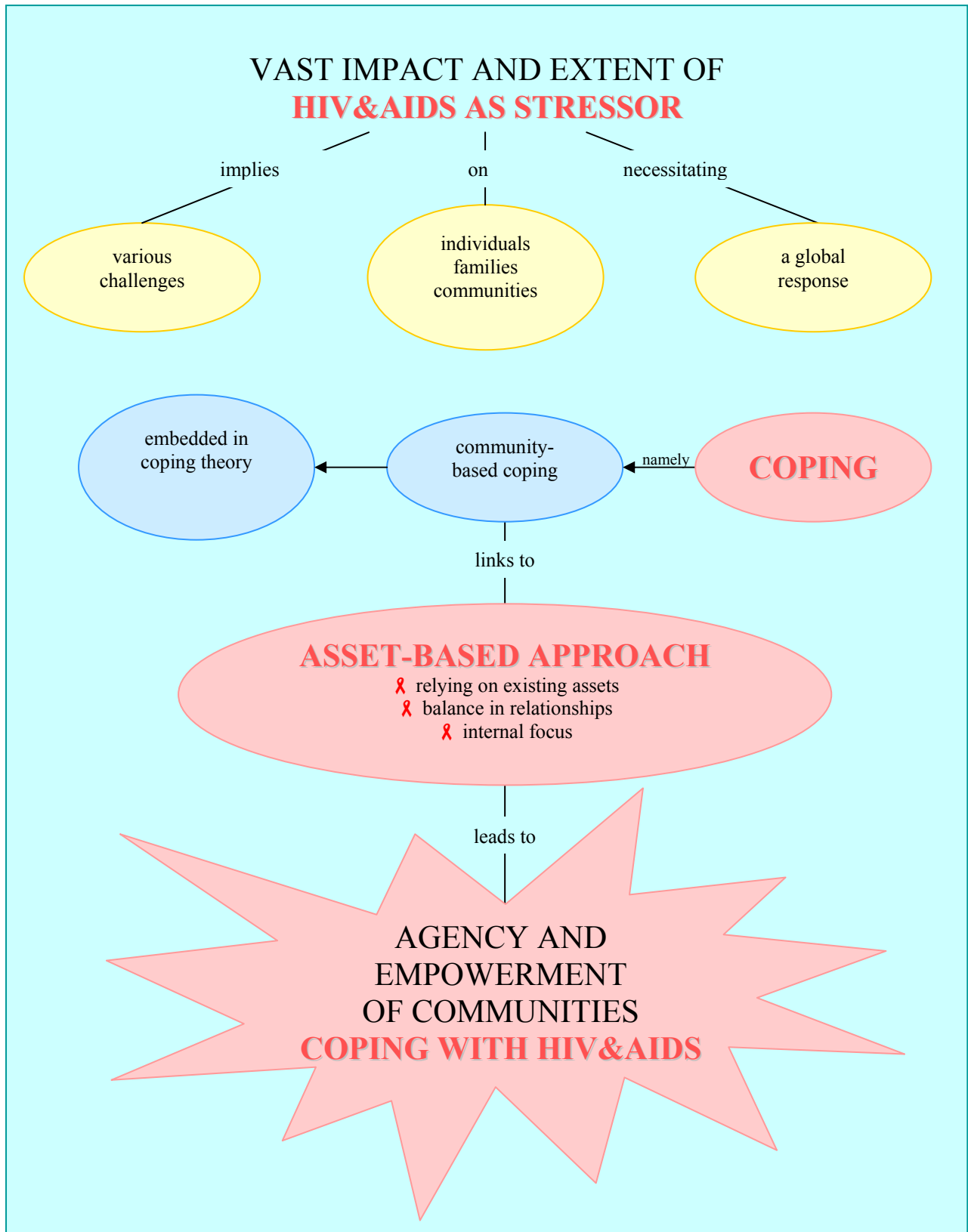
In the following chapter, I provide a conceptual framework for the study, by exploring literature on the HIV&AIDS pandemic, the theory of coping and the asset-based approach. The discussions in chapter two then serve as background to the empirical study, which is presented in chapter three.

## **CHAPTER 2: EXPLORING EXISTING LITERATURE AS BACKGROUND TO THE STUDY**

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## CHAPTER 2 AT A GLANCE



## 2.1 INTRODUCTION

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In this chapter I outline the conceptual framework of my study. For this purpose, I reviewed numerous sources on HIV&AIDS, the theory of coping and the asset-based approach (although the sources in this area are fairly limited). I therefore commence the chapter by reviewing existing literature on HIV&AIDS, followed by discussions of coping theory and the asset-based approach. In reviewing existing literature I was guided by the focus of my study, in terms of my research questions and the purpose of the study. I present the three main sections of the chapter in terms of existing knowledge, limitations in the knowledge base and where my research fits into the existing base of knowledge. In each section, I also continually identify potential areas in which my study might contribute to the existing knowledge base. I conclude the chapter by presenting my conceptual framework for this study.

By engaging in a critical discussion of the various theoretical components and after I have completed my study, I shall endeavour to elaborate on the existing body of knowledge. My focus will specifically centre on the *asset-based approach* within the context of *coping with HIV&AIDS*.

## 2.2 CONTEXTUAL BACKDROP: HIV&AIDS

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HIV&AIDS is a global pandemic impacting on individuals, families and communities in countries worldwide, including the informal settlement community where I conducted my study. Sayson and Meya (2001:542) summarise the global impact of the pandemic: '*As when a stone is dropped into a pool, ripples from AIDS move to the very edge of society, affecting first just one person in a family, then the entire family, then the community, and finally the nation*'. The ripples of HIV&AIDS have indeed reached nations across the globe.

The impact of HIV&AIDS is widespread and recognised in various sectors, such as economical, health, social and educational areas. Countries with limited resources are particularly vulnerable. In addition to challenges like these, an increase in the

number of children orphaned by HIV&AIDS results in even higher levels of financial strain, as well as the need for emotional support and provision of food, shelter and care for these children. Due to their vulnerability, as well as factors like poverty and neglect, these children sometimes end up as street children, and become involved in at-risk sexual behaviour or even child prostitution.

Before focusing on the challenges and stressors experienced by communities within the context of HIV&AIDS, I provide an overview of the extent and potential impact of the pandemic, as this serves as background information to understanding the vulnerability of the community where I conducted my study, as well as the challenges faced by the community in coping with the pandemic. I conclude the section with a discussion on required responses, once again providing the background information with which I entered the research field. Possible ways of coping with HIV&AIDS are dealt with in section 2.3.2, as part of my discussion on coping.

### **2.2.1 EXTENT OF THE PANDEMIC**

I find the statistics provided on HIV&AIDS infections and deaths to be overwhelming. Although I do not accept these as absolute figures, statistics provide me with an estimate of the extent of the challenge faced by communities worldwide. In 2005 it was estimated that 40.3 million people were living with HIV worldwide, of which 2.3 million were children under the age of 15 years. Vertical transmission of the virus accounts for most of the infections in this age group. It was further estimated that 4.9 million people were newly infected during 2005 – 4.2 million adults and 700 000 children younger than 15. Up until now, more than 25 million people have already died of AIDS, of which 3.1 million deaths occurred in 2005, including 570 000 children (Page *et al.*, 2006; Brouard, Maritz, Pieterse, Van Wyk & Zuberi, 2005; Department of Economic and Social Affairs of the United Nations, 2005a; Department of Economic and Social Affairs of the United Nations, 2005b; Shisana *et al.*, 2005; UNAIDS/WHO, 2005; Tindyebwa, Kayita, Musoke, Eley, Nduati, Coovadia, Bobart, Mbori-Ngacha & Kieffer, 2004; UNAIDS, 2004; Department of Social Development, 2002; UNAIDS, UNICEF & USAID, 2002). To me, statistics like these emphasise the extremes that the pandemic has reached, despite ongoing research and preventative measures employed since the outbreak of the HIV&AIDS



pandemic. Against the background of these statistics reporting on the global extent of HIV&AIDS, I shall now investigate the impact of the pandemic on the African continent and, in more specific terms, on local ground.

Sub-Saharan Africa is reported to have been hardest hit by the pandemic, with 25.8 million, or approximately two thirds of the people, living with HIV. In addition, the highest number of children living with the disease (90% of children under 15 years of age), as well as the highest number of children orphaned by AIDS, applies to Africa. It was estimated that 2.4 million deaths in sub-Saharan Africa during 2005 could be ascribed to HIV&AIDS-related illnesses and that 3.2 million people were infected with HIV during that year. In 2003, more than 400 000 children under the age of 15 died of AIDS in sub-Saharan Africa (Page *et al.*, 2006; Brouard *et al.*, 2005; UNAIDS/WHO, 2005; Cabassi, 2004; Miamidian, Sykes & Bery, 2004; Tindyebwa *et al.*, 2004; UNAIDS, UNICEF & USAID, 2002).

On an even closer level, I view the impact of HIV&AIDS on South Africa as one of the most intense and probably the most serious in the world. I regard both the vast rate of increase in infections and deaths, as well as the extraordinary scale of the pandemic in South Africa, as being significant. By 2004, between 2.6 and 3.1 million men, between 3 and 3.6 million women, and more than a 100 000 babies were estimated to be living with HIV – an estimated 12% of the South African population being infected with the virus. Seventy six percent of these people were in the age group 15 to 34 years. In addition, the estimation of AIDS-related deaths in South Africa for that year was 500 000 (Department of Health, 2005; Marais, 2005; UNAIDS/WHO, 2005). Statistics like these resulted in my anticipation (prior to entering the research field) that the South African community in which my study is located might have to support numerous community members living with HIV&AIDS. It made me wonder in which manner the selected community might be coping with such (theoretically) vast numbers of cases in need of care and support.

It is estimated that more than five million South Africans are presently living with HIV&AIDS and that 50% of the South Africans within the age group 15 to 24 years will die of AIDS. Nine hundred people die of AIDS in South Africa daily, whilst more than 1 500 become HIV infected. It is projected that half a million South Africans will

die annually from AIDS-related causes by the year 2008 (Page *et al.*, 2006; Brouard *et al.*, 2005; Department of Economic and Social Affairs of the United Nations, 2005a; Department of Economic and Social Affairs of the United Nations, 2005b; Department of Social Development, 2002; UNAIDS, UNICEF & USAID, 2002). The pandemic is further expected to only peak in South Africa between 2010 and 2020. In this regard South Africa is predicted to be one of five countries that will experience a negative population growth due to AIDS mortality by 2010, with the growth rate estimated at -1.4% (Richter, Manegold & Pather, 2004; Stanecki, 2002).

To me, the numerous sources on HIV&AIDS-related statistics confirm the fact that research in the field of HIV&AIDS is ongoing and relevant. However, the fact that the extent of the pandemic seems to be vaster than predicted makes me wonder as to how successful research and intervention initiatives with regard to prevention are. In addition, I am increasingly aware of the fact that communities are facing a challenge that they need to cope with, and that more research relating to possible ways of coping is continually required.

Furthermore, the high HIV prevalence rate in South Africa implies an increase in the number of orphans in the near future, rendering our country one that has not yet experienced the full impact of the orphan crisis. In my view, this prediction (that the impact of HIV&AIDS will be experienced as even more harsh in future) once again emphasises the importance of communities being prepared to cope with the impact that is foreseen. Seeking answers to questions like the following might provide insight into the existing coping practices of communities (as I also aimed to obtain in my study): *How do communities address and cope with so many cases of loss? How is daily functioning and productivity impacted upon by HIV&AIDS? How do community members cope with the emotions related to loss and grief?*

The current HIV&AIDS scenario, as described in the previous paragraphs, necessitates ongoing research as well as attempts to prepare and support communities to cope with the challenges related to the pandemic. As HIV&AIDS implies various associated stressors, communities will in future have to cope not only with an increase in HIV&AIDS-related deaths, but also with an increase in the number of children orphaned due to HIV&AIDS. Upon gaining insight into the extent

of the pandemic, I ponder on the question as to whether South African communities are ready and equipped to cope with the challenges and vulnerabilities implied by the pandemic. In this manner, I realise the potential that my study may hold for possibly contributing to the knowledge base on coping with the challenge of HIV&AIDS. Concerning the estimated numbers of future orphaned children, I question the predictions, against the background of anti-retroviral treatment (supposedly) being provided to people living with AIDS. If anti-retroviral treatment extend people's lives, future statistics on children orphaned due to HIV&AIDS might turn out not to be as steep as predicted. However, I do accept the reality that the numbers will be rising and counting for enormous numbers of children left vulnerable and in need of care.

### **2.2.2 IMPACT OF HIV&AIDS**

The Department of Social Development (2002:10) describes HIV&AIDS as the '*most urgent health, welfare and socio-economic challenge in South Africa*'. I regard the pandemic as a cross-sectoral developmental issue, impacting and posing challenges on numerous levels, such as health, economic, social, agricultural, policy level and many other areas (Brookes *et al.*, 2004; Smart, 2003b). I henceforth discuss the impact of the pandemic in terms of the developmental impact implied, the interrelatedness between poverty and HIV&AIDS, and, lastly, the sectoral impact on health care, education, the private and industrial sector, as well as the macro-economic level.

#### **2.2.2.1 Impact on the development of individuals, families and communities**

HIV&AIDS impacts on the individuals, social safety nets and households of communities – people having to cope on a primary level with the challenges implied by the pandemic. Upon becoming ill, family members might experience physical and psychological pain and suffering, and are often not able to contribute to the household income any more. As a result, people's involvement is reduced on various levels, for example in the agricultural and mining sectors. The pandemic therefore reduces labour and productivity, and by implication also the capacity to provide health services, which are urgently demanded by the pandemic (Barolsky,

2003; Ramsden, 2002; UNAIDS, UNICEF & USAID, 2002; Kelly, 2001a; Kelly, 2001b; Ngcobo, 2001; World Bank, 1999; Mkwelo, 1997).

In addition, families' expenses increase when a family member becomes ill (in order to obtain treatment, health care and healthy dietary requirements), resulting in food insecurity and ultimately the weakening of the nutritional status of the people involved. As such, HIV&AIDS intensifies poverty and negatively impacts on family life and family relationships, as well as families' access to social and economic resources. Concerning the influence on family structure, HIV&AIDS leads to an increase in single parent families, as well as children living in households headed by elderly relatives or siblings (Ramsden, 2002; UNAIDS, UNICEF & USAID, 2002; Kelly, 2001a; Kelly, 2001b; Mkwelo, 1997). Being aware of the potential impact of the pandemic on individuals, families and communities provided me with an overview of the challenges that the participants (community members) in my study need to cope with. It guided me in planning and conducting data collection activities, in terms of potential areas to explore. For the purpose of my study, I assumed that the members of the selected informal settlement community were indeed coping with these challenges at the time of my study.

Furthermore, I continuously kept in mind that some family members might start missing school or work, in order to care for those who are sick. I considered the thought that the death of a parent could result in further financial obligations (like funeral expenses), permanent loss of income, and children being orphaned and in need of care. In some cases, children (or widows without an income) might turn to sex work for an income, thereby increasing the risk to be infected with HIV. In this manner, HIV&AIDS does not merely lead to financial strain and sometimes the loss of savings, it also adds greatly to the psychological distress experienced by the person being infected or ill, as well as other family members involved. Family members experience stress with regard to being financially needy and not being able to provide for their basic needs, as well as from the illness they need to cope with. In the case of extended family members taking care of children affected by HIV&AIDS, financial demands are added to their households (SAHIMS, 2004; Barolsky, 2003; UNAIDS, UNICEF & USAID, 2002; Cross, 2001; Kelly, 2001a; Kelly, 2001b; Ngcobo, 2001; Ratsaka-Mothokoa, 2001; Townsend, 2001; World Bank, 1999; McDonald,

1998). Within the context of my study, the potential impact of HIV&AIDS on family members and family life guided me to explore the manner in which relatives are coping with the challenges implied by a family member living with HIV&AIDS, as actualised in the community in which my study is located.

#### **2.2.2.2 Interrelatedness between poverty and HIV&AIDS**

The interrelatedness between poverty and HIV&AIDS has been widely documented, with poverty being both a cause and a consequence of risk within the context of HIV&AIDS. In addition to poverty increasing the possibility of people becoming involved in behaviour that might lead to HIV infection, the impact of HIV&AIDS is intensified by poverty itself, and more so in communities where the necessary infrastructure is lacking and community members do not have access to basic services. As such, I believe that these individuals and families are facing double discrimination, firstly for living with HIV&AIDS, and secondly for suffering from poverty. Poverty leads to a decline in the quality of the lifestyle maintained by a family, not only adding to the vulnerability of people but also intensifying the harshness of the impact of the pandemic. In extreme cases, it might lead to increased levels of crime when individuals become desperate. This inevitably culminates in a never-ending circle of ever-increasing poverty and hardship (Department of Economic and Social Affairs of the United Nations, 2005a; Marais, 2005; Brookes *et al.*, 2004; Cabassi, 2004; Tindyebwa *et al.*, 2004; Akintola & Quinlan, 2003; Richter, 2003; Smart, 2003a; Clacherty & Associates, 2002; Oni, Obi, Okori, Thabede & Jordan, 2002; McDonald, 1998).

In selecting an informal settlement community characterised by poverty and limited infrastructure, I was able to perceive the interrelatedness between poverty and HIV&AIDS. Being a poverty-stricken community, the factors relating to poverty are a reality in the daily lives of the community, negatively impacting on individuals, families and the community at large. I constantly had to be aware of this link and reflect on the underlying cause for the raw data that I obtained and observed throughout, in an attempt to understand the experiences of the participants within this context of poverty.

### 2.2.2.3 Sectoral impact of HIV&AIDS

HIV&AIDS impacts on health care, education, the private and industrial sector, as well as the macro-economic level. The need for **health care** with regard to HIV&AIDS and other related illnesses has vastly increased since the disease started, in terms of both the need for medication and treatment, as well as the need for hospital care, which is often marked by limited resources. In addition, the pandemic leads to the death of health care staff, decreasing the possibility of sufficient treatment and care even further. On a general level and to summarise, HIV&AIDS leads to an increase in mortality (both adults and children), a decrease in life expectancy and a reduction in population growth, thereby necessitating an extension of health care services (Department of Economic and Social Affairs of the United Nations, 2005a; Marais, 2005; Akintola & Quinlan, 2003; Smart, 2003b; Kelly, 2001a; Kelly, 2001b; Subbarao, Mattimore & Plangemann, 2001; Broughton, 1999). During my study, I had to be cognisant of and compassionate towards this realm of decline in the provision of health services. As a result, I attempted to reflect on the impact of the limitations, but also the available resources related to the health sector, in terms of the selected informal settlement community's way of coping with HIV&AIDS.

In terms of the impact on **education**, the education and training systems have been steadily weakened by the HIV&AIDS pandemic. Besides children infected with and affected by HIV&AIDS dropping out of school, educators are also infected, thereby decreasing the workforce of the education sector. Factors like educator absenteeism; a low morale; poor school attendance by children; trauma, grief and mourning experienced in schools when people die; as well as insecurity and anxiety, further influence the quality of education that is provided in schools (Marais, 2005; World Bank, 2002; Kelly, 2001a; Kelly, 2001b; World Bank, 1999). As the core group of participants in my study were educators, I was very much aware of the potential impact of the pandemic on the education sector as well as the manner in which this impact might expand to the wider community, in terms of its coping with the challenges implied by the pandemic.

In the **private and industrial sector** HIV&AIDS reduces productivity, thereby influencing resources, increasing costs and having an effect on the market for

business products, as people are not able to buy products or pay for them after they have been purchased. On a **macro-economic level**, economic growth is influenced negatively in respect of human, physical and social capital (Marais, 2005; World Bank, 2002; World Bank, 1999). During my study, I had to constantly focus my reflections in terms of the availability of resources, but also the reality of challenges faced by the community in coping with HIV&AIDS, in both the private and industrial sectors, and on a macro-economic level. In selecting a community characterised by limited infrastructure and resources, I was faced with the reality of the sectoral impact of HIV&AIDS, such as limited availability of health care and social services.

### **2.2.3 POTENTIAL CHALLENGES AND STRESSORS WITHIN THE CONTEXT OF HIV&AIDS**

Living with HIV&AIDS implies various challenges and consequences for the individuals, families and communities involved. I henceforth explore the potential challenges implied by the pandemic in terms of the vulnerability of people living with HIV&AIDS, and secondly, the challenge of supporting others living with HIV&AIDS.

#### **2.2.3.1 Vulnerability of people living with HIV&AIDS**

People living with HIV&AIDS undergo many changes. As such, I had to be aware of, and prepared to possibly be confronted with, the **personal vulnerability** of participants, in terms of their initial reactions like anger, fear, loss, grief and denial, as well as mood swings. In addition to emotional pain, I had to regard feelings of low self-worth, powerlessness and even depression as characteristic of people having to cope with the challenge of living with HIV&AIDS. People living with HIV&AIDS might further experience mental health problems and display suicidal behaviour or thoughts, in an attempt to cope with the idea of facing death. Apart from worrying about their own illness, about their inability to earn an income, and about what will happen to them and their families, HIV infected parents also worry about their children. They are usually concerned about the possibility of their children being discriminated against, the basic survival and future of their children after they have passed away, the possibility of them being exploited and the effect that their illness and possible poverty might have on their children. During later stages of their illness, people with AIDS have to deal with the symptoms and pain of their illness (**physical**



**vulnerability**). Within the context of my study, I had to be on the look-out for feelings and reactions as mentioned in this paragraph, even for those that were communicated on a non-verbal level (Page *et al.*, 2006; Freeman, 2004; Mallmann, 2002; Gilborn, Nyonyintono & Jagwe-Wadda, 2001). On the other hand, my focus on the asset-based approach guided me in also identifying positive experiences such as spiritual growth, meaning making, support and resourcefulness, as potential responses to vulnerability and the related feelings, such as those described in this paragraph.

In addition to personal experiences and emotions (**personal vulnerability**), I continually had to remain aware of the fact that people living with HIV&AIDS have to cope with the possibility of being stigmatised and having to decide whether or not to disclose their status and to whom (**social vulnerability**). Based on stigmatisation, I had to respect the decision not to disclose and rather hide an HIV positive status, resulting in the possibility of people living with HIV&AIDS not accessing emotional and practical support (like treatment), thereby intensifying their own **physical vulnerability**. I acknowledge the possibility of even family members stigmatising relatives and discriminating against them, rejecting or isolating them. In the case of people deciding not to disclose their status to family members, they might be rejected at later stages of their illness when they require care and support, based on their initial decision to keep a secret from the family (Barolsky, 2003; Strode, Grant, Clacherty & Associates, 2001). With regard to disclosure, I support McDonald (1998), who takes disclosure back even one step further by regarding the first level of disclosure as the decision to be tested for HIV – so-called *disclosing to the self*.

I regard stigmatisation and discrimination as central challenges related to HIV&AIDS, which add to the **social vulnerability** of people who are already vulnerable. Not only does stigmatisation result in people being judged, blamed and discriminated against, it also prevents intervention initiatives from being effective. Stigmatisation might, for example, prevent people from accessing care and support, seeking information or protecting themselves and others by preventing further infections. In extreme cases, I believe that infected people might even avoid accessing the government disability grant (which might bring financial relief) and as a result increase their **physical vulnerability**, based on their fear for discrimination and isolation. I support the view

that, due to stigmatisation, people living with HIV&AIDS do not only have to cope with their status or illness, but also with discrimination and rejection by others (Holzener & Uys, 2004; Akintola & Quinlan, 2003).

Numerous calls have been made to address stigmatisation and discrimination, in order to encourage people with AIDS to disclose their status (see for example Brouard *et al.*, 2005; Monson, 2005a; Department of Social Development, 2002; Gilborn *et al.*, 2001; UNICEF, 2001; Van Dyk, 2001). In response, the study for *Save the Children* (Clacherty & Associates, 2002) revealed that the levels of stigmatisation seem to be decreasing (Strode *et al.*, 2001). Yet on the other hand, a study by Kelly (2000a) in the Eastern Cape, KwaZulu-Natal and the Western Cape revealed contradictory findings, where selected adolescents and young adults (15-30 years old) displayed more positive attitudes towards people living with HIV&AIDS, whilst participants in rural areas still displayed intolerance. As such, there seems to be a decline in the tendency to blame people living with HIV&AIDS, as well as a tendency to accept them as '*normal*' community members in certain areas. However, in rural areas (specifically in the Eastern Cape) stigmatisation still appears to be evident. Results like these emphasise the fact that different regions display different tendencies with regard to stigmatisation and discrimination against people living with HIV&AIDS. My study might contribute to the existing body of knowledge by providing insight into the levels of stigmatisation within the selected informal settlement community where I conducted my study.

In addition, my awareness of the possibility of the Eastern Cape being characterised by high levels of stigmatisation (***social vulnerability***) could guide me in approaching the research field, as I faced the challenge of exploring a phenomenon which is more often than not regarded as a *taboo* subject. My awareness of the possibility that participants might not have been willing to share their perceptions enabled me to carefully plan my data collection activities and adapt them where necessary. In addition, my realisation that stigmatisation and discrimination are still a harsh reality, allowed me to, at times, understand the responses and reactions of the participants.

Cloete (2003) relates stigmatisation to the lack of access to treatment and is of the opinion that it could start diminishing once treatment is freely available. I do not fully

agree with this statement, as I believe that stigma strongly relates to fear. As such, enhancing treatment possibilities might help in combating stigmatisation, but cannot necessarily be accepted as the primary factor in breaking down stigma. Whatever the case may be, at present stigmatisation is still a relevant challenge faced by those who are living with HIV&AIDS, that needs to be addressed as a prerequisite for enhancing their quality of life (Department of Economic and Social Affairs of the United Nations, 2005a; UNAIDS/WHO, 2005; Browde, 2003; Masindi, 2003; Siyam'kela project, 2003; Van Dyk, 2001; International HIV/AIDS Alliance, 2000). In addition to purposefully addressing the stressor of stigmatisation, Strebel (2004) suggests that stigmatisation needs to be acknowledged in revising and planning future community-based interventions. Strebel's (2004) suggestion resulted in me acknowledging stigmatisation whilst planning and conducting my field work.

Stigma related to HIV&AIDS can take on many forms and result in various reactions by the person living with HIV&AIDS or by other people of the community. In my study, I adhered to the Siyam'kela Project's (2003) differentiation between stigma on an external and an internal level. On an external level, I regard reactions such as avoidance, rejection and moral judgement as often experienced by people living with HIV& AIDS. In addition, people living with HIV&AIDS might be stigmatised by association, by an unwillingness to invest in them, or by being discriminated against or abused by others. **Avoidance** is related to the fear of casual transmission of the virus and takes on the form of others not being willing to touch or share the same objects of those living with HIV&AIDS, as well as the tendency to gossip, resulting in people living with HIV&AIDS feeling isolated. **Rejection** can reach extremes, as people who are living with HIV&AIDS might be rejected by their partners (upon disclosing their status), other family members, the wider community and even members of their church or faith-based organisations. With regard to **moral judgement**, HIV&AIDS is often linked to at-risk sexual behaviour, resulting in people being judged or labelled as immoral. **Stigmatising people by association** refers to tendencies such as assuming that people who are loosing weight are suffering from HIV&AIDS, or in cases where the cause of death is not stated, that they had died of AIDS. Furthermore, relatives or children might be stigmatised due to the HIV status of a family member, resulting in parents being secretive about their status and not disclosing it to their children. In the same manner, people working as care workers

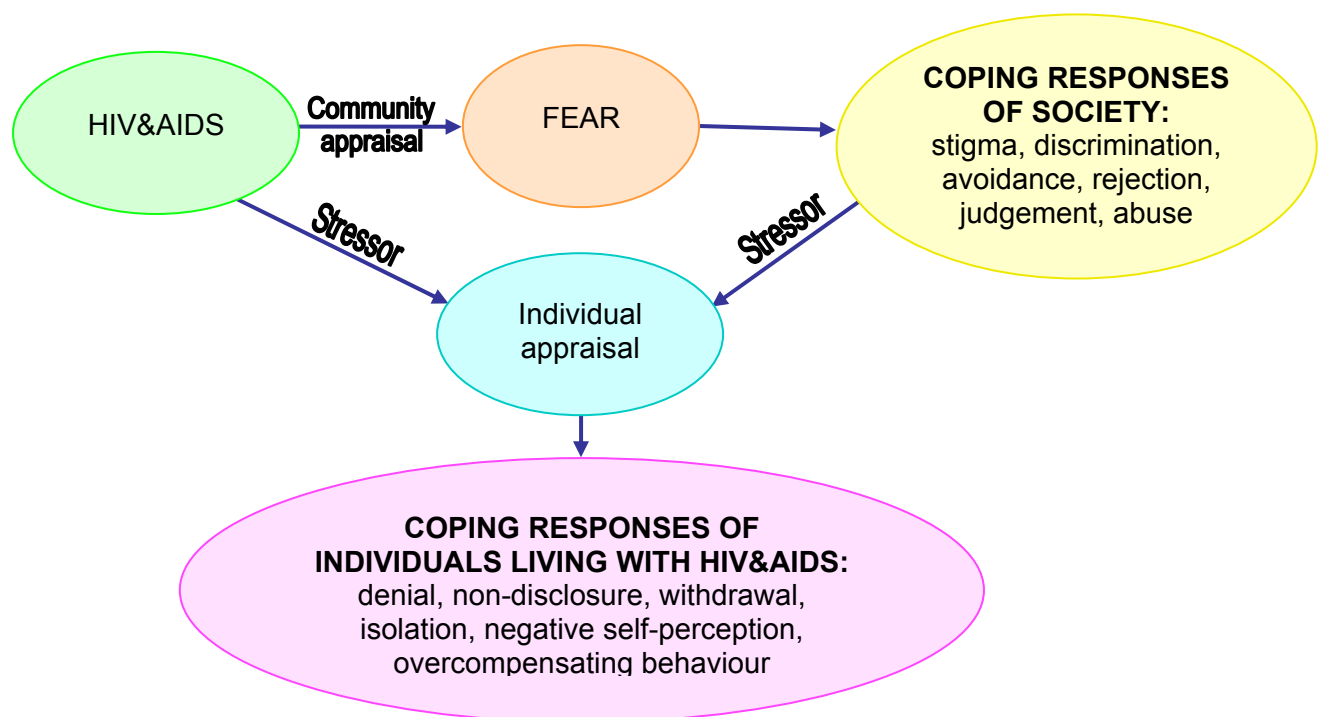
or volunteers within the context of HIV&AIDS might be stigmatised (Siyam'kela Project, 2003; Clacherty & Associates, 2002; Strode *et al.*, 2001).

An ***unwillingness to invest in people living with HIV&AIDS*** relates to people fearing disclosure, based on their fear of being marginalised due to their status within an organisation by, for example, not being included in training, development and promotion possibilities. In terms of ***discrimination***, people living with HIV&AIDS are often not able to access services such as funeral coverage, medical schemes and blood transfusions. Furthermore, they sometimes do not receive the same health services, care and courtesy as other people. Finally, people living with HIV&AIDS might be ***abused***, for example physically abused after disclosing, or verbally abused as immoral or a threat to the community (Siyam'kela Project, 2003; Clacherty & Associates, 2002; Strode *et al.*, 2001; Antle, Wells, Goldie, DeMatteo & King, 2001).

Concerning internal stigma, people living with HIV&AIDS often fear disclosure, withdraw themselves socially, perceive themselves in a negative manner and exclude themselves from certain services and opportunities. I regard reactions like these as coping behaviour and strategies, employed by people living with HIV&AIDS, in an attempt to address the challenge of their illness. People who are infected with HIV or who have AIDS usually ***fear disclosure***, based on their fear of being judged or rejected by their partners, family members or the wider community. In addition, they might fear discrimination against their family members and children, or not being promoted at work. Even caregivers looking after people living with HIV&AIDS sometimes avoid disclosure in fear of being stigmatised and discriminated against. ***Excluding themselves from services and opportunities*** such as support groups can be linked to people's fear of stigmatisation. In the same manner, people living with HIV&AIDS might ***withdraw themselves socially***, in order to protect themselves against stigmatisation and discrimination, or due to their fear of being judged or rejected. It is, however, common practice for people living with HIV&AIDS to spend time with other people who are HIV infected or who have AIDS. With regard to their ***perceptions of themselves***, people living with HIV&AIDS might experience themselves as less valuable, and that they had disappointed others. In an attempt to protect themselves from discrimination, or due to internal stigma, they might ***overcompensate*** in their behaviour. They might also tend to prove to others (for

example the church) that they are good people (Siyam'kela Project, 2003; Strode *et al.*, 2001; Mkwelo, 1997).

Within the context of my study, I relate potential reactions and behaviour that are associated with stigma on an internal level, to the coping strategies employed by people living with HIV&AIDS. I further regard the coping reactions and behaviour described in the previous paragraphs as defence mechanisms and potential ways of denying an HIV positive status. Concerning stigma on an external level, I propose that the reactions as identified by the Siyam'kela Project (2003) also be regarded as coping strategies, but as the strategies employed by people **not** living with HIV&AIDS, in response to community members who are infected or who have AIDS. As such, I viewed any such reactions (on both an external and an internal level) against the background of stigmatisation and as potential coping strategies employed by the participants. Figure 2.1 provides a summary of potential coping responses to HIV&AIDS against the background and reality of stigmatisation. Within the context of my study, insight into the ways in which community members employ these potential reactions as coping strategies might elaborate and build on the basic theory provided by the Siyam'kela Project (2003).



**FIGURE 2.1: POTENTIAL COPING RESPONSES TO HIV&AIDS AGAINST THE BACKGROUND OF STIGMATISATION**

### 2.2.3.2 The challenge of supporting people living with HIV&AIDS

Relatives of those living with HIV&AIDS face many challenges themselves, as the pandemic impacts on the whole family and requires of them to cope with a relative becoming ill and ultimately dying. The psychosocial feelings experienced by significant others (both family members and other loved ones) correspond with the feelings of a person being infected with HIV or having AIDS. Family members typically display reactions of disbelief, confusion and shock. Other feelings that are commonly experienced include uncertainty, anger, emotional numbness, despair, stress and depression. Relatives may further fear infection themselves or even be angry with the infected family member for bringing the stigma onto the family (Richter *et al.*, 2004; Van Dyk, 2001; Mkwelo, 1997). During my study, the knowledge of such potential feelings and reactions to a relative living with HIV&AIDS provided background against which I could interpret certain reactions and responses obtained during data collection. As such, my knowledge of typical feelings and experiences of relatives impacted on my exploration of their way of coping.

As in the case of people who are HIV infected or who have AIDS, family members have to cope with the possibility of stigmatisation and discrimination. They may experience stress due to their loved ones being stigmatised and discriminated against, or they may experience psychological distress if they themselves tend to stigmatise others who are infected with and affected by HIV&AIDS, and are now faced with a family member falling into this category. In addition, HIV&AIDS might overwhelm families whose coping capacities have already been stretched to their limits by poverty, as family members usually have to take over the responsibility of income generation, household tasks, caring for the children and supporting or even caring for the relative upon becoming ill. These experiences might add to the vulnerability of the whole family, as well as the levels of psychological stress experienced by family members in coping with both poverty and the challenges imposed by a family member living with HIV&AIDS (Freeman, 2004; Richter *et al.*, 2004; Tindyebwa *et al.*, 2004; Bennell, 2003; Sayson & Meya, 2001; Mkwelo, 1997; Geballe *et al.*, 1995).



In the case of a child who is HIV positive, initial reactions include shock, denial, disbelief, anger, fear and sadness. In addition, family members might lose their hope for the future. During times of illness parents often feel guilty, helpless, lonely and even depressed. Parents also have to cope with their own diagnoses in such difficult times (Tindyebwa *et al.*, 2004; Van Dyk, 2001; Mkwelo, 1997). In undertaking my field work and exploring participants' way of coping with HIV&AIDS (which might have implied coping with a relative living with HIV&AIDS), I continually considered the possibility of the participants in my study having to cope with the feelings and experiences as described in this section. However, by describing positive support initiatives, as practiced by the community members of the selected community, I aimed to provide a counter discourse for the range of stressors and challenges often associated with supporting others living with HIV&AIDS.

#### **2.2.4 RESPONDING TO THE PANDEMIC**

I support the generally agreed upon idea that the challenges posed by HIV&AIDS require a multi-sectoral, integrated (coping) response, involving international, national and regional role-players from as many sectors of society as possible, including local communities. The government, NGOs, public sector, private sector and people living with HIV&AIDS could complement each other's initiatives, establish partnerships and operate in a consolidated way, whilst protecting the human rights of the people involved. HIV&AIDS programmes might be mainstreamed into broader programmes in an attempt to address the causal and underlying factors related to people's vulnerability to HIV infection, as well as to the consequences of HIV&AIDS. Managing such an integrated approach includes components of research, formulation of goals, development of strategies and resources, provision of community support, evaluation of activities and refining of initial goals and outputs (Brouard *et al.*, 2005; Department of Economic and Social Affairs of the United Nations, 2005b; UNAIDS/WHO, 2005; Cabassi, 2004; Lucas, 2004; Strebel, 2004; Department of Social Development, 2002; Kelly, 2001a; Sayson & Meya, 2001; International HIV/AIDS Alliance, 2000; Marais, 2000; Parker, Dalrymple & Durden, 2000).



I hold the view that such an integrated approach could indeed address the challenges of HIV&AIDS faced by communities worldwide. However, despite numerous efforts employed since the outbreak of the pandemic (as reported on in the following paragraphs), I still find the extent of the pandemic to be vast and overwhelming. I inevitably ask myself the question as to whether or not the various areas of importance (as identified in the previous paragraph) are indeed being addressed, and, if not, which areas need to be addressed more rigorously. In an attempt to find an answer to this question, I explore current responses to the question in the paragraphs to follow. To me, a central intrigue is whether or not an intervention study, following PRA principles, could permit me insight into aspects that might facilitate change (or not) in terms of coping with HIV&AIDS.

In response to the vast impact of HIV&AIDS, action has been taken on a worldwide level, aiming at self-sufficient coping by communities. The first global response was seen in 1994, when the Economic and Social Council of the United Nations established the *Joint United Nations Programme on HIV/AIDS* (UNAIDS), in order to support a coordinated response from the United Nations. Examples of other global responses include the establishment of the *Commission on HIV/AIDS and Governance in Africa* in 2003 by the United Nations, upon becoming aware of the vast impact of the disease on Africa, as well as the approval of the *Declaration of Commitment on HIV/AIDS* in 2001. Furthermore, the *Strategic plan for intensifying action against AIDS in Africa*, the World Health Organisation's *3 to 5 Initiative*, the *Global Fund for AIDS, TB and Malaria*, and the United States of America's *Presidential Emergency Plan for AIDS Relief* have been developed. In Africa every Ministry of Education is required to implement an *AIDS in the Workplace Strategy*, in order to prevent further infections and create a caring environment for staff members (Department of Economic and Social Affairs of the United Nations, 2005a; Department of Economic and Social Affairs of the United Nations, 2005b; Tindyebwa *et al.*, 2004; Bennell, 2003; World Bank, 1999).

In support of orphaned and vulnerable children, a *Framework for the protection, Care, and Support of Orphans and Vulnerable Children living in a World with HIV and AIDS* was endorsed by USAID, UNICEF and UNAIDS in 2003 – as part of the *Children on the Brink* series. The framework identified five strategies in support of

children infected with and affected by HIV&AIDS, which have been adopted internationally, nationally and locally (USAID, 2005; Richter *et al.*, 2004; Tindyebwa *et al.*, 2004; UNAIDS, UNICEF & USAID, 2002). The first strategy involves ***strengthening and supporting the capacity of families to protect and care for orphaned and vulnerable children***. Supporting this primary safety net (often extended family members) for orphaned and vulnerable children might take on the form of economic strengthening and psychosocial support, improving access to basic services and education, increasing agricultural productivity, improving access to employment and markets, and providing additional ways of generating income. In addition, support might take the form of basic care for those with AIDS, or assistance to parents in drawing up wills, planning for the future of their children and discussing it with them. Secondly, ***community-based responses need to be mobilised and supported***. Communities are regarded as the second safety net for orphaned and vulnerable children and for vulnerable households, as community members might identify vulnerable children and families, assist them first-hand or direct them to local or outside resources. Strengthening community-based responses can take the form of developing community gardens, organising youth groups and recreational activities, or encouraging schools to exempt children from school fees. The third identified strategy centres on the ***strengthening of the capacity of children and young people to address their own needs, by ensuring access to essential services***. Support initiatives aim at keeping vulnerable children in school, preparing them for the future and enabling them to provide for their own needs. Interventions focus on school attendance, access to basic health and nutrition services, safe water and sanitation, protection of vulnerable children, and placement where needed.

In the fourth place, responses in support of orphaned and vulnerable children need to focus on ***ensuring that government develops policies (including legal and programmatic frameworks) and essential services to protect the most vulnerable children***. Governments are required to take action and ensure that children, families and communities are able to cope, by, for example, further developing, implementing and enforcing laws to protect vulnerable children, and by making sure that those who do not have the support of family or community members are provided with essential social services. Strategies include the development of national action plans to guide programming, the development of

Children's Acts and protection services, as well as the delivery of education, health and other essential services, by collaborating with international organisations, NGOs, religious groups, donors and the private sector. The last identified strategy involves ***raising awareness at the various levels of society, in order to establish an environment that enables support for children affected by HIV&AIDS***. An awareness of the impact of the pandemic needs to be encouraged among community leaders, policy makers, organisations and the general public, in order to establish a shared sense of responsibility. Initiatives can focus on aspects such as stigma, discrimination and social mobilisation, involving the media, faith-based groups and other stakeholders (USAID, 2005; Richter *et al.*, 2004; Tindyebwa *et al.*, 2004; UNAIDS, UNICEF & USAID, 2002).

I regard these five strategies as broad by nature and possessing the potential of addressing the challenges associated with HIV&AIDS on various levels. In my opinion, and within the context of my study, the focus on community-based responses is of particular value, as I adhere to the perception that any response to HIV&AIDS lies in the community facing the challenge. Secondly, I support the emphasis placed on enhancing the capacity of individuals facing the challenge, as I am of the opinion that individuals might take agency in coping with the challenges they face. I further propose that strategies focusing on capacity building could be related to the asset-based approach, as they propagate the idea of community members relying on themselves in order to address the challenges they face. Finally, I support the fact that the five strategies include responses on a government level and propagate an awareness at the various levels of society, as I regard the HIV&AIDS challenge as one that is faced by community members on various levels, requiring responses on the different levels, including government level. However, I wonder to what extent the five proposed strategies are at present being addressed within the South African context, and propose that further research on the evaluation of such implementations is needed in our country. I regard the intervention research that I undertook in the selected informal settlement community as addressing the second strategy, resulting in the possibility of my study making a contribution to research in this area.

Based on the suggested strategies, most governments have responded in terms of policy and law reform, national strategies, integrated development plans and models of intervention. On a worldwide level, emphasis is placed on the protection of the rights of children, as well as on quality education. Poverty is combated by striving to achieve adequate standards of living for all, in terms of adequate nutrition, clothing, housing and basic living conditions. Throughout, the goal is to enhance human capabilities and social well-being by, amongst other initiatives, facilitating access to health and social services for citizens. Countries worldwide have developed HIV&AIDS strategic plans, focusing on access to HIV prevention, basic care and support (including psychosocial support and counselling), as well as treatment. Throughout, existing capacities of communities are supported, in an attempt to enhance sustainability (Birdsall & Kelly, 2005; Miamidian *et al.*, 2004; Strebel, 2004; Smart, 2003a; Smart, 2003b; Centre for Policy Studies, 2001; UNICEF, 2001; Marais, 2000; UNICEF, 2000b; Cook, 1998). Although most community- and home-based intervention programmes focus on strengthening community capacity in order to support orphaned and vulnerable children, I believe the support initiatives can be applied to community's coping in general, thereby enhancing community members' coping by strengthening their belief in themselves and their ability to cope.

In South Africa, legal and policy frameworks have been put into place over the past few decades. A few examples of responses on local ground include the *HIV/AIDS and STD strategic plan for South Africa 2000-2005*, the *Comprehensive Plan for Care, Management, Treatment and Support*, and our *National Integrated Plan for Children Infected and Affected by HIV/AIDS*. In addition, *National Guidelines for Social Services to HIV&AIDS Infected and Affected Children* were developed by the Department of Social Development, which might be implemented by any role-player, such as volunteers, NGOs, community-based organisations and family members. HIV&AIDS has been made part of the school curriculum and an integrated *Nutrition Programme for Schools* was put into place, as well as a *Food Security Programme* (Birdsall & Kelly, 2005; Giese, Meintjes, Croke & Chamberlain, 2003; Smart, 2003a; Gow & Desmond, 2002; South Africa Department of Social Development, 2002).

Furthermore, regulations of the *Social Assistance Act* were put into operation in 1998, to make government grants more accessible to people supporting children

infected with and affected by HIV&AIDS. In 2003, a new draft *Social Assistance Bill* was dispersed and in 2002 the *child-related laws* were reviewed by the South African Law Commission. The *Child Support Grant* and *Foster Care Grant* were revised and a *Top-up Grant for Children with Special Needs* proposed. It was also recommended that children receiving social security be *exempted from school fees*. Other examples of local initiatives include the *Children's Bill*, the *National Social Security Agency Bill*, the *National Health Bill* and the *Child Justice Bill* (Smart, 2003a). However, despite such initiatives and policies being put in place, it seems that intervention has not yet reached all South African communities. Examples of communities that occasionally do not benefit from the programmes being put into place include informal settlement communities, such as the one where I conducted my study. For example, concerning government grants, people often seem to be ignorant regarding the procedures that ought to be followed in accessing financial grants<sup>5</sup>. In my opinion, and based on the hardships still experienced in numerous communities, continued research needs to be undertaken in order to investigate to what extent the policies that have been put in place are indeed positively impacting on South African communities, specifically those characterised by poverty and limited service provision.

Although national leadership is important in responding to the challenge of HIV&AIDS, I support the idea that actions also need to be planned and initiated at regional and ground level (complying with basic PRA principles). Numerous groups and organisations are currently involved in South Africa in community level responses to HIV&AIDS, such as faith-based organisations, civil society organisations (NGOs, community-based organisations, non-profit organisations and others, like women's or political organisations) and government institutions or departments. Activities target the spectrum of age groups and focus on prevention, care and support – often in an integrated manner, mutually reinforcing one another and thereby enhancing the impact, sustainability and credibility of the activities. *Prevention* initiatives include educational and awareness activities as well as specialised interventions, such as mother-to-child transmission, abstinence, condom

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<sup>5</sup> Ebersöhn, L., Ferreira, R. & Blankenship, K. *Teachers' perceptions of a disability grant. Presentation at the American Educational Research Association (AERA) Conference 2006, San Francisco, 7 April 2006.*

use and life skills. *Care and support* initiatives focus on emotional care and support, counselling services, the promotion of community care, support groups, programmes on nutrition, home-based care, income generating possibilities and support to vulnerable and orphaned children by providing free education, free health care, protection against abuse and children's homes, crèches and places of safety. In addition, aspects like financial assistance (for example government grants), shelter and placement, as well as legal assistance, are covered. *Treatment* initiatives refer to clinical treatment interventions, as well as treatment-related education (Birdsall & Kelly, 2005; Amoateng, Richter, Makiwane & Rama, 2004; Richter *et al.*, 2004; Kelly, Ntlabati, Oyosi, Van der Riet & Parker, 2002; Mugabe *et al.*, 2002; UNICEF, 2001; International HIV/AIDS Alliance, 2000; UNICEF, 2000a).

Despite the fact that numerous initiatives are undertaken in various areas of South Africa, targeting various communities, I am of the opinion that more extensive research might be undertaken on the outcome of initiatives. As a secondary outcome of my study, knowledge might be generated on the impact that such participatory intervention initiatives have in the community in which my study is located, specifically within the context of coping with HIV&AIDS. I further propose a more holistic approach to intervention initiatives, as many projects seem to be undertaken in isolation and not in support of other initiatives. By following a holistic approach, lessons might be learned from one another and unnecessary reproduction reduced.

I regard organisations involved in projects as potential resources in addressing the challenge of HIV&AIDS, which might become involved in intervention initiatives such as training programmes, provision of services, capacity building initiatives, as well as initiatives focusing on obtaining funding and networking with other organisations and people on community level (Birdsall & Kelly, 2005). However, communities with limited resources (such as rural or informal settlement communities) are often not the focus of such organisations (Mugabe *et al.*, 2002). As such, I propagate community-based responses to the HIV&AIDS pandemic, in response to the social reality and challenges faced by South African communities (especially poverty-stricken communities). Despite the intention to provide external help, the impact of the pandemic is so vast that the external resources are not always able to meet the needs. I therefore support others (Smart, 2003b; UNAIDS, UNICEF & USAID, 2002),



by proposing that the various levels of society need to be strengthened and mobilised to increase their own capacity to cope with the challenge, thereby meeting their own needs.

In terms of treatment, the South African government decided to provide anti-retroviral treatment to people with AIDS in 2003. Despite the decision, the roll-out plan has not yet been developed in detail, resulting in the situation that by mid-2005 an estimated 870 000 South Africans in need of treatment were not receiving it – mostly people in under-resourced communities, such as informal settlements (Marais, 2005). This situation does not solely prevail in our country, as only one in ten people in Africa in need of anti-retroviral therapy was receiving it by mid-2005. However, as a result of the provision of anti-retroviral treatment having tripled since the end of 2001, over one million people in low and middle income countries now benefit by indeed living longer. In addition, between 250 000 and 350 000 deaths were prevented in 2005, due to the treatment scale-up (UNAIDS/WHO, 2005). In my opinion and against the background of statistics like these, the South African government needs to address the challenge of streamlining the roll-out plan on anti-retroviral medication, in order to provide treatment to as many people as possible .

Despite numerous responses to the HIV&AIDS pandemic, the need for rapid responses remains, in particular developmental interventions and preventative responses. The need for research is continuously emphasised, especially with regard to monitoring and evaluating existing intervention initiatives, in order to determine the sustainability of programmes and in order to plan ahead. Continuous research on multidimensional levels is required, as the various disciplines might add to the understanding of the phenomenon and its implied challenges (UNAIDS/WHO, 2005; USAID, 2005; Freeman, 2004; Richter *et al.*, 2004; Strebel, 2004; Akintola & Quinlan, 2003; Kelly, 2001a). I planned and undertook my study against this backdrop of a pandemic impacting on various levels and requiring community-based responses and continued research initiatives, according to which economically disadvantaged communities cope with the challenges they face by relying on the resources available in their immediate environment. Closely related, I regard research on the outcomes of programmes and initiatives to be important, as current initiatives might influence future planning – not only during individual and isolated



projects but on a wider level, for example by impacting on future policies. As such, the study I undertook might add to the body of knowledge on potential intervention initiatives that might be applied in informal settlement communities in South Africa, as well as the outcomes thereof.

### **2.3 UNDERLYING THEORY: COPING**

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In the following section, I explore coping as the underlying theory to my study. After providing the necessary background in terms of an overview of existing coping theories, I investigate coping with HIV&AIDS in terms of the general quest for community-based coping, implying empowerment as a central concept. I discuss possible ways of coping with being infected with HIV or living with AIDS, coping with others living with HIV&AIDS, and coping with orphaned and vulnerable children.

Although coping refers to adjustments in order to address demands, the concept of coping implies more than mere adjustment within the context of my study. To me, coping entails a process that inevitably implies growth, well-being and differentiation, whereby people and the community where I conducted my study could experience certain changes. By coping with the challenges implied by HIV&AIDS, feelings of well-being, self-worth, a sense of accomplishment and hope for the future could be facilitated amongst participants (refer to Matthews & Zeidner, 2003; Ebersöhn & Eloff, 2002; Zeidner & Saklofske, 1996). I support the idea of the contextual nature of stress and coping, thereby acknowledging coping as a dynamic process that differs under different cultural, political, social, historical and economic conditions. As such, I believe that contextual factors determine the manner in which individuals cope and that different ways of coping (for example as found in my study) cannot merely be applied to situations and contexts in the same manner (Donnelly, 2002; Snyder & Pulvers, 2001; Lazarus, 1993).

Matthews and Zeidner (2003) identify two main factors influencing individuals' ways of coping with challenges. Firstly, the attributes of people facing challenges determine their ways of coping, including aspects like available resources, the individuals' sense of efficacy, their commitment, beliefs and values. Secondly,

knowledge relating to possible ways of coping and personal beliefs concerning the efficiency of the options determine the ways in which people deal with challenges. The effectiveness of coping in turn relates to the internal-external requirements of the given situation. Exploring coping with HIV&AIDS within an informal settlement community against the background as described by Matthews and Zeidner (2003) implied that I investigated participants' (community members') ways of coping by considering individuals' personal attributes, resources, beliefs and values, as well as their personal experiences of potential ways of coping with challenges.

Aldwin (1994:107) regards coping as '*the use of strategies for dealing with actual or anticipated problems and their attendant negative emotions*'. I concur with the author's emphasis on the importance of both social and cultural factors influencing the way that people experience stressful situations, as well as the coping strategies they employ in dealing with challenges or difficulties. Four factors might influence the way in which individuals cope, namely their appraisal of stress; the coping resources available; resources provided by the culture; and the reaction of other people. Culture, in turn, might have an influence on the kind of stress experienced by individuals, on individuals' evaluation of challenging situations, as well as on possible coping strategies that might be employed when coping with difficult situations (Aldwin, 1994). I regard all four of these factors to be important within the context of my study and in determining the selected community's way of coping with HIV&AIDS.

### **2.3.1 OVERVIEW OF COPING THEORIES**

Literature provides various theoretical frameworks and philosophical perspectives on coping. For the purpose of this chapter, I do not intend including all such perspectives, but merely focus on the ones that I regard as relevant in providing the necessary background to my conceptualisation of coping, as applied during my study.

Lazarus (1993) distinguishes between two main approaches to coping – the so-called traditional approach and the approach according to which coping is viewed as a process. The traditional approach to coping emphasises personality characteristics by regarding coping as a trait or style, and valuing strategies that reduce tension as

effective coping strategies. The hierarchical style or trait approach places emphasis on inner dynamics rather than on external environmental influences and forces, focusing on characteristic types of coping. This approach assumes that change cannot be related to time – an idea that does not comply with more recent theories of coping and that I do not agree with (Frydenberg, 1999). As such, and for the purpose of my study, I explored coping with HIV&AIDS not as a fixed trait or mode of behaviour, but as a process that is influenced by context and time.

The process approach, on the other hand, regards coping as an *'effort to manage stress that changes over time and is shaped by the adaptational context from which it is generated'* (Lazarus, 1993:234). In support of this approach, Ridder (1997:418) regards coping *'not as an enduring personality trait, but rather as a constellation of certain cognitions and behaviours that occur in reaction to specific stressful situations'*. As such, an individual who has to cope with a challenge relies on available personal and social resources as well as on the context in which the stressors occur. The fact that stressors and difficult situations vary, results in the idea that coping is a continuous and dynamic process that changes, due to external environmental factors, an individual's capacity to cope, as well as the interrelationship between the environment and the individual. Therefore, I regard coping as the (continuously changing) processes (including both cognitive and behavioural efforts) of adapting to and managing internal and external demands (Buchwald, 2003; Donnelly, 2002; Snyder & Pulvers, 2001; Muldoon & Cairns, 1999; Ridder, 1997; Lazarus, 1993). In applying this view to the field work that I conducted, I view coping with HIV&AIDS by the informal settlement community I selected as a process whereby community members are continually required to manage the challenges related to the pandemic – both the challenges experienced internally (such as feelings and perceptions) and those on an external level (like stigmatisation by other community members).

Relatively recent perspectives on coping build on the work of Lazarus, classifying coping theories into contextual, dispositional or integrative frameworks. Contextual approaches emphasise the role of situation-based factors, whereas dispositional approaches relate coping behaviours to person-based characteristics. These two approaches are combined in integrative frameworks such as Folkman and Lazarus'

person-environment interaction model, according to which coping implies the use of both situation-based factors and person-centred characteristics in dealing with challenges (Buchwald, 2003; Frydenberg, 2002; Frydenberg, 1999; Holahan, Moos & Schaefer, 1996). Within the context of my study, I support the view that coping implies an interactive link between environmental influences (situational factors) and personality traits. In addition, I acknowledge the influence of culture on the ways of coping employed by people when faced with challenges.

Coping entails a multidimensional process and a combination of events that continue through individuals' lives, and on which a variety of determinants have an influence. It implies a process of dynamic interaction between people and their environments, referred to as transactional coping. After experiencing demands in the environment, the individual needs to make a decision on how to manage the experienced stress. This process of cognitive appraisal of a situation is followed by certain responses and emotional reactions, in terms of coping behaviour aiming to restore equilibrium. The ultimate outcome of the decision making process is then reappraisal or a coping response, which will in turn impact on the individual's environment (Ebersöhn & Eloff, 2002; Frydenberg, 2002).

Restoring equilibrium does not necessarily imply a sense of total control, it merely aims at minimising the distress caused by a specific situation. Snyder and Pulvers (2001:4) summarise this view as follows: *'coping reflects thinking, feeling, or acting so as to preserve a satisfied psychological state when it is threatened'*. Besides these determinants (emotion, cognition and behaviour), the unique personality and personality traits of the individual coping with a challenging situation also influence the way of coping, as well as the personal and environmental resources that are available. During any coping effort, the meaning that is attached to a specific stressor (HIV&AIDS and the related challenges within the context of my study) will influence the appraisal of the stressor as being severe or not. This meaning is often based on prior experiences, memories and belief systems (such as experienced stigmatisation, discrimination and isolation) (Dirkzwager, Bramsen & Van der Ploeg, 2003; Frydenberg, 2002; Gibson *et al.*, 2002; Frydenberg, 1999).

Lazarus determined two main categories of coping, namely problem-focused coping (environment-directed strategies) and emotion-focused coping (self-directed strategies). In problem-focused coping, the individual facing a challenge actively attempts to change the challenging situation by, for example, seeking external assistance or advice on effective coping strategies. Emotional-focused coping, on the other hand, implies that the individual facing the challenging situation relies on thoughts and behaviours in order to manage the negative emotions that are often experienced during difficult times. As such, the individual attempts to accept the challenging situation as a reality and make the best of it (Whitty, 2003; Snyder & Pulvers, 2001; Williamson & Dooley, 2001). Within the context of coping with HIV&AIDS, I support Lazarus' distinction, as different people respond differently to the challenges implied by HIV&AIDS. For example, problem-focused coping might be employed by a person actively seeking information on HIV&AIDS upon becoming aware of an HIV positive status. On the other hand, emotional-focused coping might be employed when an individual relies on positive thoughts to cope with the positive outcome of an HIV test.

Whitty (2003) suggests that coping strategies be viewed in relation to defence mechanisms, as people facing difficult situations often rely on both defence mechanisms and coping strategies to overcome the challenge they face. I relate this idea to Snyder and Pulvers' (2001) description of the *avoidance-approach* way of coping, whereby an individual experiencing stress or a challenging situation will either *avoid* coping (defence mechanism of denial) or *approach* the situation, thereby relying on coping strategies. Denial might be regarded as adaptive in the short-term, as it allows the individual to come to terms with the impact of the stressor and to gradually start working on a more long-term way of coping. Within the context of my study, denial might enable an individual living with HIV&AIDS to overcome initial fear of stigmatisation and isolation, whilst accepting the fact of being HIV positive.

During *avoidance coping*, an individual will firstly analyse an experienced stressor in terms of seriousness and possible consequences (Lazarus' concept of *primary appraisal*). In the case of the stressor being experienced as having personal relevance and particularly when experienced as threatening, the individual will react with so-called *denial numbness*, denying the situation and avoiding coping. I assume

that, within the context of HIV&AIDS, where the stressor is mostly experienced as life-threatening, denial numbness might often be implemented by people living with HIV&AIDS. In the case of the stressor not being perceived as too threatening, the individual will start appraising possible responses to the stressor as it is perceived (so-called *secondary appraisal*). This will result in the perception that the stressor is overwhelming and that the resources available will not enable the individual to cope effectively, leading to the individual submitting to avoidance strategies. This in turn might result in the individual being even more aware of the stressor, experiencing intensified self-focus or disruptive thoughts and emotions, due to the fact that coping did not take place (Snyder & Pulvers, 2001; Frydenberg, 1999).

On the other hand, *approach coping* also implies an analysis of the stressor, but with the aim of lessening its threatening qualities. This is followed by an appraisal of potential responses, resulting in the individual selecting one or more suitable coping strategies and implementing either emotion-focused or problem-focused coping. Emotion-focused coping strategies (such as avoidance, wishful thinking and accepting responsibility) are often used when a stressor is perceived as uncontrollable, whilst problem-focused coping strategies (like planned problem solving strategies) are usually employed when a stressor is perceived as controllable. Within the context of my study, denial, concealment, isolation and crying are examples of emotion-focused strategies often employed by people that are infected with HIV. Denying one's status can be ascribed to the individual's refusal to accept the HIV status, whilst concealment is associated with the fear of being abandoned, or avoiding a situation whereby additional stressors could be added to uninfected family members (Brandt, 2005; Dirkzwager *et al.*, 2003; Snyder & Pulvers, 2001; Hackl, Somlai, Kelly & Kalichman, 1997).

Social support is a key concept in coping, as people facing challenging situations often rely on the support of others to cope with the challenge at hand. Social support implies three main areas of support, namely concrete, tangible and practical support; instrumental or informational support in the form of advice; and lastly emotional support (Dirkzwager *et al.*, 2003; Greenglas, 2002; Dillon & Brassard, 1999). Concerning social support, research indicates a specific strong link between coping and support by women. As opposed to men, women tend to rely on interpersonal

relationships and talking to people in their support networks, in order to cope with challenges. They access social support more easily and are more sensitive to the needs of others, as specified by traditional gender-role expectations. As women are more communally oriented, they seem to rely on colleagues as source of social support more often than men. Besides these external coping options, individuals rely on internal coping options when facing challenges, such as self-efficacy, a positive self-esteem, adaptive skills and optimistic self-beliefs (Gibson *et al.*, 2002). Within the context of my study and an informal settlement community coping with HIV&AIDS, I wonder about the levels of importance that might be placed on social support as a possible coping strategy.

Johnson and Johnson (2002) base their view of coping on such social interdependence between people. According to the *interdependent-self approach to coping*, individuals are involved in networks of interdependent relationships with family members, friends, other community members, people at church and in other walks of life. When faced with stress, people therefore rely on their social networks for support and the provision of resources. In this manner, coping is regarded as a joint process of problem-solving and social support, where individuals experience challenges within established networks that might assist them in coping, by implication employing communal coping. As opposed to interdependent coping, the independent-self approach to coping emphasises the individual as an isolated and independent unit who deals with stress independently, by relying on personal resources only. Community-based coping inevitably implies an interdependent-self approach to coping. Furthermore, I propose that an interdependent-self approach to coping might relate to the asset-based approach, which is discussed in section 2.4 (Johnson & Johnson, 2002; Muldoon & Cairns, 1999).

Lately, research has been focusing on *proactive coping*, whereby the quality of life is improved in preparation of challenges and difficult situations. As such, general resources are built up in order to promote personal growth and the achievement of goals. In addition, *preventive coping* (building resources in order to reduce the consequences of stress) and *anticipatory coping* (anticipating a challenge and dealing with it) are often the focus of research in the field of coping (Ebersöhn, 2006; Greenglas, 2002). In addition, religious coping is often mentioned, referring to the



tendency to rely on religion as the primary source of coping with difficult situations or challenges, such as life crises. The basis for religious coping lies in the fact that religion provides specific methods for people to cope with life stressors and obtain meaning and significance in difficult situations. Methods of religious coping include, amongst other strategies, *deferring religious coping* (submissively waiting for God to control the difficult situation), *pleading religious coping* (seeking help from God), *seeking spiritual support* (relying on God's love and care to obtain comfort and reassurance), and *seeking congregational support* (relying on the love and care of congregation members) (Pargament, Poloma & Tarakeshwar, 2001). Within the context of my study, I ponder upon the thought whether or not religiosity and faith might be employed as coping strategies by informal settlement community members in coping with HIV&AIDS. As I assume the selected community to be coping with the resources available to them, I propose that they might rely on religion and faith in addressing the challenges they face, such as HIV&AIDS.

### **2.3.2 COPING WITH HIV&AIDS**

I commence this section by discussing coping as being community-based by nature and implying empowerment as central concept. Next, I discuss coping in terms of coping with being infected with HIV or living with AIDS, coping by means of providing care and support to others living with HIV&AIDS, and coping with children orphaned due to HIV&AIDS. These discussions provide the necessary background against which I approached the empirical part of my study, focusing on an informal settlement community coping with HIV&AIDS.

#### **2.3.2.1 General quest for community-based coping**

It is widely documented (refer to Lucas, 2004; Mallmann, 2002; Van Dyk, 2001; Child Protection Society of Zimbabwe, 1999; Geballe *et al.*, 1995 as examples) that communities are supposed to have control over their own well-being and that any response to HIV&AIDS might be guided by the experiences of community members on ground level, as they are the people who feel the impact of the pandemic and who must find ways of facing the challenge. I adhere to Mallmann's (2002:20) emphasis on the importance of fellow community members in coping with challenges such as

the HIV&AIDS pandemic, as the *'impact of disasters is shared rather than experienced alone'*. I further support Kretzmann, McKnight, Sheehan, Green and Puntenney (1997:1), emphasising the importance of coping being embedded in the community, by stating that *'communities are made stronger when residents use their full potential by directing their capacities toward the well-being of the neighborhood'*. Community-based coping supports the *Ubuntu* principle, a philosophy characteristic of South African indigenous communities.

Loots (2005) defines community-based coping as the ability of a community to effectively deal with challenges within the community, within the specific, dynamic and multi-functional social system. In coping with challenges, community members strive towards a mutual goal, share responsibility and respect the well-being of the group. To my mind, the well-being and health of communities imply their ability to cope with challenges like HIV&AIDS, as coping often results in well-being and health. Community-level responses are steered by community members themselves, becoming aware of their own capabilities and responding to the concerns and needs of community members by relying on the resources, skills, knowledge and talents available in the community. As community involvement is encouraged for the different phases of HIV&AIDS intervention initiatives, people on community level could be involved in planning, implementing and assessing HIV&AIDS programmes. Community responses range from informal care for orphaned children by relatives and neighbours, to planned intervention by outside organisations, facilitating change in communities by involving community members (often volunteers) (Cabassi, 2004; Lucas, 2004; Browde, 2003; Cloete, 2003; Goudge, Gilson & Msimango, 2003; Smart, 2003a; Department of Social Development, 2002; Kelly *et al.*, 2002; Foster, 2001; Sayson & Meya, 2001; Smith, Littlejohns & Thompson, 2001; Van Dyk, 2001; Child Protection Society of Zimbabwe, 1999; Geballe *et al.*, 1995). I propose that this focus on well-being and community health, as well as the basic approach of relying on existing resources in order to address challenges, links with the asset-based approach, which I discuss in detail in section 2.4.

Outside intervention implies participatory research and intervention – as I implemented in my study. As I facilitated certain actions in the community (per definition doing intervention) while conducting research, I conducted community-

based activist intervention research. During the process I focused on a community instead of individuals, and worked in partnership with the community members without interfering in their performance of the usual daily activities. My actions ultimately aimed at participants being empowered and social change being facilitated within the community, in order to promote its well-being and health (Blumenthal & Yancey, 2004; Minkler & Hancock, 2003; Minkler & Wallerstein, 2003b). As such, I employed the self-help model of community development (Bender, 2004), based on my belief that community development concerns helping community members to help themselves. I merely acted as facilitator, guiding the participants to set goals and plan action steps.

In line with the basic principles of the asset-based approach (as discussed in section 2.4), pioneers in community capacity building (or *asset-based community development*) propose that outsiders (such as the government, NGOs or other volunteers) merely act as facilitators in guiding community members to firstly identify the community's challenges, needs and strengths, and secondly, to formulate and implement plans and ways of utilising the existing strengths to address the identified challenges and improve the community (Snow, 2001b; Kretzmann & McKnight, 1993). During this process, outsiders need to guard against imposing their cultural values or ideas on community members, as they might not fit into the local system. During my involvement in the selected community I adhered to the following suggestions by Mokwena (1997:67), which do not only support effective community development initiatives, but are also in compliance with the basic principles of PRA:

*Communities need professional guidance and support in initiating the process of empowerment but the professionals must appreciate the need for the community to stand on its own as soon as possible. The community must be allowed enough space to be able to make their own decisions regarding issues that affect them and to employ strategies that are in accordance with their own norms with the professional being available to help when requested or needed.*

By building community members' capacity to work together in addressing communities' challenges, community development inevitably occurs, resulting in so-called *community competence*. Community mobilisation, on the other hand, refers to the guidance of community members to accept responsibility and take action with regard to existing challenges, thereby taking ownership and regarding it as their own

priority to address (Smith *et al.*, 2001; Snow, 2001b; Kretzmann & McKnight, 1993). External agencies might facilitate this process of mobilisation, thereby assisting community members in helping themselves by, for example, increasing their decision-making powers, encouraging their ability to support other vulnerable community members, and providing training and support where needed (Richter *et al.*, 2004; Smart, 2003a; Department of Social Development, 2002; Sewpaul, 2001; Khmer HIV/AIDS NGO Alliance, 2000; Kretzmann *et al.*, 1997). As existing literature does not provide distinct guidelines in terms of the level of involvement required from external agencies, my study might contribute to this body of knowledge. As I fulfilled the role of outside facilitator during my study, I was able to explore this area of interest.

In describing community mobilisation as part of a community-based HIV&AIDS prevention and care programme implemented in Malawi, Hunter (2002) emphasises the link between the *sustainability* of social change on the one hand, and community members owning the process and the communication involved on the other, thereby *building capacity* and making communities the *agents of their own change*. Communication could strengthen relationships in the community, empower community members and build their confidence. In my opinion, self-worth and feelings of pride can in turn be relied on as assets, assisting community members in coping with HIV&AIDS. Emphasis might, however, rather be placed on debate and negotiation, instead of the transferral of information. As such, I emphasise the importance of moving away from a so-called *welfarist* approach to a long-term *development approach* (Strebel, 2004; Mugabe *et al.*, 2002; Subbarao *et al.*, 2001; Broughton, 1999; Child Protection Society of Zimbabwe, 1999). In my field work, I supported the development approach to community-based coping with HIV&AIDS, as I regard the answers to questions and the responses to challenges as being situated within the communities involved, thereby propagating the asset-based approach.

Community development initiatives imply intervention and involve role-players on various levels and from different sectors. According to this people-centred approach the focus, amongst other objectives, falls on developing the potential of individuals, families and communities. Facilitating community-based change implies certain principles, for example trusting people with their own development and believing that

the local community is the most sustainable basis for development, as people possess knowledge and wisdom that might impact on their development. Empowerment within the context of HIV&AIDS might result in community members acting responsibly and being self-reliant, in an attempt to decrease community members' vulnerability to HIV&AIDS and promote the community's health. Apart from being child-centred, family- and community focused, any intervention initiative are required to respect the basic rights of those involved (Bender, 2004; Cabassi, 2004; Green & Haines, 2002; Smith *et al.*, 2001; Karnpisit, 2000; Broughton, 1999; Buysse, Wesley & Skinner, 1999). Based on striking similarities with PRA, I summarise the human capacity development approach in terms of the following four key elements, as identified by Lucas (2004): local response, organisational change, policy and the transfer of knowledge acquired through local action and experience. I trust that the latter component will be a potential outcome of my study, where other communities can learn from the experiences of the selected community and participants in my study.

In planning and conducting my study I considered the eight core principles of effective community building initiatives, as identified by the National Community Building Network and formulated by Snow (2001a). The first principle requires that *community development and human service strategies be integrated*. Although my study mainly focused on the enhancement of human capital in terms of the community members' ability to cope with HIV&AIDS, it included the development of a vegetable garden at the school through which I entered the community, thereby integrating community development and human service strategies. In an attempt to *maintain racial equity* I approached my study with an *equity-for-all-groups* attitude, respecting role-players and their contributions as of equal importance. I *valued cultural strengths*, by respecting the cultural assets and strengths of the participants as well as other community members throughout my study. Although my study mainly involved selected educator-participants, *broad community participation was encouraged*, by extending participation to other community members as part of the projects initiated by the educators. I strived to *build partnerships by means of collaboration*, by encouraging educator-participants to form networks and build partnerships with stakeholders in the community, which they did when planning and implementing the three projects. I *started from local conditions* by starting from and

continuously working with the challenges and potential strengths of the community. Furthermore, I aimed at *supporting families and children* during my study. In regard to this principle, a direct outcome of my study was that families and children were indeed supported in the community, guided and facilitated to be able to help themselves, thereby resulting in a stronger community, in a position to address the challenges it faces. Lastly, I *built on community strengths* by employing the asset-based approach, thereby emphasising the value of assets, as well as the importance of relying on local resources and capacities in overcoming challenges.

Community level responses to HIV&AIDS are often mediated by *social capital*, which refers to the characteristics of community members that enhance cohesion and a sense of belonging, thereby encouraging community members to participate in activities that might promote the community. Within the context of my study, it entails networks that community members might rely on in order to work together towards a shared goal (such as initiating school-based projects), thereby strengthening the community. In this manner, social capital facilitates people and institutions to work together for the purpose of mutual social benefit (coping with HIV&AIDS as a community). Therefore, communities with a high level of social capital might be able to more easily cope with social challenges (Lucas, 2004; Kelly *et al.*, 2002; Ngcobo, 2001).

As families are the building blocks of communities, community-based coping implies family-based coping. The opposite also applies, as family-based coping implies community-based coping. I regard family as the *heart of the social context*. It is ironic that, on the one hand, the family is one of the most important social resources in coping with HIV&AIDS, due to the care and support provided within this context, but on the other hand, the impact of HIV&AIDS on the family is so immense. It is within the family that loss is experienced, fears faced, decisions made and alternatives evaluated. However, many functions of the family might be performed by institutions in society, such as schools, churches and social service departments, once again emphasising the importance of community-based responses to a challenge such as the HIV&AIDS pandemic (Amoateng *et al.*, 2004; Barolsky, 2003). As I respect the potential value of the relevant role-players in coping with HIV&AIDS, I explored these as both assets and potential assets during my study.



### 2.3.2.2 Empowerment as central concept of community-based coping

I support Leach's (2003b:21) definition of empowerment as '*the process or processes whereby people become aware of their own interests and the power dynamics that constrain them, and are then able to develop the capacity and the means to take greater control of their lives*'. To me, empowerment implies specific outcomes, centred on the well-being of those who are involved, in terms of an improvement of their life situations. It implies participation and agency, with the aim of actualising strengths and mobilising community resources. This might result in an increase in personal, interpersonal and economic power (Saidi, Rosenzweig & Karuri, 2003; Bartle, Couchonnal, Canda & Staker, 2002; Karnpisit, 2000; Mokwena, 1997; Sewpaul, 1993).

I adhere to the idea of empowerment implying that people who seemingly do not have access to resources, can take the primary responsibility to develop strategies whereby they can increase their power, gain control and accept agency over their own lives, by making changes where necessary. This dynamic process of capacity building usually results in individual development and growth, which in turn could add to social change on a broader level. Within the context of HIV&AIDS, empowering people implies that individuals or groups of people (such as informal settlement communities) are involved in projects, and are encouraged to address their own health concerns by finding their own solutions and accepting agency with regard to the HIV&AIDS-related challenges they face. By being empowered, the self-esteem and self-confidence of individuals is enhanced, as well as feelings of efficacy and self-reliance, building on relationships and working collectively, as opposed to relying on external resources when facing challenges. Although *outside role-players might facilitate* empowerment by providing suitable resources, ideas and experiences, I believe that the process of *assuming power and accepting agency lies within the person participating in the process of empowerment*. By being involved, community members' commitment is encouraged, as well as their co-operation, local ownership and the possibility of development being sustainable (Kabiru, Njenga & Swadener, 2003; Saidi *et al.*, 2003; Bartle *et al.*, 2002; Sims, 2002; Foster, 2001; Van Dyk, 2001; DeGraft Agyarko, 1998; Mokwena, 1997; Archer & Cottingham, 1996; Nelson & Wright, 1995; Slocum & Thomas-Slayter, 1995; Sewpaul, 1993). Within the



context of my study, I propose that community members that are implementing the asset-based approach could accept agency and be empowered during the process of intervention research, thereby being able to cope with the challenge of HIV&AIDS.

According to the *Cornell Empowerment Group* (Sims, 2002), empowerment rests on ten assumptions, to which I adhere and in accordance with which I entered the research field. I assume that people possess strengths. I value differences between individuals and their backgrounds, and view the needs of individuals within their wider contexts. I recognise the ability of individuals to make choices, and do not regard the deficit approach as suitable for empowerment efforts. I value an understanding of culture and culture-related roles and expectations as essential, as well as an understanding of patriarchy and how it influences roles and expectations. I assume power to be the centre of accessing resources and as something that needs to be understood, functioning both directly or indirectly. Finally, I assume that empowerment is directed at the reallocation of power and resources.

Mokwena (1997) provides specific strategies to empower communities, which I adhered to during my study. Firstly, I facilitated community members (participants) to realise, appreciate and utilise their assets and talents, in order for them to become aware of the fact that they are capable of helping themselves. I challenged their feelings of powerlessness, and encouraged them to take control over their lives, in order to enhance their participation in decision-making and community-based action plans. In order to support them, I supplied information that they did not have easy access to and established social support networks. I encouraged participants to participate in community issues, thereby developing ownership and evoking feelings that they are obligated to ensure success of initiatives. Lastly, I guided them to develop local leadership skills, as this can enhance sustainability of development initiatives.

### **2.3.2.3 Coping with being HIV infected or living with AIDS**

I believe that people living with HIV&AIDS have to cope with their illness in order to be able to live positively and plan for the future. Coping with HIV&AIDS implies various challenges. It often implies coping with the loss of loved ones, as well as the

physical and psychosocial symptoms implied by the disease, including the possibility of stigmatisation and discrimination. Furthermore, families living with HIV&AIDS have to cope with additional financial burdens placed upon them when individuals can no longer earn an income, and have higher expenses due to treatment and basic health care. Families often do not even have money for transport to health care facilities, resulting in them relying on home-based care. In addition, people have to disclose their status in order to access such services – something that is not always done (Swanepoel, 2005; Richter *et al.*, 2004; Nnko *et al.*, 2000).

In reaction to confirmation of their HIV positive status, and that they are faced with a life threatening, chronic illness, people often employ one of two main coping strategies, namely vigilance and avoidance. People will apply *vigilance* as coping mechanism in an attempt to reduce their levels of uncertainty and stress by, for example, actively seeking knowledge in order to use such newly acquired knowledge to cope with their illness. These individuals therefore usually disclose their status, in order to access the help and support that are available. On the other hand, people infected with HIV might rely on *avoidance* in an attempt to cope with their illness. These individuals will avoid disclosing their status, in an attempt to protect themselves (McDonald, 1998). Besides denial, isolation and crying, other coping strategies that might be employed include religion, strategies that focus on family unity and, in rare cases, a positive future perspective (Rehm & Franck, 2000). With relation to these potential ways of coping with HIV&AIDS, I hypothesise that members of the community where I conducted my study might employ a combination of these strategies, depending on the individual as well as the context.

#### **2.3.2.4 Coping as being related to providing care and support to others living with HIV&AIDS**

People with AIDS usually rely on the support of social systems such as extended family members, traditional support systems or other community members in order to cope with the challenge they face. In this manner, they rely on so-called coping resources, in other words, reasonably stable characteristics in themselves and their environments. Besides family members, support groups or self-help groups may play a significant role in the life of a person living with HIV&AIDS, by providing emotional

and social support, as well as the opportunity to learn from one another. Other potential resources include the mass media, which may convey HIV&AIDS-related information, but might not reach the spectrum of communities easily; the possibility of community home-based care; facilities such as clinics, hospitals and hospices; as well as support systems like women's and religious groups (McCausland & Pakenham, 2003; Parker *et al.*, 2000; Van Dyk, 2001; Zimba, 2000).

A strong sense of community can be identified as prerequisite for not isolating those living with HIV&AIDS, as collaboration and a sense of cohesion might result in a community sharing resources in order to support community members living with the disease (McCausland & Pakenham, 2003; Mallmann, 2002; Mkwelo, 1997). Within the context of my study, knowledge of the potential social systems guided me in exploring the ways in which participants cope with HIV&AIDS, by implication coping with being infected, coping by providing care and support to others living with HIV&AIDS, or coping with children that are orphaned due to HIV&AIDS.

#### **2.3.2.5 Coping with orphaned and vulnerable children**

Although caregivers of orphaned and vulnerable children differ across regions, these children are mostly cared for by the surviving parent or alternatively by a relative (Miamidian *et al.*, 2004; Gilborn *et al.*, 2001). Various authors (such as Brouard *et al.*, 2005; the International Social Service & UNICEF, 2004; Nyambedha, Wandibba & Aagaard-Hansen, 2003; Van Dyk, 2001; Cook, 1998) are, however, of the opinion that extended family systems are overburdened, especially in communities with limited resources, and suggest that programmes be developed to support families' ability to cope with these children. Yet, despite ongoing debates, the extended family still seems to form the primary basis of coping with orphaned and vulnerable children, with women (for example aunts and grandmothers) seemingly being the primary role-players (Amoateng *et al.*, 2004; Monasch & Boerma, 2004; Winkler, Modise & Dawber, 2004; Barolsky, 2003; Lachman, Poblete, Ebigo, Nyandiyi-Bundy, Bundy, Killian & Doek, 2002; Sayson & Meya, 2001; Boxer, Burke, Cohen, Cook, Weber, Shekarloo & Lubin, 1998). Against the background of these seemingly contradicting opinions, my study might contribute by providing insight into the selected community's way of coping with children that are orphaned due to

HIV&AIDS, situated within the broader context of coping with HIV&AIDS. In addition, based on the fact that I selected an indigenous community in which to conduct my field work, the possibility of culture and women forming components of coping exists. By exploring this as part of my study, contributions might be made in terms of the significance of culture and (African) women in coping with vulnerable and orphaned children.

Grandparents and relatives caring for orphaned and vulnerable children are, however, often old and/or impoverished. Besides the financial challenges placed on family members taking care of orphaned children, these children typically display the need for medical care, love and support within a family context, as well as the need for education. In such cases, extended families might turn to other community members for support. In the rare case of relatives or community members not being available or able to take orphaned children into their care, children might end up living in child-headed households, placed in institutions (the last resort) or end up as homeless children on the street (Monson, 2005b; International Social Service & UNICEF, 2004; Linsk & Mason, 2004; Richter *et al.*, 2004; Nyambedha *et al.*, 2003; Ramsden, 2002; Berns, 2001; Gilborn *et al.*, 2001; Ratsaka-Mothokoa, 2001; Sayson & Meya, 2001; Subbarao *et al.*, 2001; Townsend, 2001; Zimba, 2000; Geballe *et al.*, 1995).

In addition to relatives and other community members, I regard the South African government as fulfilling a role with regard to orphaned children and families taking care of them by, for example, offering financial assistance in the form of a variety of government grants, food support for impoverished families, free health care for children under six, exemption from school fees and free vocational training for young people (Richter *et al.*, 2004; Meintjes, Budlender, Giese & Johnson, 2003; Ramsden, 2002; Centre for Policy Studies, 2001; Ngcobo, 2001; UNICEF, 2001). Finally, schools seem to play a role in supporting communities coping with children infected with and affected by HIV&AIDS, by collaborating with role-players on other levels and providing assistance to the families of children infected with and affected by HIV&AIDS. Despite the fact that South African legislation requires of schools to have an HIV&AIDS policy in place, and provide for free education for children who cannot afford to pay, this is not always adhered to, as schools need the money to manage

day-to-day expenses. School-based support further includes the early identification of children infected with and affected by HIV&AIDS, addressing their special educational needs, referral and monitoring of vulnerable children, teaching learners life skills, providing school-based nutrition programmes, providing pastoral care and counselling, financially assisting children who need it, involving caregivers and guardians, and supporting children living with HIV&AIDS (Marais, 2005; Amoateng *et al.*, 2004; Brookes *et al.*, 2004; Bennell, 2003; Giese *et al.*, 2003; Smart, 2003a; World Bank, 2002; UNICEF, 2001; UNICEF, 2000b).

## 2.4 UNDERLYING APPROACH: THE ASSET-BASED APPROACH

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I now turn my discussion to the asset-based approach, being the underlying approach on the basis of which I planned and undertook my empirical study. Page-Adams and Sherraden (1997:431) summarise the emerging nature of the approach: *'Although asset-based community development is in the early stages of formation and little guidance exists about how to proceed in terms of models and implementation, the concept invites innovation, creativity and adaptation to many populations and purposes.'* Du Preez (2005), as well as Lubbe and Eloff (2004), add to this by emphasising the emerging nature of research and practice relating to the asset-based approach, leaving the field open for my study in terms of contributing to the existing base of knowledge. In addition to a range of studies by Ebersöhn and Eloff (2006; 2002; 2001), various small-scale studies are (and have been in recent years) ongoing, to build on the emerging theory of the asset-based approach, for example the studies by Coetzee (2005), Ferreira-Prévost (2005), Griessel-Roux (2005), Smuts (2005), Viljoen (2005), De Wet (2004), Briedenhann (2003) and Kriek (2002).

The asset-based approach was initially introduced in the early 1990s by Kretzmann and McKnight (1993), within the context of community development and empowerment. I support these authors by propagating that the asset-based approach might be regarded as a change in perspective rather than a comprehensive and complete approach, as it shifts the focus from external help and services being provided to a community, to empowerment and developing a

community from the inside out. In support of this line of thinking, I subscribe to Eloff and Ebersöhn's (2001) view that the asset-based approach is more than just an intervention approach, but concerns attitudes towards people, as well as strategies of intervention. As such, I regard the asset-based approach as not only implying a theory, but also relating to dynamic strategies for intervention (Ebersöhn & Mbetse, 2003). Within the context of my study, I decided on exploring the manner in which an informal settlement community is coping with HIV&AIDS by relying on existing assets and local resources, based on the reality that communities currently have to cope with the challenges implied by HIV&AIDS, and secondly on the possibility of relying on the asset-based approach in doing so.

Although the asset-based approach was initially introduced within the context of community development, it has since been applied with success in other contexts, thereby highlighting the suitability thereof for individuals or groups of people, such as families, schools and (informal settlement) communities facing (HIV&AIDS-related) challenges on various levels (Lubbe, 2004; Lubbe & Eloff, 2004). In accordance with the underlying framework of the asset-based approach, I view individuals (and their assets) on the following four levels: the individual, the local community (families, schools and peer groups), the wider community and the whole social system. Furthermore, I continually keep in mind that the various levels are constantly developing and interacting with one another (Eloff, 2006b).

Eloff (2006b) identifies various potential role-players within the context of the asset-based approach, which also applies to my study. Besides the potential assets and strengths of individuals themselves, family members, the school, classroom and members of the peer group are regarded as potential assets. In addition, community members' associations, local institutions and the broader social community can be explored. Prior to my study, these potential role-players appeared to be relevant within the context of my study, namely a community coping with the challenges related to HIV&AIDS. The various levels of contributions by the individual agents were to be explored during my field work.

I henceforth deal with the asset-based approach in terms of it being an alternative to the needs-based approach, the core of the approach and the main components or



phases of the approach. Thereafter, I elaborate on possible advantages and, lastly, the role of the facilitator.

#### 2.4.1 AN ALTERNATIVE TO THE NEEDS-BASED APPROACH

The asset-based (also referred to as *capacity-based*) approach was introduced as an alternative to the needs-based approach (so-called deficit model), which is (and has been) often applied during intervention with individuals or groups of people. I support Du Preez's (2005) suggestion that these two approaches ought not to be regarded as opposites but rather as two approaches on the same continuum, yet at different levels, of the spectrum. Whilst the needs-based approach focuses on problems, needs and deficits, I view the asset-based approach as an approach shifting the focus to that of actively discovering resources and capacities, establishing links and initiating programmes, in order to address existing challenges, such as HIV&AIDS (Eloff, 2006a; Saidi *et al.*, 2003; Sims, 2002; Fuller & Brockie, s.a.).

I prefer the use of the concept *challenges* as opposed to *problems*, as I support Minkler and Wallerstein's (2003a) view of a *problem* as a concept implying that something is *wrong* (for example with a community) and needs to be fixed. I do, however, not support the use of the term *issue*, as proposed by these authors, as, according to my view, the term *challenge* implies something that is experienced by an individual or within a community (such as vulnerability within the context of *HIV&AIDS*) that needs to be *coped* with – another concept central to my study. Concerning the concept *needs*, Fuller and Brockie (s.a.) are of the opinion that *needs* refer to resources that have not been utilised yet, therefore *threatened assets*. As such, any perceived threats might be addressed by relying on available resources – in my opinion by implementing the asset-based approach.

By focusing on challenges (problems) that need to be solved (often with the assistance of outside expert help), I regard the needs-based approach as sustaining disempowerment, dependence and the tendency to rely on outsiders during decision-making processes. In this manner, outsiders are regarded as experts who provide information and *rescue* the people facing a challenge, often being labelled as powerless and in need of guidance (Ebersöhn & Eloff, 2006; Saidi *et al.*, 2003; Sims,



2002). As a result, individuals (in my case community members) are prevented from working collaboratively in addressing a challenge by relying on the skills and capacities amongst themselves. In this regard I support Fuller and Brockie (s.a.:3), summarising this idea as follows: *'Needs divide us – assets combine us'* and further stating that *'Asset-building connects people to a common cause. It brings us together, focuses our attention, and points us in the same direction'*.

Within the context of my study, the asset-based approach (as alternative to the needs-based approach) seems appropriate for viewing existing and facilitating broadened coping repertoires in an informal settlement community. Based on the current social context and reality of South African communities being characterised by poverty and a lack of external resources, I propose that communities will increasingly rely on their own available resources, in order to address the challenges associated with the pandemic. As stated earlier, despite numerous HIV&AIDS outreach projects and campaigns launched countrywide on a regular basis, poverty-stricken communities are often exposed to such initiatives on an *ad hoc* and once-off basis. I doubt if such once-off initiatives will indeed positively impact on the targeted community. As external support and assistance are therefore not likely to provide in their existing needs, I suggest that the HIV&AIDS challenge requires an approach working from the inside out, such as the asset-based approach.

#### **2.4.2 ESSENCE OF THE ASSET-BASED APPROACH**

The asset-based approach is based on three principles, namely <sup>1</sup>assets (the skills, knowledge, talents, resources and other assets existing in the community), <sup>2</sup>an internal focus (regarding the community to be capable) and being <sup>3</sup>relationship driven (emphasising the constant building and rebuilding of relationships within the community). The approach does not deny the existence of needs, deficiencies or problems – it merely shifts the focus from constantly emphasising such challenges (which are a reality in communities) to the capacities, strengths, **assets** and resources that are available in the community and might be utilised to overcome difficulties or address challenges. *Assets* imply the gifts, talents, skills, resources and capacities of individuals, families, associations and institutions that might be utilised to address existing challenges. Closely related, *strengths* entail behavioural

and emotional abilities, competencies and attributes that lead to feelings of personal achievement and attribute to successful relationships (Eloff, 2006a; Bouwer, 2005; Lubbe & Eloff, 2004; Eloff & Ebersöhn, 2001; Rhee, Furlong, Turner & Harari, 2001; Snow, 2001b; Rudolph & Epstein, 2000; Child Protection Society of Zimbabwe, 1999; Kretzmann & McKnight, 1993). Within the context of community development a community asset can be defined as '*anything that can be used to improve the quality of community life*', including community members and their connections, knowledge and experience within the community, physical resources and local businesses (Saidi *et al.*, 2003). By choosing to explore the use of the asset-based approach in coping with HIV&AIDS, I am emphasising assets, and following an internal focus and relationship-driven approach.

As the asset-based approach is ***internally focused***, I continually emphasise the selected community's interests, challenges, priorities, creativity, strengths, hopes and power, as identified and defined by community members (participants) themselves. As such, I adhere to the idea that the challenge of HIV&AIDS be addressed within context (an informal settlement community), by re-assessing and evaluating resources and potential resources in the immediate environment in terms of the possible (and sometimes new) ways that they might be utilised in overcoming difficulties. In addition, and in accordance with the asset-based approach, I recognise the potential value of external agencies and resources, but also believe that external resources might be utilised more effectively when internal resources have been mobilised and the aim of obtaining additional (external) resources has been determined by the community (Eloff, 2006a; Bouwer, 2005; Lubbe & Eloff, 2004; Minkler & Hancock, 2003; Kriek, 2002; Sims, 2002; Eloff, 2001; Eloff & Ebersöhn, 2001; Smith *et al.*, 2001; Snow, 2001b; Emmett, 2000; Ammerman & Parks, 1998; Mokwena, 1997; Trivette, Dunst & Deal, 1997; Kretzmann & McKnight, 1993).

I regard ***relationships*** as central to asset-based community development. As such, and for the purpose of my study, I do not merely focus on the assets in the selected informal settlement community, but also on establishing and maintaining relationships between the assets, namely individuals, local associations and institutions. As individuals form part of various circles (such as families, friends,

colleagues, peers and fellow community members), community development can be facilitated when the relationships between the various role-players are enhanced. To me, this idea of community development based on relationships emphasises the applicability of the asset-based approach to traditionally rural communities (and which can be applied to informal settlement communities), which are usually characterised by close relationships between community members, and support for one another, as well as the tendency to rely on what is available when facing challenges (Ebersöhn & Eloff, 2006; Eloff & Ebersöhn, 2001; Snow, 2001b; Kretzmann & McKnight, 1993).

### **2.4.3 MAIN COMPONENTS OF THE ASSET-BASED APPROACH**

I support Saidi *et al.*'s (2003) identification of three main components of the asset-based approach, namely asset mapping, asset mobilisation and asset management. As I believe that successful implementation of the asset-based approach is based on the people involved, focusing on assets that can be utilised to address challenges, my view is that they firstly need to acquire knowledge of the accessible resources and assets available within the environment (community). As such, I regard the assessment of (community) assets and resources, with the aim of obtaining an overview of the available assets, as the first component of the asset-based approach (Minkler & Hancock, 2003; Kretzmann & McKnight, 1993).

#### **2.4.3.1 Asset mapping**

Community development (with the potential of effectively coping with a challenge like HIV&AIDS) is only possible once local members of the community become involved and committed to actively look for ways and resources that can be used to cope with the challenge at hand. To me, this implies insight by community members into the capacities, assets and abilities of the community, referring to both an individual and institutional level. Local community members therefore have the responsibility of identifying potential resources and connecting them with one another, thereby increasing their power and levels of effectiveness (Kretzmann & McKnight, 1993). Within the context of my study, such insight into available capacities and assets

seems to be the first step that needs to be actualised when implementing the asset-based approach.

My decision to facilitate participants in completing *community capacity inventories* or *community asset maps* rests on the purpose of listing the so-called *building blocks* of a community. In the first place, participants in my study had to compile individual capacity inventories, in order to obtain an overview of the knowledge, skills, abilities, talents, capacities, signature strengths, interests and experiences of community members (**individuals**), thereby relying on people and their relationships or associations as assets that might be mobilised. Secondly, I facilitated participants to compile an inventory of the repertoire of resources in the selected community, in terms of local organisations and **associations** (per definition *a group of local people working together towards a common goal*). In this manner, both formal and informal resources that might assist in addressing the challenges of coping with HIV&AIDS could be identified, for example community-based support groups, local churches and church groups, businesses, sport and political organisations, and youth and women's groups. Finally, an inventory of private, public and non-profit local **institutions** (mostly formal in nature) that might provide materials, financial assistance or other services was to be compiled, including such institutions as libraries, schools, hospitals, banks, human service agencies, parks and community centres. Although it does not usually form part of the mapping activities, I also included *risk mapping*, facilitating community members to identify the challenges faced by the community and then having discussions on how to address them, by formulating action plans (Eloff, 2006a; Bouwer, 2005; Minkler & Hancock, 2003; Snow, 2001a; Snow, 2001b; Kretzmann, 2000; Ammerman & Parks, 1998; Kretzmann *et al.*, 1997; Kretzmann & McKnight, 1993).

Concerning *personal strengths* as potential resource for coping with challenges (such as HIV&AIDS), I support Bouwer's (2005) description of three types of personal characteristics implied by the concept. Firstly, I acknowledge personal strengths as implying a positive disposition, which includes attributes like interest, being motivated, taking initiative, engaging, maintaining attention and being open and willing to identify various options and to make choices. Secondly, I view personal strengths as implying ecological resources, which refer to individuals' levels of

development, implicating their existing knowledge bases, experiences and acquired skills. In the third instance, I regard demand characteristics as part of personal strengths, as the manner in which people express themselves and respond to others, impact on the feedback they receive, as well as on the way of interpreting and perceiving experiences.

My decision to employ asset mapping was partially based on the advantages of identifying community assets, as formulated by Saidi *et al.* (2003). Firstly, in identifying assets I could obtain a holistic overview of the available resources and assets in the community. Within the context of my study, such an overview as well as an understanding of the informal settlement community enabled me to plan how to facilitate change, by setting priorities and initiating programmes. In addition, I was able to identify and eventually facilitate the utilisation of potential assets that might have been overlooked or not mobilised to their full potential. In the process, I experienced the possibility of facilitating community members to take ownership and invest in promoting the well-being of the community, which might have resulted in more effective and sustainable development. Furthermore, based on my insight into the community's assets, potential partnerships and interaction between community members, associations and institutions could be identified, as well as potential outside resources that might be contacted to complement existing resources.

Bouwer (2005) describes the asset-based approach within the framework of supporting learners that are facing barriers to learning. Applying her discussion of asset-mapping to my context results in my conclusion that a community facing the challenge of HIV&AIDS might be able to accept agency, take ownership and cope with the challenge, provided that community members are guided and facilitated to recognise and gain insight into the assets that are available to them in the community; and secondly, provided that they are steered in the direction of not merely recognising these assets, but planning how to utilise them. In this manner, I put forward that the identification of potential assets might be expanded upon to include an exploration of *how* to access them, resulting in a dynamic system of assets being utilised in overcoming a challenge (asset mobilisation).

#### 2.4.3.2 Asset mobilisation

The identification of assets is followed by action. I adhere to the suggestion that the process of *mobilising assets* implies two components: the *agency component* (referring to the realisation and appreciation of available assets) and secondly a *mutual willingness component* (concerning potential partners and supporters who might be of assistance). As such, within the context of my study, the mobilisation of assets entails the processes of forming, accessing and utilising partnerships that might be beneficial in addressing the challenge of coping with HIV&AIDS (Bouwer, 2005; Lubbe, 2004; Ebersöhn & Eloff, 2006).

Therefore, after becoming aware of and identifying assets, networks can be established and relationships initiated between individuals, institutions and associations. In this manner, a capacity inventory is not only a list of skills, it is a way of identifying potential connections and connecting capacity information, in order to put the identified skills to work when facing a challenge. This process refers to the utilisation of asset maps, thereby mobilising (releasing) the *power of the community* (Bouwer, 2005; Ebersöhn & Mbetse, 2003; Snow, 2001b; Emmett, 2000; Kretzmann *et al.*, 1997; Kretzmann & McKnight, 1993). Coetzee (2005:13) summarises this process effectively by stating that, '*for a skill, talent, gift, resource, capacity or strength to be recognised as an asset, it should be accessible, attainable and functional*'. In my study, an existing support group could only be regarded as an asset for a community member that is infected with HIV once the person has become aware of the support group and has been facilitated to start participating in the group's activities. By not accessing such a group, it would merely remain a potential resource for coping with the illness of AIDS. Yet, by accessing such a group, the group itself, as well as the members' collaborative relationships, the knowledge shared and support provided could become assets to the individual.

#### 2.4.3.3 Asset management

The third main component of the asset-based approach concerns asset management, which implies that individuals take ownership and responsibility to sustain the actions that had been initiated, such as growth that has taken place. In

my study, employing the asset-based approach might have guided community members in taking certain actions with regard to the *critical issue of coping with HIV&AIDS*. Secondly, *relationships and social capital* could be developed amongst community members, and *community-building activities and projects* initiated. Apart from *tangible* results such as these, community members experienced feelings of belief in their own abilities, as well as those of the community (so-called *intangible* results) (Saidi *et al.*, 2003; Snow, 2001b). After initiating these actions and achieving such outcomes, the challenge is now to sustain initiated actions, especially after having terminated my involvement in the community.

Sustainability is regarded as a central concept of the asset-based approach and it may be enhanced by promoting enablement and creativity. After implementing the asset-based approach, towards the end of the process, result mapping (for example in the form of photographs or verbal accounts) may provide insight into possible changes that might have occurred, as well as into the likelihood of sustainability (Eloff, 2006b; Saidi *et al.*, 2003; Snow, 2001b; Kretzmann *et al.*, 1997; Kretzmann & McKnight, 1993). I propose that the sustainability of my intervention research might only be determined a few months (or even longer) after termination of my involvement in the field. As the participants indeed accepted agency and took responsibility for identified initiatives, I predict that the projects that were initiated will probably be sustained. This is, however, a mere prediction that needs to be explored further in order to be able to reach viable conclusions.

#### **2.4.3.4 Synthesis in terms of eight basic steps**

Eloff (2006b) refines these three broad stages of the asset-based approach in terms of eight interdependent and interlinked steps, and applies them in the context of learning support and life skills facilitation. They can also be applied to community-based intervention – as employed during my study. These steps might vary from situation to situation and be followed in a linear or non-linear manner. In my study, I implemented these steps during facilitation of the asset-based approach. Table 2.1 provides an overview of the eight stages, as proposed by Eloff (2006b).



**TABLE 2.1: BASIC STAGES OF THE ASSET-BASED APPROACH  
(Eloff, 2006b)**

STEP	PROCESS	IMPLIED ACTIVITIES
1	Becoming aware of the asset-based approach	Gathering information on the approach. Becoming enabled to apply the approach.
2	Learning to focus on capacities and assets	Intentionally and constantly focusing on assets and capacities.
3	Identifying and mapping key assets	Activities such as asset-mapping, compiling capacity inventories, collaborating and participating in relationship building initiatives. Improved understanding of the context, interrelationships between systems and the potential of identified capacities and assets.
4	Asset access mapping, including relationships and power relationships	Evaluating identified assets in terms of their usefulness. Indicating access to assets, relationships between assets and power relations on asset maps.
5	Mobilising assets, in order to build strong partnerships in the immediate system	Relying on asset map information, to build strong, mutually beneficial partnerships and relationships in the community.
6	Mobilising assets, to build strong partnerships outside the immediate system	Relying on asset map information, to build strong, mutually beneficial partnerships and relationships outside the community.
7	Sustaining asset mobilisation and development	Insiders (community members) enabled to continue with collaborative efforts. Promoting empowerment and collective action.
8	Continuous revisiting, reflection, reconsidering and revising	Continuously revisiting and reflecting on the various stages. Revising steps where necessary.

#### 2.4.4 POTENTIAL ADVANTAGES OF THE ASSET-BASED APPROACH

As the asset-based approach regards people as active mediators of change, well-being and coping, individuals or groups of people are usually enabled to effectively and confidently cope with the challenges they face by means of asset-based intervention (Ebersöhn & Eloff, 2006). Focusing on the competencies of individual community members in turn contributes to the strength of the broader community. Kretzmann and McKnight (1993:13) summarise this advantage of the asset-based approach as follows: *'Each time a person uses his or her capacity, the community is stronger and the person more powerful. That is why strong communities are basically places where the capacities of local residents are identified, valued and used'*. To me, and within the context of my study, a *strong* community refers to one where community members are able to cope with the challenges related to

HIV&AIDS, thereby enhancing the general well-being of the community. My exploration of and findings on possible changes in the general health of a community, growth and quality of life, as well as the ability to cope with HIV&AIDS by relying on existing assets and local resources, could add to the knowledge base on potential advantages of the asset-based approach.

In siding with Page-Adams and Sherraden (1997), I regard asset building as a *community revitalising strategy*, based on my view of assets having various positive effects on people's (communities') well-being. Smith *et al.* (2001) elaborate even further and regard communities with a strong capacity as healthy communities, often characterised by community members being determined to address the challenges they face, caring and trusting social relationships, a sound sense of purpose and control over life – both on an individual and communal level. In addition, community members tend to be supportive of one another and display high levels of competence and self-confidence. As such, I view community members as *co-producers of health*, cooperating with one another and working together towards a positive impact on individuals' relationships, behaviour and policies (Smith *et al.*, 2001; Kretzmann, 2000; Fuller & Brockie, s.a.). I therefore believe that capacity building initiatives often form part of health promotion practice. Within the context of my study, I aimed at exploring a possible connection between relying on the asset-based approach and coping with the challenges implied by HIV&AIDS.

Besides individual capacity building and strengthening of the community, other advantages of the asset-based approach (as actualised during my study) include shared responsibility and agency by community members, immediacy, relevant and practical solutions, flexibility and a warm, caring environment. In this manner, community members took responsibility for addressing the challenges they face, within the context of HIV&AIDS (Eloff, 2006a; Minkler & Hancock, 2003).

#### **2.4.5 ROLE OF THE OUTSIDER/PROFESSIONAL WHEN EMPLOYING THE ASSET-BASED APPROACH**

Applying the asset-based approach within the context of community development, as was done in my study, emphasises my role as an outsider and as one of

continuously exploring, assessing and focusing on individual and community-based assets, as well as guiding community members to improve by utilising what they have. In fulfilling the roles of interventionist/researcher and facilitator, I adhered to the basic principles of PRA. I (the outsider or professional) therefore had to assist the community in becoming aware of, appreciating and utilising the assets and talents available within the community, thereby encouraging local leadership. In addition, I had to network, connect and collaborate with community members and stakeholders who might fulfil a role in the community. Besides establishing social support and networks, I could provide helpful information not readily available to community members and enable them to gain access to external funding, where possible (Eloff, 2006a; Kriek & Eloff, 2004; Ebersöhn & Mbetse, 2003; Eloff & Ebersöhn, 2001; Mokwena, 1997).

My role as outsider had to shift from professional dominance to a role of facilitation and collaborating with community members. Efficient facilitation had to in turn result in community members being enabled to identify assets, even in cases where they appear not to exist. In addition, the processes of identifying and mobilising assets might have resulted in the discovery of more assets, by relying on local members of the community. Being involved in the discovery of assets and being busy with information and new skills, in turn resulted in the individuals (participants) and inevitably the community being empowered (Kriek & Eloff, 2004; Mokwena, 1997).

## **2.5 CONCEPTUAL FRAMEWORK FOR THE STUDY**

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Within the context of my study, the extensive literature on the HIV&AIDS pandemic, its impact and extent, provided me with the necessary background to the community that I selected. Characteristic of informal settlement communities in South Africa and in line with available literature, the community that I selected is characterised by poverty, limited resources, a high rate of unemployment and a high rate of HIV infections. By relying on existing literature relating to HIV&AIDS, I qualify the selected community as highly vulnerable to the impact of HIV&AIDS. As poverty and HIV&AIDS intensify one another, I regard the selected community as vulnerable, due to the high levels of poverty that community members face, intensified by the

challenges implied by HIV&AIDS, such as an inability to earn an income on becoming sick, an increase in expenses and high levels of vulnerability due to emotional and psychosocial challenges. In addition, community members typically need to cope with changes in the family, where both parents and children face the challenges of coping with family members infected with HIV or who have AIDS. Furthermore, they seem to face the challenge of coping with increased household responsibilities.

Based on the statistics available, I consider the challenge posed by HIV&AIDS as serious and relevant within the South African context, in terms of challenges like an increase in HIV infections, AIDS-related deaths, the number of orphaned and vulnerable children, child-headed households, crime and poverty. As South Africa is regarded as one of the countries most severely impacted upon by the pandemic, I support the worldwide request for rapid responses on the different levels, as well as ongoing research and monitoring of intervention initiatives. I believe that prevention, treatment, care and support ought to be the focus of initiatives, but further propose that coping initiatives on ground level might be emphasised, as South Africans at present have no other option than to cope with the challenges imposed by the pandemic.

Although I highly value the important (supportive) role of the government (for example by providing financial assistance, educational support and health services), NGOs, faith-based organisations and other community-based organisations, I regard the core of coping with HIV&AIDS as being situated within the relevant South African communities. As community members experience the impact and affects of HIV&AIDS on a primary level, I put forward that they are the people that need to address the related challenges in their own unique manner and in such a way that responses fit into their unique contexts and daily lives.

In conceptualising *coping with HIV&AIDS*, I rely on existing literature on both coping theory and the HIV&AIDS pandemic. I regard coping with the challenge of HIV&AIDS as crucial, in order for individuals to be able to face the future positively. To my mind, *coping with HIV&AIDS* implies various nuances and entails different aspects. I relate *coping with HIV&AIDS* to *coping with vulnerability* – vulnerability to the possibility of

being stigmatised, vulnerability due to poverty and basic needs not being met, vulnerability to being HIV infected, vulnerability due to having AIDS, or vulnerability due to a parent, a child or family members being HIV infected or having AIDS. I view *coping with HIV&AIDS* as the dynamic process of making adjustments in reply to the various levels of vulnerability implied by the pandemic. I support Johnson and Johnson's (2002) *interdependent-self approach* to coping, according to which individuals experience challenges within specific contexts and networks available to them, within which they then employ strategies to overcome the challenges they face. I presume that there are linkages between this way of addressing difficulties and the *asset-based approach*.

In conceptualising the *asset-based approach* within the context of my study, I propagate that communities cope with the challenges implied by HIV&AIDS by relying on the assets and strengths of community members themselves, as well as on the assets and resources existing in local organisations, associations and institutions. As such, I propose that community members follow an internal approach by relying on available social support when facing challenges. In addition, I suggest that they identify resources in the external environment that might be of assistance and could be mobilised to enhance their coping.

Although I regard the ideal situation to be that people and organisations on the relevant levels become involved in responding to the HIV&AIDS pandemic, I am fully aware of the reality of South African rural and informal settlement communities more often than not being under-resourced and not the focus of external intervention initiatives. Therefore, I support the idea of *community-based responses* to the challenges implied by the pandemic, where community members themselves take the responsibility to address the challenges, by relying on their own capabilities, skills, knowledge and competencies. As such, I propose the implementation of the asset-based approach as a viable possibility of community-based coping with HIV&AIDS. In this manner, I conceptualise the asset-based approach within community-based development.

My assumption is that, by implementing the asset-based approach during community-based responses to HIV&AIDS, communities may take up agency, whilst

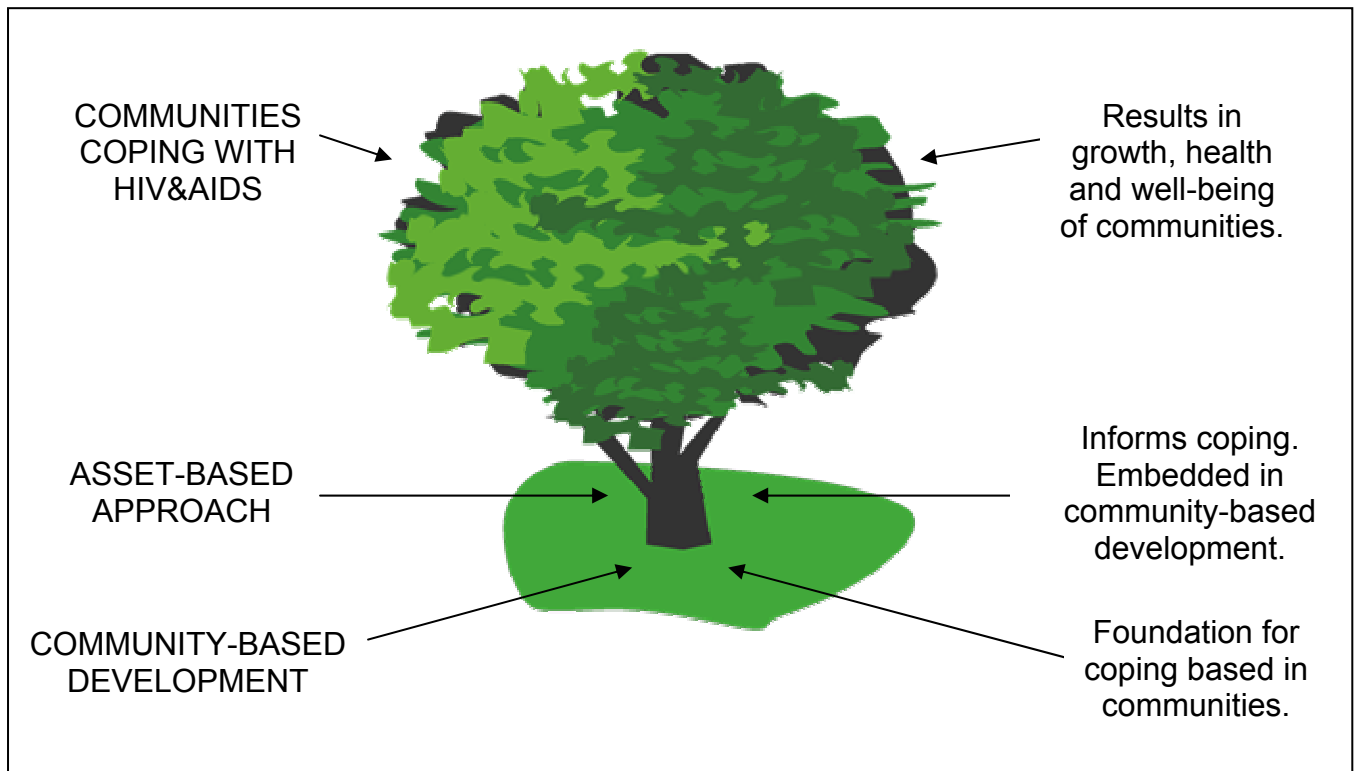
capacity might be built and change facilitated. I conjecture that agency and capacity building may consequently contribute to personal growth and the well-being of communities – thereby illustrating that communities are most probably coping.

In undertaking a study on the application of the asset-based approach in career facilitation, Coetzee (2005) identified certain asset-based principles, defining them as the basic beliefs valued by the asset-based (career) facilitator. Adapting these principles within the context of my study results in the following assumptions related to *coping with HIV&AIDS, within the theoretical framework of the asset-based approach*, as tenets of my conceptual framework:

- ⌘ Community members take ownership of the process of coping with HIV&AIDS.
- ⌘ Community members share the responsibility of identifying assets and possible strategies for coping with the challenges implied by HIV&AIDS. Whilst in the field, the facilitator (researcher) might guide and assist *'them'*, but not provide advice or address challenges on behalf of the community.
- ⌘ Community members can take up agency to cope with HIV&AIDS by being involved in the processes of identifying and mobilising available assets (PRA activities).
- ⌘ Coping with HIV&AIDS in the community requires a collaborative effort of the relevant stakeholders.

I conclude this section with Figure 2.1, summarising my conceptual framework in the form of a metaphor. In using a tree, I regard the asset-based approach as the trunk of the tree – relying on the roots and allowing growth of the leaves. In this manner, I view the asset-based approach as a basic approach that is embedded in community-based development and that informs community-based coping. I view community-based development as the foundation of coping, thereby comparing it to the roots of a tree. By relying on the principles of community-based development and by implementing the asset-based approach during coping, communities experience growth and well-being (the leaves of a tree). Growth and well-being in turn indicate the ability to cope with challenges such as HIV&AIDS.





**FIGURE 2.2: CONCEPTUAL FRAMEWORK FOR THE STUDY**

## 2.6 CONCLUSION

In this chapter I situated my study within the framework of existing literature. I commenced the chapter by describing the context of HIV&AIDS, in terms of the extent of the pandemic, its impact, related challenges and required responses. Thereafter, I discussed the theory of coping, followed by an investigation of the asset-based approach. In concluding with the conceptual framework of my study, I linked community-based coping within the context of HIV&AIDS to the asset-based approach.

In the next chapter, I describe the empirical study that I conducted, based on the theoretical background provided in this chapter. I explain the methodological choices that I made within the context of my study, and in terms of my research questions, as formulated in chapter one.



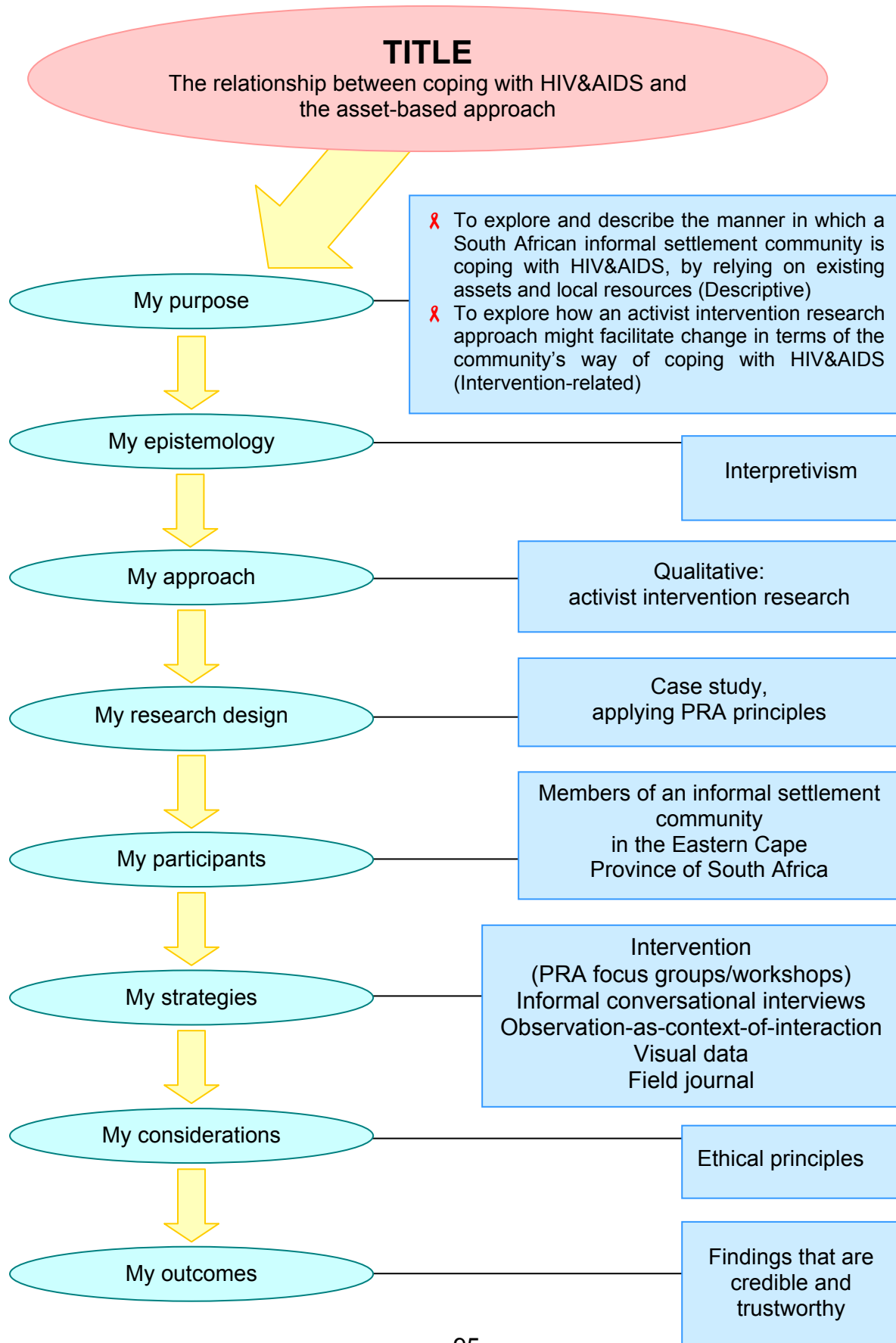
## CHAPTER 3:

### DESIGNING AND CONDUCTING RESEARCH IN THE FIELD

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## CHAPTER 3 AT A GLANCE



### 3.1 INTRODUCTION

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Chapter two provided a conceptual framework for my study. Based on the background provided in chapter two, I planned and conducted an empirical study, in order to explore the manner in which a South African informal settlement community is coping with HIV&AIDS, by relying on existing assets and local resources. Secondly, I aimed to explore possible changes that might be facilitated within the community by employing an activist intervention research approach. In this manner, my study can be regarded as both descriptive and interventionist by nature, during which PRA provided the necessary backdrop for research and intervention to collapse into one another.

