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AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
BP	Blood Pressure
CBO	Community-Based Organisation
CBD	Central Business District
CHCWs	Community Health Care Workers
CSG	Child Support Grant
CTMM	City of Tshwane Metro Municipality
DoH	South African Department of Health
DOTS	Direct Observation Treatments
DRC	Democratic Republic of Congo
DSD	Department of Social Development
FBO	Faith-Based Organisation
HAART	Highly Active Antiretroviral therapy
HBC	Home-Based Care
HBCG	Home-Based caregiver
HBCGs	Home-Based Caregivers
HIV and AIDS	Human Immunodeficiency virus and Acquired Immune Deficiency Syndrome
KZN	KwaZulu-Natal
MDR	Multi Drug Resistant
MDT	Multi-disciplinary teams
MGM	Monday General Meeting
NGO	Non-Governmental Organisation
NGOs	Non-Governmental Organisations
OAG	Old Age Grant
PLWHA	Persons Living with HIV and AIDS
SASSA	South African Social Security Agency
SHAZ	Shaping Health of Adolescents in Zimbabwe
STI	Sexually Transmitted Infections
SWAN	Social workers' AIDS Network
TB	Tuberculosis

TASO	The AIDS Organisation
UNAIDS	Joint United Nations programme on AIDS
UNISA	University of South Africa
WHO	World Health Organization

CHAPTER ONE

GENERAL INTRODUCTION AND ORIENTATION TO THE STUDY

1.1 INTRODUCTION, BACKGROUND, PROBLEM FORMULATION AND RATIONALE OF THE STUDY

The first chapter of this thesis (research report) entitled G*eneral introduction and orientation to the study,* introduces the topic chosen for the investigation and the decision to embark on this research endeavour is motivated. In addition, the research questions derived from the identified research problem are provided as well as the goals and objectives formulated to plot the course of answering the stated questions. Furthermore, the theoretical framework adopted for the study is described, and the research methodology is presented.

Locally and across the globe, international health entities, governments and non-governmental organisations (NGOs) acknowledge the role of home-based caregivers (hereafter referred to as HBCGs) in ensuring care and support for, amongst others, those who are affected and infected by HIV and AIDS. (Qalinge, 2011:51; Akintola, 2010:1; Mohammad & Gikonyo, 2005:v; World Health Organisation, 2002:9; Department of Health, 2001:2; World Health Organisation, 2000:1). The practice of home-based care (HBC) gained prominence in response to the scourge of HIV and AIDS in the early eighties, although it was mostly on a voluntary basis. However, it actually existed as far back as the 16th century mainly among French religious and charitable groups like the Madame de Chantal's St France de Sales association. They were established to comfort and assist long-term patients with chronic and terminal illness and those with disabilities within their homes (Tshabalala, 2008:1&3; Ginzberg, Balinsky & Ostow, 1984:18).

The 18th century saw several attempts to formalise HBC. Through the work of Florence Nightingale, the first graduate nurses in home nursing services served at the Women's Branch of the New York City Mission. In the state of New York, US, voluntary agencies emerged in Buffalo (Tshabalala, 2008:3; Dieckmann, 2005:9;

McClain, 1995:1). During the 19th century, the Metropolitan Life Insurance Company in the United States saw HBC becoming a type of profit-making entity, and started to offer HBC as a benefit through its medical aid as bait to attract policy holders (Brasfield, 2011:145; Hitchcock, Schubert & Thomas, 2003:33; McClain, 1995:4; Benjamin, 1993:129; Ginzberg et al., 1984:2-3).

Prior to these developments in the field of the HBC in the West, its practice and principles in Africa were already in place as part and parcel of being an African. Ubuntu, as an African worldview in many southern African cultures, promotes the notion of sharing and caring for one another. It is an expression of compassion, kindness and empathy for the betterment of everyday life and the maintenance of solidarity within communities (Martson, 2015:424; Sarpong, Bi & Amankwah-Amoah, 2016:17; Makoae & Jubber, 2012:38). Africa had its own traditional practices of caring thousands of years ago, often integrated with spiritual counselling and care (Sama & Nguyen (2008:3). In Africa, the existence of HBC can therefore be viewed as an effort to further strengthen the African value of Ubuntu already existing.

As far back as the 1940s and the 1950s, HBC was being formalised in Africa. In countries like Kenya and South Africa, women social workers were being trained in this field (Brown, 2014:148-149; the Presidency of Republic of South Africa, 2011:296). The 1978 Alma Ata International Conference on Primary Health Care was held in Alma Ata in Kazakhstan, a country in central Asia. Its call went out for commitment to the provision of comprehensive primary health care services to outpatients living in communities in all countries (Caregiver Action Network, 2013:9). Amongst other positive results, was the founding of organisations like the Island Hospice of Zimbabwe beginning to render HBC services as early as 1979 (Wright, Clark, Hunt, & Lynch, 2006:12).

The recognition of AIDS as a new disease in 1981 caused by a retrovirus, now termed "Human Immunodeficiency Virus Type 1(HIV-1) led to one of the most devastating infectious diseases to have emerged in recent history (Sharp & Hahn, 2011:1). This state of affairs brought about a massive shift in the focus of HBC as the effects of this disease began to affect many people. Health care institutions became overcrowded with the result that many HBC practitioners took a lead in

caring for and supporting patients with AIDS-related conditions and their loved ones in their own homes (Qalinge, 2011:51; Friedman, Mothibe, Ogunmefun & Mbatha, 2010:14; World Health Organisation, 2010:15; Tshabalala, 2008:1). In the year 1999, the cabinet of the Republic of South Africa mandated its Departments of Health (DoH) and Social Development (DSD) to oversee the implementation of a HBC programme (Friedman et al., 2010:7). This process led to the DoH developing guidelines for home-based and community-based care. South Africa thus took a stand by appreciating that HBC had a significant role to play in fighting HIV and AIDS in light of the fact that limited resources had led to an overcrowded and overstretched health care system (DoH, 2001:3).

Later, in 2000, the first HIV and AIDS and STI (Sexually Transmitted Infections) National Strategic Plan for South Africa was published. Its overarching framework encourages a multi-sectoral approach to guide and respond to HIV and AIDS (DSD, 2006:18). The introduction of the South African operational plan for comprehensive HIV and AIDS care, management and treatment in 2003 highlighted the significant role of South African HBCGs. Their main function was to ensure that patients adhered to ART (Antiretroviral Therapy); assessing and supporting them and promoting the importance of continuous care. They were expected to locate and reach out to those who missed their scheduled medication. Hence they were instrumental in HBC and recognised as such (DSD, 2006:19).

To lay a foundation for a clear understanding of the nature and scope of HBC in South Africa and the part social work plays in it, the discussion now focuses on these two aspects.

1.1.1 The concept "home-based care" explained

The Department of Social Development (DSD) (2006:1) provides the following comprehensive definition of what home-based care entails: home-based care (HBC) is the "provision of comprehensive health and social services, by formal and informal caregivers in the home in order to promote, restore and maintain a person's maximal level of comfort, function and health. HBC services can be classified into preventive, promotive, therapeutic, rehabilitative, long-term maintenance and palliative care

categories. Home-based care and support is the care or services that consumers can access nearest to home, which encourages participation by people, responds to the needs of people, encourages traditional community life and creates responsibilities."

1.1.2 The general scope of home-based care

From the quoted definition, four main elements are identified to paint a clear picture of the scope of HBC:

- **HBC services can either be formal or informal in nature**

In distinguishing between formal HBC and informal HBC services, Jooste (2008:33) refers to formal HBC services as those rendered by organisations that have clearly defined norms of conduct and practices. HBCGs are obliged to abide by them and are accountable for adhering to them. Health care professionals offering formal HBC admit patients to HBC programmes and, when necessary, include home visits as a follow-up service (Rödlach, 2010:243).

Informal HBC services, on the other hand, refer to those services that are provided by caregivers who are not affiliated to any organisation. They may even be family members or friends without any formal training (Rödlach, 2010:243; Jooste, 2008:33; Williams, 2007:379). Between these two categories, formal and informal, caregivers form a group of volunteers, usually called the HBCGs. They serve as mediators to link the clinic and the home while providing basic HBC for people living with HIV and AIDS (Rödlach, 2010:243).

- **The primary aim of HBC is to promote, restore and maintain comfort, function and health**

By comforting them and caring for them until their health conditions improve, HBCGs provide services that ensure that the dignity of both the patients and their families is restored and maintained (Chimwaza & Walkins, 2004:805). To achieve this, HBCGs provide care for the bedridden and home-bound patients, and assist their families

too. They help with applications for social grants, child care, and food parcels and, where necessary, arrange for external assistance using referral scripts (DSD, 2006:18). HBC services even extend beyond the death of the patients as they help with the burial process of their patients. They even continue to support the families and children who are left behind. They offer bereavement counselling and assist with with social grant procedures (Akintola, 2005:9&19). All these efforts on part of the HBCGs improve the quality of life of the patients and their families and enable the patients to die a dignified death in keeping with their wishes (World Health Organisation, in Akintola, 2005:2).

- **By its very nature, HBC renders preventive, promotive, therapeutic, rehabilitative and palliative care services**

The services HBCGs offer are now dealt with as engaging in therapy, rehabilitation and palliative care in which they aim to prevent HIV-infections and promote care services.

   o *Preventive and promotive care services*

Prevention refers to an action, or actions that are undertaken to prevent an illness from setting in (Tshabalala, 2008:109). In the context of HIV and AIDS, this would mean action to prevent being infected with HIV. In the case of those who are infected it would be aiming to prevent the deterioration of their health condition. This is one of the crucial roles played by HBC. It involves educating communities about the transmission and prevention of the HIV infection, nutrition, positive living and avoiding alcohol abuse (Zulu, Kinsman, Michelo & Hurtig, 2014:14; Zulu, Kinsman, Michelo & Hurtig, 2013:13; Wouters, Van Damme, Van Rensburg, Masquillier & Meulemans, 2012:12; Akintola, 2005:7).

Promotion services are geared towards raising awareness in communities concerning the importance of maintaining good health and taking care of themselves to protect infections and deteriorating health conditions (Tsheboeng, 2015:23; Takasugi & Lee, 2012:841; Tshabalala, 2008:109). To achieve this, HBCGs visit the homes of their patients regularly. Here the household receives nursing care and

education. Their treatment is monitored and adherence to treatment too is supported (Wouters et al., 2012:12; Waterman, Griffiths, Gellard, O'Keefe, Olang, Ayuyo, Obwanda, Ogwethe, & Ondiege, 2007:1028). They also encourage HIV-testing and help in direct observation treatments (DOTS) for patients who may be on Tuberculosis (TB) treatment.

- o *Therapeutic care services*

During a patient's illness, social workers and members of the multi-disciplinary team (referred to as MDT) develop a therapeutic relationship with the patient and their families for which they have professional expertise (Sanders, Bullock and Broussard, 2012:10). In the absence of the MDT members, it is the HBCGs who enhance these relationships by assessing and supporting the patient's adherence to ART and other therapies (Tsheboeng, 2015:23; DSD, 2006:19). Among the therapeutic services is moral and spiritual support the HBCGs provide through praying, listening and simply staying with the patients to demonstrate compassion, patience and tolerance (Akintola, 2008:124).

- o *Home-based rehabilitation*

South Africa's commitment to the provision of HBC is home-based rehabilitation (HBR) - a service that is provided in people's homes. It is a response to the World Health Organisation (WHO)'s call expressing a need for it (WHO, 2004:2). As Cobbing, Hanass-Hancock and Myezwa (2015:2) observe, with the availability of highly active antiretroviral therapy (HAART), living with HIV and AIDS has become more of a chronic condition rather than a terminal one. This means that, despite living longer due to HAART, PLWHA could be prone to impairment and disabilities that might require rehabilitation (Cobbing et al., 2015:2). The services rendered in this category involve providing practical help, for example like using crutches (Tshabalala, 2008:7). Cobbing et al., (2015:2) point out that HBC in South Africa, both in practice and in research, is lacking in the realm of HBC for PLWHA. This is despite evidence of its effectiveness in other chronic conditions such as stroke and coronary artery disease.

  o *Palliative care services*

Regarding palliative care services, Cameron-Taylor (2012:4) is of the view that HBC involves the provision of integrated and multi-disciplinary services for patients who live with an active, progressive and far-advanced disease for whom cure is no longer an option, prognosis is limited, and to whom quality of life is a concern. Tshabalala (2008:7) holds a similar view pointing out that palliative care involves symptomatic treatment, pain management, nutritional support and provision of counselling. For a patient whose disease is not responding to curative treatment this is essential. This clearly shows that palliative care cannot solely be the responsibility of a HBCG; it is rather a collective effort by members of the MDT. In other words, palliative care is a multi-disciplinary activity involving services from physiotherapists, occupational therapists, pastors and social workers (Cameron-Taylor, 2012:13-15). The main responsibility of the HBCGs at this stage is to support these initiatives. They have to ensure, among other things, that patients comply with the directives and administration of a relevant service and, where necessary, lobby for an appropriate service on behalf of the patient.

- **For easy access HBC services should be located near the patient's home**

As enshrined in the Constitution of the Republic of South Africa (South Africa, 1996), access to health care is one of the fundamental rights every person has. It is for this reason that HBC services are meant to be accessible to the patients whenever they are required. Making HBC services accessible in patients' homes is another initiative that heeds the international call to make a wide range of services available in societies. It also promotes the well-being of PLWHA in communities (Adebajo, Bamgbala, & Oyediran, 2003:110). HBCGs visit the homes where their patients live to render care and support services (Akintola, 2005:8; Adebayo, Irinoye, Oladoyin & Fakande, 2004: 51-52; Akintola, 2010:7; Akintola, 2010:3; Rödlach, 2009:426).

- **HBC encourage collective participation and community involvement**

Volunteer caregivers normally render HBC services. NGOs, community-based organisations (CBOs) and faith-based organisations (FBOs) mobilised them in the community. They are trained to visit patients in their homes to counsel, assist with household chores and educate family members about their service (Akintola,2010:2; Wringe, Cataldo, Stevenson, & Fakoya, 2010:3; Qalinge, 2011:51).

- **HBC are established in such a way that they respond to community needs**

Services HBC organisations provide are dove-tailed in such a way that they are responsive to the needs of the community. Malale (2011:23-24) explains this better by describing HBC as an innovative approach to comprehensively address the needs of PLWHA in resource-limited settings. The urgent need for HBC in South Africa, according to Aktien and Kemp (in Akintola, 2008:358), was borne from a critical shortage of nurses and other medical personnel. Poor family members who were not even skilled in health care then had to care for them. This prompted HBC establishments to respond to this situation as an alternative to hospital care.

- **HBC embraces and encourages traditional and community life, stressing a sense of responsibility**

The traditional African value of Ubuntu and a collective responsibility in fighting the scourge of HIV and AIDS are two of the premises on which South African HBC is founded. Ubuntu, as Allosopand (in Hlahane, 2008:121) describes, is about the essence of humanity that embraces hospitality, that goes an extra mile for the sake of caring for one another, and believes that a person is a person through other people. During her visit to one of the HBC projects in Soweto, for example, the then South African Minister of Health Dr Manto Tshabalala-Msimang described HBC as "centred on Batho Pele[1] and geared towards community empowerment" (Department of Social Services and Poverty Alleviation, 2005:5).

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[1] Batho Pele means people first, is a common South African practice in which another person's interest is put before your own as a way of encouraging caring for one another.

1.1.3   The role of social workers in home-based care for PLWHA

The social worker's role in HBC is one of the crucial roles that another person cannot perform (Hall, 2008:55; Jacobs & Lurie, 1984:89; Reckrey, Gettenberg, Ross, Kopke, Soriano & Ornstein, 2014:331). They generally provide psychosocial support and develop intervention programmes to prevent the spread of disease (Hall, 2008:55). Whereas Berzoff, Lucas, DeLuca, Gerbino, Browning, Foster and Chatchkes (2006:46) describe social workers as the glue that links clients and their families to desirable health, economic and social systems, Tshwarang and Malinga-Musamba (2008:292) describe them as brokers linking patients and resources. Another area of service is to lobby for the necessary material, psychosocial and spiritual resources for the caregivers (Hebert, Copelan, Schultz, Amato & Arnold, 2008:282). Hence social workers are in the forefront of the MDT. The field of palliative care and the broader health care system would benefit from the involvement of social workers in these teams through service coordination in the community. This can be achieved through conducting research, developing policies, education and practice initiatives (Walsh, 2003:3; Berkman, 1996:548). The role of Social Work in ensuring support for HBCGs who are caring for PLWHA can be understood from Hall's (2008:55) description of Social Work as a distinctly unique profession which is aimed at demonstrating leadership in multi-sectoral collaboration in responding to HIV and AIDS. Fins (2006:243) endorses the social worker's role within the MDT, pointing out that practitioners in other disciplines call on social workers to give a professional and expert opinion on a psychosocial problem of one of their patients or their families. In addition, they may be tasked with the responsibility of facilitating communication between members of the MDT team.

Under ideal circumstances, social worker involvement in HBC commences the moment a patient is discharged from a health care institution. They immediately start to develop and implement a treatment plan that facilitates patients' accommodation in the family and the community (Tshwarang & Malinga-Musamba, 2008:292). In operationalising the treatment plan, the social workers would oversee the process to ensure that patient is well integrated into the community by coordinating and linking the patient, and supply their families with the required resources and services within and around the community. This could even include tasking a HBCG to provide the

necessary care and support required (Tshwarang & Malinga-Musamba, 2008:292; Cameron-Taylor, 2012:15).

In addition, social workers play a pivotal role in efforts directed to promoting social justice by preventing social problems, addressing poverty, providing counselling to the patients and their families. Additionally, engaging in developing strategies that enable patients to improve their lives (Hall, 2008:56 & 60).

The role of social worker in the context of HBC for the ill in the family even extends to preparing the patient and the family for the patient's death. Referring to this task, Hebert et al. (2008:271) have the view that not everybody can perform this task. They emphasise that, due to their training and education, social workers are capable and can provide end-of-life care and social work services to patients and their families. In this regard, they can counsel and empower the grieving families with coping strategies to manage their emotions constructively (Hebert et al, 2008:272). Moreover, they are able to assist a dying patient with finishing unfinished business and passing on in a dignified manner. Apart from rendering services directly to patients and their families, social workers can also extend their services to the community at large. At this level, they engage in community mobilisation initiatives that address the plight of HIV-prevention and AIDS care through education and raising awareness around the community (Tshwarang & Malinga-Musamba, 2008:293).

With the nature and general scope of HBC and the role of the social worker in the context of providing patients HBC to their families and the communities, the focus of the discussion will now focus on the topic of HBCGs in caring for PLWHA.

1.1.4 The current state of knowledge on the proposed topic for investigation

Despite having been in existence for a long time and their clearly acknowledged instrumental role in fighting HIV and AIDS, HBCGs do not receive the necessary support in South Africa and across the continent. South African HBCGs have limited and inadequate support from government (Akintola, 2008:358) and work long hours within the working conditions that are emotionally taxing and they are mostly ill-

equipped. They moreover tend to have a low level skills and limited career development (DSD, 2006:4). South African HBCGs, along with those from Ghana, Tanzania and the Democratic Republic of Congo (DRC), are reported to be exposed to hostile socio-economic consequences, such as stigma and discrimination, isolation, emotional overload, patient problems, lacking support and training (Mieh, Airhihenbuwa, & Iwelunmor, (n.d:189; Marincowitz, Jackson & Fehrsen, 2004:29). On 25 July 2012, Lindile Sifile (2012), a journalist of at the local South African Gauteng Newspaper, The Sowetan put the working conditions the HBCGs experience under the spotlight. She reported on a demonstration of more than 5 000 community health care workers (CHCWs) who were mainly HIV-counsellors and HBCGs, persuading the DoH to absorb them into the mainstream DoH system so that they could receive the necessary support.

This demonstration in 2012 took place in spite of the fact that the South African DoH, as far back as 2001, acknowledged the challenges HBCGs caring for PLWHA encountered. At that time they called for collaborative efforts from various sectors, including members of the community, to support HBCGs in fighting the scourge of HIV and AIDS (DoH, 2001:1& 10-11). Similar calls were made worldwide by other authors and researchers (UNAIDS, 2016:21; Friedman et al., 2010:20; Caregiver Action Network, 2013:27; UNAIDS, 2008:10; Clark, Wright, Hunt & Thomas, 2007:707) who also advocated the necessity of a multi-sectoral and integrated response to support caregivers in the field of HIV and AIDS.

Existing evidence shows that there are no South African studies from the field of Social Work, or from its perspective that have specifically investigated the work-related challenges experienced by HBCGs caring for PLWHA, how they manage these challenges, and their suggestions for social work support. Akintola's (2005) South African study of the role that volunteers play in mitigating the burden of HIV and AIDS care in households and communities highlights the general challenges and coping strategies HBCGs employ when caring for PLWHA. His work was in the public health domain and not from a Social Work vantage point. As a psychologist, Van Dyk (2007) did not focus on the aspect of the work-related challenges but on how social workers among others, as caregivers in South Africa, managed both their experiences, feelings and perceptions as support preferences when caring for

PLWHA. Another study in Psychology looked into the psychosocial well-being of HBCGs (Valjee and Van Dyk, 2014). My proposed topic for investigation in Social Work demonstrates that the perspective of another discipline, in this case Psychology, can add value to enhance research done in another field.

When focusing on research being conducted on a Social Work-related topic as is the case in this thesis, I[2] found Qalinge's (2011:52) South African study. In it she explores the experiences and challenges HBCGs caring for PLWHA in North West face. However, she had not invited the participants in his study to offer suggestions about how they would like social workers to support them. Recently, in the same province, Tsheboeng (2015) undertook a study in the town of Mafikeng on the effects of HBC of HIV and AIDS patients on their caregivers. Its primary emphasis was on HBCGs caregiving and how social workers could assist them. In another province, Primo (2009) conducted research in Nigel, Gauteng, investigating the support HBCGs needed when implementing HIV and AIDS programmes in the field. The research focuses on the physical and mental health of PLWHA and partly covers the support HBCGs' need to determine this. It lacks attention being paid to their work-related experiences, challenges, coping strategies and their preferences for support from social workers.

When looking at studies conducted further afield, I also came across the work that Reckrey et al. (2014) did in New York City. Its topic was singularly on the critical role of the social worker in general home-based primary care. The focus was on the social worker in HBC and not on HBCG's and their work-related challenges or how they manage and cope with these challenges.

It is therefore safe to say that, at this stage, there is paucity in indigenous Social Work literature and research conducted from a Social Work perspective that focuses specifically on the topic of work-related challenges HBCGs experience in caring for

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[2] Using the first person pronoun in this report was adopted as recommended and encouraged by the research literature (American Psychological Association in Shelton, 2015:122; Starfield & Ravelli, 2006:223; Hyland, 2004:142-143; Clare & Hamilton, 2003:78; Hyland, 2002:1091).

PLWHA. How they negotiate these challenges and would like social workers to support them is not considered.

1.1.5   The research problem

In essence, the research problem connotes the contradiction or discrepancies between what is ideally anticipated to be the case and what the case actually is in relation to the phenomenon under study (Bwisa, 2008:2). In a few paragraphs, the researcher formulates the research problem that is developed from the opinions of politicians, other researchers, thinkers and professionals to elaborate on it and to argue for the necessity of the study These paragraphs will then culminate in a one-sentence problem statement which becomes the focal point of the research (Bwisa, 2008:2). Merriam and Tisdell (2016:79) refer to the problem statement as a carefully crafted essay containing three components: the context of the study, the area or topic on which the study focuses; the gap in the knowledge base which is what is currently not known, hence what the study will address; and making the significant problem to be addressed clear to the reader.

As I indicated earlier in the introduction, HBCGs who care for PLWHA have existed from as far back as the 1980s when the HIV and AIDS epidemic was in the limelight. The primary aim of their service was to relieve the pressure this pandemic places on the already overloaded public health care systems (Qalinge, 2011:51; Friedman et al., 2010:14; Tshabalala, 2008:1). Health care is thus now able to take place in the household itself (Department of Social Services and Poverty Alleviation, 2005:7). Given the fact that HBC for PLWHA been operating successfully for over three decades, one would expect the HCB-sector to be recognised and embraced within all communities. It should be well organised and fully functional especially as part of the MDT dedicated to contribute to ending the scourge of HIV and AIDS. This, however, is not the case. The reality is that HBCGs face several challenges like stigma and discrimination, the physical strain of caring, lack of support, lack of respect and recognition from the community (Zulu et al., 2014:9; Akintola, 2005:15; Chimwaza & Watkins, 2004:801; Kipp, Nkosi, Laing & Jhangri, 2006:695). These attitudes hamper their efforts to implement their mandate which is to provide comprehensive health and social services to patients in their homes (DSD, 2006:1).

UNAIDS (2008:2) confirms that the HBC programme is indeed a cost-effective strategy for both government and the private sector to respond to the scourge of HIV and AIDS. The caregivers themselves are mainly women from poor backgrounds. The impact of the burden of care on caregivers is particularly felt in rural areas at grassroots level where resources are limited (UNAIDS, 2008:2).). This is evident from the work of Qalinge (2011:53) in her study conducted in the North West Province of South Africa, entitled: "A community home-based care programme: a marginalised key community resource". She found that HBCGs were dissatisfied as not only was government neglecting and abandoning them; but their relatives and neighbours were doing so as well. They reported lack of supervision, psychological support, training, and this despite their lack of skills, as well as not recognising that caregiving is an emotionally taxing task (Qalinge, 2011:54-55). Mullins (in Valjee & Van Dyk, 2014:3) points out that HBCGs working with PLWHA who experience satisfaction in their work and are equipped to deal with its organisational challenges appropriately, are able to provide better care.

From this introductory account and the nature of the knowledge on the topic decided upon for investigation, the research problem can be delimited as follows: *there seems to be a dearth of literature and research, locally and internationally, from the ambit of social work on the topic specifically related to the work-related challenges HBCGs caring for PLWHA experience, how they manage and cope with these challenges and their need for social work support.*

Although one could argue that challenges remain challenges, they should still be understood. Regardless of the discipline, Social Work is a distinctively unique discipline that also views the world through a transformative and developmental lens. Its core aim is to address life challenges and enhance people's well-being by promoting social cohesion, empowerment and the liberation of people through social justice, human rights, collective action and respect (International Federation of Social Work, in Thompson & Thompson, 2016:xxix). This means that social workers cannot simply borrow the research studies from any other discipline to inform their practice and knowledge development since it would not be a true reflection of their professional stance. This point is better explained as "…social workers actively seek

research findings related to their particular domain of practice" (Lietz & Zayas, 2010:188).

The need to investigate and to understand the work-related challenges HBCGs caring for PLWHA experience, how they manage and cope with their challenges and their preferences for Social Work support envisages to addresses this lacuna in the indigenous knowledge base on this topic. Moreover, it aspires to add to its knowledge base and provides directives for social workers to support HBCGs caring for PLWHA.

1.1.6 Rationale for the study

The rationale of the study addresses a question relating to the significance of the study. Maree (2016:29) describes a rationale as incorporating the study's suitability to address the "stillness", "inconsistency" or "challenge" in the literature. Through the rationale of the study, a researcher builds an argument to convince the reader that their work is worthwhile and conducting it could contribute to more research and literature, social policy, effective practices or the participants' interests (Rossman & Rallis, 2012:131). For Frankel and Devers (2000:253), many examples of qualitative research pursued in certain areas fail because existing theoretical and substantive literature does not adequately capture or reflect the personal experiences of the researcher and the researched. Vinthal and Jansen (in Maree, 2016:30) believe that the rationale of a study serves two primary purposes: to explain how the researcher developed an interest in a certain topic; and to explain exactly why the researcher believes the research is worth conducting.

From these introductory remarks, the following aspects triggered my passion and interest in this topic and are shared.

My conviction is that ensuring support for HBCGs who are involved in caring for PLWHA should be based on a sound understanding of their challenges or areas where such support is necessary. Having been closely involved with HBC organisations and HBCGs in recent years, in my capacity as a HIV and AIDS coordinator and as a social worker, I had the opportunity to observe their many challenges closely. This privilege enabled me to identify a range of situations not

necessarily known to several role players, like social workers, nurses and other professionals. I also became aware of the very limited involvement of social workers in the field of HBC. This sparked my interest around social workers as available support systems for HBCGs and their coping strategies whenever they encounter difficulties.

A deficiency in the knowledge base of a certain aspect a researcher discovers could lead to a prompt to launch an investigation into an attempt to address this identified dearth (Creswell, 2014:117). In my case, this realisation provided a further reason for me to embark on this research journey. During my search for literature on this topic and other completed research that had grown from my close involvement with HBC and HBCGs. I was confronted by the paucity of general local and international Social Work generated literature and research around the phenomenon of work-related challenges encountered by HBCGs. Even less was available on their coping strategies and suggestions for Social Work support that would improve their conditions. I found studies from other disciplines, like Anthropology (Rödlach, 2009) Psychology (Van Dyk, 2007; Valjee & Van Dyk, 2014), Public Health (Akintola, 2005; 2008; 2009; 2010) and Nursing (Ama & Seloilwe, 2010) as mentioned in the introduction. However, the contribution from the discipline of Social Work on this topic was rather sparse. While Qalinge, (2011); Tsheboeng, (2015) and Primo, (2007) conducted indigenous research, and from the ambit of social work, none of them zoomed in solely, or particularly, into the challenges HBC encountered. Additionally, the topics of how they coped with such challenges and the type of support HBCGs preferred from social workers, was not tapped at all.

This lack of research and literature from a Social Work perspective does highlight the research problem as previously stated. However, it not only results in a lack of understanding of the challenges HBCGs face from a Social Work perspective, it also implies that guidelines, programmes and policies developed for HBC programmes lack an appropriate Social Work flavour. This leaves social workers practising in this field without clear and scientifically based guidelines. It is therefore, on this basis that I resolved to crack the field of HBC using the principles of the Social Work discipline. Hence, I look at the work-related challenges HBCGs caring for PLWHA experience and their coping strategies to suggest the importance of Social Work support.

I therefore anticipated this study to be beneficial for HBC in that it would serve as a messenger to deliver their suggestions to the decision makers, the management of HBC organisations and members of the MDT team. It is essential for them to consider their voices when they plan, develop and implement current programmes, policies and strategies. Given that social workers are and would benefit from support in the particular role they play in HBC, I also envisage that this study will serve as a base on which guidelines and programmes should be initiated and implemented. It is my conviction that phenomenon like the work-related challenges HBCGs who care for PLWHA experience should be explored in detail from a broad spectrum of viewpoints. My anticipation was that this approach should result in a full and detailed understanding of both its positive and negative aspects as well as inviting the HBCGs to raise their own voices on how they wish their current situations could turn around for the better. Moreover, I envisaged that this study would shed some light not only to social workers, but also enable all other role players especially within the field of HBC in HIV and AIDS to have a better understanding of the HBCGs' challenges from the Social Work disciplinary point of view. I envisaged this to clarify and enhance role players' knowledge about the role to be played by social workers in the HIV and AIDS HBC field.

I further anticipated that my study would contribute to enabling Social Work educators in training institutions to enhance their curriculum by equipping students with techniques and skills to assist them in responses to the challenges HBCGs face in an appropriate manner. I expected that the information gathered from HBCGs' own recommendations would highlight the significant role social workers can play in fighting HIV and AIDS from a multi-sectoral angle. It would lay the foundation for programmes and policies through which the scourge of HIV and AIDS within the HBC system could be more effectively addressed. In other words, it was anticipated that this study would serve as a ground-breaking effort in the field of Social Work, HBC and HIV and AIDS, particularly in South Africa.

1.2   THEORETICAL LANDSCAPE OF THE STUDY

Theory is one of the significant requirements of any academic research (Remenyi, 2014:149). Several authors (Maxwell, 2013; Alvesson & Karreman, 2011; Hennink, Hutter & Bailey, 2011; Green, 2014; Rule & John, 2015) believe that research does not exist without a theory. By theoretical frameworks, Maxwell (2013) refers to "the systems of concepts, assumptions, expectations, beliefs and theories that support and inform the research". Some scholars (Bryman, Bell, Hirschohn, Dos Santos, Du Toit, Masenge, Van Aardt and Wagner, 2011:8) go so far as to dismiss research that does not have theoretical linkages as naïve or blind empiricism. Two ways in which qualitative researchers could use a theory in their research are first, by explaining it as part of the research design and the literature review; and second, making it meaningful, useful and relevant in the research findings (Green, 2014). In this study, I proposed to use theory as part of the literature review and for founding and verifying the research findings. When used as part of providing a backdrop to and verification of the research findings, I relied on Maxwell's (2013:49) analogy of a "coat closet" to display the findings in an orderly way. The constructs and concepts underpinning theory are referred to as the "coat hooks" in the closet on which researchers hang their data to enhance its meaning. The theories used in this study were the middle range theory of care giving dynamics, the coping theory and the strength-based perspective. A discussion on these follows.

1.2.1   Loretta Williams' middle range theory of care giving dynamics

The middle range theory of caregiving dynamics emerged from the research of Loretta Williams, a registered nurse and professor from the Department of Symptom Research at the University of Texas. She coined the concept 'informal caregiving dynamics'. The idea from her inductive literature review was published (Williams, 2014:310; Williams, 2003:679) in 2003 in work that sought to develop a definition of informal caregiving. *Informal caregiving dynamics* stem from the forces that stimulate and shape change. In caregiving, relationships grow. The middle range theory of caregiving dynamics alerts the nurse to forces that allow a caring relationship to grow and develop. The *informal caregiver-care receiver relationship* enables a nurse to employ strategies for supporting the caregiving relationship (Williams, 2014:310).

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A good example of this is the relationship between HBCGs and PLWHA. For this reason this middle range theory of caregiving dynamics was adopted as one of the theoretical frameworks for the study and is now introduced.

The patient commences on the illness trajectory and enters an informal caregiver-care receiver relationship. For example, in the context of the study, this would happen when a patient is diagnosed as being HIV-positive, or progressing towards the stage of full-blown AIDS. The nature of this caregiving relationship at this point is not only shaped by caregiving relationships in the past but will also be affected by their present and future circumstances. In addition, in this informal caregiver-care receiver dyad, three interactive forces are at work that shape and stimulate this relationship to move forward. These interactive forces are *commitment, expectation management* and *role negotiation* (Williams, 2014:317) that will be introduced next.

- **Commitment as a dynamic force shaping and moving the caregiver-care receiver dyad forward**

Commitment, as described by Williams (2003:680) refers to a dedication, pledge or undertaking on the side of the caregiver towards the patient. Noted, is the point that caregivers find themselves in a situation where they say to themselves, no matter how hard it can be, no matter the challenges we may encounter, we will continue to assist these patients. This commitment is fuelled by a persistent responsibility, prioritising the patient's needs, being a supportive presence and the development and nurturing of a self-affirming, loving connection (Williams, 2014:311; Williams, 2007:381). Through a continued responsibility, caregivers remain determined to continue to care for their patients despite the difficulties (Williams 2014:311; Williams, 2007:382).

Commitment itself has important critical facets. Caregivers prioritise the needs of their patients before any other need or interest they have (Williams, 2014:311; Williams, 2007:382). Through their commitment they display a supportive presence, by being at the patient's side to comfort and encourage. Commitment flourishes through having a positive attitude (Williams 2007:382) and a "self-affirming loving,

connection" resulting from the emotional bond that develops between the caregiver and the patient (Williams, 2014:311; Williams, 2007:382).

- **Expectation management as a dynamic force shaping and moving the caregiver-care receiver dyad forward**

Caregivers and patients have expectations when entering into to caregiver-care receiver dyad. An expectation refers to the anticipation of something to occur within the caregiving relationship that will either worsen or better a patient's condition (Williams, 2014:313; Williams, 2007:382; Williams, 2003:681). It may involve having expectations about the progression of their illness or the roles and actions of caregivers or patients (Williams, 2003:380). Expectation management has five dimensions, which are: *envisioning tomorrow*, *getting back to normal*, *taking one day at a time*, *gauging behaviour* and *reconciling treatment twists and turns* (Williams 2014:313; Williams, 2007:382-383). These dimensions are now explained.

By *envisioning tomorrow*, Williams (2007:382) means that both caregivers and their patients develop some vision about the future with images spanning a continuum from being very certain and specific to being very vague and general about the patient's condition. In their envisioning of tomorrow, both caregivers and their patients may vacillate between several options. They sometimes appear to be hopeful about the future, a prospect shared by both or either of them, especially as the patient's condition seems to be improving. Alternatively, anxiety and fear confronts them when it seems as though the patient is getting worse and the possibility of life beyond death within a few weeks is bleak (Williams, 2014:313; Williams 2007:382).

Getting back to normal is the time when both the caregiver and the patient think that full recovery and the end of the illness trajectory has arrived. The patient and the caregiver feel that they can each go back to their normal lives. In this situation, the patient would be able to do things for themselves without waiting for the caregiver to come and assist them. The caregiver would return to attending personal needs and interests by that time as the patient would be in a better position to help themselves (Williams, 2014:313; Williams 2007:382).

Taking one day at a time, means that the focus fall on the present to address the uncertainties of the future. This means neither the caregiver nor the patient worry much about the future which is unknown; their concern is rather about the present which is certain (Williams 2007:382-383; Williams 2014:313).

Yet another dimension of expectation management is for the caregiver to engage in what is called *gauging behaviour*. This implies that the caregiver's explanation, prediction or reactions to a patient's condition are based on their familiarity with them (Williams, 2014:313; Williams, 2007:383). In other words, caregivers are able to gauge the patient's behaviour as they know them so well in that they recognise and can distinguish between their normal and abnormal behaviour.

The final dimension of expectation management is *reconciling treatment twists and turns* in which the caregiver comes to terms with the reality of the situation when interacting with the patient (Williams, 2007:383; Williams, 2014:313. The caregiver can, for instance, accept the fact of not having the financial means to assist the patient and nothing can be done about it.

- **Role negotiation as a dynamic force shaping and moving the caregiver-care receiver dyad forward**

Role negotiation concerns itself with the aspects of role identification, clarification and execution. It involves the caregiver *pushing and getting a handle on the caring responsibility*, *sharing responsibilities*, *attending or listening to the patient's voice* and *vigilant bridging* (Williams, 2014:315; Williams, 2007:383). These significant aspects are further unpacked below.

By *appropriate pushing,* Williams (2014:315; 2007:383) refers to efforts on the caregiver's part to ensure that the patient adheres to the rules and guidelines of the treatment regime for recovery. In the context of this study, it is particularly important for the caregivers to pay specific attention to the patient's antiretroviral treatment. *Getting a handle on the caregiver-care receiver dyad* refers to efforts made by the caregiver to cope with the demanding and additional caregiving roles because of changes in the patient's condition (Williams, 2014:315; Williams, 2007). In this

instance, for example, the caregiver may find herself providing emotional support to the families of patients alongside caring for the patient.

To negotiate roles successfully, some *responsibilities need to be shared* (Williams, 2014:315; Williams, 2007:383)*.* Here the caregiver assesses the patients' needs and determines how such needs are to be addressed and responsibilities allocated those who can assist. In the context of caring for PLWHA, the caregiver could hand the responsibility of bathing and feeding the patient over to a caring and concerned relative.

Essential to assisting the patient's adherence to the treatment regime; getting a handle on things; and negotiating sharing responsibilities which are all part of the aspect of role negotiation is a concerted effort on the side of the caregiver to listen to the patient's own voice, and not to suppress and ignore it. Williams (2003:383) advises that caregivers should heed to the patient's voice and listen carefully to their views, preferences and opinions before they make decisions about them.

Finally, role negotiation can be enhanced through *vigilant bridging* – the caregiver's endeavours to liaise with healthcare systems to address the interests and needs of the patients (Williams, 2014:615; Williams 2007:384). Vigilant bridging may entail visiting the local clinic to collect treatment or arranging for nurses to visit when a patient's condition disables them from meeting this need on their own.

The aspect of caring for the caregiver in caregiving-receiver dyad is introduced next. This entails engaging in the activity of self-care, generating new insights and receiving role support (Williams, 2014:311), enabling the caregiver to cope within the caregiver-receiver dyad.

- **Self-care as enabler for caregivers to cope within the caregiving dyad**

Self-care mainly involves caregivers maintaining own healthy habits to nurture commitment, manage expectations and negotiate roles during their caring process (Williams 2014:312). To perform self-care, four protective coping strategies come

into play - *a supportive physical environment*, *cultivating healthy habits*, *letting it out* and *get away from it.*

The first dimension is a *supportive physical environment* that requires physical accommodation, food and any other physical amenity that would conveniently enhance the relationship between the caregiving process and the caregiver and the patient. An example is providing transport for the patient to be taken to the clinic when necessary.

Cultivating healthy habits entails the caregiver taking care of herself to remain healthy enough to continue to look after the patient.

Letting it out boils down to finding ways to deal with the frustrations and challenges associated with caregiving. Talking to a confidant about some of the frustrations experienced; going out for a movie to try and forget traumatic experiences; or consulting professionals for therapeutic interventions where necessary are beneficial.

G*etting away from it* as a break from the caregiving environment is a useful coping strategy. It means leaving the normal caregiving space either physically or mentally to be on their own, trying to stop thinking about their caregiving responsibilities - in modern idiom, to preserve their sanity.

- **Generating new insights from the caregiving dyad to continue coping within this relationship**

Generating new insights about and experiencing personal growth within the caregiving dyad could be a significant driving force behind a caregiver wanting to persevere in the HBC profession and its caregiving responsibilities (Williams 2014:314).

- **Role support as enabler for caregivers to cope within the caregiving dyad**

Role support means that the caregiver does get the support needed to provide the patient with the required care (Williams, 2014:316). There are five ways in which role support can be provided:
  - *By having competent, compassionate care available for the caregiver to provide care that benefits the patient*
  - *By having and finding support for other responsibilities*
  - *Knowing that others care*
  - *Meeting the financial obligations care entails for both the caregiver and the patient and*
  - *Receiving helpful information.*

Having competent compassionate care whenever the need for it arises (Williams 2014:316) is the first point. This boils down to being sure that health care providers and family members are available to support the caregiver when patients' needs have to be addressed.

Secondly, role support involves *finding support for other responsibilities* so that the caregiver can concentrate on giving the patient comprehensive care. Such tasks are not necessarily directly related to the patient's illness but are essential for normal daily living (Williams 2014:316). This could involve chores like finding someone to assist with getting the patient an identity document or applying for a social welfare grant.

Another item that is reassuring for caregivers is to have and experience support while fulfilling their caring role. Especially important in this regard is *knowing that others care.*

Facilitating ways in which a caregiver's financial needs can be met is another form of role support. Getting the necessary financial assistance to address the needs of both caregivers and patients is essential (Williams 2014:317).

Lastly, role support can also come from *receiving helpful information* and being equipped with appropriate knowledge. This could be acquired from being exposed to continuous training to enhance their caregiving skills or advice that alerts them to avoiding conduct that could affect their caregiving dyad negatively. This enables them to perform their daily duties as caregivers effectively.

This discussion on the middle range theory of caregiving dynamics is depicted in Figure 1.1 below.

Figure 1.1: The middle range theory of caregiving dynamics (Adapted as adopted from Williams, 2014:318)

ILLNESS TRAJECTORY

Dynamic forces that shapes and move caregiver-care receiver dyad forward
Commitment
Expectation management
Negotiation

Enablers to assist the caregiver in the caregiving dyad
Self-care
New insights
Role support

Past Caregiving Relationship

Present Caregiving Relationship

Future Caregiving Relationship
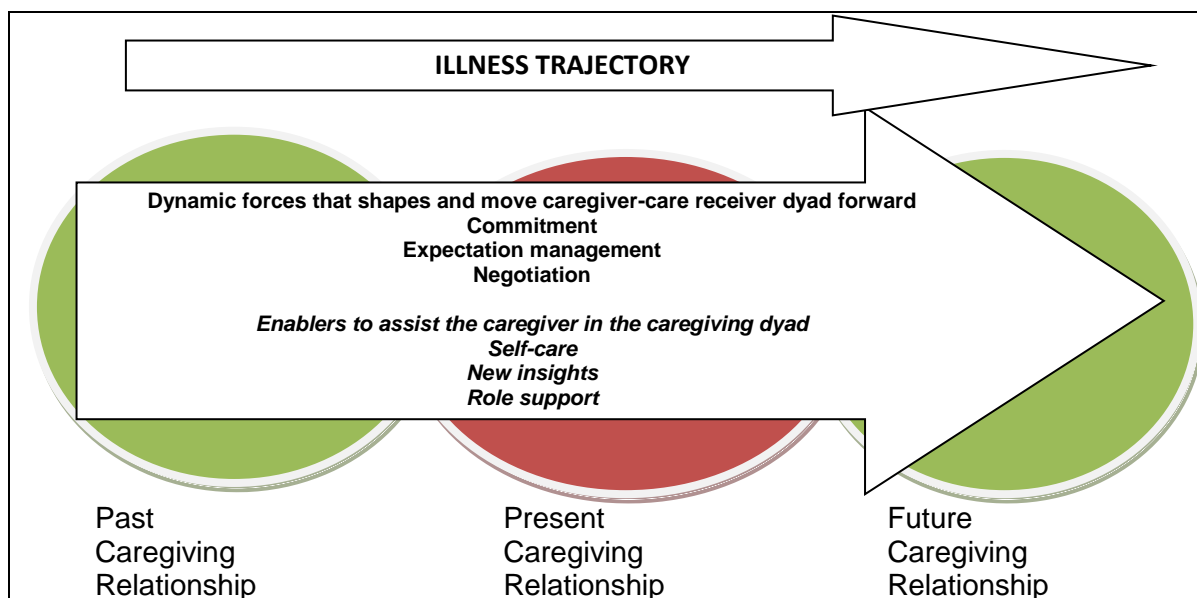
In addition to the middle range theory of caregiving dynamics, I also adopted Lazarus and Folkman's (1984) coping theory as part of the theoretical framework for the study and this will be introduced next.

1.2.2   Lazarus and Folkman's coping theory

Amongst other related issues, I also wanted to focus on how HBCGs cope with work-related challenges experienced when caring for PLWHA. For this purpose, I decided to adopt the coping theory Lazarus and Folkman developed in 1984. It has a

Psychology background and is part of the theoretical framework adopted for this study.

Demands from within the environment can tax or exceed a person's adaptive resources, resulting in stress being experienced compelling the adoption of a chosen method of coping to change the state of affairs (Barbosa, Figueiredo, Sousa & Demain, 2011:491; Folkman & Moskowitz, 2004:745; Lazarus & Folkman, 1984; Folkman, 1984:843). Coping is defined as "constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Laux & Weber, 1991:234; Lazarus & Folkman, 1984:141). It thus emerges from a dynamic transaction between a person and the environment with the person responding or attempting to respond to the environmental stressors (Frydenberg, 2014:83).

Before responding to these stressors, people first engage in some observation and assessment of their continuously changing transactional relationship with their environmental experiences through a process which is called appraisal and reappraisal (Frydenberg, 2014:83; Lazarus & Folkman, 1984:142-143). Whereas appraisal involves "evaluative judgments about events" (Lazarus (1995:31), reappraisal is a repetition of this same process. In other words, a person appraises and gives meaning to the stressor before deciding how to manage or cope with it (Outten, Schmitt, Garcia & Branscombe, 2009:149-150). As is necessary, the meaning would be re-evaluated before the response is initiated.

In deciding how to cope with a stressful challenge, an individual draws on what is referred to as "available resources". Available resources amount to the *primary assets* the person has and *the environmental resources* available (Lazarus & Folkman, 1984:159).

The following resources fall under the *category of a person's personal assets*:
- *Health and energy:* A person who is healthy and has some energy is believed to be more able to cope than those who are unhealthy and lack energy.

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- *Positive beliefs:* Believing in one's capacity is perceived to be one of a person's great assets in coping.
- *Problem-solving skills:* People who are equipped with problem-solving skills are likely to apply them when addressing challenges.
- *Social skills:* Social skills reflect a person's ability to interact with others through communication in a socially appropriate way (Lazarus & Folkman, 1984:163). It is the ability to gather a convoy of support when someone calls for guidance and support when challenges have to be faced and coping is required.

The resources identified as being in the *category of environmental resources are:*
- *Social support:* Social support a person can reckon on within the environment is emotional, informational and tangible in nature (Lazarus & Folkman, 1984:164). When enduring stressful moments, people could seek support from their fellow companions.
- *Material resources:* Material resources are material possessions, things that can be bought with money (Lazarus & Folkman, 1984:166).

First, the nature of an internal and/or external demand confronting a person has to be determined through the process of appraisal and reappraisal before a coping strategy can be adopted. Existing resources at one's disposal are considered to decide on a coping strategy. Either *the problem-focused coping strategy* or *the emotion-focused coping strategy* is chosen (Padden, Connors & Agazio, 2011:251; Laux & Weber, 1991:235; Grambling, Lambert & Pursley-Crotteau, 1998:1083; Lazarus, 1995:33).

