

ACRONYMS AND ABBREVIATIONS

AIDS	ACQUIRED IMMUNODEFICIENCY SYNDROME
ART	ANTIRETOVIRAL TREATMENT
ASSA	ACTUARIAL SOCIETY OF SOUTH AFRICA
CABA	CHILDREN AFFECTED BY AIDS
CBO	COMMUNITY BASED ORGANISATION
CCF	CHILD CARE FORUM
DSD	DEPARTMENT OF SOCIAL DEVELOPMENT
DSTV	DIGITAL SATELLITE TELEVISION
EMM	EKURHULENI METROPOLITAN MUNICIPALITY
FHI	FAMILY HEALTH INTERNATIONAL
HIV	HUMAN IMMUNODEFICIENCY VIRUS
IEC	INFORMATION EDUCATION AND COMMUNICATION
ILO	INTERNATIONAL LABOUR ORGANISATION
LCDA	LITHANZA COMMUNITY DEVELOPMENT ASSOCIATION
MSM	MAN HAVING SEX WITH MAN
NACO	NATIONAL AIDS CONTROL ORGANISATION
NPO	NON PROFIT ORGANISATION
OVC	ORPHANS AND VULNERABLE CHILDREN
PEPFAR	THE U S PRESIDENT'S EMERGENCY PLAN FOR AIDS RELIEF
PLHIV	PEOPLE LIVING WITH HIV
PMTCT	PREVENTION OF MOTHER TO CHILD TRANSMISSION OF HIV
SAPS	SOUTH AFRICAN POLICE SERVICE
TB	TUBERCULOSIS
UNAIDS	JOINT UNITED NATIONS AIDS PROGRAMME
UNDP	UNITED NATIONS DEVELOPMENT PROGRAMME
UNGASS	UNGASS UNITED NATIONS GENERAL ASSEMBLY SPECIAL SESSION ON HIV AND AIDS
UNICEF	UNITED NATIONS CHILDRENS EDUCATION FUND

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CHAPTER 1: ORIENTATION TO THE STUDY

1.1 INTRODUCTION AND BACKGROUND

This chapter presents the aim of the study, sets out the study objectives, identifies the research questions, states the significance of the study, formulates the problem statement, describes the study setting, provides operational definitions for the concepts used in the study, and outlines the structure of the thesis.

1.1.1 Global perspective of the HIV and AIDS pandemic

A brief outline of global developments related to the AIDS pandemic serves as background information to contextualise the challenges faced by orphans and vulnerable children (OVC) in South Africa. According to the UNAIDS (2010:16) Global report, about 33.3 million¹ people were living with HIV and AIDS in 2009 (of whom approximately 68% resided in sub-Saharan Africa), with 2.6 million people (about 7,200 per day) being newly infected, and approximately 1.8 million² (about 5,000 per day) estimated to have died due to AIDS related diseases. HIV and AIDS disproportionately affect women, with 16.6 million women being HIV positive worldwide in 2009. HIV prevalence fell by more than 5% in 33 countries between 2001 and 2009. The UNAIDS report also stated that the overall growth of the global AIDS pandemic, over time, appeared to have stabilised and that the annual number of new HIV infections had declined since the late 1990s, with fewer AIDS related deaths (UNAIDS, 2010:16).

Sub-Saharan Africa had the highest number of HIV infections, with approximately 1.8 million³ people infected with HIV in 2009. However, the number of AIDS-related deaths decreased significantly by 19% to 320 000 in sub-Saharan Africa between 2004 and 2009, due to the roll-out of antiretroviral treatment (ART) in public health facilities and the care and support offered

¹ The figure has increased to 35.3 million according to the UNAIDS, 2012 Global Report.

² The figure has decreased to 1.8 million according to the UNAIDS, 2012 Global Report.

³ The figure has increased to 2.5 million according to the UNAIDS, 2012 Global Report.

to PLHIV) (UNAIDS, 2010:19). In 2009, approximately 16 million children worldwide had lost one or both parents due to AIDS-related diseases (UNAIDS, 2010:19).

Due to an increased focus on the prevention of mother-to-child transmission (PMTCT) of HIV, the total number of children worldwide born with HIV decreased by 24% to 370,000 between 2004 and 2009. Reducing the number of OVC is critical in sub-Saharan Africa, particularly in South Africa, where the traditional absorption of orphans by the extended family is becoming increasingly difficult, given the fact that communities are struggling to care for HIV and AIDS-infected family members (Karim & Karim, 210:373). Regrettably, ART was introduced very late in most sub-Saharan African countries, thus denying many OVC the opportunity to be raised by their biological parents.

1.1.2 The HIV and AIDS pandemic in selected regions

An analysis of the HIV pandemic in selected regions will contribute to the facilitation of an understanding of factors influencing the modes of transmission and result in lessons and best practices. The UNAIDS Global report (2010:34-55) provided an update on key positive developments, and outlined inter-country variances in modes of transmission. For example; in Eastern Europe and Central Asia, the HIV pandemic is concentrated among people who inject drugs, sex workers, their sexual partners, and men who have sex with men (MSM). In the Russian Federation it is estimated that one third (37%) of the country's 1.8 million injecting drug users are living with HIV. As the pandemic spreads from people who inject drugs to their sexual partners, the proportion of women living with HIV is also growing; in 2009, women accounted for 45% of PLHIV in the Ukraine, compared to 37% in 1999. Ukraine has the highest adult HIV prevalence in Europe and Central Asia at 1.1 %, with annual diagnoses having doubled since 2001 (UNAIDS, 2010:38).

In North America and Western and Central Europe the main mode of HIV transmission remains unprotected sex between MSM, followed by injecting drug use and unprotected paid sex, especially in Mexico and parts of southern Europe. In France, for example, MSM account for more than half the men newly diagnosed with HIV, while they only represent 1.6% of the country's population. The number of PLHIV increased to about 2.3% in 2009 in this region (UNAIDS, 2010:50).

The UNAIDS (2010:50) global report noted that AIDS-related deaths began to decline in North America and western and central Europe after ART was introduced in 1996. In Asia and Central and South America, the trend in the number of deaths stabilised, whilst the number of deaths is on the increase in Eastern Europe.

1.1.3 The HIV and AIDS pandemic in sub-Saharan Africa

“HIV/AIDS poses an unprecedented development and human challenge, especially in Africa, and in many countries, the pandemic has cut life expectancy and robbed society of millions of people in their prime working years. It has dimmed hope of living full and productive lives for an unimaginable number of infants, children and young adults” (World Bank, 2008:9). The UNAIDS report (2010:16) noted that sub-Saharan Africa still bore the brunt of the global HIV burden. Although the rate of new HIV infections decreased in this region, the total number of PLHIV continued to rise. In 2009, 22.5 million⁴ people were living with HIV in sub-Saharan Africa. This represented approximately 68% of the total number of people living with HIV (PLHIV) globally. UNAIDS (2010:17) also estimated that 80% of all women living with HIV were living in sub-Saharan Africa (UNAIDS, 2010:17). This clearly indicates the vulnerability of women and female children.

Aside from studies conducted by the Red Cross, Family Health International (FHI) and Doctors without Borders there is a paucity of literature on community involvement in caring for those infected and affected by HIV and AIDS and the origination of community resilience.

In order to mitigate the devastating effects of the AIDS pandemic, people in affected communities provided various community-based programmes such as care and support to OVC with limited resources. Community-driven initiatives seeking to promote empowerment and capacity to respond to the AIDS pandemic fit well within the community resilience framework. As Laundau (1982:15) states, community resilience implies capacity, hope and faith to withstand major trauma and loss, overcome adversity, and to prevail, usually with increased resources.

⁴ However the figure has increased to 25.0 million (UNAIDS, 2012 Global Report).

For the human spirit to prevail across generations, people need to be able to access and utilise their biological, psychological, social and spiritual resources to cope with the impact and immediate consequences of trauma, and to be able to promote long term recovery and healing. Through community resilience a community utilises its strengths and locally available resources to enhance its efforts. For example, a study in Zambia found that primary support for OVC's came from the church, friends and relatives rather than formal organisations. The findings highlighted the need for ongoing support to create, strengthen and sustain social safety nets, community strengths, and the well-being of orphans and other vulnerable children and their families (USAID/Zambia, 2002:9).

Community resilience empowers a community to deal with development challenges in a sustainable manner. Direct community participation, supported by government and other interventions has resulted in the HIV and AIDS epidemics in certain countries in sub-Saharan Africa particularly Ethiopia, Nigeria, South Africa, Zambia, and Zimbabwe stabilising or showing signs of decline (UNAIDS, 2010:25). While communities have taken the initiative and established a bottom-up approach in dealing with OVCs, they need formal assistance which is researched, planned, and monitored.

Figure 1 below, shows that between 1985 and 2001 the percentage of HIV-positive pregnant women increased in South Africa and Kenya, while it reached platos in Botswana and Uganda.

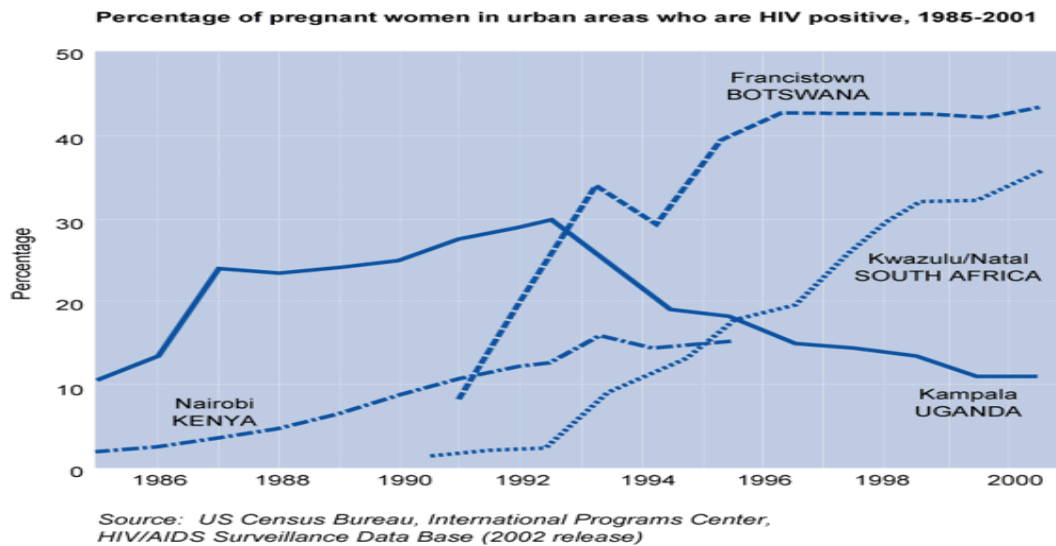


Fig 1: Percentage of HIV-Positive pregnant women in urban areas, 1985-2001, US Census Bureau (2002)

The HIV and AIDS pandemic varies considerably in sub-Saharan Africa, with Southern Africa (KwaZulu-Natal) most severely affected. Approximately 11.3 million people were living with HIV in Southern Africa in 2009. In 2009, sub-Saharan Africa accounted for 34% of the global population of PLHIV, with 31% of new HIV infections and 34% of all AIDS-related deaths occurring in 10 Southern African countries in the same year. Women are often disempowered and subservient in relationships and are therefore more vulnerable to the risk of being infected with HIV due to their position in the relationship to negotiate safe sex. This explains why women who are economically dependent on men are more likely to become HIV positive.

UNAIDS estimated that 320,000 fewer people died of AIDS-related diseases in 2009 than in 2004, when the provision of ARTs was dramatically expanded (UNAIDS, 2010:29)⁵. In the same period, PMTCT resulted in a decline of 32% in the number of children born with HIV and a 26% decline in child mortality. This was most evident in Botswana where only 890 children were born infected with HIV in 2007; a dramatic reduction from 4,600 in 1999. However, South Africa was the exception to the rule, being one of the few countries in the world where child and maternal mortality increased during the 1990s; in 2009, AIDS remained the biggest cause of maternal mortality and accounted for 35% of deaths of children under the age of five (UNAIDS, 2010:29).

⁵ In 2011, there were 33% fewer AIDS-related deaths in Africa than in 2005 and with about 8 million people on HIV treatment (UNAIDS, 2012 Global Report).

1.1.4 South African overview

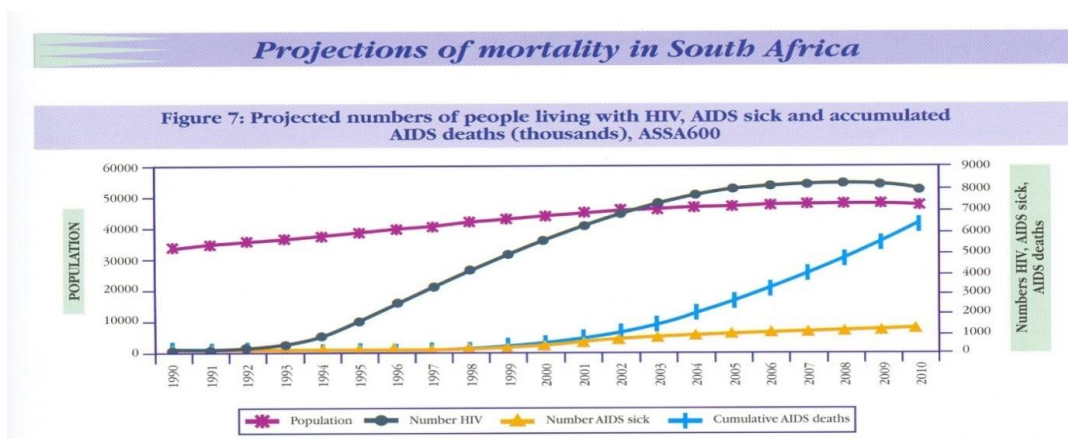


Fig 2: Projected numbers of people living with HIV/AIDS sick and accumulated AIDS deaths (thousands), Source: ASSA

Shisana *et al.* (2008), cited in the South Africa country progress report (2010:20), identified unprotected heterosexual sex as the main mode of HIV transmission in South Africa, followed by mother-to-child transmission (MTCT), intergenerational sex, multiple concurrent partners, low condom use, excessive use of alcohol and the low rate of male circumcision.

As noted earlier, community resilience is a critical strategy in combating HIV and AIDS in countries like South Africa, where the traditional absorption of orphans by the extended family has become more difficult as communities struggle to cope with the increasing burden of HIV and AIDS.

This situation is more severe in the urban areas, where there is less extended family support, high levels of poverty and children living without their parents. People who live in the urban areas have different social, cultural, religious, economic and political backgrounds. Interaction with people from different backgrounds and the increased social and geographical distance from traditional forms of family influence support and control can influence social norms and values (Van Donk, 2002:4). Poverty puts pressure on people to engage in survival strategies that put them at risk of HIV infection, such as prostitution. OVC are at particular risk as they struggle to

augment the family's income and deal with the death of parent(s) without the support of family or the community.

It is against this background that Sinomlando, a project based in Durban, has developed a memory box programme, adapted to the context of AIDS. The aim of the project is to develop resilience in children by working with their (ill) parent(s) to collect special items such as family photos, special letters, family history, jewellery or any other valuable items. These items remain with the child as a reminder of his/her parents. The memory box forms part of the psychosocial support provided to OVC especially during bereavement counselling allows them to reconnect with their past and present and helps them to develop their own resilience (*AIDS Bulletin*, 2004:27-31). This process of reconnection, continuity, and reconciliation mobilises a transitional pathway over many generations into the future. It allows households and the community to access their inherent competence and resilience in order to deal with potentially overwhelming situations (Landau-Stanton & Clements, 1993:17). Therefore, resilience enables the community to live in the past whilst connecting with it in preparation for the future.

The HIV and AIDS pandemic has had a devastating impact on families, communities, the state of the country, and most importantly on children, who are future citizens.

Unless government and other stakeholders intervene and mobilise communities to respond to the psychosocial, health and education needs of OVC, the pandemic will continue to impact negatively on the national economies of Africa. Figure 3 below demonstrates the vicious cycle of the effects of the pandemic on affected children as they are forced to respond to multiple challenges such as providing for and taking care for their (ill) parent(s) at the same time as household income diminishes, since parents are not able to provide for them.