Besides presenting and relating methodological choices to my study in this chapter, I justify the choices that I made in terms of the research questions and purpose of my study. After explaining the paradigm on the basis of which I approached the study, I describe the selected research design (*case study design applying PRA principles*), data collection and documenting strategies (*intervention in the form of focus groups and workshops, informal conversational interactive interviews, observation-as-context-of-interaction, visual techniques and a field journal*), as well as the process of data analysis and interpretation. I conclude the chapter with discussions on the strengths of my methodological choices, the challenges I faced based on the choices I made, the ethical guidelines I adhered to and how I aimed to improve the rigour of my study and enhance the trustworthiness of my findings and conclusions.

### 3.2 PARADIGMATIC APPROACH

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Research paradigms are compiled of philosophical assumptions that guide the researcher's way of thinking about the phenomenon that is being researched, as well as the actions employed. As such, I (as the researcher) entered the research field with a set of ideas or blueprint of concepts, values and methods, based on my unique and specific history, background, gender, class and race, to name but a few determining factors with regard to my specific view on reality (Chambers, 2003;

Patton, 2002; Denzin & Lincoln, 2000; Mertens, 1998). In order to best address the purpose of my study, I worked from the *interpretivist paradigm* (selected meta-theory), following a *qualitative approach* (methodological paradigm).

### 3.2.1 AN INTERPRETIVIST EPISTEMOLOGY

Interpretivism implies the interpretation of human behaviour on both a verbal and a non-verbal level, against the background of participants' life-worlds, as well as their past experiences and existing understandings thereof. Giving meaning always takes place within a particular context, implying that human behaviour, feelings and experiences can only be understood in relation to a specific context (in my study relating to informal settlement communities) (Terre Blanche & Durrheim, 2002; Webber & Ison, 1995). As such, experiences are interpreted in a personal, unique manner, implying that reality within the context of my study is constituted of various interpretations, namely mine, and those of my co-researchers and the participants. I agree with others (Grant & Shillito, 1998; Webber & Ison, 1995) that, although individuals do not share a uniform view of their life-worlds, they use communication to share their experiences of their worlds. Chambers (2003) proposes the use of the term *personal*, rather than *subjective* interpretations – the latter being a value-laden word, implying biased and unreliable outcomes or results. As I support the use of the term *personal* as opposed to *subjective*, I shall use it as such throughout this thesis.

I aimed to gain understanding (*Verstehen*) with regard to the lived-experiences and *personal* worlds of participants, in terms of their perceptions and interpretations, but by acknowledging myself as co-creator of meaning. I aim to report on experiences and perspectives as understood in a particular context, thereby *working with data in context*. Terre Blanche and Kelly (2002:125) associate *Verstehen* with *empathetic reliving* – the attempt 'to imagine and try to understand texts in their context'. I regard interpretivist research as a joint process, with different situations and effects being researched by various role-players. Besides data, interpretations and results being embedded in contexts and persons other than myself, I also acted as an instrument in the process, with my values inevitably impacting on the research process and findings, resulting in an end-product which is *personal* by nature (Henning, Van Rensburg & Smit, 2004; Terre Blanche & Kelly, 2002; Cohen *et al.*, 2001).

My decision to employ Interpretivism can be related to the aim of my study, which focuses on a deep understanding of the *personal* perceptions and views of the community members of a particular informal settlement community. Conducting my study from an interpretivist paradigm enabled me to conduct a study amongst participants in their natural environment (the informal settlement community), in order to gain information and insight regarding their ways of coping with HIV&AIDS, in terms of aspects such as existing assets, local resources, support systems, facilities, knowledge base and skills. I attempted to understand the participants in terms of their *personal* experiences, perspectives, definitions and perceptions of their everyday lives, within the unique context in which they operate and against their own unique backgrounds. As such, I did not aim to describe a single truth and reality (as I do not believe that something like that exists) or to provide objective interpretations.

In addition to Interpretivism being a suitable option to address my research questions, the basic principles of this paradigm correlate with those of PRA, supporting the methodological approach that I selected. Both PRA and Interpretivism propagate the idea that the people on ground level (the participants) are experts who hold the answers to their own, as well as other research questions. I pay heed to Chambers' (2003) recommendation not to enter the research field as a professional outsider, believing that I have the answers, as I may be influenced by my own methods, values, beliefs and attitudes, thereby preventing me from learning from local people. In my study, I further recognise the fact that a significant number of the participants are also outsiders to the community in the true sense of the word, but believe that they could share expert insight, based on their knowledge and daily involvement in the community. This also applies to data analysis, where I (as other researchers) may be prone to believe myself to be an expert – denying the abilities and creativity of people who actually understand the reality in question. Furthermore, such an approach correlates with my profession as scholar and practitioner in the field of Educational Psychology, more specifically with the theory of the asset-based approach, where emphasis is placed on the strengths and abilities of people with whom you work. In this manner, the theoretical background to my study, the selected paradigm and the methodological approach fit well and support one another.

Besides assisting me in gaining knowledge, certain underlying philosophical beliefs or assumptions guided my research approach, actions, search for meaning, and understanding of reality. Following an interpretivist paradigm, I define the nature and content of the reality that I researched (the manner in which a South African informal settlement community is coping with HIV&AIDS by relying on existing assets and local resources), as multiple, personal and internal by nature (***ontological assumption***). I regard this specific reality as one consisting of the participants' subjective experiences of their external world, and therefore I aimed to reflect the participants' perceptions in my findings. As such, I include various direct responses of participants in my discussion of emerging themes in chapter four, reflecting the voices of the participants and providing a trail of evidence. With regard to my ***epistemological assumption***, I adopted an intersubjective or interactional stance. In an attempt to narrow the distance between myself and the reality that I researched, I interacted and collaborated with the participants on a continuous basis, spent prolonged time in the field and throughout strived to obtain an *insider view* (emic perspective) (Lincoln & Guba, 2003; Terre Blanche & Durrheim, 2002; Cohen *et al.*, 2001; Crabtree & Miller, 1999; Creswell, 1998).

In considering the role of values in my study (***axiological assumption***), I acknowledge the fact that my research is value laden and biased. Despite my attempts to authentically report on the perceptions of the participants, my interpretations cannot be regarded as completely free from my *personal* (subjective) voice, due to the fact that my (and my co-researchers') background differs greatly from those of the participants – us being white, Afrikaans speaking, graduate woman entering a black, Xhosa speaking and mostly illiterate community. In addition, working from an interpretivist paradigm does not require of me to provide value-free interpretations. With regard to my ***rhetorical assumption***, I elected to employ a first-person and fairly informal writing style in this thesis, in an attempt to enable you – the reader – to *hear* my voice. I continuously strived to use language that typically relates to qualitative research. Finally, based on my ***methodological assumption***, I selected inductive research methods (for data collection, analysis and interpretation), relying on interaction and a personal relationship between the participants and myself. I remained flexible concerning my choices and revised my methodology where needed (Lincoln & Guba, 2003; Terre Blanche & Durrheim, 2002; Cohen *et*



*al.*, 2001; Crabtree & Miller, 1999; Creswell, 1998). Due to the fact that my methodology could only be finalised after completion of the data collection, interpretation and analysis, I regard my research design as emerging by nature. Detailed discussions of the research processes that I employed follow in section 3.3.

### **3.2.2 A QUALITATIVE METHODOLOGICAL APPROACH**

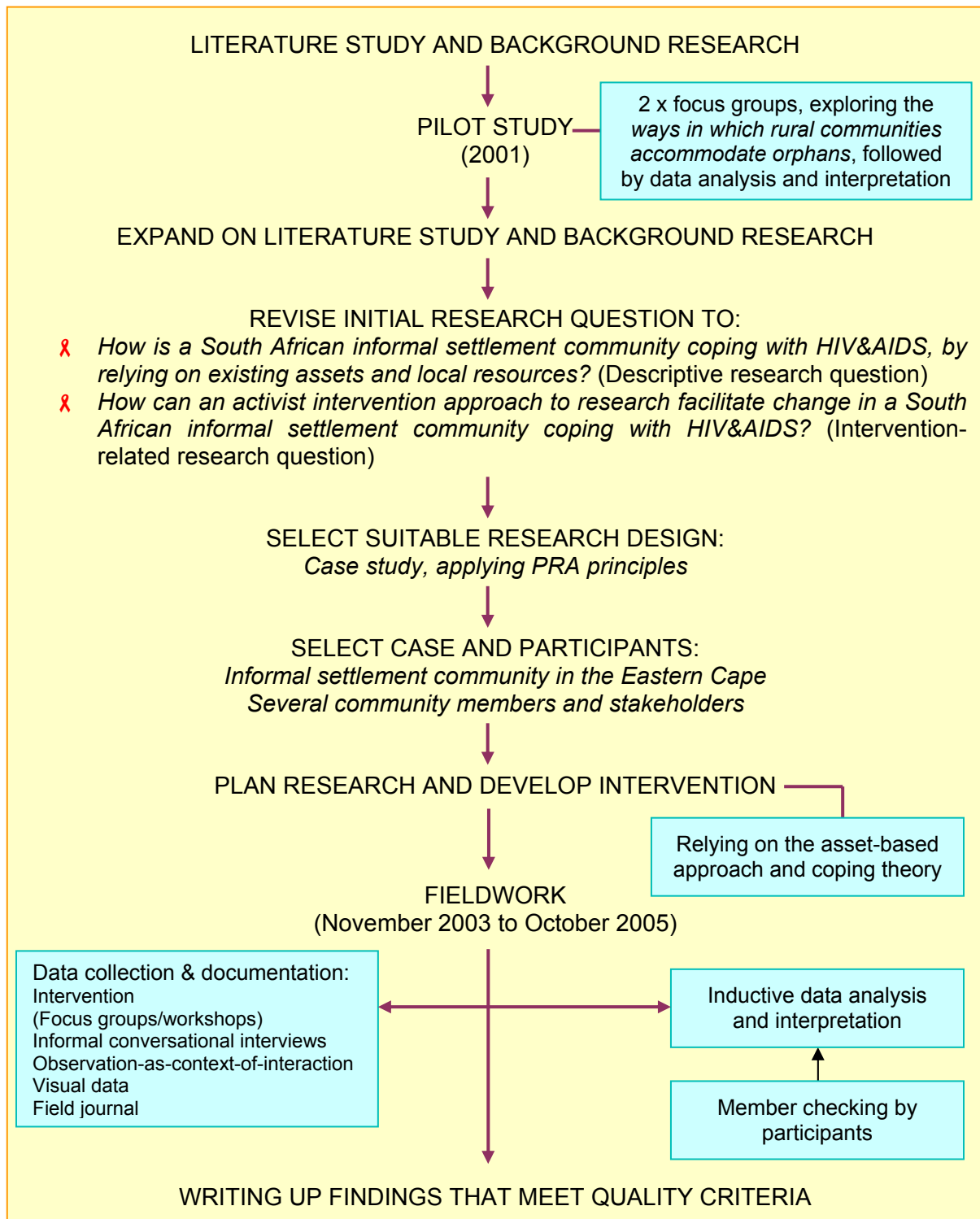
Selecting a qualitative research approach implies that I collect data in a real-world setting (field focused), working inductively. Grounding my study in this approach I focus on the perceptions, meanings and understandings of participants, with the outcome being a process rather than a product. I aim to obtain insight into and provide in-depth (rich) descriptions of naturally occurring phenomena or lived-experiences in natural situations, making sense of and interpreting that which I am studying in terms of the meaning that is ascribed to it by the participants and not as predetermined or controlled by myself. As such, by endeavouring qualitative research I aim to develop an understanding of the manner in which reality (the world) is constructed by individuals in a specific social setting, in terms of symbols, structures and social roles familiar to them. Qualitative techniques may therefore provide me with the opportunity to share in the views and understandings of other people and to explore the manner in which others give meaning to their life-worlds, themselves and others (Sterk & Elifson, 2004; Woods, 2003; Patton, 2002; Mayan, 2001; McLeod, 2001; Denzin & Lincoln, 2000). In terms of the focus on life-worlds, I (as qualitative researcher) hold the belief that emotions, motivations, symbols and their meanings, empathy and other subjective aspects are embedded in individuals' life-worlds and may, in turn, represent typical behaviour and experiences. I support others' (Denzin & Lincoln, 2000; Berg, 1998) opinion that, even though I can observe some of these aspects directly, most elements of symbolism, meaning and understanding require my consideration of my own *personal* perceptions and ideas.

In conducting qualitative research I aim to understand a phenomenon from an insider's perspective (emic perspective). This kind of research implies that I research a few cases and keep close contact with the field and participants – spending a lot of time in the field (gaining access, establishing rapport, collecting data), conducting the multifaceted, time-consuming task of data analysis, writing it up in an extensive

manner (including supporting quotations of the participants, in order for their voices to be *heard*), and being involved in a form of research that does not have set guidelines or procedures. It is like building a puzzle (Mayan, 2001), where I have to construct a *picture* that only takes form as the various parts are collected and studied. Employing such an inductive approach may enable me to be open in making sense of a situation by not imposing my pre-existing anticipations but allowing the relevant themes to emerge from raw data as the study and data analysis progress. My ultimate aim as qualitative researcher is to gain deep understanding of coping and not to generalise the findings to other populations or contexts (Babbie & Mouton, 2001; Mayan, 2001; Creswell, 1998; Mertens, 1998).

Applying the foregoing discussion of qualitative research to my study implied a study amongst community members (participants) in an informal settlement community in their natural environment. I (supported by my co-researchers and field workers) conducted the study to firstly understand the manner in which a South African informal settlement community is coping with HIV&AIDS by relying on existing assets and local resources, and, secondly, to gain insight into possible changes that might be facilitated by employing an activist intervention research approach (Bhana, 2002; Lindegger, 2002; Patton, 2002). Firstly, I identified the community's current coping strategies by means of several intervention sessions (focus groups and/or workshops) with educator-participants, as well as informal conversational interactive interviews, supported by observation-as-context-of-interaction, my field journal and visual data. I then analysed and interpreted the raw data obtained during these sessions in terms of the asset-based approach and coping theory, after which I (in conjunction with co-researchers) developed and implemented follow-up intervention sessions focusing on the various aspects and steps of the asset-based approach, including the mobilisation of available but not yet utilised assets. During these sessions I aimed to gain insight into the manner in which participants interpreted and implemented newly acquired asset-based-related competencies in terms of their community's way of coping with HIV&AIDS, as well as the changes they experienced. I documented the sessions by means of a field journal, audio-recordings and visual data techniques (PRA informed visual aids, photographs and video-recordings). Throughout, I aimed to describe the world of the participants from the inside out, in an attempt to gain deeper insight into the social reality of coping (as

it relates [or not] to the asset-based approach), as employed in the selected informal settlement community. Figure 3.1 provides an outline of my research process.



**FIGURE 3.1: SCHEMATIC PRESENTATION OF THE RESEARCH PROCESS**

My decision to approach the study qualitatively was primarily guided by the nature of my study, in terms of its research questions and purpose. Secondly, I feel comfortable applying the qualitative approach, based on my belief that the world exists of multiple realities which vary according to context and time (refer to Mertens, 1998). I wanted to explore and focus on the processes, meaning-giving patterns, as well as structural characteristics of a particular community, in order to address my research questions. I support the view of Flick, Von Kardorff and Steinke (2004:3), who describe this process as follows: *'It [Qualitative research] rather makes use of the unusual or the deviant and unexpected as a source of insight and a mirror whose reflection makes the unknown perceptible in the known, and the known perceptible in the unknown, thereby opening up further possibilities for (self-)recognition'*.

Mayan's (2001) criteria for phenomena and topics that are regarded as suitable to be researched qualitatively, apply to my study. Firstly, she regards phenomena with regard to which the existing knowledge base is limited as suitable to be researched qualitatively. Secondly, topics for which an insight into meaning is required are seen as appropriate, and thirdly, studies aiming to describe a process and not an outcome are typified as suitable. I undertook this study to [contribute to the limited literature on the asset-based approach, as well as the knowledge base relating to community-based coping with HIV&AIDS](#). Thirdly, I aimed to gain insight into the perceptions, feelings and ideas of people, and did not merely focus on the outcome, but on their process of coping with HIV&AIDS on a daily basis. In addition, I relied on PRA – being emerging by nature – and explored the process of employing an activist intervention approach to research, in terms of the changes it facilitated amongst the participants, in relation to their coping with HIV&AIDS.

In addition to these criteria, Creswell (1998) describes a viable qualitative study in terms of certain characteristics. I present the manner in which I adhered to these guidelines in Table 3.1.

**TABLE 3.1: ASSESSING MY STUDY IN TERMS OF CRESWELL'S (1998) CRITERIA FOR A VIABLE QUALITATIVE STUDY**

CRESWELL'S (1998) CRITERIA	MY STUDY
Rigorous data collection strategies, implying multiple forms of data collection and that the researcher spends sufficient time in the field.	I employed multiple data collection strategies and relied on crystallisation in an attempt to obtain a holistic perspective of the reality that was researched. I spent prolonged time in the field, undertaking nine field visits over a period of two years – varying in length between one and seven days each.
Framing the study within the basic assumptions and characteristics of the qualitative approach.	My study is characterised by typical trademarks of qualitative research such as an evolving design, myself fulfilling the role of researcher and acting as instrument for data collection, as well as my focus on the (multiple) perceptions of the participants.
Employing a tradition of inquiry.	My tradition of enquiry allowed me to become familiar with the participants' experiences and present a pure, concise study.
Starting the study with a single idea or focus.	Initially, my study originated from my interest in and motivation to understand how South African rural (and later informal settlement) communities are currently coping with HIV&AIDS, from an asset-based approach. Later on in the study, other areas of interest emerged, resulting in a research project with various secondary focus areas (described in chapter four) that were addressed by other researchers but simultaneously with and as part of my study, which I regard as the primary study.
Employing detailed methods and a rigorous approach to data collection, with data analysis and writing it up forming part of the study and the researcher verifying the accuracy of the account.	I relied on a variety of data collection methods and aimed to ensure rigorous data collection, analysis and interpretation. I attempted to provide a holistic reflection and representation of my study in this thesis, providing a trail of evidence and verifying my choices and conclusions by including relevant evidence where possible.
Writing up the study persuasively, allowing the reader to experience <i>being there</i> .	I attempted to provide detailed descriptions of the research process, relying on the participants' voices where possible, for the reader to follow my journey and share in my experiences, whilst constructing a personal experience.
Analysing data by using multiple levels of abstraction.	I actively worked from particulars to general levels of abstractions during data analysis and interpretation, as is evident in the examples included in the text and appendices.
Employing a clear and engaging writing style, filled with unexpected ideas.	I aimed to employ a clear and engaging writing style, yet you (the reader) ought to be the judge of this. I further attempted to provide believable and realistic findings, demonstrating the multi-facetness of the reality that formed the core of my study.

### 3.3 RESEARCH DESIGN AND METHODOLOGY

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The focus of my study was twofold. Firstly, I focused on the exploration and description of a particular phenomenon, namely an informal settlement community's manner of coping with HIV&AIDS, by relying on existing assets and local resources.

However, based on my methodological choice to apply PRA principles, my involvement with the particular community (initially primarily aimed at research) inevitably implied active intervention. In this regard, Versfeld (1995:149) remarks that '*The PRA process creates opportunities to research intervention activity*'.

As such, I followed an intervention research approach (Bhana, 2002; Lindegger, 2002; Patton, 2002) – intervening with a selected community whilst doing research. I now discuss the methodological choices I made and justify them within the context of my study. Themes with regard to the strengths of my choices, as well as the challenges I faced, based on the choices I made, are not included in the following sections, but addressed separately in sections 3.4 and 3.5.

### **3.3.1 RESEARCH DESIGN**

I selected a *case study design, applying PRA principles*. For the purpose of this discussion these two components will be presented separately, despite the fact that they were integrated and applied as a single design.

#### **3.3.1.1 Case study design**

I support Creswell's (1998:2-3) description of a research design as '*the entire process of research from conceptualizing a problem to writing the narrative*', as I believe that the research design links the purpose of the study and initial research questions to other methodological components and ultimately to the findings and conclusions, in a logical manner. For the descriptive purpose of my study and in order to address my descriptive research questions, I selected a single, within-site, instrumental case study design. This choice enabled me to investigate one informal settlement community in the Eastern Cape (the case) instrumentally in an attempt to explore its manner of coping with HIV&AIDS in terms of relying on existing assets and local resources, and, secondly, to explore the changes facilitated by the intervention research approach that I employed. The selected community was of secondary importance, as my primary aim was to gain insight into ways of coping and changes that occurred (Sterk & Elifson, 2004; Stake, 2000; Merriam, 1998).



Selecting and investigating this particular community supports Creswell's (1998:61) definition of a case study as '*an exploration of a "bounded system" or a case (multiple cases) over time through detailed, in-depth data collection involving multiple sources of information rich in context*'. Case study designs imply a focus on a phenomenon which is characterised by specific boundaries in terms of context, time and place. A case study design entails a detailed description of a single or a few individuals (being an individual, family, community or unit), a set of documents, an event, a programme or an activity, described within its setting (physical, social, economical and/or historical), in order to provide the necessary context (Henning *et al.*, 2004; Stake, 2000; Creswell, 1998).

Within the context of my study, I did not aim to gain generalisable knowledge, but rather to obtain a deep understanding of the perceptions of community members residing in a particular community (an informal settlement community) within a particular context (with a high incidence of unemployment, poverty and having to cope with the HIV&AIDS pandemic), environment (in the Nelson Mandela Metropole in the Eastern Cape) and time (November 2003 to October 2005). However, the possibility of certain tendencies being transferable to similar communities does exist, as other South African informal settlement communities might display a context and characteristics similar to the one described in detail in this thesis (Seale, 2000; Stake, 2000). Figure 3.2 provides a visual image of the selected community.



**FIGURE 3.2: THE SELECTED COMMUNITY (THE CASE)**

I purposefully selected the community in which I conducted my research, as often implied by Interpretivism. I identified an information-rich case, to be able to gain a



deep understanding of my topic, namely the manner in which the community is coping with HIV&AIDS by relying on existing assets and local resources, and, secondly, the potential changes that might be facilitated by employing an activist intervention approach during research (Patton, 2002; Babbie & Mouton, 2001; Cohen *et al.*, 2001; Mayan, 2001; Hayes, 2000; Creswell, 1998; Mertens, 1998; Jary & Jary, 1995).

I initially and indirectly gained access to the community *via* a gatekeeper (Creswell, 1998), whom I regard as an insider of the cultural group within which I conducted my study (being the Xhosa culture). This gatekeeper participated in the pilot study that I conducted in 2001 and is an educator at a school in the Nelson Mandela Metropole in an urban area. She liaised me with a person knowledgeable of schools in informal settlement areas in the region. Based on this person's recommendations, I selected a primary school through which I could enter the community. In doing so, I relied on *typical case sampling* to identify the case (community/school where I wanted to conduct my study), as that particular community (school) seemed to be an example of a typical average community in that region, meeting my criteria that it had to be an Eastern Cape community facing the challenge of HIV&AIDS and situated in an informal settlement area (criteria as identified during the pilot study). My selection of the case and participants is summarised in Table 3.2. My selection of participants is discussed in section 3.3.2.

**TABLE 3.2: SELECTION OF CASE AND PARTICIPANTS**

CATEGORY	DESCRIPTION	PURPOSEFUL SAMPLING STRATEGY	CRITERIA FOR SELECTION
Case	Informal settlement community (entry <i>via</i> a primary school)	Typical case sampling	A school in an informal settlement community in the Nelson Mandela Metropole, faced with challenges related to HIV&AIDS
Participants	Educator-participants	Random purposeful sampling	Educators of the selected school
	Other stakeholders and community members	Snowball sampling	Community leaders and members of the community who: ⚠ have to cope with HIV& AIDS ⚠ can be reached fairly easily ⚠ would be open in their replies ⚠ are able to communicate in English or through an interpreter

### 3.3.1.2 Applying PRA principles

I applied PRA principles in planning and employing data collection activities, as the PRA approach allows for research by means of intervention in communities, in an activist manner (Chambers, 2004). As such, I relied on PRA principles to address my intervention-related research questions, as formulated in chapter one. Due to the fact that PRA greatly determined my basic approach to the study, it seems appropriate to provide a brief overview of this relatively new and still emerging approach to research, before discussing the application of PRA principles, as actualised during my study. A discussion on the background and principles of the approach could provide you – the reader – with the necessary background against which the rest of my thesis might be read. I conclude the section on PRA by describing the way in which I relied on PRA to expand on good qualitative research within the context of my study – adding different nuances to it.

#### 3.3.1.2.1 Development of PRA

PRA originated in the late 1980s/early 1990s in East Africa (Kenya) and India, initially in the field of Agriculture. It is often regarded as a *later manifestation* of rapid rural appraisal (RRA), being an alternative and rigorous learning experience facilitated in a community, usually by a multidisciplinary team that includes community members. I do not regard PRA as a *static methodology* but as a *philosophy, orientation or flexible approach to research*, in which various data collection strategies might be employed to uncover indigenous people's knowledge and skills, in order to learn about their local conditions, identify challenges and plan how to address them. The development of PRA was influenced strongly by the concepts of capacity building and empowerment of people, by means of their own active participation and involvement in their own development. As such, I regard **intervention**, **activism** and **change** as central constituents of the approach (Leach, 2003b; Cornwall *et al.*, 2001; Percy, 1999; Ensign & Gittelsohn, 1998; Absalom & Mwayaya, 1997; Binns *et al.*, 1997; Lelo, Ayieko, Makenzi, Muhia, Njeremani, Muiruri, Omollo, & Ochola, 1995; Leurs, 1995; Chambers, 1994a; Chambers, 1994c; Mukherjee, 1993; Chambers, 1992; Heaver, 1992; Kabutha, Thomas-Slayter & Ford, 1990).

PRA is currently applied in numerous settings and across socio-economic strata. Over the last two years, researchers (although in the minority) have increasingly displayed a preference for the use of *Participatory Learning and Action* (PLA), or *Participatory Reflection and Action*, as opposed to the initial *Participatory Rural Appraisal* (Chambers, 2004). Within the context of my study, I support the use of *Participatory Reflection and Action*, despite the limited use and familiarity thereof. My preference is based on the fact that my study involved continuous reflection, followed by action, in turn leading to reflection. Secondly, I did not conduct my study in a rural area, nor did I limit it to a mere appraisal of the community's way of coping.

### **3.3.1.2.2 Core principles underlying PRA**

In selecting PRA principles, I adhere to a bottom-up approach, emphasising the interest of a regional community, the capabilities of local people and the development of their decision-making powers. My basic point of departure lies in the recognition of the facts that poverty-stricken communities have survived under difficult conditions and faced difficult challenges over the years, in spite of limited resources; and secondly, that they possess a wealth of indigenous social and technical knowledge. Hence, the approach is based on three basic beliefs, to which I ascribe. Firstly, I assume that there are *no experts*, appealing to me as researcher to be humble, to respect multiple perspectives and to be willing to learn from others. Secondly, I emphasise the notion of *local problems requiring local solutions* by relying on local materials and representations, accepting diversity, differences and complexities and continually keeping in mind that no single truth exists. In the third instance, by applying PRA principles I assume that development necessarily implies a change for the good and that it may result in the *empowerment* of local community members (as was indeed evident in my study) as well as *long-term and sustainable self-help initiatives* in communities. From a PRA perspective I regard the participation of community members as crucial to any development initiative, as it implies that community members themselves set priorities and work towards their own goals, as they are enabled to relate the identified needs and challenges with available resources, not only in the community itself but also in the wider context and on a macro-level. In doing so, a feeling that they are the owners of the process and the information that have been generated, is established (Bhandari, 2003; Percy, 1999;

Grant & Shillito, 1998; Binns *et al.*, 1997; Archer & Cottingham, 1996; Jijiga, 1994; Schönhuth & Kievelitz, 1994; Thompson, Shah & Foellmi, 1994; Wallace, 1994).

In applying PRA principles, I relied on participation, teamwork, interactive learning and shared knowledge during my study. I used joint analysis and reflections to raise local community members' awareness of their existing situation as well as their own abilities, in the process empowering them to move into action. I facilitated the process in the research field (an informal settlement community) and collaborated with local people (the participants), with the aim of uncovering information on the community's realities, challenges, opportunities and priorities, in order to identify, plan and design ways of more effectively coping with the challenges implied by HIV&AIDS. I employed PRA principles in order to initiate and sustain development in this informal settlement community, in terms of community members managing their own development by identifying challenges, followed by them planning solutions, carrying them out and evaluating them regularly. This resulted in the people facing the challenges being actively involved in making decisions, planning and implementing their own initiatives, in terms of the three projects reported on in chapter four (Chambers, 2003; Percy, 1999; Ensign & Gittelsohn, 1998; Absalom & Mwayaya, 1997; Chambers & Guijt, 1995; Lelo *et al.*, 1995; Webber & Ison, 1995; Chambers, 1994b; Jijiga, 1994; Wallace, 1994; Mukherjee, 1993; Chambers, 1992).

During my study I had to continually adhere to the core of PRA, being *changed roles and reversals*. As a result I (and my co-researchers) as outsiders could not enter the field as experts who knew what to convey and how, but merely as initiators and facilitators, seeking collaborative inquiry and defining what was important to know as the research context was created and defined. I (and my co-researchers) did not transfer knowledge and technology, but merely introduced them to the participants and facilitated them to use newly introduced methods and resources to do their own planning and initiate such plans, as well as monitor and evaluate them. Instead of imposing my (our) reality on the participants, I encouraged and allowed participants to express their own reality. As such, I regard myself as an *enabler* – who assisted and guided local community members (participants) to plan, employ and manage their school(community)-based projects, whilst learning from one another. However, I was occasionally required to provide information and experience from an external

context on possible strategies, based on the access I had to resources from the wider (different but also valid) context that could be employed to the benefit of the community (Chambers, 2004; Chambers, 2003; Grant & Shillito, 1998; Webber & Ison, 1995; Chambers, 1996; Chambers, 1994a; Wallace, 1994; Chambers, 1992).

In summary, I was required to implement four primary reversals during my research – both in thinking and in doing. A reversal of *frames* implied a movement from an etic to an emic approach, and from closed to open methods, focusing on discussions and open questions. With regard to the reversal of *modes*, I had to shift my focus from individual-focused modes of inquiry to group-focused activities, and from verbal to visual modes. The reversal of *power/dominance* implied a shift from merely gaining information to empowering participants and facilitating or starting a process of community development. Lastly, the reversal of *relations* required of me to move from being suspicious and reserved to displaying confidence and good rapport, and from focusing on the experience of frustration (and sometimes tension) to having fun (Chambers, 2003; Chambers, 1994a; Chambers, 1992).

Reflecting on my application of the *principles of PRA*<sup>6</sup> I (and also my co-researchers) focused on being relaxed and not rushing the process; listening instead of lecturing; probing instead of dominating, not suggesting answers or moving on to another topic too quickly; and being unimposing instead of the central figure (*principle of offsetting biases*) – not interrupting participants or interfering with the process. As these principles correlate with the guidelines of my training as psychologist and facilitator, I did not experience difficulty to adhere to them. In addition, I was open about what we were doing in the community, by clearly informing the participants about the purpose, background and process of the sessions. I consciously aimed to let go of the power (*handing over the stick*) and facilitate a *'they do it' approach*, by encouraging and facilitating participants to investigate, analyse, generate and take ownership of the outcomes of the process. This resulted in them learning from one another and feeling empowered as the study progressed. Although I allowed the participants to determine the process, I attempted to provide some degree of structure in order to avoid unnecessary detail and irrelevant information (*optimal ignorance/optimising*

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<sup>6</sup> Please consult the appendices (both hard copy and compact disc) for a trail of evidence in this regard.

*trade-offs*). I strived towards self-awareness and being self-critical, in order to learn from the participants (so-called *failing forwards*) and continually reflected on my own behaviour and skills, in order to improve where needed (Chambers, 2004; Bhandari, 2003; Chambers, 2003; Grant & Shillito, 1998; Absalom & Mwayaya, 1997; Thompson *et al.*, 1994; Mukherjee, 1993; Singh, 1993; Chambers, 1992).

As sound relationships and trust are regarded as prerequisites for successfully applying the PRA approach, I focused on initiating and establishing good rapport with the participants. Sound relationships encouraged their participation, especially with regard to the discussion of content which is sensitive by nature. Concerning personal demeanour, I aimed to display respect, humility, patience and interest in the participants and what they had to say. I paid attention, listened and did not interrupt, also paying attention to my own body language. I constantly conveyed the messages of ‘*You can do it*’ and ‘*You are the experts*’, and facilitated activities that participants could enjoy, own and thrive on. Furthermore, I encouraged participants to experience a sense of ownership over the information that was revealed. Besides following up on community issues where possible, I updated the participants on the progress of the process during visits (Chambers, 2004; Grant & Shillito, 1998; Absalom & Mwayaya, 1997; White & Taket, 1997; Chambers, 1996; Chambers & Guijt, 1995; Chambers, 1994a; Mukherjee, 1993; Singh, 1993; Chambers, 1992; Heaver, 1992).

With regard to the *reversal of roles and learning*, I learned from and with community members, by spending time with them and applying face-to-face interactional methods. I was flexible in my application of methods and adapted my strategy throughout the process – improvising and innovating where needed (*learning rapidly and progressively*). I also included various time frames, methods, people (participants as well as researchers) and places, in order to ensure constant cross-checking (*triangulating [as per PRA terminology]*). I aimed to keep a balance and maximise diversity and richness of information, by looking for diverse events, different processes and contradicting opinions, in the process of seeking multiple perspectives (*seeking diversity*), and in accordance with my belief that a community is not a solid entity but represents a collection of perspectives. Concerning the principle of *personal responsibility*, I did not rely on manuals, but applied PRA in the form of creative adjusted methods (Chambers, 2004; Bhandari, 2003; Chambers,



2003; Absalom & Mwayaya, 1997; White & Taket, 1997; Chambers & Guijt, 1995; Chambers, 1994a; Jijiga, 1994; Mukherjee, 1993; Singh, 1993; Heaver, 1992).

In conclusion, I adhered to the following practical guidelines, which reflect the basic principles underlying PRA, in undertaking my study (Chambers, 2004; Chambers, 2003; Leach, 2003a; Absalom & Mwayaya, 1997; Wallace, 1994):

- ✂ I read up on PRA prior to undertaking my study.
- ✂ I spent quite some time on introductions, building relationships and learning about the community.
- ✂ I informed participants at the start that we did not propose to train them, but that they would provide the answers and determine the process.
- ✂ In introducing the process I informed participants of potential benefits for them.
- ✂ I selected concrete, visual and colourful methods and activities, to which the participants could relate and with regard to which they could feel comfortable.
- ✂ I followed a '*Go with the flow*' approach, being flexible, open to change, willing to learn from my mistakes and to make adjustments when needed.
- ✂ We worked in a safe environment where the participants felt comfortable to discuss sensitive content.
- ✂ I continually watched, listened and learned from the participants – keeping in the background and allowing them to do the work.
- ✂ I respected the participants and their contributions. I was sensitive to their needs and ideas, and relied on my own better judgements at all times.
- ✂ I was prepared to deal with sensitive issues or emotions when they arose.
- ✂ I did not attempt to do too much in too little time. Instead of rushing, I allowed enough time to discover and learn with the participants.
- ✂ I facilitated and introduced my ideas and perceptions whenever appropriate.
- ✂ I made room for participants to have fun and enjoy the process.

#### **3.3.1.2.3 Adding unique nuances to qualitative research by relying on PRA**

Applying PRA principles to my study enabled me to add unique nuances to qualitative research, as it is traditionally practised. As PRA seeks empowerment of participants and change in the form of community development, applying PRA



principles allowed me to take qualitative research one step further. Whereas qualitative research usually focuses on an in-depth exploration and understanding of a phenomenon, I extended research to intervention (in accordance with the PRA approach), doing research *via* intervention and intervention *via* research. As a result, my research did indeed facilitate change within the selected community.

Although the baseline data that I obtained during the first session with the participants indicate that they were to a certain extent coping with the challenges of HIV&AIDS when my study commenced, their way of coping changed towards the end of my study. By being involved in planning and implementing the intervention research process, participants took ownership and co-determined the progress and outcome of the process (basic PRA principle). High levels of participation and contributions by participants in this manner differ from participation and contributions in traditional qualitative research, where participants are seldom involved in the planning and progress of the research process. The role that I fulfilled further implies a different slant to qualitative research, as I served as initial catalyst for the process of change to occur, and then as facilitator, researcher, developer of the intervention and mentor throughout the study, being constantly involved in facilitating change.

By being actively involved and upon taking agency, participants were empowered to take charge, plan and initiate three school-based projects in order to assist the community in coping with HIV&AIDS. As such, their involvement in the research process served to enable them to initiate community development. Whereas (qualitative) research usually implies knowledge generation by the researcher, the participants in my study actively participated in the process of knowledge generation, due to their high levels of involvement. The manner in which I integrated research and intervention subsequently resulted in them coping with HIV&AIDS differently, and even improving in this regard towards the end of my study, by developing different approaches to enhance the community's way of coping with the pandemic.

### **3.3.2 SELECTION OF PARTICIPANTS**

I purposefully selected the participants in my study. Subsequent to my initial identification of the school, I networked with the school principal, in order to gain

access to the school (educators) and eventually the community. I requested him (in collaboration with the deputy principal) to select ten educators to participate in the discussions and intervention sessions, upon which he *casted lots*, by putting the staff members' names in a hat and pulling out ten names, thereby employing simple *random purposeful sampling* (Henning *et al.*, 2004; Patton, 2002; Mertens, 1998; Miles & Huberman, 1994).

After the initial stages of my study I identified and purposefully sampled other community members (participants) to conduct informal conversational interactive interviews with. I relied on my own networking abilities, as well as the educator-participants (a few self-appointed key informants) for recommendations on and access to suitable community members who were regarded as knowledgeable and able to supply rich information concerning my area of research, thereby employing *snowball sampling*. One of the key informants (educator-participants) was of particular benefit, as she had access to stakeholders and community members, managed to establish networks and enjoyed a high status in the community. She could thus bring me into contact with other stakeholders of the community and guide me towards suitable participants. In this manner, she (in a certain sense) also acted as gatekeeper for me to enter into the wider community, with specific reference to families residing in the community. She further acted as guide and informant during some of the interviews that I conducted, as well as interpreter when needed. In addition to guidance by the educator-participants, community members who were involved as participants in turn identified others to be involved – constituting *snowball sampling* (Henning *et al.*, 2004; Sterk & Elifson, 2004; Patton, 2002; Wengraf, 2002; Babbie & Mouton, 2001; Cohen *et al.*, 2001; Fontana & Frey, 2000; Mertens, 1998; Miles & Huberman, 1994).

Although the participants in my study represent only a small section of the people to whom the study might possibly apply, I aimed to select participants that are reasonably typical of the bigger group of people that I focused on, being South African people residing in informal settlement communities (Patton, 2002; Babbie & Mouton, 2001; Cohen *et al.*, 2001; Mayan, 2001; Hayes, 2000; Creswell, 1998; Mertens, 1998; Jary & Jary, 1995). ***I acknowledge the fact that several of the participants in my study might be regarded as outsiders in the true sense of***

*the word, due to them working in the selected community but residing in adjoining communities.* Table 3.3 provides an overview of the participants, including community members that I informally encountered and with whom I conducted *ad hoc* conversations, as documented in my field journal (refer to Appendix F).

**TABLE 3.3: PARTICIPANTS IN THE STUDY**

DESCRIPTION OF PARTICIPANT	(ASSUMED) LITERACY LEVEL	RESEARCH ACTIVITIES INVOLVED IN
14 x primary school educators	Tertiary education	Intervention sessions (focus groups/workshops) Informal/ <i>ad hoc</i> interviews Observation-as-context-of-interaction
2 x school principals	Tertiary education	Informal/ <i>ad hoc</i> interviews
1 x social worker employed by the Department of Health	Tertiary education	Informal conversational interview
2 x social workers employed by the Department of Social Development	Tertiary education	Informal/ <i>ad hoc</i> interviews
2 x social workers employed by NGOs	Tertiary education	Informal conversational interviews
HIV&AIDS co-ordinator at the Department of Social Development	Tertiary education	Informal conversational interviews
1 x nurse at provincial hospital	Tertiary education	<i>Ad hoc</i> conversation Observation-as-context-of-interaction
2 x employees at children's hospice	Literate	<i>Ad hoc</i> conversations
1 x ex-employee of the South African Police Department	Literate/ <i>tertiary</i> education	Informal conversational interview Observation-as-context-of-interaction
3 x employees at NGOs	Tertiary education	Informal/ <i>ad hoc</i> interviews Observation-as-context-of-interaction
1 x catholic sister (nun) at community care centre	Tertiary education	Informal conversational interview Observation-as-context-of-interaction
1 x employee at community care centre	Literate	<i>Ad hoc</i> conversation Observation-as-context-of-interaction
1 x church minister	Tertiary education	Informal conversational interview
1 x employee at a faith-based organisation	Literate	<i>Ad hoc</i> conversations
1 x volunteer community worker	Literate	Informal conversational interview
2 x HIV infected community members	Literate	Informal/ <i>ad hoc</i> interviews
3 x HIV infected children	Primary school	Observation-as-context-of-interaction
2 x caregivers (aunts) of children infected with HIV	Low level of literacy	Informal conversational interviews
4 x family members of people infected with HIV or who have AIDS	Literate / low level of literacy	Informal/ <i>ad hoc</i> interviews Observation-as-context-of-interaction

I regard the sampling strategies that I employed as appropriate for my study, for several reasons, including the sensitivity of the HIV&AIDS topic and the associated limited insight into communities' perceptions of HIV&AIDS-related issues. Despite potential participants having to be fairly representative of the community in general, other criteria for selection include that I had to be able to reach them quite easily, that a high probability for them to be open in their replies was required (specifically important due to the sensitive nature of HIV&AIDS), and that they had to be able to communicate their perceptions, whether they were able to speak English or communicate *via* an interpreter (Henning *et al.*, 2004; Patton, 2002).

Although Webber and Ison (1995) propagate an open invitation to any community member (by implication any educator at the school) who would like to be involved, I limited the educator-participants by selecting only ten. Apart from the potential benefit of gaining more in a smaller group during discussions, I based my decision to limit educator-participants on the fact that they were initially reimbursed for their time during intervention sessions (focus groups and/or workshops). I am of the opinion that an open invitation might have resulted in the majority of staff wanting to participate, due to the financial implication of participation. I was, however, flexible and welcomed another staff member as part of the team, upon her request to participate due to her interest in the field of study. At a later stage another staff member also joined the team. No volunteer was refused participation at any stage. As my study progressed, two educator-participants terminated their involvement with the project (discussed in more detail in 3.3.3.2). With regard to the other participants (community members), I continued purposefully sampling participants for informal conversational interactive interviews until the raw data became saturated.

I based my decision to provide reimbursements (on a minimal scale) on my belief that educators are professionally trained people whose time is valuable. I regarded reimbursement of the educator-participants as the ethical thing to do, paying them in order to compensate for their time (Oliver, 2003). Being a funded project<sup>7</sup> I also had limited funds available. Furthermore, coming from a lower income group and participating in discussions after hours and over week-ends (specifically during the

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<sup>7</sup> Study partially funded by ETDP SETA, ABSA Foundation and M&SST Trust.

first few field visits), reimbursement enabled the educator-participants to cover additional costs caused by the process. With regard to reimbursing focus group participants or not, Patton (2002) reports on the observations of Reed, who indicates that the reimbursement of participants did not have an influence on their responses. Apart from financial incentives and gifts like T-shirts and nametags for the educator-participants, I handed out gifts of appreciation to other participants, in the form of fruit parcels (on recommendation of the educator-participants), as well as HIV&AIDS pins. Although some of the educator-participants initially seemed to be driven by inducements, their participation later solely relied on them taking agency and believing that they could make a difference in the community. Consequently, financial inducements were only included during the initial phases of my study.

### 3.3.3 DATA COLLECTION AND DOCUMENTATION

According to Flick *et al.* (2004:7): *‘..., background assumptions of a range of qualitative research approaches are that reality is created interactively and becomes meaningful subjectively, and that it is transmitted and becomes effective by collective and individual instances or interpretation’*. Communication constitutes a crucial part of qualitative research, implicating communicative data collection strategies like individual and group interviewing, focus groups and workshop discussions. Furthermore, a case study design implies extensive data collection, utilising multiple sources of information. My choice of data collection strategies was further influenced by the PRA principles that I applied. As such, I selected open-ended methods which are visual, flexible and creative by nature (Chambers, 2004; Ensign & Gittelsohn, 1998; Grant & Shillito, 1998; Thompson *et al.*, 1994; Singh, 1993).

I implemented planned intervention sessions (consisting of focus groups and/or workshops), informal conversational interactive interviews, observation-as-context-of-interaction, audio-visual data and a field journal as data collection and documenting strategies. In addition, I engaged in *ad hoc* informal conversations with members of the community, whenever the opportunity arose. My data collection and documentation involved a cycle of interrelated activities (Creswell, 1998), as illustrated by the following statement by Chambers (2004:7): *‘Good facilitation and empowering others demands action, reflection, learning and change, which are*

*continuous and have no end*'. Before discussing the various strategies as utilised during my study, an overview of the process is provided.

### 3.3.3.1 Overview of data collection and documentation processes

Table 3.4 provides a summary of the various field visits. I include detailed explanations of the various phases of my study in chapter four.

**TABLE 3.4: SUMMARY OF DATA COLLECTION AND DOCUMENTATION ACTIVITIES**

FIELD VISIT	DATE	RESEARCH TEAM AND RESPONSIBILITIES	PARTICIPANTS	ACTIVITIES
1	14-17 Nov 2003	<b>2 researchers*:</b> <ul style="list-style-type: none"> <li>✂ Interviewers</li> <li>✂ Facilitators</li> <li>✂ Observers</li> </ul> <b>2 field workers:</b> <ul style="list-style-type: none"> <li>✂ Observers</li> <li>✂ Makers of audio-visual recordings</li> </ul>	11 educator-participants, working in two groups of five/six participants each Several community members during <i>ad hoc</i> conversations	<ul style="list-style-type: none"> <li>✂ Informal interviews</li> <li>✂ Focus group-workshop-sessions</li> <li>✂ Visits to institutions in the community</li> <li>✂ Observation</li> <li>✂ <i>Ad hoc</i> conversations</li> </ul>
2	23-26 Jan 2004	<b>2 researchers*:</b> <ul style="list-style-type: none"> <li>✂ Interviewers</li> <li>✂ Facilitators</li> <li>✂ Observers</li> </ul> <b>2 field workers:</b> <ul style="list-style-type: none"> <li>✂ Observers</li> <li>✂ Makers of audio-visual recordings</li> </ul>	11 educator-participants, working in two groups of five/six participants each Several community members during <i>ad hoc</i> conversations	<ul style="list-style-type: none"> <li>✂ Informal interviews</li> <li>✂ Focus group-workshop-sessions</li> <li>✂ Visits to institutions in the community</li> <li>✂ Observation</li> <li>✂ <i>Ad hoc</i> conversations</li> </ul>
3	17-23 Feb 2004	<b>2 researchers*:</b> <ul style="list-style-type: none"> <li>✂ Interviewers</li> <li>✂ Facilitators</li> <li>✂ Observers</li> <li>✂ Makers of audio-visual recordings</li> </ul>	8 educator-participants, working in two groups of four participants each 11 participants involved in individual interviews Several community members during <i>ad hoc</i> conversations	<ul style="list-style-type: none"> <li>✂ Formal and informal interviews</li> <li>✂ Focus group-workshop-sessions</li> <li>✂ Visits to institutions in the community</li> <li>✂ Observation</li> <li>✂ <i>Ad hoc</i> conversations</li> </ul>
4	3-8 June 2004	<b>3 researchers*:</b> <ul style="list-style-type: none"> <li>✂ Interviewers</li> <li>✂ Facilitators</li> <li>✂ Observers</li> <li>✂ Makers of audio-visual recordings</li> </ul>	10 educator-participants, working in three groups of three/ four participants each 6 participants involved in individual interviews Several community members during <i>ad hoc</i> conversations	<ul style="list-style-type: none"> <li>✂ Formal and informal interviews</li> <li>✂ Focus group-workshop-sessions</li> <li>✂ Visits to institutions in the community</li> <li>✂ Observation</li> <li>✂ <i>Ad hoc</i> conversations</li> </ul>

\* Indicating my role during field visits.



5	19 Aug 2004	<b>1 researcher:</b> ✂ Interviewer ✂ Facilitator ✂ Observer ✂ Maker of audio-visual recordings	9 educator-participants, working in three groups of three participants each 2 community members during <i>ad hoc</i> conversations	✂ Informal interviews ✂ Focus group-workshop-sessions ✂ Observation ✂ <i>Ad hoc</i> conversations
6	29-31 Oct 2004	<b>2 researchers*:</b> ✂ Interviewers ✂ Facilitators ✂ Observers <b>2 field workers*:</b> ✂ Observers ✂ Makers of audio-visual recordings	9 educator-participants, working as a group Several community members during <i>ad hoc</i> conversations	✂ Informal interviews ✂ Focus group-workshop-sessions ✂ Observation ✂ <i>Ad hoc</i> conversations
7	28-31 July 2005	<b>4 researchers*:</b> ✂ Interviewers ✂ Facilitators ✂ Observers ✂ Makers of audio-visual recordings	8 educator-participants, working as a group Several community members during <i>ad hoc</i> conversations	✂ Informal interviews ✂ Focus group-workshop-sessions ✂ Visits to institutions in the community ✂ Observation ✂ <i>Ad hoc</i> conversations
8	15 Sep 2005	<b>2 researchers*:</b> ✂ Attend school celebration ✂ Observers ✂ Makers of audio-visual recordings	No group work involved Several community members during <i>ad hoc</i> conversations at the school's official celebration	✂ Attendance of school's official celebration ✂ Informal interviews ✂ Observation ✂ <i>Ad hoc</i> conversations
9	14-18 Oct 2005	<b>4 researchers*:</b> ✂ Interviewers ✂ Facilitators ✂ Observers ✂ Makers of audio-visual recordings	10 educator-participants, working as a group Several community members during <i>ad hoc</i> conversations	✂ Informal interviews ✂ Focus group-workshop-sessions ✂ Observation ✂ <i>Ad hoc</i> conversations

### 3.3.3.2 Intervention (focus groups/workshops)

For the purpose of my study, I integrated focus group discussions and workshop activities during intervention sessions with the selected educator-participants (transcripts and visual images included in Appendices B, C and D), relying on a combination of the advantages of these methods. Berg (1998:100) describes *focus group interviews* as 'either guided or unguided discussions addressing a particular topic of interest or relevance to the group and the researcher.' Implementing this approach, I (supported by co-researchers) facilitated discussions and interaction in small structured groups as a way of exploring and gaining insight into the views and

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\* Indicating my role during field visits.



experiences of the life-worlds of a small group of participants. Due to the non-threatening and informal atmosphere of the focus group interview, participants could speak freely and openly about their personal attitudes and opinions, sharing their views, ideas and perceptions with regard to their community's way of coping with HIV&AIDS. Within the context of my research problem, and due to the sensitive nature of the topic under discussion, I took particular care to establish a relaxed and open atmosphere (Litoselliti, 2003; Berg, 1998).

*Workshops* are regarded by Leach (2003b) as a popular way of implementing participatory principles, emphasising the importance of participants being involved in determining and formulating the aims and outcomes of the process – thereby taking ownership. In this regard, I was guided by the process and information obtained during discussions with participants, especially during the initial phases of my study, despite the broad structure and planning I had in mind prior to any contact with participants. The flexible and adaptable nature of workshop sessions supports the basic underlying principles of PRA.

Combining focus groups and workshops during intervention enabled me to observe and note the process of interaction between participants, as meaning is often formed relative to other people's beliefs and attitudes. Furthermore, it enabled me to gain access to the verbally expressed opinions, ideas and experiences of the participants. Due to the specific structure and give-and-take nature of the intervention sessions, meanings were socially constructed rather than individually created and possibly represent a diversity of experiences and opinions. During intervention, I had the opportunity to explore any contradictions and uncertainties in order to clarify them, whenever they occurred. In addition and due to the dynamic and interactive nature of group work, experiences, ideas and perspectives might have been shared that probably would not have been shared in another setting (Litoselliti, 2003; Mayan, 2001; Berg, 1998; Morgan, 1997).

Combining focus groups and workshops (in the form of intervention) enabled me to collect data relatively quickly from various educator-participants. As intervention implies a certain dynamic quality, which was evident in the group interaction, debates and disagreements, the intervention sessions represented normal everyday

conversations to a great extent, resulting in lively discussions and the generation of rich data<sup>8</sup>. In participating in intervention sessions, participants could elaborate on the information provided by co-participants, enabling me to understand their ongoing experiences. In that sense, these sessions focused on the interaction between the participants, rather than the interaction between the facilitators and participants (Wilkinson, 2004; Wilkinson, 2003; Fontana & Frey, 2000; Millward, 2000; Morgan, 1997).

Furthermore, focus groups, in combination with workshops, enabled me to address the sensitive topic of HIV&AIDS with people of a different background and culture, according to whom this topic is still stigmatised – as was evident during the various phases of my study in participants' avoidance of the use of the terminology *HIV&AIDS*. By conducting intervention in the way that I had selected, I aimed to provide the educator-participants with multiple lines of communication and a safe environment for them to share their views and perceptions, in the company of people coming from the same background and culture. Although they appeared to be reluctant at first, sound rapport (based on the time spent to establish rapport, as well as the number of sessions with mainly the same group of people) encouraged participation and honest contributions. Besides the well-established relationship of trust between myself (and my co-researchers) and the participants, regular sessions brought about firm relationships amongst participants – possibly indirectly motivating them into action, working together as a team. In addition, regular contact in an atmosphere of trusting relationships provided a safe environment in which some of the participants disclosed the HIV status of family members, despite their initial fear concerning the possible reactions of group members regarding such disclosures and the stigma still attached to HIV&AIDS-related disclosures. During later stages of the process, one of the participants herself even disclosed her positive status in an informal conversation (Wilkinson, 2004; Leach, 2003b; Litoselliti, 2003; Fontana & Frey, 2000; Madriz, 2000; Millward, 2000; Morgan, 1997).

I conducted the intervention myself, in collaboration with my co-researchers (often my supervisor). As facilitators (or moderators), we were guided by a brief outline of

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<sup>8</sup> Refer to verbatim transcripts of focus group discussions included in Appendix B as illustration.

possible questions (topic guide – refer to Appendix B) during sessions, but remained flexible to be steered by the group discussions, complying with the basic principles of PRA. We attempted to keep discussions alive and flowing, encouraging the participation of participants, and more specifically interaction between participants, eventually aiming at participant empowerment. We constantly encouraged the participation of quiet participants, managing the talkative ones and self-appointed experts in a non-threatening manner. Furthermore, we addressed the challenge of confidentiality by urging group participants to adhere to confidentiality and not discuss or convey any information outside the context of the group. From time to time, participants tended to wander off the topic. Sporadic incidents were, however, valuable when, for example, a participant disclosed a family member's HIV status (Wilkinson, 2004; Litoselliti, 2003; Wilkinson, 2003; International HIV/AIDS Alliance, 2001; Van Dyk, 2001; Millward, 2000).

In order to optimise the contributions of the participants, I (in conjunction with the participants) formulated a code of conduct for intervention sessions. At the start of the first session, I conveyed the message that participants ought to speak openly as everybody's opinions are important, I emphasised that there are no right or wrong answers and that both positive and negative remarks would be valued, as well as that consensus was not important. I requested the participants to respect others, allowing others to speak without interrupting them. I relied on thorough observation to identify participants who did not contribute spontaneously but gave non-verbal cues that they had something to contribute. In such cases I would look participants in the eye and redirect the same question or point of discussion to them, mentioning their names after initial responses by others. If dominators continued to interrupt I requested them to allow the other person to express an opinion before allowing them another turn. From time to time I would also ask a question and allow everybody to provide their answers on the same question. By moving the tape-recorder around from one to another the usually silent participants also got an opportunity to contribute, as the others respected the individual turns. In addition, better sound recordings could be obtained (Leach, 2003b; Litoselliti, 2003; Wilkinson, 2003; International HIV/AIDS Alliance, 2001; Mayan, 2001; Van Dyk, 2001).

Litoselliti (2003) suggests that the various focus groups in a series of discussions ought to be facilitated by the same person. I fulfilled the role of primary moderator for the discussions during intervention sessions, being assisted by various co-researchers. I am of the opinion that my constant presence at discussions positively impacted on the group dynamics and relationships maintained within the group, as well as between the participants and the researchers. Although Mayan (2001) propagates that the facilitator and the researcher are not supposed to be the same person, this method worked for my study, as we could support one another, elaborate on each other's ideas and be present to experience the information shared first-hand. As we (the co-researchers and myself) are trained psychologists who are currently employed as lecturers at a tertiary institution/psychologists-in-training, we have been trained in basic facilitation skills and facilitate group discussions on a regular basis. In addition, we possess basic interviewing and interpersonal skills, approach group work in a non-judgemental manner, are able to adapt during group work and have the ability to summarise group dynamics when working with groups (Wilkinson, 2004; Litoselliti, 2003; International HIV/AIDS Alliance, 2001; Fontana & Frey, 2000).

Intervention sessions commenced with an informal session during which lunch was served. In this manner, I tried to honour and respect an embedded tradition of not rushing participants and showing interest in their life-worlds at large. At the beginning of the sessions I thanked participants for their contributions and distributed informed consent forms. I emphasised confidentiality and anonymity throughout, recapped and summarised the purpose and proceedings of the previous session, and then outlined the session to follow. In addition, I communicated the draft structure to the principal of the school, as well as the deputy principal (one of the participants and contact person between me and the other participants), prior to the sessions. Participants were free to ask questions at any time during any session. I video-taped and/or audio-taped the sessions (with the permission of the participants) and transcribed the recordings after field visits. I ended most intervention sessions with an informal discussion, focusing on the participants' experiences of the process and thereby guiding future planning and discussions. At the end of each session, I provided further information when needed, debriefed participants when necessary, requested them to complete expense claim forms, and outlined and planned the next

session in terms of a suitable date and time, in collaboration with the participants. My co-researchers and I participated in a reflection and debriefing session after each session, providing me with the opportunity to formulate preliminary interpretations and proposed changes where necessary. I often used the information shared during these discussions to plan follow-up sessions and formulate questions for further pursuance (Litoselliti, 2003; Wilkinson, 2003; International HIV/AIDS Alliance, 2001).

During intervention, I adhered to the basic guidelines for planning and facilitating focus groups and/or workshops in the following way (Leach, 2003b; Litoselliti, 2003; Wilkinson, 2003; Mayan, 2001):

- ⌘ Session length: Sessions lasted between 60 and 120 minutes. I attempted to keep discussions focused and included activities instead of solely relying on discussions. Regular breaks were also planned.
- ⌘ Venue: The sessions with the educator-participants were conducted in the staff room at their school, as this venue appeared to be logistically suitable. Furthermore, the door could be closed and confidentiality maintained – supported by the fact that sessions were conducted in the afternoons, with learners no longer at the school.
- ⌘ Language, cost, duration and materials for sessions: Sessions were conducted in English, as both the participants and I (and my co-researchers) are able to communicate in English (although it is a second language for all of us). However, participants sometimes spoke other languages in private asides during sessions. Although I tried to limit such incidents and requested participants to translate such commentaries, the possibility exists that I might have lost some meanings communicated in this way.
- ⌘ Number of participants: Sessions were conducted with ten educator-participants (average). I attempted to include all participants throughout the proceedings, but not to the detriment of spontaneous contributions.
- ⌘ Purposeful/theoretical sample: I selected educators as participants in group intervention sessions, based on my belief that they are experienced members of the community who possess expertise on the topic that I researched.
- ⌘ Careful selection of participants: I decided to involve ten educator-participants, in order to compile a manageable group. I relied on the school principal for

identifying participants. Although he did initially involve the two educators who had been trained in HIV&AIDS, and are involved in the Life Skills programme at school, both of them decided not to participate (one before the study commenced and the other after the first phase of the study). Despite the fact that both of them ascribed their decision not to participate to their busy schedules, I wonder whether or not their decisions cannot also be related to the fact that they had already received training in HIV&AIDS-related matters.

- ✘ **Composition of the group:** The group was homogeneous in terms of the educators working at the same school, as well as being from the same ethnic background. Although the initial group consisted of nine women and one man, the latter withdrew from the study after the first field visit, resulting in homogeneity in terms of gender. Despite the fact that this probably had a positive impact during discussions on gender structures, the question has to be raised whether or not I obtained a balanced view. However, individual differences and contradictory opinions often occurred.
- ✘ **Number of groups:** I involved only one group of people in the series of intervention sessions and could therefore not verify the data with another group. Based on my selected paradigm this was, however, not what I had aimed at. Furthermore, I regard the educators who were involved as being representative of the rest of the staff at the school.
- ✘ **Segmented sample:** During workshop activities, the group was divided into two (sometimes three) smaller groups, which enabled me to compare the data provided by each group during feedback sessions. During discussions, the group was involved as a unit and not divided into smaller segments.
- ✘ **Over-recruitment:** I did not recruit more participants than the ten that I had planned for. Before the first contact session started one more individual requested to participate, which I allowed. During the second field visit, one of the eleven educator-participants did not return and as my study progressed, one more educator-participant withdrew, but arranged for someone else to take her place. Upon enquiry for the reasons for their withdrawal, participants cited that the first participant had to take care of his children in the afternoons (when most sessions were conducted), whilst the other participant became involved in extra-mural activities that took up her time during afternoons.



- ⌘ Incentives: I offered financial incentives to the educator-participants during the initial phases of the project, due to them being professionally trained people who shared their knowledge and experiences after school hours, despite busy schedules and a lot of work to do during afternoons and evenings. Secondly, with the study being a funded study, I had access to a limited amount of money which made it possible for me to include incentives. Besides financial incentives, I provided participants with items like photographs, T-shirts and certificates for their participation.
- ⌘ Planning follow-up sessions: Follow-up sessions were planned in collaboration with the school principal and educator-participants throughout the process.
- ⌘ Continuous reflection on the role as facilitator: I involved co-researchers during the various phases, in order to support me as facilitators and obtain different views of the sessions and discussions that transpired. Despite my efforts not to steer the process of events, I occasionally tended to guide, specifically during initial sessions. However, I focused on not doing this during follow-up sessions.

During intervention, group discussions and PRA-related techniques were employed to generate data. I employed *do it yourself* techniques, by relying on participation-based activities, guided by probing questions. I used *group meetings and discussions* (both casual and planned/structured by nature) to facilitate brainstorming activities and discussions on the community's way of utilising assets and resources, in order to cope with HIV&AIDS. In addition, informal interaction (for example during lunches) often focused on related discussions. *Participatory mapping, diagramming and modelling* formed an essential part of intervention sessions, during which participants were facilitated to create maps and spatial diagrams. In PRA, common forms of maps include social, resource and mobility maps, representing people, resources and outlets where people obtain services. For the purpose of my study, participants compiled maps to illustrate the layout of their community, as well as the nature and extent of the challenges, resources and potential resources in the community. In addition, the utilisation of resources and the extent to which resources are available and accessible to community members were explored through mapping exercises (refer to Appendix C). Furthermore, intervention sessions included *participatory analysis, presentations, planning and monitoring*, especially during



advanced stages of my study. Concerning the use of *time-lines and trend and change analysis* (adapted format), participants reflected on and discussed events of the past towards the end of my study, as well as changes that had taken place in the community, with regard to the community's way of coping with HIV&AIDS (Chambers, 2004; Chambers, 2003; Binns *et al.*, 1997; Chambers & Guijt, 1995; Shah, 1995; Chambers, 1994c; Jijiga, 1994). More detail on the specific activities included during intervention (focus groups and/or workshops) follows in chapter four.

### 3.3.3.3 Informal conversational interactive interviews

In addition to intervention, I conducted informal conversational interactive interviews (reflected in Appendix E) with key informants/stakeholders in the community, such as health workers, spiritual leaders and other community members, in order to gain insight into the community's way of coping with HIV&AIDS. Some of the interviews included personal stories (PRA technique), during which participants (both individually and in small group context) described families or households from the community who are coping with HIV&AIDS, by dealing with a relative/friend living with HIV&AIDS, or with children orphaned due to the HIV&AIDS-related death of a parent (Chambers, 2004; Chambers, 2003; Binns *et al.*, 1997; Chambers & Guijt, 1995; Shah, 1995; Chambers, 1994c; Jijiga, 1994). Interviews were audio-taped, and this was supported by observation and my field journal, as additional accounts of what transpired. I selected **qualitative interviewing** to explore the participants' experiences and perceptions of their community's efforts of coping with HIV&AIDS by relying on existing assets and resources available to them, based on my view that qualitative interviewing is an interactive process of meaning making. Being a two-way communication process whereby I, as the interviewer, attempted to make meaning of what was said by the interviewee (participant), as well as how it was said, factual information and meanings could be provided in the form of rich descriptions, experiences and personal points of view. Conducting individual interviews in this manner enabled me to gain insight into the community's challenges, practices and responses to the HIV&AIDS pandemic (Baker, 2004; Holstein & Gubrium, 2004; Miller & Glassner, 2004; Babbie & Mouton, 2001; Kvale, 1996; Mascarenhas, 1990).

My decision to rely on *informal conversational* (also referred to as unstructured) *interactive interviews* enabled me to accommodate individual differences, to be flexible and to adapt when needed, whilst participants could be spontaneous and respond according to their own familiar frames of reference. In accordance with this unstructured, open-ended approach, I was led by the interviewees and discussions that arose, in addition to my research questions and overall purpose guiding me and serving as broad interview schedule. In this manner, interviews were characterised by a thematic as well as a dynamic dimension, where the latter kept the conversation going and ensured positive interaction, within the basic outline of my specific purpose and structure (Wengraf, 2002; Cohen *et al.*, 2001; Kvale, 1996).

Although I usually started interviews by requesting the participants to share their views or tell their stories, I focused on addressing the question as to how the particular participant, close family members, or other community members are coping with HIV&AIDS during interviews. In this fashion, I followed a general plan or broad interview schedule (refer to Appendix E) but was not guided by a specific set of questions or particular words or phrases. I based follow-up questions on the replies by interviewees, as well as previously conducted interviews, allowing me to elaborate on perceptions shared by the participants and themes that emerged (Baker, 2004; Holstein & Gubrium, 2004; Miller & Glassner, 2004; Patton, 2002; Wengraf, 2002; Babbie & Mouton, 2001; May, 2001; Breakwell, 2000; Kvale, 1996).

I focused on asking open-ended, singular questions put in a clear and understandable manner. I aimed to respond in a neutral way, depending on good rapport between the participants and myself. I avoided leading and biased questions, in order to gain insight into the perceptions of the participants without predetermining their points of view in terms of pre-set categories or contaminating their responses. As such, and due to me treating responses as accounts rather than reports, my questions merely guided the participants as to the aspects or categories for discussion. I regard this type of non-restrictive interview as being suitable to explore the sensitive topic of HIV&AIDS, as it allowed the interviewees freedom to respond in a way with which they felt comfortable. Although my conceptual framework served as theoretical background in planning the interviews, I did not include any theory-based questions in the interviews, as the purpose was not to determine the

participants' knowledge about existing theory. Instead, I used informant-questions to explore the personal perceptions of participants and focused discussions on their perceived strengths, possibilities and challenges as experienced in their community, thus their current coping. In turn, the content of the interviews assisted me in my formulation and elaboration of existing theory (included in chapters five and six) (refer to Baker, 2004; Henning *et al.*, 2004; Holstein & Gubrium, 2004; Patton, 2002; Wengraf, 2002; May, 2001; Mayan, 2001; Mertens, 1998).

In conducting informal conversational interactive interviews, I employed active listening as a way of encouraging extensive discussions, in order to gain in-depth replies. I fulfilled the role of being sensitive, listening and interpreting – not only to what was said, but also to what was communicated on a non-verbal level, thereby relying on thorough observation. Where appropriate, I remained silent to allow interviewees sufficient time to formulate answers, or for whatever other reason they required time. Although I refrained from giving advice or interpreting the participants' perceptions, I occasionally employed summarising and paraphrasing in order to make sure that I had heard them correctly. I used process feedback to maintain the interviewing process and ongoing rapport, by thanking the participants and indicating from time to time that I was obtaining helpful information from them. A few interviews necessitated mirrored empathy with interviewees who displayed strong emotions. I found this to be a challenge, as I constantly reminded myself that I was undertaking the interviews as researcher and not as psychologist. However, such instances tended to steer me into the direction of psychological interviewing, resulting in me tending to take up the role of empathetic listener and facilitator of solutions, as opposed to that of researcher focusing on the exploration of perceptions (Baker, 2004; Holstein & Gubrium, 2004; Miller & Glassner, 2004; Patton, 2002; Terre Blanche & Kelly, 2002; Wengraf, 2002; Kvale, 1996; Mascarenhas, 1990).

#### **3.3.3.4 Observation**

Adler and Adler (1994:389) describe observation as the '*fundamental base of all research methods*'. In support of this statement, Baker (2004:163-164) views researchers using interviews as '*competent observer-analysts of the interaction they are involved in*'. Observation formed an essential part of the research that I

conducted – both on an individual level and in group context during intervention. During interviews, observation served as validation measure, enabling me to validate what I had heard in terms of, firstly, the participants validating the observations, but also in terms of my own judgement and personal stance. However, as I observed across cultures, I had to guard against observation bias and aimed not to overly or incorrectly interpret non-verbal communication such as body language. In addition, I had to be sensitive concerning factors that might have influenced informal conversational interactive interviews, for instance the context or setting in which the interviews were conducted, as well as the interaction and relationship between the interviewees and myself. As I was aware of these potential challenges during the course of my study, I could rely on reflexivity in an attempt to monitor myself and address the challenges (Sterk & Elifson, 2004; Angrosino & Mays de Pérez, 2000; Kvale, 1996; Adler & Adler, 1994).

I employed *observation-as-context-of-interaction*, by developing a *membership* role in the selected community, in order to observe interactions and participations in dialogue with the participants (whom I regard as research partners) (Angrosino & Mays de Pérez, 2000). I relied on both casual and formal observation. During intervention sessions (focus groups/workshops) and informal conversational interactive interviews, I used *formal observation* (supported by audio-visual recordings and documentation in the form of a field journal) to gain insight into the dynamics of the group, messages conveyed by means of non-verbal communication (keeping in mind the cultural difference between the participants and myself) and topics of discussion during informal occasions of interaction (like during lunches). In addition, I relied on *casual, unobtrusive observation* to gain insight into the context and setting of the research field, with regard to aspects such as the environment, community, families and caregivers in the community, school, living conditions and interactions between community members (Chambers, 2004; Reddy, 2003; Patton, 2002; Shah, 1995; Jijiga, 1994).

I documented my observations in the form of a field journal and photographs, wherever possible. I observed external physical aspects, such as resources, consumables and services (for example churches, medical services and support services) in the community, residential facilities, clothing and living conditions of

community members, as well as the availability of basic living requirements (such as running water and electricity). Secondly, I observed the physical location and environment of the community, as well as community members' personal living space. Thirdly, in casually observing participants, I paid attention to expressive movement, in the form of posture, body language, facial expressions and eye movements. I also paid attention to language behaviour (such as topics of discussion, stuttering or so-called *slip of the tongue* incidents), although this aspect proved to be difficult, based on the language differences between the participants and myself. During later stages of the study I relied on observation-as-context-of-interaction to establish what had been accomplished (in terms of the vegetable garden that was initiated, for example, including observing the community members involved in the garden project). In this way, I observed as an outsider, but aimed to gain insight into the insider's view by interacting with participants and community members and spending time in the field in which they performed their daily tasks. Lastly, I observed time duration in terms of the length of time that participants and other community members spent in what they were doing. By attending to these aspects, I was not only able to observe aspects such as knowledge base, skills, resources and support systems in the community, but could also pay attention to any non-verbal signals during verbal conversations with participants and other community members. Furthermore, I was able to observe people's feelings, in cases where they expressed their emotions non-verbally. Apart from observing others, I observed myself throughout the process – my background and approach to the field, as well as my interaction with the participants and co-researchers, by means of self-reflection (examples included in Appendix F) (Chambers, 2004; Reddy, 2003; Patton, 2002; Babbie & Mouton, 2001; Fox, 1998).

By conducting selected informal conversational interactive interviews at the homes of the participants, I could gain insight into the actual environments in which participants fulfil their daily tasks and capture lived visual data. I was able to observe the participants in their own time and space – interacting with other family and community members and allowing me insight into their life-worlds. Emmison (2004) calls this process *direct observation of the social contexts of participants*.

### 3.3.3.5 Visual data collection techniques

PRA often relies on visual and concrete material, based on the belief that visualisation promotes participation. By using mapping, diagramming and ranking exercises (refer to Appendix C), I could encourage participation that did not depend on the literacy levels of the participants, but on the representation of ideas by means of symbols, drawings or concrete objects. These exercises were amplified by discussions, in an attempt to gain insight into the meanings represented by the participants (Archer & Cottingham, 1996; Shah, 1995).

In addition to visual PRA techniques, I used photographs and video-tape material to supplement data generated during intervention, informal conversational interactive interviews and documentation of observations-as-context-of-interaction (Appendices C and D). Apart from documenting interactive data generating sessions, I used visual material to document the context of the research field, in terms of assets, resources, services, challenges and structures in the community. Although I did not use transect walks in its original form, I employed an adapted form thereof, by accompanying stakeholders and key informants through the community environment – observing, listening, asking questions and identifying challenges, as well as possible solutions thereof. Visual data were created in the immediate community as well as on the school premises, photographing the setting, facilities, resources and strengths (such as informative posters in the staff room). Furthermore, I employed *photo elicitation*, by requesting educator-participants to take photographs and discuss the contents thereof with me and the other participants. Involving participants in generating visual data gave them the opportunity to provide me with insight into their life-worlds and immediate community (Chambers, 2004; Emmison, 2004; Chambers, 2003; Creswell, 1998; Binns *et al.*, 1997; Chambers & Guijt, 1995; Shah, 1995; Chambers, 1994c; Jijiga, 1994).

### 3.3.3.6 Field journal

I made use of a field journal (refer to Appendix F) to include field notes and reflective thoughts. I used *descriptive field notes* to keep record of the research process, enabling me to re-visit the process when needed. Notes were made on the dates,

schedules, locations and length of intervention sessions and informal conversational interactive interviews. *Descriptive field notes* further enabled me to document my observations during field work, to keep record of the participants and of any resistance to participation. In addition, I used *reflective field notes* to document my own personal reflections, emotions, experiences, successes and areas for improvement throughout the study. I included my own preliminary interpretations, findings, insights, ideas and changes in schedule whenever it occurred. By making field notes and including reflective thoughts, I employed *reflexivity* – one of the key principles of PRA (Patton, 2002; Mayan, 2001; Percy, 1999).

Despite my intentions to write extensive field notes, I occasionally became so involved and *lost in the moment* that I forgot to make notes whilst being engaged in the field with participants. In addition to this and based on personal preference, I am not comfortable with compiling extensive written notes while engaging with people. This might be ascribed to my preferences as psychologist, according to which I regard note-making as a potential barrier between the client and psychologist. In an attempt to address my tendency not to make sufficient field notes often enough, I wrote down my observations and incidents that I could recall as soon as possible after each session. Although it is possible that I might have lost some detail information by doing this, sessions were audio-taped and most of the intervention sessions video-taped, enabling me to revisit the process at later stages and elaborate on my field notes (Sterk & Elifson, 2004; Patton, 2002; Babbie & Mouton, 2001; Fox, 1998).

In compiling field notes and reflective thoughts, I adhered to Mayan's (2001) guidelines with regard to reflexivity. I throughout allowed myself sufficient time to do reflections and recorded my notes in privacy as soon as possible after each session. Although the discussion of observations before recording them is discouraged, the fact that I (we) conducted field work in a community several kilometres away from where we resided, resulted in us travelling a distance before having the opportunity to reflect independently. We spontaneously engaged in debriefing sessions once alone whilst on our way back after sessions (especially after long and emotionally laden sessions), inevitably discussing the day's activities as well as our experiences.



I did, however, pay attention to recording my initial thoughts and avoided changing my reflections on the basis of discussions with my co-researchers.

### **3.3.4 DATA ANALYSIS AND INTERPRETATION**

I employed *inductive thematic analysis* (also referred to as *content analysis* or *pattern analysis*), often associated with a case study design (Creswell, 1998). I focused on making sense of the raw data, by working with large amounts of detailed qualitative information, in order to identify core meanings in terms of themes, patterns, categories and interrelationships, working inductively and moving from detailed themes to more general ideas and a holistic perspective on the phenomenon that was being researched, namely coping with HIV&AIDS by relying on existing assets and local resources. In this manner I was able to summarise and systematise the data, by placing specific sections of the data within the wider context of other gathered data (Henning *et al.*, 2004; Wilkinson, 2003; Patton, 2002; Mayan, 2001; Mouton, 2001; Ryan & Bernard, 2000; Creswell, 1998).

My data analysis commenced with the first step of data collection, which inevitably led to ideas for directions of analysis, patterns and themes taking shape, and hypotheses and new ideas and questions emerging and in turn impacting on the field work that followed, in turn leading to further analysis and interpretation in terms of sorting, questioning, thinking, constructing and testing preliminary ideas, followed by a repetition of the first step of the process. Initial stages of data collection provided me with new insights and guidance on where to go, whilst later stages served to deepen my insights and confirm or contest patterns that seemed to have emerged (Smith & Osborn, 2003; Mayan, 2001; Morse, 1999).

As I was involved during the entire research process, both as primary data collector and data analyst, I could start with data analysis whilst still collecting the data. In addition, being involved throughout the various phases resulted in me gaining insight into the context and interactions that took place, providing me with a basis to interpret raw data. My study involved repeated visits in order to generate and collect data, with periods of data analysis and further planning in between. Applying PRA principles necessitated such an approach, as I had to be guided by the participants.

However, I continually had to guard against hasty conclusions, as the process of final data analysis commenced only after I had completed my data collection activities, based on my preliminary understanding of the raw data, as formulated during data collection (Henning *et al.*, 2004; Litoselliti, 2003; Patton, 2002; Terre Blanche & Kelly, 2002; Ryan & Bernard, 2000).

In applying the basic guidelines for inductive thematic analysis and interpretation, I analysed and interpreted the raw data obtained from intervention sessions (focus groups and workshops), individual interviews, observations, my field journal and visual data, in relation to my conceptual framework. I firstly reviewed the data by perusing the raw data collected, thereby working with the text (namely transcripts, my field journal and visual data) in order to become familiar with the text, to obtain a general idea of what might be found and to develop a manageable classification system or categories for coding, which I discussed with my supervisor. As I was fully acquainted with the raw data, I found the generation of open coding codes fairly easy. During my initial reading I started making brief notes in the margins, serving as initial sorting process. I organised raw data and possible topics, identified related themes, patterns, similarities and differences, which later needed to be named and listed. I also employed member checking (also known as mirroring) by presenting the participants with my preliminary findings in terms of emerging themes and sub-themes (and as far as possible applying the terminology used by the participants), in order to provide them with the opportunity to confirm themes, correct me, elaborate or clarify where necessary, encouraging further discussions on the already created data base (Henning *et al.*, 2004; Smith & Osborn, 2003; Patton, 2002; Terre Blanche & Kelly, 2002; Creswell, 1998; Webber & Ison, 1995; Miles & Huberman, 1994).

After the initial phase of identifying possible themes, I conducted independent data analysis, before having it checked by my supervisor. I read through the data for a second time, in order to systematically start with the formal coding process. I followed a bottom-up approach in order to reach conclusions from specific consistent incidents, by identifying organising principles underlying the data and re-arranging possible themes and categories. I re-read sections of the raw data, up to the point where I was satisfied that the raw data were indexed, sorted and coded and thereafter grouped into suitable categories under appropriate code headings. This

step of *category formation* required of me to develop a classification system in terms of families of themes that consist of sub-themes, this process resulting in an interpretation based on my views and on information that I had acquired from relevant literature. I occasionally gained new insight, upon which I had to regroup codes. I continually aimed to identify relationships between the categories in order to *identify emerging thematic patterns and develop analytical frameworks*, thereby transforming my initial notes into phrases that could capture the essence of what had been established. Where necessary, I had to revisit identified categories, codes or even raw data. After identifying the emerging themes, I listed them in order to elaborate by *identifying any connections*. I focused on the refined nuances of meaning, attempting to make sense of the connections between themes and provide an interpretation of the lessons learned (reaching so-called *assertions*, as defined by Creswell, 1998). As a result, I was able to summarise and present the identified themes, consisting of relevant sub-themes. During this entire process of data analysis, I *constantly reflected* on my personal involvement and influence on the results, looking for and explaining any contradictions. I also referred back to the raw text regularly, in order to ensure that the structure and identified themes and sub-themes do indeed reflect the words and meanings of the participants (Henning *et al.*, 2004; Smith & Osborn, 2003; Terre Blanche & Kelly, 2002; Creswell, 1998; Mertens, 1998; Miles & Huberman, 1994).

I analysed *visual data* in an *open investigative manner*. I followed the guidelines with regard to repeatedly spending time with the images, discussing the images (such as asset maps and photographs of the community) with the participants (and co-researchers), simultaneously making use of other sources of information and the themes presented by them, as well as discussing my preliminary interpretations with my supervisor and other colleagues and fellow students (Kelly, 2002b).

In line with the underlying principles of PRA, the participants in my study were involved not only in data collection activities but also during data analysis. Firstly, participants were involved in checking my preliminary results in terms of identified themes and sub-themes (as described above), during focus group discussions. Secondly, they were involved in *participatory analysis* during participatory mapping activities, where they continually elaborated on and analysed the maps that they had

constructed. Participants revisited their original maps of the community during several sessions throughout the study, analysing and elaborating on each occasion. Throughout this process, participants provided feedback on preliminary themes and contributed to data analysis and interpretation by means of discussions, focus groups, workshops, group-based activities and presentation of ideas, as well as visual representations of progress made in the community (Chambers, 2004).

My decision to conduct independent data analysis (refer to the various Appendices) and interpretation, instead of relying on the software programme Atlas.Ti, was mainly based on my training as a psychologist and my feeling equipped and comfortable with analysing and interpreting data manually. Secondly, the fact that I completed the process of data analysis on a continuous basis throughout the study – even at times when I was in the field – influenced my decision. Thirdly, my experience, when I employed Atlas.Ti in analysing the raw data obtained during my first field visit, resulted in my preference for conducting data analysis manually. My preference was based on the fact that I had obtained similar themes analysing the data manually to those that I had obtained with the aid of Atlas.Ti (done by an external coder), as well as on my personal preference, experience and confidence with regard to manual analysis. Although I am aware of the potential advantages of implementing a software programme (such as Atlas.Ti) when elaborating on the results by illuminating links, similarities and contradictions, I regard my results as rich by nature and reflecting the voices and perceptions of the participants (refer to Creswell, 1998).

### 3.4 STRENGTHS OF MY METHODOLOGICAL CHOICES

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Selecting a **case study design** applying **PRA principles** implies certain advantages. Firstly, focusing on only one community (the case) enabled me to establish sound rapport with the participants, resulting in the possibility of gaining in-depth insight into their personal experiences and opinions (Merriam, 1998). Deciding to apply PRA principles further supported this advantage of a case study design, as one of the advantages of PRA lies in the rich contextual data provided by the approach, reporting on participants' own perspectives and points of view, with regard to existing challenges and opportunities. As an approach that focuses on the generation of

information and on the identification of challenges in order to address them, I could guide and facilitate participants to plan ways of addressing challenges and to put their plans into action, by planning and initiating three school-based projects (Ensign & Gittelsohn, 1998; Versfeld, 1995).

Another advantage of applying PRA principles lies in the fact that the participatory activities that I selected required limited and inexpensive resources. The selected activities can further be regarded as relatively cost-effective in terms of time, as extensive information could be constructed and obtained within a relatively short period of time. Due to their nature, the selected activities were not experienced as intrusive and can therefore be regarded as suitable for people with different degrees of experience, not intimidating those with limited self-confidence. Furthermore, the activities centred around concrete and interesting actions which were fun to perform, encouraging the enthusiasm and participation of the educator-participants. It focused on the life-worlds of the participants and therefore addressed their interests. The fact that the educator-participants enjoyed the activities, further improved the relationship between the participants and myself and served as preparation for discussions of a sensitive topic. Frequent monitoring, contact with participants and follow-up sessions prevented them from losing enthusiasm after a PRA session, and encouraged them to move into action when back in the *real world* (Leach, 2003b; International HIV/AIDS Alliance, 2001; Thompson *et al.*, 1994).

My decision to use **intervention** (combining **focus groups** and **workshops**) with the educator-participants enabled me to obtain extensive information from ten people (on average) during a relatively short time of one or two hours during each contact session. Facilitating group activities and discussions resulted in group members checking and balancing one another, thereby enabling me to fairly easily determine the extent to which their perceptions were consistent and shared amongst each other. Furthermore, the educator-participants seemed motivated and enthusiastic about the form of intervention activities and discussions, namely focus groups and/or workshops. They seemed to enjoy this format, possibly due to the social nature of the human being. Finally, by fulfilling the role of facilitator during intervention sessions, I was able to focus discussions and activities on the topic under investigation (Wilkinson, 2003; Patton, 2002).

### 3.5 CHALLENGES IMPLIED BY MY METHODOLOGICAL CHOICES

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Based on the methodological choices that I had made, I faced certain challenges. However, I was aware of potential challenges; reflecting on them in my field journal and attempting to address them, I could use such challenges to my advantage. I forthwith discuss the challenges implied by my methodological choices, as well as my attempts to address them. A discussion of general limitations of my study (not specifically applying to methodological choices) is presented in chapter six.

By choosing a **case study design**, I faced the challenges of identifying a suitable case and deciding whether to include a single case or multiple cases. I identified a suitable community based on the pilot study that I conducted in 2001, being a community facing the challenge of coping with HIV&AIDS in a region in South Africa that is characterised by high incidents of HIV&AIDS, as well as by the need for intervention. With regard to the second challenge, I did initially consider two cases, with the aim of comparing the research findings and conclusions, but eventually decided to focus on only one community (case). Amongst other considerations, I based my decision on the possibility of reducing the level of deepness of findings when reporting on two cases instead of one. Furthermore, due to the intensity of PRA-related research activities and involvement in the field in the form of intervention, an in-depth investigation of only one case probably provided a deeper reflection of an informal settlement community's way of coping with HIV&AIDS, resulting in layered texts to interpret in terms of existing literature. Although more cases usually imply a greater chance of addressing the challenge of limited generalisability potential, this was never my purpose, based on the interpretivist paradigm that I had selected (Creswell, 1998; Merriam, 1998).

I did not find the challenge of including enough information, in order to provide an in-depth view of the selected case, difficult to address. On the contrary, I had to remind myself that data had been saturated towards the end of the study, preventing me from planning additional return-visits. Although I relied on guidance from the participants, as well as saturation of the data, concerning when to terminate my visits, I undertook a few more field visits after I experienced saturation of the data,



possibly due to my attachment to the community<sup>9</sup>. By regularly returning to the community, my process of data collection might be regarded as time-consuming. I did not perceive this as a challenge though, as I ultimately aimed to gain in-depth understanding of the specific community's way of coping with HIV&AIDS, framed by the asset-based approach (Creswell, 1998; Merriam, 1998).

With regard to data analysis, I indeed faced the challenge of lengthy and time-consuming analysis activities, due to the amount of data that I had collected. With regard to potential limitations in terms of time, events and processes, I was guided by the school principal and educator-participants. As I am flexible by nature, and due to my study not being set in specific timeframes, I did not experience this as a challenge. I was, however, frustrated at times when tentative dates and appointments were cancelled at the last minute, usually due to school-related responsibilities and activities. In an attempt to deal with such frustration, I relied on reflection, as well as debriefing sessions with my co-researchers (Creswell, 1998; Merriam, 1998).

In ***applying PRA principles*** I faced several challenges. Firstly, I faced the challenge of earning the trust of the participants, in order for them to not regard us as outsider experts, but to be comfortable in taking ownership of the process and allowing 'us' insight into 'their' perceptions and experiences. I aimed to establish firm relationships of trust and to get the various participants involved in discussions on the sensitive and stigmatised topic of HIV&AIDS. I addressed this by spending extensive time on introductory sessions, relying on social interaction over lunch times, wearing appropriate clothes and communicating with participants in accordance with the level of communication that they determined. Although I continually strived to maintain a balance between being an outsider and acting as researcher aiming to gain an insider perspective, I could never assume that I understood everything about the community or the participants' perceptions. In addition, I constantly had to address the challenge of *othering*, by being aware of, acknowledging and respecting the differences between the participants and myself, and continuously striving to decrease any power differences (Reddy, 2003; Christians, 2000; Versfeld, 1995).

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<sup>9</sup> *In addition, I wanted to maintain a good relationship with the participants, as I am considering a follow-up study on sustainability after completion of this study and thesis.*



Applying PRA principles secondly implied the potential challenge of ignoring certain social relationships within the selected community, by implication excluding certain voices which were not heard. As the PRA activities that I selected involved only selected educators (who in fact are also outsiders to the community) at one particular primary school in the selected community, this potential limitation is a reality within the context of my study. I am aware of the fact that no community can be regarded as a homogeneous entity and that consensus cannot be reached by involving selected community members in participatory work. In an attempt to address this potential limitation, I encouraged diverse contributions during group activities. In addition, I conducted informal conversational interactive interviews with a variety of stakeholders and community members, attempting to obtain a balanced view of community members' perceptions (Leach, 2003b; Cornwall *et al.*, 2001).

In the third place, PRA poses the challenge of sufficiently assessing the quality of the outcome of the process, facilitating sustainable change and determining whether or not success will generate future success (Versfeld, 1995; Webber & Ison, 1995). In my study, community empowerment implies a degree of capability, which cannot be measured with pre-determined criteria or conventional modes of assessment. The success of the study rests on the participants feeling more empowered to cope with the HIV&AIDS pandemic than before the study commenced, and on their enthusiasm to sustain their ideas and initiatives, which could merely be determined by means of observation, analysis of the raw data and discussions with participants towards the end of the study. An analysis of the data indicates progress from a '*We're glad you are here to help and train us*' attitude at the onset of the study, to one of '*We are going to make a plan and put systems in place to cope with this challenge*', after completion of the project, implying that the intervention had been successful and that participants did in fact feel more competent to cope with the challenge at the end of my study. However, in order to reach a level of empowerment, I had to undertake several field visits over an extended period of time. With regard to verification of the results, I relied on member checking by insiders. Although my findings can only be applied to the selected community and cannot be generalised to other communities, I did not aim at obtaining generalisable findings, based on my interpretivist stance. Rather, findings of this study might be transferable in that trends might be

understood in similar contexts or settings, based on the substantial information I provide concerning my research setting (Seale, 2000; Jijiga, 1994; Mukherjee, 1993).

On a practical level I faced the following challenges in planning and applying PRA principles (Leach, 2003a; Cornwall *et al.*, 2001; International HIV/AIDS Alliance, 2001; Leurs, 1996; Thompson *et al.*, 1994; Mukherjee, 1993):

- ⌘ As the implementation of PRA requires training, I had to gain sufficient knowledge on the approach prior to me implementing the principles. I experienced difficulty in easily accessing PRA sources and had to apply various methods to obtain literature. In addition, I consulted with international experts in the field of PRA, in an attempt to become knowledgeable.
- ⌘ As the process and pace of PRA are determined by the participants, I could not plan the sessions in detail but had to approach them merely with a basic outline and proposed structure in mind. I could not follow any standard practices, as each PRA experience is unique. Consequently, I had to think on my feet and approach sessions with a sense of discovery, innovation and a willingness to adapt my ideas. Although I am flexible by nature, I at times experienced frustration when the process progressed slower than planned, and constantly had to remind myself that PRA takes time and that I must not rush or try to do too much in too little time. The fact that the process required lengthy involvement in the field might actually have been an advantage in my study, as it allowed sufficient time for participants to become committed and take ownership, by implication improving the possibility of sustainability.
- ⌘ I had to address the challenge of *changing attitudes and behaviour*, allowing the educator-participants to determine the process and sensitising them to the idea that they themselves could come up with solutions, as opposed to receiving answers from outside *experts*, thereby addressing power differences. Initially the educator-participants appeared to be sceptical about the process of them doing the work instead of receiving training from outside experts. Although I did not find it difficult to adapt to these changed roles by relying on reflexivity, self monitoring and self improvement, I did at times experience some anxiety and frustration when participants altered logistics of meetings.

- ⌘ I had to address cultural barriers, as my experiences, values and language differed from those of the participants. I continuously had to guard against bias, respected and rejoiced in the differences between the participants and myself, and on occasion had to rely on an interpreter to overcome language barriers. I specifically became aware of the reality of this potential challenge during a later stage of the study, when a Sepedi post-graduate student acted as co-researcher and could elaborate on a discussion in mother tongue during an intervention session. Based on the sound relationships between the participants and myself, I do, however, believe that I obtained an understanding of their views.
- ⌘ The educator-participants faced the challenge of sustaining their enthusiasm and moving into action with their plans, after my return from field visits. In an attempt to encourage them to do so, we constantly kept in touch. The process suggested that participants took ownership of the three identified projects, which possibly motivated them to sustain their efforts.

Successfully managing and facilitating the group during **intervention sessions** (**focus groups** and/or **workshops**) was challenging at times, mainly due to the presence of a few dominant speakers. I constantly aimed to keep discussions balanced and to involve quiet participants, as well as those who seemed uncertain about their viewpoints and did not participate spontaneously. In addition, I had to monitor the time spent on discussions and sessions. Upon reflection I am however satisfied that the sessions came to a logical closure with no need to have continued after they had been terminated. Despite the challenge I faced in handling dominant speakers, their presence also implied certain advantages for my study, such as their valuable contributions, the fact that they (especially one) can be regarded as leaders in the community, and that they acted as key informants – allowing me access to other community members. In this way, I did not have to identify and select key informants – they appointed themselves and once again determined the process, as proposed by PRA (Chambers, 2004; Sterk & Elifson, 2004; Wilkinson, 2004; Litoselliti, 2003; Patton, 2002; Fontana & Frey, 2000; Fox, 1998).

During facilitation of **focus groups** and **workshop activities**, I faced the challenge of limiting the potential impact of bias and manipulation. I attempted to approach

intervention sessions with an open mind and to convey this message to the educator-participants. I told participants that I would value an authentic reflection of their experiences, encouraging them to differ from others and to provide frank contributions instead of reaching (enforced) consensus or merely saying what they thought I would like to hear. Although I could not guarantee that the participants did indeed convey their own beliefs, the fact that the participants knew each other and are colleagues on a same level (except the deputy principal), as well as their strong and dynamic personalities, probably contributed to them making confident contributions, whether they differed from their colleagues or not. During the sessions and the process of data analysis and interpretation, I did, however, face the challenge of distinguishing between individuals' perspectives and the perspective of the group. In the case of differing opinions, the educator-participants occasionally tended to become overly involved in interaction, making it difficult to steer the discussions. In addition, participants sometimes turned to their mother tongue (Sterk & Elifson, 2004; Wilkinson, 2004; Litoselliti, 2003; Patton, 2002; Fox, 1998).

Dealing with a sensitive topic *in a group* context posed yet another challenge, as some participants initially experienced difficulty to share sensitive information. However, repeated sessions with the same group of people, as well as firm relationships, the safe environment of trust and the flexible nature of discussions (within the necessary perspective) allowed participants to overcome their hesitancy. As a result, educator-participants started sharing sensitive information early on in the process and became even more comfortable in doing so during later stages, allowing for more individual perspectives and an even deeper understanding. Ensuring the confidentiality of discussions amongst educator-participants was another challenge I had to address, the outcome of which I cannot comment upon. In an attempt to ensure confidentiality I stressed the importance thereof and, prior to the first session, requested the educator-participants to deal with information confidentially (Wilkinson, 2004; Litoselliti, 2003; Patton, 2002; Fontana & Frey, 2000; Fox, 1998).

Although Berg (1998) is of the opinion that *focus group interviews*, as opposed to face-to-face interviews, are limited in the sense that a group format implies limited possibility to produce in-depth data, my decision to combine focus groups and workshops, as well as the activities that I selected during intervention sessions,

allowed for detailed discussions. In addition, based on the underlying principles of PRA, participants were allowed to determine the process, allowing for enough time to explore whichever topic was under discussion. Berg (1998) further regards the fact that focus group interviews mainly rely on verbal data, as a potential challenge, and states that field notes might represent only a small portion of the verbal data collected. Once again, I addressed this potential limitation by combining focus groups with workshops, and by using PRA activities to collect data, which are often concrete and visual by nature, and usually initiate lively and extensive discussions.

With regard to my decision to use ***informal conversational interactive interviews***, Patton (2002) identifies two potential challenges, namely that this type of interview greatly depends on the conversational skills of the interviewer, and secondly that it requires a 'go-with-the-flow' approach. As a trained psychologist I do regard myself (and my co-researchers) as skilled interviewers, being able to interact with a variety of people in a variety of settings, arriving at insights easily and being able to formulate and put questions quickly. Furthermore, I am able to avoid any questions that might lead to interpretations by the interviewees or introduce any assumptions before posing the question (Patton, 2002, Breakwell, 2000). However, I did face the challenge of constantly reminding myself that I was not approaching interviews as a psychologist, but as a researcher. Therefore, despite the fact that I found this type of interview easy to conduct, I had to restrain myself from relying on psychological interpretations and interviewing skills. Furthermore, I had to revise the terminology that I employed to ensure that I was understood correctly by interviewees.

I further faced the challenge of conducting cross-cultural ***interviewing***. According to Patton (2002:391), '*Cross-cultural inquiries add layers of complexity to the already-complex interactions of an interview*', as miscommunications and misinterpretations might occur, due to language differences as well as differing norms and values. In my study, discussing a sensitive topic that is often still regarded as taboo to talk about in certain cultures, posed a definite challenge. I strived towards being a ***culturally competent researcher***, by being aware of this challenge and guarding against any misinterpretations. Besides being constantly aware of the cultural differences between the participants and myself, as well as how such differences could affect the research process, I strived to understand the dynamics of difference

(as both the participants and I brought our own unique history to the research interactions). During data collection I relied on firmly established relationships, a flexible approach, as well as sound interviewing skills to address this potential challenge. In addition, I employed an interpreter when necessary or mobilised other sources of information for the sake of clarification, such as the interviewees themselves or the educator-participants. As I cannot be certain that I addressed this challenge sufficiently, the possibility of misinterpretations remains. Adding to this, qualitative interviewing and the interpretation of qualitative interview data inevitably lead to *personal* interpretations, thereby implying *personal* impressions, regardless of efforts to obtain objective views (Blumenthal & Yancey, 2004; Kvale, 1996).

Miller and Glassner (2004), May (2001) and Breakwell (2000) emphasise that the responses of interviewees are based on the person of the interviewer, as well as on the social category of the interviewer (so-called *researcher/interviewer effects*). Therefore, being a white, graduated, middle-aged woman and conducting the interviews with community members of an informal settlement (of various levels of literacy), posed distinct challenges. As mentioned, I spent extended time on establishing sound rapport and communicated openness, interest, respect and understanding of the participants' situations and backgrounds in a non-judgemental manner. I also tried to dress in a way similar to that of the participants, thereby narrowing the gap between us with regard to the differences in our backgrounds. However, the possibility of participants responding to my age, gender and status cannot be disregarded, and this might have influenced the progress and outcomes of the interviews (Oliver, 2003; Angrosino & Mays de Pérez, 2000).

I experienced ***data analysis and interpretation*** as challenging. Due to the open-ended nature of the intervention sessions (combining focus groups with workshop activities) as well as the informal conversational interactive interviews, I had to inductively work with extensive raw data without starting with a theory of themes, but rather identifying themes that emerged. With regard to the potential challenge of not being able to generalise the findings of my study, the same comments apply as formulated for the selected case study design, applying PRA principles (Litoselliti, 2003; Patton, 2002; Cohen *et al.*, 2001; Breakwell, 2000; Kvale, 1996).



### 3.6 MY ROLE AS RESEARCHER

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During my study, I fulfilled the dual role of researcher and interventionist. I aimed to integrate these roles in terms of the methodological choices that I had made. Although I am also a scholar and practitioner in the field of Educational Psychology, I did not enter the research field as such. However, this does form part of my identity and approach to life and to people. In negotiating my roles as interventionist and educational psychologist within my role as researcher, I relied on continuous reflexivity by means of my field journal, as well as discussions with my supervisor.

As I entered the research field as a person coming from a different background than that of the participants, I had to constantly reflect on the potential influence of my status on the knowledge and meaning that took shape. As a result, I paid intensive attention to interactions with participants, in order to gain insight into their views. However, I had to maintain a balance between becoming too involved (with the implied danger of subjectivity and influencing judgment) and being too distant (which might have harmed relationships and inhibited understanding) – utilising so-called *empathetic neutrality*. The representation of what transpired and was found implies yet another challenge, as I am the one determining what is represented in this thesis and how (Patton, 2002; Mertens, 1998).

I support the opinion of Kelly (2002b), who proposes that interpretivist studies imply both an insider and outsider perspective. I followed an insider (emic) approach whilst collecting data and spending time in the field, trying to understand and express the perceptions, views and values of insiders (the participants) within their unique contexts. However, my study did not end with the mere understanding of the participants of their reality, but proceeded to an interpretation, thereby employing an outsider (etic) approach in order to express the interpreted perceptions, views, categories and concepts of outsiders (me and my co-researchers). As such, I did not simply aim to *understand*, but to also actively *interpret* the voices of the participants – trying to be truthful to the voices of the participants (insiders) but also attempting to address my research questions (outsider). On an even wider level, my participation



in the processes of data collection, analysis and interpretation, as well as my writing up of the findings, are in turn interpreted by others (Chambers, 2003; Kelly, 2002b).

As the perceptions and contributions of the participants remained my main focus, I aimed to attend to their voices throughout, supporting their voices with my own field journal and observations, and deriving meaning from an understanding of the phenomenon in question in their own terms (emic approach). I attempted to put myself in the shoes of the participants, in order to understand their practices and perspectives (Henning *et al.*, 2004; Kelly, 2002b; Babbie & Mouton, 2001; Denzin & Lincoln, 2000). I do realise though that the interpretations carried my *personal* voice, based on my own experiences and unique background. I am fully aware of the fact that the differences in language, culture, worldviews and beliefs between the participants and myself posed a distinct challenge. Furthermore, as I could only rely on the data that were reported during field visits, I do not truly have an insider view of the day to day living of the particular community. As such, I can only present my attempt to represent multiple perspectives – one of a possible many.

My role as researcher can be summarised in terms of certain specific functions that I fulfilled (refer to Henning *et al.*, 2004; Mertens, 1998). After *exploring possible research sites*, I *obtained the necessary permission* and *negotiated entry* into the community (*via* the school that I selected). Throughout the study, I networked with the principal and deputy principal (contact between the educator-participants and myself), to keep them informed of the visits, that were confirmed in writing to the principal prior to each visit. I aimed to *enter the research field* in the least disruptive manner possible, conducting meetings after school hours, when most of the learners and other educators had left. During the first meeting I focused on establishing firm rapport, in order to gain educator-participants' trust and enthusiasm to participate.

Furthermore, I fulfilled the role of *acting as research instrument*, being the primary instrument for data collection, analysis and interpretation. I had to continually reflect on who I am, as well as what the assumptions, values and biases were with which I entered the research field. I relied on a field journal and regular debriefing/reflection sessions with my supervisor and co-researchers, in order to identify changes that needed to be made. I had to cross certain boundaries, like class, race, culture and

often age. From time to time, I had to rely on an interpreter to overcome language barriers. With regard to the role of *speaking for the other*, I tried not to speak on behalf of the participants, but merely report their perceptions. Finally, I had the responsibility to *focus on my area of inquiry*, a role that I experienced as challenging. Although I was flexible and open to changes (adhering to PRA principles), I constantly had to remind myself to stay focused and not allow my exploration to spread beyond my research focus area. As I gathered such rich and extensive information, this was not always an easy task (Henning *et al.*, 2004; Mertens, 1998).

### 3.7 ETHICAL CONSIDERATIONS

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Prior to entering the research field (*via* the selected primary school), I obtained the necessary ***permission to conduct research*** from both the Department of Education (region Eastern Cape) and the principal of the school (refer to Appendix A). I obtained ***voluntary informed consent*** (Appendix A) from the participants prior to their participation in the study, in terms of both their participation and the recording of discussions. Consent was obtained after providing the participants with the necessary information to decide whether or not they wanted to participate. During initial contact sessions I focused on the nature, purpose and process of my study, as well as the data collection strategies that were to be employed. I also emphasised the fact that the confidentiality and anonymity of participants as well as that of the data would be respected, and that participants could withdraw (themselves or their contributions) from the study at any time if they wished to do so. Two participants did indeed withdraw from the study (based on valid reasons – as mentioned earlier), but arranged for other participants to replace them. No participants withdrew their consent or any raw data provided by them (Oliver, 2003; Durrheim & Wassenaar, 2002; Cohen *et al.*, 2001; Christians, 2000; Creswell, 1998; Punch, 1998).

In order to ensure ***confidentiality, anonymity*** and ***respect for the privacy*** of the participants, I do not include any identifying information with regard to the exact setting and school in which I conducted the study in this thesis, protecting the identity and privacy of both the participants and their location. I omitted or changed the names in raw data, and will destroy the recordings and transcripts after completing

the study. I undertook not to invade any participant's privacy, despite the fact that I employed observation-as-context-of-interaction during data collection. In the cases where I conducted interviews at the homes of participants (a highly private setting), I gained their consent for visiting them prior to my visits and conducted the interviews in a place of their choice, where they allowed me to observe them. My relationship with the participants and the interpreters that accompanied me might have positively impacted on the participants inviting me into their personal spaces and natural environments (Oliver, 2003; Durrheim & Wassenaar, 2002; Babbie & Mouton, 2001; Cohen *et al.*, 2001; Barrett, 2000; Christians, 2000; Punch, 1998).

I paid attention to the ethical principle of **debriefing subjects**, by inviting participants to ask questions or pose requests for more information whenever they experienced the need to do so. As visits and meetings commenced with lunch and informal discussions, participants had ample opportunity to clarify whatever they were uncertain about, on a regular basis. Apart from inviting them to ask questions in order to clarify uncertainties, I explained the potential outcome and benefits of the study to the participants and their community at the beginning of the study, and also throughout the entire process, namely that their participation might enable them to reflect upon a challenging issue with which they are confronted in their daily lives, resulting in their insight and understanding of a relevant dilemma and eventually empowering them in terms of their own abilities and skills. During the process, they had the opportunity to clarify their own thoughts and learn from the process (Oliver, 2003; Durrheim & Wassenaar, 2002; Barrett, 2000; Christians, 2000; Punch, 1998).

I adhered to the ethical guideline of **protecting the welfare** of participants to the best of my ability, by preventing them from harm (so-called **nonmaleficence**). No participant was exposed to *physical risks or harm* other than those faced during their normal day to day living. However, I had to pay attention with regard to *emotional* and *psychological harm*, due to the sensitivity of HIV&AIDS. I was open and honest about the fact that we were dealing with a sensitive issue and that it needed to be respected as such. I relied on firm relationships of trust, as well as skills, such as active listening and empathy, to keep participants from harm or to stabilise them in case they experienced discomfort, for example due to the content discussed or them being personally threatened by HIV&AIDS. During group activities I had to be

sensitive and debrief some participants after they had disclosed the HIV status of family members, resulting in them experiencing discomfort. As I dealt with such incidents immediately, I did not experience the need to refer any participant to another professional. Finally, the possibility of participants being *harmed by data analysis and the reporting of data* when reading reports on the study, and being able to identify themselves, does not apply to my study, as the outcome (namely the empowerment of the participants) can be regarded as positive and might probably result in them feeling proud of their participation (Durrheim & Wassenaar, 2002; Babbie & Mouton, 2001; Barrett, 2000; Hayes, 2000).

With regard to the ***use of deception***, I did not withhold any information from participants pertaining to my study, neither did I mislead them in any way. By employing PRA principles, I followed an open approach during which participants were involved and informed about the purpose and process of the research throughout (Oliver, 2003; Babbie & Mouton, 2001; Cohen *et al.*, 2001; Barrett, 2000; Christians, 2000; Hayes, 2000; Punch, 1998). Finally, I paid attention to the principle of ***accuracy***, reporting on and including accurate data. In reporting on my study in this thesis, I did not falsify or fabricate any data, neither did I omit any data obtained. I continually guarded against manipulating the data and reflected on potential challenges. I believe that the research team of this study (being trained psychologists) is competent with regard to the functions that they fulfilled and the procedures that they followed. Besides facilitating group activities, observing, conducting interviews and dealing with emotions and sensitive issues, we were constantly on the look-out for available resources in the community to which we could refer participants, for example with regard to questions on disclosure or the application for government grants. As such, we identified hospitals, clinics and social services during the study – based on the contributions of the participants, but also on our own exploration of resources (Durrheim & Wassenaar, 2002; Christians, 2000).

### 3.8 QUALITY CRITERIA

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I support Patton (2002) and acknowledge the fact that the quality of qualitative data analysis can be enhanced by means of rigorous methods, the credibility of the

researcher and an underlying philosophical belief in the value of qualitative inquiry, thereby valuing qualitative methods, purposeful sampling, inductive analysis and a holistic way of thinking. This implies that I (as qualitative researcher) need to reflect upon my own voice and perspective, in order to maintain a balance between a self-analytical and reflexive approach on the one hand, and an authentic understanding of the phenomenon under study in its complexity, on the other. The ultimate aim of producing a rigorous study lies in the value of trustworthiness, in other words whether or not the research audience can be convinced that a study is worth taking note of and that the findings do indeed represent reality (Babbie & Mouton, 2001).

**Trustworthiness** can be enhanced by the actions of outsider-researchers (how they interact, facilitate, deal with biases, react to empowerment and apply the principles of PRA), by continuous observation (of the process, interactions, cross-checking and adjustments that take place, whether information is distorted and whether participants are committed or not), and by reflective judgement (being self-critical, sceptic and self-aware but also sharing with peers and local people, inviting critical reviews). Within the context of PRA, the quality of qualitative studies further relies on **relevance**, which refers to the practical usefulness of a study in terms of learning and action. Relevance implies that personal responsibility and optimal ignorance be combined, by employing appropriate processes and focusing on what is relevant. Secondly, a commitment to *getting it right* is required, by relying on the purpose of and the dynamic process itself to maintain the enthusiasm and motivation of participants and to facilitate their commitment. This process requires continuous reflection and often implies a spiral, as participants are energised by fun activities, resulting in them moving into action, reaching success, becoming more energised, and so forth. In order to meet the criteria of *trustworthiness* and *relevance*, I relied on critical self-awareness, not regarding myself as the expert, but being open to listen, learn and facilitate rather than to speak, teach and control. I was also aware of the potential biases and thoughts throughout my study, reflecting in my field journal and having discussions with my co-researchers. I focused on not wanting to achieve too much in too little time and supported participants to bring their plans into action (Chambers, 2003; Thompson *et al.*, 1994).

In an attempt to add *rigour* to my study, I applied certain strategies propagated by Mayan (2001). In an attempt to *ensure investigator responsiveness* I aimed to remain flexible and sensitive, continually striving to be responsive during data collection, analysis and interpretation activities. I employed ongoing analysis, in order to plan follow-up sessions. During data analysis I aimed to stay open and revise poorly supported ideas, despite any initial potential value. Secondly, I attempted to *enhance methodological coherence* by selecting data collection and analysis methods that would best address my research questions. My selected paradigm, context, purpose of the study, research design and data collection strategies support one another and correspond logically. I was, however, flexible and open to changes when needed. Concerning the strategy of *effectively sampling participants*, I believe that the participants in my study represented the perceptions of the members of the community, possessing the necessary knowledge on the topic that I explored. Saturation of data supports this belief. I followed the strategy of *collecting and analysing data concurrently*, conducting these two processes simultaneously, in order to enable me to check data, maintain focus and monitor and confirm my conceptual task of analysis and interpretation. I also aimed to *think theoretically*, thereby constantly reconfirming emerging ideas. I checked and re-checked my data according to existing literature (chapter five) and aimed to explain correlations and contradictions. As such, I could build on existing theory but also develop new theory where appropriate. I henceforth further discuss the quality of my study in terms of the credibility, transferability, dependability, confirmability and authenticity thereof.

### 3.8.1 CREDIBILITY

The qualitative concept *credibility* is used in parallel with the (positivist) quantitative term *internal validity*. Credibility implies that I feel confident that my observations, data interpretation and conclusions are supported by raw data, thereby corresponding with the perceptions of the participants. Credibility answers to the question as to what extent the findings are truthful, in other words whether or not the trail of evidence is persuasive. Credibility implies professional integrity, intellectual rigour and methodological capability (Lincoln & Guba, 2003; Patton, 2002; Mayan, 2001; Seale, 2000; Creswell, 1998; Fox, 1998; Mertens, 1998).



I employed certain procedures and strategies in order to meet the criteria of credibility (Oliver, 2003; Woods, 2003; Kelly, 2002a; Patton, 2002; Babbie & Mouton, 2001; Mayan, 2001; Seale, 2000; Creswell, 1998; Fox, 1998; Mertens, 1998). Table 3.5 provides a summary of the strategies that I employed.

**TABLE 3.5: STRATEGIES TO ENHANCE CREDIBILITY**

STRATEGY/PROCEDURE	MY STUDY
Prolonged and extensive engagement, supported by continual observation in the field.	I undertook nine field visits over a period of two years, supporting my primary data collection activities with a field journal and observation, as well as audio- and video-recordings. I guarded against hasty conclusions and continued with field work until data saturation occurred. I placed high priority on a firm relationship of trust between the participants and myself, attempted to learn about the community and not be misinformed. I constantly reflected, in order to make decisions relevant to my study and its purpose.
Clarifying researcher bias and progressive subjectivity.	I was aware of and continually reflected on my subjectivity and biases, attempting to remain open-minded and gain insight into my personal orientations and prejudices that might influence my research and interpretations. I monitored my developing interpretations and kept record (in a field journal) of the process of change that took place.
Crystallisation/triangulation.	Discussed in more detail below.
Using a field journal and extensive field notes.	I used a field journal to describe the research context and environment, as well as document observations. In addition, I reflected on my own experiences, feelings, competencies, biases and assumptions about the research, with the aim of making adjustments where needed.
Providing rich and thick descriptions.	I aimed to provide rich, thick descriptions of the case, participants, setting and research process. As a result, the findings of this study might be transferred to other communities with similar characteristics.
Peer review or debriefing.	My initial ideas were reviewed and commented on (both informally and at more formal forums) by colleagues. During the process of data collection, analysis and interpretation, my supervisor and co-researchers served as reviewers, critical thinkers and people who guided me and allowed me to reflect and debrief, especially after sensitive and emotionally laden sessions with participants.
Member checking.	I verified emerging themes based on data collection and preliminary analysis with the participants throughout the study, by reflecting on the themes and my interpretation of the previous visit at the start of each following visit, inviting participants to verify, correct and/or elaborate. Participants were therefore involved to reflect on the accuracy and credibility of my account of their perceptions. I did not provide the participants with detailed data transcripts, analysis and interpretations to read and edit or confirm – I verbally requested their input on my report of preliminary findings and interpretations. Occasionally I summarised sessions at the end, in order for participants to correct what I may have misinterpreted or perceived incorrectly.
Providing an audit trail.	I include examples and evidence of aspects such as my ideas, field notes, raw data, data analysis and interpretations in this thesis, thereby providing a trail of evidence of the research process that I followed. This might enable any reader to gain an understanding of my decision trail whilst undertaking my study.



With regard to **triangulation** of the data, Janesick (2000) proposes the use of the term **crystallisation** in qualitative research, as this concept '*recognizes the many facets of any given approach to the social world as a fact of life*' (Janesick, 2000:392). Although both of these two terms imply a process of relying on multiple perspectives by involving various methods, participants and data analysts with the aim of clarifying meaning and obtaining a deep understanding (Chambers, 2003; Stake, 2000); Richardson introduced the concept *crystallisation* in 1994, alluding to the characteristics of a crystal, namely that it '*combines symmetry and substance with an infinite variety of shapes, substances, transmutations, multidimensionalities, and angles of approach... Crystals are prisms that reflect externalities and refract within themselves ...*' (Richardson, 2000:934). According to Richardson (2000:934) crystallisation '*provides us with a deepened, complex, thoroughly partial, understanding of the topic*'. Therefore, whilst triangulation aims at getting at the '*truth*' from various perspectives, crystallisation aims at viewing one phenomenon from various perspectives in order to obtain layered, multiple views or meanings.

I used various forms of **crystallisation**. **Crystallisation** is evident in my variety of data collection strategies, in order to gain manifold views of findings by obtaining verification from diverse sources. In addition, I used the same methods with multiple sources of information (participants) and on different occasions, in order to confirm findings, thereby using **crystallisation of sources**. Thirdly, I relied on **theory/perspective crystallisation** by approaching the data on the basis of various theories and perspectives (refer to chapter two) to interpret my raw data. By conducting the data collection activities in collaboration with either my supervisor or a co-researcher, in an attempt to balance out *personal* influences and be able to identify researcher effects, I employed **investigator crystallisation**. Finally, **analyst crystallisation** was actualised as my supervisor assisted and monitored me during data analysis and interpretation, although I was primarily responsible for doing the analysis (Flick, 2004; Kelly, 2002a; Patton, 2002).

In addition to crystallisation, I aimed to be accurate and provide detailed descriptions of the research process and context, as an attempt to ensure credibility. I identified factors that might challenge my conclusions throughout my study and while in the field, in order to reach conclusions that can be believed and taken as accurate, by

truly reporting on the experiences and perspectives of the participants. I engaged in reflection and documented personal and professional information that might have had an influence on data collection, analysis and interpretation in this thesis, as well as on my field journal (Appendix F).