Problem-focused coping refers to the actions or behaviours individuals adopt to modify their relationship with the environment that is the source of stress. Either the environment itself is modified or the person modifies their own behaviour towards it (Padden et al., 2011:251-252; Lazarus, 1995:33; Lazarus, 1993:238).

In the case of *emotion-focused coping*, people neither directly deal with the environment nor their own behaviour; they rather sort out their attitudes to their

appraised meaning of the stressor (Padden et al., 2011:251; Grambling et al., 1998:1083). Only once they have successfully changed their attitude towards the stressor can they can change the way they think and even feel about the situation even though its realities have not changed (Lazarus, 1995:33).

The process of coping, according to Lazarus (Padden et al., 2011; Lazarus, 1993) is founded on the following principles:

- To understand coping, researchers should understand coping thoughts and actions separately from their outcomes to determine their independent adaptiveness or maladaptiveness (Padden at al., 2011:251; Lazarus & Folkman, 1984). In other words, the researcher's main interest should concern what caregivers do in trying to address their difficulties as opposed to the outcomes of their actions.

- Coping thoughts and actions are determined by a particular threat or stressor at a given time (Padden et al., 2011; Lazarus & Folkman 1984). This is mainly because human beings react to threats or stressors in different ways as they evolve in their lives. Since various stressors have different meanings as they happen over time, they prompt a range of different reactions. This suggests that researchers should understand that what is stressful for one caregiver in one context, might not necessarily be stressful to the same caregiver in different context.

- Understanding coping depends on acknowledging that consistencies and inconsistencies arise in what individuals think (both independently and interdependently) and do in their effort to cope with stressors or threats across diverse spectrums (Lazarus, 1993). Hence the researcher should understand that the coping mechanisms their participants adopt are not one-sided. The focus should not only be on a single situation, but the researcher should also look at the various intrapersonal and interpersonal aspects of the setting.

- The actions and thoughts a person has when responding to stressful events is what is important when applying coping theory (Padden et al,, 2011; Lazarus, 1993).

- Coping is an ongoing cognitive and behavioural effort to manage specific external and/or internal demands that are appraised as effectively taxing or exceeding the resources of the person (Padden et al., 2011:251; Lazarus, 1993). Coping should not be understood as a once-off event because it is process caregivers actively engages in when attempting to mitigate the impact of stressors on their resources.

- Coping aims to achieve two main objectives: to lessen emotional distress associated with the stressor or threat; and to eliminate or prevent the source of stress directly (Folkman & Moskowitz, 2004:751; Folkman, 1997:1216; Folkman, 1984:844; Lazarus, 1993:238). People tend to adopt either the problem-focused strategy or emotion-focused strategy when coping with their stressors. This would depend on the outcome of their appraisal and reappraisal of their transaction with their environment.

1.2.3 The strength-based perspective

The strength-based based perspective is linked to the 1922 work of Richmond focusing on social case work, the 1957 work of Perlman which focused on the problem-solving process using case work (Chapin, 1995:507). Influential too in this regard is the 1971 work of Schwartz titled "On the use of groups in Social Work practice", which generally promoted the clients' strengths as opposed to their pathologies (Chapin, 1995:507). It is one of the theories that are commonly used in the Social Work discipline (Bernard, 2006:198; Weick, Rapp, Sullivan & Kisthard, 1989:352). As the name suggests, it focuses on the strengths and capacities that we as human beings have to cope with various difficulties (Weick et al., 1989:352).

This perspective is not problem-focused but rather asset-focused in that it looks at and appreciates the ability human beings have to keep going despite these

difficulties, challenges and adversities. The strength-based perspective operates from the stance that people's very preoccupation with challenges often obscures the heroic elements of strengths they possess (Blundo, 2013:41; Saleebey, 2013:41&15; Early & GlenMaye, 2000:119; Chapin, 1995:507; Weick et al., 1989:351). It does not mean that human beings do not have difficulties and challenges though; the meaning is rather that they have the ability to prosper against such odds (Saleebey, 2013:15; Early & GlenMaye, 2000:123; Song & Shih, 2010:24). The strength-based perspective is founded on the philosophical elements of *liberation and empowerment; heroism and hope*; and *alienation and oppression* as the drumbeat that awakens anxiety and evil (Saleebey, 2013:7-11).

Through the *liberation and empowerment* element of the strength-based perspective, it is believed that there are always possibilities and opportunities for people enabling them to unleash their innate potential, strengths and wisdom (Saleebey, 2013:8). Examples of such possibilities and opportunities are, *inter alia*, policies, institutions, communities, families and colleagues. This means that even though people are surrounded by challenges and atrocities, we must also believe that they are also surrounded by opportunities (Rhee, Furlong, Turner & Harari, 2001:7; GlenMaye, 2000:120). Furthermore, one should understand that for liberation and empowerment to happen, there must be some element of hope and heroism which is triggered by internal hope and belief (Saleebey, 2013:8).

By *heroism*, Saleebey (2013:8) implies "the desire to transcend circumstances, to develop one's own powers, to face adversity down, to stand up and be counted". In other words, human beings have mechanisms that enable them to surpass the challenges and difficulties they encounter in their lives (Smith, 2006:27; Rhee et al., 2001:7). In the pursuit of understanding human beings, cognisance must be taken of the heroic inner forces enabling them to overcome adverse circumstances if they have confidence and a sense of certainty (Saleebey, 2013:19).

Another philosophical element relating to the strength-based perspective is *alienation and oppression* that are seen to give rise to anxiety and evil. Basically it cannot be denied that the world in which human beings find themselves is full of evil things that they find overwhelming and difficult to handle. However, this should not

obscure understanding human beings as capable of rising above the effects of adversity through inner strength (Saleebey, 2013:10; Song & Shih, 2008:24-25).

The decision to incorporate the strength perspective as part of the theoretical framework for this study was based on consideration of the daily working conditions caregivers caring for PLWHA face. Essentially, they have to find a way to deal with their experiences of difficulties and challenges. For this to happen successfully, their resources and opportunities ought to be harnessed in some way. Drawing on their inner strength they are discerned as remaining hopeful and performing acts of heroism in the face of limitations and their experienced challenges. These aspects should be revealed, in that the strength-based perspective is intermingled within the thinking of Social Work and its service delivery model. The South African Department of Social Development too embraced this approach in 2005 (DSD, 2005:10). I found it fitting to adopt this perspective as part of the theoretical framework for my studies. Discussion on the six principles of the strength-based perspective underpinning Social Work endeavours (Saleebey, 2013:17-21; Saleebey, 2006:16-20) follows.

- **Each individual, group, family and community has strengths**

Human beings possess a treasure of inner resources (Saleebey, 2013:17; Song & Shih, 2010:24; Early & GlenMaye, 2000:19). It is common knowledge that certain individuals or groups of people encounter tremendous stressful conditions. This does not necessarily mean that they do not have internal strengths that could enable them to transcend difficulties. Researchers seeking to fully understand life situations should therefore not be tempted to turn a blind eye to anyone's internal strength.

- **Trauma and abuse, illness and struggle may be injurious sources of challenges, but they also offer some opportunities**

What this principle means is that human beings can emerge as heroes and heroines from their respective difficulties and challenges (Saleebey, 2013:18). When practised, it would encourage both social workers and researchers to undo their

traditional ways of seeing people who are going through certain challenges as the victims. The abused, the damaged and others have the wisdom, talents, skills and internal powers to disallow all sorts of negative things to overshadow their lives. The opinion Rhee et al. (2000:7) explained it better: "challenges are actually welcome because they have the potential to provoke growth and development". This means that aspirations should overshadow challenges although acknowledging problems is essential (Song & Shih, 2010:23). What this principle teaches is to appreciate that, as much as people are confronted with daily work-related challenges, they have internal wisdom, skills and talents that enable them to rise above these experiences. These innate attributes should be unveiled through knowledge of their life situations and research to understand how they strive to achieve this.

- **Assume not knowing the upper limits of the capacity to grow and change and taking individual, group and community aspirations seriously**

This principle assumes that there are no restrictions on individual abilities to rise and improve their conditions and remain only committed to their ambitions (Saleebey 2013:19; Song & Shih, 2010:24). This should be the basis on which both scholars and social workers should seek to understand both the client and research participants' life situations. The emphasis on the unlimited capacity of people to grow does not mean that there are no constraints on their abilities or capacity to transcend beyond their challenges (Saleebey, 2013:19; Early & GlenMaye, 2000:119); it rather assumes that they have unlimited ability to grow and transcend (Saleebey, 2013:19). Researchers working with a strength-based perspective should, in their pursuit of knowledge, see the participants as full of unlimited potential; and also unveil this potential to grow and change.

- **Clients are best served through collaboration with them**

As Early and GlenMaye (2000:120) describe, collaboration begins with the people sharing their experiences about how they pursue their goals and produce outcomes. Hence, when applying this stance not only to the service of helping in the field of Social Work, but also to research in general, engaging in conversation is essential.

Irrespective of whether one is engaged in research or in rendering social work services, one needs to enable the clients and participants to enlighten the social worker and the researcher. With their knowledge and experiences of their own life situations they are better informed. In Early and GlenMaye's (2000:110) view collaborating with clients [i.e. caregivers in this context] through dialogue as partners and experts in their own lives as vital when operating from a strength-based perspective. They *must be encouraged to define and describe their* situations in their own way. Within the context of this study, this principle reminds researchers that, in their pursuit of understanding HBCG's experiences, they are not experts; the HBCGs are. Therefore, both parties in the conversation should be treated as partners in their pursuit of knowledge. What makes this process a collaborative one is that, although the researcher comes with a set of questions to be answered, it is the participants who have to provide the answers to these questions.

- **Every environment is full of resources**

This principle basically means that despite the challenges human beings experience in their environments, each of their environments should be seen as full of resources. This availability of resources could enable them to liberate themselves (Saleebey, 2013:20; Early & GlenMaye, 2000:123). People live their lives in a world that is surrounded by different people and institutions that are full of resources to help them overcome various difficulties with which they are confronted. Song and Shih (2010:25) document that these resources should be investigated and utilised. Moreover, social workers and researchers in the field who simply overlook the existence of these resources would not have an adequately detailed understanding of the people of concern to them or their daily life situations (Song & Shih, 2010:25).

- **Caring, caretaking and context**

Caring for one another in human nature is innate and an important moral aspect. Three rights to care can be stipulated: first, all families are allowed and assisted to care for their members; second, all paid caregivers should provide support and quality care to those in need; and, third, all people who need care should receive it

(Stone in Saleebey, 2013:21). Since this study concerns HBCGs, this principle certainly talks directly to it. Researchers, who are pursuing understanding in this context, should be mindful that caring for one another is an inherent characteristic of the nature of human beings.

1.3   THE QUESTIONS, GOAL AND OBJECTIVES OF THE STUDY

The main questions, goals and objectives of this study are presented in this section.

1.3.1   Research questions

Research begins with a question or questions that interest the researcher as identified from studying the existing literature or the researcher's own experience. Answers should come from collected data (Litchman, 2014:30; Bless, Higson-Smith & Sithole, 2013:71; Hennink, Hutter & Bailey, 2011:33; Gray 2009:175). To this, Yin (2011:312) adds that the initial stated questions are to be addressed through a research study's findings and conclusions. Remenyi (2014:162) has the view that research questions give direction to the entire research process. Without the research question, research could even cease to exist. For Marshall and Rossman (2016:82), the research question should be formulated widely and in such a way that it allows for exploration, yet not so focused that it limits the study to its disadvantage. For this reason, Sandberg and Alvesson (2011:23-24) urge researchers to produce innovative research questions, suggesting these should: expose new research problems; resolve long-standing controversies; provide an integration of different approaches; and challenge old beliefs. In the light of these introductory pointers about the research question in the research process, and my take of the fact that research questions in essence focus on the "what" it is to be researched, I formulated the following research questions at the outset of this study:

- What prompted/motivated HBCGs to involve themselves in caring for PLWHA?
- How is it for HBCGs to care for PLWHA?
- What are the work-related challenges experienced by HBCGs whilst caring for PLWHA?

- How do HBCGs caring for PLWHA cope with their work-related challenges experienced?

- How and with what would HBCGs caring for PLWHA like to be supported by social workers in managing their work-related challenges?

The research questions as observed by Merriam and Tisdell (2016:78) are closely linked to the purpose statement or the aim of the study which is presented in the next sub-section.

1.3.2 The goal of the study

The purpose statement as described by Rossman and Rallis (2012:129) is a paragraph that captures the sentiments of the study. Creswell (2013:134) uses the term "purpose statement" as a synonym for the term "research goal". In Creswell's (2016:94) opinion, the term "research goal" is used interchangeably with the concept "study aim" and it reflects the overall objective or intent of the study. The research goal aims to guide the researcher's decisions in the process to ensure that the study is worth doing and to justify the execution of the study by explaining why the results and conclusions matter (Maxwell, 2013:23). Creswell (2014:109) advises researchers to incorporate the central phenomenon of the study, the participants and the place where the study is to be conducted whenever they formulate the purpose statement. In following this advice, I formulated the following aim for this study: to *develop an in-depth understanding of HBCGs experiences in relation to caring for PLWHA, the work-related challenges they experience in this regard and their coping strategies they employ to address these challenges and to proffer suggestions on how they would like social workers to be supported in overcoming their challenges.*

In answering the stated research questions and operationalising the stated goal, I proposed objectives to be focused on next.

1.3.3 The objectives of the study

In defining the concept "research objectives", Grove et al. (2013:708) refer to a "clear, concise, declarative statements that are expressed to direct a study". For Farragia, Petrisor, Farrokhyar & Bhandari, (2009:280) and Kothari (2004:37), research objectives aim to explain in detail how the specific research questions will be answered. In other words, the research objectives clearly guide the researcher on which data should be collected and from whom to get the answers to the posed research questions. The following objectives were initially formulated at the outset of the study:

- To obtain a sample of HBCGs who care for PLWHA within the municipal boundaries of Region 1 in the City of Tshwane Metro Municipality (hereafter referred to as CTMM);

- To conduct individual face-to-face semi-structured interviews facilitated by open-ended questions in order to explore. –
  - *the motivations of HBCGs that prompted them to become involved in caring for PLWHA*
  - *HBCGs' experiences in relation to caring for PLWHA*
  - *the work-related challenges experienced by HBCGs whilst caring for PLWHA*
  - *the coping strategies HBCGs employ to manage the work-related challenges experienced whilst caring for PLWHA*
  - *how and with what would HBCGs caring for PLWHA like to be supported by social workers in the managing their work-related challenges;*

- To sift, sort and analyse the data using Tesch's eight steps for qualitative data analysis as cited in Creswell (2014:198)

- To describe –
  - *the motivations of HBCGs that prompted them to become involved in caring for PLWHA*

- o *HBCGs' experience in relation to caring for PLWHA*
- o *the work-related challenges experienced by HBCGs whilst caring for PLWHA*
- o *the coping strategies employed by HBCGs to manage the work-related challenges experienced whilst caring for PLWHA*
- o *how and with what would HBCGs caring for PLWHA like to supported by social workers in the managing their work-related challenges.*

- To conduct a literature control to verify the findings

- To draw conclusions on HBCGs experiences in relation to caring for PLWHA, the work-related challenges they experience in this regard; coping strategies they employ to address these challenges and their suggestions on how they would like to be supported by social workers in overcoming their challenges.

- To forward some recommendations as guidelines for Social Work support, specifically on how social workers can support HBCGs in their duties as caregivers caring for PLWHA and the managing of the work-related challenges they experience in this regard.

1.4   RESEARCH METHODOLOGY

Research methodology involves the description, explanation and justification of the research methods (Kaplan cited in Carter & Little, 2007:1318). It explains how the study is approached by analysing the principles of the research methods, rules and discipline-specific traditions and theories (Payne & Turner, 2008:336; Fochtman, 2008:185.

Hesse-Bibber and Leavy (in Nieuwenhuis, 2016:51) use the analogy of a bridge that links the researcher's philosophical stance and the research methods to explain the aspect of "research methodology". The research methodology in this regard informs the researcher on how to travel through the process guided by this bridge (Nieuwenhuis, 2016:51). Carter and Little (2007) emphasise that research

methodology points to the research process in terms of the research approach and design. The research methods, on the other hand, actually refer to the methods and techniques the researcher adopts to conduct the study within the chosen approach and design. With reference to aspect of research methods, Payne and Turner (2008:336) hold a similar view when noting that research methods refer to specific research techniques and procedures used in the actual research study. These are selecting a sample, collecting, analysing and interpreting the data. In view of the above, for the purpose of this study, I will introduce the *research approach and design* adopted in this section. In the next section the research methods and techniques with reference to sampling, the methods of data collection, analysis and verification will be introduced.

1.4.1   Research approach

In view of Streubert and Carpenter's (2011:19) suggestion that once the researcher has identified and clearly formulated the research problem, the research paradigm follows. I decided to adopt the qualitative research approach for this study. As defined by Grove et al. (2013:705) it is a systematic, interactive, subjective approach used to describe life experiences and to give them meaning. When conducting research using the qualitative research's perspective, researchers follow a systematic process that will eventually enable them to gain an understanding of the subjective life experiences of the participants. Hennink, Hutter and Bailey (2011:8) elaborate and point out that the qualitative research approach allows the researcher to examine people's experiences in detail from their own perspectives. Research methods like in-depth interviews, focus group discussions and observations are used. In other words, qualitative researchers use a variety of methods to understand how the participants make sense of their life experiences.

In another definition, qualitative research is referred to as a naturalistic approach to the world. In it the researcher studies things in their natural settings using interpretive material such as field notes, interviews, conversations, photographs, recordings and memos to transform and make the world visible (Denzin & Lincoln, 2011:3). For Van Maanen (in Merriam & Tisdell, 2016:15), the term qualitative research is an umbrella term covering an array of interpretive techniques that "explore, describe, decode,

translate, and come to terms with meaning, not the frequency of certain more or less naturally occurring phenomena in the social world". In Bless et al.'s (2013:394) opinion, qualitative research uses various methods to qualify words and descriptions used to investigate and document social reality.

Deducing from the description of the concepts 'qualitative research' and approach' are some salient characteristics inherent to it. This approach is introduced now.

- **Qualitative research is a systematic research approach**

Qualitative research is a process that evolves systematically. Rossman and Rallis (2012:3) describe it as a process of conceptualising, describing, conducting and writing up what is learnt. As Creswell (2016:3) explains the researcher begins this process by formulating a question. Once answered it would assist in resolving the problem. Once the question is formulated, the data must be collected from the participants and analysed. The participants are purposively chosen to answer the questions asked. The answers are eventually used to assist in resolving the research problem. The researcher will then report on the research findings by either writing a thesis, a dissertation, journal articles or a proposal for funding for further research (Creswell, 2016:3). It is crucial; however, to state that this process is not a linear process, it is an interactive process as explained below.

- **Qualitative research is an interactive approach**

The interactive nature of qualitative research is highlighted by Alston and Bowels (2003:10) who state that, reality is socially constructed through interactions and therefore cannot be separated from experience or measured from outside. Denzin and Lincoln (2011:11) explain that qualitative research is made up of the three interconnected activities, theory, method and analysis; or, alternatively, ontology, epistemology and methodology. Ontology in this context speaks to the so-called gendered multi-cultural researcher from a particular background who has certain beliefs and traits. With these the research site is approached with a set of ideas and frameworks that guide a set of questions, the epistemology. These are then

answered through certain procedures, the methodology (Denzin & Lincoln, 2011:11). Apart from the researcher's own characteristics, Yin (2011:8) highlights the role of theory in this interactive approach in which the researcher is driven by certain desires to explain the research site or phenomenon using some existing or emerging theoretical concepts (as introduced under Section 1.2 in this chapter). All these continue to shape the entire process, including the researcher's final reporting and interpretation of the meanings created by the participants.

- **Qualitative research is a fundamentally subjective approach**

In qualitative research, the research participants' experiences, feelings, perceptions and knowledge are regarded as subjective and can therefore be understood properly if they are learnt from the participants' own point of view. Gray (2009:167) highlights the subjective nature of qualitative research through his description of qualitative data as open for multiple interpretations. In other words, the data which is generated through qualitative means is subjected to being interpreted in various ways.

Subjectivity is associated with qualitative research involving researchers as individuals, their biases, values, personal biographies, gender, history, culture and socio-economic aspects all influence their understanding and interpretation of the world (Creswell, 2014:187; Rossman & Rallis, 2012:9). The subjective nature of qualitative research as shaped by both the participants and the researchers therefore leads to another feature of qualitative research which is the presence of some form of self-disclosure or reflexivity on part of the researcher.

- **The researcher is part of the instruments of data collection**

It is the researcher who develops the data collection tools, enters the field, identifies and recruit the participants. Arrangements are made to conduct the interviews, analyse the data and eventually report on the findings. This means that the entire process is "filtered through the researcher's eyes and ears" (Creswell, 2014:43). This does not mean that qualitative research is simply biased research. Qualitative researchers, as observed by Creswell (2016:8-9), are self-conscious researchers

who are aware that their cultures and backgrounds shape the process. Advantageously, it ensures that these features are incorporated in their reports through the technique of reflexivity (introduced further in the next sub-section, 1.6.6). Reflexivity is a process through which researchers declare their personal background and how they shaped their interpretation of their modus operandi during the research study (Creswell, 2014:247; Darawsheh, 2014:561; Rossman & Rallis, 2012:47; Jootun, & McGhee, 2008:42). This means that qualitative researchers not only pay attention to the unfolding research process, but also how their own thinking and background play themselves out during this unfolding process of research.

- **Qualitative research's primary orientation is towards the natural world**

Qualitative researchers are more interested in the natural environments in which the phenomena of their interest occur (Creswell, 2016:6; Nieuwenhuis, 2016:53; Creswell, 2014:185; Streubert & Carpenter, 2011:23; Rossman & Rallis, 2012:8). This means that before a researcher can begin to understand the interaction between and the mutual influence of people's experiences within the world around them, where their behaviour takes place requires observation, they should study action as it occurs naturally, causing as little disruption to people's lives as possible (Yin, 2011:8; Henn, Weinstein & Foard, 2006:76). This natural context, as Creswell (2016:6) describes, can be the families, their friends, homes, work or any other context in which people interact. In the context of this study, the natural context was envisaged as the HBC organisations, the communities and households in which HBCGs perform all care-related activities.

- **Qualitative research focuses on the life experiences and the meanings people attach to such experiences**

A central question of interest for qualitative researchers is how people make sense of their world in which they go about their everyday activities. They tend to be most interested in knowing about their life experiences and the meaning people attach to them in their daily lives. Yin (2011:8) sees the identified events and ideas that emerge from the qualitative research process as representing the meanings that people attach to their real live experiences. Similar sentiments are held by Kalof,

Dan and Dietz (2008:79) who assert that the tradition of qualitative research addresses processes in the social world. Cultural symbols, personal experiences and an array of phenomena underlie people's motivation to engage in daily activities and the meaning attached to them. Obtaining a detailed understanding of lives comes from people expressing themselves through their own language in conversation in their own setting. These meanings and ideas can then be reported in the form of written quotations that represent the voices of the participants (Creswell, 2016:6).

- **Qualitative research is by its nature a holistic approach**

As described by Litchman (2014:42), qualitative researchers are not interested in the components of the phenomenon; their interest is on the phenomenon in its entirety. In this holistic process of qualitative research, the researcher strives to understand the meanings people attach to their lives, the context in which these meanings are understood, the participants' impressions during this process of understanding meanings (Litchman, 2014:45). Qualitative research therefore captures the social, institutional and environmental conditions in which people create meanings to their lives (Yin, 2011:8). This implies that the qualitative researcher should remain vigilant to capture every event that can emerge during this process of knowledge creation.

- **Qualitative research is a complex research approach**

Qualitative research, as Creswell (2016:14) describes, is "a complex subject with moving parts". The complexity of the subject of qualitative research lies in its entire research process. The self-conscious researcher attempts to acquire a detailed and holistic understanding of the participants' continually changing experiences happening in their daily lives. For this, multiple methods must be used, while, at the same time, taking note of how their personal backgrounds shape their understanding (Creswell, 2016:8; Rossman & Rallis, 2012:8). It is through qualitative research that this complexity of human life with its multiple themes can emerge from the process of data analysis derived from multiple voices from participants (Creswell, 2016:13).

What makes this approach even more complex is that the researchers use multiple methods of data collection to develop an understanding of the phenomenon (Denzin & Lincoln, 2011:5). Participants are situated in a complex context and are from diverse backgrounds (Yin, 2011:9). Adding to the complexity of qualitative research is its dynamic nature. The researcher gets involved in long periods of immersion in the diverse cultures of the participants. The dynamic interviews that the researcher conducts gives rise to the unique pace of each participant's responses (Litchman, 2014:38). In other words, the researcher is studying a phenomenon which is part of the dynamic context which is continuously changing.

- **Qualitative research functions best as an emerging research design**

Qualitative researchers aim to develop an understanding of the phenomenon from the participant's experience and allow their engagements with the research site realities and the participants to inform the process. This calls for the adoption of the idea of an emergent research design (Creswell, 2014:186; Mathani, 2004:58), as the research as planned cannot necessarily be strictly followed. As the research proceeds, it is reviewed and sometimes the plan and its elements have to change as deemed necessary.

1.4.2 The rationale for choosing qualitative research approach

In this section, I justify my decision for planning to choose qualitative research as the research approach to guide the study. Creswell (2014:20) identifies the three main factors: research problem and questions, the researcher's personal experience and the advisers and audience as the factors that influence the researcher's choice of the research approach. These specific three driving forces influenced my intended choice of qualitative research approach strongly.

Qualitative research is particularly appropriate when the research problem develops from a gap in the literature (Creswell, 2014:20). A case in point is the need to highlight the voices of the supressed participants and the existence of problems in a real-life situation. Earlier in the discussion (see sub-section 1.1.5 and 1.1.6 above), I indicated that this study was borne from an identified dearth in the literature from the

ambit of Social Work on work-related experiences and challenges HBCGs caring for PLWHA experience; how they manage these challenges and their suggestions for social work support. This lacuna in the literature translates into a suppression of the voices of these groups and therefore perpetuates marginalisation. Their involvement with HIV and AIDS, the condition which continues to ravage humanity, despite the international commitment to put an end to it. This affliction represents a real problem out there that needs to be addressed.

Regarding to personal experiences, Creswell's (2014:20) opinion is that the researcher's skills and personal preferences play a role when considering an approach to guide their research. Here I found my training in Social Work with interviewing as the primary mode for understanding what our clients in our domain were going through, and my involvement in qualitative research since 2006 particularly influential. I felt comfortable with interviewing as an instrument for data collection (both in counselling and in research) and for this reason the qualitative research approach became a natural way for investigating the identified research problem.

To conclude this section, when determining the approach to follow when undertaking research, two options seem to appear. Creswell (2014:20) notes that the researcher, in deciding on the approach to follow, can consider the audience the research findings is intended for or the advisers' specialised research interests and expertise. The qualitative research approach adopted for conducting this study within the Social Work discipline aimed to accommodate both these options. It was my intention through the use of the qualitative research approach to provide a vivid word picture portraying the work-related experiences and challenges of HBCGs in caring for PLWHA, how they cope, and their needs for Social Work support directed at the fraternity of social workers as audience the research findings are intended for. Another factor that prompted me to incorporate the qualitative research approach as part of the study plan at the outset was my supervisor's specialised research approach. He is also a social worker by profession, and a professor specialising in qualitative research. Having common pursuits would be likely to enhance our relationship in my growth in this field.

1.5   RESEARCH DESIGN

The concept 'research design', according to Ragin (in Flick, 2007:37) refers to a plan that covers all aspects of the study for collecting and analysing evidence that will enable the researcher to answer the research questions – it guides the research being done (Ravitch & Riggan, 2017:57; Creswell, 2016:278). Yin (2011:75) admits that a research study without a design does not exist. However, what distinguishes the research design of a qualitative research study from being the same as any other research design is its resistance to strictly upholding the initial plan as set. With this being said, Maxwell (2013:3) cautions that the concept of a research design in qualitative research should not be understood as a logical strategy that must be followed blindly in sequence. It rather tends to be a flexible and inductive process involving interconnection and interaction between its different components. For this reason, Ravitch and Riggan (2017:57) contend that a research design is shaped by its research questions. Flick (2007:50) suggests that the research design should be constructed as a process of planning, clear decision making and reflection about the steps of constructing a design.

Based on the introductory remarks on the nature of qualitative research design, I proposed adopting a phenomenological research design and an explorative, descriptive and contextual research strategy of enquiry which is introduced next.

1.5.1   The phenomenological research design

One of the research designs that I decided to adopt for this study is phenomenology orientated. Phenomenology is an avenue qualitative researchers use as a research design to develop comprehensive descriptions of how the research participants experience the phenomenon under investigation directly (Creswell, 2016:280; Grove et al., 2013:703; Streubert & Carpenter, 2011:73). Phenomenological researchers believe that reality is socially constructed from the participants' everyday world and this stance enabled them to understand their personal experiences at first hand (Denscombe, 2007:77-79).

Phenomenological research can be traced back to Edmund Husserl (1859-1938), a German philosopher and a mathematician who introduced the concept of the "life-world," one that is not readily accessible because it constitutes what is taken for granted (Fochtman, 2008:186). One of the assumptions specific to Husserl's "philosophy of transcendental phenomenology" was his belief that human consciousness perceives experience and can be studied like any object of scientific study (Lopez & Willis, 2004:727). Martin Heidegger (1889-1976), who was a fellow professor and a personal assistant to Husserl, went on to develop his own tradition in phenomenology, referred to as "'existential or interpretive phenomenology" (Fochtman, 2008:187). This resulted in two main types of phenomenological approaches: Husserl's "descriptive phenomenology" and the post Husserl's "Hermeneutic phenomenology" also referred to as "interpretive phenomenology".

With descriptive phenomenology, the researcher becomes attentive, open and ready to listen to detailed descriptions of a participant's lived experiences, then writing their own descriptions of what was described. Descriptive phenomenology emphasises the need to explore, analyse and describe a phenomenon through direct interaction with it. Personal biases are suspended through what Husserl calls "bracketing" – the process which consciously and actively seeks to strip away prior experiential knowledge and personal bias. This is done to not influence the description of the phenomenon at hand (Tuohy, Cooey, Dowling, Murphy & Smith, 2013:18; Wojnar & Swanson, 2007:173). In practical terms, descriptive phenomenologists propose that the researcher should withhold consulting in-depth literature reviews prior to an investigation to neutralise biases, preconceptions and personal knowledge (Deutscher in Wojnar & Swanson 2007:173).

On the other hand, "hermeneutic" or "interpretive phenomenology" states that understanding an individual person cannot occur in isolation of their culture, social context, or the historical period in which they live (Wojnar & Swanson, 2007:174). This implies that the meaning participants attach to their lives takes place in a social context. If these aspects are also interpreted in this vein understanding the phenomenon will be further enriched. It is also essential that all researchers who are part of the team working on the same research study apply the same process of interpretation and visualise the same context. Understanding the phenomenon and

the context requires that values and presuppositions are not separated to serve a common purpose (Tuohy et al., 2013:18).

Phenomenological research designs are selected as they are based on their appropriateness to answering research questions (Englander, 2012:15; Streubert & Carpenter, 2011:87). As indicated earlier under sub-section 1.3.1, this study set out to provide answers to five grand-tour research questions, all of which, by their very nature, require unique answers from the individual participants about their lived experiences. Aspects to consider are: the HBCGs' motivations for becoming involved in caring for PLWHA; their experiences in caring for PLWHA; their work-related challenges experienced; the coping strategies they employ to manage the work-related challenges; and their suggestions for Social Work support to address their work-related challenges experiences.

In the view of Creswell's (2016:262) and that of Streubert and Carpenter (2011:87), phenomenological research is appropriate when the researchers wish to develop a detailed description of the participants' lived experiences of a chosen phenomenon.

My decision to adopt the phenomenological research design as part of the strategy for enquiry for this study was influenced by my personal contact with HBCGs' while I was practising as a social worker. Their experiences shared in relation to caring for PLWHA, and observing their work-related challenges evoked in me the desire to delve into this topic. Amongst others I wanted to find out from them how they would like to be supported by social workers in terms of the work-related challenges experienced. Focusing on these aspects is highly personal and has a unique meaning to each individual caregiver who has lived the experience of caring for PLWHA. The phenomenological research design was therefore anticipated to enable me to gain such an insight from the interpretation and description of each individual participant based on their lived experiences.

1.5.2 The explorative research design

The explorative research design was another research design that I decided to adopt to look for answers for my research questions. The term "explorative research design" refers to research studies which are undertaken to gather data in areas of enquiry where very little is already known (Grove et al., 2013:370; Polit, Beck & Hungler, 2001). As indicated earlier (see sub-section 1.1.5 and 1.1.6) the dearth of literature and research (locally and internationally), especially from a Social Work perspective on the topic specifically related to the work-related challenges experienced by HBCGs caring for PLWHA, how the manage and cope with the challenges experienced and their need for Social Work support prompted me to include the explorative research design to explore this phenomenon about which little is known.

1.5.3 The descriptive research design

A descriptive research design, as in explorative research studies, has as its main objective the accurate portrayal of the characteristics of persons, situations, or groups (Polit et al., 2001:460; Grove et al., 2013:632). In essence, qualitative research is descriptive (Mathani, 2004:57) and researchers conducting qualitative descriptive studies need to stay close to their data and bring words and events to the surface (Sandelowski, 2000:334). The purpose of description is threefold: to reveal the concepts and complex pattern of relationships between the concepts observed; to disclose the intricacies surrounding the phenomenon; and to explain why things happen as they do (Mathani, 2004:57).

Since I planned to describe the insights in detail, I decided that the strategy of enquiry would include a descriptive research design. Such description was possible through exploring the various dimensions and facets of the chosen topic fully.

1.5.4 The contextual research design

When I present the features of qualitative research (see sub-section 1.4.1), I made reference to the fact that the natural context in which the study is conducted has to be included. In other words, as a qualitative researcher I will have to account for all aspects of the phenomenon under study as it materialises within its context (Mason in Topping, 2015:165; Boeije, 2010:34-35; Munhall, 2007:42; Hentz, 2007:350). Hennink et al. (2011:288) recommend that the *subject context*, the *theoretical, cultural, physical* and the *methodological contexts*, as well as the *context of issues and implications* involved be reflected throughout the research process. The *context of issues* will be dealt with in the discussions on the research findings and the *context of implications* discussed in the final chapter reporting the conclusions and recommendations of this thesis.

To set the scene for this study, the introduction, background, problem formulation and rationale of the study attempted to introduce the *subject context* and provide a justification for embarking on this research endeavour. The theoretical frameworks (see Section 1.2 above) provided the *theoretical context* through which the phenomenon under study was to be explored. The intention with these adopted theoretical frameworks for the study was also to serve as a coat closet with the hooks in the closet serving as structures on which to hang the data to be used as part of the literature control when the findings are presented.

The *methodological context* relates to the qualitative research approach adopted for this study. How the methodological context crystallised will be discussed in Chapter Two of this report.

The chapter focusing on the presentation of the research findings covers a range of contexts. These are:

- The *cultural and physical contexts* which encapsulate the various beliefs, values, norms, behaviours and experiences of the caregivers and their demographic characteristics,
- The contexts and conditions under which HBCGs perform their caregiving duties, and,
- The geographical borders of study and where the data was physically collected

I also intended to expose my own beliefs, values and presuppositions as a researcher as part of the cultural context since they also play a role in shaping the research process.

1.5 RESEARCH METHODS

Under this sub-heading the research methods or the practical activities of research in terms of sampling, data collection, data management, data analysis and reporting (Carter & Little, 2007:1318; Payne & Turner, 2008:336) are presented.

1.6.1 Population, sample and sampling techniques

The term "population" refers to a group of people from whom the conclusions related to a topic being investigated are to be drawn (Babbie, 2014:119; Rubin & Babbie, 2013:372; Grinnell & Unrau, 2011:570; Carey, 2009:41; Grinnell & Unrau, 2008:552). While Marshall and Rossman, (2016:106) express the opinion that well formulated research questions point researchers to who need to be selected as the population for a study, Babbie (2014:119) asserts that the entire research methodological process state the population for a study and sampling methods to be used to procure the sample. Given what Marshall and Rossman said, I went back to research questions to get clarity on the population for this study. Consequently, I defined the population for this study as "*all caregivers who directly provide HBC services to PLWHA through the HBC organisation within the municipal boundaries of the City of Tshwane Metropolitan Municipality in Region 1*".

My intention to demarcate the geographical boundaries of my study had to mainly accommodate budget-related restrictions. For this reason, I planned not to include all caregivers in the population who met the criteria of inclusion (presented further on), but to draw a sample from the identified population. Realistically speaking, it is practically impossible to study the entire population in the chosen field. For this reason, both Marshall and Rossman (2016:110) and Babbie (2014:119) advise researchers to rather draw a sample from the population. Given my interest in acquiring an in-depth understanding of the experiences of HBCGs in caring for PLWHA, their work-related challenges and coping strategies to negotiate these

challenges, as well and their preferences for social work and this pointing to the depth and not the breadth of the research, I intended to draw a sample from the stated population. A sample refers to a group of people drawn from a population and studied to gain some understanding of the entire population (Bless et al., 2013:395; Yin, 2011:99; Seidman, 2006:52; Bouma & Ling, 2004:113).

With reference to the aspect of sampling in qualitative research, Patton (1990:196) states that all sampling types in qualitative research fits well under the umbrella of purposive sampling. In addition, qualitative studies focus on relatively small samples the researcher selects purposively (Hennink et al., 2011:84-85; Coyne, 1997:627).

For this reason, I intended to use purposive sampling as a sampling method to deliberately select participants whom I deemed suitable for providing detailed information about the phenomenon under study as Creswell (2016:109), Merriam & Tisdell (2016:96) and Yin 2011:88) advise. The degree of openness and flexibility that characterise purposive sampling (Flick, 2007:27) allows the researcher to select information-rich cases. These could provide useful answers to the research questions (Morse in Coyne, 1997:628). I planned to use the following criteria of inclusion to assist me to recruit information-rich participants.

- The participant had to be 18 years old or older, of any gender, from any racial group and had to have at least six months' experience in the direct delivery of HBC services to PLWHA.
- The participant had to provide HBC services under the auspices of an HBC organisation.
- The participant had to participate voluntarily and willingly.

I intended to use snowball sampling as method for participant recruitment to select participants purposively. Snowball sampling means that after a researcher has interviewed a participant or made an observation, a reference to other potential participants is requested (Creswell, 2016:115; Merriam & Tisdell, 2016:98; Babbie, 2014:200-201). I envisaged asking the recruited participant to refer me to other individuals who meet the required stated criteria of inclusion, by asking them if I

could speak to them or ask them to contact me so that I could find out whether they would be willing to also participate in my study.

In order to reach out to my participants, I had in mind to follow the following procedure: I planned to begin by identifying home-based organisations that render services to PLWHA and then negotiate access using emails, telephone or site visits to these organisations through their gatekeepers[3]. Based on the interest I got, I planned to follow it up by meeting with the concerned parties to further explain the aim of the research, the procedures for participating in the research, as well as the ethical considerations to be adhered to during this research project. Following approval of my request to conduct a study by the organisations, I intended to then negotiate to meet with caregivers where I would make a request for volunteers who meet the above-mentioned criteria and willing to participate in the study. I also planned to prepare the participants for the study and once they were prepared and ready to participate I would then request them to assist me in identifying other potential participants who would meet the set criteria and who may be interested in the study.

Given the general consensus in the research literature (Merriam & Tisdell, 2016:101; Nieuwenhuis, 2016:82; Streubert & Carpenter, 2011:91) that in qualitative research, the sampling sample size is determined by the principle of data saturation, I planned to adopt this principle. Data saturation means that the researcher begins to hear the same things when interviewing the participants without any new knowledge coming in (Merriam & Tisdell, 2016:101; Streubert & Carpenter, 2011:455). I intended to continue to collect data until, in consultation with my supervisor; I reached a state of data saturation.

1.5.2 Preparation for data collection

Researchers need to be thoroughly prepared before they begin the process of data collection (Nieuwenhuis, 2016:37; Babbie, 2014:126; Rossman & Rallis, 2012:146; Streubert & Carpenter, 2011:33). Rossman and Rallis (2012:146-147) are of the view that researchers must prepare for data collection by ensuring that interview-

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[3] A gatekeeper refers to someone who control access to the research field (Flick, 2007:117).

guides are well formulated, suitable participants are recruited and informed about the strategy and purpose of the research. In identifying, recruiting the participants and preparing them for data collection, I proposed adopting the procedure that is described below.

Prior to entering the field, my plan was to first seek approval and ethical clearance for the proposed study from the UNISA (University of South Africa) Department of Social Work's Research and Ethics Committee. Subsequent to this approval, and in following the recommendation for researchers to gain permission from gatekeepers before they enter the field that has been decided on (Bless et al., 2013:35; Rossman & Rallis, 2012:161; Johl, & Renganathan, 2010:42; Hunn, 2006:146), I intended to visit clinics, and hospitals within the demarcated geographical area I decided on for this study. I would introduce myself and the study to those in charge of these facilities and request them to link me to the HBC organisations in their respective areas. In addition, and as proposed by Yin's (2011:144) call for researchers to know where and when to conduct their field work, I intended to also initiate contact with some of the HBC organisations that I already knew by physically visiting them, initiating telephone contacts or sending emails to request permission to conduct a study among their HBCGs.

Once this process was observed, I intended to make an appointment with a management representative of each HBC organisation I could locate to officially introduce myself and explain the purpose of my study in detail. Van der Burgh (in Fouché, 2002:283) explains that requesting access from the gatekeepers not only ensures that the researcher follows the necessary procedures, but that it also enables potential participants on the ground know what the project seeks to accomplish. At this stage, I also planned to request permission from the authorities to spend about three days at an organisation to be acquainted with the organisation's policies, rules and operational procedures so that I would not find myself in violation of their rules and guidelines.

On completing the above process and getting permission to conduct a study from the HBC organisation authorities, I planned to schedule appointments with caregivers as a group in each organisation. I intend to introduce myself and the purpose of my

study in detail to build rapport. Rapport is a warm and open relationship of trust established between the researcher and the participants (Babbie, 2014:325). A trusting relationship between the researcher and the participants is part of the mechanisms for enriching rigor (Rossman and Rallis, 2012:156), and part of the ethical obligations researchers should uphold (Yin, (2011:138). In my meeting with the caregivers (potential participants) in the different organisations, I planned to inform them about the purpose and the procedures of the research. I also intended to inform them of the risks and benefits involved in participating, their rights and responsibilities (Babbie, 2014:326; Bless et al., 2013:30; Rossman & Rallis, 2012:73; Streubert & Carpenter, 2011:61; Flick, 2007:72.

I further intended to leave some documents (Addenda A, B and C) so that they could familiarise themselves with them in order to make informed decisions on whether to participate in the study or not. My intention in this instance was to allow them ample time to familiarise themselves with the aim of the study, the risks and benefits involved and not to rush into making a decision about whether or not to participate. Once they had indicated their interest to participate in their study, I would once again revisit the aim of the study, the activities they should engage in as participants and the ethical considerations to observe during the study. I would also request them to sign the informed consent (See Addendum B) testifying to the fact that they are participating voluntarily and willingly, having been comprehensively informed about the research.

1.6.3   Method of data collection

Data collection refers to methods to be employed, measuring instruments to be used and activities to be conducted in view of collecting information that will provide answers to the research questions formulated at the outset of the study (Grinnell & Unrau, 2011:562). As described by Rossman and Rallis (2012:168-169), qualitative data collection is a discovery process, with the researcher uncovering aspects of the participant's reality. In collecting the data, researchers use techniques that allow for a systematic process of collecting the data about the participants and their natural settings (Elmusharaf, 2012:3). In qualitative research, the methods of data collection customarily used are *inter alia* interviews, observations and focus group discussions

(Bless et al., 2013:21; Streubert & Carpenter, 2011:33; Mack, Woodsong, McQueen, Guest & Namey, 2005:3). These are all determined by the research question, the sensitivity of the subject matter and available resources (Streubert & Carpenter, 2011:34; Devers & Frankel, 2000:267).

In this study, I anticipated using individual face-to-face semi-structured interviews as the method of data collection. DeMarrais (in Merriam & Tisdell, 2016:108) defines an interview as "a process in which a researcher and participants engage in a conversation focused on questions related to the research study". An interview is a two way "meaning making partnership" and a "knowledge-producing conversation" (Hennink et al., 2011:109) between the researcher and the participant for the former to learn about the ideas, beliefs, views, opinions and behaviours of the latter (Nieuwenhuis, 2016:92-93; Bless et al., 2013:58). The use of interviews, as observed by Merriam and Tisdell (2016:108), is particularly appropriate given that it is impossible for the researcher to observe all behaviours, feelings or people's interpretations of their world. For Streubert and Carpenter (2011:37), interviews, even in the context of research, are by their very nature therapeutic in that they give voice to an experience and therefore promote the worth of participants to being heard. This feature was anticipated to be significant for the participants of this study who might be going through difficult experiences in their work environments.

In conducting the interviews, the researcher uses questions contained in an interview-guide (see Addendum F) to gain insight into the aspects inherent in the topic under investigation (Merriam & Tisdell, 2016:110; Bless et al., 2013:21; Flick, 2007:78). Hennink et al (2011:112), explain the concept interview-guide as a list of questions the interviewer uses mainly as a memory aide during the interview – these questions guide the interview as it covers all aspects related to the topic that needs to be explored.

Research interviews range through a continuum from being highly structured through to individual face-to-face semi-structured interviews, to unstructured interviews (Merriam & Tisdell, 2016:110; Nieuwenhuis, 2016:93; Edwards & Hollard, 2013:29-30; Streubert & Carpenter, 2011:34). Highly structured interviews prescribe to a set of standardised questions to be asked and a fixed order in which they have to be

asked, (Merriam & Tisdell, 2016: 109; Nieuwenhuis, 2016:93; Streubert & Carpenter, 2011:34). Individual face-to-face semi-structured interviews involve a guide with specific items and considerable latitude given to interviewers to explore in their own way matters pertaining to the research question being asked (Merriam & Tisdell, 2016:110; Nieuwenhuis, 2016:93). Unstructured interviews do not have pre-planned questions and interviewees are afforded more flexibility in sharing their experiences in their own way with minimal introjection from the researcher (Merriam & Tisdell, 2016:111; Edwards & Hollard, 2013:30).

As mentioned in the introduction part to this section I planned to conduct the individual face-to-face semi-structured interviews which will be recorded through the digital recorder for data collection in this study. Englander (2012:14) is of the view that the choice of interviewing as a data collection tool normally comes from the researcher's interest in meanings of a phenomenon as lived by the participants. Sometimes a stance is taken against predetermined questions when working from a phenomenological frame of reference. However, both Chan et al. (2013:4-5) and Englander (2012:26), make allowance in the context of a phenomenological research design for individual face-to-face semi-structured interviews facilitated by open-ended questions and probes to be prepared in advance to steer and guide the interview. Chan et al. (2013:4) justify such an allowance as a precautionary measure to prevent the researcher from prompting with leading questions.

I anticipated that individual face-to-face semi-structured interviews would allow the participants to pace themselves with minimal guidance via the open-ended focused questions in the interview-guide during their interview. I expected them to satisfy my interest in the meaning they attached to experiences in relation to caring for PLWHA. Extending the conversation to also comment on the work-related challenges they experience, the coping strategies they employ to address these challenges and how they would like to be supported by social workers in overcoming these challenges. Rossman and Rallis (20102:169) think that gathering rich qualitative data requires focused but clear questioning, listening and observation skills. Nieuwenhuis (2016:93) urges researchers to be attentive to the participant's responses. In heeding Rossman and Rallis and Nieuwenhuis' suggestions above, I intended to

use, in addition to the open-ended questions, further probing, paying attention to and listening with empathy as my interviewing skills during data collection.

Probing is one of the interviewing skills that is used by the researcher to ask for more information that the participant might not have been satisfactorily provided when answering the interview questions (Remenyi, 2014:142). To obtain such information, Nieuwenhuis (2016:94) proposes that researchers use the following types of probing:

- Detail-orientated probes: These are probes used mainly when the researcher wants specific detailed answers from the participants.
- Elaboration probes: In using elaboration probes, the researcher's aim is to develop a full understanding of the answers provided by the participants. In this case, the former requests the latter to provide examples or to tell them more about the provided answer.
- Clarification probes: With clarification probes, the researcher aims to check if they really understood the participants. This may take a form of paraphrasing the answer to enable the participant to confirm if they were understood or not.