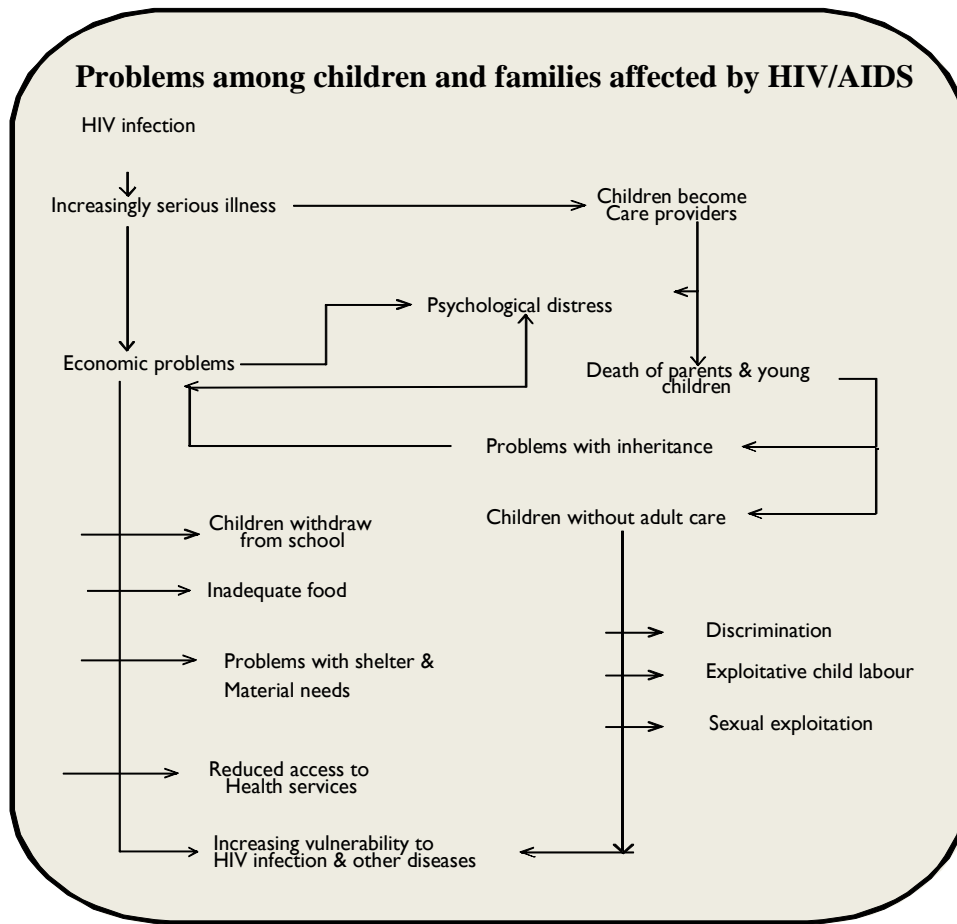


Fig 3: Problems among children and families affected by HIV/AIDS, Source: Williams, 2005

Fig. 3 demonstrates that children affected by HIV suffer poverty, psychological challenges and are vulnerable to HIV infection. Research suggests that children who grow up in poor households are likely to be trapped in a vicious cycle of poverty and are more likely to be infected with HIV (Van Donk, 2002:5). Children who grow up in resilient communities are more likely to develop their own resiliency to respond to such circumstances, although it is regarded “un-educational” for a child to be exposed to such circumstances. Children’s well-being is heavily compromised as they face the possible death of their parent(s). Resilient communities have the capacity to absorb the effects of the pandemic, such as orphanhood, providing support and care to OVC’s.

For instance, they will demonstrate an ability to assume adult responsibilities in the household such as caring for a sick parent, and taking care of their siblings, although this has the potential

to affect their schooling in the long run. It is therefore important that the community provide the necessary adult support for children growing up in such situations. An organisation such as Lithanza Community Development Association (LCDA) provides such support to children in order to harness and develop their own resiliency. Bonnie (1991:4) stated that commonly identified attributes of resilient children include responsiveness, flexibility, empathy and caring, communication skills, a sense of humour, and other pro-social behaviour. Bonnie (1991:3) adds that, to be successful, prevention interventions should focus on enhancing and creating a positive environmental context - family, schools, and communities reinforcing positive behaviours. Resilient communities tacitly influence other sectors of the community such as schools to develop their own resiliency. "A school can serve as a protective shield to help children withstand the multiple vicissitudes that they can expect of a stressful world" (Bonnie 1991:3). In support of this view Dlamini (2004:38) maintains that schools and communities can help develop resiliency in children by:

- a) providing a caring and supportive environment;
- b) setting and communicating high and clear expectations;
- c) providing opportunities for meaningful participation;
- d) increasing bonding;
- e) teaching life skills;
- f) setting clear and consistent boundaries.

The high levels of stigmatisation and politicisation attached to HIV and AIDS in South Africa in previous years have declined somewhat and the country has recorded significant progress relating to HIV and AIDS policies and programmes. For example, in 2007 the National AIDS Council was revamped into a multi-sectoral institution providing high level leadership and coordination. It is chaired by the Deputy President of South Africa, with a Deputy Chairperson from civil society. The comprehensive plan for the management, treatment, care and support for AIDS was developed with an increased domestic budget to support HIV and AIDS programmes (UNAIDS, 2010:1).

It is hoped that such political leadership, comprehensive programme design and implementation will mitigate the impact of the HIV and AIDS epidemic on vulnerable groups in society, especially children.

Resilient communities are characterised by protective factors such as caring and support, high expectations and participation to exert direct influence on the youth to choose a safe lifestyle, especially in the context of vulnerability. Such youth will be able to engage in activities that will stop the spread of the AIDS pandemic (Iscoe, 1974:607-613). It is the researcher's view that (youth) resiliency has contributed significantly to a reduction in HIV prevalence among young people. The family, school and community play critical roles in increasing children's resiliency. This is crucial for children who grow up in the context of the AIDS pandemic, as discussed in previous sections.

1.2 PURPOSE OF THE STUDY

The purpose of this study was to explore and attain an in-depth understanding of community resilience strategies on the challenges faced by OVC affected by HIV and AIDS between the ages of 13-15 years in Benoni, Ekurhuleni Metropolitan Municipality (EMM), Gauteng Province.

1.3 OBJECTIVES OF THE STUDY

- a) To explore community understanding of HIV and AIDS and its impact on the Benoni community.
- b) To explore the specific challenges experienced by OVC in Benoni.
- c) To understand community resilience related to OVC affected by HIV and AIDS in Benoni.

1.4 RESEARCH QUESTIONS

- a) What is the nature of the Benoni community's understanding of HIV and AIDS and its impact on the community?
- b) What specific challenges are faced by OVC in Benoni?
- c) How does community resilience related to OVC assist the community to address some of the challenges confronting OVC in Benoni?

1.5 SIGNIFICANCE OF THE STUDY

Community resilience has been associated with community responses to:

- a) Major natural disasters such as cyclones,
- b) in the context of national security,
- c) supernatural events with an unexpected major impact on the general community;
- d) families struggling to respond to a particular situation, for instance families living with an alcoholic; families with a member living with a disability, such as a child with hearing loss.

However, since the child-headed family grew and developed out of the HIV and AIDS pandemic in this country there is a paucity of studies that have documented community resilience strategies as a response to the challenges faced by OVC affected by HIV and AIDS in South Africa.

The researcher (a development practitioner with a special interest in community resilience and community development programmes) strives, through this study, to add scientific value and contribute to ongoing research on community resilience strategies and community-based models in OVC programming. De Haan *et al.* (in Moss, 2010:6) note that research on resilience is important as it can assist service providers to identify factors that are instrumental in shaping adaptive pathways and to design appropriate interventions.

1.6 STUDY ORIENTATION

Evidence indicates that caring for OVC affected by HIV and AIDS places an additional burden on the already overstretched welfare sector and drains state resources. For instance, in 2003, the Department of Social Development (DSD) acknowledged that the current social services system cannot cope with the large number of children who are in need of care and support as a result of HIV and AIDS (UNICEF, 2003:33).

The AIDS pandemic affects children intensely through its devastating impact on their parents and communities in addition to their own risk. In addition to the trauma of watching their parents die, children also often experience the stigma that communities and even relatives attach to this particular disease. Due to limited survival options, children growing up in such a situation face the risk of exploitation, abuse and consequently of becoming infected with HIV themselves (Red Cross, 2007:01).

A situational analysis of OVC in four districts in South Africa (Skinner & Davids, 2006:10) found that there was a rapid increase in the number of child-headed, parentless households, and a correlation between poverty and orphanhood. These challenges forces communities to rely on their own initiative to deal with this phenomenon with limited resources and government support.

1.7 PROBLEM STATEMENT

It is estimated that there are 1.91million⁶ AIDS orphans in South Africa - close to half of them have lost their parents to AIDS-related diseases and there are many more children living with sick and bedridden caregivers. About 150,000 children are believed to be living in child-headed households (UNICEF, 2012 and Statistics South Africa, 2009:8);). Due to the impact of the AIDS epidemic, caring for OVC has become one of the critical challenges facing South Africa to day, with Ekurhuleni Metropolitan having the second highest number-21,403 of maternal orphans in Gauteng (DSD, 2010a). Clearly, this demonstrates the destructive nature of the AIDS

⁶ However, this figure has grown to 3.7 million orphans according to the UNICEF, 2012 Report.

epidemic to the family systems, which have been completely overwhelmed by the growing number of OVCs that need to be taken care of. Support systems, such as the extended family, are taking strain and this spills over to the community that serves as safety net for OVCs. The extended family and the community are the most important sources of support for children who have lost their parents to AIDS or other illnesses. OVC support programmes are mainly initiated by community-based organisations, faith-based organisations and non-governmental organisations (UNICEF, 2003:33).

Therefore, this study examines community responses to challenges faced by OVC affected by HIV and AIDS in Benoni. This will be investigated by exploring community interventions in OVC programmes. LCDA is a community-driven initiative established to respond to such challenges, and will form part of this explorative research.

1.8 STUDY SITE

Benoni is situated in EMM in Gauteng province. EMM was established in 2000 as one of six metropolitan municipalities as a result of the restructuring of local government. Ekurhuleni accommodates a population of approximately 2.8 million, which constitutes about 5.6% of the national population and makes up 28% of the Gauteng population. The population density is approximately 1,425 people per km², making Ekurhuleni one of the most densely populated areas in the country and the province. The average population density in Gauteng is 605 people per km², and it is 40 people per km² for South Africa as a whole (Ekurhuleni Growth and Development Strategy, 2011).

Ekurhuleni's economy is larger and more diverse than other municipalities in Southern Africa, with a total annual budget of R21 billion. It accounts for nearly a quarter of the Gauteng economy which, in turn, contributes more than a third of the national Gross Domestic Product. Ekurhuleni contributes approximately 7% to the country's spending power and about 7.4% to national production (Ekurhuleni, 2011:28).

EMM is a modern urban area, with modern infrastructure such as a well-maintained road network, airports, railway lines, telephones, electricity and telecommunications on a par with

developed countries, and supporting a well-established industrial and commercial complex (Ekurhuleni, 2011:34).

Despite its modern economy and sophisticated infrastructure, approximately 27% of the local population is living in poverty, with a 27% unemployment rate. The majority of the municipality's inhabitants live below the poverty line on the urban periphery, far from job opportunities and social amenities and with limited transport facilities. Many people in Ekurhuleni still live in overcrowded informal settlements without adequate access to social infrastructure and with limited access to emergency services (Ekurhuleni, 2011:14).

EMM is known for its gold mining activities which attracted migrants from different parts of South Africa and neighbouring countries. The adverse impact of the migrant labour system cannot be underestimated in disrupting the family system, particularly in the apartheid South African context, where men were forced to move to urban centres on their own in search of work, leaving their partners and families in the rural areas and only returning home periodically depending on the distance involved. Research suggests that people in such situations are more likely to have multiple concurrent sexual partners, thus exposing their partners to HIV infection (Lurie, Williams, Zuma, Mkaya-wamburi & Garnet, 2003:17).

As depicted in Figure 4 below, the district with the majority of maternal orphans in Gauteng in 2009 was the City of Johannesburg Metropolitan Municipality at 29%, followed by the EMM at 25%. Together these districts are home to approximately 54% of the Gauteng's maternal orphans.

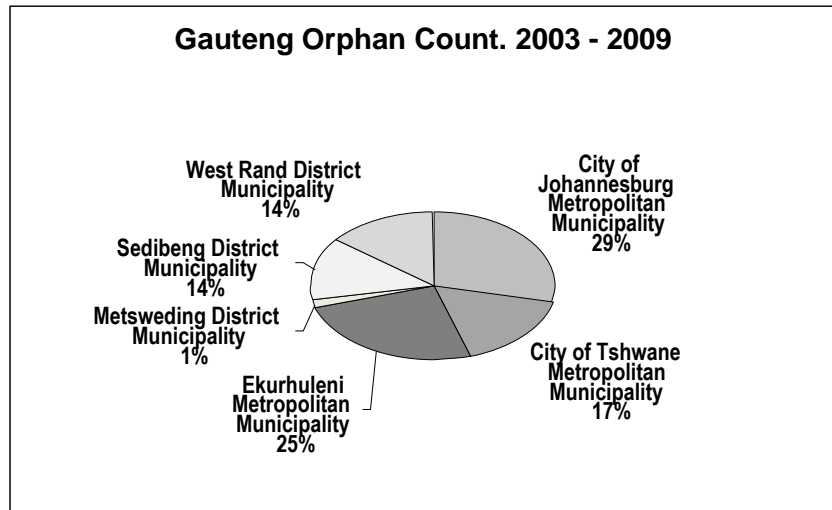


Fig 4: Gauteng orphan distribution, Source: Department of Social Development, 2010a

There was a sharp increase from 16,423 orphans in 2003 to 21,403 in 2004 (DSD, 2010a). HIV prevalence (34.0%) in EMM is higher than the average (30%) for Gauteng (Department of Health, National Antenatal Sentinel HIV; Syphilis Prevention Survey 2010:42).

Challenges experienced by poor communities include the following:

- a) HIV and other poverty-related diseases, such as TB (all strains),
- b) Inequitable access to health care facilities (Ekurhuleni, 2011:15).
- c) The challenge of caring for OVC.
- d) High rates of infant and child malnutrition, as well as crime and domestic violence (Ekurhuleni, 2011:16).

Against this background, the LCDA, hereafter referred to as the “community” was established in March 2004 as a community-based intervention to empower the community to directly respond to the AIDS pandemic; with a special focus on OVC and the elderly who provide care and support to their grandchildren in Benoni. The organisation also provides basic services to the Wattville community and two informal settlements outside Benoni.

This study will focus on OVC-related services and programmes such as:

- a) The drop-in centre
- b) Material support, food parcels and house visits

- c)The school holiday programme
- d)The child care forum (CCF).

It is in this context that the research study will explore community resilience initiatives addressing OVC challenges in Benoni.

1.9 RESEARCH DESIGN AND METHODS OF THE STUDY

A detailed description of the research methods used in this study is covered in chapter three. This section, however, is a preliminary overview of the research design and methods that were used in this study.

This research study employed qualitative methodological approaches with a view to explore and understand community resilience strategies responding to the challenges faced by OVC affected by HIV and AIDS in Benoni.

This research study is based upon fieldwork consisting of interviews with nine (9) key informants, being the social worker; community leaders; two schools teachers and community members, Five OVC, eight guardians and two focus groups of learners (5) in each group from, two schools using purposive sampling methods (non-probability). In total thirty two (32) people participated in this study. A combination of data collection techniques was used with a structured research guide.

1.10 OPERATIONAL DEFINITIONS

For the purposes of this study the following terms and concepts are defined:

Child

Any person under the age of 18 years (DSD, 2005:12).

Child Care Forum

A forum consisting of a locally-based organised group which is committed to caring for children within the local community established in line with DSD guidelines (2005:5).

Community Resilience

Community resilience is a multidimensional construct used to describe a community's ability to strengthen its response to deal with crises or disruptions in its midst. Such crises may be current, anticipated, or unexpected. A resilient community becomes proactive and establishes solidarity with an expectation of positive growth (Wyche, Pfefferbaum, Norris, Wisnieski, & Younger, 2011:18). Wilson (2009:25) defined community resilience as the capacity to forge solidarity, to sustain hope and purpose and to adapt and negotiate creatively with the challenges presented. The local collective becomes pro-actively engaged in purposeful ways that help them recreate a sense of place, at homeness and voice.

Kulig *et al.* cited in Wilson (2009: 61) further developed this definition by arguing that the goals of community resilience are broad in order to meet various community needs and may include problem solving, inter-agency relationships, resource acquisition, policy development and implementation, and communication.

For researchers such as Gurwitch, Pfefferbaum, Montgomery, Klomp, & Reissman (2007:61-62) resilient communities are mainly characterised by [inter]-connectedness, commitment, and shared values among community members; participation by community members in the affairs of the community and support and nurturance of the needs of community members.

The above definitions fit the context and description of a community struggling to provide for OVC with limited resources and also provide a theoretical base for community participation and empowerment.

Orphans and Vulnerable Children

The DSD (2005:5) defines an orphan as a child less than 18 years of age whose mother, father or both parents have died from any cause of death and can be distinctively defined as a:

- Single orphan- a child who has lost one parent
- Double orphan- a child who has lost both parents

- Maternal orphan- a child whose mother has died (includes double orphans)
- Paternal orphan- a child whose father has died (includes double orphans)

For the purposes of this research an orphan refers to a child under the age of 15 years who has lost both parents. A vulnerable child refers to a child whose parents or guardian is so chronically ill that they cannot provide for him/her.