### 3.8.2 TRANSFERABILITY

*Transferability* (the qualitative parallel for the quantitative [positivist] concept *external validity*) refers to the *dependability* (parallel to the quantitative term *generalisability*) of the findings of a study, in other words whether or not the findings are applicable and can be transferred to other contexts. This relies on the possibility of the data being representative of the wider population (Lincoln & Guba, 2003; Patton, 2002; Ryan & Bernard, 2000; Seale, 2000; Creswell, 1998; Fox, 1998; Mertens, 1998).

As my study focused on a specific informal settlement community, involving only selected community members whose voices do not necessarily represent those of the total community, my results and findings cannot be generalised and applied to other settings. However, generalising the findings of a qualitative study is not the explicit aim of Interpretivism. Furthermore, not presenting transferable findings is in accordance with the underlying principle of PRA, namely that different communities are unique and characterised by their own unique resources, features, challenges, priorities and preferences, and that findings are not required to be applied to other communities (Henning *et al.*, 2004; Patton, 2002; Babbie & Mouton, 2001; Janesick, 2000; Mukherjee, 1993).

It may be true that other researchers or readers of this thesis may feel that the findings can be transferred to similar contexts, settings and/or participants, but the onus of determining the extent of similarity between the research field and the identified context then lies with such external parties and not with the researcher (being me). As findings may help us to understand trends, it could be possible to apply them in similar contexts or communities. As such, as researcher, I include substantial information for the reader to be able to decide whether or not the findings might be transferred to a similar setting (Henning *et al.*, 2004; Patton, 2002; Babbie & Mouton, 2001; Janesick, 2000; Fox, 1998; Mertens, 1998).

In an attempt to enhance the possibility of other researchers indeed being able to apply the findings of my study to other settings – based on their knowledge of my study as well as that of the other settings – I endeavoured to provide rich and detailed descriptions of the research context, background, place, culture, time and process, with the aid of descriptions and visual aids (photographs, included in Appendices C and D). As a result, other researchers (readers) may compare my research site to potential sites of their choice, thereby regarding my findings as possible answers in other contexts (so-called *representativeness*) (Kelly, 2002a; Janesick, 2000; Seale, 2000; Mertens, 1998).

### 3.8.3 DEPENDABILITY

*Dependability* (or *auditability*) is the qualitative term used in parallel with the (positivist) quantitative term *reliability*. It considers whether or not the same findings would emerge if a study were to be repeated, in other words whether or not the findings could be replicated (Lincoln & Guba, 2003; Babbie & Mouton, 2001; Seale, 2000; Fox, 1998; Mertens, 1998).

Dependability implies a certain degree of consistency with regard to the measuring instrument, which is usually the researcher when conducting a qualitative study. In theory, dependability requires of various researchers to reach the same conclusions. However, in reality qualitative research (such as mine) acknowledges a naturalistic paradigm and the fact that social reality is constantly changing. As opposed to reliability which implies stability over time, this qualitative study implies change. In addition, the fact that I, as a researcher (in the roles of observer and interviewer, for example) had a significant influence on the process and outcomes, results in the fact that the same findings cannot be guaranteed on other occasions. Furthermore, as PRA implies creative interaction and diversity, the outcome of similar studies will inevitably be different every time, resulting in the limited possibility of reproducing my study (Chambers, 2004; Babbie & Mouton, 2001; Fox, 1998; Mertens, 1998).

In an attempt to meet the criterion of dependability (thereby making it possible to obtain similar findings when conducting my study in a similar way with the same or similar participants), I aimed at providing extensive documentation of my data,

methods and decisions, as well as predicting possible changes that might occur in my descriptions and reports in this thesis. This provides a so-called *dependability audit*, identifying possible changes that would need to be investigated in any future attempt to repeat my study and obtain similar findings (Babbie & Mouton, 2001; Seale, 2000; Fox, 1998; Mertens, 1998).

#### **3.8.4 CONFIRMABILITY**

The criterion of *confirmability* (with the quantitative parallel being *objectivity*) answers to the question whether or not researcher bias can be ruled out, with regard to the findings of the study – or, in terms of Interpretivism, be monitored and reflected upon. As such, confirmable findings imply data and interpretations that can be related to its sources, rather than being mere fabrications of the researcher (being me) (Lincoln & Guba, 2003; Patton, 2002; Creswell, 1998; Fox, 1998; Mertens, 1998).

Observer and researcher bias can be regarded as a given during any qualitative study, as our values inevitably influence the way in which we interpret data during qualitative analysis. In an attempt to answer to the criterion of confirmability of my findings, I acknowledged such bias from the outset and involved others throughout my study. I employed the strategy of reflexivity by constantly reflecting in my field journal. I relied on co-researchers during data collection and involved participants during data analysis and interpretation, by reflecting preliminary interpretations to them, for their views and further elaboration. In addition, my supervisor supported me in ensuring that my interpretations and conclusions are indeed supported by the data. Lastly, I aimed to provide extensive detail and examples of the logic that I employed to interpret raw data in this thesis. I include a chain of evidence (so-called audit trail), as illustration of my interpretations and the processes that I employed to reach conclusions (refer to chapters four and five, as well as the various appendices) (Babbie & Mouton, 2001; Seale, 2000; Fox, 1998; Mertens, 1998).

#### **3.8.5 AUTHENTICITY**

The criterion of *authenticity* is used to determine whether or not a balanced view of the various perspectives, views, beliefs and values of the participants is provided by

the researcher. Authenticity of a qualitative study is determined in terms of fairness and implies ontological, catalytic and tactical authenticity (Lincoln & Guba, 2003; Mertens, 1998).

I tried to meet this criterion by including a range of different perspectives (realities) and contributions obtained during my study, also reporting on contradictions and conflicting values – thereby adhering to the criterion of *fairness*. In addition, *ontological authenticity* was obtained by the participants' views and experiences of their life-worlds becoming more enriched as the study progressed, resulting in their better understanding of the community's way of coping with HIV&AIDS. In order to enhance *ontological authenticity* and report on changes in the constructions of participants, I employed member checking and an audit trail. Furthermore, my study was characterised by *catalytic authenticity*, as the research initiated action, as well as *tactical authenticity*, as community members were empowered to take action (being an underlying principle of PRA) (Lincoln & Guba, 2003; Seale, 2000).

### 3.9 CONCLUSION

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Based on the literature review in chapter two, I planned and conducted an empirical study in an informal settlement community in the Nelson Mandela Metropole, in order to explore the community's manner of coping with HIV&AIDS, by relying on existing assets and local resources. Subsequently I also explored possible changes that might be facilitated by the activist intervention research approach I followed. This chapter focused on a detailed description of the research process that I employed.

I described and justified my research methodology in terms of my research questions and the purpose of my study. In addition, I paid attention to the strengths of my methodology, as well as the challenges that I faced. I also reported on the ways in which I attempted to address such challenges. Furthermore, I described my role during the study, as well as the manners in which I adhered to ethical principles, and persistently attempted to obtain trustworthiness. In chapter four, I report on the results of my study, followed by a discussion and interpretation of the findings in chapter five, against the background of existing literature.

## **CHAPTER 4:**

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## CHAPTER 4 AT A GLANCE

### RESEARCH QUESTIONS:

- ⚡ *How is a South African informal settlement community coping with HIV&AIDS, by relying on existing assets and local resources?*  
(Descriptive research question)
- ⚡ *How can an activist intervention approach to research facilitate change in a South African informal settlement community coping with HIV&AIDS?*  
(Intervention-related research question)

DATA COLLECTION  
Field work  
Nov 2003 to Oct 2005  
Phases 1-7

RAW DATA:  
Transcripts  
Field journal  
Visual data

DATA ANALYSIS  
Thematic analysis

CATEGORIES  
**EMERGING THEMES**  
SUB-THEMES

## 4.1 INTRODUCTION

---

In chapter three I described the empirical part of my study, conducted over a period of two years in an informal settlement community in the Eastern Cape. My selected research design as well as other methodological choices were justified in terms of my research questions and the purpose of my study, as formulated in chapter one.

In this chapter, I report on the results of my study. As my study progressed, a few research questions emerged that related to my study, yet addressed separate issues. As a result, four other researchers became part of the intervention research, conducting forth-flowing intervention sessions (under joint supervision of myself and my supervisor), building on the results of my study. In order to provide a holistic view of the results of my study, I include brief discussions and the results obtained from these forth-flowing interventions. During the intervention sessions that were facilitated by these four researchers, I fulfilled the role of field worker, in addition to my role as researcher.

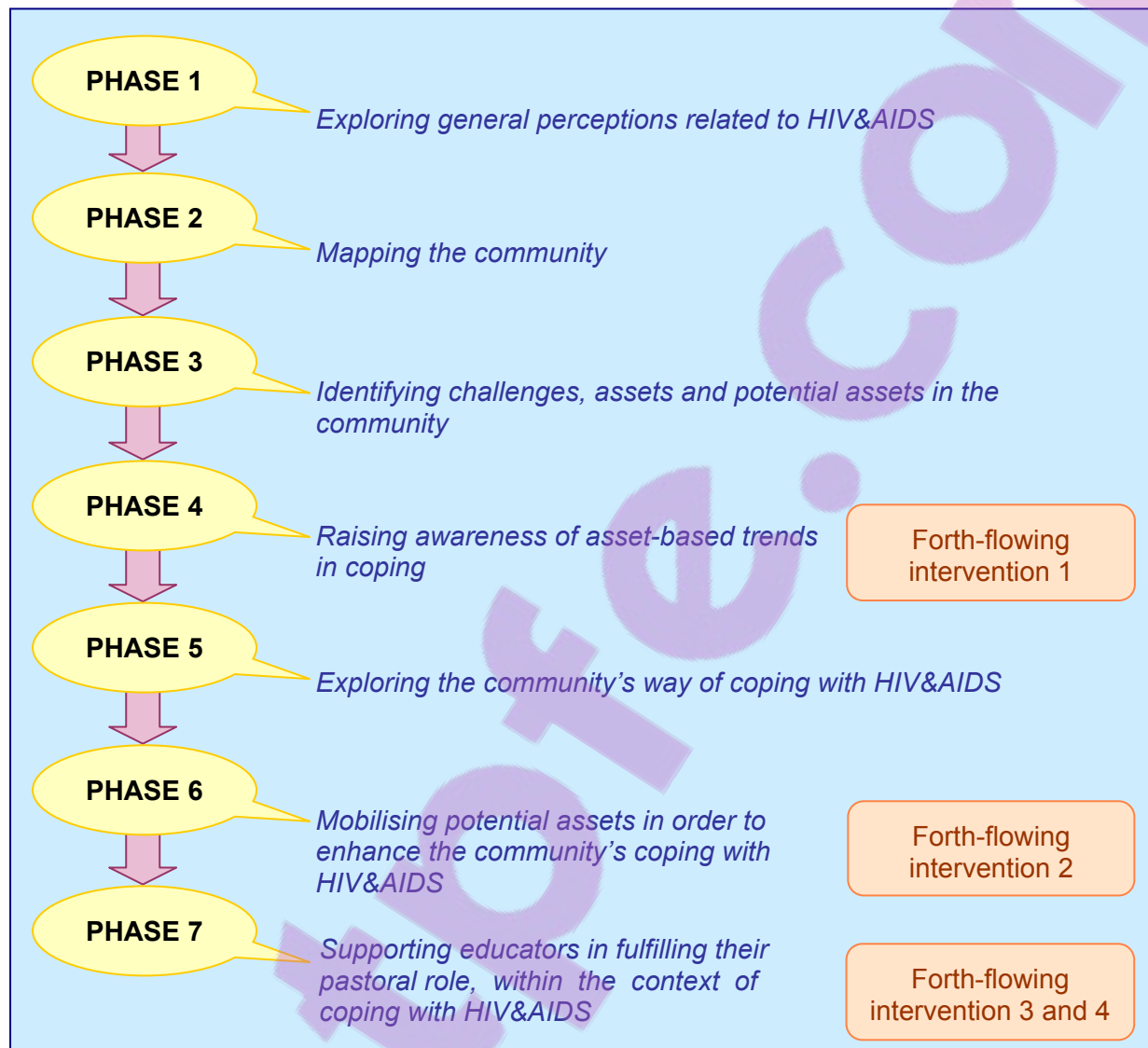
I commence the chapter by describing the objectives, processes and outcomes of the various phases of my field work. This is followed by a discussion of the themes that emerged during thematic analysis of the raw data (transcripts, visual data and my field journal). Verbatim responses and visual images are used to enrich my discussions. In chapter five I relate the emerged themes to existing literature.

## 4.2 COURSE AND PHASES OF THE FIELD WORK

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I conducted nine field visits during the period November 2003 to October 2005 (refer to Table 3.4). These visits included various intervention sessions (consisting of focus groups and/or workshops) with educator-participants, as well as numerous informal conversational interactive interviews and *ad hoc conversations* with stakeholders and members of the selected community. To supplement my contact with participants, I made video-recordings, audio-recordings and took photographs of interactions, as

well as of the community. The field work that I conducted can be divided into seven phases, focusing on distinguishable yet interrelated aspects. The various phases are summarised in Figure 4.1, followed by discussions thereof.



**FIGURE 4.1: PHASES OF MY STUDY<sup>10</sup>**

#### **4.2.1 PHASE 1: EXPLORING GENERAL PERCEPTIONS RELATED TO HIV&AIDS**

During phase one I was guided by the following questions:

<sup>10</sup> Data collected during phases 1, 2 and 5, as well as my pilot study (refer to section 1.1.1) constitute baseline data, according to which I could later monitor change (or the absence thereof), subsequent to the intervention phases.

- ⌘ *How do community members perceive HIV&AIDS and the challenges related to the pandemic?*
- ⌘ *How does the community cope with HIV&AIDS? (also part of phase five)*

#### 4.2.1.1 Objectives for phase one

As background to my study, I firstly aimed to explore the general ideas, concerns and perceptions that the educator-participants (as representatives of the wider community) held with regard to HIV&AIDS. In addition, I aimed to explore the community's way of coping with HIV&AIDS and the challenges implied by the pandemic. In line with the basic principles of PRA, I constantly had to remind myself that I had to be flexible and guided by the participants in the processes planned, as well as during the progress of the field work.

#### 4.2.1.2 Processes involved during phase one

Phase one was (mainly) completed on the first day of my first visit. After initial introductions and an explanation for our presence and proposed future involvement in the community, eleven educator-participants were involved in a focus group discussion and workshop activities. The first part of the session entailed a one hour ***focus group discussion***, exploring the participants' opinions, views and general concerns relating to HIV&AIDS, as well as the community's current way of coping with the challenge. The focus group discussion was supplemented by ***observation***, ***photographs***, ***audio-recordings*** and ***field notes***.

#### 4.2.1.3 Outcomes of phase one

Educator-participants initially appeared to be sceptical about our presence and the reason for us being there. However, they became more relaxed after I had explained the purpose of our presence and involvement, and participated well during the initial discussion on HIV&AIDS, in reply to the question on *their perceptions regarding*

*HIV&AIDS and how the community was coping with the challenge* at that time. As a result, I<sup>11</sup> was able to reach the objectives that I had formulated for this phase.

Most of the participants contributed and displayed a willingness to share their views with us, despite a few dominators and a small number of silent participants. I did, however, constantly strive towards involving all participants in the discussions. The participants' relatively extensive responses may possibly be ascribed to sound rapport, established during lunch time, prior to the focus group/workshop activities. During lunch, and the introductory part of the session, I (and my co-researcher) consciously focused on establishing relationships of trust, in order to enable us to facilitate an open and lively discussion on a sensitive topic. The transcribed focus group discussion is included in Appendix B.

---

<sup>11</sup> In the following two chapters, 'I' implies '**I, in conjunction with the participants**', as the participants actively participated and co-created knowledge, in accordance with PRA principles. In the same manner, '**my**' results and '**my**' findings imply the results and findings that I obtained based on the collaborative efforts of the participants and myself (as well as my co-researchers).

<sup>12</sup> My reflections include *personal reflections, reflections on my applied methodology and reflections regarding theoretical hypothesis and preliminary findings*. These aspects might be reflected upon separately or in an integrated manner.

*On phase one – excerpt taken from my field journal<sup>12</sup> ...*

*On our way to the community I experienced feelings of excitement but also uncertainty. Although I had planned the session and felt that I was ready to enter the field, I speculated as to whether or not my ideas would work out, to what extent we would be accepted by the participants, whether or not they would all turn up and be willing to participate, whether or not I would succeed as facilitator within a group of people who in so many ways differ from us ...*

*These feelings of uncertainty and hesitation were soon replaced by excitement and amazement, with me feeling overwhelmed. All participants turned up (in fact, one more joined), they participated in all activities (yet initially with suspicion) and shared their amazing stories. Yet on the down side, many (but not all) of the participants appeared to be there primarily due to the fact that they are going to be reimbursed for their time.*

*The lengthy lunch and socialising component was successful in establishing rapport and paved the way for a rich discussion on HIV&AIDS. However, it emphasised the fact that I will have to be flexible and be guided by the pace of the participants – which seems to be much slower than the one I had planned.*

*After our first meeting and discussion with the educators I was left speechless by my experience. In the heart of this poverty-stricken community with seemingly limited external help and resources lies a school with amazing educators and so much potential – indeed a huge asset to the community! Yet they don't seem to believe in themselves and the role that they are already playing ... I feel humble.*

*I am happy that my selected methods worked well today. I believe that the focus group discussion allowed all participants to make contributions, within the safe environment of a group. Participants could also support one another and elaborate where they wanted to add information or differ from someone else.*

*Although it is still early days (literally), I get the idea that this community (more specifically the participants) might (from a PRA perspective) benefit from the research. They have so much to offer and possess such a wealth of skills and compassion – yet they seemingly do not believe in their own abilities. This could be mobilised! The participants seem to be convinced that outside resources can assist the community in facing the challenge of HIV&AIDS and that we might be of valuable assistance to them. However, and in this regard, a distinct need to be informed on HIV&AIDS related issues seems to exist.*



#### 4.2.2 PHASE 2: MAPPING THE COMMUNITY

During phase two I was guided by the following questions:

- ⌘ *What does the selected informal settlement community 'look' like?*
- ⌘ *Which resources and potential resources are present in the community? (also part of phase three)*

##### 4.2.2.1 Objectives for phase two

During the second phase of the field work I aimed to obtain an overview of the community, in terms of existing structures, resources and facilities. I attempted to facilitate the educator-participants' awareness of available and potential resources, based on them constructing an overview of the community. This process of compiling a *community map/social map* (PRA terminology) was completed by the educator-participants during my first visit to the community.

##### 4.2.2.2 Processes involved during phase two

I (supported by my supervisor fulfilling the role of co-researcher) conducted two **intervention sessions** (combining a focus group discussion and workshop activities) with the eleven educator-participants for this phase of the study. During the second half of the first session of field visit one (on a Friday), the participants were provided with stationery (namely cardboard, coloured pens, scissors, glue and magazines) and requested to divide themselves into two groups. Both groups were asked to compile an outline of the community (in writing and/or in terms of pictures), guided by discussions within the smaller groups. Two facilitators (my supervisor and I) monitored the process. After completion of their maps, both groups displayed their maps and reported back to the bigger group, during which participants were allowed to further elaborate.

At the end of the session, two volunteers were requested to go out into the community the following day (Saturday) and take photographs, in order to elaborate on their *community maps*. I provided them with disposable cameras and met with them on the Saturday to have the photographs developed. During the second intervention session (on the Sunday), the two groups used the photographs to elaborate on their initial maps, providing visual representations of the mapped landmarks in the community. Each group again explained the content of their maps. In addition to the intervention sessions, I relied on **observation**, **visual data** and documentation in my **field journal** to obtain an overview of the community.



**FIGURE 4.2: EXAMPLES OF MAPPING ACTIVITIES CONDUCTED DURING PHASE TWO**

#### 4.2.2.3 Outcomes of phase two

Two *community maps/social maps* were compiled by each of the two groups – one in writing and one consisting of photographs. Photographs of the compiled maps are included in Appendix C<sup>13</sup>.

The educator-participants explained the lay-out of the community by referring to existing infrastructure, landmarks and facilities, such as the national road, salt lake adjoining the community, schools and churches in the community, the fire station, shops, street vendors, brick houses and shacks. By the end of this phase, I had obtained an overview of the community, as perceived by the participants – thereby achieving the formulated objectives for phase two.

#### *On phase two – excerpt taken from my field journal ...*

*One of the biggest highlights of my first field visit was to see how PRA (which I had thoroughly studied in theory) could be put into practice. Involving the educator-participants in visual concrete activities worked so well! Not only did it result in the planned outcomes for the visit, it also led to lively discussions, energy and excitement amongst all present. I am convinced that a mere discussion on the lay-out of the community would not have resulted in the rich information co-generated by using mapping activities, as proposed by PRA. I am therefore satisfied that I employed a suitable approach and methods.*

*However, I did not only experience the positive outcomes of employing PRA principles in practice. The potential hurdles of PRA that I read about prior to my field work also became a reality. I had to constantly remind myself that the participants were to determine the process, agenda and the pace of activities. Although a flexible approach during sessions came easily, it took me a while to accept the idea that we were not going to be able to finish all the activities planned for the first visit. We in fact only managed to address half of my ideas ... thus reflecting the golden rule of "The participants determining the process..."*

*At the end of our first visit to the community, after four days of hard work, I am*





<sup>13</sup> Please note that the pictures of cows, calves and snakes included on the maps in Appendix C did not form part of phase two of the study and do therefore not reflect the community maps in their original format.

*exhausted, yet overwhelmed by the great response I received. I am excited about my study and happy about the way that I facilitated activities over the past few days. I am already looking forward to the next visit. Although the participants still seem to be cautious when discussing HIV&AIDS related issues, they are progressively becoming more open and appear willing to share their perceptions with us. Some of them, however, indicated the stigma attached to the pandemic within the community, constantly refraining from using the term HIV&AIDS.*

*Based on the participants' contributions and my own observations of the community, I want to predict that the asset-based approach may be suitable as theoretical framework in analysing this community's way of coping with HIV&AIDS. The school, principal and participants themselves are great assets to the community, although they do not seem to be aware of the fact yet. In addition, we identified various resources and potential resources in the community, some of which were also mapped by the participants as part of the mapping activity.*

#### **4.2.3 PHASE 3: IDENTIFYING CHALLENGES, ASSETS AND POTENTIAL ASSETS IN THE COMMUNITY**

During phase three I was guided by the following questions:

-  *What are the main challenges (by implication needs) experienced by the community?*
-  *Which assets and potential assets can be identified in the community?*
-  *How might the identified challenges be addressed by relying on available and potential assets and resources?*
-  *How might HIV&AIDS-related challenges be coped with by relying on existing assets in the community?*

##### **4.2.3.1 Objectives for phase three**

Phase three was guided by the objectives of identifying the challenges faced by the community (at the time of the study), as well as the assets and potential assets available in the community. Furthermore, this phase aimed at identifying possible ways of coping with identified challenges (such as HIV&AIDS). This process of

identifying challenges and *assets* (asset-based approach) was initiated during my first field visit and concluded during the second visit.

#### 4.2.3.2 Processes involved during phase three

Phase three once again involved ***mapping activities*** and entailed the creation of *resource maps* (PRA), in other words *asset-mapping* (asset-based approach). Educator-participants were guided to focus on the positive aspects in their community and within themselves, the rationale being that an awareness of assets might guide the way in which community members (participants) cope with or address challenges. The process of creating *resource/asset maps* was integrated with the production of *mobility maps*, where the utilisation and optimal use of people and other resources and potential resources in the community was highlighted.

After completing the *community maps/social maps* during the second session of my first visit, the participants were requested to categorise the various components of their community maps as challenges, resources (*assets*) or potential resources (*assets available but not yet mobilised*). For this purpose, they had to paste pictures on their maps, namely snakes next to the challenges, cows next to the resources and calves at potential resources. I selected these symbols as I regarded them as traditional and familiar to the indigenous culture of the participants. Participants related to the symbols quite easily.

My second field visit flowed from this session. Educator-participants had to work from their initial maps and list the challenges the community faced (again using the snake as symbol) on a separate poster. Secondly, they had to identify ways of addressing these challenges, by focusing on the resources (*assets* and *potential assets*) available in the community. For this purpose, the symbol of a *knobkierie*<sup>14</sup> was used, to '*kill the snakes*'. Participants again worked in two groups, made use of discussions in their small groups to guide their mapping activities and provided feedback to the bigger group after the separate activities had been completed.

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<sup>14</sup> *Club/knobstick*





**FIGURE 4.3: EXAMPLES OF ACTIVITIES CONDUCTED DURING PHASE THREE**

In addition to the data generated during *intervention sessions* (focus groups and workshop activities), *informal conversational interactive interviews* with other participants (refer to Table 3.3) provided data on the challenges, resources and potential resources (*assets*) as experienced by the community. Although individual interviews did not always necessarily and primarily focus on *challenges*, *assets* and *potential assets*, these topics often did form part of the discussions that transpired. In addition, we (the research team) constantly *observed* (and *visually captured*) the community and identified challenges, assets and potential assets, relying on the asset-based approach as theoretical background. My *field journal* supplemented these data collection activities.

#### **4.2.3.3 Outcomes of phase three**

The educator-participants were able to categorise the various components included on their initial community maps as challenges, resources or potential resources. During my second field visit, the initial maps served as the basis to facilitate follow-up discussions, during which the educator-participants summarised the challenges, as well as ways to address them, by relying on resources and potential resources (*assets*) in the community. Against the background of the specific context and nature of my study it is noteworthy that educator-participants did not identify HIV&AIDS *per se* as a challenge faced by the community, but indirectly in terms of several HIV&AIDS-related issues (such as poverty, a high incidence of tuberculosis, children orphaned by HIV&AIDS and at-risk sexual behaviour) that emerged.

Refer to Appendix C for the relevant posters compiled and to Appendix D for photographs of assets (both utilised and those not yet mobilised), taken during field visits. The challenges, assets and potential assets identified during individual interviews are reflected in the transcribed interviews (Appendix E). Based on the raw data generated during the described data collection activities, I can conclude that my objectives for this phase were successfully addressed.

*On phase three – excerpt taken from my field journal ...*

*On our way to the school, I wondered whether or not all of the educator-participants would turn up, as two months had passed since our first visit. As with our first visit, I was a bit anxious and uncertain about the activities I had planned, and whether or not they would be appropriate and suitable to generate the raw data I aimed to obtain.*

*Once again, I was astonished at how well the activities worked out. Participants easily identified with the symbols I selected, enjoyed the sessions, participated with enthusiasm and created rich and extensive raw data. Nine of the eleven educators that participated during our first visit turned up, with one withdrawing from the study and one becoming involved in extra-mural activities, sending a replacement. In addition, a new participant joined us, once again resulting in eleven participants. All of the educators were glad to see us and visibly more relaxed with us being there than during our first visit.*

*The willingness of the participants to be part of the study and – even more important – make a difference in the community is truly remarkable. However, in spite of their enthusiasm and motivation to make a difference, they initially still tended to focus on the problems of the community and external support addressing them. During our facilitation we had to constantly redirect participants to the resources and potential resources as ways for the community to solve problems and face challenges. In response to our attempts (towards the end of the visit), participants demonstrated insight into the basic principles of the asset-based approach. Based on the assets and available, but not yet utilised, resources that the participants identified, I can reach the preliminary conclusion that the community is indeed relying on some assets available to them in order to cope with the challenges they face, including HIV&AIDS. However, several assets do not seem to be utilised – maybe necessitating the process of asset mobilisation?*

*We returned from the community, satisfied with our efforts, filled with admiration and exhausted after the facilitation of energy-laden sessions. I am thankful for the participants' contributions, energy and positive attitudes, making field visits such wonderful and fulfilling personal experiences!*



#### 4.2.4 PHASE 4: RAISING AWARENESS OF ASSET-BASED TRENDS IN COPING (FORTH-FLOWING INTERVENTION 1 – IN PROGRESS)

During the intervention sessions and informal conversations that transpired during the first two field visits, the educator-participants revealed a distinct need for basic knowledge regarding HIV&AIDS. At that stage they seemed willing to assist community members and the learners in their school, but voiced their concern of not possessing the necessary knowledge to answer HIV&AIDS-related questions and indicated that they would like to be informed and knowledgeable on the topic. The only two educators that seemingly displayed confidence in their existing knowledge on the topic were the Life Skills educators, who had attended HIV&AIDS workshops presented by the Department of Education.

As a result, a Masters student<sup>15</sup> accompanied me for two field visits, during which she conducted *individual interviews* with six educators (in order to determine their specific needs), upon which she planned and presented an *intervention* for ten educator-participants. This part of the intervention study took the form of *workshops*, focusing on facilitating an awareness amongst the educators of the existing asset-based trends in their current manner of coping. In addition, basic information related to HIV&AIDS was discussed and action plans formulated by the participants, focusing on aspects such as dealing with AIDS-related conditions; nutrition; emotionally supporting a person living with HIV&AIDS; and dealing with a parent and/or a learner infected with HIV (both in general and in the classroom).

After completion of the intervention, Viona and I facilitated a *focus group*, during which the educator-participants indicated that they felt enabled and better equipped to cope with the challenge of HIV&AIDS. Apart from displaying increased confidence with regard to answering HIV&AIDS-related questions when approached by family members, learners or other community members, they also displayed confidence that they would be capable to better support community members infected and affected by HIV&AIDS.

---

<sup>15</sup> Ms Viona Odendaal, MEd (Educational Psychology).

*On phase four – excerpt taken from my field journal ...*

*Viona accompanied me during the third and fourth field visits. I wondered how her presence might impact on the educator-participants and the dynamics of the group – she being a new face and yet another outsider entering a semi-closed circle ... I was happy when the educator-participants accepted her in the same manner which they accepted Liesel and me up until now. I do, however, partially ascribe the ease with which Viona established rapport with the participants to the firm relationships of trust that had been established already. During field visit four, I faced the challenge of telling the educator-participants that they would not be receiving reimbursements from visit five onwards, as the funds were exhausted. Despite my anticipation that they would show resistance, the participants accepted this fact fairly easily, indicating that they were there to make a difference in the community, and that it was no longer about the money.*

*I experienced Viona's intervention as beneficial part of the participatory intervention initiated by my study. Viona's intervention afforded me the opportunity of spending more time in the field and in the presence of the educator-participants, strengthening relationships and constantly learning more while in the field. I could sense that the participants appreciated the fact that I kept on returning – honouring my commitment of being involved in the community for a lengthy period of time and adhering to the basic principles of PRA. As such, I got the idea that I lived up to their expectations and that they in turn respected my commitment, once again strengthening our relationships of trust even further. During the individual interviews that I conducted, I appreciated Viona's support as field worker. In the same manner, I benefited from fulfilling the role of field worker whilst she conducted her individual interviews – elaborating on my existing base of raw data.*

*On the other hand, I did initially experience concern with regard to the potential (negative) impact that Viona's intervention might have on the future progress of my study. I could not be sure whether her intervention would support or compromise my project, as her intervention aimed at raising an awareness of coping within the educator-participants. I speculated about the possible impact that such an awareness might have on future coping strategies, as employed by the participants... Upon reflecting on my concerns I, however, soon realised that Viona's intervention is a piece in the participation and intervention puzzle that will contribute to the final end-product, as she focused on addressing a need identified by the participants during the first phases of my study. As such, Viona's intervention supplemented mine, thereby adding to the bigger participatory picture.*

#### 4.2.5 PHASE 5: EXPLORING THE COMMUNITY'S WAY OF COPING WITH HIV&AIDS

During phase five I was guided by the following questions:

- ⌘ *How is the community currently coping with HIV&AIDS and the challenges implied by the pandemic?*
- ⌘ *To what extent do community members rely on existing assets and local resources (asset-based approach) in coping with HIV&AIDS?*

##### 4.2.5.1 Objectives for phase five

Phase five aimed at exploring the selected community's way of coping with HIV&AIDS. As such, I explored the community's coping with the challenges implied by HIV&AIDS, for example coping with being infected with HIV, coping with a family member infected with HIV or who has AIDS, and caring for children orphaned due to HIV&AIDS. My basic assumption was that the community was coping by relying on the resources, structures, beliefs and practices already available and embedded in the community. As a result, I focused on exploring the manner in which the community was coping with that which already existed, thereby relying on the basic principles of the asset-based approach. As the participants, as well as my (and my co-researchers') personal observations could provide insight into this area of investigation, this particular phase of my study took place over the entire course of the study, although it was the primary focus of field visits three and four.

##### 4.2.5.2 Processes involved during phase five

I conducted twelve planned ***informal conversational interactive interviews*** (refer to Table 3.3) to explore how the community was coping with HIV&AIDS at the time when I conducted my field work. I relied on my own networking abilities, interviews with stakeholders who could refer me to other possible interviewees and the educator-participants to identify suitable people to interview. I strived to involve stakeholders at the various levels and conducted interviews with educators, the principal of the school through which I gained access to the community, social workers (employed by the Department of Health, Department of Social Development,

NGOs and faith-based organisations), the HIV&AIDS co-ordinator in the area (employed by the Department of Social Development), health workers (at the provincial hospital and clinics), employees of NGOs, a church minister, community members taking care of children orphaned due to HIV&AIDS, community members who were infected with HIV or those who had AIDS at the time of my field work, as well as those with a family member infected with HIV or diagnosed with full-blown AIDS. I also attended an awareness campaign of a mental health organisation and visited clinics, the provincial hospital, a community care centre and local hospice for children who have AIDS. Two of the interviews were conducted in Xhosa, resulting in me relying on an interpreter<sup>16</sup>.

Besides formally planned informal conversational interactive interviews, I further gained information during ***ad hoc conversations*** with community members and stakeholders, for example, during lunch times or when encountering community members. In addition, ***discussions during intervention sessions, observation, my field journal*** and ***visual data collection*** added to the raw data I obtained.

#### 4.2.5.3 Outcomes of phase five

Conducting individual interviews, having informal conversations, constantly observing the community and interactions taking place, documenting my observations in my field journal, and gathering visual data, provided me with a view of the community's way of coping with HIV&AIDS (addressing my objective). Besides gaining insight into the way that HIV positive community members are facing the challenge of their illness, I obtained an understanding of how community members deal with family members or friends who are infected or ill, as well as how they accommodate children orphaned due to HIV&AIDS. Phase five can be related to phase three of the study, which focused on assets (both utilised and those not yet mobilised), as the community relied on such assets to cope with the HIV&AIDS challenge. In addition to the maps and visual data included in Appendices C and D, the transcribed interviews (main source of raw data for this phase) are included in Appendix E.

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<sup>16</sup> One of the educator-participants, able to communicate fluently in both English and Xhosa, acted as interpreter. Prior to the first interview, I briefed her on issues of confidentiality, as well as her responsibility to merely interpret what I and the interviewees said and not to add her own nuances or omit any detail. I am comfortable with the way in which she acted as interpreter, although I am cognisant of the possible loss in meaning and nuances that usually accompany language barriers.

### *On phase five – excerpt taken from my field journal ...*

*I gathered extensive information from the individual interviews I conducted. Despite my initial concerns pertaining to whom to involve and how to gain access to them, I was able to schedule and conduct numerous interviews without too much difficulty. One interview led to another and towards the end of my field work I had to force myself from making more and more appointments, meeting more and more people. To be quite frank, I even believe that the last few interviews were probably not necessary at all, as data saturation had probably been reached by the end of the fifth field visit. However, I was already so involved in the community and my process of investigating various possible resources at that stage, that I simply continued exploring. I relate this to the fact that I experienced some difficulty to negotiate my roles as researcher and interventionist, constantly having to remind myself that I entered the community as researcher and therefore had to remain focused on fulfilling that role.*

*I found it easy to conduct the individual interviews. I relied on the interviewing skills that I possess and established sound rapport without difficulty during all the interviews. With the exception of one, all interviewees were willing to contribute after I had explained the purpose of my study and the principles of confidentiality and anonymity to them. Based on my experience in the field and the rich data that I obtained, I regard my choice of informal conversational interactive interviews as appropriate for exploring ways of coping with HIV&AIDS, as employed by the community.*

*At the end of this phase, I was also able to identify asset-based trends (such as community members' reliance on aspects like faith, inner strength, family and friends when faced with challenges) in the data I had obtained on the community's way of coping with HIV&AIDS. These trends suggested that the community members may be relying on the asset-based approach in coping with the pandemic.*

*The interviews with the caregivers of the orphaned children (HIV infected), as well as those conducted with participants who were infected with HIV and the family members of infected individuals, were difficult. Visiting the homes of infected community members and their families and seeing the children living with AIDS was emotionally laden and painful. One of the lowest lows of my field work was most definitely the death of one of the children whom I met during a visit when conducting an interview with her aunt, who was taking care of her at that stage. Also, observing the fear, bewilderment and confusion in the eyes of the persons living with AIDS, as well as in the eyes of their loved ones, brought a lump to my throat. I am so grateful that I always had a co-researcher by my side, to debrief with after an emotionally difficult interview!*



#### 4.2.6 PHASE 6: MOBILISING POTENTIAL ASSETS IN ORDER TO ENHANCE THE COMMUNITY'S COPING WITH HIV&AIDS (FORTH-FLOWING INTERVENTION 2)

The identification of latent but seemingly not yet mobilised assets in the community (phase three) necessitated intervention from a PRA perspective, in order to facilitate the educator-participants to mobilise and access such assets. I am of the view that it would have been unethical to withdraw from the community without facilitating the process of asset mobilisation.

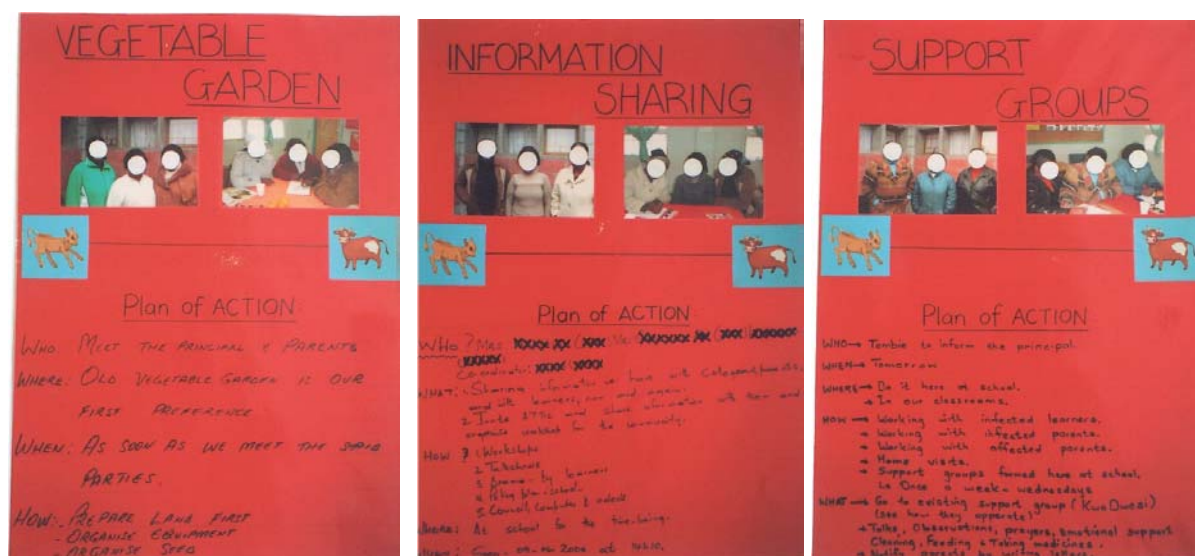
As my study primarily focused on the exploration of the community's way of coping with HIV&AIDS, a Masters student<sup>17</sup> became involved in the participatory intervention to address the question as to *how educator-participants could utilise their knowledge of assets in terms of the community's coping with HIV&AIDS* (Loots, 2005). She participated during the fourth and fifth field visits, conducting three **intervention sessions** (consisting of **focus group** discussions and **workshop** activities) with the educator-participants, aiming to explore educator-participants' *asset mobilisation* (asset-based approach), in coping with HIV&AIDS. In addition, I facilitated a follow-up discussion during an **intervention session** during the sixth field visit, in order to monitor the progress of the three projects that the educator-participants initiated during this phase, thereby monitoring their mobilisation of assets. As during the other phases, we also relied on **observation**, **field journals** and **visual data collection techniques** in collecting and documenting raw data.



**FIGURE 4.4: EXAMPLES OF ACTIVITIES CONDUCTED DURING PHASE SIX**

<sup>17</sup> Ms Mathilda C. Loots, MEd (Educational Psychology). Study completed in 2005 (please refer to list of references).

Following from Loots' (2005) part of the intervention, the educator-participants initiated three projects in the community. After identifying the proposed projects and potential assets to be mobilised, they formulated action plans and strategies to reach their goals. The educators divided into three task teams, each team focusing on a separate project. They were responsible for putting the planned strategies into action between field visits, reporting on and mapping their progress during follow-up sessions. As an outcome, a school-based *vegetable garden*, *support group* and *information centre* for HIV&AIDS infected and affected members of the community, were initiated and established by the educator-participants at the school.



**FIGURE 4.5: POSTERS ON THE PROGRESS AND FURTHER ACTION PLANS FOR THE THREE SCHOOL-BASED INITIATIVES**

The three projects further resulted in certain secondary outcomes. The *information sharing task team* (supported by Loots and myself), for example, developed a draft HIV&AIDS policy document for the school. In addition, each educator-participant formulated a personal *declaration of commitment* during the initial stages of planning the projects. Educators involved in the project selected a name for themselves as a team (namely *Masizakheni*, meaning *Let us build together*) and (upon their request) nametags stating their names next to an HIV symbol were made for them. Educators proudly wore these identifying nametags for the rest of the duration of my study, possibly indicating pride and ownership in terms of their participation.





**FIGURE 4.6: EXAMPLES OF THE OUTCOMES OF PHASE SIX**

Findings from Loots' (2005) section of the intervention research study indicate that, apart from the educator-participants mobilising potential assets in the community, the educators experienced feelings of empowerment and accomplishment after planning and successfully initiating the projects. They also showed insight with regard to the asset-based approach. As a result of their initiatives in the community, parents became more involved at the school (both men and women, not only maintaining the vegetable garden but, for example, also volunteering to assist in cleaning the school), and community members seemed to become more willing to disclose their status to selected staff members (mainly the *support team*).

This enabled the educators who participated in my study (and inevitably also other community members they encountered) to better support community members living with HIV&AIDS. Educators supported community members emotionally (by regularly visiting them), spiritually (by praying for and with them), materially (by providing vegetables, food parcels and clothing to those in need), socially (in terms of contact and visits) and on an informative level (by providing basic information on HIV&AIDS-related issues). In this manner, Loots' (2005) intervention (as participatory extension of this PRA intervention research) facilitated the empowerment of not only individuals but also of the school where she (I) conducted her (my) study, as well as the wider community in coping with HIV&AIDS.

*On phase six – excerpt taken from my field journal ...*

*Tilda's part of the intervention formed part of the broader participatory work that I had been doing over the past few months. I was excited to see whether or not the educator-participants would be able to apply the knowledge that they had obtained on asset-based principles. Up till now, they displayed potential skills as well as the motivation to utilise their skills in making a difference in the community, yet they seemed to lack the confidence to take action.*

*The outcome of Tilda's section of the intervention research study was truly amazing. Although participants displayed motivation and energy to put their plans into action after the first intervention session, I pondered on how much would have been accomplished during our next field visit ...*

*Standing next to of a large vegetable garden (on the school premises) upon our return, left me feeling humble and ashamed. How could I ever have doubted the participants' motivation to make a difference and set the wheels rolling? – in fact doubting my own theoretical assumptions regarding coping, agency and the asset-based approach! Their feelings of joy, pride and accomplishment cannot be expressed in words! The three identified projects in an attempt to mobilise potential, but not yet utilised, resources demonstrated a success in terms of participatory research!*

*Tilda's intervention enabled me to distinctly link the theory of the asset-based approach to the community's coping with HIV&AIDS. After identifying assets and potential assets in the previous phases of the study, the educator-participants were facilitated into action. They applied their knowledge of potential resources, as well as the knowledge obtained on asset-based principles, in putting their plans into action. By doing this, they were not only empowered themselves – they also seemed to have empowered other community members in coping with HIV&AIDS and its related challenges.*

*In addition to the work prior to her intervention, I relate the research outcomes of Tilda's intervention to the methodology she employed. Building on my previous field visits and relying on symbols and methods which the participants were familiar with, proved to be successful. Relying on group activities where participants were not provided with the answers but facilitated to come up with solutions themselves, further contributed to the research outcomes.*

#### 4.2.7 PHASE 7: SUPPORTING EDUCATORS IN FULFILLING THEIR PASTORAL ROLE, WITHIN THE CONTEXT OF COPING WITH HIV&AIDS (FORTH-FLOWING INTERVENTIONS 3 AND 4 – IN PROGRESS)

As my study progressed, and during later stages, educator-participants expressed the wish to acquire skills that might be employed to support or counsel people psychosocially. Memory box making and body-mapping were identified as two potential skills that might be utilised and assist educators when supporting people psychosocially. As a result, two Masters students facilitated intervention sessions in this regard, addressing questions on *the possible use of memory box making in supporting vulnerable learners*<sup>18</sup>, and *educators' use of body-mapping in fulfilling their pastoral role*<sup>19</sup>. They accompanied us (my supervisor and myself) during the seventh and ninth field visits, during which they conducted three **intervention sessions (focus group/workshop combination)** with the educators who were involved in the project.

The first session entailed an introduction to the techniques of memory box making and body-mapping, and a discussion of the basic principles thereof, after which the educator-participants had to implement the techniques with learners (or any other community members) before our next field visit. During follow-up sessions we conducted *focus groups*, exploring the educators' experiences in applying the techniques, the outcome of their intervention in terms of the learners' (community members') reactions and application possibilities of the two techniques, in fulfilling their (the educators') pastoral role. Besides the intervention sessions, we relied on **visual data collection strategies, observation and field journals**.

Preliminary findings of these two forth-flowing interventions indicate that the educator-participants experienced both the techniques favourably and as being suitable to incorporate into formal classroom activities. Apart from the techniques contributing to a warm classroom climate, they enabled educator-participants to establish closer relationships of trust with learners, providing them with more insight

<sup>18</sup> Maria Mnguni, MEd (Educational Psychology).

<sup>19</sup> Malize McCallaghan, MEd (Educational Psychology).

into the life-worlds of learners. However, educator-participants found it challenging to employ the techniques with very young learners (Ebersöhn & Ferreira, 2006).

Furthermore, the techniques occasionally resulted in learners displaying intense emotions, which the educators experienced as overwhelming and difficult to deal with. Therefore, although memory box making and body-mapping might be used by educators as first level intervention skills during fulfilment of their pastoral role, the techniques do not seem to provide educators with the necessary skills to deal with intense emotions (Ebersöhn & Ferreira, 2006).



**FIGURE 4.7: EXAMPLES OF ACTIVITIES CONDUCTED DURING PHASE SEVEN**

*On phase seven – excerpt taken from my field journal ...*

*Maria and Malize's interventions maybe constitute some of the last pieces of my puzzle. It aimed to address the needs of the participants, paying honour to them determining the process and agenda. This is PRA in action! As always, the educator-participants contributed and shared their experiences openly during the sessions. By now, they were acquainted with the basic principles applied by PRA and the methods we rely on.*



*During this phase of the study, the already present assets of the educator-participants were expanded on further. Based on their willingness to make a difference and their motivation to help people in need of support, their skills were built on. In empowering them, the underlying principles of both PRA and the asset-based approach were adhered to – all adding to the community's way of coping with HIV&AIDS.*

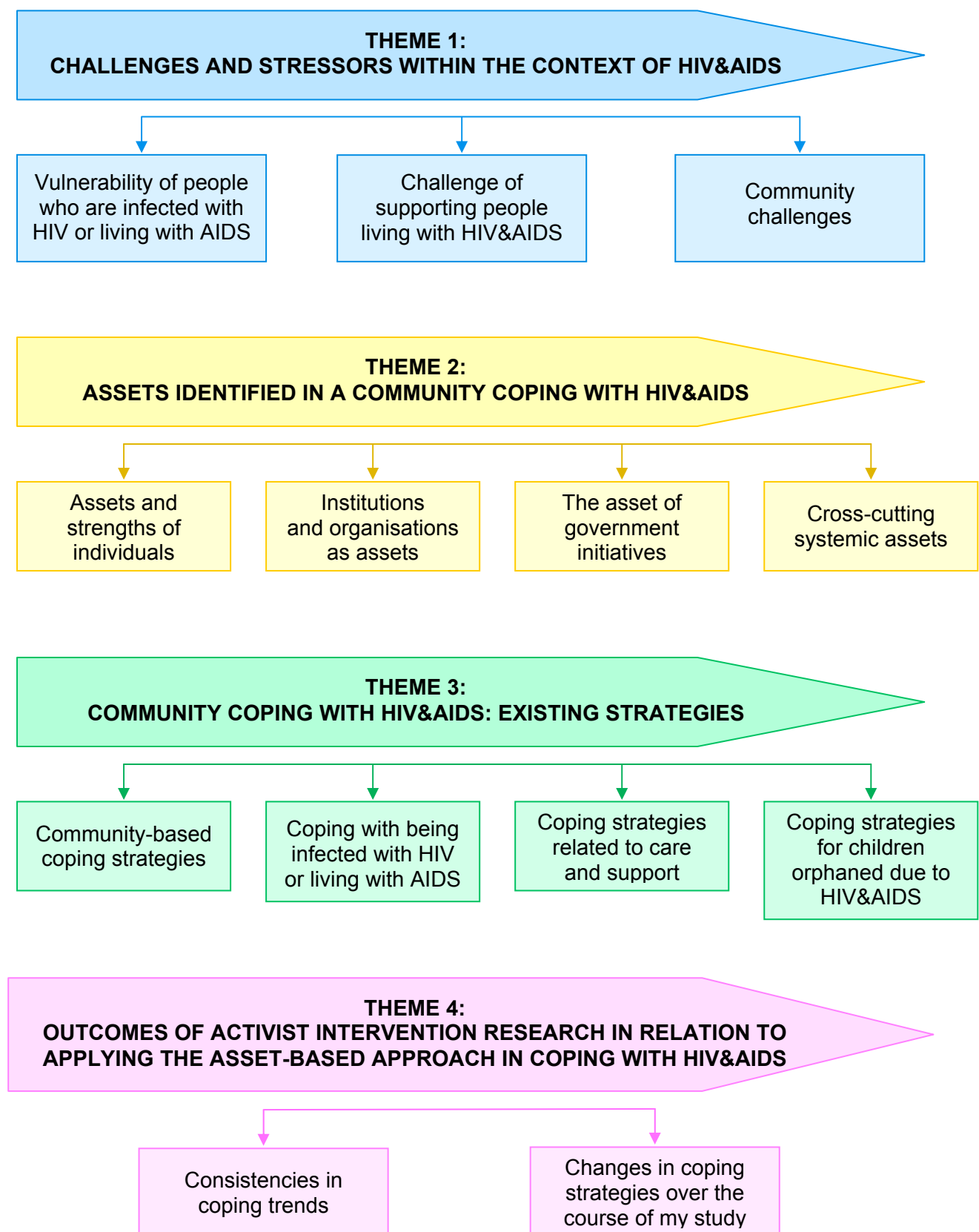
*We are on our way to the community – possibly for the last time during this study. I am quiet ... reflective. The past two years have been enriching and fulfilling in many ways – both professionally and on a personal level. Conducting research in the field with people who experience the challenge of HIV&AIDS on a daily basis, whilst employing PRA principles, broadened my skills as a researcher.*

*Despite the challenges I faced, I had the opportunity to learn and in the process gain invaluable experience, insight into my area of interest and confidence as a researcher. As I strongly believe that I still have much to learn from this community, I am already contemplating the feasibility of a follow-up study in the near future ....*

### 4.3 RESULTS OF MY STUDY

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In the next section I present the results of my study, as derived from the themes that emerged during data analysis, but also keeping in mind the categories proposed by the various phases of my study. Results are presented in terms of the main themes that emerged, each consisting of several sub-themes. Discussions are enhanced by verbatim responses where relevant. As an introduction to my discussion, the results that I obtained are summarised in Figure 4.8.



**FIGURE 4.8: OVERVIEW OF THE RESULTS OF THE STUDY**

#### 4.3.1 THEME 1: CHALLENGES AND STRESSORS WITHIN THE CONTEXT OF HIV&AIDS

I henceforth report on the results relating to challenges and stressors within the context of HIV&AIDS. I structure the section according to the following emerged sub-themes: vulnerability of people who are infected with HIV or living with AIDS; challenges associated with supporting people who are infected with HIV or living with AIDS; and community challenges within the context of HIV&AIDS.

##### 4.3.1.1 Sub-theme 1.1: Vulnerability of people who are infected with HIV or living with AIDS

I report on the vulnerability of people who are infected with HIV or living with AIDS in terms of the emerged categories. The categories are personal vulnerability, physical vulnerability, social vulnerability and cultural vulnerability.

###### 4.3.1.1.1 Personal vulnerability

Apart from regarding the general community as being *traumatized* by the pandemic, participants focused on the *vulnerability of individuals* (community members) who are infected with HIV and those who have AIDS. Awaiting the results of an HIV blood test awakened feelings like: *I was shivering, I was laughing of fear - because the way I was scared to hear the results. I was shivering because I thought the results are going to be positive* (visit 1, educator 1 during focus group 1, p16).

Participants identified *shock*, *denial* and *anger* as typical *initial reactions* upon receiving the news of being HIV positive or having AIDS. Participants noted that people infected with HIV often *avoid discussing* their disease or *resist support* from others. One of the participants summarised the tendency to deny and avoid discussions on an HIV positive status as follows: *Even if your brother becomes angry at you and say: "Leave me alone", that's also a form of denial...* (visit 1, educator 2 during focus group 1, p9), whilst another participant stated: *It's a symptom of denial that aggressiveness...* (visit 1, educator 3 during focus group 1, p13). In addition to feelings such as shock, denial and anger, participants revealed that people



sometimes *lose hope* during the initial phases of their illness: ... *because that person has lost hope...* (visit 2, educator 6 during focus group 2, p22).

#### 4.3.1.1.2 Physical vulnerability

According to the participants, community members infected with HIV are often **vulnerable due to the conditions they live in**. Social phenomena like *unemployment* and *poverty* seemed to be significant challenges faced by the community at the time of my study, leaving community members living with HIV&AIDS in *need of nutritious food, medical care and treatment*, but not always in the position to afford it, as summarised: *And that medication is damn expensive and the unemployment rate is too high – they cannot afford it* (visit 1, educator 5 during focus group 1, p11). With regard to this statement, it needs to be noted that anti-retroviral treatment was not offered to people infected with HIV free of charge at the time of the focus group discussion. As treatment is provided free of charge at present (although not in all areas yet), this statement might no longer be applicable.

Participants noted the possibility that people with AIDS (in the later stages of their illness) may apply for a **disability grant**. Although the participants regarded the disability grant as a *financial resource* (asset), they also attached negative connotations to the grant, thereby regarding the disability grant as a *potential social challenge*. Participants reported that people receiving the grant sometimes seem to *abuse the grant*, by spending the money on, for instance, liquor instead of utilising the money to provide in their basic needs, such as healthy food: ... *and they will abuse that money...* (visit 1, educator 9 during focus group 1, p6) and another response: ... *with that money, they don't buy uh... food or education. They just enjoy themselves with that money* (visit 2, educator 3 during focus group 2, p18). As a possible solution, some participants suggested that the South African government rather provide food parcels instead of money. However, other participants were of the opinion that the people who intended to abuse the grant would continue doing so, by selling the food parcels, in order to obtain money for items like alcohol.

Another negative connotation linked to the disability grant by participants lies in the tendency of community members trying to *access the grant, in order to receive an*

*income*. Two significant trends were identified by the participants. Firstly, participants held the perception that some community members would deliberately have sexual intercourse with a person infected with HIV, in order to *be infected* and eventually qualify for the grant. The following response explains this possibility: *They want this money, they don't care. They want it [it referring to the HI virus] 'cause they are going to get money now, you see. They are going to get it* (visit 2, educator 1 during focus group 2, p17).

Secondly, participants indicated the perception that community members who do qualify for the disability grant would *provide others with their own blood samples*, in order that they may also apply for the grant. This was due to the application procedures not being adhered to optimally during the initial phases of my study (*The clinics are not following the procedures correct* – visit 1, educator 10 during focus group 1, p7). Participants were of the opinion that the *statistics of HIV infected* cases were not correct: *And then somehow somehow the government will get confused because of the statistics* (visit 1, educator 11 during focus group 1, p7). It should, however, be noted that this perception might have changed towards the end of my study, as the procedures in applying for the grant were reported to be more strictly monitored at that time. The following response (taken from a discussion during one of the last field visits) emphasises the possibility of application procedures being monitored more closely: *... because of the abuse of the grant, the disability grant, the government is very strict now* (visit 6, educator 9 during focus group 3, p13).

#### **4.3.1.1.3 Social vulnerability**

Categories that emerged under this sub-theme are stigma, disclosure and at-risk sexual behaviour. In the following sections I discuss how these categories and sub-theme are present in the raw data I obtained.

##### **(a) Stigma**

According to the participants, the selected community seemed to *stigmatise* HIV&AIDS to a *great extent*. Besides *avoiding discussions of the topic*, participants noted that community members also *refrained from admitting* that people are dying of

AIDS. One participant declared: *They will just say it was something from TB or something else... It is not easy to talk about this, to say this* (visit 1, educator 1 during focus group 1, p9). Due to the apparent stigma attached to HIV&AIDS and community members seemingly denying the possibility of being infected, they tended to *avoid testing their status*, as stated by a participant: *... they don't want to go and take the tests* (visit 1, educator 7 during focus group 1, p10). Another participant related this aspect to her own feelings: *So now, if you are taking that life cover... I don't want to go and do that blood test, I'll rather leave that life cover. I don't want to do the blood test. For the time being now, I'm still fresh...* [fresh referring to *being healthy*] and later: *No, no, no! I don't want to go for testing. I don't want to know my status* (both contributions visit 1, educator 9 during focus group 1, p16).

It is worthy to note that even the participants, who seemed prepared to discuss the sensitive issue of HIV&AIDS, indicated the stigma attached to the pandemic, merely in the manner in which they provided responses. During individual interviews, participants would often *avoid using the terminology HIV&AIDS*, as illustrated by the following response: *... because everybody is coming there, you see, even those that are not living with the, with the ... this disease* (visit 3, ex-employee of the South African Police Department during individual interview 8, p5). Even during some of the very last intervention sessions, one of the educator-participants still refrained from using the words *HIV&AIDS*: *Like I was angry at first with this disease ...* (visit 6, educator 9 during focus group 3, p31-32). This educator's hesitancy to use the term might, however, probably be ascribed to the fact that her brother had been diagnosed with AIDS. However, the hesitancy of this particular educator did not represent that of the entire group of educator-participants, as several of them became comfortable with using HIV&AIDS-related terminology as the study progressed, for example making contributions like: *And they know that these vegetable we are going to take it to those houses that have a HIV and AIDS people who are suffering* (visit 6, educator 7 during focus group 3, p4).

## (b) Disclosure

Issues relating to the *disclosure* of being HIV positive or having AIDS are presented in terms of a general lack of disclosure, reasons for not disclosing, consequences of

not disclosing and reasons for disclosing. Participants reported that community members who are infected with HIV seemed to **avoid disclosure** of their status, as emphasised by responses such as: *I think in our community it's not easy for the people to come out and say in the public: "I'm HIV positive"* (visit 3, church minister during individual interview 1, p1). This tendency seems to apply to the different levels of people in the community: *You see, how can we blame others, as even the professionals they don't want to disclose* (visit 2, educator 9 during focus group 2, p25). However, participants repeatedly indicated their *ability to identify people with AIDS* in the community, as illustrated by responses like: *... and you could see the parent is very sick, the symptoms...* (visit 1, educator 3 during focus group 1, p5).

In the case of community members who did decide to disclose their status, participants were of the opinion that such disclosure was only done within the circle of a *selected audience*, mostly family members. Participants mentioned a few rare cases, where individuals apparently preferred to refrain from disclosing to their family members and rather disclosed to their friends (who might support them), due to them not wanting to cause sadness amongst their family members. One participant (a lady diagnosed with AIDS) reported on her decision not to disclose to her family:

Researcher: *May I ask you why did you decide to keep it a secret from your family but disclose it to your friends?*

Participant: *Because they are so weak you know. I'm the last born at home and they put all their hope in me, you know. And I've got this little child, so I was unable to tell them at the time I was diagnosed because I knew that they were going to feel pity for me and get lots of worries, you know. But at the end I did tell them.*

Researcher: *So you were actually being strong for them?*

Participant: *Yes* (visit 4, community member infected with HIV during individual interview 11, p4).

Participants often related **reasons for** people infected with HIV or who have AIDS **not disclosing** their status to *feelings of fear*: *The only thing that I would suspect why people are hiding this is because they are probably afraid, some individuals interpret to be positive as you are positive because you are corrupt, maybe you are linked with a prostitute or maybe you've been going with truck drivers* (visit 3, school

principal during individual interview 3, p10). Participants further identified the *stigma* apparently attached to the disease within the community as a potential cause for community members who did indeed disclose their status being *subjected to rejection and isolation*. Responses such as the following serve as examples:

- ✂ ... *because we have fears that they are going to chase me out, you see... out of their lives* (visit 1, educator 9 during focus group 1, p5).
- ✂ ... *you'll become the laughing stock in the community* (visit 3, church minister during individual interview 1, p10).
- ✂ *that people are now fearing because you are being isolated immediately you disclose* (visit 3, school principal during individual interview 3, p10).
- ✂ ... *if you ... I hear that you are HIV positive I won't speak to you again!* (visit 3, ex-employee of the South African Police Department during individual interview 8, p4).
- ✂ *What happened ... when she disclosed her status to her husband, her husband left her* [resulting in a divorce] (visit 3, ex-employee of the South African Police Department during individual interview 8, p5).
- ✂ *The only thing that I can add is that if you are HIV positive, sometimes your marriage gets broken, relationships, friendship also, but fortunately for me it was only my marriage* (visit 4, community member infected with HIV during individual interview 11, p10).

According to the participants, the tendency to *stigmatise* and *isolate* people infected with HIV or those living with AIDS did not only apply to adults, but included the entire community where I conducted my study – thereby also affecting children, as stated in the following words: *The reason why I don't disclose is even the neighbours will talk. Sometimes the neighbour will be reluctant for her child to play with mine or she want to, to, to send her to somewhere but she won't be able to do that, so that the child can feel that I'm alone and I'm not accepted and that will contribute to her health* (visit 3, caregiver 2 [aunt] during individual interview 2, p12). Participants further mentioned that community members often avoided disclosing the status of a family member who had died of AIDS, due to concern for the family members left behind, as: *the one who stays behind, is going to be labelled by his own people* (visit 1, educator 2 during focus group 1, p14).

Participants indicated the view that community members are often *ignorant* concerning basic information relating to HIV&AIDS, apparently resulting in members of the community *fearing to be infected themselves* when in close contact with an infected person. In addition, participants highlighted the tendency of the community to relate HIV&AIDS to *at-risk sexual behaviour*, evidently resulting in community members judging the people who are infected with HIV or living with AIDS. In this regard, participants indicated that members of the community very seldom disclosed their status to the church. A church minister (participant) replied as follows when asked about possible reasons for people not disclosing their status: *I would say that it's because HIV is always associated to sex. Then if you are HIV positive, it has got that bad flesh, that maybe you didn't behave in a good manner. Eh, you have AIDS because you didn't ever behave, your behaviour was bad* (visit 3, church minister during individual interview 1, p9-10). During an interview with a social worker, discussing the possible role that the church might play in preventing community members from disclosing, she made the following comment: *Then you won't participate in nothing at church. Because if you are HIV positive it's because of your sin, you've sinned in the eyes of the Lord* (visit 4, social worker 2 during individual interview 10, p9). Yet on the other hand, a few (though the minority) participants indicated positive experiences when they did indeed disclose their status to the church, such as: *... so I did tell my priest and the other church group members, and they give a lot of support* (visit 4, community member infected with HIV during individual interview 11, p5).

Furthermore, based on a few early cases (covered in the media), during which people who disclosed were rejected and even harmed, community members infected with HIV reportedly sometimes avoid disclosing their status in *fear of being harmed*. A few participants referred to examples, such as: *If you can notice it, you will remember even in Gauteng, Lulu, that lady who disclosed that, then they stoned her to death*, and also: *Even the other lady, who was the activist, they raped her and killed her because she disclosed her status* (both contributions visit 3, caregiver 1 [aunt] during individual interview 2, p12).

Participants regarded the main **consequence** for community members infected with HIV who did **not disclose** their status, to be that they *prevent* themselves from



receiving *help and support*. One of the participants compared the community members avoiding disclosure to those disclosing their status in the following manner: *Some who didn't come out with this, it is difficult to give them help, but those who talk about it – it's easy for anyone to help* (visit 1, educator 5 during focus group 1, p4). Another participant summarised the effect of not disclosing: *But if you don't have a denial problem, it is easy for the doctor, your own doctor, to help you* (visit 1, educator 3 during focus group 1, p12). In this manner, community members who reportedly needed treatment might have prevented themselves from receiving the necessary medical care: *... they wait until late, because sometimes by denial they wouldn't get those... eh... medicines* (visit 2, educator 9 during focus group 2, p21).

In the minority of reported instances where community members infected with HIV **did indeed decide to disclose** their status, it was only done to a *selected audience*, such as social workers, friends or family – apparently often **for the reason of receiving help**, in the form of *financial support* (from family members and in the form of a disability grant), *emotional support*, as well as *guidance* (from friends and family). One participant stated: *... the reason for the disclosure is because of the money* [quotation taken from a discussion on the disability grant that people with AIDS can apply for] (visit 1, educator 11 during focus group 1, p7). During another interview, the participant responded: *They disclose to the social worker only because eh ... some of them they want a grant. They only disclose to them because there's no way of getting a grant without being recommended by the social worker* (visit 3, church minister during individual interview 1, p6). **Reasons for disclosing** do, however, seemingly also include support on a wider level (and not merely on a financial level), as explained: *There's some ... some of the people are disclosing their status because they need help, they want ... they don't want to die, you see* (visit 3, ex-employee of the South African Police Department during individual interview 8, p4).

According to the participants, community members living with HIV&AIDS who have accepted their status occasionally disclosed with the aim of *being role-models* to other community members, with regard to *accepting their status and living life positively*: *I am somebody who is HIV positive and living with AIDS ... I support people and help them to disclose ... Yes, there's life after HIV* (visit 3, person

infected with HIV [ATICC employee] during individual interview 7, p3). As a result, community members who have disclosed their status sometimes seem to strive towards *educating and informing the general community* about the reality of HIV&AIDS. They apparently display the tendency to attend funerals of people who have died of AIDS and disclose the true reason for death. This does not, however, appear to be the norm, but refers to a minority of the community in which I conducted my field work, as indicated by the participants.

### (c) At-risk sexual behaviour

According to the participants, community members infected with HIV or those with AIDS often display at-risk sexual behaviour. The perception exists that they tend *not to practice safe sex*: ... *then they will tell us that they don't want to use condoms because they must have it flesh to flesh* (visit 4, social worker 1 during individual interview 10, p20). In addition, participants noted that community members infected with HIV sometimes *infect others on purpose*: *What she was saying is that she is HIV positive and she said she is not going to tell anybody cause she is not going to die alone* (visit 2, educator 6 during focus group 2, p17).

Linked to this idea, a perception emerged that community members who are infected with HIV and those living with AIDS often display a '*don't care*' attitude, not being concerned about their own sexual behaviour or falling pregnant, and, by implication, about the future of more children. One participant summarised this tendency: ... *they know about the situation and they know about the status. But they keep on* (visit 2, educator 10 during focus group 2, p16). The following excerpt serves as yet another example: *I have a brother who, who is HIV positive and, and his girlfriend ... his girlfriend is pregnant for the fourth time!* (visit 2, educator 2 during focus group 2, p10).

#### 4.3.1.1.4 Cultural vulnerability

It emerged that the Xhosa culture is perceived to be both a *social asset* and a *social challenge* within the context of my study. As the *core of the community's way of coping* with HIV&AIDS seems to stem from their culture and community members

supporting one another, culture is seen as a significant component of *coping*, as reported by the participants. The *ubuntu*<sup>20</sup> principle seemed to be operationalised by community members, in order to support one another during times of difficulty. This strategy is illustrated in the following response: ... *he used to say: “man is my brother not by blood but because we share the same burdens”* (visit 3, school principal during individual interview 3, p12). Refer to section 4.3.3 for further elaboration on the positive connotation to culture.

On the other hand, participants identified several potential challenges relating to HIV&AIDS that are based on their culture and add to the vulnerability of community members infected with HIV or living with AIDS. For example, *multiple female partners* appear to be acceptable within the Xhosa culture, whether the man is married or not. In addition, participants did not seem to regard Xhosa women to be assertive enough to demand that safe sex be practiced within marriage, even in the case of a husband being unfaithful. The phenomenon whereby Xhosa women submit themselves to their husbands was illustrated by a participant in the following words: *If you say to your husband okay, let's use a condom. We always say so, but we are forced not to use it... You are not ready for a fight and you are not ready that your marriage are going to fall apart. You give him what he wants, because he is your husband* (visit 1, educator 9 during focus group 1, p25). With regard to at-risk sexual behaviour (as evident in the selected community), participants identified the *lack of sex education by parents* within their culture as a potential contributing factor to children behaving promiscuously. One of the participants explained: *I can talk with other kids, but not to mine*, and later: *Like we don't talk about these things with our kids – it's not like this with us. Even when we are washing, our kids look away*, and then: *we as blacks...* (visit 1, educator 3 during focus group 1, p29).

Furthermore, some participants related the *hesitancy to disclose* to the African culture. The following fragment serves as illustration of this idea, taken from an interview with an aunt caring for a child infected with HIV and orphaned by AIDS:

Participant: *We as blacks we are not like you, we laugh at each other when you disclose of that. Even the kids next door, if they can, they could know that*

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<sup>20</sup> *Emphasising the importance of community and collectivism.*

*this child is suffering from this thing, they'll laugh at her and insult her about the, the, the HIV status.*

Researcher: *Why would they laugh?*

Interpreter: *It's like that to our culture. That's why many people don't disclose.*

(visit 3, caregiver 1 [aunt] during individual interview 2, p11).

#### **4.3.1.2 Sub-theme 1.2: Challenge of supporting people living with HIV&AIDS**

Participants indicated the *ability to identify* people in the community suffering from AIDS, despite the hesitancy of such community members to disclose their status. For example, one participant responded: *You could only know when you see that this person is eh ... becoming sick and very thin and then you'd start realising when you see the symptoms, but they won't say that we are HIV positive* (visit 3, church minister during individual interview 1, p5).

According to the participants, supporting people infected with HIV and those with AIDS comprises of a variety of aspects. To them, support firstly seems to imply *acceptance of people who are infected*, thereby not rejecting or isolating them. Secondly, support implies that others support the person living with HIV&AIDS by providing *financial support, food parcels and supplements* (*... even in the community if you can go to give them food parcel* – visit 1, educator 7 during focus group 1, p2). In addition, *advice* might be given and *recommendations* made with regard to changing the person's lifestyle to a healthy one, illustrated in responses like: *... sometimes they will ask questions and you must know that you are going to answer all those questions* (visit 1, educator 9 during focus group 1, p1). Lastly, others are required to display a *caring attitude* by, amongst other things, regularly visiting individuals infected with HIV and *counselling* them when needed. The following responses illustrate the component of home visits: *... she visits their homes and take them something, whatever she has she gives to them at their houses* (visit 6, educator 1 during focus group 3, p6), and: *But if, even if we can go and visit her, you'll see that at least now she is better* (visit 3, ex-employee of the South African Police Department during individual interview 8, p3).

Although participants appeared to be *willing to support* other community members (or family members) infected with HIV, they often *lacked the confidence* to do so, because of their own perceived *lack of sufficient knowledge*. Furthermore, most of the participants did not appear to perceive themselves as *sufficiently skilled* to provide the necessary emotional support. In the words of one of the participants: *We want to support them, but we don't know the way to support others* (visit 1, educator 9 during focus group 1, p2). As a result, participants indicated a *need to be informed* on aspects such as appropriate diet requirements, food supplements and a healthy lifestyle when diagnosed with AIDS.

Apart from the reported lack of knowledge amongst the community members involved in my study, participants mentioned that many *myths* and *misconceptions* seemed to be believed by community members, occasionally resulting in people being *hesitant to get involved* with or support a person infected with HIV or who has AIDS. This may possibly sometimes lead to community members (even family members) being afraid to assist a person with AIDS, as highlighted by the following response by an educator: *And still they don't believe that you can use the same chair as the infected person and whatever. So someone does not want to be ignored if he's HIV positive, so they still want to keep it from their families, they are afraid of that* (visit 2, educator 1 during focus group 2, p8). In addition to this apparent lack of knowledge and skills, participants' hesitance to support those infected with HIV or diagnosed with AIDS, seems to be linked to the stigma attached to HIV&AIDS. Participants indicated that they often refrain from providing support in order to protect the person, as other community members might observe them providing support and as a result conclude that the person is HIV positive. Statements like the following illustrate this hesitancy to support community members living with HIV&AIDS: *But I can't just give them special food, because there will be stigma. They will ask: "Why are they eating special foods?" We want to give them the support, but how are we going to give them the support?*, (visit 1, educator 9 during focus group 1, p2), and: *And even in the community, even in the community, if you can go to give them food parcel, they ask: "Why those houses?"* (visit 1, educator 7 during focus group 1, p2).

With regard to *professional counselling*, participants indicated that people being tested for HIV do indeed receive *pre- and post-counselling* at the clinic where they

are tested, yet to a limited extent. However, participants mentioned a few examples where the *testing* of community members was *not dealt with sensitively*, resulting in such community members having negative experiences. Participants indicated a definite *need for more extensive counselling* and even psychotherapy. Yet, possibly due to stigma attached to psychological services in South African indigenous cultures, participants noted that counselling services are seldom accessed: *Even with us educated people, we seldom see psychologists – we believe in general practitioners... We don't use psychologists. The only time that they get the counselling, a little bit, is when they are told about the results* (visit 1, educator 5 during focus group 1, p10).

#### **4.3.1.3 Sub-theme 1.3: Community challenges**

I discuss community challenges in terms of two emerged categories. The categories are general challenges and challenges specifically related to HIV&AIDS.

##### **4.3.1.3.1 General challenges**

Participants identified *poverty* and *unemployment* as central challenges faced by the community, as evident from responses like: *Cause financially, the problem is money...* (visit 2, educator 8 during focus group 2, p6). During an interview with the school principal, he provided some background on the community: *The neighbourhood in the sense that quite more of them are ... those infected or affected families are mostly below the poverty line type of families* (visit 3, school principal during individual interview 3, p1-2). A Catholic sister (nun) at the community care centre supported his view: *In my opinion, one of the biggest problems is poverty* (visit 3, Catholic sister during individual interview 4, p1).

Another distinct challenge identified by the participants relates to *at-risk sexual behaviour*, more specifically to the tendency of children (girls) to become involved in various sexual relationships (often with adult men). Participants related the tendency of young girls to become involved in sexual encounters to poverty, by stating that young girls provide sexual favours in return for payment (thereby becoming involved in *child prostitution*), in an attempt to combat poverty and earn the necessary money



to meet their basic needs. The following response sums it up: *To sleep around is only because they want to get some money* (visit 2, educator 11 during focus group 2, p4), and further on during the discussion: *It's poverty, that's why! ... only because they want money and then they get the, the disease from them. You see! Sugar daddy, sugar daddies!* (visit 2, educator 7 during focus group 2, p4). Another participant spelled it out in clear terms: *They must sell their body in order to get something ...* (visit 2, educator 2 during focus group 2, p6), thereby clearly indicating *child prostitution*, which is also evident from the following response: *So she was sleeping with this guy because this guy was paying the school fees, buying uniform, doing everything for her* (visit 4, social worker 1 during individual interview 10, p13).

A closely related issue revealed by participants pertains to *multiple sex partners* (*And she knew that she's not the only woman for this guy, there are also others* – visit 4, social worker 1 during individual interview 10, p13) and *teenage pregnancies* (*they are 14, 15 and 16 years of age and they are pregnant* – visit 4, social worker 2 during individual interview 10, p8). Other social challenges reportedly faced by the community include *alcoholism* (*most of the parents they are alcoholic* – visit 4, social worker 2 during individual interview 10, p8), *domestic violence* and *child abuse* (*and that boyfriend was beating her* – visit 4, social worker 1 during individual interview 10, p17), and also *And it's because the parents are not really taking good care of the children, most of them they abuse their children* (visit 4, HIV&AIDS co-ordinator at the Department of Social Development during individual interview 12, p12), *child neglect* (*Well that child must maintain her own home because her mother is alcoholic* – visit 4, social worker 1 during individual interview 10, p17), *crime*, *substance abuse* and *early school drop-outs* (*she was supposed to do standard 9 but she dropped out of school two years ago, because she didn't have money and her mother didn't ask her even one single day why she didn't go to school* – visit 4, social worker 1 during individual interview 10, p17).

With regard to the geographical lay-out of the community, participants viewed the *salt lake* adjoining the community as a challenge (problem), as indicated during mapping activities (refer to Appendix C). During discussions of mapping activities, participants ascribed their opinion of the salt lake as being a community challenge to factors like water pollution, illnesses and health problems originating from the lake, children

swimming and dying in the lake, and the lake occasionally flooding the main road of the community.

Participants noted the process of *accessing the resources (assets)* available in the community as yet another challenge that might be related to poverty and the lack of money to pay for transport. Participants (during informal conversations and discussions whilst mapping activities were taking place, as documented in my field journal) reported that community members on occasion die because they are too weak to walk to the nearest hospital or clinic, not having money to travel to the provincial hospital (which is 3½ kilometres from the centre of the community), and due to a *lack of sufficient ambulance services* and community members not having money to make a telephone call in order to summon the services that are indeed available. During an individual interview, a participant for example stated: *The clinic it's very far away ...* (visit 4, social worker 1 during individual interview 10, p6) (with the clinic being 700 meters from the centre of the community). In addition, the *lack of sufficient health and social services, as well as police services* in the immediate community were also mentioned in informal conversations, observed by me (and my co-researchers) and mapped as part of the workshop activities (refer to Appendix C). For instance, despite the fact that social workers was reported to be employed in the area by the Departments of Health and Social Development, as well as three faith-based organisations and NGOs, I could trace only one social worker permanently employed in the community at the time of my study (refer to Appendix E, specifically to the individual interviews with the employee of the ACVV<sup>21</sup> [visit 4, individual interview 9, p1-2], as well as with the HIV&AIDS co-ordinator at the Department of Social Development [visit 4, individual interview 12, p17-18]). As a result, participants voiced the opinion that the employed social worker was overworked and not able to address each and every family in need of support. In general, the social workers involved in the area appeared to feel overwhelmed with the task at hand, as summarised in the following excerpt: *... because some of the social workers, in fact most of them, say they are overworked* (visit 4, HIV&AIDS co-ordinator at the Department of Social Development during individual interview 12, p1).

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<sup>21</sup> Afrikaanse Christelike Vroue Vereniging / Afrikaans Christian Women's Association.

#### 4.3.1.3.2 Challenges relating to HIV&AIDS

Participants identified several challenges relating to HIV&AIDS. Apart from the general *challenge of coping with HIV&AIDS* (and other illnesses such as tuberculosis) in the community, participants indicated the *need for a change in attitude* by community members, as people apparently tended to judge and label other community members living with HIV&AIDS. One of the participants stated: *That means that we must change our community, we must change the communities* (visit 1, educator 10 during focus group 1, p9). Another participant elaborated: *we must as a community educate ourselves about this, then there will be no stigma* (visit 1, educator 1 during focus group 1, p14). The idea of *educating the community* in order to *overcome the stigma* attached to HIV&AIDS is indicated by responses such as: *If we educate a community, then no one will be afraid to be tested* (visit 1, educator 5 during focus group 1, p17). Furthermore, participants recorded the tendency of community members to *deny* and *not disclose* their HIV status as challenges, resulting in the members of the community infected with HIV or living with AIDS *not receiving* the necessary *treatment*.

*Taking care* of community members infected with HIV or those with AIDS was voiced as yet another challenge. In this regard, a *need for more home-based care services* (external aid) was expressed, as community members do *not seem to know how to support* people with AIDS. Participants indicated community members to occasionally be ignorant or *misinformed*, fearing infection if they were to get involved: *That's a major problem when it comes to bathing, most of the people they don't want to bath them* (visit 4, social worker 2 during individual interview 10, p17). Participants further identified the possible link between *at-risk sexual behaviour* and *ignorance* or *misconceptions* (*And then I found out these girls were confused about the AZT thing because they thought if you are pregnant and HIV positive you are going to get a vaccine to prevent your child to have HIV and whatever. So they thought the AZT is going to protect them, now they can sleep with the boys* – visit 4, social worker 2 during individual interview 10, p10).

*Orphaned children*, and related to that, *ill and dying parents*, were identified by participants as other challenges faced by the community. During a discussion on the

effect of a HIV&AIDS-related death of a parent on a child, educator-participants indicated the *need for counselling services* for such children (as well as the other members of the community). In response to the limited services that are available in the community, educators explained their role: *We are their counsellors, we are their psychologists you know. And if you are teacher, if you are a teacher, you are supposed to do it all, you see. You're supposed to do it all!* (visit 2, educator 4 during focus group 2, p11). Building on this discussion, participants further indicated the *need for being supported* themselves, due to the effect that dealing with such cases have on them personally (*It affects you as a teacher ...* – visit 2, educator 8 during focus group 2, p12). When in need of support, educators seemed to rely on one another and apparently did not receive any external support at the time of my study.

#### 4.3.2 THEME 2: ASSETS IDENTIFIED IN A COMMUNITY COPING WITH HIV&AIDS

For the purpose of presenting my results on available assets in the community where I conducted my study, I combine the aspects identified as resources with those that emerged as potential but not yet utilised resources. I therefore discuss *assets available* in the community, whether or not they have been utilised optimally by community members. In identifying potential assets, I considered the following comment by one of the participants: *But at the end of the day, make sure that these resources are acceptable to people and that they are accessed, you know, when you talk in terms of accessibility and acceptable by them* (visit 4, HIV&AIDS co-ordinator at the Department of Social Development during individual interview 12, p20).

##### 4.3.2.1 Sub-theme 2.1: Assets and strengths of individuals

I structure my discussion on assets and strengths of individuals in terms of the categories that emerged. The categories are assets and strengths of community members; and skills related to networking and negotiation.

###### 4.3.2.1.1 Assets and strengths of community members

Participants often emphasised the tendency of family members, friends, neighbours and community members to support other community members facing challenges or

being in need of support. Apart from basic support to other community members, participants identified the few *community members owning vehicles* as potential assets during mapping activities, as they could assist others with transport, for example to the hospital or clinic. *Volunteer workers* also seemed to play a significant role in supporting others. In this manner, I conjecture that community members can probably either be regarded as assets (resources) or potential assets (resources). Several of the participants emphasised the importance of not focusing on outside help, but rather getting community members involved in taking the initiative. The following comment by a social worker is significant: *So I'm for job creation, not for hand-out* (visit 3, social worker at provincial hospital during individual interview 6, p4). I wonder if this *attitude* may in itself be regarded as an asset, as it focuses on empowerment.

*Support groups* were identified as another (potential) asset for community members living with HIV&AIDS. According to the participants, support groups in local communities are usually initiated by volunteers, often by people being infected with the HI virus themselves. During the time of my field work and based on my observation and various inquiries during individual interviews and *ad hoc* conversations with members of the community, I could only trace one operating support group in the selected community, facilitated by a faith-based organisation. Participants reported the closest volunteer-initiated group to be situated in the neighbouring community. According to the participants (specifically those directly affected by HIV&AIDS), support groups meet on a regular basis (usually once a week), in order to provide each other with spiritual and emotional support, as well as to share information on how to deal with the symptoms related to AIDS, what to include in a diet, which medication and food supplements to take, or any other kind of information that they acquire. Members belonging to a support group were also reported to occasionally visit one another at each others' homes (refer to individual interviews and *ad hoc* conversations with community members infected with HIV). As such, they become like a family: *When I'm with them it's like I'm with my family. I get lots of love and I become very happy with them. So when Friday is coming I feel something inside of me, like oh, my "family" is coming, you know and it's hard when you are going to be parted* (visit 4, community member infected with HIV during individual interview 11, p4).



#### 4.3.2.1.2 Skills related to networking and negotiation

I observed that the *principal of the school* where I conducted research displayed good *negotiating skills*. For example, based on his negotiation powers, the school had an agreement with an organisation in the Netherlands at the time of my study, providing support in specific areas of growth. In addition, at the time I interviewed him, he was in negotiation with a NGO to sponsor computer training for the staff of his school,. The principal summarised his attempts: *What I'm trying to say is, there are quite a number of incentives for the teachers in the community, and I am going to keep on trying, I want to go and unlock other opportunities for the community in which I find myself in* (visit 3, school principal during individual interview 3, p11). My supposition is that the principal's negotiating skills be regarded as an important potential asset, which might be utilised to *negotiate for further support* by organisations such as NGOs or faith-based organisations.

In the same way, one of the *social workers* at the provincial hospital described a bead work project that she had initiated, where unemployed women do beadwork which is sold, often to international supporters (refer to Appendix E, individual interview 6, p4). I propose that such initiatives by stakeholders of the community may indicate potential *networking powers* which might be utilised further (potential asset on the macro-level). Other examples of skills relating to networking and negotiation that were evident in the community at the time of my field work include the skills of the *HIV&AIDS co-ordinator* of the region (observed by me and indicated during visit 4, individual interview 12, p12: *... but I provide the NGOs but sometimes I go to them, for instance if I've got a crisis*), as well as employees of the ACVV and NGOs (indicated during individual interview 7, p6 and individual interview 9, p17) who were reported as regularly networking with other organisations (both on government and non-governmental level), in an attempt to negotiate external assistance to community members in need of support.

#### 4.3.2.2 Sub-theme 2.2: Institutions and organisations as assets

Categories that emerged under this sub-theme are: the community care centre, educational institutions, political-related assets, NGOs, assets related to health, and



faith-based organisations. I discuss how this sub-theme and categories are present in the raw data in the following sections.

#### **4.3.2.2.1 Community care centre**

During mapping activities (refer to Appendix C), educator-participants identified the community care centre as a potential asset to community members. I further relied on informal inquiry from other participants and community members, observation, visual data in the form of photographs (Appendix D) and an individual interview with the founder of the centre (Appendix E – individual interview 4, Appendix G – documentation on the care centre), in order to explore the facilities the care centre offers. Based on my investigation, I determined that the care centre was initiated close to the community (actually situated in the neighbouring community) by a Catholic sister, and that the centre is run by volunteer workers and with the financial support of external organisations. The centre serves the immediate communities and apparently addresses problems such as illnesses (including HIV&AIDS), poverty, alcohol abuse, substance abuse, malnutrition and people in need of medical care, spiritual guidance or psychosocial care. In addition, services seem to be provided to senior citizens, illiterate adults and pre-primary and primary school children. The centre is said to be operated in accordance with the philosophy that people coming to the centre must not receive *hand-outs* but give something in return, for example collect cans that might be recycled. Community members are apparently also encouraged to become involved in self-help projects.

With regard to the potential value of the community care centre as an asset to community members of the informal settlement community where I conducted my study, I wonder whether or not community members will indeed access the services offered by the centre. As the centre is situated in the neighbouring community (yet close [approximately 1 kilometre] to the centre of the community where I conducted my study), I propose that community members might not perceive the centre as an asset in their immediate environment. I raise these questions based on my data collection activities, during which it seemed evident that institutions and professionally employed participants were mainly aware of the centre and the

services it provides, as opposed to community members at ground level who did not regularly identify the centre as an asset.

#### **4.3.2.2 Educational institutions**

Being central institutions in the community, the *schools* (namely two primary schools, two high schools and several crèches), *school principals* and *educators* were identified as important assets by the participants in my study. The potential role that schools and educators might play in guiding other community members is summarised in the following contribution: *I think that we as a school, as teachers, it is our responsibility to call the community to train the people* (visit 1, educator 4 during focus group 1, p12). With regard to the *parents of the school*, participants viewed only some of the parents as assets, as illustrated by responses such as: *We didn't say they're coming to school all of them. No, they're coming to school some of them, you see* (visit 2, educator 9 during focus group 2, p21). In addition to the identification of schools, the *university* close to the community was also indicated as a potential asset by the participants and observed by us (my co-researchers and I).

Based on my observations, *ad hoc* informal conversations, planned data collection activities and, I suppose, also the outcomes of my research, the school where I conducted field work emerged as an institution fulfilling a significant role in meeting the needs of community members infected with and affected by HIV&AIDS. The school principal, for example, summarised the school's involvement and commitment to support the community in the following manner: *And this year we have declared that we are going to make a difference, and not in the classroom alone, but the communities. In the next five to ten years they must always remember that there have been the teachers in the year 2004 that have been very concerned with the plight of the communities in which we find ourselves in* (visit 3, school principal during individual interview 3, p8).

With regard to the learners, the school seemed to fulfil the role of identifying vulnerable learners (those with a dying parent, orphaned by AIDS or infected with HIV themselves) and taking care of them, for example by providing food and support: *What the teacher did is she gave him a bread, a loaf of bread everyday* (visit 2,

educator 2 during focus group 2, p12). Although the following contribution was made by the principal only after I've been involved in the community for three months, it emphasises the school's efforts to support the community: *we are starting to get hold of the NGOs so that they can be given some clothes and the meals and with the meal again it can make a difference to one's life* (visit 3, school principal during individual interview 3, p2). Furthermore, educators-participants reported that HIV&AIDS was included as a topic of discussion at meetings (with staff but also with parents) more regularly towards the end of my field work. In addition, the school apparently invited social workers and others to address such meetings from time to time.

I regard the *knowledge* and *positive attitudes* of both the educators and the school principal (that were reported on, observed and noted in my field journal) as a key asset in supporting the community. The following excerpt serves as evidence: *You want to give help, you want to give help, because you could see this person has no one to help her. Even if it's financial, just a little bit. Not that much solution, you see, just to like buy food parcel or give her something, like fruit* (visit 2, educator 6 during focus group 2, p24). Another participant emphasised the school's and educators' *willingness* to make a difference: *But we want to do more, we want to do more. Like we said last time, that we wish to have a garden here in our school* (visit 2, educator 3 during focus group 2, p28). However, in dealing with learners whose parents had died, educators reported on their own experiences of difficulty and the need for support. Educators apparently had to rely solely on themselves, their knowledge (yet another asset) and the resources available amongst themselves in supporting vulnerable children: *I will go to my colleague and eh..., trying to help this child and afterwards I will see this is how we helped each other. And we are giving care to each other* (visit 2, educator 1 during focus group 2, p12).

#### **4.3.2.2.3 Assets related to political organisations**

Participants identified *meetings by political parties*, as well as *unions* (such as the Union of South African Provincial Teachers or Women's unions) as assets. Some participants suggested that such meetings might serve as *information sessions*, during which community members might receive basic information on issues like

HIV&AIDS: ... *particularly it's predominantly African National Congress area and in a number of meetings that I have attended, they will always speak about the sketch of the HIV AIDS* (visit 3, school principal during individual interview 3, p3). In addition, participants indicated (and I observed) that the *African National Congress* has an office situated in the community, which, I propose, could be utilised as an asset.

#### **4.3.2.2.4 Non-governmental organisations (NGOs)**

Participants identified several NGOs as potential resources during intervention sessions, individual interviews and *ad hoc* informal conversations, for example the Ubuntu Education Fund, Barnabas Trust, LAMULA and the AIDS Training, Information and Counselling Centre (ATICC). Even though participants seemed to be aware of the potential services that might have been provided by NGOs, participants were of the opinion that such services were not utilised to their full potential at the time of my field work. My investigation revealed ATICC to be the most prominent NGO in the community where I conducted my study and, at certain levels, involved in the community. Participants, for example, reported that ATICC materially supported selected families in need and presented workshops in the area that might be attended by community members. The following excerpt was taken from my interview with the school principal, reporting on the potential role of ATICC: *They conduct workshops. They make pre- and post-counselling. They also provide clothing and food, especially for the families that have need, that's what they do* (visit 3, school principal during individual interview 3, p6).

Several participants (employed by NGOs and the Department of Social Development) remarked that the particular (selected) *community had been neglected* by external service providers in the past and that outside agencies could become more involved in supporting the community: *Yes, when you mention that area ... there's always something that I've neglected with that area* (visit 3, ATICC employee during individual interview 7, p1), and: *You know that area is a little bit neglected, because our social workers are working there but as I say they are not really doing what they are supposed do* (visit 4, HIV&AIDS co-ordinator at the Department of Social Development during individual interview 12, p5). I conjecture that NGOs may have the potential to offer valuable assistance to the community where I conducted

my study (as in other geographical areas), but they seemingly still need to be mobilised. According to the participants, the potential value of NGOs can firstly be ascribed to the *training and workshops* they might present in the community. Secondly, NGOs are regarded as a *potential financial asset*, as participants appeared to perceive NGOs as a source of funding or other related initiatives to support community members infected with HIV or those who have AIDS.

As mentioned, participants identified ATICC as a *prominent (potential) asset* in the community. Participants indicated awareness of the services offered by ATICC, but indicated that such services were not fully utilised in the community at the time of my study. Based on the contributions by educator-participants during intervention sessions, as well as individual interviews with stakeholders, community members and an employee at ATICC (refer to Appendix E – Individual interview 7; Appendix F – Documentation on ATICC), it became evident that this NGO provides services such as *training, information and counselling services* to community members at a variety of levels. ATICC appeared to present *workshops* on HIV&AIDS, both on introductory and advanced levels, to professionals (such as nurses, educators and business people), community members, significant groups in the community (like traditional healers) and lay-workers. With regard to traditional healers, the ATICC employee whom I interviewed, stated that workshops focus on aspects like sterilisation of instruments and hygienic measures when treating patients, treating symptoms related to AIDS in traditional ways, as well as educating traditional healers regarding the fact that AIDS cannot be cured. Community-based workshops apparently focus on educating community members in terms of basic HIV&AIDS-related information, where to obtain medication in case of being HIV positive, supporting a person living with HIV, sexually responsible behaviour and living positively with AIDS. For this purpose, peer educators are trained and employed, emphasising one of the basic principles of ATICC (as reported by the ATICC employee), namely *training the trainers*. In addition, ATICC organises and facilitates *health forums* at clinics in communities (targeting areas with a high infection rate), where volunteer community members were indicated to be involved in training other community members, paying *home visits* to people infected with HIV or living with AIDS, and assisting in areas like gardening. Services such as home-based care training are also offered.

According to the ATICC employee I interviewed, ATICC *facilitates sectoral forums and council meetings* on a broader level, involving other NGOs, the South African government, schools, clinics, tertiary institutions, representatives of particular groups in the community (for example traditional healers), businesses and local companies, in order to discuss the initiatives employed in the community and to prevent duplication. ATICC seem to also focus on *marketing and fundraising campaigns, networking* with partners such as the South African Broadcasting Corporation (that I propose to be yet another asset) in order to support orphaned and vulnerable children and families in the form of food parcels, clothing, counselling and support. On an international level, ATICC is reportedly also supported financially by companies abroad.

#### **4.3.2.2.5 Assets related to health**

I relied on observation, as well as intervention sessions, interviews and *ad hoc* conversations in identifying *clinics, hospitals* (one provincial hospital and one treating tuberculosis patients), *doctors, nurses* and *social workers* as important (potential) assets, specifically within the context of supporting community members infected with HIV or having full-blown AIDS. Despite my observations and reports by participants indicating that these facilities and services were limited and not situated within the community itself at the time of my field work, participants appeared to recognise the potential of such facilities. Responses such as the following illustrate this idea: *... the clinic, that's where they're going to get help* (visit 2, educator 9 during focus group 2, p23).

Participants alluded to the following possible services which might be provided by these facilities and people: *medication (treatment)*, the *provision of information* and *pre- and post-counselling* (both on mental health issues and aspects like nutrition). Based on interview data and my observations, I ascertained that pre- and post-counselling were provided to community members being tested for HIV, yet to a limited extent. Participants suggested that this service could be developed further in order to address the need for counselling, not only of community members with AIDS but also of their family members. The possible role that *ministers* may play in *counselling* community members was also mentioned by participants. Furthermore,



in informally conversing with stakeholders and community members I determined the existence of a *hospice* situated in the area, which I visited and observed. I regard the hospice (approximately ten kilometres from the centre of the community) as a potential asset that might support community members living with HIV&AIDS, despite the fact of it being situated relatively far from the centre of the community.

#### **4.3.2.2.6 Faith-based organisations and churches**

Participants' identification of churches, ministers and church workers as (potential) assets are supported by my observations, despite the seemingly negative connotation to churches stigmatising and being judgemental of people living with AIDS. However, in the case of community members disclosing to the church, participants regarded this institution as an asset, as illustrated in the following excerpt: *... so I did tell my priest and the other church group members, and they give a lot of support. They give advice, emotional support ...* (visit 4, community member infected with HIV during individual interview 11, p5). Participants indicated that churches, ministers and church workers might assist community members with *household chores* (like cleaning), *visit them at home*, *support them emotionally* (support groups, the church-based social worker or auxiliary worker), *support them spiritually* (prayer group) or *financially* by providing money or food. With regard to potential assistance to church members, the church minister with whom I conducted an interview (Appendix E – individual interview 1, p14) regarded his (the *minister's*) *knowledge* of the churchgoers and their needs as an asset, possibly as a means to identify needs and organise assistance.

Concerning *traditional healers*, participants acknowledged traditional healers as a *potential asset* to community members. However, participants often appeared to experience traditional healers in a *negative manner*. Although community members infected with HIV reportedly tend to initially visit traditional healers (*So since they didn't come back with a tangible reason, they thought the white people cannot see the cause of her illness. So she said, let me use the black thing – let's take it to the traditional healer. She knew that she's HIV positive but she was not ready to tell them* – visit 4, social worker 1 during individual interview 10, p12), the outcome of such visits seems to often be regarded in a negative manner (*So if you drink a*

*traditional healers' medication and you are already infected with HIV, it can make you more sick because they are very strong* – visit 4, social worker 2 during individual interview 10, p11).

Participants (supplemented by my own investigation, observation and field notes) also identified the ACVV (Afrikaanse Christelike Vroue Vereniging/Afrikaans Christian Women's Association), a faith-based organisation, as an *important potential asset* for the community. I visited and observed the organisation's regional offices to be situated approximately five kilometres from the community. Based on my observation and reports by the participants (refer to Appendix E – individual interviews 9 and 10 with employee's of the ACVV), supplemented by documentation on the organisation (Appendix G), the ACVV appeared to be involved in supporting the community at the time of my field work. Involvement in the community included the *services of a social worker*, operating from a school in the community. As reported by an employee of the organisation (Appendix E – individual interview 9), the social worker however appeared to be overworked and not able to deal with the full range of cases, as a result mainly focusing on child neglect and abuse in the community. Other services offered by the organisation at the time of my study included a weekly *youth group* (focusing on discussions and offering annual camps) and *women's groups* (where women receive support, education and acquire skills, in order to generate income) (refer to Appendix E – individual interview 9 and Appendix G – documentation pertaining to the organisation). In order to be able to facilitate such groups in the community, the ACVV reportedly initiated *fundraising projects* and mobilised a physical resource in the community, namely a local church, where they could conduct meetings (*Since we don't have a community hall, we are using that church* – visit 4, social worker 1 during individual interview 10, p4). During meetings, the organisation apparently provided attendees with food/refreshments, in my view *addressing community members' basic needs*. In response to the lack of sufficient facilities, members of the organisation indicated that they were planning on building a *community centre* in the community (after obtaining money from the *national lottery*). Participants voiced their opinion that the community centre could offer them with their own premises in future, from where they held the prospect of empowering community members, to be able to help themselves. The following statement illustrates the potential value of the planned community centre (translated from Afrikaans): *And we*

*are very excited about this new service centre and everything that we are going to build, because if you can change that into a one stop service centre – a welfare centre ...* (visit 4, ACVV employee during individual interview 9, p17).

Both my interview and observational data indicated the ACVV's involvement on an individual level in the community as being supportive by nature, for example, by providing *food parcels* to families in need. Furthermore, the organisation started a *crèche* for needy children in the community, in my view providing in their basic physiological needs on a daily basis. Employees of the organisation reported that the organisation initiated and maintained a few *food gardens in the community*, apparently providing seed (when available or received from a sponsor), guidance and support.

Within the context of HIV&AIDS, the social workers situated at the ACVV offices (therefore not the one already mentioned as being situated at the school) reportedly facilitated a *support group* in the community where I conducted my study on a weekly basis (*yes, we do have a support group but it's a new thing* – visit 4, social worker 1 during individual interview 10, p3). During weekly meetings, guidance was reportedly provided on nutrition, treatment and a healthy lifestyle (of people living with HIV&AIDS or in support of others), how to live positively with HIV&AIDS and supporting people living with HIV&AIDS emotionally. In addition, *home-based care* seemed to be provided by the social workers and home visits paid to community members preferring not to attend the support group. Furthermore, social workers reported that they assisted community members in *applying for financial grants* (such as the disability grant) in cases where individuals were eligible to qualify for such a grant (*Then, if we find that this one can qualify for a grant then we go, we just tell her: "You do qualify for a grant, this type of a grant, you can go to hospital D." Then we write a letter and ask hospital D to help us with this person* – visit 4, social worker 1 during individual interview 10, p17). The social workers also indicated their involvement at schools, in *giving talks* to learners at the schools in the area when requested to do so, on topics related to life skills, including HIV&AIDS (*... it was Mrs M, that approached me to come to school Z, to help her with the life orientation* – visit 4, social worker 1 during individual interview 10, p5). Lastly, the ACVV was reported

to regularly *network* with other NGOs in support of communities in the area, in the form of workshops, providing in basic needs or providing counselling services.

#### 4.3.2.3 Sub-theme 2.3: The asset of government initiatives

Participants identified *government grants* as a potential financial asset to community members (also refer to the discussion in section 4.3.1.1.2). At the time of my field work, many community members were reportedly receiving financial support in the form of a foster care grant, disability grant or child support grant. I view these grants as assets to selected community members. However, I also propose that the government grants were potential assets to other community members at the time of my study, as the participants reported that some members of the community (also those living with HIV&AIDS or taking care of a child orphaned due to HIV&AIDS) were apparently still in the process of applying for, or even ignorant about such grants.

Based on the interview data I obtained (refer to Appendix E – various individual interviews with stakeholders and community members), the *Departments of Education, Health and Social Development* were identified as assets/potential assets for the community. The Department of Social Development was reported to collaborate with the Departments of Education and Health, in order to provide *training, workshops and basic treatment, care and support services* to the community, focusing on aspects such as life skills. In addition, the HIV&AIDS co-ordinator of the Department of Social Development (Appendix E – individual interview 12, p26) reported that she co-ordinated volunteers and caregivers involved in home-based care, providing them with *training and guidance*, in collaboration with NGOs. The Department further focused on *facilitating support groups* in the community (for men, women, people living with AIDS, orphans and child-headed households). Other mentioned *programmes co-ordinated* by the Department of Social Development and facilitated in the communities (yet not in the community where I conducted field work) include programmes on victim empowerment, child protection services, substance abuse and HIV&AIDS (Appendix E – individual interview 12, p26).

Both the Departments of Health and of Social Development employed *social workers* during the time of my study, which, I propose, might serve the community. Despite some of the social workers being situated at the provincial hospital (not paying home visits) and the social workers allocated to the community (one per district) apparently not being able to address existing needs and at times not doing the work they are supposed to do (based on interview and observational data), I propose that available social workers be regarded as potential assets. Furthermore, during the individual interview I conducted with the HIV&AIDS co-ordinator of the Department of Social Development, she mentioned that the Department of Social Development provided support to community members in the form of *food parcels*. In addition to this, I regard the fact that the Department has an *HIV&AIDS co-ordinator* situated in the region (approximately 8 kilometres from the selected community) as an asset, as she might, apart from providing individual support to community members in need of support, facilitate government HIV&AIDS initiatives such as the *National Action on Children that are Affected by HIV and AIDS* (NACA), as reported on during our individual interview (Appendix E – individual interview 12). I propose this lady to be an important (potential) asset, as I observed her as being dedicated to her work and committed to helping people in need. She represented the Department on an inter-sectoral forum and in the local AIDS council at the time of my field work, taking on individual cases to attend to. As such, she could reportedly provide *support* by *placing children* in foster care, *providing food and food supplements*, as well as *assisting families with grant applications*.

#### **4.3.2.4 Sub-theme 2.4: Cross-cutting systemic assets**

I henceforth present the results of my study relating to cross-cutting systemic assets. I structure the section in terms of the categories financial assets and other assets.

##### **4.3.2.4.1 Financial assets**

Participants (supplemented by my own investigation, observations and field notes) identified *several bodies* as potential resources which might provide financial support to the community. On a macro-level, I regard the *pay-out by the national lottery to the ACVV* as a financial asset. Furthermore, participants mentioned that *NGOs*

appear to be *raising money* in order to support the community. In addition, participants identified the *South African government* as a financial asset, providing potential support in the form of *food parcels*, as well as *government grants*.

Based on the data generated by participants during mapping activities, observation and visual data in the form of photographs (refer to Appendix D), *shop-owners in the community* (three shops and one butchery) were identified as potential assets. However, I wonder whether shop owners would indeed assist community members who are in financial need. On the other hand, participants reported that *schools* and *educators* supported community members in material need (*She is getting food here at school ...* – visit 6, educator 3 during focus group 3, p11). On an even closer level (micro-level), participants identified *family members* as regularly providing *money and food* to relatives in need (*... if she has money she must give him* – visit 3, sister of a person living with AIDS during individual interview 5, p11).

#### **4.3.2.4.2 Other assets**

By relying on the mapping activities facilitated during intervention sessions, my own observation and visual data, I identified the *availability of electricity and running water* as assets in the community. I observed water to be provided by means of community taps. With regard to *communication networks*, I observed and visually captured (Appendix D) that community members might access the *post office* and *public telephones*. Furthermore, educator-participants identified the *fire station* as well as *bus and taxi facilities* as resources during mapping activities. Participants further mentioned that the *South African police* (situated in a neighbouring community) and *correctional services* could be employed for crime prevention and child protection. At an *agricultural level*, I observed that the community possesses several *open areas*. I wonder what the possibility is for these open areas to be utilised for vegetable garden purposes. On a wider level, participants identified the *media* as a potential asset, as community members often receive information relating to HIV&AIDS *via* television or radio. The school principal summarised the potential role of the media: *The media seems to be playing a predominant role, into spreading the news for the people to understand that HIV AIDS is indeed a reality and that it is among people* (visit 3, school principal during individual interview 3, p2).



At the school where I conducted my study, I observed and visually captured internet facilities and a library (of which I attended the official opening – Appendix D), which I view as additional assets available to the community. I further propose that potential future projects identified by educator-participants be regarded as potential assets (namely soup kitchens, poverty alleviation projects, gardening projects and bead work projects), as educators' motivation and enthusiasm might assist the community in coping with the challenges it faces.

#### **4.3.3 THEME 3: COMMUNITY COPING WITH HIV&AIDS: EXISTING STRATEGIES**

The manner in which the selected community was coping with HIV&AIDS at the time of my investigation is presented in terms of the relevant sub-themes. The sub-themes that emerged are community-based coping strategies; coping with being infected with HIV or living with AIDS; coping strategies related to care and support; and lastly coping with children orphaned due to HIV&AIDS.

##### **4.3.3.1 Sub-theme 3.1: Community-based coping strategies**

Despite the community experiencing HIV&AIDS in a negative manner (*The community has all been traumatized by this HIV/AIDS*) (visit 2, educator 8 during focus group 2, p8), participants were of the opinion that the community itself needs to *take responsibility* for addressing the challenge of HIV&AIDS and support community members living with AIDS. The following responses summarise this idea: ... *because it's not about helping people at your workplace, help your community, do it for community, you see* (visit 3, ex-employee of the South African Police Department during individual interview 8, p17), and: *We need to call in everybody ... teachers, reverends, NGOs, everybody must be involved, you see. It's not only one body's problem, it's everybody's problem. So to fight this everybody must stand up to help those who can't help themselves, you see* (visit 3, ex-employee of the South African Police Department during individual interview 8, p7).

I view *culture* as a central component within the context of community-based coping. After a lengthy discussion during the third intervention session on the community's way of coping, I summarised my understanding as follows: *Your culture is the*

*foundation of your coping*, and the participants responded: *Yes! Yes! Yes!* (visit 2, several educators during focus group 2, p30). In line with the traditional African (including the Xhosa) culture, participants (family members) regarded themselves as being part of a unit that supports one another in times of difficulty (for example after the death of a parent due to AIDS), as emphasised by one of the participants: *The reason why I cope, it's because I know that it's my sister's child and my sister's child is my own child. What I want to do is for her not to feel that she has lost her mother, she must know that her mother is still alive, which is myself. So that I can take her as my own child. So that's why I'm coping, I'm taking her as my own child* (visit 3, caregiver 2 [aunt] during individual interview 2, p10). On a wider level (and possibly applying to the community *per se* and not only to the needs of family members), the following response highlights the tendency of community members to support others that need assistance: *... and then they take responsibility to be giving some food into the next door neighbour* (visit 3, school principal during individual interview 3, p1).

Religiosity, in terms of *prayer* and *faith in God*, seems to be another central component in attempts at coping with HIV&AIDS, as identified by the participants and highlighted in responses such as the following: *I do cope because in everything you do you must pray, if you pray and you believe then God will hear you* (visit 3, sister of a person living with AIDS during individual interview 5, p3). Participants frequently emphasised prayer to be one of the first actions to be taken after a person has disclosed a HIV positive status. In the words of one of the participants: *And they prayed and they prayed and they prayed*, and: *And I said to him pray because you have strength and I'm sure you are going to be okay, because I can see that you have faith and you are strong* (both contributions visit 1, educator 5 during focus group 1, p4).

I suggest that faith might be linked to hope, optimism and expectancy (thereby being *positive* about personal *abilities* and the *future*). A participant summarised these important facets of coping by saying: *... because if you don't have faith, nothing will come right - you must believe that. What I believe in is that if you want to live, you will live, if you want to achieve something, you'll achieve that, you see* (visit 3, ex-employee of the South African Police Department during individual interview 8, p15). Participants further elaborated on the importance of a *positive attitude* in overcoming

difficulties in the following manner: *So if you are positive you can be able to do anything, that's true* (visit 3, school principal during individual interview 3, p13). Another participant remarked: *... this is the kind of extra that you can approach life with, they are making the most of what they have in that way* (visit 3, catholic sister during individual interview 4, p1).

With regard to the potential value of *inner strength* and *perseverance* when coping with challenges, a participant remarked: *For those who are strong, the life is still there* (visit 1, educator 9 during focus group 1, p13). In addition, *acceptance* and then *hope* were also voiced as important ways of facing challenges and coping with difficulties: *Ja ... through the hope which we gave them, then they could cope, because we were visiting them now and again, now and again and we explained to them that they mustn't eh ... worry, that they can cope with the situation. But the problem is you have to accept it ... that you are HIV positive and you can also live a longer life if you take, eh use the medication and you take a right diet* (visit 3, church minister during individual interview 1, p2). With regard to *hope* and *acceptance*, the following response is appropriate: *And they don't believe in death and I will definitely say that that is the one thing keeping people together here, saying that it's okay. And they can still laugh and they can still be nice to each other ...* (visit 3, catholic sister during individual interview 4, p1).

#### **4.3.3.2 Sub-theme 3.2: Coping with being infected with HIV or living with AIDS**

Participants expressed their view that the first step in coping with being HIV positive or having full-blown AIDS, lies in the *acceptance* of one's condition, as illustrated by the following words: *I said that they must accept it. Eh ... in order for them to be strong, you have to accept that I have the status ... treat it as if you have the diabetes or high blood or something of that nature. Then you can carry on with your life ...* (visit 3, church minister during individual interview 1, p4). Participants further indicated that community members living with AIDS have to rely on their *own abilities* and *inner strength*. Although other members of the community ought to *support* them, they need to fulfil the primary role, as explained by a few participants: *You need to be strong. You, you need to love yourself first you see ... I must help myself first, then the rest will follow*, and: *If you don't fight this disease, who do you think will*

*fight it for you? ... God helps those who want to help themselves* (both contributions visit 3, ex-employee of the South African Police Department during individual interview 8, p7). Furthermore, participants were of the opinion that people living with HIV&AIDS were required to have *faith* and be open to receive *support*, thereby allowing others to help them cope with the challenge of their illness: *But if you want to I will help you* (visit 3, ex-employee of the South African Police Department during individual interview 8, p7).

According to the participants, coping with HIV&AIDS (being infected) might imply a *change in lifestyle*, in terms of following a healthy diet and taking food supplements as well as medication. Upon being identified as HIV positive or diagnosed with AIDS, participants stated that community members often tended to *collect as much information as possible* on HIV&AIDS. A lady who was living with AIDS at the time of my study summarised her experiences: *But when I was diagnosed that I'm HIV positive, I became to seek knowledge* (visit 4, community member infected with HIV during individual interview 11, p5). Despite the fact that participants reported that the majority of the community tended to avoid disclosure due to denial and stigmatisation, participants also identified a few people infected with HIV who indeed disclosed their status and *lived positively*. Several participants emphasised the following idea, which may be one ideal way of coping with being HIV infected or having AIDS: *And she must know that to be HIV positive doesn't mean that you, you are dying* (visit 3, ex-employee of the South African Police Department during individual interview 8, p2).

#### 4.3.3.3 Sub-theme 3.3: Coping strategies related to care and support

Participants indicated that family members often find it *difficult to cope with relatives being HIV positive*, as stated by the sister of a person with AIDS: *Yes I'm supporting him but even to me it's painful, you see* (visit 3, sister of a person living with AIDS during individual interview 5, p15). Although participants revealed that the family members of people living with HIV&AIDS rely on the basic means of coping, such as *prayer* and trying to *maintain a positive attitude*, such family members initially undergo *phases of shock* and *denial*. Family members were, however, reported to apparently *take responsibility* to look after relatives infected by HIV in most cases:

*But we accepted it, we must accept it ... because we are going to look after him* (visit 3, mother of a person living with AIDS during individual interview 5, p2).

Within the community where I conducted my study, participants identified family members' *need for information* as a typical immediate reaction to finding out that a member of the family is HIV positive. According to the participants, such a need to be informed can be related to family members' need to be able to guide and support their relatives living with HIV&AIDS. Participants refined this need for information by stating that community members (family members) *require guidance* on aspects such as healthy eating habits or a healthy diet, food supplements, treatment options and ways of supporting a person with full-blown AIDS, both emotionally and with regard to practical issues, like assisting the person to bath. In fulfilling their role as *primary caretakers*, family members reportedly also provide *financial support*, *advise* infected or sick relatives to go to the clinic or hospital and *accompany them* during such visits. They thereby seemingly take responsibility for *identifying and accessing assets* in the community, such as hospitals, doctors, counselling services and a disability grant, as reported by the participants. However, participants further voiced the challenge that members of their community face in, more often than not, having to *deal with infected relatives' feelings* of denial, anger, fears and frustration, as illustrated by responses like: *Now he's acting like a baby, you see. Acting like a baby, who wanted to be cared for*, and also: *He ... usually he has that aggression, gets cross quickly, you see* (both contributions visit 3, sister of a person living with AIDS during individual interview 5, p13, 15).

The *lengths to which family members would go* in order to support an infected relative became clear during my interview with a lady whose sister is living with AIDS. The interviewee related her story by explaining that she was previously employed by the South African Police Department and had a medical fund, whilst her sister was unemployed and could not afford medication at the time her sister discovered that she had AIDS. As a result, the interviewee *was untruthful* about her own HIV status (moving between doctors and clinics to prevent them from finding out the truth). She reportedly informed the doctors she visited that she had been tested and diagnosed with AIDS several years ago, but had not been emotionally ready to take medication during the time of the diagnosis. She then continued by indicating to



the doctors she visited that she would like to obtain medication at that stage (at the time when her sister became ill). According to the interviewee, she for several months obtained medication for her sister *via* her (the interviewee's) medical aid, until the medical aid investigated the matter and apparently discovered the truth. The interviewee reported that she consequently lost her job and had to repay the medical fund for the medication she had obtained. Reporting on the incident, the interviewee stated: *I know that what I did was wrong, but I was trying to help my sister ... I was not worried about myself and that I can go to jail and loose everything for what I've done, I was worried about her* (visit 3, ex-employee of the South African Police Department during individual interview 8, p10).

Although participants identified family members (in general) as the primary source of care and support to other members of the community living with HIV&AIDS, I realised, as my field work progressed, that participants seldom referred to the role that men fulfil. Reports on care and support to others centred around *women* supporting others, for example the *women* supporting her sister (previous paragraph), the *sisters* and *mother* supporting their brother and son who is living with AIDS (referred to in previous paragraphs), the *aunts* with whom I conducted an individual interview looking after relatives' children, the educators becoming involved in my study being *women*, to mention but a few examples. Based on this realisation and my hypothesis that women might be fulfilling the central care and support role within the community where I conducted my study, I made the following comment during an individual interview with family members of a person living with HIV&AIDS: *I'm starting to get the idea that it's all about women. It's the women that pray and it's the women that support. What is the role of the men?* Participants confirmed my hypothesis by stating: *It's like that to, to ... in our culture, you see, the man doesn't want to take responsibility for others* (visit 3, family members of a person living with AIDS during individual interview 5, p14). I further tested my hypothesis during *ad hoc* informal conversations with participants, for example during lunch times, upon which my idea of women fulfilling the primary role in supporting others was confirmed.

Apart from the family supporting other family members, it emerged that close *friends of the family* serve as a *basic support system*, not only to infected/sick individuals but also to the rest of the family. Furthermore, participants indicated that *colleagues of*



*family members*, as well as *volunteer workers* could offer a supportive role in praying with the family member whose relative has been infected, thereby providing support on a wider level. The following response serves as an example: *I talked to this woman at work, and then we talked and then we prayed* (visit 3, sister of a person living with AIDS during individual interview 5, p15).

#### **4.3.3.4 Sub-theme 3.4: Coping strategies for children orphaned due to HIV&AIDS**

Participants reported that *family members* usually take children into their care when they are orphaned due to their parents dying of AIDS: *Usually with us as the black people, the family take the children ... most of the people they, they have families. So when the parents pass away, the family they take the children* (visit 3, church minister during individual interview 1, p8). Grandparents and aunts appeared to be the primary caregivers in the community where I conducted my study, as revealed by responses like: *It's the relatives, maybe the grandmother or maybe the aunt or whatever, the relatives. As I've explained to you, we have very extended families, so there's always someone from the family that is taking care of the child* (visit 4, social worker 1 during individual interview 10, p16), and: *Usually it used to be the grandparents, but sometimes if there are no grandparents the sisters and brothers, they are taking the children* (visit 3, church minister during individual interview 1, p9). Only two participants mentioned the option of *children's homes*, but regarded this option as a last resort and added that children's homes are limited in number in the area and not easily accessible to community members.