In applying the skill of attending, I aimed to heed Rossman and Rallis' (2012:169) suggestion and pay attention to participants' emotions, interest and fatigue. This was expected to signal if it was the right time to redirect the question, probe or even proceed with the interview itself. Babbie (2014:326) also acknowledges the interviewer can only collect rich data that is significant by paying attention. As Seidman's (2006:78) suggests, I listened carefully on the three accepted levels: first, urging researchers to listen to facilitate internalising what the participants are saying. Second, researches must listen to the inner voice by becoming more sensitive and taking the participant's language seriously (Seidman, 2006:79). On the third level, Seidman (2006:79) urges researchers to listen while at the same time remaining aware of the process taking place and its substance. In other words, the researcher should remain conscious of time and the aspects already covered in the interviews.

Another skill that I envisaged applying during my interviews was empathy. Empathic listening is one of the crucial skills qualitative researchers embarking on

phenomenological research use (Finlay, 2012:182). In her description of empathic listening, McNally and Rao (in Finlay, 2012:182) urges researchers to engage in what they call "feeling into another's experience". It basically means that researchers should put themselves in the participant's situation and imagine the experience from their perspective. This brings the researchers closer to the participant's experience; hence they will understand it better.

1.6.4 Pilot testing

Because a researcher cannot predict how interviewees will interpret the questions asked as formulated in the interview-guide, Hennink et al. (2011:120) suggest that the method of data collection to be followed and the questions in the interview-guide be pilot-tested. I therefore planned to conduct a pilot study using the same proposed methods, and in the settings, similar to those of the main study. A pilot study is a smaller version of a proposed study conducted with the aim to try out the research method of data collection to identify potential problems that could affect the quality and soundness of the results. If needs be, the methodology might have to be refined (Grove et al., 2013:703). Findings of a pilot study are analysed to determine whether modification to the version is required, or if it can be rolled out as it is (Kumar, 2015:305). The information is not used in the main study. In other words, a pilot study enables the researcher to assess any methodological risks and hindrances that might be encountered when the questions are used for the proposed study. Necessary adjustments are fine-tuned prior the commencement of the proposed study. As In the proposed study, the pilot study involves application of the same methodological procedures as described earlier in the discussion to conduct some interviews which will be recorded digitally to enable the researcher to ensure data accuracy and trustworthiness. Following the recording of the interviews, I intended to record, code and analyse data. Once this process is completed, I envisaged the findings to serve as a guideline as to whether to modify or substitute any part of the research methodology.

1.6.5   Method of data analysis

Data analysis implies a sequence of selections made by researchers about how they interact with the data (Ravitch and Riggan, 2017:111). For Marshall and Rossman (cited in Gibson & Brown, 2009:4), it refers to the continuous process of searching for general statements about relationships and underlying themes. This process considers the fit of each piece of data in relation to all the other pieces. During analysis, a researcher continually moves back and forth between initial and later interviews, identifying units of meaning, coding and interpreting the data as they go along (Grinnell & Unrau 2008:388).

In qualitative research, the process of data analysis involves preparing and organising the data that comes as text data as transcripts, or image data as photographs. It is then reduced into themes through a process of coding and condensing the codes. These then culminate as figures, tables or discussions (Creswell, 2013:180).

In this study, Tesch's eight steps (in Creswell, 2009:186) of data analysis were used. I planned and intended to analyse the data in this way:

- I had in mind to transcribe the interviews word-for-word and then form an overview of the gathered information by reading through all the transcriptions and making notes of the salient aspects and information that came to mind.

- I then intended to choose one transcript and read it through carefully while asking myself, "What am I reading here?" "What is it all about?" "What does this mean?" Through engaging in this process of critical reflection, I anticipated uncovering some themes and patterns in the data which I planned to write down.

- I planned to repeat the previous step for all the transcribed interviews whilst compiling a list of themes and sub-themes as they emerge from the data.

- I intended to allocate a fitting abbreviation for each of the themes and sub-themes and then return to the dataset and place an abbreviation next to each segment of data relating to a specific theme and or sub-theme.

- On completion of this I planned to proceed by grouping matching and related themes and/or sub-themes matching together.

- My intention was to eventually take a final decision about the abbreviations for each theme and sub-theme and arrange them alphabetically, in preparation of the process of re-coding, should I be required to do so again.

- By using the cut-and-paste method, I planned to assemble the data material (storylines) belonging to each theme and sub-theme in one place and conduct a preliminary analysis.

- Once the entire process is complete, I intended to prepare myself to engage in the activity of re-coding, if required. If not, I planned to begin the process of compiling the chapters in which the research findings were to be reported.

1.6.6 Methods of data verification

Data verification concerns itself with the question of quality and applicability or validity of the study conducted and reported Yin (2. 011:78) is of the opinion that a study could be considered valid if the researcher can with confidence prove that the data was properly collected and interpreted so that the conclusion arrived at contains accurate reflections of the real world and is representative of the world that the researcher studied (Yin, 2011:78).

Qualitative researchers need to ensure some level of trustworthiness in the research to establish this confidence (Whittemore, Chase & Mandle, 2001; Morse, Barrett, Mayan, Olson & Spiers, 2002; Lietz, Langer and Furman, 2006; Eisner, 1991; Guba & Lincoln in Morse et al., 2002). Trustworthiness is demonstrated when the findings reflect the meanings as described by the participants as closely as possible (Lietz et al., 2006:444). In line with the consensus among qualitative researchers (Merriam & Tisdell, 2016:239; Nieuwenhuis, 2016:123-125; Bless et al., 2013:236-237; Streubert & Carpenter, 2011:48; Lietz & Zayas, 2010:191; Shenton, 2004:64), and referring to the seminal work of Guba and Lincoln (1990) who developed criteria for evaluating qualitative research through credibility, transferability, dependability and confirmability, I have adopted these as strategies for data verification. They are concepts that work together to achieve trustworthiness.

- **Credibility**

Credibility, as noted by Streubert and Carpenter (2011:48) is demonstrated when the participants recognise the research findings as their own experiences. This means that the researchers must report the findings in such a way that they truly represent what the participants reported. The following are some of the strategies scholars proposed to enhance a study's credibility and which I planned to adopt (Nieuwenhuis, 2016:123; Rossman & Rallis, 2012:65; Shenton, 2004:64-69):

  o *Early familiarity with the culture of the research site*

Shenton (2004:65) recommends that researchers familiarise themselves with the culture of the research site as soon as possible. While planning my research I also planned to visit the HBC organisations that had caregivers caring for PLWHA in their service personally as their work aligns with my investigation. I planned to arrange spending time at their premises with their permission to fully understand their culture and operational procedures.

  o *Triangulation*

Triangulation, as a strategy to add to a study's credibility, refers to the use of different methods of data collection, theories, data or even researchers in one study (Merriam & Tisdell, 2016:259; Rossman & Rallis, 2012:65; 2007:120). Padgett (2008:186) explains the concept triangulation as the use of "two or more sources to achieve a comprehensive picture of a fixed point of reference". Intending to interview different caregivers I planned to employ what is called the "triangulation of data sources" (Krefting, 1991:216). In addition, I expected the selected theoretical frameworks adopted for this study to illuminate the phenomenon being investigated as part of the literature control related to theoretical triangulation (Krefting, 1991:216). I planned to draw them from the disciplines of Nursing, Psychology and Social Work.

o *Ensuring honesty in participants when collecting data*

The strategy of ensuring honesty when engaging with the participants is not only for credibility (Shenton, 2004). It is also an ethical obligation through which researchers are urged to avoid deceiving participants and to ensure accurate information is provided (Creswell, 2016:51; Creswell, 2014:98; Rossman & Rallis, 2012:74; Flick, 2007:69). My intention was to ensure that participants are honestly informed about the purpose of the study, its aims and objectives along with the possible risks and benefits involved (see Addendum B).

o *Iterative questioning*

The aim of iterative questioning as Shenton (2004:67) describes is to enable the researcher to prevent deliberate lies from the participants by employing some probing techniques. As indicated earlier under the methods of data collection, probing was envisaged as one of the skills that I planned to implement during my interviews with the participants. My anticipation was that in addition to assisting me to get rich data and clarify any misunderstandings, it would also enable me to bring discrepancies to light and constructively confront misunderstandings on the part of the participants.

o *Engage in frequent debriefing sessions*

Frequent debriefing sessions between the researcher and peers are also highlighted as a strategy for ensuring credibility of the study. One of the advantages of peer debriefing is that it enables researchers to make informed choices in methodology, and ensures the substantiation of the themes and patterns that emerges from the data (McBrien, in Streubert & Carpenter, 2011:49). In Merriam and Tisdell's (2016:249) opinion, peer debriefing can either be done by a colleague who is familiar with the research, or someone who is new to the topic. In the case of this study, I planned to make use of continuous supervision meetings with my study supervisor who will expose my bias and misunderstandings.

o   *Peer scrutiny of the research project*

From planning to engage in research methodological discussions with fellow colleagues who are also busy with their postgraduate studies and colleagues in the field of HBC, I would have enriching support and peer scrutiny. They would assist me to remain focused, address my biased suggestions and keep me on the straight and narrow with my studies. I also planned to utilise the services of an independent coder who is well versed in analysing qualitative data. The aim was that the prepared dataset be analysed independently from me. The plan was that in consultation afterwards, my study's supervisor would facilitate a consensus discussion between the independent coder and myself to allow for the participant's stories to be authentically and credibly reported.

o   *Researcher credibility*

In highlighting the significant role of the researcher in shaping the credibility of the study, Meriam and Tisdell (2016:243) state: "human beings are the primary instruments of data collection and analysis in qualitative research, interpretation of reality are assessed directly through their observations and interviews." This means that the entire study is determined by who the researcher is and how the researcher did conduct the entire process. Marshall and Rossman (2016:260) explain this better when stating that a credible researcher enhances the chances of the credibility of the entire research process. My experience as a field social worker for nine years and my professional engagement with caregivers caring for PLWHA as part of my work-related responsibilities was expected to be a valuable experience. My experience in qualitative research dates from 2005 when I was an undergraduate student to as recently as a lecturer involved in providing postgraduate supervision in qualitative research. With this background, and my desire to study further, I felt I 'would demonstrate my credibility and ability to execute this project.

o   *Engage in reflexivity*

As indicated earlier in the introduction of the qualitative research approach (sub-section 1.4.1 above), the researcher is part of the research process and therefore inseparable from it. As a result of this, Carcary (2009:12) admits that "we are biased by our background, knowledge and prejudices to see things in certain ways and not others" and recommends that we therefore need to considerably reflect on our part in and influence on the research. In other words, it is imperative for qualitative researchers to not only pay attention to what and how they ask about their interest, but it is also vitally important to pay attention to themselves and the impact of their presence in the research process. The process is called "reflexivity", through which researchers understand their roles in relation to participants by questioning their own attitudes, thoughts, reactions and habitual actions (Clancy, 2013:13). It entails looking, with a critical conscience, at their backgrounds, gender, power relationship and how these shape their relationships with the participants (Clancy, 2013:13) In adhering to the reflexivity strategy, I intended to keep a field journal, as suggested by Streubert and Carpenter, (2011:34) and analyse my background, perceptions, experiences and interests and their influence during the research process.

o   *Conduct member checks*

Member checking is a credibility strategy through which researchers take the data back to the participants for verification. It has to be a true reflection of what they shared with the researcher during the interviews (Creswell, 2016:279; Marshall & Rossman, 2016:230; Maxwell, 2013:126; Flick, 2007:117). Merriam and Tisdell (2016:246) see this strategy as crucial help for the researcher to rule out the possibility of misrepresenting the participants' meanings. It also offers researchers an opportunity to understand their own bias and misunderstandings. In this study, I envisaged adopting this strategy by presenting the transcripts to the participants so that they could confirm if indeed the data truly reflect their experiences.

o *Perform thick description*

Another strategy to assist enhancing credibility is providing a detailed account on the setting, people and events of the research and its methodology (Creswell, 2016:281). In doing so, other researchers can interpret and understand the event or process well (Merriam & Tisdell, 2016:259; Denzin, in Rossman & Rallis, 2012:195). In this study, I planned to prepare a thick description of the setting and participants of the study to ensure that my findings were backed by adequate evidence. I wanted to do this in the form of direct quotes from the interviews as (Merriam & Tisdell, 2016:257) mention. I also gave a comprehensive account of how the research methodology planned was applied.

o *The researcher's authority*

I anticipated that my authority in relation to qualitative research and its methodology would benefit the credibility of the study. I was introduced to the qualitative research methodology and conducting research from this approach during my undergraduate studies in 2006. In this year, my first independent study on qualitative research with a focus on child abuse was completed. In 2010, I was awarded a Master of Sociology Degree in Social Behaviour Studies from the University of South Africa. I had conducted an investigation with a qualitative approach titled "anticipated and enacted stigma among female outpatients living with HIV: the case of Chris Hani Baragwanath Hospital, South Africa". From this study, I managed to co-publish an article with my supervisor, Professor Gretchen du Plessis, titled, "dealing with HIV-related stigma: a qualitative study of women outpatients from the Chris Hani Baragwanath Hospital".

My acceptance of an employment offer in 2013 as a lecturer at UNISA has exposed me to other research done and academic opportunities. Particularly participating in teaching, marking and evaluating other students' qualitative research work submitted work as well as my postgraduate research supervision, all contributed to my authority as researcher. In addition, my involvement in the field of HIV and AIDS HBC as a social worker and the field of Social Work practice in general also bolstered my research authority.

- **Transferability**

By transferability Marshall and Rossman (2016:261) refer to the ways in which the findings of a study are applicable to other contexts that were not part of the study. Other researchers could also use them for situations if their research questions were similar. In order for researchers to enable interested parties to conduct a transferability audit they must provide a thick or detailed description of the setting, participants and the research methodology employed (Merriam & Tisdell, 2016:256). In order to provide the tools for future researchers to such an audit, I planned to devote Chapters Two to Four of this report for a comprehensive account on how the research methodology was applied and for the presentation of the research findings.

- **Dependability**

As defined by Marshall and Rossman (2016:262), dependability entails the researcher accounting for the changes in the phenomenon and the research design as an understanding of the research setting increases. In Nieuwenhuis' (2016:124) view, dependability can be upheld by keeping a journal of the decisions made throughout the process to enable others to follow. In this study, I envisaged upholding dependability by keeping a journal. I intended to use it to record a detailed context during reporting for the reader to identify any changes which might occur during the process. Presentation of the current chapter (Chapter One) was initially a research plan or proposal. The next chapter (Chapter Two) explains how this plan was implemented together with the continuous cross-referencing. This will enable the reader to identify anything that might be in contrast with the initial plan to enhance the dependability of the study, and to assess if I had accounted for the diversion from the initial research plan.

In addition, dependability also talks to the consistency of data, assessing ''whether the findings would be consistent if they were replicated with the same subjects or in a similar context''; and consistency is established by the strategy of dependability (Guba cited in Krefting, 1991:216). The researcher planned to employ the services of an independent coder to code the data and he did the same. Subsequently, and on

completion of this process, the researcher, the independent coder and supervisor would engage in a consensus discussion to finalise the list of themes and sub-themes will be finalised. These will have emerged from the processes of data analysis.

- **Confirmability**

Confirmability enables the researcher to prove the transparency of their studies that others will use to confirm their findings (Marshall & Rossman, 2016:262). In Streubert and Carpenter's (2011:49) view, researchers should demonstrate confirmability by leaving an audit trail for others to follow the steps and the process that was followed to reach a conclusion (Streubert & Carpenter, 2011:49). Reflexivity was adopted as a strategy for applying the principle of confirmability.

As introduced earlier under sub-section 1.4.1, reflexivity requires that researchers remain self-conscious and continuously examine their role and influence, being constantly aware of how they shape the entire research process (Streubert & Carpenter, 2011:34). In upholding confirmability, I anticipated explaining the process that was followed during the entire process in detail. Quotations from the participants' voices were expected to substantiate the findings.

1.7   ETHICAL CONSIDERATIONS

Ethics in research, according to Gray (2009:576), signifies standards of conduct, values and how they affect the researcher and the participants. Creswell (2016:49) urges researchers to remain mindful of ethical issues that emerge throughout the research process and to constantly be prepared to actively address them. The general aim of research ethics is to protect the researcher, the research participants and other interested parties. Importantly, it also serves to maintain professional research standards, promote public confidence in research and minimise legal risks (Gibson and Brown, 2009:60). In this study, I anticipated to uphold the ethical principles dealt with in the sub-sections that follow.

1.7.1   Obtaining informed consent

Research participants have the right to be informed about the circumstances and processes in which they are involved. According to Christians (2005:144), the two main conditions for proper respect for human rights in research are:

- o The subjects and participants must voluntarily agree to participate. In other words, they must not be forced, either physically, psychologically or in any other way, to take part in the study.
- o The agreement between the researcher and their participants must be based on full and open information.

In addition to these conditions, Strydom (2002:65) recommends that there must be adequate opportunity for participants to ask questions before the study commences, as well as during the investigation.

In adhering to the ethical principle of obtaining informed consent, I envisaged conducting an information session with participants where I would outline the whole research process, its goals, objectives, their ethical obligations and their right to withdraw during any stage of the project. I planned to express my expectations from them, stressing I would give them an opportunity to ask questions whenever they feel uncertain. I planned to facilitate the signing of the informed consent forms once the potential research participants understood the proposed research and its processes, freely agreeing to participate. As the study progresses, I intended to enable participants to ask questions frequently and when necessary. Clarifying uncertainties and keeping the process as transparent as possible are essential ethical objectives.

1.7.2 Anonymity and Confidentiality

Before the data obtained from research with human subjects can be shared with other researchers or archived, it must be anonymised or redacted. It is obligatory that individuals, organisations or businesses are not identifiable (Corti, Van den Eynden & Bishop (2014:118). By anonymity, Kalof et al. (2008:193) refer to the removal of all links between a research participant's data and their contact information to conceal their identity. For Polit et al. (2001:82), "anonymity occurs

when even the researcher cannot link a participant with his/her data." According to Corti et al. (2014:122), "for the anonymisation of qualitative material, such as transcribed interviews, textual or audio-visual data, pseudonyms or vaguer descriptors should be used to deal with any problematic identifying information." Greener (2011:51) points out that the two main arguments for anonymity lie in both the practical aspect of anonymity and its ethical aspect.

Practically, offering anonymity results in participants being more honest, feeling that they can say what they believe without being concerned about whether their answers will in some way be used against them (Greener, 2011:51). The practical aspects of anonymity therefore encourage trust and openness. Participants can express themselves freely in a conducive environment. In practice, Greener (2011:146) adds that anonymity means that researchers have to be organised in the way that they store data – making sure that it is stored and reported on safely with source concealed. The management of information is discussed further on in this section. At an ethical level, anonymity is described as assuring participants that participating in the research will neither result in adverse consequences for them nor subsequent harm. They need know their right to anonymity (Greener, 2011:51).

When a researcher assures participants of anonymity, information links back to specific participants has to be secured to make this impossible (Babbie, 2014:68; Kalof et al., 2008:194). Confidentiality too must be maintained. The researcher must commit to using procedures that will prevent such identification from being available to anyone but the research team (Babbie, 2014:68; Kalof et al. 2008:194). Confidentiality is a pledge that any information the participant provides will not be publicly reported or made accessible to parties not involved in the research (Polit et al., 2001:82). In upholding the principles of anonymity for the proposed study, I envisaged to implement the following measures:

- **Avoid using real names of participants**

Using real names of participants can easily result in a linkage of the research data to that person. This will result in a breach of the ethical principle of anonymity. My intention here was to use pseudonyms instead of real name to conceal the individual's identity to stop the possible linkage.

- **Avoid using identifiable characteristics of participants**

Although I anticipated presenting a section of the demographic features of participants, this was expected to be a bit general to avoid easy identification of the participants. The use of specific features like a caregiver with a disability from Soshanguve was expected to be avoided as I believed it would easily expose the participants and therefore compromise the ethical principle of anonymity.

- **Avoid using specific names and addresses of the research sites.**

The use of specific names and addresses of the research sites can also compromise the ethical principles of anonymity in that participants can be easily located. In the case of this study, I intended to use pseudonyms to replace the real names of the organisations from which the participants were sourced and the areas which they were serving.

With regard to confidentiality, Kaiser (2009:1632) acknowledges that qualitative researchers face a conflict between conveying detailed, accurate accounts of the social world and protecting the identities of the individuals who participated in their study research. In applying confidentiality one can adopt either the dominant or the alternative approach (Kaiser, 2009:1634). Under the dominant approach data cannot be collected anonymously, without any identifying information in some way. Then researchers must collect, analyse and report the data thoughtfully without compromising any aspect of their identity. (Kaiser, 2009:1634). The alternative approach, on the other hand, regards the interviewee as a participant whose answers are extremely important and valuable. During the preparation time prior to

the actual interview, the researcher makes a special and appreciative effort to present their role simply for them to see how they fit into the picture and will be useful. Involving them like this makes them better informed about the setting of the study, how the information they give is likely to be used, the target audience and how the study results will be disseminated. The practical steps to be taken to facilitate dialogue with the participants are explained and the consent process, although already finalised, is revised (Kaiser, 2009:1636).

In this study, I anticipated adopting a combination of both the dominant approach and the alternative approach to address the ethical principle of confidentiality. In adhering to the dominant approach through the consent form statements, I envisaged assuring confidentiality at the beginning of the data collection phase.

During data cleaning, I envisaged purposefully removing identifiers to create a clean dataset that would ensure anonymity and address the ethical obligation of confidentiality. I planned to do this using the "find and replace" tool in word processing programs to change names of people and places. In adopting the alternative approach to confidentiality, I intended to ensure that the participants were fully informed about the process of data utilisation and the study's potential audiences (see Addenda A, B, C & D). I also committed not to disclose information provided by the participants to anyone other than my supervisor who would be following and guiding the research process. Even in this exceptional case, my plan was to ensure that any clue that could easily identify the participant would be removed. The participants would be fully aware of this and had consented to this form of disclosure (see Addendum B).

1.7.3   Management of data

By data management, Corti et al. (2014:2) mean "all data practices, manipulations, enhancements and processes that ensure that the research data are of high quality, are well organised, documented, preserved, sustainable, accessible and reusable". Researchers should also make sure that data is securely stored in such a way that it does not compromise the ethical principles of informed consent, anonymity and confidentiality (Corti et al., 2014:2; Gibson & Brown, 2009:62).

In this study, I proposed to ensure that all data, with reference to the digital recordings of the interviews, the transcribed interviews and notes are safely stored on my personal computer. I intended to ensure that would be the only person with access to it and it would be password protected. To avoid any loss of data, I planned to save all copies of the data on a flash disc with password protection as a backup. In the case of requests from any institution or third parties, I envisaged avoiding using real names and any other information that was obvious. The exact names of the organisations from which the participants were recruited, the areas where they served and their management details were to also be also meticulously anonymised to prevent identification.

1.8   CLARIFICATION OF CONCEPTS

In the sub-sections to follow the concepts central to this study are clarified.

1.8.1 Experience

The term "experience" can be defined as a conscious event; an event that is lived through, or undergone, as opposed to one that is imagined or thought about (Van den Bos, 2007:354). Collins (2010:581) holds a similar interpretation when he says the term experience refers to the totality of a person's perceptions, feelings and memories. For Pindani (2008: vii), experience means "the occurrence, incident or even an activity ensuring a lesson learnt by the affected person. It can be pleasant or unpleasant." In this study the term "experience" means the collective of feelings and emotional reactions resulting from the conscious, lived through event of caring for PLWHA by the HBCGs.

1.8.2 Managing

The concept managing comes from a verb "to manage". There are various definitions of the concept managing. According to the Paperback Oxford Dictionary (2012:439), managing means ability to cope despite difficulties. The two concepts manage and cope in this study therefore mean one and the same thing. Coping as defined by Abbott (in Canada, 2013:93) means a process of shifting behaviours, thoughts and

feelings that individuals use when interacting with their situations to avoid life stressors harming them. For the purpose of this study, managing would encompass how HBCGs caring for PLWHA manage or cope with the work-related challenges they experience.

1.8.3 Work-related challenges

Before the concept, work-related challenges can be understood in context, it was crucial to first have an idea of the concept "challenge." When defining it, Collins (2010:287) refers to it as "a demanding or stimulating situation". In another definition, Kwanisai, (2014:3) refers to a challenge as something that stimulates a person by testing their strength, skill or ability. This implies that the work situation as such makes it difficult for a person to use their skills and abilities to execute their duties. Within the context of this study, the term work-related challenges refer to any work-related situation or event which makes it difficult for HBCGs to perform their normal duties of caring for PLWHA.

1.8.4 Home-based Care

What the different definitions of the concept "HBC" from various literature sources (provided below) appear to have in common is that HBC is providing care to patients in need of health and social services in their respective households. For Tshabalala (2008:2), HBC refers to "a service that offers basic support services to people who need assistance with activities of daily living at home". Mohammad and Gikonyo, 2005:2) clarify this concept in a very similar fashion. For them, HBC means that individuals receive care from their own family members in their own home supported by skilled welfare officers and communities address their physical, health, spiritual, material and psychosocial needs. The DoH (2004:1) defines HBC as the act of providing health care services including care towards a dignified death within the persons' own homes by formal and informal caregivers for the promotion, restoration and maintenance of their maximum level of comfort, function and health. For the purpose of this study, I adopted the definition of home-based care as provided by the WHO which views a home-based care as any form of care which includes physical, psychosocial, palliative and spiritual care activities provided to the patients within

their homes. The aim is to ensure hope and maintain the independence and quality of life to the patients and their families through high quality and appropriate care (UNAIDS, 2008:2; WHO, 2002:6).

1.8.5 Caregiver

As defined by the WHO (2002:6), the concept caregiver is a person who provides any form of care to ill people in their homes. Such care includes physical, psychological, palliative and spiritual activities. For the WHO (2004:12), a caregiver is "a person who provides support, assistance, formal and informal, with various activities to persons with disabilities or long-term conditions, or persons who are elderly. This person may provide emotional or financial support, as well as hands-on help with different tasks. Caregiving may also be done from long distance". In another definition of a caregiver, Tshabalala (2008:33) states that a caregiver is anyone who provides care, with formal caregivers being members of an organisation and being accountable to its norms and practice and informal caregivers being individuals who are not affiliated to any organisation. In the context of this study, a caregiver was defined as any person who provides physical, psychological, palliative and spiritual care to PLWHA through a particular organisation, be it an NGO, a FBO, or a CBO.

1.8.6 Caring

The concept "caring" is rich in meaning. For Mayeroff (in Ranheim, Kärner & Berterö, 2012:78) caring means to help other people grow and actualise themselves. Caring is executed through solid actions that demonstrate caring as value, an attitude, a will, an intention or commitment on the side of the carer (Ranheim et al., 2012:78). In another definition, Andershed and Olsson (2008:599) refer to caring as, "a nurturing way of relating to a valued other person, towards whom one feels a personal sense of commitment and responsibility". For the purpose of this study, the concept caring was defined as the act of providing physical, emotional, spiritual care and support to a PLWHA by HBCGs. It involves, among other things, a HBCG who would wake up in the morning and go and visit one or more patients in their homes or households to clean their rooms, cook for them, bathe them, counsel them, monitor their treatment

compliance, accompany them to the treatment centres, link them to required resources, lobby for their external support. The act of caring further extends beyond the patient to the loved ones with support in a form of bereavement and comfort provided to the loved ones on the death of the patient.

1.8.7 People living with HIV and AIDS

A definition of PLWHA was found in AIDS Info (2015:138) as referring to infants, children, adolescents and adults infected with the HI-virus and living with AIDS.

1.8.8 HIV and AIDS

HIV is an abbreviation for the human immunodeficiency virus that enters and destroys the body's immune system (Musingafi, Ragonye and Zebron (2012:3). It leaves the person looking healthy but highly infectious and able to transmit the virus to another person. Once it enters the human body, HIV destroys the T-cells or CD4 cells whose main responsibility is to protect the human body against any infections. It replicates itself by prompting the immune system to respond with antibodies to fight the virus. This causes the body to lose more CD4 cells becoming ineffective since the HI-virus attacks them. This process eventually results in a dysfunctional immune system which therefore leaves the body vulnerable to other infections which will eventually result in AIDS-an acronym for Acquire Immune Deficiency Syndrome. On reaching the state of AIDS, the person begins to the show signs and symptoms of AIDS-related diseases. The term AIDS is therefore the medical designation for a set of symptoms and opportunistic infections that show that the person's immune system is impaired (Sharp & Hann, 2011:1). As the immune system continues to decline the body becomes more prone to infections that will simply cause further illnesses due to the weakened immune system.

For the purpose of this study, the phrase, people living with HIV and AIDS (PLWHA), refers to people who have been diagnosed with Human Immunodeficiency Virus and who have been clinically confirmed to have a weakened immune system that has resulted in some AIDS-related diseases.

1.8.9 Social Work

In their definition of Social Work, Pincus and Minahan (in Higham, 2006:9) describe Social Work as concerned with the interaction between people and their social environment which affect their ability to accomplish their life tasks, alleviate distress and realise their aspirations and values. The purpose of Social Work is (1) to enhance the problem-solving and coping capacities of people, (2) to link people with systems that provide them with resources, services and opportunities, (3) to promote the ineffective and humane operation of their systems and (4) to contribute to the development and improvement of social policy".

This study has chosen to adopt the definition used by the International Federation of Social Work (in Thompson & Thomspon, 2016:xxix) referring to Social Work, as a practice-based profession and an academic discipline with has several aims. This are listed as promoting social change and development, social cohesion and the empowerment and liberation of people. The principles of social justice, human rights, collective responsibility and respect for diversity are fundamental. Social Work is reinforced by theories of Social Work, social sciences, humanities and indigenous knowledge and engages structures to address challenges encountered by human beings and enhance their well-being.

The mission of Social Work is to enhance human well-being and help meet the basic needs of all people with particular attention to the needs and empowerment of people who are vulnerable, oppressed and living in poverty (National Association of Social Workers in Hepworth, Rooney, Rooney & Strom-Gottfried, 2013:5).

1.9   FORMAT OF THE RESEARCH REPORT

This report is planned to comprise five chapters according to the accompanying brief overview of each. In this Chapter One, the reader was introduced and orientated to the study with specific attention being placed on the introduction and orientation to the study, the rationale of the study and the research problem. The theoretical landscape too is presented elaborating on the middle range theory of caregiving dynamics (Williams, 2014:310; Williams, 2003:679), the coping theory of Lazarus

and Folkman (1984) and the strength-based perspective. Following this the reader is introduced to the questions, goal and objectives that guided the entire research process. The research methodology in which the philosophical grounding of the study was highlighted along with the adopted qualitative research approach and the research design, the research methods, the ethical considerations, clarification of key concepts, the format of the report were also introduced.

In Chapter Two, I provide a discussion of how the research plan as given in Chapter One was operationalised. I begin this chapter by providing the motivation for dedicating this chapter to the application of the research process as proposed in Chapter One. This is then followed by a detailed explanation of how the qualitative research approach, the research design, the research methods, participant recruitment, data collection, data analysis, data verification, the ethical principles were operationalised throughout the research process. This chapter concludes with a chapter summary.

In Chapter Three, I introduce the reader to the first part of the research findings which addresses the motivations and challenges of the caregivers who care for PLWHA. A presentation of the demographic particulars of the participants and a snapshot of all themes, sub-themes and categories open the chapter. This is then followed by a detailed discussion of the two themes along with their sub-themes and categories accompanied by reference to relevant literature as a control measure. A summary of the chapter concludes the discussions.

In the fourth chapter, part two of the research findings is documented with attention focusing on the experiences, coping strategies and suggestions of HBCGs on how they could be supported to overcome their challenges in working with PLWHA. Six themes along with their sub-themes and categories are introduced and discussed in detail through literature control while a chapter summary concludes it.

Chapter Five of this report is the last chapter that aims to present the reader with a summary of the research findings and the recommendations. Recommendations made are directed to enhancing policy, legislature and practice within the field of HBC. A summary concludes the chapter.

1.10 CHAPTER SUMMARY

This chapter served as an introduction and orientation in which the reader was introduced to the phenomenon under investigation. In introducing the phenomenon, an overview of HBCG was provided by tracing its roots from the 16th Century France charity works. Following on was an account of how it developed in Africa and then within the South African context. The concept home-based care was defined. The scope of the topic under investigation was highlighted its current state noted. In setting the scene for the argument of the strategic relevance of this study, the research problem was presented followed by the rationale for the study. Three theoretical landscapes were adopted to understand the phenomenon and the main questions, goals and objectives which guided the study were introduced. In further explaining how the study would unfold, I introduced its research methodology adopted by highlighting qualitative research as its approach. The research design that was adopted was phenomenological, explorative, descriptive and contextual. Details around how the participants were anticipated to be identified and recruited, how the preparation for data collection was to be done, how the data was actually to be collected, analysed and verified were introduced under the section of the research methods. The details around what the ethical principles which were to be upheld were given and key concepts clarified. The format of the research report concluded the chapter. In the next chapter, details around how the qualitative research process was enacted are provided.

CHAPTER TWO

AN APPLIED DESCRIPTION OF THE QUALITATIVE RESEARCH PROCESS

2.1   INTRODUCTION

In Chapter One of this report the chosen research topic and qualitative research methodology as planned and adopted for investigation was introduced. This chapter provides an account of how this plan was executed during the fieldwork by focusing on the aspects of qualitative research process.

2.2   A MOTIVATION FOR WHY AN APPLIED DESCRIPTION OF THE QUALITATIVE RESEARCH PROCESS IS REQUIRED

Qualitative research, in general, can help to promote an understanding of individuals' lived experiences as they find expression in their thoughts, ideas, feelings, attitudes, perceptions and behaviour by enabling researchers to make sense of the happenings taking place in daily life. It is all about how people interpret and describe their experiences (Merriam & Tisdell, 2016:15; Öhman, 2005:37). To elicit such understanding, researchers design methods appropriate to the unit of analysis and implement them to capture the envisaged understanding. This process of seeking understanding does not happen haphazardly. It is rigorously planned and executed. On this note, I thought it best to begin with a description of the how qualitative research plan, as proposed in Chapter One, was operationalised. Proceeding from this angle will not only help me understand how the process unfolded, but will also assist the reader to make a connection between all the activities which eventually, steered the process of knowledge production.

By nature, the qualitative research process is a flexible, fluid, evolutionary, dynamic and non-linear process (Rossman & Rallis, 2012:9; Yin 2011:77; Creswell, 2009:176). Hence researchers do not adhere strictly to prescribed rules and guidelines for implementation. Qualitative researchers rather bring conceptual

frameworks, or a research plan with guiding principles into the field but these are not cast in stone. The proposed research plan presented in Chapter One is an example. This plan can be changed, modified and refined once in the field as new discoveries are made (Rossman & Rallis, 2012). Given the fluid nature of the qualitative research process, various authors underscore the fact that qualitative research design decisions are not "pre-determined blueprints" (Mathani, 2004:59), or "an off-the-shelf process" and but rather a "do-it-yourself process" (Maxwell, 2013:03). Even if the researcher follows a do-it-yourself process, it must be made transparent. The qualitative researcher has not only to both explain the content of decisions, but also the process that led to them (Mathani, 2004:59). It is for this very reason that it is deemed necessary that this chapter be devoted to a description of how the proposed research plan for this study was applied.

In addition to the motivation already given for why this chapter was necessary, I was committed to leaving an audit trail of my fieldwork. Lincoln and Guba (1985:290) pose this question: "How can an enquirer persuade his or her audiences (including self) that the findings of an inquiry are worth paying attention to, worth taking account of?" An audit trail becomes relevant when this probing question is asked to strengthen qualitative research rigour (Thomas & Magilvy, 2011:151). Koch (in Carcary, 2009:15) endorses this view by stating that one way of establishing a study's trustworthiness is by leaving a footprint behind enabling the reader to audit the events, influences and actions of the researcher. Seal (in Carcary, 2009:15) refers to it as "reflexive methodological accounting". Scholars (Thomas & Magilvy, 2011:153; Tray, 2010; Carcary, 2009:15-16; Shenton, 2004:71) aver that this method determines if the research study was executed astutely. The researcher is obliged to provide a thick, detailed description of the methodological plan and how it was applied. In addition, and to answer to methodological transparency, a description of how the research process was planned and applied needed to be documented in a clear, logical and an explanatory fashion that it leaves a progressive blueprint that can be repeated (Finlay, 2014; Padgett, 2008). Proceeding in this manner for this study was an effort to ensure transparency.

Following on my commitment to allow for a future audit to determine the transferability of the research findings was another motivating reason for devoting

Chapter Two of this research report to describe how the research methodological plan was applied during the fieldwork. Transferability in the context of qualitative research is concerned with determining "the extent to which the findings of a particular inquiry have applicability in other contexts or with other subjects/participants" (Thomas & Magilvy, 2011:153; Lincoln & Guba, 1985:290) .On the question of who has the responsibility to execute a transferability audit, Laarson (2009:32), in incorporating Lincoln and Guba's viewpoints on the matter, postulates that the readers of the report and future researchers are bequeathed with the role of adjudicator. Their function is to determine whether the findings fit or resonate with the contexts to which they are being transferred. Essential is that the original researcher meets the obligation to provide sufficient descriptive data such an audit trail needs (Laarson, 2009:32; Shenton, 2004:70; Lincoln and Guba, 1985). If this is done, the reader of the report can make the call to determine the transferability of the research findings critically. Shenton (2004:70) provides pointers concerning the types of information that must be sufficiently covered to conduct a satisfactory transferability audit. These items are:

- The criteria of inclusion that accommodate the required restrictions
- The types of people contributing to the dataset
- The numbers of participants involved in the fieldwork
- The data collection methods employed and the sites where the data was collected
- The numbers and length of the data collection sessions
- The period over which the data was collected.

Before proceeding with the description of how the planned research turned out, I will orientate the reader by illustrating how the fieldwork and its related activities fit in with its qualitative research framework. A schematic presentation (see Figure 2.1 on the next page) of the qualitative research process and its sequential phases as Grinnell and Unrau (2011:55) proposed cast light on this matter.

Figure 2.1: Phases of the qualitative research process (Grinnell & Unrau, 2011:55)
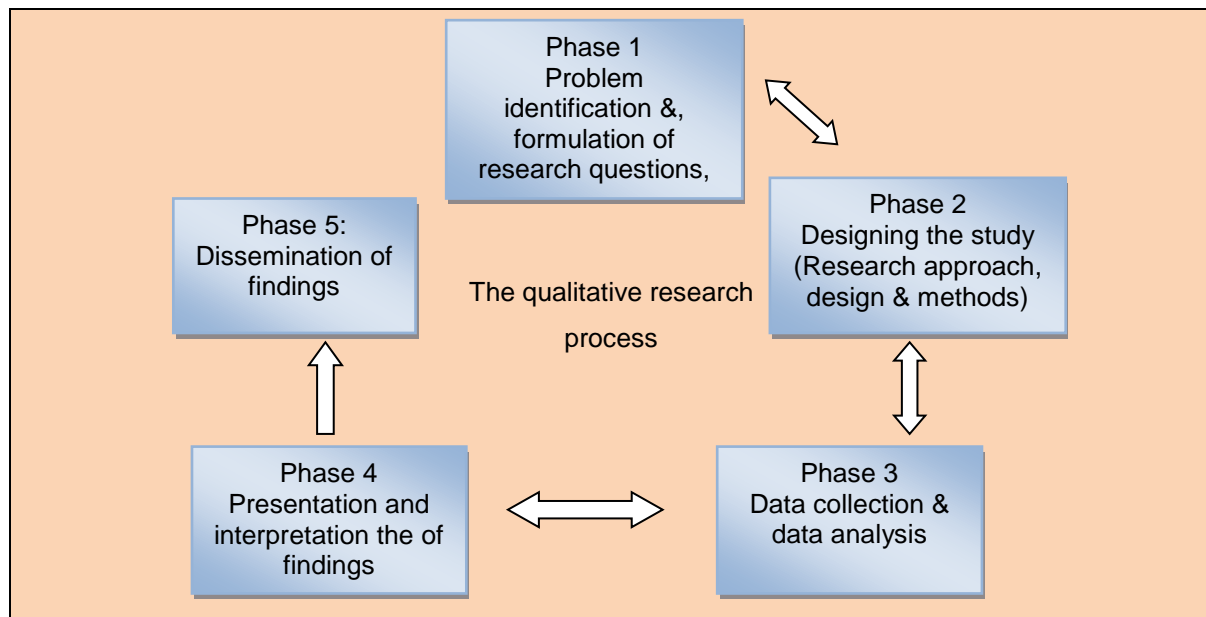
Looking at the Figure 2.1, and by viewing the qualitative research approach in an interlinked sequence-phased fashion, Phases 1 and 2 pertain to the research plan (presented as part of Chapter One). They address the aspects of identifying the research problem, developing the research questions, goal and objectives and outlining the research design.

The third phase involves the actual implementation of the research plan as outlined in Phases 1 and 2. This is where the researcher enters the field to engage in research-related activities with appropriate participants. Identifying and recruiting organisations, negotiating access with gatekeepers to get to potential participants recruiting and preparing them for data-collection are the tasks to be executed. Then data is collected and analysed to prepare research findings.

Phase 4 involves the actual interpretation and presentation of the information collected to which Chapters 3 and 4 of this report are devoted. Themes, sub-themes and categories emerging from the data analysis process are compared and contrasted with existing literature to perform the literature control. Finally, in the fifth phase the research results and findings are presented for further dissemination to affected stakeholders and academics.

In the ensuing discussion, the focus details how the research plan was applied.

2.3   THE NATURE OF THE QUALITATIVE RESEARCH APPROACH

Although the concept qualitative research was introduced in the first chapter (see Chapter One: sub-section 1.4.1), expounding on it sets the scene for the discussion to follow. Creswell (2014:4) explains: "Qualitative research is an approach for exploring and understanding the meaning individuals or groups ascribe to a social or human problem. The process of research involves emerging questions and procedures, data typically collected in the participants' setting, data analysis inductively building from particular to general themes, and the researcher making interpretations of meaning of data. The final written report has a flexible structure. Those who engage in this form of inquiry support a way of looking at research that honours an inductive style, a focus on individual meaning, and the importance of rendering the complexity of a situation".

Taking a closer look at this definition, one gets an idea of the following ten main features or characteristics (bulleted below) inherent to the qualitative research approach. These features resemble the characteristics of qualitative research as presented in the first chapter (see Chapter One: sub-section 1.4.1) and will be by way of a summary briefly mentioned and then an account will be provided on how these features were applied during the fieldwork.

- **Qualitative research makes use of an exploratory way to develop understanding of the phenomenon under study**

Qualitative research is particularly appropriate when a topic or a phenomenon about which little is known is to be explored (Nieuwenhuis, 2016:4; Babbie, 2014:94; Yin 2011:112; Padgett, 2008:15). To realise this, the researcher embarks on a qualitative research endeavour to enter the field with an open mind. Understanding the phenomenon from an insider perspective means the perspective of the researched is the point of departure (Elliot & Timulak in Nieuwenhuis, 2016:53; Mathani, 2004:56). When using a qualitative approach to investigate a phenomenon, it is all about the individual participants and the meanings they attach to their experiences. Uncovering

a meaning in this way adopts an explorative frame of reference (Mathani, 2004:55). The qualitative approach to research is also not prescriptive. Restrictive measures are not imposed as they may limit a participant's answers. A rigid, structured interview or closed questions are not used. As per the original plan, individual face-to-face semi-structured interviews and open-ended questions were used. This allowed the participants freedom to answer them to facilitate exploration of the topic being investigated.

- **The main interest for qualitative researchers is the meaning people attach to the phenomenon under investigation**

Qualitative researchers believe that when human beings interact within their social world, meanings are created. It is these meanings that interest them. In other words, reality emerges because of the interaction between people and institutions. Moreover, their search for meaning takes place where they live during their lifetime (Flick 2007:12). Qualitative researchers are interested in extracting these social meanings which people attribute to their experiences, circumstances and situations as well as those meanings that are entrenched within the text and other objects (Hesse-Biber & Levy in Nieuwenhuis, 2016:53; Bless et al., 2013; Flick, 2007). It is all about how individual participants think and feel about and respond to phenomena (Bless et al., 2013:17). In applying this characteristic to my study, I was interested in the meaning caregivers attach to the experience of caring for PLWHA and how they manage their work-related challenges associated with care provision as a service.

- **The qualitative research process is guided by questions and procedures that come from the field**

This characteristic is inherent to qualitative research as it implies that the researcher's plans and procedures are tentative, and depend on what transpires from the field (Mathani, 2004:56). Brown (in Litchman, 2014:40) explains the emergent nature of qualitative research succinctly: "we don't always know until we're well into the project where we are placing our emphasis. Often we change directions and take new tacks in the midst of the work, due to our own realisation about the

material, and in part from the ongoing interpretation with people". Qualitative research is conducted in a fluid environment that requires flexibility and adaptability of plans. Qualitative researchers should be responsive to this need at any stage of the process. It calls for a modification of the original plan to adapt to the dynamic fieldwork environment (Litchman, 2014:40; Mathani, 2004:56).

This truism became apparent in my case as what transpired in the field did not happen according to the proposed plan. I had to be flexible and had to embrace the idea of an emergent design, a characteristic of qualitative research as Yin (2011:77) and Creswell (2009:176) document. The initial plan was to delimit the municipal boundaries to only one[4] of the regions in the CTMM, Pretoria, Gauteng. This was later amended as the geographical boundaries of the study area had to be extended into the other regions. These lay in Gauteng, Limpopo and North West provinces. The decision was necessary for two reasons: funding from the National Research Foundation was made available; and I still lacked adequate information after my interviews with the participants in Tshwane.

This resulted in the initial population for the study comprising "all people who directly provide HBC services to PLWHA through an HBC organisation within the region one of the municipal boundaries of the CTMM", to be amended to "all people who directly provide HBC services to PLWHA through HBC organisations from Gauteng, North West and Limpopo provinces".

- **Data collection occurs in the participants' natural settings as opposed to simulated settings**

Qualitative researchers are committed to the naturalistic perspective and to the interpretive understanding of human experience. In other words, what is of interest to qualitative researchers are the experiences of participants as interpreted by participants themselves within their day to day living and working environments

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[4]As indicated in Chapter One (sub-section 1.6.1), the main reason for choosing region one of the CTMM was the lack of enough funding and being able to access to a large enough number of participants who were available, willing to participate and would provide the necessary enriching data. .

(Nieuwenhuis, 2016:53; Denzin & Lincoln, 2013:13; Streubert & Carpenter, 2011:22; Merriam & Tisdell, 2016:15).

For Streubert and Carpenter (2011:22) and Mathani (2004:56), qualitative researchers adopt an emic perspective; they explore the insider's view with utmost respect for the individual's perspective and their own space. Nieuwenhuis (2016:53) believes that a qualitative researcher's main interest is to examine various social settings and the individuals who inhabit these settings to obtain answers to questions. Qualitative researchers can choose to visit participants in the field where they live, work, attend schools to observe and/or interview them (Baxter, Hughes & Tight, 2010:66; Ivankova, Creswell & Clark 2016).

In adhering to this feature of qualitative research I went to the HBCGs in their respective organisations were they work. I conducted interviews focussing on aspects related to their daily experiences in caring for PLWHA, their work-related challenges and the coping strategies they employ to manage the challenges mentioned. Twelve organisations were visited and interviews were conducted in their operational settings such as the board rooms which were used for administrative work and meetings and in one organisation (Marashea HBC) within the church which was both serving as an organisation's office as well as the church.

- **Qualitative researchers adopt an inductive approach for data analysis**

An inductive approach for data analysis means that raw data is used to develop themes that are later used to inform the theory eventually leads to understanding (Du Plooy-Cilliers et al., 2014; Merriam & Tisdell, 2016:17). Qualitative researchers begin by collecting bits and pieces of data that is then combined and organised to build concepts. This process eventually enables gaining an understanding of the phenomena under investigation (Litchman, 2014; Merriam & Tisdell, 2016). Researchers do not begin with theories and literature and then descend on the field to merely collect the data. An in-depth understanding of the phenomenon being investigated emerges from the data that was collected from a specific social setting (Du Plooy-Cilliers et al. 2014:235).

In my study, the inductive approach to data analysis was operationalised by implementing the eight steps of data analysis as proposed by Tesch (in Creswell, 2014:198). Digitally recorded interviews were conducted with the participants and subsequently transcribed word-for-word and analysed. From this I could derive themes, relate sub-themes, and even categorise.

- **The qualitative researcher as interpreter of meanings derived from data**

The meanings of data obtained have to be interpreted especially in qualitative research. Lewis and Nicholls (2013:55) note that data gathered from face-to-face interaction involves subjectivity. The participants subjectively, directly and explicitly articulate their thoughts, feelings, ideas, attitudes and perceptions related to the phenomenon under investigation during the individual interviews and/or focus group discussions with the researcher. It is the process underlying their interpretation that represents the meaning attached to it. These interpretations are further interpreted by the researcher in reporting the study findings, similarly acknowledging the fact that personal traits (on the side of the researcher) like class, gender, race, cultural and ethnic perspectives have the potential to taint data interpretation (Denzin & Lincoln, 2013:23).