Resilience

“Resilience refers to a dynamic process encompassing positive adaptation within the context of significant adversity” (Luthar, Cicchitto, & Bekcker, 2000:543). Green (2007:25) observed that resilience entails *more* (emphasis mine) than merely surviving, getting through, or escaping a harrowing ordeal. Masten (2001:227) describes resilience as a dynamic process, encompassing positive adaptation of the individual within the context of significant adversity, and adds that this same adversity can result in different outcomes. Similarly, Saleebey (in Moss 2010:25) defines resilience as the ability to bear up in spite of those ordeals.

Common elements arising from these two views of resilience, is that, though the process initially requires a state of adaptation and/or survival (getting through a harrowing ordeal), it also requires meaningful directional action and implicitly strengthens the individuals involved at a psychological level (by ‘bearing up’).

Vulnerability

Harvey (2003:31) defines “Vulnerability as a degree of exposure and sensitivity to livelihood shocks; or, in short, living on the edge”. For the purposes of this study vulnerability is defined with specific reference to children who are affected by HIV and AIDS and/or are exposed to multiple risks such as neglect, exploitation and who may have limited access to social services (Richter, Manegold & Pather, 2004:4).

Community-based Organisation

This refers to an organisation established by the local community to address or respond to a specific situation or challenge, whose leadership usually emanates from the same community.

1.11 OUTLINE OF THE STUDY

Chapter 1

Chapter 1 introduces the study, provides background information, states the aims and objectives of the study, describes the significance of the study, defines the problem statement, provides information about the study setting, lists operational definitions and outlines the structure of the thesis.

Chapter 2

Chapter two focuses on a review of the relevant literature on challenges faced by OVC and the conceptualisation of community resilience.

Chapter 3

Chapter 3 outlines the research methodology, the design of the study, data collection methods, data analysis, reliability and validity and ethical considerations. It concludes with the limitations of the study.

Chapter 4

The research findings are presented and analysed in Chapter Four.

Chapter 5

Chapter 5, the final chapter, consists of a summary of the findings, recommendations and conclusion/s.

1.12 CONCLUSION

The conclusion provides a background to the problem and contextualises the problem in the global context. The following chapter will provide a literature review, focusing on the challenges faced by OVC and the meaning of community resilience.

CHAPTER 2: LITERATURE REVIEW AND THEORETICAL FRAMEWORK

2.1 INTRODUCTION

Chapter 2 explores the current literature pertaining to the impact of HIV and AIDS on children, with specific reference to the impact of HIV and AIDS on OVC, challenges experienced by OVC, current legislation/policies pertaining to OVC, the rights and needs of children and government intervention to protect OVC. The literature review will assist the researcher to contextualise the challenges faced by orphans in Benoni in the global context, to draw similarities and appropriate lessons and locate such lessons within the community resilience framework.

2.2 IMPACT OF HIV AND AIDS ON CHILDREN IN SELECTED REGIONS

The impact of HIV and AIDS on children varies according to different regions. For instance, in India the HIV and AIDS pandemic shows signs of abating; the HIV prevalence among adults aged 15-49 years was 0.34% in 2007 and has decreased to 0.29% in 2009. It was estimated that about 2.27 million people were living with HIV in India in 2008 (India Country Progress Report 2010, UNGASS).

Interestingly, the AIDS epidemic in India is not generalised; as a result the concept of OVC as described in the sub-Saharan African context is not applicable. Instead India has jointly adopted the preferred terminology of children “affected” by AIDS (CABA) with the national AIDS control organisation (NACO), UNICEF and other development partners (India Country Progress Report, 2010:55, UNGASS). There are no reliable official data documenting the number of “affected” children (orphans) in India; however a UNICEF report estimated that approximately 1,500,000 children had been orphaned by AIDS; and 7,000,000 children lived with HIV-positive parents (vulnerable children) in 2009. This lack of reliable data on OVC could be due to the fact that the impact of the AIDS epidemic has not begun to fully emerge in India (www.crossroadsinternational.org).

Yet, it is estimated that India has the largest number of AIDS orphans in the world and this number is expected to double in the next five years. UNICEF (2011:14), estimate that children of parents living with HIV in India are heavily discriminated against and denied access to basic amenities, especially health and education services.

India, thus, in addition, has a grave problem of fostering and condoning child prostitution and trafficking. Child prostitution is socially acceptable in some sections of Indian society through the practice of *Devadasi*. Young girls from socially disadvantaged communities are given to the 'gods' and they become "religious prostitutes" (Sterlace-Accorsi, 2011). According to statistics, there are approximately 11 million children live or work on the streets of India. These children are involved in commercial sex, crime, gang-related violence and drug trafficking. Such ingrained practices have attracted criticism from other cultures, particularly Western cultures (Consortium for Street Children, 2009:4).

It can be argued that, although India has a lower HIV prevalence amongst the adult population than most countries in sub-Saharan Africa, the country is confronted with multiple challenges affecting children such as AIDS-related stigma and discrimination, poverty, illiteracy, child labour, child prostitution, street children and the emergence of child-headed households. To date there is no empirical evidence suggesting a causal link between these challenges and the AIDS epidemic in India.

In Brazil about 630,000 people was living with HIV and AIDS in 2006. HIV prevalence among the general population remained stable at around 0.6% from 2004, with a 0.4% infection rate among women and 0.8% among men. It was estimated that about 217,091 people died from AIDS-related illnesses between 1980 and 2008. There are no official data on the number of children orphaned by AIDS in this country (Brazil Country Progress Report, 2010:13, UNGASS) The children's rights portal (2012) estimates that there are approximately 3.2 million orphans in Brazil. As in other countries, Brazilian children are confronted with a range of challenges, including poverty, child labour, child marriages and violence.

Children from poor families suffer poverty, lack of access to health care and water, and starvation. Poverty compels children to drop out of school early and seek employment in order to augment the household's income. It is estimated that 25 to 30% of Brazilian children are employed in agricultural areas, particularly on sugarcane plantations, and in coal mines; more than 400,000 children are employed as domestic workers. North Brazil is infamous for its poverty. In this region, children often live on the streets and are confronted with violence on a daily basis. The environment in which they live is deplorable, with child trafficking, drugs, prostitution, hard labour, begging, and sexual exploitation representing daily challenges (Children's Rights Portal, 2012).

A recent study revealed that 36% of young Brazilian woman are married before the age of 18; such marriages have adverse health and psychological effects on young girls as they are often raped and frequently become victims of sexual exploitation. Brazilian children are exposed to gangs, rape, prostitution, and sexual exploitation; children as young as five years play the role of messenger between dealers and are therefore familiar with gang life from a very young age (Children's Rights Portal, 2012).

2.3 IMPACT OF HIV AND AIDS ON ORPHANS AND VULNERABLE CHILDREN

“AIDS today in Africa is claiming more lives than the sum total of all wars, famines and floods and the ravages of such deadly diseases as malaria...” Nelson Mandela (Closing address at the 3th International Aids conference, Durban: 2000), stated. Because those dying from AIDS are often parents, who leave behind vulnerable children and orphans.

In sub-Saharan Africa, 2.3 million children were living with HIV in 2009 (UNAIDS, 2010). It was further estimated that South Africa had about 1.91 million AIDS-related orphans (Statistics South Africa, 2009:8); a comparison with other African countries is provided in Table 1 below. It shows that there is considerable variance in the number of orphans in sub-Saharan African countries. While the number of orphans exceeds one million in some countries, in others, children who have been orphaned by AIDS comprise half or more of all orphans nationally. In some countries, a larger proportion of orphans lost their parents to AIDS than to any other cause

of death - meaning that, were it not for the AIDS pandemic, these children would not have been orphaned (UNICEF/UNAIDS, 2010).

<i>Number of AIDS orphans in 2009</i>	
Nigeria	2,500,000
South Africa	1,900,000
Tanzania	1,300,000
Uganda	1,200,000
Kenya	1,200,000
Zimbabwe	1,000,000
Zambia	690,000
Mozambique	670,000
Malawi	650,000

Table 1: Number of AIDS orphans in 2009, Source: UNICEF/UNAIDS: 2010

“Neither words nor statistics can adequately capture the human tragedy of children grieving for dying of dead parents, stigmatised by society through association with HIV and AIDS, plunged into economic crises and insecurity by their parent’s death and struggling without services or support system in impoverished communities” (Van Den Berg, 2006:24).

The figure below depicts the geographic spread of maternal orphans in South Africa from 2003 to 2009. According to a study conducted by the DSD (2010a) there were approximately 905,453 maternal orphans by the end of 2009 in South Africa.

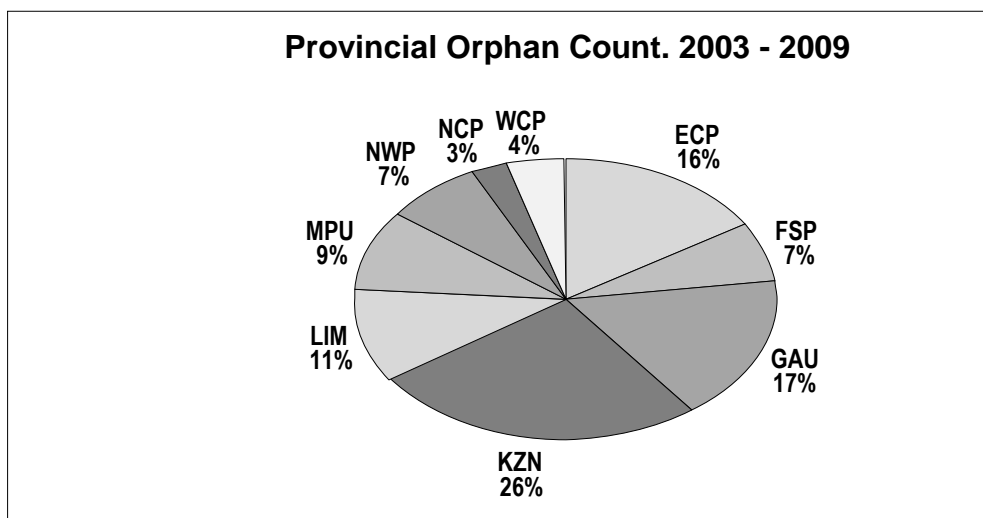


Fig 5: Geographic spread of maternal orphans, Source: Department of Social Development 2010a

These maternal orphans account for about 4% of all children living in South Africa. Data on the number of paternal orphans is scarce, because, at present, recording the father's death on a child's birth certificate is optional in South Africa. Despite this limitation, the data on maternal orphans provide a clear picture of the challenge of orphanhood in South Africa. It is important to examine the nature and extent of maternal death as this impacts on a child's well-being and living conditions.

Levine (2001:23) argues that AIDS has not only altered the demographics of society, but has denied children the opportunity to be raised by their biological parents. Poor communities are often compelled to find alternative arrangements to mitigate these challenges. As children face increased vulnerability, the response to HIV and AIDS shifts increasingly to a long term challenge of poverty reduction, human development and social protection. There is a direct relationship between poverty and HIV/AIDS as the poor are the most vulnerable to HIV and AIDS (Van Donk, 2002:4). This is despite the government's attempts to develop pragmatic policies and programmes to protect OVC against poverty.

Key amongst such policies is child support grants, nutritional support for learners and the adoption of no fee public schools. Unfortunately, these programmes, whilst well-crafted, often don't reach OVC, as they are undermined by bureaucratic delays, poor coordination; lack of

capacity and budgetary constraints at the national and provincial government levels. This undermines and frustrates programme implementation at the community level.

Traditionally, in African societies the responsibility for taking care of children has always been shared with the extended family, such as the deceased father's nearest male relative, such as a brother or a nephew, inherits the deceased's wife and children. Similarly, if a mother dies, the husband would marry a close female relative of the deceased, who would then be obliged to regard any of his children as her own (UNICEF, 2003:15). Forster (2000:56) argues that in the past, the sense of duty and responsibility of extended families towards family members was almost without limit. Traditional African life was based on the spirit of "*ubuntu*", characterised by brotherhood, a sense of belonging to a large family, and by groups rather than individuals ("through the group the individual obtains his/her identity" (Eze, 2008: 388). The extended family provided a sense of security and support and shared assets. Even though a family might not have sufficient resources to care for its existing members, orphaned children were taken in through the principle the sociologist's principle and interpretation of altruism (my interpretation). Hence the famous African saying "there is no such thing as an orphan in Africa" (Van Den Berg, 2006:44). "It takes a village to raise a child", says the African proverb. African tradition dictates that the child belongs to the community and therefore the responsibility to raise and provide for children is a shared responsibility.

Another traditional way in which children have moved between households is through fostering. In many sub-Saharan African countries it is common for children to be raised away from home, either by relatives or non-relatives. Parents may choose this option because they are unable to take care of their children themselves, or to save money, or provide the children with better economic opportunities, particularly education. The foster family also gains from this arrangement, especially if it does not have its own biological children or they are looking for extra hands to assist with domestic chores. In some sub-Saharan African countries a high proportion of children, 20% or more, may not be living with their parents (UNICEF, 2003:15).

Unfortunately, due to the impact of the AIDS pandemic and Westernisation of traditional African societies, such long-standing community coping mechanisms are collapsing (Barnett &

Whiteside, 2003:197). Extended families are mostly unable to support orphans. “In the past, people used to care for orphans and loved them, but these days, they are so many, and many people have died who could have assisted them, and therefore orphan hood is a common phenomenon, not strange, the few who are alive cannot support them,” observed a widow in Kenya (cited in UNICEF, 2003).

Other broad factors that contribute to the weakening of the extended family coping mechanism include the effects of labour migration, the cash economy, demographic change and urbanisation (Van Den Berg, 2006: 45). It is the researcher’s view that orphans growing up in urban communities are more disadvantaged compared with their counterparts in the rural areas, where they can still rely on the extended family and some form of traditional lifestyle, albeit in a limited way.

2.4 CHALLENGES CONFRONTING ORPHANS AND VULNERABLE CHILDREN

The nature of childhood

“Childhood should be a happy time for all children. It should be a time when children have opportunities to grow, learn and develop; receive love and care; play freely and be active; feel safe and protected; be healthy; and be listened to when they share their views on matters that are important to them” (Xingwana, 2011), therefore without burdens such as HIV and AIDS causing their parents to die (my interpretation).

Death as a common experience

Desmond & Gow (2002:3) argued as far back as 2002 that every child in South Africa would feel the impact of HIV and AIDS. As [uninformed] parents, other family members, teachers and at times their peers, died, they would grow up in a society where death is a common experience, affecting them emotionally, economically and psychologically. More than a decade later, this prediction has come true. OVC’s are confronted with a range of interrelated socio-economic and psychosocial challenges; for the purposes of this study, the researcher will focus on the following broad challenges:

2.4.1 Economic Deprivation and Schooling

Research by Davids, Nkululeko, Mfecane, Skinner & Ratale, (2006: 2), indicated that challenges to the orphan(s) commence before the death of a parent or both parents, as the household's ability to provide care and support is undermined. In countries badly affected by the AIDS pandemic, household income with parental HIV and AIDS infliction has been found to be 20-30% lower than those with non-afflicted parents. A study conducted in Welkom (Skinner *et al.* (2006)) found that the average monthly *per capita* income in households where at least one person was known to be HIV-positive was less than half the income of non-affected households (R335 *versus* R741). This demonstrates that households affected by HIV and AIDS are more likely to experience food insecurity; show a tendency to borrow money and sell more of their productive assets which are essential to sustain their livelihoods (UNICEF, 2003:17 citing Booyesen, 2002). The situation is worse in women-headed households as they are likely to experience severe food shortages. Women's lack of property and inheritance rights in many African countries results in property grabbing - a phenomenon common in most sub-Saharan African countries - makes them and their children more vulnerable to HIV, poverty and poor nutrition (UNICEF, 2003:20; Red Cross, 2007:13).

Barnett & Whiteside (2002:202) maintain that economic deprivation, in the broader sense, may result in disrupted schooling, which leads to early school drop-out due to lack of basic necessities such as school fees, uniforms and adequate food. Children whose parent/s are infected with HIV and AIDS are less likely to have proper schooling, due to dwindling/disappearance of household income due to parental death, orphans are placed in extended families and the primary care giver caring for the orphan is mostly not able to pay for school fees and basic necessities.

Additionally, orphans may lose the right to property inheritance and in many cases are forced to work in order to augment the household's income. UNICEF (2003:27) reported that a survey conducted in Uganda found that 26% of older children staying with parents living with HIV and AIDS said that their attendance at school had declined, citing the need to stay at home to care for sick parents, increased household responsibilities and falling household incomes.

2.4.2 Children Assuming Adult Responsibilities

Gumede (2009: 21) argues that when the health of HIV infected parent/s begins to fail, the basic needs of the children may be seriously compromised, as the parent loses his/her job due to bad health and or household income is redirected to medical care. In such a situation the child will be forced to take care of the ill parent. Role reversion is common, since older children may have to assume the responsibility of taking care of the ill parent and perform other general household and child care responsibilities. This is known as *child-headed households* and may lead to a vicious cycle of socio-economic and psychosocial problems. Many parents find it difficult to share the seriousness of their illness with their children due to stigma, fear and the rejection associated with HIV and AIDS, having a vast psychological impact on children causing anxiety, depression and confusion, depriving children of the opportunity to prepare for the death of their parent (Red Cross, 2007:11). In view of this, communities are compelled to provide a wide range of services including home-based care, treatment and support to families and caregivers. Allowing children to care for their ill parent (s) is common in the context of the AIDS pandemic. Child-headed households provide an alternative form of care and support for children and, with sufficient community support, may prove to be a viable option.