Although the idea emerged that the majority of orphaned children are taken in by *extended family members* within the selected community and the context of my study, participants also indicated that *some families* are *not willing* to take care of orphaned children, resulting in *children being left on their own* after the death of a parent. The following answer was provided in response to a question relating to the caregivers of orphaned children: *The grandparents. But in other families they just leave them there. They're left alone* (visit 2, educator 6 during focus group 2, p9). In cases where extended family members do not fulfil the role of caregivers, participants identified *neighbours* as important sources of *assistance and support*.

Participants explained the potential roles that neighbours might fulfil as taking care of orphaned or vulnerable children, or supporting others who are looking after these children. Participants appeared to value help of this nature, as illustrated in the following words: *The neighbour asked can they come to school? And I asked: Are you going to be able to take care of him? She said: Yes! I will be able to, I will do everything for that kid ... And I realise it so much, that neighbour wasn't just a neighbour, he's a real neighbour, because he could see the need of this kid!* (visit 2, educator 4 during focus group 2, p31).

In the case of family members taking care of their relatives' children who had been orphaned, participants indicated the tendency for such family members to *rely on possible resources and services* available to them, such as *government grants*. However, participants voiced the opinion that family members caring for relatives' children might experience *difficulty in applying for and accessing these grants*, due to the apparent lack of knowledge concerning the correct procedures to be followed. Participants further reported that these community members (family members) might, as a result, *rely on the resources that they can indeed access*, such as *doctors, clinics, nurses and social workers*, in order to assist them in the application process. Unfortunately, participants regarded some members of the community to be *ill-informed and ignorant about the resources* that are available. However, participants acknowledged the possibility of community members not having the *financial means* to travel to the nearest clinic or hospital. Medical and social support services were also identified as limited in the community (based on interview data and my observations), resulting in family members supporting the children of relatives *not receiving the potential support* available to them, such as counselling for the children in their care.

In addition to families approaching others for help, participants mentioned that family members might be *assisted voluntarily by the community* (such as neighbours) or the *school* (both the *principal* and the *educators*, who appeared to sometimes extend their help on a wider level, by involving *social workers* or *NGOs*). With regard to other community members, *support* was reported to be provided at *various levels*, as illustrated by responses like the following: *I'm getting from the neighbours, they are trying to help me ... Sometimes they give me food so that I can cook for us, they*

would give me flour so that I can make bread for us. Sometimes they'd give me even money so that the child [HIV positive] can buy something here at school to eat. It's with her ... the neighbours are taking good care of her. The neighbours are giving me whatever they've got, food or even they sometimes buy shoes for her (visit 3, caregiver 2 [aunt] during individual interview 2, p7). On the other hand, participants reported on some families supporting orphaned relatives apparently *not receiving support from other community members*, having to primarily *rely upon themselves*, with some help from relatives. During an interview with an aunt of a child infected with HIV who was in her care, she remarked: *No neighbour is helping me. We are helping us by ourselves, by trying by all means to get whatever is good for the child* (visit 3, caregiver 1 [aunt] during individual interview 2, p7).

Participants framed *coping with orphaned children* in their community as involving more than the provision of a home for the children orphaned due to HIV&AIDS. As orphaned children might experience intense emotions in the period before, during and after the death of a parent, participants regarded the provision of *basic support and counselling services* as another component of *coping with orphaned children*. Educators identified feelings and behaviour like fear, sleepiness, concentration problems, a decrease in scholastic performance, loneliness and sadness as typically displayed by children orphaned due to HIV&AIDS. Educators reported on their ability to observe such feelings and behaviour, enabling them to *identify vulnerable children*. As a result, *educators* seem to play a significant role in supporting orphaned and vulnerable children of the community: *We are helping these kids out of our own potential* (visit 2, educator 10 during focus group 2, p15), and another participant's opinion: *I would try and be a parent for that child ... I will try by all my means that, so that she will feel comfortable and she can not feel that my mother is not here ... I'm your mother, if you've got a problem come to me* (visit 2, educator 3 during focus group 2, p15).

#### 4.3.4 THEME 4: OUTCOMES OF ACTIVIST INTERVENTION RESEARCH IN RELATION TO APPLYING THE ASSET-BASED APPROACH IN COPING WITH HIV&AIDS

Two main sub-themes emerged under this theme: coping trends that stayed the same during the course of my study, and changes in coping strategies during the

course of my study. In the following sections, I discuss how this theme and sub-themes are present in the data I collected and analysed.

#### **4.3.4.1 Sub-theme 4.1: Coping trends that stayed the same during the course of my study**

By relying on observations, continual reflection, as well as the data obtained during individual interviews and intervention sessions with participants, I was able to identify a few coping trends remaining consistent throughout the course of my study. The importance of relatives and, to a lesser extent, neighbours and other community members was emphasised by numerous participants throughout my study. As such, I identified relatives and other community members as central coping components in the community where I conducted my study. I relate the importance of family and friends to the culture embedded in the selected community, as the culture of participants was highlighted as underlying component to their willingness to assist community members in need, from the very first visit to the last. In addition, participants' emphasis on prayer, faith and religion, as potential ways of coping with challenges, remained constant throughout my study.

With regard to the demographic lay-out of the community and therefore the available local resources that could be relied upon in coping with HIV&AIDS, I did not observe significant changes (refer to Appendix D, which includes visual data on the community – captured over the period of two years). In this manner, I propose that the community where I conducted my study had to rely on similar resources towards the end of my study as at its outset. Outside resources and infrastructure appeared to be limited in the community – both at the start and end of my study, implying that community members had to rely mainly on themselves and the assets in their immediate community in order to cope with the challenge of HIV&AIDS throughout my study. With regard to the community-based resources initially identified by participants during mapping activities (Appendix C), I also did not observe any changes as my study progressed.

Concerning financial resources available to community members, the need for finances and financial assistance was emphasised by participants during the entire

course of my study. I relate this need (as illustrated in the constant referral by participants to accessing government grants) to the fact that poverty prevailed in the community. However, based on stigmatisation and secrecy appearing to remain social challenges within the wider community, community members did not seem to be better equipped to access government grants as my study progressed. Despite the levels of stigmatisation seemingly decreasing amongst the group of educator-participants and selected community members becoming more willing to disclose their HIV status as my study progressed, this tendency cannot be applied to the broader community.

Finally, educator-participants displayed the need to be informed throughout the entire course of my study. During initial phases, they indicated a distinct need to acquire basic HIV&AIDS information, including skills with regard to potential manners in which they could support other people living with HIV&AIDS. As my study progressed and the educator-participants mobilised such HIV&AIDS-related knowledge and skills, they seemed to rely on newly acquired knowledge to identify further areas in which they would like to be knowledgeable and skilled. During the final phases of my study, educator-participants, for example, indicated the need to obtain counselling skills, in order to be able to support community members coping with HIV&AIDS.

#### **4.3.4.2 Sub-theme 4.2: Changes in coping strategies during the course of my study**

Four categories emerged under this sub-theme: changed levels of self-awareness and self-confidence which resulted in feelings of empowerment, changed levels of support to community members living with HIV&AIDS, becoming actively involved in community development, and changes in the wider community. I henceforth discuss how this sub-theme and categories (which concern the intervention-related purpose of my study) are present in the data I collected and analysed.

##### ***4.3.4.2.1 Increased levels of self-awareness and self-confidence, resulting in feelings of empowerment***

During the initial phases of my study (more specifically during our first meeting), participants showed limited awareness of the assets situated within themselves and

their immediate community. Despite my observation of a variety of measures already taken in terms of coping (like providing material support, emotional care and spiritual support to other community members in need), educator-participants displayed the *need for expert advice and training* by outsiders: *We want to receive the workshops first, so that we can give* (visit 1, educator 3 during focus group 1, p16). They indicated their *need to be knowledgeable and informed* on HIV&AIDS-related aspects, in order to be able to support community members (as well as family members) infected with HIV and answer the questions posed to them. Themes that participants identified as areas where they required guidance include aspects such as *dietary requirements* of people living with AIDS, *treatment and supplements* to be taken, the procedures to be followed in *applying for a disability grant*, and *how to provide basic support* to people living with AIDS. Participants further voiced the opinion that *all educators* need to receive basic HIV&AIDS training and that training must therefore not be limited to a few selected educators (reported to usually be the Life Skills educators).

Early in the study – towards the end of the second intervention session (field visit 1, day 3) – educator-participants displayed an *awareness regarding their own abilities* to make a difference, as voiced: *We can do this. We can do this. Like I think we must contact ...* (visit 1, educator 10 during focus group 1, p15). This comment was made by a participant in response to my question as to how educators themselves might assist the community in coping with the challenge of HIV&AIDS. As the study progressed, educators confirmed this awareness in their own abilities: *I didn't know what I'm capable of doing, but you did make sure that I know what I can do ...* (visit 6, educator 9 during focus group 3, p31), as well as *confidence in their efforts*: *At least we are trying our best. We are trying our best, you know* (visit 2, educator 8 during focus group 2, p29), and later: *... but today I can stand here and say school G has progressed on that, and school G is the light of community X, because where parents can get help there is a light* (visit 6, educator 9 during focus group 3, p32). Being seemingly aware of their own existing and potential coping strategies resulted in the participants displaying enthusiasm and motivation to take action, by initiating the three projects mentioned.



Towards the end of the field visits educator-participants distinctly indicated how *proud* they were of *what they had accomplished*. They talked openly about *HIV&AIDS* (despite one participant still avoiding the terminology) and wore *their HIV&AIDS nametags* with pride (*because we were not afraid wearing these nametags* – visit 6, educator 1 during focus group 3, p6), showing the community who to approach for help. The change in educator-participants' *general posture and self-confidence* that took place as my study progressed is highlighted by the photographs included in Appendix D. The *positive experiences of being empowered* voiced by educator-participants are highlighted by the following selected responses, taken from a focus group session conducted towards the end of my field work:

- ⌘ *I've been wanting to help people living with HIV and AIDS but I didn't have a breakthrough. But for me being part of this team, now I got a chance to do whatever I wished for. Inside myself I'm feeling great that there's a lot that I'm doing for the community who are infected or affected with HIV and AIDS, through you* (visit 6, educator 7 during focus group 3, p33).
- ⌘ *You know what, it was something that I was thinking about it, but I didn't know how to start it ... What I was doing for the community, there was nothing I was doing. I want to thank you because now I feel proud that there is something I'm doing for the community. I am the light here in this community now ...* (visit 6, educator 5 during focus group 3, p33).
- ⌘ *Okay when you came here, I, myself was like a stagnant water because I had a vision, but my vision needed somebody to stimulate it to be out. Like I was angry at first with this disease, I didn't want even to talk about it because I was affected because somebody in my house is infected. I didn't want anything to say about this disease. But the second week or third time you visited us, something was taken off my shoulders because I learnt to talk about this. I learnt to see what is happening in the world with a real eye. And as we were always gathering every time, I saw that this one can help me, that one can help me, this is a support group for me, I am counselling myself. Then I said also to myself, this thing is a blessing in disguise to me, because now I can talk to my family about this* (visit 6, educator 4 during focus group 3, p35).
- ⌘ *Yes, I didn't know what I'm capable of doing, but you did make sure that I know what I can do, because if you didn't come, I wouldn't have known that I*

*can do something for the community that I'm working for, for the people in my church, and they trust in me ... You've shown us that we are able, we are capable of doing things but we don't use that capability of doing that, but since you came here, look at the garden ... Today we are proud of being teachers that can help our nation* (visit 6, educator 9 during focus group 3, p36).

#### **4.3.4.2.2 Increased levels of support for community members living with HIV&AIDS**

As an outcome of my study (and its forth-flowing components), the *school* emerged to become an even more *prominent asset* in the community than before, characterised by an increase in referrals of vulnerable children and their families to the school. Educator-participants related the increase in numbers of children and parents approaching the school for support and assistance, to the possible positive message conveyed to the community with regard to the school: *There was a conflict before between us and the parents, but I think now they believe in us, they know that we want to work with them ...* (visit 6, educator 9 during focus group 3, p30). I ponder about a possible link between these increased levels of children and parents approaching the school on the one hand, and reduced levels of fear of discrimination in the case of disclosure, on the other.

*Educators*, towards the end of my study, seemed to more readily realise their significant role regarding their involvement in learners' well-being, as illustrated by the following response: *And then we promised them we will be their parents, we are going to take care of their children, we will be part of their children* (visit 6, educator 2 during focus group 3, p25), and also: *... if they* [referring to community members – parents as well as children] *are sick they can report at school, we phone ATICC so that he can send a social worker, someone to help them* (visit 6, educator 1 during focus group 3, p3). Within the context of supporting others living with HIV&AIDS, educator-participants displayed decreased levels of stigmatisation towards the end of my study. They wore their nametags with pride, indicating their participation in an HIV&AIDS-related project to people they encountered, as illustrated in the following contribution: *... and they could see that we are wearing this* [indicating nametag], *because we were not afraid wearing these nametags, even anyone who can maybe*

*ask, we don't mind, because we know what we are struggling for* (visit 6, educator 1 during focus group 3, p6).

Apart from focusing on the learners, educator-participants mentioned that they started *supporting the community on a wider level* as my study progressed. One participant, for example, reported a conversation between her and a community member whom they (the support team) had supported: *But what made me so excited is the following day when she came, she didn't even have a tear on her eyes and she said I came here to thank you. I didn't know that I could get help, even the nurses at the hospital prayed for me and said why did you take so long? And I told them it's only when I got information at the school, it's only now that I'm ready. They prepared a grant for her, they gave her a cream...* (visit 6, educator 3 during focus group 3, p11).

As a direct outcome of the second forth-flowing intervention, educator-participants initiated three projects, as already reported on. Apart from the reported *emotional support* and *providing information and advice*, the school's vegetable garden appeared to *provide in basic needs* of community members: *... now we haven't got money to buy food, now she's getting food from school, she's getting vegetables. I told her the way to eat you see, and I also told her to ask the clinic nurses to tell her more about what she is suffering from so that they can add more on what we have told her you see* (visit 6, educator 3 during focus group 3, p11). In support of community members living with HIV&AIDS, the support team *obtained donations* from outside agencies, in order to provide such families with *support parcels*, consisting of vegetables (from the community garden), clothes and other food supplements. Members of the HIV&AIDS team (educator-participants) further mentioned that they started *assisting* community members in *applying for the disability grant* as the study progressed by, for example, referring them to the right person or institution where they could apply for the grant.

#### **4.3.4.2.3 Becoming actively involved in community development**

Besides initiating change in terms of the three school-based projects, educator-participants were visibly more focused on community development towards the end

of my study. Based on their own feelings of accomplishment, empowerment and agency (as voiced during intervention sessions, observed by me, noted in my field journal and documented as visual data), educator-participants identified *other potential projects* that they would like to initiate in future, expanding on the work that they had already done. They indicated that they were planning to start a *soup kitchen* at school, using vegetables from the garden, thus providing in learners' nutritional needs. They also discussed the possibility of negotiating with outside companies in order to *obtain funding to build a hall*, from which *income generating projects* (such as bead work) might be operated, involving unemployed parents.

Educator-participants' willingness to initiate projects and approach external agencies towards the end of my study highlights the change that occurred, from displaying the need for external assistance (as voiced at the onset of my study) to taking agency and initiating projects of their own volition. Responses like the following serve as illustration: *I thought I was going to learn from you when you first came here* (visit 6, educator 6 during focus group 3, p34), vs. *I phoned a certain guy at the municipality ... And then that man said he's going to send someone here at school ... Then they said I must write a letter then ... I wrote the letter ...* (report on the possibility to expand the vegetable garden) (visit 6, educator 1 during focus group 3, p3). In addition, a change in attitude could be observed with regard to their reasons for participating in the intervention. Whereas they initially appeared to be motivated to participate due to the financial benefit received, they seemed to relate their participation to the desire of making a difference in the community during the later stages of my study.

Educator-participants acknowledged the *potential positive impact* that they might have on the community. Towards the end of the field work, responses such as the following were often provided: *because we know we are helping the entire community* (visit 6, educator 1 during focus group 3, p3). They were also positive about conveying agency to other members of the community: *... and we wanted them to know that HIV is here to stay so that they can be capacitated too, so that they can know where to get help* (visit 6, educator 4 during focus group 3, p5).

#### 4.3.4.2.4 Extending changes to the wider community

Participants reported that the school's involvement in the community (*we are no longer educators now, we are community workers, because we are here to work in this community* – visit 8, educator 3 during focus group 3, p38) led to the community responding in a positive manner. Based on the educators' increased levels of empowerment, other community members seemed also to be empowered. In the participants' view, community members seemingly experienced the school as being more tolerant with regard to vulnerable community members and as a source of information and support, as the study and the three initiatives established by the educators progressed. In addition, parents' levels of involvement were reported to have increased, resulting in parents, including men, voluntarily providing their services at school. Educator-participants, towards the end of the study, described their school as a community school, summarising the collaborative approach as follows: *We are a great team. We didn't know that in a school we can work together, parents and teachers like this* (visit 6, educator 3 during focus group 3, p9).

As a result, participants reported that more children infected with and affected by HIV&AIDS entered the school, partially ascribing this increase in enrolments to the school's involvement in supporting the community in coping with HIV&AIDS. Apart from being more involved, parents also seemed to be more willing to disclose their status, yet sometimes only to the support team. During visit six, an educator-participant reported on the progress and activities of the support team: *And the parents are coming, are free now to disclose, they come in numbers to come and disclose their status since they have seen that we are, here at school G, there is a group of HIV and AIDS, they come and disclose to us then* (visit 6, educator 3 during focus group 3, p4). In response to a question with regard to the possible reasons for the increase in community members disclosing their status, the following answer was provided by an educator-participant: *Okay, the reason for this is because when the information team tell them about it, when we put them on the programme, we told them that since they know nothing about HIV and AIDS, they can come to school to get help. The only thing that the teachers can give them is to give them help and to show them the right procedures to take and give them the advice, good advice, that's*

*what the information team can do because they know nothing about this* (visit 6, educator 7 during focus group 3, p23).

#### 4.4 CONCLUSION

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In this chapter, I reported the results obtained during my study. In addition, I briefly reported the results of the forth-flowing interventions that emerged, as they add to a holistic view of the results. Results were discussed in terms of the themes that emerged during my thematic analysis of the raw data, namely transcribed interviews and focus group/workshop sessions, my field journal and visual data.

In the following chapter, I interpret the results of my study and present it as findings, thereby firstly exploring the manner in which the selected informal settlement community is coping with HIV&AIDS by relying on existing assets and local resources, and, secondly, by exploring possible changes that might have been facilitated by the intervention research approach I employed. In addition, I relate my findings to existing literature. In case of possible contradictions, I attempt to explain such inconsistencies within the context of my study.

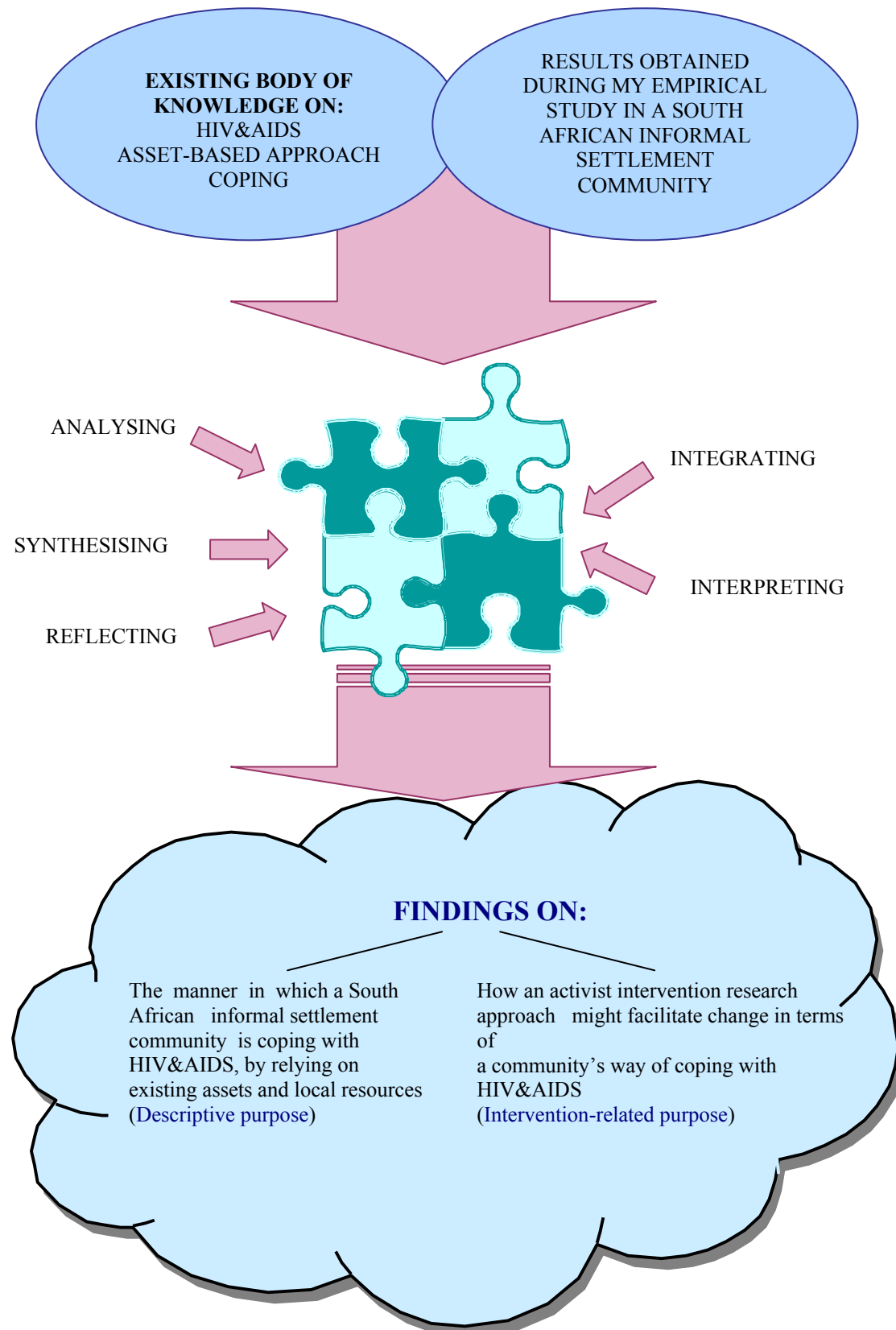


## **CHAPTER 5:**

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## CHAPTER 5 AT A GLANCE



## **5.1 INTRODUCTION**

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In the preceding chapter I presented the results of my study, in terms of the themes and sub-themes that emerged during data analysis. In this chapter I integrate and interpret the results in order to present my findings. I structure my discussion in accordance with the structure I relied on in the previous chapter.

In addition to presenting a synthesis of my findings, I relate my findings to existing and relevant literature. I highlight correlations, as well as discrepancies between the findings of this study and those reflected in existing literature. In the next and final chapter of my thesis, I reflect on my research questions in terms of my findings, before I come to final conclusions.

## **5.2 FINDINGS OF THE STUDY – SITUATED IN EXISTING LITERATURE**

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I now present the findings of my study in terms of the structure I relied on in the preceding chapter. After discussing findings which relate to the challenges and stressors faced by the community where I conducted my study, I present the findings I obtained with regard to the assets and potential assets identified during my study. This is followed by a discussion of the community's way of coping with HIV&AIDS, after which I conclude by presenting findings with regard to the outcomes of my study that may be related to the selected methodological approach I employed.

### **5.2.1 CHALLENGES AND STRESSORS FACED BY THE COMMUNITY, WITHIN THE CONTEXT OF HIV&AIDS**

I henceforth discuss the challenges and stressors faced by the informal settlement community where I conducted my study. I refer to the experienced vulnerabilities related to HIV&AIDS, the challenge of supporting people living with HIV&AIDS and finally the challenges as experienced by community members.

### 5.2.1.1 Vulnerability related to HIV&AIDS

The participants in my study indicated vulnerability as a community challenge within the context of HIV&AIDS. Both individuals and the broader community experience vulnerability on various levels. On an individual level, vulnerability is experienced in terms of emotional (personal), physical and social aspects, thereby influencing the holistic functioning of the people involved. With regard to **personal vulnerability**, people infected with HIV or living with AIDS display feelings of shock, fear and anger, as well as a tendency not to disclose their status. This finding is supported by the work of authors like Tindyebwa *et al.* (2004), Van Dyk (2001) and Mkwelo (1997). I regard non-disclosure as a defence mechanism, initially employed by individuals infected with the HI virus during the phase of denying their status. This tendency of HIV infected people avoiding disclosure, which inevitably results in people living with HIV&AIDS preventing themselves (and their children) from accessing care and support by others, is highlighted in existing literature. For example, the Department of Social Development (2002), Ratsaka-Mothokoa (2001), as well as the International HIV/AIDS Alliance (2000) view stigma and discrimination as primary challenges with regard to people accessing care and support.

Brandt (2005) elaborates by emphasising that, in spite of the potential of disclosure allowing for social support and health benefits, the fear of rejection, social isolation, discrimination, violence and changes in relationships continue to be challenges faced by people infected with HIV and living with AIDS. This approach correlates with the emerged theme that the fear of disclosure ultimately remains a reality faced by communities infected with and affected by HIV&AIDS. Despite some of the community members being more willing to disclose their status towards the final parts of my study, the general view remained that disclosure might result in rejection and isolation. As a result, community members tend not to disclose their HIV positive status, thereby denying themselves care and support, thus again promoting a vicious circle – once again resulting in increased levels of vulnerability (also refer to Clacherty & Associates, 2002).

The results that I obtained with regard to community members avoiding disclosure for fear of being rejected, further corroborates the International HIV/AIDS Alliance's

(2000) view that the fear of disclosure is based on fear for discrimination of the individual, as well as the wider family. The Alliance propagates the important potential role that NGOs might play in promoting a non-discriminatory environment, thereby reducing stigma and discrimination, positively impacting on the well-being of people living with HIV&AIDS. In my study, participants also identified the potential role of NGOs in raising awareness of HIV&AIDS within the community, which might positively impact on decreasing stigmatisation of the pandemic.

**Physical vulnerability** and the need for physical care are closely related to emotional care and support. Tindyebwa *et al.* (2004) emphasise the fact that people infected with HIV and living with AIDS, who reside in communities with limited resources, still have limited access to basic HIV&AIDS and supportive care, even anti-retroviral treatment. The International HIV/AIDS Alliance (2000) adds to this discussion and regards it as unfortunate that people in communities characterised by poverty and limited service provision are often not able to access treatment. During my study, participants similarly indicated that community members (who do indeed decide to disclose their status) often do not have the financial means to obtain treatment and medical care. In some cases community members will even die of AIDS as they do not have money for transport to the nearest hospital, or to make a telephone call in order to obtain ambulance services. In addition, the lack of sufficient clinics and counselling services in the area contribute to the challenge as experienced by the community where I conducted my study. With regard to the provision of medical treatment, the fact that anti-retroviral treatment is supposed to be, but is not yet, sufficiently provided in each and every South African area, further intensifies the challenge of physical vulnerability.

The provision of anti-retroviral medication implies a *possible future impact* regarding the government grants that community members might apply for. According to the HIV&AIDS co-ordinator of the Department of Social Development for the Nelson Mandela Metropole, the provision of medication ought to extend the lives of people. As a result, less children might be orphaned in future, leading to a *decrease* in applications for *foster care grants* by relatives looking after orphaned children. On the other hand, applications for the *disability grant might increase* due to people living

longer and eventually reaching the advanced stage of illness where they qualify for the grant, instead of dying at an early stage of AIDS.

In addition to the lack of sufficient medical treatment, participants in my study related physical vulnerability to the inability of individuals and families to fulfil their basic needs, emphasising the interrelatedness between poverty and HIV&AIDS. Ratsaka-Mothokoa (2001) also found poverty to be a related challenge experienced by people living with HIV&AIDS. This author takes the impact of poverty one level higher, by ascribing some families' lack of coping to poverty, based on the fact that poverty results in a lack of food (nutrition) and people subsequently solely depending on external help in the form of, for example, food parcels provided by external agencies like NGOs. This finding of Ratsaka-Mothokoa (2001) does not support the results that I obtained, according to which impoverished and vulnerable families rely on resources within the close community in order to cope with the challenges they face, and not on external assistance or outside support.

Besides poverty and the lack of financial resources to meet basic needs and obtain medical treatment contributing to the physical vulnerability of community members, participants in my study identified government grants as a potential challenge, adding to the vulnerability of those living with HIV&AIDS. In correlation with the results that I obtained on community members often experiencing difficulty in accessing and obtaining government grants, a study by Clacherty and Associates (2002) for *Save the Children* found that participants in that study also experienced problems in accessing government grants that might support them to financially cope with the challenges brought by HIV&AIDS, for example, having to care for an orphaned relative or not being able to work and earn an income due to AIDS. One of the biggest challenges appears to be a lack of sufficient information with regard to application procedures, in order to access grants, as indicated by Clacherty and Associates (2002) and also indicated by the participants in my study.

Apart from the difficulty experienced when applying for, or accessing government grants, participants in my study held the perception that the disability grant is often misused, thereby adding to the vulnerability of the community in general. I relate the perceived misuse of the grant to poverty and to it being a potential means of making



ends meet, as indicated by the participants in my study. Marais (2005) supports this idea by emphasising the fact that the disability grant is often the sole income for a person qualifying for it, referring to a study by Nattrass in Khayelitsha in Cape Town, which revealed that the disability grant contributed 40-50% of the total income of households that received the grant. As such, I regard the disability grant as an important source of income of poverty-stricken people in South Africa.

Cloete (2003) supplements this line of thinking by reporting the tendency of young women in the Eastern Cape (where I also conducted my study) to have themselves tested in the hope of being HIV positive, in order to qualify for the South African disability grant. In this manner, the disability grant can be regarded as a way of combating poverty by people experiencing scarce possibilities of income generation opportunities. Yet on the other hand, the criteria for qualifying for the disability grant are quite strict and require an advanced stage of AIDS. As a result, people who set out to become infected with HIV in order to obtain the grant, will probably not be able to do so with immediate effect.

There are striking similarities between the themes that I identified with regard to stigma and disclosure (***social vulnerability***), and existing literature reporting on these HIV&AIDS-related challenges. In correlation with the results I obtained, Smart (2003b), for example, reports that HIV&AIDS-related stigma and discrimination are not limited to the people infected with the virus or those living with AIDS, but also influence their families. As a result, relatives affected by HIV&AIDS are often subjected to stigmatisation and discrimination on various levels, even within their immediate community. The International HIV/AIDS Alliance (2000) broadens the potential impact of stigmatisation and discrimination by reporting on NGOs paying regular home visits to people living with HIV&AIDS, in order to provide psychological and pastoral support, and prayer sessions with the people. The majority of these volunteers were found to identify themselves as working with *chronically ill people*, with very few mentioning HIV&AIDS, for fear of the possibility of being stigmatised and discriminated against.

The results of my study further relates to those of the Siyam'kela project (reported on by Masindi, 2003), where it was found that stigma impacts on three main levels

within the South African context, namely on disclosure, people living with HIV&AIDS not accessing essential services, and people's levels of innocence/guilt being judged. With regard to *disclosure*, stigma might result in rejection by partners (as also indicated by the participants in my study), problems surrounding the care of orphans and vulnerable children, and fear of disclosure at the workplace (not mentioned during my field work). In my study, the majority of community members tended to avoid disclosure to the wider community, and, in rare cases, even to family members – whom they wanted to spare sadness. As a result, people infected with HIV or living with AIDS, avoid discussing their status, thereby not availing themselves of care and support by others. In the case of individuals residing in the community where I conducted my study deciding to disclose their status, it appeared to be to a selected audience (namely social workers, family or friends) and mostly with the aim of accessing care and support – both financially and emotionally. In the minority of cases, community members disclosed their status based on their desire to live positively, be exemplary and educate other community members about HIV&AIDS. Yet, some of the community members were, as a result, isolated and rejected, even by their partners.

Concerning people infected with HIV or living with AIDS *being judged as immoral*, (Masindi, 2003), as well as Clacherty and Associates (2002) report the tendency of others to label people living with HIV&AIDS as displaying at-risk sexual behaviour. The results that I obtained during my study correlate with this finding, as I found that the community where I conducted my study related at-risk sexual behaviour to people living with HIV&AIDS, and tended to judge them. Consequently, people very seldom disclose their status to the church, as the church is regarded as an institution that discourages immoral behaviour and might be judgemental of a person being HIV infected.

Comparing the results that I obtained with regard to stigmatisation to the categorisation of stigma as suggested by the Siyam'kela Project (Siyam'kela Project, 2003; Clacherty & Associates, 2002; Strode *et al.*, 2001; Antle *et al.*, 2001) displays several similarities. On an external level, participants in my study indicated several of the categories identified during the Siyam'kela Project (2003) (refer to chapter two, section 2.2.3.1). Participants in my study identified reactions of avoidance based on

the *fear of being infected* (which I found might be related to the presence of myths concerning the transmission of HIV and/or ignorance concerning basic information on HIV&AIDS), *rejection* (by partners, relatives and the broader community) and *moral judgement* (by the community and churches). In addition, participants indicated *general discrimination and abuse* against people living with HIV&AIDS (for example by partners or the church), as well as *stigmatisation due to association* (where community members indicated their ability to identify people living with HIV&AIDS or dying of AIDS, based on aspects like weight loss, or where family members and children were stigmatised, based on their association with people living with HIV&AIDS). Participants in my study did not, however, explicitly indicate an *unwillingness to invest in people living with HIV&AIDS* or *discrimination against people living with HIV&AIDS, in terms of accessing services*, as external stigma-related factors. Concerning internal stigma, my findings further correlate with the categories proposed by the Siyam'kela Project (2003), as participants identified the *fear of disclosure* (related to the fear of being rejected, judged or discriminated against), *social withdrawal*, *negative self-perception* and *personal exclusion from certain services and opportunities*, as internal reactions related to stigma. I relate these reactions, as identified by the Siyam'kela Project (2003) and confirmed during my study, to coping strategies employed by people dealing with HIV&AIDS. On the one hand, those living with HIV&AIDS might cope with their illness by denying and not disclosing their status, withdrawing and socially isolating themselves from society and perceiving themselves in a negative manner, which might result in overcompensating behaviour. On the other hand, society might cope with people infected with HIV or who have AIDS by stigmatising and discriminating against them, judging, avoiding, rejecting or even abusing them.

In reaction to the need to urgently address the challenges of stigmatisation and discrimination, Kelly (2000a) reports on a study conducted in the Eastern Cape, KwaZulu-Natal and the Western Cape, revealing that young people (15-30 years of age) are becoming more informed on basic HIV&AIDS-related facts and tend to practice safe sex more often. Contradictory to Kelly's (2000a) finding, participants in my study hold the perception that community members infected with HIV or living with AIDS often display at-risk sexual behaviour. Of particular concern is the tendency of young girls to become involved in at-risk sexual behaviour, such as

multiple partners and sexual relationships without the use of contraceptives (also supported by the findings of Eaton, Flisher & Aarø, 2003). I partially ascribe the contradictions between this theme emerging during my study and the findings of Kelly (2000a), to the high level of poverty experienced by the community where I conducted my study, resulting in community members (including children) going to whichever lengths (even prostitution) to be able to survive and meet their basic needs. In this regard, Campbell (2000) emphasises the fact that safe sexual behaviour and prevention of HIV infection often take second place to addressing basic needs when faced with poverty, thereby explaining the tendency of young girls to provide sexual favours in return for money.

Kelly (2000a) further found that selected young people tend to display positive attitudes towards people living with HIV&AIDS, despite participants in rural areas (amongst others the Eastern Cape area included in the study) still displaying intolerance and negative attitudes. The results that I obtained, according to which community members still seem to stigmatise HIV&AIDS and discriminate against community members infected with HIV or who have AIDS, seems contradictory to Kelly's (2000a) finding that selected young people tend to be more tolerant with regard to people living with HIV&AIDS. This contradiction might be ascribed to the difference in age groups between the participants in my study and those in the study conducted by Kelly (2000a), with Kelly focusing on young people (15 to 30 years of age) and my study including different age levels. In addition, I conducted my study in a poverty-stricken community, which might display similarities with rural communities, thereby corresponding to Kelly's (2000a) finding that some people (in rural areas) still display negativity and intolerance. Another possibility might be that citizens of the Eastern Cape (as reported on by myself as well as by Kelly) might tend to maintain stigmatisation to a greater extent than other areas of the country. These potential explanations, however, are mere hypotheses that need to be researched further in order to establish accountable findings.

In relation to **cultural vulnerability**, my study indicates the Xhosa culture as being a potential contributing factor concerning at-risk sexual behaviour (multiple partners, not practicing safe sex and a lack of sex education by parents), as well as the tendency not to disclose a HIV positive status within the culture. In the 2004 AIDS

review, Kometsi (2004) emphasises the dominant position that African men hold over women as a contributing factor to their perception of masculinity. Due to the patriarchal power men often possess in the home (characteristic of African cultures), women might tend not to insist on practicing safe sex or having only one sexual partner, thereby increasing their potential vulnerability, as also indicated in my study. The theme concerning women's tendency not to disclose their HIV positive status to their husbands in fear of being rejected can further be related to the way in which power positions are socialised in terms of gender, in conjunction with the stigma attached to HIV&AIDS (also refer to Barolsky, 2003).

#### **5.2.1.2 Supporting people living with HIV&AIDS**

Within the informal settlement community where I conducted my study, community members appeared willing to support other members of their community infected with HIV or living with AIDS, by means of material, as well as emotional and spiritual care and support. Participants indicated that they are able to identify community members living with HIV&AIDS, despite the hesitancy to disclose, which seems to be a reality in the community. However, participants displayed a lack of self-confidence and indicated the need to be informed on HIV&AIDS-related issues, for them to be able to support those infected with HIV or living with AIDS. Both educators and the community in general indicated such a need to be knowledgeable, in order to answer the questions of learners, colleagues and community members.

This need to be informed (as identified in my study) is supported by the findings of a study by Clacherty and Associates (2002), during which community members also indicated the need to be educated. Aspects that were identified as important to be informed on include the importance of community members supporting others living with HIV&AIDS instead of rejecting them, thereby addressing the challenge of stigmatisation; as well as HIV&AIDS-related facts on transmission. I propose that this need to obtain basic HIV&AIDS knowledge might be related to the extensive media coverage of HIV&AIDS-related issues, numerous HIV&AIDS campaigns and inclusion of HIV&AIDS programmes in various sectors of society over the last few decades – raising awareness amongst community members without necessarily providing detailed information. Secondly, the fact that community members often

face the reality of themselves, a family member or friend being infected with HIV or living with AIDS, might also result in the need to be informed.

In addition to the need to be informed, participants identified a general need for emotional support for both adults and children living with HIV&AIDS, as central to supporting others living with the disease. However, the participants further highlighted the occasional hesitancy of community members to become involved in caring for and supporting people living with HIV&AIDS, based on myths and misconceptions, especially relating to the transmission of the virus. This trend not to get involved agrees with the findings of a study by Clacherty and Associates (2002).

#### **5.2.1.3 Challenges faced by the community**

As mentioned in section 5.2.1.1, poverty, unemployment and at-risk sexual behaviour were identified as general challenges experienced by the community where I conducted my study. According to the information provided by the ACVV (2004) (a faith-based organisation), 80% of the residents in the community have no income. The infrastructure of the community is underdeveloped and both informal housing (shacks) and more formal housing (occasionally a combination of the two) are present. The community is characterised by low educational levels and various social problems. Participants highlighted teenage pregnancies, alcoholism, domestic violence and child abuse, child neglect, crime, substance abuse, early school drop-out and difficulty in accessing resources in the community as such challenges. Not surprisingly, the results that I obtained on poverty and its associated social challenges within the context of HIV&AIDS is widely supported by existing literature, highlighting the interrelatedness between HIV&AIDS and such social challenges (refer to Oni *et al.*, 2002; Sogaula, Van Niekerk, Noble, Waddle, Green, Sigala, Samson, Sanders & Jackson, 2002; Kelly, 2000c as examples).

In my view, and based on my observations and data obtained during the time spent in the field, community members might get involved in at-risk sexual activities for two primary reasons. Firstly, at-risk sexual behaviour might be relied upon in an attempt to combat poverty (as discussed above), with children reportedly getting involved in activities like child prostitution in order to obtain money to make ends meet.



Secondly, at-risk sexual behaviour might be employed as a defence mechanism or a way of acting because of anger and fear, in an attempt to address emotional needs. Subbarao *et al.* (2001) summarise these two ideas, in reporting that orphaned children who are emotionally vulnerable and financially in desperate need often get involved in exploitative situations like prostitution, in order to survive.

Within the context of HIV&AIDS, participants identified the need to address stigmatisation (for example by educating the community), as well as the challenges of taking care of people with AIDS or orphaned children. These challenges are intensified by the lack of sufficient social services in the community, as well as the difficulty experienced by community members to access health and social services, which might in turn be attributed to poverty. In addition, it emerged that community members supporting others are in need of support themselves. Challenges related to carers being in need of care themselves are widely documented as part of the reality of HIV&AIDS, for example by Richter *et al.* (2004), Smart (2003b), Clacherty and Associates (2002) and the International HIV/AIDS Alliance (2000).

### **5.2.2 ASSETS AND POTENTIAL ASSETS IN THE COMMUNITY**

Numerous assets were identified in the informal settlement community where I conducted my study, which might be relied on when coping with HIV&AIDS. In addition, several potential assets that have not yet been utilised by the community and which might be employed during coping initiatives, came to the fore. In this regard, one of the participants (namely the HIV&AIDS co-ordinator of the Department of Social Development in the Nelson Mandela Metropole) highlighted the importance of assets (and potential assets) meeting the criteria of *accessibility* but also *acceptability*, as also emphasised by Eloff (2006b), as well as Bouwer (2005).

I found the assets identified in my study to comprise *individuals*, local *organisations and associations* (for example a community-based support group and community churches), as well as *institutions* (like schools, hospitals, clinics and the community care centre). As such, the emerged themes on assets conform to the basic categorisation of assets proposed by Ammermann and Parks (1998), as well as Kretzmann and McKnight (1993). In addition, the assets I noted also correlate with

the extended and refined categories proposed by Eloff (2006b), namely assets related to *individuals* (skills, knowledge, characteristics, experiences and values embedded in community members), *schools* (in terms of leadership and management, human assets, technical assets, assets related to structures and procedures, as well as assets related to the identity and strategy of the school), *classrooms* (such as resources, books in the school library and a positive classroom atmosphere), *families* (being supportive and providing assistance to relatives living with HIV&AIDS), *peer groups* (in the form of care and support), *citizen's associations* (such as churches, faith-based organisations and NGOs), *local institutions* (for example hospitals, clinics and the community care centre) and the *social system as a whole* (such as the media and political structures).

The assets that were identified during my study further adhere to Snow's (2001b) classification of assets, as participants identified assets related to *individual talents and skills of community members*; *associations and networks of relationships* (such as volunteer workers and church-based support groups), *institutions and professional entities* (NGOs and faith-based organisations); and *land, property and other physical assets* (referring to the community and the buildings situated in the community, for instance church buildings, school premises and shops). In addition, *economic assets* were identified in the form of a few shops situated in the community, as well as *agriculture* and *community-based experience, general skills and capacities*. However, and in contrast with Snow's (2001b) proposed classification of assets, within the community where I conducted my study, consumer spending power cannot be regarded as a significant economic asset, because of the high rate of poverty inherent in the community.

I henceforth present the assets that were identified during my study as being available to community members in coping with HIV&AIDS. I use the same structure I adhered to in presenting my results in chapter four.

#### **5.2.2.1 Assets relating to individuals**

In response to Kretzmann and McKnight's (1993) question whether or not everyone have capacities, I found the first possibility to be true. In my study, participants

identified assets related to individuals on a number of levels. For example, it emerged that community members who were living with AIDS at the time of my field work possess strengths such as the ability to establish support groups, and support one another spiritually by, for example, praying together, despite the general tendency to marginalise people with AIDS and label them as weak. Other community members were found to possess assets like being supportive and willing to assist others during challenging times. On a broader level, the negotiation skills of community members and key role-players were identified as assets, which might indirectly facilitate support of community members living with HIV&AIDS. The potential of educators to support and negotiate with community members (volunteers) was, for example, demonstrated by the three school-based projects that were initiated and sustained until (at least) my last field visit.

Besides identifying strengths and assets within individuals, participants highlighted the strengths of families and neighbours, referring to the potential support provided by relatives, neighbours, friends, volunteers and support groups. My observation that family and neighbour unity may be regarded as an important asset in communities coping with HIV&AIDS is supported by Fuller and Brockie (*s.a.*), who conducted a study on rural health within the context of the asset-based approach (asset-building). The authors found that health in rural communities are not merely related to physical well-being, but also includes aspects such as community culture and the tendency of community members to know and collaborate with their neighbours. My application of this finding in rural communities to the informal settlement community where I conducted my study, highlights the possibility of similarities between rural and urban informal settlement communities – both often characterised by poverty.

#### **5.2.2.2 Assets relating to institutions and organisations**

In my study, various institutions and organisations were identified as assets, namely a community care centre, schools, assets related to political organisations, NGOs, health-related assets and faith-based organisations. Participants placed strong emphasis on the role of schools and educators, in terms of care, support and assistance (for example in the form of food) provided to learners as well as the wider

community. Attaching such prominence to schools and educators conjoins with several other studies focusing on the role that schools and educators might play in assisting community members addressing the challenges they face (in my study coping with HIV&AIDS). I regard schools (being local institutions) as community-building assets and support Kretzmann and McKnight's (1993:173) view of the *'growing number of ways in which local schools are becoming the center of a web of relationships which can drive the community-building process'*. This approach proved to be applicable to my study, as the school where I conducted intervention sessions unlocked a variety of possibilities for relationships, once the school (educators) became accountable in terms of taking agency and leading the community. For instance, the school (educator-participants) co-ordinated the establishment of a community garden, information centre and support service in the community, thereby promoting the community's way of coping with HIV&AIDS and, by implication, community development. In addition, networks were established and relationships built with other organisations and institutions, not only within the community, but also on a wider level. Furthermore, the parents of learners were identified and mobilised as assets, which in some cases still needed to be utilised.

In rating the school where I conducted intervention as a valuable asset to the community (in terms of its facilities, educators, the principal, materials and equipment) I support Eloff (2006b), as well as the following comment by Kretzmann and McKnight (1993:210): *'What this means is that each local school should be seen not only as an "educational institution" but also as a rich collection of specific resources which can be used for strengthening the social and economic fabric of the entire community'*. Furthermore, the following comment also holds true to my study (Kretzmann & McKnight, 1993:210): *'... at the same time local schools that have fully integrated their resources within the community will become the best and most certain guarantee for that community's increased future strength and prosperity'*.

In support of the views formulated by Kretzmann and McKnight (1993), a study by Saidi *et al.* (2003) identified and successfully used schools as centres of community development. I directly relate this finding to my study, as the educator-participants initiated a vegetable garden, support service and information centre at the school – thereby implying the school to be a centre of community development, contributing to

the community's way of coping with HIV&AIDS. In this manner I regard the primary school where I conducted intervention as a *health promoting school*. During a study by Kelly *et al.* (2002) in a rural poverty-stricken community in the Eastern Cape Province, one of the activities included encouraging *health promoting schools*, where the Departments of Health, Social Development and Education, schools, educators, parents and learners were to be mobilised in an integrated attempt to addressing the challenge of coping with HIV&AIDS and related poverty. One of the activities that Kelly and his colleagues attempted was the establishment of vegetable gardens at schools, as was successfully conducted by the educator-participants in my study.

With regard to the establishment of support services, the manner in which educator-participants effectively initiated a school-(thereby community)-based support service during my study, corresponds to suggestions formulated at a workshop held in 2000 and focusing on orphans and vulnerable children (UNICEF, 2000b). During the workshop, delegates made recommendations as to the role of schools and education systems in support of orphaned and vulnerable children, within the context of HIV&AIDS. Suggestions were made in terms of the various roles of schools, such as identifying orphaned and vulnerable children, free education for needy children, as well as the provision of psychosocial support. In addition, delegates suggested that schools might become focal points in communities or even *one-stop orphaned and vulnerable children support centres*, where meetings could be held, support provided to caregivers and from where feeding schemes could be operated. Although the support service as initiated during my study did not directly focus on orphaned and vulnerable children, supporting community members in general might inevitable also positively impact on the manner in which the challenge of orphaned children are coped with by the community.

Besides schools being regarded as assets in the community's coping with HIV&AIDS, I found NGOs to be (potential) assets in the community where I conducted my study, with participants identifying ATICC as an important (potential) asset. In the same manner, Clacherty and Associates (2002) found NGOs to fulfil an important supportive role, as they might provide food, emotional support and advice on accessing grants. For example, one of the communities involved in the study by Clacherty and Associates (2002) provided a shelter for adolescents, offering physical

and emotional support. The authors do, however, emphasise that provision of such supportive services by NGOs is still rare within the South African context. This correlates with my observation that, despite participants' awareness of NGOs, they are often not yet utilised to their full potential and therefore remain potential assets that need to be mobilised. In this manner, I regard some NGOs as potential assets that might provide support in the form of training, material assistance or counselling services. As a result, I support Clacherty and Associates' (2002) opinion that the provision of services by NGOs cannot be generalised across South African communities, as different communities have different key role-players that might provide support and assistance.

In addition to the assets described in the previous paragraphs, it transpired that political meetings and organisations, clinics, hospitals, doctors, nurses, social workers and faith-based organisations seem to be important (potential) assets in the community where I conducted my study, despite such institutions and services being limited by nature. The fact that community members infected with HIV, or those who have AIDS, tend to deny their condition and avoid disclosure, may however add to the situation that doctors, clinics and hospitals sometimes remain only potential assets, not being mobilised. Despite the services being available to community members living with HIV&AIDS (such as treatment and counselling services), they often seem not to access them, possibly based on their own fears. Yet, political organisations, health-related institutions and faith-based organisations might fulfil an important supportive role and could take shared responsibility in a community's coping with HIV&AIDS, as also propagated by authors such as Birdsall and Kelly (2005), Amoateng *et al.* (2004), Tindyebwa *et al.* (2004), Kelly *et al.* (2002), Mugabe *et al.* (2002) and the International HIV/AIDS Alliance (2000).

#### **5.2.2.3 Assets relating to government initiatives**

During my study, government grants emerged as an asset to certain community members (those who have already accessed such grants), albeit still a potential asset to others (those who were in the process of applying, or ignorant about the grants). Whatever the case may be, government grants seem to be an important source of financial assistance to community members coping with HIV&AIDS. In the



case of a person facing extreme poverty, the government grant often to a certain extent provide in meeting basic needs (in this regard also refer to the discussion included in section 5.2.1.1). In addition, the government might provide information, treatment, care and support to community members, for example in the form of workshops and social services. Providing such assistance and implementing government policies in support of communities living with HIV&AIDS, answers to the role that governments are supposed to fulfil in addressing the pandemic, as described by authors like Birdsall and Kelly (2005), Miamidian *et al.* (2004), Smart (2003a), Centre for Policy Studies (2001), UNICEF (2001) and Cook (1998).

#### **5.2.2.4 Systemic assets**

Several assets and potential assets emerged relating to financial support (for example by individual community members like friends, neighbours and educators, the South African government, NGOs or the national lottery on a macro-level), agriculture (open areas in the community) and available services in the community (such as electricity, running water, communication networks, public transport facilities, the fire station and the police station in the adjoining community), which might support community members in coping with challenges. In addition, I regard the school's library, internet facilities and on a macro-level the media (mainly in the form of television and radio) as important (potential) assets, which might provide community members with information on HIV&AIDS-related issues, thereby making them knowledgeable and more able to cope with the challenges implied by HIV&AIDS, such as a healthy lifestyle, nutrition and treatment options. In this regard, I wonder as to why only a few selected participants identified these resources, and, secondly, what the implication for accessing these assets thus might be. In a similar manner, Parker *et al.* (2000) highlight television and radio, as well as print media (such as newspapers and magazines) as important sources of communication with community members in widely spread communities.

However, it needs to be borne in mind that not every South African citizen has access to a television, and that printed media is mainly directed at literate people. Radio seems to be the most suitable way of communication, as it implies a wider reach than television and might be utilised in the form of, for example, talk shows,

advertisements, interviews, documentaries or music. In addition, outdoor media, such as billboards and mobile media like taxis and busses might be utilised to distribute information (Parker *et al.*, 2000) – potential assets that were not identified by participants during my study. In addition, I did not find folk media (such as songs, dances and riddles) to be regarded as potential ways (asset) of conveying information on HIV&AIDS, as indicated by Parker *et al.* (2000). Concerning the potential value of workshops in communicating with people in communities, the results I obtained relate to those of Parker *et al.* (2000), as participants identified workshops as potential source of information and support that could be provided and presented by NGOs, government institutions, health-related institutions or faith-based organisations.

Adding to the discussion on the media being an asset as described in the preceding paragraph, Kretzmann, McKnight and Puntenney (1999) report on the relationship between newspapers and neighbourhoods, specifically referring to the potential value of the media in assisting communities in coping with the challenges they face. As participants did not identify newspapers as an asset in my study, I regard local newspapers (and even media coverage on a wider scale such as billboards or advertisements on mobile busses or taxis – refer to Parker *et al.*, 2000) as a *potential* asset to the community where I conducted my study, which might provide community members with HIV&AIDS-related information. In addition, local newspapers might report on the three initiatives established by the educator-participants in the community. By reporting on the manner in which the educator-participants initiated the three projects and enhanced community development, other similar communities might gain and also apply related strategies in addressing the challenge of HIV&AIDS, or even other relevant social challenges they face. However, mobilising the media in this manner ought to be explored further.

### 5.2.3 COMMUNITY'S CURRENT WAY OF COPING WITH HIV&AIDS

I now present my findings on the community's way of coping with HIV&AIDS. I refer to coping being community-based, coping of community members being infected with HIV or living with AIDS, coping strategies related to care and support in the

community where I conducted my study, and lastly the community's way of coping with children orphaned due to HIV&AIDS.

#### **5.2.3.1 Community-based coping**

During my study, it emerged that the selected informal settlement community where I conducted my study is coping with HIV&AIDS by relying on themselves, their own abilities and the resources available in the immediate local community (thereby implementing the asset-based approach). This tendency of coping with the assets and resources that are locally available, contradicts the suggestions and perceptions of several authors. For example, Smart (2003b) criticises the tendency to presume that communities are able to cope with the HIV&AIDS challenge and voices the opinion that communities' coping mechanisms seem to have been used to their full potential and at a level that cannot be exploited further. In addition, Subbarao *et al.* (2001) are of the opinion that communities at ground level are not able to effectively cope with the challenge of taking care of the high numbers of orphaned and vulnerable children. Furthermore, Ratsaka-Mothokoa (2001) found the participants in her study to hold the opinion that many people living with HIV&AIDS are not coping, especially those who are unemployed and experiencing poverty and a lack of emotional and social support from others.

I ascribe contradictions between the themes that emerged during my study and the views and findings of the authors cited in the previous paragraph to the theoretical context from which I approached and conducted my study, namely the asset-based approach. Approaching a research field from the asset-based approach implies a focus on strengths and possibilities, as apposed to emphasising deficiencies, problems and challenges – often actualised by people not following a strength-based approach. Although I continually acknowledged the challenges and realities faced by the community where I conducted my study, I aimed to shift my focus away from these challenges towards that which is good and already working to the benefit of the community's coping with the pandemic. In addition, one of my primary assumptions with which I approached the community was that it is coping with the challenges brought by HIV&AIDS. This, however, is a personal stance, which needs to be explored further in order to obtain a clear understanding of possible reasons for the

contradictions mentioned between the results that I obtained and the findings of the authors cited in the preceding paragraph.

As such and by being guided by the asset-based approach during my intervention, despite some of the participants (community members) in my study experiencing the effects of the HIV&AIDS pandemic as very harsh, they were still able to identify possible resources they could rely on in coping with the challenge. They further acknowledged the fact that they are indeed coping by relying on the assets and resources in their immediate community, no matter how difficult and challenging they experienced this process of coping to be. They relied on themselves and their fellow community members to make the necessary plans and mobilise the relevant assets in order to, for example, support others living with HIV&AIDS or take children into their care when needed.

The tendency of community members to support vulnerable people (including children) within the context of HIV&AIDS might be related to countrywide initiatives that focus on supporting the capacity of families to protect and care for their children, which have been employed in our country over the last couple of years. In addition, South African citizens might be benefiting from responses focusing on social development, education and welfare, in an attempt to deal with the HIV&AIDS pandemic in an effective and integrated manner (Mugabe *et al.*, 2002; Gow & Desmond, 2002). Although it seems clear that such initiatives are not regularly employed in poverty-stricken communities (such as informal settlement communities) and the question is often raised as to whether or not the general public is indeed benefiting from such policy-orientated responses, the possibility of indirect influences of government policies and support remains. These communities can, for example, benefit from government grants, free schooling for children or being more informed or aware of HIV&AIDS-related issues. My study's indication of community members finding their own ways of addressing the challenges related to HIV&AIDS, is supported by the opinion of Gibson *et al.* (2002), according to whom communities spontaneously develop ways of dealing with trauma and life's difficulties. In support of the results that I obtained, these authors highlight the tendency of community members in need of support to rely on other community members (such as relatives or neighbours), in order to cope with the challenges associated with HIV&AIDS.

Karnpisit (2000) also describes the application of a holistic development approach, as part of the National Development plan of Thailand in addressing the HIV&AIDS pandemic. This approach requires a paradigm shift from a top-down approach to a bottom-up approach, emphasising the importance of community members at ground level being involved in planning and initiating their own development, as was done during my study. The approach ultimately aims at empowering community members, thereby enhancing agency and fostering self-reliance. This approach correlates with both PRA principles and the asset-based approach, as I integrated and applied it in my study. In line with the approach reported on by Karnpisit (2000), I supported a bottom-up approach and also aimed at community members taking agency for the challenges they face and coping with HIV&AIDS, by relying on available assets and resources based in the community (also refer to Eloff, 2006a; Kretzmann & McKnight, 1993).

During the course of my study, the importance of community (principle of *Ubuntu*) in coping with HIV&AIDS (or life challenges in general) was highlighted within the selected community (Xhosa culture). Such emphasis on the importance of collectivism within the Xhosa culture is supported by the following statement of Mbiti (in Van Dyk, 2001:124), describing the importance of the community within the African culture: *'When he suffers, he does not suffer alone but with the corporate group; when he rejoices, he rejoices not alone but with his kinsmen, his neighbour and his relatives whether dead or living. Whatever happens to the individual happens to the whole group, and whatever happens to the whole group happens to the individual'*. The emphasis that was placed on collectivism by the participants in my study is further substantiated by Walker (2002), who found that the psycho-social support of people infected with HIV or those living with AIDS ought to be provided within the community by community members themselves, as indeed seemed to be the case in the community where I conducted my study.

As such, culture and family emerged to be at the heart of coping with HIV&AIDS, as evident in the informal settlement community where I conducted my study. The potential importance of culture and family is supported by Amoateng *et al.* (2004), who emphasise that *'the maintenance of traditional family values and traditions has enabled many people to cope with the stresses of oppression and separation'*,

thereby implying cultural values or the culture of families, such as African families in South Africa. Based on the African culture and the high value placed on family as embedded in culture, community members take collective responsibility for coping with the challenges related to HIV&AIDS, such as caring for children orphaned due to the pandemic (Barolsky, 2003) – as found during my study.

In addition to family and culture, I my study indicated religiosity and, closely related to it, being positive about personal abilities and the future, to be central components in coping with HIV&AIDS. Participants' perception that hope, optimism and expectancy enable people to cope with the challenges they face reflects the basic principles of Positive Psychology. The theory of Positive Psychology propagates that emphasis be placed on intrinsic strengths, assets and positive intrapsychic domains during difficult times, thereby relying on positive aspects when coping with difficult situations (Ebersöhn & Eloff, 2006; Keyes & Haidt, 2003). With regard to religiosity, the participants in my study highlighted the tendency of community members to often rely on religion and faith in coping with the challenge of HIV&AIDS. This tendency is supported by Boevig (2006), who contemplates spirituality as a coping response. The author specifically refers to religious coping, which she regards as a potential way of coping with life stressors.

Despite my study indicating that informal settlement community members tend to rely on available social support systems when facing a challenge, and the fact that this trend is widely supported by existing literature (as indicated above), Amoateng *et al.* (2004) hold a contradicting opinion. According to Amoateng *et al.* (2004), African people in South Africa are assumed to have strong social networks, yet they in fact have less access to social networks than other population groups in South Africa. This seemingly contradictory view I obtained might be explained in terms of the possibility of urban communities (reported on by Amoateng and colleagues) not possessing strong bonds, where extended families might have been replaced by nuclear families. However, in the case of families not holding strong familial bonds, other support systems appear to take the place of extended family members, such as neighbours, community members or faith-based organisations that are, for example, regarded as potential sources of social and material support within the context of my study.



### 5.2.3.2 Ways of coping with being infected with HIV or living with AIDS

Whitty (2003) relates coping strategies to defence mechanisms and is of the opinion that people employ both coping strategies and defence mechanisms when faced with challenges or stressful situations. The results that I obtained during my study corresponds with Whitty's (2003) opinion, as it emerged that community members infected with HIV regularly display initial reactions of denial and non-disclosure, thereby employing defence mechanisms, within the context of the informal settlement community where I conducted my study. Upon considering and accepting their status, they tend to employ specific strategies to address their illness, like seeking treatment and support, making the necessary lifestyle changes and obtaining information (thereby employing active coping strategies). This process of coping with their HIV positive status further relates to the *avoidance-approach* idea of coping with challenges, as formulated by Snyder and Pulvers (2001) (refer to section 2.3.1).

Brandt (2005) reports on a study by Olley, Gxamza, Seedat, Theron, Stein and Taljaard, exploring coping strategies among South Africans, with specific reference to coping with being infected with HIV or having AIDS. The findings of Olley and colleagues indicate differences in the coping strategies employed by recently infected men and women. Whilst men tend to become involved in substance use and other risk-related behaviour, women often rely on planning and religion in an attempt to cope with their illness. During my study religion and faith also emerged as important coping strategies, as well as the tendency of people infected with HIV or who are living with AIDS to abuse substances. I did not, however, distinguish between reactions (coping strategies) by the different genders. Hence I am not able to conclude whether or not the indications of my study support or contradict those reported on by Brandt (2005).

### 5.2.3.3 Coping in terms of care and support

Participants in my study indicated that people infected by HIV and those living with AIDS might be supported in terms of material assistance, advice and emotional care and support. This perception on care and support to others living with HIV&AIDS is corroborated by the findings of Nnko *et al.* (2000) that support to people living with

HIV&AIDS include financial and material support, as well as regular visits to them. In addition, the World Relief HIV/AIDS Team (2003) also state that people living with HIV&AIDS need the comfort, love and care of their family. Central components of comfort that might be actualised by family members comforting a person living with HIV&AIDS include being together as a family at home, communicating with one another, touching people suffering from AIDS in a loving manner, assisting them when they experience pain and discomfort, praying and reading the Bible together, doing future planning and seeking the assistance and support of a church leader, such as a priest or pastor. These actions relate to several of the main components of coping, as identified by the participants in my study. It further corresponds with the potential value of support groups, as highlighted during my study.

The results that I obtained with regard to caring for and supporting others living with HIV&AIDS are further confirmed by the findings of Rehm and Franck (2000), who conducted a study on long-term goals and normalisation strategies of children and families affected by HIV&AIDS. The findings of their study indicate support by relatives, with specific reference to extended family members, as primary coping strategy with regard to HIV&AIDS. Secondly, these authors emphasise the potential role of spiritual and religious beliefs and practices. In support of this finding by Rehm and Franck (2000), Pargament *et al.* (2001) discuss the possibility of religious coping, with people relying on their religion as a primary resource to cope with difficult situations or challenges (also refer to Boeving [2006], reported on in section 5.2.3.1). In my study, personal religion, faith and prayer were identified as important coping strategies when supporting relatives or community members living with HIV&AIDS, thereby correlating with the idea of religious coping. However, with regard to the potential role of churches, participants revealed ambivalent feelings – being judged by the church based on an HIV positive status but being strengthened by means of services and prayers.

Correlating with the results of my study indicating that family members take primary responsibility of caring for and supporting relatives living with HIV&AIDS, Nnko *et al.* (2000) report on a study with care providers of people with AIDS. According to the study by Nnko and colleagues (2000), family members fulfil the main role with regard to caring for people with AIDS. Findings of another study (Bos & Leutscher in Nnko

*et al.*, 2000) further indicate that mothers, sisters, wives and daughters are the key role-players in the African culture, emphasising the importance of women in supporting people living with HIV&AIDS. This finding corresponds with my identification of (African) women as fulfilling an important supportive role and often form the core of support for coping efforts in the community where I conducted my study, based on the high level of inner strength they possess.

The socialised tendency of women to fulfil a caring role towards others in need of support, as highlighted during my study, is further substantiated by Amoateng *et al.* (2004), as well as Greenglas (2002), who report on the important link between social support and women's coping with challenges. During difficult times, women tend to rely on other women, who face similar challenges. Marais (2005) supports this finding in regarding the tendency to care and support for others as being embedded in the nature of women. In addition, Van Dyk (2001) acknowledges the inherent strength and autonomy of African women as important in overcoming challenges, as African women have in the past been mobilising and organising themselves in order to face challenges and meet the needs in their communities, by relying on available resources within the family, neighbourhood and other informal networks.

Ulin (in Van Dyk, 2001) adds to this line of argumentation by regarding African women's solidarity as their best source of strength for coping with the challenge of HIV&AIDS. The author mentions that this powerful asset is especially evident in women's groups. Although the indications of my study centre around the capacity of women *per se* and not on their roles within the context of groups, future research may further investigate the significance of the fact that the team of educator-participants consisted of women only (since the second visit onwards), as well as the potential impact this might have had on the outcomes obtained in initiating the various projects. Inner strength was especially noticeable within the support group that was established, supporting other community members by relying on their own perseverance. Despite educator-participants' indication that they were in need of emotional support themselves, they also relied on the strength within the group by supporting one another, whilst supporting others.

As in my study, Nnko *et al.* (2000) found that family members are sometimes supplemented by friends and neighbours – depending on the relationship between them and the person living with AIDS. Apart from relying on relatives, neighbours and community members in general, Greenglas (2002) reports on the potential role of colleagues, which might be linked to women's tendency to seek support from the possible resources comprising their social networks. The results of my study confirm this idea, as the participants in my study also indicated that both people infected with HIV or living with AIDS, as well as their relatives are supported by colleagues at work. By relying on family, friends, colleagues and other community members in coping with the challenge of HIV&AIDS, the informal settlement community where I conducted my study employed the *interdependent-self approach to coping*, as propagated by Johnson and Johnson (2002).

Within the context of my study, I relate community members' tendency to rely on the support of others to the idea of *coping by means of social support*. Dillon and Brassard (1999) conducted a study among adolescents coping with the AIDS-related death of their parents, during which a relation between coping and social support was indicated, with adolescents receiving social support from others, such as family members and friends, amongst other strategies, by talking with them. In addition to the support provided by family, friends and other community members, people infected with HIV and who are living with AIDS rely on social and health services for support (Amoateng *et al.*, 2004) – or, to a lesser extent, religious groups and community-based organisations (Nnko *et al.*, 2000). However, possibly due to the limited availability of such services in the community where I conducted my study, the results that I obtained do not fully support the findings of these authors. Yet, I regard social, health and religious services as important *potential* assets in the community where I conducted my study.

In addition, NGOs emerged as sources of potential support for community members infected with HIV or who are living with AIDS. This potential value of NGOs is substantiated by both Walker (2002) and the International HIV/AIDS Alliance (2000), who highlight the significant role that NGOs might fulfil in providing care and support to people living with HIV&AIDS by, for example, presenting workshops, providing material support, initiate care and support projects, and networking with other

stakeholders to provide care and psychosocial support. The various potential ways of supporting a community in coping with HIV&AIDS were also identified by the participants in my study.

#### **5.2.3.4 Caring for orphaned children**

In my study family members reportedly tend to take children orphaned due to HIV&AIDS into their care (supported by friends and neighbours). This trend is supported by some authors, yet contradicted by others. For example, Mugabe *et al.* (2002), Ratsaka-Mothokoa (2001), Anderson *et al.* (1999), as well as Geballe *et al.* (1995) found extended family members, friends and community members to be the main sources of support to children who are orphaned due to HIV&AIDS. In addition, the church is regarded as a potential support system. This latter finding is not fully supported by the results I obtained during my study, as some of the participants in my study experienced the church as being morally judgemental of people living with HIV&AIDS (refer to my discussion in section 5.2.1.1). However, some of the participants regarded the church as potential source of support (section 5.2.3.3).

On the other hand, based on the findings of a study by Clacherty and Associates (2002) conducted in rural and informal settlement communities in the East Rand, Bloemfontein and KwaZulu Natal, the authors question the generally agreed upon belief that orphaned children and children whose caregivers are living with HIV&AIDS, will be supported by local community members. According to the findings of the study by Clacherty and Associates (2002), the stigma attached to HIV&AIDS outweighs community members' willingness and sense of duty towards others who are infected with HIV or who are living with AIDS. However, in the various communities, a few adults could be identified as caring and willing to fulfil a protective role in children's lives. In addition, Smart (2001) argues that traditional models of surrogate child care have become less able to take care of children orphaned due to HIV&AIDS and that poverty-stricken communities in particular are in need of outside support. Based on the results of my study I do not support these ideas, as I found orphaned children regularly to be taken into informal care by extended family structures in the community where I conducted my study. A possible explanation for the contradicting findings might lie in the tendency of extended

families to be replaced by nuclear families, particularly in urban areas. As such, Smart's (2001) view might apply to communities characterised by nuclear families. It might also be possible that the community where I conducted my study had been accommodating orphans in the past, merely adapting to the increased numbers of orphans, by relying on the same way of coping that has been followed over the years, despite expectations that families will not be able to handle the increase in numbers of orphans.

The manner in which the selected informal settlement community appeared to be coping with children orphaned by HIV&AIDS correlates with the community-based approach proposed by Ramsden (2002). According to the community-based approach family members and neighbours ought to assist each other on various levels in taking care of orphaned children. They might further be supported by groups in the community (such as religious organisations, educators, social workers and support groups – as also identified in my study) and rely on resources in the wider community (like NGOs and government resources – also emphasised during my study). Results from my study support the following summary by Ngcobo (2001), who conducted a study on positive responses in coping with orphaned children and concludes that *'the community through extended families still holds the key to coping with the problem'*.

Yet, children orphaned due to HIV&AIDS are often taken in by elderly relatives (like grandparents) or already impoverished relatives (Ramsden, 2002; Townsend, 2001; Mkwelo, 1997). In this regard and in relation to the tendency of extended family members taking orphaned children into their care within the context of my study, I noted that such families experience additional financial challenges. These trends with regard to coping with children orphaned due to HIV&AIDS is supported by Cross (2001), who explored the manner in which rural people cope with orphaned children. Concerning the levels of poverty, Cross' (2001) findings indicate that participants' levels of poverty were increased after taken orphaned children into their households. In addition, the author found other relatives, and to a lesser extent neighbours, as the agents providing support (whether financial, material or emotional by nature) to the families who have taken children into their care. My interviews with people caring for orphaned children revealed similar tendencies.



The opinion of the HIV&AIDS co-ordinator of the Department of Social Development in the Nelson Mandela Metropole that an increase in anti-retroviral medication might result in less children being orphaned by HIV&AIDS in future, is supported by existing literature. Monasch and Boerma (2004) conducted a study in sub-Saharan Africa, reaching a similar conclusion, namely that anti-retroviral treatment might prevent a rapid increase in children orphaned by AIDS in the near future, in particular in cases where fertility is low. Meintjes *et al.* (2003) reached the same conclusion, based on their study in six sites across five provinces in South Africa. However, I speculate to what extent the provision of medical treatment might on the other hand result in an increase in at-risk sexual behaviour, thereby possibly increasing pregnancies and eventually the numbers of orphaned children in the community.

Within the context of my study I did not obtain any results relating to child-headed households, despite the possibility of this option being documented in existing literature. For example, Walker (2002) conducted a study on child-headed households in a farm worker community in Zimbabwe, concluding that any community can play a role in assisting children in child-headed households. Although community members might not be able to offer material resources to others, they are able to offer social and emotional support by, for example, paying home visits, loving and caring for others. Despite the fact that my study did not directly indicate child-headed households, I relate Walker's (2002) findings to my study, as I also noted that community members who are in financial need and not able to support others financially, do provide assistance in the form of food, advice and moral support. I further relate this way of support in different formats to the African culture, according to which people work collaboratively and support one another during times of difficulty.

In conclusion of this section, I relate the results that I obtained during my study with regard to the selected community's way of coping with orphaned children, to that of the Khmer HIV/AIDS NGO Alliance (2000), who conducted a study on children affected by HIV&AIDS, identifying the needs experienced by affected children in Cambodia, as well as possible resources to address their needs. These resources might be compared to the assets (resources) identified in my study (refer to section 5.2.2), as both studies concern ways of coping with the challenges posed by

HIV&AIDS. The Khmer HIV/AIDS NGO Alliance (2000) firstly identified *resources of children*, such as siblings who might offer support, care and advice, except in cases where they have to compete for resources. In my study, siblings were not identified as potential assets in supporting children coping with HIV&AIDS, possibly due to the fact that I did not obtain children's perceptions but merely focused on that of adults who might not think of children as being potential resources. Secondly, I regard *resources of families* as potential assets, as grandparents and other relatives might support a family when a parent is sick, take care of children orphaned due to HIV&AIDS, act as role models and provide education on life skills. In my study, the family was identified as primary source of care and support to those in need of emotional assistance. *Resources in the community* include neighbours, community leaders, community associations, educators and traditional healers as potential sources of emotional support, practical support (like assisting with household tasks), material support, treatment and taking care of children, as also found during my study. Next, *resources provided by people living with HIV&AIDS* can take on the form of support groups. Although support groups did not emerge as a primary coping strategy, the potential of such groups seemed significant. In addition, people living positively with HIV&AIDS appeared to serve as role-models to other community members and might possibly impact on attitudinal change in the community.

With regard to *resources provided by businesses*, none of the participants in my study indicated local businesses as potential resources that might provide financial and material support or work opportunities – thereby generating income, possibly due to the high level of poverty in the community. Concerning *resources provided by NGOs*, NGOs emerged as important potential assets as they might support the community in terms of counselling, workshops, and assistance in obtaining funding or combating social problems in the community. Towards the end of my field work, educator-participants mobilised this potential asset, by contacting a NGO to request funding for a community hall, which could serve as basis for income generation projects that community members might benefit from. Lastly, *government resources* might include HIV testing and counselling facilities, trained government health and social workers, national guidelines and strategies on HIV&AIDS, provincial hospitals, plans for home-based care programmes, and HIV&AIDS being part of the school curriculum (Khmer HIV/AIDS NGO Alliance, 2000). These aspects were indeed

identified as potential ways of supporting the community in coping with HIV&AIDS by the participants in my study.

#### **5.2.4 OUTCOMES OF INTERVENTION RESEARCH IN TERMS OF A COMMUNITY'S APPLICATION OF THE ASSET-BASED APPROACH IN COPING WITH HIV&AIDS**

UNICEF (2000b) propagates an approach to coping with HIV&AIDS during which individuals, family members and community members are involved and empowered to develop their own strategies and put them into action, in order to cope with the challenges related to HIV&AIDS, thereby implementing the asset-based approach. The first step, as identified by UNICEF (2000b) and which was also actualised in my study, requires that an awareness of the challenge needs to be raised, followed by community members initiating strategies. In my study, such awareness resulted in community members experiencing themselves as capable of coping with the challenges of HIV&AIDS, subsequently leading to participants initiating three school-based projects.

Such an approach during which community members identify possible ways of coping with a challenge often require facilitation by outside agencies, yet does not imply that outsiders formulate the strategies to be implemented, as emphasised by the Khmer HIV/AIDS NGO Alliance (2000). I found this to be the case during my study, as the community where I conducted my study was indeed able to implement community-based responses in coping with HIV&AIDS but needed facilitation to do so. Although participants initially indicated that they were not fully able to cope, they were aware of their abilities to do so towards the end of my study. I henceforth discuss the outcomes of my implementation of an activist intervention research approach, relating it to the application of the asset-based approach in supplementing the selected community's coping with HIV&AIDS. I discuss both the tendencies that remained constant, and the changes that occurred as my study progressed.

##### **5.2.4.1 Consistent coping tendencies**

Applying the asset-based approach, integrated with the application of PRA principles within the context of my study results in a few ideas on communities' coping with

HIV&AIDS. Firstly, it supports my initial assumption that informal settlement communities have been in the past, and are at present, able to cope with HIV&AIDS by relying upon themselves and the resources available to them within their local community. This idea remained constant throughout my study. Not only did individuals possess certain skills, capacities and assets that might contribute to the community's response to the challenge of HIV&AIDS, I also identified the community as entailing local associations and local institutions that contribute to the community's coping. Secondly, I found that in order to facilitate sustainable coping, potential assets that are not yet mobilised need to be accessed and utilised, and relations formed between the various role-players, as this could result in the community being empowered to effectively cope with the challenges implied by HIV&AIDS. Therefore, by employing the asset-based approach communities can take agency, thereby enhancing the possibility of sustainable coping (refer to Ebersöhn & Eloff, 2006; Snow, 2001b; Kretzmann & McKnight, 1993).

The reality and prevalence of stigmatisation and secrecy with regard to HIV&AIDS and its related issues remained constant during the entire course of my study, within the context of the broader community (refer to my discussion on stigmatisation-related findings in section 5.2.1.1). However, the educators who participated in my study displayed decreased levels of stigmatisation towards the end of the study. Closely related, selected parents of learners of the school appeared to be more willing to disclose their HIV positive status – but then only to selected educators at school – in order to obtain advice, guidance care and support. This can, however, not be accepted as the norm, as the majority of the community appeared to stigmatise and refrain from disclosure.

Participants displayed certain needs during my study, namely the need to be informed and continuously acquire new skills, as well as the need for money, in order to combat poverty (also refer to section 5.2.1.1). As such, the condition of poverty remained constant during my study, resulting in the participants having to rely on themselves and the resources in their immediate environment in coping with challenges, such as HIV&AIDS. Apart from relying on family members, friends and other community members as sources of support, religion, in terms of faith and

prayer, emerged as central constant components of coping, as experienced by the community where I conducted my study (refer to my discussion in 5.2.3.1).

#### **5.2.4.2 Changes in coping strategies**

I discuss the changes that occurred based on the intervention participatory research approach I employed in terms of the changes experienced by the participants, as well as the changes applying to the wider community where I conducted my study. I conclude the section with a final overview of results relating to the approach I selected.

##### **5.2.4.2.1 Changes experienced by the participants**

During my study participants became aware of their own capabilities and strengths, as well as the resources in the community – referring to individuals, associations and institutions. This result is supported by the findings of a study by Buysse *et al.* (1999), indicating that community members displayed an increased awareness regarding their community's needs and resources after completion of the study. Based on the fact that both Buysse *et al.*'s (1999) and my study followed intervention research approaches and involved discussions amongst community members, focusing on possibilities and resources in the community, I propose that facilitation and communication with and between community members might result in them becoming aware of what already exist but have not been utilised optimally yet.

In the same manner that my study's results highlight the value of asset-mapping, Moore's (1999) report on the Savannah communities project emphasises the potential value of mapping assets in a community. As a result of the mapping activities included in Moore's (1999) project, community members were able to recognise the strengths available in their community, as well as consider ways of utilising potential resources and strengths. One of the outcomes was the development of a programme that, amongst other things, focused on training and support. In a similar manner, the outcomes of my study also relate to community members (participants) recognising the assets and strengths in the community, the

sharing of information and supporting of those in need of support – within the context of coping with HIV&AIDS.

Based on their awareness of their own abilities, existing assets and local resources, educator-participants in my study became more motivated and enthusiastic to take action and assist other community members in coping with HIV&AIDS. Increased levels of motivation and feelings of empowerment subsequently resulted in them initiating the three school-based projects. Related to this finding, Kabiru *et al.* (2003), as well as Page-Adams and Sherraden (1997) report on the value of assets and being aware of assets. These authors indicate that assets positively impact on self-efficacy and life satisfaction, and therefore on the personal well-being of people. Within the context of community-based intervention focusing on adult literacy programmes, Archer and Cottingham (1996) also report an increase in self-realisation and self-esteem amongst participants. These authors relate such positive outcomes to the implementation of PRA, which supplements the asset-based approach. Participants' awareness of available assets (also within themselves) seemingly resulted in them feeling more competent regarding their own and the community's ability to cope with the challenge of HIV&AIDS is confirmed by the findings of the studies reported on in this paragraph.

Holmstrom (1996) further supports trends like these by emphasising the positive outcome of the presence of assets in people's lives, reporting on a survey conducted by the Moorhead Healthy Community Initiative (MHCI) in 1994, according to which children thrive when they have more assets available, as assets are regarded as means that enrich people's lives. Relating this principle to my study emphasises the importance of people being aware of the assets they possess and have access to. Facilitating community members (participants) to purposefully identify and mobilise available yet unused assets, had a positive impact on the community's level of functioning and way of addressing the challenge of HIV&AIDS within the context of my study. Secondly, in identifying and initiating the three school-based projects, educator-participants did not only take agency and experience feelings of pride, they also enabled other community members to believe in their own abilities and face challenges more positively. In accordance with one of the MHCI's criteria for measuring success, namely a change in attitude, the community members involved



in my study did indeed display a change in attitude – from feeling helpless and relying on outside experts, to believing in their own abilities and skills. As an outcome of becoming involved and initiating the three mentioned projects, the social capital of the community increased as my study progressed (as also found in a study by Kelly *et al.*, 2002).

I relate participants' increased awareness of existing assets and potential but not yet mobilised assets towards the end of my study, to two main factors. Firstly, approaching my study from the asset-based approach implied facilitating an awareness of assets amongst participants. Secondly, my decision to apply PRA principles supplemented the facilitation of an awareness of assets amongst participants. In this regard, Chambers (2003:125) – in his discussion of the advantages of PRA – refers to the response of a villager in Zimbabwe during a study: *'We did not know we had all this information,'* and later to that of a Sri Lanka villager after employing PRA during a Self-Help Support Programme, stating: *'We could do what we never thought we could do'.* The participants in my study acknowledged similar feelings of being capable and able to address challenges. My results are further supported by several of the proposed outcomes of PRA, which were obtained in my study, namely that participants learned from the process, gained confidence, owned the outcome of the process (thereby taking agency), obtained new knowledge, broadened their capabilities and discovered things about themselves (such as their strengths) (Chambers, 2004; Strand, Marullo, Cutforth, Stoecker & Donohue, 2003). These outcomes (as obtained during my study) further correspond with Kretzmann *et al.*'s (1997) distinction between tangible (the three projects) and intangible results (participants' change in attitude, feelings of empowerment, self-belief and hope for the future) of asset-based development initiatives.

Participants' high levels of motivation and involvement (participation) in my study resulted in positive outcomes, thereby correlating with the outcomes of a community prevention initiative which was launched in the Western Cape (South Africa) and reported on by the Department of Social Development (2002) in the following terms: *'Recognise that a lot can be accomplished with limited resources, as commitment and altruism are strong impulses that often produce incredible useful results. Such actions should be encouraged'.* Leach (2003b) emphasises the potential value that

participation and the active involvement of participants within the context of PRA hold for the facilitation of change. Besides the importance of participants' involvement, the author highlights the importance of becoming aware of and then utilising available resources in an attempt to build capacity and take agency of the process of community development. In my study, both these facets contributed to the participants taking agency and facilitating change in the community, thereby implementing the asset-based approach in coping with HIV&AIDS.

By being actively involved in the research process and becoming aware of their own abilities and strengths, participants were seemingly empowered as my study progressed. They were increasingly willing to mobilise their potential, by participating in decision-making, as well as developing and implementing action plans to initiate the three school-based projects, thereby facilitating change and becoming involved in community development. They displayed improved levels of confidence to address the challenges faced by the community. Participants also displayed the ability to establish community-based social networks and social support systems, in order for them not to have to rely on outside help and formal structures. Yet, they were able to effectively communicate their needs to selected identified outside agencies. They, for example, spontaneously approached an external agency for financial support towards the end of the study, based on their own feelings of confidence and belief in their abilities. This process of being empowered is widely documented in existing literature on both PRA and the asset-based approach (refer to Strand *et al.*, 2003; Mokwena, 1997).

In this regard, Eloff (2006a), points out that the focus of the asset-based approach on the resources and capacities inherent in individuals and their environments in itself also has an empowering and enabling effect on the outcome of the process. In support of Eloff's (2006a) view, Mahoney, Lafferty & Nutter (2003) report on a study on asset-building and the enhancement and advantages of an asset-based school environment, concluding that their manner of data collection is an asset-building activity in itself. In the same vein, I regard the methodological approach and data collection activities I chose (specifically the intervention activities) as asset-building activities, as it facilitated feelings of empowerment amongst participants. Not only did the educator-participants (and also some other participants) participate actively,

provided input and initiated projects; they also gained an understanding of the asset-based approach during the process of data collection and documentation. This theme on participation facilitating empowerment is supported by the findings of Kriek (2002), Lockett (2000), Feikama, Segalavich and Jeffries (1997), Dinnebeil, Hale and Rule (1999), as well as Webster-Stratton (1997).

The emphasis on the processes implied by the asset-based approach corroborates with the findings of Kretzmann *et al.* (1997), who report on the implementation of a capacity inventory as a method to enhance community development. These authors found that capacity inventories could, amongst other positive outcomes, result in people (community members) being *organised to address issues* (challenges) in the community. One of the outcomes of the second forth-flowing intervention of my study was the three projects initiated by the educator-participants. Firstly, the participants initiated a vegetable garden (involving community members) thereby addressing poverty and indirectly the community's way of coping with HIV&AIDS. In addition, the participants initiated an information centre and support group in the community, assisting community members to address the challenge of HIV&AIDS. As such, my (our) findings correlate with that of Kretzmann *et al.* (1997) concerning community members being able to address challenges. A second possible outcome identified by Kretzmann *et al.* (1997) relates to the *building of trust and social capital by means of connections and links*. In my study, the educator-participants displayed the potential to bring those living with HIV&AIDS into contact with others, in order to become part of a support group in the community, supporting one another in facing the challenge.

Kretzmann (1997) describes an empowered or strong community in terms of four basic criteria, which correlates with the results of my study, thereby indicating that the community was empowered by means of the educator-participants implementing the asset-based approach. According to Kretzmann (1997), an empowered community is a community in which the assets have been discovered, listed in the form of an inventory and made visible. In my study, participants compiled maps in order to identify available assets. Secondly, an empowered community is a community in which the assets have been put to use during strategic planning for the future. In my study, participants relied on potential and available assets to plan and

initiate the three school-based projects. Thirdly, assets need to be connected with one another in terms of new strong networks, consisting of mutual and beneficial relationships. In my study, participants established new networks and collaborated as a team (relying on a combination of assets) in order to support the community in coping with HIV&AIDS. Lastly, community members (and their assets) need to be involved in obtaining and managing resources outside the community, as was done by the participants during my study.

In my study, feelings of empowerment therefore resulted in community members taking responsibility. This finding correlates with the findings of Ebersöhn and Mbetse (2003:326), who relate capacity building being facilitated amongst community members, to individuals taking ownership and responsibility for the development of their career education process: *'Instead of the community playing victim to negatives, they chose to mobilise themselves as mutually supportive and caring change agents. Their approach to career education is not that of passively complaining and waiting for the government to save them. The control and power for their career education initiatives and solutions are internally situated.'* With regard to taking responsibility within the context of HIV&AIDS, I regard the Community-based Options for Protection and Empowerment (COPE) project described by Hunter (2002) as an example of an effective community mobilisation project. The outcomes of this project include that communities found their own solutions during the project, by taking responsibility to care for and support those infected with and affected by HIV&AIDS. Similar to my study, the COPE project facilitated community ownership, psychosocial support and community members being informed about HIV&AIDS. In addition, communities (participants) successfully mobilised resources within the community as well as on an external level (as was done in my study), in order to enhance food and income security. By identifying challenges and solutions themselves, their capacity to cope with orphaned and vulnerable children was developed, resulting in higher levels of social capital (Richter *et al.*, 2004; Strebel, 2004; Hunter, 2002). In my study, community members' (participants') identification of solutions positively impacted on the community's coping with HIV&AIDS.

The intervention research approach that I employed complies with one of the suggestions of Miamidian *et al.* (2004), namely community-level intervention, where

community mobilisation, community fundraising, income-generating initiatives, the promotion of linkages to developmental institutions and the provision of child care were suggested. As minimum requirements for such initiatives, Miamidian *et al.* (2004) suggest active involvement of community members in planning and management of initiatives, the use of local resources, and ownership by community members. Initiatives are suggested to be facilitated by outsiders or initiated by community members themselves. In conducting my study I adhered to these suggestions, thereby implying that community members might have been able to take agency of the process, as was found to indeed be the case.

I further relate the results obtained during my study to Lucas' (2004) description of yet another example of a successful community response to HIV&AIDS, namely the Salvation Army Change Programme in Zambia. The programme resulted in human capacity development, by building on local resources and strengths, facilitating community members to take action with regard to prevention, as well as caring for and supporting those infected and affected by the disease. It focuses on the strengths of individuals, families and communities, encouraging community members to recognise the ways that they are already responding to HIV&AIDS so that they can build on what is already there. As such, emphasis is placed on local community members' resourcefulness and innovative ideas of addressing the challenge, thereby on their way of coping (Lucas, 2004; Foster, 2001; Cook, 1998). This once again correlates with the asset-based approach, as employed during my study and enabling a selected community to better cope with HIV&AIDS.

As my study progressed, educator-participants clearly displayed the ability to rely on their own resourcefulness. They started supporting community members living with HIV&AIDS, by referring them to professional services and assisting them in applying for the disability grant by guiding them on the correct institutions to approach. In this manner, the results of my study correspond with those of Kretzmann, McKnight and Puntenney (1998) (in an adapted format), who report on the potential use and positive outcomes of employing a so-called *local capacity listing and referral service*, that might be utilised to refer community members to other suitable role-players who might assist or support them in overcoming challenges. In my study, this potential resource was used in an adapted format (simply by enquiring and then memorising),

as the participants did not rely on formal lists and information capturing systems to capture their information. However, the way this method was employed by the educator-participants, resulted in similar positive outcomes as that obtained when relying on formally captured lists. Yet, relating this method in its initial format to the participants might assist them even further in providing information to and supporting community members in coping with HIV&AIDS.

Concerning the possibility of extending positive changes to the wider community, selected individuals (primarily the educator-participants) were initially empowered during my study. However, as any community consists of individuals, the strengths and possible areas of improvement of the community represent that of its individual members. As such, the empowerment of the selected community members inevitably resulted in them going out into the community and in turn empowering other community members, by involving them in the initiatives that were planned and put into action. The empowerment of the broader community is supported by Mokwena (1997), who reports on various studies relating to the relationship between the empowerment of individuals and that of communities.

Moore (1999), as well as Puntteney and Moore (1998), report on a programme (the *Grants for Blocks* programme, initiated in 1993), which aimed at getting communities to initiate and implement community improvement projects by relying on local community members to address community challenges. The programme resulted in a variety of projects relating to aspects such as crime prevention, youth development, the presentation of workshops and improving the facilities and appearance of the community. In addition, it led (just as in my study) to an increase in resident empowerment, in the form of higher levels of involvement in initiatives focusing on the improvement of the community (neighbourhood), self-advocacy and taking the lead in the community. The following comment was made, referring to the *Grants for Blocks* programme: '*If you get a community together, you've got the power to do anything*' (Puntteney & Moore, 1998:1).

Despite the main difference of this programme involving financial assistance from an outside source, the main findings of the programme correspond with the empowerment of educator-participants in my study in turn resulting in other



community members becoming involved and actively taking part in coping with the challenges related to HIV&AIDS. As a result, the cohesion and relationships amongst community members most probably also improved, as found by Puntenney and Moore (1998) during the *Grants for Blocks* initiative. Both my study and the one reported on by Moore (1999), as well as Puntenney and Moore (1998), emphasise the positive outcome of community members being empowered to plan and implement self-help activities, in order to cope with challenges faced by the particular community. The following two examples of responses in the *Grants for Blocks* initiative directly correlate with responses that I obtained during my data collection, as reported on in chapter four: *'People have always had good ideas, they know how to solve their problems, but they need a little help. Grants for Blocks has helped us put our ideas into action'* (Puntenney & Moore, 1998:21), and: *'The beauty of Grants for Blocks is that it is a way to encourage resident involvement, and that involvement spills over into all sorts of other activities that are happening around development and improvement issues'* (Puntenney & Moore, 1998:43).

By supporting HIV&AIDS infected community members, the educator-participants (support group) enhanced the community's way of coping with HIV&AIDS. For example, by providing advice, physical support and paying home visits, individuals living with HIV&AIDS could be supported to better cope with the challenge of their illness. In addition, caregivers of orphaned children could be supported, in order to allow for such orphans to remain and be cared for within their community and tradition. Furthermore, other relatives, friends and community members provided help and assistance to those looking after orphaned children. These results relate to the Child Protection Society of Zimbabwe (1999), who suggests such initiatives as part of a support programme for orphaned and vulnerable children.

During the later stages of my study, the educator-participants acknowledged the significant role of their school in the community's coping with HIV&AIDS. In this regard Ford (1996) emphasises that community-based development depends on reliable and strong local institutions, being the school in my study. During discussions on the value of the school to the community, one participant labelled the school as a *'community school'*. As community schools refer to schools that are run by communities, where no school fees or uniforms are required and where teachers of

the close community are used, often on a voluntary basis and with limited training, the possibility exist that the particular participant did not clearly understand the concept. She might have referred to the '*school as a comprehensive community-based organisation*', which – per definition – implies that the school is the centre of activity and service for the community (Richter *et al.*, 2004; Kelly, 2000b; UNICEF, 2000b). On the other hand, the participant might have been of the opinion that the way in which the school was accepted in the community reflected something of the concept of *community schools*. Based on these uncertainties, I am not able to explain this result and will have to explore further in order to be able to do so. However, the importance of the school and the educators in assisting community members to cope with HIV&AIDS is not to be doubted.

#### **5.2.4.2.2 Changes in terms of community development**

During my study I found that the selected community was able to cope better with the challenges related to HIV&AIDS towards the end of my study, based on community members' implementation of the asset-based approach. This result is supported by Lubbe and Eloff (2004), who summarise the possible use of the asset-based approach in coping with challenges. Although these authors describe the asset-based approach within the context of Educational Psychology, the following view can be applied to my study: '*In partnership with parents, other caretakers and teachers, the assets of the family or community can be identified, then mobilized and expand in order to help them optimally cope in their daily lives (i.e. emotional health for life)*'.

As an outcome of the intervention research I conducted and facilitated in the community, community development was enhanced. In this manner, my study can be related to Snow (2001b)'s discussion on community development, according to whom positive changes in a community might be ascribed to the process of utilising assets in the community, being an indication that asset-based community development has occurred. In my study, the selected informal settlement community therefore underwent community development whilst implementing the asset-based approach. Visible changes that occurred and are indicative of the community development that took place include the establishment of the vegetable garden, support service and information centre, as well as community members becoming

more involved in community activities. In addition, the educator-participants identified several potential school/community-based projects (like a soup kitchen at school, initiating income generation projects and building a hall) that might be initiated in future, once again building the community.

Measuring the outcomes of my study in terms of the two criteria for successful community building as identified by Kretzmann *et al.* (1997) strengthens my conclusion that my study did indeed result in community development. Firstly, a belief in the capacities of local community members (and the educator-participants, who started viewing themselves as key role-players in solving [addressing] the problems faced by the community) was built and secondly, these capacities were mobilised in order to result in concrete outcomes, namely the vegetable garden, information centre and support service provided by the school. Results from my study correlate with that of Kretzmann *et al.* (1997), who report on six community groups implementing the asset-based approach (more specifically compiling a *capacity inventory*) and the positive outcomes of the processes in terms of community building, for example by identifying community members to be involved in addressing challenges, initiating community-based projects to address challenges and developing the capacities of community members in order to cope with challenging situations.

Based on the results obtained during my study, I regard the selected community (or rather school) involved in my study as an *AIDS responsive community*, a concept used by Kelly *et al.* (2002) in describing the rural community where they conducted their study. In my study, the challenge remains to extend on the activities initiated by the educator-participants and to apply it on a wider scale in the community than at the time of my study. The *launch day* planned and held by the rural community in Kelly *et al.*'s. (2002) study correlate with the *official celebration day* (which included the official opening of the school) planned and conducted by the school where I conducted my study in September 2005. This serves as an indication of the potential value of interventions in poverty-stricken and rural communities, where community members have to be made aware of their capabilities, in order to move them into action in facing the challenges associated with HIV&AIDS.

Kelly *et al.* (2002) conclude that the Eastern Cape rural community where they conducted their study might be used as a showpiece for similar and surrounding communities, as the project effectively connected AIDS responses and community development. In addition, the community complied with the national Department of Health's white paper which propagates community participation as part of health promotion and health service provision. The authors do, however, voice their concern regarding the sustainability of their intervention and remark that outside assistance might be needed in order to sustain the activities already started, in terms of aspects like advice networking. On the other hand, Moore (1999), as well as Punttenney and Moore (1998), are of the opinion that programmes such as the *Grants for Blocks* initiative holds the value of accomplishing sustained neighbourhood improvement, by achieving resident ownership (agency). By taking ownership, community members participate in the various areas of such initiatives and take on leading roles in the community. Applying these findings to my study result in my hypothesis that the initiatives facilitated in the community where I conducted my study will most likely be sustained, as the educator-participants (and subsequently also other community members) took agency of the various initiatives and its outcomes, and were (are) indeed involved in the various areas of the projects as members of the team but also fulfilling a leading role in the school and community. This idea is, however, a mere hypothesis that needs to be further explored.

#### ***5.2.4.2.3 Concluding findings related to the activist intervention research approach that I employed***

The activist intervention research approach I employed during my study correlates with the community-based intervention approach proposed by Trickett (2002). I firstly facilitated an assessment of the community in terms of challenges, assets and potential assets, as well as the various role-players in the community. Secondly, I paid much attention to building up a good collaborative research relationship between the community members (participants) and myself. I continually kept the context as well as the culture of the community members in mind. Lastly, my intervention research resulted in community development and an impact on the community's way of coping with HIV&AIDS.

The intervention research approach that I employed further correlates with the three areas of the COPE project, as described by Hunter (2002). I firstly conducted intervention sessions to raise awareness of HIV&AIDS and its impact on the selected community. Secondly, I facilitated community action towards taking agency in coping with HIV&AIDS. Thirdly, I (and my co-researchers) facilitated initiatives to be planned and implemented at community level, in order to better cope with the pandemic. The finding that educator-participants were mobilised to facilitate change in the community correlates with the following statement by Parker *et al.* (2000), discussing the value of participatory strategies in addressing HIV&AIDS: *'Individuals drawn into participatory communication activities often make marked changes to their own behaviour, and become catalysts for change at community level'*.

In conducting intervention, I adhered to the principles underlying interventions at community level, as formulated by Miamidian *et al.* (2004). Reflecting on the outcome of my study, I found that my intervention did indeed assist the selected community to do what it has been doing in a better way, that facilitation assisted in unlocking the capacities of the participants (community members) and that my intervention involved only a small core of community members, but in turn served to catalyse involvement on a broader community level. During my study, I further confirmed community ownership to be the basis of effective community action, and that community-based initiatives may commence with a collaborative effort of identifying areas of shared concern, but also of assets.

The specific steps I employed during community mobilisation are similar to those suggested by Richter *et al.* (2004), as well as Kretzmann and McKnight (1993), thereby qualifying the process as the *asset-based approach put into action*. After raising awareness of the impact of HIV/AIDS amongst participants, I facilitated a sense of ownership. In the process I included activities of mapping existing assets, capacities and resources in the community, identifying existing challenges, and planning how to manage these challenges by relying on internal resources. This implied the mobilisation of available but not yet utilised assets in the community. Throughout, I monitored the process and adjusted activities when needed. During intervention sessions I found Cook's (1998) principles for effective community development and Hunter's (2002) guidelines for mobilising a community, to be

valuable. Therefore, I spent prolonged time in the field, during which I continually focused on being culturally respectful, involving as many stakeholders as possible, constantly building relationships of trust, collaborating and communicating with the participants and building on existing strengths. I also encouraged participants to develop strategies and take action in coping with the challenges they identified, thereby facilitating empowerment and enhancing community ownership or agency.

In describing the process of effectively planning and conducting culturally appropriate community mobilisation, Cook (1998) mentions three basic steps as a possible strategy to follow in supporting families and communities. I applied these steps of assessment, analysis and action (so-called 'Triple A' approach) during my study. By employing this approach, I observed that facilitators can indeed assist community members in building on their own strengths, and developing strategies to address the challenges they face. During the assessment phase, I acted as facilitator and conducted interviews with stakeholders in the community, with regard to the community's way of coping with HIV&AIDS. During the analysis phase, I analysed the information that I collected and then requested feedback from the participants. After providing the participants with the collected information, they were facilitated to formulate plans to address the identified challenges. Finally, during the action phase the participants decided on plans and put them into action. The final step in the process entails a re-assessment of the intervention in order to determine whether or not it had been successful and plan on further steps to be taken.

The steps I followed also relate to most of the proposed strategies of The Child Protection Society of Zimbabwe (2001), as implemented during community-based orphan care programmes. The suggested process (which corresponds with the processes described in the previous paragraphs) firstly involves that awareness be raised about the challenge within the community. The second step relates to documenting the extent of the challenge by assessing the needs and keeping a register, finding out what community members can do (identifying resources and potential areas for growth or the development of resources), and monitoring the progress of the programme. These actions were conducted during the intervention sessions I facilitated with the educator-participants, as well as during individual interviews with members of the community. Thirdly, the community needs to be



mobilised into action by, for example, establishing partnerships with outside resources, networking with stakeholders and mobilising volunteers from the affected community to plan and take action. During my study, I focused mainly on the latter of these three steps, although the first two were also actualised. Next, the Zimbabwean programme focuses on making ends meet, helping to educate and train children, and improving legal systems to help children. Within the context of my study I included these final steps in an adapted format, as the participants were mobilised to assist community members in facing poverty and generating income (for example by means of the vegetable garden), educate colleagues, community members and children with regard to HIV&AIDS, and lastly assist community members in applying for government grants in cases qualifying for the grant.

In reporting on the Salvation Army Change Programme in Zambia, Lucas (2004) assesses the facilitation process as being successful, based – amongst other things – on the establishment of community gardens as a way of providing food and income, as well as an increase in community members responding actively to the HIV&AIDS challenge. Assessing my study solely in terms of these criteria implies that intervention and the participatory choices I employed during my study were effective. However, it is my view that various other aspects and outcomes need to be considered in determining the accountability of my study. Thus I cannot conclude that my study has been effective, merely based on these two isolated criteria.

### **5.3 CONCLUSION**

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Building on the results of my study that I presented in chapter four, I structured my discussion in terms of findings accordingly in this chapter. I continually related my results to existing literature, indicating similarities as well as contradictions. In the case of contradictions, I attempted to provide possible explanations.

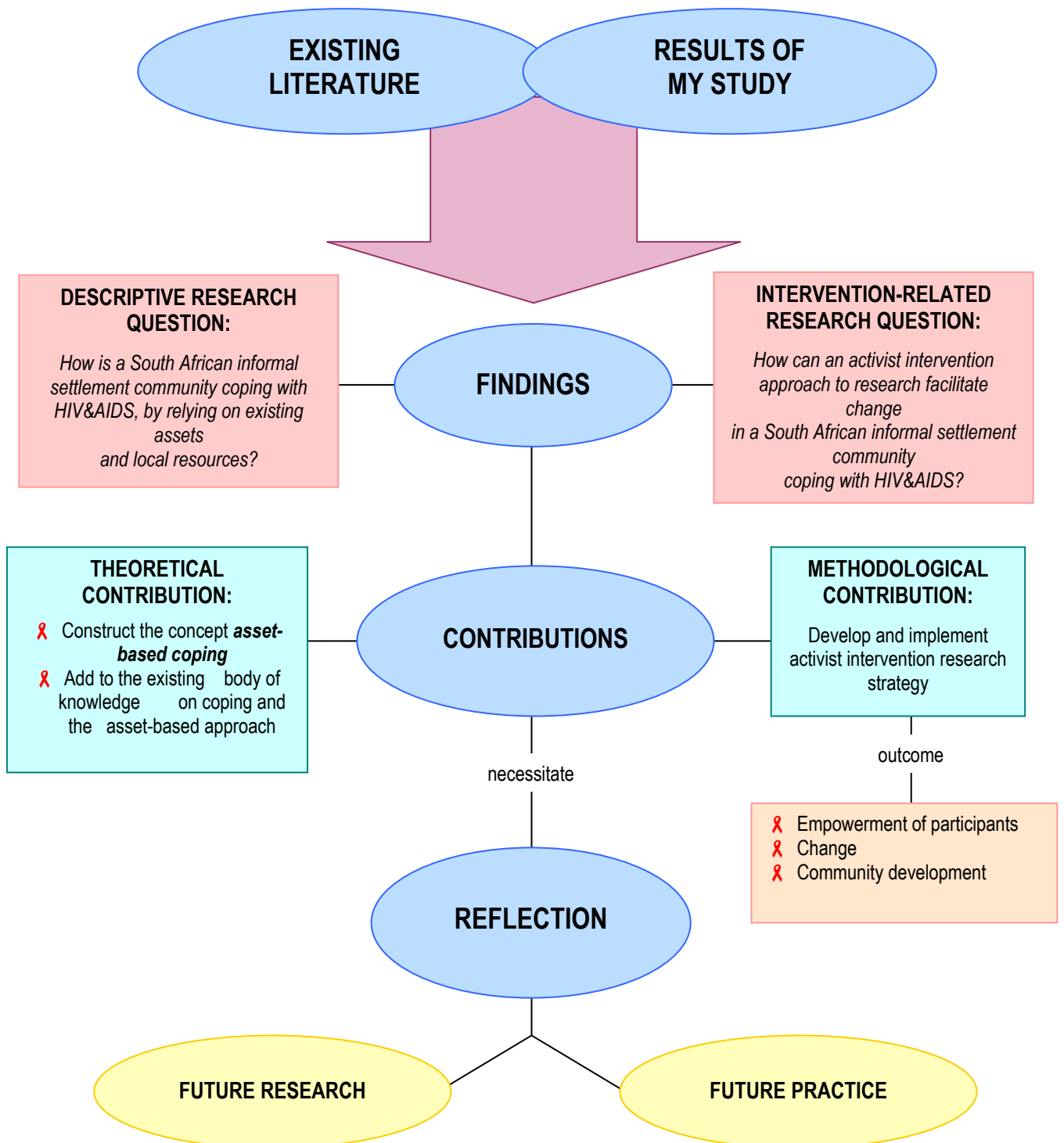
In the next and final chapter of this thesis I summarise chapters one to five. I reach final conclusions by reflecting on my research questions in terms of cumulative findings resulting from this chapter. I conclude my study with recommendations for future research projects and practice.

## CHAPTER 6: CONCLUDING THE JOURNEY AND RECOMMENDING FOR THE FUTURE

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## CHAPTER 6 AT A GLANCE



## 6.1 INTRODUCTION

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In chapter five I presented the findings of my study in terms of existing literature on HIV&AIDS, coping theory and the asset-based approach. In this chapter I provide a summary in respect of chapters one to five, followed by a final synopsis of my findings and conclusions in terms of my research questions, as formulated in chapter one. I present these conclusions in accordance with my secondary research questions, thereby indirectly addressing the following central research questions that guided me throughout my study:

- ⌘ ***How is a South African informal settlement community coping with HIV&AIDS, by relying on existing assets and local resources?*** [Descriptive research question]
- ⌘ ***How can an activist intervention approach to research facilitate change in a South African informal settlement community coping with HIV&AIDS?*** [Intervention-related research question]

After final discussions of my findings in terms of my secondary research questions, I provide concluding reflections on the contributions, strengths and challenges of my study, as well as a reflection on my own qualifications and preparedness in entering the research field. I conclude the thesis by presenting the outcomes of my study, followed by recommendations for future research and practice.

## 6.2 OVERVIEW OF THE PRECEDING CHAPTERS

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**Chapter one** focused on ***setting the stage*** for my study. I introduced my area of interest and explained my rationale for undertaking the study. I related my decision to work within the context of HIV&AIDS to the relevance and need for research in the area of *HIV&AIDS*, as well as my concern as to how communities are coping with the challenges implied by the pandemic. I justified my decision to focus on *coping* in terms of the reality that communities facing the challenges associated with HIV&AIDS are required to respond to them in an appropriate manner, in order to

enhance their own well-being. Finally, I linked my decision to rely on the *asset-based approach* to its focus on strengths and abilities within individuals, groups and communities, thereby implying that effective coping with HIV&AIDS is situated within communities at ground level – being a philosophy that I support.

Based on the introductory orientation and discussion of the rationale of my study, I stated the purpose of my study and formulated my research questions, which are twofold. My first purpose and central research question is descriptive in nature, and focused on exploring the manner in which a South African informal settlement community is coping with HIV&AIDS, by relying on existing assets and local resources. My second purpose and central research question concerns the outcome of the activist intervention approach to research I employed, exploring changes that might be facilitated by this approach (thereby methodological and intervention-related in nature). After formulating my research questions, I briefly introduced the contribution of my study and identified the assumptions with which I approached the study. I clarified key concepts, stated the paradigmatic perspective with which I approached my study and provided a brief overview of my research design, methodological choices, ethical considerations and quality criteria. I concluded chapter one by providing an overview of the thesis in terms of its six chapters.

In ***chapter two I explored existing literature as background to my study*** and presented my conceptual framework. I firstly examined existing literature on HIV&AIDS, in order to provide the contextual backdrop of my study. After presenting the extent and impact of the pandemic, situating it within the South African context, I focused my discussion on potential challenges and stressors implied by HIV&AIDS. I included discussions on the challenges faced by individuals living with HIV&AIDS, as well as by others caring for and supporting people living with HIV&AIDS. I concluded my discussion on HIV&AIDS by current responses to the pandemic, highlighting the importance of continuous research, especially focusing on the outcome of interventions and programmes that are currently provided in communities.

In the second part of chapter two, I explored existing literature on coping. I referred to a few selected theories on coping, which seemed to be relevant to the focus of my study. Next, I discussed community-based coping, relating it to my focus in terms of



a discussion on community-based coping with HIV&AIDS. I highlighted empowerment as central activist concept to community-based coping. In exploring existing literature on coping, I became aware of the possibility that my study might add to existing literature on coping within the context of HIV&AIDS, in terms of specific coping strategies that might be employed by community members facing the challenges implied by the pandemic. I continued by exploring existing literature on the asset-based approach, which I found to be emerging in nature. After situating the asset-based approach as alternative to the needs-based approach I discussed the asset-based approach in terms of its core principles, main components and potential advantages. During my literature study I posited that my study might contribute to the existing knowledge base on the asset-based approach, in terms of its potential application value when coping with HIV&AIDS.

**Chapter three** includes my discussions and justification of the choices I made in ***designing and conducting research in the field***. Based on my integration of the theory on the asset-based approach with PRA principles, I followed an activist intervention approach to research – doing intervention *via* research and research *via* intervention. I employed a case study design applying PRA principles and utilised intervention (focus groups/workshops), individual interviews, observation, a field journal and visual data as data collection and documentation procedures. After justifying my choices in terms of my research questions and purpose of my study, I described the manner in which I conducted thematic data analysis and interpretation. Next, I summarised the strengths of my selected methodology, followed by a discussion on the challenges I faced, as well as the manners I employed in an attempt to address these barriers. I concluded chapter three with detailed discussions on the ethical guidelines I adhered to whilst in the research field and the manner in which I strived to enhance the quality of my research, in terms of qualitative quality criteria.

In **chapter four** I ***reported on the results*** I obtained during my study. As an introduction, I described my research process in terms of the seven main phases of my study. This was followed by my presentation of the results I had obtained, in terms of the themes and sub-themes that emerged during data analysis. The four main themes that emerged relate to the challenges and stressors experienced by

community members within the context of HIV&AIDS, assets available in the community that might be relied on in coping with HIV&AIDS, existing coping strategies employed by community members in coping with HIV&AIDS, and outcomes of the activist intervention research approach I followed in relation to employing the asset-based approach in coping with HIV&AIDS. In presenting my results, I included verbatim quotations, as well as references to the visual data, field notes and reflections included in the various appendices.

After presenting the results I obtained in chapter four, I interpreted them in terms of my conceptual framework (included in chapter two) and presented them as findings in **chapter five**. I ***related my research findings to existing literature***, by comparing and integrating my results in terms of the knowledge base existing on HIV&AIDS, the theory of coping and the asset-based approach. I emphasised correlations and also highlighted contradictions between the results I obtained and those reflected in available literature. In the case of contradictions I aimed to provide possible explanations for such differences.

### **6.3 CONCLUSIONS IN TERMS OF MY RESEARCH QUESTIONS**

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I henceforth provide final conclusions on my findings, by relating them to my secondary research questions. By providing discussions in terms of the secondary research questions, I also indirectly address my central research questions. Section 6.4 includes reflections in terms of my primary research questions.

#### **6.3.1 SECONDARY QUESTION 1: *WHAT ARE THE PERCEPTIONS OF A SOUTH AFRICAN INFORMAL SETTLEMENT COMMUNITY WITH RELATION TO COPING WITH HIV&AIDS?***

Within the context of the community where I conducted my study, coping with HIV&AIDS implies, amongst other things, caring for and supporting others living with HIV&AIDS. To the community members of the community where I undertook my study, such care and support entails acceptance of the person living with HIV&AIDS, material support (in the form of food, clothing and other supplements), emotional and

spiritual support. Although I found community members to hold the view that others are supposed to provide advice and information on HIV&AIDS to those living with the disease, the participants in my study indicated insufficient confidence to do so, which they related to their perceived lack of sufficient knowledge on HIV&AIDS-related issues. In addition, participants stated that community members generally do not know how to support others. However, upon further investigation, I found that many community members (participants) do indeed possess basic HIV&AIDS-related knowledge, which might be utilised when supporting other community members living with HIV&AIDS – thereby coping with the pandemic.

Closely related to the need for community members to be informed, participants in my study indicated that a change in attitude is required amongst community members with regard to HIV&AIDS. I found that stigmatisation still strongly prevails in the informal settlement community where I conducted my study, often resulting in community members who are infected with HIV, or who have AIDS, being rejected, discriminated against or morally judged, based on the reported link between HIV&AIDS and at-risk sexual behaviour. According to the participants, stigmatisation might be addressed by attitudinal changes in the community, which might, in turn, address the tendency of those living with HIV&AIDS to deny and not disclose their status. In my study, I found only a few community members displaying positive attitudes with regard to HIV&AIDS and other community members living with the disease. In selected cases, community members living with HIV&AIDS who decided to disclose their status, appeared to maintain a positive attitude in their daily lives, informing other community members and setting an example.

In spite of the finding that community members (participants) regarded care and support to others living with HIV&AIDS as important within the context of the community where I conducted my study, I found myths and misconceptions to be preventative factors for community members providing such support to others. In addition, a hesitancy to support other community members living with HIV&AIDS often seems to be related to stigmatisation – where the people who are supposed to support others stigmatise them, or on the other hand fear being stigmatised themselves by becoming involved with a person living with HIV&AIDS. In selected

cases, community members would avoid supporting others living with HIV&AIDS, in an attempt to protect them and their families from being stigmatised.

In terms of the support needed by people living with HIV&AIDS, community members of the community where I conducted my study indicated a need for more efficient counselling services within the community. Besides the participants' perception that the individuals living with HIV&AIDS are in need of counselling, they emphasised the importance of counselling to the families of those living with HIV&AIDS. In addition, a need was identified for counselling services for children infected with and affected by HIV&AIDS, as well as for community members supporting others on a regular basis, such as the educators that established the support service in the community.

### **6.3.2 SECONDARY QUESTION 2: *WITH WHICH CHALLENGES DOES A SOUTH AFRICAN INFORMAL SETTLEMENT COMMUNITY HAVE TO COPE, WITH SPECIFIC REFERENCE TO THE HIV&AIDS PANDEMIC?***

In my study I found individuals, families and the community at large to experience vulnerability on a personal, physical, social and cultural level. Upon finding out about an HIV positive status (of oneself, a friend, relative or other acquaintance), community members typically experience feelings like anger, shock, fear and helplessness, leaving them vulnerable. Instead of addressing such feelings, the findings of my study indicate that community members often avoid talking about HIV&AIDS or dealing with the feelings they experience, adding to their personal vulnerability. In this manner, silences and avoidance behaviour result in them denying themselves (especially those who are living with HIV&AIDS) the possibility of obtaining care and support. Closely related, community members indicated the tendency to avoid testing their HIV status, thereby also preventing themselves from possibly accessing treatment, care and support they might need. On the other hand, by denying their status and/or illness, people living with HIV&AIDS protect themselves from the possibility of being stigmatised, rejected or discriminated against. As such, they shift their focus away from the possibility of living with an incurable disease (with the implied possibility of dying) towards a focus on living their daily lives.

I found stigmatisation and discrimination to be prevailing realities within the community where I conducted my study, resulting in said denial of an HIV positive status and the lack of disclosure, thereby further intensifying the vulnerability of community members. Denial and the tendency not to disclose were related to the fear of being isolated, rejected or avoided. In this manner, some of the initial coping strategies employed by society in coping with individuals living with HIV&AIDS (such as rejection, discrimination and avoidance) reinforce some of the initial coping strategies (or rather defence mechanisms) employed by those living with HIV&AIDS (like withdrawal, isolation, denial and non-disclosure), and *vice versa*. Thus, in an ironic way, initial stages and manners of coping (which is supposedly a positive action) might add to the vulnerability of community members living with HIV&AIDS (having a negative adverse effect).

I further found that participants related the lack of being informed on HIV&AIDS-related issues to the tendency of avoiding, rejecting and discriminating against community members living with HIV&AIDS, due to the fear of being personally infected when caring for or supporting others who are infected. As such, myths and misconceptions related to the transmission of HIV, as well as the possibility of being rejected and even harmed by others upon disclosing ones status, often result in individuals keeping their HIV positive status a secret. In the case of individuals indeed deciding to disclose their status, such disclosure is usually done within the safe environment of the family or selected friends, or alternatively to social and/or medical workers, in order to obtain treatment, care and support, as well as access to the disability grant.