In other words, what the researcher interprets in this context becomes the subjective perspective of what was interpreted subjectively by the participants themselves. Consequently, the subjective role played by the researcher results in lack of neutrality and objectivity (Ormston, Spencer, Barnard & Snape 2013:22). In defence of this subjectivity, Mathani (2004:57) postulates that subjectivity is inherent in all social processes, including the qualitative research process. However, to demonstrate the trustworthiness of the research findings, I vouched to be reflexive and made my influence on the research process known. I found using reflexivity as an introspection tool was most effective. Kingdon (2005:624) label reflexivity as "a confessional mode of representation" because the researcher declares subjectivity up-front and uses "own reflecting, intuiting and thinking" as primary evidence.

In this study my subjective role as an interpreter of the meanings of data was tainted especially by my Social Work training in the in the Rogerian Person-Centred Approach. In reflecting on the feedback from my supervisor who had scrutinised the transcribed interviews with the participants I had submitted. I realised I was only drawn to how the caregivers felt about their work-related challenges. This was especially so with the first interviews that I had conducted. The focus had to be revised. In addition, I also initially displayed a lack of confidence to venture into probing in depth the work-related challenges of the caregivers.

Upon reflection of the first attempt to analyse the data as collected, and by listening to the digital recording of the interviews again, I could see another shortcoming. I was too subjectively immersed in the participants' stories. This resulted in some aspects being probed in great depth, while others were neglected. This was rather apparent in my interview with one of my participants, Letsatsi. She spoke about how she was scared to express her anger if her patient was moody, and attributed this moodiness, innocently to the nature of their conditions. Instead of asking her to elaborate more and clarify this, I simply moved on to ask her about her experiences as an HBCG.

As I was using reflexivity as an introspection tool, my subjectivity was further evident during the transcription of the interviews. I noticed inconsistency as I was more inclined to note the laughs with most of the participants (Mokete, Letsatsi, Mamadee, Segwagwa, Kgomo, Nakedi, Paul, Carol, Viola and Zulu) than other non-verbal actions. These did occur, such as rubbing hands, looking down and other body movements which clearly passed my recognition and documentation. This I think happened because it is basically impossible to capture every single response in every interview process; some of the things will slip through unnoticed.

- **The structure of the report is written in a flexible manner**

Although I mentioned in Chapter One (see Section 1.9) that the report will be presented in a standard format, flexibility in reporting does allow for some modifications where necessary. The non-prescriptive and flexible manner typical of a qualitative research report means that the researcher is not restricted to a single

specified structure. Their own preferences for presenting qualitative research and what transpires in the field tends to guide its presentation. Qualitative research does not operate through what White, Woodfield, Ritchie and Ormston (2013:372) call a "made-to-measure" structure "that will work for every qualitative study." The flexible and non-linear nature of qualitative research means that researchers can decide to present the report in any format they deem suitable. In reaffirming the researcher's choice when it comes to reporting, academic and general audiences also acknowledge the use of first-person pronouns in qualitative research (Padgett, 2008:203). Hence I adopted this mode.

The structural and linguistic flexibility allowed for writing this report also accommodates my affinity for presenting information visually, to focus on narration and to illuminate the process followed progressively.

- **Qualitative research looks at the complexity of the situation holistically**

For qualitative researchers, the social world is far more complex than can be imagined. It is characterised by complex "politics of representation" (Denzin and Lincoln, 2013:43). This complexity is only captured by studying its representations as doing so directly will never be possible. As Streubert and Carpenter (2011:20) point, out the social world is embedded in the multiple realities held by individuals who actively participate in these social actions. That is why the need for a holistic approach is required to capture its complexity to make understanding it possible.

For researchers to understand the social world, they should understand the unique reality that every individual has and which is created out of social actions. These individual realities should not be seen as pieces of experiences. They too should be understood simultaneously and with the same holistic perspective as the way in which the social world is understood. Padgett (2008:2) believes that what makes qualitative research complex is that the very same subjective reality in which researchers are interested, is dynamic and in a state of flux. This requires intense involvement from the researcher in the process of knowledge creation based on this premise.

Taking cognisance of Padgett's viewpoint, I found useful pointers from Nassaji (2015:129) on how to holistically comprehend the complex world of my interest and topic under investigation. He advises qualitative researchers to collect information-rich data from various sources to understand the individual participants together with their opinions, perspectives and attitudes. However, at the same time, the researcher has to pay close attention to the unfolding process that depends significantly on the researchers themselves and how they act out their roles during this process.

In trying to gain this holistic understanding, I began to execute the original plan purposively. Adopting the recommended described way of obtaining enough valuable and useful information from a range sources during the fieldwork phase. I selected participants who had first-hand knowledge of and experience in the topic under investigation. I also remained with the original plan of using individual face-to-face semi-structured interviews facilitated by open-ended questions for data collection. As a method, it allows the participants to share their experiences and perceptions very freely, which was an important asset for this research.

In reflecting on myself too as an instrument for the collection of data, I realised I played several roles, some of them at the same time which rather complicated my own contribution at times. I simultaneously had to be the interviewer and an observer, as well as the scribe jotting down my observations to build the research trail. In fact, I was all over the place attempting to obtain a holistic account by ensuring that I followed each method correctly. The sequence of the interview was based on the participants' responses, yet I had to be sure that all the research questions were covered and adequately addressed with each participant when in discussion with them. Trying to get this right was indeed a challenge.

In the process of ensuring that I got the research question adequately covered, and not falling into the trap of asking leading questions, I bracketed myself by adopting Chan, Fung and Chien's (2013:4) advice to use open-ended questions, to focus on the topic and to probe, guide and not dictate the interview.

Whilst the decision to transcribe the digitally recorded interviews myself was a time-consuming activity, it proved to be most worthwhile. In a few instances, the task became rather complicated as there were some instances where participants' voices were totally inaudible. To overcome this problem, I resorted to relying on field notes or even contacted that person to ask for clarity on that specific question. This entire exercise was beneficial as it afforded me another opportunity to better understand the research topic holistically.

Finally, I found myself confronted by a mountain of data which was now supposed to be analysed. To maximise the value of this method of analysis had required me to go through each interview individually closely. As per the suggestion of Tesch in the work of Creswell (2009:186), I had identified themes that emerged from the interviews. Moreover, I did this more than once. Although this undertaking took many hours of intense concentration and sometime made me feel it would never end, it certainly contributed to me gaining a holistic understanding of the subject I had undertaken to research.

- **The focus is on individual meanings as opposed to collective meanings**

The meanings participants attach to their experiences are of paramount importance to the qualitative researcher. Denzin & Lincoln (in Ivankova et al., 2016:309) strongly believe that individuals have their own individual convictions of reality and therefore ought to be understood from the constructivist position that tolerates multiple meanings of individual experiences. Like any other qualitative researcher, I believed that my participants were unique human beings with equally unique experiences that could only be clearly understood from acknowledging their individual perspectives.

Each participant's views were therefore captured as unique. The context in which they expressed such meanings was also treated thus. In this vein, I recorded each interview separately and took notes on their own individual context that prevailed at that moment. Once this process was completed, I then transcribed the meanings as expressed during their interview. I saved these with the documented context notes for each participant. In ensuring the uniqueness of each meaning, I coded each

interview individually to develop storylines, which also only belonged to that participant.

Having revisited and expanded on the characteristics of qualitative research and providing a description of how this was applied during this study, I proceed to address the research design.

2.4   THE RESEARCH DESIGN APPLIED

Earlier in Chapter One (Section 15) a definition of the concept, research design, appears. Four research designs were proposed for this study. To illuminate the meaning of the concept "research design" for the reader, Yin (2011:75) refers to it as "logical blueprints". These serve as0 a logical plan so that the study findings address the intended research questions. These link the research questions, the data to be collected and the strategies for analysing the data to conclude the research.

Flick (2007:79) cautions qualitative researchers against simply rigidly executing design plans from the beginning of the study to its end. Promoting the idea of an "emergent design" as one of the distinctive characteristics of qualitative research, researchers are encouraged to adopt a flexible, iterative and continuous design (Creswell, 2014:186; Maxwell, 2013:3; Grinnell & Unrau, 2008:449). Upon entering the field to implement the research design, being flexible is an advantage. It means that the researcher is open to changing the process as the study progresses. Adapting to changing conditions that might arise in the field is advisable (Merriam & Tisdell, 2016; Flick 2007:79). I retained the phenomenological research design as accepted in the initial plan, complementing it with an explorative, descriptive and contextual strategy of inquiry (see Section 1.5). Expanding on this procedure and how it was applied will be dealt with next.

2.4.1   A phenomenological research design

Although the phenomenological research design was mentioned in Chapter One (see sub-section 1.5.1.) by way of introduction, its implementation is now elaborated on and explained. Various authors (Nieuwenhuis, 2016:77; Creswell, 2014:14;

Englander, 2012:16) indicate that the initial consideration for deciding to adopt the phenomenological research design acknowledges that an individual has experienced a selected phenomenon. As one of the qualitative strategies of inquiry, it begins by accepting the vantage point of an individual who has experienced the phenomenon under investigation. It then proceeds to develop a first-hand understanding of it. *Lived experiences* are central to a phenomenological research design (Streubert & Carpenter, 2011:72). Litchman (2014:114) refers to lived experiences as those happenings that are part of our daily lives. The ultimate role of the researcher in phenomenology is to extract the essence of that experience through a reductionist process or bracketing (Litchman, 2014:114; Streubert & Carpenter, 2011:77; Finlay, 2012:176). The researcher operating from a phenomenological vantage point asks: "how is it for you?" or "what is it like to …"

Although there is general consensus among researchers about the nature and aim of phenomenological research (Nieuwenhuis, 2016:77; Creswell, 2014:14; Litchman, 2014:114; Finlay, 2012:176), there are some discrepancies when coming to its application.

In this study, the application of the phenomenological research design was guided by Finlay's (2012) five mutually dependent suggestions: embracing a phenomenological attitude; entering a lifeworld through a description of experiences; dwelling with horizons of implicit meanings; explicating the phenomenon holistically; and integrating frames of reference. Discussion on the implementation of these steps follows.

- **Embracing the phenomenological attitude**

Embracing the phenomenological attitude requires the bracketing of personal habitual taken-for-granted understandings and past knowledge (Finlay, 2012:176). By bracketing, Tufford and Newman (2010:81) refer to, "a method used by some researchers to mitigate the potential deleterious effects of unacknowledged preconceptions related to the research". This action is expected to increase the rigour of the final product. Bracketing means that the researcher either sets aside or suspend his pre-existing knowledge, values, experiences, interpretations and

understandings of the phenomenon. Engagement follows with what Finlay (2012:175) calls "seeing with fresh eyes" to gain a new perspective of the phenomenon being investigated from the research participants. Several qualitative researchers (Litchman, 2014:116; Haggman-Laitila, in Streubert & Carpenter, 2012:76) disagree with the practice of bracketing in qualitative research. Their general claim is that complete reduction of someone's ideas could be practically impossible, given the intimate nature of the relationship that researchers have with the world (Litchman, 2014; Merleau-Ponty in Streubert & Carpenter 2012:76; Seidman, 2006). In such a case, researchers are therefore urged to identify and acknowledge those ideas and immediately put them under strict scrutiny (Litchman 2014; Seidman, 2006).

In this way, researchers should have a clear understanding of the role pre-existing ideas play during the research process instead of trying to prove objectivity. Identifying, acknowledging and exposing a person's pre-existing ideas by keeping a reflexive journal is a type of bracketing (Morrow, 2005:254; Streubert & Carpenter, 2011:27; Dowling, 2006:10).

When embracing the phenomenological attitude during the research process in which I was engaging, I kept a journal. I recorded my reflections on how my own knowledge, experiences, values, beliefs, roles and status could be influencing my own study. This journaling helped me to put my preconceived ideas and notions aside. I was then comfortably able to allow the participants in my investigation to give me their take on the phenomenon being investigated without prejudice or bias.

- **Entering the lifeworld (through descriptions of experience)**

When using phenomenology as a qualitative strategy of inquiry the researcher must enable participants to express themselves as directly, openly and freely as possible to reveal their lived experiences (Finlay, 2012:180). Inviting them to share their experiences that relate to the phenomenon under study is a sound approach.

To invite the caregivers as participants to share and describe their work -related challenges in caring for PLWHA, I posed open-ended questions focused on these

aspects. In addition, I probed to elicit further exploration in an atmosphere of empathy. Applying empathic listening allowed me to be aware of and sensitive to the feelings, thoughts and experiences of the participants. Shipley, (2010:129) would endorse this comment and Tufford and Newman, (2010:93) point out that it allows for a participants' voices take precedence to that of the researcher.

- **Dwelling with horizons of implicit meanings**

By dwelling with horizons of implicit meanings, Finlay (2012:185) encourages researchers to engage in-depth with the phenomenon by going beyond participants' words and reflections. Within the messages participants express are meanings that can only be uncovered and understood through in-depth engagement.

This process can be achieved by following a rigorous analytic approach to enable a researcher to become deeply involved in dwelling with the horizons of implicit meanings to identify them. The eight steps for analysing qualitative generated data analysis as proposed by Tesch (in Creswell, 2014:198) as given in Chapter One (sub-section 1.6.5) and applied assisted in this regard. Finlay (2012:186) advises a researcher to set time aside to dwell with the raw data until the implicated and layered meanings evolve.

Listening to the digital recordings and reading the transcripts over and over again, gave me a chance to develop a deepened understanding of the meanings implied within the participants' articulated experiences. As I engaged in this process, I found myself reliving the interactions I had with the participants - it brought back memories of fieldwork. For example: I recalled the tears Lenyalo shed while sharing the feelings of pain that she had experienced when the family of the patient she "went all out" for to care for until she got better, accused of her of theft.

- **Explicating the phenomenon holistically**

Explaining the phenomenon holistically requires that a researcher become absorbed in and unwraps the layers of meaning. Then finds ways to explicate the phenomenon

so that it comes alive (Finlay, 2012:187). This Finlay (2012:188; 190) states, can be achieved through exposing the layers of the phenomenon to develop a comprehensive understanding of both the manifested and hidden meanings by examining the data closely. The developed understanding must be reported by way of a thick description of the phenomenon and the process leading up to understanding it. It must also be documented in a systematic and logical manner to create rigorous and evocative findings (Finlay, 2012:174; Yin 2011:213). This also paves the trajectory for a dependability audit discussed further in this chapter (see sub-section 2.9.3).

The eight steps as proposed by Tesch (in Creswell, 2014) employed for analysing the data were prominent in facilitating the process of unwrapping layers of the phenomenon. By listening to the digital recordings of the interviews conducted and reading the word-for-word transcriptions of the interviews over-and-over, I could gain an insight into the context, what the participants were saying, how they said it and the feelings associated with what they were sharing. In my interview with Mokete, for example, I sensed feelings of sadness when sharing his experiences of being devalued by people because of the caregiving job that he is doing. Similarly, I perceived the despondency in my interview with Selinah when sharing how she and other colleagues went as far as to fabricate reports because they felt that even if they did play by the rules of present statistics on how many home-visits they have conducted, their work was not really appreciated.

- **Integrating frames of reference**

Integrating frames of reference means that the researcher now integrates individual interpretations of the lived experiences of the participants as they themselves shared. An in-depth understanding of the phenomenon under investigation, this then comes to the fore (Finlay, 2012:191). Uncovering the relationships and meanings that knowledge and context have for each other becomes a reality (Guba & Lincoln in Streubert & Carpenter, 2011:84).

In addition to achieving such integration, the researcher incorporated other confirming and divergent frames of reference in this study by consulting scholarly

literature from the disciplines of Nursing, Psychology, Social Work, Sociology and others as a means of literature control.

In summary: I employed phenomenology to uncover the essence of ""what is it like to care for PLWHA by using probes to search for common themes (Streubert & Carpenter 2011:82). To uncover the essence of the experience, I applied what is called "reductive phenomenology". This type of phenomenology relates to the process of suspending or putting one's own values and assumptions in abeyance to allow for a detailed and purest description of the phenomenon under investigation (Streubert & Carpenter, 2011:83). In addition, I also waited until the data analysis was done and the themes emerged from the data before I engaged in an intensive review of the literature for literature control, and the integration of other confirming and/or contrasting frames of reference. The research journal (as mentioned earlier in this chapter) was also used to identify and document the values, roles, emotions, perceptions which I, as the researcher developed throughout the research process.

Apart from applying phenomenology to uncover the essence, and the use of reductive phenomenology, I also employed hermeneutic phenomenology. Hermeneutic phenomenology aims to achieve an understanding of the phenomenon under study through exploration and description (Streubert & Carpenter, 2011:86). For this reason I incorporated the explorative and descriptive research design as part of the strategy of inquiry, as part of the original plan.

2.4.2 Explorative research design

In continuing the introductory remarks made about explorative research in Chapter One (see sub-section 1.5.2.3), Bless et al. (2013:57) explain that the purpose of explorative research is to determine the "breadth and scope" of the phenomenon being studied. It seeks to uncover knowledge around subjects where very little is known either in practice, research or literature (Marshall & Rossman, 2016:78; Bless et al, 2013:16; Du Plooy-Cilliers et al. 2014; Gray, 2014). Stebbins (in Nieuwenhuis 2016:55) argues that for the phenomenon to be explored effectively, researchers must approach it with what he calls "two special orientations" which are: *Flexibility in looking for data, and open-mindedness about where to find such data.*

Regarding Stebbins' suggestions above, I (as stated earlier in this chapter) as planned decided to only include one region within the CTMM as the population for this study from which to draw a sample. When I arrived at the conclusion that the pool of possible participants in this area would not afford me the opportunity to explore the required breath and scope for my study, I exercised flexibility and expanded the population for the study to also include the other regions in Gauteng as well as in North West and Limpopo provinces.

2.4.3   Descriptive research design

Earlier on in Chapter One, sub-section 1.5.3 the concept of a descriptive research design was introduced as one of the proposed strategies of inquiry adopted for this study. Further concept clarification is provided as well as an explanation of how the descriptive research design was applied in this study. The descriptive research design is primarily aimed at describing, rather than explaining a phenomenon (Bless et al., 2013:390). By employing this type of research, the researcher is predominantly interested in a detailed description of the features and dimensions of a phenomenon under investigation (Bless et al., 2013:57; Du Plooy-Cilliers et al., 2014; Gray, 2014; Nassaji, 2015:130; Rossman & Rallis, 2012).

The descriptive research design gave me the opportunity to report on the explored experiences of HBCGs in caring for PLWHA. It concerned how it was to care for the patients, their experiences of their work-related challenges and how they managed them (see Chapters Three and Four of this report).

The purpose here was to provide a picture of a phenomenon as it occurs naturally (Gray, 2014). Claiming to provide a detailed picture of the phenomenon as it naturally occurs would be incomplete without touching on the context in which it prevails. The issue of context also relates to the holistic nature of qualitative research which emphasises looking at the phenomenon holistically (Finlay 2012:187; Rossman & Rallis, 2012:9; Gummesson, 2006:169; McDonald, 2005: 469; Groenewald 2004:48). It was on this point that the contextual research design was adopted along with the already mentioned research designs, as presented below.

2.4.4 Contextual research design

The natural context in which people make sense of their lived-experiences is crucial for qualitative researchers (Marshall & Rossman, 2016:3; Creswell, 2015:8; Creswell, 2014:185; Lewis & Nicholls, 2013; Ritchie & Ormston, 2013:31; Rossman & Rallis, 2012:8; Hennink et al., 2011:288). Rossman and Rallis (2012:8) understand the concept, context, as the situation in which life occurs; a setting where people work, study, play, eat, drink and love. Denzin and Lincoln (2013:8) are of the view that the research questions depend on context which, in turn, determines the research practice. In other words, the contexts in which events leading to obtaining answers to the research questions unfold will determine the practice or implementation of the research practice. For, Lewis, and Nicholls (2013:54), if the context matters for a research, then observational data may also be required. This means that the researcher should be observant and note the events that unfold during the process.

Hennink et al. (2011:288-290) suggest that research should incorporate the contextual research design as strategy of inquiry. The range of contexts that the researcher should be mindful of and reflect on is broad. It includes subject context, the theory, cultural, physical and methodological contexts, and the contexts of issues and implications.

The subject context, according to Hennink et al. (2011:288) explains the historical, political and/or demographic origins of the topic - its history and evolution (refer to Section 1.1 in Chapter One). HBC initially had its origins in the 16th Century in France and North America and served to care for patients with long-term chronic and terminal illnesses and those with disabilities. With the advent of the HIV and AIDS pandemic, public health care system became overwhelmed by the response to PLWHA. The expansion of HBC organisations to also care for PLWHA resulted (Qalinge, 2011:51; Friedman et al., 2010:4; WHO, 2010:15).

When coming to the theoretical context, the remark made by Silverman (in Ritchie & Ormston, 2013:28) is particularly relevant: "Without theory, research is impossibly narrow. Without research, theory is a mere armchair contemplation". For Hennink et

al. (2011), the theoretical context calls for the positioning and theoretical founding of the phenomenon under investigation using appropriate theories. The middle range theory of caregiving dynamics (Williams, 2014; Williams, 2007; Williams, 2003), the coping theory (Folkman, 1984; Lazarus & Folkman, 1984; Folkman & Moskowitz, 2004; Barbosa et al., 2011) and the strength-based theory (Saleebey, 2013; 2006; 2002) were adopted to illuminate, understand and interpret the phenomenon of work-related challenges of HBCGs working with PLWHA.

The cultural context is addressed when the researcher describes the sociocultural characteristics of beliefs, behaviours, norms of the study population (Hennink et al. 2011:288 & 289). The physical context refers to the geographical characteristics of the study site. It could include the physical layout, available services, amenities, and proximity to facilities, towns and road conditions (Hennink et al., 2011:289). In Chapter Three, the participants' accounts will be presented and point to the physical contexts in which they render care services to PLWHA. Being mindful of the cultural context, I did not simply take the participants' answers to my questions without reflecting on and even exploring their relevance to culture. For example, in African culture, it is inappropriate and disrespectful for a younger woman to bathe an older man. I also observed the physical locations where the interviews were conducted. Reporting on this aspect will be in the Chapters Three and Four where the research findings are presented.

By methodological context, Hennink et al. (2011:288) alludes to the entire process of research. The setting where the interviews were conducted; the time when it took place; the way it was conducted and the language used; and the challenges encountered required noting. These aspects are dealt with later in this chapter.

Hennink et al. (2011) advises that the issues concerning the subject context should be clearly illuminated in the research findings. For this reason, direct quotations conveying the participants' experiences when caring for PLWHA and their work-related challenges that result from this service and how they manage them should be provided. Context-related recommendations should flow from the researcher's reflections on the research findings (Hennink et al., 2011:289-290) (See Chapter Five of this report for the context-related recommendations).

2.5 THE RESEARCH METHODS AS APPLIED

The concept, research methods, as explained in Chapter One (see Section 1.6), refers to the strategies and/or tools the researcher used when designing the study. How the data is collected, analysed and verified has to be stipulated (Durand & Chantler, 2014:176; Hesse-Bibber & Leavy in Nieuwenhuis, 2016:51).

In the ensuing discussion, the proposed research methods as planned are revisited, expounded on and a description provided on how they were utilised in the study. Any diversion from the original plan specifically related to the chosen research methods, and the addition and adoption of other research methods will be highlighted and justified.

2.5.1 Population, sample and sampling techniques

Although the term population was introduced in Chapter One (see sub-section 1.6.1) expounding on it is deemed necessary to further set the scene for its application. The term population refers to the total group of people or entities of concern in a research study from which a sample is drawn to obtain required information (Grinnell & Unrau, 2008:552; Wiid & Diggines in Du Plooy-Cilliers et al., 2014:132).

In the context of qualitative research, the activity of drawing a sample is referred to as participant recruitment (Hennink et al., 2011:84). It entails selecting individuals from the population for inclusion in the study using sampling techniques.

In reporting on how the plan relates to the aspects of the population from which it was drawn, the sample and sampling techniques panned-out during the fieldwork, I decided to integrate the pointers as recommended by Du Plooy-Cilliers et al. (2014:132) for this purpose:

- **Determining the research population group**

To determine the characteristics of the population for recruiting the sample, I revisited my research questions (see Chapter One: sub-section 1.3.1). Appropriate

people would be those who could provide the best answers to the research questions. They had to be information-rich on the topic being investigated (Hennink et al., 2011:85). My decision to look for information-rich participants was informed by suggestion Streubert and Carpenter (2011:28) gave. It intimated that the sampled participants should originate from a population of people who had experienced the phenomenon by having participated in it.

Initially, the plan was to identify the population for this study as all caregivers who provided HBC services directly to PLWHA through an HBC organisation in Region 1 of the municipal boundaries of the CTMM. However, on entering the field, I came to conclusion that the pool of possible participants in this area was not large enough to find the sample I needed. This meant that I would not have an opportunity to explore the breadth and scope of the topic under investigation adequately. I subsequently, and after consultation with my supervisor, decided to expand the boundaries of the delimited study area to also include the other regions in Gauteng, as well as the North West and Limpopo. I continued to search for participants who were information-rich about the topic purposively (see original plan in Chapter One: sub-section 1.6.1). To assist in the process of deliberately finding participants, I established parameters (to be presented next) for my recruitment campaign.

- **Establishing the population parameters**

Once I have arrived at the conclusion that the HBCGs caring for PLWHA were the most suitable people to answer the research questions, I then had to establish criteria for inclusion. Du Plooy-Cilliers et al. (2014:133) refer to these as the population parameters that assist in the process of deciding whom to include and to exclude from the study as participants to interview. The originally proposed criteria of inclusion (see Chapter One sub-section 1.6.1) had to be adjusted to accommodate the extension of the boundaries of the specified population. The participants who were eventually included in the sample had to be –
  o *HBCGs aged (18 years and older) of any gender, from any racial group*
  o *attached to any HBC organisation in from Gauteng, North West and Limpopo*
  o *caring for PLWHA*

- *willing to participate out of their own free will and sign an informed consent form to attest to this.*

By employing the criteria of inclusion mentioned, I recruited participants from 12 HBC organisations from the mentioned provinces: one of these HBC organisations from Limpopo; two from North West; and nine from Gauteng. The process leading to identifying these HBC organisations and participants is discussed in the next section (see 2.6).

- **Distinguishing the actual population from the target population**

The population parameters were established to assist in distinguishing between the target population and the accessible population. The target population refers to everyone or everything that falls within the population parameters. The accessible population only refers to the section of the population that we can include in our study (Du Plooy-Cilliers et al., 2014:133). The issue of selecting individuals from the population for inclusion in the study relates to sampling, or participant recruitment. The techniques employed in this regard are presented below.

To purposively, and with the aid of the mentioned criteria of inclusion, recruit participants, I used snowball sampling (see original plan for this study, Chapter One: sub-section 1.6.1). With snowball sampling, one participant is used to find another possible participant. The researcher will have asked an interviewed participant for a referral to another person whose characteristics match the criteria of inclusion (Litchman, 2014; Hennink et al., 2011:100; Streubert & Carpenter, 2011:29; Yin, 2011:89). This strategy led to the procurement of six participants, four of whom were from the minority racial groups that are usually very difficult to locate. The main reason for this strategy was the anticipated problem of procuring suitable but hidden representatives of the population required for this study. The topic itself is a particularly sensitive one, especially within cultural minorities groups. These categories are where this study's potential recruits would be found. Other scholars (Ellard-Gray, Jeffrey, Choubak & Crann, 2015:6; Cohen, Phillips & Palos in Streubert & Carpenter, 2011:29) too are aware of this problem.

To establish contact with possible participants, I used formal and informal networks as an alternative recruitment strategy. Formal networks are groups or associations to which a researcher is affiliated (Hennink et al., 2011:96). It could even be an organisation to which prospective participants for a specified research endeavour might belong. They would have to comply with this specific study's population criteria. The formal networks in this case are the HBC organisations in which HBCGs are employed. I arranged meetings with HBC organisations I found after contacting them. I considered them as gatekeepers in my chosen field of interest in which my research lay. My ultimate aim of this initiative was to get permission from them as HBC organisations to help me find potential participants for my proposed investigation that I would discuss with them. Ten prospective participants were recruited in this way.

Concerning the aspect of the sample size in qualitative research, I took cognisance of Yin's (2011:89) claim that "there is no formula for defining the desired number of units for each broader or narrower unit of data collection in a qualitative study". Hence, I remained with what I had outlined in the research plan. I could not set a fixed sample size at the outset of the study, but was guided by the principle of data saturation (see Chapter One: sub-section 1.6.1).

To recap the meaning of data saturation, the concept refers to the stage in the process of data collection where the new information being gathered no longer triggers new insights. This would indicate that all possible variations of the phenomenon were totally covered. The processes of participant recruitment for data collection would subsequently be discontinued (Charmaz in Creswell, 2014:189; Streubert & Carpenter, 2011:455).

Both Litchman (2014:251) and Lathlean (2015:472) advise that researchers should analyse the data immediately after collecting it. I went along with this advice in that after every interview, the digital recordings of the interviews were transcribed word-for-word. Afterwards, and while reading through the transcripts, I asked myself, does this interview differ from any of the previous ones? If so, how do they differ? I then recorded the differences and new issues in a notebook for later and further consideration. By posing these questions, I gradually became aware of the fact that

the same information was being shared by different participants. After this trend was confirmed and clearly noticeable, I arrived at the conclusion that I had reached the point of data saturation and halted the data collection process. After engaging with all the transcribed interviews, the independent coder also confirmed that the point data saturation had been achieved.

While the methods of participant recruitment are now dealt with, how the participants were recruited individually is described below.

2.6   PARTICIPANTS RECRUITMENT

The recruitment of research participants, especially using gatekeepers, was not a simple or smooth ride. Loh (2013:2) shares this sentiment by stating that gatekeepers do not simply give access to anybody who comes through their gates. The activity of participant recruitment is a process of negotiations and renegotiations that requires much patience. An outline of how I navigated my way from searching for HBC organisations that renders services to PLWHA, to the Internet and informal networks to access participants. I continued contacting people and negotiating access to gatekeepers and possible participants to recruit them for participation in my study until I concluded the fieldwork.

2.6.1 The pre-recruitment phase in view of recruiting participants

During what I regard as the pre-recruitment phase, I was mainly involved in searching for organisations where I could find suitable participants. Concerning the recruitment of participants, research literature (Creswell, 2016:109; Bless et al., 2013:69; Hennink et al., 2011:96) recommends that researchers use various ways to engage with it. Using the Internet and formal and informal networks for recruitment is suggested. Following this recommendation, I ventured out and did a Google Search for a list of "South African HIV and AIDS care organisations". I looked for organisations under the Hospital and Palliative Care Association (HPCA) website. Here I found six suitable HBC organisations: Cherish HBC[5], Tsatsawani HBC[6],

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[5] The organisation's real name is substituted with pseudonym to ensure participant's anonymity.

Genoeg HBC[7], and Sentebale HBC[8], Fountain HBC and Calvary HBC[9] located in Gauteng, Limpopo and North West respectively.

On closer scrutiny of these organisations, one (Calvary HBC) turned out to be a private residential place and another (Fountain HBC) was simply no longer in operation. In the end, I was left with four organisations that had HBCG caring for PLWHA whom I could approach for permission to conduct the research in their facility and would allow me access their caregivers.

By simply walking into hospitals and welfare organisations to enquire generally if they had caregivers among their employees caring for PLWHA, I secured the other two organisations. I eventually recruited participants from Tintswalo and Gomorrah HBC[10].

I also scrutinised my own resource list which I used when I was still practising as a social worker. I used it for referring clients for external services. In doing so, I located another organisation, Sodom HBC[11], which I approached for possible participants. By way of snowball sampling participants referred me to one other organisation (Tanzania HBC[12]) where I eventually recruited four participants for participating in my study. In the table on the next page a summary is given of how each organisation was identified and contacted with the aim of negotiating for permission to conduct the research:

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[6] The organisation's real name is substituted with pseudonym to ensure participant's anonymity.

[7] The organisation's real name is substituted with pseudonym to ensure participant's anonymity.

[8] The organisation's real name is substituted with pseudonym to ensure participant's anonymity.

[9] The organisation's real name is substituted with pseudonym to ensure participant's anonymity.

[10] The organisation's real name is substituted with pseudonym to ensure participant's anonymity .

[11] The organisation's real name is substituted with pseudonym to ensure participant's anonymity.

[12] The organisation's real names is substituted with pseudonym to ensure participant's anonymity.

Table 2.1: Identifying and initiating contacts with HBC organisations

Identifying method	Organisation(s) identified	Progress during the pre-recruitment phase
Google	Cherish, Tsatsawani, Genoeg, & Sentebale HBC, Fountains HBC and Calvary HBC.	Emails were sent and calls made and appointment secured except for Calvary & Fountains which did not respond
Colleagues & student (informal network contacts)	Mnaka, Rhodesia, Marashea and Oppas HBC	Telephonic contact was initiated with both organisations for appointments and secured
My own visits	Tintswalo and Gomorrah	Negotiation for an appointment was made verbally and an appointment secured
My previous resource list	Sodom HBC	contact was initiated and an appointment date for further negotiation secured
Referral by HBCGs	Tanzania HBC	Organisations were visited, an appointment was made and discussions held with gatekeepers

2.6.2 Preparing to negotiate for access to participants with HBC organisations

In view of preparing to negotiate for access to participants with HBC organisations, I spent a considerable amount of time preparing for the field. I familiarised myself with the HBC organisations identified by reading up on the organisations' objectives and policies, in instances where I could access information in this regard. Subsequently, I compiled a list of the organisations identified containing the names of the contact persons and/or gatekeepers, their telephone numbers and email addresses. On completion of this task, I then started sending out emails and making calls to request an appointment for negotiations with management. The manner in which the negotiation process unfolded is highlighted in the next section.

2.6.3 Negotiating access to the participants within the HBC organisations

Research literature (Creswell, 2014:96; Litchman, 2014:102; Shenton & Hayter, 2004:223; Seidman, 2006:43-44; van den Hoonard, 2001:33) highlights the significance of seeking permission to conduct a study. Shenton and Hayter (2004:223-224) state that negotiating access requires a lot of convincing and is a two-phased process. In the first phase, the researcher sought to negotiate access to organisations. These organisations are regarded as the gatekeepers as they have the decision-making power to decide whether to permit the researcher to conduct the study, and if so, allow the researcher access to the participants.

The second phase should concern negotiating access to individual participants who will then exercise their right to decide on whether they want to participate in the study or not (Shenton & Hayter, 2004: 223-224). The latter relates to participant recruitment. In this context, Cassel (in Clark, 2010:487) notes that the gatekeepers oversee physical access by view of permitting or refusing the researcher access to and contact with the research group [the participants]. The participants are in charge of social access in that they have the power to grant or refuse the researcher entry to the research group itself or the participants. The account of how access was negotiated with the HBC organisations and the caregivers employed in them became participants is provided next.

- **Cherish HBC**

Cherish HBC organisation is situated in one of Pretoria's suburbs. It serves as a hospice where patients are admitted for care and provides a HBC service where HBCGs do some follow-up visits to patients who had been discharged. This organisation had several directorates which were headed by a social worker, a psychologist, medical doctors and a dietician respectively. The organisation had its own vehicles that are used to transport HBCGs to their patients. They offer services to communities mainly affected by HIV and AIDS, crime, child-headed households, unemployment, poverty, gender-based violence and other problems.

As indicated above, Cherish HBC was identified through Google and following its identification, an email with a formal letter attached requesting to conduct my study (see Addendum E) was sent to this organisation on the 25 March 2015. The next day (26 March), I received a reply on my email in which the sender notified me that she had forwarded my request to the management committee. She would inform me once a decision was made. On 7 April 2015, the manager, via email, informed me that management had approved my request.

Upon receipt of this email, I telephonically requested an appointment with the organisation's manager to clarify my request. At this stage, the overall aim of the study, my responsibilities as the researcher, ethical issues, the potential participants' risks and benefits, issues of funding of the study, the duration of the interviews and the use of recording devices were clearly spelled out. This ensured that management understood what the study was about. I also spent some time at the organisation to familiarise myself with the organisation's policies, objectives and procedures. Through this I learnt about the organisation's business and avoided compromising some of its objectives and procedures. The manager then also arranged for me to meet with the HBCGs individually. Another appointment was scheduled to brief the HBCGs separately.

On the day, I met with the HBCGs they were briefed individually about the process and ethical protocol. This was explained in Setswana as this was the language they understood. A letter containing information about the research and requesting their

participation as well as the informed consent form (see attached Addenda A, B and E) were handed to them for further reading. The remainder of the time was then devoted to chatting with them about their work. I developed a general feeling about the organisation and the HBCGs' duties. Another appointment was scheduled with the potential participants[13] for further discussion on the ethical protocol statement, the informed consent and information documents along with the ethical issues involved in my study. On the appointment date, I took time to explore the potential participants' questions related to the information given to them, individually.

Three individuals (Mpshe, Segwagwa and Lenong[14]) from this organisation agreed to participate in the study. They signed the consent forms and a follow-up interview was scheduled for the interviews. Details around the interviews are discussed below (see sub-section 2.7 of this chapter).

- **Tsatsawani HBC**

Tsatsawani HBC organisation is situated in one of the rural areas of Limpopo province. It is headed by a community member with health care, prevention and support services being provided to the surrounding farms, the rural areas and informal settlement areas. Other services around the area where this organisation was located were a shopping complex, a police station, few tuck-shops, a clinic, a primary school and a church. The main common problems affecting the communities served by this organisation were mainly children who are reported to be working in tuck-shops owned by foreign nationals; substance abuse by mothers who end up neglecting their children; and the problem of HIV-infections. HBCGs had to walk to their patients' families. Just like Cherish HBC, Tsatsawani was also identified through an internet search engine. After using Google, I contacted the organisation via email with a formal request to conduct a study under the auspices of the organisation. The first email was sent to the secretary on 25 March 2015. Since a response was not received, I send a follow-up email on 26 March 2015 to check if

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[13] Potential participant refers to HBCGs whom I considered to have the likelihood of indicating their willingness to participate in this study.

[14] Participants' real names substituted with pseudonyms in a form of animal names to ensure anonymity.

the first email was received. On the same day, I was notified by email that I had been granted permission to conduct a study.

Upon receipt of this email, I contacted them telephonically and requested an appointment to meet with the organisation's secretary and the assistant manager. I proposed 8 May 2015 as a possible date. The authorities then confirmed the date. Realities related to my job necessitated that I ask for a postponement. It emerged during the time lapse the secretary forgot to inform the participants about the postponement and all HBCGs gathered there on 8 May hoping to meet me. She only recalled that I had requested a postponement when she called me to check if I was still coming. As my work-related pressure eased, I proposed another date in August which was also confirmed.

On the day of the appointment, I introduced myself to authorities and the secretary, presented my proposed study, its aim along with the ethical protocols to be observed, as well as the information and informed consent documents. I then spent time familiarising myself with the organisation, reading through some information brochures and chatting informally with the secretary about the nature of the organisation. Later on, the secretary took me to the HBCGs whom she said had already been briefed about the purpose of my study. Upon meeting with HBCGs, I introduced myself and apologised for the previous miscommunication which had resulted in them waiting for me on the day I had to postpone. I then presented the purpose of my visit and the information contained in the letter requesting them to consider participating in my research.

Since the organisation was far, about 200 kilometres from where I live, I wanted to conduct the interviews the same day for cost-effectiveness reasons, if they felt ready for the interviews. I engaged in further discussions with the potential participants individually, to clarify matters related to the research, what their involvement would entail, as well as what their rights were. I gave them a written version of what I had discussed and requested them to familiarise themselves with the documents further for more discussion when they came back. This was done and further discussion took place individually with potential participants.

Uncertainties were clarified and ethical issues and procedures were highlighted. This process resulted in three HBCGs (Yena, Zulu, and Ching[15]) indicating their willingness to participate in the study. Further individual discussions were held with them to ensure that they were ready for the interviews once they had indicated their readiness for the interviews and information and informed consent forms were signed (see Section 2.7 of this chapter for details around the interviews), the interviews were conducted.

- **Genoeg HBC**

Genoeg HBC is situated in a small town in the North West, a province in South Africa. This organisation provides social services to communities in the CBD (Central Business District), the townships and informal settlements around the town. Issues relating to having access to clean drinking water dominated their work. A few government department buildings, a primary school, a magistrate's court, a hospital and a police station surrounded the organisation's centre of activity. HBCGs were using taxis to conduct their home visits.

As indicated earlier, my Internet search (by way of Google Search where I typed in the words "list of South African HIV and AIDS care organisations" and later accessed the web for the Hospice and Palliative Care Associations) yielded four organisations, with Genoeg HBC being one of them. Upon identifying this organisation, I send an email to formally request permission to conduct a study with the information and informed consent documents (Addenda A and B) along with the formal letter attached to this email on 4 February 2015.

After not getting any feedback from this organisation, I followed-up and managed to speak to the secretary who indicated that she did receive the email and she will forward it to the Sister[16] in charge of the organisation and will return to me in due course. Three weeks passed without getting any feedback and when I decided to once again follow-up telephonically. She again promised to come back to me as they had many patients to attend to and everybody was busy.

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[15] Pseudonyms substituted real names to ensure participants' anonymity.
[16] By a Sister, the secretary was referring to a nurse who was overseeing the organisation.

On the 3 April 2015, I decided to visit this organisation as I was not getting any feedback from my communication with them. Upon arrival, I met the Sister in charge together with the secretary. I introduced myself and explained the purpose of my visit. I also handed out the hardcopies of the documents attached to my first email to them. They acknowledged receipt of this email with the attachments. I was then granted verbal permission to conduct a study. I was introduced to the HBCGs and on the same day I held a brief meeting with them where the purpose, logistics and the ethical protocol of my study were discussed. I provided them with the written documents containing the information discussed (see the attached addendum A and B) for further interrogation at their own time.

Another appointment was scheduled for Friday 17 April 2015 which was the day on which there was no work pressure and the HBCGs were free. On the day of the appointment, I met with each of the HBCGs individually, to give them an opportunity to ask and address questions and to clear up any uncertainties.

Two HBCGs (Kgomo and Jini[17]) indicated their willingness to participate and the informed consent documents were signed. Another appointment for the interviews was scheduled for 8 May 2015 (see Section 2.7 of this chapter below for the interview process).

On the day that I visited the organisation for the first time I also allocated time to go through their organisation's policies and procedure documents to just have a general idea of its aims and operation.

- **Sentebale HBC**

Sentebale HBC was also one of the organisations identified during my Google Search. This organisation was founded by a retired nurse from Great Britain. It is situated in an informal settlement next to a taxi rank in Gauteng province. There is a secondary school and a clinic next to this organisation. Unemployment, crime and substance abuse were some of the prevalent social ills in the community this

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[17] Participants' real names substituted with pseudonyms to ensure anonymity.

organisation services. HBCGs from this organisation receive R2 000.00 monthly stipend. The organisation drops HBCGs off at a central point and later picks them up once they are done with their home visits.

I sent an email to the secretary of this organisation with the request for permission to conduct my research. During a follow-up telephone call I was informed that my request to conduct research was approved.

Next, I requested an appointment with a management official through the secretary to come and present the aim, logistics and ethical protocol related to my study. A meeting date was set for Thursday 5 February 2015. The topics mentioned above were presented to management and their staff at this meeting. I also had the opportunity to meet with the HBCGs and inform them in greater detail about my study. They were provided with a written version that detailed the information presented (see Addenda A, B, C and D) to interrogate and to assist them in deciding whether or not to participate in the study. I also set time aside to engage informally with one of the members of management about the organisation's mission, its operation and the challenges they often encountered.

I met with the HBCGs the next Thursday, 12 February 2015 to address any other questions concerning the information presented about the research, and to ascertain who would be willing to participate voluntarily. Malume, Nakedi, Dineo and Cassie[18] indicated that they would like to participate. I engaged with them individually for the signing of the informed consent documentation (see Addenda B and C). Malume and Dineo were interviewed the following week, while Cassie and Nakedi, were interviewed later (Refer to 2.7 for the interview process).

- **Mnaka HBC**

Mnaka is situated in Gauteng on the East Rand. This organisation serves as a regular drop-in centre for orphans and vulnerable children and is an HBC organisation. It renders prevention, care and support services in the townships in an area where crime, violence, unemployment, poverty and teenage pregnancy are rife.

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[18] Pseudonyms substituted participants' real names to maintain anonymity.

Very much like Sentebale, the HBCGs conduct home visits for this organisation and are dropped off and collected at a central point. Mnaka's HBCGs also received a monthly stipend of R2 000.00.

Mnaka was identified through a formal network link. One of my colleagues who works for the Gauteng Regional Department of Social Development (DSD) whilst also doing some contract work for UNISA, brought this organisation to my attention. She agreed to obtain the organisation's contact number and details of a person I should speak to about my research. A week later I received the information and I immediately contacted the organisation telephonically, introduced myself and the research project that I was engaging in, with a request to conduct research at this organisation. Permission was granted immediately and I arranged to meet with the HBCGs on Thursday, 19 February 2015, as they normally meet on Thursdays.

On the day of the meeting, 19 February 2015, I first met with the HBC manager of the organisation and informed her, about the aim of the research, what participants would be expected to participate in and the ethical protocol. Concerns were clarified and questions posed to me addressed. In my meeting with the manager, I discovered that the organisation had only one HBCG as the rest of the staff members were child care workers.

I met with Mamadee[19] individually, informed her verbally about the research and asked her to consider participating. I also gave her the letter requesting individuals to participate in my research, and the informed consent document (see Addenda A, B, C and E) to study. Based on the information presented, she agreed to participate and I arranged to meet with her a week later to interview her. As I did at the other organisations, I also spent time at this organisation familiarising myself with the its mission and operations by reading the information brochures available and chatting to the secretary. On the day of interviewing with Mamadee, I emphasised that her participation was completely voluntary and that she could withdraw at any stage of the process if she so wished. She then indicated that she was willing and ready to

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[19] Pseudonym substituted participant's real name to ensure anonymity.

participate. After signing the informed consent document (Addendum B), I interviewed her.

- **Marashea HBC**

Marashea is situated in a rural area in a central South African province, North West. It was founded by a traditional doctor who also has the title of Reverend. The organisation is housed in the offices of the church. It is situated next to a school and a clinic with a social worker occupying one of the offices in the clinic. HBCGs received R800 for their services. This organisation does not provide any transport for the HBCGs and sometimes they have to walk 10 kilometres to reach patients.

A contact from my informal network, a classmate from my undergraduate studies, as it so happens, was employed at the clinic next to this organisation during the time I was looking for participants, and gave me this organisation's details. I established contact with the manager telephonically on 26 March 2015 to formally request permission to conduct the study. Approval was given straight away and an appointment for a formal briefing with the manager and the HBCGs about the research, research procedures and ethical protocol took place on Friday 24 April 2015. The HBCGs usually gather on a Friday to address their administration-related issues. The letter requesting individuals to participate in the research and the informed consent documents (see Addendum A, B, C and E) were also distributed. Whilst distributing Addendum B, two of the HBCGs disclosed to me that they were illiterate. I spent additional time with them to once again explain what was contained in Addenda A, B, C and E. I gave them about a month to consider whether they wanted to participate and scheduled to meet with them on Friday 22 May 2015 to inform me of their decision. At this meeting, I allowed time for questions and clarified concerns. Two of the three HBCGs (Martin and Pekwa[20]) decided to participate and were subsequently interviewed. On the day of my first visit to Marashea, I also engaged informally with staff to learn more about this organisation and how it operated.

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[20] Pseudonym substituted participants' real names to ensure anonymity.

- **Oppas HBC**

Oppas operated from the private home of the founder in Pretoria and who was also the only caregiver. Its mission is to provide HBC to patients suffering from various conditions. His house is in the city centre near some government departments, schools and shopping centres. He uses his own transport to do home visits. He relies mainly on donations and sponsorships from individuals and organisations to render this service.

I became aware of this HBC organisation through a fellow colleague at my current place of employment, a contact from my informal network. I contacted the potential participant, Paul, by email on the 23 February 2015 and secured a face-to-face meeting with him for Thursday, 19 March 2015. When I met with Paul[21], and after introducing myself, I explained the aim of the research and ethical protocols to him. I enquired about his organisation, its mission, how it operates and the nature of the services they were delivering. Afterwards, I handed him Addendum B, the written version of what was shared verbally. I allowed him some time to work through it to make an informed decision about whether or not he would love to participate in the research. I met Paul again the following Friday. He agreed to participate and indicated that he was prepared to do so. After signing the informed consent documentation, I interviewed him.

- **Tintswalo HBC**

Tintswalo HBC is linked to one of the metropolitan municipalities in Gauteng. It functions both as a hospice and an organisation providing HBC services. This organisation is headed by a retired, registered nurse and provides services to patients within the CBD. HBCGs have to walk to conduct home visits. HBCGs receive a monthly stipend of R1 500.00 for providing care, supporting and monitoring the patients taking treatment.

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[21] Pseudonym substituted participant's real names to ensure anonymity.