Possible benefits for children include the following:

Firstly, children will have an opportunity to stay together as they may not want to be *separated* from their siblings and are not forced to go to an *orphanage*. One study in South Africa, for example, demonstrated that child-headed households are formed when brothers and sisters insist on staying together and refuse to leave their deceased parents' home (Maqoko, 2006:724). Research in Zimbabwe has also indicated that child-headed households are more frequently established if there is a child considered capable of caring for his/her siblings, or if a close relative is living nearby that can provide 'supervision' and control (UNICEF, 2005:17).

Secondly, although orphanages may seem a logical solution to growing orphan populations and may also be appealing because they can provide food, clothing, and education, orphanages often fail to meet young people's emotional and psychological needs (UNICEF/UNAIDS/USAID, 2006:19). This failure, and its long-term corollaries, supports the conclusion of an early study in

Zimbabwe that countries – and children – are better served by programmes that “keep children with the community, surrounded by leaders and peers they know and love” (Powell & Moirrerera, 1994). Community members know best who are the OVC, what their needs are and through a process they identify them and build their capacity to improve their well-being responsibility and ownership, stigma attached to being an “AIDS orphan” is decreased and their needs are attended to (FHI & USAID 2001:11).

Thirdly, children may establish their own child-headed households out of fear of being mistreated or exploited in foster families. This fear is not groundless, as a study in Tanzania showed that 50% of foster parents accepted orphans because they wanted to employ them as domestic workers (UNICEF, 2006:30). There is also some evidence that orphans may experience discrimination within the household. A recent study in Mozambique documented discrimination in allocation of resources in poor households against children who are not direct biological descendants of the household head (Ibid, 13).

2.4.3 Stigma, Discrimination and Exploitation

Gumede (2009:23), citing Richer *et al.* maintains that children whose parents are presumed to have died due to AIDS related-illness are often thought to be HIV-positive themselves and are consequently stigmatised, adding to their low self-esteem and resulting in social exclusion. As one 16-year-old girl put it: “*They treat you badly. You don’t feel like walking in the street, they give you names. They whisper when you pass. They take it that when one person in the house is sick, all of you in that house are sick*” (World Bank, 2006:04). Labelling of orphans is very common, especially in poor communities, and may cause long term psychological effects.

Another source of trauma for orphans is separation from their siblings. Even older children are distressed by separation. In a study conducted among a group of older orphans in Uganda who had been separated from their siblings, 44% said that they felt sad about the separation and 17% per cent said it made them feel isolated (UNICEF, 2003:31).

Exploitation is another concern, especially in sub-Saharan Africa, which already has a higher proportion of children working than any other region; 29% of children aged 5 to 14 are economically active. As their parents become progressively more ill due to HIV and AIDS, children take on an increasing number of responsibilities. Girls take responsibility for more household chores, while boys take over agricultural tasks or bring in an income by working as street vendors (UNICEF, 2003:29).

Physical and sexual abuse is also common among orphans in extended families where the limits of care and support have been exceeded. In some instances, children are not taken in by relatives and they end up heading their own families. Others opt to move to town and start working as “house girls”, or even commercial sex workers (Nasaba, Defilippi, Marston, & Musisi 2006:6). A rapid assessment in Zambia in 2002 found that children of 15 years old were engaged in prostitution; almost half (47%) had lost both parents and 24% had lost one parent. The need to earn money was the main reason given for entering prostitution. Their daily earnings ranged from 3,000 to 33,400 kwachas (about \$0.63 to \$7); the majority, especially the younger children, rarely made as much as 10,000 kwachas (\$2.10). On average, the children slept with three to four clients each day (UNICEF, 2003:30).

2.4.4 Psychological Effects

Children react to stress in different ways. Many will find it difficult to talk about their worries and feelings. They may internalise their feelings, believing that they are abnormal in some way, and suffer from low self-esteem, depression or anxiety, and become aggressive, abuse drugs and alcohol, or engage in anti-social behaviour (UNICEF, 2003: 32). Gilborn *et al.* cited in Gumede (2009:4) found that 40% more orphans suffered from post-traumatic stress with clinical symptoms such as withdrawal from society; feelings of guilt; low self-esteem; aggression; anxiety and depression than other children. Children who are abandoned by their extended family tend to become street children and engage in antisocial behaviour or prostitution, as previously discussed. This places them at high risk of HIV infection. In the absence of adequate social welfare structures this can lead to juvenile crime.

2.5 CHILDREN LIVING ON THE STREETS

“The AIDS epidemic has vastly increased the number of orphans in Africa; caring for them in the extended family is desperately hard. Levels of care are variable, and some end up on the streets of the cities, hardly a preparation for the future as a member of a households or community, least of all as citizens. As these orphans grow into youth and adulthood, deviant behaviour causing disruptive societal order in the context in which the way they will live their lives (my insertion)” may emerge (Bray, 2003:07). Children find their way onto the streets because of multiple survival deprivation such as poverty, overcrowding, abuse, neglect, family disintegration and HIV and AIDS (Consortium for Street Children, 2011:13; DSD, 2010b:5).

Street children are the most vulnerable category of children at risk, as they are exposed to assaults such as rape and prostitution that make them more vulnerable to HIV and other related diseases. They are equally the most marginalised in society due to their family background, because most might have lost their parents due to AIDS (Lefeh, 2008).

Although anecdotal evidence (UNICEF) suggests a global increase in the prevalence of street children, it remains difficult to estimate numbers, although it might run into tens of millions across the world. In 2011, the Consortium for Street Children indicated that UNICEF estimated that about 100 million children were growing up on urban streets around the world (Consortium for Street Children, 2011:4). *It is outside the scope of this study to attempt to formulate a correct definition of the concept of street children.*

The challenges confronting street children in South Africa are similar to those experienced in Brazil and India; poverty, prostitution, abuse and violence, family destruction due to AIDS and vulnerability to contracting HIV and AIDS (Bray, 2003).

2.6 POLICIES PROTECTING CHILDREN IN SOUTH AFRICA

In order to protect the rights of children and to address the challenges they face, particularly OVC the South African government has adopted a series of legislative and policy measures.

2.6.1 Rights and Needs of Children

The challenges identified in the previous sections directly violate the basic rights of children as guaranteed in the South African (SA, 1996) constitution - Chapter two, section 28 (1), which states that every child has the right to:

- a) A name and nationality from birth;
- b) Family care or parental care, or to appropriate alternative care when removed from the family environment; to basic nutrition, shelter, basic health care and social services;
- c) Be protected from maltreatment, neglect, abuse or degradation;
- d) Be protected from exploitative labour practices; not to be required or permitted to perform work or provide services that are inappropriate for a person of that child's age, or place at risk the child's well-being, education physical or mental health or spiritual development, moral development or social development. Children's best interests are of paramount importance in every matter concerning the child.

The South African policy framework for orphans and other children made vulnerable by HIV and AIDS (2005:11) states that the South African government is a signatory to international conventions such as the Convention on the Rights of the Child and the African Charter on the Rights and Welfare of the Child.

Based on these conventions, children's rights are underpinned by four major principles:

- a) The right of the child to survival, development and protection from abuse and neglect.
- b) The right to have a voice and be listened to.
- c) That the best interests of the child should be of primary consideration.
- d) The right to freedom from discrimination.

Children's basic rights and wellbeing are constitutionally protected and include psychosocial and material needs. In order to give meaning to the children's rights enshrined in the constitution, the South African government has passed a series of laws and enacted programmes to protect OVC.

Cited by the South African Policy Framework for Orphans and other Children made Vulnerable by HIV and AIDS (2005), and the Presidency (Republic of South Africa, 2009:5), the Social Assistance Act (Act No. 13 of 2004) provides for social and financial assistance (children's grants) to children upon fulfilment of certain criteria as amended in 1997; the Child Care Act (Act No. 74 of 1983) and the Child Care Amendment Act (Act No. 96 of 1996) that deals with the protection of children; the South African Schools Act (Act No. 84 of 1996) that makes school attendance compulsory for learners between the ages of 7 and 15 years, and provides for learners such as OVC to be exempted from paying school fees; the National Health Act (Act No. 61 of 2003) that provides for free primary health care for children under the age of 6; and the Medical Schemes Act (Act No. 131 of 1998) protects children and/or their care givers against unfair discrimination based on their HIV status.

2.6.2 Government Intervention to Protect Orphans and Vulnerable Children

Following its mandate as the custodian of OVC-related programmes, the DSD adopted the Policy Framework for Orphans and other Children made Vulnerable by HIV and AIDS in South Africa (DSD, 2005: 7). The framework aims to promote enabling legislation, policies and programmes. To encourage flexibility, effective harmonisation and coordination between legislation, policies and regulations within and between government departments and between stakeholders at all levels, are also set up at national, provincial, and local coordinating structures to coordinate OVC-related programmes/activities and empower communities to establish different programme models for OVC care, creating a positive environment for community-based programmes.

The National Guidelines for Social Services to Children Infected and Affected by HIV and AIDS (DSD, 2001) were designed to assist organisations and persons providing services to children infected and affected by HIV and AIDS, and to ensure that community-based care and support

takes community needs and cultural practices into account and protects the rights of children. This is the most relevant guideline for this study and. has the following key objectives:

- a) To provide information on establishing and implementing special programmes such as home/community-based care and support;
- b) To provide clarity on the development of community-based structures including CCF, child care committees (DSD, 2005).

These policies not only protect the rights of OVC but also empower communities to initiate community-driven OVC programmes. It is in this context that this research study will explore community resilient initiatives addressing the challenges facing OVC in Benoni.

2.7 CONCEPTUALISATION OF COMMUNITY RESILIENCE

Having examined the literature on resilience theory, the researcher is of the view that the historical development of this theory remains a highly complex and contested academic debate. However, there is general understanding that the expansion of the resilience concept from the individual, to family and community remains a challenge. For instance Van Breda (2001:142) states that historically *resilience theory has considered the community as a risk factor which makes life difficult for families and communities*. This is because the community has often been considered the primary source of social “stressors” - including poverty, crime, political instability, discrimination and a lack of community resources. “As resilience theory has evolved, increasing attention has been given to the community as a source of protective factors.”

Gurwitsch *et al.* (2007: 3) define resilience as the capacity of an individual or community to cope with stress, overcome adversity or adapt positively to change. It is the capacity to bounce back. Resilience is not regarded as a quality that is either present or absent in a person or group but rather a process which may vary across circumstances and time. The key question is, what is a resilient community? The United Nations Development Programme-UNDP (2002: 2) asserts that “a resilient community is one that takes intentional action to enhance the personal and collective capacity of its citizens and institutions to influence the course of social and economic change”.

A resilient community has a vision of its future and a sense of direction. For a community to be resilient, its members must put early and effective actions in place, so that they can respond to adversity in a healthy manner. If residents, agencies, and organisations take meaningful and intentional actions before an event, they can help the community re-establish stability after the event. Resilience implies that after an event, a community may not only be able to cope and recover, but that it may also change to reflect different priorities arising from the disaster (Gurwitsch *et al.* 2007:1).

Frey (1998:1) observes that HIV and AIDS affected communities' resilience has become an important concept in human sciences especially in the past two decades. Communities continually change and evolve in response to different situations. Community resilience is emerging as a key strategy for responding and minimising the impact of extreme events that threaten to wipe out human beings, such as floods, war, hurricane and diseases (Harrald, 2010:23). Green (2007:41) defines resilience as, "People's internalised capacities and the associated behaviours that enable them to maintain a sense of integration in the face of adversities, to recover from trauma following adverse events to overcoming the odds of life's transitions with competence, and successfully handle stressful events that are perceived as harmful".

On the other hand, Walsh (2006: 6) states that "resilience is the capacity to rebound from adversity, strengthened and more resourceful. It is an active process of endurance, self-righting and growth in response to crisis and challenge."

It is clear from the literature that resilience means different things to different people and situations and hence is not easily definable. For instance, Laundau (1982:15) maintains that community resilience means community capacity, hope and faith to withstand major trauma and loss, overcome adversity, and to prevail, usually with increased resources, with competence present in all human beings. For the human spirit to prevail and be perpetual across generations, communities need to be able to access and utilise their biological, psychological, social and spiritual resources to cope with the impact and immediate consequences of trauma, and to be able to promote long term recovery and healing. Resilience enables the community to leave the

past whilst connecting with the past in preparation for the future. While a universal definition of resilience remains elusive, it is clear that resilience means the ability to cope with challenges.

2.7.1 Community Resilience and the HIV/AIDS Epidemic

Community resilience is critical in the context of HIV and AIDS, which can destroy families. The process of reconnection, continuity, and reconciliation mobilises a transitional pathway over many generations into the future. This allows households and communities to access their inherent competence and resilience in order to deal with potentially overwhelming situations (Landau-Stanton & Clements, 1993:17).

It is clear that resilient communities have the capacity to survive/recover when confronted by external shock and disaster, in this instance the AIDS epidemic which not only destroys individual households but whole communities. While several articles have described what constitutes community resilience or what resilience means in the face of disasters, far less is understood of community resilience in the context of a community-driven response to mitigate the challenges affecting children affected by HIV and AIDS. For the purposes of this study a working definition of resilience has been adopted, as follows: “***The capacity of an individual, community or system to adapt in order to sustain an acceptable level of function, structure, and identity***” (Edwards, 2009: 5). Therefore, resilience refers to a range of activities designed and implemented by the community to recover from major disasters such as the AIDS epidemic. This includes mobilising and organising the community to provide ongoing assistance to its vulnerable members; in this case, OVC. This study examines how the Benoni community is responding to the challenges facing OVC.

In summary, this research will adopt an approach to families and communities based on the assumption that before disaster strikes, they are healthy and competent. Their competence becomes less available when they no longer have access to an extended support system and/or resources. In order for them to access this natural link and competence they need to be able to retain or regain a connection with their families and natural support systems, their daily patterns and rituals, their sense of meaning, their spiritual support system and their culture (Landau, 1982).

2.7.2 Key Elements of Community Resilience

Gurwitch *et al.* (2007: 61-68) identify the key elements in building resilience that are present in every community and every family. Taken together, they can increase communities' and families' ability to successfully deal with and recover from adversity.

These elements are:

a) *Connectedness, commitment, and shared values*

A shared history, customs, beliefs, and values enable children and families to feel part of a particular community. Their connectedness to the community is influenced by various factors such as:

- i. How families perceive their own well-being as part of the well-being of the overall community.
- ii. How families perceive respect and sensitivity towards their own identity with reference to ethnic and cultural identification.

Gurwitch *et al.* (2007: 61) maintain that families with a high sense of connectedness are more likely to make a strong commitment to the common good of the community, which increases trust in community leaders and increases compliance with messages and instructions in the event of an emergency. Children will also feel connected through positive relationships with their families, friends, schools, and organisations.

b) Participation

Gurwitch *et al.* (2007: 62) define participation as actively contributing to the community. Families are more likely to participate in their community when community leaders encourage active involvement; they believe their contributions and ideas are valued by community leaders; and they can see the benefit of being involved for themselves, their children, and the entire community. In order to increase participation in a multicultural community, families must believe that others respect them and value diversity. Children's resilience can be enhanced by providing them with space for direct participation in the family, school, cultural or faith-based

organisation, and extracurricular activities. Resilience is further increased when children feel that their contributions to the group are meaningful and appreciated. However, participation may increase if families perceive such programmes as helping their children face and overcome adversity, thus building their resilience. Blackman, Stephenson, Gourley & Miles (2004:5) define child participation as children influencing the issues affecting their lives by speaking out or taking action in partnership with adults. There are different forms of participation. Tokenism is the lowest level of participation, where children are involved in some way, but not very meaningfully. At the other end of the spectrum, child initiated and directed participation involves children taking a leading role (Blackman *et al.* 2004:15). Stakeholder mobilisation and participation is critical in the context of the AIDS pandemic as no single individual acting alone can defeat the pandemic. It will take a concerted effort by all community role players to fight it. Community members can play different roles such as participating in awareness raising campaigns, caring for the terminally ill and providing ongoing care and support to OVC.

c) Structure, roles, and responsibilities

Communities need a clear organisational structure in order to function productively on a daily basis. In the aftermath of a disaster, the roles and responsibilities of residents may change; examples include child-headed and granny-headed households. As discussed earlier, these are new sociological phenomena. It therefore becomes necessary to define the exact roles of such households especially in the context of access to social services such as child support grants and foster care grants. Conflict about roles can adversely impact resilience. Knowledge of roles and responsibilities during disasters will enhance a community's acceptance of directives and compliance with procedures (Gurwitch *et al.* 2007:63).