In addition to the negative impact of stigmatisation and discrimination, I found that community challenges like poverty, unemployment and at-risk sexual behaviour (sometimes employed in reaction to and in an attempt to combat poverty and meet basic needs) further intensify the vulnerability of the community. Poverty inevitably leads to individuals experiencing the need for nutritious food and medical care, but often not being in the position to afford it, or have access to the resources that might provide in such needs. Other social challenges that might negatively impact on vulnerability, as experienced by the selected community, include teenage pregnancies, alcoholism, domestic violence and child abuse, child neglect, crime,

substance abuse and early school drop-outs. Within the specific geographical lay-out of the community where I conducted my study, the adjoining salt lake was identified as a challenge, based on the health-related threats it implies. As such, I found the members of the community where I conducted my study as experiencing challenges on a daily basis – constituting their social reality. These challenges necessitate community-based responses, as the possibility of receiving outside help in overcoming the challenges they face seems rare and poses yet another challenge to the community, requiring of it to cope with the assets and resources available in the immediate community.

Within the context of HIV&AIDS, the members of the community where I conducted my study, face the potential challenge of firstly accepting and coping with their own HIV positive status. In addition, I found that community members increasingly have to cope with other community members being HIV positive or having AIDS, by advising and supporting them. Closely related to this challenge, the community (often the educators, school and family members) has to cope with vulnerable children being orphaned due to the HIV&AIDS-related death of their parents, or being infected with HIV themselves. In the case of the latter, educators further have to cope with the challenge of sensitively guiding other learners in the school on how to cope with fellow learners who become ill or seem to be tired.

Another challenge (yet also an asset with regard to community-based coping – refer to section 6.3.3) I found to be prevalent within the informal settlement community where I conducted my study, relates to the basic beliefs and common practices embedded in the Xhosa culture, which seem to add to the vulnerability of community members. Based on the acceptance of men being involved in multiple sexual relationships and the patriarchal position held by Xhosa men over women, the married women of the community seldom insist on safe sex practices, thereby adding to their vulnerability. Furthermore, participants linked the hesitancy to disclose to their culture, preventing people living with HIV&AIDS from accessing treatment, care and support. In addition, the hesitancy of Xhosa people to provide guidance in respect of sexual behaviour and its possible consequences to their children (as practiced within the selected community) might further contribute to at-risk sexual behaviour and people (children) being ill-informed.



Finally, accessing the resources that are indeed available to community members and that might assist them in coping with the challenges they face, was perceived as yet another challenge faced by the particular community. For example, due to a lack of money, community members of the informal settlement community where I conducted my study, often do not have the means to pay for transport to the provincial hospital or nearest clinic. This lack of financial resources occasionally results in people dying within the vicinity of a hospital, because they are too weak to walk there and not able to afford transport or make a telephone call. In addition, social and health services appear to be limited in the selected community, thereby also negatively impacting on the community's access to care and support. Despite the Departments of Health and Social Development, faith-based organisations and NGOs apparently involved in the community, I found only one social worker to be stationed in the community on a permanent basis at the time of my study. This results in the challenge of one person having to provide crisis intervention to the whole community, with no time left for home visits or specific counselling within the context of HIV&AIDS. Although other social workers appeared to be available for providing services in the community, community members had to contact or visit them in order to obtain their services, which, as stated above, in itself poses a challenge. With regard to the possibility of government grants being accessed as a way of financial support to individuals/families, community members often seemed to be uncertain about the procedures to employ in applying for the grants, thereby preventing them from accessing a potential financial resource.

### **6.3.3 SECONDARY QUESTION 3: *HOW DOES A SOUTH AFRICAN INFORMAL SETTLEMENT COMMUNITY CURRENTLY COPE WITH HIV&AIDS?***

One of the potential contributions of my study relates to the possibility of my findings adding to the existing knowledge base on coping. I found that the community members of the informal settlement community where I conducted my study rely on a range of local resources and employ various strategies, in coping with the challenges they face (as described in the preceding paragraph). As such, I found that the selected community relies on community-based coping in coping with HIV&AIDS. Various assets and resources related to community members, institutions and organisations could be identified, for the community to rely upon in coping with the

challenges implied by the pandemic. On an individual level, family members, friends, neighbours, other community members and the local support group are regarded as the primary source of support to people living with HIV&AIDS and in helping them cope with the challenges they face. In coping with children who have been orphaned due to HIV&AIDS, I found that grandparents and aunts primarily fulfil the role of caregivers. They are usually supported by other family members and neighbours.

In my study emphasis was therefore placed on the supportive role of the extended family, with specific reference to the support provided by women. Besides the socialised tendency of women in general to nurture and care, I further relate the focus on women as caring agents to the culture of the particular community, as the Xhosa culture is also characterised by distinct role differentiation within the family, with women fulfilling the caring and supportive role. As such, I found family and culture to be core concepts in the selected community's way of coping with HIV&AIDS, despite my finding on culture potentially contributing to the challenges individuals face (refer to section 6.3.2). As such, I categorise culture as fulfilling a paradoxical role in the lives of the community members of the selected informal settlement community. On the one hand, it adds to the vulnerability of community members, yet, on the other hand, the *ubuntu* principle of the Xhosa (African) culture directly relates to community members supporting others in need, enabling them to better cope with, for example, HIV&AIDS. Furthermore, I sense some irony in the fact that the women of the selected community appear to be more vulnerable due to the submissive role of women within the Xhosa culture, yet they are the ones fulfilling the primary responsibility in supporting and caring for others.

Other core components of community-based coping, as identified during my study and employed in the selected community, include faith in God, religiosity and prayer. This can be related to inner strength, hope, optimism and expectancy, also often relied upon by community members in coping with their own HIV positive status or that of a relative or friend. Some practical actions identified by the participants in my study as ways of coping with HIV&AIDS include gaining information, changing lifestyle, following a healthy diet and maintaining a positive approach to life.

With regard to assets and resources related to local institutions and organisations, I found that local schools, principals and educators fulfil a significant role in helping community members cope with the challenges they face, based on both the services they provide and the positive attitude of the staff. At the school where I conducted my study, for example, vulnerable learners and their families are supported in terms of food, emotional support, home visits, references to the Department of Social Development and advice on how to access government grants.

My decision to involve educators at a selected school as participants in the intervention research I employed might be related to my findings highlighting the importance of schools and educators. Upon reflection, I wonder to what extent this theme would have emerged in the case of me entering the community through a NGO, faith-based organisation or hospital, involving participants from another context in PRA activities. However, in addition to schools and the university close to the community being identified as important components of community-based coping responses to HIV&AIDS, the community care centre in the adjoining community, the provincial hospital and hospital for tuberculosis in the area, hospice for children (although quite a distance from the centre of the community), community clinics, doctors, nurses and other health and social services seemingly assist community members in addressing the challenges they face.

In addition, several NGOs (with ATICC being the most prominent) and faith-based organisations (with the ACVV being prominent) were identified as assets to the selected community. Although the findings of my study indicate that most of these institutions were not actively involved in the specific community I selected at the time of my study, their involvement in communities in the close vicinity implied the potential of them also providing services like training, counselling and material support in the community where I conducted my field work. With regard to churches, participants indicated ambivalent feelings as to whether or not the church and church ministers might be relied upon in coping with HIV&AIDS-related challenges. On the one hand, my findings indicate that the churches and ministers of the community seem willing to assist those in need of support, yet on the other hand, community members indicated the perception that the context of HIV&AIDS sometimes results in the church judging individuals as being immoral. As such, the majority of the

community where I conducted my study do not appear to rely on the support of the church in coping with HIV&AIDS.

The negotiation skills of key role-players in the selected community further turned out to be an asset to the community, as it might unlock opportunities for individual members of the community. Other sources that might be relied upon in coping with the challenges implied by HIV&AIDS include the media, meetings of political parties, community-based groups (such as women's or youth groups), as well as the South African government (in terms of government grants, material assistance, providing treatment, care and support, free education and other services alike). Government's decision to provide anti-retroviral medication free of charge to people living with HIV&AIDS is a distinct potential asset, which might be utilised to address the vulnerability of community members living with HIV&AIDS, by providing in their need for treatment against the background of poverty and a lack of financial means to meet this need. However, the fact that the roll-out plan on anti-retroviral treatment is still in the process of being streamlined result in this asset remaining a potential asset to many communities at present.

Finally, the members of the community where I conducted my study displayed an awareness of various potential assets, despite them not always mobilising these assets optimally. For example, the community indicated a distinct awareness of the government disability grant, which, as financial asset, might assist individuals in coping with physical vulnerability. However, community members often indicated that they were not fully aware of how to access the grant. Furthermore, the finding relating to participants' perception that the disability grant occasionally may be abused, might indicate an attempt to combat extreme levels of poverty in the short term, but could potentially add to the vulnerability of the community in the long run, thereby intensifying the challenges already faced by the community.

#### **6.3.4 SECONDARY QUESTION 4: *WHICH ASSET-BASED TRENDS EXIST IN CURRENT WAYS OF COPING WITH HIV&AIDS?***

My study, more specifically the findings on asset-based trends within the context of coping with HIV&AIDS, might contribute to existing literature relating to both coping

theory and the asset-based approach. My finding that the community where I conducted my study was employing community-based coping throughout the course of my study, implies that community members rely on available and local resources within their immediate community to cope with the challenges related to HIV&AIDS. In this manner, community members were already focusing on available assets in addressing life challenges when I entered the community. Relying on assets and strengths further implies the identification of assets and resources (asset mapping), even though it might be completed on a subconscious level.

As my study progressed, community members (participants) identified additional assets and resources that might be relied upon in coping with the challenges associated with HIV&AIDS. Subsequent to my initial intervention, as well as the forthcoming interventions of the study, some of these newly identified potential assets were mobilised by the educator-participants, demonstrating application of the asset-based approach. The fact that the community was internally focused and relationship driven throughout my study, result in me concluding that the community was indeed partially relying on the asset-based approach in coping with HIV&AIDS prior to the inquiry, and increasingly did so as my study progressed and individuals' (participants') awareness of the asset-based approach increased. The fact that no significant external resources (other than the interventions as part of my study) were introduced to the community during the course of my study further confirms the community's implementation of the asset-based approach in coping with HIV&AIDS. Yet, towards the end of the study, individuals' focus changed towards being more aware of potential assets and resources and mobilising them to a fuller extent.

#### **6.3.5 SECONDARY QUESTION 5: *WHICH CHANGES IN COPING PATTERNS MIGHT BE FACILITATED BY EMPLOYING INTERVENTION RESEARCH?***

Based on the findings of my study I may conclude that the community members of the community where I conducted my study were coping with the challenges they faced at the time of my first field visit, by relying on the resources (however limited in nature) available to them. At that time, however, community members (participants) seemed to be unaware of their own abilities and the fact that they were indeed coping. They displayed limited self-confidence and the need to be informed and

trained by outside experts, in order for them to support other members of the community. As my study progressed, participants' levels of self-awareness and self-confidence increased, resulting in them being able to recognise the role they are fulfilling in the community and realising their own coping potential.

By being part of the process of research, actively participating in planning, initiating and evaluating activities and initiatives, participants were empowered. They took agency of the process of enhancing the selected community's coping with HIV&AIDS and enthusiastically steered the process. By being empowered and facilitated to become more actively involved in making a difference in the community, educator-participants successfully identified, planned and initiated three school-based projects, namely a vegetable garden, information centre and support service. The positive outcomes of these projects in turn resulted in feelings of accomplishment and enhanced levels of motivation and pride. As a result, educator-participants experienced their involvement in the intervention research project as rewarding and wore their identifying HIV&AIDS nametags with pride. They also declared their commitment to contribute in supporting the community with regard to coping with HIV&AIDS during the fourth field visit.

By increasing their levels of support to community members in terms of, for example, visiting community members living with HIV&AIDS and supporting them by providing food parcels, emotional and spiritual support, the educator-participants directly enhanced the community's way of coping. In addition, they were able to provide others with information, give them advice and be examples to community members in providing support to others, thereby improving positive coping responses to challenges like HIV&AIDS. In addition, the vegetable garden provided community members with the nutrition needed to cope with illnesses related to HIV&AIDS but were not necessarily always able to afford, prior to the intervention.

By initiating the three school-based projects, educator-participants therefore became involved in community development, thereby facilitating change in the community. As these projects enhanced the community's way of coping with HIV&AIDS as well as due to the educator-participants' levels of empowerment, community members were in turn empowered to better cope with the challenges the community faces. As an



outcome, parents of the school became more involved and experienced higher levels of self-worth. They were also able to, in turn, support others on a more advanced level towards the end of my study.

Employing an activist intervention research approach therefore facilitated change with regard to the selected community's way of coping with the challenge of HIV&AIDS, specifically in terms of community members' increased levels of confidence. As opposed to participants displaying an almost helpless attitude at the start of my study and indicating the need for external support, the educator-participants were aware of their own coping abilities towards the end of the study, as well as of the fact that the community (participants) itself (themselves) holds the key to answering questions and addressing challenges. Despite the tendency of educator-participants to constantly seek more information and new strategies that might be employed in coping with the pandemic, they seemed to cope with more confidence at the time when I completed my field work.

I relate the tendency of educator-participants constantly seeking information and skills to support others, to them being aware of their potential to help others (indicating their reliance on assets, thereby the asset-based approach). In addition, the educator-participants in my study appeared to be faced with the challenge of coping with HIV&AIDS themselves (being it a relative, a friend, a learner or themselves living with the disease). In facing this challenge of coping with HIV&AIDS, the participants were continuously seeking ways to address questions (their own, as well as those posed to them by other community members) and feel more able to cope and support others. In addition, I relate educator-participants' need for knowledge and supporting skills towards the end of my study, to their feelings of empowerment and the awareness that they are in the position, and have the ability, to support others, which developed as the study progressed. As they were able to take agency in coping, they constantly kept on seeking ways to enable themselves to fulfil their responsibility in the community – perceived by them to be one of care and support.

Furthermore, by being involved in the identification of local assets and resources that might not have been utilised yet but might be relied on in future, educator-

participants could actively become involved in utilising such assets. They were able to identify future school/community-based projects towards the end of the study (namely a soup kitchen, community hall and income generation projects), based on their belief in their own abilities and the positive outcomes of the (first) three projects they initiated.

#### **6.3.6 SECONDARY RESEARCH QUESTION 6: *HOW CAN PARTICIPANTS' IMPLEMENTATION OF THE ASSET-BASED APPROACH INFORM COPING WITH HIV&AIDS?***

Participation in the intervention project provided participants with the opportunity to experience and become aware of the asset-based approach. Such awareness of the asset-based approach provided the educators who participated with the necessary background to apply asset-based trends to coping with HIV&AIDS. Although the community was coping with the challenges implied by the pandemic at the outset of my study, participants (community members) seemed to be unaware of their coping successes. Subsequent to the intervention I employed, participants' way of coping and the confidence with which they employed coping strategies changed towards the end of my study.

Against the background of the purpose of my study and the characteristics of the selected community, the school and its educators seemed an apt choice to access the community. As the school and educators involved in my study appeared to be respected as key role-players of the community, they could take the lead and introduce asset-based trends in coping to other community members. Due to the educators seemingly being viewed as role-models, other community members could follow their example in implementing the asset-based approach. As such, the educator-participants' awareness and implementation of the asset-based approach might in future influence other community members to also focus on the mobilisation of potential assets in coping with life's challenges. This is, however, a mere hypothesis, which might be investigated during future research projects.

The manner in which the educator-participants applied the asset-based approach resulted in, amongst other things, the establishment of the vegetable garden, information centre and support service at the school. As an outcome, parents

appeared to become more involved at the school by, for example, being involved in the vegetable garden project as volunteers. In addition, parents of learners displayed an increased willingness to disclose a HIV positive status to selected educators. In the same manner, members of the community tended to more often bring vulnerable children to that particular school. Towards the end of my study these (visible) changes resulted in other educators reportedly indicating the desire to also become involved in the intervention project.

Based on the educator-participants' implementation of the asset-based approach, the community's patterns of coping were thus impacted upon. By actively relying on and mobilising the available assets and resources in the immediate community (thereby employing the asset-based approach), participants (and by implication community members) were enabled to employ *approach coping* and actively respond to the challenges implied by HIV&AIDS, as opposed to relying on *avoidance* or denial as potential ways of coping. As such, implementing the asset-based approach enabled the participants (and other community members) to actively address the challenges they face. Furthermore, by relying on the resources within the immediate community, and greatly depending on other community members in coping with HIV&AIDS, the asset-based approach can also be related to the interdependent-self approach to coping, as actualised within the context of my study.

## **6.4 FINAL REFLECTIONS**

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### **6.4.1 REFLECTING ON POSSIBLE CONTRIBUTIONS OF MY STUDY**

I henceforth present the potential contributions of my study in terms of the primary research questions I formulated in chapter one. As such, I firstly refer to potential contributions to the existing base of knowledge on the asset-based approach, with specific reference to coping with HIV&AIDS. Secondly, I discuss potential contributions in terms of research methodology, specifically with regard to my implementation of an activist intervention research approach.

#### 6.4.1.1 Theoretical contribution: *How is a South African informal settlement community coping with HIV&AIDS, by relying on existing assets and local resources?*

In answering my first (descriptive) primary research question, this study adds to the growing body of literature on both the asset-based approach and coping with HIV&AIDS. Within the context of my study, the asset-based approach did indeed provide the necessary theory and background against which I could plan and conduct my study. In addition, the asset-based approach directed the strategies I employed during data collection, thereby guiding my own, as well as the educator-participants', intervention research activities.

Based on my findings of a community redefining their social roles and relying on the assets and resources available in their immediate environment in response to the challenges posed by the HIV&AIDS pandemic I now construct the concept **asset-based coping**. Although the existing literature on asset-based assessment and asset-based intervention is increasing, the concept of **asset-based coping** has not yet been formally introduced. In this manner, I regard the outcome of my study in terms of constructing this concept as innovative in nature, adding to the knowledge base on both coping (within the context of HIV&AIDS) and the asset-based approach.

**Asset-based coping** anchors the concept of coping within the asset-based approach. Based on the information I obtained during my study, I define **asset-based coping** as the ability of a community (or an individual) to deal with one or more life challenges (such as HIV&AIDS), by identifying and mobilising existing assets (such as local resources, skills, knowledge and networks) within the community and amongst other community members, as well as external resources available to the community. As such, I regard **asset-based coping** as an active, productive way of coping, which implies agency and taking personal responsibility for effectively responding to life's challenges. **Asset-based coping** will inevitably result in enhanced levels of empowerment (in individuals, families, groups or communities), culminating in advanced levels of health and well-being. In this manner, I view **asset-based coping** as a positive psychological way of coping, as it emphasises the way

in which individuals, groups and communities enhance their own well-being in facing challenges. Within this framework, I view circumstances as opportunities rather than problems or challenges.

Against the background and reality of the challenges posed by HIV&AIDS, individuals and communities are required to cope with the pandemic. I propose **asset-based coping** as one coping possibility, as many individuals and communities (such as informal settlement communities) face the further challenge of limited external resources and often having to rely on what they have available in their immediate community. By employing **asset-based coping**, communities (individuals and groups) characterised by poverty and limited resources might be enabled to experience some levels of accomplishment and empowerment, thereby possibly compensating (to a certain degree) for often being marginalised.

#### **6.4.1.2 Methodological contribution: *How can an activist intervention approach to research facilitate change in a South African informal settlement community coping with HIV&AIDS?***

Addressing my second (intervention-related) research question highlights the contribution of my study within the field of research methodology. The manner in which I combined research and intervention, by relying on an integration of theory (asset-based approach) and practice (PRA), is unique and innovative in nature. This resulted in the activist intervention research approach I employed, doing research *via* intervention and intervention *via* research.

The manner in which I applied PRA principles within a case study design, resulted in me adding different nuances to qualitative research. I value the high level of participation of the educator-participants as of particular importance. To my mind, the fact that they were actively involved in the planning and progress of the intervention research activities contributed to the positive outcomes of the process. Active participation, together with the fact that they were regarded as research partners and experts, resulted in the educator-participants experiencing feelings of self-worth, as early in the process as by the end of the second intervention session

(first field visit). Subsequently, they took agency of the process at an early stage and enthusiastically participated through the various phases of the study.

Another significant outcome of the activist intervention research approach I employed was the empowerment of the educator-participants. Feelings of being empowered increased their motivation to make a difference in the community, consequently resulting in change. Besides the educator-participants experiencing positive change on a personal level, change was also evident in the community at large. Based on the three school-based projects that the educator-participants initiated (yet another outcome and contribution of the intervention research I facilitated), community development was initiated, indicating positive change on a broader level. In addition, the intervention research activities that the educator-participants participated in, enabled them to extend their own levels of empowerment to the wider community, facilitating positive change amongst individual community members. The extent of the latter deems further investigation.

Furthermore, the fact that PRA has not been widely applied on local ground allowed me to explore the application value of a new and emerging research approach within the South African context, more specifically within the context of an informal settlement community. As such, my study might contribute to the existing knowledge base on PRA, with specific reference to the application of PRA principles within the South African context and within the field of coping with HIV&AIDS. The manner in which I applied PRA principles within the framework of a case study design and against the background of the asset-based approach, further allows for a possible unique contribution within the field of qualitative research.

As an outcome of my study, I developed an activist intervention research strategy, which might be adapted and implemented in similar or other research contexts. The format of the activities allows room for the strategy to be expanded and implemented by researchers, community members or other stakeholders of communities. For example, the possibility exists that the educator-participants involved in my study could apply the intervention research strategy I developed in neighbouring schools, thereby extending the outcome to neighbouring communities in their area, which supposedly face similar challenges and have access to similar resources than the



informal settlement community where I conducted my study. Finally, the outcomes of my study might impact on the development and enhance the effectiveness of future community-based intervention initiatives to be employed in South African communities that have to cope with HIV&AIDS, or any related life challenges, more specifically informal settlement communities.

#### **6.4.1.3 Profession-related contribution: *How might educational psychologists gain from my experiences?***

By describing how a South African informal settlement community is coping with HIV&AIDS by relying on existing assets and local resources, I provided information on the perceptions and ways of doing of community members residing in an informal settlement. As children function within families and on a wider level within communities, this study might assist educational psychologists in gaining some insight into possible ways that children who reside in South African informal settlement communities cope with daily challenges. The findings I obtained in terms of the available assets and local resources could further provide insight with regard to potential resources that communities (children) might rely on in coping with the challenges they face. By relating the asset-based approach to coping, knowledge might be added to the emerging body of knowledge on Positive Psychology, which is increasingly studied and relied upon by practicing educational psychologists.

Secondly, this study could contribute to the existing body of knowledge on the potential role that educational psychologists might fulfil in communities, in terms of potential intervention initiatives. The past few decades have been marked by a shift in the focus of educational psychological practice, moving away from one-on-one intervention towards group work and prevention, which often focus on community involvement. The manner in which I planned and conducted an intervention within an informal settlement community serves as an example of a possible way of facilitating community development and change. Although I approached and intervened primarily as a researcher, the strategies I employed might be adapted and applied as basic intervention or prevention, instead of research. In addition, the way in which I facilitated community members to become involved might serve as an example to educational psychologists who plan community-based projects.

The progress and outcome of my study further highlights the potential role that educators play in the lives of not only the learners in their classrooms, but also of their families and even other community members. My findings highlight the level of support which might be provided in communities by educators. As this study demonstrates that it is possible to facilitate successful collaboration between educators and researchers, the potential value of educators in becoming partners in research and/or intervention initiatives is emphasised. Educational psychologists could successfully collaborate with educators in order to improve the well-being of not only children, but also their family members and other members of their immediate communities.

#### **6.4.2 REFLECTING ON THE GENERAL STRENGTHS OF MY STUDY**

I regard the way in which I employed an activist intervention research approach as a source of strength for my study, as it enabled me to simultaneously conduct research and facilitate intervention within a community facing the challenge of coping with HIV&AIDS. Secondly, I regard the central role that reflexivity played in my study as another source of strength. Regular reflective sessions (as part of PRA) facilitated self-analysis, independent discovery, and reflection amongst myself, my co-researchers and the participants, helping us to build self-confidence – me in being an interventionist/researcher, and the participants in being partners in research and agents of change in their community. By involving the educator-participants to such an extent and based on my repeated visits to the field over an extended period of time, we (both the participants and the research team) were enabled to learn more about ourselves and strengthen belief in ourselves and our abilities, whilst being guided to also respect the perspectives of others.

Furthermore, involving the educator-participants as research partners possibly enhanced their levels of motivation and enthusiasm, as they could experience themselves as part of the process and main agents in determining the progress of the process. This probably resulted in them taking agency, owning the process and in turn enhancing the meaningfulness of my findings. The educator-participants' involvement probably motivated them into action, ultimately resulting in the establishment of the three projects at the school. Besides them becoming aware of

their own abilities to support their community in coping with the life-threatening disease of HIV&AIDS, they appeared to have developed a sense of responsibility – not only at school but also in the wider community and even beyond. As a result, they seem to have expanded on their own capacity to initiate coping strategies, by implication facilitating change in the community's initial responses to HIV&AIDS.

My background as scholar and practitioner in the field of Educational Psychology proved to serve as another strength in my study. Based on my training in Educational Psychology, I found it easy to facilitate groups, conduct interviews and allow participants to take the lead and generate solutions. Being schooled in Positive Psychology and the asset-based approach further enabled me to focus on strengths, assets and potential assets fairly easily, within a context which might easily be perceived as disheartening, due to the scarcity of external aid, resources and support. Refer to section 3.4 for a detailed discussion on the strengths of my study related to the methodological choices I made.

#### **6.4.3 REFLECTING ON POTENTIAL LIMITATIONS OF MY STUDY**

In this section, I reflect on potential limitations of my study, which might be related to certain general challenges I faced whilst conducting the study. Refer to section 3.5 for detailed discussions on the challenges I experienced, based on the methodological choices I made.

Upon entering the research field as a white, Afrikaans speaking, graduate woman, I experienced distinct challenges. The direct manner in which I experienced my *otherness* whilst doing research in a Xhosa speaking, poverty-stricken and mostly illiterate community, resulted in me identifying with Chambers (2003:xviii), stating: *'I am trapped inside a skin, a separate, fallible, self-centred person. I see and construe things in a personal way, unable to escape being who I am ... Others have other realities and see and construe things differently'*. However, I aimed to address the potential limitation of being influenced into personal and biased findings, by constantly being aware of the likelihood thereof and reflecting, by asking myself: *'Did I hear what the participants tried to tell me? Did I see what they wanted me to see?'*. In addition to a field journal, frequent debriefing sessions with my supervisor and co-

researchers, the firm relationship that I established with the participants, as well as regular reflective sessions with participants (in accordance with the PRA approach) provided me with ample opportunity to clarify issues that I was uncertain about.

Due to the differences in background and languages between the participants and myself, I had to rely on an interpreter for two of the individual interviews. As such, I opened my study for added layers of meanings, interpretations and biases. Although I tried to address this potential limitation by clearly explaining her role to the interpreter prior to the first interpreted interview, I cannot vouch for it that she did not add her own opinion to the contributions made by the interviewees. At times during the interviews the interpreter elaborated on what had been said by the interviewees in her own words, with me being aware that those particular sections reflected her contributions and not necessarily that of the participants. In the result, I could not always be certain that I obtained an understanding of the participants' perceptions. However, as the interpreter I relied on also forms part of the community, her contributions might have added further richness to the data I obtained.

I experienced various challenges in relation to my selection of participants. As I selected the participants purposefully, I faced the possibility of selected participants not reflecting the perceptions of the broader selected community. In addition, some of the participants reside outside the informal settlement community where I conducted my study, leaving me with the uncertainty as to whether they provided me with their perceptions *on* the community (being *outsiders*) or with the perceptions *of* community members (moving towards becoming *insiders*), based on their daily involvement and encounters with community members. In an attempt to obtain balanced insight into the perceptions of the members of the informal settlement community where I conducted my study, I aimed to select participants from various levels of the community. I could, however, have included more participants residing in the community. In addition, I did not conduct an interview with a traditional healer and am therefore relying on the perceptions of others, concerning the role that traditional healers play in the particular community. In the same vein, I only included educators from one school in the community, again leaving me with the uncertainty as to whether or not those educators also reflected the perceptions of educators employed at other schools in the community. I did, however, have an *ad hoc*

conversation with the school principal of the secondary school in the community, gaining insight into his perceptions.

With regard to the selected educator-participants, the fact that all of them are women is yet another potential limitation to my study, as this implies the possibility of biased information. However, the fact that the school principal and several of the other interviewees are men, ought to allow for a balanced view in the data I obtained. Furthermore, the fact that I strongly relied upon the voices and contributions of the educator-participants leads to the question as to whether or not my findings would have been the same, had I more heavily relied upon community members outside the teaching profession. In addition to the potential limitation posed by the composition of the group of educator-participants, I faced the challenge of dealing with dominant speakers in the group, who might have inhibited other participants, by preventing them from voicing their true views. I attempted to guard against this tendency by the manner in which I (we) facilitated group discussions. I consciously aimed to involve each and every participant during discussions and group activities, in order to obtain everybody's standpoints, and constantly be aware of and reflect on the power relations within the group. In addition, my co-researchers and I regularly reflected on the contributions of dominant participants, as well as possible ways of facilitating balanced discussions.

I further faced the challenge of facilitating group discussions and activities on a topic that is sensitive in nature, often stigmatised and avoided during discussions. Being aware of the possibility that participants might not want to reveal information relating to HIV&AIDS prior to entering the research field, I spent much time in establishing rapport and building sound relationships of trust between the participants and myself (and my co-researchers), as well as between the educator-participants themselves. This strategy proved to be effective as the participants shared their views without being overly anxious or hesitant.

Despite my training in the field of Educational Psychology implying certain strengths (refer to the previous section), it also resulted in certain challenges. Due to the sensitive nature of my research topic and the fact that I have been trained to provide therapy to people in emotional distress, I constantly faced the challenge of

distinguishing between interview research and counselling, specifically in the case of interviewees or participants displaying hardship or grief. Although I did create opportunities for debriefing when needed (which I regarded as the ethical thing to do), I strived to overcome this challenge of successfully fulfilling my role as interventionist/researcher, by means of self-awareness and constant self-reflection.

With regard to the intervention research strategy that I developed, I faced the challenge of developing a strategy by relying on limited available literature, based on the emerging nature of both the asset-based approach and PRA. In terms of the application of PRA principles, I had to rely on first hand experience due to the scarceness of completed research on the use of PRA in the South African context (specifically in informal settlement communities), as well as in the field of Educational Psychology. I again relied on reflexivity and regular consultation sessions with my supervisor in order to monitor the progress of my study and make adjustments where needed. Prior to and in preparation of entering the research field, I spent extensive time on reading up on PRA (despite the challenge to obtain sources within South Africa) and also consulted with international researchers.

In applying the activist intervention research approach as I planned it, I had to facilitate the educator-participants to fulfil the role of research partners, actively participating in the process of generating knowledge. Introducing the idea of us (my co-researchers and I) not being present to convey knowledge and guide them (the educator-participants), but to learn from and with them, resulted in initial scepticism. However, based on the positive outcomes of the sessions included in the first field visit, as well as feelings of enablement, participants soon accepted the responsibility for creating solutions and steering the process.

The fact that I did not in this thesis include step by step detailed descriptions of the activities that I used as part of the intervention research strategy that I developed and employed, might be regarded as a limitation, as the possibility of reproducing the strategy within another context is thereby limited. I do, however, believe that I have included sufficient detailed descriptions for other intervention researchers to plan a similar strategy. Closely related, the findings of my study cannot be generalised to other communities. However, I did not aim to obtain generalisable findings, based on



the interpretivist paradigm I selected. On the other hand, my findings might possibly be transferred to communities characterised by similar circumstances, based on the knowledge of such communities (held by a reader of this thesis) and against the background of my detailed descriptions of the research context.

In terms of the literature I studied and relied upon in planning my study and interpreting the results I obtained, a more extensive literature review on community-related theory might have added value to my analysis and interpretations of the data I obtained. Literature on *community work* and *Community Psychology* might, for instance, have provided more insight into the dynamics of relationships amongst community members, as well as between the various role-players and stakeholders implied by the concept *community*. An exploration of the dynamic processes involved between people in relationship to their contexts, assets and facilitators working with them, might also have explained the changes that occurred within the selected informal settlement community. As such, insight might have been gained regarding the potential processes that could have contributed to community members initially being dependent and vulnerable, but later experiencing feelings of empowerment and taking responsibility for change within the community.

In reflecting on the findings I obtained, I realise that I could have provided a more detailed description of my baseline data, by describing in more definite terms how the community was coping with the challenges related to HIV&AIDS prior to the intervention I facilitated. Although I explored this throughout the various sessions and interviews I conducted, a more comprehensive description of the data I obtained could have provided more extensive background against which the changes that occurred might have been read and interpreted.

#### **6.4.4 REFLECTING ON MY QUALIFICATIONS AND PREPARATION FOR UNDERTAKING THE STUDY**

According to my view, I was in a good position and well-prepared to conduct this study. Based on my ongoing work in the education sector and as lecturer at a tertiary institution since 1993, I had established an extensive network of educators in and around the Nelson Mandela Metropole by 2002, whom I could approach to assist me

in facilitating the conducted study in an informal settlement community in the region. In addition, I conducted a pilot study in the Eastern Cape during 2001, in the form of focus groups with educators, which provided me with practical experience, baseline data and insights that could help to guide and enhance my research process.

By being a lecturer by profession, as well as a scholar in Educational Psychology, I could approach the study from a perspective that focused on the human aspects of research. I regard such an approach as suitable for conducting research in the area of coping with HIV&AIDS, due to the sensitivity implied by the phenomenon. My experience as lecturer and educational psychologist enabled me to build good rapport with participants without difficulty, thereby opening the field for addressing a sensitive issue.

In reflecting on my own strengths that might have contributed to the facilitation of change, I can draw from strengths related to me as a person, as well as a professional. I believe that my dedication and commitment to become involved in the community and stay involved for as long as necessary might have had a positive impact on the changes that occurred, as I modelled commitment and motivation by regularly making contact and returning to the community. In respecting the participants as experts and research partners, I possibly conveyed the message that they are highly valued, which in turn probably motivated them to stay involved and take action. In addition, I am of the opinion that I displayed the necessary empathy and understanding for the challenges the community faced, allowing me to establish and maintain firm relationships with the participants. Lastly, I relied on my networking abilities in planning and arranging field visits, intervention sessions and interviews.

## 6.5 OUTCOMES OF MY STUDY

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The following outcomes have already been obtained, based on this study:

- ✘ The establishment of a vegetable garden, information centre and support service at the primary school in the informal settlement community where I conducted my study.

- ⌘ The identification of a soup kitchen, community hall and income generation projects (like bead work) as potential future community-based initiatives in the selected community.
- ⌘ Formal presentations:
  - ▶ Ferreira, R. & Ebersöhn, L. *Exploring the effectiveness and sustainability of asset-based coping with HIV/AIDS infected and affected children*. Paper presentation (as part of a symposium) at the 9<sup>th</sup> South African Psychology Congress, September 2003.
  - ▶ Ebersöhn, L., Ferreira, R. & Richards, A. *Port Elizabeth Outreach Project*. Presentation at the HIV & AIDS Research and Skills Development Seminar, hosted by BE @ UP, August 2004.
  - ▶ Ebersöhn, L. & Ferreira, R. *Reflecting on educators' use of memory box making in their pastoral role*. Presentation at the EASA Conference 2006, January 2006.
  - ▶ Ebersöhn, L., Ferreira, R. & Blankenship, K. *Teachers' perceptions of a disability grant*. Presentation at the American Educational Research Association (AERA) Conference 2006, San Francisco, April 2006.
- ⌘ Article submitted to an academic journal in January 2006 – currently under review: Ebersöhn, L., Ferreira, R. & Blankenship, K.M. *Disability grant in the context of HIV/AIDS: Financial asset and social dilemma*.
- ⌘ The activist intervention research strategy I developed is currently in the process of being replicated in three South African communities, with the purpose of doing a comparative study (Loots, M.C. and Olivier, H.). Although the methodology is not reproduced, the intervention I developed is replicated according to the steps I followed. The projects that are already initiated in the two communities are a bead work project and a vegetable garden.

In addition to the outcomes already obtained, I regard the following as further possible outcomes of my study:

- ⌘ Publication of the findings of my study in academic and/or professional journals in the form of articles or reports.
- ⌘ Informal presentations at academic institutions or meetings.

## **6.6 RECOMMENDATIONS**

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Based on the findings of my study, I consequently make recommendations. I include recommendations with regard to further research, practice and future training of educational psychologists.

### **6.6.1 RECOMMENDATIONS FOR FUTURE RESEARCH**

Both PRA and the asset-based approach identify sustainable community development and change as ideal outcomes of community-based intervention research. Based on the positive change and community development that occurred during my study, I recommend that a follow-up study on sustainability be conducted in the informal settlement community in time to come. As the need for ongoing research in the field of HIV&AIDS is continually emphasised, with specific reference to research on the outcome of intervention initiatives, a study on sustainability could add to this area of research. In addition to a study on sustainability, and in accordance with basic PRA principles, I will facilitate a stakeholder discussion and disseminate a report to stakeholders of the community, with regard to the findings of this study.

Closely related to a study on sustainability, a further study might be undertaken in the community, in order to explore the manner in which the asset-based approach is applied within the broader community, expanding on my findings, which mainly relate to the implementation of the asset-based approach by educators, as well as to their perceptions of other community members. In this regard, a study might, for example, focus on the possible establishment of relationships between the participants and the potential assets they identified.

As this study involved an in-depth case study, additional comparative studies might be developed and undertaken to explore whether or not it is predictable when a community is likely to rely on existing internal assets in coping with challenges, and whether or not specific pre-conditions might be related to or associated with such a strategy of relying on existing assets and local resources when faced with

challenges. In the same field of interest, another study might be conducted on potential contexts in which pre-conditions should be present, in the case of a community relying on the asset-based approach when coping with challenges.

In addition, a range of studies might be undertaken focusing on the potential application value of the activist intervention research strategy I developed, within a variety of contexts. The studies by Loots (in progress) and Olivier (in progress) are, for example, exploring the application value of the strategy I developed in both rural and urban South African contexts. In addition, a study might be conducted on the possibility of the educator-participants who participated in my study applying the strategy in neighbouring schools, to monitor educators' capacity as well as the empowerment of neighbouring communities. Based on the findings of such a study, further application by the second group of empowered educators might be explored on a wider national or international level. With regard to the facilitation of change, future studies could also focus on potential catalysts, stimulants or factors other than intervention in the form that I implemented it, which might facilitate community empowerment and change, by implication focusing on the identification and mobilisation of existing assets and local resources.

In the field of coping, a number potential studies can be suggested. Based on the fact that the cultural context in which individuals learn to cope with challenges determines their perception on the definition of *effective coping*, research might be undertaken in order to explore what the community members of the informal settlement community where I conducted my study, perceive to be entailed by the concept of *coping*. Such an investigation could add to the emergence of embedded knowledge in Psychology. Furthermore, a study might be conducted on the manner in which coping relate to religious coping within this particular community. Another area of research might include the differences (or not) in women and men coping with HIV&AIDS within the selected community. I also recommend that studies be conducted on the provision and outcome of anti-retroviral treatment and, subsequently on the impact of anti-retroviral treatment on government grants. Findings on studies of this nature could provide insight into the potential outcome of anti-retroviral treatment. Finally, another study might focus on exploring the perceived (asset-based) use of government grants in relation to combating poverty.

### **6.6.2 RECOMMENDATIONS FOR PRACTICE**

Based on the outcomes of my study, I recommend that the activist intervention research strategy that I developed be applied on a wider scale (as is, or in an adaptive format). As the strategy provides a cost-effective way of providing an HIV&AIDS-related intervention initiative to communities across the range of literacy levels, communities might be empowered in comparable communities. I further propose that such an application on a broader level might be facilitated by institutions like NGOs, or faith-based organisations. As coping with HIV&AIDS is required to be situated within communities within the South African context, application of such an intervention might result in wide-scale empowerment. A written programme guideline might assist in developing such (related) empowerment programmes, providing an example of an innovative community-based strategy for coping with HIV&AIDS.

With regard to the informal settlement community where I conducted my study, I recommend that the NGOs, Department of Social Development and faith-based organisations extend the training, counselling and support services already provided in other communities in the Nelson Mandela Metropole, to the community where I conducted my study. In this manner, the potential services that might be provided by such institutions will be mobilised in support of the community's way of coping. As educator-participants have demonstrated their networking capacity, they may also be able to apply their competencies in order to access the above-mentioned services.

Within the immediate community, I recommend that the participants who were involved in my study informally convey their newly acquired knowledge and skills to community members. In this manner, their own empowerment might be extended to address empowerment in the community, thereby possibly enhancing the community's way of coping with HIV&AIDS.

### **6.6.3 RECOMMENDATIONS FOR FUTURE TRAINING OF EDUCATIONAL PSYCHOLOGISTS**

The findings and outcomes of this study might be utilised during the training of future educational psychologists. Training could firstly include exposure to the intervention and specific strategies I developed and employed, thereby highlighting one possible



way of becoming involved in community work, whilst simultaneously doing research. The intervention I employed may therefore serve as an example of how educational psychologists can collaborate with community members on ground root level, in order to act as agents of change. In the same manner, related interventions might be developed that focus on preventative initiatives.

Secondly, the findings of this study might be relied upon in highlighting the potential role of educators, working in collaboration with educational psychologists. Not only might educators be involved in facilitating intervention and ultimately change amongst learners, their families and within the wider community, they may also be involved in collaborative research projects. As such, this study might serve as an example of a joint project between researchers and educators, providing basic principles that might be employed by educational psychologists in involving others (like educators) during intervention with either individuals or groups of people.

## 6.7 IN CLOSING

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At present, the challenge of coping with HIV&AIDS is relevant – not only on a global, but also on local ground, and in local communities characterised by limited external aid and support. In this study, I explored one possibility of coping with the challenges implied by the pandemic, within the context of a South African informal settlement community.

I determined that the particular community is coping with HIV&AIDS by relying on existing assets and local resources. As such, I related coping to the asset-based approach and constructed the concept *asset-based coping*. In order to facilitate an awareness and application of the asset-based approach amongst participants, I developed an activist intervention research strategy, whereby participants were empowered to employ new approaches to coping, based on their awareness and newly obtained knowledge on the asset-based approach. As an outcome of their involvement and based on their experience as being empowered, the participants could facilitate change and development in the selected community, from a school-based perspective.

My study demonstrates the potential value of focusing on existing resources when facing challenges. Instead of focusing on challenges or experienced problems, findings in my study suggest that a focus on factors and resources that are available and which might be relied upon in coping, may in turn result in positive change and development. I conclude with a statement by Lao Tsu, 700 BC (in Foster, 2001:1), summarising this idea: '*Start with what you know, build with what you have*'.

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## REQUEST FOR INFORMED CONSENT

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14 November 2003

Dear Sir/Madam

I am a PhD student at the University of Pretoria and am currently conducting a research project on the manner in which informal settlement communities are coping with HIV&AIDS. For this purpose, I have selected your community as participant to the study. The findings of the study will be used to inform other communities in future capacity building initiatives.

I herewith kindly request your assistance in this regard, as you are the expert in the ways that your community functions and copes with this challenge. The study will take place during the period November 2003 to June 2005.

For the purpose of the study, I kindly request you to participate in three to four workshops and discussions, which will be audio-recorded. These discussions will later be followed up by individual interviews with identified community members who are currently coping with HIV&AIDS. Here I once again ask for your assistance. All information provided by you will be treated confidentially and anonymously. You are also free to withdraw from the project at any stage if you wish to do so.

If you are willing to assist me, please complete the form attached and return it to me.

Kind regards

---

Ronél Ferreira

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## CONSENT FORM

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Having read the letter attached, I declare that I am fully aware of the nature and purpose of the study conducted by Ronél Ferreira. I understand that all information will be treated anonymously and as strictly confidential. I am further aware of the fact that I may withdraw from the study at any stage during the process if I wish to do so.

I hereby consent to participate in the workshops and discussions to be held during the next few months.

Signature ..... Date .....

11 November 2003

Mr S Snayer

District Director: Port Elizabeth

Department of Education: Province of the Eastern Cape

Private Bag X3915

**NORTH END**

6056

Dear Mr Snayer

**REQUEST TO CONDUCT RESEARCH AT**

**PRIMARY SCHOOL**

I am a PhD student at the University of Pretoria and am currently conducting a research project on the manner in which informal settlement communities are coping with HIV/AIDS, by relying on the local resources available to them. For this purpose, I have selected an informal settlement community in the Port Elizabeth region (namely ) as participant in the study. The study will take place during the period November 2003 to June 2005 and the findings will be used to inform other communities in future capacity building initiatives.

For the purpose of the study, I kindly request the permission of the Department of Education to conduct workshops and discussions with selected staff members (10) of Cebelihle Primary School in Govan Mbeki, on existing resources in the community as well as current ways of coping with HIV/AIDS. These discussions will serve as first phase of the study and later be followed up by individual interviews with identified community members who are

currently coping with HIV/AIDS. During these discussions the selected educators will be requested to arrange meetings with community members and act as translators when necessary, for which they will be remunerated. Workshops and discussions will take place after hours in order not to interfere with the educators' work.

All information provided will be treated confidentially and anonymously. Any person will also be free to withdraw from the project at any stage should he/she wish to do so.

Please complete the form attached with regard to permission by the Department of Education and return it to me by mail or fax (fax number 012-4205511).

Kind regards

---

Ronél Ferreira

☎ 083 258 774

11 November 2003

Mr SM M

The Principal: Primary School

Street

Township

**PORT ELIZABETH**

6001

Dear Mr M

**REQUEST TO CONDUCT RESEARCH AT**

**PRIMARY SCHOOL**

I am a PhD student at the University of Pretoria and am currently conducting a research project on the manner in which informal settlement communities are coping with HIV/AIDS, by relying on the local resources available to them. For this purpose, I have selected your community as participant in the study. The study will take place during the period November 2003 to June 2005 and the findings will be used to inform other communities in future capacity building initiatives.

For the purpose of the study, I kindly request your permission to conduct workshops and discussions with the staff of your school. These discussions will later be followed up by individual interviews with identified community members who are currently coping with HIV/AIDS. Information provided will be treated confidentially and anonymously. Any person will also be free to withdraw from the project at any stage should he/she wish to do so.

If you are willing to assist me, please complete the form attached and return it to me.

Kind regards

---

Ronél Ferreira

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**PERMISSION TO CONDUCT RESEARCH AT ..... PRIMARY SCHOOL**

---

Dear Ms Ronél Ferreira

Having read the letter attached, I hereby grant / do not grant you permission to do research at ..... Primary School, by conducting workshops and facilitating discussions with some of the staff members at my school.

Signature .....

Date .....

**FIELD VISIT 1 – 14 NOVEMBER 2003**  
**FOCUS GROUP 1**  
**11 x EDUCATOR-PARTICIPANTS**

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**TOPIC GUIDE:**

- ⌘ Community's perceptions on HIV&AIDS.
- ⌘ Challenges faced by the community.
- ⌘ Community's current way of coping with HIV&AIDS and the related challenges.
- ⌘ Assets and resources available to community members which might be relied upon in coping with HIV&AIDS.

KEY OF ABBREVIATIONS
R: Researcher
EP: Educator-participant

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R: We had such lovely discussions over lunch, now we would like to continue. Could you please tell us about this community's perceptions about HIV&AIDS. What do community members know? How do they feel about HIV&AIDS? What are they wondering about? What do they want to know? How do they cope with the pandemic? Please talk about questions like these.

EP9: Okay ... what I know is, **if you have information**, let's say you have an *advanced* – **you must know what you are going to talk about, the information**, because **sometimes people in the community will ask questions and you must know that you are going to answer all those questions**. And if you don't know, if you don't know a question – you must tell them: "*No I don't know this*", otherwise you will be caught out and find out. And you **must be patient and you must be organized**. You

Need to be informed

Other community members in need of advice



- must be flexible, because most of them are very touchable, you see. If they are very touchable, sometimes they don't want to talk about this. They don't know that you know that they know ... even my brother he is HIV positive and his girlfriend and by the time they heard the news, he was so surprised and so worried, but after that he don't want to talk about that – he forgot about that. We told ourselves life must go on ... and they don't want to talk about it all the time, because by the time you are talking about this all the time, you get scared, it is as if you are scared then, you see, and if, the way that you are going to support them is the way they must take care of themselves. Because if you know the diet, you can tell them: *"I like you to eat this"*. But if you support them in a group situation, let's say here at school, I can't just give the child let's say food, spinach or eh special food, here at school they are eating bread and milk, sometimes bread and jam. But I can't just give them special food, because there will be stigma. They will ask: *"Why are they eating special foods?"* We want to give them the support, but how are we going to give them the support?
- R: The children specifically?
- EP7: Yes, the children specifically. And even in the community, even in the community, if you can go to give them food parcel, they ask: *"Why those houses?"*
- EP2: You see, the other people will eventually find out and ask: *"Why are you just giving those people this? Why aren't you giving other people also? Why are doing this?"*
- R: It seems as if you are concerned and don't want to label children and families by treating them differently?

Support requires patience, being organised and flexibility

Vulnerability of people living with HIV&AIDS

Avoid discussions

Initial reaction to finding out about HIV status= do not want to disclose/discuss due to fear

Support others to:  
-taking care of themselves  
-diet  
-providing food  
-providing knowledge

Stigma

Willingness to support

Don't know how to support

Support to food Stigma

Stigma/labeling

- EP9: Yes, yes. We want to support them, but we don't know the way to support others.
- EP4: I want to say that, let's say my brother or my sister is HIV positive, we as a family don't have to give him or her something different. We must eat the same thing at the same time, knowing that it is okay for his or her condition and not something different from us.
- EP3: I like to differ from that, because even if you've got diabetic, even if you've got cancer, the menu, even in hospital, are different because you are ill. You know the situation, you can not put yourself at risk. Even those HIV people, if I know that someone in my house, say my husband is HIV positive and I'm not HIV, I have to cater for him. Even the children that is HIV, you have to cater for them. Unless the problem is where there is a denial. As long as they are not going to disclose it, they are going to suffer, because I cannot suffer giving my child the diabetic food because I'm diabetic.
- EP10: It's like my child. This evening he is with my mother and my mother is a diabetic. So we cater for her, because the porridge she is suppose to eat, must give him energy, and the supplements.
- EP2: Yes, and she must take extra vitamins.
- EP10: So, it must be totally different, not ... eh, unless you are making a full meal for the whole family, otherwise you must go an extra mile for the HIV people. Because they must get the supplements and all the vitamins they can get, because you want them to survive. If you are going to give them whatever, whatever, you are not prolonging their lives.
- R: I'm hearing two things now. I'm hearing when it is in the family where there is already disclosure, there can be differences because the family knows, but on the other hand when it's, for example, in the school, or in

Support  
-willing to help  
-don't know how

Support people  
living with  
HIV&AIDS by:  
-not isolating  
-accepting  
status (within  
family)

Support ito:  
-special  
menu/diet

Special  
treatment (within  
family) of people  
living with  
HIV&AIDS

Denial  
Non-disclosure  
Results in  
vulnerability

Support ito:  
-special  
treatment  
-special food  
-supplements  
and vitamins

Misconception

the community, you would like to be there for the people, but you don't want to label them to be different.

EP10: But I think even here at school, my idea that I want to share with my colleagues here, is that, like if the mother of the child, or the people concerned, can come to us and say: "Okay, my child has AIDS", that people wants the child to be given support. So we must, if we are going to give the support, we must also say to that parent, we must change our attitudes here at school. If we are going to cook, maybe maize, we give them with soap, those little ones, because in a classroom situation they will see that this one is suffering.

Support ito:  
-acceptance by wider community  
Coping requires change of attitudes

Ability to identify people living with HIV&AIDS

R: They will know?

EP10: They will know that this one is suffering. So we must support them here at school. But the consent must be given to us.

Vulnerable children

School as source of support

EP5: Sorry, can I get in? Okay. If we can say, this whole situation is revolving back to disclosure. And if there is someone, like you have said, some who didn't come out with this, it is difficult to give them help, but those who talk about it, it's easy for anyone to help. To show that the most that got denial, the only thing that we know is what we heard other people talking about them and you see them in clinics, you can see the symptoms of this because we are all educated. You could see the symptoms and know that this one is suffering from this. Even though you cannot tell them, that is the denial situation. Some of them, like a woman in our church, she is dying because we cannot give help to her because each and every time we go there to visit and pray, she doesn't want to talk. So what is the use of praying for something like this, because I'm sure that if she's in denial with us, I'm sure she's in denial with God. If you say: "God help me with this", you must tell what it is you need, like help in what. Then what is happening is, you could see the symptoms. All of the symptoms were there, it's the fever ... Even in the working situation, there are some colleagues. We heard about them,

Non-disclosure  
Related to challenge in providing support

Denial  
Stigmatisation and gossiping

Ability to identify Denial  
Being aware, but cannot talk about it and cannot support

Support ito:  
-home visits  
-praying

Denial

Ability to identify /see symptoms

but we cannot go to them, they are **not yet ready to talk** about it. Because they **know their fears**. Even if they can die, we **cannot say that they are dying of this**, because it could be TB. Even if **we are able to help them, we cannot** ... The only people that I see most of them that are talking, are those **who are illiterate**, because I've got a parent in my classroom, **but nobody knows** – it's only myself. There is a child who has been raped, and I could **see the symptoms** to the child, but **I couldn't say anything**, but the parents came to my classroom saying that the symptoms were coming like this and when I asked them: "*When are you taking the child to the clinic?*", they said: "*For what? The child was raped.*" You understand, now it hurts me ... **and they prayed and they prayed and they prayed**, because I said: "*Oh Lord, this is a child. She didn't do nothing, please help her*". As a result now, she is doing very well now. It's like I know now, because that's why **I have to go outside and ask for help for that child**, so that I can help that child. And the second person who **disclosed** to myself, and **nobody knows about it**, is a parent whom I had a child too, **and you could see the parent is very sick, the symptoms** were there. And the parent said: "*Mam, I don't have to hide anything, I've gone through to some of those groups and you could see myself*". And I said to him: "**Pray, because you have strength and I'm sure you are going to be okay, because I can see that you have faith and you are strong.** But what I am going to do, I will take care of your kid".

Hesitant to discuss due to fears  
Result: cannot support  
Denial  
Hesitant to use HIV&AIDS terminology  
Want to help, but cannot  
If not literate: talk about it  
Confidentiality=important  
Ability to identify (see symptoms)

Prayer as way of coping

Support by: seeking outside help

Disclosure to educator  
Confidentiality=important  
Ability to identify (see symptoms)

Coping:  
-prayer  
-faith  
-inner strength

EP9: Okay, I'm going to talk about myself, about my home. As I told you, my brother is HIV positive and practically **it is not easy if you are staying with that person**, you see. He told us that he is HIV positive, but as I told you that, after that, we are not talking about that, you see. We are not everything, **we are not going to talk about that**. Even if I have HIV, I won't say: "*Why this person is not disclosed?*", because this person did not disclose him or herself. Because I know that if it comes to me, it will not be easy, because **we have fears that they are going to chase me out, you see ... out of their lives**. It is not easy, it is **not easy to talk** about this, but in the **family you have to tell them**. What I am saying is

Difficult to cope with HIV positive relative

Avoid discussions on HIV&AIDS

Avoid disclosure due to fear of rejection  
Difficult to discuss topic  
Importance of disclosure within family

that people are different, people are differ. **My brother is very angry.** He is a, eh ... what can I say? ... he is not one that will say: "*Don't do this because I am ill*", he will say: "*Hey! Leave me alone! I'm living my life! You see, leave me alone!*" It's not easy. **You want to help, but you can't help because of his anger.** If you are talking to them, if you are talking to him, he will say: "*Leave me alone! I'm living my life*". I will say: "*No, I'm going to die, though we are all going to die*". It is not easy to say: "*Don't do this, do this and this*". And sometimes, and sometimes they are **getting that payment,** they are getting that **grant,** that R780, with that money, **they go out and spend it – in liquor.** They are enjoying themselves with that money.

Feelings of anger if HIV positive  
Sometimes don't want help

Willing to support but support is rejected by HIV positive person

Governmental grant=asset

Misuse of grant money=challenge

R: Are you referring to the disability grant?

EP9: Yes, but that R780 is too much. **That is suppose to be enough to buy food, but they are misusing it,** you see. Because they say: "*It's my money and I am going to do with whatever I like to do with it*". And some people now, they **are looking for the HIV person so that they can share the blood, because of that money.** Do you understand now what is really the problem? That is why I say to them it is like a joke, you see, and now they are **sharing the blood,** you see.

Grant as asset

Misuse of disability grant

Purposefully get HIV to qualify for grant

R: So if I understand you correctly, they also want to be infected so that they can get the money too?

EP9: And then when you ask them: "*What did you do with your money?*", they will say: "*Why don't you get HIV – this is my money, I'm HIV ... Why don't you get HIV? This is my money!*"

Misuse of disability grant

R: So they say: "*This is my AIDS, this is my money*"?

EP9: Yes. It's my AIDS, it's my money.

R: This is new information for me, that you can get a disability grant if you have HIV and AIDS.

EP9: And I'm sure the government can change the style and give them a full bursary of money and they will abuse that money too.

Misuse disability grant

EP7: The government must help so that they could support themselves, so the government must help that they can get the food.

EP9: It would be better if the government could make food parcels, and that R780 is enough for that. They must not, not to give them money, because they can buy anything they would like to buy.

Purpose of grant: basic support and food  
Rather give food parcels

EP11: I would also like to add on that. Sometimes the reason for the disclosure is because of the money. They disclose, but then they have not yet accepted it. And then somehow somehow the government will get confused because of the statistics. Because now what happens is, if I'm HIV positive and I go to clinic with my blood and I give blood so that everybody can get the grant. And now the numbers are going up, but it's only one person that is HIV positive.

Disclosure: to qualify for disability grant

HIV/AIDS statistics not accurate

R: Why do they want to be tested so many times?

EP11: So they, to get the grant.

Grant as asset

R: Now I'm totally confused. One blood?

EP11: Yes, one blood for many people.

R: But don't they ask for an ID or something?

EP11: No, so that's what is happening.

R: So you are actually saying that the statistics is wrong?



EP11: That is the reason why they disclose.

Disclosure, in order to qualify for grant

EP10: The clinics are not following the procedures correct, because they are suppose to get full detail of that person, and ID number, and they are not doing that.

Procedures of testing questioned

EP11: As a result now, what is happening now with this grant ... sometime in October it was stopped because the numbers exceeded the eh, ... And they see this fresh person, waiting to get the money.

EP10: But now I just want to say that once I was saying that they are afraid in their homes, to talk about this thing. If you are strong, if you are strong and you are counselled, you are suppose to talk about it so that that person must belong to you.

Willing to talk if counselled

Inner strength

EP9: Aa-a (*shaking head*). I want to correct you. No, no ... I want to correct her on something I said. In my house we don't want to talk about it, because my brother becomes angry, he becomes angry. If he is not angry, we can talk about it, but when you correct him to do this, he will say to me: "Leave me alone! I'll do what I want to do."

Others avoid discussions  
HIV positive: feelings of anger

EP10: That is why I'm saying that the whole family must go for counselling so that they can see that I am not at school anymore but my family is supporting me. For if you don't, if you don't talk about something that is eating you in your family - what are you doing? You are suppose to talk about it, even if it is going to hurt somebody in your family, you must talk about it.

Family should receive counseling and support  
Family=source of support  
Discussions favorable

R: You mustn't try to avoid conflict?

EP9: Yes. Because, my brother too. Sometimes he becomes angry and he is taking medicines from somebody we don't know. Then we ask him: "What is this medicine for?", and he say: "Somebody said it helped me, it helped me". But then I say to him: "No, what you are going to take is the

Anger

Coping:  
-Treatment  
-Community support



*medicine that the doctor say you must take. Not everything that somebody said is helping him. If somebody is giving you the medicine, saying this has helped him, come to us and show it to us – we want to see”. So if you are strong and you are counselled, that’s what they need.*

Coping:  
-counselling  
-inner strength

R: Where do you go for counselling?

EP9: Unlike my brother, unlike my brother ... my brother is a heavy weight. I don’t want to be kicked by him ...

R: So every family will be different?

EP2: Even if your brother becomes angry at you and say: “Leave me alone”, that’s also a form of denial, that is something you must talk about.

Anger=denial  
Avoid  
discussions

EP8: That’s right. And also, you have to change the diet. But if you want to give a special dish for him, he won’t eat it. You have to change the way they live.

Need for change  
in diet and  
lifestyle in order  
to cope

R: The lifestyle?

EP8: Yes, the lifestyle.

EP10: Sometimes you have to eat the food, even if you don’t want to.

EP1: There is something that I’ve noticed ... in funerals ... they don’t want to talk about this. They don’t want to say this person has died because of this or this ... As a result, if maybe someone have just said that he was HIV positive, maybe other people they will also say but now, they don’t want to say it at funerals. They will just say it was something from TB or something else, that it’s ... It is not easy to talk about this, to say this ...

Avoid  
discussions

Participants  
avoid use of the  
term HIV&AIDS  
Stigma

Deny cause of  
death due to  
stigma

EP10: That means that we must change our community, ja (nodding head) ... we must change the communities.

Challenge:  
Need for change  
of attitude in  
wider  
community

- EP7: Here at school, we **don't want to say they have it**. I had a parent in my class who died. I called her and she came in. She was very sick, she **said she had, that she had the flu** and that she doesn't want to go to the doctor. I said: "*You must go to the doctor and you have to be tested*". She said: "No, **I have been tested**. *There's nothing wrong, it's just this flu*". She said: "**No, I'm going to be fine**", but she was sick and as a result she died, not having gone to the doctor. But this is the problem, and that, her child is still in her class (indicating educator-participant 2) – she is still alright.
- Denial, related to stigma  
Denial
- R: Who is taking care of the child?
- EP7: There are **aunts and uncles that are taking care of her**. They **don't want to go and take the tests**, even if the child is sick now. They **don't want us to get in**, because if we get in, then we see and we can help and advise, then I'm sure **we could make a difference**, but **they don't want us in**. Because they will not tell us if there is a problem and come forward.
- Extended family taking care of orphans  
Avoid testing  
Deny and avoid help & support  
Aware of own ability to support  
Want to support but not allowed
- EP2: They **don't tell us** ... they **don't disclose** and their health goes down, because **they don't tell anybody that they are HIV positive**. And then they don't eat right, because some of the people they **don't want to disclose** and go for help and **find out more about the disease**, you know. Like, "**What must I eat to boost the immune systems?**", and things like that, that's why they **don't want to disclose**. They just go on for a couple of years.
- Non-disclosure  
Secrecy  
Need to be informed  
Don't want help =denial, leads to non-disclosure
- EP1: There is a teacher here at our school, she is having a child in her class. She could **see that the child was suffering**, she know that this child was sick, until that child was admitted to hospital and then the parents came and said that she was HIV positive. That is why we are saying that **parents don't want to come and tell us what is happening**.
- Ability to identify Vulnerable children  
Non-disclosure
- EP5: Another thing is, what I am saying is that the kids **needs counselling**, they need to go for different sessions. Even with us educated people,
- Need for counseling

we seldom see **psychologists** – we believe in general practitioners. When we get ill, we must go to the doctor. **We don't use psychologists.** The **only time that they get the counselling, a little bit**, is when they are **told about the results**. Then, before they are told, they get just a little bit of group counselling. Another things is, with the **doctors** now, they are making use of this **grant**. They are doing what they say is viral load, in order for them to get expensive medicine. You know what frustrates one more, is when it is said that: "*No, the count is too low*", then even this medication is ... is killing this person. This is number one. Number two is, in some areas it is said that you have to be on a certain stage in order for you to **get that grant**. You just, let's say I've been tested and I'm HIV positive, I won't get that grant, not unless I'm just nearly to be fully blown. Then I will be able to get it.

Stigma attached to psychologists

Limited counselling when told about test results  
Group counselling  
Assets: doctors, grant

Grant=asset: criteria to qualify for grant

R: In other words, you have to be very sick to be able to get the grant?

EP5: Exactly. You must have a history of you going to the clinic, seeing that you are at this stage, then this stage and then it is quick with the clinic. But if you go to the doctor, ugh ... and that **medication is damn expensive and the unemployment rate is too high – they cannot afford it.**

Need for medication  
Cannot afford it due to poverty  
Unemployment

R: Where do the people go for counselling? Because *L*, you spoke about counselling for families, but mentioned that there is not a lot of counselling and *E*, you also said that there is a need for counselling.

EP10: Okay, let me help you. If you want to go for counselling, if you are a family, you don't want to listen to people. You take your money and **go for counselling or you go to a clinic**, because before the tests you get the prior counselling and then, **after the test, the whole family is included**. Because that is why I say you are going to be strong if you are going for counselling.

Basic counseling received at clinic when tested and HIV positive  
Family benefits

R: So the counselling you are talking about is situated in the clinics and done by the nurses? What about social workers? Do they give counselling?

EP10: If you are using medical aid, or you can go and pay money.

R: Have any of you been trained in counselling?

EP10: No, not in counselling.

Educators not  
trained in  
counseling

R: Have any one of you received training in HIV&AIDS information?

EP11: Yes, I have, at the Department of Education.

One educator  
trained in  
HIV&AIDS

R: Based on your training, do you have as special task assigned to you here at school?

EP11: I am suppose to teach the grade 6 and 7.

R: Is it life skills training?

EP11: Yes, but it's not just about that. There's more to it, and it's not just training.

Part of life-skills

EP3: Okay, now I want to say something. What I want to say is that as long as there is going to be denial, because the counselling is done before you get the test, prior, before you get your results. But if you don't have a denial problem, it is easy for the doctor, your own doctor, to help you. Because if you can get to our GP's, it is written boldly that if you've got this and this it's this. So you've got the chance to talk to your doctor. How can your doctor smell it? How can the doctor smell that you are HIV? It is up to you to tell the doctor: "Doctor, I've got this problem". Then the doctor can tell, uhm can make you to do all those things where you find out that you have got HIV. It is your duty to tell your doctor.

Denial  
Pre-test  
counselling  
Doctors=  
potential asset  
(not used due to  
denial)

Should take  
personal  
responsibility  
Disclosure  
favorable  
People  
uninformed about  
this asset

And even if you don't tell, you are not ready to tell your family, somebody, ehm ... who is going to counsel you? It's yourself, you see. People doesn't know about this, especially those who are illiterate. But to come to the denial situation, if ... let's go back to what we've said about the parents. If the literate, the people who are educated, have got a denial problem, what will happen to those who are not educated? So we cannot say that the parents they don't say anything – it happens even to us, those who can understand this things. So it will be difficult for them, unless we people who understand about this things, accept them. Then it is easy for them. You can go to that parents and say: "Look, I've got this problem. You think I'm educated, we are all educated in this room about HIV. I'm HIV. Talk to me so that I can help you". If it doesn't happen to those who are educated, what about those who are not educated? We mustn't take blame to the parents. And the parents sometimes can see you, eh ... on your attitude to what you are talking about. So you must check even the attitude. It's like when I talked to her about her brother who is aggressive. It's a symptom of denial that aggressiveness, because he is not yet ready. He has not yet been counselled, you see. That's why he is so aggressive. One day here at school, there was a lady, a lady who ... That lady, he came to school with another lady who was HIV infected. She called us at staff and that lady, N, had a nice body, but she's almost dead now, having that virus. She has got a child, but you cannot say anything about N. N was going to be sick for a long time, unless she got counselling and was told about her eating habits. And when N addressed the kids, she asked the kids: "What can you say about myself?" And the kids said: "Nothing. You look beautiful, you are pretty". She said: "There's nothing I don't know about myself. I'm HIV positive". And N, I'm sure God is going to bless N and she is still going to have 20 years. She is still working there and there are many more. If you can switch the radio, you can hear about this. But let's come to the disclosure at the funeral. You cannot talk about death certificate, because at any funeral there are not a death certificate, let's put the death certificate aside. The doctors said, like we've said in the beginning: "You've got pneumonia, you've got TB",

People  
uninformed about  
this asset  
(especially  
those who are  
illiterate)

Denial

Acceptance=  
important  
(relates to fear  
of rejection)

All people avoid  
discussing  
=taboo

Positive  
attitude=  
Important

Aggression  
Denial leads to  
aggressiveness  
People not  
ready/prepared  
and therefore in  
need of  
counselling

Positive  
outcome of  
counseling:  
-guided on diet

HIV positive  
=living positively

Radio: asset

Denial at  
funerals:  
cause of death  
denied

HIV&AIDS-  
related illnesses

- when you see the symptoms. It's up to the family, and even the family, there are two things that make them not to disclose. It is difficult to disclose on a funeral situation, once the wife is left behind. Because now I have to disclose upon my husband and I'm not yet ready, we are married. Then my husband died and then, on his funeral, I cannot disclose if I'm not ready, because it will too affect me worse. You can disclose about your child, knowing that he is not married so that you can teach other kids, but it's different on how you take it to strangers.
- R: That's right.
- EP10: That's why I say that the community workers must be well trained – they must talk about this. If the community ... the community is about parents, it's about everybody. If the community is well groomed in this, even in the funerals, you can just say this one died of AIDS, whether it is my husband or whoever, as long as we have courage in this.
- EP2: The problem now is that the one who stays behind, is going to be labelled by his own people, do you understand?
- EP10: No, what I'm saying is that before this happens or whatever, we must as a community educate ourselves about this, then there will be no stigma.
- R: Where should this education come from?
- EP10: Education must come from people who are trained.
- EP4: Coming to that, I think that we as a school, as teachers, it is our responsibility to call the community to train the people.
- R: If I listen to what you are saying, you seem to be pretty trained yourselves. I can understand that you are saying that there is a need for some counselling skills, but you are all well informed, you know about
- Ability to identify  
Non-disclosure  
Non disclosure:  
-not ready  
-afraid of  
personal effect  
Community  
needs to be  
informed and  
attitudes  
changed  
Stigma related  
to disclosure  
Community  
needs to be  
educated to  
address stigma  
Need for  
external help  
Education as  
asset  
Need to be  
trained by  
experts/trained  
people  
Educators=  
asset to train  
community

lifestyle supports and all sorts of things – you are already well trained in HIV&AIDS.

EP3: To get back to what I've just said. It was 2002 when I got pregnant. Then I got to the gyno, then I went to the gyno, because when you are pregnant at the 8<sup>th</sup> month you've got to go for a blood test. But I couldn't remember myself taking blood test during those 8<sup>th</sup> months. But I do remember myself, when I was close to 8<sup>th</sup> month, the doctor gave me a list that I must go to 4<sup>th</sup> floor, and I've told my colleagues this story. Then I took this list, and I like to read, because what I remember, when a teacher in the olden days could give you a letter, you will take it to another one and she will spank you. When I took this, I was so pregnant. Then I took this letter from the doctor and I was going to the 4<sup>th</sup> floor and something said: Read the letter! **And when I read the letter I saw HIV!** And what strike me was my husband who had the affair. And when I got to the lifts, I stopped there and asked myself: "*To which floor am I going to? 4<sup>th</sup> floor*". And this thing, I was holding it like this. And you know the doctors write lists like these, and say HIV, so **I think: what are they going to do with this big tummy? And what about myself?** Why didn't he tell me earlier? But now look, when I got into the door, I could see a very thin **nurse** with a small face, a lady with legs that are just like sticks. And I said to myself: "*Is she going to counsel me now?*" And I said to her: "*This, what does this mean?*", and I point to the HIV. So they said: "*No, no. You've already done this. So now you come for the booking, for your bed.*" And the nurse said; "*Do you see myself like this? No, I got sick, that's why I am like this. I don't have HIV, but I'm like this*". And when I talked to S and some of the others, they said: "*No, they know that nurse is like this. She is sick, that's why she looks like that*". So, I just want to **tell you, that it is not easy for the first time.**

Difficulty relating to HIV: Shock in case of the possibility of HIV positive status

Concern due to possible status

Counseling by nurses (=asset)

Dealing with HIV= difficult, results in denial

R: Yes, it is not easy.

EP3: What happened is, when I got home, I was relieved. And they said I must give him this letter, and my husband I was teasing him, and I said:



*"Look what you did with that girl that you got? I'm HIV now. I'm HIV."*

And my husband said: *"No, no!"* And I said: *"That's what you did!"*, because I want him to get shocked too, because I got shocked. So it was his turn now, whereas I knew about it. And then I could see tears and I said: *"I told you, I told you!"*, and he said he will go to the doctor tomorrow and I said to him: *"Beware of what you are doing beside me, be faithful, because I also nearly died"*. So that's what happened.

Shock, fear and sadness when confronted with the possibility of HIV positive status

EP9: So now, if you are taking that life cover ... I don't want to go and do that blood test, I'll rather leave that life cover. I don't want to do the blood test. For the time being now, I'm still fresh. If it is something that will take me to the blood test, I will say no. Because I'm still fresh and there's nothing wrong. And even for those people who are sick, even for those people who are HIV positive – if they are still fresh and healthy, they will say leave me alone I'm still alright. But when they are very sick, they can do everything because they are ... uhm ... you can do whatever you want to do. You can give them a weak porridge because they are sick. But when they are still fresh, when they are still healthy, when they are still strong – they don't care. They can do whatever, they can eat whatever. They will only be serious when they are very sick. Do you understand what I mean? For those who are strong, the life is still there.

Avoid testing due to fear of being HIV positive

Avoid possibility of being HIV positive  
If feel healthy, avoid testing

Others supporting sick people  
Avoid testing when healthy

Inner strength, result in hope

R: Please help me understand something. Are you saying that you don't want to go for testing?

EP9: No, no, no! I don't want to go for testing. I don't want to know my status.

Avoid testing  
Deny possibility of being HIV positive

EP1: I want to tell you about my brother. This is how it happened now. I was phoned by my sister to let me know that my younger brother was sick. I asked them: *"Did you go to the doctor?"*, and they said that my brother didn't want to go to the doctor. I told them they must come and we can arrange for a doctor that will be able to help him, for my brother's sake

Avoid support and potential treatment

because he was in a bad condition. And then I phoned him and ask him how does he feel and he said: “Sissy, *I don’t want to go to the doctor, but I was forced because now I can see with my condition I need to go*”. He was tested. He told me he was sitting in the passage and ... I was *shivering, I was laughing of fear - because the way I was scared to hear the results*. I was shivering because I thought the results are going to be positive.

Fear results, thus avoid help

Fear possibility of being HIV positive

EP5: And he’s a teacher.

EP1: Yes, he’s a teacher. But fortunately the results were negative. That is why I am saying – *It is not easy, even if you feel that you are sick, to go for the test.*

Avoid testing due to fear of being HIV positive

R: Why do you think one should go for testing, even if you are healthy? Why is it necessary?

EP1: Because sometimes when you think you are healthy, you’ve got this. You must go.

EP9: Most of the ladies know their condition when they are pregnant. *Because they are forced to be tested.* Do you understand what I mean? I don’t want to hear while I’m still alright. I will be forced to go there to be tested.

Tested when forced to do so  
Avoid possibility of being HIV positive

EP10: That’s why I want to come back to what we’ve said. *If we educate a community, then no one will be afraid to be tested.*

Educating the community and changing attitudes, as way of coping

EP11: But how are you going to do that?

R: That is a very good question, let’s talk about it.

EP11: We are supposed *to lead by example*, because what will happen is this, and what the *government has already started*, is for teachers to be

Educators= potential asset (example)  
Government= asset

tested. We are supposed to be the ones who are first to say I've already done it. And the reason why this thing is going up and up, is because everything is always done late and then I'm already HIV positive. We have to start by educating people on what are the causes of HIV AIDS? What happens after you find out? We are supposed to be the ones doing that. Once I was told that, I was watching out and I was telling myself I was failing my community, and after that I tried to talk to them, but the problem is, people are not serious. And what we have been saying about people not disclosing at funerals – there are no need to disclose that. Because you see, even in this place, AIDS is not a disease, so you won't say that person died of AIDS. They will say it was TB. But what you are supposed to do, is to try and persuade the people to change their lifestyles. That is the best thing to do.

People need to receive basic HIV/AIDS information in order to cope  
Educators can educate

AIDS denied in the community as a disease  
HIV&AIDS related illnesses  
Deny AIDS  
Community needs to change lifestyle to cope

R: Yes, and you can even do if from here. How can you as educators, here at school support the people of the community to cope with HIV&AIDS?

EP10: If we are not suppose to get permission somewhere, if we are not suppose to get permission from somewhere, we can do this. We can do this. Like I think we must contact health workers first to come here, we must contact health workers to come and help us here at school. From there, the principal or the management of the school are suppose to make means that we can use our school as a center.

Belief in their abilities  
Motivated to take action  
Network with outside experts

Educators and school as potential assets

R: What do you mean by that?

EP10: The management must allow us to use the school to reach this. The community must not see us as educated people, they must see us as people that want to help the community.

Change in attitude in community required  
Motivated to help

R: Also as friends who want to help the community, but also as people who know someone that is infected with HIV, with some even being infected themselves.

Inside assets= community members  
Motivated to help

- EP10: **Because we are affected here.** Mrs Z is having a child, she has a child in her class. The teachers, the school is having these people, you know, and this is affecting us. **In order to support these people, we want to help the community.** **I think we must all go and do this.** HIV&AIDS =challenge  
Want to support/help community  
Positive attitude
- R: I like your idea of making your school a center of health. Who else can be involved? It is you, the community members, health ... who else?
- EP11: **ATICC** NGOs= potential assets
- R: What is ATICC?
- EP10: **AIDS Training** what what what ... I'm not sure. Training by NGOs as potential asset
- R: In other words the NGOs. Who else?
- EP11: **The workshops that the department always invites us to attend,** at the NGOs. Department workshops as asset
- R: Which NGOs are involved in this community?
- EP9: I don't know. We are not sure. **It's only the counsellors.** Counsellors as asset
- EP10: But **I think we can get the people who own shops here as our help.** If you can go and talk to them, because the people's needs – they cannot manage them on their own. Because they have got the money, they can help the community to get to those needs, I think so. Shop owners (community members) helping other community members
- R: What about faith organizations?
- EP3: Even if we are doing this thing, it was said **on the television** that we must **also include the reverends and the priests** and all those people, because this is where most of the people meet like at the churches. Because the problem with the churches is they **hide these things as if they are not** Assets: -television -church and ministers  
Stigmatisation and avoidance

- happening, but they are still there. **Because they don't want to talk about sex.** They **must invite nurses**, like at our church we invite nurses to talk about AIDS. We invite nurses to talk about the diseases, like herpes and all those things. It is very important that the **churches must also be involved**. Coming to what she has said (*indicating educator-participant 11*), before doing anything, we also **need workshops**. Because when we are going to these people, we must be able to answer. We must be able to help, to say this, this and this. This is the way to do this, this is the way to do one and two, or one and three, because this people don't know nothing about this.
- R: Do you mean that you as teachers want to present these workshops, or do you want to receive the workshops?
- EP3: **We want to receive the workshops first, so that we can give them.**
- R: And who do you think should provide the workshop training for you?
- EP3: Okay. If the **ATICC or the department can do it**, **not to take one teacher from the school, but to take all the teachers**, and at the workshop it will be so nice to talk about these things, because it is going to happen in our schools. They've also been to USAPT.
- R: What is USAPT?
- EP3: **USAPT is Union of South African Provincial Teachers**. It is the party for teachers. What is happening, they went to those workshops, now they came back and as a result, the day when they made the report it was like a workshop. As a result now, they said **every teacher should receive these workshops**. **It is so nice to deal with this, because they make everything so clear for me** when we were there, but it was a short time. They said they are going to make more workshops so that we can **go to the communities and apply back what we have learned**.

Churches: deny and avoid topic

Potential asset:  
-nurses  
(information provision)  
-churches

Need for training  
Need to be knowledgeable

Need for training  
to be able to train in turn

ATICC/  
Department=  
outside trainers  
All educators  
need to be trained

Union as potential asset

Workshops as potential asset, providing clear guidelines and training

Possibility of applying knowledge in the community

R: Now I would like to know, you have actually spoken a little bit about children and a lot about adults. When you spoke about children, you said that you want to be careful in your classes, you don't want to distinguish these children from the other children, and the other thing you mentioned is that sometimes the parent comes to school, but not always, and then discloses the status. What else can help you identify vulnerable children? In your school, is there a system to identify children who are infected with HIV?

EP3: No, no. What that lady was saying about the food that was taking place, we heard that of another school, that's why she raised that point.

R: Are they growing vegetables?

EP3: What they were doing at that school, they ... those people who have HIV AIDS, they are giving them a special diet. **They are doing everything for them, and as a result they are well.** That's what we heard about them.

School as potential asset

R: And here? I remember when we had lunch, *B* I think it was you that mentioned the child that collapsed from hunger in your class. What about the idea of not only providing nutrition for HIV&AIDS children, but for all children in the school, because most children will benefit from nutritional food?

EP2: **Many children get food, it's just the brown bread.**

School as asset (provide in basic needs)

R: That's why I am saying, brown bread is one kind of nutrition, but how about having a vegetable garden where most of the children can benefit?

EP2: Yes, then they can get something from it.

EP7: Yes. In our country unemployment is such a problem. If **there's no work, there's no money,** there's no food, you get hungry children in the

Unemployment

schools. So if we cannot only distinguish children who have HIV AIDS, or who are orphans ... if we can work with all our children and say **many of our children are vulnerable**, let's not label some. Let's try and help them.

Vulnerable children

EP10: I think **you are a blessing in disguise by coming here and give us talks about this, because I think the management of the school must change its policy from today.** Because here at school, the pupils that are getting the feeding are the grade 1's up the grade 3's, while the whole school are suffering.

Positive about outside help and guidance  
View outsiders as experts  
Could change school policy – providing food to all children  
Motivated to change

EP2: But it's the policy of the department to say only those children should receive food.

EP10: But what about internal?

EP2: Yes, that can maybe happen.

R: What are you saying, *M*?

EP2: I'm saying that the management must help but the departmental policy cannot change, but now she (*indicating educator-participant 10*) is saying that **maybe we can do something internally, here at school.**

School as potential asset: general health of children  
Motivated to help

EP1: I was sent to a meeting, and it was said that from next year it will not only be bread they get. As a result we are having a certain lady who is coming here, she is going to see management. She is going to do some facilitation about this issue.

EP11: Not to the management?

EP1: No, she has come to the management first. She will invite others now to join. I'm trying to say is that from next year it's not only going to be bread.



R: I'm hearing two things now. I'm hearing that there's the confines, or the boundaries of what government says and what the school policies are, but I'm also hearing about this other school you spoke about, that says: *"Policy says this, but what can we in the school do?"* And when you said you wanted to get community members involved, they can maybe help in that garden at the other school. If there is so much unemployment in the community, to get the children and the community to work with that garden, for example.

EP2: Some of these children, they just come to school to get a piece of bread because there's nothing at home. Because there is nothing at home. Poverty/hunger  
School support  
in basic needs

EP10: And sometimes they cannot help for not having money, we must use them to help in the garden. Instead of taking their kids away, we must tell the parents to do work for us. Poverty  
Community  
members' role  
as potential  
asset

EP3: I want to get in here. Those vegetable garden here in the community, it's only the seeds that are needed. Rain are coming from Above to make that to grow, you see. So everything that is happening, God is happening by purpose. Because there are this disease, and most of the people don't have money, and for this virus you must depend on greens. Greens are coming from soil, soil that can be done by people who are illiterate. So what we need to do is to motivate, because if we can go outside there is a lot that we can do, but you can see a lot of grass and weeds. Instead they will see the cabbage, or the spinach, or the vegetables. The parents need to be motivated. And the other thing that I want to highlight to you is: do you know what is killing our nation? It's the confidentiality of this thing, this pandemic, being HIV positive, because ever since it was told that it is confidential, because no one knows about my status and you can see I'm a bit fat and fit, and any man could see a fit person out of myself. But because of confidentiality, knowing my status, I could easily accept your proposal – knowing that I'm HIV positive. Knowing that it is wrong, because what is happening, even in our community, people are so stupid sometimes, because why is

Assets:  
-community  
garden  
-rain  
Challenge: need  
for seeds  
Avoid  
HIV&AIDS  
terminology  
Poverty  
Role of  
educators in  
motivating  
change in  
community  
Aware of own  
abilities  
Community  
members as  
potential asset  
Avoiding topic/  
confidentiality  
issue

- this thing easy now? **It is easy to go to you and sleep with you.** Why don't you strike in your mind why is it easy now? Even those people who are still okay, it is easy for them to say yes, yes, yes. Yes is like good morning, good morning, good morning. **Knowing that at the end of the day, they will be 10 like this one who will die, knowing that I will not die alone.** That is a thing that is killing our nation, that I am not going to die alone.
- EP10: Okay, on that issue. That is why people who find out that one has AIDS, and accepted my proposal and slept with me, become angry. Because you know your status, you are suppose to say that I'm infected, to say: "*I love you, but let's use condoms. I want you to be responsible*" – that's why **people are killing each other because they don't want to be responsible,** I don't want you to have this eh ...
- EP2: They **say I don't want to sleep with her with a rubber on.**
- EP3: They say: "*Do you eat a sweet with a paper or do you want to eat a banana with the peel on?*" So that's where the problem lies. **Even if you know your status, you have one particular responsibility of condomising.** Even I have to be honest enough to tell you: "*Take it or leave it, I'm HIV positive. If you want me, put a condom on. If you don't to, you don't want me*". **If you could see on the TV** – a man that has got an affair and that women, her parents told her: "*You can't go on like this*". They have got 5 years – the man is HIV positive and the women negative, **because they were honest with each other.**
- EP5: I also want to say that it also **goes back with us to our culture.** In our culture it is said that a **man can't sleep to one person.** And it will be **difficult for myself after twenty years saying to my husband: "Let's use a condom".** The very first thing is: Why? So it is easy for me to be infected. Even if I can be as faithful as possible, it is not so easy.

At-risk sexual behaviour

Spreading the virus on purpose

People don't take responsibility for their status  
At-risk sexual behaviour

Not practicing safe sex

Importance of acting responsibly

Television as asset and source of information

Coping by taking responsibility for HIV status

Culture as challenge:  
-multiple partners  
-avoid condom use  
-women submissive to husbands

R: So you are saying that in your culture it is okay for a man to have more than one partner?

EP5: Yes.

R: And you are also saying you can be in a marriage for twenty years and if your husband does not want to use a condom, you'll have to stick to his decision and avoid conflict?

EP10: If the man has come to the point **where he is unfaithful**, you must separate, because **I don't want to die**. I want to see my kids when they grow. You must go separate, you can't just get the disease for nothing.

At-risk sexual  
behaviour  
Fear of dying

EP3: To add on what she is saying, it is not an issue, it is not an excuse. It is an excuse because it will not happen to ... the married man know he is married. But even if you could see **your husband is not faithful**, it is alright to say: "*No, let's check again*". It's coming back to: why don't you go for the test again? To **those people who are unmarried, they are doing it purposely**, because if you are not married, it is your duty to say: "*Take it or leave it*". To the little ones who are still at school, it is their responsibility to say take it or leave it. It is ABC – its either you Abstain, or you **Condomize** or B, I don't know the B.

At-risk sexual  
behaviour

At-risk sexual  
behaviour

Safe sex as  
prevention  
(coping)

R: Be faithful

EP3: Be faithful, yes. So, **it all comes back to us**. I cannot say: "*I know my husband is moving around but okay, I take it*". No, I **must tell him: "No, my life is also in danger"**.

Need to take  
responsibility  
themselves

R: Are you saying that women should learn to be more assertive?

EP3: Yes.

EP9: I wonder how many of us here are saying to the young ones: “No, *let’s use this*”. Because you are not ready at that time to say that, you know. If you say to your husband: “Okay, *let’s use a condom*”. We always say so, but **we are forced not to use it**. But **you know that he will go out**, you are not ready for your marriage to end, **you are not ready for a fight and you are not ready that your marriage are going to fall apart**. You give him what he wants, because he is your husband.

Unsafe sex practices:  
-related to culture  
-avoid conflict  
-to maintain marriage  
-women submissive

EP10: But what about the consequences?

EP9: **You will suffer, you will suffer**. And you are not yet ready for your marriage to fall apart. How many of us ... how many of us here use the condoms?

Vulnerability=  
related to culture

EP1: I want to reply by saying: right enough, **it is not easy to say you want a condom**. But now, **if you can see that your husband he is unfaithful**, now you have got the right to say that you want it. **It is your right!**

Difficult to demand condom use, especially in marriage  
Despite right to do so

EP7: I want to again talk about this denial. I have a friend who is married and has HIV, and the **husband doesn’t want to use the condom** and now she is HIV. I’m sure the husband is also HIV now. She tells me he does that, **he is in denial**.

Difficulty to use condoms:  
-difficult to be assertive  
-avoid conflict in marriage  
Denial

R: I want you to talk some more about the children. What do we tell our children about HIV&AIDS? Do you know if parents talk to their children about HIV&AIDS? Do parents tell their children if they are HIV positive?

All: No.

EP9: Let’s talk about this point. Tell me, why do **HIV positive woman become pregnant** although they know that they are HIV and then they don’t want to terminate the pregnancy? Although they know it will leave orphans, **everyday we are talking about the orphans – a lot of orphans, but they**

At-risk sexual behaviour  
Potential increase in orphan numbers  
High number of orphans

still become pregnant, although they know that they are HIV positive.  
Do you understand what I mean?

R: Yes, I do.

EP9: Why don't they accept to terminate the pregnancy?

EP10: I think the answer there is this – they **want to prove a point**. They want to prove a point. You know what? If you are HIV positive, and you said to that one or even if you didn't say it to him, and you want the other person to know that, even if they see how tired are you, you don't want them to know that I am HIV. I am going to prove a point that I am going to be pregnant and you will see my child, although the consequences will follow.

Prove a point  
Denial

R: So it is denial?

EP10: **It's denial, it's denial!**

Denial

EP11: I don't think they get pregnant to prove a point and secondly, it's against the law to terminate a pregnancy. It is not that they want to get pregnant and then to have that child.

EP10: But even then, even if you are not HIV and then you become pregnant, you are tested and you know your status, now is ..., you can terminate the pregnancy because you are not going to care that child. **It is not okay to see when a child is sick**. If you go to this hospitals, **their parents are dead already and now the child is suffering**. But again, because **I'm not responsible or I don't want to be responsible, I get pregnant**. Why? **It's denial**.

Challenge of  
coping with  
vulnerable  
children  
Lack of  
responsible  
sexual  
behaviour  
Denial

EP5: Again, to what you are saying ... I'm going back again to say **cultures play an important role**, because our **parents don't talk with us about sex first of all**. They don't even tell us what are the consequences. They are

Lack of sex  
education by  
parents=related  
to culture

still continuing with that. Even with us here, right here, we don't even know if our parents had the will or whatever. The only thing that is happening is that we fight when they are dead. We fight about the house, because nothing is being said to the children, absolutely nothing. You just go out and find out yourselves.

Avoid discussions on HIV&AIDS and death

R: Do most of the parents not talk to their children about HIV&AIDS or death?

EP10: But I think there is no need, there is no need.

No discussion, related to cultural belief

EP3: What is happening now, is that we are taking the blame to our parents. Now the parents are us. I've got a 16 year old, she's (*indicating educator-participant 9*) got a 21 year old. This century is another century, being us as parents. What are we as parents going to do with our children, because most of our parents died long ago.

R: Do you talk about sex with your children?

EP9: Yes, but not in a formal way. For instance, I've got 2 children - the one is a 21 year old and the other one is 18. When I am talking about sex, I said to them ... I talk like this: "*If you have many girlfriends...*", you see, I shout! I don't talk to them in a formal way. I say: "*If you have many girlfriends, you will see my dear, you will have HIV – you will have AIDS*". That is the way we are talking to them, we don't sit down and talk to them in a formal way with detail. I am talking about myself now.

Lack of formal sex education by parents

Lack of sufficient sex education by parents (related to cultural beliefs)

EP4: My children are still like this and this (*indicating small*), the one is 5 years and the one is 3. So they are still small.

EP9: If I have condoms, I just go to their rooms and put it in their cupboards. I don't tell them: "*Here at the condoms*", I just take the condoms and put it. I don't want to know what they are doing when they are busy, you

Reluctance of parents to talk about sex-related matters with children

know. But what I did – I just take the condoms and put it in their cupboards.

Secrecy of sex-related topics

R: So sex education is still limited, it's still a taboo?

EP9: Yes. I can talk with other kids, but not to mine.

R: And what do you do (*addressing educator-participants 1*)?

EP1: I just talk to them when they start showing, then I'll say you must talk with them.

Limited discussions with children

R: What do you tell them?

EP1: I just tell them that: "*If you go with a man, you can get pregnant*".

EP10: They are saying that communication is the best policy for our homes, but we don't do that. But now, a word of advice: Kids are seeing these things on TV, but they are naughty because they want to proof it on their own bodies, and its carelessness. Even if you talk, they just want to do it.

Lack of communication on sex-related issues  
Television as source of information about sex (potential asset)

EP2: You know, even here at school we have sex education, but we are not trained on how to answer these children's questions, and I understand there are teachers for that. So I think we need to get some ... maybe learn how to approach these kids at school, because all that we know is that what we hear on things like that.

Sex education presented at school  
Lack of trained educators on these topics  
Need to be informed, to cope

EP1: I was for training, but you know, you can't even look at them. So I think it's for us to be trained.

One trained educator

EP11: I want to know: In our classes, eh ... in our school, we've got different age groups. We've got the little ones, then around 10 and then the



bigger ones. So, some of the information is catered for the older ones, so you cannot just give it to all of them.

R: Yes, it has to suit the age group.

EP9: And even now, I will give lessons to a specific age group, because these younger children, they like to go to their homes and say *Mrs D* has done this and this and this.

R: In other words you need the parent's consent?

EP10: Yes, you need the consent.

EP3: What I can say, now ... I just want to say, it's like my daughter asked me one day – she was 14 years, now she is 16. She asked me: "*When is the right time to get involved*". And I asked her: "*Where did you hear that?*" And I said, "*Okay, one day I will tell you*" Uh!! One day? One day is too far! And I asked her: "*Why do you ask such question*", and she said: "*I got a form from school that I have to fill in and discuss everything*". And I said to her: "*Show me your form*", and she answered the form and wrote that age 16 is right to get involved. And she answered that herself, you see. And that shows that **even at school they are talking about it**, you see. Even us as **parents, we have to ask them why, so that you can be involved.** **Like we don't talk about these things with our kids** – it's not like this with us, even when we are washing, our kids look away.

Avoid conversation

Sex education by (pot assets):  
-school  
-parents

Avoid discussion on sex-related topics-related to cultural beliefs

EP3: What we were saying is, **we as blacks**, we said to a vagina is a cow, but how can it be a cow if it's between your thighs? We want to make a child a fool. But they think how a cow with horns put his head between your thighs? So when we, they talk about men they say puti – you don't tell him, but when he ask you say all men have got this, because look at the 3 year old when she saw the 8 year old: "*My, my, come and look at this*", and she was pulling it, because she could see that hers was not

Behaviour and (lack of) sex education =embedded in culture

- like his. And we didn't say anything about it, but she could see it was not like hers.
- Lack of information by parents, influencing sex education
- EP10: I think when you come back again, you will see the difference.
- Predict change  
Motivated to take action
- R: Tell us what you mean.
- EP10: Because we will be up to the principal to ask what is going to happen? We want to save the community.
- Positive attitude to make a difference and change the community
- R: You can't leave everything to the principal.
- EP9: No, in our school it is like this. The parents, the community, came to our school before and asked the principal if they can plant there and we can have the veggies, everything, you see. But the principal said no. So that's why, so we are going back to the principal now and ask him to accept those parents to come back and plant here at school, because it will help the teachers.
- Identify potential asset and make action plans to mobilise it
- R: And this must then be for the school and not for themselves?
- EP9: No, even for themselves, that will be fine. They will give us ... We, eh, they will donate what they plant, you see. We will get something from them.
- School/educators supporting the community
- R: But it should be for the school, and then maybe if the parents feel that they are doing something for their children, it will make sense to them.
- EP9: No, if we say they can plant for us here at school, they will come and steal. They will come and steal. But if you say they can plant for them and then we'll get something, maybe a quarter, that will work.
- Crime (theft) as community challenge
- R: I understand what you are saying.

EP9: Then they will not come and steal, because then they will steal their own. Maybe if they will come here and plant for the school, they will steal.

Ownership as  
way of  
preventing crime  
(cope)

R: Okay, I think we need to wrap up this discussion, so that we can go on. Thank you for all the information, we will definitely continue this discussion in January.

EP9: Are we finished now?

R: No, we are not finish for today. We are still going to do some posters. I just wanted to say thank you for the information that you shared. And I think you didn't only share information – I think you got some ideas of what you would like to do. That's excellent!

EP10: If it wasn't for you, we wouldn't get the ideas.

Appreciate  
outside  
facilitation  
Acknowledge  
role as catalyst

R: We did it together.

## FIELD VISIT 2 – 23 JANUARY 2004

### FOCUS GROUP 2

#### 11 x EDUCATOR-PARTICIPANTS

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#### TOPIC GUIDE:

- ⦿ Challenges faced by the community.
- ⦿ Assets and resources available in the community.
- ⦿ Potential ways of coping with challenges (such as HIV&AIDS) in the community, by relying on existing assets and local resources.

KEY OF ABBREVIATIONS
R: Researcher
EP: Educator-participant

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R: We learned so much from you last time when we were here and it was such a privilege to be here. And you made such nice posters – this is very valuable. When Liesel and I went home we discussed our visit and told one another that you are such a huge resources to this community and that you've got so much potential and things within yourselves that you can give to the population. So when we got home I took the video and wrote down everything that everybody said, and then I looked at what you said and then I made some conclusions. So we want to start with that today. We want to tell you about our conclusions and then you must please tell us if its correct and if you agree, if we heard you correctly. Because sometimes people say something and other people don't understand exactly what they mean. They say one thing but others understand something else. That's why we want to tell you what we think

Resources  
available

you said to us last time and then you can say: “Yes, *it’s okay*” or “No, *that’s not right. That’s not what we meant*”. If you want to, you can also add things to what you said last time. That will be the first part of today and after that we will work on the posters again. So let’s start. Last time we asked you about your concerns regarding HIV&AIDS and what this community think about the pandemic – what are the perceptions regarding HIV&AIDS. We think that you basically told us about several things that are good and then you also identified several things that you are concerned about, your worries. Let’s start with the good things. The first thing that you identified is resources and institutions in and around this community that is actually helping the people of the community. You mentioned agricultural things like the vegetable garden one road down and that it only needs seeds, because you get rain often. So agriculture is actually a good thing in this community to help the people overcome problems. Another thing that you said is that the community members themselves – the aunts and the uncles, grandfathers and grandmothers – is taking care of the children and that they are good resources.

Resources available in and around the community

Still need to be mobilised

Extended family=resource/asset

EP3: Yes, they help.

R: Another thing that you said is that the government is helping indirectly by presenting workshops and training people, like the workshop that K attended as part of her life skills training. You also said that the government helps by giving treatment and grants, so there are multiple ways in which the government is helping. The next thing you mentioned as being good in the community is mental health services or counselling that sometimes take place, even though you said that it is not always taking place and that there is a need for counselling, you did say that sometimes there is a little bit of counselling and that the counselling is for mental health and also for nutrition.

Government as resource

Mental health/ Counseling services

Need for more-not yet mobilized

Counselling for mental health and nutrition

EP6: Yes, they take care of that.

R: Then you said that the schools in the community are very good resources and that the teachers look after the children and that they identify the children with problems, give them food, support them and care for them. So the schools and the teachers are good resources.

EP6: **Yes!** (several participants agree)

R: Those were the good things that you identified. Is there something that you remember saying on the things that are good that we didn't mention now? Something like a resource in your community which we might not have picked up? Can you remember something? And if you cannot, it's also fine.

EP3: You've said them all!

EP6: Yes, all is there.

R: Okay! The second thing that we thought you told us that day was that there are also certain barriers, certain things that make it difficult in the community – things like stumbling blocks that lead to it that people can't cope. The first thing that we heard you saying related to cultural ideas and that cultural approach is sometimes a barrier. You mentioned that in your culture people sometimes believe that men have to have many wives and that that can spread HIV&AIDS.

EP: **Ja!** ... and that it is actually a problem for the community.

EP2: And even if, even these people they have many girlfriends or eh boyfriends, you know. Most of the people are poor and more of them are women and they solve their problem by, by eh sleeping around. Ja, by

sleeping around. You know, if she can get a men who is going to support her. And then: "If this one is not working, okay I'm going to leave this one and get me another one. Or it will be better if I can have two boyfriends or three boyfriends, so that I can get money from here and here and there", you see. That's the problem, that's the problem! To sleep around is only because they want to get some money.

Multiple sexual partners/encounters

Due to poverty

At risk sexual behaviour to get money (combat poverty)

R: They see it as a solution to their problem.

EP10: It's poverty, hmm ... It's poverty, that's why! Some other kids, some other girls, only they are ..., some other's are young and have a, a old man, you see, only because they want money and then they get the, the disease from them, you see! Sugar daddy, sugar daddies!

Poverty= Problem

Young girls sexual intercourse with older men to get money-spreading HIV/AIDS

R: B, did you want to say something?

Deny terminology

EP1: No. She was saying it.

R: But how prevalent is that? How often does it happen? It sounds like it's girls and men, né? Because you said that some men, even though they're not married, may have many girlfriends. So unmarried men will have many girlfriends, married men might have girlfriends outside their marriage and young girls will have sugar daddies. So if you say, let's take an example, if there are ten people in a room, how many of these people – boys and girls, men and women – will have many girlfriends and boyfriends? Is it one out of ten or five out of ten? How often does it happen?

Multiple sexual partners/encounters

Young girls sexual intercourse with older men

EP6: Plenty! (other participants agree) It depends on that family.

Degree of problem: high/high incidence rate



EP8: It depends on that family and if it does struggle to get money, struggles to get food. So in fact those children go in a way and depend on the uncles and aunts.

Poverty/need for food – results in higher incidence rate

R: Does this have to do with unemployment and poverty, or also with parents who died maybe from HIV&AIDS where the children are orphaned and are then also at risk of sleeping around? (*all participants agree*). So sleeping around is seen as a way of getting money and not be poor?

EP4: Yes! You know what's happening is, if my parents passed away, you see, and now I'm left behind, even if I'm young and maybe my parents died of this, like eh, disease. Then, with sleeping with that, the, the people or the, those men or those guys with money in the community, will take care of this little girl. Because when you take a chance like this and get the result with this and then you know that you are not going to get it anywhere, you see, that is the problem. And because this little girl knows that I won't get it anywhere, it is all about the money. (*all participants: money, yes*).

At risk sexual behaviour in order to combat poverty and get money

Avoid terminology

Men abusing young girls

Lack of hope  
↓  
Involvement

EP6: There is a place here, there is a place with the trucks, big trucks, you know. Most of the girls, most of the girls they like to wear some sexy clothes, né and go get those trucks, some other they're married. My cousin who is driving the trucks, né, he even get a girl there. It's like: "*When I need it I get the girl there*". Because they know, they know they will get the girl in the truck, 'cause there are a lot of trucks, and there are many girls there in the trucks, those big trucks né, who goes to Jo'burgh and around. So this girls they just go there at night and have it there.

Young girls involved in sexual activities with adult men

R: Okay, so this sounds like a reality. And it's a reality that does not only have to do with HIV&AIDS, but it's a reality that does lead to people

dying. What I want to know now is: how does this community cope with these young girls and these men, based on your culture? It seems to me, when you're talking about this, to me as an outsider it seems that you're so used to it. But what will you do about it?

- EP9: It's a mess, because if you are try to convince that person next door, they ask: "Are you going to be able to help me? Are you going to buy me the things that the sugar daddy is buying me?" Then if you say no, so they will do this, even though they are sure this is wrong. If we were able to help the problem we should have solved this problem, but how can you help in this needs, 'cause it's financially, the problem is money. But financially you cannot even help if it's your relative to do that, and you don't like it, but what if she will ask you: "Are you going to give me what she, what he is giving me?" And if the answer is no: "Well, let me continue with it, I know that I'm at risk but I get money."
- Reason for involvement: material gain
- Other community members not able to address financial needs
- Financial needs of community members

- R: I can understand that, but what I mean is, women through all the ages and all societies have been doing this because women don't always have power, and what some women do have is the ability to use their bodies, so it's something that has always been there. But if there's a threat of people dying because of that, does that change the way in which you try to deal with the girls or not?

- EP3: I think the community is coping with this. The community has all been traumatised by this HIV AIDS. And that made the community to take it. They are apparently, they ... They must sell their body in order to get something. So with the deaths that are occurring, it's nothing, because they say we are all together in the community and so.
- Community is coping
- Traumatised by HIV/AIDS
- Child prostitution= way of coping

- R: If I'm hearing you correctly, you are saying that a way of coping is through selling your body, that that is in fact coping?

EP7: Ja. You know, for example, last year in March my sister in law past away because of AIDS, you know. Okay, so I called eh, my family, the young ones, you know, and I told them that we saw her, she suffered a lot. She was sick for a long time. And they said: "Yes, yes, ~~it was so terrible~~". You know, even we were afraid to wash her, you see. But eh, I don't know. They seemed as if they will not go that way. Do you understand what I mean? (R: Yes) For that time being it was bad, but after some few months, maybe by October, one, one of my in-laws, she was pregnant! How? Because no safe sex. I told her to use eh, to use condoms so that they can be safe, but I don't know how she, how she can be pregnant after she knew that one of our sisters has passed away because of AIDS, you know. To me there is, it seems as if they don't care. They don't care, even they always like to say: "*I know you're going to burry me*", you see. That is way I always say it is like a joke to them. You see, we sympathise with them and when this thing happens in the family we are all traumatised, you know, because we know the results, we know what is going to happen when time come, you see. It all traumatise us in the family. But they don't care! They do not care! They always say: "*I know you are going to burry me*". If you write, if you say: "*I have a policy for them*" then they say: "*Yes! My sister take the policy for me*". So something like that, it's something like that. It, and it traumatise us, it traumatise us. And to them, it is a joke! It is like a joke, it is like a joke.

Partial disclosing of family member

Ill informed-fear of HIV/AIDS if affected (eg.family member)

At risk sexual behaviour

People don't realize seriousness of the pandemic

Two reactions= traumatized and don't care attitude

R: And it's the young people?

EP7: Yes! It is the young people. It happens in the married wife, in a married couple. because I know after that they will be with others, you see. And, you see, I told you last time that it will bother me that I'm HIV positive but I get pregnant. Who is going to look after that child? And the reason and the option to terminate, to terminate the pregnancy, you know. But they

Multiple partners

Concern about orphans

don't want to. Who is going to look after that kid? Who is going to look after that kid? It means they don't care! They do not care!

Ignorance by  
general  
community  
members

R: Who does look after the children?

EP4: The people who ... all the cousins, anyone, but some other families, but some other families, they don't want to take those children. They're left in the house alone!

Orphans cared  
for by:  
-extended family  
-child-headed  
households

R: But mostly? Are the children usually looked after by family?

EP5: The grandparents.

R: The grandparents?

EP6: Yes! The grandparents. But in other families they're just leave them there. They're left alone.

R: In your community, has there been an increase on orphans? Do you see more orphans?

EP2: Yes! I have a brother who, who is HIV positive and, and his girlfriend ... his girlfriend is pregnant for the fourth time! What is going to happen?  
And those children are not, are not having problems. But ~~she keeps on!~~  
She keeps on! You see!

Partial  
disclosure family  
of members  
status  
Increase in  
orphans

At risk sexual  
behaviour

EP5: Yes, I don't know! I don't know whether the treatment is making them fertile. I don't know, but they're supposed to use condom.

Educators feel  
community  
members not  
responsible-  
should be

EP2: Ja, they're supposed to use condom, you, know.

R: It seems that there is a general agreement that there's more orphans. How do you know? How do you see this? What is the evidence that you see more orphans?

Increase in orphans

EP9: Here at school it's easy for us, ~~because some of them they are~~ registered. We always find evidence if you ask them: "Where is your mother?", and then the mother has passed away. So we usually get that in the stats that show with registration. Sometimes they come and you find both parents have passed. If they come with the other parents, for so and so's mother or so and so's father. And through the year they report to us that their mother has passed away. And even some other, those children they don't do well because they are traumatised.

Orphans identified :  
- at school registration

-tell teacher

-traumatized

R: Do these children receive any kind of counselling or, or special care?

EP3: No! If I can say, we are their psychologists ~~the teachers~~, the teachers, because you are very well to them. We are trying to give them the best, the best life, you see. There's no, I, eh, there's no psychologist that, there's no counsellor that is special, you see. We are their counsellors, we are their psychologists you know. And if you are teacher, if you are a teacher, you are supposed to do it all, you see. You're supposed to do it all!

Lack of counseling to orphaned children

Educators fulfill role as counselors/ Psychologists

R: That's true.

EP2: But sometimes it's difficult times because some children won't tell us. For example, there is a teacher who managed to identify this child, but you are not a psychologist, you're not a doctor but you are trying. Now it was a disclosed one, the child was taken into the hospital to help this child. Sometimes it's difficult because they don't tell us but if you know,

Want to help but doesn't feel equipped enough

Lack of disclosure

it's like, you realise the problem. If you happen to know the child will be sick, you will be accommodating the child.

R: How will you go about to do that?

EP1: By giving support that is accommodating the child in class and you must support that child and be kind.

Want to help by supporting and accommodating children in class

EP2: Ja, kindness, ~~because if she feels a secret you must quickly take care of it. And also, they are easy to cry, you know. They like to cry.~~

Way of supporting – kindness

R: They are often sad and grieving.

Child experiences sadness

EP7: Eh ... ja, and now you take that trauma, ~~you take that, you take eh, what~~ can I say? It affects you. It affects you as a teacher, you know. It affects you as a teacher, because you are loosing, eh seeing this child everyday. And now it works and now it doesn't work.

Negative effect on educators

R: Who takes care of you?

All: Nobody! Nobody!

Educators in need of care/support to them

R: Do you take care of each other?

EP9: Yes, yes. Sometimes.

Some support one another

R: You are a resource to each other?

Potential resource/asset

EP9: Yes! (All agree) Like if I, if I have noticed, if I notice in my class this one, that there is a child with withdrawal symptoms. I will go to my colleague

Educators approach each other for help and support

and eh, try to help this child and afterwards, I will see this is how we helped each other. And we are giving care to each other.

R: It is sad to see an adult grieve, but it must be heartbreaking to see a child.

EP3: Mmm! The one child passed away. It was very bad, very bad!

R: What will you do if you find out about a child that has been left on his own, you mentioned it earlier that sometimes the parents will die and just leave their children in the house. What do you do then?

EP3: What we did nè! It's like *Mrs N*, eh ... last year, her, she had a child who was alone who was left alone at home. What we did, what the teacher did is, she gave him a bread, a loaf of bread everyday. ~~But what we did, we went to the home~~ and she was, eh ... that one, the big one *M* was staying next to the squad. We went there with the police squad and found that it was locked, because this boy was staying in the house. Fortunately she was staying with the sister, and the sister was staying with her boyfriend.

Supporting orphaned children left alone in the house:  
-provide food  
-home visits

Family and friends taking care

R: How old was this boy?

EP3: He was thirteen, fourteen.

R: And the sister?

EP3: The sister was, was ... eh 18, already at matric. Now we found out what was happening with the sister. We found out that this sister doesn't want to escort him. It was only the boyfriend who was at least having a good

Other community members helping



time. So we said: *"It is, it is not going to help you, its not going to help you to rely on the boyfriend if the sister doesn't want to be with him".*

← Educators  
identifying and  
helping

EP6: She doesn't give a damn!

EP3: Therefore we found out about the possibility to stay here in Soweto with that grandfather. The grandfather fortunately knew this boy and he take that boy with him. So that boy stays there now. Everyday therefore we find a loaf of bread on my, on top of the poverty and we give that boy, we give that boy everyday.

← Extended family  
as potential  
asset

← Child-headed  
household

← School supports  
with food

R: Did you pay for it out of your own pocket?

EP3: No, the school nutrition gave that.

R: Continuously?

EP3: Ja! But the boy's got appetite.

R: So in fact you realised that this child was in need of assistance?

EP6: What we also did is, we took university forms and we apply for a bursary.

← Educator  
support

R: You said that you can see when a child is vulnerable, how do you see that? Say you have 40 children in front of you, how do you which one needs attention?

← Identifying with  
children

EP6: Oh, it's easy! It's very easy. First thing is, if you look at the performance of the, the kids in the class. then you do everything that you can to improve, to improve those and the others and then maybe there's one, for example this one boy who cannot. Then you take him aside and be

← Educator  
identifying  
children due to  
bad  
performance

... or be left with him and try to get every information from him. Its then that she, he starts to open, and speaks openly and tell you everything.

Relationship of trust

R: And then?

EP3: And sometimes they're afraid, tired, everyday ... Everyday they are sleeping in the class, so sometimes you speak and you can see they're far away from you, especially with the young ones. (*other participants agree*)

Symptoms:  
-fear  
-tiredness  
-concentration problems

EP5: And even in the daily news you see it, you like to, you like them to talk, you know. And then even in the mornings you see it and then you know, okay, that's the reason.

classroom activities

EP3: Sometimes, eh, you know sometimes you find that a child is, like especially the, that one with the grandfather, then all of a sudden that child, it seems, you find out that she is not like she was before.

-changes in child

R: So you have to be very observant.

Educator=  
observant

EP3: Yes, you must look at the behaviour of the child. ~~You must ask about the home:~~ "With whom did you stay?" He will tell you with the father. "So where is your mother staying?" So then you find out that also there is no hope.

Observing change in behaviour=  
inquiry

R: Do you ever become so tired that you don't even want to know?

All: No, no!

Educators positive about their involvement/ truly caring

EP10: Because those things that happen, always in the day, you see, when you could see that there's something wrong, you got a problem that

particular moment or when you are dealing with the whole class some of the children who is usually here at school, it's the emotional disturbance of the kids. Because they easily cry and when a child is emotionally disturbed you could see she, she or he can not concentrate – she cries. And when you call that kid : “Come. What's wrong?” It's then that you start to hear the problem. And for us, for us it's difficult to know when did this things started. Because when you call the parent, the parent doesn't come to school or anyone who can assist you, so that you can help this child. We are helping these kids out of our own potential.

Emotional problems:  
-Sadness  
-Concentration problems  
-Vulnerable  
-Inquire about feelings  
-Attempt to help parents sometimes not co-operative

R: You are. Z, did you want to say something?

Educator helping/ supporting children with what they have to deal with

EP4: The parents are the one's who say: “We are sick”. (other participants agree) “We are sick!”

No external help

E3: For example today there was a parent here, N's father. One time she gives them two, eh, kids but unfortunately this one passed last year. Now this children came one day, one was crying. I asked, and then I asked them: “What is wrong?” “I stay with my mother, I stay my mother”, she cried. It was then, it is then that I found out that they are staying with their mother instead of their father. So how we managed to know is, she cried and I knew something was wrong. Uhm ... the other one is, they are new, now yesterday in my classroom and the child's new in this town and there's no parent. The aunt – a young girl, young aunt, because I was so shocked that the aunt was even coming, she asked me if I didn't notice that the child was crying and I said to her: “They are still new, you see”, I will get used in them. She said: “When we go back from school, when we go back home yesterday she was a crying and she could see her eyes when there is something wrong with the kid”. And when she asked the kid and the kid she said somebody was bothering her, eh, eh, within the classroom. And she disclosed to me and I said: “Thanks, for

Educators support-inquire

Disclosure

me to know, because if you didn't tell me this, I should have not known about this. And the child would suffer and you would have tell me that the child, he would not want to go to school". And I said: "You know what, now what happened, I would try and be a parent for that child", because sometimes if that child can get love from me because her mother has passed away last year, late last year, so he left, he was left alone, together with the younger one who's two years old. So whoever take care of the private needs? The young auntie took care of her. So those children, I said to her I was so glad she came to school and talked to me, because this thing is going to affect this child and in a way, in his learning progress, you see. Now what I'm going to do as a teacher? and I've told her, because she told me: "We are not working, my husband is doing chores like he did gardening". And I won't leave her, because she told me she must bring some people money. And I said to her: "Because you can't be here it's a new problem now, and be able to buy that kid this. So on Monday, don't worry. I will try by all my means that, so that she will feel comfortable and she can not feel that my mother is not here. If my mother was here I should have had this. So, to, to, to rub away that, that loneliness". Like what I will do on Monday I will call that child and I will tell her that: "Now I'm your mother", and I will take the whole class because that's what I used to tell them: "I'm your mother, if you've got a problem come to me. Here at school I'm your mother when you are here".

Educator support:  
-fulfill parenting role/substitute parent

Extended family= caregivers

Negative effect on children

Unemployment

Financial support

Loneliness /sadness

Educator= parenting role= support children

R: I am hearing two things. On the one hand, I hear that there are some people who are neglectful and do not care whether they live or die, but on the other hand I hear many caring stories from each one of you. I'm hearing about caring aunts, and caring grandfathers, and I think that's extremely special, because that's probably how the two things are balanced.

Negative about life

Educators= caring

Extended family=care

EP10: To pick up on that question of what can the community do or what are the community doing about these people that is giving money everywhere to those young kids. You see, what is happening is that they are not afraid of death, what I can see, because, let's look like this example. There are, there are seven girls who in this house but four of them they went to Gauteng and when they come back they guide the three girls. But only two, the other one got pregnant, the other one she's pretty? I don't know anything what she is doing, here at the next doors, you see. But what surprises me, they know the situation of this girls, you see, those lads, the neighbours, they know about the situation and they know about the status. But they keep on How can you have an affair with somebody that you know that is having this thing? You see. That's where I can see that they're not afraid or the ... the thing is, for that matter I'm going to die and I'm not going to die alone. When then later me and M was left by, by, alone, what happened? Three of them passed away the same day, same day. They all, they all, is because when you got me then you are going to buy me a *dop*. There is something like the tap.

At risk sexual behaviour

Avoid terminology

Don't fear death transfer virus

R: This is too quick for me! What are they going to do?

EP3: If you're going to buy me a tap, then she'll be equal.

R: Oh, a drink?

EP3: Ja! You can have this one. This man doesn't mind or this man is not jealous of her having a affair with this one, you see. It's going around, she and the other one – this man. She was from this house.

Multiple sexual partners

R: I'm sorry, but I still don't understand. You are going to buy me a *dop*?

EP3: Ja!

R: To drink?

EP3: Ja!

R: But what does that have to do with the three of them dying at the same day?

EP3: What we're saying is that they are moving around. They are, they are staying like this (*indicating with hands*). Their houses are so close, you see. They are in the same area, but I know your status and now it's easy for me that I can sleep with you and you know you got it, you see. So the dad, when the dad comes, he doesn't say: "*I'll go that side and that side*". It happen just there, you see, that carelessness, because if I know that you, your status and I know that I love you, you see? Why don't I use a condom? That's why I said we die alone, die alone.

Multiple sexual partners

Transferring HIV

At risk sexual behaviour

EP6: But the one day, the previous one, the girl passed my house. We talk to each other but I managed to hear him. What she was saying is that she is HIV positive and she said she is not going to tell anybody cause she is not going to die alone. Those others they will get it.

Transferring HIV on purpose

EP9: And because of this grant, and because of this grant, they deposit, it's 780 per month, ne? 780.

R: The disability grant?

EP1: Ja, the disability grant, it's 780 per month. And because of that, everybody wants that money. They want this money, they don't care. They want it 'cause they are going to get money now, you see. They are going to get it.