I knew about this organisation from being previously employed as a social worker. I decided to personally go and meet with them again and requested permission to conduct my research. On arrival, I met with the secretary; I introduced myself and requested to see the person in charge of the HBCGs. I was then informed that the social worker in charge of the HBCGs was not available and that I had to send her an email outlining my request. I also left Addendum B and E (information and informed consent – a document explaining the details of my research and a formal letter requesting to conduct a study) with the secretary. As she requested, I sent an email to the relevant social worker on 2 April 2015.

On 17 April 2015, I received an email informing me that I was granted permission to conduct a study but that the HBCGs were not yet informed as they worked different shifts. I acknowledged receipt of the email telephonically on the same day and forwarded some suggestions on how HBCGs could be told about my study. She undertook to get back to me on this. After not coming back to me, I decided on 11 June 2015 to do a follow-up on the matter. She suggested I make arrangements directly with the HBCGs with whom she agreed to arrange a meeting for me.

A meeting date was set for Thursday 11 June 2015 with the HBCGs. I presented the aim of my research, its procedures and the ethical protocol to be observed during the research verbally and in writing (see Addendum B). I then requested them to consider participating in the research. We agreed to meet again on 18 June 2015 to inform me about their participation decision. On this day, only Letsatsi[22] arrived and expressed her willingness to participate. Together we revisited the informed consent document; she signed it; and I interviewed her.

- **Gomorrah HBC**

Gomorrah HBC is situated on the western side of Pretoria in the CTMM, Gauteng. This organisation was founded by a bishop of the Anglican Church and is currently headed by a retired nurse. It has eight HBCGs who provide services to the nearby communities plagued by the social ills of poverty, domestic violence, unemployment, child-headed households and substance abuse among young men.

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[22] Pseudonyms substituted participant's real name to ensure anonymity.

Gomorrah HBC has its own transport for transporting HBCGs to undertake a home visit. At the time of this study when data was being collected (May 2014), Gomorrah HBCGs were receiving funds from the Provincial DoH, and its HBCGs earned a monthly stipend of R2 000.00.

I became aware of Gomorrah as an HBC organisation when I visited the local district and academic hospitals to make some general enquiries about HBC, HBCGs and HBC-organisations. I visited Gomorrah personally and met with the administrative officer who immediately spoke with the Sister in charge about my request to conduct research at the organisation. I could not get immediate approval as they both informed me that a formal request was required, and I had to direct it to its Board of Directors.

I submitted a formal request, via email to both the Sister in charge of the HBCGs and the administrative officer on 24 March 2014, and on the 25 March 2014 I received approval of my request. Subsequently, I requested the administrative officer to arrange a meeting with the Sister in charge of the HBCG, and the date for this meeting was set for 16 April 2014 and was confirmed. On the day of the meeting the administrative officer introduced me to the Sister in charge of the HBCGs and I informed her of my research. I also enquired about the organisation, its mission and the nature of services rendered. She then introduced me to the HBCGs. I introduced myself and informed them verbally and in writing about what my research entailed, what would be required from them and the ethical protocol to be observed. I requested them to consider participating based on the information I had shared with them. The decision concerning participating and any uncertainties and questions resulting from this were clarified at a follow-up meeting that was scheduled for Thursday 23 April 2014. Three HBCGs turned up for the meeting but only Noko and Mokone[23] ended up agreeing to take part in the study. The other person refused to participate as she wanted to be remunerated for doing so. Her decision was respected.

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[23] Pseudonym substituted the participants' real names to ensure anonymity.

Noko and Mokone signed the informed consent forms. Noko was interviewed on 23 April 2014 and her interview was used as a pilot study[24], while Mokone made an appointment for Thursday 30 April 2014. When I arrived on the day arranged for the interview I found that Mokone was present but otherwise occupied to be interviewed and we postponed it for a week later. When I arrived for the second time, I was informed that he was on leave. When trying to make another appointment, he told me that he had changed his mind about his previous decision to participate and had decided to withdraw, a decision which I respected.

- **Sodom HBC**

While consulting the resource list I used for client referrals when I was still a practising social worker in Hammanskraal[25], I came across the contact details of Sodom. Sodom HBC is situated a few meters from the district hospital on the northern side of Pretoria. At the time when the fieldwork was in progress, this organisation had six HBCGs in their employ with a retired nurse at the head. The organisation then had one vehicle that was mainly for management use to attend to administrative responsibilities. As a result, the HBCGs had to walk to a patient's home to attend to their needs. Visits were taking place in a community where unemployment, poverty, drug abuse and domestic violence were prevalent. At the time when I was contacting them for information, and liaising with them as HBCGs, the organisation was receiving funding from the DoH and the HBCGs received a monthly stipend of R1 500.00.

On the 12 January 2015, I decided to call the administrative officer of this organisation and requested permission to come and conduct a research study. She then promised to take the request further to management and get back to me. On the 19 January 2015, I received a telephone call that invited me to come and present my request at their management meeting on Monday 26 January 2015. I briefed management about the study, what it entailed and the ethical protocol I would observe, and allowed time for questions. The meeting then informed me that they

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[24] The interview conducted with Noko did not form part of this study and her data was also not included since it was a pilot study.

[25] Hammanskraal is a local area outside Pretoria.

wanted to discuss the request further and would get back to me in due course. While at the organisation, I asked for copies of their information brochures to familiarise myself with its operation and goals. Two days later I was informed that I was granted permission to conduct research at the organisation. I then requested the secretary to arrange an appointment with HBCGs, and this was confirmed for Monday 9 February 2015.

On the day of the meeting, the manager introduced me to six HBCGs and allowed me to present my request about my research and my request which was for them to consider participating in it. I supplemented what I had shared verbally with them by providing the HBCGs the information letter requesting their participation and the informed consent form document (see Addenda A, B and C); and requested them to go through these documents to assist them in making an informed decision about participating. I permitted time for questions and for their expressing of concerns and uncertainties which I addressed. I made a follow-up appointment to meet with them on Monday 16 February 2015, to ascertain who would like to become part of my research study. At this meeting Mokete, Lenyalo and Selinah[26] indicated their willingness to participate, whilst the other three decided not to participate for personal reasons. This decision I respected. I proceeded with the signing of the consent forms and later in the next week started with interviews.

After the interviews, participants were asked if they knew any HBCGs whom I could approach about possibly participating in my study and they provided me with the names and contact details of two HBCGs. This practice is an example of snowball sampling (Hennink et al., 2011; Litchman, 2014; Streubert & Carpenter, 2011:29; Hays & Singh, 2012:169). By way of this sampling technique I could recruit Amelia and Wenzani[27] from Tanzania HBC as participants.

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[26] Pseudonyms substituted participant's real names to ensure anonymity.

[27] Pseudonyms substituted participant's real names to ensure anonymity.

- **Tanzania HBC**

Amelia and Wenzani, whom I recruited through snowball sampling, were employed at Tanzania HBC centre. Like Sodom, Tanzania HBC was just few kilometres from one of the district hospitals on the northern side of Pretoria. This organisation was founded by a retired nurse. HBCGs from this organisation were receiving a monthly stipend of R1500.00. The communities which this organisation served were mainly affected by unemployment, poverty, gender-based violence and substance abuse. HBCGs had to either walk or catch a taxi to reach out their patients because the organisation had only one vehicle which was used by management for administrative purposes. The HBCGs have to pay their taxi fare out of their own pockets.

I contacted Amelia and Wenzani[28] on 14 April 2015, notified them how I had obtained their details and explained the reason for my call. They were quite interested in the study and requested more information. An appointment was then scheduled for the 29 April 2015. Amelia and Wenzani also invited the management of Tanzania and the other HBCGs to attend the information meeting about my research project. I presented the letter requesting an individual's participation and the informed consent document to everyone present at this information meeting. At the end of this session I was granted permission to conduct the research and another meeting was scheduled for Thursday 14 May 2015 for further briefing. After the meeting, I spent some time with the manager who took me through some information documents of the organisation.

On the briefing day, I addressed the questions raised and, apart from Amelia and Wenzani who had already agreed to participate, Viola and Xhathula[29] too became participants. On Thursday 28 April 2015, I met with the interested prospective participants individually for the signing of the informed consent forms. Amelia and Wenzani were then interviewed on that day while Viola and Xhathula were interviewed on a later date, 4 June 2015.

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[28] Pseudonyms substituted participant's real names to ensure anonymity.

[29] Pseudonyms substituted participant's real names to ensure anonymity.

- **Rhodesia HBC**

Rhodesia operates as an HBC skills development and drop-in centre. This organisation is situated in one of the industrial areas of Pretoria, which has turned out to become an informal settlement area mostly for foreign nationals. The organisation has only one HBCG who was walking to her patients' houses. The common problem reported in this community was mainly unemployment and drug abuse. Rhodesia was headed by a pastor and mainly sustained itself through donations from the church. The HBCG was receiving a monthly stipend of R2 500.00 for the work she does.

I became aware of Rhodesia as HBC organisation through one of my informal network contacts who was one of the undergraduate students in our Department placed in a district hospital and who alerted me to this organisation. I personally visited the hospital and enquired about HBCGs in the employ of this organisation. The student who referred me to the HBCG gave me the details of her manager and suggested that I send her manager an email, introducing myself, the research project and a request for permission to conduct the research. I then sent an email with a formal letter requesting to conduct a research study at their centre, together with the information and informed consent document on 31 March 2015. On 7 April 2015, I received a response notifying me that my request for permission to conduct a study was granted.

I met with manager and the HBCG (Vanessa[30]) on 13 April 2015 and briefed them about the research. In addition, I also handed Addenda A, B C and D to the HBCG for further perusal. She undertook to call me and inform me whether or not she would participate. She phoned on 5 May 2015 and informed me that she was willing to participate. An appointment was then scheduled for 18 May for further discussion. When meeting with her on the appointment day, I found that she had already signed the form consenting to participate, and was just waiting for me to come and interview her, which I did on the same day.

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[30] Pseudonyms substituted participant's real names to ensure anonymity.

Having explained the process of negotiation of access and how the participants were recruited, the focus of the discussion shifts now to the aspect of data collection and how it materialised.

2.7   COLLECTING THE DATA

As per the original plan, (see Chapter One: sub-section 1.6.3), individual face-to-face semi-structured interviews facilitated by open-ended questions were used for collecting data from the recruited participants as Edwards and Hollard (2013:20) advise. The initial decision to employ this method of data collection and to remain with it was informed by the fact that one of the research objectives was to explore the experiences of HBCGs related to caring for PLWHA; the work-related challenges they experienced; how they managed these challenges, and how they wanted to be supported by social workers. I was convinced that this type of interview would afford me the opportunity for exploration. Similarly, it would allow the participants to freely and authentically speak about the topic under investigation. In addition, Edward and Holland (2013:30) note that individual face-to-face semi-structured interviews "allow [participants] to talk from their own perspective using their own frame of reference and ideas and meanings that are familiar to them." Conducting face-to-face interviews, for me, meant going to the field to collect data. When referring to fieldwork in the context of qualitative research, Pole and Hillyard (2016:3) contend that data is collected first hand by the researcher and for this personal engagement and interaction between the researcher and participants in the research setting is required. The decision concerning the employment of the individual face-to-face semi-structured interviews was supported by Lewis and Nicholls' (2013:56) stance that: "very complex systems, processes or experiences are generally best addressed in one-to-one exchanges because of the depth of focus and the opportunity for clarification and detailed understanding."

In view of facilitating individual face-to-face semi-structured interviews, Edwards and Holland (2013:29) observe that researchers typically design a list of questions or series of topics to be covered in the interview in a form of an interview-guide (see Addendum F for the question that I have formulated to facilitate the interviews). However, when it comes to a pre-designed list of questions, Chan et al. (2013:4)

state that the researcher should not have a pre-determined set of questions but formulate questions in response to the cues and information shared by the participants. This standpoint is especially applicable when phenomenology is followed as a strategy of enquiry, which was the case with this study. Englander (2012:26) maintains a similar view. In his article, entitled, *The Interview: data collection in descriptive phenomenological human scientific research*, he suggests that the researcher working from a phenomenological frame of reference can have an opening question (or a request), for example: "Can you please tell me about your experiences as a HBCG", with the remaining questions flowing from the response of the interviewee focusing on the phenomenon being investigated.

Despite this stance taken against pre-determined questions when working from a phenomenological frame of reference, both Chan et al. (2013:4-5) and Englander (2012:26), make an allowance for individual face-to-face semi-structured interviews facilitated by open-ended questions and probes prepared in advance to steer and guide the interview. Chan et al. (2013:4) justify this as a precautionary measure to prevent the researcher from posting leading questions. In addition, with these questions merely being a guide, the interviewer is free to further probe what the participant shares (Chan et al., 2013:4). I decided to follow the route of having an interview-guide with open-ended questions (see Addendum F), but did not apply them rigidly. Instead, and to respond appropriately to what was shared by the participants, I took note of both Seidman's (2006:97) and Arendell's (in Hoffman, 2007:318) advice and remained on my toes by listening attentively. Both authors are of the view that by listening carefully to how the participants respond to the questions posed, and the information they share is useful. It enables the researcher to make calculated moves when pacing the interview, probing a specific aspect in greater detail, or shifting the direction and focus from one topic to another (Seidman, 2006:97; Arendell in Hoffman, 2007; 318).

Apart from using the formulated questions to explore the topic under investigation, and to structure the interview, I also used active listening and probing for clarification as research-related interviewing skills. Several scholars (Yin 2011:26; Whiting, 2008:37; Seidman, 2006:78&83; Edwards & Holland, 2013:72) recommend this. In addition, I remained cognisant of the phases in the life cycle of individual face-to-face

semi-structured interviews, as identified by Whiting (2008:36-38) in his work entitled*, Semi-structured interviews: guidance for novice researchers* in approaching each of the interviews with the recruited participants. These pointers are discussed in the next section.

- **The apprehension phase**

In the beginning, the interview is characterised by elements of strangeness and uncertainty, Whiting (2008:37) suggests that the researcher start the interview with a more general conversation to create a relaxed atmosphere. I was mindful of this and the need to break the ice so to speak. Hence I started out by enquiring in general from the participant about what prompted them to get involved in being a HBCG and their experiences in this service.

- **Exploration phase**

During the exploration phase, Whiting (2008:37) recommends that researchers continue to use open questions and probe frequently enabling participants to engage in a more in-depth description. In observing this, I narrowed the focus of the interview by looking at the experiences of caring for PLWHA; their work-related challenges in this field of work; how they managed the challenges; and their need for Social Work support, specifically by employing broad questions to explore these aspects.

- **Cooperative phase**

The flow of conversation during the cooperative phase should be smooth and the atmosphere more relaxed (Whiting, 2008:38). These phase characteristics were noticeable, especially during the interviews with Vanessa and Mokete in that they were so relaxed that they even laughed and cracked some jokes.

- **Participation phase**

This phase is characterised by spontaneous and active participation on the part of the interviewee, which can be a rare occurrence. Whiting (2008:38) suggests that this should be to the extent that the interviewer takes on the role of the student, while the interviewee becomes the teacher. I experienced elements of this phase during my interviews with Vanessa and Mokete in that they actively participated in the discussion in such an informed and spontaneous fashion that, at times, I felt that I was learning from experts.

- **The phase of concluding the interview**

This is the phase where the researcher draws the interview to a close. Whiting (2008:38) advocates that this should be opened by announcing the last question to be covered and, after interrogating it, summarises the aspects covered before asking for some last comments from the participant and thanking them for their contribution. I observed this protocol in all my interviews.

2.7.1 Conducting the pilot study

In Chapter One (see sub-section 1.6.4), I mentioned that a pilot study would be undertaken. In recapitulating the meaning of the concept, pilot study in the context of a qualitative inquiry, Prescott and Soeken (in Kim, 2010:190) explain that a pilot study refers to "a feasibility study comprising of small-scale versions of the planned study, trial runs of planned methods, or miniature versions of the anticipated research in order to answer a methodological question(s) and to guide the development of the research plan". The primary aim of the pilot study is to provide an opportunity to practise by testing and refining one or more aspects of the final study, be it the research design, fieldwork procedures, data collection instruments, or analysis plans (Yin, 2011:37). It gives researchers an opportunity to adjust their chosen research methods and determine flaws in data collection tools.

In this study, one interview was piloted with one participant (Noko) from Gomorrah HBC, to specifically assess whether the questions included in the interview-guide covered the depth and breadth of the topic under investigation and to assess my research interviewing skill. The transcribed version of the interview was submitted to my supervisor for scrutiny and feedback. His feedback was that I failed to probe frequently and that my responses to what the participants shared resembled what he labelled a 'person-centred therapeutic interview'. We also interrogated the wording of the question, "What is your experiences in caring for PLWHA?", and decided to add the following question, "How is it for you to care for PLWHA?", as I had failed to probe into this aspect. As mentioned in Chapter One (see sub-section 1.6.4), the results of a pilot study do not form part of this study. It rather prepared me in terms of the protocol and effort involved to negotiate with gatekeepers with the view of requesting permission to conduct the research and to have access to the participants.

2.7.2   Recording the interviews

Interviews serve no purpose in a research study unless they are recorded for further interrogation (Litchman, 2014:253; Seidman, 2006:114; Merriam & Tisdell, 2016:131; Bryman et al., 2011:231). Without audio-recorded interviews, a researcher is often not able hear the verbal utterances of the speakers clearly or recall every word and innuendo of the conversation to provide a genuine and accurate version of the interview process for a detailed and accurate written narration (Seidman, 2006:116; Bailey, 2008:127; Creswell, 2014:210). In other words, this means that without the recordings, the researcher will find it difficult to be convincing about the data and other aspects of the valuable data collection tools. It is important to have evidence that the study was conducted in a credible manner and that the receiving audiences can depend on the information gathered (Corden & Sainsbury, 2006). Nieuwenhuis (2016:94) recommends that notes be taken along with the interviews as this will assist in reviewing them and in allowing for additional questions to be asked at the end of the interview or on another meeting.

Various devices for recording interviews such as Skype and smartphones exist but the Voice Recognition Software has proven to be reliable (Litchman, 2014:253). Rubin and Rubin (in Whiting, 2008:36) recommend the use of digital voice recorder which has proven to be easy and effective to use.

In addition to recording the interview process, researchers may also write down their thoughts and feelings before, during and after the interview (Chesney in Whiting, 2008:37). However, this should be done in such a way that the participants' rhythm or pace is not disrupted. As proposed in the research plan (see Chapter One: sub-section 1.6.3 and the attached Addendum B, clause 2.6), the interviews of the current study were recorded using the digital voice recorder. The main reason why I opted for this type of device was based on my experience of the overall quality of the recording, as well as its portability which made it easy to even to put it inside the pocket or hang around the neck like a necklace.

In addition to digitally recording the interviews, and transcribing them verbatim, I followed Koch's (2006:92) point about keeping a journal with notes on the content and process of interaction, along with my reactions to happenings for self-reflection. In defining the meaning of the concept, journal, in the context of qualitative research Grinnell and Unrau (2011:567) describe it as "a written record of the process of an interpretive research study. Journal entries are made on an ongoing basis throughout the study and include study procedures as well as researchers' reactions to emerging issues and concerns during the data analysis process."

The topical framework suggested by Lamb (2013:85) on what to include in a research journal was adopted for this study. (See Addendum H for this topical framework and an excerpt from my research journal). Each page of the journal was titled, "the research journal". The date on which the events occurred and the places where they took place were recorded on each journal page. The inscriptions in the journal were structured in two columns. The topics to be observed and recorded were listed in six rows on the right-hand side; and on the left-hand side the outcomes of the exercise were jotted down. My journal inscriptions were organised according to the following headings as Lamb (2013:85) suggests.

- **The purpose and objectives of the day.** This included mention of action like negotiating access to participants and organisations with their name(s) stated, together with my aim and objectives to achieve that day.

- **The preparation of the activities for achieving the objectives of the day***.* In this column, I briefly explained how I prepared myself for that day, the activities that took place and how the day unfolded in the sequence of events. Reading through the government resource database to identify organisations. Things like browsing the website, and recording the details of organisations were also noted in the appropriate column.

- **The challenges encountered.** This column included all the challenges which I encountered during day. This included things like organisations which were listed on the websites of HIV and AIDS organisations with wrong telephone numbers, organisations; which were listed as HIV and AIDS service organisation while they did not offer HIV and AIDS-related services.

- **The resolutions implemented to resolve challenges.** Efforts to address the challenges were noted in this column where things like my decision to simply put the organisation aside and not even bother to follow-up or in some instances where I would try to search for correct telephone numbers through other identified organisations.

- **The achievements of the day.** In this column, I recorded what went well during the process I was following. Things like being convinced of the three organisations which clearly met the inclusion criteria and were ready to be contacted were noted in this column.

- **Reflections on the process***.* This column was reserved for experiences such as my feelings about the activities, challenges and achievements. For instance, I recorded how I felt about three organisations which simply did not meet the criteria, Was I disappointed and feeling hopeless? Did I develop

some courage and confidence despite all these challenges? I also included in this column, the skills and role that I saw dominating the process.

2.8   ANALYSING THE DATA

The concept, data analysis, as introduced in Chapter One (see sub-section 1.6.5) involves breaking these volumes of data into smaller units to reveal their characteristic elements and structure (Dey in Gray, 2014:607). It entails a process of bringing order, structure and meaning to the mass of data (De Vos, et al.in Du Plooy-Cilliers et al. 2014:232). Qualitative research data analysis is purely inductive in nature (Creswell, 2014; Du Plooy-Cilliers et al., 2014; Gray, 2014; Srivastava & Hopwood, 2009:7). By inductive data analysis, Srivastava and Hopwood, (2009:77) state it is a type of analysis in which "the patterns, themes and categories of analysis come from data; they emerge out of the data rather than being imposed on them prior to data analysis." Gray (2014:607) recommends that, in analysing the data, researchers should go beyond description by interpreting, understanding and explaining as well. The primary aim of the data analysis process in qualitative research is therefore to ensure precisely that the mammoth amount of data collected is further simplified for the reader to understand. As proposed in Chapter One (see sub-section 1.5.5), this study's data analysis procedure was guided by steps for qualitative data analysis as proposed by Tesch (in Creswell, 2014:198).

- **A description of the application of Tesch's eight steps of qualitative data analysis**

The steps of qualitative data analysis as proposed by Tesch (in Creswell, 2014:198) are presented below. Although they appear in a linear form, Creswell (2014:196) believes that the process of qualitative data analysis is cyclic in nature and in practice. It is an interactive process and develops with other phases of the qualitative research process.

o   *Organising and preparing the raw data for analysis*

In this study, the processes of data analysis started with the raw data, that is, the digital recordings of the interviews conducted. They were typed over word-for-word and formatted in preparation for data analysis. It must be noted at this stage that data analysis was not just a separate stage of the process; it was rather part and parcel of the entire process. To make sense of what the participants were saying, I jotted down some notes on a separate page both during the interviews, after the interviews and during the phase which was dedicated for data analysis. This process is further discussed below:

o   *Getting sense of the whole by reading through all the transcribed interviews*

Once the data was prepared and ready to be analysed, I read through all the documented data collected to get a feeling of the whole. Whilst reading, I reflected on the actual interviews I had done and also made a note of the ideas and thoughts that came to mind based on what I read in the transcripts.

o   *Searching for underlying meanings*

Once I developed a general idea of what was shared by participants, I went back to the raw data and this time around I pulled out the interview conducted with Mokete. What grabbed my attention about this interview was that it was one of the longest and most information-rich interviews. I then read this interview with undivided attention trying to identify and understand the underlying meanings. These meanings were recorded. On completion of this, I did the same with the remaining twenty-four interviews.

o   *Compiling a list of all topics and clustering them together*

Whilst reading through the transcripts with the view of uncovering the underlining meanings of what was shared by the participants I also looked for central issues that were beginning to emerge. These were listed as topics and I clustered related topics. Resulting from these 16 main topics were identified.

- *Abbreviating the topics in view of data coding*

At this stage, a unique abbreviation was allocated to each of identified topics. For example: the topic *"motivation to become a caregiver",* was abbreviated as "M". I then went back to the transcribed interviews and when coming across a segment of data corresponding to a topic I entered the corresponding abbreviated code in the margins next to the relevant text.

- *Transforming topics into themes and reducing the list of themes*

I reduced the initial list of 16 topics to 12 themes. Following the consensus discussion between the independent coder and myself facilitated by the supervisor the 12 themes were further reduced, by clustering together some of the themes. We arrived at nine themes with related sub-themes and even some categories related to the sub-themes. Table 3.1 in Chapter Three gives an overview of the themes, sub-themes and categories that emerged from the process of data analysis and consensus discussion, based on the data collected.

- *Deciding on the themes and alphabetising the final themes*

A final decision regarding the abbreviations for each theme and their related abbreviations was made along with the rearrangement of abbreviations in alphabetical order to ease the process of re-coding should the need for that arise.

- *Performing a preliminary analysis*

The data material which belonged to each theme and category was then cut and pasted under its appropriate theme and category as applicable and a preliminary analysis was then done.

- *Recoding existing data where required*

As recommended by Tesch (in Creswell, 2014:198), the recoding process was repeated just to make sure that all the data material had been appropriately placed

under the correct themes and that no useful data was thrown away. This recoding exercise enabled me to include what had I regarded as useless data material in some of the categories.

In the next section a description is provided on how the data was verified.

2.9   VERIFYING THE DATA

As indicated in Chapter One (see sub-section 1.6.6), data verification has much to do with the quality of the study. Lincoln and Guba (in Lietz and Zayas, 2010:443) suggest that for a qualitative study to be endorsed as a rigorous study, it must achieve "trustworthiness – a study that represents as closely as possible the perspectives of the research participants". It is not disputed though, that researchers are also human beings with their own values, perceptions, experiences, needs and opinions which can somehow influence their interpretation and reporting of the data (White, et al., 2013:376; Gringeri et al., 2013: 55; Warin, 2011:807). It is for this reason that Lietz and Zayas (2010:191) call for measures to ensure that the perspectives of these participants are authentically gathered and presented in an accurate manner in the research findings. Various authors (Elo, Kaariainen, Kanste, Polkki, Utrainen & Kyngas, 2014:2; Loh, 2013:5; Bryman et al.,2011:44; Sinkovis, Penz & Ghauri, 2008:696; Shenton, 2004: 64-73) refer to following four criteria for ensuring trustworthiness as proposed by Guba and Lincoln. The latter recommendation was accepted as part of the original plan (see Chapter One, see Section 1.6.6) as the criterion to adopt to ensure trustworthiness.

2.9.1 Ensuring credibility

By credibility, Guba and Lincoln (in Lietz & Zayas, 2010:191) refer to the degree to which a study's findings represent the meanings and multiple realities (Öhman, 2005:278) of the research participants. In other words, credibility relates to proving that neither the whole research process nor the data were fabricated. Highly credible studies as Bless et al. (2013:236) describe are studies with a clear demonstration of the relevance and internal logic of the research questions, the research design and the data collection and analysis methods. In striving to uphold and achieve

credibility, I adopted the following generally accepted strategies (Houghton, Casey, Shaw & Murphy, 2013:13; Lietz & Zayas, 2010:191-195; Shenton, 2004:64-69; 252):

- **Early familiarity with the culture of the participating organisations before data collection**

In fulfilling the strategy of early involvement with the culture of participating organisations, I found my previous experience of being a social worker and an HIV and AIDS coordinator who was involved with HBC organisations to be valuable. The reason for this was that HBC organisations used HBCGs to provide care services to PLWHA and I knew the nature of their services. I did not solely rely on these experiences though. I took time to go through the websites of these organisations, where available, and even visited them to understand their mission statement content, visions and objectives. This early familiarity found me in a difficult and compromising situation as I seemed to be violating their policies and codes of practice in some instances. Visiting one organisation namely, Marashea HBC which did not have a website, was a challenge as there were no documented guiding procedures although a passion and common understanding among its members became evident and I was able to understand and appreciate the philosophy that drove it.

- **Triangulation**

Triangulation involves the use of different datasets, methods and/or approaches to improve the validity of research findings (Babbie, 2014:121; Maxwell, 2013:128; Bryman et al., 2011:45; Hesse-Bibber & Leavy, 2011:222; Farmer, Robinson, Elliott, & Eyles, 2006:377). Four types of triangulation are outlined and listed below (Denzin, in Padgett, 2008:186-187):
   o Theoretical triangulation: the use of multiple theories or perspectives to interpret a single set of data
   o Methodological triangulation: the use of multiple methods to study a single phenomenon

- Observer triangulation: the use of multiple observers to achieve inter-subjective agreement on the study of a single phenomenon
- Data triangulation: the use of more than one data source.

In this study, theoretical triangulation was upheld through the adoption of three theories: the strength-based perspective; the coping theory; and the middle range theory of caregiving dynamics that three disciplines use freely, Social Work, Psychology and Nursing. The perspective and theories adopted did not only illuminate the phenomenon being investigated, but also to serve as coat closet with different hooks on which to hang the data (Maxwell, 2013:49) to verify the research findings. Observer triangulation would have required me to employ a co-researcher which was not possible as the extra cost fell out of the scope of the budget for this research. However, methodological triangulation was used in that I employed various research interviewing skills while conducting the individual face-to-face semi-structured interviews. The context in which the interviews were conducted, as well as the non-verbal communication of the participants were observed and recorded as field notes while my own experiences about the whole process were reflected upon and documented in the research trail. Triangulation of data sources was observed by interviewing 26 participants (one of whom being a pilot study and therefore not included in this study).

- **Tactics to help ensure honesty in participants when collecting data**

As another strategy for ensuring credibility, Shenton (2004:66) recommends that researchers be honest and transparent throughout the research process to ensure that genuine participants are the ones who are taking part in the study while allowing those that are not interested to freely decide not to participate. I made it a standard procedure for this study to ensure that every time I met with the participants the information document requesting their participation and informed consent (see Addenda A, B, C and D) were read and discussed with them. This practice enabled one of the prospective participants to decide not to participate after learning that the study did not include any form of remuneration beforehand. She could decide not to participate because as an honest researcher, I could clearly explain every aspect of the study, particularly her right to decide not to proceed at any time of the study.

- **Iterative questioning**

Credibility can also be upheld through the probing technique to uncover deliberate lies (Shenton, 2004:67). Probing was one of the main interviewing skills utilised in the study. Participants' stories were not simply taken without request for clarification and elaboration to ensure that indeed what they are sharing was an in-depth and in-breadth account of their experiences. In some instances, one question would be rephrased differently and once again posed to the participant to confirm the meaning of the shared experiences or simply to make sure the participants understood what the question to answer it correctly as was required of them.

- **Frequent debriefing sessions**

Frequent debriefing between researchers and supervisors can enable the researcher to identify shortfalls, challenges experienced and preferences (Houghton et al., 2013:14; Lietz & Zayas, 2010:196; Shenton, 2004:67). I engaged in frequent discussion with my supervisor where various research methodological issues were discussed. For example: each interview was transcribed and submitted to the supervisor for critical scrutiny and later discussion was held to interrogate the interviewing skills used and the experiences and opinions that emerged. This afforded me an opportunity to identify my strengths and weaknesses when coming to probing. I found myself having to do some follow-up consultation on three interviews after they were seen to be flawed and poorly probed during one of these frequent debriefing sessions.

- **Peer scrutiny of the research project**

Researchers (Shenton 2004:67; Houghton et al., 2013:14; Ware, 2008:6) call for colleagues, peers and academics to scrutinise and challenge the assumptions a researcher makes in a research project prior to its finalisation. I made provision for this through my interaction with my supervisor who is a recognised and experienced researcher specialising in qualitative research, publishing in a range of discipline-related social science fields of expertise. He has maintained a close and critical look

at my research since its inception. In addition, data was also given to an independent coder who was experienced in qualitative research to independently attend to coding the collected data which required close examination and accurate interpretation. Her coding report was then compared with my own as a strategy to produce credible research findings.

- **A researcher's reflective commentary**

Researchers can, through reflective research and reflection observe and record their experiences throughout the research process to achieve what Guba and Lincoln (in Shenton, 2004:68) call "progressive subjectivity" or the monitoring of the researcher's developing constructions. For Alvesson and Skoldberg (2000:5), reflection refers to the interpretation and the launching of critical self-exploration of one's own interpretation of empirical material, including its construction. In simple terms, it means that researchers interpret the experiences of their participants and from this they then critically explore their own experiences of the interpretations and try to make sense of them to write about.

The strategy of reflective commentary was implemented in this project by using a research journal in which I recorded my reflected experiences of the study throughout the process (see the attached Addendum H). This exercise enabled me to put them on record especially when feeling intimidated by a senior participant. Upon reflection, I came to realise that I was too emotionally involved during two of the interviews which hampered me somewhat when needing to perform in my role as the interviewer. I was also able to see how my values, age and background played a role in the study and this in itself enabled me to improve my approach and techniques, such as focusing more on probing, and preparing me to go forward and with more confidence.

- **Researcher credibility**

Being the main instrument of the entire data collection process, I had to concentrate of being vigilant. The researcher's credibility is particularly instrumental in ensuring

the successful implementation of any research method (Shelton, Smith & Mort 2014:271). The successful implementation of any research method is dependent on the researcher's integrity. Maykut and Morehouse (in Shenton, 2004:68) recommend that the researcher disclose personal and professional information about the phenomenon under study. Patton (in Shenton, 2004) adds that information around funding should be made available. Padgett (2008) shares similar views with Maykut and Morehouse and Patton through her observation of "the researcher's unique position as an instrument of data collection…imposes special burdens as well as opportunities". For Merriam and Tisdell (2016:260), "it is training, experience, and intellectual rigor of the researcher that determines the credibility of qualitative research''. This means that the role played by the researcher's unique features are critical aspects that form part of trustworthiness of the research.

My passion for marginalised and vulnerable groups such as the HBCGs can be traced as far back as from my own childhood when I was exposed to various forms of abuse and maltreatment which ultimately inspired me to enrol for the Bachelor of Social Work at UNISA with the aim of helping those who may have experienced what I had gone through. This further resulted in some interest in research which developed from my fourth-year qualitative research project in 2005 that focused on abused children.

After completing my qualification, I started to practise as a social worker in various fields such as the juvenile justice, the child welfare, general Social Work practice and the Medical Social Work covering many issues of social concern. It was exposure to the field of Medical Social Work that sparked my passion for research in the field of HIV and AIDS and inspired my decision in the year 2007 to enrol for a Master in Social Behaviour Studies degree with HIV and AIDS as the main focus, specialising on the stigma HIV-infected female out-patients experience. From this study, I managed to co-publish one article guided by my supervisor, Professor Gretchen du Plessis from UNISA. Later on, in 2013, I resigned from practising as a social worker to join UNISA as an academic tasked with teaching group work as a method in Social Work intervention.

As a lecturer, UNISA affords me more experience in qualitative research by attending workshops and training sessions; conducting qualitative research classes for Fourth- year Social Work students; and assisting with the marking and overseeing post-graduate Social Work assignments. I also served as an internal examiner for two Master's dissertations, one focusing on *"Adherence to Antiretroviral Therapy by adolescence in Maseru: influencing factors and Social Work support"* and another on *"The factors that influence social workers in establishing community based-care and support services for older persons".* Having worked with HBCGs where I witnessed the challenges that they encounter on a daily basis, I decided to launch a full investigation into their experiences and challenges in working with PLWHA. This study was funded by the South African National Research Foundation (NRF) through the Thuthuka (Fund No: 94082) with purely administrative related conditions such as provision of quarterly progress reports, and accounting on expenditure. It was also funded by UNISA through the AQIP (Academic Qualification Improvement Programme) with similar conditions.

- **Member checks**

An important strategy for ensuring credibility is member checking (Shenton, 2004:68). Member checking as described by Padgett (2008:190) can be an important tool for minimising researcher bias. In implementing the member checking strategy was done in this study by securing an appointment with a sample of participants to discuss the interviews that I had conducted with them and to decide whether what was captured was indeed a true reflection of what they said. To achieve this, participants were given hard copies of the interview transcripts so that they could read them and determine if indeed they reflected what they said. To those who were illiterate, I had to read through the interviews so that they could make their own determination of its credibility.

- **Thick description of the phenomenon under scrutiny**

A thick description of the phenomenon under scrutiny, along with a detailed description of the process observed in the creation of knowledge around the nature

and dynamics of the phenomenon can earn the confidence from the reader and avow trustworthiness of the study (Merriam & Tisdell, 2016: 256-257; Yin, 2011:213; Shenton 2004:69). Rich or thick description, can be achieved if the researcher delves deeply into the topics both during the data collection and the description phase of the process (Webster, Lewis & Brown, 2013:87). As Rossman and Rallis (2012:269-270) note, "thick description details the physical surroundings, time and place, or actions, events, words, people and interactions on the scene."

In addressing the strategy of thick description for this study, I extended the depth and intensity of interrogation when questioning the participants to gather as much data from them as I could while making notes about their non-verbal messages at the same time. In doing so, I replicated the kind of practice Rossman and Rallis (2012:169) describe as "… strong questioning and listening skills, as well as finely honed observation skills." An example bearing testimony of this was when requesting Mokete to share his work-related challenges in caring for PLWHA. While he was talking, I realised he had been deeply hurt. When sharing about the general treatment that he receives from the community with me, he even shed some tears.

Another method of achieving a rich account of a participant's own voice is to document their own words captured during the interview. In this report, Chapters Three and Four are rich in the voices of the participants along with descriptions of the physical and social conditions under which the interviews were conducted.

- **Examination of previous research findings**

The final strategy to satisfy the principle of credibility is to examine examples of previous research findings from the work of other scholars to determine if this study's findings are congruent with their findings. Efforts to satisfy this strategy were implemented by comparing the themes, sub-themes and categories with existing literature to determine if they corroborate or differ from existing literature (see Chapters Three and Four of this report).

2.9.2 Ensuring transferability

The second principle for ensuring trustworthiness is transferability to assess the probability that this study's findings have meaning for other researchers in a similar situation (Houghton et al., 2013:16) Bryman et al., 2011:285; Streubert & Carpenter, 2011:49). Several authors (Barush, Gringeri and George, 2011:13; Houghton et al., 2013:13-16; Koch, 2006:92; Shenton, 2004:69) recommend that a detailed description of the context, the research methods and the raw data be effected to allow its transferability to be determined.

Detailed descriptions of the events that transpired during the various processes used in this research were clearly outlined both in the original proposal and in this section of this chapter to enhance transferability. These included a clear description of how the research process was conceptualised, the detailed description of the activities that took place in the research context, such as identifying participants, negotiating with organisations and prospective participants, conducting the interviews and how data was collected and eventually analysed.

2.9.3 Ensuring dependability

Once credibility of the study is achieved, then dependability is also assured (Shenton, 2004:71; Streubert & Carpenter, 2011:49). In their brief discussion of dependability, Bless et al. (2013:237) call for the exact presentation of how data was collected, recorded, coded and analysed along with examples to justify this process to further enhance dependability. They (Bless et al., 2013:237) further urge researchers to observe this process "thoroughly and carefully" to maintain trust in their study.

For Du Plooy-Cilliers et al. (2014:259), dependability addresses the quality of integration between the methods of data collection and analysis, and the theory generated from the data. In line with Shenton's (2004:71-72) recommendations for researchers to ensure dependability of their studies, the following sections were clearly addressed in this study:

o The research design and its implementation: The detailed description of the research design as planned and implemented was clearly presented under Section 2.4 of this chapter where a demonstration regarding how the phenomenological, explorative, descriptive and contextual research designs was implemented.

o The operational details of data gathering: Sections 2.6 and 2.7 of this chapter has clearly presented the process that was followed in gathering the data from searching of organisation from Google to individual contact with each organisation and its participants culminating into the termination of interviews with each individual participant recruited.

o Reflective appraisal of the project: Accountability in relation to the reflexive appraisal is provided under section 2.3 of this chapter under the feature: "the qualitative researcher is an interpreter of the meanings of data" in which detail around how my personal traits, values, beliefs assumptions and attitudes as a researcher contributed to enhancing or inhibiting the research process.

In addition to the above strategies, dependability was further strengthened by using an independent coder who was very well versed in independent coding and qualitative research.

2.9.4 Ensuring confirmability

As described by Lincoln and Guba (in Nieuwenhuis, 2016:125), confirmability refers to "the degree of neutrality or the extent to which the findings of a study are shaped by the participants and not by researcher bias, motivation or interest".

To successfully convince the reader that indeed the data was the participant's own story and not the researcher's, several authors (Barusch et al., 2013:16; Elo et al., 2014:7; Tracy, 2010:841; Morrow, 2005:225) advise that rich direct quotes from the participants be included in the final document. Some authors (Barusch et al., 2013:16; Houghton et al., 2013:14; Shenton, 2004:72; Sandelowski, 1994:480) recommend that the researcher comes out and owns up to the factors that

influenced their decisions throughout the process to maintain the audit trail. To enable readers to track every step undertaken during the process would be commendable. For Streubert and Carpenter, (2011:49), confirmability can be satisfied if the researcher records all the activities over the time taken to complete the research study so that others can follow the same process and hopefully arrive at the same conclusions this researcher reached.

In this study, my possible biases and viewpoints were clearly identified, acknowledged and reflected upon through reflexivity (see section 2.3 of this chapter under the feature: "the qualitative researcher is an interpreter of the meanings of data"). Each participant's own story is in the form of direct quotations from the interviews conducted with them together with a clear illustration of how the themes that eventually informed the final conclusions emerged is presented in Chapters Three and Four of this report.

2.10 APPLICATION OF THE ETHICAL ASPECTS CONSIDERED

In highlighting the significance of observing the ethical principles of qualitative research, Shaw (2003:11) remarks that, "naivety about ethics is itself unethical." Ellis (2013:18) holds a similar view and urges researchers to develop ethical awareness as early as during the first stage of the research process. Here they should be mindful of the participants' possible risks and benefits. This awareness, Ellis (2013) believes, will trigger plans to put ethical issues in place and be addressed. Similarly, Walcott (in Warin 2011:807) advocates a balance between risks and benefits that can be achieved through practices of openness and transparency. Moreover, the balancing act does not belong to a separate stage of an academic investigation, but can arise at any stage throughout the entire research process (Wallcott in Warin, 2011:807). Several authors highlight the value of complying with and acknowledging their institution's Review Boards' ethical protocols during their research endeavours (Litchman, 2014:74; Yin, 2011:44-45; Mertens & Ginsberg, 2008:492; Maree, 2016:44).

I followed this advice and sought obligatory ethical clearance for my study from UNISA's Social Work Departmental Research and Ethics Committee (DR&EC) prior

to commencing with my study. I vouched to comply with the ethical principles adopted in the original approved plan or proposal for this study. An account of how the ethical principles were applied is presented next.

2.10.1   Obtaining informed consent

Informed consent means that the researcher is obliged to give potential participants adequate information which should enable them to make informed decisions on whether or not to take part in such study (Babbie, 2014:507; Streubert & Carpenter, 2011:454; Bryman et al. 2011:378; DoH, 2015:24; Streubert & Carpenter, 2011:454; Mishna, Antle & Regehr, 2004:453). Another important issue raised (Gray, 2014; Webster et al., 2013:88; Warin, 2011:807) concerns the importance of having the content of the informed consent used revisited regularly. I have adhered to the requirements and principles of the academic institution under whose auspices I registered for pursuing my doctoral studies as stated in the accompanying informal consent form (Addendum B).

I ensured that immediately after meeting potential participants, and every time before the interviews commenced, each interviewee was well informed and had a full understanding of the nature of the study, my responsibilities as a researcher, their rights as participants and the risks and benefits involved in the study. I decided to make the ethical obligation of obtaining informed consent a standard procedure (see Addendum B) at the first meeting with them. This process was implemented in the following manner.

Once the gatekeepers and management officials had granted permission to meet with the HBCGs in their organisation, I requested an appointment to meet with them either individually or as a collective, so that I could introduce myself and my study to them. During these meetings, I would explain the purpose of the study in detail and afford them an opportunity to ask questions whenever they had one. Once the first briefing meeting was completed, I would then give them copies of the letter containing the information about the research and informed consent document (see Addenda B) so that they could go through them in their own time noting any questions they wished to ask when we met again about over a week by personal

arrangement. Another appointment was then scheduled for further discussion and where necessary clarity was provided for those who had some questions. During this time there would also be detailed discussions on the information and informed consent documents to make sure everybody understood what the study was all about, why it was important for them to participate and, if they decide to participate, what the risks and benefits would be.

All the details around the study were provided and, once I was satisfied that they understood what they could expect while involved with the study and the entire process, I would proceed to facilitate the signing of the consent form documents. This process was observed with all the organisations except two: Tsatsawani and Marashea. The two were exceptions because of the following circumstances: Tsatsawani was situated at about 200 kilometres from where I was staying and travelling back and forth would have negatively affected the study budget in some way or another. In this case particularly, I ensured that I remained very patient during our first meeting when explaining the study to them to be completely sure that they all understood what to expect. The consent forms were completed and signed the same day after I was satisfied that those willing to participate understood what the study was all about. In the case of Marashea HBC, the HBCGs could not read or write. I had to spend some time explaining the information and informed consent document with them in simple Setswana language which is the language with which they were conversant. What was different about the procedure in this organisation was that the participants were not given the copies to read on their own. Instead more time was dedicated to simple discussions with them until they gave their verbal consent.

2.10.2 Ensuring confidentiality and anonymity

For a young researcher like me, qualitative research can be a tricky exercise; just like two sides of a coin. On the one side of the coin, transparency can be achieved through a demonstration of producing an in-depth and comprehensive description as highlighted earlier in the discussion. A rich and thick description is one of the critical measures to determine trustworthiness of a typical social science research study. On the other side of the coin, in the context of work like this, researchers are cautioned

not to disclose too much of a participant's details as they may find themselves in ethical hot water. The tricky part of this section that focuses on ethics, relates to a question of what to disclose and what to reveal. As Webster et al. (2013:96) describe, confidentiality means not disclosing who has taken part, nor reporting what they say in such a way that could identify them or be attributed to them. It should be the researchers only who know the source of data; even in presenting the findings, they should ensure that participants cannot be identified (Streubert & Carpenter, 2011:64; Vainio, 2012:687). The critical role of confidentiality in qualitative research is further reiterated by Bless et al.'s (2013:32) call for researchers to ensure protection of sensitive and personal information participants provide.

Regarding anonymity, Bless et al. (2013:33), explain that anonymity means that a participant's data must never be associated immediately and obviously with their name or any other identifier. Vainio, (2012:686) has a similar opinion and describes anonymity as an ethical principle that involves "modifying the empirical data, so that the research participants cannot be identified." This means that the researcher does not record a participant's name at any stage of the research process (Du Plooy et al. 2014:267) to avoid exposing their identities." Vainio (2012:688) acknowledges the involvement of organisations in research (as is the case in this study) and recommends that they too should be anonymous to protect its members. Vainio (2012:686) contends that anonymity has become a bone of contention that has resulted in two camps of researchers, where some consider it to be "possible", "desirable" and "not difficult to achieve" while the others consider it to be "unachievable", "an illusion" and even "unethical".

My conviction of anonymity along with confidentiality is that they are critical principles upon which all other ethical principles rest. Anonymity and confidentiality play a significant ethical role during the informed consent stage as there might be some of the determinants for the participants' decisions on whether to participate or not. Breaching anonymity and confidentiality, for instance, could result in the participants' sensitive information being linked to their identities. This could, in turn, result in perceptions of members of the public (some of which could be derogatory or discriminatory) about the participants. This could, in turn, compromise their integrity, resulting in pain on the participants (compromised the principle of avoiding harm).

Both anonymity and confidentiality were therefore considered to be critical principles hence implementation of the following strategies:

- The real names of the organisations from which participants were sourced were camouflaged using pseudonyms to avoid easy linkage of such information with a specific participant.

- Specific details, for example, of the areas the participants serve; the location of the HBC organisations involved; the composition and demographics of their families; or information on certain details was simply avoided to minimise the risk of exposing the participants' identity.

- Pseudonyms were used to hide each participant's real name and true identities.

2.10.3 Avoiding harm

Although avoiding harm was not initially included in the research plan, its necessity was later realised during the research process. In respect of "avoiding harm" as an ethical obligation, Posel and Ross (2014:35), underscore the fact that we are obliged, as researchers, not only to avoid any form of harm to our participants, but also to respond to instances where it prevails. By harm the DoH (2015:78) means "anything that has a negative effect on participants' welfare, broadly construed; its nature may be physical, emotional, psychological, social or legal."

Although I assumed that the participants involved in this study would not come to any form of harm, I did not totally rule out this possibility. Hence I heeded Litchman's (2014:57) recommendations for avoiding doing anything that might harm them. I tried to not only avoid any form of harm but also remained vigilant at the same time, ready to respond should they experience anything harmful.

Before starting with the data collection interviews, I first gauged the mood of my participants and enquired about their general well-being. I also explored any factor that could hamper the process before I started any of the interviews. I always checked with the participants if they felt ready to begin with the interview by asking them directly.