Just as residents play different roles and have different responsibilities in the community, family members also have roles and responsibilities in their homes. Parents need to help children learn what is expected of them within the home, at school, and in the community. Children should also know what to do in the context of the AIDS epidemic (prevention, caring for an ill parent, life skills etc). When children's roles and responsibilities are clearly defined, rather than vague or inconsistent, they are better able to manage difficult situations. This may help reduce worry and anxiety in a difficult situation (Gurwitch *et al.* 2007:66).

d) Support and nurturance

Community resilience is enhanced when families perceive that community leaders are supportive. Families feel more supported when they have opportunities to:

- i. Express concerns and ideas related to the community.
- ii. Provide feedback to leaders.
- iii. See their concerns addressed by actions.

Community leaders demonstrate support of families by facilitating community growth (Gurwitch *et al.* 2007: 64). Diverse communities show increased resilience when families from different cultural, ethnic, and religious backgrounds are recognised and supported for their unique contributions. Community activities to highlight diversity are ways of supporting and respecting this aspect of the community. Resilience in children and families is enhanced when they feel supported and nurtured by others. This support may come from individuals in various settings: school, cultural and faith-based settings, and places of employment (Gurwitch *et al.* 2007:66).

e) Critical reflection and skill building

According to Gurwitch *et al.* (2007:67) critical reflection entails self-evaluation of how prior situations were handled. This allows for the identification of:

- i. Successes or strengths.
- ii. Areas needing improvement.
- iii. Challenges or barriers to implementing planned responses.
- iv. Unanticipated problems.
- v. Solutions.

Critical reflection is one avenue for growth. By continually studying how problems are managed, new goals and improvement can be put in place (Gurwitch *et al.* 2007:65). This includes but is not limited to monitoring community-based programmes to evaluate their effectiveness and efficiencies, especially HIV and AIDS prevention programmes and OVC support programmes.

Through critical reflection leaders are able to identify skills and areas that need improvement. This is also true within families; feedback from parents and other adults can guide children to make positive changes in their behaviour and relationships. Children also learn new skills from important adults in their lives, increasing their capacity to handle problems. Leaders identify

skills that the community and its families will need in the event of a disaster and begin building those skills prior to a disaster. For example, by learning how to manage symptoms that typically arise in the aftermath of a disaster (e.g., anxiety, fear); children become generally more resilient when faced with such events (Gurwitch *et al.* 2007:61).

f) Resources and social capital.

Resources are the assets available for use by families and communities; they include money, property, materials, skilled people and goods. Resources are considered part of the infrastructure of every family and every community. In the simplest terms, resources fall into the category of basic needs, such as food, clothing, transportation, and shelter (Gurwitch *et al.* 2007:66).

In a community, resources extend beyond the economic and physical to include human and social capital. The World Bank, cited in UNDP (2002:2) asserts that “social capital is not just the sum of the institutions which underpin a society – it is the *glue* that holds them together”. Social cohesion is critical for societies to prosper economically and for development to be sustainable. It also enables the community to transcend individual family limitations as the community works together to achieve a common vision. In the context of HIV and AIDS, PLHIV are not discriminated against and OVC are not labelled and stigmatised.

Understanding how physical and social capital can complement each other to achieve the goals of a community can enhance a community’s resilience. Identifying available resources prior to a disaster allows for more effective planning, as well as for the identification of potential resource needs from outside the community (Gurwitch *et al.* 2007:66).

After a disaster, communities generally tend to pull together and work for the common good. However, it is likely that after the initial threat ends, conflict will arise over how resources are allocated. It is in this context that trust, mutual relationships and networks become critical, as they constitute the key forms of social capital (UNDP, 2002:4). Resilience in children is enhanced when they have social resources to draw on. Such resources are found in many different groups and environments, including their families, friends, schools, faith-based organisations and from extracurricular activities. How children utilise these social resources can

affect their ability to handle adversity. The more effectively children are assisted to access appropriate social resources; the more resilient they can be, argue Gurwitch *et al.* (2007:66).

g)Communication

Gurwitch *et al.* (2007:67) maintain that without effective, clear, and accurate communication, efforts to enhance resilience in children, families, and communities are limited. In order to enhance communication, it is critical to consider the following:

- i. Communities must use messages that are easily understood by adults and children of all ages. This also applies to information, education and communication materials, better known as IEC, especially in the context of HIV prevention awareness or community awareness programmes about the situation of OVC.
- ii. Leaders may need to develop multiple messages with consistent themes in order to address the varied families and neighbourhoods within a community. For instance, the consistent use of condoms to prevent HIV and AIDS and messages discouraging stigma against PLHIV and OVC.
- iii. Leaders should provide parents and caregivers with “talking points” on how best to discuss an issue with all stakeholders, for instance sex education.

Gurwitch *et al.* (2007:68) assert that these elements are interrelated. For example, families are more likely to participate in community activities when they feel connected to the community. Through connectedness and participation, families gain an understanding of the community structure and their roles and responsibilities. Community support of families and children further increases their resilience.

After communities respond to disasters and resources are expended, leaders are able to critically reflect and assess how effective the response was and make improvements before another event. Communication is essential to all these elements. Only through clear, consistent communication will information be heard, utilised, and lead to productive change for managing future situations and enhanced resilience.

The UNICEF (2011:3) observes that there certain dimensions of resilience can offer crucial insights into how the humanitarian community can identify entry points for better supporting community resilience. These dimensions are:

- a) *flexibility* – the ability to change, including the speed and degree of adjustment;
- b) *diversity* – the variety of actors and approaches that contribute to the performance of a system’s essential functions;
- c) *adaptive learning* – the integration of new knowledge into planning and execution of essential functions;
- d) *collective action and cohesion* – the mobilisation of capacities to jointly decide and work towards common goals;
- e) *Self-reliance*– the capacity to self-organise, using internal resources and assets, with minimal external support.

In this chapter the researcher has shared the relevant literature on the AIDS epidemic. It may be concluded that socio-economic factors such as poverty, poor infrastructure, and limited access to health care services exacerbate the AIDS epidemic. In most cases it is often the OVCs who are directly affected by the AIDS as family structures are destroyed and the community overwhelmed. In most cases it is poor communities who suffer most. However, through community resilience affected communities engage in various community driven initiatives to address some of the challenges experienced by OVCs.

CHAPTER 3: RESEARCH METHODOLOGY

3.1 INTRODUCTION

Building on prior information, this chapter addresses the methodological aspects of the study that employed a qualitative design. Data were collected in Benoni community during January and February 2012. Follow-up interviews were conducted in March 2012 to address knowledge gaps. This chapter presents the study design, including the data collection and analysis that were utilised to gather information and data analysis methods. It discusses the sampling methods and presents the selected sample of research participants. It also highlights some of the challenges experienced during data collection and concludes with the limitations of the study.

3.2 RESEARCH DESIGN

This research study employed qualitative methodological approaches with a view to exploring and understanding community resilience strategies responding to the challenges faced by OVC affected by HIV and AIDS. Creswell (1998:15) maintains that qualitative research as a process of understanding is based on distinct methodological traditions of inquiry that explore a social or human problem. Exploratory research seeks to establish how people cope in the setting in question, what meaning they give to their actions and what issues concern them.

Babbie (2006: 2) states that “ultimately, scientific inquiry comes down to making observations and interpreting what you have observed.” It should be noted that descriptive statistics were merely presented in table format for ease of reading and interpretation, but the study is in essence qualitative.

This research study is based on fieldwork consisting of interviews with nine (9) key informants, five (5) OVC, eight (8) guardians and two focus groups of learners consisting of five (5) in each group. In total thirty two (32) people were interviewed in Benoni. Since the study constituted exploratory research, the following data collection methods were employed: Face-to-face interviews using a research guide and focus group discussions; the primary data included the transcripts of the interviews. The other data collected from the LCDA included programme

documents such as beneficiary registers, minutes of meetings, volunteers' handbooks, diaries and life stories.

3.3 SAMPLING TECHNIQUES

Prior to commencing with data collection, the researcher negotiated community entry through LCDA. This helped the researcher to gather basic information beforehand about the Benoni community and services provided by LCDA to OVCs. This also assisted the researcher to pilot the research guide with a few participants from the community. The research guide used during the pilot study contained the same questions and was administered to people with the same characteristics as those that will participate in the research study (de Vos, Strydom, Fouche, & Delpont, 2006:331). The pilot study enabled the researcher to establish a relationship and create a rapport with the community. It also helped the researcher to estimate the time the interviews would take and identify possible challenges, gaps and areas of emphasis during probes. All the identified concerns were taken into cognisance during the actual data collection. The pilot test group discussion lasted more than two hours. It confirmed the relevance of the research guide with few modifications in the set of questions.

This study employed a 'purposive sampling' method (Babbie 2006:166). The selection of the research respondents – both for the face-to-face interviews and the focus group discussions – was purposive, taking into account different attributes like awareness and participation in the Lithanza programme, programme beneficiaries, community status i.e. leadership role, age, etc. With this in mind the OVC sample was selected from both genders within the age range 13-15 that were beneficiaries of the LCDA programme. In-depth research requires informed respondents, not just responsive respondents – that is, people whom a researcher chooses on purpose, not randomly. Thirty two (32) respondents, i.e. eight (8) males and (24) twenty four females were recruited to participate in this study. The key informants included a social worker, community leaders, two school teachers and community members. This sample size was the most appropriate for this study based on the complexity of the phenomenon understudy and local demographics. To a certain extent the interviewees (OVCs) were almost a "captive audience" in the sense that they were selected because of what happened to their parents/guardians.

3.4 METHODS OF DATA COLLECTION

As noted earlier, this is a qualitative research study that is exploratory in nature. The researcher employed a combination of techniques to collect research data, rather than using a single technique. A combination of data collection mechanisms is appropriate for a study of this nature to ensure reliability (de Vos *et al.*, 2006). The key data collection methods employed in this study included:

3.4.1 Face-to-Face Interviews

In-depth, semi-structured interviews based on the research guide were conducted with research participants. This data collection method is best suited to qualitative research since it allows interaction between the researcher and the respondents. It allows participants to use their own words and phrases and share their experience without being limited by structured questions (Struwig & Stead 2001:18). This is appropriate in an exploratory study of this nature, where the researcher had little insight into the study subject. Using the research guide interview method, the researcher gathered evidence from key informants, children and guardians. All the face to face interviews with the learners were conducted in Lithanza offices, and the interviews with other respondents were conducted at the comfort of their home or offices. This ensured minimum disruption of their routine programme and saved on travelling costs. Local languages (seSotho, isiZulu and isiXhosa) were used during the interviews to allow for free participation by the respondents. The interviews provided the researcher with a narrative account of the challenges faced by OVC and how the resilient community of Benoni responds to such challenges.

3.4.2 Focus Group Discussions

Focus group discussions were also held with children benefiting from Lithanza programmes in their schools; two separate discussions were held in two schools, consisting of five participants each. The focus group discussions were conducted after school to ensure no school disruption as a result of the study. All the learners were active in CCF in their schools. The aim of these discussions was to understand the nature of the support mechanisms provided by the learners to

one another and the nature and extent of orphanhood within the school environment, as well as to ascertain the general relationships between OVC and understand learners' perceptions of OVC and resiliency. The focus group discussions took 60 minutes on average. A relaxed atmosphere was created by allowing learners to share stories, jokes and their career plans.

This method was selected due to its advantage in acquiring a deeper understanding and gathering detailed information from the study's target groups.

3.4.3 Documentation Study

This took the form of an analysis of the relevant projects documents (desktop analysis) at the Lithanza office in Benoni; it involved understanding the nature, functioning and historical development of the LCDA and its relationship with the community.

3.5 DATA ANALYSIS AND INTERPRETATION

Qualitative data analysis is an iterative process (Strauss & Corbin, 1990:68) by which a researcher studies transcripts of the data in order to understand the relevant aspects. Creswell (1998:139) states that qualitative analysis transforms data into findings. The researcher used thematic analysis to compare and analyse the different perspectives of the research participants (key informants, guardians and OVC) to identify similarities, differences, patterns, and themes in order to make sense of the data collected, whilst at the same time identifying any inconsistencies and contradictions.

This information was then matched and compared against the research objectives and research questions. The literature on challenges experienced by orphans and community resilience was consulted to substantiate the research findings.

In some instances verbatim quotes from participants were used to concretise the research. Strauss and Corbin (1990:68) recommend explicitly using actual phrases of the text – the words of real people. In the researcher's view this method of data analysis is the most appropriate to fulfil the objectives of this study as it integrates the different perspectives, taking the contextual specifications and uniqueness of each participant into consideration.

For the purpose of this study, the following key documents were analysed:

- a) Programme documents from the LCDA;
- b) OVC policy documents;
- c) Legislation/policies related to community resilience and empowerment.

3.6 DATA RELIABILITY AND VALIDITY

The multiple methods of data collection assisted the researcher to easily validate and cross check the findings building on the strengths and weaknesses of each data collection method. However, specific steps were taken to ensure reliability and integrity of the data. For instance, the researcher collected the data himself. The researcher provided clarity, specificity (the focus of the study), and built relationships with interviewees so as to give them the opportunity to understand and interpret the research questions that were asked, particularly with the focus groups. The researcher focused to the research guide in order to avoid biasness. The researcher asked the same questions to each interviewee. Interesting to note, all the interviewees (excluding the children) accepted and answered the questions consistently and no objections were made through that process. The researcher conducted follow up interviews to ensure data reliability and correct the gaps.

3.7 ETHICAL CONSIDERATIONS

This research was conducted in line with ethical academic standards and included seeking ethical clearance from the Department of Sociology-UNISA before data collection commenced, voluntary participation by the research respondents, protecting the rights and privacy of the participants, maintaining confidentiality, seeking consent from participants, avoidance of harm and informing respondents about their right to decline to answer any question or withdraw from the study any time (Babbie, 2006:520).

No false expectations were created that respondents would benefit from this study, either directly or indirectly. The researcher explained to all respondents that this was not an intervention study;

however, once completed the community will be able to access the study and be at liberty to engage with its contents.

3.7.1 Confidentiality

The respondents were informed that their confidentiality is guaranteed and their identity will remain anonymous. This is in line with basic human rights principles and provides protection against stigma and social exclusion. To ensure confidentiality participants were not asked to provide their identity documents, names or residential addresses (Babbie, 2006:523).

3.7.2 Informed Consent

In order to protect the integrity of the study, all participants were requested to sign a letter of consent. In the case of children, assent forms were signed by their parents or guardians as per statutory requirements. No participant was coerced to participate in this study; participation was purely voluntary (Babbie, 2006:521).

3.7.3 Provision of Debriefing, Counselling and Additional Information

The researcher collaborated with a local counselling organisation which provided debriefing and counselling services where necessary, particularly to OVC, as some children might not have healed from the death of their parents. Fortunately, no serious cases were encountered.

3.8 CONCLUSION

It is acknowledged that the methods utilised for a research study must be appropriate to the organisational capacity, education, skills and resources available in the community and that they should be sensitive to local conditions, culture and internal dynamics in order to achieve success and sustainability.

CHAPTER 4: PRESENTATION OF FINDINGS AND DISCUSSION

4.1 INTRODUCTION

Building on the previous chapter, this chapter presents a summary of the demographic details of the respondents, the study findings and the analysis and interpretation of the data. The data are presented in themes based on the research objectives and the questions that emerged from the analysis of the field notes taken during the interviews and the document review. The respondents' responses are quoted verbatim in some cases to strengthen the research findings. The purpose of this study was to explore community resilience strategies in response to challenges faced by OVC, with a particular focus on teenagers between the ages of 13 to 15 years affected by HIV and AIDS in Benoni, EMM, Gauteng.

The findings presented in this section include two focus groups discussions with learners in two primary schools in Benoni. The two schools have active CCFs that were established by Lithanza to assist OVC at the schools according to the DSD (2006) guidelines for establishing CCF.

The findings are divided into the following broad themes:

- a) Community understanding of HIV and AIDS and its impact on the community.
- b) Challenges experienced by OVC in Benoni.
- c) Community resilience related to OVC affected by HIV and AIDS.