Transfer HIV to get AIDS grant

R: Let me re-cap this. So they're going to get money. If you're a young girl or you're not working, you're going to sell your body for a sugar daddy and then you get money. And if you get AIDS, you will get more money, so you're actually not worried because you're going to have money for the rest of your life, is that what you are saying?

Unemployment

Child prostitution get AIDS to get grant

Misspent grant

EP3: Yes! And even with that money, they don't buy uh... food or education. They just enjoy themselves with that money. That is why...

R: What were you going to say, *E*?

EP6: I think a condom is not the solution, because they don't care about it.

R: But they don't care about death either.

EP11: That's because they need education. If you educate them ... workshop them.

Need for community to be involved

R: What do we need to educate?

EP11: Condom use. It's all about education. If you don't talk about condom, that mean there's no education. By saying use a condom, that educate that essence, to use condom so that you can get safe, you see. By saying, what I'm saying is, if you want to do it, there's no problem, do it. But do it, knowing that it kills! But if you want to do it to be safer that is an order on the education, so I don't think the government is not doing something about this, because it is something that has been done by the government. The radios, the clinic, the peer group, the families, you see. Even, even what we said last time, that I take condoms from anywhere and I put it on my children so that they could see that this is the condom

Community needs to be educated-safe sex

Government= Asset

Assets



that they were supposed to use. If I want to be involved with sex, let me use condom. This is education, what is, she was looking what education is. But what they are doing the government and all, is doing a good thing by trying. But what the government is trying to address, is to let them live longer. They must use that money so they can buy food, mattresses, and things like that.

Promote safe sex

Government=asset

R: Are you saying the government shouldn't necessarily provide money?

EP11: Not money, yes! Not money to buy liquor.

Providing food-basic living things/grant instead of money

EP3: Ja! They must rather use vouchers, ja!

Disability grant's format should change

EP2: Or maybe it will be better if they can get food parcels ... food parcels and education, you know. Because what they are going to do with vouchers they are going to sell the vouchers to others. That's our tragedy, that's our tragedy. Even if they can get food parcel ... even if you get to the bus, it's our tragedy. If you want, you can take even a flower and, and send it next door. The problem is to buy to us. Because the problem are that if you buy they'll even rob you. We lie easily, to buy stolen things, you see. Because they are cheaper, we buy it. We don't want to go to shop. So I don't think it's that problem.

Need for food parcels and education

Crime

R: Is that part of your culture?

EP8: Ja! It's cultural behaviour.

Cultural barrier

EP5: There was only shacks here, no, no houses, no big houses. But, they built, eh ... the government built the houses, they built houses. What they did, they sell houses and go to, go to shacks, go to shacks. So what

Government and houses=assets

Poverty-poor living conditions

must the government do now, what else? Because they don't want to be ashamed.

R: I ant to come back to the cultural aspect. Last time when you discussed culture, you said that it is difficult to get the parents involved at the school, because it sounded like culturally they weren't as involved as you would like them to be. But today you are mentioning quite a lot of parent involvement, even if it's a grandparent or an aunt who are involved in the school. Can you maybe explain that to us? Maybe I misunderstood last time?

EP6: The parents that doesn't come to school are the parents of those kids, that they're the parents. We didn't say they're coming to school all of them. No, they're coming to school some of them, you see. That's why we are saying, that's why we take our problem to ourselves for those people that have parents that doesn't come to school, you see. This is the 50/50, you understand? This is the 50/50. Then for those who are having no parents its where we could see the guardians, the aunts are coming and trying to help you.

Some parents=asset – potential

Extended family= caregivers= potential assets

EP2: The parents who have the problems doesn't come. If for instance she is sick, she won't help. It's when she dies, then the other one or the neighbour will come and tell you of the problem. But while she's alive she won't tell you nothing about it.

Neighbours support

Fail to disclose

R: That was one of the other barriers you discussed last time – denial because of stigma. (*participants agree*) Let's go over the barriers you mentioned last time quickly – I think we've discussed all of them again. You mentioned cultural aspects, denial, the whole thing about education or counselling about the HIV status, financial barriers, the HIV grants, the issue of stigmatisation and the treatment of people to themselves

Denial-stigma

Barriers

and by others. I think we've discussed all these barriers. Something that has changed since last time we came here is that last year the government had not yet decided to give anti-retroviral treatment and now it is available. How does the community handle is? What is everybody saying, now that the treatment is available?

Barriers

EP3: Not yet! All gets medical aids, TB treatment. And it's when they get it, when they admitted it, those, you see, those, HIV related illnesses, ja, then you're going to get treatment. Otherwise they just stay at home, with no treatment, no medical aid! Even if you go to hospital and get discharged, some of them didn't want to go to, like public hospi, hospital like the whites, because no one wanted to be seen there in the department. They know the department, go to this department. So if somebody in that area could see you in the department, that's a denial, he could notice that and get there. So they are not going there.

Lack of treatment except on admission-for related illnesses

Hesitant to go to hospital

Stigma- avoid disclosure

Denial

R: It sounds like the community is still in denial, even though people can now get treatment?

Stigmatization

EP3: Ja! Ja, because they are going to get that stigma.

EP9: Sometimes the problem is with our brothers and sisters, they wait until late, because sometimes by denial they wouldn't get those, eh ... medicines. Because they would wait until somebody defines that. Because by going to directly eh, ... the clinic, that's where they're going to get help.

Avoid disclosing due to denial

Clinic=asset

Stigma relates to way of transferal

R: So the stigma is not related to the dying, but has to do with how you were infected, do I understand you correctly?

EP7: And they've got that position, forgetting that it's not like that, because sometimes you can get HIV without ..., by drug or blood transfusion, you see.

R: Or mother to child. Or being married to a person but not knowing how that person was before you got married.

All: Yes, yes.

R: Okay, let us move on to the next aspect. I think we've also mentioned a lot of it already. The third main thing that you spoke about last time when we were here is that there is a lot of needs in the community. You spoke about the need for a change in attitude by the community members in general, not to stigmatise others, not having more than one sexual partner, not sleeping around etcetera. The second thing you mentioned was the need for education ~~we discussed that earlier on~~, and the third one is a need for external help, ~~in other words other people coming in and helping you by providing help, like food parcels.~~ (participants: Ja! Ja!)

Needs:

- change in attitude
- change in sexual behaviour
- need for education
- need for external help

EP6: Ja, because sometimes like, like myself. The problem that I've talk about, you see. You have to go ... You want to give help, you want to give help, because you could see this person has ~~no one to help her~~. Even if it's financial, just a little bit. Not that much solution, you see, just to like buy food parcel or give her something, like fruit. So that he can get that plan, you understand, ~~or do something. When you go there and you could see that uh-uh, there's nothing I can do, you see. When you go there without giving hope to that person, you understand, because that person has lost hope, everything, you see. But if you could do something~~ then it's when you know that when, like, like ... when we talked to this woman, she's very sick, she's lost, she's lost, but I could

Educators want to help

Educators able to identify need

Financial support

Assistance in qualifying for grant

Want to provide hope

Want to help

see a denial. ~~Because she is talking about other things,~~ running away from what is happening, what she's seeing. Then when the dad, he talk about that, when you are, when you seek, but we didn't mention this, you, you look lots of money, you see. And the result now, I haven't got much for begging. And she was begging and she's now haven't got enough. So what we did when we went there as women union, you see, we go there for prayers. And when I got there, it's like okay, the, the daughter was cutting a little orange, you see, but we were going there without a parcel of fruit, but for prayers. Prayers must be supported by something, you see. Yet we know we are praying for God, but what else are we coming with? So what we did then is we said to, to the women what about having a collection? A collection and I said forgive myself let us have a collection. And I took my last money in the bank, so that even if just by being here I got something to give to you, you understand?

Denial

Women union=asset

Prayers=way of coping

Want to do more/give

Provide in material needs

R: So it has to be functional?

Positive about help they give

EP7: Ja, and we felt happy when we did that! Just a little bit. When, when we go to this houses, what you need to do is to adjust a little bit so that, so that, during that, they're still needed. They love you.

Benefit= appreciated

R: Is this women's group you talk about based in the church?

Church=asset

EP6: It's from the church side, ja. She was, she was asked and then she could see. But there are other groups that come, that do various things, like support groups. Ja, supporting groups, for ploughing, vegetables, that stuff and supporting the people who are sick. But they don't know they've disclosed.

Support groups

Support=home visits

R: Is it home-based visits?

EP6: Eh, ja, because you cannot go to a person like that one who have a denial and say: "*We'll come to you to give this and this*", you see. "*Why do you give me this?*"

Denial leads to/implies no help

R: So how do you approach it?

EP7: In May or June we know this. Then we ask: "*What are you doing to our kids?*", you see. Because you could see what comes up there, so what I can do is to try and help by this way, you see. So the better way to do it is like this, but it will be difficult for someone who is not educated, who is not interested sometimes.

Educators want to help

EP2: They'll ask you: "*Who was the child? Who was here last year?*" and then he's dropped out. He was in *Mrs N's* class, class. This boy came to ask for a, uhm, a, a transfer. I asked him why?, because he left early. So I though it's a chance to save him, but I could see there's something like a neglect. I'm trying to, to say the teachers also come early to assist. You know I told this boy: "*Boy I don't know who gave you a transfer. Because I don't know why you were supposed to come here?*" I took my car and went eh to *A's* place, with *A*. I found out he stays only with his granny, his old grandmother, you know. You know we get to sit here in a big house, but it's pathetic. I asked from the mother: "*Why is A coming to the session? Why, where is he going, because he was our learner.*" We know he's falling, eh, on supplements. "*Where is he going? He's a kid!*" The grandmother told me: "*Madam, this boy, his father passed away last year. His mother is sickly, you know. In a, very sick, and suffering from HIV. He was infected due to HIV and also this boy is sick. Right now he doesn't have the school shoes*". But he took, she took all the medicine and showed me, you know. You know, I found that this grandmother doesn't have money to come and register at school. That is why now they take him away. I don't know how it will go, because they was

Educators identify needy

Educators help wherever possible

Extended family= caregivers

Individual infected

Poverty

- saving. What I did is I told the mother: "Come over and talk, about the question of money especially", because they wanted to see him focus. Educator wants to help
- EP1: It's something, you see. It's nice to have, because if they put you as if they didn't care, it's hard. You should be glad that people care. But because of the symptoms that you see, this child is doing the wrong thing. Then you must say: "Let we go and check what is happening". Educator able to identify
- EP6: You know what, I don't blame those parents or people who are, who, who doesn't want to disclose their status, because, because even a, even those professional, professional supporters, they don't want to disclose, they don't want to disclose. They just keep quiet, you know. Avoid disclosing  
But, but you know what, although we are not going to be able to give something to each or to give something, we give like eh, emotional support, you know. You give them support, you give them support, but they don't want to disclose their status. Educators want to support
- R: In other words not disclosing is also a way of coping? Non disclosure= Coping
- EP9: Mmm! Mmm! Ja. You see, how can we blame others, as even the professionals they don't want to disclose? It's not that, it's only because they are, it's not that they are, it's not that they, because of the ... being illiterate! It's only because they don't want to, because professionals even they don't want to. General phenomenon (not restricted to illiterate)
- R: You've actually raised the issue of generating solutions to cope many times today, and this is just another example, because what I hear is that you teaches at a school, assisting and supporting and teaching learners but sometimes giving emotional support and the women's groups are also giving support, and the community members, the grandparents and Community= generating ways of coping



the aunts and the uncles, so that's the whole idea of generating ways to cope, it's already happening in the community.

EP9: But we want to do more, we want to do more. ~~Like we said last time, that we wish to have a garden here in our school.~~ A big garden with a lot of vegetables there and we want a garden because to help eh, to plant vegetables, everything so that everybody can get some. As you know, that we have children that are HIV positive, it will be easy for us if we have a garden here, you see.

Educators want to do more  
eg. veg garden  
(generating ideas to cope better)

↓  
Get better solutions to challenges

R: And even children who are not HIV positive – children who are under nourished or malnourished.

EP3: Ja, it will be easy for us to do that. We are doing it because there is poverty.

← Poverty

R: You know what? Sometimes I get so angry at the media, because it tells about all the bad things that are happening. That is why we couldn't stop talking about you after our last visit. Because here you are, you are magnificent people doing all of this. You are telling us about all the things that you are doing and I am just astounded!






EP1: But the government doesn't want to come to the ground and understand. But the government is doing the AIDS things, they're trying, and we want to do more!

↖ Looking for outside help and government= asset


↖ Educators want to do more to help

R: I'm not saying it's the government. I'm saying it's television and radio that tell the people all the terrible stories, like rape and so on.

EP6: For instance, last year there was the district at Q where the children liked to have, to go there, those schools all around. Then what we did as a school is we signed papers and sold chips.



EP8: Even for us the teachers it was good. Now, what we did as a school, ne,  Educator/school helping create solution  
is we go out to the clinic, the clinics, so that they, the nurses can come to  Clinic/nurses= Asset  
the school to inject the children for the infections, to help them! At least  
we are trying our best. We are trying our best, you know. ~~Those who~~  Educators believe in their attempts  
were suddenly committed like *M*, who did it, the child who are, he, he is  
in her class. The, the nurses of the clinic could come to *M* to monitor if  
the child is drinking the treatment, is taking the treatment, because the  
parents didn't care!  Clinic and school=outside  
 Parental neglect

R: So you help in monitoring the medication program?

EP8: Ja, the teacher has to take a form to say that you'll see to it and *M* had to write a letter and send that child with another one so that we could see  Educator identifying problem and come up with solution  
that he did go to the clinic for check-ups, and that child ended up to  
receive treatment. But the parents are there, the parents. But if that  
parents, if it was said that it's a toyi-toyi, they are the first ones to come!

R: What are you saying, *B*?

EP1: It's our tradition. It's our tradition, to do so, to help.

R: You know, I'm thinking that we have identified cultural aspects as a  Cultural= both barrier and resource eg. Care and kindness  
barrier, but I actually think we should also put it as a resource, because  
some of the things you are doing relate to you culture, ~~for example~~ all  
your kindness and the care you provide. 

All: Ja! Ja.

- EP6: And you know, and you know what? You white people ne, you don't care about the others. Look like in the houses, you don't know who is staying next door to you. You don't care! You just mind your own business. You don't know what is happening next door. To us, you know what is happening in the area, you know your area. Because we care, we know each and every house.
- Community= huge asset/support one another
- R: Your culture is the foundation of your coping
- Culture as foundation of coping
- EP4: Yes! Yes! Yes! (*several participants responding*) Look, what is happening now is the parent told me. And here it is community and she said: *Mrs G*, I've got a child who I want to register, I, I am able to register. And I said: "What's wrong with him?" He was a drop-out, he fight and the, the reason was, he hasn't got shoes to come to school. That was the excuse of the kid, you see, but it was really that he got no shoes to wear. You see it was the neighbours who phoned me, the parents went away. The father go this way, the mother goes this way. So they were left behind with the granny, grandmother. The grandmother then divided the kids, she doesn't like this one. She like the... those, she like the others that are from the hostels. Then, this, this were the neighbour, asked: "*Why you don't take care of her?*". She said, eh she said: "*No! I don't like this one because he is, I just don't like him, that is why I don't take care.*"
- Educators identify potential problems
- Neighbours/ community members care=asset
- Extended family take care
- EP4: You see, then the pa... the neighbours ... The neighbour asked can they come to school? And I asked: "*Are you going to be able to take care of him?*" She said: "Yes! I will be able to, I will do everything for that kid." As a result, I go to the deputy, I talk to the deputy, and I went to the deputy and I said to the deputy: "*Deputy, that is the problem*", and I realise it so much, that neighbour wasn't just a neighbour, he's a real neighbour, because he could see the need of this kid! You see. And
- Neighbours/ community members care=asset
- Educators making plans to cope with problems
- Neighbours identify problems and make plans

what is that to us? I think, I told this kid to come to my home to take a lunch, every morning! I ... I, even will pay school fees for this child, and he said: "I will do everything for he, him". And we said, what we are saying are we promised to do for the child and as the teachers, M. together with myself, we promised to take care of him.

Taking care and helping financially – educator and neighbours

Educators believe in themselves-positive

R: Last time when we were here, you kept on saying you want to receive training, but now, while you are talking, I am thinking you should give training to others.

Educators experiences= resource

EP9: It's experience, 'cause, eh, the reason why we know this is, it is happening around us.

R: And you are making it happen! Okay, I think we should end here. It's been a long week for all of you and it's after four already.

**FIELD VISIT 6 – 29 OCTOBER 2004**  
**FOCUS GROUP 3**  
**9 x EDUCATOR-PARTICIPANTS**

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**TOPIC GUIDE:**

- ⌘ Reports on the progress of the three community-based projects.
- ⌘ Educator-participants' experiences of their involvement in initiating the projects.
- ⌘ Outcomes of the activist interventionist research strategy.
- ⌘ Educator-participants' experiences of the activities and processes employed during phases one to five.

<b>KEY OF ABBREVIATIONS</b>
R: Researcher
EP: Educator-participant

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R: Today we're here for two reasons. The one reason is that we would like to hear from you what happened since our previous visit, the one on the 19<sup>th</sup> of August. We would like to know what you are doing in the community garden, how you did it, what you do with the clothes and basically everything that you are doing. The second question we would like to ask you is: if you think back over the last year and about our visits, what do you think worked, what was good, but also what do you think we might have done differently. Let's start with the three projects. What are you doing at present? How far are you in the process and if you plan to do some more things, what do you plan? Who would like to start?

EP1: Let me start. First of all, as we have promised, we met with the principal and we asked for a place where we should start our garden. That is why

we used that place. And then I phoned, of course I met my friend who told me that I have to contact *clinic Z*.

R: Which friend is that?

EP1: She is working as somebody who's dealing with community people, especially those that have poverty. She is one of those ladies who are having that project of feeding some people. It's a project, some ANC things. Now that lady has told me that I have to contact *clinic Z*, as there's a certain lady there who's going to give me some seeds. I phoned *clinic Z* and got hold of that lady and she promised to come and give us some seeds. She came really, it was late that day and it was a closing day. She came with a lot of seeds and I called the parents to come. In fact *Mrs N* is having something to do with active schools. So there are parents who are cleaning the schools as we are sitting here, who used to come and clean our school here, assisting us in every aspect that we do here at school.

R: So active schools is another project? 

EP1: Ja, it's the other project. So we said then, we have to make use of those parents, those that are taking part in assisting the schools. Those are the parents that are going to benefit in the garden and we told the parents that we are also going to ask from them whatever we want, because we're going to organise some seeds and some crops for them. Now we got the seeds and then I shared it for them. Then I phoned the municipality, the PE, Mandela Metropole. I phoned a certain guy at the municipality, in fact I was eh, I've written all these things, it's there. I phoned this guy, I was interested now in equipment because we wanted to have some tools, we don't have tools here at school. And then that man said he's going to send someone here at school, really the two, one gentleman and a lady came, and I told them about the policy that we have, that we are earning in this and this and then they were very excited in the sense that they said they would give us a tractor. But because

now the panels have already flooded there, therefore we cannot be able to be given a tractor, what they are going to give us is only the seeds. Then they said I must write a letter then asking for the seeds. I wrote the letter, I don't think it was even two weeks, they came with a big van here with the seeds. It was only the onion and cabbage. They gave us lots of seeds and then I called the parents, they shared among themselves. The seeds that you see there are the products of us assisting those parents. They didn't buy for themselves. So we've managed to have that done. As a result, now we don't have a problem. What we said to those parents, we said if teachers want the crops that are grown there they must buy them, but for us, those that are wearing these HIV nametags, we are going to go, if we want to, to ask, because we know we are helping the entire community. So we have a chance for those across there, to ask for the parents whom I think we are doing it for them.

Believe in own ability

R: In other words you can get vegetables from the parents to put in the food packages?

EP1: Yes, but for other teachers they buy, because we know people are going to make use of those parents, to ask for their names. Although we are having an aim in those things, therefore we said let them, the teachers, buy those things in order for them also to get some money.

EP7: Ja, to get something back.

EP3: To add more on that, not all of us with these tags, only the support group can get it, because we as the support group, T, N, we know which days we always give those parents the bags. We told them to come on Wednesdays to come and collect the veg. It is not all of us who ask those parents for the veg, only the support group, because we have already sat down with them, we already sat down with them, we told them everything and then we told them that we are going to support them with vegetables but all of them know which day they are going to collect the veg.

Support group



EP7: Okay, what is happening is, that as we all agreed that when we meet that garden, we did make a promise that we are not going to label, like as if it's a HIV garden. No we didn't label it, that's why we use parents and the parents don't know that behind whatever they are doing we are going to see eh, there is a aim, the aim is that on Wednesdays we ask for a supply of vegetables. And they know that these vegetables, we are going to take it to those houses that have a HIV and AIDS people who are suffering, who cannot do anything for themselves, that's what they know, that we are taking the vegetables so that we can help those people who cannot do things for themselves, that's why we showed them the nametags. They know very well, if you've got a nametag, they know that we've got those houses that we have to help them. So they work so nicely because they know that even themselves, they are helping on the other side, you see.

R: What about the other days? Can they sell the vegetables then?

EP3: Ja, for the teachers, for the entire teachers. We encourage them to sell the veg so that they can have money to buy paraffin. It's sort of a project that they have to benefit also for themselves.

R: Do you have something like a soup kitchen or some place where you can take some of that vegetables and make soup?

EP6: At the moment we haven't got a soup kitchen, that's why we give those parents some veg. But I'm sure on our year plan for next year ~~we are going to have a soup kitchen~~ because we could see there is a need for it, for the children. Potential project

EP3: And the parents are coming, are free now to disclose, they come in numbers to come and disclose their status since they have seen that we are, here at school G, there is a group of HIV and AIDS, they come and ← More disclosure

disclose to us then. I usually refer them to Z, who is information sharing team. And I also refer them to the support group. So it's really working.

Information sharing

EP2: Yes, as an information team we had a meeting here at school, it was a parent's meeting. In our agenda we said let's include the HIV and AIDS, it is then that we managed to announce to parents that there are teachers who are trained here, and there are those projects that are here at school. Therefore any parent who's having a problem at home must come. It is then that they came to inform Mrs N and then they are referred to the support group, so that is how we connect.

EP4: Every parent meeting that we have here at school, HIV and AIDS is on the programme for information.

R: Please explain what that means?

EP4: When we are having meetings, we have to put on the agenda anything about HIV and AIDS, so that we can keep them updated. Because sometimes on this meeting there are parents who are not, who were not on the previous meeting you see, and we wanted them to know that HIV is here to stay, so that they can be capacitated too, so that they can know where to get help. You see that's why we have to include in each and every parent's meeting, because they are not only suffering, even their children, they've got children at home you see, even if though their parents are their parents, that's why we are doing it.

Goal= empowering community members

R: That makes sense.

EP4: And even on, to add more on that, on August, early September, I and Mrs N we went to Old Mutual. Last week on 23<sup>rd</sup>, we had a banquet at Great Centenary Hall and then we went out early on September asking for the sponsors. We went to Old Mutual asking them to buy a table for R1000, when we addressed everything, trying to explain what we are hoping for, why we are doing the banquet, we want to upgrade our media

centre, we want to have some field and a hall ~~so that our parents can do their sewing and hand work there in the hall~~. They said to us: “No, we are not going to give you R1000, what we are going to give you is we are going to give you between R30 000 and R40 000 as long as you are doing good work”. I told them that we’ve got a garden, that the parents are working there, if you want to say, we add HIV AIDS and the community. They said okay, and we told them that even that garden is not even, we want the field to be levelled and we need a hall. They said to us: “Okay, what you must do, draw a plan”, and they gave us the form so that the principal can fill those forms and they said we must draw a plan and a business plan and a quotation of those things that we want to do. Now we’ve got a problem, we are stuck about quotations. But they said: “No, we are going to give you between R30 000 and R40 000”. We are still busy with that.

Income  
generating  
activities

R: I don’t understand?

EP1: We have to bring two or three quotations so that they can see which one is reasonable. And to add on that, the reason why Old Mutual was so excited is to see that we have here the HIV and AIDS programme. Otherwise, if they didn’t mention that, he should not have been asked, because they said they are going to come, to take photos for the vegetable garden and they could see that we are wearing this ~~(indicating nametag)~~, because we were not afraid wearing these nametags, even anyone who can maybe ask, we don’t mind, because we know what we are struggling for.

Participants  
positive about  
HIV/AIDS/proud

EP4: And they asked us if we are there as a committee, I said: “*There is a committee, we are, there is an existing committee, we are the committee with the parents who are working there in the garden*”. We want them to give us more because we’ve got a need, for instance some parents want to do bead work, we haven’t got those beads to give to them, we haven’t got the resources, we haven’t got money to buy those things, that is why

we want help. We haven't got a hall, we need to have a hall so that the parents can use that hall in sewing, in building.

R: What is so wonderful is that last year when we were here for the first time, you also said this. You said you didn't have resources, November last year, and now you say we did this, we are going to Old Mutual, they are going to give us money, we are going to draw up a business plan. All the ideas are there and you are putting actions behind them and running with it. It's magnificent!

EP4: Yes, and then, then we took that business plan from deputy, do you remember that plan, the policy, we took that policy plan to Old Mutual so that they can see that there is something that we are doing.

EP3: Now let's move on to the support group.

EP8: Before that, we, the vegetable garden team, I think you said we can also phone ACVV, then they said that there are meetings that they used to have in this area, so they are going to tell me or to give me their programme when to come at *township X*. I'm still waiting then for the fax from them. I want to join those meetings because they said it's then that I'm going to be advised and to be told where to go if I want something. Otherwise, with them, they cannot, there's nothing that they can give us but they are just going to advise where to go to get some help. So I'm still waiting for them.

R: Tell us more about the parents that you involved. You started with the ones that work here at school, is it still only those or have other parents joined? And how many parents are involved in the community garden presently?

EP9: There are so many parents, but we have told ourselves that we'll make use of parents with kids here at school, only parents with kids here at school, that is what we are trying to do with all the parents. As a result I

think we are going to have numbers of children, because they are coming here, even those that ..., there were two parents who came here, they came to me to say Deputy, what strategy do you use, because we hear about the garden. Now, there were two parents who came here to ask permission to be part of the school and I told them unless you have kids here in our school. Then they said: "*We don't have kids*", so I said to them: "*It's unfortunate of you, otherwise, but we consider those that are having kids here*".

R: You need to have criteria.

EP2: Yes, but you know even our outside appearance, ~~now you can see, the~~ parents, even the men, you know men are stubborn, but they are trying to assist us.

Change in attitude (culture)

R: What do the men do? How do you see the change in what the men are doing?

EP2: You know, they always come to school and clean the plants. They came and cleaned the plants and then they cleaned the doors. They were the volunteers, they volunteered themselves.

Men involved

EP6: What is happening, again thanks for that vegetable garden, because we used to have animals moving around the school, but seeing that the parents are having the garden here at school, are having plots, they are taking care of the school too, you see. The gate is always locked, there is no burglary since we did that, no vandalism, nothing. Everybody have an eye to the school because he or she knows that: "*I've got a garden there and I have to look after my vegetable*". So they are having a duty in a way to take care of the school. They are very responsible, it's a community school.

Community take responsibility

Community school

R: I remember that you said last year, that the parents thought that the teachers are different from them and now it seems that you are more of a team, the parents and the teachers?

EP3: We are a great team. We didn't know that in a school we can work together, parents and teachers like this. You see this is so great, but let us move to the support group.

Parents and educators collaborate

R: Tell us about the support group.

EP3: Okay, let's move to the support group so that we can touch on all the groups. They are on information, she is on the garden, ja (*indicating fellow educator-participants*). So after a meeting there was a great improvement, after the meeting where the information team had talks with the parents. We received some parents, we had two parents previously you see who disclosed, except the kid that we know that they are sick. You see, it was like that with the parents that they used to disclose their kids, you see, knowing that they are in our classrooms. But it was worse now, we had a step forward because they did come forward and it's a very touching moment. It needs somebody who has a heart. It touches us a lot in the sense that we have to pray all the time. We did get those parents, they did come to school, one of them you could see that she was very sick and she didn't disclose for a long time. She got pregnant, after getting pregnant, she didn't know that, but she could see the symptoms but she didn't know she's HIV and when I asked her, on our talks she delayed herself because if she had told the nurses that: "*Can't you please take my blood so that you can check if I'm HIV or not?*", because she did go to the doctor and the doctor said you must go to the clinic and ask for a HIV test and if they tell you that you are positive you must terminate the pregnancy. But she didn't do it because she wasn't ready at that time. So she got through that and she got sick. What happened is that when she was in hospital, after giving birth. You see, they were told everything, after giving birth, and she could see a file and it's written there "*HIV*" because the nurses couldn't tell her, because

More disclosures

Prayer=central

Doctor=advice

Clinic=resource

she wasn't ready and she didn't say that take my blood so that you can check so and so. It is up to you to tell them, you see that's what I told her because she was complaining to me, so that I can see for myself. And I said the nurses cannot tell you because sometimes you are not ready, it's your duty to tell. The only thing that the nurses could do is when they tell them the whole people who were pregnant to tell them: *"We are doing it like this and that. We did take blood but we don't check your status, it's up to you to come to us so that we can check your status"*. She got sick. And when the doctor came to her and asked: *"Did they tell you the result?"*, because you could see she was very sick, then the doctor asked her, if the doctor said: *"Did they tell you your status?"*, she started crying and the doctor moved back and didn't tell her. She was discharged and she wanted to see her child because she didn't have a chance to see her child. Then after that meeting here at school, he came to school, then I was called, she was crying the whole time I was talking to her. But it was during school hours, I couldn't call C and the others you see, and the principal called me.

R: What do you usually do? Do all three of you talk to the parents together?

EP3: Ja, it used to be the three of us.

R: In a private office?

EP3: In the private office, but that day the principal asked myself to go there, because it was during school hours and I asked them not to disturb me and I talked to her and I showed her what we received from you and what I've learnt from the books and what I know. She was crying the whole time and she stopped working, she hasn't got an income, she doesn't know what to do with the child and I tried to convince her. After that I told her that what you can do now, if you're ready, you can go back to the clinic and talk to one of the nurses and ask them now your status, it's after that that we can do whatever we can do. Fortunate enough, she got a friend who is HIV positive and who is helping her, like trying to

Friend/ HIV positive and friend supports her



convince her I'm HIV, but look, nobody knows that I'm HIV but I can tell you now because I know your status you see, but she was crying all the time. But what made me so excited is the following day when she came, she didn't even have a tear on her eyes and she said: "*I came here to thank you. I didn't know that I could get help, even the nurses at the hospital prayed for me and said why did you take so long? And I told them it's only when I got information at the school, it's only now that I'm ready". They prepared a grant for her, they gave her a cream, and I told her that you have to get a cream you see, because you told me that you haven't got money, so you have to go to the clinic you see, because there are some things that you cannot do, that you have to refer them, they gave her a cream and that cream is doing very well, I don't want to lie but when she came to school the other day and I said: "*You look nice, can you see yourself?*", and she was so excited, full of smiles, I was so glad.*

Prayer  
School prepare for disclosure  
Grant  
Financial need  
Clinic=resource  
School/ teachers refer

And she stopped breast feeding the child, but she didn't even at first because she was sick. She is getting food here at school and she is so excited and the child likes that nutritional food because she's not breast feeding, now we haven't got money to buy food, now she's getting food from school, she's getting vegetables. I told her the way to eat you see, and I also told her to ask the clinic nurses to tell her more about what she is suffering from so that they can add more on what we have told her you see. So I'm so excited. Now the other one, I'm going to my other case now.

School provides for needy

R: First tell us about the parcels you give to people?

EP7: In the parcel, we got those food parcels from Cadbury, there is a lady who is working at Cadbury.

Networking

R: How did you get to contact her?

EP7: She is on the support group at my church. She had a sister who passed away who was HIV positive, that's why she decided to be on a support group in her work at Cadbury. So what they did at Cadbury, they gave them food parcels so that they can give to people whom they know that they are HIV positive. So that lady contacted me, and she told me that: *"I've got these soups and all these things"*. And I said: *"Can't you give it to me because I've got some houses that I used to visit and some people that can get the food?"* And she was so excited and I went to collect them, that is the food that you are seeing here. And the clothes, we collected some clothes. We could see that they need clothes even for their kids you see, that's why we asked the school to donate some clothes, even the principal has got some clothes parcel, he is going to bring it, even other teachers, they are so excited to contribute the old clothes. And then it's the vegetables. They are coming on Wednesday because they have to eat greens.

Arranged parcels

R: Do you include African potato?

EP7: Not yet, African potato is what we are telling them, meanwhile we don't have it. This it's Becko, fortunate enough it's a Vitamin B – they are getting it from the clinic, all of them. And if they are running short of that Becko, we've got medical aid, we are going to supply them with Becko, we did bring even some Becko that we have, so that if they are running short of Becko, because they are getting it in a clinic.

Supplement

R: Is the medical aid bringing the vitamins to the school?

EP7: Ja, we want to help, and Becko is not that much expensive, but it's expensive to them because they are not working. We're trying to show them that we are here to help.

EP3: I'm coming to that one now. There is a parent who had a daughter, and the daughter is HIV positive from 2000, her husband is so furious he doesn't want to see the daughter and the husband is asking when is she

going to die. He's a step father, the mother is not working, she has to hide food for her daughter because she's not working. She has to take food from her cupboard but he husband mustn't see it.

R: Are they staying together?

EP3: No they are not staying together, the mother, eh, what she did, she went to ask for a plot, she is staying by herself, she is 22 years old, she has got two kids, the other one is safe but the other one is – but she said she is not infected at all because she did use AZT while ~~she was pregnant~~, she is a brave child because she could speak and she is not afraid, she talked to us, she has got two beautiful girls. She is getting the grant, the other one is one, she is getting the grant, so we are also helping her with food. We are helping the mother so that she can take food for her, she did come to school to take their share, they are staying far away. Disclosed

EP9: But we still have a problem, you know. We are trying to organise for her, but still we are having a problem now, because of the abuse of the grant, the disability grant, the government is very strict now. When we phoned the ATICC they told us that the CD count must be below 200 because of the abuse of the disability grant. But we are trying to get hold of a grant, but we did get for that one, because at the clinic they did everything for her, but she is taking treatment. Abuse of disability grant  
School assisting in getting a grant

R: You are really helping them. I want to hear from the information team now and then we can go back to the cases. Tell us about what the information team did, and about that evening that you planned, when you invited the parents and when HIV and AIDS was on the agenda. What did you discuss? What did you tell the parents?

EP6: You know Ronél, because these parents are coming to school timeously and meeting with the support group, usually if they are having a problem, since we assigned N to report to when they are having problems. So we only do capture some problems and the problems are not too much now

because they are coping well, you know they are doing well with these support groups. So instead of coming to us now, at information, we are referring them straight to the support group because some of them are very ill.

Coping well

R: It sounds as if the need for caring is currently more than the need for information and prevention, is that correct?

EP6: Ja, we only give information to their kids, how to take care of them, but the good thing of it is the thing done by the support group ~~because really~~ they must be supported by Ford, by Biko, supported by everything.

Information to individuals

Networking

R: Do you think the information group should continue?

EP6: Ja, it must carry on because most of the time they get the information from the parents meeting.

EP8: We are working hand in hand with them.

EP3: Yes, because even we as the support group, we have to take part of the information, we are doing also the information, it's a sort of a glove.

Collaborative approach

EP2: I was going to say the same thing that *T* has just said, after we have the parents meeting, the parents did come to my class, trying to get more advise from me. Then I refer them to *T* so that she can try to give a little more support to them, because she has got the transport, she visits their homes and take them something, whatever she has she gives to them at their houses.

EP6: You know Ronél, the thing is, if the case is being reported, it's not easy when you visit the parents and they say: "*This one is doing this and this one is doing this*". So the one who goes to that house must do it all. It's not easy to separate.

R: In other words you started doing each other's chores?

EP6: Ja, as long as one is empowered.

Empowering  
community  
member

EP8: Okay, further on the information. Now we've got the books and we teach kids about some of the facts, because some of the kids are sexually active now, and their ages are 15 to 16 some of them. We teach them how to handle a condom, how to use it, when to use it. But I think there's a shortage of female condoms, because they don't know how to use it and it's different, it's too different to this one because this one is easy, the male one and this one, you take it the whole day, 8 hours with yourself and to these kids, it's not easy.

R: Do you only teach the children in your class or do you teach all the children?

EP8: No, the phase 2 children because they are older than these.

R: Who teaches them?

EP8: No, I do the teaching.

R: And you see all the kids?

EP8: Yes.

R: Boys and girls together?

EP8: Boys and girls together, but sometimes some boys are naughty, they don't want to go there because they know they are sexually active, they know what is going on there. They use sometimes big names that we don't want to share with you, we're just giving them the basic of how a child cares for themselves.

R: Do you find the formal curriculum on Life Skills useful to help the children, to give information? Or do you just give outside information?

EP8: The information that I'm giving them is the information that is in those books, that are supplied by the government, but there are teachers who were trained last year, currently they are not doing it because they are waiting for the curriculum as a learning area.

EP6: But what the department did after those two teachers went to the course, they did supply us with Life Skills books, from Grade 1 to Grade 7, that's why I told the deputy that those teachers must make use of those books because we are using them. Even the lady, *Mrs S*, the lady who is working at the department, who supplied those books used to phone at school and ask if we are using those books, that's why I say to deputy: *"We must make sure that other teachers are using those books because some of the teachers are using those books"*.

R: How many of them?

EP6: It's almost like eh ... 30 percent, especially those teachers who did attend the course, they are using the books.

EP8: There is another problem, sometimes they don't want their kids to learn anything about sex because they're saying they are turning them in other words, so we don't know really because some of the kids, once you start talking about this they want to be excused.

R: How do you deal with that?

EP8: I excuse them, because you will find that the principal is saying that the policy of the department is silent about that, they are silent about the child, the parent must let the child, must allow.

EP6: But in future what we had to do, we had to start with a parent, especially the information, our information committee. They had to start with the parent, like when they are educating the parent about this, they have to tell them that there is a need for their kids to know or they can ask from them: *“How do you feel if we can?”*, but we are going to do it in future, like next year.

EP8: But the parents, before, before we started all these things, before we started talking about the HIV, we called the parents, but you know if you come the parents they don't come all.

R: That was before?

EP8: Ja, but not now, especially now they are seeing we are working together with them and they are getting help, I'm sure they will understand what is taking place.

EP6: Ja, and they can tell them why do we have to do that. Because if we can start now to educate the young ones, that means we will have a greater nation, they will grow up knowing what is wrong and right, and that means even the number of HIV and AIDS infected will decrease. But as long as the parents can understand it, it will be easier to talk to the kids you see.

Positive future perspective

EP2: Okay, the problem sometimes is, the parent is reluctant in front of an educator to say: *“Okay I can be with you in this, I can say this in my house”*, but I had a problem last week, two boys, these boys are not sleeping at home. Seemingly there's an open house where they sleep with these girls and these boys are here at school. So when the parent came, I referred this parent to the teacher who is the class teacher and who heads this course of Life Skills. Then the parent is saying: *“I've got my culture, there's no white man or a book can say to me I can do this or that in my house”*. So some parents are reluctant, though you want to empower them they are reluctant. He or she cannot come to you and



say: “*Okay, I will be with you, I will do this in my house*”, but at the back he knows what he’s going to do.

R: Do the majority of the parents feel like that or the minority?

EP8: Few of the parents are open when they come to me, few of them are open, because they don’t want to acknowledge the fact that their kids are sexually active, they don’t want to see, if eh, they say their children are young, they are not involved in sex, but they will see it later when the problem is there.

EP2: And most of the parents here in this community are backward, you see, they still have those traditional minds, they don’t want to speak out about HIV, though they know HIV is something that exists, you know. It’s only because ... eh, even we educated people, we don’t want to talk about HIV in our houses, in our children’s presence, it will be difficult for uneducated people to talk about it, you see, but we are trying by all means and we are going to try. It will take time for anyone, even for yourself to be convinced. As long as there is reinforcement, we must stick on reinforcement, talking about it, talking and talking, at the end they will understand about it.

Hesitant to talk about HIV with children at home

Perseverance

EP3: Let’s talk more about the 22 year old girl who has two kids. What we want for her is to go back to school next year in January, she said she wants to go back to school because she was doing Grade 9, but the problem is the young child, the young kid is still young, she is still breast feeding, I don’t know what the risk of that is, because she’s HIV positive.

EP6: She did use the AZT, the child is negative, but she’s still using breast milk, because she doesn’t have money to buy milk.

R: What she can do, *M*, is to send her information to us, there are people working at the university and they developed a very easy way to take breast milk and sterilise it so that the mother don’t transfer to the child

when breast feeding, and it's so easy. It's just a little steel pot, and you boil water and put the water into the pot, then you take out an empty jar and you express the milk in that bottle and you put the bottle in the boiled water for a few minutes, and when you can put your finger in the bottle, then that milk is fine for the baby to drink, so if they use that procedure then a person who is HIV positive can give breast milk to the baby, if she follows that procedures correctly.

EP6: Because the one, when we asked some advice from somebody else, she was afraid that the child can bite the mother's nipples and can contract HIV.

R: Blood is not a problem, the milk is the problem. The HI virus is in the milk.

EP6: Because we did tell her that she must stop breast feeding because maybe the child was safe because she did use AZT when she was pregnant. But what is she going to do? She hasn't got food to feed this child, she hasn't got money to buy milk, she depends on the breast feeding.

Give advice



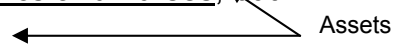
R: Doesn't the clinic provide formula milk?

EP6: Not all of them, but that child did go to the clinic to take treatment and all those things you see, but the only clinic that I know that distributes milk is *hospital D*, but we have to see how to get in touch with them, contact somebody.

EP8: Or even if you've got some more booklets, because sometimes we want to give a booklet to her so that she can read for herself, to get more knowledge but we haven't got those books, the only ones that we've got is for ourselves.

R: Have you thought about contacting some of the NGOs for information and booklets?

EP8: Ja, for booklets and even the pamphlets, because we must have them, because sometimes you are talking to them, but you need something to give, especially those books, they are nice because they've got Xhosa part of each so it's easy for them to understand.

R: What about social workers? We've spoken about clinics and nurses, but I don't hear any of you talk about the social workers? 

EP2: At the clinic they refer them to social workers, it's so nice when you send them to the clinic because they refer them to the social workers.

R: Do you refer them to social workers?

EP2: No, it's the nurses who refer them to social workers. We haven't got a social worker who can work with us. The only social worker, who used to help us, is from ATICC, but that social worker, when we phoned her the week before last, she has been promoted to Johannesburg, but the other one assigned to us have not yet worked with us, we couldn't get hold of her, but we are getting her.

EP3: Ja, they used to help us, even if you phone them they used to bring food parcels, but now since she has stopped working there, we haven't received any food parcels. They used to have those visits, ask for an address and go for a visit, but she is new, we haven't met her.

R: You can also consider contacting Grace Ngwaba at the Department of Social Development, she's a social worker and she said that she will be able to give you information and contact detail.

EP6: I've got something else I want to share with all of us. I was watching TV, it was on Tuesday night, this happened in Uganda. I'm sure where, but

she was asking the girl if, what happened, eh ... there was a little girl who was married in Uganda and she was 16 at that time, then the husband went to work at Johannesburg, when he came back, the husband was HIV but didn't tell the girl, the wife. Then the wife slept with a man for almost a year, there was nothing wrong. Then after a year, this girl wanted to go back to school, didn't know what is happening with her. She then went to school, there at school, because she doesn't know. She was a runner, in athletics, she was playing netball, all the school kids are doing that, then she fainted, they took her to the clinic and the clinic took her blood and then, after two weeks she was called. At that time she was with nobody to support her. She heard the news that she's HIV positive. She kept quiet, from that day to date. When they visited her home, there was nobody, she was staying with her husband and her husband was a furious man, this girl became thin and thin, the neighbours were very far from their house, then at school she told one of her teachers, she said: "I think I must tell you that I'm HIV *positive*" then the teacher said "*You are going to infect other kids, you are supposed to be killed*". The educator told the chief, the chief told the subordinates and they called her and then eh ... They called her, they said: "*With whom did you sleep after you heard your status*", she said: "*Nobody*", they said: "*Where do you sit in the classroom, do you sit next to a boy or next to a girl?*". And she said: "*I'm sitting next to a boy?*". She suffered inside, because eh .. eh, emotionally she was not talking to anybody, and that educator was wrong because he should have known what is happening, but because of the culture, the chief and the subordinate was reluctant to inform the whole vicinity about this. So I wish that if that girl goes back to school she must have one teacher to tell her that: "*My status is like this, that I was supported by some members at school G, so if you are having a problem with me, just refer myself to school G*". It must come from within, within her, it's not something to be forced.

EP4: To the story that Z relates to us, that means, let's take it the way she related the story to us, that means even if that child, she can tell her

teacher, she is not quite sure how her teacher is going to react, let her be ready first and then she can see what kind of a teacher she has. Sometimes if she's a good teacher, maybe sometimes there will be some things, or some topic that will touch on HIV and AIDS and she could see how she is going to react, is when you start trusting somebody else, it's not easy just to get to a school or to get to a situation where you can go and say I'm HIV positive.

R: You say there's an increase of people coming to school. What do you think are the reasons for that?

EP7: Okay, the reason for this is because when the information team tell them about it, when we put them on the programme, we told them that since they know nothing about HIV and AIDS, they can come to school to get help. The only thing that the teachers can give them is to give them help and to show them the right procedures to take and give them the advice, good advice, that's what the information team can do because they know nothing about this.

Increase in disclosure

Reasons: can get help and advice (from school)

R: Yet they know they will not be judged?

EP3: Ja, it's confidential. Mind you, they can tell you about the visits, the people who are staying together, both of them are HIV, you see, you can tell them maybe about our visits.

R: How many families are you supported at the moment?

EP3: At the moment, and I'm talking about the parents, four parents excluding the kids that we used to talk to you about, excluding them, that means they are coming, even now the other parent came to us you see, talking about their children. We said to them: "*You must take time, you come to us when you think they are ready to talk to us, don't force them to come us you see*". They did come to us, say: "*Look I've got someone, I've got my child who's HIV positive you see, may I bring her to you?*" But the

four of them, we have four houses that we are supplying with food, clothes, vegetables you see but they who are coming and even ourselves we don't want them to come in big numbers so that we can control them, it would be so nice if you get them bit by bit so that you can have time for them. Because if they can come in numbers, maybe sometimes they will come just to get vegetables to fool us, because the ones that are coming to us, are the ones that we could see they are weak and they need help.

R: And child-headed households, do you have more houses where there's only children living?

EP1: We have 7 or 8 children here at school.

R: How do you help those households? How do you support the child-headed households?

EP7: You know, what is happening with them is they are the one that we organise for, like with ATICC. ATTIC used to bring food parcels to go to them when they are sick but some parents they come to school, but when you see the child is absent, to disclose the child but the parents vanished, you see. But those we have are getting help, even the others were getting a grant of R130, it changed to the disability.

R: What does ATICC do and what do you do?

EP9: It is, they give food parcel, they are getting food parcel, they are getting information, we are working hand in hand, what to eat, you see, if they are sick they can report at school, we phone ATICC so that he can send a social worker, someone to help them.

Disclosure



Get help and advice and food parcels and social worker

R: And the function of the support group?

EP7: We pray all the time, whatever we are doing is based on prayers because when they stop crying, is when we pray and we've told them: *"You must also pray all the time, you must know that even if no one can love you but God loves you"*.

Prayer=central

R: Yes, and they often need love, they miss to be hugged.

EP3: No, what is happening here at school is and what we've told their parents, because they are young. When we went to those houses, *M* is going to tell you, when we start talking, we know they've disclosed their status. We will tell them that: *"You know what, we are your friends, when we are sitting here, we are sharing everything, if you have a problem you must know that you've got a friend at school"*, you see, we don't go there sort of as a teachers or educators, no, we go to them as friends, even those kids who are here at school, like the other one, they used to come to me, like *T*, she is my friend because I hug them. When they go to stadium I say: *"T, here is something, you must buy fruit for yourself"*, you see you create that atmosphere of trust. I've got someone who loves me, I've got someone whom I can go to and talk you see, but we don't say why we love *T* you, and *T* would say: *I know there's somebody who loves me at school*", you see, that's why we create that atmosphere of trust and love.

Support as friends

Trust and love=important

EP2: Another one is, when we visited the other house there, *B*'s mother told us that: *"My child came to me last week and said my teacher said to me those parents don't love you"*, you see there was a parents day, and that parent was not there, she didn't come to school and the teacher said to them: *"Those children that their mothers did not come to school and were not here, they don't love them"*., You see, in a Xhosa way that can help you. And then that child went home and cried and said: *"Mother my teacher says this and this"*. And then, that sick mother was crying to us, she said: *"I'm so worried I can't go to school, I was sick"*. Then I said: *"Okay, next time we will be your parent of your child, we will go to their classes and tell the teacher you are sick"*. *B*'s mother was very sick and

Take care of children



she was very emotional about it because her child was crying because she did not come to school. And then we promised them we will be their parents, we are going to take care of their children, we will be part of their children, she is quite a caring mother, she was so hurt when the child came and she was very sick. The time when we came there she said I'm so glad that you came but the thing that made me.

EP7: Yes, but sometimes the children don't know and we tell them: "*Because she doesn't know you are sick because you didn't even write a letter to tell that you are sick*". That's what we used to say to those parents who doesn't care, but starting from today, because she wanted to come to school: "*I can go to school and tell her that I've got this and this*" and said: "*There's no need for that because we know as support group we have to give you a support*". What is going to happen, we are going to talk to the teacher and what happened really here at school, I called the teacher concerned and I told the teacher what happened, the teacher was so worried you see, and I said: "*We know what happened but I want to tell you about the mother's child, the mother's child is very sick, sometimes she cannot come to school, but you can give us the report so that we can be the mouth for her when she is sick. So starting from today, you must know that she cares for her child and she is a sick woman, if she's okay she can come to school, but if she's got a problem contact the support group so that it help you deal with the problem.*" And what you can do now is to go back to your classroom, to create that atmosphere of trust, go to the classroom and tell that little boy that you know why the mother wasn't there and you excuse yourself because you know that her mother is a caring mother". So she said: "*I'm so worried but I will go to my classroom to create that atmosphere of trust to the child and tell the child I know your mother was sick that's why she wasn't here*".

Supporting by  
taking over  
parent  
responsibilities

R: It seems that you are directly supporting the community and also indirectly the teachers and then you are also spreading the word to the teachers.

Supporting:  
-community  
members  
-colleagues

EP3: Ja, and look Ronél, when we visited those homes, I can see that, I could see that even the affected, the people that live together need support because when we visited that home, the mother who is taking care, the grandmother, she was crying but she was so excited to see that there are teachers who care about them you see. Because even ourselves, we told the mother that: “*You are a great mother, did you know that you are a great mother? You took care of a neighbour who got sick, you take it to your home that means you’ve done a great job and you must keep it up*”. And that mother, you see, was motivated because now she’s taking care of two people, her daughter and the friend of the daughter who’s staying with them.

Affected needs support

Taking care of family and friends

R: Do you ever talk about their status, like tell the mother and the child together “*Child, your mother may die and then this is what’s going to happen with you*”?

EP3: No.

R: Have you discussed the testament or the will for the mother with her?

EP3: Not yet.

EP4: We’ve got a poem in our Grade 5 prescribed book, this poem is about HIV and living together. It goes on and goes on and at the end it says: “*I’m here today but I don’t know about tomorrow, we are here today, we won’t be here tomorrow, I’m sick today and I may be sick but I wish you to be my companion*”. It is sad and in my view you can explain more and more. And while you are explaining, you can see they want to talk and when they talk you know that they understand everything, they know what grief is, they know if the one is not here it is because of this. People know and they will come and support us, we will depend on some others.

EP7: That's why we encourage the living together so that if one of them can pass away, they can take care of each other, it's so nice when you see people living together, living and caring for each other.

R: Tell us, do you give like legal advice, counselling for legal assistance to, for example say: *"If I die this must happen, the child must live with these people, these possessions are going to this child"*?

EP4: Sort of like a will?

R: Yes, does the support group tell them to write a will, to tell the child: *"Listen your mum said, maybe you will stay with this aunt or the grandmother and it is written by your mom in a legal document, so nobody can take you away from what is their property"*.

EP8: But in our culture, it automatically goes that way.

EP9: But we need to advise them. ~~You know some of them are illiterate, they don't know how to write, they don't know how to do anything. We need to advise them~~ and once you advise them, the support group once they are there, in those houses, they need to advise and ask them if after she or he is gone who is going to look after them.

Advise them  
with regard to a  
will

EP7: With our culture it's like this, if we can say, like the question that she is going to ask is *"Am I going to die tomorrow?"*, that's why she's asking me such a question. Unless we can do that if we have been dealing with these houses for a long time, we must check for the process, after we can see that okay these people understand us and we can, like on our talks, when we sit down and talk say *"Did you know that one day you are going to die"*, but now it's too soon, because now we are giving them strength even though we can see that they are very sick, we say: *"No you are going to be alright, be strong, it doesn't mean when you are sick you're going to die"*. We cannot mix those two things, so if we say: *"Did*


*you write anything about your kids?”*, they will say that we can see from them that they are going to die.

EP3: Yes, we have to select the words.

EP7: We have to say: *“You are sick, or if you are sick you have to write something so that your children must stay with your aunt”* or something like that.

EP3: But it is wrong when we do that, you cannot use those words when they are sick, it's a process. On our process when we could see that they are working, they are doing their chores okay, it's when we can start saying that now, when they are okay doing the whole thing, not while they are sick.

Sensitive approach



EP4: I was going to say it's one thing to advise them to have something written down, as to who is going to take care of my kids when sometime I die, but it's difficult for us to do that. Each and every time we must always give them hope that they are going to get well, so if we mention something about death they will become very sick and die at an early stage without having prepared themselves for their kids, you see.

Provide hope



R: I believe you have to start with what is tradition, and be respectful and even more so with something such as HIV and AIDS. But I also think we must not be blind to the fact that people die from AIDS and then children are left without a parent and their biggest fear is uncertainty. Children are not dumb, they know that people die, they can see it.

EP7: They do talk about those things, but we must do it at the right time. We are going to do it, if it's a good thing.

R: Yes, wait for the right time and then consider helping them to also keep a birth certificate for the child, all those important documents so that this

child and the aunt know that this is all the formal legal documents of that child.

EP7: At the end we have to teach them about the memory box, but it's a start now, but when we could see that we are working hand in hand with them, it's only then that, on that memory box everything will be there.

Potential asset/  
next project

EP9: Ja, even us, if there is somebody who's selling insurance, we do take insurance policies. It's for our children, we are preparing because we don't know when we are going to die, but to us it's different because we are not sick. There's no stigma, otherwise they must know that they must do it. Even themselves, they've got that thing on their mind, that I want to leave my child with my sister, I don't him to stay with my uncle, they have got it, it's to brainstorm it in a way.

R: Okay, I think we can wrap up the first part of today's session. I think we've got a good idea about all three of the projects and it sounds like it's going great! For the second part of today we would like to know: if you look back over the last year, what do you think what worked and what should we have done differently?

EP6: You know what, I want to thank you because we were sitting here doing nothing and then you came to us. The first time you came here I thought it will be a workshop, it will be a once off thing. I said it's not a thing I was thinking, I was looking for, what is this now, these people are coming to us, these people come to us, they want us to talk, talk, talk, talk, talk.

Participants  
empowered

EP9: I agree, but I say now we must keep on working, we must keep on sharing.

EP7: You know, like I joined you later but I don't regret that, but I'm with you now, for me being here with you, I've been wanting to help people living with HIV and AIDS but I didn't have a breakthrough. But for me being part of this team, now I got a chance to do whatever I wished for. Inside

Empowered in  
the process –  
by serving the  
community

myself I'm feeling great that there's a lot that I'm doing for the community who are infected or affected with HIV and AIDS, through you.

EP5: You know what, it was something that I was thinking about it, but I didn't know how to start it. I said you, have a light, why I don't use it, I am a candle, why I don't use this light to the community that I'm working in. I was doing nothing, but I was thinking of myself. Brenda Fassie passed away but when Brenda Fassie passed away, everybody was talking about her work, she did everything for the people. Brenda Fassie died but her work is still living, it's still with us. And what am I doing as a person? What I was doing for the community, there was nothing I was doing. I want to thank you because now I feel proud that there is something I'm doing for the community. I am the light here in this community now, when they saw me, when the people see me here in this community they can see *Mrs M* as on HIV team, *Mrs M* she's a real teacher. To be a teacher you are like a minister, you've got a mission, there is something to do, you must do something, like Jesus, Jesus was a teacher. Now what kind of a teacher is going to come just to school and teach the children and then leave. What am I doing for the community? Are you supposed to teach netball for the community? I'm supposed to teach them anything that I know, but now I feel great because in my school there's a garden, in my school there are some people that are coming in and out. In this school there were no people coming in for help, they would just ask for the work of their children and then they go out, and now they were coming for help, they know they will get help. Thank you again.

Feel enabled  
and skilled =  
Empowered

R: M, when you said that we wanted to talk, talk, talk, talk, talk, what do you think, what should we have done differently, that first day we came?

EP6: You know what, in the first day, I said to *Mrs J*: "*I'm not coming again because they just ask us, what do you know, how do you know?*" I thought we will have pens, and pencils and write and write and write, and look at the board and write and write.

R: You thought you were going to learn?

EP6: Yes, I though I was going to learn from you when you first came here, and then your teaching was different, it is knowledge, we work together, we share the knowledge and it is great and then I said: "*When will we meet again?*", and then when you came again we were so happy. Your project was not boring because we helped.

← Links to methodology

R: So actually you liked the fact that you talked and talked and talked? (*laughing*)?

EP6: Ja, everybody is free to talk, we don't just listen, everybody is free to talk you know, and as you know, I like to talk.

R: So you like the participation?

EP6: Ja, but even, later I was so worried that the time was too short, if you came at 14:00 and left at 16:00, I say I wish we started at 08:00 to 17:00.

R: Do you suggest longer sessions?

EP6: Yes, but not after school, during weekends.

Recommendation – for improvement – longer sessions and weekends

EP3: Yes, after school is difficult, sometimes you came here at 15:00 and we are staying far and then by 17:00 we are panicking, but I need to be with you 5/6 hours.

R: Which day would be best?

EP3: Sunday, because we want to be with you for a long time.

EP9: Now let me speak to that question of the past year. When you came here, I, myself was like a stagnant water because I had a vision, but my vision needed somebody to stimulate it to be out. Like I was angry at

Need facilitation  
At first experienced:  
-anger towards HIV  
-hesitant to discuss



first with this disease, I didn't want even to talk about it because I was affected because somebody in my house is infected. ~~I didn't want anything to say about this disease.~~ But the second week or third time you visited us, something was taken off my shoulders because I learnt to talk about this. I learnt to see what is happening in the world with a real eye. And as we were always gathering every time, I saw that this one can help me, that one can help me, this is a support group for me, I am counselling myself. Then I said also to myself, this thing is a blessing in disguise to me, because now I can talk to my family about this. We can see this as a diabetic, we can see this as a fever which came to our house, it's not a separate disease. Now you want the difference because you came here. Ronél, it was a blessing in disguise, really because there's a light in our community now, through you and because of us there's a light in our community. There was a conflict before between us and the parents, but I think now they believe in us, they know that we want to work with them. They must not chase us away, we want to support them, they must believe in us because of you. Thank you.

Avoid terminology  
Discussing  
Enabled to identifying assets  
Discuss with family  
Community= better off due to teachers input  
Parents believe in teachers  
Community-teachers= Partners

EP2: For me also, at first when I came here I came for advises ~~because I'm~~ one of the people who are affected with this disease. I had not idea how to support my family and like M, I had that thing that I am a teacher, I must do something, but I had that fear of going out alone. I wanted a group so that we must discuss, so that we must have information from other people, to help the community. We had visions but we could not put them in action. So we are very thankful for your help, you helped us a lot. Thank you very much.

Initially came for advise  
Needed guidelines and advice  
Feared to help

EP1: And now we can care.

R: You've been caring all along, you must just believe in yourself.

EP9: I'm so glad because we've recorded what you are saying, the evidence, this is a legal document. Because first when you came in here, we thought that we are going to be receptive, to get everything from you, but

it was vice versa. You came here really as a lecturer, coming to the students, wanting to get information from them, it was really a good education to us because everything, we didn't know we are capable of doing some things. You get everything from us, we didn't know that we've got such a knowledge, like a pot full of knowledge. You came to us, saying to us that: You've got something, give us that something". We didn't know, you know what happened, on the bible, I just want to quote: "Moses didn't know that he had something in his hand until God said to Moses, look at your hand, what do you have in your hand?" He said: "I have religious stick" and then God said: "Use that stick". We didn't know that we had a wooden spoon (referring to a symbol used during PRA activities) and we have to use a wooden spoon. Firstly you are a big wooden spoon. Yes, we are wooden spoons but you are a big wooded spoon who can steer teachers to do something, you steered us, we steered the parents. So it's a sort of a circle, you see. Again, you are an eye opener, you opened our eyes. All along we thought that we've got good, that our side is very good, until you came and took out us and showed us what it is that was in our eyes, that membrane, you took a membrane out of our eyes so that we can do something for our nation. You helped because, eh ... I didn't know that, I'm sure everyone here knows her strong point or her weak point. I couldn't see my strong points. Yes, I didn't know what I'm capable of doing, but you did make sure that I know what I can do, because if you didn't come, I wouldn't have known that I can do something for the community that I'm working for, for the people in my church, and they trust in me. What I learnt here is what I'm doing in my church. You've shown us that we are able, we are capable of doing things but we don't use that capability of doing that, but since you came here, look at the garden, there was land that was not used, it had nobody to work on but since you came we've got a farm out of that land, we've got a *plaas – is nie 'n tuin, is 'n plaas, groot plaas ook.* Today we are proud of teachers that can help our nation. You know what, when you first came to this school, when we wanted to have the motto of our badge, we said we must be the light of this nation. We have to be the light of this community because we knew that this community

Empowered and feel enabled

Mobilised to go into action

Expected expert advise

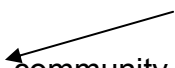
Feel skilled and proud

Feel they are leading and helping the community

has got illiterate parents, and we wanted to be a light, but today I can stand here and say school G has progressed on that, and school G is the light of community X, because where parents can get help there is a light. And it's true that, you can forgive me please, it is true that when you educate a woman, you educate a nation, when you educate a man, you educate an individual.

R: When we came here, we saw all these beautiful woman and there was one man. And you started talking, telling us what is going on, and that you thought that you were not doing anything. That first time we drove out here and we thought to ourselves: "*But they are doing so much!*". We thought maybe we shouldn't even be here because you were already doing so much and then we thought: Okay, maybe what we were supposed to be doing here is to tell you that you are doing so much because it didn't seem as if you knew that.

Acknowledge  
important role in  
community



EP8: You know what, we are no longer educators now, we are community workers, because we are here to work in this community.

R: Okay, I think that wraps it up for today.

# Mapping activities



Getting to know one another



Starting with a clean sheet



Mapping the community

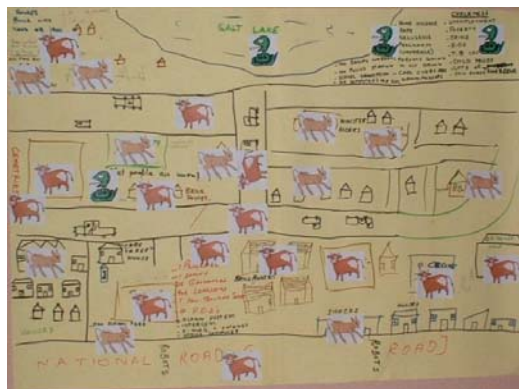
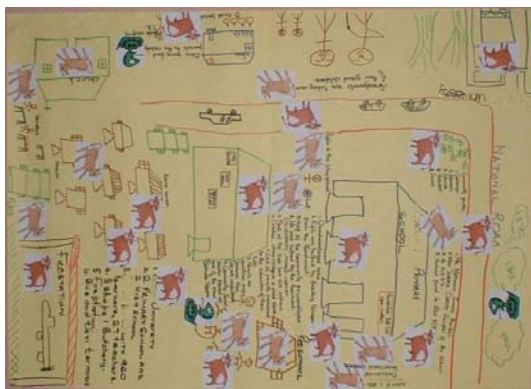


Mapping the community by means of photographs





Identifying challenges (snakes), assets (cows) and potential assets (calves)



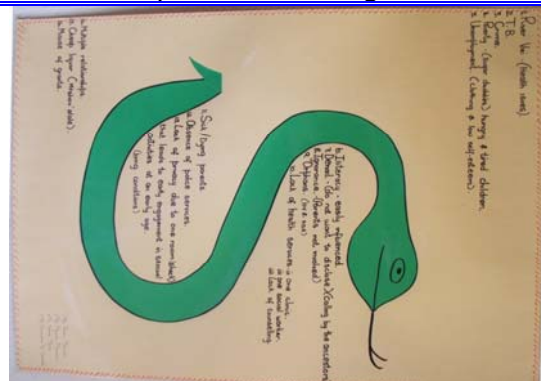
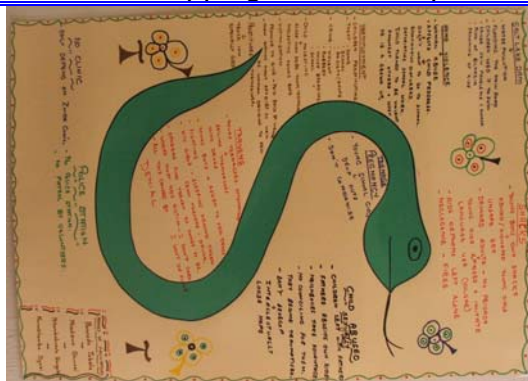
The community mapped



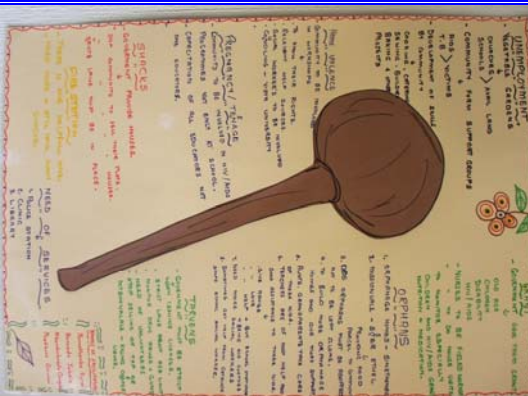
Mapping community challenges



Mapping assets and potential assets to cope with challenges



Community challenges mapped



Community assets mapped

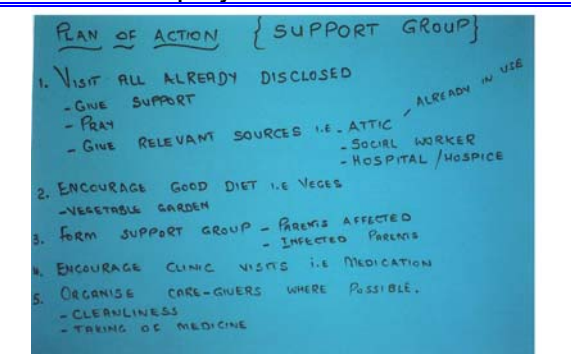
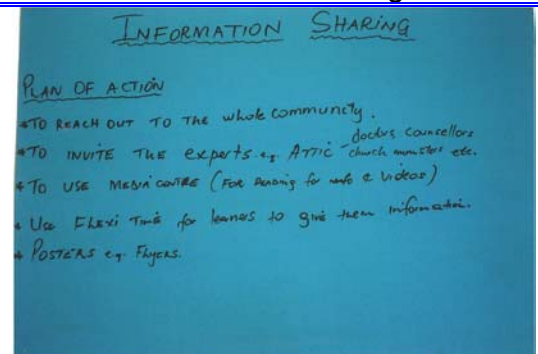




The educator-participants



Planning the three school-based projects



Action plans



From barren land to a vegetable garden





A team called Masizakheni



The participants:  
Self-confident, proud and enthusiastic

**DEDICATION:**  
INVOLVEMENT IN  
HIV/AIDS INITIATIVE AT  
XXX PRIMARY SCHOOL

XXXXX  
8 June 2004

“ I am very much dedicated to the HIV and AIDS information and support group. I am affected because one of my family members is infected with the virus. It has been my wish and hope to give help to the sick, because I have the heart to do so. I once had a learner in my class who was infected. The parents disclosed it to me in a late stage. I feel great because I spent most of my time visiting that sick child at hospital and home. I am looking forward to help and share what I know and understand about HIV and AIDS with the community, so that everybody understand exactly more about it and take precautions.”



# The Community



Informal housing



Informal housing



Informal housing



Informal housing



Communal water point



Informal housing



Informal housing



Salt lake adjoining community



Informal housing



Informal housing



# Assets and potential assets



University



Welding shop



Bottle exchange



Vegetable shop



Supermarket



Dr's Surgery



Supermarket



Telephones





High school



Vegetable shop



Primary School



Principle of primary school (Interview 3)



Clinic (neighbouring community)



Government office  
(neighbouring community)



Hospital



Hospital ward (not used)



Communal water point



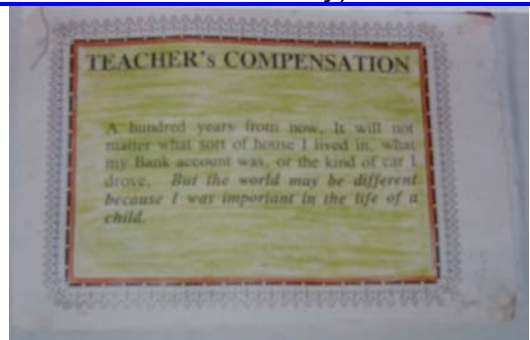
Hospice



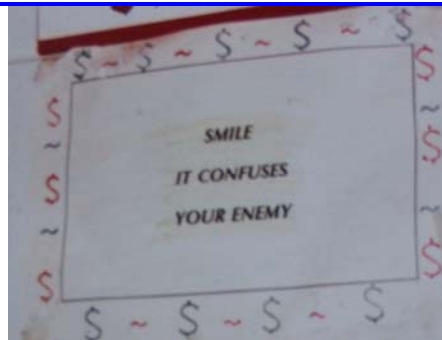
Community care centre (neighbouring community)



Traditional healer



Slogan in teachers' staff room



Slogan in teachers' staff room



Classroom at primary school



School media centre





Inside media centre at primary school



Computers in media centre at primary school



Pre-school in community



Parents from the community that tend the garden

**FIELD VISIT 3 – 18 FEBRUARY 2004**  
**INDIVIDUAL INTERVIEW 1**  
**CHURCH MINISTER**

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**BROAD (FLEXIBLE) INTERVIEW SCHEDULE:**

- ⌘ Which resources and potential resources can be identified in the community?
- ⌘ How is the selected community currently coping with HIV&AIDS and the challenges implied by the pandemic?
- ⌘ Which role is the church currently fulfilling in supporting the community – both in general and with regard to coping with HIV&AIDS?
- ⌘ Which potential role might churches/religious institutions fulfil in future?

KEY OF ABBREVIATIONS	
R:	Researcher
P:	Participant

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R: I'm busy with a research study in *community X*, asking the following question: *How is the community coping with HIV and AIDS and the challenges that are associated with the pandemic?* My basic assumption is that the community is coping. I understand that it is sometimes difficult and that the community also experience great needs, but I believe that they are coping. What I would like to find out from you is: *What does this community do to cope?* In other words: *What do community members use? Do they, for example, rely on other people to help them? Or maybe on NGOs, clinics, churches, ministers? What is your perception?*

P: Okay, I think in our community it's not easy for the people to come out and say in the public: "I'm HIV positive."

Non-disclosure

R: Is it still difficult to disclose?



P: Ja, it's still a problem. But I'll tell you about the experience which I had, I think it was last year, whereby I was doing my PhD with the University of Fort Hare. In one of our practical subjects we had been asked by the lecturer to go and make a counselling to the people who are living with HIV in, in, in *township N*. So I think it was a man and also the wife, and I think we were three students. One eh ... it was a small lady and the other one was old, the middle aged, and mine was an old man who was about 52. Ja, then I think it was **through the ministers** and **also the nurses who were assisting**, because I was there as the minister and **a certain white lady, was also assisting them by tablets**. Ja ... **through the hope which we gave them, then they could cope**, because we **were visiting them now and again**, now and again, and **we explained** to them that they mustn't eh ... worry, that **they can cope with the situation**. But the problem is **you have to accept it** ... that you are HIV positive and you can also live a longer life if you take, eh **use the medication** and you **take a right diet**. So that, that was the, I think it was my first time to account men who are living with AIDS. But since I was going there, Wednesdays, sometimes Fridays, I could see the change.

Asset: Minister

Asset: Nurses

Medical treatment

Hope as a way of coping

Home visits as support to others

Asset: knowledge/ advice from others

Belief in ability to cope

Accepting status

Medical treatment

Diet/nutrition as a coping strategy

R: Tell us about the change?

P: I mean now, that kind of the attitude whereby you don't need to see people, eh ... you **don't want to talk** eh ... but they became friendly with, eh, to me and then we started talking, then we started to, to eh, to pass the jokes, then **that tension was, was lost**. Then I could see now when I go there, sometimes they say: "*Why you didn't come last Friday?*" You see, eh they were expecting me now at a certain time to **visit them and to talk with them**. So it was the eh ... **they could cope**, but unfortunately at the end of the year, I received the news that the husband passed away.

Avoid discussion

Healthy relationships in supporting others

Home visits as support to others

Supported to cope by community members

R: Was the husband the one that was HIV positive?

P: And also the wife, but the wife was not ill. He was HIV positive, the husband. He did have it bad.

R: I see.

Belief in ability to cope

P: Ja, so that was the, my first time. So I think, I think they can cope. It was due to the medic..., it was the medication of the clinic, I think the sister of the clinic next to township N was counselling them and giving them tablets.

Treatment

Assets related to health: clinic, nurses

Counselling

Treatment

R: I'm hearing a lot of things. You are saying that the medication helped and that the right diet helped. And you are further saying that the support you and the nurses gave them and the regular visits you paid made it easier for them to talk about their status and accept it, that you assisted them in accepting their status, and that that also helped them to cope. Were there any other people or means of support to them, like family members? Or were it only you and the nurses?

Lack of social support

P: Ja, they, eh ... they didn't have a family here in Port Elizabeth because the guy was coming from Port Alfred. So he was not very long staying in that area. But concerning that they didn't disclose that to the neighbours, so they only ... they could only see when we visited with the home that there is a problem, but they never disclosed their status.

Avoid disclosure due to lack of support

Stigmatisation  
Identify others

Non disclosure

R: Never to the neighbours, throughout the process?

P: Never, throughout the process.

R: So they only trusted you and the nurse?

P: Ja, and there was also another minister of the Salvation Army ... he, she also helped them. It was three of us. Sometimes it was my turn, sometimes it was the turn of the Salvation Army, eh minister and the

Trusting relationship as basis for support & disclosure  
Asset: minister  
Care and support in coping

- nurse. Sometimes we arrived at the same time because we were checking, now and again, what is the situation. Care and support
- R: And you said that they experienced a lot of acceptance from your side and that you conveyed the message that *"It's okay and you must have faith and accept it and carry on"*. That's the kind of message that you gave them?
- P: Yeah, I said that they must accept it. Eh ... in order for them to be strong, you have to accept that I have the status ... treat it as if you have the diabetes or high blood or something of that nature. Then you can carry on with your life, eh ... you keep eh in touch with the counsellors and the, and the nurses, then you carry on with your life. Your life will be normal because I gave them the typical example of that lady who was diagnosed in 1989, but even today eh ... she's still strong. Accepting status  
Inner strength  
Assets: counsellors, nurses  
Living a normal life
- R: She's still living.
- P: Living and not sick. And I said that the, the best way of dealing with it is to accept it and to say: *"Well, I have HIV, I, I'm HIV positive, I cannot die because of that."* So, so they listened to us. Accepting status  
Counselling by minister
- R: And after the husband passed away, did you still went to see them, or did you stop then?
- P: No, I couldn't because it was eh, eh ... I, I finished studying last year. So even this year I thought that it was just the opening, I couldn't make it, just to go now, not visiting because I am a student, but just for my interest to see what is taking place. Ja.
- R: Tell me about this community, here in Port Elizabeth. Are there a lot of community members infected with HIV?

- P: No, there are a lot of people, but you won't hear them saying that they are. You could only know when you see that this person is eh ... becoming sick and very thin and then you'd start realising when you see the symptoms, but they won't say that we are HIV positive. High HIV infection rate  
Non-disclosure  
Ability to identify  
Non-disclosure
- R: Also in your church – they still don't disclose?
- P: I don't know any in my church but the latest one ..., although I was not told, I buried just two weeks ago. He was very thin, ja very thin, very very thin, and to me, I said that maybe she is HIV positive, but it was never been discussed or disclosed to me, that she had the status. Only last Saturday when we had a funeral, one of our congregation whereby the sister of that gentleman felt that my brother was killed by AIDS, he was HIV positive, he does have AIDS. So only last week on funeral, I hear eh ... people disclosing that: "This is because of AIDS." Ability to identify  
Non-disclosure  
Disclosure: at funeral
- R: Do you provide support to such families?
- P: We can, we can provide if we have eh ... well, the information. Potential asset: support by church
- R: But you only received that at the funeral?
- P: Only on the funeral.
- R: What about the family that stays behind?
- P: The family ... It was, it was this weekend that we heard of that, so it's now when we are going to make a follow up. Support by church
- R: Will you support them?
- P: Ja, because my wife was working with the people who are HIV. Eh eh ... she was very interested in this HIV eh courses, then she did went to the, eh that International Aids Conference in Durban. She was there and she Asset: minister's wife

had a lot of books, then she had one while she was here, eh here in this area, eh ... **social worker**. Then they used to ask her, eh if she's present, to **assist the people** who are living with HIV and AIDS.

Potential asset  
ito: support by  
social worker

R: Your wife?

P: My wife.

R: What did they do to assist people?

P: **Giving the counsel**, the counselling. **She did a lot of courses** which deals with this business of counselling.

Counselling

Asset:  
knowledge

R: Do I understand you correctly that it was your wife and the social worker in the area that provided counselling to the people, but that they are not willing to disclose, resulting in you not knowing when community members are infected with HIV?

P: Uhm ... ja. **They disclose to the social worker only because eh ... some of them they want a grant. They only disclose to them** because there's no way of getting a grant without being recommended by the social worker. Ja, sometimes the social worker, eh, **she used to ask also my wife** – but the previous one, this one is new.

Disclosure to  
social worker in  
order to obtain  
grant

Disclosure to  
selected  
audience

Potential asset:  
minister's wife

R: And the social worker then helps them to apply for the grant or refer them for the grant?

P: Yes.

R: Does it often occur that community members approach the social worker and disclose their status because they want a grant?

P: Ja, I think it's like that because people now are for the grant, they are coming now and again, although sometimes I don't know eh ... what they ..., because the social worker cannot tell me that they came.

Asset: Grant

Confidentiality

R: Do you think it will be possible for me to have a conversation with the social worker?

P: With the social worker?

R: Yes.

P: When are you going to have that? When are you going to come?

R: I'm here for the whole week, I'm leaving on Sunday and then I'll be returning in March again.

P: Okay, so the whole week you are here?

R: Yes, I might meet with her on Friday or Saturday.

P: What I will do, I'll get your telephone number and I will make an appointment with her and also with the auxiliary worker over here, they are working with these people who are HIV positive. Then I will phone you and say: "Okay, come on such and such a time." I will arrange it for you.

Asset: church  
auxiliary worker

R: Thank you, that will be very helpful. I would like to ask you another question. We know that there are many HIV and AIDS cases present in South African communities – that is the reality we face. In your opinion, which sources or resources do members of this community use to cope with HIV and AIDS – in other words to cope with their sorrow and the challenges they face?



- P: I think the better sources for them to use is the **social workers** and the, the **ministers** and the **psychiatrists**. These are the people who can help. Assets: social workers, ministers, psychiatrists
- R: Are there psychiatrists present in this community?
- P: No, I'm not sure of that, because I did not see any office of the psychiatrist, but I've seen them in *community K*.
- R: You've mentioned that community members rely on the social worker and sometimes the ministers, as support base. Could you please elaborate?
- P: For **support base**, ja, but for the **medication** I'm not sure if they have the support or no support, because our **clinics** they **don't have the supplies**. That is such a **problem**, not everything is in our clinics. Some of them they are suffering **because they don't get help**. Support by social workers  
Treatment  
Potential asset: clinics  
Challenge: lack of medical supplies
- R: And what happens when a parent dies, what happens to the children?
- P: Usually with us **as the black people**, the **family take the children**. I don't know, most of the people they, they have families. **So when the parents pass away, the family they take the children**. Asset: culture  
Asset: family  
Family = caregivers to children
- R: And they look after them?
- P: Ja, but once upon a time I had that idea ... if we have, I, I thought that, that the **orphanages they are the best places of keeping the children**, but it's **unfortunate they are rare**. So now, because now **people they take children because they are related** eh ... to the person who passed away, but **they don't give them the good treatment sometimes**. Orphanages to cope with children  
Lack of orphanages  
Relatives as caregivers to children  
Need for proper treatment of children
- R: Tell me about that. What do you mean by that?

- P: They don't ... You see people, they **don't want to take responsibility**. If you have your own children **you don't want more children** than what you have. For instance, if my sister passed away, I have two children and she, she has four or five. Then **I have to take that responsibility**, ja, it will be seven children. Then you'll find that some, eh some of the people eh ... no, they **can't cope** with that. Extended family = caregivers, despite their hesitancy  
Extended family = caregivers of children  
Challenge of not coping
- R: Do they then neglect the children or what do they do?
- P: **Sometimes**. Possibility of neglected children
- R: In your experience, is it most often the brothers and sisters of deceased relatives who take care of the children, like the uncle and the aunt? Or is it more often the grandparents?
- P: Usually **it used to be the grandparents**, but sometimes if there are no **grandparents the sisters and brothers**, they are taking the children. Grandparents, uncles and aunts as caregivers
- R: But they sometimes experience difficulty in coping with all the children?
- P: Yes, **they encounter new problems**. Challenge of caring for orphaned children
- R: Who supports them? Are there other people supporting these families?
- P: Yes, a little bit. Because you see, one of the problems, **if maybe I pass away because of the HIV, I don't say to the people that my brother passed away because of HIV**, you see. Then **it's not easy for other people to give the support**, but it could have been easier if they said: *"Okay, it's because of this."* Then I have this burden on my shoulders. Non-disclosure  
Lack of support due to non-disclosure
- R: Why do people avoid disclosing their status?
- P: I would say that it's because **HIV is always associated to sex**. Then if you are HIV positive, it has got that **bad flesh**, that maybe **you didn't behave** Non-disclosure due to stigmatisation, moral judgement

in a good manner. Eh, you have AIDS because you didn't ever behave, your behaviour was bad.

moral  
judgement, at-  
risk sexual  
behaviour

R: So people almost fear that others might say they were promiscuous or that they weren't behaving morally appropriate? Is that what you're saying?

P: Ja, you'll become the laughing stock in the community. Ja, because they don't want that, they don't want that.

Stigmatisation

R: Tell me, what kind of support services do you offer in your church to community members, or to church members?

P: Uhm ... can you just repeat that?

R: What kind of support do you offer for your church members? What do you do? For example, do you visit people when they are sick or what does the church do to help the members of the church who need support?

P: Oh that. I think that is the only thing which we do, is to make the home visits, and if we see eh ... maybe there are that kind of a family, they don't have, they have nothing, then we will recommend in our church council that we give the support which we can give, maybe something to help, to eat.

Home visits by  
church  
members  
Poverty

Support by  
churches  
Material support  
(food)

R: Are you referring to people who are unemployed and in financial need? Are those the ones you support by visiting them at home and providing them with food? Is that what you mean?

P: Ja, them, and secondly those who are, maybe the old ladies who cannot be able to clean the house at a certain time, eh ... the women they assist them to clean up the house if the granny's staying alone.

Elderly support  
with household  
task (church)

R: Who is involved in providing these services? Only you, or do you have a team of church members helping you?

P: Not a team as such, it will ... that will be difficult. Maybe today I, I, when we see the programme, we conduct eh ... I say: "Man, can't you help me eh ... with her?" Then, at a certain stage they do eh ... work themselves, because I, I, I don't touch all areas. I'm working area X and also area Z, so I can't be able to be there all the time. So the, the leaders of the groups ... eh, we call it *Manyanos*, the women's gathering, they do it.

Limited time to support  
Asset: church support groups

R: What does that mean?

P: *Manyano* is a unit. Ja, I can say ... I, we have a sort of organisation whereby all women they belong. Those who are wearing the new church uniform, they belong to *Manyano*. Always on Thursdays they are coming together as a pray gr..., eh a prayer group and the youth they're coming together on Tuesday to a prayer group, and men they are coming on Saturdays.

Prayer=central  
Assets: prayer support group at church

R: *Manyano*. It's a lovely word. And they pray together?

P: Ja, together. So if man eh ... is, is sick or it, there's been a problem, then there are ... that men's *Manyano*, they are visiting the man. And if you belong to the youth, eh ... then that *Manyano* of youth they are visiting all the people who belong to that *Manyano*. And also the women is like that.

Supporting other community members  
Home visits by church groups

R: What kind of challenges do you deal with? Is it only people being sick and unemployed or do you also deal with things like abuse?

P: We deal with the bereaved mostly. The abused, eh ... is not, not here, the abused is not .., we don't have eh ... most of the people. The abused, we don't deal most of the time with that.

Challenge: bereaved people

R: The social worker will deal with it?

P: Ja, I think they disclose to the social worker.

R: So you basically deal with illness, bereavement and unemployment?

P: Ja, or, or if people they have, eh ... they are up in any area, if something else is happening, eh then **we give the support to them.**

Support by  
church

R: Whenever needed?

P: Yes.

R: And if I understand you correctly, you yourself are like the co-ordinating body. You will hear about a problem, find out what is going on and then divert the case to the specific church group that will provide the support. Is that correct?

P: Ja, ja. So as a minister I'm working with all *Manyanos*. If we have a problem, say for instance eh of a woman who is sick or eh ... expelled from the job or the firm has been closed, then I don't only ask women. I ask also the members of the **church council, even the youth, that we go and have a service there.**

Support by  
church: home  
service

R: So you decide which one is appropriate and then you ask whoever is available?

P: Ja, if maybe from, from the youth or from the women, eh it was .., I got a report of that nature, then I just organise other *Manyanos* - men, youth and all, the whole congregation. So say, okay, eh ... if we got that on Sunday, we say on Monday eh ... **at six o'clock we are going to have a service there.** Then if, if the youth, eh ... they have to render the services on Tuesday, they are coming together. Then the women they are coming together on Thursdays. Ja, so they visit eh women, eh ...

Support by  
church: home  
service

that is their programme. And the men, the, they're coming together on Saturdays, eh ... they continue with their programmes.

R: You are certainly providing various services – it's the praying of the *Manyanos* every week, the home visits and the services that you provide to people that need support.

P: If people are sick, ja. But in, in a normal situation, I'm not with them eh ... on Tuesday and Thursday and Saturday. But if one of their members, if there's a problem which needs the minister, then I go.

Church supporting sick people

Minister=provide support

R: And apart from having a service you then also ask the church council to support with food, and you might ask other members of the church to help with tasks like cleaning the house or paying home visits.

P: Ja, eh ... sometimes eh, eh, eh ... without going to the church council I just know the people in the congregation and say: "Well, can you borrow us, can you buy for us certain things?" The people whom you know, but eh: "I have this family and there's nothing in the family, then can you help us with that?" And I'll go to somebody else in the congregation and say: "Can you support us with that, eh because the situation here is very critical." So I, I could see people who can manage.

Asset: minister's knowledge

Community members supporting one another (material needs)  
Minister as facilitator of support

R: Because you know your people?

P: Yeah, because we have got professionals, eh ... we have got the people who are not professionals but will manage everything, so we just consult sometimes.

R: So you as the church minister have knowledge about the resources in the church – who you can ask for help?

Asset: minister's knowledge

P: Yes.





R: And I assume that you will be able to provide the same kind of service to people being infected with and affected by HIV and AIDS, if they were willing to disclose?

P: Yes, if they are willing to disclose. I think at a certain stage there was a gentleman who, who came here after the service. Unfortunately I was not in and then eh, he does not belong to our church and he disclosed in the church. Then the, the, eh the brother, who was there, they, they collected some money. Within no time, more than eh ... R50 he got it, because he was eh..., he was going down and he felt eh .. that I must get into church so to disclose my status. So they supported that man.

Disclosure  
Supporting other  
community  
members, even  
if unfamiliar  
(money)  
Disclosure clue  
to state of dying  
Supporting  
fellow  
community  
members

R: They supported him. Are you perhaps aware of any HIV and AIDS support groups that operate in this area?

P: Oh, the person who can tell you about that is the one whom I'm going to ask, eh, the social worker and that auxiliary worker who are assisting them. He does work, eh she does work with the support groups.

Assets: social  
worker, auxiliary  
worker

R: I will ask her about it then. Thank you for all the information that you've provided me with. Is there anything else you can think of?

P: Not, not at this stage.

**FIELD VISIT 3 – 18 FEBRUARY 2004**  
**INDIVIDUAL INTERVIEW 2 (INTERPRETED INTERVIEW)**  
**CAREGIVERS (AUNTS) OF CHILDREN INFECTED WITH HIV**

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**BROAD (FLEXIBLE) INTERVIEW SCHEDULE:**

- ⌘ How are you coping with the children in your care?
- ⌘ What are the main challenges you have to cope with in looking after the children in your care?
- ⌘ Which resources in the community assist you in coping with the challenges you face?
- ⌘ Which potential resources might assist you in coping with the challenges you face?

<b>KEY OF ABBREVIATIONS</b>
R: Researcher
P1: Participant 1
P2: Participant 2
I: Interpreter

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R: (*directed at interpreter*) Please tell these two ladies that I am aware of the fact that they look after the children of relatives who have passed away and that I also know that the children they care for are infected with HIV. Please request them to tell me about their background. Who are they? How did it come about that they are caring for the children? How are they related to the children?

P1: I am the aunt of the child. She's the daughter of my sister. The mother started, got sick in 2000. After that the younger boy, who lived with the elder one, the younger boy got sick.

R: How old is the younger one?

P1: Okay, the other one he was 5 years. The other one who ... the younger brother who passed away he was five years old. The, the first one who passed away is their mother, then the younger brother of the one who's here at school passed away, following her mother, he was ... he was five years old. Then her, their father got sick. So the father passed away last year. He went to Ladysmith in ... in Natal. After their father passed away when he was in Ladysmith, the daughter, L, got sick. It was last year. It was last year. Ever since the, the, the child is not feeling well.

R: When did the mother pass away?

P1: In 2000 the mother passed away.

R: Do I understand correct that when the mother passed away, the father took care of L?

P1: Yes, their father took care of them.

R: And then he passed away last year and now you are taking care of L?

P1: Yes, we are two sisters. We are taking care of the daughter L.

R: How old is L?

P1: She is eight years old.

R: Tell me about the time when L started getting sick?

P1: L started last year to get sick. She started here at school and got that sickness. We took her to the doctor and the doctor find out that she was HIV. The doctor took L and he ... because she was sick, he took the

Asset: Doctor

Child infected with HIV

blood from her to see what was wrong. Then they called us to tell us that L she was HIV positive.

R: Did the mother or the father disclose their HIV status at any stage?

P1: No, the father and the mother didn't tell anyone. They were hiding that they eh, they were HIV. They started to eh, we started to ... it was that time when I took the little boy to hospital. They took the blood test and told us that the younger boy is HIV positive, it's when I suspected that the father and the mother were HIV positive. It's when the father disclosed that.

R: To whom did he disclose?

P1: He told the family, his wife's family that he was HIV positive. He asked a permission to go to Ladysmith so that he can die there, not here in Port Elizabeth.

R: And now the two sisters are taking care of the children. How are you doing it?

P1: L is staying with my sister, who's at work now. I accompany L when she's coming to school, up to the gate. When she's from school I took her and when my sister is from work she took her so she can take care of her. So we are doing turns in taking care of L.

R: Do you and your sister stay close by, close to one another?

P1: We are staying like eh ... in sort of eh ... we're nearer to each other.

R: How did you decide that both of you will take care of L?

P1: When my sister is in the job, doing her ... eh at work, I am taking care of L, taking her to school and then after school, taking her from school and

taking care of her. Then when my sister is coming from work she will take care of L. So we are taking turns to take care of her.

R: Do you and your sister also have children of your own?

P1: Yes, we've got kids, but mine eh, are older than L. My sister has got a child who's the same age as L, the other one is in high school. They are two, the other one is in high school, the other one is the same age as L.

R: Thank you. Could you (*addressing participant 2*) tell us your story, please.

P2: T was staying with my mother in *community m*. My mother is 87 years old now. T is my sister's child. Her mother passed away in 2000, in April in 2000.

R: The mother of T?

P2: The mother of T, the real mother, biological mother.

R: In April 2000 and then she went to stay with your mother?

P2: Ja, at Motherwell. The reason why I took her from my mother in Motherwell, we found out that she was raped. Since my mother was old, I decided to take her with me.

R: When was that?

P2: In 2002. So I take her with me so that I can take her to clinic. The reason why I noticed her to take her to clinic, I found out she has got sores all over the body. So at clinic they took blood so that they can test it and they found out that she was HIV positive.

R: Please continue.

P2: The person eh, the perpetrator who did that to her was taken to the police station. She wasn't taken to jail, she was taken to police station. When I was trying to find out what happened to him I found out that they took him away from the police station. When I asked them: Why do you take him out of the police station while the case is not over?, Mr Jonas, the policeman, told me that the case is over. And I had to sit down and take care of *T*'s health. I used to take her to the doctor, sometimes she got convulsions. Now I'm still staying like that. The reason why I disclosed to the teacher, I disclosed to the teacher so that if he found that *T* is confused or *T* got convulsions she can know, so that the teacher cannot get shocked when these things happened, so that *T* can get also help from the teacher. The teacher told me that she'll look after the kid, after the child, the teacher promised that she will look for the correct medicine that can help *T*. It's when the teacher could tell it, she could know that when *T*'s not at school, she is at the clinic. That's why I reported it.

R: Do you have other children of your own?

P2: Yes, yes. There are two.

R: How old are they?

P2: The other one is 18 years old, the other one is 11 years old. *T* will be 11 years old.

R: Do you have a husband or a friend staying with you, or is it only you and the three kids?

P2: I don't have a husband. My husband passed away, it was last year.

R: So it's you and the three children at home?

P2: Yes.

R: (*addressing participant 1*) Do you and your sister stay with any other relatives or husbands?

P1: Yes, my sister has got a husband and myself I've got a husband.

R: I just want to confirm, your sister is staying with her husband and the two children and then it's you and your husband and the two children?

P1: That's right.

R: (*addressing both participants*) Both of you are facing a lot of challenges because you have taken children of relatives into your care, children who are also sick. What do you find difficult?

P1: There are some times where I got eh, where I got **loss of money**, where I **couldn't get money to buy her things that she needs**. Sometimes she wants fruit but **I couldn't have money to buy her fruit**. Sometimes the money, the **grant money it has not yet arrived**. But the **social worker has promised** me that, that they are going to try by all their means so **that we can get money in time, so that she can get help**.

R: (*addressing participant 2*) And you?

P2: With me, after my husband passed away I found out my **health has changed**. I had to go to the doctor and the **doctor diagnosed** me with high blood. And I said, eh I found out that the, the, the trauma of my husband passing away, I've mixed it with the sickness of T. On the other hand **I have no money** because **my husband wasn't working**. Even if I'm trying by what I'm **getting from the neighbours**, they are trying to help me, so I took the high blood treatment, so that I can eh, eh get pension.

R: How do your neighbours help you?

P2: Sometimes **they give me food** so that I can cook for us, they would **give me flour** so that I can make bread for us. Sometimes they'd give me

Community members (neighbours) supporting one another

Food  
Money

Care and support



even money so that the child can buy something here at school to eat. It's with her ... the neighbours are taking good care of her. The neighbours are giving me whatever they've got, food or even they sometimes buy shoes for her.

R: (*addressing participant 1*) Do you agree with that? Do your neighbours support you?

P1: No neighbour is helping me. We are helping us by ourselves, by trying by all means to get whatever is good for the child. My husband is doing some jobs and my sister's husband is doing some jobs, so that they can have something. But they are getting paid on fortnight. Sometimes during that first week we get short of something. Because L is like this, when she wants something, like even if she wants something to eat, she wants that thing now.

R: (*addressing participant 1*) How much is the grant that you receive?

P1: We have not yet received the grant, but the social worker said we're going to get R700.

R: (*addressing participant 2*) If I understood you correctly, you are also still awaiting a grant?

P2: Yes, I'm still going to the social worker so that we can do something like that.

R: Are you going to contact the social worker?

P2: Yes, I am busy with, eh in contact with the social worker. I'm supposed to go to court to make an affidavit on Thursday. I to date didn't attend it because I left the child behind, because I didn't know I had to go with her. Now I've given a date for 28<sup>th</sup> of June to go to court to make an

affidavit so that the child is my sister's child, so that they can prepare grant for her.

R: What kind of a grant will they prepare?

P2: They said for **foster care**, not for *T* being sick.

Asset: Foster care grant

R: (*addressing participant 1*) And the grant that you refer to, is that the disability grant or for foster care?

P1: Ja, it's **the disability grant**.

Asset: Disability grant

R: Tell me about the difficulties you experience. Did you go to the social worker or what did you do?

Asset: hospital & social worker

P1: We went to **hospital D**. We talked to the **social worker** about the child who's not, eh **who's sick**. We've told them that the child ..., we told them that the child has been infected with HIV AIDS. We were given a social worker to attend us, *G* is her name, and she made all this possible for us. She took us to court. *G* was very shocked on Monday to learn that we have **not yet received the grant**, because we've last got a grant, grant on the 23<sup>rd</sup> of October last year.

Vulnerability of children

Challenge: obtaining/accessing grant

R: How did you hear about applying for the grant? Is it common knowledge?

P1: I went to **hospital D**, that's where I got the **information**. Because that lady *G*, the **social worker** who were working on that case, she told me that she, **she can qualify for the grant**.

Informants (assets) about grant: hospital & social worker

Ways of coping

R: Both of you are supporting these children. I would like to know: How do you do it? What do you have that help you cope – within yourself but also in other people? You mentioned the neighbours, you mentioned the

grants and the social workers, but what else? Who else help you and how?

P1: What happens is that, eh when I notice that she's going to get sick or she's get a symptom of getting sick, I ran quickly to the **doctor** so that she can get help.

Asset: doctor/family

R: So the doctor is somebody who helps?

P1: Ja. If she get sick at night I take her straight to the **doctor**, but during the day, during the day I take her to the clinic, took her to the **clinic**.

Asset: doctor/clinic

R: Are we talking about the clinic just opposite the national road?

P1: We are using *clinic D*.

I: (*addressing researcher*) You know the police station you went to, there is a **clinic down there in that area**.

Asset: clinic in neighbouring community

R: And the doctor, where's the doctor?

I: There are **nurses** there, no doctors.

Asset: nurses

R: But when you say you take her to the doctor, where do you go?

P1: I am using my money to take her to the doctor at K. There's a **doctor** there opposite the traffic department, I take her to that doctor. So I am using the money out of my pocket to take her to the doctor. The doctor charges R55.

Asset: doctor in neighbouring community

R: Who or what else help you?

P2: I used to take T to **Dr P** here at Z. We are paying when we take her there, R90.

Asset: doctor

R: Where is this doctor?

P2: Here at Z. It's a surgery.

R: Here in the community?

Challenge:  
community  
limited Doctors

I: Not this community, just across the national road, there it's Z area.

Asset: doctor in  
neighbouring  
community

P2: So we used to take T to the doctor. Sometimes we used to take her to hospital D because they said, they told us that each and every month we have to take her to hospital D, so that she can get medication.

Assets: doctor  
hospital

Treatment

R: Who told you that?

Informant:  
doctor

P2: It's the doctor who took care of her at hospital D. So he said that we must bring her every month, so that she can get medication.

R: I want to know more. Who and what help you cope with the challenge of caring for these children?

Challenge:  
coping dying  
loved ones

P1: The reason why I cope with this is that I saw my sister got sick in front of me. I was worried because I didn't know what she was suffering from, she was saying she didn't know why she was sick, but when I heard that she was HIV positive, it's when I accepted it. I took it that it might happen to me and I would ..., if it might happen to me I would accept it. When I saw it on their kids it was worse, but I, but I, I accepted it. So that's why I'm coping.

Denial / non  
disclosure

Acceptance of  
others living with  
HIV/AIDS

Acceptance as  
coping  
mechanism

R: (addressing participant 2) And you?

Challenge:  
coping with  
vulnerable  
children

P2: The reason why I cope, it's because I know that it's my sister's child and my sister's child is my own child. What I want to do is for her not to feel that she has lost her mother, she must know that her mother is still alive,

Strong family  
bond as basis of  
coping

which is myself. So that I can take her as my own child. So that's why I'm coping, I'm taking her as my own child.

Maintaining legacy as coping mechanism

R: So what I hear – and please tell me if I'm wrong – I hear that both of you want to help your family. I hear that there are people helping you, you and your sister helping one another (*addressing participant 1*) and the neighbours helping you (*addressing participant 2*). I hear that you do have some money available – although it's very little and that you need more money. I hear that there are doctors, clinics and social services that you use. What else are you relying on in this community? Are there any other things in this community that help you? What about churches or traditional healers, for example?

P1: On Sunday I just go to church and come back again. I don't go traditional healers.

Traditional healers not regarded as assets

P2: On Sunday I used to take T to the church, but not to consult traditional healers.

R: Does the church in any way support you or don't the people at the church know about the children's status?

Churches not supporting community members

P1: The churches know nothing.

Non-disclosure

P2: I didn't tell the church.

Non-disclosure

R: Who knows about the details?

P1: It's the family only and the teachers here at school, the teachers who work with these kids. Not all the teachers know, only the teachers who are teaching these kids.

Selected disclosure : Family Educator

Selected disclosure

R: May I ask why you are so secretive about it? Why don't you tell the church?

- P1: We as blacks we are not like you, we laugh at each other when we disclose of that. Even the kids next door, if they can, they could know that this child is suffering from this thing, they'll laugh at her and insult her about the, the, the HIV status.
- Cultural challenges
- Non-disclosure due to stigmatisation
- Stigmatisation
- R: Why would they laugh?
- I: It's like that to our culture. That's why many people don't tell the status. If you can notice it, you will remember even in Gauteng, Lulu, that lady who disclosed that, then they stoned her to death. Even the other lady, who was the activist, they raped her and killed her because she disclosed her status. So it's like that with us. I'm sure the reason why those ladies were killed, it's their previous boyfriends whom they know that, oh now they are disclosing, now what about myself, you see? It's like that in our culture. It's difficult sometimes, it's the other things that make ... Because what is happening in our culture, we mind the thing of next door. You don't mind your own business, you want to know what's happening next door, not minding your own business, that's the problem with our culture. You want to know: *oh, there is an ambulance next door, I wonder what she's suffering from.* Then if you said: "I've got TB", when there is an argument or the children are fighting, they'll say: "she's like that because she's got TB", you see. That's the way we grow up.
- Stigma related to culture
- Non disclosure
- Fear of death and being harmed
- Role of culture in stigma
- Culture as asset: involvement of neighbours
- Challenge ito of stigmatisation
- Culture is embedded
- R: Why don't you tell the minister?
- P2: The reason why I don't disclose is even the neighbours will talk. Sometimes the neighbour will be reluctant for her child to play with mine or she want to, to, to send her to somewhere but she won't be able to do that, so that the child can feel that I'm alone and I'm not accepted and that will contribute to her health.
- Non disclosure due to fear of being stigmatised, rejected
- Fear of rejection/ Isolation
- I: You know what, it's because..., it's happening even to us educated people, you see. You don't want your child to play with that one, thinking
- Perception to be/outsider

- that because he's HIV your child will also be positive, HIV positive. It's that manner that she's talking about (*referring to participant 2*).  
Stigmatisation  
Inaccurate  
HIV/AIDS  
knowledge  
myths
- R: The information that you have about HIV and AIDS, where do you get your information?
- P2: We know nothing about it. Lack of  
information  
regarding  
HIV/AIDS
- P1: I saw it on my sister's child in 1997. She was very sick in my house, so she died. We know nothing about the HIV and AIDS.  
Challenge:  
coping with  
death of  
relatives  
  
Lack of  
knowledge
- R: (*addressing participant 1*) What did the doctor tell you, when you took L to the doctor?
- P1: The doctor called me that time during the results and he told me that you mustn't be shocked when I'm going to give you this news and tell you the news, it was like that. The doctor doesn't give me, didn't give me any education about this.  
Challenge: Lack  
of HIV/AIDS  
training/counsell  
ing
- R: Any counselling?
- P1: No counselling. Lack of  
counselling
- R: Do the children know about their status?
- P1: We told L that she is sick. She knows that, we've told her that. When she came back from school she told us that the other child insulted her. The child here at school, in fact the child said: "You look like a HIV person, child". So it's when we told the child: "Yes, you are sick."  
Stigmatisation—  
insults and  
discrimination
- R: How did she react?
- P1: We told her not to take care of that because she's not that sick.



R: Did you tell her to keep quiet and not to tell other people?

P1: We said she mustn't take care of that because the children at school are naughty.

Avoiding disclosure

R: (addressing participant 2) And T, does she know?

P2: I didn't tell her nothing. But she could see that she got sick but she doesn't know why, or what is she suffering from. It's because we are afraid to tell her, because my sister ... eh ... we've told my sister's child that she was HIV positive, because he got scared. That's why he deteriorated and got sick. So thereafter we told her that she was going to get sick little bit more, because she's a little bit older.

Vulnerability = denial, avoid disclosure, fear

R: I want to return to your discussion on the things that are good in the community that helps you cope. Do you receive any help from school?

I: It's the help that we were talking about the other day. Like the one case where the child was infected here at school and they said: "You look like a HIV child." Then she went back home and tell the aunt that someone at school swear at her. Then the aunt told her that you musn't worry about this people. Yes, you know you're sick, but you musn't worry about it that the truth are noted at school. That gave me an impression that we must talk to our kids here at school, you see, so that they musn't laugh at each other.

Asset: school

Stigmatisation

School as source of support

R: I want to return to what you said, that the hospitals are helping and also the social services and neighbours, and that the people in the community are assisting one another, helping one another. What about the school and the teachers? Do they help in any way?

P1: The principal called me here at school, together with the present teacher. They said they are going to phone for me the social worker. They really phoned the social worker. The social worker came to me the following

Asset: School  
Principal  
Educators  
Social worker

- day, having the **food parcel** for us. She told me that she's going to do that three times, three times a day. She would give me groceries **until we get the grant.**
- Food support
- R: How did the principal know to call you?
- Potential asset: grant
- P1: **In the classroom L got sleepy and the teacher called me.** We came to school and we told the principal, we **disclosed to the principal** and then we **disclosed to the teacher** so that when, you see, she's with her in the **classroom she can take care of her.**
- Educators identifying problems
- Selected disclosure
- Disclose in order to receive help & support
- R: (*addressing participant 2*) And you?
- P2: I didn't tell the principal. **I just told the class teacher** which is **my friend**, so that when she could see that the concentration, there's no concentration in the classroom, *T* has got a problem at that time.
- Selected disclosure to friends & educators
- I: But what happened was that, I had to meet the principal. So **I told the principal, so that we could get help.**
- Disclose in order to get help
- R: Do you think that the school supports you?
- P2: They help me at school because the **teachers here got ... take care of T.** Even here at **school they look** at her. Even once we did go to *hospital D*, the **teachers did go to hospital** when he was, when she was admitted last year.
- Asset: School-teachers as care & support
- R: Are there any support other than the neighbours, or the school or the sisters in the community?
- P1: No.
- P2: No.

R: No support groups? Might it be because the people don't know about the details?

P2: Ja.

P1: Yes, maybe.

R: And you, do you support one another?

I: They don't know each other.

R: But will you be able to support one another?

P2: Yes, I think so.

Potential asset=  
caregivers  
supporting one  
another (not  
mobilised yet)

P1: We can help each other.

R: You might learn from one another and be there and care for one another.

I: Yes, they can help each other. Like maybe with getting the grant, you see, all those things. Even telling each other what to use when she gets sick, because it can help, you see.

Potential asset:  
shared  
knowledge &  
experience  
between  
caregivers

R: Have you perhaps heard about *Sister E*?

P1: I know about *Sister E*.

P2: I don't know about her.

R: (*addressing participant 1*) What do you know about her?

Poverty

P1: She's helping the poor people. If you go there and put your problems down on the table, she can be able to help you.

Potential asset:  
*Sister E* (not  
fully mobilized  
yet)

R: (directed at participant 1) Have you ever visited her?

P1: I did go once. She gave me food parcel and a dress.

Asset: Sister E  
food provision

R: I would like to continue with our discussion on social workers. Are you aware of any social workers in this community other than the one at hospital D?

P1: There is a social worker in this community, but she's only working in school G, and she's very busy and she's dealing with the ... eh, not the problems like these. She's dealing with the children who cannot cope, but not eh these, and she's very much busy. She's working alone in this whole community, especially helping children from that school.

Asset: social  
workers

Challenge:  
limited services  
in community

Challenge:  
social worker  
overworked

R: You are very special people, because you look after other people's children. What makes you special, what good characteristics do you have?

P2: (laughing) We love these kids, because it's our chil..., it's our sisters' kids. We love them.

Asset: Strong  
familial bonds &  
love

R: And you've got the support of the family?

P2: Yes, we've got that support of the family.

Asset: Family as  
support system

R: Thank you very much. Is there anything that you would like to know?

P2: Sometimes when T is sick, when she's not okay, how can I get help? Can I take her to the psychologist or who?

R: A psychologist is a good start, because she was raped as well.

I: I will talk to the principal because the psychologist here is very much busy, even if you've got a referral letter. I will ask the principal to take

Asset: principal

Challenge:  
limited  
psychological  
services

these kids, because they need counselling. But even if we've got the social worker, that would also help a lot.

Need for counselling to vulnerable children

R: (addressing both participants) Is it in order with you that S (indicating interpreter) tells the principal?

P1: Yes.

Asset: Educator

P2: It's good like that.

R: One last question: Do you think there's anything else in this community that is already here, but are not being used but that can be used?

P1: We are planting vegetables at another school, a high school here and I'm part of it.

Potential Asset: Vegetable garden in the community

R: Tell me about that?

P1: We go as a community, go there and plant for ourselves, at the next school, it's a high school.

R: How did you get involved in this project?

P1: There was a meeting, and they said that if you want to have a garden, you can go there. So when you're walking through the National road, they are using that land there for planting the vegetables.

Asset: agriculture

R: Tell me more, where did you get the seeds to plant?

P1: They are coming from the office from the ACVV. They're helping a lot because they are working with that social worker to take care of the kids who are, who have problems, the poor kids.

Asset: ACVV & social worker

Vulnerability of children

R: So that is another thing that helps you cope, as you can now provide for your own food.

P1: Yes, and it, that plot is not far from the ... eh, from my house.

R: Thank you ladies.

**FIELD VISIT 3 – 19 FEBRUARY 2004**  
**INDIVIDUAL INTERVIEW 3**  
**SCHOOL PRINCIPAL**

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**BROAD (FLEXIBLE) INTERVIEW SCHEDULE:**

- ⌘ How is the selected community currently coping with HIV&AIDS and the challenges implied by the pandemic?
- ⌘ Which challenges are faced by the community?
- ⌘ Which resources and potential resources can be identified in the community?
- ⌘ How does your school and staff support community members in coping with HIV&AIDS?

<b>KEY OF ABBREVIATIONS</b>
R: Researcher
P: Participant

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R: *Mr M*, you are aware of my research and that I am trying to determine how this community is coping with HIV and AIDS. Could you please share your perspective on this with us? In your opinion, who and what does this community rely on to cope? I know, for example, about you and the teachers at your school that care and identify children that need support, calling in the parents, helping wherever you can, but what else?

Poverty

P: I wonder whether I'm going to say they cope or they don't cope, I'm not very sure. But I have gone to some families in relation, in particular with those that are having kids infected. What I've discovered is that the neighbourhood is sometimes a burden to them. The neighbourhood in the sense that quite more of them are ... those infected or affected families are mostly below the poverty line type of families. And because

Asset: school  
(provide food)

Community  
Lack of being  
informed.  
Neighbourhood  
(Community  
members)

Identify those  
living with  
HIV&AIDS

Identify needs

Support by  
neighbours/com  
munity



of that, you would have to give something to eat for the kids, they would be observed here at school, because the community do not observe or do not see that, do not understand that probably, at times do not understand that there is somebody that is positive, but at times observe the loss of weight of that particular individual and become concerned, saying probably it's because of the meal and all the likes, and then they take responsibility to be giving some food into the next door neighbour. So the neighbours can also help.

Another thing that I think is very important is the media. The media seems to be playing a predominant role, into spreading the news for the people to understand that HIV AIDS is indeed a reality and that is among people. And another point is that I don't want to seem to be praising ourselves, we are not praising ourselves but we speak about HIV AIDS in a number of meetings that we have. For an example, on the 27<sup>th</sup>, that is Friday next week, we called parents to speak to them as to, to speak about only few things. We don't have a big meeting, we don't have a long meeting, we've got only two items, that purports the academic excellence, to speak about what do we expect from them and again we speak about the social responsibility that we are going to do, not only to the kids that are positive, but to the affected and infected parents as well, because what we have started ... we are starting to get hold of the NGOs so that they can be given some clothes and the meals and with the meal again it can make a difference to one's life. Then again seeming to be boasting, one mother has requested that we submit the names of those that are most suffering here at school. We have collected the name of the kids to the mother, though she's having a link with a rich white man, because he's working for Life Line and that is the person that is very concerned about the plight of the poor people in relation to HIV AIDS.

Okay, why is the community coping? They are coping because that they have faith. One, amongst other things, that I think they believe in is that God cannot just give it or give up, either than that. Now there's nothing more I can speak about in relation to coping, that's why they cope.

R: You mentioned that the media is playing a role. What kind of media are we talking about in this community?

P: We sometimes have **flyers** around here, we sometimes, more often than not, have the **radio and TV, speaking volumes about HIV AIDS** and, here at school **we invite social workers to come and speak about the epidemic and it's spread to the community**. It's like multiplication of information. **We always say one parent that receives information must multiply it to ten other parents**, other families, you know. That is the type of eh media that I'm talking about. And there are **too many meetings** as well here, particularly it's predominantly **African National Congress** area and in a number of meetings that I have attended, they will **always speak about the sketch of the HIV AIDS**. I've been also addressing the communities of this area, wearing a different cap. **I've got two caps**, not this one. I'm also a member of the **Communist Party** which is an organisation that is concerned with the suffering of our people across the colour lines. When **given a chance to come and speak to the communities**, we don't also leave out to speak about the ways and means in which ... that they live without being employed. We speak of what we call eh, the co-ops. When few families around could collect some money, maybe R20, R20, and so on and so on, they start to buy paraffin, they sell, they get the profit, they multiply, they buy more paraffin and they buy bed, tables and so on and so on, basically part of the co-ops and that also plays a role. We speak about the value of the eating, the reason, you know the failure of the government as well, to be limiting to help every family with food – we would understand therefore that this is a capitalistic country, it cannot help a family to eat and the interest of the capitalist country is the profit and not the people, that's what we believe as communist as well. But we are saying the **government is also making a difference** but it is **not enough for people to manage to eat**.

Media as asset: flyers, radio, TV (informative)

School network with social workers – to provide information

Community members as source of information

Asset: political parties & meetings

Principal as informant

Political meetings informative

Asset: government

Challenge: poverty and hunger

R: If I understand you correctly, the political involvement might in other words also fulfil a supportive role in the community?

P: Exactly, exactly. You know, in a family shack dwelling area, because this was 100% shack dwelling area until brick houses were built, but it's a semi-shack dwelling now, because there are still shacks around here, there are the people that always have a hope and whenever a meeting is being called, they come out in big numbers because they always expect for, you know, the work that is going to be delivered on the day. So the meetings are well attended. Maybe I would have to be blamed, they stand in the corners, but sometimes there are no halls, you will get them standing even outside and attending to the meetings.

R: What is the role of traditional healers in this community? Do they play a role in helping the community cope?

P: I would not know, but I would suspect when people are confused, when people are not very sure of whether there is HIV or AIDS, they would go to the sangomas to go and get some help. And I would not be able to say they are really playing a role because it's only from the experience that you can say indeed they play a role. Other than that, there are also false prophets, that they think that they can make a difference. Do you know what I'm saying? One needs a lot of money for say HIV AIDS, knowing that it's a highest illness in the country now that kills, that false prophets say they can be in a position to cure it. So I don't know whether they play a predominant role, but I suspect they don't have a role to play for people.

R: Faith in God seems to play a bigger role in this community?

P: Yes. This area is predominantly church going people, it's predominantly a church going community and a predominant church going community always has faith and hope that God will provide. Do you get what I'm trying to say? They have a hope that one day this disease will come to an end, and that is part of faith, you know.

Hope as coping mechanism

R: Does the church provide a lot of support? Do they, for example, have support groups that can go out and support people or are you not aware of any such activities? Or is it only when people disclose that they are supported?

P: I, we, there's a stigma and people seldom disclose in this community.

R: Why?

P: Because of the stigma. But some disclose naively, they don't disclose what they want to disclose and apparently when both parents pass away, probably the guardian manages to say to the community I've got this child that is HIV positive and both parents have died because of related sicknesses. But the disclosure is very rare to happen. I've got one child here who is affected, not infected – the mother was buried during December holiday, and that was never disclosed. The mother used to come and assist here at school. That's one example of a family that never disclosed. But on the day of the family I attended that funeral, on the day of the funeral the friend was a speaker, we normally have a lot of speakers in our funerals. The friend was a speaker, the friend stood up to say: "It was two/three years ago when my friend disclosed to me that she's positive, and today I'm proud to say that she was living her life good and that she lived her life for three more years". And then apparently, it, probably it's an assumption that the woman has died of HIV AIDS related sickness, that the husband is also HIV positive, because when he came into my school sometime this week, he was carrying a very bad face with sores and to me, by indication it might be that. But what I'm trying to say is disclosure is very rare, it's only naïve people that are disclosing. And what is very bad is, they don't have confidence. That's what is lacking, that I've observed. They will tell this child is positive and open about it but there was no pre- and post-counselling, so people were not even exposed to counselling. Both parents have passed without disclosing and then the mother or the guardian that remains does not know what about counselling, what about

the importance of being confidential, but some kids are seemingly are taking strain. Yesterday there was one child here, you might have seen her, she was sitting there. She normally comes there every break period.

Principal providing food (poverty)

I have this food about everyday for her, she is confidently coming to this office, sitting there every break. But I've spoken to ATICC, they've already given her some support and all the other children that need it too.

Asset: NGO (ATICC) (food support)

R: ATICC seems to be an important resource in this area?