To respond to harm, I ensured that I had budget item for a professional counsellor who could provide and be committed to having a debriefing session should a need arise as the research process progressed (see Addendum I).

2.10.4   Debriefing participants

Qualitative interviews can elicit intense discussion of painful past events and experiences (Padgett, 2008:69). This was no different in this study. I was mindful of the fact that participants are involved with terminally ill patients, some of whom die during the caring process. I was aware of the possibility of the interviews unveiling some of these painful experiences which they had gone through and which could make them feel emotionally overwhelmed. Streubert and Carpenter (2011:67) warn that it would be irresponsible for the researchers not to grant participants who are emotionally drained an opportunity to talk about their experiences. Researchers are advised to make the necessary arrangements for further professional intervention (Pagdet, 2008; Webster et al., 2013: 98; Streubert & Carpenter, 2011:67). This arrangement was made through the social worker who was practising under the auspices of the Catholic Women's League (see Addendum I). However, no referrals were made as no incidents arose that that required a professional debriefing session.

2.10.5   Managing and protecting the data

As an ethical obligation, it is expected of academic researchers to ensure protection of their data at all times (Remenyi, 2014:45). This means that researchers need to take reasonable and responsible steps to safeguard the data in such a way that it does not affect any of the abovementioned ethical principles adversely. Alongside the importance of ensuring sound and ethical storage of data is fact that we, as researchers, sometimes find ourselves overlooking safeguarding our personal computers and websites. These are not likely to live forever and relying solely on them for data storage will never do us any justice (Michener, 2015:5; Corti, Van den Eynden, Bishop & Woollard., 2014:88). It was on this point that Michener (2015:5) and Padgett (2008:132) urge researchers to ensure that proper planning for data storage and accessibility for retrieval during the life of the project is ensured.

As much as researchers are urged to ensure proper and reliable data storage plans, it is important that these plans are exercised within commitment to the study's ethical parameters. While developing plans, remain mindful of questions like knowing who will have access to your data for the duration of the research and how will this access be controlled. I did not simply overlook this exercise for this study. Given the tendency for and nature of our computers to be unreliable, hardcopies of the interview transcripts were printed and stored safely in a personal file in my house where I was the only person who could access them. In the case of soft copies, folders were created for each organisation with transcripts of each participant saved in the folders of their respective organisations. To ensure control of access, these folders were password protected. Given the fact that field notes were in a form of hardcopies, a backup was created by scanning the field notes and saving them along with their respective interview transcripts in the respective organisational folders. Email conversations were also saved within the respective organisations' folders.

2.11   CHAPTER SUMMARY

In this chapter, I have demonstrated how the qualitative research, as the research methodology which guided this study, was implemented. The opening of the discussion around how the process was applied was started through the motivation for the necessity of a separate chapter dedicated to the applied description of the qualitative research process.

This motivation was then followed by a detailed discussion of how the process unfolded from the start to the end with specific attention being placed on how the characteristics inherent to qualitative research were interpreted and applied and how the phenomenological, explorative, descriptive and contextual research designs were implemented. The detailed account of the implementation of the research methods showed that specific attention was directed to how the research participants were identified and recruited from their respective HBC organisations. How they were prepared for their interview and that is was conducted and recorded yielding data that was analysed according to a defined process.

My account of the implementation of the research methods was immediately followed by explanation on how the process of data verification was done. In this section, attention was given to the data verification strategies of credibility, transferability, dependability and confirmability as proposed by Guba and Lincoln (in Shenton, 2004). Finally, I also accounted for the implementation of five ethical principles: obtaining informed consent, ensuring confidentiality and anonymity, avoiding harm, debriefing participants and managing and protecting the data. A chapter summary which highlighted the main topics the chapter covered concluded this second chapter.

In the next chapter, I present the first part of the research findings that concerns the HBCGS motivations for caring for PLWHA and the work-related challenges they face.

CHAPTER THREE

RESEARCH FINDINGS (PART ONE): THE MOTIVATIONS AND CHALLENGES OF CAREGIVERS IN CARING FOR PEOPLE LIVING WITH HIV AND AIDS (PLWHA)

3.1   INTRODUCTION

In Chapter Two of this report, the focus was on the qualitative research process, illuminating how it was applied when the fieldwork was carried out. In this chapter, I present the first part on the research findings that emerged from the processes of data collection, analysis and the consensus discussion that took place between the independent coder and myself which was facilitated by my supervisor. The results relate to the findings concerning the HBCGs' motivations for and the challenges experienced when caring for people living with HIV and AIDS (PLWHA). In providing the context for the discussion, I will commence by presenting the participants' demographic particulars. This will be followed by a tabulated account of the themes, sub-themes and categories that emerged from the process of data analysis. Storylines inform each of these divisions along with a literature control for comparison purposes.

3.2   THE DEMOGRAPHIC PARTICULARS OF THE PARTICIPANTS

This section heeds the call from Hennink et al. (2011:288) who urge researchers to make a description of the socio-cultural characteristics of the study population available (see Chapter Two: Section 2.4.4). Creswell's (2016:110) suggests a table format for a detailed profile of the participants in their research work. Hennink et al., (2011:288) believe that socio-economic and cultural characteristics can be highlighted with data about the participants' belief systems, behaviours and, norms that are relevant to a study's topic. For Hlengwa (2011:77), the low- income status common among HBCGs, their educational and social status, gender and marital status too are some of the socio-economic and demographic factors associated with the physical and mental problems associated with the work of HBCGs. It is because

of this scenario that the biographic profiles of the twenty-five HBCGs who took part in this study are presented in this chapter (see Table 3.1). The reader's attention is drawn to their ages, social memberships, position in their households, their dependants, years of experience as an HBCG and their household income which, I believe may somehow have played a role in becoming involved in the care work of caring for PLWHA. The demographic particulars of the participants are presented in Table 3.1 together with some additional information on the next few accompanying pages.

Table 3.1: The demographic particulars of the participants

Name (Pseudonyms)	Age	Gender	Race	Family composition – The family composition of the HBCG comprises	Caregiving experience	Household income	Educational qualification	Province
1. Amelia	31	Female	Black	*The HBCG, her children and mother*	2 years	*R1840 [1500.00 Stipend & R 340 Child Support grant (CSG)]*	Grade 12	*Gauteng*
2. Mokete	43	Male	Black	*The HBCG, his wife & two children*	7 years	*R5180 (Stipend for him and his wife who is also a caregiver)*	Grade 12	*Gauteng*
3. Dineo	28	Female	Black	*The HBCG, mother & little sister*	4 years	*R3280 [Stipend & CSG)*	Grade 12 & counselling	*Gauteng*
4. Zulu	24	Female	Black	*The HBCG, her mother, a sister & two brothers*	8 months	*R2680 (R1500 Stipend & social)*	Grade 10	*Limpopo*
5. Yena	30	Female	Black	*The HBCG, her mother, uncle & her two children*	2 years	*R2100 (Stipend & OAG)*	Grade 12	*Limpopo*
6. Xhathula	42	Female	Black	*The HBCG, her husband & three children*	3 years	*R2180 (OAG & R1500 stipend)*	Grade 12	*Gauteng*
7. Paul	45	Male	White	The *HBCG* only	23 years	*R5200 (Stipend & stage decoration project)*	Grade 12	*Gauteng*
8. Vanessa	38	Female	Indian	*The HBCG and her four children*	6 years	*R 3520 (Stipend, CSG & OAG)*	Grade 12 & counselling	*Gauteng*

9. Kgomo	56	Female	Black	The *HBCG* only	10 years	*R 1500.00 (Stipend)*	Grade 10	*North West*
10. Jini	40	Female	Coloured	The *HBCG*, her husband & an only child	10 years	*R1500.00 (Stipend)*	Grade 11	*North West*
11. Letsatsi	38	Female	Coloured	*The HBCG, her three children, her mother and two brothers.*	2 years	R2000 (Stipend)	Grade 12	*Gauteng*
12. Selinah	58	Female	Black	*The HBCG, her husband and three children*	4 years	*R6180 (husband's salary, stipend & CSG.*	Grade 12	*Gauteng*
13. Wendy	42	Female	Black	*The HBCG and her husband.*	12 years	*R 1500 (Stipend)*	Grade 12	*Gauteng*
14. Martin	58	Male	Black	*The HBCG only*	3 years	*R800 (Stipend)*	Grade 9	*North West*
15. Cassie	39	Female	Black	*The HBCG and her two children*	7 years	*R2280 (Stipend & CSG)*	Grade 10	*Gauteng*
16. Mamadee	31	Female	Black	*The HBCG, her brother and sister.*	2 years & 3 months	*R2000 (Stipend & siblings salaries)*	Grade 12	*Gauteng*
17. Legong	38	Female	Black	*The HBCG, her own two children & her late sister's two children*	5 years	*R 3360 (OAG & stipend)*	Grade 12	*Gauteng*
18. Pekwa	45	Female	Black	*The HBCG, her mother, sister, her two children and sister's child*	3 years	*R2560 (Stipend & CSG)*	Grade 11	*North West*

19. Segwagwa	47	Female	Black	*The HBCG, her husband & three children*	8 years	*R1020 (Stipend &CSG)*	Grade 12 & Basic First Aid	*Gauteng*
20. Lenyalo	45	Female	Black	*The HBCG, her mother and her four children*	*2 years*	*R3780 (OAG & stipend)*	Grade 9	*Gauteng*
21. Mpshe	39	Female	Black	*The HBCG and her two children*	7 years	*R2180 (Stipend & CSG)*	Grade 10	*Gauteng*
22. Nakedi	38	Female	Black	*The HBCG and her two grandchildren*	12 years	*R2680 (Stipend & CSG)*	Grade 10	*Gauteng*
23. Viola	27	Female	Black	*The HBCG and her aunt*	2 years	*R1500 (stipend)*	Grade 9	*Gauteng*
24. Ching	38	Female	Black	*The HBCG, her child and her boyfriend*	4 years	*R1840 (stipend & CSG)*	Grade 10	*Limpopo*
25. Malume	34	Female	Black	*The HBCG, her mother (pensioner) & two children*	9 years	*R3780 (stipend, CSG & OAG)*	Grade 10	*Gauteng*

As seen from their profile (Table 3.1), twenty-two of the HBCGs were females and three of the twenty-five participants were males. This trend corroborates with existing body of evidence on caregivers who care for PLWHA (Orner, 2006:237; Schneider, Hlophe & Van Rensburg, 2008; Marincowiz et al., 2004) which shows that a HBCG is generally a female. Although there may be inadequate empirical evidence to substantiate the reasons for most people in caregiving work to be women, it is generally known that caregiving is women's work (Maes & Kalofonos, 2013:57; Akintola, 2005:6; Kohli et al. 2012). This opinion cannot be totally ruled out.

Participants were between the ages of twenty-seven and fifty-eight. On closer scrutiny eleven participants respectively were between the ages of twenty-seven and thirty-eight years of age and thirty-nine and forty-eight years of age and three participants fell within the age bracket of forty-nine to fifty-eight years of age. These demographics mirrored parts of literature that revealed variations in the ages of HBCGs. Orner[31] quoted in Akintola's (2008:121) study for instance found that the ages of HBCGs caring for PLWHA range between eighteen and sixty-nine. For Claxton-Oldfield, Jefferies, Fawcett and Wasylkiw's (2004:80) Canadian study, which focused on the motives for joining a palliative care volunteer programme among palliative caregivers, the ages of HBCGs who are generally involved in palliative care ranged from thirty-seven to thirty-eight. Among Schneider et al.'s (2008) participants who were HBCG caring for PLWHA in the Free State, South Africa, the ages of these CHCWs were between thirty-years and fifty years.

The racial classification revealed that two participants were Coloureds, one was white, one was an Indian and twenty-one were black. The studies consulted that focused on HBCGs caring for PLWHA (Cataldo, Kielmann, Kielmann, Mburu & Musheke, 2015; Kohli, Purohit, Karve, Bhalerao, Karvande, Rangan, Reddy, Paranjape & Sahay, 2012; Akintola, 2005:6; Akintola, 2010:3-4; Olang'o, Nyamongo & Aagaard-Hansen, 2010:233-234; Orner, 2006:237; Takasugi & Lee, 2012:840; Singh, Chaudoir, Escobar and Kalitchman (2011:841; Claxton-Oldfield et al.,

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[31] Orner's study focused on the psychosocial impacts of caregiving on caregivers of PLWHA in Khayelitsha, Gugulethu and Delft in Western Cape, South Africa (Akintola, 2008:121).

2004:80-81; Schneider et al., 2008) do not account for racial classification among HBCGs. This observation seems to contribute to the dearth of literature in confirming or contrasting this demographic category.

Educationally the participants' qualifications varied from Grade 9 to a tertiary qualification, with twelve of the participant having Grade twelve, seven of them had Grade ten, three Grade nine and two having Grade eleven. Among those with Grade twelve, one had a certificate in Basic First Aid and two had a basic counselling certificate. This data supports some of the existing works (Takasugi & Lee, 2012:840; Olang'o et al., 2010:234; Akintola, 2010:4) that claim that most of the HBCGs caring for PLWHA lacked a tertiary education. Unlike what I have found in this study, in Claxton-Oldfield et al.'s (2004:80-81) Canadian study of the motivations for palliative care volunteers, a university or college education was common.

The family composition revealed that three participants were staying alone, five stay with a partner and children, seventeen were either with their own children, parents and an extended family member or with parents and siblings.

The scenario painted in Akintola's (2005:06) South African study focusing on the role of HBCGs in mitigating the burden of HIV and AIDS care in households and communities in KwaZulu-Natal (KZN), most HBCGs were unemployed. Being engaged in care work was also the case in my study with all the participants' income coming only from a state social grants or a stipend. The stipend ranged from R800.00 to R2500.00. This variation was due to the governments' funding of limited number of HBCGs, which was also the case among the AIDS volunteers who took part in Akintola's (2010:3) South African study that explored the HBCGs' motivations to care for PLWHA in KZN. Another study by Akintola, (2005:22) that focused on the HBCGs' role in mitigating the burden of care in households and the communities in South Africa's KZN revealed that a combination of stipend, the social grant and family members' salaries resulted in a total family income of between R800.00 to R6180.00.

Generally the demographic profile of this study has mirrored what already exists in the body of literature (Claxton-Oldfield et al., 2004:80-81; Takasugi & Lee, 2012:840; Marincowitz et al., 2004; Steinitz, 2003; Olang'o et al., 2010:234) in that the caregiver involved in care work is a woman aged eighteen years and older; from any geographic area; affiliated to Christianity or other social groups outside the caregiving role; with either a basic or tertiary level of education; and from a poor economic background.

3.3   THEMES, SUB-THEMES AND CATEGORIES THAT EMERGED FROM DATA ANALYSIS

The process of data analysis and the outcome of consensus discussion between the independent coder and myself as facilitated by my supervisor resulted in nine themes, thirty sub-themes and fifty-five categories that are depicted in Table 3.2 overleaf. Themes One and Two will be presented in the remainder of this chapter, whilst the rest of the themes will be presented in the next chapter (Chapter Four) of this thesis.

Table 3.2 Themes, sub-themes and categories that emerged from the process of data analysis

Theme	Sub-theme	Category
Theme one: HBCGs' accounts of their motivation to care for PLWHA	• HBCGs' desire to help people as their motivation to care for PLWHA	o Calling as HBCGs' desire to care for PLWHA o Passion as HBCGs' desire to care for PLWHA
	• HBCGs' personal experiences as their motivations to care for PLWHA	
	• Opening up a career path as their motivation to care for PLWHA	o Having employment or advancing the prospects of a full-time employment as career-related reasons for caring for PLWHA o Previous training and voluntary work as HBCGs' career-related reasons for caring for PLWHA o The need to become a nurse as a HBCG's career-related motivation for caring for PLWHA
Theme two: HBCGs' work-related challenges in caring for PLWHA	• HBCGs' experiences in relation to the challenge of negative attitudes held by some community members	o HBCGs' challenges with some community members who think caregivers are also HIV-positive – a misconception o HBCGs' challenges with some community members who are afraid of stigma o HBCGs' challenges with some community members who deny or do not accept their HIV-positive status. o HBCGs' challenges with some non-welcoming and judgmental members of the community o HBCGs' challenges with some members of the community

		who reject, ignore or avoid them
		○ HBCGs' challenges with some community members who think their work in useless and beneath them
		○ HBCGs' challenges with some community members who spread rumours
		○ HBCGs' challenges with some community members who do not want to listen to their information on HIV and TB
	• HBCGs' patients-related challenges experienced	○ HBCGs' challenges with moody patients
		○ HBCGs' challenges with patients' non-compliance with treatment
		○ HBCGs' challenges with patients who lose hope
		○ HBCGs challenges with older and male patients who refused to be bathed by younger and female HBCGs
		○ HBCGs' challenges with patients who use substances
	• HBCGs' challenges in relation to the patients' relatives	○ HBCGs' challenges with poor reception by some of the patients' relatives
		○ HBCGs' challenges with lack of appreciation of their services by patients' relatives
		○ HBCGs' challenges with relatives who neglect the patient and rely on them for care and support.
		○ A HBCG's challenge with relatives who receive grants for the patient and not use it for the patient's benefit

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	• HBCGs' challenges in relation to working in unsafe conditions when caring for PLWHA	○ HBCGs' challenges with vulnerability to rape ○ HBCGs challenges with vulnerability to getting TB ○ A HBCG's challenge with the odour of AIDS
	• HBCGs' challenges in relation to colleagues	○ A HBCG's challenge with colleagues who disclose patients' HIV status ○ A HBCG's challenge with colleagues who avoids her
	• HBCGs' challenges in relation to the attitudes of other role players	○ HBCGs' challenges when working with the clinic staff ○ The negative attitudes of other professionals as a challenge for the HBCGs ○ HBCGs' challenges when working with social workers
	• HBCGs' challenges in relation to their own organisations	○ HBCGs' challenges with lack of transport ○ HBCGs' challenges with lack of training and low stipends ○ HBCGs' challenges with limited resources ○ A HBCG's challenge with organisational protocols ○ HBCGs' challenges with the way their organisations were managed ○ A HBCG's challenge with racial segregation in her organisation and its resultant effect on her
Theme three: HBCGs' accounts of their feelings and	• HBCGs' negative feelings and emotions associated with caring for PLWHA and their work-related challenges	○ HBCGs' feeling of sadness about their care work and its challenges ○ HBCGs' feelings and emotions of discouragement

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emotional reactions to their care work and its challenges		because of caring for PLWHA and their work-related challenges
		o HBCGs experiencing feelings and emotions of failure due to their work-related challenges
		o HBCGs feeling sorry for or having pity on their patients
		o HBCGs feeling pain due to the nature of their care work when witnessing the pain and suffering their patients experienced
		o HBCGs' feelings and emotions of fear of getting infected with HIV and fear of doing wrong things
	• HBCGs' accounts of feelings and emotions of happiness associated with care work	
Theme four: HBCGs' accounts of community members' positive attitudes and perceptions towards them because of their work of caring for PLWHA	• Community members welcomed and appreciated the HBCGs • A perception that community members think a HBCG is brave to care for PLWHA	
Theme five: HBCGs'	• Family members and friends understand and	

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accounts of the attitudes of their families and friends towards them because of their work of caring for PLWHA	appreciate the HBCGs' work • Family members and friends reacted negatively to the HBCG's caring for PLWHA • Family members and friends lack understanding for HBCGs' involvement in caring for PLWHA • Family members and friends are concerned about a HBCG's low remuneration.	
Theme six: The coping strategies used by HBCGs to manage the work-related challenges experienced in caring for PLWHA	• HBCGs cope through support from their employers • HBCGs cope through counselling and support groups • HBCGs cope by networking with other organisations and by referring cases • HBCGs use self-help or self-motivation to cope with their work and its related challenges • HBCGs cope with their work-related challenges by having faith in God	
Theme seven: HBCGs' suggestions to management on	• HBCGs' suggestions to management to visit patients	
	• HBCGs' suggestions to management to provide resources	o HBCGs' suggestions to management to provide transport o HBCGs' suggestions to management to provide more

how their work and working conditions could be improved		equipment and supplies o A HBCG's suggestion to management to appoint more male HBCGs o HBCGs' suggestions to management to appoint other professionals to assist in caring for PLWHA.
	• HBCGs' suggestions to management to provide training.	
	• HBCGs' suggestions to management to provide better or increase stipends	
	• HBCGs' suggestions to management to provide them with psychosocial support	o HBCGs' suggestions to management to arrange for counselling and debriefing support o HBCGs' suggestions for management to arrange for team building
Theme eight: HBCGs' suggestions on what they, as HBCGs, could do to manage their work-related challenges		

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Theme nine: HBCGs' suggestions on how social workers could support them to improve their work-related challenges	• HBCGs' suggestions to social workers to provide them with Social Work services	o HBCGs' suggestions for social workers to provide them with counselling, support, debriefing and team building o HBCGs' suggestions for social workers to motivate them o HBCGs' suggestions for social workers to provide them with training o HBCGs' suggestions for social workers to liaise and negotiate with management for better salaries for the HBCGs o A HBCG's suggestion for social workers to undertake home visits
	• HBCGs' suggestions to social workers to provide Social Work services to patients, their families and communities	o HBCGs' suggestions for social workers to assist in resolving patients and family Social Work-related problems o A HBCG's suggestion for social workers to educate and involve the community

Evolving from the above table, the first two themes with their related sub-themes and categories (where applicable) will now be presented. Quotations from the transcribed interviews will be used to fulfil various functions. As Sandelowski (1994:480) explains: "to provide evidence for some point the researcher wants to make [that is, to substantiate themes, sub-theme or categories], to illustrate or provide a more concrete example of an idea, to represent the thoughts, feelings or moods of the persons quoted or to provoke a response in the members of the audience for the research report". The themes, sub-themes and categories, with the supporting storylines will be subjected to a literature control in view of comparing and/or contrasting the research findings.

3.3.1 THEME ONE: HBCGS' ACCOUNTS OF THEIR MOTIVATION TO CARE FOR PLWHA

As discussed in Chapter One sub-section 1.2.1, the theory of informal caregiving dynamics holds that caregiving is a process through which the HBCG and the patient bring their experiences which somehow shape how they relate to one another during the caring process (Williams, 2007:379). Various aspects of the HBCGs' experiences somehow played a role during this caring journey. Research on caregivers who are caring for PLWHA (Greenspan, McMahon, Chebet, Mpunga, Urassa & Winch, 2013; Maes & Kalofonos, 2013:55-56; Rödlach, 2009:430; Akintola, 2005:9; Ramirez-Valles & Brown, 2003:3) indicates that becoming a HBCG, like any other career can be prompted by a variety of reasons. In this study, HBCGs' answers to a question concerning the HBCGs' reasons for being involved in caregiving gave rise to three sub-themes and five categories which are discussed further below:

3.3.1.1 Sub-theme: HBCGs' desire to help people as their motivation to care for PLWHA

Analysis of the participants' answers to the question relating to what motivated their desire to be a caregiver gave rise to the sub-theme: HBCGs' desire to help people which was filtered further and gave rise to two categories: a calling as a HBCG's desire to care for PLWHA; and a passion as a HBCGs' desire to care for PLWHA. These categories are further discussed below:

- **Calling as HBCGs' desire to care for PLWHA**

The participants' responses to a question around their reasons for being involved in caring generally related to their belief in caring as a calling. Segwagwa, Paul, Jini and Dineo specifically mentioned that for them caring for PLWHAs was a calling and this belief had motivated them to do so.

Paul and **Dineo** were very specific in their explanation that for them caregiving was a calling from God. This is what **Paul** said: *"I feel that I can fulfil my calling from God, to love other people… Because God says clearly in His Word, love God and love your neighbours".*

Just like Paul, **Jini** believed her work was a calling from God: *"At that time I did not know anything about palliative care. But I developed the strength and decided to throw myself into it* [referring to caring] *because I thought it was a calling that God had for me".*

The motivation for caregiving as driven by God and religious values emerged in Akintola's (2010:4) South African study focusing on the HBCGs' motivations to care for PLWHA in KZN among caregivers. One of the participants in this mentioned study believed that she was an extension of God's work on earth by using her hands to reach the sick. In a Zimbabwean study, which looked at the HBCGs' motivations and concerns regarding HBC, Rödlach (2009:428) found that HBCGs were motivated by religious values as they believed that they are duty-bound to give hope and comfort to the sick and their families. In other words, for many HBCGs, the patient comes first.

Although Segwagwa did not explain where their calling came from, they also believed caring was a calling. **Segwagwa** shared her stance: *"that is why I say is a calling to me. I develop this need to help these people* (referring to PLWHA). *Most of the time I like to put myself in the shoes of such people because I do not know what will happen to me in the future".*

Dineo spoke about caregiving as a calling along the following lines: "*Yeah, I have been a caregiver since 2011. To me is a calling because I have been passionate to care for people regardless of whether they are orphans or any other person. Since then I got involved in caregiving until today*".

HBCGs' believe in caring as a calling also emerged in another study of Akintola (2005:10) focusing on the role of HBCGs in mitigating the burden of HIV and AIDS care in households and communities among PLWHA in KZN among HIV and AIDS volunteers. In this group, altruistic reasons stood out as drivers of the HBCGs' involvement in caring for PLWHA. These participants do not put reward as a priority, but the patient's interests. As defined by Batson (2008:3), altruism refers to a "motivational state with the ultimate goal of increasing another's welfare." In other words, the care and support those who are sick and unable to care for themselves are first on the list of priorities people for those who are driven by altruism. They remain passionate to and are more concerned about the welfare of others.

Since altruism is closely linked to the concept of a calling, its attributes clearly clarify a finding of this study. Batson (2008) identifies it as a form of helping behaviour, not a motivation; having a concern for moral behaviour; and choosing internal rather than external rewards when acting to help another person. This means that the HBCG not only act as mandated by their respective organisations or because they receive some form of incentive, but because they want to help somebody. Altruism thus implies some elements of goodness and morality on part of the person who is actively rendering help and they are not just futile actions of an HBCG. Altruistic people are inclined to have peace of mind once they helped someone who needs care thus avoid the feeling of guilt and pain when they see a helpless patient suffering in pain (Batson, 2008). The HBCG who helps patients in pain experience a feeling of relief (Clary, Snyder & Ridge, 1992).

Jini and Paul's view that HBC is a "calling from God" is confirmed in Schneider et al.'s (2008) work, in the Free State, who too have observed similar situations of religious identity and altruism among CHCWs in South Africa and elsewhere in Africa as drivers for their care work involvement. Close to the research theme for this study, is Akintola 's (2010:4) reflection of what was found among a group of South African

volunteers in HIV and AIDS programmes catering for the needs of suffering of PLWHA patients in great need of care. For these HBCGs, the interests of their patients came first and theirs came last. They vowed that their patients would continue to be served regardless of whether they received any form of incentive or not. The participants were found to be highly passionate about caring for the sick and believed it was a calling for them and a self-fulfilling exercise (Akintola, 2010:4).

Tanzanian studies conducted by Greenspan et al. (2013) in Morogoro region and Pallangyo and Mayers' (2009:486) in Dar es Salaam, looked at the motivations and experiences of CHCWs and informal caregivers caring for PLWHA. They expressed commitment to their work in the belief that their work was a calling. Similarly, Maasdorp (2011) found in a Zimbabwean study focusing on the challenges of staff support in hospice care that most of the dedicated HBCGs caring for PLWHA were mainly motivated by their belief in caring for the sick as a vocation rather than a job.

- **Passion as HBCGs' desire to care for PLWHA**

To care was part of Kgomo and Dineo's nature and they were passionate about caring as the following quotations attest:

Kgomo stated: *"For me, I have realised that I was born with this passion of caring for patients. That is why now I have this passion. Mostly we get patients who are very critical so I am used to it, I like it"*.

Dineo's sentiments corroborated with Malume who also has a passion for care work: *"Before I can start working here, I had this passion to work with people especially the older people. And eventually my manager called me to ask me to come and work here and when I get here, I then started by working with young people. So, I can say is a kind of work that requires one to have passion. If you do not have passion you cannot cope because we encounter many challenges… this kind of job is not about education or anything else, it is about calling"*.

The UNAIDS (2000:15) state that simple compassion for others who are suffering is a common motivation for caregivers who volunteer their services. What is expressed by these two participants in this study's fieldwork is also highlighted by other HBCGs researchers (Akintola, 2010:5; Naidu, Sliep & Dageid, 2012:120). Their HBCGs also cite the love for caring for PLWHA as the reason to get involved in caring. Naidu et al. (2012:120) describe passionate HBCGs as the "compassionate doers" and "natural helpers" who were not only compassionate towards the sufferings of others, but also possessed the love for people from an early age and always acted to help those who were suffering. Similarly, Wringe, Cataldo, Stevenson and Fakoya (2010:5) highlight passion as one of the motivations for HBCGs to be involved in caring.

For HIV and AIDS caregivers who took part in Singh et al.'s (2011:842) South African cross-sectional survey of the impact of ongoing HBC programme on HBCGs in KZN, study of "stigma, burden, social support, and willingness to care among caregivers of PLWHA in home-based care South Africa" conducted in KZN, passion was demonstrated by more than a half of the HBCGs who continued to care for PLWHA; three quarters of them did so without any form of payment. In the US, a study in Chicago aiming to examine the activities, motives, consequences and deterrents to community involvement in caring for PLWHA among the Latino gay men caring for PLWHA, Ramirez-Valles and Brown (2003:2) found that HBCGs felt that working towards the goodness of others provided them with an identity of a caring and good person and elevated their sense of self-worth.

The sub-theme "HBCGs' desire to help people as their motivation to care for PLWHA" resonates with Williams' middle range theory of caregiving through the variable or principle of commitment as one of the dynamic forces that contributes towards the progression of the caregiving dyad (Williams, 2014:311; Williams, 2007:381). As defined by Williams (2014:317), commitment is an undertaking the caregiver gives the patient. Through this sub-theme, HBCGs' reflected commitment as they believed that caring is not any other type of work, rather a calling for which one should exercise commitment by remaining passionate. Thus, commitment therefore became the force that enabled them to continue to care.

3.3.1.2 Sub-theme: HBCGs' personal experiences as their motivations to care for PLWHA

From the middle range theory of caregiving dynamics, caregivers and their patients bring their past and present personal experiences to the fore and somehow shape their expectations about the future of their caring relationship (Williams, 2014:317). As explained in Chapter One (sub-section 1.2.1), the middle range theory of caregiving dynamics is founded on the premise that caregiving is a trajectory which evolves through the past and present experiences to include the reasons why HBCGs are involved in caregiving. Walters and Watts (2011:510) state that HBCGs' motivation and decision to become involved in caring for the sick may result from own personal experiences. This was found to be one of the reasons in this study in which Mpshe, Dineo and Xhathula cited personal experiences from their own families as the reason for them deciding to offer their services by caring for PLWHA.

Regarding personal experiences prompting **Mpshe** to care for PLWHA she stated: ""*For me it started when I was nursing my grandmother in 1998. So, it happened that she fell sick and there was no one to look after her and I was still in school by then. So, I could see her lying there feeling pain, wetting herself and there was no one who could look after her during the day. So, when I come back from school I was the one who would bath her and make sure that she remains clean. It happened that she passed on and after her death I developed this interest in the conditions of those people who are sick while in their homes… So, that is when I developed the skills to turn her around on my own because there was no one to help me...then told myself that I want to study nursing so that I can take care of the patients. And I wanted to be very different from other nurses that I used to meet because whenever I consult I would not get love, I would not get satisfaction at all whenever I consult. They would scold you, be impatient with you and not explain anything to you then when you leave the place you are more stressed...And my grandmother's condition traumatised me as well because I was worried and wanted her to recover so that I can also focus on my school work. So, I could see that these people do not provide a required service because sometimes I would take her for treatment and they would simply turn us away without any treatment*"*.

Dineo also shared how a personal experience led her to becoming an HBCG: *"I met the caregivers from this organisation when they visit us because my mother was sick. When they knock, I had to welcome them as I was excited for a change that would eventually leave my mother in a good health status. However, my mother was not willing to welcome them. She eventually opened up and allowed them to help her. That is when I taught myself about this illness until today"*.

Like Dineo, **Xhathula** also shared how the experience of a having a family member living with HIV led her to her to involvement in care work: *"The reason why I like to be a care worker is because we have HIV person and at home we didn't know for about 10 years. She didn't tell anyone. I was still at school, I think I was in Grade 11 or matric, we did find out when she gave birth as you know when you give birth babies are taken to the hospital. When we got there, she kept quiet. They were twins. I was holding one, she was holding another one and they said: 'you know that positive children are not supposed to be given water', and when the nurse comes to us I asked her if we lost or what, because we hearing her talking about positive people, what's happening? The nurse asked if she didn't tell us that she is positive and she said that one of the twins may be positive and when we ask our sister she asks "didn't you know?" We were shocked because I had a little information and my mom didn't know a thing, and then that's when I joined; I learnt how we have to treat her"*.

The role of the participants' personal experiences prompting them to become involved in caregiving is documented in the literature on HIV and AIDS caregivers (Thabethe, 2011:790; Akintola, 2005:10; Claxton-Oldfield et al. 2004:79; Ramirez-Valles & Brown, 2003:7). Akintola (2005:10), in his South African study explored the role of volunteers in mitigating the burden of HIV and AIDS in households and communities as HBCGs in Durban, KZN, South Africa. Some of his participants' involvement in caring for PLWHA were motivated by witnessing a family member dying an AIDS-related death and having a sick daughter. For Ramirez-Valles and Brown (2003:7), a research finding from their study focusing on the activities, motives, consequences and deterrents among Chicagoan Latino gay men in caring for PLWHA was the fact that they themselves had received assistance from

community volunteers in the past and they therefore believed that it was their turn to pay back to the community.

In the case of Claxton-Oldfield et al.'s (2004:79) Canadian study focusing on the motives for joining a palliative care volunteer programme, personal experiences as cited by the participants who were palliative caregivers was the fact that they felt guilty that one of their loved ones had passed on when they were not present. Therefore they deemed it necessary to honour their deceased family member through caregiving. In the case of Thabethe's (2011:790) South African research on the socio-economic context of care and women's perspectives on caregiving conducted amongst HBCGs of PLWHA in KZN, it was found that they were involved in caregiving because they were infected with HIV and AIDS themselves.

3.3.1.3   Sub-theme: Opening up a career path as their motivation to care for PLWHA

As noted by Williams (2014:313), the caregiving dyad is characterised by expectation management by both the HBCG and the patient as one of the principles that keeps the trajectory moving forward. In managing these expectations, both the HBCG and the patient engage in five dimensions namely, envisioning tomorrow, getting back to normal, taking one day at a time, gauging behaviour and reconciling treatment twists and turns (Williams, 2014:313). The idea of envisioning tomorrow may be intertwined in career-related reasons for getting involved in caregiving. Many HBCGs are temporarily or voluntarily engaged in caregiving. The motivation for this is to find permanent or better employment, opportunities to practise and implement skills acquired through previous training or voluntary work and an opportunity to fulfil their ambitions of becoming, for example: a nurse. Caring for PLWHA is for some HBCGs merely a journey and not the destination; rather an opportunity and the means to address career aspirations – envisioning a better tomorrow.

The responses of the participants on what motivated them to become involved in caring for PLWHA, allowed for this sub-theme on opening up a career path as motivation to care for PLWHA to be presented under four categories, to be presented next.

- **Having employment or advancing the prospects of a full-time employment as career-related reason for caring for PLWHA**

Unemployment forces people to look for employment everywhere. Some resort to taking any job whilst they are on the lookout for a better paid position. This was the case with Cassie, Mpshe, Letsatsi, Mamadee, Segwagwa, Vanessa, Viola, Nakedi and Zulu who cited their need for job as one of the reasons why they got involved in caring for PLWHA. Although the stipend was in this case inadequate to address all the their needs, the participants found it was better than having no income at all, as also mentioned by Schneider et al. (2008). Mpshe and Cassie's accounts made this clear:

Mpshe felt that sitting at home and do nothing was not a good idea for her: *"When I was at home, I then told myself that this is the time to stand up to go and look for work now, and I am going to look for a job where I initially wanted to work in (referring to the place in Pretoria). I just went out...I didn't know where* [the] *hospice is situated but I went straight there… It's a miracle for me. I then entered into the … hospice".* She mentioned that she was pregnant at the time, but still requested to speak to the manager who saw her and interviewed her – "*He was asking me questions like where do you come from? Why did you leave the old age home? I told him everything and he then said you are employed but you are going to start by volunteering and I said is fine".*

Cassie explained how her need to find employment led her to caregiving: *"I became a caregiver because I was desperate for a job after an organisation was opened in Soshanguve. I then became trained at this organisation and from there I had to go and work in the field. As I began to work, I then developed the love after being touched by the way people were sick. I then learnt to understand the patients".*

This need for having a job like caring for PLWHA to open up a career path resonates in the literature consulted (Zulu et al., 2014; Naidu et al., 2012:118; Wringe, et al., 2010:5; Akintola, 2008:121; Schneider et al., 2008; Claxton-Oldfield et al., 2004:81; Walt, Perera & Heggenhougen 1989; Clary et al. 1992). Scholars generally highlight the need for employment as one of the motives behind the HBCGs' venturing into

caring for PLWHA. In their Sri Lankan study aiming to understand the motivations of unpaid volunteers and the feasibility of relying on volunteers to support primary health care policies, Walt et al. (1989) found that sixty-nine per cent of their community health workers were involved in community health caregiving in the hope that it would lead to paid employment. Steinitz (2003:57) states that, in most instances when HBCGs quit their caregiving job, it is mainly because they had found full-time employment in an urban area.

For Wringe et al. (2010:5), HBCGs participate in a HBC programme because they view it as their stepping stone to formal employment. Both Akintola (2010:3) and Thabethe (2011:790) following up on their respective investigations into volunteers' motivations to volunteer in AIDS-related caregiving and the cost-effectiveness of community HBC, arrived at the conclusion that HBC-organisations train and equip their HBCGs with skills that could be useful in their search for employment in palliative care organisations, suggesting that some HBCGs may join a caring work organisation with the hope of acquiring some skills which would place them in a good position for future employment. Naidu et al. (2012:120) call these types of participants the "hopeful helpers" who decide to be involved in caregiving with the hope that it will ultimately lead to some gainful employment.

- **Previous training and voluntary work as HBCGs' career-related reasons for caring for PLWHA**

Some of the HBCGs cited their previous experience in caring as one of their reasons to care for PLWHA. The following quotes were extracted from transcripts of the interviews conducted with Letsatsi, Segwagwa, Vanessa and Viola who clearly expressed their previous involvement in caregiving either as a student or as a volunteer as the main reason for their involvement in caring:

Letsatsi referred to starting out as student studying for ancillary nursing and then eventually being employed as a care worker stated: *"I didn't know the place* [referring to Tintswalo HBC[32]]*, I came as a student doing practical and they saw how I was a*

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[32] Tintswalo HBC is an organisation from which Letsatsi was recruited.

hard worker and after completing with my practical they called me to come and be a reliever when their staff are on leave or when there are more patients…I was generally ready for everything".

Segwagwa started as a student and later became a volunteer*: "So I continued until I started to volunteer in emergency medical services until I got involved in a hospice. As we were busy volunteering at the ambulances, someone came and told us that she heard that* [Cherish[33]] *hospice is offering some training. By that time the Cherish hospice was still in X* [name of a suburb]*. Then we went there and attended that eight weeks' course and received some certificates…"*

Vanessa started volunteering at schools and then became a student in care work: "*I joined a group (by) volunteering at schools...and at the same time I got retrenched...and then I decided I needed to do something else…And then I went and did the care worker course, and then at time they put me in a hospice in Pretoria… And in there it came to the HIV/AIDS Unit… Nobody wanted to work in those two units, especially us that were students coming in just for practical. We were just like, no... Many people completely understood HIV/AIDS; I didn't at that time, I didn't. I still didn't understand all the dynamics, the medical dynamics of HIV and AIDS. I knew transmission, prevention…I was not totally educated about it. I wouldn't have done it any differently. I still would have worked with them".*

Viola also started volunteering initially for personal reasons: *"Caring for people, I'm HIV-positive and then when I look at other positive people, they struggle, they don't know information as I got information so I thought about being a volunteer to help people to understand what is HIV. Like somewhere somehow, I didn't get HIV like other people, I was raped in 2009 so somewhere somehow when you walk around people are criticizing you saying you are HIV-positive, that you sleep around with people, they don't know that HIV can affect you in different ways so that's why they say so. I started to volunteer and to teach other people that HIV doesn't affect you only by sleeping with many people, it can be transferred in many ways".*

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[33] Cherish hospice is the HBC organisation from which Segwagwa was recruited. This organisation also has the admission facility that enables it to serve as a hospice.

Nakedi told me about her experience which started some years ago, in 2011: *"I started working here in the year 2011 but before I could work here, I was a caregiver in a private hospital. I started from [Nana[34]] hospital and then to [Molodi[35]] hospital where I was also working as a caregiver and from there that is when I come here to do fieldwork"*.

Zulu who found her previous training as a HBCG had some years ago before she learnt she was HIV positive was coming back to her and she shared how the training she had had persuaded her to be involved in caregiving: *"I trained for the home-based care in 1998. I don't regret my decision to join this organisation. I can also provide counselling for myself about my patients"*.

The participants' narrations in relation to their previous involvement in caregiving as one of the reasons for caring for PLWHA mirrored Akintola's (2010) findings through his category, "putting one's skills and competences to good use". In it some of his participants who were previously involved in caring for someone, realised the importance of continuing to put their experience into practice to the benefit of others. In another South African study that describes the characteristics of volunteers who remained active in the HBC projects among HBCGs caring for PLWHA in Tzaneen, Limpopo, Marincowitz et al. (2004) report that most of the HBCGs were previously involved in other health-related voluntary work. Their main reason to return to HBC was their need to contribute their acquired skills and training in caring for the PLWHA.

Similarly, Zulu et al. (2014) found in their Zambian study focusing on the motivation to become community health assistant (CHA) to work in rural districts was that most of their participants reported one of the motivations for them to apply for ta caregiving job was their previous training in psychosocial counselling, community mobilisation, testing for malaria and HIV/AIDS peer-education. This was also found among the volunteers who took part in a Canadian study of the motivation for palliative care volunteers conducted by Claxton-Oldfield et al. (2004:80). In the latter

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[34] Pseudonym substituted the hospital name to ensure anonymity of the participant is secured.

[35] Pseudonym substituted the hospital to name ensure anonymity of the participant is secured.

case, participants reported that they became involved in caregiving because they deemed it imperative for them to contribute using the training they had received. This category focused on the topic of "Previous training and voluntary work as HBCGs' career-related reasons for caring for PLWHA", ties in with Williams' (2014) assertion that the caregiver-care-recipient dyad is influenced by past caregiving experiences. In this case, previous training received and voluntary work engaged in by the HBCGs were their motives.

- **The need to become a nurse as a HBCG's career-related motivation for caring for PLWHA**

Ching reported that she aspired to become a nurse and believed that caring for PLWHA would bring her closer to her dream and mentioned this as her motive behind caregiving: *"I like working with people and it has been my dream to be a nurse from my childhood. That is why I am a care worker and I like to change people's lives like many people outside they don't have information about their health, when they sick they don't do a thing about it, like if I'm not working here they won't listen to me when I'm trying to give them some information because they don't take me serious so when I'm working here is when I can change people's lives, I can be free to talk to them"*.

What Ching expressed is confirmed in the literature. In a Canadian study of the motivation for palliative care volunteers to take part in the volunteer programme conducted by Claxton-Oldfield et al. (2004:79) one of the twenty-two reasons cited by the participants (palliative care volunteers) to get involved in voluntary palliative care was that they wanted to work in the medical field, though they did not specify the field. For Akintola's (2010:6) South African study of AIDS volunteers' motivations to care for PLWHA in KZN, participants got involved in caregiving to "stay true to their dreams" of being a nurse.

3.3.2 THEME TWO: HBCGS' WORK-RELATED CHALLENGES IN CARING FOR PLWHA

Looking through the lens of the strength-based perspective at the difficulties encountered by the HBCGs in their care work, and how they manage the difficulties and challenges encountered (described further on) the resemblance of what Saleebey (2013:9) calls "the heroism of everyday is apparent. Supporting caregivers to cope within the caregiver-receiver dyad and manage the work-related challenges being introduced under this theme, Williams (2014:318), in her middle range theory of caregiving dynamics mentions five ways of providing role support (see Chapter One: sub-section 1.2.1) as enabler for caregivers to cope within the caregiving dyad. The ways of supporting entail the following:

- providing competent, compassionate care to the caregivers for the benefit and utilisation by the patient
- providing support for caregivers in their other responsibilities like relatives who would, for example, take the responsibility for providing for the basic needs of the patient
- assist with establishing a convoy of support such as community members, relatives of the patients and fellow caregivers and other professionals to assist them in their caregiving duties
- provide the necessary financial and other resources and/or supplies to enable them to execute their care duties and ensure that the patient adheres to their prescribed treatment
- avail a wealth of helpful information, or a well of information from which the caregiver can draw to assist them in the caregiving-receiver dyad

In the ensuing discussion, the work-related challenges in caring for PLWHA as shared by the participants will be presented.

3.3.2.1   Sub-theme: HBCGs' experiences in relation to the challenge of negative attitudes held by some community members

Community members' negative attitudes towards the HBCGs and their HIV and AIDS care work created many challenges to HBCGs as exemplified in the following discussed categories.

- **HBCGs' challenges with some community members who think caregivers are also HIV-positive – a misconception**

Walking through the communities when they visit their patients in their respective households is not an easy exercise for HBCGs. As mentioned by Mokete, Jini, Vanessa, Yena, Viola, Dineo, Lenong, Lenyalo, Xhathula, Zulu, Ching, and Mamadee, community members generally believe that the HBCGs are also infected with HI-Virus and some did not even want to be associated with the HBCGs. This category and the challenges the HBCGs experienced in their community as reflected in the following participants' accounts are presented.

Mokete pointed to this challenge along the following lines: *"What is difficult is being associated with them* [referring to the PLWHA]. *Like as you interact with PLWHA, people tend to think that you are somehow affects you directly and you cannot do this job unless you are also HIV-positive. That is why you find even people who did not disclose their status, when you walk equally with them, they tend to remain behind because they tend to say, let not people see me walking with this person because if they see me I am going to be associated because he is working with PLWHA".*

Jini stated: "*I do this work, and the moment you do this kind of work, they would think that you are also sick. Yes, there are those who are sick but they tend to believe that everybody who does this kind of work is sick. They would say we help these patients because we are also sick. And this is wrong. So, those are some of the things that make some of the caregivers to be hurt".*

Vanessa's experience is similar: *"…they assume … because you choose to do this work, they believe you are infected…"*

Yena mentioned that: *"When people see us in blue and white uniform they think we have AIDS, we always experiencing that kind of stigma and discrimination"*.

Viola emphasised the misperceptions held by the community as her main challenges: *"Most of the challenges I meet is when we visit people to their homes, they think all of us are HIV-positive even when we at work people think that people working in NGO are positive so when you knock they say 'we are fine, we don't want to talk about AIDS'…maybe they think we are all positive because when you enter their crib they say 'no we do not have AIDS'…well some gentlemen were gathered there we were trying to teach them about HIV and TB, when we approach them they started to say, 'no we do not have AIDS' so even other people when seeing us entering in one house they say there is someone who is HIV-positive at that particular house and we don't work only with people having HIV/AIDS"*.

Lenong very vocally stated: *"They diagnose us through the families. When we go to the families to care for the sick then they just think, they think these people are caring for the sick patients diagnosed with HIV, it means they are also diagnosed because all what we do is to bath the patient but we use precautions. But as we use precautions, but as we use precautions they say, 'why they use gloves? Why must they? Because they are the same diagnosis'… we get stigmatised…they just say it and they don't have a proof"*. Later on, in the interview she again said: *"they say she has been bathing patients for sixteen years… she might be HIV, she might be full-blown even because she is now a carer she might be a good complier (*referring to treatment*). This is stories that they tell even to the friends"*.

Lenyalo mentioned how her being slim and the fact that she is caring for a PLWHA is misconstrued by some members of the community: *"As you see my body is so small, people would say there is no way that this person can work with people living with HIV and AIDS if she is not sick herself; she also has AIDS that is why she is working with people living with HIV and AIDS. Or when they see you coming to the*

hospice, they would say it means she also has AIDS. At times is boring because you don't know how to explain to this person that it does not mean that you have AIDS".