4.2 DEMOGRAPHIC SUMMARY

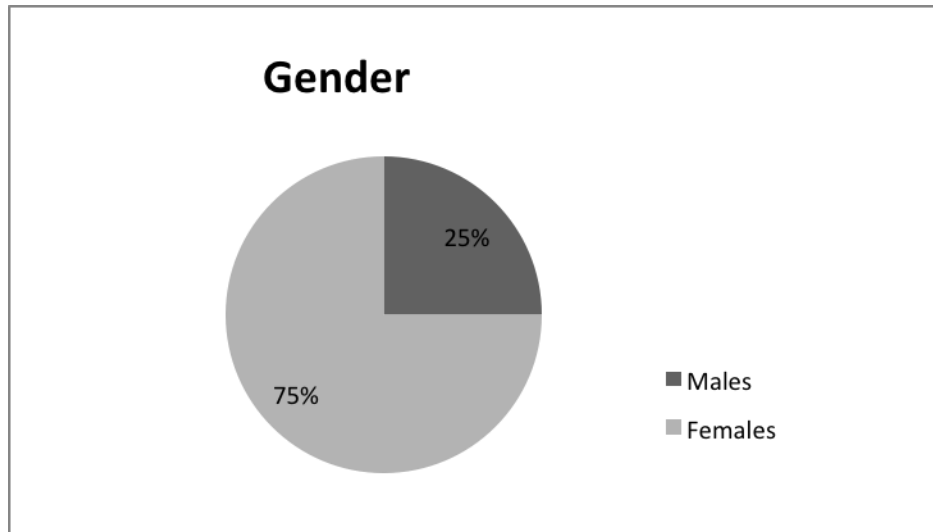


Fig 6 Gender distribution of respondents

Figure 6 shows that the majority (75%) of the respondents were female, with only 25% being male. This reflects the reality on the ground and confirms the findings of the literature that women and girl children are the hardest hit by the AIDS pandemic, both directly and/or indirectly (UNICEF, 2003:20; Red Cross, 2007:13). As presented in chapter two, women are often disempowered and subservient in relationships and are therefore more vulnerable to the risk of being infected with HIV as compared to their male counterparts.

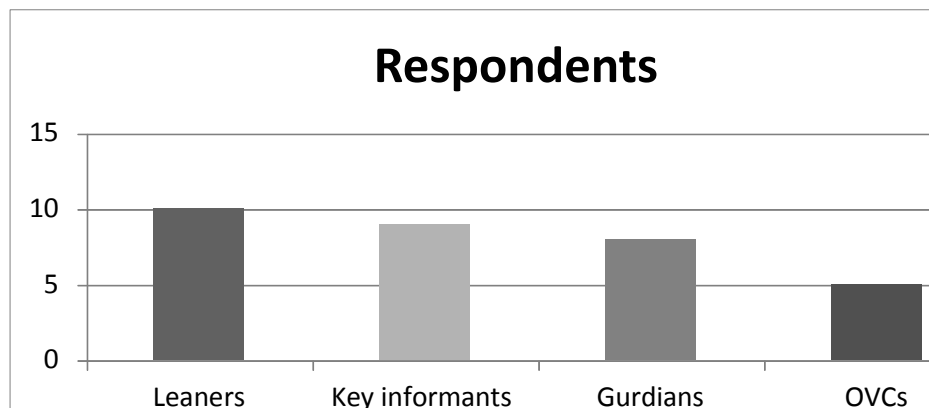


Fig 7 Respondent's segmentation

Figure 7 provides detailed information about the respondents who participated in this study. Ten (10) learners represented the two CCFs with five (5) in each focus group discussion, while five OVC (direct beneficiaries) participated in the face-to-face interviews. Nine (9) key informants and eight (8) guardians also participated in the face-to-face interviews. The key informants included a social worker from the DSD, three (3) community leaders, two (2) school teachers representing the two schools and three (3) community members. All the respondents have a relationship with LCDA directly as project recipients or indirectly through their support.

4.3 COMMUNITY UNDERSTANDING OF HIV/AIDS AND ITS IMPACT ON THE COMMUNITY

The research data provided a clear account on the impact of the AIDS epidemic in Benoni. All (100%) of the respondents were directly or indirectly affected by the epidemic, as most reported having attended the funeral of a relative or friend within the past 24 months. Based on their personal experience of HIV and AIDS, respondents were aware of its devastating impact at household level and in the community. The community members shared moving stories about how the epidemic has taken away their beloved children, spouses, mothers and fathers.

For the elderly, the situation was even worse as they were burying their own children, contrary to normal expectations. Furthermore the high number of OVC provides clear account of the impact of the epidemic on this community. It is evident that the demographics of this community have been highly affected. Respondents were also aware that the community has a primary responsibility to initiate community-based programmes to care for OVC as government programmes are overwhelmed. Anecdotal evidence revealed that there has been a decline in the number of funerals in this community, which could be an indication of the success of the intervention programmes implemented by the government, particularly the highly publicised government ARV programme in public health institutions. This finding is consistent with research which reveals a decrease in AIDS related mortality since the inception of the ARV

programme⁷ in public health care facilities in South Africa. Furthermore, according to Stats SA (2013) the life expectancy of South Africans has increased by a year to 59.6 (57.7 for males and 61.4 years for female).

In reflection to the impact of the AIDS epidemic in this community some participants had this to say: *“The problem is very serious, before the availability of ARVs we used to bury many people in this community. We were overwhelmed with funerals starting from Thursday, Saturday and sometimes even on Sundays. It was difficult; my wife will go to one funeral whilst I attend the other funeral on the same day. But I must say that things have changed now we no longer burying so many people but we are still burying those who refuse to take ARVs due to the fear of stigma”*(Community member).

“It’s difficult to give you the exact number but they are many (OVC) for instance in the school where I am teaching - we have registered more than 200 in our programme; imagine how many schools are in this area” (Teacher).

Despite the high number of OVC in Benoni/Ekurhuleni, the community has not conducted an empirical study to determine the exact number of OVC. Evidence suggests that service providers are operating in a fragmented manner without a reliable baseline. For instance, the DSD could not provide the exact statistics for 2011 as they were still waiting for final verification by the provincial office; they rely on quarterly figures which are processed by the provincial office. On the other hand, the community-based organisations are only exposed to the OVC they are servicing, as is the case in the schools. There therefore seems to be a serious gap in OVC data in Benoni. As argued in Chapter two the high number of OVC’s indicates the severity of the AIDS epidemic.

It is evident from the data that this community is confronted with a high number of OVC. This confirm that HIV has broad social and economic consequences for children and their families,

⁷ Almost 2 million people are now on ARVs’, compared to fewer than 1 million people in 2009. It is the largest ARV programme in the world (UNAIDS, Global Report).

but orphans and vulnerable children, including those living in families affected by HIV, frequently do not receive any type of support (UNICEF, 2013:20). Individual households cannot cope alone and are struggling to make ends meet. This affirms the findings of the literature review; for example, UNICEF (2003: 14) has observed that the AIDS pandemic has deepened poverty and exacerbated deprivation. The DSD, (2010b:5) affirms that poverty is one of the factors that push children to the streets. The responsibility of caring for OVC is a major factor as extended family networks have been overwhelmed and cannot provide care to OVC and adults suffering from HIV and AIDS. Many communities are experiencing large increases in the number of families headed by women and grandparents; these households are often progressively unable to adequately provide for the children in their care. The epidemic has deepened poverty and exacerbated myriad deprivations as presented in fig: 3. Van Donk, (2002:5) contends that children who grow up in poor households are likely to be trapped in a vicious cycle of poverty and are more likely to be infected with HIV. Therefore, stronger linkages between HIV programming and broader national social protection efforts and community-based services are needed to ensure that more children and families receive the support they need (UNICEF, 2013:20).

The most positive solution to these challenges is to be found within the community rather than at individual household level.

“We are overwhelmed but coping very well given the history of AIDS denialism⁸ in South Africa” (Anglican Priest in Benoni). This respondent also mentioned how the previous government fuelled the AIDS epidemic through mixed messages especially on ARTs, lack of political leadership and lack of funding for community based interventions. According to this respondent the current challenges may be attributed directly to poor political leadership. However, community and faith-based services have a long tradition of providing HIV-related services in rural and remote areas (UNICEF, 2013:21). Therefore, the concerns raised by this respondent are well justified.

⁸ The Treatment Action Campaign defines AIDS denialism as the promotion of one or more of the following pseudo-scientific views: (1) HIV does not cause AIDS, (2) the risks of antiretroviral outweigh their benefits and (3) there is not a large AIDS epidemic in sub-Saharan Africa.

4.4 CHALLENGES EXPERIENCED BY ORPHANS AND VULNERABLE CHILDREN IN BENONI

The findings of this study reveal that OVC's in Benoni are faced with multiple challenges, similar to those discussed in the literature review, but with a few distinct variances. These challenges are grouped into four (4) sub-themes:

4.4.1 Non-disclosure by Parents

The majority (90%) of the respondents attested that their parents did not disclose any information regarding their HIV status and/or illnesses; as a result they (children) expressed a deep sense of regret that they were denied the opportunity to discuss their parents' health before they passed away. They felt that such openness in communication would have enabled them to deal better with their parents' illness and death and allowed them to heal. As a result of nondisclosure they have many unanswered questions about the deaths of their parents. This has ripple effects as they are not able to address issues such as inheritance, family genealogy and cultural rituals as many are migrant families from the Eastern Cape, KwaZulu-Natal and a few from Mozambique and Zimbabwe. (Keep same theme in same paragraph) For instance, one participant emphasised that even though he felt that he needed to know more about his father's condition, he was too young to ask him or any family member such kind of questions; this would have been considered ill-discipline as children are not supposed to confront elders, even though he was taking care of his father and performing general household duties including caring for his siblings. This happened at the same time that he was recovering from a similar trauma since his mother also died of HIV and AIDS.

The guardians and care givers from LCDA confirmed that it is a common practice for ill parents to hide their illness or HIV status in Benoni. This situation puts children in a vulnerable position as they are forced to guess the reasons for their parent's death, probably experience stigma and are uncertain about their future as there is nobody to provide them with psychosocial support. Non-disclosure by parents of their HIV status is controversial as this may expose children to HIV infection since they provide primary care to their ill parents. In the African context children are not supposed to be assertive when dealing with their parents. For instance, it is a taboo for

children to wear latex gloves when taking care of their parents. This clearly demonstrates the contradiction between some cultural practices and universal HIV prevention. It therefore remains a challenge to balance the two.

Regardless of these challenges, the researcher was impressed with the high level of HIV and AIDS awareness amongst respondents, particularly children, as most expressed suspicion about the conditions surrounding their parent's death. One of the children said:

“Although my mother did not say anything about her sickness, I knew that she was suffering from HIV and AIDS, at school they teach us about it. I kept on denying it but I knew that she will die one day” (Child, 12 years).

When another respondent (13 years) asked her mother about her illness, her mother told her that she was being bewitched by jealous neighbours due to her progress since she had bought a new electric stove. The respondent said that at night she would be instructed by her mother to burn “*imphepho*” (incense) and sprinkles the house with “*intelezi*” (traditional concoction to protect the house from evil spirits). This was routine practice until her mother was hospitalised and diagnosed with TB and HIV; she died a few weeks later.

It was evident that the respondent had a close relationship with her mother and was fortunate as her mother later disclosed her illness to her. This provided the respondent with the opportunity to grieve and find closure. The respondent felt that if her mother had disclosed her condition earlier and gone to hospital, she would have been alive today, as she has seen many people in the neighbourhood living a healthy life with HIV.

Parents' non-disclosure of their illness is a common practice in most poor households and demonstrates the contradictions between traditional African belief and the science of HIV. It is also an indication of the fear of stigma and discrimination, as children with HIV-positive parents are often thought to be HIV positive themselves and are consequently labelled, thus perpetuating stigma and social exclusion (World Bank, 2006:04; Gumede 2009:23; Red Cross, 2007:11)

Failure on the part of parents to disclose illness may leave permanent scars - feelings of fear, blame and isolation - in children which may take a long time to heal. The majority of these children are raised by their grandparents who are not always able to provide for their basic needs, including psychosocial support.

4.4.2 Economic Deprivation and Disrupted Schooling

OVCs' are trapped in a vicious cycle of economic deprivation as they are not able to access the things (such as new clothes, warm winter clothes, computer games, eating lunch/supper out, transport to school, meat, access to DSTV) they would like to access, like other children. Children, especially adolescents, are brand-conscious, and OVCs' have that same desire, since they observe that their peers wear brand name clothes, and also, as most peers do, want to do the same. Almost *all* the respondents spoke with longing of material things (chocolates, Christmas clothes and gifts, special brand toys, such as Spiderman for boys and Barbie for girls) that they had when their parent/s were still alive and which they now have to do without. Although these children have internalised the death of their parents, this could be an indication that their feelings of grief have not been dealt with directly. This could be because their parents did not disclose the nature of their illness. Such a longing for material things is understandable as these are teenagers between 13 and 15 years of age who do not deserve to be trapped in such a situation. Despite these challenges, no respondent complained about starvation or hunger, indicating that the community intervention programme was reaching almost all children.

Almost all the children (95%) showed a high level of appreciation for the support provided by the community, even though this did not fulfil all their needs. This did not, however, affect their values and aspirations, or involvement in anti-social behaviour. Instead, they were composed, respectful, and visionary and showed interest in living a normal life like their peers. All the children were attending either primary or secondary school at the time of the interviews. They were in different grades, ranging from Grade 5 to Grade 9. This is despite the fact that some were forced to drop out of school for a while when their parents were ill or immediately after their deaths. It was interesting to note that almost all the children were satisfied with the level of service provided to them by the community as they had more time to attend to their school work and had the opportunity to play with friends after school.

“When I was eleven years I had to break from school in order to take care of my mother since there was no one from my family willing to help my mother when she got sick” (this is one amongst many such testimonies) (Child, 15 years).

“When my father was ill, I was not able to attend school every day as I had to cook, clean the house and sometimes assist him to bath”(Child, 14 years).

“I was always late at school because I had to cook porridge for my mom and wash my two young sisters before dropping them at crèche, there was no money to pay for the transport and sometimes there was no food in the house - I will eat at school - the church people gave us food. It was very hard” (Child, 15 years).

The support provided by schools, i.e. school fee exemptions, free school uniforms, nutritional support (school feeding schemes) and support from other learners are some of the positive outcomes motivating OVC to attend school on a regular basis. Children’s access to the education system in South Africa is extensive. The introduction of the child support grant and no-fee schools, together with school fee exemptions, greatly improved access to basic education for learners from poor communities. In 2009, 98.5% of children aged 7 to 15 years attended school, up from 89.3% in 1996 (UNICEF, 2010:9). Moreover UNICEF (2013:21) suggests that social protection has already proven to have an impact not only in support for children and families already affected by HIV, but also in preventing HIV and improving treatment and care outcomes.

With regard to this view one respondent had this to say:

“Why should I not go to school when at school I get breakfast and lunch; and after the school I eat my supper here” (with reference to the Lithanza dropout centre), argued one respondent (Child, 12 years).

In support of this: *“We cook nutritious food daily and we have developed a standard menu with fish, rice, baked beans...the kids love our food”* (Guardian).

Another respondent: *“In this community we work together to ensure that all our children go to school, we want to break the cycle of poverty”* (Community leader).

“We feed and support all children especially those who do not have parents, we do not discriminate against any child” (Community member).

Such testimonies define community resilience and demonstrate the success of government programmes to support children as discussed in Chapter Two, which include child support grants in lieu of school transport and the school feeding scheme to mention a few. Child poverty was not identified as the major challenge as most OVCs’ have access to integrated services provided by the community. It is apparent that communities, through community intervention, are able to break the cycle of poverty through investment in basic needs and education for OVCs’.

4.4.3 Children Caring For an ill Parent With AIDS and Child-headed Households

It is unusual for young children to care for ill parents, but due to the impact of the AIDS pandemic at household level it has become a common practice for children to provide basic care, bearing in mind that they have the right to still be children, and grow up within a family context with parents teaching them the skills of life and protecting them. A large number (85%) of the children were providing basic care to their ill parents (Community leader). These children are vulnerable as their parents are not able to support them physically and emotionally. In other words, they cannot depend on their parents for support like in any normal family situation. This compromises their wellbeing as children.

Contrary to research by Gumede (2009: 23); the World Bank (2006: 04); UNICEF (2003:29-31); Nasaba *et al.*, (2006:6) and the Red Cross (2007:11), very few respondents mentioned any form of exploitation, sexual abuse or risky behaviour as a way of supplementing household income; however, this is not conclusive, as this finding was limited to research respondents. This could be attributed to community interventions such as:

- a) leadership and awareness raising campaigns, including HIV and AIDS prevention, behaviour change, leadership and self-esteem programmes;
- b) material support;

- c) psychosocial support; and
- d) community engagement.

Again, contrary to negative perceptions of child-headed households, it is apparent that for some orphans (65%), a child-headed household is a better option after the death of their parents. It is a way of avoiding some of the challenges associated with staying with relatives, such as stigma, discrimination and abuse. In order to assist such children the DSD has developed some guidelines on child headed households in order to provide clarity. However this issue remains controversial as there are serious concerns about children being responsible for a household.

In a typical “normal” household with healthy parents, all members of the household assume specific responsibilities based on their capability and age. In a child-headed household it is assumed that no definite allocation of such responsibilities as all the responsibilities are assumed by the *eldest child* regardless of their gender and age. He/she must assume the responsibility of being the mother and father and ensure that there is enough food for his/her siblings. Despite this, most child household heads (65%) in this study managed to find some joy and satisfaction in being the head of the household despite their limitations. They attributed this to the support provided by the community. For instance, each child-headed household was allocated a volunteer care giver/guardian that provides adult supervision and additional support. These volunteers visit different households on a daily basis, ensuring that there is enough food to eat, that children attend school on a regular basis and assist with other household duties.