ATICC/NGO'S as asset

P: Ja, ATICC it becomes a very serious resource and mostly next year it's going to be even much more important. It was not focussed in this area until this year. Then I attended a workshop, when I told them of the plight of the communities of the area and now they have already attended to three kids here at school and they promised next year they have decided to be more involved, in good time so that they can do almost everything to make a difference to the children.

Asset: principle as networker

Support by ATICC to vulnerable children

R: What is ATICC's role? How can they help this community?

ATICC/NGO'S as informative workshops

P: They conduct workshops. They make pre- and post-counselling. They also provide clothing and food, especially for the families that have need, that's what they do. And they are working hand in glove with a number of NGOs and organisations, they are housed at Vista house, which is a municipality area in town and they've got a very good man by the name of H, a good man, he knows his work.

Counselling Providing in basic needs (clothing & food) poverty networking

R: Please tell us about the NGOs that are involved in the community?

Assets: ACVV, ATTIC (combat poverty and allow for job provision)

P: The very obvious one are probably Holland link, that is ACVV. ACVV plays a role meeting the needs of the communities of the area. That is one predominant NGO that plays a role in the area, and it also creates jobs to some parents, bead making, basket making and also providing some manufacturing work like making tracksuit of schools and employ

the communities that cannot afford it. That is ACVV, that plays a very serious role in the area.

ACVV as important asset

R: Who is the contact person there?

P: I know of an auxiliary social worker, B. Her office is there in AP, she's operating from there. Then there's also the white ladies, the very old white ladies that sometimes visit here, it's very unfortunate, but it's deep too Afrikaner names.

Asset: social worker

R: The reason why I ask is that I have been trying to contact them, the ACVV, but without success.

P: I can try and get hold of B, then you can be able to get hold of ACVV, because they are playing a very predominant role. Then there's also something that takes place at clinic Z, which is led by a man called M, who is also an auxiliary social worker, that looks very seriously into the plight of the most suffering people of the area. The M I heard is the same one that's there at the clinic, near the university. It's there by the mission, you just pass their, and this M he's a very good man, he does the best work.

Asset: principles networking ability

Asset: clinic/social worker

Asset: clinic, principle's knowledge

R: Thank you, I will also try to contact him.

P: But having said this, it is indeed very painful, the ignorance some of the parents are still having. It is very painful, the ignorant, the educated people are still having over the problem. It is very painful but we do get some workshops that are done via the course of the Department of Education. We seldom see officials of the Department of Education, to become part of such workshops, because some people are by nature corrupt, when they don't see any supervisor, they even make workshops half way – do you get what I'm saying? And it is indeed painful to me, not to hear in various principals meetings the manager of the area. For me, the great concern of the Department is teaching and learning which is

Challenge: community members sometimes ignorant

Asset: department of Education (workshops/information)

Asset:  
department of  
Education  
(teaching and  
learning)

good. But you cannot take teaching and learning in isolation with a social problem of the communities. You can't, what I mean is it's like, we cannot at this school be an island within South Africa. And this year we have declared that we are going to make a difference, and not in the classroom alone, but in the communities. In the next five to ten years they must always remember that there have been the teachers in the year 2004 that have been very concerned with the plight of the communities in which we find ourselves in. The very unfortunate part of it initially, is that teachers as well can be part of the problem.

School as asset  
/resource in  
community

Assets:  
educators

What I'm trying to instil and it's happening gradually, it's that all have got to understand that we are the part of the community. Most hours of the day we are here and we are going to be here most of the more than 20 years we are going to stay within this area, and therefore you become a part of that community, by virtue of also your employment. I hope and I wish when you shall be coming down to school in future, we must continuously know of the importance of the value of the community and the norms and value of the community in which people are finding themselves. The norms and the values of this area might not be same as the norms and the values of the area where I stay and for us to be able to work very well in the environment, is to be able to understand the norms and values of the community.

School regarded  
as part of the  
community

School as asset

Asset: school's  
insight into the  
community

R: Please tell us more about the school's declaration that you mentioned?

P: You see, one of the important things to me is that by nature all people are different, each one is unique. We've got different ways in which we present ourselves to the learners. But it is important the manner in which we handle the HIV cases. They need to be loved, the manner in which you speak to the kids becomes very much important. Because not all kids are homogeneous in the class, some are infected and affected and they easily get traumatised. And whoever is HIV positive, is easily being stressed and stress complicates. So this is one other important thing as to how do you handle your children. Some people they are character

School as  
supporting  
and loving to  
those living with  
HIV&AIDS

vulnerability of  
children



into shouts, but how do we manage ourselves and how do we handle the kids? I'm known here to be a spoiling father at the school. I don't know how many times kids have been turned away in this area by the teachers, because what I do, I go with them, they go around with me, and I handle them like they my children. So I'm said to be a very spoiling father because in order to be able for the learners to be able to learn, show them love to them. And shouting, shouting your anger, you are not sending the message by shouting. You talk in a proper manner, you talk. You don't have to shout to show anger, you don't have to shout, you say it calmly. You talk very nicely, then you make a difference.

Principals and teachers-basic respect & love to all children

Asset: Loving teaching approach

R: Please continue.

P: You seem to be very willing to work. I think the school's strategy as well, maybe does not necessarily speak very much on our programme. But what I'm going to say is, it must be good at times. You blow it out in a breath, you tell them it's a confidential, then you work with the willing parents to come out and to expose what you have managed to unlock as the hidden people. But that we will need their agreement to that type of an arrangement. When you call the press you say the plight of the almost poor, these are the kids of the infected and these are the parents that are affected. My view of that is, I know the press can break you, but it can also build you. My interest here is to make the point that a good Samaritan can as well see how can they assist this type of families. There are people waiting outside there to assist with the families that are impoverished, that are positive, but they cannot be able to assist them when they don't see them. And the people in the area must also understand this indeed exist within this area of operation.

Asset: school's respect of confidentiality

Potential asset: Media school role in helping to identify how to support them  
Outside help-poverty

R: Why is HIV&AIDS stigmatised to such high levels? Is it about morals? Is it about shame? Is it a cultural thing? What is your view?

P: It's so difficult to understand. It is indeed very difficult to understand. We would have to move from the case in which a woman in Soweto

Non-disclosure due to fear of death

disclosed and then was killed. And supposedly to be the turning curve in the plight of the HIV positive people. If you compare the lady that was killed and the young Johnson, that guy Johnson, who died a hero but that lady died a villain. It's in the sense that Johnson, as young as he is, went around the world and told the people indeed that this exists. The only thing that I would suspect why people are hiding this is because they are probably afraid, some individuals interpret to be positive as you are positive because you are corrupt, maybe you are linked with a prostitute or maybe you've been going with truck drivers. You know these are the type of attachments to one who is positive, and that's not looking into whatever else. So the moral issue becomes a big problem here, that people are now fearing because you are being isolated immediately you disclose. And more often than not, most people stand to move away from you, because you are positive, and not positive enough to understand that you can live longer, as long as you know yourself, because people can live short lives because they don't know themselves. They don't have safe sex and they can live their normal life, the virus is still hiding somewhere within one's human body, you know. So I think the one that is positive is supposed to be worried to be very healthy, and to be very fortunate to know the status than to die by sudden death, because you did not know that you are positive. Because when the virus goes down you go, when it goes below 200 you go.

R: Is there anything else that you can think of, that might add to my understanding of this community's way of coping?

P: What I want to say to you is that I wish you to apply whatever you learn here. I believe that the one who is educated but does not manage to apply it in real life, in daily life, that person is illiterate. You cannot be known to be highly schooled but then not apply the knowledge that you got from the institution. I wish that you can be successful and I'm 100% sure you will be successful, by the way. Your approach to it is very obviously, by hook or by crook you have to go through. But the only thing that is needed, after you have acquired, you have to apply in a real

life situation because some people are studying and when it comes to real life operation you don't see them anywhere.

R: Thank you. *Mr M.* It is my wish that this study will make a difference in this community.

P: You know it's indeed very unfortunate, researchers can sometimes make a lot of damage. And even now there's a big wall in between ourselves in this country, some people they can live in a luxury life, not understanding what's happening in the other communities within your own country. But all the positive people shall never fail.

R: That's what you said the other day.

P: I'm telling you, **positive people shall never ever fail**. I continually tell teachers, I continually tell parents, I've come up with a project now. After the 27<sup>th</sup> they are going to clean the school, that's going to happen. **They are going to be given computer lessons at the Technikon**, for 80 teachers and parents.

Asset: principles  
positive attitude,  
negotiation  
powers

R: That's wonderful!

P: Yes, that's an incentive to pay for them to come and clean the school and for the school to be in a active programme. We will be able to **access resources**, paint will be available immediately, **this is what I've got in one of the NGOs**. And then I'm also **working with people from Netherlands**. What I'm trying to say is, there are quite a number of incentives for the teachers in the community, and **I am going to keep on trying, I want to go and unlock other opportunities for the community in which I find myself in.**

Principle as  
asset:  
-networker  
-initiatives  
-positive attitude

R: You are constantly on the look-out for opportunities.

P: Yes. So imagine, they are going to be transported from here to Technikon free, and the company will pay for them to go to that

Assets: external  
funding  
agencies

workshop. And the kids at this school is going to be the centre of arts and culture, because **there are people that are funding the school**, they want to convert one of the classrooms to be an art class. They are doing visual arts, they've got a number of activities they do and we'll have a workshop with one lady. **Then our kids are going to get to a national competition of drama** and they are going to be transported from here to Technikon to be trained seriously on art, and to be able to learn at the early age as to how to write their own scripts. These are the **opportunities that I'm trying**, so that we can look at the kids that are going to, at the end go to Grade 12 and to the universities, they might, they must have something to do. That's what I'm also trying to do.

R: It certainly is a lot of opportunities.

P: And it's **because of positiveness**. You know, my teacher, *Dr H* said to us: "*If you are positive and you want to, you can go and break the wall*", which was a greatest exaggeration. I normally say to the kids: "*There I put R50 on the wall, go fetch it. Because if you are positive, you can go, you will think as to how do I go there. Then you go around and look for a ladder, you go up the ladder, you get that R50*", it's a matter of being positive and not to say things cannot happen. That's what we do. So if **you are positive you can be able to do anything, that's true.** Yes, *Dr H*, he was a good man, he also ... he used to say: "man is my brother not by blood but because we share the same burdens". He was a clever man.

R: *Mr M*, thank you very much.

**FIELD VISIT 3 – 19 FEBRUARY 2004**  
**INDIVIDUAL INTERVIEW 4**  
**CATHOLIC SISTER AT COMMUNITY CARE CENTRE**

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**BROAD (FLEXIBLE) INTERVIEW SCHEDULE:**

- ⌘ How is the selected community currently coping with HIV&AIDS and the challenges implied by the pandemic?
- ⌘ Which services are provided by the community care centre in the selected community?
- ⌘ Which role is the community care centre fulfilling in supporting the community in coping with HIV&AIDS?

<b>KEY OF ABBREVIATIONS</b>
R: Researcher
P: Participant

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R: Please tell us about this community, the challenges it faces and the ways in which it is coping with challenges such as HIV&AIDS. Secondly, please tell us about the services that the community care centre provides in the community, in assisting members of the community in coping with HIV&AIDS.

P: In my opinion, one of the biggest problems is poverty. You know, some people still say it doesn't exist but the reality is that it is mind-boggling, you know. That is the reality and we cannot get the poverty to go away. Now eh ... this morning for instance, there's a woman in there with me, she's 29, 30, and her mother is very sick, and her mother would be in her mid-fifties and this woman had a partner who committed suicide. But it was going very bad with them, to the effect that they had nothing in the

Challenge:  
poverty

Challenge:  
Illnesses

Suicide/loss of  
hope

house to eat. And he had, you know he had TB and there was no possibility, no way that he could get work. He used to come out and walk around and walk in the suburbs and collected the people's cans and that kind of things, you know. And he did that every week, you know, but anyway, he just couldn't keep facing the poverty. Now she's left with six children, you know. Now there's no school fees, there's no school shoes, there's no eh ... none of the school requirements. And sometimes they come here, having nothing. So that is the reality, and the school fees and all that. Now, what we do with the people one to one and I even found myself saying to M yesterday; "It's just wonderful we have such a passion for the people", you know, that we like talking to them and we are liking that. We say: "Poverty can attack you, yes that's true, but the ability that you have within yourself is more important." And they don't believe in death and I will definitely say that that is the one thing keeping people together here, saying that it's okay. And they can still laugh and they can still be nice to each other, they can still make space in the seating accommodation out there. I admire them even for that. The idea that they all trash together and somebody comes and they can see that woman is pregnant, she's having a baby or she's very sick, they'd still make space for her and give her their place. Now I see myself, that is a great policy for any person to have. It sounds stupid, you know, but that they have this, where as we are a bit more fortunate, you know. And I have to be honest here, this is the kind of extra that you can approach life with, they are making the most of what they have in that way.

Now, you know, I think the thing that we can give the people here is our time, our love and our care. And that I think is a challenge for every one of us to do, you know. And uhm ... you know it's then, when people realise, I actually have to ... just say I am HIV and you are not, and then you make me realise it's okay. Yes, I do have this illness but basically we have the same strength, you know. And whatever that is, I don't know, but it's kind of building a relationship with each individual and when we do it with one it just spreads. Now just take for instance, we

had a woman here two/three years ago, and she was very hypertensive and she was living with a **man who was very abusive**, you know, and he said to her I want to have a big family. He wanted to prove to his neighbours that he was a real man. He used to say that to her. So she had baby after baby after baby, you know. So anyway, **at the age of 32 she got a stroke**. So I said to her: "You leave the last baby to him to see to and you go for a walk." And she said: "No, I can't do this." I said: "Okay, if you cannot do that don't come to me next week", I said to her: "You deserve that time", I mean I knew she didn't want to **lose her friendship** with me and the **relationship** that we had over the years. I said: "You give him the baby and let him realise what it is about", I mean a crying baby with **no food** for the baby, you know. So anyway, I said: "Come back next week and tell me you have walked five times in seven days." She came back and told me she left him with the baby, the baby cried every evening of the week for its mother and she went for a walk and she felt so good when she came back. Anyway, **she began a walking club**, and now she has a walking club together, you know.

Challenge:  
abuse/violence

coping with  
illness  
community care  
centre  
Outsides serve  
to inform, guide,  
counsel and  
provide  
friendship  
Challenge:  
poverty

Community  
members  
supporting one  
another (sense  
of community)

R: That sounds amazing.

P: Yes, it is amazing. Now **that woman had nothing** and that **man was not able to work**, he had a car accident, you know. Anyway, that was another story. But that was just one private affair but it **still did not fill that empty tummies of the children**. But they had a mother that was more patient with them. She had now achieved a partner that knew I cannot have another baby. She knew that he would now understand that they had a family and **that they had nothing to feed another baby**, there's no more babies in that house now. That child now has gone to school. And it was great for him to get that experience and it was great that she, you know, that she really in a sense would say **her friendship with me that we kind of value**, that she wasn't prepared to sacrifice this, you know. Anyway, now her blood pressure has gone down and she's better, doing the vegetables and all. She never comes here anymore. That was a good one. But look, the thing is that we'd all love to believe there are no

Poverty –  
unemployment

Support by  
professionals/  
volunteers



poverty and I suppose in a rich country like South Africa, you know really we are part of the outcome of apartheid, we know we are. And I think you know, they have learned to say I need this or I need that, but now we don't create a system of hand-outs here. So what I think it is, the system of apartheid is that just because I have a different colour skin I don't have the same rights and that is really being mean to people. And that is what we are trying to correct, but that is a huge struggle. For example, before I was speaking to a psychologist, we were all supposed to be able to speak to a psychologist. Like I remember at my sister's home one day she said to me: "*I feel so sorry for these people, especially the babies that have to grow up.*" And I mean we all know that, these people often suffered and have babies that grow up and suffer. And the people here, you know, they grew up here, they're living here, they were so inferior and it is so imbedded in them. It is imbedded in the people, you know. And I thoroughly agree with the philosophy that people have it in them to help themselves and cope with HIV and all this, but the reality that we are working with here is that it's a world of pushing the limits. It's a war that should be pursued, you know, that we fight against it and that one day it's true, it will be true that I have it in me to fight this.

Focus on empowering community members

Negative outcome of apartheid

Belief community can cope/able to cope

Life=challenging

R: Do you attend to the people of area X, do they also come here?

P: We attend to all. Yes, very much so.

Community centre as potential asset

R: And do the people approach you or how does it work? Do they just come here? What is the procedure?

P: The people, some people actually know they can get help here. They can get like nutrition and attention here and they tell each other. We also stress amongst the people that anybody and everybody is welcome, because we believe if you need help you can come here and they always come, day by day, and sit in the long queues and wait for help.

Community centre  
-support  
-medical assistance  
-nutrition

Community members share information= strong communal feeling

R: How many people on average per day? More or less?

P: It's such a difficult question to answer ... I would say ... It varies, but it's a lot of people and families everyday. The queue is very long ... All the people that want to come and need help, they just come. And then there's also the school, you see, that's the thing, the school also has a section. And when people come to me that has children that's not in a school, I see such families everyday, I'd say, I then tell them to go the teachers. You know, if the person says maybe the children isn't in a school.

R: You refer them to the teachers?

P: Yes, the teachers.

R: How many staff members are assisting you here?

P: We're thirteen all together helping at the clinic. Uhm, I'll ask *M* to check the statistics and tell you, because that would give you a rough idea of how many we see per year. It is mind-boggling, you know. And that includes those for HIV and AIDS, the infected and the affected. It is a factor you know, because mentally the people who are not infected they are affected. They are affected and literally they become as infectious, you know, because all they can think about is the infected.

R: The whole community is affected.

P: Yes, absolutely. Absolutely. And then to see the poor little children, you know just looking at them and their dying mothers. You should see them when they stare at their mothers. They know that she's sick, you know, but ... it's just so sad.

R: Do you have a lot of people disclosing to you?

- P: I, ... Yes, a lot of them do. **I would recognise it anyway**, because of what they say to me, when I ask them: *How are you feeling?* and they will remember when they came before that, and then we will talk and then eventually they will say that they're HIV positive. **They would tell me in various ways. Some don't, but a lot of them they do.**
- R: I ask this, as non-disclosure seems to be one of the challenges faced by this community.
- P: Ja, well, we have a lot of **stigma**. It's like, seeing that my mother won't allow me to cook, they won't eat when I cook, you know. **They won't sit beside me, those kind of things, they won't touch me.**
- R: A lot of myths.
- P: Ja, and the thing is that, how will I say, they know that **they will be isolated from the community, they even look funny.** I had one lady like that and I really took care of her, but anyway she suddenly became special, you know. So anyway, another one came to me after a while and she asked about this lady and I said to her: *"I don't know that she has AIDS"*, you know. *"It's a pity if she has AIDS, but she can get treatment"*, but **she didn't want to disclose.** I don't think we will ever be able to get into the mind of a person who's got AIDS, you know, because it's like a person who has cancer, **they need the treatment**, you know.
- R: Do you assist community members who are HIV positive or living with AIDS with grant applications? Do you give them guidance on how to access governmental grants?
- P: Yes, I do, and then **we also try to help where we can.** I find myself give them help. I'm often going **out there, trying to get donations from the private sector for me to buy the food supplements,** which is sometimes expensive.

Ability to identify people living with HIV&AIDS

Disclosure to trusting volunteer/ Sr E

Stigmatisation based on myths and misconceptions

Avoid disclosure due to:

Fear of isolation/ rejection and being different

Non-disclosure

Need for treatment to cope

Community centre:  
-advice  
-getting donations  
-medication  
-assisting with grant application

R: *Sister E*, thank you so much for your valuable time and the video on the centre that we could watch. I'm sure that I will get the necessary detail about your centre in this brochure and if I have any other questions, I will ask *M*. Thank you for making the time to see us.

P: You're welcome.

R: Thank you! Your centre is a great asset in this community.

P: Thanks, Ronél. I try to help where I can. But I think, just by being there for them and loving them and believing in them they are already helped. We don't care whether or not they're positive or whatever. The mere way that they believe makes it easier, however difficult it is. And another important thing is acceptance, you can't do anything without accepting your situation and give it your best way, which is whatever.

Sr E as assets  
in coping:  
-presence  
-willing to help  
-loving and  
-accepting

R: I get the idea that the faith of the people of the community is one way of them coping with HIV – it seems as if the community is religious and rely on their belief systems in difficult times.

P: Ja, they do believe in a higher power, that there is a higher power helping them.

Faith central to coping

R: What is the role of traditional healers in the community?

P: They are important to some, and some will go there if they get the chance.

Traditional healers role is limited

R: Thank you once again for all the information.

P: You're welcome.

**FIELD VISIT 3 – 19 FEBRUARY 2004**  
**INDIVIDUAL INTERVIEW 5 (INTERPRETED INTERVIEW)**  
**FAMILY OF A PERSON LIVING WITH HIV&AIDS**

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**BROAD (FLEXIBLE) INTERVIEW SCHEDULE:**

- ⌘ How are you coping with a family member who is living with HIV&AIDS?
- ⌘ What are the main challenges you have to cope with related to the fact that a relative is living with HIV&AIDS?
- ⌘ Which resources in the community assist you in coping with the challenges you face?
- ⌘ Which potential resources might assist you in coping with the challenges you face?

<b>KEY OF ABBREVIATIONS</b>
R: Researcher
PS: Participant sister
PM: Participant mother
IF: Interpreter and family friend

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R: *T (indicating interpreter)* told me that your son has been diagnosed with AIDS. Could you please tell us about the time when he found out about his status. How did it happen? How did you feel? What did you experience during that time?

PS: She (*indicating participant mother*) was **in shock** and **it was a burden**. Now when we had the problem, we had to sit down and tell her that. Before we talked to our, to our brother, we talk first to the woman, my mother ... and my mother understands and then after that we talked to our brother. And we all **understood that HIV is not a thing that you can**

Initial reaction of family: shock & being burdened

List of research project topics and materials

Hospital as asset: counselling

Family as caregivers

die of now, you can live longer, because we can see it even through my mother. Because even she is diabetic, but she is living good.

R: Where did you get this information, your knowledge on HIV and AIDS?

PS: The problem was that my mother was sick, she's a diabetic. Then the hospital said that they will take him, and counsel him because he was very sick. And you have to understand now, my mother is sick, I must look after her. And it's then when I felt that I must go to learn ... this thing, home care. Then after that I came to become ... a home care in home nursing. A home care home nurse ... has to care.

R: That's true. How did your brother find out about his status? How did he decide to go for a blood test?

PS: He felt sick, ne. At the time he wanted to close the door and after 30 minutes he was asked to, to, to open the door, and then now he started out saying something ... but he was coughing and fighting here at the house. Then we as a family we sat down, but it's not us who saw that this man is sick, it's my other younger sister and she phoned. My sister then she phoned and then said no, something is wrong, because we could see what he was doing now is not the same thing he used to do, he was not like that before. Then his friend talked him into going.

R: So Z new first. Did he first tell her and then he you and then you told your mother?

PS: Yes.

R: How was it for the family during that time?

PM: It was a difficult time to everyone ... to everyone. First I said: "Not in this house, not in this house!" I could not accept something like this in my house. But we accepted it, we must accept it and that one (indicating

*participant sister*), we are so happy in this house because it happened to us, but what is difficult is because **we are going to look after him** but we didn't know what is wrong with him, but we thanked him because he **opened up and then we looked after him**.

Acceptance of relatives

Family as care & support

R: It is challenging to deal with something like this. Please tell us about the challenges you have to cope with. What is difficult?

PS: My brother he is a generous man, the second thing ... **he didn't want to go to hospital**, the third thing is, he said to everyone, **he didn't want to eat right**. We had to sit down **and fight with him**, but in a right way. We talked to him, you see, but in the right way. ~~And then the minute he decided to go to~~ **hospital**, *hospital E* because we talked to him and he decided to go there, it's not us who send him here. The hospital gave him a date and said that he must go back there. It was last year when he was admitted, then we used to be with him, **he has got that courage to want to go to hospital** because **he could see that he was very sick**.

Reactions to being infected: anger and denial deny treatment

Hospital as asset to people living with HIV&AIDS

Courage of people living with HIV&AIDS

Awareness of own illness

R: Was his health deteriorating at that stage?

PS: During that time, yes. It was early last year. Maybe February.

R: Did he take medication then? Did he start with medication at that stage?

PS: **That's right**.

Asset: treatment

PS: Ja, ja.

R: Please continue. What happened then?

PS: Yes, after, after Z took him to hospital, then the **doctor** arranged that he's supposed to be admitted and treated in that **hospital** that I told you, the hospital. So it's when **he got the treatment there**. He, he, he wasn't an

Asset: Doctor

Hospital

Treatment



outside patient, they had to treat him inside hospital so that he can be very much better than he was.

R: How did you, as his family, cope during this time? How did you deal with it?

PS: I do cope because in everything you do **you must pray, if you pray and you believe then God will hear you**. But now, there were times whereby **it was difficult for us because** when we go to that place he don't eat the food, he only **share to all the people** and now we found out that even it's that food you sent him. Sometimes you, you, you **give him money** because he likes money, he would say "*I want money*". You buy for him, he says he's going to buy oranges because they mos said he must eat fruit and all that, the **nurses at the clinic said** that. Then he would **share to all the people**, maybe he only has this R10. I told myself that if I gave him this R10, I will come next week Monday, he will have this, those fruits, but when I come in he has nothing, he only has food, because **he share with other people**. Now you feel that: "*Hey man, this man, why you're doing this?*", but you can't shout him, because **he shouts you first** and say: "*Where's the fruit and all that and all that?*", you see. You **must tolerate**, you see, **you must deal with that**.

Faith and prayer as way of coping  
Challenge of coping with relative living with HIV&AIDS  
Care and support into money  
Feelings of collectivism  
Asset: nurses at clinic (information provision)  
Communal belief/collectivism  
Feelings of people living with HIV&AIDS Anger due to status  
Challenge of coping with the feeling of a relative living with HIV&AIDS

R: Who helps you to deal with it?

IF: What was happening there at the **hospital** ~~is ... because I know what happened there~~ (*laughing*). He could see that the other people are very more sick than himself, then he should feel pity for them, not for himself. As a result what happened there, they ... usually when somebody had to wash for the whole day, he would take that somebody because the nurses got tired, asking this gentleman to wash but **her brother used to take that gentleman or that somebody**, that patient and **wash him himself because he wanted those to get healed**, you see. That is the type of person he is. So sometimes, what we are trying to say, they gave ... he, he gave them a difficult time, because sometimes, it's **far away to go visit**.

Asset: hospital  
Community members supporting one another  
Challenge to visit relatives in hospital

- him, so **they had to leave some money** so that he can stay for four days or for two days or something, but **he would share that money amongst others**. You see, at the end he's left with nothing.
- PS: Ja, **even food, he would share everything**. So it becomes **difficult for us to cope with him** because sometimes you will take this and **this is your last money, it's the last food** ... you prepared the food and you know that this **food is healthier** for, because you know mos this **hospital**, the government is doing nothing but they are there. Even the nutrition that they got is ... it's better here in our house than to go there, you see, but they are there so that they can get **good treatment** that they are not going to get here, you see. But we bought for him the **vitamin supplements** so that when he's there he must also take the supplements.
- R: Who is helping you with money to buy these things? Is it only you and your mother and your sister?
- PS: Yeah, it's **me, my mother and my sister Z**, and even this one *S (indicating interpreter and friend)* ... **she supports us**.
- PM: Ja, **she supports us a lot, this one** *(indicating interpreter and friend)*.
- R: So it's the family, the sisters, the mother and the friend, helping with food and money and emotional support. And you mentioned that the hospitals and clinics help.
- IF: **The family is very much supportive**. I remember one time, because he didn't want to go to this hospital, they asked me to come so that I can talk to him, so that he can go to hospital because they **could see that he, he, he was sick**, because he get cold and was coughing as we had said. **So I talked to him** and I promised him that **I will visit you** and you know your mother loves you, she's going to miss you, she's going to visit you and you know your family. You see, he is **healthy because of this family support**, because the family means a lot, especially his mother.

Financial support by family

Community members share financial resources (support one another)

Support one another, (food)

Family members find it difficult to cope

Poverty

Diet is important

Assets: government, hospital

Family members support and provide: financially food supplement

Family and friends as care and support

Family as primary care and support

Ability to identify people who are ill

Friends as sources of care and support

- IF: (addressing participant mother) You spoil him. She (indicating participant mother) loves him like a younger one. Family as source of love
- R: Tell us about that. Family as source of love
- IF: She loves him. She doesn't want anyone to touch him.
- PM: He's the only son, and he's somebody that never would get cross. He liked to, to, to laugh with everybody.
- R: Has this changed?
- PM: It's changed yeah, because he's sick now. Changes in people living with HIV&AIDS
- R: How difficult is that for you? Difficult to deal with HIV status of family member (son)
- PM: It's very difficult as a mother.
- IF: It's really difficult, because sometimes she would phone Z at work and say: "Z, your brother doesn't want to eat, your brother doesn't want to drink the ... his pills". So Z had to come here and talk to the brother, but he's a good listener, because when somebody talk to him he would listen. Resisting care and support  
Family as source of care, support and advice
- R: How old is he?
- PM: 45, 46.
- R: Who else support you?
- PS: Nobody.
- R: Nobody else?

- PS: There is a lady here who is a nurse, she's the other one who supports us. Asset: nurse
- R: How does she support you?
- PS: She comes here and talk to my mother and all that. Nurse: as asset  
home visits and  
counseling
- IF: She gives them support instead of counselling because knowing that she's a diabetic (*indicating mother*), you see. So that she can accept that more than she accepted it.
- R: What about the church? Do the people at the church know that he's HIV positive?
- PS: Yes, we shared with our church friends. We disclosed it. Disclosure to  
church friends
- R: Did you discuss it openly?
- PS: Ah-ah, no. We only shared with our friends. Selected  
disclosure:  
-friends only  
-church friends
- R: Only with your friends? And at church?
- PS: Ah-ah, no. Only our friends.
- IF: There are some people at the church who knows ... the friends. They (*indicating participant mother and sister*) don't hide this thing. That's why they get help easy because they talk about it and their brother, even that one talk about it. Disclosure leads  
to care and  
support
- PM: That one talks to everyone.
- IF: And he doesn't have a problem to disclose it. disclosure
- R: Do the people at church that knows about it also support you?

PS: Ja, they also support me. **The friends support us there in church**, ja.

Asset: church as care and support

R: And your other friends?

PS: It was to me ... the time I heard about it ... I'm working shifts, even now I'm working shifts. When I come in, I heard this rumour. Then at work I have to hold up at work because I'm a care person, then I, **I didn't work like the way that I used to work**, and then my friend asked me what was wrong - the coloured. I said: "*No, I have a problem of this and this and we are hurt about this and this*". Then she called the other girls at work who's coloured people, she called the other girls and **everyone was saying: "Sorry people, sorry people, sorry" to me**. Even last year we had something here, I didn't know that they noticed my brother, my brother was here. Then they told me that ... they told me that my brother is looking very, very nice. We share with ... you share with us, **now we pray for you**. I just thanked them. You know, because they are younger than me but **they helped me**.

Becoming aware of status of brother: influence on work initial difficulty in coping hurt

Colleagues/community supporting one another in handling the news of infected relative

Prayer as way of supporting others

Colleagues as source of support

R: So the people at you work know too?

PS: Ja, because **we shared it**, because this **man share also with the people**.

Disclosure to family's colleagues leads to support

R: Are there any people that had contact with you before your brother disclosed but are now avoiding you?

No rejection based on disclosure

PS: **No**, because I support people also. If somebody, if my friend has something I support her and other people. That's why I had **lots of support when I had this problem**.

Community members as source of support to people with a relative living with HIV&AIDS

R: Does your brother receive a governmental grant?

Assets: grant and doctor

PS: Ja, the **doctor** gave him the **grant on investigation**. But the doctor cut it down, they cut it to ... he was there for three months, and then he come

there and had to eat the food outside, though in the clinic he had it for three months.

Asset Clinic

IF: What happened is that last year when he was admitted there, he's supposed to stay for six months, they used to stay there for six months. So what happened to him, three months was inside, there by **hospital E**, then the three months he was **treated as an out patient**, taking his treatment here in ... **at the clinic**, not far away from here. Then, **what** happened is **they prepared a grant for him**. When he went out of hospital, the grant was already approved.

Assets in coping with HIV&AIDS: Hospital, Treatment, clinic, grant

R: So the hospital assisted with that?

Hospital as aid helping to access grants

IF: Ja, ja, ja. They do **organise for them**, for the people who are admitted there.

R: Why do you think some people don't want to disclose their status?

PS: Sometimes the **people like to gossip**, ne, **about your health, in our culture**. It's when a, a, a person don't say, because it's because of you ... ya, talking about their health and all that. You don't come and help. The only thing, if you come ... if a person come to my place, the only thing is, **he's going to gossip about my brother**. We heard about that thing ne, but we don't like to fight with the people, they are like that. There's **a lady here, who, who talk about my brother**, that he's coming here, he's not coming to *hospital E*, because he's about to die. And it's like that. **That's why people don't want to talk about their health, you see**. To other families, **in other families, they not even wanted to come inside, because of this disease ... in our culture**. I will give an example now here in my area. In this corner there are **two guys who died already of AIDS**, and in this street, in two houses, there's a girl from uhm, from Jo'burg, **she died yesterday because of AIDS**, and **they don't want to share with the people because the people are going to gossip**.

Lack of disclosure related to stigmatisation (gossip)

Challenge stigmatisation based on culture

Non-disclosure: avoid gossip

Isolation due to status relating to culture

HIV-related deaths

Non-disclosure due to gossip

- IF: That's why they also **did suffer because of the disclosure**, but they didn't take care of that, knowing that **they supported their brother**, as you have heard, if you have heard it correctly. They were talking as if their brother is going to die now, so they're going to buy food and be with them on the funeral. In our culture and we understand it, **it's really our culture**, and it's the **gossip we never had**. If they should have taken that gossip and take it as an issue, they should have suffered also, but because they **don't care**, knowing that the person who has got this HIV virus has no problem, and they, they, they are **sad as a family** also haven't got a problem with that. So it's difficult for an outsider even if he can talk to whenever he wants to do that, you see, but some, the families are not always the same, **some when they hear those things, they got hurt, got fights**.
- R: (*addressing interpreter*) But you, as a friend, seemed to have been very positive?
- IF: Ja, ja, ja. **I was very much positive**.
- R: You almost stood up against the gossip. You didn't push them away?
- IF: Ja, ja.
- R: What has changed over the past two years? What is different? For example, are you making special meals now?
- PS: It didn't change, because we have, we used to **eat veg and all that, fruit** and all that, because of my mother.
- R: Because she is diabetic.
- PS: Yeah, and we **don't use too much oil**, because of my mother. Now my brother, he, he didn't have a problem with that. You know he didn't take
- Disclosure leads to negative experience
- Family as source of support
- Culture relating to stigma  
In order to cope - ignore gossip - don't care attitude
- Sadness experienced by relatives
- Pain and conflict caused by gossip
- Friend as source of support- being positive
- Healthy eating habits as components of coping



oil, he looked after himself. Instead he ate all, like ... even ... we were giving him supplements ... that is good for what he is suffering from.

Supplements provided by family in taking care and supporting

R: Is there anything else that has changed? Or did life just go on?

PS: The life just go on, but we had a problem with him, you see, because I don't know whether it's in his mind, he likes money too much you see. He must have money every time, when I asked: "What are you going to do with this money?", he would say: "I'm going to buy the fruit" but every time we buy a fruit here. He always eat fruit, even if you don't have fruit. Today we don't have the fruit but tomorrow we are going to have, because we know that they must eat fruit, we must eat fruit also.

Coping with relatives status

Difficulty in coping with relative living with HIV&AIDS

Financial needs

Practice it

Family informed about healthy eating habits

IF: So it's like what you've heard yesterday about that woman who said that the daughter needs it, when she needs something she really craving for that thing, it's the same case.

R: Is there anything in your personal life that has changed?

PS: Nothing's changed to me, ne, but the problem is this, I give him the money all the time and ... but if he has money he gives me money now and after 5 minutes he wants his money back. Now there's nothing changed to me. If he wants his money I would, I give him his money back, you see, because he's my brother and I want to support him, you see. The only thing I can do ... if I go to town and buy fruit for him, he will sit there and say: I want money, you see. The only thing I must do for him, for me, you know I can't change because if I change I will hurt him, you see. The only thing I must do, I must give him the money if I have money. Even Z, Z can't even pass him, then: "Can't you give me R5, I want to buy cold drink?", you see. She can't change, if she has money she must give him.


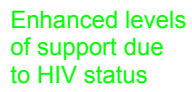
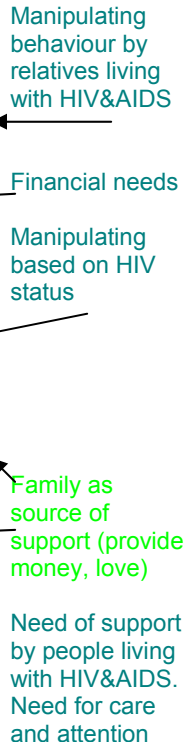
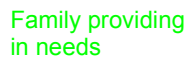
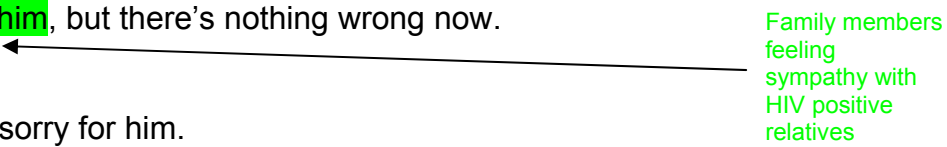
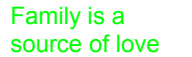
Financial support by family members

Family supporting one another

Financial demands

Family share what they have (money) as a way of support

R: Would you have done that a few years ago too?

- PS: **No.** 
- R: It seems that you are even more supportive now than what you used to be. You have always been supportive but now you are doing even more? 
- IF: **Ja.** You know what he is trying to do, the way I see it, he is trying to, to, to draw their attention. He wants to see if they care for him, you see, by doing that, asking, knowing that: **"If you don't want to give me I will see that you don't love me"**. It's the way they are saying things. But it's not like that. **Sometimes you don't have money** really, you see, but you need to have it, but on that particular day, money is not always there. But to them, especially men, they like to do that, you see, to see to it **if you do care about me**. Like his doing to, to, to his mother. He likes to ask money, knowing the mother is a pensioner, you see. But his **mother is very much supportive, if she has got something she use to give him.** And she'll even **love him and stay with him**. So it's changed. Now he's acting like a baby, you see. **Acting like a baby, who wanted to be cared for**. 
- R: (*addressing participant mother*) What is your experience? Has your son changed? 
- PM: Mmm, ja. **I give him things, give him nice things.** And he likes to buy things like drinks and another things like apples. He likes to be ... but I always **feel sorry for him**, but there's nothing wrong now. 
- R: Tell us about feeling sorry for him.
- PM: Even before ... as a mother, you know. **I want to give him that warmth.** 
- R: That love.
- PM: **That love, yes.** You can even love because that one ... You know mos the babies like to cry, and he's like that.

R: Has he always been like that, or is it only now?

PS: It's now, it's only now. **It's the behaviour, now that has change**, because the ... there are the .. Z's daughters, ne, now it doesn't mean he doesn't love them, you see. He loves them but he has got that thing inside, that I don't know how to say .... **He gets cross**.

Changes due to HIV status  
-need for love  
-anger  
-behaviour

R: Is it aggression, or a bit of anger maybe?

PS: **Ja, and letting that anger out**, but not in uhm ... in that manner, you see, but there is this thing that, I need to make him see that it's not a good thing to do, you see. So there's this **changing of the behaviour**.

R: What does he say about his illness? Does he talk about it?

PS: Ja. Last time he said he, he was **in shock** the time that the doctor told him. **Everyone was in shock**, if me ... but I didn't want to see, so that he could see that I'm in shock because he does talk openly, you see and we were sitting here, listening to him.

Initial feeling of infected person  
Shock

Shock experienced by all family members

Reaction to HIV positive status:  
-aggression  
-gets cross easily

IF: Yes, responding to him. He ... usually **he has that aggression, gets cross quickly**, you see. So that's what they noticed about him. He, **he, he don't want anyone to touch him sometimes, you see**.

HIV infected people Avoids contact/isolates himself

R: It wasn't like that before?

PS: Ja, ja. **It wasn't like that before**.

Changes due to HIV Status

R: What is the most difficult about illness? What is your biggest challenge?

PS: The only thing is I ... is that **I don't want him to get sick again** because I always think about the people we **all see on TV** and all that because I can't ease that pain, you see. **I pray that he must not be in pain**, even if he is getting cough or what what, I want him to, you know, **die quickly**, I

Family as a source of empathy

Asset: TV

Prayer as way of coping

Avoid pain and suffering (family members)

don't want him to suffer because I feel this thing. Yes **I'm supporting him** but even to me it's painful, you see

Family  
-support but  
hurting

R: Did he receive some information on HIV and AIDS from the clinic and the hospital? Did they give him some information?

PS: I don't know because **I thought that a person there in the clinic** counselled him, because he didn't hide this thing. **And people like to** hide it. Many people, before he got his results some person provided ... **counselled him**, because the people don't want to open when they tell you. You are going to treat a person thinking that it's something else when it's HIV AIDS, but that one, with everyone here, we heard it, **he told us all**. But now we are, **we must pull our socks** because this one is our only brother and **we need him**, you see. When ... I told you mos ... I **talked to this woman at work**, and **then we talked and then we prayed**. We said: "*No, we must close the door and pray and say thank you God*", you see. Z was not here at that time, she only knew as she was coming from the school. Then I said no ... But after that we went to the kitchen, you see mos that, it was Z's daughter. Even then they said we are so grateful about that, because **now we know how, how to treat him**.

Counseling at  
clinic: asset

Avoid disclosure

HIV&AIDS  
counseling

Disclosure

Family as  
source of  
support

Family needs  
each other

Colleagues as  
source of  
support

Prayer as way  
of coping

Disclosure leads  
to knowledge/  
insight on how  
to treat a person

R: I get the idea – and please tell me if I'm wrong – that in your culture you support one another to a great extent. You really support and help one another and you're there for one another. But I'm starting to get the idea that it's all about women. It's the women that pray and it's the women that support. What is the role of the men?

PS: **There's no role of men.**

Women central  
of care and  
support in the  
culture

R: So it's actually the women in your culture supporting men and other women?

IF: Ja, ja. **So they are having that overload.**

R: What is the role of men then?

All: (*Laughing*)

PS: (*laughing*) Nothing ... Even if it's ... it's like, it's a mother, if it's a married couple they've got a daughter or a son, then the, the, **the husband will tell his wife that: "You must take me away of this, you can deal with it", you see.** It's like that to, to ... **in our culture**, you see, **the man doesn't want to take responsibility for others.**

Women as strength  
↓  
Culture related  
↑  
Women as responsible for supporting others

PM: Yeah, example *T* (*indicating the interpreter and family friend*) supported him too much, this one (*laughing*).

Friends as source of support

R: Tell us about that?

PS: *T* (*indicating interpreter and family friend*) used to go to that place and now he said to me when maybe *T*, she, she don't come there for a week. He just said: "Oh, **she must come back, must come back, she must come, oh!**"

Friend as source of support

IF: (*laughing*) He wants me to come and visit him because what he told them is that: "Oh, *it's T who'd take me here, now she doesn't want to come and visit me*". So **I had to go there and visit him.** Oh, he's such a nice guy.

Friend supports (crisis at hospital)

R: (*addressing participant mother*) What is the most difficult for you, about his illness?

PM: Sometimes he is **not even drinking water** and sometimes he ... he is **suffering.**

HIV positive:  
-influence on eating  
-pain

R: He's in pain?

PM: **Yes.**

R: It's difficult for you to see him suffer, to see him experience pain?

Difficult for family to see suffering and pain

PM: Ja ... ja.

PS: And then after that the problem that he has with money, it was difficult, and even there it was difficult.

Challenging to cope with relative living with HIV&AIDS

Financial demands

R: So if I hear you correctly, you find it hard to see him suffer, and also to deal with his demands that you should give him money?

PS: Mmm, ja.

IF: What they are trying to say is that, you know when you are craving with something that you know it's gonna give you eh eh ... So when he, he is eating fruit, he's got that relief that I got what I want, you see. It doesn't mean that he's after money. He wants this money to buy things so that he can fulfil that need of wanting the ... that particular thing, you see. And now the problem, I saw the other thing that causes it, it's because he was working. Now he, he, he doesn't earn anything now, you see. You know mos when you're used to get your, your salary or your wage at the end of the week, now you got sick, you are not, you, you, you are no longer getting that money. So you, you, you want to ... you see, because you know that if I was working, I was about to do all this by myself, but now, you know, he's used to getting money because he was working. But now he stopped working because of the illness.

Needs to fulfil

Unemployment due to illness

R: When did he stop working?

IF: Last year, when he started getting, uhm getting sick. When he started getting sick, when he was admitted at hospital then he never come to work again, because ... the other thing that contributed on his health is the chemicals that he was working with. They contributed a lot, because he was coughing, getting cold because of the chemicals, and also the water there. It was bad for his lungs.

Bad working conditions

R: It damaged his lungs?

PS: Ja, and **one of the lungs collapsed**.

Health problems  
due to bad  
working  
conditions

PM: Last night he **complained**.

R: Please tell us more?

IF: Ja, because those are the symptoms. **You know mos it can cause the ..**  
**eh eh eh .. that damage**, but it takes a long time to do that. But what **I**  
**suggest him that he must go to the doctor**, you see, so that he can help,  
the sooner the better, you see. Because it has got something to do with  
his eyes as well, you see, but I **will suggest that he must go to the doctor**  
that he can complain that now the eyes ... he has got a problem. He  
needs to report this.

Family as  
source of  
information,  
give advice

family as source  
of advice

PM: Ja, he is slowly loosing his sight, **he's getting blind**.

Health problems

PS: When someone dies, ne, if someone passes away, ne and he was living  
with you, you, you won't even hear the news and all that. They **don't talk**  
**about it, don't talk**. **But he talks about it the whole time**, I don't know why  
is it. **I think maybe he's afraid**, ne. You now, he makes it a point that  
whenever, if it's raining or what, he's **going to these funerals, because**  
**that person was with him there in hospital**.

Avoid  
discussions  
about death

Family:  
Continuous  
discussions  
HIV positive  
person-fear

HIV positive  
people support  
one another

R: How do you feel when you hear of somebody that has died of AIDS?

Feeling sorry for  
HIV positive  
people

PS: I **feel sorry for him**, because ... and even if, even if his voice is not right,  
he's talking too loud to people, hey ... **shouting to people**.

HIV positive:  
anger

R: It's again that anger?

IF: Ja, ja. That's what Z was saying to me, that they **don't want to tell him**  
**when somebody passed away**, because they've noticed that when

Family avoid  
telling HIV  
positive member  
about deaths



someone, whether it's a friend or someone whom they've slept together there by the hospital, when he'd passed away, he, he, he's got that feeling that: "*Maybe I'm the next one to go.*" He's that scared, you see. So sometimes they **don't want to tell him**, but it happens that he could hear it somewhere. Ja, he's going around, moving around, you see.

Family avoid telling HIV positive member about deaths due to fear

R: Thank you very much, ladies and good luck. I know it's a long and challenging road. But I think your positive attitude and your faith and your friends and family that are supporting you are helping you.

PS: Ja, we just keep on **praying**.

Prayer as central component of coping

R: And it's like you said, if you look after yourself, it's like living with TB or being a diabetic.

PS: But **what is important is to live longer**, as long as he's living and as long as he's alive, that's good.

Hope

R: Thank you once again for sharing your story and feelings with us. We know that it is a sensitive and difficult topic to talk about and appreciate it that we could talk to you.

**FIELD VISIT 3 – 20 FEBRUARY 2004**  
**INDIVIDUAL INTERVIEW 6**  
**SOCIAL WORKER AT PROVINCIAL HOSPITAL**

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**BROAD (FLEXIBLE) INTERVIEW SCHEDULE:**

- ⌘ How is the social worker at the provincial hospital currently supporting community members infected with HIV or living with AIDS?
- ⌘ Which procedures are followed when community members infected with HIV or living with AIDS want to access social services at the provincial hospital?
- ⌘ Which health services are provided in the area supporting community members living with HIV&AIDS?

<b>KEY OF ABBREVIATIONS</b>	
R:	Researcher
P:	Participant

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R: Could you please tell me about the procedures a person infected with HIV or who has AIDS should follow when reporting to you and, secondly, about the different services you offer to these patients.

P: The person is referred to us by the doctors, usually to get advice on how to get the grant. And then you tell the person that he must bring his folder and also the letter saying that he's HIV positive.

Assets:  
Doctors-referral  
Medical social  
worker at  
hospital: advice  
on financial  
grant

R: In other words, people infected with HIV should bring you their letters?

P: That's right. Some of them they have got a letter from the clinic or private doctor, but with others it's written on the folder, you know, that you are HIV positive. Then you must phone the Department of Welfare, on the

Assets:  
-clinic  
-doctor

first floor, to **apply for a grant**. In other words you must see to the registration first.

Asset:  
Department of  
Welfare  
provides grant

R: So registration needs to take place first and is done on the first level?

P: To the Department of Welfare, yes.

R: Can patients come here to the hospital for registration at the Department of Welfare or do they need to go to the office in *N*?

P: No, you must not mix issues. Department of Welfare works with Department of Pensions, so they are one body, but the Department of Pensions are working with the Department of Welfare. So if you apply for a grant, you must go to the Department of Pension, it's still the same building, and they are there for social security. So you go for social security, then you go to see ..., there's a person you see that then recommends the grant. You take that form, that is the medical form, which is signed by the doctor who approved it, you take it to the pension office where they draw up the application, so that you can get your first payment after a certain time. And then once it goes to the Provincial Office in *B* you get a letter after some time to say your application has been approved, telling you to go to this particular pay point on this particular day to get your grant.

Definite  
structured  
procedures to  
follow in  
applying for a  
grant

R: Do you perhaps know what is the CD-4 count and the viral load criteria for the disability grant in this province?

P: No, **you must go to the doctor to get the grant**.

Asset: doctor  
assist in  
receiving grant

R: The doctor?

P: **Ja, the social worker does not recommend a grant.**

R: I understand that, but what I would like to know is: What is the CD-4 count and viral load criteria to qualify for the disability grant in this province?

P: The doctor can tell you that.

Asset: Doctor provides information on HIV/AIDS

R: Thank you, I will ask a doctor. I would like to continue with our discussion on the social services you provide here at the hospital. Do you see people coming from *area X*, do they also come to this hospital?

P: They come if they are sick, but they must start from their clinic, you know the primary health care. That goes together with the hospital.

R: So they first go to the clinic and then they come here.

P: Yes, if there's a need, if the clinic requires assistance.

R: Is the clinic in *area X*, are you referring to *clinic M*?

P: *M clinic*, yes.

R: Is that where *Sister E*'s centre is or is there another clinic?

P: No, the clinic is next door.

R: Now I'm getting the picture.

P: Yes, that centre is the community centre and the clinic is the clinic.

R: Is the clinic run by an organisation?

P: No, the clinic falls under the Metropole. Their head office is in town.

Assets:  
Clinic  
Hospital  
Community centre  
Resources

R: I suppose here at the hospital you also do pre-counselling and post-counselling?

P: Yes, this is done.

Hospital provides pre and post counselling

R: Do you deal with a lot of HIV infections?

Poverty

P: Yes, that's the problem we have with poverty. Hence you get a grant. Because if there was employment, other people would continue working or get a job because the major problem is not necessarily that they get sick quickly. You find that some of them are really fit. But if you are poor and you get HIV, get infected by AIDS, you are going to get a grant. But you must talk to the lady at the clinic to find out about the grant.

Unemployment

Grant

R: I will definitely do so. I also wanted to ask you: Are you situated only here at the hospital?

P: Yes, we are called medical social workers

Medical social workers at hospital

R: So you don't go out into the community?

P: Yes, we are for hospital, you know, this section. But we have a lot from outside coming here.

R: The reason that I ask you this is that it seems that there are not many social workers working in area X, going into the community?

P: You see, social workers work according to certain areas. That's why even those patients who come here, you know, come here because of ignorance. We must then explain to them: "your office is this side, that's where you must go". But the Department of Welfare will tell you about the social services, that's why I would like you to meet with the lady there ... because I work with her and I also respect my people's health.

R: I will try to get a hold of her today or if I cannot, I might meet with her in March when I return. But I will phone her in the mean time and tell her that you referred me to her and that I will be contacting her.

P: Yes, because we work together.

R: I will definitely phone her and tell her that you referred me to her.

P: Okay ... And another place you must go is in the City Metropole, it's called ATICC. ←

NGO's ATICC

R: Yes, we are going there this afternoon.

P: I think that there you can get all the information, because the clinics work with us, you know. They work together ... the whole Department, in other words they network with us. They're ... It's just like different departments in the hospital and they all work together for the benefit of the patient.

Networking in wider community and on Departmental level

R: Thank you very much. Is there anything else that you can tell us about the services you provide?

P: You know, as I have said the **problem is poverty**. We have poverty. If only, you know, there can be job creation, there will be less people **demanding for the departmental grants**. That is my take ... and you can imagine if everybody is going to get a grant who is going to work. So I'm for job creation, not for hand-out. **The job creation is very important** ... very, very important, you know. Hence here **I have my project**, that one of HIV and AIDS (*Participant shows researcher and field worker a few salt and pepper sets decorated with bead work*). **It's for ladies who are HIV**. You can also buy some of these, so that you can say you've made a contribution to them. I've got ladies who are HIV positive who make it, and then once it is sold they get the payment.

Poverty

High demand for grants

Medical social worker=initiator of financial income/job creation

R: That's wonderful. How much is one?

P: The bottles are R20 each. I say to them, you know: "*Rather than wasting time at home or twining and whining about your status or drinking, why don't you do something so that you get pocket money?*" Because, you know, it helps a lot if you don't get a grant, you know to get something, having made it with their own hands.

Medical social worker=encouraging/motivates people to work

R: In which area do you run this project?

P: What happens, the ladies come here and I've got a room here in which they work.

R: So they're from all over and then they come here and work?

P: That's right. And again, **because of poverty**, you know, a person **works** **and then when the grant comes, disappears** ... you won't see them here again. And because it's not a funded project, it just depends on people like you coming to buy. You find that some of them are not committed but there are those who are enjoying it.

Poverty

Lack of work ethos

R: Yes, because you are creating an opportunity for them.

P: For them, ja ... and mostly **I'm supported by whites from overseas**, who becomes involved with the project and buy.

Support on Macro-level-international

R: Do you market the salt and pepper pots on the internet or how do you go about getting in contact with people from overseas?

P: You find that what we do is we take these bottles of theirs and just show them to some of the staff people here. We don't go to internet or what ... because we **don't have the facilities of internet**.

Lack of facilities



R: I understand. Thank you once again for all the information and your valuable time. May we perhaps have a look at your project, where the ladies are working?

P: Yes, I will take you there now.

**FIELD VISIT 3 – 20 FEBRUARY 2004**  
**INDIVIDUAL INTERVIEW 7**  
**ATICC EMPLOYEE**

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**BROAD (FLEXIBLE) INTERVIEW SCHEDULE:**

- ⌘ Which services are currently provided by ATICC in the selected community?
- ⌘ Which role is ATICC currently fulfilling in supporting the community in coping with HIV&AIDS?
- ⌘ Which potential role might ATICC fulfil in future?

KEY OF ABBREVIATIONS
R: Researcher
P: Participant
PIH: Person infected with HIV

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R: Please tell us about ATICC'S involvement and the services that you offer in *area X*.

P: To be honest with you, it's an area that ... well, what shall I say? We concentrated there, but because it's only two of us operating there, it's ... uhm ...

R: Two is very little.

P: Yes, when you mention that area ... there's **always something that I've neglected with that area**. I've just been there about a week ago for a staff meeting with one of the schools, because one of the **principals attended a workshop** and then the person who was facilitating it mentioned that we offer what we call the *Back to School campaign*.

Limited involvement in area

Principals= network request workshops

That's where we provide them with uniform and shoes. We go to companies and raise funds and then target the orphans, vulnerable and the destitute ... or whatever. So the principal got to know about this. So he phoned and we had to respond without assessing the room because we transferred it. So we simply brought the stuff, but when we got there we realised that the room doesn't qualify at all but it's because we were there. And it's an area that I wouldn't visit at all, but I went there that time.

Provide uniform and shoes

Fundraising networking with external companies assist vulnerable individuals

Principal requested help

Area neglected (help by ATTIC)

R: I can understand that, and also that you try to reach as many people as possible.

P: So we ... Actually, we are a centre that was started in 1989. I can give you a background ... a copy of where we started.

R: Please, that would be of great help.

P: Ja, uhm ... It was started by the then Department of Health and then there were four of these centres if I'm not mistaken, that is Cape Town, Johannesburg, Botswana and then the local one. So the Cape was fortunate in that they had Cape Town and this one. And around 1991 it was a centre, one in Queenstown and one in Umtata. So when we started operating in 89, we covered the entire Eastern Cape through the then former Transkei and Ciskei. We couldn't go in there, but there were other people covering it. Then after 1994 the province was divided into five regions – that is region A up to E. So we're actually region A, which is worse than the others.

R: Of the Eastern Cape.

P: Yes, we're the Western part of the Eastern Cape, but that has changed now. We no longer refer to region A, we've got the Metropole now. And we do training, but not only training. We also do counselling ... We train the community here – training for nurses, business people ... and then

Provide HIV training(counselling)

there's training for the **community**. And where people cannot speak English, we've got to do **training in Xhosa**. There's training for **traditional healers**, because if you want something, we realise that from time to time, **before people come into the centre or any health facility** for that matter, **they will go to a traditional healer**. So whether we like it or not we've got to bring them aboard. And at times we realise that you find the same people ... they're **concerned about their health** and when you train them, they cannot be part and parcel of the problem, for instance, you know, the means that they use for sterilising and so on. So if ten people is living in a household and if one of those people is HIV positive, then the healer must not be responsible for spreading the virus. So we train them that they mustn't use one blade, they know about it. **They know that they cannot treat it**, they know that they cannot get rid of the HIV virus but they can be able to stop the running stomach if that person has diarrhoea. They've got their own muti to deal with that and formula's that they use ... In Xhosa we say *futha, gapa, si*, that means you steam it – the person – and then you induce vomiting and then use enema.

Training(various languages)  
-Professionals  
-Community  
-Traditional healers

Traditional healer=resource in community/ then centre/ health facility

Training (traditional healers)  
-basic health issues

-Provide basic HIV knowledge

R: So they use an enema?

P: Yes, that's the formula that the traditional healers use, but they know that if you're HIV positive it can result to something else. So from time to time **they consult us**. If they know that things ... that they cannot handle it, they phone me. And then I would **refer the person to hospital** and then I **make arrangements** and phone the nearest clinic and they then deal with it. They keep condoms, they keep the information that we have got. So provincially, if we want to do something, we call on them. We've got a file specifically for them. They've got their leadership, although from time to time it changes (*person enters*). This is actually *G (introducing person)*. Eh ... I don't want to say anything, she can tell you her story ...

-Available for consultation

-Referral service to hospital

-Network with local clinics arrange help/assistance

PIH: Hi, I am G. I also work here at ATICC and I am somebody who is HIV positive and living with AIDS.

R: It's an honour to meet you. And it is wonderful that you seem to have overcome the challenge of disclosing that seems to be such a big problem in this area. So you say you work here?

PIH: Ja, I support people and help them to disclose. And we are a few people here that support each other.

ATTIC:  
-support HIV positive individuals  
-encourage and guide them to disclose  
-HIV positive supports one another

R: That's great! And you're certainly the right person to do something like this.

PIH: Ja.

R: Thank you for introducing yourself.

P: Yes, I always say there's life after HIV.

Living with HIV

R: There's definitely life after HIV.

P: And she's getting married.

PIH: (giggles) Yes. What else?

P: That's all, thank you.

R: Thank you for sharing with me (*Person G leaves*).

P: She's actually in the leadership of the traditional healers, the present one. We also train them. Most of the time we are saying the same thing ... to deal with diarrhoea is almost the same method that is followed by the medical profession. In their own way they will make eggs and some herbs but when you look at it, it's one and the same thing. At the end of the day they are able to stop diarrhoea and the person will recover. They've got muti that can actually keep other people healthy and strong. So we've got training specifically for that and we bring them together so

ATTIC:  
-on the look out for misconceptions  
-correct them

that we don't find people thinking that they can cure this and whatever, so if there's someone in the township claiming that they can get rid of the HIV virus, I phone them and ask: "*Are you aware of this?*", and then they will sort it out and come here. **We will then bring that person on board and we educate that person.**

-educative role

R: How do you get them to come to the training? Do you advertise or do you phone them? Or is it by word of mouth?

P: Well, uhm ... Well, as I have mentioned we are also marketing this place. We eh ..., we have got partners, like the SABC is one of our partners. Usually DJ's would fight about me being on board on their programmes. For instance, last Thursday **I was on the air** from twelve midnight right up until half past one, it was a programme on condom use. Others were phoning in as far as from North West, I had no idea that they were watching.

ATTIC:  
networks on  
national level  
eg. SABC and  
Radio

R: So it was like an awareness campaign?

P: Ja, we **had built up to a national event**. South Africa selected the Western Cape for a competition, so we had a national event, so it built up to that event, **when we were launching**. There were many teachers and great ones, even now they're downstairs.

Awareness  
campaign  
(national level)

Advertising

R: We saw all the people when we entered the building.

P: Yes, there's a group maybe sitting outside, maybe next to the flowers ... Did you see them?

R: I can't recall. We were in such a hurry, we just quickly passed the people in the foyer.

P: They are the peer educators as well. Now the **peer educators** is something that we've started about three years ago, in the year 2001,

Peer educators

where we train these peer educators to actually target high transition areas. Now what we mean by high transition areas is that it is areas where people are likely to go in and come out with a new partner. If you need a new partner, that's the place to go. So we're actually targeting those places. So we are educating the ladies who are frequenting the men, so they can get into these shibeens and educate the people. They do plays and then the audience becomes involved. They don't stand there lecturing, they do drama and then people are involved.

ATICC as education provider

ATTIC: focuses on at risk sexual behaviour

Way in which they address it=drama, community members get involved

R: It's interactive, almost like entertainment.

P: Yes, people are involved and then from there they sensitise them about STD's, HIV, where to get medication, where to go if you want to know about living positive with the virus, where to go and all those things. So from time to time after they've been to the area, you'd find an informant saying: "Hey, everybody is rushing because of those educators". That's what they are there for. So we've got that problem, so we've been introducing these plays to all these areas. We have introduced it to areas like H, L and therefore M, and they've actually agreed that we can do it. But now the problem is, we'd like to start ATICC in all the areas outside of town. So slowly we're actually involving them, but we've got to approve them until that time. So besides the training and the counselling, we've got health forums along the clinics with community members. If you want something in that clinic you get in touch with the health forums, then you organise with them. They have to have their own special training, as people are going to go around helping. They're involved with the gardening as it is happening there, they're involved with education, they're volunteers within the clinics. Besides that, we train people in some of the work, you know the ones who have gone within the mental health or the clinics and we also train these. Now when we train, when you train people who don't have education at all, they're going to talk and address them in their own language so that they can understand in detail what is involved, what's different between HIV and a person who has developed from this, or what is to say proper AIDS disease – so it's

Providing practical information:  
-STD's  
-HIV medication  
-Living as HIV positive

ATTIC: targets whole area

ATTIC:

-training  
-counselling  
-health forums  
-volunteer workers  
-education and help in community



... There's actually a launch on this that is due. For instance, after the partnership you can see outside, **we've started doing the sectoral forums** ← Sectoral forums  
**where we also involve other departments**. So we have meetings, if you look here (*indicating a document on the wall*), these are the dates of the **local council meetings** ← Networking with local council and if you look here, we've got dates on the sectoral forums. It's usually on Thursday, we usually meet at **hospital D.** ← NGO's= resource  
**So all NGOs are on board there.** ← And then you've got the businesses, you've got some **companies** ← involved and then from there, they get their own representatives. You'll also have a **representative from the traditional healers, being a member of his local area** ← Networks on National level: -companies -traditional healers -tertiary institutions -educators, which is set by the portfolio committee. And then we've got tertiary institutions on board and some of the teachers. So, whatever happens, if there's a new NGO, if it's in the news, that NGO has got to attend to the local one and say: "Hey, I'm from Johannesburg and this is what I do", **so that they can see they don't duplicate.** ← Monitor involvement of NGO's

R: Do you have a list of all the NGOs involved in this area?

P: We've got files.

R: When I return in March, would it be possible for me to have access to that file?

P: Yes, I can prepare it for you.

R: That would be very helpful, thank you.

P: For instance, we have got NGOs that are being supported by Botswana. So I actually have learnt Volkswagen has got a community trust operating within, that is being supported by ... they call it *Catholes homes*, based in Germany. So we have been saying that you are actually funding some of the NGOs, and the department also is trying to, but they don't tell you that's the department. So Volkswagen has actually depended on them, these NGOs have actually received funding or they } National and International networking and supporting Also Department involved in networking and funding

are going to receive it. So we check on our side which are being supported by the department. And now we've also got our own list of all NGOs.

R: I would appreciate insight into that list, as I am trying to determine what exactly is going on in *area X*.

P: Well I can make a copy of it. You don't have to wait much. From here, where are you going? Because I can actually sit down to share all the information that you want. For instance, you said you want to know what is happening in our files, what do we do. Because we are doing training, some of the files are not with me, I have to borrow them. The people we are using here are not ours, it's actually people who did the training and now come and do the training.

Empowering role

R: Is there a specific course like for teachers or is it exactly the same for everybody?

P: I wouldn't say ... eh ... basic AIDS education is the same for everybody, but now as I've told you, if I'm going to the community, I've got to change and address them in their own language. But now when we speak of life skills, we've got modules specifically for teachers within education, who should be different to others ... how to approach young children and all those. But now when you deal with others it changes it. When you deal with traditional healers as well, you've got to change and approach them according to some of their beliefs, for instance they do things their way. So we have to find out about their ways before we start. So you know that if you want to start at eight, they've got to gather there by half past seven, so they've got to do what we call *inhlompho*. So if you don't know how to deal with them, you will run late in the programme. And you cannot stop them when they do that. There are days when they get off to do certain things, you've got to wait until you're going to hear things. So allow them to do that. And when you address them, how shall I say, it's

Basic AIDS education=generic

Community visits and involvement

Mother tongue

Specific training, eg. For teachers

Profession-related/based approach

Guided by cultural needs and habits

like a pyramid. You also have some of the traditional healers to address others **according to their needs**, ~~not according to what you want.~~

Focus on communities needs

R: Not according to ATICC's needs.

P: So you listen to them, how do they approach certain things, and then within that you bring them the information that is relevant.

R: Tell us about the training programme you offer to teachers.

P: The training programme ... Uhm, I would say, the course that is happening here at the present moment, this one (*showing pamphlet*), this is what we do.

R: The basic A?

P: The basic one, yes. Now from here, which is a five day programme..., and then today they are doing counselling, it's a three day basic and then **two day counselling, just to deal with a person living with HIV, how to go about.** And then from this group then they can go on, if there are **nurses** within the group then they'll be able to attend the training that we do that is according to the minimum standards. That is a ten day counselling course. And then there's also the five day counselling programme. But we're also **training lay counsellors**, ~~although they won't be trained so strictly, but they must have the information as to how to deal with a person when they have to. So this one (*indicating pamphlet*) is a basic one.~~

Basic counselling, training:

-Dealing with a person living with HIV

Training:  
-nurses  
-lay counsellors

R: Do everybody start with this basic one?

P: Yes, everybody starts with it, even teachers who are now being trained by the Department, using other people. All have got to start here first.

R: May I please have this pamphlet?

P: I've actually prepared this for you.

R: That's great, thank you! You say that you have health forums at the clinic, is that at all clinics?

Health forums at all clinics

P: All clinics

R: So the clinic in *area X* will also have a health forum?

P: It will have a forum.

R: And the forum is organised by ATICC?

P: Not really. There's nursing management who are responsible for the health forums, but when it comes to training, ATICC provides it.

Responsible:  
Nursing  
management

R: So you do the training for them.

P: We do the training.

R: Now I understand.

P: Yes, before people become community workers, they can't be community workers without getting the first basic training. And that's part of the reason why they are there. So all the forums have been trained. So when you train all the forums, in conjunction with the nursing management and the ministers in charge in all the areas, we will do the training together and then have a three day HIV and AIDS basic information programme and then they will slot in whatever they've got with them. For instance, there's a course going on in W, in the health centre. We have just spent five days there. But I didn't go there myself, I have to use somebody who actually started this week to do this course, within the home-based care. And then they'll carry on with their training, I

Basic training  
for community  
members and  
forums

Training:  
nursing  
management  
and ministers

think it will be for nine days or so. So the five days one, it was the basic one.

R: If I hear you correctly, ATICC is involved with training across various levels. It trains professional people and community members and lay people, it trains people across the range. And you've got a basic five day package and then also advance levels.

Summary:  
Training basic /advanced level=  
-Professionals  
-community members  
-lay people/workers

P: That's right, yes. And you cannot get, for instance, to the ten day course if you have not attended that basic one. We are not accepting you.

R: So the training is the one leg and then the other leg is counselling?

P: Yes, the other leg is the **counselling**, which is the continuation of phase one. Even the training, ... (searching for document) ... no, I don't have it here ... The training will start around, if not the 3<sup>rd</sup>, then the 8<sup>th</sup> of March there will be training, for the whole Metropole. Now within that training we'll usually train ..., have four courses per year where we train all people. Then they are supposed to know what to do with HIV and AIDS and a lot of those things. For example, if you are going to give birth and it is proved that you are HIV, if people are during the latest stage of their pregnancy and are given the neveropine, they've got to join. You've got to join if you are HIV positive and pregnant. So this one lady is responsible for that. She **attends sessions at hospital D with pregnant mothers and educators and also go in where they are**. Their work is to market, if you are pregnant you need to test to see if you are HIV positive. It's about prevention of the mother to child transmission.

Counselling

Community based sessions= hospitals with -pregnant mothers -educators -community visits

R: Preventing the mother to transmit the virus to the child.

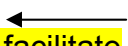
Advocate responsible behaviour

P: **Yes.** I would give you a manual but unfortunately I don't think it has come back, because I'm going to run a course. The ones that we have seen we will actually use them. I'm responsible for the training, I'm actually

Prevention

the master trainer for the board. If the board has got to train other trainers, I've got to train them.


R: Training the trainers.

P: Yes, training those trainers. And then those **trainers will again facilitate and train.**  Empowering and spreading the word

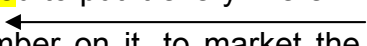
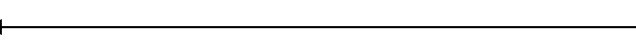
R: That sounds great.

P: Now you may look at my office and think: "*Hey, what's going on?*" Now there behind you is some of the material, it has to remain there because I've got to take it to my car. It's actually the material that the other trainers are using, they don't have the place to keep it. So the master trainer has got to see to it that everything is made the same. Now if you look in the corner, there's some other material on information for learners. I will love to show you the content of that material some other time.

R: Thank you, we can get it at a later stage.

P: And although it is information that is prepared for learners, the approach is not the same. And what I've realised is that when they train these teachers, those who **attend the courses, they will go back and tell the others and they will tell the others and then it goes like that.**  Trained people share with others

R: Do you perhaps have a brochure on all the work that ATICC does?

P: Yes, I shall prepare it for you and leave it down at the front desk. Then you can pick it up from there. It actually tells you exactly what we do, we also use it to market this place. We've **networked** to put it everywhere in the **Metropole**. It even has our cell phone number on it, to market the place. It's actually a **hotline.**  Marketing network target whole Metropole hotline 

R: Thank you very much. When will I be able to get this from you?

P: I can prepare it today and leave it downstairs by half past four. I'll put it in a package and drop it there.

R: Thank you! Tell me, what is the cost of the courses you offer?

P: Well, it's actually funded by the government. ATICC was actually started by the Department of Health, because of the content ... training people to be responsible, and sexually responsible, having information on HIV and AIDS and those things.

Government  
funded courses



R: I understand. Thank you very much for your time and all the information. I really appreciate it.

P: Okay, thank you.



**FIELD VISIT 3 – 20 FEBRUARY 2004**  
**INDIVIDUAL INTERVIEW 8**  
**EX-EMPLOYEE OF THE SOUTH AFRICAN POLICE DEPARTMENT**

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**BROAD (FLEXIBLE) INTERVIEW SCHEDULE:**

- ⌘ How is the selected community currently coping with HIV&AIDS and the challenges implied by the pandemic?
- ⌘ Which resources and potential resources can be identified in the community?
- ⌘ How are you coping with a family member who is living with HIV&AIDS?
- ⌘ What are the main challenges you have to cope with related to the fact that a relative is living with HIV&AIDS?
- ⌘ Which resources in the community assist you in coping with the challenges you face?
- ⌘ Which potential resources might assist you in coping with the challenges you face?

<b>KEY OF ABBREVIATIONS</b>	
R:	Researcher
P:	Participant

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R: Please tell us about your sister – what happened and when did it happen?

HIV positive  
family member

P: My sister was diagnosed in 1994. When, after she was diagnosed in 1994 she never told anyone. The only thing that she does everyday, up until 1999, 1999 when she got sick. When she got sick I took her to the doctor. That's where I found out that she was diagnosed in 1994 but up until now she doesn't want me to tell anybody. Nobody except me in our family knows that she's living with this virus. Whether I can say

Family as  
support

Avoid disclosure

everybody now are asking themselves, because if ~~you can see her~~, you won't even ask, **she changed** a lot, so breaking off hair, all those things, you see, and now she was like me but now she's darker. But it's not easy for me to tell them that this person is living with AIDS, because she **doesn't want everybody, nobody to know that**.

R: Why doesn't she want the people to know?

P: I really don't know now, because she already lost her daughter. Uh, what happened was that her daughter passed away last year November - 2003 November. In 2002 she was involved in a car accident. She was visiting a friend when it happened. After that she was admitted at uhm the hospital, East London. I think she was in a coma for a month. After that we found out that she is paralysed, she can't walk again and can't speak well, all those things. Then we tried to take her from that side to PE, at least because **in our family the, the, we don't have parents at the moment, so we are trying to help each other**. And the most of uh, the **family are not working**, ~~so we are two who are trying to help in our family.~~

R: How do you help, what do you do?

P: Uhm ... If I've **got money I have to buy for them. If there's a problem I have to try to solve their problem. I, I'm treating them like my children** now, especially my sister because when somebody is ill, and the only thing that she thinks about is dying. So she needs someone who can move that out of her mind, but it's too difficult because I can be willing to do that but she's **supposed to have faith first**, ~~you see.~~ And she must know that to **be HIV positive doesn't mean that you, you are dying**. But in her case now she's fully blown AIDS, she's not HIV any more. So, I think it was August ne, last year, her daughter was sick in August last year, then they took her to hospital, she was admitted I think in August up until, because she died on the second November. But when I was in hospital on Sunday or Saturday, because she died on Sunday, they uhm, the sisters told me that what is really going on because they were talking

about it, the accident and, and all those feelings. Then I asked them: “*What is really going on?*”, because I thought if that uhm accident because was through her illness. But when the eh, eh, that sister was trying to explain to me, I realised that no, maybe before she got involved in that accident, she was HIV positive, but **she knew nothing about that then**. So, **what makes her not to cope anymore is to hear that really she’s HIV positive too**. So they transferred her to *hospital E*. That’s where she died. So after we bury her sister, your ... her daughter, then after that I sat down with my sister, I said to her: “*We are living an African life, why can’t you tell your son?*”, because she’s got a 21 year old son, “*Why can’t you tell him that?*”, because he wants to know what is wrong, because he is **old enough to see what is going on**. But he wants to hear that from somebody. So I don’t want to be that person to tell him that, I asked her: “*Why can’t you tell him that you are dying because of HIV AIDS?*” She said **she doesn’t want him to find out**. But I told her that they’re suffering now because they want to know what is wrong. Maybe they can, **even they can help you with other things**, because sometimes if **she’s ill, there’s no way for her to wake up, even if she wants to go to toilet, she cannot go from here to the toilet**. You see. **So who’s going to clean her?** You see. So I told her: “*You must tell your son*”, but up until today **she has not done so**. But if, even if we can go and visit her, you’ll see that at least now she is better.

Unaware of status being HIV positive: devastating (cannot cope)

Able to identify in others

Avoid disclosure

Family= informant/ advisor

Family=potential resource, if they know

Potential to assist with basic chores

Avoid disclosure

R: But she still doesn’t want to disclose?

P: No ... no.

R: Why doesn’t she want to disclose?

P: I really don’t, I don’t know, because, I really don’t know.

R: What about other people in the community, why don’t they disclose?

- P: In this ... Here in Eastern Cape, I will talk about Port Elizabeth, There's some ... **some of the people are disclosing their status because they need help**, they want ... they don't want to die, you see. Because before, if you ... **I hear that you are HIV positive I won't speak to you again!**
- R: Why not?
- P: I really don't know where that came from but it was like that before, up until ...
- R: Is it only in this area, or is it in your culture, or is it all over?
- P: I uhm, I think all over. **We blacks, I will talk about blacks, you see.** It's what happened. **If we hear that you've got this disease nobody will talk to you.**
- R: So then you'll reject the people who are sick?
- P: Yes, yes, yes. But up until, because what is going on, because before, it was few houses who've got this disease around, you see. **So now each and every family now is infected.** So I find that now it's a challenge to to to everybody, whereas some **other people they don't want to disclose their status.** There is that... Last ... I think 2001 there is my neighbour who stays in that house. I, I, **I like to help, you see.** After I found out that my sister is living with the disease, that makes me to go out you see, to **get some help to, to get the knowledge,** you see. What must I do? What am I not supposed to do about it? And really that helped a lot. And there is a friend of mine. **This friend of mine is living with this disease.** She's working for ATICC, but I don't know what ATICC mean. There's a house in area X, so she's **doing counselling there.** If you can, if you can see her, she is **very helping,** she is like me, you see. **She's the one who who make me see that really to help this disease.** It's like a challenge, you see, because when you have this disease, you know what are you dealing with, you see. You know what you're supposed to do. You know

Disclosure, in order to get help

Fear death  
Stigma=  
rejection when  
they disclose

Culturally  
related

High HIV  
infection rate

Avoid disclosure

Community  
members=  
support others

Family=knowled  
ge/seek  
information

HIV positive  
friend

Community  
members:  
-counselling  
-helping  
-information

what you are not supposed to do if you want to live. Because before we thought that if people are going to die because they don't have money to buy eh, eh medicines and all, all that stuff, but as I ... I just think medicine is not important. Yes we must use eh, eh medicines, but before you have to, you have to, to, must learn to love your family, you must accept what you have. And you, you ... I don't know ... How can I say it? The problem is, some other people they think that if you've got this disease, tomorrow or the day after you are going to die. But what I found out is that you can have this disease, you can live for more than 20 years.

Medicine:  
important

More important:  
loving you family  
and accepting

Family members  
seek information

R: Where did you get your information? You said you went out and you wanted information.

P: Uhm ... I like to, to ... there is a group here at K. It's people from area X, K, KD, J and the extension W. They formed a, eh eh group, you see. All those people, they met each other at the clinic. So they used to go to the clinic and discuss their problems there. But one lady told me that they are, they are not feeling comfortable there, at the, at the clinic because everybody is coming there, you see, even those that are not living with the, with the ... this disease. So what they do now is they visit. Today they are coming to my house, tomorrow to your house something like that. Then afterwards I said to this lady: "I want, I want, I want to go there, I want to share some views with you, can I go there?" Then she said: "Okay, I have to go to them and speak to them first and I'll come back to you." Really, this lady came back to me and I went there. I found that those people are, are, are positive, you see, are positive ... they know what they want, you see. And they are 100% sure that they are going to survive, you see. Then some of them are not using drugs because they don't have money to to to use drugs, some of them they are using drugs. Like this friend of mine I was talking about, uhm ... she's married, she's Mrs N. Her husband is a policeman. What happened ... when she disclosed her status to her husband, her husband left her. Even now she is on divorce process. That is very terrible.

Support groups  
in community

Clinic based  
support groups

Stigma  
Avoid them

Living positively  
HIV

Financial  
needs=medicine

Disclosure leads  
to rejection/  
divorce

Because what I know, in that couple I, I, I just tell her that your husband is on denial, because you can't be ... If you are positive he's supposed to be positive. But she said uhm her husband said he was tested and he's negative. So nobody's got the proof about that. It's what he is saying. So he asked for the divorce. So she has to divorce her husband because of this ...

R: Because she disclosed her status.

P: So it's one of the things that make people not to disclose their status. Some of other people they would, they say that I didn't invite the, the, this disease, you see. So I won't tell anybody, I will just sleep with this one, sleep with that one – even if, you see. That is why this disease spread so fast, because nobody wants to stand up and say: "I do have this, you see, so that we can protect those who are innocent." You get what I'm saying?

R: If you think back of your sister, how is she coping or how are you coping with her being HIV positive?

P: I am coping very well with her. But I am not happy, because what will make me more happy if she can stand up and tell everybody in our family that I've got this. So that they can know that even if there is somebody else in our family, all of them they can come out so that we can, we can try to help each other because I used to tell them that if you've got a problem come to me, I am not good, I'm not perfect, but I am willing to help, I am willing to share what I already know, you see, especially about, about... because really I am concerned about this disease, it is killing our children, our sisters and brothers, our mothers, you see. So I cannot let it go just like that. Uh, Uh... I... Yesterday I went to, to, to area X. There's uhm, uhm sixteen year old daughter who's really sick there. I was so frustrated when I found out that nobody wants to go inside that house. I don't know why because by touching that person, that doesn't mean that you'll get this disease. By cleaning that person, that doesn't mean that

you'll get this disease. By, by touching ... because those people need to be loved, you see.

R: Why do you think are they ignoring her? Why don't they want to enter her house?

P: Some other people are not, well are not educated about this, you see. That's why I told you before that we need to go out, you see. We need to call in everybody ... teachers, reverends, NGOs, everybody must be involved, you see. It's not only one body's problem, it's everybody's problem. So to fight this everybody must stand up to help those who can't help themselves, you see. Even if we don't have money, we can go just there, to, to see that, to show them that everybody's caring about these people, you see. They've got brothers and sisters outside who cares about them. That's the only thing I, I, I think that can help people. And we must try to teach them that even if we don't have money, try to make something for your own living, you see. You can go and uh ... you can go and get something somewhere else, you see, to try to make yourself healthy. Because what I know, even if you can get treatment, if you don't eat well, I don't think you can, you can make it. If you are not happy about who you are, I don't think you can make it, you see. You need to be strong. You, you need to love yourself first you see, so that the rest will follow. You, I, I cannot say that I, I don't, I, I, I don't believe that I, I, I do have this disease then I will expect the treatment that you are giving me will help me, I must help myself first, then the rest will follow.

Lack of information in general community (misinformed)

Potential resources=community based challenge-all need to be informed and involved to help support

Community needs to support

Fulfil in own needs/initiate solutions

Client=important

Acceptance of one self and status=important

Inner strength and love=important

Coping=person based

R: Tell me about that sixteen year old of yesterday. Who... How is she coping?

P: Oh... Not very well... because she's in denial. She doesn't want to believe that she is HIV positive. Then I spoke to her and told her: "You've got something in your body and that thing is in your body, if you don't fight it, it will cost your life, do you want to die?" She said: "No." Then I

Denial-them not coping

Community members: provide information =support



ask her: *"If you don't fight this disease, who do you think will fight it for you? But if you want to I will help you."* Then she asked me how, then I asked her: *"Do you believe in God, and do you went to... do you go to church?"* But I asked her: *"Do you know that God is alive?"* I prayed and I prayed, and prayed... then after that I asked her: *"How do you feel now?"* She said she feels better. Then she asked for water. I bring water for her, then I said to that lady they must uhm, because our water here is not... eh eh, sometimes you find out that the water is infected, after you drink it. Then I asked her to boil her water first before drinking it. Then, every time if she says she wants water, give her boiled water. Then I said to this lady: *"Why don't you stand up?"* and she said: *"Her knees are ... I think she's feeling weak because she doesn't want to eat, she doesn't want anything, if she eats something that thing will come out again".* Then I said to her: *"It will be like that because you are ... you don't know what are you dealing with up until you make up your mind".* Then I asked the lady, because I asked: *"Where is the girl's parents?"* Then she said: *"The parents are in East London."* But I told her that this girl needs somebody who's going to look after her. You see I didn't want to ask her so many questions, because ... I must ask her where did she think she got this disease from so that we can call in that boy, maybe we can help even that boy or maybe that boy doesn't even know that he's got this disease. Then I promised her that I will come again on Sunday afternoon. Maybe I will try to find something for her, like e-pap. You know e-pap? You don't know e-pap? It's a porridge, I think it's R6.50 at Shoprite Checkers, it's like a, it's like a Maltabella, you know Maltabella? It's something like that, at least you can use it as a drink so that at least you get strong, then after it, it will be easy for her to to to eat everything because even if she drinks something like Amasi, it will come out again. People used to say that, but I don't believe that, people used to say that berries are not okay for those who are living with this virus, but I don't believe in that. I really don't believe that. But eh, we are listening to different people, everybody is trying to say what they know. Let me go back to my sister's case.

Faith in God and prayer=central

Community members= source of information

Basic care

Community members= -support -responsible behaviour propagate

-provide food

Utilising all possible sources

After I found out that my sister is living with this disease, I do have a medical aid. Then I went to my doctor. Then when I went to my doctor I said to my doctor: *"Look doctor, I was diagnosed in 1999 that I'm HIV positive but then I didn't want to use treatment but now I'm ready, I want to use treatment, I want you to organise something for me."* Then he said: *"Who tested your blood?"*, then I said *doctor M*. Then he asked: *"Why didn't he organise something for you?"* Then I said: *"I was not ready then to use the treatment but now I do need treatment."* Really, he prescribed something for me, antiretrovirals, or something like African potato tablets, and the other tablets, big tablets which you take one a week. So every month I must go to him to get a prescription to go to the pharmacy to get the, the medication. From 2000 up until last year. Then what happened, I was sleeping here at home, somebody phoned and said: *"You are losing your benefit, why don't you apply for, for chronic because we do have chronic for, we do have treatment for our members. If you can apply, you can go to your doctor he'll apply chronic for you, we'll bring your treatment straight to your house every month?"* *"What treatment now, what are you talking about?"*, I asked her. Then the lady said: *"You are HIV positive."* I said: *"No! Me, I'm HIV positive? No, no, no, no, no, no! I'm not HIV positive."* Then the lady said to me: *"You are not Mrs XS K?"* I said: *"I am. I am not HIV positive"*. Then the lady dropped the phone. After ten to fifteen minutes, my phone rang again. My doctor's receptionist asked me: *"What are you doing?"* I said to her: *"About what?"* She said *"You were here and said that you are HIV positive. Now you said you are not HIV positive, you are trying to to to to get my, to to put my doctor in trouble now."* **Then I realised that I lied.** I said: *"Okay, okay, I will fix that."* Then the lady phoned again. I had to admit to the lady that I was HIV positive, because now I know that my doctor would have a big problem because of what I said. So I told them that **I was trying to help my sister, I know that what I did was wrong, but I was trying to help my sister.** Then they asked me: *"Do you know that what you're doing was very wrong?"* I said: *"Yes, but I am willing to say that I was wrong."* So my medical aid was terminated there and then, I am paying R600 every month for what I've done. Otherwise I've got sick,

Family members  
lie to help HIV  
positive  
members

because I was so frustrated. I was, I I I was worried about my sister. I was not worried about myself and that I can go to jail and loose everything for what I've done, I was worried about her, because I know that she already started this medication. Maybe after some time now, because I won't afford to buy it every month for her now. So maybe after two or three months after, maybe she got sick. Really, after two months she got sick and she, she nearly died that time. Then, what I've done, I just sat down with her and told her: *"There's nothing now that I can do for you unless you help yourself. The only thing that you can do now, I can see that really it's too late, but maybe it isn't too late at all. Try to accept this thing."* Then after if you get... eh, eh because another thing that she was doing, she was drinking a lot. Then I asked her: *"Why, because you are killing yourself."* *"The problem is I cannot sleep at night"*, she said. Then I tried to to to to open her mind, saying that: *"What makes you not sleep at night, because those people who are living with it, they don't know what is going on, you see. Now you are trusting yourself by killing yourself, at least tell that one that you've got this disease."* Then she said: *"I cannot do that but I will try to accept that I am living with this disease."*

Coping= in person himself

Acceptance=im portant

Alcohol abuse

Sleeplessness

Avoid disclosure

Really, after that ... I could see that she, she's a fighter, because the nurses were, were were telling me so many things, that she won't make it. Because I asked the nurses that I could see that she, she was loosing her strength, you see because she was loosing too much of water, then I asked them to, to, to ... what do you call it? You call it drip, I don't know if you know it. So they said: *"No, they cannot do that now, it's too late for us, for her to, to, to give that now. As a result, tomorrow, we are discharging her."* I went back to, to the wards again and told her: *"Tomorrow you're going home."* Then I called some members of the family and told them this lady won't make it, we must try and prepare something for her so that when she dies everybody must be involved, because a funeral is too expensive in our days. Everybody was so frustrated, was so frustrated but the miracle that happened, because up

Strength lies within themselves

Family=support

until now she is still alive. Whereas if you can see her, she's not in a, a, a right situation, you see.

R: Is she taking medication at the moment?

P: No, except eh, eh Biko... It's difficult here to get uhm medication but she is got now eh, because my doctor tried to help her to get a pension. So she's earning pension so that she can, she can ... (paused, phone ringing) Can I answer? Sorry.

Resource

Pension= financial resource (potential)

R: You were saying that your sister is not taking medication but your doctor is helping her to get the pension?

P: Ja, she already, she's earning pension every month. So that if she's sick at least she will have money to go to the doctors, she can buy food, you see, healthy food for her and try to look after herself, because me alone, I cannot afford to do that.

Receive grant

Diet=healthy food=important

R: Tell us about the time after your husband died. Last time when we spoke, you mentioned that first you didn't cope but that you started to cope later on. Please tell us about that time?

P: Uhm ... what happened, my husband died, it was on the ... it was Tuesday, on the 5<sup>th</sup> of January 1998. My husband was working at ..(unclear) police station. That day he was working the second to ten ... two to ten. Then, before ... Before, I think in 1995, in 1996, we were separated. He moved out of the house. I've got two sons. So he was having an affair... So he moved out of the house, okay, for two years. Then, in 1997, I think it was on the 23<sup>rd</sup> of June, he came back, we tried to discuss our problems and start and rebuilt our marriage again. Then everything, from that day everything went smooth. On that day he came home, I think it was five past five because I was watching Days of our lives. Then he said to me I must cook early. When he's doing two to ten I must cook early because at that time I was not having an oven to warm

Coping with the death of a spouse

At risk sexual behaviour

his food, so I like to cook around nine o'clock because I know that half past ten he would be at home. So he said to me I must cook early that time, that day, he will come at home at least eight o'clock. Then after Days I started preparing my food. Half passed eight I went to bed. After that... Maybe I just gone to sleep, I don't know but I woke up at about five to twelve. When I look, I saw nobody is here. I realised that he was not home. I thought: "*Where is he now?*" I thought to myself that oh, maybe he decided to go back, you see, to what he was doing before. When I tried to sleep I hear that there is someone who is knocking at my front door. I peeped through the window, I saw that there are so many cars, police cars outside. What's going on, maybe there is an accident or what, I think. Then I came in, I turned to open the door, I found that it's Reverend, pastor, eh ... police chaplain. They came in and asked if I am alone. I said: "*No I'm not alone, I'm with my kids.*" Then they asked me: "*Where is your husband?*" I said: "*He went to work but never came back, I don't know.*" They start eh ... they said eh: "*Because your husband was involved in an accident.*" Then I stand up and asked: "*Can I go to my room and wear my clothes and come back?*" They said: "*No, wait.*" Then somebody bring water for me, give me water to drink. At least now, I uhm ... after that time I see my blood was trying to ... eh, eh, you see. Then one lady asked us to, to, to, **to pray, really we prayed.** When we were busy praying, I read that ... I, I **listened to one lady** who was saying that they are feeling sorry for me, you see, at my age, that I can loose my husband that way. I thought that I couldn't know what happened after that because the following day I was in hospital. Then I was uhm ... summoned on the next day again. So we went to the police station where I said that my husband was shot last night. It was him and his colleague. Eh ... there's a woman who was fighting with her husband. Then the woman was, uhm went to the police station to try to ask the police to help her, because she was looking for her clothes at her home and the husband was refusing to let her take her clothes. Then my husband said to this lady: "*No, this case is not our case. Go to the social workers or to the lawyer*", you see. Then the lady went out and phoned 10111. When the lady phoned 10111, then it was radio control who sent

Prayer=1st  
resource=  
Central

Community  
members and  
colleagues=  
support

my husband there. Then my husband said to this radio control: “No, control, this woman was at the station a bit earlier, then I tried to explain to this lady that this is a, a marriage problem, so she can go to the social workers or to her lawyer.” Then the control said to my husband: “Please help because this lady wants to go to work on the following day, so she needs clothes.” Really my husband and his colleague went to that house, but they never came out alive. My husband was shot while he was sitting on the chair, trying to help.

So what happened, uhm ... I tried to, to, to, to make myself strong, you see ... tried to cope with that up until we buried him. After we bury him, two weeks after, because I was admitted on the 29<sup>th</sup> of January, up until towards month-end of February, I was lying on the bed, early in the morning, I wanted to go to toilet but I couldn't stand up. Then I called my younger brother because after the funeral I asked my younger brother to come stay with me. Then I called him and said: “I want to go to toilet.” Then he said: “Why don't you wake up and go to toilet?” I then told him that: “I cannot stand up, don't know why.” He said: “You are lying”. When I tried to stand up I just couldn't. After that, he called one of my neighbours, they took me to hospital. After that, then I was admitted. Uhm ... it was very painful, it was very, very, very bad. I thought then that I'm dying, I will never walk again, I will never see my children again. The doctors were trying to help me, every.. everybody was trying to help me, but eh eh ... I think then I was not able to help myself. Up until, up until one time one woman came to me... my children were there, it was Sunday afternoon. This lady said to me: “These are your children?” I said: “Yes.” “Do you think about them?”, she asked. I said: “Too much, but there's nothing that I can do, I can see now that I am living for my children.” Then the lady said to me: “There's nothing that I can say to you except to tell you that you need to be strong, not for yourself”, and then that's when she left. In that Sunday evening I couldn't sleep, I really couldn't sleep. I was thinking that, really, if I can die now what is going to happen to my children because I don't have parents, there's no one that I eh eh ... no one in my family members who can look after my children

Coping lies with being strong inside yourself

Family support one another in difficult times to cope

Last hope

Inner strength=way of coping

Decision to get well



the way I want. **So I realised that, the only thing that I can do was to fight now**, to stand up so that I can look after my children. Since that day, even my doctor couldn't believe, because he used to send somebody to, to, to, to train me and do all the stuff, but I told him that I don't need that anymore, when I'm ready to stand up I would stand up. Three days after, I woke up early in the morning because I used to ... the nurses were used to wash me because I couldn't even wash myself. So that day I woke up early, five o'clock in the morning, I went to the toilet. When my doctor came in on that morning, I was busy preparing my bed and I told him: "*Today I want to go home.*" He said to me, because I was, I've got three operations. He told me: "*You are not well, the operations are still wet and all those things.*" I said: "*No, I need to go home now.*" Really, the following day he said: "*Okay, I will discharge you the following day.*" Then they discharged me, they gave me goals and all those things, I came back home. **It was my brother who was caring for my children. I never went back to my doctor** except the day of moving out of hospital.

Will to be cured and to live

Family members looking after children

From that day I felt that **I have the courage**, living is about challenges. It's about **accepting your, your, your problems and dealing with your problems in an open mind**. So since then that's how I got back on my feet.

Courage

Acceptance=1<sup>st</sup> step in coping

R: And if I understand you correctly that is the way that people in this community cope. It's with their faith (Yes) and with other people supporting them (Yes) and other people helping them (Yes) and maybe a healthy diet (Yes). Is there anything that I'm leaving out?

Summary:  
Cope:  
1.Faith  
2.Community members support/help  
3.Healthy diet

P: Yes, uh and sharing, you see, and **sharing**. **I think sharing ... to, to accept your, your, your problem is the most important thing, you see. It's the main thing, because if you don't have faith, nothing will come right - you must believe that.** What I believe in is that **if you want to live, you will live, if you want to achieve something, you'll achieve that, you see.** So it's what I used to tell people that don't rely on drugs, because even I don't believe in drugs. You see, I don't believe in drugs, but I don't say that if

Community members sharing

Accepting=important

Faith=important

Positive attitude and belief/faith



somebody wants to use drugs they cannot use it, you see, but before ...  
 learn to accept it, have faith, have somebody, one person so that if you ...  
 ... because sometimes ... we are living, now people ... most of us are  
 not dying because of this disease, it's because of, they've got a lot of  
 stress, they don't have people to share their problems with, because they  
 are ... there are those who feel afraid of that people who are laughing at  
 them, you see. But in fact I used to tell them I don't mind, if you tell, you,  
 you, you tell me your problem then I went to my neighbour and, and uhm  
 talk about that problem of yours to my neighbour ... it's my own problem,  
 not yours, you see, because the minute you, you, you take out your  
 problem you'll be very relieved, you see. So if, because by telling me  
 your problem, that means you trust me, you see, that's why ... that's  
 what make you share your problem with me. So if I go up and down and  
 talk about it to other people it's not your problem, it's my problem. I will  
 answer to God, on my day, you see. Don't mind that. The most  
 important thing is, is, is ... you know that by taking it out of you, at least  
 you will be relieved, because most of the people now are, are, are dying  
 because of stress, you see, because they don't have people to share  
 their problems. That is the most important thing, and you must believe.  
 You must believe in God, you see. You must believe in God, because if  
 you want God to help you, I know that you will get that help, you must,  
 you must ... Now is the time for us to demand, you see, if we demand,  
 everybody's got ... I'm talking about myself, I want to live twenty years  
 more for my children. I demand that to God everyday, every now and  
 again because he knows that I want to live, not for me, for my kids, so he  
 can't let me down. He can't let me down. That's what we need to do, you  
 see. That's what we need to do. But it will take time to other people to  
 understand that. That's why I, I, I, I said to you before that we need  
 something like workshops, so that everybody, everybody must be there,  
 you see, because some other people are just looking for their relatives,  
 for their family members. Go out and help another person's life, that will  
 make something to your, to you too. But some other people they just  
 don't want to be forward so that they can be involved to other things, it's

Strengths:

Accept it

Faith

Support system

Stress then

Support=  
important

Fear – stigma

Share problems

Tell other  
community  
members=relief

Relationship of  
trust=important

Community  
members  
sharing in other  
problems-taking  
burden

Having a  
support  
system=brings  
relief

Religion and  
faith in God

Need for  
informing  
people(all  
community  
members)

Family=primary  
support system

something like that, but I do know that most of the people are going to survive in our five years to come.

R: The sixteen year old girl that you saw yesterday, is it just a friend?

P: No, what happened there is that I saw the problem of eh family members in area X, so when you come to me about your project I listened to you. Then after, if I, I, I, I will see that I can do this, I can help you in this project, you see. Before, I will tell you about myself, about where do I come from, some other people they don't know me before, they just know me now, so they don't know where I'm coming from, you see. So it's what I used to do that, I would tell them that I am coming from a poorest poor, poor, poor family, but you won't believe. You won't believe because I told myself that God helps those who want to help themselves. So I just told myself that I want to be one of those people who help themselves and help others. So it was something like that. So those, since that day, those ladies came to me again and said: We've got a problem that side, people are dying, nobody wants to be involved in these things, you see. Because there are, there are NGOs in our areas, there are social workers but I don't know what is going on, because it's not about helping people at your workplace, help your community, do it for community, you see. Because really we need our communities, you see, especially those children who are from, from, at the age of ten up to twenty-one, you see. They know nothing, so they need people who can show them that there is future outside, but you must, you must try to take things slowly, you see. So they need somebody who can teach them, you see. Somebody, eh ... not a person who's going to, to, to, to shout at them, to be harsh on them, somebody who'll be in that position so that they can really understand what is going on outside. Because most of the people who are dying now is our youth. Our youth are really dying and it's my concern, because we need those children, you see. We need those people to, to, to be our future teachers and doctors or ... But if, if we are not ... we don't want to help them now, where are we going?

Family=support

Coping lies within PLUS God's HELP

Community members help one another

Community members support and look for help

Mobilising assets

Resources

Future perspective=important

People need to be informed

Need for a positive future perspective

Community members help

R: I want to ask you one more question. Tell us about that group that works in the community, the one that you went to, to get your information from. Do they meet regularly and do they go to people's houses or what do they do?

P: What they are doing, every Wednesday they meet, there is a hall here at K, so they meet there to ... if, to, to share their views. Then, if there are, one of them is sick or what, they are visiting each other at their homes to help each other.

Home visits

Community based support group

R: So they are like a support group?

P: Ja, it's a support group.

R: Do you know of any other support group in *area X*?

P: No, no. I don't know in *area X*, but in that support group, there are people from *area X* that also goes there, but there is few of them, you see. That's why I said that we need, we need to go out to this areas, you see, and, and, and try to, to, to, to explain to them that, that ... Don't feel ashamed of yourself, you see. Stand up for your rights because to have this disease, it's your own right, you see. It's your own right and it's something that you can, you can live with. If I don't want to, to, to stand up for myself, who can stand up for me? No one, you see. And if I already have it, it won't just go away, you see, it's something that it will be there for the rest of my life, you see. But the only thing that is important, if you know what are you getting.

Need to inform and motivate HIV positive people

Crux of coping lies within yourself

R: And accept it.

P: Yes, that's right.

R: L, thank you very much for your time and for sharing your story with us.

P: It's a pleasure. I must tell you, I was having a **meeting yesterday five o'clock at the police station** ~~with our youth~~. I'm a co-ordinator of the youth in this area. Really, our youth are involved in drugs. Our youth are involved in **rapes, car thefts, house breaking**, all those things, you see. Now I was trying to ... **trying to get some help from NGOs** and our **counsellors** ~~to try to, to, to do something, to do something about our youth~~. But what is happening now, I'll just say, maybe because the, the, our elections are, are, are coming very soon, it's what makes them not to respond, because without our local government we cannot move, you see. We cannot move. They must be involved, each and everything that we are doing, you see. So on Sunday, one policeman killed an eighteen year boy, Sunday morning. That boy was trying to rape his cousin. So that person died on the spot. It was very, it was ... when I hear that, I was feeling very sorry for that boy, but as long as nobody feels what I feel, I'm not sure because we ... we don't think eh ... we are different people here, coming from different places, you see. Some they don't have interest in these children, because I tell them, from our last meeting I just tell them that: ~~Why can't you sit down people and check, what makes our crime rate high?~~ Is it **poverty**, or is, is, is it because those kids doesn't have something to do or what? Because I don't believe that I can make that to my son, then when he has reached eighteen years he will go out and steal your things, you see. There is something wrong somewhere somehow, so we need to check from those things, really what is going on because those children are our children, you see. But uhm ... our meeting was so successful yesterday.

Resource

Youth problems:  
-drug abuse  
-sexual abuse  
-crimes

Potential resources

Crimes

Poverty

R: You've been working hard this week. Thank you for your time!

**FIELD VISIT 4 – 4 JUNE 2004**

**INDIVIDUAL INTERVIEW 9**

**(interview conducted in Afrikaans)**

**ACVV EMPLOYEE (CO-ORDINATOR/SOCIAL WORKER)**

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**BROAD (FLEXIBLE) INTERVIEW SCHEDULE:**

- ⌘ What are the main challenges faced by the selected community?
- ⌘ Which resources and potential resources can be identified in the community, which might be utilised to address the challenges the community face?
- ⌘ Which services are currently provided by the ACVV in the selected community?
- ⌘ Which role is the ACVV currently fulfilling in supporting the community in coping with HIV&AIDS?

KEY OF ABBREVIATIONS
R: Researcher
P: Participant

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R: Ek is besig met navorsing in *gemeenskap X* en probeer verstaan hoe die gemeenskap MIV&VIGS hanteer, hoe hulle daarmee “cope”. Vertel my asseblief van die dienste wat julle binne die betrokke gemeenskap verskaf en wat jou persepsie is oor die wyse waarop die gemeenskap die eise van die pandemie hanteer.

P: Wel, ons het 'n maatskaplike werker wat binne die gemeenskap werk en na sewe jaar min of meer die gemeenskap dek. Sy het 'n kantoor by die een laerskool, wat die skool gratis gee. In ruil daarvoor ondersteun ons die skool waar ons kan – finansiële of met vaardighede wat ons het waar

Community based social worker at a primary school Support Networking

ons hulle kan ondersteun. Op hierdie stadium van die geveg het ons, ja uhm ..., so ons kantoor is daar, maar ons probeer om uit te brei.

R: Mmm?

P: Ja, ons het aansoek gedoen by die **Lotto, vir 'n sponsor, en ons het dit gekry!** Nou **wil ons 'n hele dienssentrum**, soos wat ons hier het, in *gemeenskap X* **bou**. Ons het nou Maandag 'n vergadering met die argitek gehad, ons wag fisies net vir ons eerste paaient wat uitbetaal moet word, dan gaan ons begin bou. Behalwe hierdie grond het ons ook **ons eie crèche in gemeenskap X**. Daar is 58 kinders op hierdie stadium wat geregistreer is daar, maar dit is ons, die ACVV se gronde. Dit is nogal redelik groot, en die crèche is ons fase een, die **dienssentrum is ons fase twee** en fase drie gaan meer 'n **gemeenskaps-service centre** basies wees. Ons het ook, wat baie goed is, 'n salarisvergunning gekry vir die koms van 'n **dienssentrumorganiseerder**. En dit is hoekom ons maatskaplike werker ook hier is vanoggend, want ons betrek haar – sy's alreeds betrokke by ons groep wat ons het, en dan sal sy, net soos wat ons dienssentrumorganiseerder dit hier doen, sal sy dit dan daar gaan doen. **Ons wil probeer om al die dienste wat ons hier apart het en kan lewer aan die gemeenskap ook aan daai kant te doen**. Die ding is, dis **ons gemeenskap, ons is verantwoordelik daarvoor**. Daar is **bitter min – volgens my – ander NGO's verteenwoordig daar**. En dit is 'n **baie behoeftige gemeenskap**. So, **Departement Welsyn of Sosiale Ontwikkeling is ook betrokke**, maar meer met gevalle waar dit nie soseer oor bemagtiging van die gemeenskap gaan nie. Dit is meer krisis-ingrypend, jy weet.

Lottery=financial asset  
Service centre=potential asset

Creche in Community

Community centre planned  
=potential asset

Co-ordinator to be employed=  
potential asset

Planned to extend service provision to community  
=potential asset  
Responsible to support community  
Limited NGO involvement in Poverty  
Government involvement

R: Ek verstaan.

P: En wat lekker is van hierdie crèche is dat, ons het geen statutêre werk nie. Geen. Ons is **verantwoordelik vir gemeenskapsontwikkeling en bemagtiging** in *gemeenskap X*. So alles wat ons doen is gefokus of gemeenskapsprojekte en **nie op gevalle-werk nie**. Want jou satutêre

Focus on community development and community empowerment  
Not individual cases

werk vat gewoonlik 80% van jou dag se tyd. So, umm, alles wat jy doen is net **gemeenskapsgerig**. So dit maak nogal 'n baie groot verskil. Ons het op hierdie stadium ook 'n **jeuggroep**. Ek dink dit gaan deesdae meer na 'n **vrouegroep**, want ons moet aanvaar ons **kan nooit iemand wegwys nie**. As jy dertig is en jy wil deel word van hierdie groep dan word jy aanvaar. Ons **leer vir hulle handvaardighede**, hulle het vir my so 'n lys gegee; hulle wil naaldwerk doen, hulle wil leer brei, hulle wil leer hekel, hulle wil lapverf. Al daai tipe van goed wil hulle doen, en ons probeer om al daai vaardighede vir hulle aan te leer as, op die ou end van die dag 'n **inkomste-genererende projek**, want hulle kan dit maar gaan verkoop en die inkomste is hulle sin. Ons kom elke Maandag en Woensdag bymekaar vir twee ure. Op 'n Woensdag is dit basies hulle handwerk en op 'n Maandag sal hulle dinge doen soos 'n **opvoedkundige onderwerp wat hulle moet bespreek** of hulle kan hulle **bybelstudiegroep** doen. Dit hang maar af wat die groep se behoefte is. Ons het so een keer in twee maande 'n vergadering met hulle om te beplan vir die volgende twee maande om seker te maak ons spreek aan wat hulle wil doen. Hulle dink dit is baie maklik om in die roetine te val van 'n program vir die volgende twee maande, want hulle kry hulle program vooruit, elke maand, van wat hulle op die Maandag en Woensdag gaan doen. Hulle dink dis baie maklik op die ou end van die dag as jy eers in hierdie roetine van werk is en jy sit die program neer van dis wat ek gedink het julle moet doen vir die res van die maand. So ons probeer sover as moontlik – as hulle vandag sê hulle is nie lus hiervoor nie en hulle wil eerder iets anders doen, dan doen ons dit. So, **ons is redelik oop vir verandering**.

Community-focused

Youth group

Women's group  
(nobody is turned down)  
Focus on skills development

Income generating potential

Educational discussions and Bible study

Flexible to change

R: Waar vind hierdie byeenkomste plaas?

P: Umm, by die **wit kerkie op die hoek**. Ons het hierdie kerkie, dit is een of ander geloof, ek kan nou net nie op die naam kom nie, umm ... Maar ons gebruik dit absoluut gratis. Alles wat ons doen word daar gedoen. Ons **fondsinsameling** as hulle iets maak en dit verkoop, is dit daar, ons jeuggroep word daar aangebied, die naaldwerkers doen dit ook daar – so is dit net meer gerieflik en meer privaat. En dis nie 'n groot saal nie,

Church in community= asset

Fundraising (coping with financial needs)



dis nie eers die helfte van die saal hier binne nie. So dis 'n baie klein saaltjie wat die atmosfeer net half beter maak – dis nou nie hierdie groot skoolsaal nie. So dis op hierdie stadium gratis, wat baie goed is, maar ook baie primitief in terme van daar is elektrisiteit maar ons het sover as moontlik vir hulle 'n kas met al hul goed in voorsien. En dis koud, in die winter is dit verskriklik koud, jy't eintlik 'n mat nodig en daai tipe van ding en dis hoekom ons graag ons eie sentrum wou gehad het. Net om dit meer gemaklik en gerieflik vir hulle te maak. En hulle moet voel dit is 'n mooi omgewing en 'n meer rustige omgewing, wat hulle gaan motiveer om op die ou end uit hul pad te gaan om deel te neem.

Need for proper facilities

Coping ito being motivated

Nee weet jy ek sê altyd as jy gebore word in 'n omgewing en jy leer dis hoe dit is, gaan jy nie noodwendig weet wat jy mis nie. Maar as jy vir hulle indring en sê dis hoe jou omgewing kan wees, sal hulle ook daaruit leer. En op die ou end van die dag is dit ook ons doel. Om vir hulle 'n gemaklike plek te gee daar waar ons alle aktiwiteite vir hulle kan aanbied, waar hulle bemagtig kan word en dat hulle dit dan ook kan verder vat. So dit is die groepe. Toe ek hier begin het, was die groepe minder, daar het so vyf of ses gekom. Ons staan nou op so 15. En spesifiek wat ek nou net gesê het, hoe moet jy byvoorbeeld lewe inblaas? Hoe kan jy, want ek weet nie wat voor my tyd gebeur het nie. Maar dis ongelooflik as jy hulle eers begin motiveer en ook hoor wat hulle behoeftes is en sien hoe hulle deelneem en ook na vore kom, ons is nou besig om handskoene te brei – glo dit of nie, want dit is wat hulle wou gehad het. En geel serpe vir hulle kinders en 'n serp vir die winter. En ons het 'n donasie van wol gekry, so hulle is aan die brei. En ons het 'n naaldwerkinstruktrise wat ook, sy is die heeltid by ons woonstelle, en ook weer eens geld van die Lotto af, wat dit alles moontlik maak. En ons het genoeg fondse om fisies te koop wat hulle nodig het, wat baie lekker is.

Focus on empowerment and sustainability as ways of coping

Motivation and dedication

Donations= assets

R: Dis wonderlik!

- P: En ek sal vir jou sê, **hierdie Lotto is baie welkom**, maar ons wag nou al baie lank en hulle sê hulle weet nie wanneer ons eerste paaient gaan kom nie. Maar ek kla nie hardop nie, want hulle het letterlik vir elke maatskaplike program waarvoor ons aansoek gedoen het, het hulle gegee.
- R: Fantasties.
- P: Ja, dis ongelooflik. Dis so lekker, want gewoonlik as jy dink hierdie ding gaan werk moet jy hom ses keer gaan omdraai en kyk of iets anders beter gaan werk of nie dalk goedkoper is nie. Dis so lekker, nou gaan jy in, jy kry wat jy nodig het en jy weet dis wat hulle gaan en kan gebruik. So dit maak nogal 'n reuse verskil. Ek dink as die Lotto besluit nou draai ons krane toe, gaan dit 'n groot aanpassing wees vir baie. So dis basies dit vir vanjaar se groepe. Dan het ons ook ons **weekgroep**, in dieselfde kerk en dit is 'n groep wat basies laerskool en hoërskool georiënteerd is. En weet jy, die **groep groei ook geweldig**. Hulle het begin met so 12, 13 kinders, en op hierdie stadium kom daar so 22 tot 23 op na 25. En dit is 'n **voorkomings- en opvoedingsgroep**, maar basies doen hulle nie fondsinsamelings en sulke tipe van goed nie. Ons doen baie **jeugkampe met hulle en sportontwikkeling** met daai spesifieke groep. En dis maar basies **voorkomingsprogramme, op hierdie stadium is hulle besig spesifiek met die hele HIV, die disease, seksvoorligting**, al daai tipe van dinge is hulle besig mee. En ons het nou van die 11de tot die 13de Junie 'n **jeugkamp** vir hulle. En ons het vir hulle 'n **workshop** vir Saterdag gereël van iemand uit die gemeenskap wat – Dinsdag het ek hulle ontmoet vir die eerste keer – hulle is besig met 'n **HIV-support group**, maar *D* gaan julle meer daarvan kan vertel. Miskien ken julle al die mense, hulle is al gevestig maar hulle wil graag uitbrei, en hulle kom bied fisies die *workshop* vir die jeug aan vir die hele Saterdag. So ons probeer om **sover moontlik van die gemeenskap se hulpbronne gebruik te maak om hulle eie mense te bemagtig**, wat beter is as wat ek byvoorbeeld gaan, want dan kan hulle in hulle eie taal bemagtig word wat, ek dink, 'n groot verskil maak op die ou einde van die dag.

National lottery as financial asset

Weekly group

Growth in group

Prevention(HIV) and educational

Youth camps and sport development

Prevention programmes: -HIV&AIDS -sex education

Youth camp Workshop

HIV support groups

Mobilising community resources to empower others (=asset-based approach)

R: Hoe gereeld vergader die groep?

P: Een keer 'n week, ook op 'n Dinsdag, vir so uur en 'n half in die middag, van reg na skool tot so vier uur toe. Partykeer, as hulle dit baie interessant vind, gaan hulle oor die tyd. En vir al hierdie groepe voorsien ons vir hulle broodjies en tee, maar nie vir die jeuggroep nie. By die jeuggroep drink hulle koeldrank en wat ook al, maar almal kry hulle eetdingetjie, soos vir die menses wat op 'n Woensdag daar is, kry basies 'n dish met so gebakte ete, met groente en sulke tipe van dingetjies in. En die kinders by die crèche kry e-pap.

Provide in basic needs:  
-food  
-food supplements

R: Ek het al baie daarvan gehoor.

P: Ek het al e-pap geëet. Dit werk soos wat hulle sê dit moet, maar ek eet dit nie elke dag nie, want dis nie baie lekker nie. Maar in elk geval, ek het nou al hierdie mense ingetrek om 'n presentation te gee oor hierdie e-pap, en elke week as ek soontoe gaan moet ek daarvan bestel – ek voel al soos 'n rep vir e-pap, want ek moet bel en die aflewering doen en al daai goed.

R: Hoeveel kos dit?

P: Weet jy, dit is R10 vir 'n 25 gram pakkie, en uit een pakkie kan jy 20 kinders voed. Want jy eet mos net so een of twee opgehoopte eetlepels dan meng jy dit met óf water óf melk. En dit bou jou immuunstelsel, dit gee vir jou energie, en sê nou maar jy eet dit agt uur die oggend en tien uur drink jy 'n glas water, dan sit dit fisies uit in jou maag dan voel jy versadig en asof jy nou net 'n maaltyd gehad het. En ek belowe vir jou, ek eet my ontbyt sewe uur in die oggend, en twetse opgehoopte eetlepels is te veel vir my want ek eet dit saam met joghurt en teen twee uur daai middag is ek nog nie honger nie. En e-pap se vitamien en minerale is gecoat – dit het een of ander lagie om sodat dit nie teen mekaar kan werk nie. So jy kry fisies al jou vitamien en daai voedingswaarde wat jy nodig het in. Dit boost dan jou immuunstelsel.

E-pap: nutritious and inexpensive  
-combat hunger and malnutrition

En jy maak dit ook nie met gekookte water nie, want uit die aard van die saak brand dit al daai voedingswaarde dood. Maar jy kan lou water, of lou-warm water of lou melk of wat ook al kan jy maar bysit. Vandat die crèche dit nou probeer gaan dit beter met die kinders, maar hulle voel nogsteeds dis te duur, en hulle sê die kinders hou nie daarvan nie want jy kry dit in *strawberry* en *vanilla*, en ja, hulle sê die kinders hou nie daarvan nie, ongeag van die geur. Maar weet jy, as kinders net daai twee eetlepels inkry per dag, hoef hulle geen ander groente of enige iets anders te eet nie. So ons gebruik dit ook vir ons jeuggroep en baie van die bejaarde vrouens wat sukkel met hulle gesondheid en met diabetes gebruik dit ook. Ek sukkel geweldig met my bloedsuiker en as ek daai pap geëet het, het ek nie soveel probleme nie. Dit werk basies vir alles. Dit help met hulle gesondheid ook.