Xhathula explained this misconception fuelled community members' negative attitudes to the HBCGs caring for PLWHA along the following lines: *"…some people say care workers are HIV-positive... It's the thing that we hear when we passing by as you know people they will talk but will not tell you face-to-face it's what they think... people do not believe that a young person can care for person with HIV, they say you help them because you are positive as well".*

Zulu recounted*: "They think that I am HIV-positive too. Community members have a way of spreading the news. Gossipmongers spread the news and there is no way of running away from it".*

In a South African study on the experiences of social support by HBCGs caring for PLWHA by Fynn (2011:122) in KZN, HBCGs reported that they could not trust the community members because they laugh at them, ridiculed them and even believed that they also have AIDS. This is an indication of the stigma by association that HBCGs endure that is not due to a HIV-positive status, rather to their association with PLWHA (Haber, Roby and High-George, 2011:541; Van Dyk (2010:412; Bennett, Ross & Sunderland, 1996:145). The problem with being stigmatised is that it may discourage HBCGs to approach the community members openly and transmit important information on HIV and AIDS issues which can destroy their commitment and morale. In their exploratory South African study focusing on stigmatisation of HIV and AIDS health care workers based on their association with PLWHA, for example, Haber et al. (2011:541) found that a stigma is in a form of labelling that results in status loss and discrimination forcing some HBCGs to leave AIDS work altogether.

Contrary to what my participants reported, HBCGs who care for PLWHA in Casale et al.'s (2008:4) exploratory study conducted in South Africa, outside Durban reports that instead of negativity, they received support from members of the community which gave them hope and courage. This study explored how personal experiences of support for caregivers influence their health positively.

- **HBCGs' challenges with some community members who are afraid of stigma**

Another challenge Cassie, Malume, Kgomo, Selinah, Lenong, Vanessa and Paul encountered was that as they walk around the communities, they come across some of the members who were afraid because some other HBCGs stigmatise them for being PLWHA.

Cassie explained: *"...people are afraid that we may abuse them or we may laugh at them because this is a cursed disease. It came in a form of curse. Even though it is an illness, when it arrives it was mistakenly associated with sex. So, it means your sexual life was not right and is not everyone who is sick due to the wrong sexual lives. So, people start hiding themselves because they are scared that people will start judging them once they realise that they are sick…They are afraid that so and so knows me and will end up telling people about my status, so they will not be open to tell you that they are sick."*

Malume's take on this was the following: *"There are those who have even given us some names. They would say, 'when you see this people you must know that there is HIV/AIDS somewhere'. So, people* [referring to members of the community] *are afraid to even call us for help because they know that once we come the people will know that they have someone who is living with HIV/AIDS".*

Kgomo gave a detailed account of one of the community members who shied away from her because of fear of being stigmatised: *"Another woman who once called me and said, there were some people from Johannesburg who were moving around the community testing people for their HIV status and she was tested positive. And she called me to come and tell her how does an HIV-positive person feel like and how does she look like. I then asked her if she went to the clinic to test after she was told such news and she said no, then I asked her if I can make an appointment for a HIV test because that is the only way that you can know your status. We then agreed but later on when we were supposed to go she gave me some excuses and eventually said, those people who tested her are crazy as she is fine she is not sick… I think she feared what people would say about her, more especially because she was an*

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older woman. She feared what people would say about her as I always make turns at her house. People don't feel comfortable when our car make turns at their respective houses. They say, the moment I agree that you can come and help me you would start coming with the car here and people would then begin to realise that something is not well in this house. That is what they are telling us".

Attesting to this general fear of being stigmatised was **Lenong** who shared her experiences of the reaction she gets from community members when she is travelling with her marked organisation's vehicle: *"…it happens once you stop the car, then you getting in, especially if you want the address* [and ask] *is this address 1281* [and they say] "No, *no, no!, you are working with those people with HIV, please don't park next to our gate, we don't have an HIV-positive person in here. They just say before you even ask. I have met them...there were those common families that could say no, no, no, no, no, don't enter. Then… you just turn and back* (off)". Later Lenong further elaborated when stating*: "if they see Cherish[36] vehicles* [the name of her HBC organisation] *they think of nothing but death. She just thinks that now I am in a death sentence. This car means that now I am in a late stage. It means if am gonna be cared by these people it means I am gonna be taken to their hospice where people die"*.

Vanessa painted the following word picture of how members in the community suffer in silence because of the fear of being stigmatised: *"… most of the time the stigma doesn't allow us to go out there and look for counselling for the entire family…* [as a result] *… that person will die quietly; they'll say it was cancer or something that's happened. Then at the end of the day we* [referring to the family members] *are so negative about the disease that we don't have enough information … So, my thinking of negativity is ignorance, stigma, non-disclosure, becoming a burden, or maybe being the breadwinner, or maybe leaving children orphaned. In this community, I found many aspects of why people become negative towards us working in the field. Sometimes just hearing they were HIV…"*.

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[36] Cherish HBC is a HBC organisation from which Lenong was recruited.

Paul referred to the challenge experienced as follows: *"I think sometimes the fear of stigma is so bad that up to today, I am staying in a block of flats with fifty-four flats not of one of them even if I put a notice on my door will approach me directly and say, I am HIV-positive. I think they are just scared to come to my front door that other people will see that they approached me. I have met some of them at the clinics but where I stay, they don't want to be associated because of the stigma, yeah"*.

Ideally the role of the HBCG is to relieve the family from the burden of care by supporting and teaching them relevant skills to care and support the patient. This, according to Akintola (2005:15), is however, not the case in practice given the nature of the stigma and discrimination shown towards PLWHA, from the side of the community. This results in household members detaching themselves from the patients and therefore compelling the HBCG to assume the full role of a primary HBCG to the patient because of their fear of stigma from the community. For Waithera (2011), "stigma" is a powerful tool that is used to marginalise, exclude and exercise power over individuals who have features that appear to be like the effects of HIV and AIDS.

Stigma can rightfully be regarded as a powerful and discrediting social label that radically changes the way individuals view themselves and are viewed as persons (Goffman, 1963; Link & Phelan, 2001; Petros, Airhihenbuwa, Simbayi, Ramlagan, & Brown, 2006; Visser, Makin, Vandormael, Sikkema, & Forsyth, 2009). This means that people become rejected, discriminated, avoided and labelled because of the association with HIV and AIDS that they believe has been acquired from some immoral acts. In a Kenyan study of a community's attitude towards HBCG for PLWHA, Olenja (1999) found that some of the participants believed that the community is not obliged to sympathise with PLWHA because they were believed to be promiscuous. PLWHA in this situation found themselves not wanted in their own communities. Similarly, Campbell, Nair, Maimane and Sibiya (2008:510) revealed in their South African study that focused on factors most likely to facilitate or hinder mobilisation of community resources that HBCGs caring for PLWHA and their patients felt isolated and rejected by their community, resulting in both, the HBCG and their patients, battling without emotional support.

In his classic book entitled, "Stigma, notes on management of identity", Goffman (1963) describes a stigmatised person as someone who is "not quite human" and whose life chances are reduced due to some form or immoral acts. Such a person is perceived and treated in a derogatory manner and may even be rejected, discriminated isolated or even labelled because of their condition. In preventing and managing exposure to stigma, rejection, discrimination, isolation or even labelling, the stigmatised person or the person who is vulnerable to being stigmatised resorts to isolating himself from others (Salmen, Hickey, Fiorella, Omollo, Ouma, Zoughbie, Salmen, Magerenge, Tessler, Campbell, Geng, Ghandi, Bukusi & Cohen, 2015:333). Others may in turn internalise perceptions and beliefs held by the stigmatisers by also believing that they do not deserve to be perceived and treated with dignity like any other person and therefore begin to reduce themselves into tainted human beings (Greeff, Phetlhu, Makoae, Dlamini, Holzemer, Naidoo, Kohi, Uys & Chirwa, 2008). The person may then begin to dissociate himself from the general public and spend most of the time alone.

Stigma can also be tribal in form (Goffman, 1963), with people who are associated with PLWHA also receiving some form of stigma due to their association with PLWHA. It is therefore not surprising to find family members of PLWHA and communities where they reside frowning on any situation that has to with HIV and AIDS. This would include a family or community member living with HIV and AIDS, the HBCGs who care for PLWHA, or generally anything that has to do with HIV and AIDS and HBCGs, that would expose them to related to being stigmatised. The main concerns for the person who fears stigma is to avoid anything that can lead to it. This person may go as far as to compromise his own health and well-being or that of a loved one or a community member as long as the stigmatising situation can be avoided. It is therefore not surprising for members of the community to shy away from family members of PLWHA who, in turn, shy away from their own family member or even the HBCGs who are caring for such a patient (Goffman's 1963; Ogunmefun, Gilbert & Schatz, 2011).

As described by Kasimbazi and Sliep (2011), stigma results in HBCGs and their patients becoming isolated from the community at large and battling without community support. It is therefore not surprising that HBCGs, as the storylines

revealed, find community members ignoring them and leaving them isolated. It is mainly because they cannot afford to live their lives in isolation. The existence of stigma within the communities has been noticed by Steinitz (2003) who recommends that HBC services should have an inclusive approach and services offered to everyone in need not just to PLWHA. This Steinitz (2003) believes will minimise the fear of stigma as everybody will know that HBCGs are working with everybody, not only PLWHA.

- **HBCGs' challenges with some community members who deny or do not accept their HIV-positive status**

Amelia and Xhathula's accounts illustrate this challenge that is presented as a category:

"Sometimes, we come across people who do not want to accept their status. When the person falls ill at a later stage, it is the only time that they decide to seek medical attention" **[Amelia]**.

"There are some people who are positive, like if HIV was transmitted through sharing a same plate we would be infected because they like to leave things everywhere and also are ignorant it seems like they take a blame of being HIV+ and then they want to spread it to everyone and that's what I hate the most like there are those who have not accepted yet so they want to infect all" [**Xhathula**].

It is crucial for HIV-infected patients to come to terms with their HIV-positive status before they begin treatment (Duckert & Vaagte, 2011:51). This is, however, not always the case as some patients battle with denial until their condition deteriorates. What my participants reported is supported by the findings from the Tanzanian study by Lyimo, Sutterheim, Hospers, de Glee, Van der Ven and de Bruin (2014:98). They found in their study of the interrelationship between stigma, disclosure, coping and medication adherence that denial was one of the contributing factors for non-adherence to ART.

In terms of the coping theory which was adopted as one of the theories through which the phenomenon under investigation could be understood, denial is some form of emotion-focused coping mechanism adopted for coping with a stressful encounter (Ben-Zur, Breznitz, Wardi & Berzon (2000:160). As indicated earlier (see sub-section 1.2.2), the individual who is confronted with stress, in this case the HIV-positive diagnosis along with the deteriorating health condition, will resort to an appraisal which would then enable the person to change the personal meaning of the stressful event. Through denial, the meaning of an incurable HIV-positive diagnosis along with the AIDS symptoms may for instance simply be interpreted as witchcraft. It is therefore not surprising for my participants to highlight denial as one of their challenges. As observed by Lawson, Gardezi, Calzavara, Husbands, Myers & Tharao (2008:9), denial and stigma discourages people from HIV and AIDS testing and receiving care and treatment. Although my participants could not highlight any gender dynamics in relation to denial, Lawson et al. (2008:26) found in their study of HIV and AIDS stigma, denial, fear and discrimination in Toronto among PLWHA that men were more likely to be in denial than their women counterparts due to their belief that men are not supposed to seek any help even if they are in pain.

- **HBCGs' challenges with some non-welcoming and judgmental members of the community**

Walking through the communities was reported to be one of the challenging activities for HBCGs who took part in this study. Nakedi, Ching, Paul, Dineo, Selinah, Lenyalo, Mokete and Pekwa referred to the non-welcoming and judgmental attitudes displayed by members of their communities as one of the challenges through which they had to go.

Nakedi shared the following: *"Actually they* [referring to the members of the community] *do not like us. Especially after we arrived here. I am not sure whether they think we are the ones who brought AIDS here. So, whenever they see us they see AIDS walking on the street...when you conduct your visits you would come across them especially when they are in group. Let us say is a group of boys or these women who play some cards under a tree at a family where you are supposed to go in. As you enter they would begin laughing while you are still at the gate. Yeah,*

and you could see that they are not laughing at what they are busy with, they are laughing at you. And even as you get closer to them and begin to introduce yourself, they would continue to laugh and ask funny questions".

Ching spoke about the community's non-welcoming attitude towards the HBCGs along the following lines: *"Some people not only the patients when they see us they don't want us, they don't like us they think we brought bad news to them"*.

Dineo was particularly frank when sharing her experiences about her visit to the patients in the community: *"There are those who would welcome us and who even like our job. Some as you enter they would increase the volumes on the music and TVs; they won't even give you chairs nor welcome you. They would say 'Your person is not here'. Some patients end up being stubborn as well due to the family's attitudes towards us. As the family, would make statements like 'these people who come here every day are embarrassing us because of you'. Sometimes they would tell him/her 'either you go out and look for your own stands* [place to stay] *because you are here, they come here, and even the neighbours can see them coming here'. So, the patient will in turn be stubborn towards us"*.

Selinah pointed to the non-welcoming attitude of members in the community by way of being called names: *"And when we go out for field work, there is a name that we are called with called 'boMmamakaka'* [those who wipe faeces]. *When you enter in the household, you find that is only few people who would take you serious"*

Ideally the health and well-being of the communities are likely to be enhanced if members of the community are cooperating with HBCGs and remain highly involved in lobbying for the interests of PLWHA to influence policy development (Campbell, Foulis, Maimane & Sibiya, 2005:808; Ramirez-Valles & Brown, 2003:2). This may be through the skills transfer, in which HBCGs transfer their caring skills to ordinary members of the community. Given the expressions made by the above-quoted participants, it is clear that my findings are contrary to this general assumption.

In turning to literature related to this challenge experienced by HBCGs around the non-welcoming and judgmental members of the community, Takasugi and Lee (2012:843) found in their Kenyan study aiming to ascertain the motivational drivers of CHCWs that the support and recognition received by HBCGs from their community was incentive for the HBCGs. Zulu et al. (2014) in their Zambian study focusing on the motivation for CHAs' experiences of working in rural districts found that health care assistants were welcome and free to sit and talk to the members of their community, it made them to feel excited about their work.

Based on the accounts from their participants (twenty-five nurses and forty guardians of children living with HIV and AIDS) in Zimbabwe, Campbell et al. (2012:127) reveal in their study aiming to explore the social facilitators of child ART adherence that some of their participants reported that members of the community and the church did not really support the HBCG's work. This could be explained as due to the stigma being perpetuated in a form of gossip that deterred some of the members from disclosing their HIV-positive status. Similar accounts are shared by the participants in my study. Akintola's (2005:13) South African study focusing on the role of volunteers in mitigating the burden of HIV and AIDS care in households and communities among HBCGs in KZN found that community members believed that HBCGs were irresponsible because they leave their own children to care for other people without any payment. Some HBCGs were even called "fools" while volunteering work was often called "nonsense" by some members of the community (Akintola, 2005:13). The impact of the negative attitudes held by members of the community (as shared by the participants in my study) has also not gone without recognition by researchers such as Campbell et al. (2008:510). They report that patients find it difficult to disclose even to their HBCGs because of the non-welcoming and judgmental attitudes which are generally held by members of the community.

- **HBCGs' challenges with some members of the community who reject, ignore or avoid them**

In latching on to the previous category, Lenyalo, Mokete, Paul and Pekwa experienced that, despite being there to relieve relatives and members of the community of the burden they carry, for their own patients, they are still often rejected, ignore or even avoided – people do not want to be associated with them.

Lenyalo spoke of outright rejection by members of the patient's family: *"You find those who would reject you the moment you knock at their door. They would say 'your HIV-people are going to irritate us; we do not have sick people here, things like that'. They will call you names such as 'these ones who clean people's faeces', we do not want them here".*

Mokete, along the following lines, spoke of being ignored some of the community members: *"…they tend to ignore you. There are some other things I realised lately because people want you when they have problems. When they do not have problems, they keep themselves far away from you… The reason why I say people distance themselves is that you will find them walking very far from you and they will come to you sneaking for help … They come to you because they feel that the problem is getting too heavy for them. So, when they do not have some problems, they will come and have some negative words about you. That is why even now they are addressing HIV as KFC* (Kentucky Fried Chicken) [A derogatory term used by the locals to refer to HIV and AIDS] *because of amagama'mathathu* [A derogatory name referring HIV and AIDS]. *So, when they see us walking they would say, these ones are working for KFC* (implying that they are working with PLWHA)".

Paul shared how some people did not want to associate themselves with him for the fact that he was a HBCG caring for PLWHA: *"But I think there are few people there* [referring to the church he is attending] *that do not want to be associated with HIV-positive people that just don't talk to me. And I would have a table with HIV-pamphlets during the World AIDS-day and church goers will just pass there without even picking up a pamphlet on HIV…I think they don't want to be associated with someone with HIV. There is lots of stigma still and discrimination. And I think another*

thing is that people think they know the facts about HIV … but my bad experience is that if you really talk to them, they are getting infected and they know nothing about HIV".

Pekwa also admitted that members in the community did not want to associate themselves with her and avoiding her: *"Okay there is a funeral or wedding. You come in on Friday and the family have given some women from the neighbourhood some vegetables to prepare for the wedding or funeral, you arrive there late and find that they were talking about you and your work. So, the moment you take a cabbage and try to assist in peeling, people will mumble and go as far as to ask...all of those who were with you in a group to join their groups. So, you will eventually find yourself peeling the whole bag alone...I think is because they are still disgusted by people who are living with HIV and our patients in general".*

These accounts shared by the participants corroborates with the findings from Kasimbazi and Sliep's (2011:104) South African study of unpaid volunteers and perceived obstacles in ensuring care and support for PLWHA conducted in KZN which found that community members were shying away from joining the HBCGs in their work due to fear of contracting HIV and AIDS through other modes of infection. The same study reported that tension between the community workers and the HBCGs prevailed; with the former suspecting that the latter may be paid salaried work and therefore did not deserve to be supported in the work because they are being paid for it.

In another South African study of the experiences of social support by HBCGs caring for PLWHA conducted among HBCGs caring for PLWHA by Fynn (2011:116-117) in Ethekwini Municipality of KZN, it was found that the HBCGs felt neglected and isolated by both the government and the community members. One participant from this study (Fynn, 2011) shared her experiences of a household which exploited her and when she tried to report such a household to the community meeting, no measures were taken to support her, resulting in HBCGs deciding to remain quiet and suffer the exploitation in silence. In addition, the participants in Fynn's (2011:117) study reported that fellow community members would refuse to even assist them to voluntarily transport the patients to the health care centres. They

would agree to do so, on the condition of payment, a situation which in turn would force the HBCGs to borrow money for this purpose which they then had to repay out of their own pockets (Fynn, 2011:117). Six of the ten HBCGs in Fynn's (2011:122) study reported that they did not receive any support from the community and that members of the community were mocking and frowning upon their work. This treatment in turn made the HBCGs to believe that community members were uncaring and spiteful.

- **HBCGs' challenges with some community members who think their work in useless and beneath them**

Another challenge Dineo, Ching, Mokete, Pekwa and Lenyalo highlighted, specifically, was the fact that some of the community members did not take their care work seriously and believed care work is useless and of a lower standard.

Dineo referred to this challenge along the following lines*: "I think they think that the kind of job that I am doing is useless. Some still think that we work only with HIV and they are sick and they do not want to seek help from us because people will recognise that they are infected".*

Ching stated: *"Those who do not treat us well when we greet them they do not respond; according to them we are useless".*

Mokete also shared that in the eyes of the community doing care work is a useless job when stating: *"I am doing another job that is why even people don't want this thing* (referring to care work). *That is why you find that in most cases you will find that some other people end up saying if you do this kind of job some people think that is just an odd job which is useless in most cases".*

Mamadee proclaimed that she felt undermined by people because of doing care work: *"What I do not like is the way people look at me. Some undermines me. They would say Oh, she is working there…Maybe is because I am not getting enough salary, I am not driving a car and you are always on feet. Others would just look at the way you dress and say she is working for free there".*

Pekwa shared how others look down on her as a HBCG: *"I think they think that the kind of work that I am doing is not work at all. I think they undermine this kind of job. I used to hear them passing remarks such as, 'even if I can be poor, I will never do this kind of work of bathing patients and doing all this sort of things'...I once heard people saying, 'you see where Pekwa is working, they bath HIV-positive people and remove the nappies, so you would never know whether when they do that they put on some gloves or not'. So, I ended up even observing this thing when we are in the neighbourhood where as women we normally gather together in preparing for weddings and funerals, when I try to assist in peeling some vegetables, people do not feel comfortable".*

Lenyalo spoke about how some of the members of the community undermined her and thought she was from a very poor background which forced her to involved in caregiving: *"What I don't like mostly is being undermined by people, for someone to think that I am doing this job because I do not have a choice … When you work with PLWHA people tend to think that you are deep in poverty and that is why you are a caregiver…You will find that as you walk on the street to the patients' houses, people tend to think that you do not have a job and you therefore decided to wipe off the patients in the community. They do not respect us and they do not see any goodness of what we are doing. They will even end up calling you for unnecessary things like taking care of their grandparents in your spare time and end up not paying you"*

This challenge of being undermined by members of the community experienced by the participants in my study resonates with the participants (CHAs) who took part in Zulu et al.'s (2014:12) Zambian study that documented the motivations of CHA working in rural districts. They reported that they were undermined by community leaders. These leaders refused to mobilise people for meetings when the CHAs asked them to do so. The same challenge was noted by Campbell and Foulis (2004:8) who believe that this challenge is a result of the stigmatisation of PLWHA by members of the community. Zulu et al. (2014) postulate that the lack of confidence on part of the members of the community towards the HBCGs can be attributed to the CHAs' role hierarchy in the main health services network. In other words, the limited work that HBCGs do along with lack of sufficient equipment to fully perform all their health-related activities place them at risk of being undermined by

the members of the community. In further confirming the challenge experienced by the participant in my study, an example is quoted from Akintola's (2005:13) South African study of the role of volunteers in mitigating the burden of HIV and AIDS care in households and communities in KZN. One of his participants reported that her neighbour undermined her work to such an extent that even when she approached her for assistance, with a request for sugar, she would pass remarks and say, 'she is a good Samaritan who help others instead of looking for a job'.

- **HBCGs' challenges with some community members who spread rumours**

Gossiping and spreading rumours about PLWHA and their loved ones, was a challenge mentioned by **Amelia** when stating: *"We know that the community does not warm towards the* [Tsatsawani[37]] *vehicle. Even when we give someone a lift in the* [Tsatsawani] *car, people jump to conclusions. They spread rumours about the people they saw in that car. When they see, us wearing our uniform and going in someone's home, they spread rumours that there is an HIV-patient in that home…* [even] *sometimes we go into homes just to share information with people. That's the nature of some communities".*

Amelia's challenges are confirmed in the literature consulted (Koto & Maharaj, 2016:57; Campbell et al., 2008; De Klerk, 2011:158). In their Lesotho study, which focused on the difficulties faced by health care workers in the area of AIDS in Maseru, Koto and Maharaj (2016:57) state that gossip and rumours among the community members does not spare even the health care workers. In another South African study that considered support of PLWHA and their HBCGs in Entabeni, KZN, Campbell et al. (2008:511) reveal that while some participants shared stories of gossip and rejection, others mentioned that not all members of the community engage in gossiping and spreading rumours. They spoke of gestures of support from members in the community – i.e. sharing food with the PLWHA and their families.

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[37] Tsatsawani is an organisation from which Amelia was recruited.

- **HBCGs' challenges with some community members who do not want to listen to their information on HIV and TB**

Kgomo, referred to this challenge when pointing out that as she walks through the communities to share information on HIV and AIDS prevention, TB and other health-related issues, she would come across members who would simply demonstrate lack of interest in what she had to share. She shared the following in this regard: *"Some especially those who do not think they would have HIV, do not want to be told about HIV and AIDS. Even a mere TB, they do not want to hear anything about those diseases. So, people do not want us next to them because they know we are going to tell them about HIV and AIDS. Even if you are there to screen TB, they would say they are fine they don't want to be screened. So, as we do the door to door campaigns we do find patients who were not aware that we are there to help them. So, people don't understand especially with HIV and AIDS …believe that is better to live with that disease that you do not know"*.

This challenge mentioned by Kgomo was also mentioned by the participants in Hlengwa's (2011:77) South African study of perceived stress factors and social capital among volunteer HBCGs of PLWHA, conducted in thirteen semi-rural communities outside Durban, KZN. In this study, HBCGs in reported that no one in their surroundings wanted to talk about HIV and TB. This contrasts with the findings of Chimwaza and Watkins' (2004) in their Malawian investigation on the perceptions held by caregivers caring for PLWHA on providing care to people with AIDS symptoms among caregivers of patients with symptoms of AIDS. It reports that in Malawi there is generally some open discussions around HIV and AIDS which goes as far as to name those who may be infected and affected. TB was found to have been spoken about a lot and some people were of the view that they have been over informed to the extent that they were even bored by HBCGs who always preach the concept of HIV and AIDS and TB (Chimwaza & Watkins, 2004).

In view of the participants' utterances in this sub-theme, it seems apparent that the members of communities in which they were working hindered the establishment of support facilities as means to help caregivers in their caregiving-recipient dyad as suggested in the middle range theory of caregiving dynamics (Williams, 2014:381).

3.3.2.2 Sub-theme: HBCGs' patients-related challenges experienced

Among the challenges that emerged during the HBCGs' caring process were those that were closely related or linked to their relationship with their patients. These included the sudden moodiness of the patients, the patients' failure to comply to the treatment as prescribed, the patient's hopelessness, older patients or males who would not want to be cared by young or female HBCGs, and patients who are HIV-positive and yet battle with drugs and substance abuse. These will now be presented as categories.

- **HBCGs' challenges with moody patients**

One of the challenges amongst many mentioned by Viola, Wendy, Mokete, Letsatsi, and Xhathula, specifically during their interaction with the patients was the general moodiness of some of the patients.

Viola spoke about the patients' moodiness and referred to the challenge she had with one of her patient due to this: *"Their moods because they are always moody…You can't understand them, especially after taking their medication they become moody".* When asked to give an example of this Viola said: *"I was greeting her in the morning and she was so moody she didn't respond…maybe the time she looked at her medication she started to think her things or what I don't know".*

Wendy during various times in the interview with her referred to the patients' moodiness: *"But sometimes when we try to speak to the patient she doesn't respond and when we took a break maybe waiting for the water to be hot so that we can give her a bath, she shout at us saying 'why are you sitting there, get in here and do you work' such things…and say 'when you are here you came for me, come inside and leave those people'"* She added: *"They are impatient like sometimes they don't want to be helped by people from around, they want people from outside"* She later on admitted: *"What I dislike is their moods, them being impatient, sometimes a patient with HIV/AIDS can harass you… Sometimes it's because they have not accepted their status, so sometimes they think about the disease and the treatment, maybe*

the treatment haven't start to work, so those things create stress to the patient who just found out about the disease"..

Mokete interprets the patients' silence as moodiness and shared the following in this regard: *"…like for example when you are out to somewhere when people call you because there is someone who is sick in the house and they need you to provide services. Sometimes you get there and find that a person is quiet. Even if you try to ask questions she/he will remain mum like a deaf and you would even ask yourself, 'how could a person do that whilst you are there to help him/her?' You will begin to ask yourself whether he does not take you serious and when you ask in the house what is wrong with the patient, they will tell you that the person is normal and he used to talk and they do not understand why he is not talking all of the sudden"*.

Letsatsi, who also encountered moodiness as a challenge amongst her patients, shared with me how she dealt with such challenges: *"I can say there are a lot of challenges because the patients … are not always mentally stable…* [They have] *attitudes. Sometimes before you can talk to them you must observe them before you start any interaction with them… and if you realise that he/she is not in a good mood you can go and talk nicely to him/her and build relationship before you can try to help her"*.

Xhathula relayed the following incident around a patient's' mood swings: *"There was a time when we went to see this other guy and he was ignorant but you could notice that it is mood swing moment because he was rude. Sometimes his family members come to us saying he does not want to eat; does not want to take his medication. That guy used to insult us when we walk in through the gates, closes the door and bars it"*.

What these participants highlighted supports on of the findings in Valjee and Van Dyk's (2014:5) study. Some HBCGs who took part in their study focused on the impact of caring for PLWHA on the psychosocial well-being of palliative caregivers in KZN reported that patients would scream at them for unknown reasons. The moodiness of PLWHA can manifest in outbursts of aggression which can explain that

patients abuse the HBCGs (Cataldo et al. 2015:7; Guerra Demain, Figueiredo and De Sousa, 2012:71).

The patients' moodiness, according to Miller, Bishop, Herman and Stein (2007:209), affects both the HBCG and the patient. A burden is placed on the former and lead to HBCG depression. As far as the patient is concerned, it may also result in depression and physical impairment.

- **HBCGs' challenges with patients' non-compliance with treatment**

Nakedi, Lenong, Lenyalo, Vanessa, Martin, Zulu, Pekwa, Kgomo, Amelia, Malume, Segwagwa and Martin were the participants who highlighted the challenge about patients who did not comply with their prescribed treatment despite being supported. A few of the participants' direct words will be quoted to amplify and encapsulate the breadth and depth of the challenge mentioned:

Nakedi did not only spoke about non-compliance, but also provided a glimpse into the reason for patients' not compliance*: "You will find that they think* [once the treatment starts to take effect] *they are healed and leave the treatment. We would be surprised when a wife comes to report that you are no longer going to work [meaning that the patient has now relapsed and is so sick that she can't even go to work] …the last time we left him he was well. So, as we find him coughing and lying on a bed, you feel like is a waste of time because others are waiting for us and now he is taking us back while he was better. And we even taught him everything and most importantly that he is not supposed to leave treatment."* Regarding the reasons behind non-compliance she stated: *"… most of the patients do not default because they want to. Some of them are far from the clinics and they can't reach them. They do not have money, they are not working, and there is not income. So, we would sometimes blame them but as they explain their situations we would understand why they defaulted".*

Lenong expressed her frustration with and dislike for patients who were not complying with treatment: *"Our challenges, my challenges. PLWHA don't want to comply …They denying their diagnosis"* … *"I dislike a patient who deny medication*

who even if you try to pop him [i.e. cheer him up] *just say, 'I want to die, the Doctor said this and that I don't want medication and I don't accept this diagnosis because why me? I can die anytime is fine'.* [The ones] *who take medication and put it under the pillows and throw it under the water and hate a nurse that is coming in to tell me what to eat and to drink medication I dislike so… I dislike that type of patient … she lets the family gets miserable, she corrupts the family because she just think she is gonna die and she don't die all what she will do she end up hurting herself because if she don't comply and she doesn't take the medication then automatically she is gonna run mad and the family won't do anything about that…I had patients like that, who just passed away simply because they were incompliant and they were not ready to listen to what the nurses were saying and who have been fighting the family for calling the nurse because they don't want the cars stopped in the gate because the car is diagnosing. So, I had plenty of patients who passed away because of that kind of attitude".*

As this extract indicates, Lenong found the non-compliant patients to be not only hurting themselves, but the family as well. The moment the patient becomes chronic, the situation becomes the family's responsibility. This is also the case upon death when it is the family that has to take over and ensure that they are buried.

Lenyalo was concerned and frustrated by those patients who do not comply with treatment and eventually place the lives of others at risk: *"I hate it when you help a person who does not appreciate your help. Like for example you visit someone who is living with HIV and at the same time has TB and you want such person to live and eventually take care of his/her own children. At the end, such a person does not see the importance of that, she/he abandon the TB treatment and does not think that your life also gets at risk the moment she/he leaves the TB treatment and you will eventually be infected or her/his own kids. This is the main thing that I our patients make me feel angry. They do not see the importance... most of the people you find that they are sick and coughing and you take an effort to take him/her to the clinic where she will receive treatment. You will then make some follow-ups to ensure that she/he takes treatment and the next moment you come you find that he/she is not taking treatment or he/she has left to relatives and left the treatment"*

For **Vanessa**, participants who were not complying with treatment were engaging in risky life styles that even put others at risk: *"When they take risks. Sometimes they're not compliant to change their lifestyle, and then you will find they take risks. Yes, they are still human beings; they want to live life to the fullest, but then they go and put other people's lives in danger. And also, when they abuse either alcohol or drugs, and then next week when you come back after the weekend it's your problem. And they're very sick. But they have done things over the weekend to make themselves very sick, or when they go home to visit or whatever, sometimes they're out of the community and you can't keep an eye on them. So, it's like now you must police them as well, and that you can't do. It has to be free will, and that is very annoying, when you're going to police them to do stuff"*.

Lenyalo pointed to the fact that some of her participants had to interrupt their treatment mainly because of a lack of food: *"The challenges that we encounter are mostly that the patient is staying only with children and she/he is unemployed and does not even get a grant. So, she/he will end up not taking treatment because there is no food in the house"*.

Zulu explained similar reasons for not complying*: "You find people who stop taking treatment. These ones don't want to take medication on an empty stomach. They tell us that they get dizzy when they take their medication. The others tell us that they don't have enough food and that is why they stop their treatment. That is the response we get from them when we ask why they default on treatment"*.

Kgomo referred to non-compliance regarding sexual behaviour: *"Problems that we face is that we teach them how to protect themselves and others when having sex but most of the women fall pregnant. They fall pregnant while they are sick. Sometimes the baby born with illness and the mother dies and leaves the baby and sometimes the baby dies"*.

This was also echoed by **Amelia**: *"What I don't like is when a person who knows that he/she is HIV-positive and continues to practice unsafe sex. It is not good for a person to spread the virus deliberately…The other one is when a pregnant woman neglects to go to the clinic to get treatment. They know that they have to take the*

drugs that stop the virus from spreading to the unborn child. Time is of essence in such instances".

Martin's account point to a lack of will on the part of the patients to comply: *"…when you talk to these patients, they will take your advice, you will even accompany him/her to the clinic where she/he will be given a follow-up appointment which he/she will also confirm, but later on once they finish the treatment, they will wait for you to take them again to the clinic even if they can go there on their own. So, they do not cooperate".*

One of the crucial roles of HBCGs is to ensure that PLWHA take their treatment as prescribed to reduce AIDS-related deaths and increase their live span (Root & Whiteside, 2013; Nozaki, Dube, Kakimoto, Yamada & Simpungwe, 2011:831; Kabore, Bloem, Etheredge, Obiero, Sebastian, Doykos, Ntsekhe, Mtshali, Afrikaner, Sayed, Bostwelelo, Hani, Moshabesha, Kalaka, Mametja, Zwane, Shongwe, Mtshali, Mohr, Smuts, & Tiam, 2010; Hinkin, Hardy, Mason, Castellon, Durvasula, Lam & Stefaniak, 2004:2). Increasing compliance regarding treatment not only serves to ensure healthy PLWHA, it also reduces the number of AIDS orphans as parents would be living longer and be healthier. Compliance to ART is particularly significant for PLWHA and for the ART programme to be successful (Nokazi, Dube, Kakimoto, Yamada & Simpungwe, 2011:831; Monreal, Cunha & Trinca, 2002:9; Chesney, 2000:171). Given the critical importance of adherence to treatment, it is therefore not surprising for HBCGs to be concerned when patients do not comply with their treatment. This is one of their challenges because they as the caregiver appear to be useless in the eyes of community members.

Since, Nakedi, Lenyalo, Zulu and Martin touched on the reasons for non-compliance, I deemed it necessary to consult the literature on this issue regarding PLWHA. Chesney et al. (in Hinkin et al., 2004) looked into the factors that contributed to non-adherence to AIDS treatment and found among a total of one-hundred and forty-eight PLWHA in Los Angeles that sixty per cent of their participants reported that they simply forgot to take their treatment. Cheever and Wu[38] (cited in Wang, Zhou,

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[38] Cheever and Wu's study focused on adherence to medication by PLWHA (Wang et al., 2009:388).

Huang, Li, Fermie & Williams, 2009:381) report that forty-eight percent of patients who are on ART have adherence problems, with drug use being one of the factors interfering with adherence. For Hinkin et al. (2004), cognitive impairment and drug abuse were identified as some of the factors that contributed to non-adherence with cognitive impairment leading to further disease progression and a worsening of cognitive function. In other words, the patient's inability to make informed decisions somehow rendered them to disregard the importance of adherence to treatment which in turn leads to their poor ability to make informed decisions when it comes to taking treatment. Wang et al. (2009:381) share similar sentiments through their association of drug abuse with unstable life style which can affect adherence to ART. The challenge and frustration experienced by the participants in my study in relation to PLWHA' non-compliance corroborates with Van Dyk (2007:58) who found in her South African study that was about occupational stress experienced by caregivers caring for PLWHA, that HBCGs are frustrated when patients refuse to heed their advice about treatment. Instead they follow traditional beliefs and misconceptions around HIV and AIDS healing.

Failure to adhere to treatment on the part of the patients as demonstrated in this study is contrary to what Muhammad and Gikonyo (2005) found in their study. It focused on operational challenges and limitations faced by HBCGs caring for PLWHA in the World Bank's Multi-Country HIV and AIDS programme (MAP) among HIV and AIDS caregivers from eight MAP countries. Compliance with HIV and AIDS treatment was reported by participants as one of the indicators of support for PLWHA. Hermann, Van Damme, Pariyo Schouten, Assefa, Cirera and Massavon (2009:8) found in their study aiming to highlight the experiences and new opportunities in the primary health care CHCWs' programme in Ethiopia, Malawi and Uganda that the role of HBCGs is highly significant in ensuring compliance with treatment among the Zambian and Ugandan patients. It is a really great achievement of success for the HBCG when chronic and helpless patients begin to do things for themselves because they complied with the advice the HBCG gave and accepted treatment as prescribed,

The significance of my participants' concerns about treatment adherence can be understood through a study titled "antiretroviral therapy in resource-limited settings:

decreasing barriers to access and promoting adherence" conducted by Mukherjee, Ivers, Leandre, Farmer and Behforouz (in Wouters, Van Damme, Rensburg, Masquillier & Meulemans, 2012) in Haiti in which HBCGs' support for PLWHA lowered the rates of treatment failure and facilitated access to primary health care services. Similarly, Valjee and Van Dyk (2014:6) found in their study of the impact of caring for PLWHA on the psychological well-being of the palliative caregiver in KZN that non-adherence to treatment by patients angered the HBCGs. It often contributed to helplessness on the part of the HBCG, a justification of the reactions of my participants.

Among some of the factors contributing to non-compliance, Monreal et al. (2002:9) highlight the characteristics of the therapeutic programme, the health guidance professionals, the patient and society in general. For Chesney (2000:171), factors that contribute to non-adherence to ART can be categorised into four groups: (1) patient-related factors such as drug use, alcohol abuse, age sex, ethnicity, active depression, lower level of education, lack of self-efficacy, extreme anxiety, extreme pain, no change in health status; (2) medication-related factors such as dosing complexity, number of pills or food requirements and side effects; (3) patient health care provider-related factors which may include the quality of relationship between the health care worker and the patient and (4) those factors that relate to the system of care such as the patient's dissatisfaction with past experience of health care system which may result in the patient avoiding the system.

- **HBCGs' challenges with patients who lose hope**

Yena was particularly concerned about and challenged by patients who would not trust her; be discouraged and lose hope along the caring trajectory. She (Yena) *stated: "Not to be trusted by a patient; and when she* [referring to one of her patients] *doesn't think she can do something and I don't like to see them give up, I would like to see them have hope, having dream with their lives"*.

Optimism and hope as Grønlie, Nesje and Dageid (2011:167) describe, are psychosocial beliefs known for increasing and protecting mental health during difficulties. This means that without hope and optimism, PLWHA are more vulnerable due to poor mental health. It is therefore not surprising that HBCGs celebrate and

appreciate hope expressed by their patients because it signifies healing. Yena's concern in this regard finds support in what Rödlach (2009:427) found in his Zimbabwean study. It focused on the motivations and concerns of HBCGs caring for PLWHA in which his HBCGs reported concerns about their patients' hopes. Furthermore, HBCGs caring for PLWHA in Rödlach's (2009) study would even ensure that their inability to provide food for their patients did not diminish their hope by put emphasis on prayer which they believed would preserve their hope.

This concern about patients losing hope as articulated by Yena as a work-related challenge impedes on the activity of "*envisioning tomorrow*" which Williams (2014:313; Williams 2007:382;) sees as a force in the middle range theory of caregiving dynamics to move the caregiving-recipient dyad forward.

- **HBCGs' challenges with patients who use substances**

Paul referred to the challenge of patients who are under in the influence of alcohol, as it complicates the task for the HBCG. This was for him, from the beginning and even up to now, difficult to cope with, as he did not know how to manage the situation. He spoke about this along the following lines: *"…in the beginning I didn't know how to deal with a person who is abusing drugs or up to now I hate to support somebody that has alcohol problem because they will waste most of your time when they are under the influence of alcohol. They will phone you in the middle of the night and make an hour or half an hour talk over the phone while they are under the influence of alcohol, so they actually waste your time, that is for me difficult up to now when someone is under the influence of alcohol and at the same time HIV-positive do deal with"*.

Resulting from the challenge experienced by Paul is the observation Remien and Mellins (2007:558) make that substance abuse of PLWHA is one of the factors associated with poor adherence to ART. Hinkin et al. (2004) postulate that abusing drugs, such as cocaine, contributes to non-adherence to treatment amongst PLWHA. The drugs used may suppress the patient's immune system by rendering it dysfunctional, therefore exposing the individual to more infections (Klinkenberg & Sacks, 2004; Chander, Himelhoch & Moore, 2005). For Wolfe, Carrieri and Shepard (2010), PLWHA who are on drugs are at the highest risk of death. Another concern

in this regard is the fact that the safety of the HBCGs is compromised when caring for a patient abusing and under the influence of drugs (Uys 2002:101).

- **HBCGs' challenges with older and male patients who refuse to be bathed by younger and female HBCGs**

Many of the female participants in my study found themselves having to care for male patients and, in some instances, patients who were older than them. This was reported as challenges since these male patients refused to be cared for by female HBCGs. Those who were older refused to be cared by younger HBCGs. Among participants who voiced this challenge were Nakedi, Wendy and Pekwa.

Nakedi explained the challenge she had when she specifically had to care for the older males: *"You find things like men who would refuse when we bath them who would refuse when we change the nappies...He would refuse to be bathed and we would then start by explaining that you see you are staying alone and you can't bath yourself, so we must bath you. There was another one who would take all his clothes and leave underwear and begin to take a bath while wearing underwear and at times he would ask us to make the washing cloth wet for him and put some soap on it and then ask us to go outside. I would also feel bad because I could also see that this one is my father's age…He would even say, I am not going to be bathed by this children and when the wife is around we would simply leave him for the wife to take over but when the wife is not around we would take time to explain that we must bath him because patients are supposed to bath every day because once your condition gets complicated we don't want to take you with dirt to the hospital of clinic".*

Wendy shared her experiences of patients who are impatient and who were uncomfortable when she had to care for them: *"They are impatient like sometimes they…feel shy to be helped by young people".*

Pekwa also expressed her concern about older patients: *"The challenges mostly encountered are when coming to work with old people whom when we are supposed to bath them they would refuse and say they can't allow themselves to be bathed by a child".*

These participants alluded to the suffering from a condition like AIDS. This means that, at some stage, a patient might be so critically ill that they are not able to even bathe themselves. This becomes a challenge particularly in African culture where young caregivers are not supposed to see the naked body of an elderly patient. This is a sign of disrespect on part of the caregiver and a cultural shock for the patient (Tshabalala 2008:16). It could also be the case with male caregivers and female caregivers alike who find themselves caught up between patients hiding their private parts from the HBCG while still needing care from them. For Makoae (2009:21), male patients' reluctance to be bathed by female HBCGs may be attributed to their deliberate effort to conceal some of the symptoms of AIDS which might have affected their genitals. Their need to preserve privacy and circumvent clumsiness creates an awkward situation (Makoae, 2009:21).

The challenges experienced by some of the HBCGs who took part in my study in relation to older and male patients' refusal to be bathed by younger and female HBCGs finds support in what was revealed in a paper titled, "HIV and culture confluence – 'changing the river's flow': possibilities and challenges in programming" presented by Chingandu, Chibukire and Mojapele in (2010). At an AIDS conference in Johannesburg, South Africa they highlighted the danger of some cultural beliefs and practices when it comes to addressing the issues of HIV and AIDS. These researchers (Chingandu et al., 2010:15), amongst others, note that some cultural arrangements that promote the superiority of men over women and encourage treatment of women as second-class citizens in their communities and homes, cause difficult situations like this to arise. Leclerc-Madlala (2001:41) identified this kind of practice in South Africa's KZN through her study that sought to understand the cultural roots of non-medical representations of AIDS. How people think and respond to the disease is a critical issue to recognise. She found that the recurring perception of women as being naturally unclean and blamed for the misfortunes [like HIV and AIDS] that befell the community still prevailed.

Although my study could not provide evidence about to this point, I did find evidence in the literature about it. Valjee and Van Dyk (2014:5) believe that HBCGs may eventually find themselves in a situation where they are more comfortable with patients of their same gender and even age group and consequently neglecting

those who are older or of the opposite gender. Pallangyo and Mayers (2009:487) also highlight the cultural significance of gender and age in caring. They state that women accept all other care-related duties except for bathing men. Clearly the issues of gender and age can mismatch when coming to caring. It does not seem to be something that is only found among older and male patients as emerged in my study. Makoae (2009:21) found in her study in the Lesotho Berea district of caregivers' experiences with the bodily care of AIDS patients before ART was introduced that even young patients of the opposite gender appeared to have some reservations when it came to being cared for by HBCGs of the opposite gender. In this study, it was found that a young man had refused to be bathed by an older woman HBCG (Makoae, 2009:21). This means that one should not rule out the issue of gender and age mismatch when caring for PLWHA.

3.3.2.3 Sub-theme: HBCGs' challenges in relation to the patients' relatives

Apart from the community members' and patient-related challenges presented in the previous sub-themes, the HBCGs also spoke at length about challenges experienced with the families of patients. What was reported was the non-welcoming attitude of family members and the cold reception they received; some family members were unappreciative of their services; some neglected their family member patients and left all the caring responsibility to the HBCG alone. Furthermore, some of the family members received a social grant for the patient, yet did not use the grant for the patient's benefit. These aspects will now be presented as categories:

• **HBCGs' challenges with poor reception by some of the patient's' relatives**

Not all families were cooperative and warm towards HBCGs. This was despite the HBCG's role in voluntarily assisting the family by taking care of their patients. Some of HBCGs were not even allowed to enter the house except where the patient was while others managed to enter but received cold shoulder treatment. Sometimes they were simply left alone in the house. Another experience was that family members who were supposed to assist them by supplying the means and/or money to care for the patient did not come personally or arrange alternative help. Dineo and

Martin specifically referred to the poor reception received from some of the relatives of the patients.

Dineo shared how disappointing it was for her when she was turned away by household members of the patient's family: *"…as a resident of this area, when I knock off some people will approach me and say there is a patient in a particular household and when I get there I would be told that I must leave"*.

In further underscoring this category, **Martin** is quoted as stating: *"The challenges that we often encounter is that there are some of those who do not take us serious when we enter their household. They give us some unwelcoming looks and actions...I mean families of the patients...They don't see any value in us..."*.

Dineo and Martin's challenges experienced about the poor reception received by some of the relatives of patients corroborates with similar findings in the literature (Kasimbazi & Sliep, 2010; Motswasele & Peu, 2008; Campbell et al., 2008:511; Akintola, 2005:15). In a study of the experiences of informal caregivers HBC in the Odi sub-district of the North West Province in South Africa, Motswaesele and Peu's (2008) participants mentioned the hostility of patients' family members towards them and refusal to cooperate with them.

In Akintola's (2005:14-15) South African study focusing on the role of volunteers in mitigating the burden of HIV and AIDS care in households and communities among HBCGs caring for PLWHA in KZN, the poor reception of the HBCG by relatives took on another dimension. On one hand, the patients were willing to be cared for, while on the other hand, the household members did not welcome the HBCG appropriately.

Contrary to this finding from Akintola's (2005:14-15) study, Cain, Maclean and Sellick, (2004:269), in their Canadian study that examined the influence of palliative care services on caregivers of cancer, HIV and AIDS and illnesses of later life in Toronto, Thunder Bay and Ottawa reported that some relatives in the patient's households negotiated with the patient who was rejecting the HBCG's help to accept it. They themselves were not always available to care for him.

Similarly, Rödlach (2009:426) found in his Zimbabwean study on the motivations and concerns of HBCGs caring for PLWHA in Bulawayo townships, that patients were rejecting HBCGs who were known to members of their communities. This was due to their fear of stigma, forcing many HBCGs not to wear their uniforms and not to provide anything that would link the family to them. Despite the poor reception received from the relatives in patients' household, some participants from Akintola's (2005:12) South African study on the role of volunteers in mitigating the burden of HIV and AIDS care in households and communities among HBCGs caring for PLWHA in KZN, continued to visit the patients until the family changed their attitude and accepted them and also welcomed them into the household.

Campbell et al. (2005:809) mention the sad state of affairs in their study with the title, "Creating contexts for effective home-based care of people living with HIV/AIDS" where families of HBCGs caring for PLWHA were not only found to be non-welcoming to the HBCGs, but were depriving the sick family member from receiving treatment by going so far as to hide them from the HBCGs. On the other hand, and in the same study, some patient's relatives were caring and compassionate towards the sick member and therefore welcomed any form of support for their ailing family member (Campbell et al., 2005:809). Both Motswasele and Peu (2008) and Cataldo et al. (2015) report that some their HBCGs who participated in their studies mentioned that they enjoyed "privileged access" and "intimate access" to the homes of their patients. Moreover, they, as an informed HBCG, had also facilitated some supportive interventions.