Furthermore, neighbours provide *ad hoc* support on issues requiring conflict mediation and discipline. Interestingly, some children have transcended their circumstances as they are not separated from their siblings, which is a common practice in such situations. This could be regarded as the source of their strength.

For instance, one girl said: “*I am happy that I am able to see my little two sisters every day, I wash them and accompany them to school, imagine if they were in Libode*⁹” (Child, 15 years).

⁹ A small rural town OR Tambo District in the Eastern Cape.

A boy (15 years) who is the head of his household said: *“My father died in late 2008 and was followed by my mother in mid-2009. I started being responsible for the household immediately after my father’s death, my mother was sick and because no relatives wanted to take care of us including my granny, but I am happy because we are coping very well with support from the community.”*

Another respondent (community member): *“We teach them to take care of each other as there is no such thing as a good extended family, things have changed, people are cruel they all want to benefit”.*

This refers to the abuse of child support grants by some extended family members. Anecdotal evidence suggests that this practise is widespread in South Africa, particularly among extremely poor households. It has been alleged that there are people who “farm” children in order to collect more money from the child support grant as the money is paid per child. This money is used for other purposes rather than to support the children.

There are exceptions to any situation. One boy (14 years) reflected on his painful experience of being teased by friends that he was a “father” whilst still being a child himself. Another girl (13 years) shared her painful experience of being labelled and stigmatised by neighbours. In both situations the community acted accordingly to avoid this type of situation to be repeated.

4.4.4 Emotional, sexual and economic exploitation, stigmatisation and discrimination

Losing a parent is a huge emotional trauma, but some of the children suffered the additional ordeal of abuse whilst in the care of an extended family. This included taking their parents’ belongings without informing them, being forced to perform routine household duties which could easily be shared with other children in the household, scolding and shouting at them in front of other children for no valid reason, referring to them as ill-disciplined or discriminating against them when buying special gifts.

For instance, one respondent had this to say:

“My relationship with my aunt is bad because she did not take good care of my father’s belongings including the money she got from my father’s employer”(Child, 13 years).

It was also evident that in such situations children are denied access to documents such as identity documents and death certificates and can’t access their clinic cards and birth certificates, thus making it difficult for them to access social grants. This destroys their future prospects and eventually their livelihoods as they can’t be registered at schools without these essential documents. Such children fall through the safety net and eventually end up in the streets and engage in antisocial behaviour.

One respondent said: *“My aunt shouts at us (referring to her siblings) and she tells us that we have no place to go to, we are eating her children’s’ food, our mother never saved money for us therefore we should be grateful that she is losing by keeping us in her house. She even said, if we were in the Eastern Cape she would have arranged for me to marry to an old man so that I can send her money to feed my sisters”*(Child, 13 years).

A Community Leader had this to say: “OVCs’ are labelled and often suspected of being HIV positive, but I must say that since community took the responsibility things are changing and more children are provided with basic serves [services] and there seems to be some acceptance due to the awareness campaigns conducted by Lithanza”.

Therefore, whilst the community has taken the necessary steps to protect some children, some orphans are still vulnerable to financial exploitation, which includes the misappropriation of inheritances, homes, and property by surviving adult relatives. This undermines their livelihood and makes them vulnerable to exploitation. As argued in literature review by Gumede (2009:23), Richter, Manegold & Pather, (2004:4), emotional, sexual and economic exploitation, stigmatisation and discrimination remain some of the basic challenges affecting OVCs. It is through community engagement approach that this community will be able to address HIV-related stigma and discrimination while providing support to children and families living with HIV. Community-driven advocacy helps identify and publicize obstacles to HIV treatment

access, addresses stigma and discrimination, and promotes human rights and changes to obstructive and discriminatory laws and practices (UNICEF, 2013:23).

4.5 COMMUNITY RESILIENCE RELATED TO OVC AFFECTED BY HIV AND AIDS

The Benoni community has taken decisive steps to ameliorate the impact of the AIDS epidemic on OVC. This includes the establishment of the LCDA. The idea of establishing Lithanza came from a former primary school teacher who could no longer bear to see the pain and suffering of neglected children in her community. She mobilised the community to support her and established a community action committee to investigate the possibility of establishing a community-based organisation.

The sole mandate of the organisation was to respond directly to the challenges experienced by OVC in Benoni. *“Lots of kids had problems and nobody cared for them, they were labelled as naughty. When I spent time with them I noticed they came from broken families and were staying with grandparents and were angry at their father who has moved in with a new girlfriend after the death of the wife due to AIDS related illness”.*

The situation was worse for girls, as the mother would move in with the new step-father. In many instances this opened opportunities for sexual abuse of the child. Many mothers were not prepared to listen when their daughters reported such incidences to them and in worse scenarios, even if they reported nobody believed them. The DSD (2005: 4) confirms that this is often the case: *“...orphan girls may be preferred than orphan boys for adoption because they can provide domestic labour, sexual diversion and in many instances a bride price”.* In every community there are champion “gatekeepers” who take up the plight of vulnerable groups by mobilising the community to respond to challenges. They might initiate as individuals but will organise the entire community to participate in such initiatives.

This affirms the findings of the literature review regarding the centrality of the seven key principles of community resilience defined by Gurwitch *et al.*, (2007:61-68) as: (i)

Connectedness, commitment, and shared values; (ii) Participation; (iii) Structure, roles, and responsibilities; (iv) Support and nurturance; (v) Critical reflection and skill building; (vi) Resources and Social Capital and (vii) Communication. The narrative account confirms that Lithanza has observed the same key principles in its quest to build community resilience related to OVC affected by HIV and AIDS in Benoni. It is important to note that, as observed by the researcher, this process does not have to follow a linear approach nor a mechanical development process. In the case of Lithanza, the process has been organic and driven by the needs of the community.

The LCDA is registered with the DSD as a non-profit organisation (NPO) in accordance with the NPO Act No 71 of 1997, and provides a range of services supporting OVC in Benoni including: caring for OVC, supporting PLHIV and AIDS and supporting elderly citizens. Community members form an integral part of the organisation through direct representation on the executive committee, which meets on a regular basis. To ensure transparency and accountability, the constitution of the organisation stipulates that a detailed financial and programmatic report should be presented at least once a year in an annual general meeting. The project director is responsible for day-to-day administration and is supported by the programme staff and full-time volunteers.

The organisation is open to all OVC in Benoni. A child can be referred to Lithanza by an educator, a community member, or a health care institution. With regard to the latter, project staff members encourage the development of referral networks between the community and health care institutions, to assist identification and reach child-headed households and OVC. Children can also apply for assistance, but typically volunteers identify and refer most OVC.

The LCDA collaborates with other government departments and agencies particularly the DSD and the Department of Home Affairs, to ensure that children obtain access to social grants and are placed with foster parents. UNICEF (2010:5) attests that the expansion of the child support grant has been instrumental in reducing child poverty, especially the depth of poverty, both because of its good targeting and because children are often more concentrated in poorer households; more than 10 million children benefited from the child support grant in 2009.

Therefore, access to the child support grant is a critical mechanism supporting children out of the economic deprivation trap and poverty. It is reliable, sustainable and can assist in restoring the dignity of OVC. Vulnerable children are integrated into the LCDA through door-to-door campaigns and home visits by volunteers and caregivers. The following programmes were investigated by the researcher as part of this study.

4.5.1 Key Programmes

Drop-in centre. This programme provides fresh cooked meals to OVC after school and on weekends, except Sundays. Also linked to this centre is the homework assistance project, which ensures that all children are provided with the necessary support to complete their homework before going back to their respective homes, as some are staying with illiterate grandparents who do not have capacity to assist them. During this time children are exposed to mental stimulation in the form of exercises, games and life skills and have access to the residential auxiliary social worker who provides group and individual sessions. Complicated cases are referred to professional social workers and/or reported to the police for further follow up and investigation. In December 2011, the centre provided nutritional support to about 278 OVC. The numbers are not cumulative as they are only based on new children entering the programme.

The centre was established in line with a set of DSD guidelines and receives financial support from the DSD. The department supports community-based drop-in centres that seek to provide holistic care and support to OVC as long as they promote the key principles outlined by DSD: (a) Best interests of the child; (b) protection; (c) development; (d) participation and (e) non-discrimination (DSD guidelines for the establishment of drop-in centres). The DSD has developed a set of guidelines to guide the community when establishing such centres such as, the minimum requirements; list of proposed activities and standard operating procedures to ensure standardisation, efficiency and the protection of children's rights.

Material support, food parcels and house visits. All registered children receive food parcels on a monthly basis. Shoes are provided at the beginning of the year and the children attend a Christmas party. House visits are conducted by assigned volunteers to provide support and assist

with other household responsibilities. This intervention is provided to vulnerable children staying with ill parents and to child-headed households. This mitigates abject poverty and economic deprivation; it has been estimated that approximately 12 million (65%) of South African children live in poverty (UNICEF, 2010:2). OVC in particular are highly affected by poverty in South Africa and in this case in Benoni, and therefore any activity that provides material support is much appreciated by children. At the Christmas party OVC are given gifts and other items sponsored by the local chamber of commerce. The respondents had the following to say about the services provided by Lithanza care givers:

“I enjoy spending time with the aunt as I always share stories with her, she listens to my stories and she always assures me that things will be better one day” (Child, 12 years).

“The aunt does not shout at us like my grand parent who scolded us and called us with names which we do not like” (Child, 13 years).

“I like them, they share their love including the little things they have with the community, they are the greatest gift to this community, and we are indebted to them” (Community member).

These testimonies show that the OVC appreciate the services provided by the care givers as they move from one household to another providing love and emotional support to children affected by the AIDS pandemic.

School holiday programme. This provides a combination of programmes to ensure that children are provided with psychosocial support during the school holidays. For some OVC this is a lonely period as they have no extended families to visit like other children, nor do they have the means to participate in entertainment activities. The programme focuses on edutainment as it combines life skills and sporting activities. Three respondents shared their experience of this programme:

“During school holidays I always think about my daddy and mummy, I wonder what life would have been with them around... I wish I could take a train or bus and go far away” (Child, 12 years).

“I do not like school holidays as I am constantly reminded that I do not have a mother as she died in June. It was a very cold winter day; there was no paraffin to warm the house” (Child, 14 years).

“I wish we had more resources and volunteers to bridge the gap” (Community leader).

Child care forum. The programme was conceptualised by the DSD for implementation by community-based organisations. It can be accessed close to home, encourages participation, responds to the needs of people, encourages traditional community life and creates responsibilities (DSD Guidelines for establishing CCF, 2006:4). During the initial stages there were no implementation guidelines, with CBOs receiving minimal support from the DSD. Because of its awareness of the enormous challenges confronting OVC in Benoni, Lithanza was one of the few CBOs that volunteered to implement this programme. The initial stages were mainly characterised by trial and error. The programme aims to develop and build children’s resilience within school.

Lithanza has a group of trained school facilitators who work with assigned teachers in seven schools in Benoni to set up CCF. A typical CCF will have a teacher, a facilitator and an executive committee elected amongst learners. The executive committee receives mentoring and support from the assigned facilitator whilst the teacher acts as the liaison person between the committee and the school. It emerged during the focus group discussions that learners enjoy the non-interference by adults as this provides them with an opportunity to discuss their “stuff”, as one learner put it. Members of the CCF are usually drawn from diverse backgrounds. The researcher observed that the majority of these learners are well respected by their peers as they possess good leadership skills and some of them are OVC.

The sole responsibility of the CCF is to mobilise learners to support OVC in their school. This can be achieved in various ways such as: material support e.g. toys and clothes which are discreetly distributed to needy children *via* the school or Lithanza depending on individual learners’ circumstances. The CCF also hosts awareness raising days focusing on stigma and discrimination and bullying of OVC.

Interestingly, once they became aware of the stigma attached to the nutritional support provided to the learners (school feeding schemes), schools encouraged all learners to use the school feeding scheme; no lunch boxes are allowed in the two schools that the researcher visited. This was discussed with the CCF in consultation with the School Governing Body. It is through such small initiatives that schools are transformed to benefit all children, ensuring that no stigma is attached to OVC. The respondents said:

“We started small but we are reaching more children, ideally we would like to be present in all schools in order for us to reach all children in this community” (Care giver).

“More and more schools are inviting us, we need more hands, the challenges are there but we are addressing them” (School facilitator, Lithanza).

“My attitude has changed towards people living with HIV and orphans, I am grateful to the consistent reminder by my child who attends the Lithanza programme” (Community member).

Other broad initiatives include organising and hosting community awareness campaigns on topical issues such as HIV and AIDS awareness, child abuse and exploitation, gender-based violence and alcohol and drug abuse. All these programmes are implemented in collaboration with various stakeholders, e.g. parents, SA Police Services which normally participate in crime awareness campaigns, child and women abuse campaigns, the DSD which assists the community with social grant applications and statutory cases, business, which provides funding and food, schools and faith-based organisations.

“Despite all their pain, grief and lack of material support, it is fulfilling to see children having their hope restored again without being worried about their next meal as they know that someone will provide for them. We can’t pretend to replace the love of their biological parents but we are there for them... we want them to be the doctors, teachers and lawyers they always dream of being” (Guardian).

CONCLUSION

This chapter has presented and discussed themes that emerged from the qualitative study. Chapter six will present a summary of the study, conclusion and recommendations based on the main findings.

CHAPTER 5: CONCLUSIONS AND RECOMMENDATIONS

5.1 INTRODUCTION

This chapter concludes this study. It commences with a presentation of the study's overall conclusions, taking into account the objectives of the study as well as the study questions. The chapter also provides a summary of the findings; discusses the limitations of the study and provides recommendations for implementation and future research.

5.2 SUMMARY OF THE FINDINGS

This study has adequately addressed the research questions based on the three study objectives:

- i. Community awareness and understanding of HIV and AIDS and its impact on the community;
- ii. Challenges experienced by OVC; and
- iii. Community resilience related to OVC affected by HIV and AIDS.

5.2.1 Research Question 1: What is the nature of the Benoni community's understanding of HIV and AIDS and its impact on the community?

It was found in the research that there was general consensus amongst the respondents regarding the severe impact of the AIDS epidemic, particularly on OVC in Benoni. The respondents were not able to pinpoint the exact number of OVC in Benoni; this is due to poor data collection and monitoring across all spheres of government. The most reliable data available are the number of maternal orphans provided annually by the DSD; presented in previous relevant sections. However, there is general acknowledgement that current government intervention programmes have had a positive impact; in particular ARV programme and child support grants.

The flexible legislative framework which promotes community intervention (community based care programmes) and empowerment in OVC programmes was also noted as a positive factor. This legislative framework empowers communities to design their own programmes taking into consideration contextual issues and the uniqueness of each community. The framework enhances community resilience. FHI (2001:3) maintains that appropriate government policies are essential

for the protection and wellbeing of OVC and their families. These policies should prohibit discrimination in access to medical services, education, employment, housing, and protect the inheritance rights of widows and orphans.

5.2.2 Research Question 2: What specific challenges are faced by orphans and vulnerable children in Benoni?

The study found that the range of challenges experienced by OVC in Benoni included: (i) Non-disclosure by parents, which can be attributed to stigma and fear of discrimination; (ii) Economic deprivation and disrupted schooling due to the direct impact of the AIDS epidemic on the household; and (iii) Children caring for an ill parent with AIDS and child-headed households. The death of parents due to an AIDS-related illness had a negative impact on children.

The respondents strongly agreed that being an AIDS orphan at a young age poses significant challenges at various levels. This finding concurs with the literature review, which provided a detailed discussion on challenges experienced by OVC in countries like Brazil, India and elsewhere in South Africa. OVC and their families are confronted with severe threats to their well-being including isolation, loss of income and reduced access to education, shelter, nutrition and other necessities.

When families and children are forced to focus on mere survival, attention is diverted from factors that contribute to long-term health and well-being. It is widely recognised that the problems faced by AIDS-affected children and households result either directly or indirectly from the economic impact of HIV and AIDS (FHI 2001: 4). The challenges experienced by OVC in Benoni are not unique; therefore, South Africa can draw lessons from other countries.

The narrative account of study participants' responses has therefore confirmed the findings of the literature on the challenges facing OVC.

Research Question 3: How does community resilience related to OVC assist the community to address some of the challenges confronting OVC in Benoni?

The study found that the Benoni community has harnessed its resilience and adopted community-based programmes that promote community participation, stakeholder engagement and multi-sectoral HIV and AIDS programmes.

These are a clear indication of visionary leadership which is determined to mitigate abuse, exploitation, stigmatisation and discrimination against OVC. Given support and the opportunity to do so, children have the capacity to champion their own development by supporting one another. Adults should create a suitable environment to build children's resilience.

The study found that the children supported by the LCDA in Benoni have access to the following services, such as Material support, child protection, psychosocial support, educational support, life skills and HIV prevention and referrals for additional services such as health care and statutory assistance i.e. foster care and obtaining birth certificates.

The researcher therefore concludes that the Benoni case study shows that community resilience provides a viable option for supporting OVC affected by HIV and AIDS. Government should continue to support such initiatives as they empower affected communities and thus ensure sustainable OVC programmes.