Dan is ons terug by die crèche. Sover as moontlik probeer hulle om elkeen in 'n spesifieke area te wees sodat die hele area bedien kan word. Hulle koste per maand beloop so R60 per kind, baie van die ouers betaal nie want hulle het fisies nie daai R60 nie. En wat vir my goed is van die crèche is hulle wys niemand weg nie want op die ou end van die dag – ongeag of die ouers die geld het of nie – daai kinders het leer nodig. Dis hoekom ons so 328 kinders het. Hul probeer die beste van die behuising maak. Hulle doen aansoek by die munisipaliteit en elkeen, waar ook al, individueel doen dan aansoek. Ons doen vir hulle aansoek by die jeugshuis, wat vir ons op hierdie stadium redelik goed ondersteun. So hulle het nogal daai fondse gekry en hulle fondse word uitbetaal aan hulle onder ons leiding. Sê byvoorbeeld hulle moet gaan vir 'n *educational course*, sal ons hulle fisies gaan haal en ons vat hulle soontoe. Maar 'n groot behoefte is kos, want hoe gaan hulle aan al hierdie kinders kos voorsien? Soos ek gesê het, hulle eet agt uur, tien uur, twaalf uur en drie uur. Jy kan vir die ouers vra dat hulle net 'n broodjie insit – maar al die ouers doen dit nie. Daar is baie kinders wat met 'n leë rugsak by die skool aankom. So hulle het 'n baie moeilike taak. Op hierdie stadium is ons, ek kan nie vir jou sê watse vennootskap dit is nie, want hulle vra, en ons moet gee. En dit is nie vir my bemagtig

Crèche in community as asset

Financial need

Crèche accommodating all children

Assist in obtaining funds and external aid

External funding as asset

Poverty and hunger

nie, want ons is op dié stadium besig met *hand-outs* en dit moet gestop word. Die ongeluk van die saak is daar is 'n president geskep. Ek het 'n ongelooflike lelike vergadering nou die dag gehad, ek is nuut, ek kom met al hierdie inligting wat gebruik moet word, want dit is nie hoe dit werk nie, en ek kry dit van alle kante af. Daar is baie wat ons raadpleeg en wat ons soebaat hulle wil deel word en hulle wil op ons lys kom – wat ek met alle mag en krag wil keer. Ons is hier om finansiële ondersteuning vir hulle te gee. Ons vat hulle een keer 'n kwartaal op 'n uitstappie. Al daai administratiewe werk doen ons. En toe laat weet hulle net nou die dag ons moet nog die vervoer betaal ook, toe sê ek vir hulle dis waar ek nou die streep trek. In 'n mate het julle 'n inkomste gehad. Ek is bereid om julle 50% te help maar ek gaan nie die ander 50% betaal nie. En hulle was kinderlik ongelukkig met my. Maar ek het hulle so ver dat hulle aan die einde van die maand gaan hulle betaal, die totaal was R600. Ons sal die R600 betaal maar hulle moet vir ons R300 terugbetaal. Want hulle moet daai verantwoordelikheid leer – ons kan nie net gee nie.

Hand-outs not favourable

Financial support in community  
Take community members on outings

Focus should shift to empowerment instead of hand-out

So, die crèche het, die werk wat hulle fisies in die gemeenskap doen is goed, hoe hulle daai kinders oplei, baie keer gaan ons tydens ons besoeke en kyk fisies wat hulle met die kinders doen. En ek moet sê: ek sal een van my kinders soontoe vat want hulle kry die stimulerings wat hulle nodig het. Maar net om die hele konsep en persepsie om te draai van ons gee – dit werk nie. So dit gaan 'n baie lang proses wees. Hulle dink op hierdie stadium dat, van ons kantoor se kant af het hulle gevoel iewers moet ons ons losmaak van die crèche, maar dit kan jy ook nie doen nie, want dan doen jy nie meer jou werk nie. Bemagtig hulle dan, dat hulle kan voortgaan op hulle eie. So dis baie moeilik, ook as hulle aansoek doen vir befondsing. Hulle kan byvoorbeeld nie, nou doen ek aansoek by die Lotto vir hulle en namens hulle, maar kan hulle nie ook gaan aansoek doen nie? Want op die ou end van die dag kry nie een van ons nie as gevolg daarvan. So ons het ... baie van ons donateurs en plekke wat ons befonds het vir ons briewe uitgegee en gesê: asseblief, doen een persoon aansoek namens almal, nie ses verskillendes nie. Dis

Crèche provides in educational needs of children

Focus on empowerment

baie moeilik – die vertroue is nog nie daar nie. So dis baie moeilik om daai insig te ontwikkel dat ek niks van hulle wil ontnem nie. Ek gun hulle alles wat hulle toekom. Maar as jy in die verlede kon aansoek doen, nou kan jy nie meer nie. So ons het nou vir die 30ste Junie 'n vergadering met hulle. Om al hierdie befondsings, die voor- en nadele, en hoe alles gedoen moet word, alles fisies met hulle deur te werk in die vorm van 'n *workshop* wat *Mev V* ook gaan doen. Omrede sy langer hier is het ek gevoel laat sy dit behartig, want hulle het meer vertroue in haar as in iemand wat hulle nie ken nie. Laat sy aan hulle verduidelik ons steel fisies nie hulle geld nie. Maar dit is net die prosedure wat gevolg moet word. En dit moet baie goed *gescreen* word en deurgewerk word en reggestel word, so dis 'n lang proses.

Ja, so dis dan deel van hulle behoeftes wat ons aanspreek. Van 'n meer professionele kant probeer ons ook om **voorkomingsprogramme** met hulle doen. Die eerste dag was dit vir my so vreemd, toe ek die crèche gaan besoek, toe begin al die kinders te huil. En ek kan nie verstaan hoekom huil hulle nie. En ek is nie die taal magtig nie – wat dit baie moeilik maak, maar ek verstaan dit al bietjie van dit wat ek opgetel het. En hierdie kinders huil, en as die een begin huil, dan huil die ander een harder. Ek wonder later wat gaan aan, het ek iets verkeerd gedoen? En dan groet ek hulle of ek speel met hulle of wat ook al en toe sê iemand, nee dit is omdat jy wit is, hulle het nog nooit 'n witmens gesien nie. En dit was vir my ongelooflik – dit was die eerste keer wat ek dit ondervind, ek het dit nog nooit in al die skole wat ek besoek het, in al die ander crèches wat ek besoek het en al die ander areas het ek dit nog nooit ondervind nie. Dit was vir my 'n *eye opener* – ek het nie geweet dit is moontlik nie. En dis baie moeilik – ek kan nie die workshop aanbied nie want hulle verstaan nie Engels nie. So hulle moet in hulle moedertaal die opvoeding en die poppespel of wat hulle ookal beplan moet hulle vertaal, en dis hoekom ons hulpwerkers dan verantwoordelik gaan wees daarvoor.

Prevention  
programmes

Dan het ons 'n **groentetuin-projek**. Ek dink jy kan dit sien van die uitdraaipad af – hulle het mos daai muur, en reg langs daai muur, 'n hele strook grond so af waar ons groentetuine is. Ons het ses groepe waar daar omtrent 300 mense is altesaam wat verantwoordelik is vir die groentetuine. *J sal julle ook meer daarvan kan vertel. Die idee was basies oorspronklik om **werkskepping en inkomste te genereer**. Op hierdie stadium word dit nie bereik nie want die stukkie grond wat elkeen het is baie klein. En op hierdie stadium **lyk die tuine chaoties, want die goedjies is droog en dit lyk nie asof die groentetuin bewerk word enigsins nie**.* Toe het hulle 'n vergadering gehad so twee weke terug en hier is 'n lysie van aankope wat ek moet doen ten opsigte van alles wat ek moet gaan koop, want hulle het in hierdie tyd soos die inskakeling van al die nuwe personeel en ons hulpwerker is af op kraamverlof, so nou het hulle uit tyd gehardloop en die lysies gegee maar niemand het nog terugvoering gegee nie. **So hierdie groentetuine moet net weer op die been kom. Almal is nog daar, maar hulle wag fisies nog net vir die saad**. So teen die einde van volgende week sal ons die saad hê, dan kan hulle weer aangaan, maar soos ek sê daar's baie min – party kan byvoorbeeld 'n sakkie uie of 'n sakkie wortels verkoop, maar ek meen ons praat hier van twee of drie rand wat nie regtig 'n verskil in hulle lewensomstandighede gaan maak langtermyn nie. **Maar ten minste voorsien hulle vir hulle kinders en hulself**. So dis ons groentetuine – hulle brei nie uit nie. Die mense wat betrokke is – dis 'n groep van 300 wat betrokke is, maar vir die afgelope hoeveel jaar wat hulle betrokke is het ons nog nie uitgebrei nie. Ons beplanning met die nuwe dienssentrum is om dit dalk te verskuif soontoe, omdat ons fisies die grond daar het daarvoor, dan het ons 'n groter mate van beheer – die **hulpbronne gaan beskikbaar wees, die water gaan nader wees**, jy weet al daai tipe van goed. En dis nog een van die redes hoekom die tuin so chaoties lyk, die water moet fisies gaan haal word.

Vegetable garden project

Employment opportunities and income generation

Vegetable garden neglected

Vegetable gardens = potential assets

Provide in basic needs for family

Resources and water available

R: By die skool waar ek werk het die onderwysers ook die behoefte uitgespreek om 'n groentetuin te begin. Sal julle oop wees daarvoor dat hulle julle kontakvir raad, want daar is water en daar is grond en hulle wil



graag die ouers van die gemeenskap betrek om dit te bestuur. Sal dit in orde wees dat hulle jou bel?

P: Definitief. Enige tyd! Want weet jy, **hulle het definitief die vaardighede – hulle weet wat om te doen**. Dis net 'n geval van as die hulpbronne daar is, maak dit dit net soveel makliker. En dis dan maar al van ons groentetuine. Soos ek sê, op hierdie stadium moet ons nou net dringend die saad en die dinge by hulle kry want dan kan dit weer van die grond af kom. Maar op hierdie stadium, ek gaan julle nie eers wys hoe dit nou daar lyk nie.

Educators  
perceived to be  
skilled

Dan **doen ons lewensvaardighede by van die skole**. Die twee hulpwerkers gaan nou, hulle het gister begin met hulle nuwe vaardighede met die kinders en dit is 'n langtermynprojek. Hulle het fisiese materiaal wat hulle opgelei is in, dis lewensvaardighede wat die vorige werker met hulle gedoen het. En hulle het fisiese programme wat hulle alles met hierdie kinders doen. En hulle vat nou maar so standaard vir standaard – so dit vat 'n tydjie. Die **behoefte het van die skole af gekom, hulle het ons fisies gekontak** om te hoor waar is ons en wanneer begin ons. So hulle het gister die eerste keer begin met hierdie lewensvaardighede-program, en soos ek sê, dis langtermyn. Ek dink as jy regtig gaan kyk na wat jy alles kan doen, daar is so baie onderwerpe wat jy kan bespreek met die kinders en wat jy voorkomend en opvoedkundig en al hierdie tipe van goed kan doen. Dit kan jou fisies vir 'n jaar en plus besig hou. Wat lekker is, is hulle is twee, wat maak dat hulle in kleiner groepe kan werk, wat die kwaliteit van hierdie tipe van diens wat jy lewer kan verhoog. Want ek voel, al bereik jy 15 kinders per jaar, dit is baie beter as daai 500 wat jy op jou statistiek het en eintlik het jy nie eers een bereik nie. So ek het 'n kleintjie dood as iemand vir my sê hulle gaan 'n praatjie gee, want op die ou end van die dag moet jy evalueer of jy regtig 'n impak gemaak het of nie. Ek meen, vat dit van jouself hoe maklik jou gedagtes dwaal as iemand daar voor staan en praat. So dis waarmee ons besig is by skole.

Life skills  
programmes at  
schools:  
involvement

Networking with  
schools

Dan het hulle ook 'n karate-klub, maar ons is nie direk meer betrokke nie. Die hulpwerker het dit ook, sy het dit begin en sy het basies die hulpbronne daargestel vir die gemeenskap. Dis nou jammer, ek het eergister of wanneer het ek al hierdie hele tydskrif wat die man vir my gegee het – maar ek het hier iewers 'n prentjie – van hierdie ou, hy's die eerste swart man wat 'n kaptein is van die Springbok karate-klub. Hy't vir my hierdie ding gebring, maar hy rig 'n honderd kinders af, plus minus 'n honderd, dis eintlik al 'n bietjie meer as 'n honderd, gee hy gratis karate-klasse voor, van vyf tot sewe, een keer 'n week in die gemeenskap, by 'n skool. En hy lewer hierdie diens absoluut gratis aan die gemeenskap. Toe het hy ons hulp gevra met die uitrustings spesifiek, maar dit is ongelooflik duur. So wat ek vir hom gesê het is dat ek in my nuwe Lotto-aansoek gaan ek hom inskryf en dan watse befondsing hulle dan ookal toestaan, indien, kan ons net so aan hom gee. Sover is hy gewillig om dit te doen en was bereid om dit van die begin af gratis te doen. Partykeer sal die kinders 'n R5 betaal, maar hulle is so arm wat dit baie moeilik maak want hulle moet byvoorbeeld R10 inskrywingsgeld vir toernooie betaal. En as jy fisies nie daai R10 het nie, dan het jy dit nie. En as jy moet kies tussen 'n karate-klub toernooi en brood en melk op die tafel vir die aand vir die kinders, gaan jy dit definitief nie vir die karate-klub gee nie. So daar is duidelike belangstelling, want daar's oor 'n 100 kinders wat al deelneem, en hy groei per maand hierdie groep. Maar dis hoekom ons gedink het, finansieel kan ons nie op hierdie stadium help nie, maar ons kan dalk van ons vrouegroep vra om later miskien van die uitrustings te maak, maar selfs daai materiaal is baie duur. So dis nie moeilik om daai uitrusting te maak nie want hy vou mos net so oor die broek, maar die materiaal is net so duur en ons het fisies nie die finansies nie, want ons het nie begroot daarvoor nie – om dit te gaan aankoop nie. So die plan met hulle is dan definitief nou om hulle in die nuwe Lotto-begroting in te skryf.

Karate club as asset

Support by women's group

En dan, daar was op 'n stadium 'n netbal groep. Ons het hulle netbalklere alles hier want hulle het 'n netbaldag gehad wat doodgeloop het in die tyd wat ek nou weg was en ons beplan om dit nou weer te

Netball group

begin. Maar ons kry mense uit die gemeenskap – daar's van die skoolkinders wat miskien in die eerste netbalspan speel wat bereid is om die wat nog nooit eers aan 'n netbalbal gevat het nie byvoorbeeld klasse te gee na skool – na ure – en dan skryf ons hulle ook in die toernooi in. Net vir blootstelling, basiese oefening, want die fisiese en die emosionele en al daai goed werk ook maar saam. En dieselfde met krieket. Daar is van die kinders wat graag wil krieket speel en baie van jou gevalle wat uit die gemeenskap kom is kinders wat dalk nie so betrokke is by die skool nie of dalk lankal skool opgegee het, en dan is daar van die jeug wat byvoorbeeld in ons jeuggroep is wat bereid is om van hierdie kinders fisies op te lei. So dis basies wat ons doen vir sportontwikkeling, maar dis meestal vir die jonger kinders – die jeug.

Classes to children – physical stimulation -emotional well-being

Other children supporting vulnerable children

Dan het ons een keer per jaar 'n sportdag vir bejaardes en gemeenskap X word ingeskryf, want ons is een tak. Dan, vir die oefeninge wat ons hier doen vat ons fisies van hierdie mense wat meer ondervinding het van die oefeninge wat hulle doen oor 'n baie lang tyd, gaan uit na die gemeenskap toe, hulle gaan leer vir hulle fisies al die verskillende aktiwiteite wat hulle moet doen vir die dag. Hulle elkeen het 'n dans vir die optog – dis eintlik nogal 'n groot ding in hulle lewe. En toe verlede jaar het hulle blykbaar 'n beker gewen, gemeenskap X het die beker vir oumensies vir die beste sportgees gewen, want daar was een of ander pastoor of predikant wat die musiek moes gebring het, toe daag die ou net nie op nie. Toe het hierdie bejaarde groep, het toe begin sing. Hulle is mos ongelooflik talentvol wat musiek aanbetref. En hulle het sommer, man, blikke gevat en dit gebruik as dromme. En hoe hulle die hele spangees en musiek vir die dag voorsien het en hierdie hele optog toe kon laat voortgaan het met hulle insette wat hulle gelewer het en toe het hulle die beker gewen.

Sports day for the old-aged

So, hulle maak my mal op hierdie stadium, vra aanhoudend wanneer is die volgende datum. So ons weet nie, ons sal eers na die 14de Julie weet wanneer die volgende datum is. Maar dis ook 'n groot dag vir hulle. Daar is al die verskillende mense van Uitenhaag en Jeffreys, en al daai

plekke kom bymekaar en dis die verskillende spanne en takke en wie weet wat, wat alles teen mekaar kompeteer. En in 'n mate is dit meer ontspanning as wat dit regtig bemagtiging is maar hulle word ook blootgestel aan soveel ander goed wat hulle nooit in hulle gemeenskap gehad het nie. En daai goed kan weer vorentoe na hulle gemeenskap uitgedra word en daai diens wat daar gelewer word. En dis ongelooflik hoe baie energie die bejaarde mense het. Dis ongelooflik. Hulle het meer energie as vandag se tieners, dit belowe ek vir jou.

Dan, ons het vier **individuele plasings** – streekshofplasings. Vier lêers, dis die enigste gevalle-lêers wat ons het. Hierdie gevalle kom al jare saam met hierdie tak spesifiek. Dit is almal wat se biologiese ouers fisies oorlede is of net spoorloos verdwyn het. Maar soos ek sê, ons doen nie statutêre werk nie, daardie kinderhof-verrigtinge is al lankal afgehandel. Ons is fisies net verantwoordelik vir die verslae en daai tipe van dinge. Maar dit is my verantwoordelikheid, die hulpwerker doen dit uit die aard van die saak nie. En dan besoek ons hulle nou maar net so een keer in twee weke, een keer 'n maand om te kyk gaan die plasings nog goed. Meeste van hierdie kinders, as daar klein kindertjies is, is hulle by ons crèches ingeskakel, die tieners is by ons jeuggroep ingeskakel en dit gee ons ook 'n beter mate van beheer en kontrole. So daai diens gaan glad nie uitgebrei word nie. Hulle het, op hierdie stadium het hulle gevoel ons moet daai lêers termineer en oorplaas na die Departement, waarmee ek 'n groot probleem het want die ACVV lewer hul diens al vir die afgelope 15 jaar plus. Dit gaan nie tot voordeel van die kind wees om nou ewe skielik by 'n ander persoon te eindig nie. So ek het gesê die meeste is tieners, ons het een kind van 5 jaar oud op hierdie stadium, so die meeste is tieners, jy weet, 15, 16. Agtien jaar is nie so ver weg nie, so as jy 15 jaar teen 3, 4 jaar vat, ons gaan aan met die diens, ons gaan klaarmaak, termineer en dan is dit klaar.

Social support to individual cases

Maar dis sleg, weet jy, **daar is fisies net nie die personeel om daai diens te lewer nie. So ek dink as jy regtig moet gaan kyk – daar is ongelooflik baie gevalle-werk binne die gemeenskap en fisies nie die personeel om**

Limited social services, lack of staff  
Great need in community

daai diens te lewer en waar kinders moet verwyder word, om daai diens te lewer nie. Wat baie sleg is want die Departement dink ek nie bereik almal nie. Daar is mense wat 3, 4 jaar al wag net vir 'n grant. Die tendens was op 'n stadium, toe hierdie toelaag net uitgekom en bekendgestel is, dat nou neem almal almal se kinders aan vir 'n grant, want dis vir my 'n vorm van inkomste. Maar die probleem kom in by die prosessering by die Departement, dis so ongelooflik stadig, julle sal weet wat daar aangaan, maar dit werk nie. En nou moet hierdie kinders versorg word, hierdie 3 of 4 kinders moet versorg word. En intussentyd is daar geen vorm van inkomste nie.

Department cannot meet community's needs  
Backlog in grant applications

Grants as income =asset

Dan het ons ook vakansieprogramme vir die jeug, dis maar meestal vir die laerskoolkinders, meer ontspanningsaktiwiteite omdat daar geen fasiliteite is vir ontspanning in die areas nie. So hulle doen opvoedkundige en ontspanningsprogramme gedurende die vakansie. Hulle sal speletjies met hulle speel, kompetisies hou dat die kinders kan pryse wen. Hulle gee byvoorbeeld aan die einde van die vakansieprogram 'n groot partytjie. Net as, dis nie veel bemagtiging nie, maar meer, soos ek sê, as ontspanning net vir die kinders. En ook om hulle besig te hou, want ledigheid is baie sleg. Ons sit hier met 'n situasie waar kinders van 15, 16, besluit het ons is nou klaar, ons gaan nie verder skool nie, hulle kry fisies nie werk met hulle kwalifikasies nie. Hulle is ledig en die volgende stap is dan raak betrokke by al hierdie dinge wat aangaan. Ons het nou kinders wat betrokke is by 'n absolute dwelmnetwerk. En dis al die kinders wat fisies niks het om met hulle tyd te doen nie. So hoe anders moet hulle, hulle word partykeer in geld betaal, ander tye word hulle met dwelms betaal. Hulle word afhanklik gehou, so dis hierdie bese kringloop. So veral vir die kleintjies, elke vakansie, of dit nou 10 dae vakansie is, maar nie oor Desember-tye nie. Meestal vir die veiligheid van die werker word daar nie vreeslik baie met die gemeenskap gelol oor Desembere nie. Spesifiek Kersfees, tussen Kersfees en Nuwejaar, omdat alkoholisbruik hoog is. En dis familie-tyd ook maar meestal, so daar word nie vreeslik aktiwiteite oor daardie tyd aangebied nie. Maar die vakansieprogramme word vir al die ander

Holiday programmes for the youth  
Recreational

Children involved in substance abuse

vakansies aangebied en soos ek sê dis maar hoofsaaklik vir die laerskoolkinders. Nou in die April-vakansie was daar oor die 100 kinders elke dag wat gekom het, en ek moes die dag 'n 100 appels gaan koop en 'n 100 eiers gaan koop vir al die aktiwiteite wat hulle aan het. Maar ook, ons het befondsing van die Lotto af gekry vir hierdie vakansieprogramme. So ons kan dit doen.

R: Is hierdie programme oop vir die kinders van *gemeenskap X*?

P: Ja, absoluut vir die hele gemeenskap, wie ook al belangstel. Weet jy, *even* die *life skills* program, die jeuggroep, almal. Dit is absoluut daar vir die gemeenskap. Hoe meer dit bywoon, hoe beter. Want so kan jy uitbrei.

Dan het ons ook nuwe projekte wat beplan word. Die hulpwerkers het gevalle-werk wat hulle doen. Van die gevallewerk wat hulle doen moet hulle uit die aard van die saak soms na my verwys of andersins na die ander maatskaplike werker, afhangend, vanuit die assessering, wat hulle vind die probleem is. As hulle nie in staat is nie of wat ookal, uit die aard van die saak, moet hulle verwys. Hulle is bekend met die gemeenskapshulpbronne, so sou daar 'n aansoek wees – mense wil weet hoe gaan jy te werk om aansoek te doen vir 'n ongeskiktheidstoelaat of die jeug het 'n probleem, verwys hulle basies en stuur die gemeenskap in die regte rigting in. Ek meen *L* werk al vier jaar, so sy het baie inligting rondom die maatskaplike veld en basiese inligting wat hulle kan voorsien aan die kliënte. Hulle sien so gemiddeld, weet jy nie vreeslik baie nie, omdat hulle meestal nie op kantoor is nie – nie vreeslike kantoorafsprake nie maar meer in die gemeenskap – maar hulle sien so gemiddeld tussen 25 en 30 kliënte per maand. En dit gaan meestal oor **grant probleme** wat hulle ondervind. Daar is ook baie **gesinsgeweld, alkoholmisbruik, en dan probleemtieners**. Dis nou maar wat ek die kort tydjie wat ek hier is uit die bestuursnotas en goed uit kon kry. Dis van die dienste wat hulle lewer, maar die meeste van die dienste moet hulle verwys. En as hulle nie weet nie, kan ek vir hulle die

Community challenges:  
-grants  
-family violence  
-alcohol abuse  
-child-related problems

verwysing gee en dan kan ons verder verwys. So daai diens word ook gelewer.

Dan wil ons graag 'n tipe van 'n nuusbrief begin om uit te gee in die *gemeenskap*, nie soseer as 'n fondsinsameling nie maar ons wil hom graag vir so 50c na R1 toe verkoop net om die uitgawes te dek, want ons het nie befondsing daarvoor gekry nie. Maar basies, wat dit gaan wees, is om vir die *gemeenskap* in te lig ten opsigte van die dienste wat die ACVV lewer binne die *gemeenskap* en om dit te bemark in die *gemeenskap*, maar ook om van ander te hoor en met ander te skakel en daai dienste wat gelewer word vir ander ook daar te wys. En miskien as daar 'n groot gebeurtenis is in die *gemeenskap* om dit daar in te sit, net as middel van kommunikasie. Wat ek dink op hierdie stadium, ek myself weet nie eers hoeveel hulpbronne daar in *gemeenskap X* is nie, maar ek glo daar's sin in om die kommunikasiekanale tussen almal oop te kry, mekaar bewus te maak van wie doen watse diens, en oorvleuling en duplisering te voorkom op die ou end van die dag. Want weet jy, soos byvoorbeeld, ons wou 'n home-based care projek begin spesifiek vir *HIV* en *AIDS*, toe kom ons op hierdie *support group* af, so jy moet baie mooi koördineer dat jy eerder saamwerk, ook ter wille van die befondsing wat jy het. Stoot dit alles daarin en lewer eerder een goeie diens as wat dié een hier sukkel en dié aan daar.

Planned newsletter to be distributed in the community

Information on available services

Networking ability

Support group in the community

Networks

So die twee projekte is nog in beplanning. Dis wat ons graag wil doen, maar soos ek sê: stop die bus dat ons net eers die mense bymekaar kry en kyk hoe ons die diens kan aanbied en wat ons alles moet doen. Weet jy, en dit is *gemeenskap X*.

R: Het jy dalk enige agtergrond oor *gemeenskap X*, byvoorbeeld die persentasie werkloosheid?

P: Dit sal in ons *service plan* wees, ek kan vir jou 'n afskrif maak as jy wil. Ek dink dis dalk nog 2001 se sensus, maar jy sal alles daarin kan kry, werkloosheid, opvoedingspeil, en so aan.



R: Dankie, dit sal baie gaaf wees as ek so 'n afskrif kan kry.

P: Laat ek net gou kyk of ek vir jou alles kan gee. Ja, "80% of the residents have no income." Ek gaan hierdie stukkies ook vir jou gee, dis maar net die motivering vir wat ons gedoen het – net vir so klein bietjie agtergrond. So dis basies wat ons in *gemeenskap X* doen. Uit die aard van die saak kry ons slegs subsidie van die staat af as ons dienste lewer in die benoemde areas. En absoluut alles wat ons doen se fokus word soontoe geskuif. En ons is baie opgewonde oor hierdie nuwe dienssentrum en alles wat ons gaan bou, want as jy dit kan verander in 'n one-stop service centre – 'n welfare centre – en jy't kantore, dan kan jy al die NGO's betrek wat ook meer gespesialiseerde dienste lewer en byvoorbeeld afsprake maak met mense wat miskien die behoefte het vir berading of *detox* of *whatever*.

80% of the community without income = poverty

Service centre  
= welfare centre  
= potential asset  
Networking possibilities with NGOs

Die grootste werk gaan wees om die gemeenskap in kennis te stel van die dienste wat jy lewer. Want dit is so baie die geval, jy het die hulpbronne in jou gemeenskap, maar hulle is nie bewus daarvan nie. En weet jy, dit is ongelooflik, hoe bemagtigde mense ander kan uitbuit wat nie bemagtig is nie. Nou die dag sien ek 'n vrou – ek was besig met die groep, deel van die bejaarde groep – hier vertel sy my gou van haar probleem met haar gesinsgeweld. Ek sê vir haar, jy kan óf vir my wag, óf as jy besluit om 'n kriminele saak te open, kan jy solank polisie toe gaan en die kriminele saak open en sodra ek klaar is kan ons gesels. Of andersins, as jy glad nie vervoer of geld het nie, wag vir my dan kan ek jou vat. Maar dan moet sy twee ure wag. Toe sê sy vir my sy gaan eers polisiestasie toe en dan gaan sy terugkom. En ek wag en ek wag, ek was naderhand so bekommerd ek ry en gaan soek haar en ek kry haar nie. En weet jy, sy kom toe terug en nou het ek vir haar al die inligting so kortweg gegee wat sy benodig. Sy kom toe nou terug en ek sê vir haar ek was so bekommerd oor jou, waar was jy? Intussen sit hierdie kantoor vol, want my mense wag vir my en ek kom nie hier uit nie. Sy sê toe vir my, nee, die polisie het vir haar gesê dis nou maar 'n familie probleem

Resources available but community members unaware (asset-based approach)

en eintlik nou maar 'n huweliksprobleem tussen haar en haar man en sy moet dit nou maar uitsorteer. Hulle weet nie wie het nou vir haar gesê sy moet 'n kriminele saak open teen hierdie fisiese geweld wat plaasgevind het nie. Weet jy, hulle gee vir haar hierdie *soppy* storie, maar ek vererg my. Nou het sy nie die naam van die persoon wat haar gehelp het nie, maar ek is toe polisiestasie toe en ek gaan praat met daai superintendant. Ek sê vir hom, kyk, ek weet nie wie dit was nie maar dit was een van jou mense, en dis net heeltemal onaanvaarbaar. En dis die mense wat die diens moet lewer, en kyk wat sê hulle vir die mense. Dit maak my so kwaad, want op die ou end van die dag is daai ou net so skuldig soos die res. Sulke goed frustreer my so, want dis mense wat opgelei is, wat 'n diens moet lewer, en hulle doen dit nie.

R: Dis waar.

P: En dis basies al inligting wat ek vir jou het van *gemeenskap X*.

R: Baie dankie. Dit help baie.

**FIELD VISIT 4 – 4 JUNE 2004**  
**INDIVIDUAL INTERVIEW 10**  
**SOCIAL WORKERS EMPLOYED BY ACVV**

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**BROAD (FLEXIBLE) INTERVIEW SCHEDULE:**

- ⌘ What are the main challenges faced by the selected community?
- ⌘ Which resources and potential resources can be identified in the community, which might be utilised to address the challenges the community face?
- ⌘ Which services are currently provided by the social workers employed by the ACVV in the selected community?
- ⌘ How is the community currently coping with HIV&AIDS and the challenges implied by the pandemic?
- ⌘ Which role is the ACVV currently fulfilling in supporting the community in coping with HIV&AIDS?

KEY OF ABBREVIATIONS	
R:	Researcher
P1:	Participant 1
P2:	Participant 2

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R: I am busy with research in *area X*, focusing on the way that the community is coping with HIV and AIDS. For that purpose, I am trying to obtain as much information as possible on existing services and projects in the area, including social services. Could you please tell us about your involvement in the area and about the different services you render? Where is your office situated?

P1: It's at *school G*, in *area X*. When you go into the area you get the first turn, then there's a second turn and if you're at that second turn, then you are very near to the school.

R: Which services do you offer in the community – in general but also relating to the community's way of coping with HIV and AIDS?

P1: We do have a **few gardens** that consist of plus/minus 325 people in different places in this area. There is one that is close to *school Z*, for that people, for that community as a whole, and then there's a second one, that is when you enter *area X*. Before you turn there is a big place there, that has been having ... that has being fenced.

ACVV services  
in the  
community



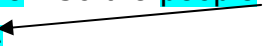
R: I've seen it, yes.

P1: Ja, that's one of our food gardens.

R: It does not seem to be operational at present?

P1: No, it's operating, but the thing is there's **no water there**. So the **people have to carry water there and we also don't have seeds**.

Need for water  
and seeds



P2: Another organisation promised to give us some seed, to give us free, but they didn't bring it here, so now the people have to buy their own seeds and most of which they **cannot afford to buy the seeds, because most of them they are not working**.

Financial need



Unemployment



P1: So we have food gardens all over, except at *school Z*, but we do have another one near to that school. It's like for each and every area we do have a food garden.

R: If a school wants to start a vegetable garden, will you be able to assist them? For example, if a school's teachers want to start a garden, will you be able to give them advice on what to do?

- P1: Yes. And if we've got seeds, then we can give it. **That's what we do, if we've got seeds we give it to people that we know can use it.** And then we've also got a support group, yes, we do have a **support group** but it's a new thing.
- R: Tell us about that?
- P1: It's a support group that consists of different ages, with the people that are HIV positive.
- R: How many people are in the support group, more or less?
- P1: Plus/minus 17.
- R: And do they meet regularly?
- P1: They **meet only on Tuesdays.** There are other people that we know about that's HIV but **they are not ready yet to go to the support group, so we do home visits only to them.**
- R: Where does the support group meet?
- P1: At the **one church in the community**, the one there at the first ... eh no, at the second turn.
- R: I have seen the church.
- P1: Yes, **since we don't have a community hall, we are using that church.**
- R: You mentioned that you are aware of community members being infected with HIV. How do you become aware of these community members?
- Provide advice and seeds if available
- Community based support group
- Weekly group meetings
- Denial
- Home visits
- Resource
- Mobilising community assets

- P1: They do come to us, maybe someone will tell them about us and then they come to us. Disclosure to ACVV
- R: At the school? Resource
- P1: Yes, at the school yes, and, or maybe the family tell us: "I've got someone that is sick at home and they will not come", but we always tell them: "No, first ask this person about me, if I can come and visit. I cannot just come, I must get a permission from him or her." Then that's how we know of other people. Disclose in order to be visited and supported- told by the family
- R: So you do go out into the community to work there?
- P1: Yes, we do go out and prepare them to also go, to attend the support group.
- R: Who facilitates the support group?
- P1: There are two ladies, they are in the same age group with us. They've been trained by LAMULA, it's another NGO. They help us, these two ladies, because they were trained by LAMULA to do home-based care and also I've been trained for the home-based care. So what I do, I teach people in area X to do a home-based care, so that we can be able to help the people that are sick at home, with different diseases, not just specifically HIV. So these ladies, they are the ones that are more in support groups, since we are doing various things. So there's a lot of things that we are doing, not just concentrating on the HIV and AIDS things. So they are the ones that are doing everything, but we do go there and assist them wherever we can. External resources  
Trained people= facilitators  
Resource: trained people involved and  
Home based care  
ACVV assist /facilitates
- R: Were you also trained by LAMULA?
- P1: No, I've been trained Barnabas Trust.

R: Is that also a NGO?

P1: It's **another NGO**, yes.

Resource

R: How do you think, how do community members who are HIV positive gain from the support groups? For example, do they get emotional support, do they get practical guidelines on what they should eat, or what do they gain from the support group?

P1: We **teach them about the healthy food** that they're supposed to eat. We **give them emotional support**. Also, others will find that they thought it's only me that is having this, but then they see other people and they find that they are healthy, they also become like okay, like they are able to accept their situation. And also, sometimes we will find out this person doesn't know **nothing about HIV** and now the doctors tell him you are HIV positive, you have to accept it *etcetera etcetera*. But they don't know nothing what is HIV, so we're also **teaching them about the HIV virus**. And also we teach them the life skills so that they can have something to do with their own hands. And then if there's something that we can give them, whatever it is, we also give it out to them for free.

Goal of support groups=  
-basic HIV info  
-information on diet  
-emotional support  
-relate to people in similar situation  
-accept situation  
-life skill training

R: Do you provide them with treatment or medication?

P1: No, there's **no medication** that they are getting, it's only the supplements or maybe food. And then there are others ... like maybe if someone is having chills or whatever, and they do have some medication that has been homemade medication, they give it to them also.

Medication for specific symptom

R: Could you tell us about your **involvement at the schools** in the community?

P1: At *school Z*, from last year we've been approached by the life orientation teacher, *Mr N*, but last year it was *Mrs M*, that approached me to **come to school Z, to help her with the life orientation**. And then last year after the

School visits and provide education at schools eg. Life orientation (per request)



end of the year *Mr N* said: “*May you please carry on again this year, because we’re going to need you?*” So we asked him: “*What do you want us to prepare for the children?*” So he asked us to prepare about the peer pressure, so we were doing peer pressure with the children. And then we found a lot of problems around, because we give the children a chance to share whatever that they want to share. So we find that due to their peer pressure, they are already involved with the criminal things, that’s what I was discussing with the supervisor. And then we decided okay, let’s start first with the principal, let’s speak also with the children so that they know that if they share something to us we cannot just keep it to us, but if it involves the criminal things, they can allow us to share this with the police or with their parents and whatever. So that they can get help, because we cannot just sit and we don’t do nothing, but we want to listen and help them also. So there’s a lot of things that we found out yesterday when we were there at *school Z* from the school children.

Problems

Crime

Resource

R: When we spoke to Deirdré this morning, she told us that the ACCV is widely involved and co-ordinates various programmes in the area. She told us about your youth programmes, the support group you also mentioned, and also the life orientation programmes and food gardens. Which other resources are you aware of that exist in the community, other institutions that might also assist community members in coping with HIV?

P1: I’m not aware of any other people.

R: And services like *Sister E’s* clinic?

Two clinics but very far

P1: No, that clinic is not in the community. They are rather using *clinic Z*, if they need to go to clinic.

R: Where is *clinic Z*?



- P1: It's very far away, both of them are, I think the same distance away. They don't have a clinic in *area X*, but fortunately our council is building one for us now – a clinic. It's not in the centre of the whole community but it's there in *area X*, there for the people. Clinic to be built
- R: So from *school Z*, which will be the closest medical clinic to go to?
- P1: *Clinic Z*, just across from the National road, close to the university.
- R: Yes, I have seen that clinic.
- P2: But I'm a hundred percent sure that when they built a clinic in *area X*, *clinic Z* is not going to take anyone from *area X*, they are going to turn them to the new clinic.
- R: Yes, because that clinic is quite far from the centre of the community.
- P2: Let's get back to our services. We also do *crèche visits*, like talking to the crèche on what they are busy doing and then you see how can you help. Crèche visits:  
-help where needed  
-identify problems and refer to clinic Like we found that there was a child that was having a rash to the whole body, and then this child was not healthy, so I asked the clinic to approach them, to hear if they cannot have a *mobile clinic* just to come in that area. But they say since we are in the process already of having ours, they will not be able now to do it.
- R: So if I understand you correctly, the members of this community go to *clinic Z* if they need to visit a clinic.
- P2: Yes, I also know of some clients of mine that are HIV positive and they are getting to that clinic for their babies. Clinic
- R: I sense that people in this area do not often disclose their HIV positive status. Why not?

- P1: It's because of ... especially to this *area X*, people they still ..., **they are having different beliefs about this**. For instance, if someone is HIV positive and they come and see me, the first thing that they think is they think maybe this person is bewitched, they only talk of the traditional things, they **don't care about medical things, education and whatever**. **They will only think, maybe this child we have to send to a traditional healer**, that is why the child is like this and whatever. And then they **will take the child to a sangoma** then, so that this child can get to the sangoma, they don't think about HIV and they **think someone is bewitching this child and whatever**. So the child decided to keep quiet. And the parents ..., **other parents they don't want to talk about sex yet and if you talk about HIV and AIDS it's sex involved**, and they don't want to listen, they are having ignorance. So the children, sometimes the mothers, they are **not aware that their children they are already sexually active**, so the child who is HIV positive is afraid to tell the mother because the mother thinks the child is still a virgin. **And still they don't believe that you can use the same chair as the infected person and whatever**. So someone does not want to be ignored if he's HIV positive, so they still want to keep it from their families, they are afraid of that. And in *area X*, **most of the parents they are alcoholic**, you know. Then someone will tell you maybe: "*I can tell my mother, but my mother is going to get drunk and tell other people, so I cannot tell her*". Since we are having extended families, very big families, you will find that the families maybe is divided into three, this group is not in good with this one and whatever. So if **I tell my aunt, my aunt is going to tell this aunt and this aunt**, etcetera. So there's a lot of things that are involved.
- R: It almost sounds as if they're not aware of the common existence and high levels of HIV and AIDS, together with the fear of rejection, together with the taboo to talk about these things, together with the possibility of gossip by other family members – it's a variety of things.
- P1: And you know, I was speaking with a group of children last year ..., they are **14, 15 and 16 years of age and they are pregnant** and most of them
- No disclosure: misinformed/ myths  
And ignorance lack of belief in medication and education  
Traditional healer=answer  
Believed to be bewitched  
Stigma- HIV/AIDS is sex related-ignorant (taboo)  
HIV disclosure: reveals sexually active  
Misinformed Fear of rejection and isolation  
Alcoholism  
Fear other people knowing  
Fear gossip  
At risk sexual behaviour

they are friends. I was so worried about the whole process when I saw them, like they were so playful, they thought they are having dolls, whereas they are having babies. So I went to them and I said *"Come on, let's talk, why are you all pregnant?"* And then I found out that these girls were confused about the AZT thing because they thought if you are pregnant and HIV positive you are going to get a vaccine to prevent your child to have HIV and whatever. So they thought the AZT is going to protect them, now they can sleep with the boys. Because they thought that they won't get it, if they get pregnant they won't have HIV because they are going to get a cure. So I had to explain that to them, then they say: *"You don't know what are you talking about, we hear this from the nurses"* or whatever, then I say: *"No, maybe the nurse didn't have enough time to explain to you exactly what she's saying, she thought that you do understand, not knowing that you've got your own understanding, so this is not the way, it's going like this."*

At risk sexual behaviour due to misinformed

Ignorance

R: What is the role of the church in this community? Does the church support members of the community who are HIV positive? Does it encourage people to disclose? Which roles does the church fulfil?

P2: No, the church don't do that. My own church is a Christian church and they believe that no sex before marriage. So they see no point to talk about HIV, because as a Christian you are not supposed to have sex before marriage. They don't care what are you doing after hours, because surely the children will go and do sex, no matter what they are saying. So they will only tell you not to come, not to participate in anything in the church if they find out that you've got a boyfriend and whatever. Then you won't participate in nothing at church. Because if you are HIV positive it's because of your sin, you've sinned in the eyes of the Lord. I always ask my mother: *"Mum, do you understand other people they didn't know nothing about the Lord, and now they are born again Christians?"* They go to the Christianity with this virus, and they didn't know maybe, and now in the marriage, they get married with someone and then in their own marriage they find that this person is HIV

Church avoids discussing sex-related topics such as HIV/AIDS

At risk sexual behaviour

Church rejects in care of sexually active (children)

Judgemental

positive. Because even if you want to get married with someone, you must not be involved, but have a courtship, and you must not tell this person. You must go to the reverend and tell that the Lord showed me this person, so I want to get married. And then the reverend is the one that is going to come to me and say: *“So and so wants to get married to you.”* No matter if I also love this guy, I must say: *“Give me a chance, I will go and pray”*, and then maybe for three months I will pray and pray and then I will come back to him and say yes. So the pastor is going to tell this guy that I said yes, then we get married. They don’t check if this guy is HIV positive or where did he come from. All these things I will only see in my marriage. **And if I ask these things they will always ask me: “You don’t trust the Lord? The Lord is there for you, and the Lord is going to guide you.” They will never tell you something that is not right. So it’s like they are having an ignorance with the HIV.**

Ignorance

R: What is the role of traditional leaders? Do they play a role in helping the community cope or not?

P1: I always say to the people, especially to my clients: *“I don’t have a problem with the traditional healers’ medication, but they are very strong.”* I’m telling you they are very strong and secondly, most of them they are not healthy, not healthy because they are not sterilised. **So if you drink a traditional healer’s medication and you are already infected with HIV, it can make you more sick**, because they are very strong. For instance they will cook most of them, most of the medication they cook it. And then when it’s cooked, and then all the ... eh, I don’t know what you call it, but you know the ... eh ... if they are going to cook it, they are not going to mix it with another water when you drink it, you will only drink it as it is. And then you find out it’s very strong and it’s not good, and it go into your own mouth because it’s very strong, even the smell it’s very strong and then you drink something like that. Surely you will become sick more and more. It can be helpful, but also it’s too much maybe for you if you are HIV positive.

Negative effect of traditional healers medication

- R: Does this community still believe that traditional healers can help them? Cure them?
- P1: **Yes** For instance, I've got a client of mine that was sick, but fortunately she **usually attend the HIV and AIDS programme** that we do have in the community. So she always say when we talk: *"If I can be HIV positive, I will accept it."* So then she found out that she's HIV positive, and she **really accepted it**, ~~but she became sick maybe after two months~~, she was really sick. And then she went to the **hospital**, ~~to hospital D~~ and then she was very sick. At *hospital D* they didn't say nothing to her, but she knew what was wrong with her, she was HIV positive **so they said it's the flu that made her like this**. So since they didn't come back with a tangible reason, they thought the white people cannot see the cause of her illness. **So she said: "Let me use the black thing – let's take it to the traditional healer."** She knew that she's HIV positive **but she was not ready to tell them**. So they take her to the traditional healer, that traditional healer said: *"The ancestors want you to be a traditional healer"*, so it's a long process. Then she had to go to the sea, stay in the bushes, for that whole long process. She had to stay in the bushes, using this medication and whatever, and she was so frustrated, so she kept coming to me, saying: *"I don't know what to tell them because I know what's wrong with me, but I'm not ready to tell them. But look now I have to go to these places and you know that I'm sick, what must I do?"* I said: *"I don't know, it's up to you. If you think you can tell them, just tell them, instead of going, because you are going to be sick in the bush and this wind it will never help, they will just keep quiet. So the best thing is to tell them if you are ready."* And that was the only solution that helped. She just told the family: *"I'm not sick, this woman is lying."* So it's only then that they allowed her to go. And now she's fine.
- R: And it sounds like she is now living a healthy lifestyle.
- P1: Yes, she's really fine now.

Traditional healer=regarded as resource by community members

HIV/AIDS programmes in community

Acceptance=important

Resource

Avoid identification

Traditional healer=resource

Avoid disclosure

R: You referred to the HIV and AIDS programme that is running in *area X*. What are you referring to?

P1: I usually ask the **ATICC or NABWA** to come to our area.

NGO's running HIV/AIDS programmes in the community

R: What is NABWA?

P1: It's an **organisation that helps people that are HIV positive**. I think all the people that they employ there are HIV positive, **so they already disclosed**, so they are the ones that are helping people. So I usually ask them maybe to come and do a **workshop for a week**, then I put pamphlets all around the community and invite people to come to the **church**, and then they teach them for a week about HIV and AIDS and STDs. And I do that maybe once or twice a year.

Organisation in wider community

Disclosure

Workshop on HIV and STD'S

Resources= Church ACVV- organising it

R: Who attends these workshops?

P1: **General community leaders**, usually a **lot of people**. Or you know on the first day a lot people, maybe tomorrow we've got new faces, the ones that didn't come yesterday and then some that came yesterday. But if I do it for the whole week then we end up having many people and they really like it. Because NABWA usually bring someone that is HIV positive and then on the last day that person tells them: "*You know what, I'm HIV positive.*" So then **they become very shocked**, that this person who was teaching them about HIV is actually HIV positive. They are then shocked, because they will tell her whatever they think about HIV positive in the week ... They will say: "**I will never stay with someone that is HIV positive**", so they will say all these bad things about what they **think**, and then at the end of the day they are very shocked that they've already done that, staying with someone that is HIV positive. So it's quite challenging.

Workshops for general community leaders

Community members

Disclosure: others are shocked

Stigma= rejection of HIV Positive community member

R: Workshops like these are actually a great resource to the community. To what extent do you cover HIV and STDs in your youth programme that is



offered to high school children? Do you also educate them or is HIV and STD knowledge only included in the life orientation subject at school?

P1: No, we do have a **group of children** that are from the age of 15 years. We meet them every Tuesdays at 14:30 at the church, it's the ones that we are going to the **camp with next week**. We are having a camp and **we invited two ladies that I want to teach them about HIV and AIDS and STDs**.

Weekly group programme

Youth Camp: information session on HIV/AIDS

R: Do you teach them about other topics as well?

P1: **We teach them about various things**, like date rape. And they were very shocked that there's something called date rape. I found out they do **go to the tavern and the guys do buy alcohol for them and they thought it's natural to sleep with these guys if they want to, there's nothing wrong with that**. That they cannot say no if they eat their money, **if they used their money for them, they see nothing wrong to say no. If it's a boyfriend, they are forced to have sex, he has got the right because he is your boyfriend**. So they were asking me that kind of questions – they didn't understand when I said it's a rape. They say: "*Whereas it's your boyfriend, it's a rape?*" I say: "*Yes, whether it's your boyfriend, you don't owe him.*" So they **keep on asking me different questions**, because this date rape thing, they didn't understand it. So there's a lot of things that we teach them, even domestic violence. They thought it's natural if their mother or father is being beaten and whatever, they being chased out and not sleeping at home and whatever. They **didn't know that they have a right to report this**. Because they thought it's a in thing like this, even next door it's happening, it's happening, so there's nothing wrong with that.

ACVV= source of information, teach people not informed

At risk sexual behaviour

Children-sexual favours for money

Form of abuse

Uninformed

R: If I understand you correctly, this community is characterised by high levels of domestic violence and alcoholism, poverty and unemployment. What else? What about prostitution?

- P1: Yes, because most of these children, their parents are **not working**, and they **need lot of money**. I have a client of mine that is HIV positive now, because of the elder boyfriend that usually supports her with everything, and is not a Xhosa person, it's these people that are coming from Africa, North Africa up there, so they come here. **So she was sleeping with this guy because this guy was paying the school fees, buying uniform, doing everything for her.** And she knew that she's not the only woman for this guy, there are also others, he also helps the children to pay whatever, and this child is 14 years old. And now this guy was sick, and then when she went there and she told this guy: "**I don't want to be involved with you anymore**", this guy said: "**You can leave, I don't care but you must know that you are HIV positive**". So she was crying and then she came to me.
- P2: Yes, the other day I was near to the church and stopped there. There were two ladies, small children, I know these children. Two children were coming, they went to that car wearing short things and whatever. And then this guy will come after 5 o'clock and stand there and then **these ones would enter the car and go with this white man and then they don't know when they are coming back**, and I was looking for the one. But the following day I found out she's there. I asked her about this, and then she said: "*Where do you think the food comes from? You must not ask me that, because I am getting food and the school fees is being paid, you must not argue where this food comes from.*" And **this child is pregnant, 17 years old**. So they use them. And there are these guys that are called Fishermen that come also to area X, it's also their own boyfriends. There's a lady that is my client, she's having eight children from the fishermen. Every time the fishermen is coming, they are leaving this woman with another child, he always leaves this woman pregnant. He **doesn't support the children when he's gone but when he's back, then he gives this woman money**.

Unemployment

Financial need

Sexually active for money

Multiple sexual partners

Purposeful transmission

At risk sexual behaviour

Child sexual abuse and prostitution

Sexual favours for money

Child pregnancy

At risk sexual behaviours for money

- R: I want to ask you something else. If, for example, children are orphaned when their parents die of HIV and AIDS, who takes care of the children – in this community?

P1: It's the relatives, maybe the grandmother or maybe the aunt or whatever, the relatives. As I've explained to you, we have very extended families, so there's always someone from the family that is taking care of the child.

Relatives take care of children  
Extended family members will take care

R: And if an adult gets sick, for example when a person discloses and is HIV positive, who will support that person? Like a mother who is HIV positive and becomes sick, who will help her, take care of her and maybe bath her?

P2: That's a major problem when it comes to bathing, because most of the people, they don't want to bath them. Like for instance, I was having a client of mine that was very sick, and every time I visit her she will always say: "If I can only get a bath, there's nothing else that I need", and then if I ask her: "Can I wash you?", then she would say: "No, I'm afraid because if you wash me and then the family will know that I'm talking about them to you." So when it comes to bathing, they are really having a problem here. That is why I think the home-based care is needed to the community, because if we can have this thing, then we can teach them how to bath someone that is bed ridden and then we can provide them with the hand gloves, you know, and teach them everything. So then this person can feel secured, because they are really afraid to wash someone that is bed ridden, there's only a few people that do that.

Basic care-looking after(bathing) Problematic

Fear  
Home based care=a need

Fear to touch HIV positive person (myths/misinformation)

R: Who supports the community members who are HIV positive?

P2: There's no one.

R: What about the support group you mentioned?

P1: No, not really. Like there are a few neighbours that can be allowed to come to your house if maybe there's someone that is sick. There are a few people that can be allowed to come in, especially if this person is HIV positive, because they thought he is not so concerned. But it's

Neighbours= supportive  
Isolate themselves

because they always close their doors, they are not allowing people to come in.

Avoid disclosure  
Due to fear of  
rejection-due to  
gossip

R: You mentioned home-based care. Do you provide home-based care services in the community or do you know of possible places or institutions where the members of the community might go to obtain grants?

P1: Yes, like Barnabas Trust. I've done the workshop with them, and then I've asked the kit from them, and then they said they are going to give me a kit. But I don't know whether they are going to give me kit for myself only or a kit for different people. But on that time they told me that the glass are very expensive, when we were busy doing the workshop. Because I've asked the same question – that in these houses you cannot leave the kits, if we know about the people they will want us to leave for them their own kits, whether we do come and deal with them or not, but they will also need a kit definitely. But they say the glass are very expensive and these things are very expensive, so I don't know.

NGO'S  
providing  
workshops to  
community  
members

R: Are you aware of any home-based care services that are already provided in the community or is it still a need that should be addressed?

P1: Yes, it's still a need.

Need for home  
based care

R: Is there anything else that you can think of, in terms of help that is provided to community members in coping with HIV and AIDS?

P1: No, nothing else.

P2: Maybe just the thing that, uhm ... it's like there's a cry for help in this community. There are children that want to go to school but because of their home situation they cannot, they do not go ... they are forced to not go to school because their parents are alcoholic, they don't wake up the children, they don't buy shoes, they don't do nothing for these children.

Poor home  
conditions/paren  
ting

Alcoholism

Child neglect

So it's then that the children can say: "Okay let me go to school today, let me not go to school today." So their parents are ... they make no difference. For instance on Wednesday, a child that came to us on Wednesday, this child is 23 years old and **she was receiving a foster grant** but now the **parents stopped having the foster grant and now they don't want to give her money to carry on**. And this **child doesn't have shoes, and this child doesn't have a uniform** and she was doing standard 9, but this time they don't want to carry on anymore. And then another child, **she's staying alone** now. Her mother is deceased and the father got another wife, but this wife was afraid of this child, the wife didn't like this child, because she was already 19 years old and she was doing standard 10. So they keep on fighting with this child. So this woman decided to move out of the house, so the father moved out with her, with his wife and with the two small children and this child want to go to school but there is no one that is supporting her. So we went to the Department for the support, for the **maintenance** from the father, but the **father stopped working**.

Financial need  
Material need  
Child-headed household  
Lack of support (financial)  
Unemployed

- P1: Yes, so who's going to take care of that child? She was doing standard 10 and then she failed that year. She failed that year and then I begged her to go again the following year, of which **I begged her with nothing on my hand, but I keep on saying please don't give up**, go back to school again, at least you still have a uniform and the shoes, you still have them. But I don't know in the end what's going to happen and the school fees is very expensive for them. And **then that child decided to have a boyfriend that is going to stay with her in the house, and that boyfriend was beating her**. And then I had to beg her again to chase out this boyfriend. If she want to go back to this boyfriend she must not stay at her home, he can come and visit and not stay together. So there's a lot of problems here. Even this child that is cleaning our office, we are paying that child the money to clean our office, and it's R100 a month, it's nothing. Well, **that child must maintain her own home** because her **mother is alcoholic**, so that to buy paraffin and whatever for her family, she has to go to school with this R100, she has to buy everything for her and she wants to go to
- ACVV= motivational support  
Domestic violence  
Child: responsible for own needs  
Alcoholism

school and she's doing standard 8, she was supposed to do standard 9 but she dropped out of school two years ago, because she didn't have money and her mother didn't ask her even one single day why she didn't go to school. It didn't make any difference. And now her mother is contacting her time again saying: "*You thought that you are better than us since you are at school, you are not better than us, you are still the same*", and she's only doing standard 8, for God's sake. But she's treating her as if she's doing medication and now she's very high minded compared to them. But she's trying her best to maintain her home. But she can't do that all alone.

School drop-out

Financial need  
Mother's don't  
care/neglect  
children

R: I would like to find out more about the role you fulfil in assisting community members obtaining grants. Does that form part of the services you provide?

P1: No, but we only ... we do case work, where people come to us and we listen to their problems. Then, if we find that this one can qualify for a grant then we go, we just tell her: "*You do qualify for a grant, this type of a grant, you can go to hospital D.*" Then we write a letter and ask hospital D to help us with this person. But we don't do it ourselves.

ACVV individual  
case support

With regard to  
grants:  
-advice  
-identify  
-referral letter

R: Can you provide me with information about the different grants? How much are the different grants? What are the qualifying criteria for the various grants?

P1: There's the maintenance grant, that is from zero to eleven years this year. It was zero to nine years last year but this year it's to eleven years, and then next year it's going to be thirteen and fourteen years. And this grant is only R170 per month.

R: Who qualifies for this grant?

P1: The people who are getting a salary that is less than R1200 and the unemployed people only. You get it per child, up to six children.

Information on  
grants=potential  
financial  
resource

P2: And then there's a foster grant. I'm not sure, I think it's R560 and this one is for foster. Do you know what is meant by foster?

R: As I understand it, foster care is when a person takes care of a child who is not his own.

P2: Yes, and then there's pension, where a woman must be 60 years old and upwards, and a man must be 65 years old. And its R740. And there's also the disability grant and it's also R740.

R: And within the context of HIV and AIDS, one of the criteria is a low CD-4 count?

P2: Yes, it must be less than 200, the CD-4 count. And the viral load must be 400, or something like that.

R: Which process should be followed to apply for such a grant? Can the people who want to apply go to *hospital D* or do they need to go to the Department of Social Development? Where do they go?

P2: Yes, they need to go to Social Development or to *hospital D*, on the side of the Social Development even at *hospital D* it's there. And then this person must be a South African citizen, and this person if married must bring in the marriage certificate, if divorced that divorce letter also, and a birth certificate or an ID, like anything, something like that. Sometimes they even ask for a title deed, but that's what I don't understand why they need it, but sometimes they do that. And sometimes if you were working and now you want a pension, they usually also want a letter or something, for the month that you stopped working, the salary advice, proof of how much did you get from your work, so that's all those things that they need.

Procedure concerning grant application



R: If you think about this community, community members face various challenges they have to cope with, for example HIV and AIDS, yet they



keep on living and carry on with their lives. What is it that makes this community cope? What do community members have working in their favour?

P1: It's like, okay I think, before I answer you there's something I want to tell you before I forget. Like there's a tendency, we teach them about condoms, that they must use condoms and then they **will tell us that they don't want to use condoms** because they must have it flesh to flesh, and it's not right to have one boyfriend because at the end of the day if you are HIV positive because of that one boyfriend you are going to cry. But if you are HIV positive and then you find that you were also having lots of boyfriends then you will understand that it's also my own fault. And another thing, they say if you come in through sex, when you were born you were born through sex because through sex you get pregnant, it's **good to die through sex again**. And everyone in that matter is going to die, no matter you die of what, but everyone is going to die in that matter.

Unprotected sex-practice sex with multiple partners

At risk sexual behaviour" don't care attitude"

P2: So if you are speaking with this child and then you try to convince the child, and then when the child answer you like this, you just have to know what to say. I wish I can have something else to blow their minds, but I find that I wonder what must I say now. But you **keep on trying, you keep on trying, you cannot just stop**. And I think, the thing is, here in area X they see most of the things, that it's natural when some other things happen, because next door it's happening in front of others, so it's a natural thing. That is why they are very shocked when you tell them this is not right, this is not supposed to happen, and then there's only few houses that don't believe you and they start to put that into action.

ACVV workers wanting to make a difference

R: Is there anything else that you think we should know on this community's way of coping? How do you cope with all the challenges you face?

P1: **It's my family**. Because on Monday when I went back home I was crying, crying because in the morning I was having a five year old boy that has been abused, his tongue was cut, the chin was beaten and the child has

Family: way of coping (main reason)

been stabbed by the boyfriend of the mother. And it was difficult for me to take this and then my boyfriend went to work to fetch me and I'm having a four month old baby, so he went to fetch us and then I just broke down. And he was busy talking on the way and then I said: "You know what, I'm not in the mood, but I'm going to tell you why, I will tell you when we are at home." So I said that so that I can tell my family also at the same time, because I won't be able to tell him and then when I'm at home I have to tell again, because if they find me at home that I'm not fine, they were going to ask me what's wrong. So when I was at home, I decided let me say this, they kept on saying: "Are you fine? Are you having a headache?" Then I told them ... It was difficult to finish even one sentence without crying and then I was very angry with this woman, I even wanted to beat her, because I found out she is lying, she doesn't want to tell the truth and she's still willing to go back to this guy, that guy ... and it was not the first time, the child was lost a few days ago, but she didn't do nothing and now Saturday this child get this, so I was very angry with this woman. Then I tried to go out because I couldn't stay with this woman in the same office. I went out with her to ... so that I can also speak to her. I was a little bit fine but every time I speak to her, she lied and then I just changed immediately, but my mother prayed, she's a Christian, and my boyfriend also started crying. I've got a nine year old child, she was also crying now. I felt very hurt, and I wanted to take this child from this woman, but I knew I won't be able to look of this child because I'm afraid of the blood, you have to clean the tongue because the tongue was white and I know that this child only needs that tongue to be cleaned so that the tongue will be a little bit better, but if I take this child from this woman to my home, we have to do it and I won't be able to do it, so I hate to feel unable to do something. That is what really makes me sad, I just left that child like that, I didn't do nothing. I was unable to do something to this child, so that's what really frustrated me, so my mother prayed and asked God to help and whatever, but I was crying.

Physical abuse

Social workers  
need for  
personal  
supportFamily=support  
systemFamily=support  
Prayer=central

R: It is frustrating to feel that you are not able to make a difference. Thank you for sharing your feelings with us.

P2: Because you know, the children of area X they are very poor, but there's a lot that they can do if given a chance. They have big dreams these children, you know. I was saying to some ladies, if I can only get a sponsor and have a centre in the community, whereby I will take all the children that want to go to school, but because of their situation at home it's hard. But when the schools are closed they must go back to their homes, because I want them also to understand their home situation so that they can know they are having a responsibility to make the difference. Because if I put them in the hostel and then they don't go back to their homes, they won't make a difference to their homes. Something like that, I think that's one of the greatest needs they really need in area X, or maybe even a group of people whereby they can say I can adopt one child at my own home, maybe give R50 per month just for the school things. Then I think they can carry on. I hear that there are people from overseas that are helping children in South Africa and school Z fortunately was one of the schools that have children like that. I went there to ask if it can also be done to another school, to other children that are staying at home, but they said no. Like for instance if you can drive through area X, you will ask yourself: "Who are these children that are not in school?", if there is still a lot of them, and if you can go only to one child and ask: "Why are you not at school?", definitely they will say, it's their own parents. Another child, she was eleven years old, she was not at school, the whole community kept asking about her and buying things this, go and buy this, come again.

Positive future perspective

Bad home conditions

Personal responsibility to cope

Need to take care of children

Financial need

Children are not attending school

R: yes, he was like a runner

P1: Another child that is seven years, the child was nine years old, he has never being to school. He was raped by a woman, this one slept with this child continuously, so he asked the child: "Go and buy this for me", and when the child comes back: "Sleep with this woman, with this child",

School neglect

Sexual abuse

and the husband is at work, but if that child was in school, surely this won't happen and this child didn't know what's wrong or what is it because he's still having a mind of a small child, he is the friend to the nine year old. **So there's a lot of children that are not at school and those**

School neglect

children is the same children that tomorrow that they are going to be **criminal and we cannot do nothing with them.**

Loss of hope

R: Thank you, ladies. Good luck with the great work you do.

**FIELD VISIT 4 – 7 JUNE 2004**  
**INDIVIDUAL INTERVIEW 11**  
**COMMUNITY MEMBER LIVING WITH HIV&AIDS**

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**BROAD (FLEXIBLE) INTERVIEW SCHEDULE:**

- ⌘ How are you coping with HIV&AIDS?
- ⌘ Being HIV positive, what are the main challenges you have to cope with?
- ⌘ Which resources in the community assist you in coping with the challenges you face?
- ⌘ Which potential resources might assist you in coping with the challenges you face?

<b>KEY OF ABBREVIATIONS</b>	
R:	Researcher
P:	Participant

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R: Please tell us about yourself. Where do you work? At the clinic?

P: Yes, I'm a voluntary worker.

Resource

R: Tell us about the work you do at the clinic.

P: I'm an interpreter sometimes, and a DOT supporter. I'm helping people giving treatment and sometimes the sister in charge asks me to help with the counselling.

Volunteer  
worker:

-interprets  
-give treatment  
-counsels

R: Please explain your role as DOT supporter.

- P: DOT stands for *Directly Observed Treatment*. It's a course you can do, for the voluntary work. Like I was helping the people who take **TB treatment**.  
Treatment for TB
- R: And you work from the clinic?
- P: **Sometimes at my house**, for some of the patients.  
Work at:  
-clinic  
-home
- R: L told me that you also provide support to people who are HIV positive?
- P: Ja, **we do have a support group**.  
Support group
- R: Please tell us about that support.
- P: It's called *Lithemba*, which means **hope**. We **comfort each other, and advise each other on some treatments** like herbs. If I've got a headache, what can I use, if I've got Shingles, what can I use? Things like that. Sometimes we ... eh, at the clinic they told the patients to contact me. Then we gather together every Friday at one to train in the **community hall, that's where we meet**. There we **encourage each other, we comfort each other, all those things, we give each other hope**.  
Give one another practical advice on how to treat common symptoms  
Community hall=physical resource  
Regular(weekly) support sessions  
Encourage each other-comfort each other  
Give hope
- R: You also mentioned that you provide information. Where do you get your knowledge and information from?
- P: I've been **trained for basic HIV education, and for basic counselling**. I did attend a workshop in Bisho for AR, these anti-retrovirals. And I got my training as volunteer from **ATICC**, when **they came to the community hall**.  
Training provided=resource  
ATTIC=resource for training  
Community based training
- R: How many people form part of your support group?
- P: It's plus/minus 70, but it's not this community's people only, it's from **K, KS, G and V. You know, some people don't like to go to support groups in their own areas**, so they prefer coming here at *area X*.  
Avoid open disclosure in community

R: So it's 70 people coming from all over?

P: Ja.

R: Are most of the people infected with HIV?

P: They are all infected.

R: How did it start and who is part of this support group?

P: There was a lady, *M* from *K* and *T*, she was working at ATICC but now she's working with Dr J, they formed the group in 1999, so I joined them last year in April.

R: Are they still involved at all or are you on your own now?

P: **M has formed another support group** at *K* and *T* is busy, so we only meet sometimes with them.

Community members initiating and running support groups

R: What are the most valuable things you gain from the support group?

P: When I'm with them it's like I'm with my family. **I get lots of love and I become very happy with them.** So when Friday is coming I feel something inside of me, like oh, my "family" is coming, you know and it's **hard when you are going to be parted.**

Support group like family HIV positive supporting one another

Loving positive environment

R: I get the feeling it's about people that truly understand?

P: It is.

R: Are you willing to tell us about your illness.

P: I'm surviving. At first I was so frustrated, I was on and off in the hospital, **but I'm a fighter**, so I'm surviving.

Initial feelings= frustration



R: It's a great challenge to live with HIV and AIDS. How do you cope? I get the idea the support group helps, but what else?

P: I do have my friends. When I was diagnosed, I thought of telling all my friends. I kept it a secret with my family, they only knew that I'm HIV positive late last year, but all my friends knew about it.

Friends=main support (disclosed to them)

Family=support Disclosed later only

R: May I ask you why did you decide to keep it a secret from your family but disclose it to your friends?

P: Because they are so weak you know. I'm the last born at home and they put all their hope in me, you know. And I've got this little child, so I was unable to tell them at the time I was diagnosed because I knew that they were going to feel pity for me and get lots of worries, you know. But at the end I did tell them.

Not disclose: protect family from worrying and sadness and loss of hope

R: So you were actually being strong for them?

P: Yes.

R: And your friends?

P: I got all the support I need from my friends, my family, and my doctor, and he also encouraged me to tell my family.

Support

Doctor: advisor

R: And now you've got the knowledge to live a healthy life?

P: Before I was diagnosed I was just sitting here, doing nothing, you know. But when I was diagnosed that I'm HIV positive, I became to seek knowledge.

HIV positive: need to gather information

R: Where did you get your knowledge from? From the workshop and the doctor?

P: Ja.

R: Where else?

P: And the other people who are HIV positive.

Other HIV  
positive people

R: You primarily refer to people helping you. Do you have any other assets in the community that really helps you, any resources in the community?

P: No, not really. But I'm also busy doing painting with the church group, with the other members of my support group. We meet every Thursday from nine to four.

Skills  
development

R: Who leads this group?

P: The name of the lady is P. She's at the church?

R: Does the church support community members who are HIV positive in this area? If it does, what role does the church plays?

P: The church does support us. You see, I'm a Methodist, so I did tell my priest and the other church group members, and they give a lot of support. They give advice, emotional support and ... uhm ...

Church=  
Supportive  
=Resource

Provide advice/  
Knowledge

R: Spiritual support?

P: Ja, spiritual support.

R: Are there any NGOs that you know of that work in this community, helping families or people who are HIV positive or living with AIDS?

P: No, there are NGOs, but they don't get involved.

NGO=potential  
but not  
mobilised

R: It's only ATICC that has these training programmes from time to time?

- P: Ja, and there's the other group, Ubuntu Education Fund at *street H*, they also give training and support. ← NGO: -training and -support
- R: Do they also offer training courses?
- P: Ja.
- R: So if I hear you correctly, the way that you've been able to cope with this challenge is by means of the helping support of families, friends and the church – people caring for you and giving advice? Summary: -support by family, friends and church
- P: Ja. ← -people caring and giving advice
- R: And that's the core, not external people and organisations?
- P: No.
- R: After you've disclosed and during the time that you went through that difficult stage, what kind of support did your friends offer?
- P: There's a friend of mine, she lives now in Uitenhage, she is very supportive. When I was lying in hospital she bought everything for me, pyjamas, food and she also took care of my child. } Family of friends -provide support and food -material needs -look after children
- R: It seems as if such support helped you carry on with your life.
- P: Yes, and I wanted to show people that HIV is alive and that you do not only see the people on TV, that HIV is living inside the people whom you know. It's not only the Nkosi Johnson and other people that are living far. All people must know and realise that HIV is amongst us. Need for change in community belief
- R: How did other people react to that? Your friends supported you, but what about other members of the community?

P: You know, there are stupid people as usual. You know, **I've been called names like:** *"Here she goes, the so-called AIDS"*, or they would say: *"Aidsana"*, that silly name, but I didn't care about that. I know the virus is in my blood and not in me. I've got that **positive attitude towards** them and I also told them that it's of no use to laugh at me, because you've got kids, you are still having sex, you are working with people, so we won't know when AIDS come to you.

Disclosure HIV positive:  
-called names  
-laughed at

Positive attitude=asset

R: Were these people in your close environment?

People gossip

P: Ja, they are people in my area. For instance, **my neighbour is a nurse but she was gossiping.** All the neighbours knew that I'm HIV positive because she told them, but I didn't care. I just confronted her and said: *"You can do whatever you want to do, but I know that one day maybe your child will be HIV positive or you will get another sickness except HIV."*

R: It certainly is a challenge to face others. When did you disclose to your friends for the first time?

P: The very first day I was discharged from hospital, that was in 1999.

R: Has the community and people changed since 1999? Has it become easier? If people disclose now, will others accept them easier and if so, why do you think it has become better?

P: Because **if a HIV positive person die, we go to the funeral wearing those t-shirts you know, with that emblem. And we stand and tell all the people who attend the funeral that this person was HIV positive.** It's high time that we have to tell the people that this person was HIV positive, there's no use of saying she's got pneumonia or TB or whatsoever, **we have to tell them that he had it and educate them also.**

Need to educate community and make aware

Need for community to acknowledge to accept aids

Few people propagating this

R: It's almost like raising people's awareness?

P: Yes.

R: When you go to funerals, does the whole support group go?

Avoid disclosure

P: No, **there are those who are still living in the shade**, they don't want to be seen, they don't want to be known. **But those of us that don't care, there are still more of them who don't care of what people say.**

Tendency to accept status and not mind others comments

R: Are you aware of another support group in the area, besides the one you belong to?

P: I just heard that they just opened another one, but I don't know where, it's new.

R: And does your support group do home visits?

Support groups

P: **Ja, we do have a committee** for the ones who do **home visits** but only to those who live around here.

R: Tell us about home visits.

P: They can do home visits at any time, because there are **those who are diagnosed but don't accept that they are HIV**, so you have to visit them regularly. Then some **individuals will go to their houses** and help them accept, but it's only some people that can go. Like, for example, if a person discloses to me then I've got a right to go there **but I can't tell the group** that so and so is HIV positive.

HIV positive: difficult to accept status

Individual community members support home visits

Confidentiality

R: I understand. So if I hear you correctly, the role of the members of the support group is to support one another emotionally, spiritually and with advice, and also to support people who have recently been identified or diagnosed, and to help them live positively.

Summary:

- P: Ja, and sometimes we have to share food. Like if someone has nothing to eat, you have to share with them. Provide food if in need
- R: Please tell me about the diet of people living with HIV&AIDS, based on the knowledge that you received at the ATICC workshop. What should you eat and what should you avoid?
- P: I've also got some knowledge from the Skills Factory, when I went to a two day workshop. They are giving information and what they did with us is, they just gave us wellness management. They taught about wellness management, how to live, something like exercises and they gave us some script with herbs and how HIV positive people should eat, so they taught us mostly about nutrition. Skills workshop= information source  
Sources of information on:  
-wellness  
-living positively  
-exercises  
-food and nutrition
- R: How did you find out about the workshop?
- P: We were organised by G, who's a social worker working in the Department. She took some people from the group, from our group, we were nine and then one from area M and then she organised transport for us and we went there to area S to attend. HIV positive attend workshop as information source=want to elaborate knowledge  
Social worker initiated and organised and provided for transport
- R: What did you learn there about healthy eating habits?
- P: You know, the diet is difficult, because if you are HIV you have to eat. You can't stay for the whole day hungry, because you will get fits. So with the diet you have to stick with carbohydrates, proteins, calcium and if you don't have those things, you have to get supplements. Like for calcium you can use folic acid tablets, which help when you are feeling dizzy. So with diet it's difficult to follow diet, because some people don't get the disability grant and they don't have any money to buy those things, but you have to stick on fresh fruit and fresh vegetables and then, if you get diarrhoea from something, you have to stop using it. Knowledge on HIV positive persons diet

R: Your support group primarily focuses on infected people. What about the affected people, such as family members and children of people infected with HIV?

P: For children who are infected, there's a group at Ubuntu. I think they start from plus/minus seven years to thirteen if not fifteen years. So Ubuntu is helping them. I think there is also a group, I forgot the name now, for affected mothers, brothers and sisters, but I don't know where, and I'm not sure about that.

Support group for infected children

Also support group for affected family members

R: Is there anything else you think I should know?

P: The only thing that I can add is that if you are HIV positive, sometimes your marriage gets broken, relationships, friendship also, but fortunately for me it was only my marriage.

Disclosure of HIV positive status can lead to

R: What kept you going through that difficult time, because it must have been very disappointing? Who or what helped you to cope?

P: Not so much, because my husband was a play boy. He used to leave me, so I knew that one day there would be a result of this, so I was not that much disappointed. But , they supported me.

At risk behaviour

Support from friends

R: Are you taking any medication?

P: I was last year, but when I got sick I had to stop in December. So in January I was going to take the medication again, but only to find that my husband took me out of his medical aid.

No money for medication

R: Which medication did you take before?

P: I was using tablets, nevaropine, which is viramune, ridex, herbet ds and zaret, but at the moment I'm not using it.



R: Tell me about e-pap and the value of e-pap?

P: It's too bad, I did try it once but I couldn't continue with it, it tastes bad. I just tried it once.

R: And the African potato, what does that help for?

P: It's an anti-biotic, but I've never used it. I just take vegetables supplements, Vitamin B.

R: Thank you for your time and for sharing your story with us. I can see that you are living positively and that you've accepted HIV. Good luck with the challenges you face.

## FIELD VISIT 4 – 7 JUNE 2004

### INDIVIDUAL INTERVIEW 12

#### HIV&AIDS CO-ORDINATOR AT THE DEPARTMENT OF SOCIAL DEVELOPMENT

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#### BROAD (FLEXIBLE) INTERVIEW SCHEDULE:

- ⓧ Which challenges are faced by the selected community?
- ⓧ Which resources and potential resources can be identified in the community?
- ⓧ Which services are provided by the Department of Social Development in the selected community?
- ⓧ How is the selected community currently coping with HIV&AIDS and the challenges implied by the pandemic?
- ⓧ Which role is the Department of Social Development currently fulfilling in supporting the community in coping with HIV&AIDS?
- ⓧ Which potential role might the Department of Social Development fulfil in future?

KEY OF ABBREVIATIONS
R: Researcher
P: Participant

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R: Please tell us about your position.

P: I'm the HIV AIDS Co-ordinator for the Nelson Mandela metropole, for the Department of Social Development. I'm the District Co-ordinator and then we've got seven service offices. So area X falls under Z.

HIV/AIDS co-ordinator on sdistrict level for Metropole/Department of Social Development



7 service offices (headed by HIV/AIDS representatives)

R: I see.

P: Then, under Z service office there is J, that is a HIV AIDS rep. So it's myself as the District Co-ordinator, reporting directly to the district managers, then we've got seven service officers and seven reps from all those areas. So that's why they normally say: "*If you want something to HIV and AIDS, go directly to Grace*" (*indicating herself*), although they are there for that area. Our main focus is the focus groups, women, men, people living with AIDS, children, child-headed households and also orphans. What I do, I'm supposed to be a co-ordinator, but I'm playing both roles, the role of facilitation co-ordination, and the role of a hands-on worker because some of the social workers, *in fact* most of them they claim that they are overworked. So which means they are not in a position to handle all the cases. As you all know, that if you talk in terms of funds, you've got most cases that are orphans, there's many emergencies. The children are left alone as child-headed households because the parents die. Then what we do in such cases is we place them in foster care.

Support groups  
-women  
-men  
-people living with Aids  
-children  
-child headed households  
-orphans

Social workers overworked/need for more assistance

Child headed households

Placement in foster care

R: You are a social worker by profession?

P: Yes, I am a social worker by profession, since 1992. So what we do, we place them in foster care, they are the people that are doing the placement. My role is that, because I'm the HIV and AIDS co-ordinator, I'm representing the department in the inter-sectoral forum and in the local AIDS council where there are most of our stakeholders in the metro, so all the cases come directly to me and then I will refer them to the respective offices. So we place them in foster care, some of them we place them in adoption, due to financial problems, but mostly we place them in foster care. The alternative placement like residential case is our last resort because we're preaching home-based care. The Department has made funds available for home-based care, where we're looking at ..., no, in fact as the Department because we are doing that in partnership with Health and the Department of Education. So the Department of Education is focussing on their life skills programme and the Department of Health, although they are focussing on treatment, care and support.

=representation on local/ council level

Refer case

Financial needs

Home based care

Department funding

Partnerships with Departments Services:

we are mainly focusing on care and support, where we visit people that  
are living with AIDS and encourage that they disclose as early as  
possible. For instance, if a person is living with AIDS, we support them  
with food supplements, give them food parcels, and those that qualify for  
the grants, we give them grants.

Partnerships  
with  
Departments  
Services:

Food  
supplements  
and provision

Grant provisions

R: Do they need to apply for the food parcels or how do you get to know about the people who are HIV positive?

NGO's=referral  
purpose

P: They are referred by NGOs in the communities and by the other home-  
based care carers in the community, because we're working closely with  
the Council of Churches, ~~specifically~~ Hope World Wide and others. So  
what they do, they will identify the people they think are needy. Then I  
will do the assessments, although the social workers ~~are supposed to do~~  
that. Then I will do the assessments and if they are really needy and  
they meet our criteria, because in terms of our criteria we focus on child-  
headed households, on orphans, on TB patients and people that are  
living with AIDS and also the people who have no source of income, let's  
say the people that have no money for their next meal. So those are the  
four categories that we do. Then in terms of the food supplements, we  
focus on infected and affected. Those are the boxes of our food  
supplements (*indicating boxes in her office*). So we do get so many  
referrals, but I must say the need is more than what we can offer. There  
is an element of creating dependency as far as those food parcels are  
concerned, because we're giving them food parcels for three months and  
after that we're not there. But there should be continuity because the  
idea is for us to give them food parcels and they must be involved in  
programmes or they must be linked to social security to access the  
grants. If you've got children that are orphans they must be linked to  
social services in order to access the foster care grant.

Home-based  
care carers in  
community

Resources

Social workers  
do assessment  
if meet criteria  
then provide  
with support

Programmes  
offered

Grant's  
available

R: Are grant applications finalised within three months?

P: No, unfortunately not, because as I say there is a backlog and also there's a shortage of staff, most of our people are leaving the country and they are not replaced, unfortunately. So that's why you'll find that I'm playing all these roles. Therefore I start early, I take work home, I'm working Saturday and Sunday, there's no way that you can finish your work.

R: So you provide the food parcels for three months. What happens after the three months have passed?

P: After the three months they are supposed to be already in our system to access the foster care. ~~Then the social workers will do the investigation,~~ so that they can place them in foster care.

Arranges  
placement in  
foster care

R: But where do they get food if they don't have an income?

P: Unfortunately the system works according to three months, the food parcels that we have, the two programmes, then after that there's nothing, unless the social worker can mobilise something within the community.

Community=  
potential  
resource for  
survival

R: Tell us about the two programmes you talk about?

P: The food programme is the National Food Emergency Programme, and then there's also the National Integrated Programme, and that one is focussing on home-based care. At the moment we're focussing on *M area*. We've got 45 volunteers that are doing home visits and what do you call it when they go to these houses and do home care, where they wash the patients. So we've got those patients that are caregivers, rendering services to people that are living with AIDS.

Wider area:  
Volunteers  
home based  
care and home  
visits

Basic care

R: Do you train them before they go out into the community?

- P: Yes, we train them on basic HIV and AIDS, we train them on home-based care, we train them on trauma, because some of them are exposed in stressful situations, in traumatic situations. Then also we identified that they need to be trained on dealing with loss, because some of them are not used to that.
- R: And there are 45 caregivers?
- P: Yes, for *M area*. The rest of the metro is catered for by the other NGOs, because we've got many NGOs such as Hope World Wide, whose got their home carers, ACVV, they've got their home carers, then there's another organisation that is focussing on home-based care, they call it CHI, that is Community Health Initiative. Then there's also Zwapa, Zwide Women's Association, they've got a poverty programme and they also have home carers. There are many NGOs.
- R: Are you aware of any home carers working in *area X*?
- P: In *area X*? I will have to really find out. I think ... I think the ACVV is working there, but I will have to find out who co-ordinates them.
- R: I have already met with the ACVV co-ordinator of the area, thank you. So you're not aware of any other NGOs working in *area X* at this stage?
- P: What about the CMR?
- R: I met with them too.
- P: Who else? ... You know that area is a little bit neglected, because our social workers are working there but as I say they are not really doing what they are supposed do. They are focussing on foster care and also adoption and also they are focussing on the placement of these children. But you will find that in terms of the resources, linking those people there in that area with other resources that are there in the area they are not
- Training of volunteers
- Home-based care, trauma, and dealing with loss.
- Several NGO's: home based care and carers
- Resource
- Limited services/help-social worker
- Area-under resourced

really doing that. And the area itself is under resourced. Because with our programme, the home-based programme, unfortunately it's focussing on area M.

R: Where's *area M*?

P: *Area M* is the other side of PE on your right, some 19 kilometres from here. It's a little bit further than here, but it's the area that is characterised with a high rate of unemployment, high prevalence of HIV and AIDS, all the social pathologies, as a result it's getting all the attention. That is the problem that we are having, we are focussing that side, maybe now is time for us to move this side.

R: Resources are always limited.

P: Ja, there will never be enough, but whenever we've got a programme that is coming, I mean we've got Urban Renewal there, we've got the NIP, now they've got ... uhm, now we're opening a Social Development complex that's going to have all the people under yard, you see, like a multi-purpose centre. But at the same time we need to focus on this side of the metro. Maybe even with other NGOs as well, I know there's one centre, because it is one of our focus areas, to fund the centres, so I'm providing them with soup. Do you know the centres where you have a couple of activities that are run in the centre, focussing some there, focussing on street children, some are focussing on orphans and neglected children, some focussing on people living with AIDS. So what they do, you provide a meal before the children go to school because they don't have parents and when they come back from school we also provide them with a meal. And from there, the volunteers will maybe be assisting the children with their homework, school work and all that. So they provide lots of services in these centres, like for women they're doing their bead work, poverty alleviation programme, men and women are focussing on gardening projects, and so on. But in PE we are just providing soup, they are just providing meals. I'm trying to maybe guide

Resources else where

Potential resources:  
NGO's=  
providing food,  
assisting with  
homework

Services



them to see maybe the need to involve more children, to involve women so that they could have something that is measurable, not have a child that is going there just to have food and from there to the streets again.

R: Are you aware of such a centre in or near *area X*?

P: There is a lady that is operating at *area X*, eh ... Sister E. And then there's also another lady but she's doing both areas, *area N* and *area X*, it's S, she's got a soup kitchen, and then there's J's soup kitchen, she's right at the back of the university. So she covers some of the people from that area.

Volunteer worker

Soup kitchen

R: And the main goal is combating hunger?

Focus=fighting poverty

P: Ja, it focuses on that, but if maybe they could expand the programme, expand maybe and let the people be involved in other projects, it would be better, But it's not easy, because there are no resources, but they can maybe guide them and let them start at home, so that if you give them these food parcels, give them rice and mealy meal that is there, they can take vegetables from their gardens.

Limited resources

Potential asset: food

R: What does the food parcel normally consists of?

P: It's 10 kilograms of rice, 10 kilograms mealy meal, a package of sugar, 2 litres of fish oil, and there's also a bucket, and inside the bucket there is 2.5 kilograms of samp, and also beans, tea bags, peanut butter, soap, washing and bathing soap. It's a month's supply and the value of that parcel is R200.

Resource

R: And it's government funded?

P: Yes.

R: I've heard a few people mention e-pap. Are you at all involved in providing e-pap to children that are HIV infected?

P: Yes we do. We do, because there is a guy that is providing e-pap, he normally phones me because some of the people will come to me for assistance so they provide me with e-pap, then I provide it to the infected. But as a department we are providing the supplements from Nutrimo, there's porridge there, there's a beverage, there's also a drink. So it's four packs that are there, four 1 kilogram packs as supplement, they are from Nutrimo. This year we provided for 426, because they are divided. We've got 24 districts in the Eastern Cape, each district got 426, that is the number of people that we need to identify, the infected people. And it's a supply of three months. We give them one box per month. Now this is our last supply (*indicating supplies in her office*), it's the remainder of my June supply and from there we will continue doing that, but in three months time.

Food provision/  
supplement

R: If I understand you correctly, you had to identify 426 infected people per area. What if there are 500? Will you help the first 426?

P: What I've done is I've provided the 426 that was given by the Department and then from there the others I've given them e-pap.

Food provision/  
Supplement for  
all in need for 3  
months

R: In other words you always try to help, you never show people away?

P: I always try to help. And we are the Department, so they would also expect us to provide. So what I do, I uhm ... you know, it's like a joke when you say it, but I provide the NGOs ~~but sometimes I go to them~~, for instance if I've got a crisis. Like I once had a case of a ten year old, taking care of a four year old. So what I did was, I went to the Salvation Army, because at that stage we didn't have anything. Like now, after these food parcels, this is the last lot that I'm having. And after that we are going to wait for the funding from the provincial office and give them three months. But it's a programme that's going to run for three years.

Seek assistance  
from NGO's if  
cannot provide=  
Networking

So maybe we will be in a position at least to alleviate poverty even if it's by 20%.

Poverty  
alleviation  
attempt

R: Even if it's for one person, it does make a difference.

P: Ja, it makes a difference.

R: Grace, please tell me about the grants. How does it work? For example, what are the criteria to apply for the disability grant, do you know?

P: It's supposed to be a CD count of 200. ~~I think we take the criteria from~~ Department of Health. But last year, I would say 2002/2003, we had an influx of people that were coming to ask for the disability grant. Now, the head of department had to write a letter saying that by virtue of being HIV positive doesn't necessarily mean that you qualify for a grant, because the people were just coming. You go for a test and after you go for the test you come to the department of Social Development for the grant.

Criteria for  
disability grant

High demand for  
disability grant

R: It sounds like easy access to money?

P: Exactly, and we could see that in our budget. Then, if the bulk of our budget is going to the grants, we cannot afford it, so then they started to guide the people, so that they know that they won't really qualify. It was such a problem, people were not happy with that, because most of the people, there's an increase in the people that are getting infected. But if you look at that, unfortunately our criteria says you get it when your CD count is 200, which means some of them they only access the grants when they are at the verge of dying. And also, some of them don't even get the grant, because their relatives they would claim the grant and unfortunately some people are deceased without even accessing the grant. But I must say that with the introduction of anti-retroviral we might change our criteria and say there will be more people that will be living, because with the anti-retroviral people will live longer. Then what we need to do as the Department of Social Development is maybe to clean

Department  
informing people  
about the grant

Increased  
infection

Strict criteria for  
grants access

Relatives  
accessing grant  
(people dead)

Hope for future  
with anti-  
retroviral  
provision

our house and be ready for that. When they roll out the anti-retroviral, what are we saying, people will live, there will be more chronic people than people that would be dying. There will be lesser maybe demand on the people that are needing foster care grants because the foster grant people are dying, leaving their children. So more children will stay longer and more parents will live longer, they will be taking care of their children, which means, maybe we need to provide the grant.

Hope for longer life expectancy with anti-retroviral provision

Maybe increase in grant?

R: Yes, only time will tell.

P: Exactly, because the department is not ready yet. We've been asked ... we received a letter from the Metro. So we've been asked what is the plan for the roll out. We need to look at that because Health, they decided on their own without involving us as Social Development. I'm not sure whether we are ready in terms of our budget, because we will be getting more people that will be in need of the disability grant.

Challenge to Department of Social Development

Prepared higher demand for grant

R: Please tell us about the application procedures for governmental grants. Do qualifying people apply here at the Department?

P: They apply here at the department, but because we've got seven service offices, we've got an office in *area M*, we've got an office in *Z*, we've got an office in *N*, we've got another office for in Uitenhage, so they can apply in all those areas.

R: And the closest service point to *area X* would be *Z*? They fall under *Z*?

P: It's not so close, but it's closer than the other offices. And now I'm afraid they are going to travel more than they used to, because those people, I only heard on Friday that they will be coming here, which means they will have to catch a taxi to access that. I don't know whether maybe the people from *Z* will decide to have a satellite office in those areas because that could be an option, to have a satellite office in *area X*. You know, it's so difficult.

Problem= travelling expenses

R: Could we talk some more about the grants?

P: Oh, yes. Then we also, okay, you know the type of grants that we offer as a department?

R: I know about the foster care grant, the disability grant ...

Foster care grant as resource

P: Yes, the foster care grant is for the foster children. It's R500, it went up to R540. Then there's the child support grant that will provide for the children that are under the age of eleven, which is R170 per month and the person's income must be less than R800, less than R800 and they say in urban areas is between R800 and R1000 and for rural as well they've got an amount. So that is child support grant. Then we've got care dependency grant, which is provided to the children that are disabled, physically handicapped, mentally handicapped and also infected children can access that grant. That's now R740. Then we've got granting aid, it's for the people, like we've got the people that are disabled, or that are receiving the disability grant, R740 and the people that are pushed by wheel chairs. The person that is assisting the person that is disabled, or the person that is receiving the disability grant qualifies for that R100, it used to be R100, so that is the granting aid. Then there's the old age pension, for females 60 and for males 65 years, which is R740, and then there's also social relief. Under the programme social security they also provide social relief in cases of disaster, and in cases of people that are waiting for the grant they also get food parcels, for social relief or distress. I think that's all under the grants. The idea when they started with the child support grant was that the people that are receiving child support grant should be involved in programmes, because it started with R150, so they should be involved in programmes, because initially it was for children that are under the age of seven. So there were programmes that are running for people with children under the age of seven, now it's under the age of eleven but people are not motivated when they get money. Although it's not so much, they are not

Child support grant as resource

Dependency grant as resource

Old age pension

Social relief as resources


Provide food parcel

Handling money: not motivated

motivated, some of them are not really motivated, they just want the grant.


R: Could you provide me with some background information on *area X*, as you know the area. What are the greatest social challenges in that area?

P: Poverty, unemployment, rape, domestic violence and mostly drug abuse. And also child neglect, ~~most of the cases there are from that area.~~ I think maybe because of the high rate of alcohol abuse, ~~the children in that area are neglected by the parents.~~



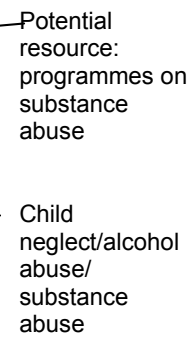
Social challenges

R: Yes, I have often observed children not attending schools when we go into the area in the mornings.



Abandonment

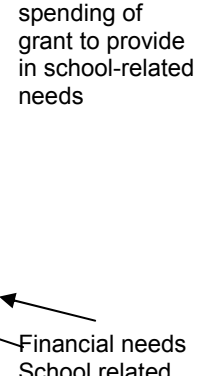
P: Exactly, and abandonment used to be very high, the abandonment and maybe ... eh ... you know, as I'm talking to you now, I'm just thinking, maybe we need to focus on programmes that are really focussing on substance abuse, ~~because I know when I go to those schools you will get a child with, it's Monday today, but you can't understand why the uniform is dirty and the shirt is not clean. And it's because the parents are not really taking good care of the children, most of them they abuse their children, even if they receive the grant, to an extend that if you do supervision there you must know that you will always end up with something that is wrong. I wouldn't say it's illegal but I don't think we are expected to monitor the foster care grant, but then you will be directly involved, going out into the community, you know.~~



Potential resource: programmes on substance abuse

Child neglect/alcohol abuse/ substance abuse

You know, I used to have cases where, if a grant is going to be paid on a Wednesday, I would go there as early as half past seven so that when she gets to the pay point, when she gets the money I take her straight to Maka. Then we would go straight to Themba La Bantu, where we then buy school uniform because Mr M complained that some of the children are not paying school fees, they are not paying. Their school needs are not met, they don't have school uniform, no shoes, even an underwear.



Monitor spending of grant to provide in school-related needs

Financial needs School related needs

When I used to go to Themba La Bantu to buy, then I know this month with this grant I will just buy school uniform or shoes, you know the basics, school uniform, shoes, underwear and socks. The next month I'm buying the jersey and the books, and so on.

R: That must have been time-consuming?

P: Exactly, but I used to do that. And imagine, at the stage I was doing that, I was a social worker playing the role of being a social worker and also playing the role of being an HIV co-ordinator at a district level and also an HIV co-ordinator at regional level. And thanks God, the regions were phased out because after they were phased out I had to focus on the metro. And there are so many challenges because of the NGOs in all areas, we've got all the NGOs and now my duty is to facilitate training of the NGOs. The people that are there in those areas, they should empower and capacitate those NGOs, but I'm not playing a role of a co-ordinator, the people are overworked, they can't fulfil that. Then because it's our mandate to identify community initiatives, especially those that are focussing on home-based care and provide funding for those organisations and also if we can capacitate them in forms of any training that we could offer, so that whatever that they are doing is in line with our policy, because most of them are complementing our services. Because I mean, we can't do it alone as a department.

Facilitate training in NGO's- empower and capacitate= mobilise potential resources

Capacitate other organization

R: That's true.

P: Yes, so it's quite a demand on my side, because you're looking at that as well and most of the people, in order for them to render a proper service, I must be there in the community so that I could tell them that the role of the Department of Social Development in HIV and AIDS is focussing on care and support and under care and support they are focussing on placement, alternative placement of children, that is foster care, adoption and institutional placement, which is our last resort. But mainly we focus on home community based care. And home community based care

Care and support



focus on people that are living with AIDS. And you know, I was looking at my operational plan and I was saying: “*You know, there’s so much that I’m doing that is actually not my job*”, because if you could look at my operational plan then you would wonder why I’m like a Jack of all trades.

R: You certainly seem to be involved in various activities.

P: You know, I will provide training on home-based care, focussing on the social aspect, because you know the programme of 59 days, the programme on home-based care that is provided by Health – the training programme, in their curriculum they are not focussing on the social aspect. So I need to now do that training. So they will always ask me: “*Grace we need you for this, Grace we need you for that*”, and okay, that’s part of my job but at the same time I feel that what I need to do is be there in the community, so that I can make a difference. How I wish that social workers can work as a team! As I say that we’ve got seven people, how I wish that those people could really go out into the community and be more visible, because you will find that I’m more visible than them. And they just shift the responsibility to Grace. Because for instance, take an example of the food parcels, my duty to provide the food parcels and then actually they must distribute it. They must identify the families for me and after identifying the families they must assess those families but I do that, even now I’m on my way to do that. I’m going to do the assessment in area M, so that I can distribute other food parcels. But there’s no way that I can sit and say this is not my job, because if I’m not doing that, there won’t be a difference in the community. People are waiting there, they don’t know the others, but they know Grace. There are also roles that I’m performing at provincial level, and they asked me to attend a meeting in Pretoria and then when I come back there’s something that they want me to implement, because there’s also a structure, the National Action on Children that are Affected by HIV and AIDS, they call it NACA. They are supposed to have a provisional action which is PACA and we are supposed to have a district action at this level and from there it cascades down to LACA at local

Present training programme on home-based care (collaborate with Department of Health)

Want to make a difference in community

Challenge: social workers not doing there work-shifting responsibilities

Social workers not doing their work

Few people doing much

Variety of action plans to be implemented in the community HIV positive related programmes

level. So we are busy doing that. So you run to the province to make sure that the structure is in place, you come back to the district, you would make sure there's structure and you facilitate the establishment of the structure at grass root level as well, and then there's also so much that needs to be done in terms of guiding even the social workers around the programme, because the programme is demanding.

R: Tell us about that health system programme?

School based programme to be implemented

P: It's a programme that is run by different stakeholders, by Health, Education, Social Development, NGOs and everything. In a certain area you need to have the programme, which means you need to identify the resources in that area so that when there's a problem, you know where to refer exactly. So we have this structure, there must be levels of this structure, but it is run by the school principals as the co-ordinators. The school principals should initiate it as co-ordinators, maybe the first step would be that the principal should call a meeting with the stakeholders, a social worker from that area, HIV AIDS co-ordinator, nutritionists from Health, school nurse, somebody from Education on life skills, you must be in a position to identify the people, looking at the problems that are existing, must have SAPS and Correctional services. So if the programme, if you say substance abuse is a problem in that area, we need to call SANCA, then SANCA must be on board. Then you have the meeting where you are going to introduce us all, like the organisational meeting where all the stakeholders go and from there we elect a steering committee that should run the programme. When there are big events like the Child Protection unit for instance, we have those people. Each and every person will focus on their mandate, I will focus on child protection, looking at the infected or affected orphans and children abandoned and abused and all that. Then you might have a police officer that will be focussing on crime prevention and then youth development as well, you have various stakeholders that will be focussing on that. The principal must be in a position to identify that these are the problems that I see that we encounter in this area, by

Various role players

Principal to initiate

Programme inclusive

Identify resource and get them involved

Potential resources

Programs eg. Child protection

looking at the children. If you say, for instance, that most of the children they come to school with empty stomachs, then I say the high rate of poverty is the focus. Then what do we say, Social Development must be involved and also Department of Health must be involved with their nutritional programme. So it's actually the purpose of that structure, the way I see it is to bring the resources closer, to make the resources accessible. Now this is something that is in the pipeline, it's something that needs to be done. All the schools are supposed to have that.

AB approach-link with: focusing on resources and accessing them

R: Is there a policy document stating this?

P: It's supposed to be, but I don't know what happened. If you can ask maybe the Department of Education, because I'm going to this meeting first. Maybe they will have something, because what I used to have I left it with the social workers from that area. It's just a workshop document from the findings, you know, like a situation analysis of some kind. Then from there we developed an operational plan. If, for instance, you say poverty, how are you going to alleviate poverty, then we talk in terms of income generating projects, such as the gardening projects, whatever and all that. So there is this professor from Rhodes University, I can't remember her name, but she initiated it and she was leading it.

Proposed plan to address problems – not yet on the ground (in pipeline)

R: Grace, will it be in order for the teachers at the school where I work to contact you if they need advice, as they should be starting an initiative like this within the near future. Will it be okay for them to contact you for guidance?

P: It's okay.

R: But I don't want to add to your work load.

P: No, it's okay. I know they probably won't be impressed with me because *Mr M* referred 3 cases to me. Then, even though I'm not supposed to go out, in this particular case, I took the car and ran to that family but when I

got there, the child is ... she was at that stage full-blown. I left the e-pap.  
I left the food parcel. Then my duty was to refer that case to the social  
worker. And you know, to be honest, I was so disappointed to hear that  
there's been a social worker that has been working on that case, and yet  
there was no improvement. And it was the social worker from our  
 Department that is operating from hospital D.

HIV positive  
 child- provide  
 food  
 supplements  
 refer to Social  
 worker  
 Social worker  
 not doing their  
 work in the area  
 = problem

Hospital based  
 Social worker  
 from  
 Department

R: If I listen to you and from everything that I've gathered during our  
 conversation, it seems like *area X* is kind of a neglected area at this  
 stage. However, the people still seem to cope. What do you think, why  
 or how does the community manage to cope?

P: I would say maybe it's because of the community involvement. The  
community members they help each other, but I would say some credit  
 must also go to the NGOs, like Siphuthando and the CMR. I know the  
CMR is working there, there's a social worker B, and also child and  
family welfare. And I would say maybe the two schools, the teachers play  
 a role, because some of the resources, they access them through the  
 schools. Mr M has been doing quite a wonderful job and also the  
teachers from school G. So for example, the children, the parents would  
be called by the teachers at school so that they could see a social  
worker. And you know with the social workers, if there is a teacher  
 involved, it's better. Because the people are not really educated about  
their rights, so they sometimes would sit at home not knowing what's  
 going on, then the school teacher would phone and ask: "How far are  
you with that case?" You see, that's terrible, but it's the truth. I hope I  
 won't loose my job by saying that (*laughing*).

Community  
 involved with  
 each other

NGO's  
 Social workers  
 Schools  
 Educators  
 Principal in  
 school

Schools and  
 teachers refer to  
 social worker  
 and advise to go  
 for follow up

Community  
 members ill  
 informed

R: Could you please tell us about this hospital across the street?

P: *Hospital E?* It's a TB hospital, but I suppose a lot of HIV cases.

P: Do you know what the capacity of the hospital is?

- P: No, I don't know the capacity, but what I know is that they are ... uhm, they are dying like flies. Unfortunately when you go there, you go in and park your car on the other side. When you go in, you will see a person that has just died covered with a white sheet, when you get out you see another one and I'm so scared to go there. I don't know how the social workers is coping there. The social worker from *hospital E* has been sick, I don't know, maybe it's due to the work. I don't know whether it's work related stress, but she's been sick almost the whole year. She works there and arranges the grants for the people there and also maybe arranges home visits.
- R: Is she from the Department?
- P: Department of Health.
- R: As I understand it, the social workers that work in this area are either employed by the Department of Health or by your Department or by the ACVV or CMR?
- P: Those that are in hospitals are employed by Health, then you've got seven social workers in those seven service office areas that I mentioned, they are appointed by the Department, then you've got those that are appointed by child and family welfare, CMR and ACVV. And then there's also FAMSA.
- R: Grace, thank you for all the information. Is there anything else that you would like to add that might help me to understand how the community in *area X* is coping with HIV&AIDS?
- P: Nothing that I can add. But what I can do, let me see if I do have it ... (*searching for documentation*), this is the national guideline for services to children infected and affected (*handing over a document*). There's a lot of information in there that might help you, there's information on the

High TB related deaths

Difficult to cope with

Social worker arranges grants and home visits

Department of Health – hospital based

Department of Social Development: 7 social workers in 7 service offices Appointed by Child and Family welfare- CMR ACVV

FAMSA= Another organisation

options for child care, types of financial assistance, the statutory business plan, home community based care, you might find it helpful.

R: Thank you so much. This is a great resource, thank you.

P: It's a pleasure, and it can maybe guide you, because it has everything about Social Development in there.

R: Thank you! Is there anybody that you would suggest I talk to, that could provide me with information? I have already spoken with the teachers, with people of the churches, to you now, to Department of Health at the hospital.

P: What about ATICC?

R: Yes, I've been to ATIC, and I've also met with *Sister E*.

P: I can't think of somebody else now. But you know what I forgot to tell you about us in the Department is that we've got programmes that are running, like HIV and AIDS programmes, with the co-ordinator – myself, and then we've got a co-ordinator for victim empowering, that is a programme that is focussing on domestic violence, abuse and all that and then we've also got a programme on care for the elderly. Then there's a programme on substance abuse and also a programme on child protection services. So those are the programmes that are running. They are led by social workers within the Department, so that you could really focus.

8 programmes  
led by Social  
workers – by  
Department of  
Social  
Development

R: And to summarise your task, and I'm sure I'm going to leave out something, your task is to co-ordinate the food parcels and the applications for the grants and to assist all the people that is infected and affected, as well as do assessments, which is actually not part of your job yet you do that, as well as organise the home-based care programmes. And then you also organise the volunteers and train them, and attend all those many meetings. You are involved with the Department of Health,

you also work with Education, other stakeholders and NGOs. Is that correct?

- P: Yes, but mainly it should be the home-based care programmes. And I have to attend that inter-sectoral forum in the local AIDS forum, because you know, it's like, uhm, this thing is like a guide. What you need to do is to focus on the implementation and preventative programmes, co-ordinate the programme, implementation of educational programmes on HIV and AIDS, targeting all vulnerable groups. Those are the children, infected and affected, the women and their children, then you develop an implementation plan to integrate HIV and AIDS issues into all the departmental programmes. So the programmes that I mentioned to you, like social security that is dealing with grants and poverty alleviation where it's my duty to link the people, for this programme I must monitor and evaluate the implementation plan, alleviate levels of poverty through food security and income generating programmes, that is in line with the community development principles and practices. Then we've got the co-ordination of identification and assessment of TB patients and HIV infected and affected people. And I also co-ordinate the distribution of nutritional programmes and dropping centres and soup kitchens, like the one that I mentioned, like the food supplements and also the soup kitchen. And this involves distribution, co-ordination of the distribution of food supplements to HIV and AIDS and TB patients.
- Networking role
- Alleviate poverty by:  
Community Development
- Identify and assess TB and HIV/AIDS
- Distribute nutrition and programmes
- Organise and run soup kitchens-provide food supplements to HIV positive individuals

- R: That surely keeps you busy! Grace, thank you once again. Is there anything you would like to add?

- P: Just that if you need any support or more information I will make a plan. Or maybe if you are coming again and would like to have a meeting, I will meet with you. Otherwise, I would like to know about your projects, because it looks like you are bringing the resources to the people.



R: It's about making the community aware of resources that are already there.

P: But at the end of the day, make sure that these resources are acceptable to people and that they are accessed, you know, when you talk in terms of accessibility and acceptable by them. So what we need to do is to look at the community involvement first, ~~maybe we can assist you with~~ regard to that. We can look at that, mobilise the community with the teachers, maybe have a steering committee because what they want, what they are going to do now, if I heard you correctly, is to have a team leader in that school, and then that team leader will make sure that the programme works. Then maybe our role there will be to support that person and guide that person. ~~Then what I need to do is maybe on our~~ side as the social workers, maybe guide them and say this is what we need to do because that could really help us, ~~even if they would say as a school we are dealing with this office, if you want to come as social~~ workers you can come on Wednesday. Because as we don't have resources, we don't have an office in that area. But maybe if the community could have access to just have one social worker it will make a difference. So we would really love to help.

Link with AB approach: resources should be acceptable and accessible

Community involvement

Mobilise assets

Support and guide community members

School= community asset

R: Thank you, Grace. I will keep you informed and also tell the teachers to contact you.

**14 November 2003**

On our way to the community I experienced feelings of excitement but also uncertainty. Although I had planned the session and felt that I was ready to enter the field, I speculated as to whether or not my ideas would work out, to what extent we would be accepted by the participants, whether or not they would all turn up and be willing to participate, whether or not I would succeed as facilitator within a group of people who in so many ways differ from us ...

These feelings of uncertainty and hesitance were soon replaced by excitement and amazement, with me feeling overwhelmed. All participants turned up (in fact, one more joined), they participated in all activities (yet initially with suspicion) and shared their amazing stories. Yet on the down side, many (but not all) of the participants appeared to be there primarily due to the fact that they are going to be reimbursed for their time.

The lengthy lunch and socialising component was successful in establishing rapport and paved the way for a rich discussion on HIV&AIDS. However, it emphasised the fact that I will have to be flexible and be guided by the pace of the participants – which seems to be much slower than the one I had planned.

After today, I am left speechless by my experience. In the heart of this poverty-stricken community with seemingly limited external help and resources lies a school with amazing educators and so much potential – indeed a huge asset to the community! Yet they don't seem to believe in themselves and the role that they are already playing ... I feel humble.

I am happy that my selected methods worked well today. I believe that the focus group discussion allowed all participants to make contributions, within the safe environment of a group. Participants could also support one another and elaborate where they wanted to add information or differ from someone else.

Although it is still early days (literally), I get the idea that this community (more specifically the participants) might (from a PRA perspective) benefit from the research. They have so much to offer and possess such a wealth of skills and compassion – yet they seemingly do not believe in their own abilities. This could be mobilised! The participants seem to be convinced that outside resources can assist the community in facing the challenge of HIV&AIDS and that we might be of valuable assistance to them. However, and in this regard, a distinct need to be informed on HIV&AIDS related issues seems to exist.

**17 November 2003**

This weekend I could see how PRA can be put into practice. Wow, it works great! Involving the educator-participants in visual concrete activities worked so well! Not only did it result in the planned outcomes for the visit, it also led to lively discussions, energy and excitement amongst all present. I am convinced that a mere discussion on the lay-out of the community would not have resulted in the rich information co-generated by using mapping activities, as proposed by PRA. I am therefore satisfied that I employed a suitable approach and methods.

However, I did not only experience the positive outcomes of employing PRA principles in practice. The potential hurdles of PRA that I read about also became a reality. I had to constantly remind myself that the participants were to determine the process, agenda and the pace of activities. Although a flexible approach during sessions came easily, it took me a while to accept the idea that we were not going to be able to finish all the activities planned for the first visit. We in fact only managed to address half of my ideas ... thus reflecting the golden rule of "*The participants determining the process...*"

At the end of our first visit to the community, after four days of hard work, I am exhausted, yet overwhelmed by the great response I received. I am exited about my study and happy about the way that I facilitated activities over the past few days. I am already looking forward to the next visit. Although the participants still seem to be cautious when discussing HIV&AIDS related issues, they are progressively becoming more open and appear willing to share their perceptions with us. Some of them, however, indicated the stigma attached to the pandemic within the community, constantly refraining from using the term HIV&AIDS.

Based on the participants' contributions and my own observations of the community, I want to predict that the asset-based approach may be suitable as theoretical framework in analysing this community's way of coping with HIV&AIDS. The school, principal and participants themselves are great assets to the community, although they do not seem to be aware of the fact yet. In addition, we identified various resources and potential resources in the community, some of which were also mapped by the participants as part of the mapping activity.

**23 January 2004**

On our way to the school today, I wondered whether or not all of the educator-participants would turn up, as two months had passed since our first visit. As with our first visit, I was a bit anxious and uncertain about the activities I had planned, and whether or not they would be appropriate and suitable to generate the raw data I aimed to obtain.

Once again, I was astonished at how well the activities worked out. Participants easily identified with the symbols I selected, enjoyed the session, participated with enthusiasm and created rich and extensive raw data. Nine of the eleven educators that participated during our first visit turned up, with one withdrawing from the study and one becoming involved in extra-mural activities, sending a replacement. In addition, a new participant joined us, once again resulting in eleven participants. All of the educators were glad to see us and visibly more relaxed with us being there than during our first visit.

The willingness of the participants to be part of the study and – even more important – make a difference in the community is truly remarkable. However, in spite of their enthusiasm and motivation to make a difference, they initially still tended to focus on the problems of the community and external support addressing them. During our facilitation we had to constantly redirect participants to the resources and potential resources as ways for the community to solve problems and face challenges. In response to our attempts (towards the end of the visit), participants demonstrated insight into the basic principles of the asset-based approach. Based on the assets and available, but not yet utilised, resources that the participants identified, I can reach the preliminary conclusion that the community is indeed relying on some assets available to them in order to cope with the challenges they face, including HIV&AIDS. However, several assets do not seem to be utilised – maybe necessitating the process of asset mobilisation?

**10 June 2004**

Viona accompanied me during the third and fourth field visits. I wondered how her presence might impact on the educator-participants and the dynamics of the group – she being a new face and yet another outsider entering a semi-closed circle ... I was happy when the educator-participants accepted her in the same manner which they accepted Liesel and me up until now. I do, however, partially ascribe the ease with which Viona established rapport with the participants to the firm relationships of trust that had been established already. During last week's visit, I faced the challenge of telling the educator-participants that they would not be receiving reimbursements from visit five onwards, as the funds were exhausted. Despite my anticipation that they would show resistance, the participants accepted this fact fairly easily, indicating that they were there to make a difference in the community, and that it was no longer about the money.

I experienced Viona's intervention as beneficial part of the participatory intervention initiated by my study. Viona's intervention afforded me the opportunity of spending more time in the field and in the presence of the educator-participants, strengthening relationships and constantly learning more while in the field. I could sense that the participants appreciated the fact that I kept on returning – honouring my commitment of being involved in the community for a lengthy period of time and adhering to the basic principles of PRA. As such, I got the idea that I lived up to their expectations and that they in turn respected my commitment, once again strengthening our relationships of trust even further. During the individual interviews that I conducted, I appreciated Viona's support as field worker. In the same manner, I benefited from fulfilling the role of field worker whilst she conducted her individual interviews – elaborating on my existing base of raw data.

On the other hand, I did initially experience concern with regard to the potential (negative) impact that Viona's intervention might have on the future progress of my study. I could not be sure whether her intervention would support or compromise my project, as her intervention aimed at raising an awareness of coping within the educator-participants. I speculated about the possible impact that such an awareness might have on future coping strategies, as employed by the participants... Upon reflecting on my concerns I, however, soon realised that Viona's intervention is a piece in the participation and intervention puzzle that will contribute to the final end-product, as she focused on addressing a need identified by the participants during the first phases of my study. As such, Viona's intervention supplemented mine, thereby adding to the bigger participatory picture.

**15 June 2004**

I gathered extensive information from the individual interviews I conducted over the past few months. Despite my initial concerns pertaining to whom to involve and how to gain access to them, I was able to schedule and conduct numerous interviews without too much difficulty. One interview led to another and towards the end of my field work I had to force myself from making more and more appointments, meeting more and more people. To be quite frank, I even believe that the last few interviews were probably not necessary at all, as data saturation had probably been reached by the end of the fifth field visit. However, I was already so involved in the community and my process of investigating various possible resources at that stage, that I simply continued exploring. I relate this to the fact that I experienced some difficulty to negotiate my roles as researcher and interventionist, constantly having to remind myself that I entered the community as researcher and therefore had to remain focused on fulfilling that role.

I found it easy to conduct the individual interviews. I relied on the interviewing skills that I possess and established sound rapport without difficulty during all the interviews. With the exception of one, all interviewees were willing to contribute after I had explained the purpose of my study and the principles of confidentiality and anonymity to them. Based on my experience in the field and the rich data that I obtained, I regard my choice of informal conversational interactive interviews as appropriate for exploring ways of coping with HIV&AIDS, as employed by the community. I am already able to identify asset-based trends (such as community members' reliance on aspects like faith, inner strength, family and friends when faced with challenges) in the data I had obtained on the community's way of coping with HIV&AIDS – thereby suggesting that they may be relying on the asset-based approach in coping with the pandemic.

The interviews with the caregivers of the orphaned children (HIV infected), as well as those conducted with participants who were infected with HIV and the family members of infected individuals, were difficult. Visiting the homes of infected community members and their families and seeing the children living with AIDS was emotionally laden and painful. One of the lowest lows of my field work was most definitely the death of L a month ago, whom I met in February when conducting an interview with her aunt, who was taking care of her at that stage. Also, observing the fear, bewilderment and confusion in the eyes of the persons living with AIDS, as well as in the eyes of their loved ones, brought a lump to my throat. I am so grateful that I always had a co-researcher by my side, to debrief with after an emotionally difficult interview!

**29 October 2004**

Tilda's part of the intervention formed part of the broader participatory work that I had been doing over the past few months. I was excited to see whether or not the educator-participants would be able to apply the knowledge that they had obtained on asset-based principles. Up till now, they displayed potential skills as well as the motivation to utilise their skills in making a difference in the community, yet they seemed to lack the confidence to take action.

The outcome of Tilda's section of the interventionist research study was truly amazing. Although participants displayed motivation and energy to put their plans into action after her first intervention session, I pondered on how much would have been accomplished, when we were on our way to the school today. Standing next to a large vegetable garden (on the school premises) upon our return, left me feeling humble and ashamed. How could I ever have doubted the participants' motivation to make a difference and set the wheels rolling? – in fact doubting my own theoretical assumptions regarding coping, agency and the asset-based approach! Their feelings of joy, pride and accomplishment cannot be expressed in words! The three identified projects in an attempt to mobilise potential, but not yet utilised, resources demonstrated a success in terms of participatory research!

Tilda's intervention enables me to distinctly link the theory of the asset-based approach to the community's coping with HIV&AIDS. After identifying assets and potential assets in the previous phases of the study, the educator-participants were facilitated into action. They applied their knowledge of potential resources, as well as the knowledge obtained on asset-based principles, in putting their plans into action. By doing this, they were not only empowered themselves – they also seemed to have empowered other community members in coping with HIV&AIDS and its related challenges.

In addition to the work prior to her intervention, I relate the research outcomes of Tilda's intervention to the methodology she employed. Building on my previous field visits and relying on symbols and methods which the participants were familiar with, proved to be successful. Relying on group activities where participants were not provided with the answers but facilitated to come up with solutions themselves, further contributed to the research outcomes.



**18 October 2005**

Maria and Malize's interventions maybe constitute some of the last pieces of my puzzle. It aimed to address the needs of the participants, paying honour to them determining the process and agenda. This is PRA in action! As always, the educator-participants contributed and shared their experiences openly during the sessions over the past few days. By now, they are acquainted with the basic principles applied by PRA and the methods we rely on. The already present assets of the educator-participants could be expanded on further. Based on their willingness to make a difference and their motivation to help people in need of support, their skills were built on. In empowering them, the underlying principles of both PRA and the asset-based approach were adhered to – all adding to the community's way of coping with HIV&AIDS.

We are on our way to the community – possibly for the last time during this study. I am quiet ... reflective. The past two years have been enriching and fulfilling in many ways – both professionally and on a personal level. Conducting research in the field with people who experience the challenge of HIV&AIDS on a daily basis, whilst employing PRA principles, broadened my skills as a researcher.

Despite the challenges I faced, I had the opportunity to learn and in the process gain invaluable experience, insight into my area of interest and confidence as a researcher. As I strongly believe that I still have much to learn from this community, I am already contemplating the feasibility of a follow-up study in the near future ....