5.3 LIMITATIONS OF THIS STUDY

This study focused on the Benoni community and OVC serviced and supported by the LCDA. The findings of this study are therefore limited to this community.

5.4 RECOMMENDATIONS

The following recommendations are empirically founded to the extent that this study has proven based on research objectives, research questions and research findings:

5.4.1 To Lithanza/Community

The researcher observed that non-disclosure by parents is a clear indication that stigma and discrimination are still attached to HIV and AIDS in Benoni. This issue therefore needs to be addressed by the community. *As the core recommendation, the community should intensify its campaign against stigma and discrimination related to HIV and AIDS and help parents to disclose their status/illness.* The memory box programme should be explored as a possible intervention in this regard, supported by other programmes. “Before a parent dies it is essential that the parent have access to psychosocial support. Programs have begun to effectively establish support groups for infected adults whereby they can discuss and gain support for their own needs. The memory box (e.g., containing photos, identification books, diary or letters etc.) is a simple tool that can assist parents to recount the family, cultural history, and memories of children’s childhood activities. The development of memory box is also structured so that it leads, in a comfortable way, into possible will-writing and disclosure” (FHI, 2001:5).

It was interesting to note that, despite these households being situated in poor neighbourhoods in a township, there was a high level of “*ubuntu*” which is a clear indication of community resilience in Benoni. It was observed that with solid community support, child-headed households provide a sound alternative form of care for orphans, as children are not separated from one another, their friends and familiar surroundings, and are able to draw strength from one another. This form of household should be strengthened and supported in order to maximise its benefits. Most importantly, a proper referral system should be put in place, in collaboration with NGOs in order to address the challenges faced by OVC in Benoni. It is evident that the challenges require the mobilisation of outside stakeholders and resources.

5.4.2 Non-Governmental Organisations

The few NGOs present in Benoni should provide technical assistance, capacity building and funding to community based organisations in Benoni. This will ensure sustainability of the programmes and community based ownership. They should also assist the community to develop

comprehensive monitoring and evaluation systems in order to enhance community programmes. Such systems will provide the community with reliable data on OVC in Benoni.

5.4.3 Government

Mitigating the impact of HIV on the OVCs' in Ekurhuleni is a particularly formidable task. Therefore, government especially the DSD should conduct a rapid survey on OVC challenges and programmes implemented by the community. This will enable government to link OVC to programmes within proximity. The DSD should ensure that there is adequate financial support for community based OVC programmes. This will strengthen community resilience with regard to OVC. Moreover, government should facilitate synergy between government departments supporting OVC and integrate them within the child's rights framework.

5.5 ISSUES THAT NEED FURTHER RESEARCH

There is a need for further research on community based interventions regarding caring for orphans since the number of OVC's are on the increase. Government should also investigate a best model for funding community based OVC programmes with fewer requirements.

5.6 CONCLUSION

The impact of the AIDS epidemic is likely to persist well into the future. In order to mitigate the impact of the AIDS epidemic, the researcher argues that community resilience should be located within the broad framework of community participation and resilience should be understood as a process of community participation, not merely as a concept, that normalises resilience as part of day-to-day living, as is the case in Benoni Community resilience provides a practical intervention framework whilst connecting the community with the future to restore hope and strength. Gurwitch *et al.*, (2007:61-62) observe that resilient communities are characterised by [inter]-connectedness, commitment, and shared values among community members; participation by community members in the affairs of the community; and support and nurturance of the needs of community members.

This study has achieved its objective of exploring and attaining an in-depth understanding of community resilience strategies on the challenges faced by OVC aged 13 to 15 years affected by HIV and AIDS in Benoni, EMM, Gauteng. The themes generated by the study allowed for an understanding of the nature and meaning of the challenges experienced by AIDS orphans and how community resilience can assist affected communities to respond to such challenges.

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ANNEXURES

Annexure A: Request Letter

**Project Director
Lithanza Community
Development Organisation
11 August 2011**

RE: Permission to Conduct Research Study

Dear Ms Thalitha Khoza

I am writing to request permission to conduct a research study at your organisation. I am a final year student, studying for a MA (Social and Behavioural Studies in HIV/AIDS) at UNISA. I am in the process of writing my dissertation. The research topic for my study is entitled “Exploring challenges faced by OVC affected by HIV and AIDS in Benoni-Ekurhuleni Metropolitan”.

The main objectives of my research study are:

- a) To explore community understanding with regard to HIV/AIDS and its impact to the Benoni community
- b) Explore specific challenges experienced by OVC in Benoni
- c) To understand community resilience related to OVCs affected by HIV and AIDS in Benoni

Based on the above objectives, I request your organisation to allow me to recruit and interview six OVCs affected by HIV and AIDS between the ages of 13 and 15 years. I also hope to recruit (parents/guardian or social worker/s) of these children to anonymously complete their own 1-page semi structured questionnaire of which a copy is enclosed. If approval is granted, the interviewing will take place after school at home or another quiet setting. Parent participants would complete the survey at the comfort of their home.

Interested participants, who volunteer to participate, will be given a consent form to be signed by their parent or guardian (copy enclosed) and returned to me. Since this is qualitative research, I would also like to request your organisation to provide me with access to other primary

documents relating to OVCs such as life stories, beneficiary registers, minutes of meetings, volunteer's handbooks diaries and programme related documents.

I will also request information relating to community intervention and programmes developed to deal with the plight of OVCs. Most of the data I will be collecting during the study will be collected from Lithanza Community Development. I also request you to allow me to organize a focus group discussion for all participating parents/guardian or social workers in order to obtain inputs from them as well.

The survey process should take no longer than 3 weeks. The survey results will be pooled for the purposes of the dissertation and individual results of this study will remain absolutely confidential and anonymous. Once the study is completed I will facilitate a feed- back meeting with all the research participants. No costs will be incurred by either your organisation or the individual participants.

Your approval to conduct this study will be greatly appreciated. I will follow up with a telephone call in the near future and would be happy to answer any questions or concerns that you may have at that time. You may contact me at my email address: 31625967@mylife.unisa.ac.za alternatively: ngonyama.luyanda@gmail.com

If you agree, kindly submit a signed letter of permission on your institution's letterhead acknowledging your consent and permission for me to conduct this survey/study at your organisation.

Yours sincerely,

Luyanda Ngonyama

Annexure B: Oral Informed Consent for Guardians/Social Worker

Introduction

Good day, I am Luyanda Ngonyama. I am a final year student, studying MA (Social and Behavioural Studies in HIV/AIDS at the Department of Sociology at UNISA. In order for me to finish my studies I am required by the University to conduct a research. I have chosen to research about the programmes implemented by your community in order to assist orphans and vulnerable children based in your community. This will require me to interview orphans and vulnerable children affected by HIV and AIDS between the ages of 13 and 15 years here in Benoni. I have been informed that you are living with a child in this house who lost a parent or both parents and that is why I would like you to participate in this interview.

Confidentiality and Consent

I am going to ask you some personal information that some people may find it difficult to answer. If you are not comfortable or find it difficult to answer some of the questions please say so and I will stop the interview. Please note that all the answers are strictly confidential, which means that I am not going to share them with anyone. Your name will not be written in this form to protect your identity. I would greatly appreciate your willingness to participate in this interview. Please also note that you might be requested to participate in a follow up interview but this will depend on your availability and willingness.

Due to the sensitive nature of this interview we have arranged for a debriefing session (psychosocial support) after the interview with Lithanza Community Development

Would you be willing to participate?

If you want to contact the researcher or the research supervisor during office hours, please call:

Research Supervisor: Dr. Denise du Toit (012 6532896)

Researcher: Luyanda Ngonyama: 012 395 9097

I(Full Name of Interviewee).....SignatureDate.....

(Certify that informed consent has been verbally given by the respondent)

I (Full Name).....Signature.....

Interviewer.....Date

Annexure C: Oral Informed Assent

Introduction

Good day, I am Luyanda Ngonyama. I am a final year student, studying MA (Social and Behavioral Studies in HIV/AIDS at the Department of Sociology at UNISA. In order for me to finish my studies I am required by the University to conduct a research. I have chosen to research about the programmes implemented by your community in order to assist orphans and vulnerable children based in your community. This will require me to interview orphans and vulnerable children affected by HIV and AIDS between the ages of 13 and 15 years here in Benoni. I have been informed that you are living with a child in this house who lost a parent or both parents and that is why I would like you to give permission to the child to participate in this interview. This must be explained to children.

Confidentiality and Consent

I am going to ask the child some personal information that some people may find it difficult to answer. If the child is not comfortable or find it difficult to answer some of the questions she/he must say so and I will stop the interview. Please note that all the answers are strictly confidential, which means that I am not going to share them with anyone. The name of the child will not be written in this form to protect his/her identity. I would greatly appreciate your willingness to allow the child to participate in this interview. Please also note that the child might be requested to participate in a follow up interview but this will depend on his/her availability and willingness. Due to the sensitive nature of this interview we have arranged for a debriefing session (psychosocial support) after the interview with Lithannza Community Development. Would you be willing to allow the child to participate? If you want to contact the researcher or the research supervisor during office hours, please call:

Research Supervisor: Dr. Denise du Toit (012 6532896)

Researcher: Luyanda Ngonyama: 012 395 9097

I(Full Name of Interviewee).....SignatureDate.....

(Certify that informed assent has been verbally given by the guardian/social worker)

I (Full Name).....Signature.....

Guardian/Social Worker.....Date

Annexure D: Interview Guide with key Informants

1. Based on your understanding how serious is the impact of HIV/AIDS in your community?
2. How many households do you know exists without living parents (child headed households) in your community?
3. What do you think is the reason for the increase in the number of parentless households in your community?
4. Does your community talk openly about HIV/ AIDS? What is the perception and attitude towards people living with HIV and AIDS?
5. How does the community treat OVCs? Are there any negative perceptions or attitudes about being an OVC in this communality?
6. From your own observation, how do other children relate to OVCs, do they play with them, if no why?
7. Who are the main stakeholders providing assistance to OVCs and how does the community cope with the current situation, what are the main community interventions/ programmes?
8. How does the community support OVS's to deal with ill-treating, abuse, exploitation, discrimination isolation etc?
9. Does the community provide OVCs with shelter, food, clothes, school fees, books, and school uniforms or any other assistance in this regard to OVS's and how often?
10. What type of support does the community provide directly to OVCs affected by HIV and AIDS to deal with the death of their parents?
11. Does this intervention include formal psychosocial support?
12. Would you consider this intervention adequate and sustainable?
13. In your view, what aspects of the current support are most efficient?
14. Would you like to share other challenges that we have not discussed?
15. In your perception, are OVCs positive about the current support your community provides to them and why?
16. In your perception, what do you think that they like least about the current support?
17. What do you recommend to improve the existing intervention?
18. What is your understanding of a resilient community and what do you think are the key characteristics of a resilient community?

19. Would you consider your community as resilient in the way it responds to challenges confronting children orphaned by AIDS?
20. Does your community always respond in this manner when confronted with similar challenges?
21. What do you think are the main strategies/factors this positive response?
22. What are the key coping strategies adopted by your community to respond to social challenges particularly OVC challenges
23. What keeps/ unites this community in its efforts to address OVC?
24. Do you have any community champions/role models dedicated to work with OVCs and what is their role towards community mobilisation?
25. What do you think are the main challenges related to community based response?
26. What would you consider as the key lessons from this intervention?
27. Are you happy to be part of this community
28. We are coming towards the end of our interview is there any information that you would like to share with me?

Thank you very much for making time for this interview

Interview conducted by:

Name.....

Location.....

Date of interview.....

Annexure E: Interview Guide with Guardian/Social Worker

- 1.1 How is your community organized, do you have community leaders and structures addressing social challenges such as HIV and AIDS? If yes, describe the community structure, the main leaders and their role; the organisations and the challenges
- 1.2 Based on your understanding how serious is the impact of HIV/AIDS in your community? For example, have you noticed an increase in the number of child headed households?
- 1.3 Does your community talk openly about HIV and AIDS and what is the perception of the community towards people living with HIV and AIDS?
- 1.4 Do you know the number of OVCs in your community and do you think their number is increasing?
- 1.5 Do people in your community discriminate against OVC's? If yes, why?
- 1.6 From your own observation, do other children play with OVCs, if no why?
- 1.7 Does your community work together to respond to challenges faced by OVC especially neglect, exploitation, abuse, discrimination etc?
- 1.8 What type of support does the community provide directly to OVCs affected by HIV and AIDS to deal with the death of their parents?
- 1.9 Does the community provide material support such as shelter, food, clothes, school fees, books, or any other assistance in this regard to OVS's and how often?
- 1.10 Does this intervention include formal psychosocial support?
- 1.11 Would you consider this intervention adequate and sustainable?
- 1.12 In your view, what aspects of the current support are most efficient?
- 1.13 In your perception, what do you think that they like least about the current support?
- 1.14 Would you describe your community as working together to provide care and support to OVCs?
- 1.15 What else would you like to share with me regarding the provision of services by your community to OVC's?

Thank you very much for making time for this interview

Interview conducted by:

Name.....

Location.....

Date of interview.....

Annexure F: Interview Guide with Orphans and Vulnerable Children

1. How does it feel to be a child without parents/someone taking care of you when growing up in Benoni?

Probes:

- 1.1 What do you like?
- 1.2 What don't you like?
- 1.3 How would you like things to be?

2. Did someone tell you why your father/mother died?

Probes:

- 2.1 Who told you?
- 2.2 How were you told?
- 2.3 How old were you?
- 2.4 Did you have a chance to say good bye to your father/mother at the funeral?

3. Understanding the family situation before the passing of your mother/father?

Probes:

- 3.1 Did she/he tell you that she is too ill and will die due to AIDS (related illness)?
- 3.2 Did she/he prepare a memory box for you so that you can keep all the special photos and other items for remembrance?
- 3.3 Did you take care of the one who was ill?
- 3.4 Did you help by cleaning and preparing food in the house when your mother/father was too ill?
- 3.5 What did you learn about HIV/AIDS?

4. Did your mother/father tell you who will look after you when she/he is dead?

Probes:

- 4.1 Where will you stay?
- 4.2 Who will look after you (food, clothing, schooling etc) for you when she/he died
- 4.3 What will happen to the house (inheritance and property protection)?

5. Did anything change in the way you live since the death of mother/father?

Probes:

- 5.1 Where do you stay?

5.2 Who helps you with food, clothing, cleaning etc?

5.3 Did you eat this morning?

6. Do you have a brother or sister?

6.1 Where are they?

6.2 Are they happy?

6.3 Who helps them?

6.4 How often do you see them?

7. Do you have friends to play with?

Probes:

7.1 If not, why?

7.2 Do they call you ugly names that you do not like (stigma and labelling)?

7.3 What are those names?

7.4 Do you play with them?

8. Psychosocial needs

Probes:

8.1 How are you feeling?

8.2 How often do you feel happy?

8.3 How often do you feel unhappy?

8.4 What makes you happy?

8.5 Do you ever feel worried?

8.6 What makes you feel worried?

8.7 Did you ever feel like running (where?)?

9. Life overview and future plans

Probes:

9.1 What do you like most about how you live now & include example?

9.2 What you do not like about your current life?

9.3 What would you like to be when you grow up?

9.4 Who do you like most in your life?

9.5 What help do think you need to be what you like most?

10. Community support

Probes:

- 10.1 Do the people around provide you with things like clothes, school fees, books, school uniforms, and talk to you about mommy/daddy's death?
- 10.2 What do you like most about the people living here's help?
- 10.3 What do you like least about the help from the people living here?
- 10.4 Are you happy to stay with the people around you?
- 10.5 Who do you like most in the people who live around/with you?
- 10.6 Who do you like least and why?
- 10.7 What other things/activities do you see here helping children like you?
- 10.8 Are you happy about the help you receive?
- 10.9 What else would you like to be helped with?

11. We are coming to the end of our interview, is there anything you would like to share with me?

Thank you very much for making time for this interview

Interview conducted by:

Name.....

Location.....

Date of interview.....

Annexure G: Permission Letter



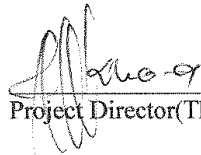
02 October 2011

RE: Permission to Conduct Research -Student no: 31625967

Dear Mr. Ngonyama

With reference to the above matter, permission has been granted. I will appreciate if could visit the Lithanza office to finalise logistics i.e. date; research questions, criterion, venue etc. We are looking forward to assist you in this project as we hope it will strengthen our community.

Yours sincerely,



Project Director(Thalitha Khoza)

UNIVERSITY OF SOUTH AFRICA

EXPLORING COMMUNITY RESILIENCE STRATEGIES ON CHALLENGES FACED
BY ORPHANS AND VULNERABLE CHILDREN AFFECTED BY HIV AND AIDS IN
EKURHULENI METROPOLITAN MUNICIPALITY, GAUTENG

by

LUYANDA GEORGE NGONYAMA

NOVEMBER 2013