- **HBCGs' challenges with lack of appreciation of their services by patients' relatives**

Paul singularly, voiced this challenge of lack of appreciation of the HBCGs' work by the patients' family when stating: *"I did support an HIV-positive person, an unemployed one. We did try and find a place for him to stay, we did bring food parcels to him, we did even buy magazines and books to read, we did find a job for him to work as a caretaker, as a security man in a building where he was also staying at that stage and we have provided him with clothing, we have provided him with furniture and everything that a person needs…he was not part of any family and*

therefore I was involved getting him with his family again and I did phone them and I did make that attachment again. And every now and then his mother will phone me and say tell him that time I will phone to the telephone box nearby, the Telkom call box, so I will go down to him and say, listen at that time your mother will phone you, for instance…they were not concerned about him. They were satisfied he is getting treatment and they didn't really care about him at all. Later when he got very ill we phoned them; I have arranged for him to get admitted to the [Cherish[39]] hospice and he died three days later… [Cherish hospice] *did support the family very well. You know what that family has done, they taken all the furniture, all the books and all his clothing and donated to the hospice that cared for him for three days, and I was caring for him for more than five years"*. He further explained: *"I would expect them to say thank you to me that is all. Don't want money from them I don't want anything from them… They were greedy, they were just taking their possessions and go…and disappear"*.

The challenge highlighted by Paul is confirmed in another South African study, which looked at the coping mechanisms adopted by volunteers who were caring for PLWHA outside Durban. In this study Akintola (2008:360), found that some of the family members had refused HBCGs access to their home and even insulted them. Contrary to the challenge experienced by Paul, Guerra et al. (2012:72) in their study of the motivations, fears and benefits of volunteers in an intervention programme for people living with dementia, found that the family members of their patients appreciated their work. However, initially they had felt insecure by their presence in their houses. Similar sentiments were shared by some of the participants in Thabethe's (2011:790) South African study among HBCGs caring for PLWHA. This particular study focused on the socio-economic context of care and women's perspectives of HBCGs. These participants had mentioned that one of their motivations to care for PLWHA was that their contributions were acknowledged and appreciated by families in local homes where they provided their care services.

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[39] Cherish HBC is a HBC organisations to which Paul had to refer one of his patients for admission since they had admission facility.

- **HBCGs' challenges with relatives who neglect the patient and rely on them for care and support**

Family members respond differently to a relative who is HIV-positive. Some may reject this family member whilst others accept the situation if the person is HIV-positive and supports them (Smith & Rapkin, 1996:86-87).

From Kgomo, Pekwa, Martin, Mokete, Mpshe, Segwagwa, Selinah, Lenyalo and Lenong's accounts it became clear that family members were abdicating their responsibility of caring for the relative living with HIV and AIDS and transferred this to the HBCGs. A few of the participants' direct words will be quoted to strengthen and endorse this and the breadth and depth of this identified challenge.

Kgomo shared the following in this regard: *"What I hate is when the patient has a normal family and that family doesn't take any responsibility and shift all the responsibility on you, although both us as caregivers and the family members must join hands to care for the patient. So, our people have told themselves that once they have a patient, they do not do anything to assist him/her. If the patient … needs some nappies, they would simply say, 'I am not paid, the caregivers will come and change the nappies'.* Kgomo elaborated further*: "Currently I am taking care of a patient who stays with her aunt. Sometimes I would not go there due to ill-health. So, when I get there I would find the patient in wet clothes with dirty nappies and when I ask her aunt why didn't she assist the patient, she simply say, I am not paid by anybody. You are getting paid so you must do it. And sometimes she would even break my heart by saying things like but why can't this patient of yours die?".*

Pekwa voiced her frustration with families who neglect their relative living with HIV & AIDS along the following lines: *"What I don't like is…Those* [referring to the relatives of the patients] *whom when you come they shift the whole responsibility of the patient on you. Remember a patient is supposed to be shared, you cannot own a patient, is not possible… you would explain to them that this person is supposed to take treatment three times a day. The next day when you get there you would find that the patient was not given treatment as they were waiting for you to come and do that and even prepare porridge for him/her".*

Martin was particularly detailed in his explanation: *"…the moment I enter in a particular household to execute my duties, you find that you are not taken serious by the family members – the parents and siblings of the patient. They will answer me in such a way that I get hurt. So, if you ask them to prepare some water, a child or a wife will ask me, 'what for?', while knowing very well that I am here to bath their father or husband. This child or wife who has all along been with the patient now will leave that particular household while knowing very well that I cannot prepare water, I cannot switch on their stoves without any member of that household around. They would leave me and the patient alone in that household. They know very well that when I get there I ask them to prepare water, soap and cloth so that I can do my job but the moment you enter, they leave the house…I'm here for the patient who is sleeping in the house. So, I will be waiting there for her/him so that she/he can do what I ask him/her to do, bath the patient and leave for the next one…I would be thinking that I am not welcome in that household…I would be thinking is that I am not there for her/him, I am there for the patient."* He elaborated further on this topic later in the interview and said: *"…once the medication is finished, they* [referring to the relatives] *do not take any initiative to support the patient to go and collect some at the clinic. This happens even if I explain to them that a person who is living with HIV must always have medication. He must not spend a day or two without medication".*

Mokete referred to this challenge along the following lines: *"Families are different. To some it* [referring to caring for a relative living with HIV & AIDS] *becomes a major concern for the family to get some help while to some, the person who is concerned about getting help is the patient himself/herself. At times the family has its own problems and they often feel that you are going to unveil their secrets…Sometimes patients reveal their complains about the families to us … So, we would try to tell them* [the family] *that they must be involved because we are there for a short period and they spend a lot of time with the patient. So, in such instances the family response becomes negative and is like we are there to disorganise them. That is why most of time they are uninvolved and leave the whole responsibility of caring for the patients on you"*

Mokete added an example of the family's behaviour towards the patient*: "I still remember another case that we had where a patient found it difficult to even go to the toilet and she would botch herself inside the house. When you get there, it appeared that as if the problem is on the patient while the main problem was in the household and the way she was being treated. So, as we get there we shouted at the patient thinking that she is the one with a problem and only to find that she is denied access to the toilet. She always locks herself inside the room and the family does not contribute anything".*

Mpshe also spoke about families abdicating their responsibility to the HBCGs by stating: *"Most of them,* (referring to the relatives) *once we arrive, they say, 'yeah, here they are, it is their job' …they put everything on us, you see".*

Lenong straight-out said: *"Our challenges, my challenges. PLWHA… they are being neglected by the families".*

From analysing my participants recorded narrations, many of them appear to be in sharp contrast to the viewpoint Kohli et al. (2010) hold which supports the assumption that having a relative living with HIV and AIDS brings a family closer together and sustains their already existing bond. This happens because everybody plays their role in caring for and supporting the patient. Kohli et al.'s contention differs from that of Carin, Maclean and Sellick (2004) who postulate that family relationships tend to breakdown as the emotional strain associated with living with HIV and AIDS affects all family members not only the one whose HIV-positive status has been confirmed.

Other cases of research participants who reported having neglected a relative who, as a patient, relied on HBCGs for care and support were in the literature reviewed for this study on HBCGs' experiences. Cataldo et al, (2015); Pandani, Malawi & Nondog, (2013:2); Mashau & Davhana-Maselesele, (2009); Rödlach, (2009:426) and Motswaesele & Peu, (2008), in general, reveal that the relatives of the patient in the household would neglect them and even leave them dirty while waiting for the HBCG to come and bathe them. Motswasele and Peu (2008:29) reported in their South African study done in Odi district in North West province to describe the experiences

of HBCGs caring for PLWHA that they found total neglect of patients in their families in instances where wounds had not been dressed resulting in maggots thriving.

Whilst the necessity of both emotional and physical support for the patient from partners, friends and families is emphasised, it is also linked to treatment adherence which, in turn, results in better health and even a prolonged life span for PLWHA (Mosack & Wendorf, 2011:5-6) Moreover, many of the affected households are ill-equipped to offer HBC to their relatives (Akintola, 2005:15). Similarly, Faulkner (1995:13) warns HBCGs to handle the issue of families who are reluctant to assist in caring for their sick relative, with caution. This reluctance and neglect may not be deliberate, as some patients' families may be so overcome by the situation, and be overwhelmed by complex emotions such as fear, bitterness and anger that inhibit their ability to care. Nevertheless, this challenge raises a point that cannot be ignored.

While literature was found to confirm the challenge of relatives who neglect the patient in the family and rely on the HBCGs for care and support, as was experienced by a substantial number of my participants, a body of literature was also found testifying to the fact that family members are generally compassionate, caring and sacrificial towards ill relatives (Valjee & Van Dyk, 2014:5; Kohli et al., 2012:5; Kabore et al., 2010:587; Nokazi et al., 2011:834; Campbell et al., 2008:511). Kabore et al., (2010:587) in a study conducted in Maseru Lesotho; Ladysmith, South Africa; Katima-Mulilo, Namibia; and Bobonong in Botswana, documented the changes in patients' clinical outcomes over time as measured by CD4 cell count, health-related quality of life and adherence to ART. The outcome was that three hundred and thirt-seven of their five hundred and eighty-seven participants reported that, although they did not receive any financial support from their families, they did receive, inter alia, encouragement, psychological support and physical care. Similarly, Mosack and Wendorf (2011:5) and Valjee and Van Dyk (2014:5) found that family members were involved in assisting the patients in their family circle with getting medication.

Although this point did not emerge from my study, Smith and Rapkin (1996:87) state that sometimes it becomes the patient who is not willing to be cared for by the family because they do not want to feel overprotected. This, from an outsider perspective,

could appear as though it is the family that does not want to care for the patient in the family. Although there is no evidence about this in my study, its possibility of happening cannot be totally overlooked.

- **A HBCG's challenge with relatives who receive grants for the patient and not use it for the patient's benefit**

Martin was the only participant who voiced his experiences relating to this challenge by stating: *"…you find the family is receiving the grants on the patient's behalf but the poor patient doesn't benefit anything from the grants. As you enter such households you will find that the patient is dirty and she/he did not eat anything but yet the family receives the grants for him/her"*.

It is reported that the prevalence of HIV is higher among households in the lower income bracket, downgrading them further into destitution (Demmer, 2011:878; Hardy & Richter, 2006:88; Shisana & Simbayi, in Booysen, 2004:46). One of the aftermaths of HIV and AIDS is its impact on the household income, resulting in a situation where the household is locked into what Booysen (2004:46) calls, "the spiral of underdevelopment". In South Africa efforts to address these spirals of underdevelopment are provided by the Constitution of the Republic of South Africa Act 108 through its Section 27(1) (c) which allows for people who are unable to address their basic social needs to receive assistance from the government through the Department of Social Development (Hardy & Richter, 2006:85). In the case of PLWHA, this type of social assistance is likely to come as a disability grant which is used to address any condition-related need, such as food that is prescribed by a dietician (Hardy & Richter, 2006:92).

Martin's challenge experienced is confirmed in one of the findings by Van Dyk (2007:58) in her study of occupational stress among caregivers caring for PLWHA. She found that patients' families received grants for children living with HIV and AIDS but the children did not benefit from it. This was contrary to the findings of

Vorster, Eigelaar-Meets, Poole and Rossouw[40] (in Hardy & Richter, 2006:88) which revealed that all beneficiaries of the social grants from the Western Cape DSD provincial budget spent their social grants on food that was shared among all the family members, including any patients. In addition, one of the HBCGs in Hardy and Richter's (2006:91) South African study that explored the intersection of social security and access to ART, shared her experience with PLWHAs who, as patients were supporting their families with their social grant. The patients, did not have a problem if their grant was used to benefit the entire family. Like Hardy and Richter's (2006:91) participants, Dada and Sliep (2011:135) state that in most cases the disability grants were intentionally used for other people in the patient's immediate family. It can therefore be suggested that it is not a strange thing for members of the family to benefit from a patient's social grant.

When matching this sub-theme and its categories concerning the HBCGs' work-related challenges experienced in relation to the patients' relatives with the aspect of role support as enabler to assist the caregiver to cope within the caregiver-receiver dyad as espoused in Williams' middle range theory of caregiving (Williams, 2014:316) it becomes evident that in some instances the support of the caregivers from the side of patients' relatives was lacking. As mentioned in Chapter One (see sub-section 1.2.1), the caregiving trajectory progresses smoothly if the HBCGs' are supported in their caregiving role, amongst others, by patients' relatives who assist with some of the caregiving responsibilities.

3.3.2.4 Sub-theme: HBCGs' challenges in relation to working in unsafe conditions when caring for PLWHA

Some of the challenges the HBCGs experience were connected to unsafe conditions in which they were working. Among these challenges, HBCGs highlighted their vulnerability to rape and to infections as presented in categories below.

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[40] A study by Vorster, Eigelaar-Meets, Poole and Rossouw's aim was to profile the social security beneficiaries in the Western Cape Province of South Africa (Hardy & Richter, 2009:96).

- **HBCGs' challenges with vulnerability to rape**

Another response the participants as HBCGs provided to the question of the challenges encountered was their vulnerability to rape. This emerged as participants shared their concerns about some of the incidences in which they found themselves alone in a vulnerable situation with male patients who could easily rape them. Lenyalo and Jini referred to the potential for being raped as a challenge for them in their work.

Lenyalo explained: *"For some males as you conduct your visits they will take advantage and once you enter they would want to rape you. So, we even resorted to check if we can see any females in the houses and if we don't see females we decide not to enter".* She gave an example of such a situation: *"…we met this man who wanted to take advantage. I went to that household alone and I was explaining to him about sicknesses and health issues including the importance of using condoms, he then said let's do it practically. When I tell him that we can't do it practically he started arguing with me saying that I cannot come with condoms in his house and expect to teach him as a man about condom and not show him how it works".*

Jini also explained the challenge of potential rape: *"So, I remember one day I had to do visits alone…So I went to this patient and found that he had his other male friend. So, when I got there I found that they were busy having sex. I was scared and kept asking myself what if they grabbed me and raped me. So, those are some of the challenges that we face".*

Gilson, Walt, Heggenhougen, Owuor-Omondi, Perera, Ross & Salazar (1989:524-525), for instance, state that HBCGs often find themselves working alone in remote areas trying to reach the hard-to-reach population groups. Such a situation could serve as a safety hazard as in most cases there are no measures in place to ensure their safety. Although my search for published literature on the topic of HBCGs caring for PLWHA's vulnerability to rape did not generate any results, in 'The Guardian Newspaper', Roy Carrol (2008) points to the general unsafe conditions characterised by violence in which AIDS activists find themselves working. Roy

(2008), for instance, reports the story of Lorna Mlosana, an AIDS activist who was raped and murdered after it was discovered that she was living with HIV and AIDS. This account highlights of the HBCGs' potential vulnerability to rape.

- **HBCGs' challenges with vulnerability to getting Tuberculosis (TB)**

Amelia and Zulu expressed the fact that their care work with PLWHA rendered them to be vulnerable to getting TB, as a challenge and this was evident in the following remarks:

Amelia explained: *"Seeing that we work with HIV/AIDS and TB patients, it becomes dangerous to our health sometimes, especially when we are in close contact with a person who has TB, but does not take precautionary measures to protect those who are around them from getting infected. Sometimes, a person coughs or sneezes while we are screening them. We cannot screen a TB patient without wearing a mask. If we were to consult or screen patients while wearing masks, patients are likely to be offended by the mask. You know how our people are. The biggest challenge is when you come into contact with TB or MDR* [Multi Drug Resistant] *patient".*

Zulu spoke as follows about this challenge: *"As home-based care workers… we go to homes to visit patients, when we do the screening* [for TB] *we do that without any protection. We take the sputum and refer them to the clinic. Firstly, I don't have the power to diagnose TB. In other cases, a patient presents symptoms of TB. Even family members may display the symptoms. The patients inform us later that they tested positive for TB. These conditions are not safe for caregivers because TB is infectious"*

This challenge of vulnerability to getting TB, referred to by Amelia and Zulu, resonates with Smart's (2009:10) opinion where HBCGs are believed to be found to be vulnerable to TB infections due to their daily proximity to patients. It is therefore not uncommon see the findings like those of Pallangyo and Mayers (2009:488) and Davids, Setswe, Lewa, Majaja, Naidoo and Clayton et al. (2009) who point to the fact their HBCG participants are afraid of being infected, especially when the patient had

not disclosed a HIV-positive status. Koto and Maharaj (2016:54) emphasise the fact that HBCGs are concerned about their safety of becoming HIV-infected given the high level of exposure to AIDS patients in the type of work. Similarly, Okeke (2016:37) reports in his Nigerian study that examined the relationship between the efficacy of social support and self-efficacy in building and managing the emotional well-being of caregivers of PLWHA in Oyo State that some of the HBCGs faced the risk of being infected with TB and HIV due to their frequent contact with patients. Moreover, this fear of contagion, according to Koto and Maharaj (2016:56), could even lead to poor service delivery as a HBCG might decide to avoid some patients simply because of their personal fear of contagion.

- **A HBCG's challenge with the odour of AIDS**

Vanessa highlighted the odour of AIDS as a challenge, which she found difficult to rid herself from; she spoke as follows about this: *The last stage of AIDS is the smell. It takes me months get rid of the smell. I always feel that I can smell them. Even if I haven't been for a few days, but I'll still be smelling them all the time and it takes me months after that person has died to get rid of the smell. I don't know why, but I hate that smell. I don't think that I smell like that, practically, but I think it's up in my mind…so I don't think that people smell me, but I think because in my mind I don't like the smell it stays with me for a long time. And I can smell it on me, but if I ask them at home, smell me; am I smelly? No, 'mummy, what are you talking about?' Or I'll ask my partner, and he'd ask me, 'what are you talking about? Where were you today?' Then I'll explain to him, and then he'd say, 'oh, here we go again', because I don't get rid of it quickly, but nobody can smell me. But if my kids at home cannot smell me, and they are the most honest, then I know the smell has got nothing to do with it".*

Working with patients with diseases that give off distasteful odours and have ugly signs of it, is a difficult task for caregivers (Parry, 2001:70). The challenge of odour relating to AIDS was also reported in the findings from a Lesotho study in which participants reported that they were disgusted by things such as faeces, vomit, other body fluids and their odours. This work was done before the introduction of ART in the Berea district (Makoae, 2009:23) as an attempt to understand the caregivers'

experiences with the bodily care of AIDS-patients. Another study which highlighted HBCGs' challenges regarding the smell of AIDS was the one Rödlach (2009:425) conducted in a Zimbabwe. It focused on the motivations and concerns of HBCGs caring for PLWHA. The participants reported of PLWHA that the odour was caused by persistent diarrhoea that could not even be washed away and was common in some households in the area.

3.3.2.5 Sub-theme: HBCGs' challenges in relation to colleagues

Another set of challenges HBCGs experienced during the process of caring were connected to their relationship with some of their colleagues. First, there were those who did disclose a patient's status; and second, those HBCGs who openly rejected them as colleagues. These two emerging categories also came up in this research.

- **A HBCG's challenge with colleagues who disclose patients' HIV-status**

Zulu reported that one of the things that she does not like about caring for PLWHA is when caregivers reveal the patient's status to others: "*What I don't like about taking care of patients is when a caregiver discloses the status of a patient...When you work with people, you should be able to keep a secret...Yes you have to respect that clause* [referring to the confidentiality clause].*"*

Just like any other professionals or paraprofessionals who work with PLWHA, HBCGs are also bound by the ethical principle of confidentiality (Makoae & Jubber, 2008:37). This means that they are not supposed to share any of the information they have about the patient to anyone else without their consent. Confidentiality is not only beneficial for the patient who should know and understand what is happening to their body; it also benefits the relationship between the patient and the HBCG to allow for a warm and trusting atmosphere so that the patient feels free to share anything that bothers them with their carer in confidence.

In a study conducted by Olang'o et al. (2010:233) on the topic of attrition among HBCGs of PLWHA where they interviewed PLWHA, HBCGs and health care

providers, they had to drop one of the research assistants as the participants feared that she would divulge their HIV-positive status.

From Akintola (2008:361) comes the idea that this type of action of disclosure from a HBCG links to the stressful nature of their work in which they find themselves caught-up between maintaining confidentiality on the one hand and liaising with another person for additional support. The same stance is held by Van Dyk (2007:56) who believes that HBCGs find it stressful when they cannot talk to anyone about their patients and their condition and find themselves ending up breaching the confidentiality arrangement they have to honour.

- **A HBCGs challenge with colleagues who avoid her**

Vanessa in particular referred to the fact that colleagues avoid their company as a challenge, when stating: *"They - [referring to colleagues in other units] didn't want me. They never even shared lunch with me, and yet we all share lunch...My colleagues, they never shared lunch with me. It was me and another woman. They didn't share lunch with us. They'll give us, but they won't take from us".*

In highlighting the significance of ensuring support for each other among HBCGs caring for PLWHA by their colleagues, Maslanka (2010:196) wrote that support from colleagues is even more important than either the support that one gets from a spouse or a supervisor. Contrary to the challenge Vanessa experienced around being avoided by certain colleagues, the AIDS volunteers who took part in Maslanka's (2010:206) study on burnout, social support and AIDS volunteers in New York City reported good collegial relationships characterised by reciprocal support. Similarly, in Fynn's (2011:115-116) South African study, the HBCGs reported that receiving support and comfort from their colleagues with whom they share problems in meetings and where possible solutions for overcoming difficulties are given, contribute to providing optimal treatment, care and support of their patients.

It is noteworthy that role support is one of the enablers of the caregiving dyad in the middle range theory of caregiving dynamics (Williams, 2014:316). Role support from colleagues would enable the HBCG to offer competent and compassionate care. Having the support from colleagues would provide assistance with other

responsibilities whenever needed and the caregiver would have peace of mind by simply knowing that colleagues would be available to offer helpful advice and information. However, the caregiving trajectory can be compromised and not go forward if the responses from this study's participants and observations are not noted. Disclosing a patient's HIV-status and HBCGS experiencing isolation from colleagues appears to be threats to important and necessary role support. Another consequence is that it is likely to result in a break in trust between the HBCG and the patient as well as among the HBCGs themselves.

3.3.2.6 Sub-theme: HBCGs' challenges in relation to the attitudes of other role players

Any palliative care is strengthened by the nature of collaboration between its multi-disciplinary members (Maasdorp, 2011). In this study, this kind of practice was found to be ironic as participants recounted the attitudes displayed by other role players towards them as a challenge. This referred specifically to the attitude of the staff at clinics, colleagues and other professionals. These challenges are further discussed as categories below.

- **HBCGs' challenges when working with the clinic staff**

The conduct and behaviour of the clinic staff towards the HBCGs emerged as one of the challenges that affected the HBCGs' performance negatively. Whilst Martin and Kgomo were the only participants expressing their satisfaction with the necessary support which they received from the clinic staff, Kgomo, Jini, Letsatsi, Malume, Mokete, Mpshe, Nakedi, Segwagwa and Vanessa shared only challenges experienced in this regard.

Martin found the clinic staff helpful and spoke about this as follows: *"I get very good treatment especially when I come with the patient who is weak. I would then ask the patients that I have found on queue so that they can allow him/her to go straight into the consultation rooms due to weakness and I always get cooperation."*

Kgomo spoke in general about positive experiences with the clinic staff when stating: *"I do not have anything to say apart from that we take our patients ourselves to the clinic, we push them in wheelchairs to the clinics…The treatment is not bad. Once you arrive, you simply take the file and the patient is attended to. We don't have to queue to get the patients to be treated"*.

As stated above, and contrary to Martin and Kgomo's positive experiences at the clinics and with clinic staff, Kgomo, Jini, Letsatsi, Malume, Mokete, Mpshe, Nakedi, Segwagwa and Vanessa had negative experiences which they articulated as challenges. A few of the participants' direct words will now be given to explain and stress the breadth and depth of this particular challenge.

Jini was very vocal about the treatment received from the clinic's nursing staff and said: *"Sometimes the sisters* [i.e. the nursing staff] *undermine us because we are the caregivers … at the clinic you would find sisters who would undermine you. As a caregiver … our work is an odd one and it appears as if we are not human beings. So, some would be nice to you and others would not be nice at all"*.

Kgomo also shared a particular experience when confronted with a negative attitude during her interaction with one of the staff members at her local clinic: *"The sister who was in charge asked me where did I get this type of patient and I explained that I was called by her mother who was old to come and help. She then asked me, 'why don't you take her to Senoni'* [a local community where the patient originates] *where she comes from? Then I said, 'Sister, this is her local clinic because she is currently from Dikenywa*[41]*'. I then asked if they do not take such kind of patients and it was then when she called an ambulance. She then looked at me and said, "You guys go all around the community to collect patients like these ones?"*

Malume recalled the following incident testifying to the bad treatment received from staff at clinics and hospitals: *"I still remember we once accompanied one male patient and we were even told that 'it does not mean that if you are caregivers you will be treated special, you must queue just like any other person'…This is the kind*

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[41] Dikenywa is a pseudonym for a local community where the participant was staying.

of treatment that we get from professional people, those people whom we are actually doing a job easy for them. Professional people whom when you accompanied a patient and the patient vomits, they would expect you to clean it. You would even see the person moving away to show you that it is your job to clean. So, they look us down as caregivers and they discourage us a lot".

Mokete also described the negative attitudes towards care workers as a challenge in her work*: "…people sometimes need some special attention such as being accompanied to …clinics. Then we would take them there personally …the treatment is bad. When you get there and introduce yourself and say you accompanied the patient to get some treatment and ask them to assist him/her so that you can take him/her back home because others are waiting for you in the field, then they will say you are not special, and you must wait just like any other person on queue and yet you are on duty like any other professional. So … we are not recognised at all! We are just treated like any other person who accompanied their patients.* He recalled one incident: "*we waited for hours and hours without getting any help and ended up leaving the patient with one of the relatives…because…we tried to seek some help but we could not…they see caregiver as nothing who cannot tell them anything because he is not even a professional".*

Nakedi admitted: *"And when we get to the clinic they would start by shouting at us. They know that we are responsible for that area where the patient comes from and they would start shouting us and asking where have we been when a patient deteriorates up to this extent. And you know how nurses are; they would start shouting at you before they go to the patient. Where have we been when a patient doesn't come to fetch treatment?"*

Adequate support from nurses and community care workers around the areas in which HBCGs work is the main factor which motivates their willingness to care for PLWHA in the future (Singh et al., 2011:843). In a South African study, which considered adherence to TB therapy for HIV-positive patients, Rowe, Makhubele, Hargreaves, Porter, Hausler and Pronky (in Duckert & Vaagte, 2011), recommended that for a good service with maximum adherence to treatment to prevail, there should be a welcoming clinic environment for HIV-positive patients which ensures their

confidentiality, encourage staff to be friendly and supportive and to streamline services to avoid long waits.

Given the participants' accounts, it is apparent that, for them, this type of environment remains a superstition so-called by Rowe et al. (in Duckert & Vaagte, 2011). My participants' experiences concur with those of the HBCGs who took part in Schneider et al.'s (2008) South African longitudinal study aiming to document and evaluate the implementation of ART rollout in the Free State province where it was found that relationship with other healthcare workers was bad, with some even expressing intentions to quit care work altogether. Like the participants in my study, some of the participants in Akintola's (2005:21) South African study of the role of volunteers in mitigating the burden of HIV and AIDS care in households and communities in KZN also shared the experiences of having to wait long in queues at the clinics with bedridden patients while some patients whose areas did not have a local clinic were refused help and referred to clinics further away. The disregard displayed by some of the nursing staff for the care work rendered by my participants resonates with a similar experience by the participants in Rödlach's (2009:426) Zimbabwean study of the motivations and concerns of HBCGs caring for PLWHA in Bulawayo townships. Some of the HBCGs in this study felt disregarded by the clinic staff to the extent that they felt the clinic staff did not trust them, nor appreciated their work.

In spite of the challenges my participants experienced, and the literature quoted about the negative treatment of HBCGs from nursing staff and at clinics, there are traces in the literature consulted that point to the fact that HBCGs do receive support from the clinic staff (Fynn, 2011:117; Singh et al., 2011:843; Motswaesele & Peu, 2008; Schneider et al., 2008; Akintola, 2005:12-13). In their study which focused on the changing roles and relations of care among HBCGs in Zambia, Cataldo et al.'s (2015:10) HBCGs reported a close relationship with clinic staff who appreciated their work and believed that it made their work lighter. Similarly, Motswaesele and Peu's (2008) South African study of the experiences of HBCGs caring for PLWHA conducted in North West in the Odi district highlighted a positive relationship that HBCGs had with their patients along with support they received from the local clinics. In another South African study, which looked at "stigma, burden and willingness to

care among HBCGs of PLWHA in home-based care" in KZN, Singh et al. (2011:843) report that HBCGs not only experienced support from the nurses and community care workers from the clinics, but they also expressed their willingness to continue to provide care and support to their patients because of the availability of clinic personnel. Although some of the HBCGs who participated in Fynn's (2011:117) study of the experiences of social support among volunteer caregivers of PLWHA in Ethekwini municipality, KZN, South Africa, reported that HBCGs who were known to the clinic staffs were given preferential support treatment, all caregivers reported that they generally received support from the clinic staff.

- **The negative attitudes of other professionals as a challenge for the HBCGs**

Two of my participants, Vanessa and Viola, highlighted the negative attitude of other professionals as a challenge.

Vanessa explained: *"They see us as stupid...Because when you make a referral, it's like, 'agh what are those again…because that person has been coming, so what report do you need from me?' It's like from higher sending a report down. It's easy to do that. They don't find it easy to send a report down...We are just people that knock on doors. We don't have qualifications to knock on doors. We don't need them…you must know some of us come into the field with no education at all or training…They look at you like you want a report. Who are you? Then if I tell my boss, if I tell him, 'can you please request this thing* [referring to the report]'. *He will get it now-now, no questions...They think because you sit there the whole day, you don't have to do, you're stupid, you only know how to push that wheelchair".*

Viola, in her account, did not only refer to the negative attitudes of other professionals, but to those of government officials as well*: "Even the government does not care about us…They don't care. Like let's say a care worker dies, you won't see any one from department at the funeral of that care worker but if a nurse dies they will come and we working harder than nurses…I think we are not visible or maybe is it because we are not registered, I don't know… and we working harder than nurses at hospital, nurses ask for the medication, doctors check the patients, us*

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… at the field we have to pick them, bath them, change their nappies, feed them until they recover, then take them to the hospital, and also we walking under the hot and rainy weather. We do not have a transport to take us to the field, if you get a patient having injuries you have to use your own airtime to call an ambulance and sometimes that patient doesn't have food and it has to take its medication, you have to take your pocket money for lunch and buy her food, you understand".

Professionals who undermine HBCGs and their role in communities have become one of the main concerns for HBCGs. For Uys (2002:102), this undermining attitude is attributed to a lack of assertiveness on the part of the HBCGs, a claim which could not be confirmed in my study. In the study (Uys, 2002:102) that describes the practice of HBCGs caring for PLWHA at the South African Hospice Association's seven sites, some of the participants declares that when they had to fetch medication for helpless patients the nursing staff at the clinic turned them away saying that patients had to come themselves to collect even if it meant that the HBCG had to carry them (Uys, 2002:102). Hermann et al. (2009:3) write that, in many instances, HBCGs found themselves working with professionals who generally undermine their crucial contribution because they occupy the lowest level in the health care system. Schneider et al. (2008:184) relay from their South African longitudinal study on the implementation of ART rollout in the Free State that patients often call a HBCG caring for them "sister" implying the status of a nurse, irrespective of the nature of their training as a nurse. Some nurses would interpret this as a good relationship with their patient, whereas others could be aggravated whenever they heard this being done. In the same research, it is reported that HBCGs find themselves being turned away from staff meetings where practising nurses are involved simply because they are HBCGs (Schneider et al. 2008:184) - clear evidence that in some instances the HBCGs are neither recognised nor appreciated.

- **HBCGs' challenges when working with social workers**

Social workers are among other role players who are involved in the caring process with HBCGs (Bennett et al., 1996:149; Cameron-Taylor, 2012:15; Akintola, 2008:362; Gwyther, Altilio, Blacker, Christ, Csikai, Hooyman, Kramer, Linton, Raymer & Howe, 2008:88; Arno, 1986:1326). It emerged during the interviews that

one of the issues that HBCGs did not like was working with social workers. Paul and Vanessa were particularly vocal in expressing their frustrations when it came to working with social workers.

Paul, who particularly hated working with social workers, provided a comprehensive account of the challenges he encountered when working with some of them: *"I hate to work with the social workers, especially those from the government departments and the hospitals because they always know better and they don't know the background of the patient. There was one social worker who was busy with PhD in supporting HIV-people. She was so jealous when her patients phoned me in the afternoon as she was only working from seven o'clock to twelve. She said but is my patient and I said but is also my patient and I supported him for five years because I referred him to the hospital. Social workers don't want to work with the community; they don't want to work with care workers. They pretend to but they don't really want. They want to be in control and arrange things".*

Vanessa, in substantiating this category stated: *"But the social workers, otherwise I feel should be the ones serving us to serve them* [referring to PLWHA]. *But if we have to go out there and say this and that and that a caregiver needs, you can forget it because they're going to say it's demands…They* [the social workers] *need to leave the office. They need to come into the field. Yes, we know they're qualified. Before they got qualified they started out to work these communities…They were here in these communities with us. As soon as they qualify, you don't see them anymore…They're not in communities. We are the ones that do the referrals. We are the ones that do the ground work, and when we see we can't continue any further we've to refer…But on the other hand, I'll tell you about caseload…Or maybe it's a demand from the Department…I don't see why they (social workers) have a problem to come to the community…And even when you call them, they tell you about the car, but when they were studying they walked to us. Every day they walked, they rode the train. Now when you call them and they work for the Department of Social Development, they tell you there's no car available. They will come when there's a car available. And even so, when the car is available they might even forget about you. Then you have to start follow-up again…social workers don't help us, they don't. They help themselves to a qualification, better standing in life, and then it's like the*

easier cases get handled…Our OVCs become a big problem to us, because they don't do their follow-ups. Then those OVCs then fall on us. And especially if it comes to HIV/AIDS we find many of our children orphaned, and what the families are doing, they got clever with the foster care grant, so they're going all into that route, and the children are the ones that are suffering…And social workers are not following up. They're not doing follow-up. They are begging us to follow-up".

Ideally social workers are presumed to play a critical role in palliative care through their commitment to social justice and providing expertise perspectives, knowledge and skills, rendering support and education, intervening professionally with patients, families and interdisciplinary teams with the overall aim of eradicating health disparities (Harper, 2011:22; Hunt & Maasdorp, 2009). From Walters and Watts' (2011:510) observations, the social worker plays a crucial role of liaising with others to address the dehumanised relationship between health professionals and patients. Paul and Vanessa's challenges experienced with social workers in their HBCG roles echo Hunt and Maasdorp's (2011:557) contention as they state that social workers are not being perceived as part of an integrated health care system, but as a luxury service. Resulting from this is also an improper understanding of the social worker's role and the underutilisation of social workers. The fact of the lack of support from social workers highlighted by Vanessa and Paul is also confirmed as one of the findings in Kang'ethe's (2008) study. In this study concentrating on the challenges and bottlenecks resulting from referral systems and the effectiveness of caregiving by HBCGs caring for PLWHA in Botswana and Kanye, the HBCGs reported that they did not receive adequate psychological and emotional support from health care providers and social workers.

3.3.2.7 Sub-theme: HBCGs' challenges in relation to their own organisations

Some of the challenges care workers voiced concerned issues in their own organisation that they encountered in their daily operation. These are divided into the following categories and presented below: lack of transport; lack of a decent stipend and training; limited resources; the protocols care workers must adhere to; care workers who disclose patient's status; working alone; working with social workers; and management's attitude.

- **HBCGs' challenges with lack of transport**

Some of the patients who are serviced by HBCGs reside in areas that are located few kilometres away from HBC organisations, and this becomes a challenge for HBCGs whose organisations do not have means of transport they can use. For these HBCGs, they either must walk to reach these patients or use their own personal money to pay for public transport. This challenge was raised by Mpshe and Amelia.

Mpshe stated: *"The first challenge that we had was transport to reach them. Knowing that I have four patients who are all bedridden and that they are all scattered, it was a serious challenge for us…"*

Amelia spoke about this challenge along the following lines: *"We walk long distances in the sun. Sometimes when it rains, we are forced to seek shelter where we can find any. We know that patients need our attention but we also need to keep ourselves safe so that can we can continue to serve the community".*

One of the main advantages of the availability of HBC services for communities is that it reduces the cost of transport for the patient and their family members (Kohli et al., 2012; Motswaesele & Peu, 2008). This means that the money which was to be used for transport will now be saved to address other family needs. Paradoxically, this relief for the patients and their families' transport costs results in some challenges for HBCGs, who are confronted with a transportation challenge to reach out to these families that are, in most cases, scattered at some distance away. Sometimes they must take patients to the clinics and have to accompany them (Davids et al., 2009:3).

This challenge of lack of transport as one of the concerns highlighted by participants is also articulated in the literature consulted (Valjee & Van Dyk, 2014:6; Takasugi & Lee, 2012:842; Campbell et al., 2008:510; Motswaesele & Peu, 2008:28; Akintola, 2005:21; Mohammad & Gikonyo, 2005:14). In their Kenyan study to ascertain the drivers of volunteers to volunteer their services, Takasugi and Lee (2012:842) report that a lack of transport was a particular challenge when HBCGs had to work in rainy

seasons and during the night. For some of the participants in Akintola's (2005:21) South African study of the role of volunteers in mitigating the burden of HIV and AIDS care in households and communities, the lack of transport coupled with the distance between a clinic and the community it served forced some HBCGs to resort to transporting patients to the clinics on their backs or in wheelbarrows.

In addition to the lack of transport, HBCGs have to deal with the additional challenge of getting to patients in dangerous areas in some instances. In their South African study Campbell et al., (2008) investigated factors likely to facilitate or hinder the mobilisation of community resources in Entabeni in KZN. They reported on instances shared by HBCGs where ambulances could not enter some parts of the community as drivers feared being hijacked resulting in some patients being carried in wheelbarrows or on people's backs to get to places where ambulances could be reached. This danger could also be a risk for HBCGs.

- **HBCGs' challenges with lack of training and low stipends**

Selinah, Lenyalo and Mokete's accounts gave rise to this category.

Selinah felt that her seniors were not taking their training needs seriously when she shared: *"… as I indicated that they do not take our work seriously. They could have supported us to study further. Our CEO would come and tell us about his network from other places including the SETA. He is also one of the committee members at July[42] hospital. He once promised us that he would train us for auxiliary and years went by. I don't know why. What's boring me about this work is that caregivers are not improving. You can take fifty caregivers you would find that only one has progressed. …It destroys your morale because even when you visit patients you do not go with that passion. You just go and work. We no longer have patience with our clients, where we would sit and ask them how they feel and things like that. I just go and look at him and write report. I do not do my job the way is supposed to be done because I am discouraged"*.

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[42] The hospital's real name is substituted using a pseudonym to maintain is anonymity as a participant.

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For HBCGs to provide the required care and support for their patients and their families some form of training on how to perform this service is necessary (Duckert & Vaagte, 2011; Walters & Watt, 2011; Steinitz, 2003; Gilson et al., 1989:524). Lack of training and poor training has been a concern from as far back as the late 1980s in which HBCGs from countries like Botswana, Colombia and Sri Lanka received inappropriate training and/or training that was either too complicated or which lacked practical components (Gilson, et al. 1989:524).

Training does not only contribute to ensuring delivering of a quality service, but is also a motivational factor to build HBCGs' confidence (Cataldo et al., 2015; Valjee & Van Dyk, 2014:2; Takasugi & Lee 2012:843). In Takasugi and Lee's (2012:841) Kenyan study, one of the drivers that led to people volunteering is the provision of training for HBCGs. From valuable training they would gain confidence in their skills and knowledge and this would then contribute to improving the health of their communities. For Wringe et al. (2010:5), training is one of the significant strategies to ensure a HBCG's credibility and legitimacy both in the communities in which they work and within the established health care systems. Without training a HBCG could feel unappreciated, not valued and demotivated (Mutale et al., 2013; Greenspan et al., 2013; Akintola, 2005:21; Marincowitz et al, 2004). Hermann et al. (2009:3) not only calls for training for HBCGs, but for the use of standardised guidelines that would ensure that HBCGs are equipped with a practically oriented training that integrates communication and counselling skills.

Acquiring new skills through training builds confidence and creates some form of recognition which would foster appreciation of the work of HBCGs and, in some instances, be a substitution for direct financial reward (Takasugi & Lee, 2012:843).

It therefore becomes understandable for participants like Selinah, who in addition to the lack of training, also added her dissatisfaction with the low stipends as a challenge and stated: "*… our stipend is very low … Other caregivers from other organisation are also complaining about things like stipends … Mostly we would meet as caregivers at the workshops organised by FPD where we would develop some friendships and start talking about things like stipend and then we would*

compare ourselves with others and eventually realise that we are all working in this bad conditions". Mokete and Lenyalo had the same opinion.

Mokete spoke about the low stipend he receives and its demoralising effect in this exert: *"Well sometimes because of pressure you can even thought (think) to go because when we talk about stipend, we are talking about something which is not sustainable because it does not have any increase and there is no benefits…I even thought about that because sometimes there is a lot of stress and…I even thought of finding another job because this thing that I am doing is straining me because it puts stress on me because I see one and the same thing every day. Always when I go out I will be dealing with the case of a human being and is difficult. Sometimes it would be better if you were operating a machine somewhere because the machine is straightforward. Unlike a human being whose problems eventually affects you."*

Mokete's confession about jumping ship due to the low stipend and its demoralising effect on him is not in any way peculiar. Marincowitz et al. (in Akintola 2010:2) describe a picture of what happened in Limpopo, South Africa when 27% of the group of HBCGs in their study who cared for PLWHA were just like Mokete and generally dissatisfied ended up quitting the , while an additional 5.5% become inactive within twelve months of receiving training.

Lenyalo contributed to the discourse around feeling dissatisfied with the payment care workers receive by explaining: *"Caregivers are earning very little money and at the end they end up saying, I work very hard but I do not earn enough. I end up feeling discouraged and telling yourself that is just the same, why am I not just sitting and not go there. So, you get bored when to go to the patients and as you get there you find that you are just like the patient who is also hungry, you have been walking in the sun, and you do not have money for transport".*

The lack of training and remuneration my participants highlighted was also emphasised in Wringe et al.'s (2010:5&6) literature review on existing HBC programmes, as some of the factors contributing towards unfavourable working conditions of HBCGs that led to poor retention of this workforce. The dissatisfaction was also reported in the studies of various other researchers (Cataldo et al., 2015:6;

Valjee & Van Dyk, 2014:6; Takasugi & Lee, 2012:842; Mohammad & Gikonyo, 2005:14). The prospect of training and the expectation of a decent stipend or any form of reward could, in turn, nurture commitment on the part of the HBCGs who would now begin to take their work more seriously because it is more like that of nurses and other health care workers (Cataldo et al., 2015:5; Zulu et al, 2014). Mohammad and Gikonyo (2005:14) too confirm that HBCGs respond positively with commitment whenever they are satisfied with their remuneration. In a study conducted in Zambia by Cataldo et al. (2015:4), on the roles and relationships of care among HBCGs, it is emphasised that the acquisition of new knowledge raised some expectation of monetary and material reward. Thus HBCGs begin to see their work as more on par with formal health care workers who receive duly paid remuneration. The absence of wages, Glenton, Scheel, Pradhan, Lewin, Hodgins and Shrestha (2010) point out, will jeopardise the existence and sustainability of the very aim of the HBC organisation's existence.

The gloomy picture my participants painted and which research and literature confirm as quoted, is, however, not the norm. A South African longitudinal study conducted by Schneider et al. (2008) in the Free State explored and evaluated the implementation of the ART rollout not only underlined the availability of ongoing training for HBCGs, but also accentuated the efforts to standardise their remuneration and create career paths for them.

- **HBCGs' challenges with limited resources**

Limited resources within their organisations challenged Viola, Selinah and Mokete and hampered their performance in their care work.

Selinah referred to the challenge of limited resources along the following lines: *"Just … last week the manager came to tell us that we must go back to the TB patients and come with some reports. We never had a problem of going there; the problem is that we do not even have equipment for visiting a TB patient. We do not have protective masks, we do not have the scale, and we do not have a BP* [blood pressure] *machine. You just go to the patients and check him/her with your own eyes and write a report. We once went to a patient and did the same. The next day when*

we go, the daughter said we must stop coming to her, because they just ask me how I am feeling and write and leave. And we do not have a nurse who can at least go with us … As you arrive at work you find that there is no one who can listen to your challenges. So, the next day we visit the same household. Obviously, they will never welcome us because we are just there to ask them how do they feel".

Viola' voiced her challenges in connection with limited resources as follows: "*…many people are sick and we don't get ambulances when we need them urgently especially when one is critical and the hospital can't send us an ambulance, so sometimes a person dies in our hands and family think that you the one who have killed her, those are the challenges we meet and also we need material".*

Mokete who found himself helpless and frustrated by his inability to address the needs of his patients due to lack of resources stated: *"… like for instance when they* [the patient] *start to have some social problems like lack of food and you want them to eat so that they can take treatment - I find myself encouraging him/her to eat but he does not have any food to eat. So, it gives you stress because you want him to eat but there is no food. Maybe sometimes when you try to connect to the social workers for aid like the social grant so that he can get some food you are still confronted by a long process. You need to go there and maybe she will not get such help here and now and you cannot provide such kind of help …I feel very bad because that means I have failed to help that person because the resources are not enough and they are limited…When I come, she may expect another bread which I may not have at that moment."*

Limited resources have not only become a challenge among the HBCGs who work with PLWHA, but are also rather a general problem within the overall health spectrum (Akintola, 2010:2; Campbell et al., 2005:808; Orner, 2006:236; Ncama, 2005:33). It is therefore not surprising that HBCGs in this study reported that they work under resource constrained conditions that affects their work negatively. Limited resources, which are so characteristic of the context in which caregiving is provided, in turn, prolong and exacerbate the caring period (Cataldo et al., 2015; Davids et al., 2009; Rödlach, 2009; Watermal in Wringe et al., 2010:5; Orner 2006; Akintola, 2005:13-22). As described by Kohli et al. (2012:1), the impact of HIV and

AIDS on community resources places a huge burden on the HBCG. HIV and AIDS may erode the economic status of the family due to the medical costs and other demands that may be required to care for the patient, leaving the family without economic means to address some of their needs (Campbell & Foulis, 2004).

Once available resources are depleted, the HBCG, in many instances, becomes the one who must plan to ensure that the patient is not negatively affected. In such a case, a family may turn to the HBCG who may also come from an organisation that lacks adequate resources, thus unable to offer further assistance. A Tanzanian study by Pallangyo and Mayers (2009:486) investigating the experiences of caregivers in Dar es Salaam, reveals that, in some situations, patients find themselves unable to have access to meals due to poverty. It is in this situation that a HBCG is expected to plan to ensure that the patient has eaten before taking prescribed medication. In situations like these, HBCGs may end up having to use their own resources for the patients' benefit (Cataldo et al., 2015; Ama & Seloilwe, 2011:57; Rödlach, 2009).

Lack of resources to perform HBC activities like not having HBC-kits, drug guidelines, training manuals, personnel and training material are just some of the resource-related challenges HBCGs encounter (Mohammad & Gikonyo, 2005; Davids et al., 2009). The lack of such resources may result in a lack of trust in the community regarding the HBCG's level of health services; they lose respect and credibility in the community (Takasugi and Lee, 2012:842). It is also a situation that diminishes the HBCGs' motivation at all levels.

This state of affairs is confirmed in a literature review by Wringe et al. (2010:5) on existing HBC programmes and the possibility of their expansion in the context of ART. It was found that a lack of resources can contribute to the HBCG's feelings of powerlessness, and their ability to appropriately and continuously address their patients' needs. This severely impedes the quality of their service delivery. Steinitz (2003) advocates that resources should be available that HBCGs in order to make a valuable contribution to the community through their commitment to their work and earn the recognition in the community as being skilled.

- **A HBCG's challenge with organisational protocols**

Dineo highlighted the protocols laid down by the organisation as a challenge. These limited her in trying to fully exercise her duties effectively: *"What I do not like is the protocols. Things like, one is not supposed to be too emotional. Like we are told that we must help the patients but we should not overdo it. For example, when we go around the community, we go with some purses with money and you will find a patient who needs financial assistance at that time. Before you can provide such help, you need to go back to the office to report first so that you can get authorization. When you check is Friday and you will only come back to the patient on Monday, once I take money and give the patient without permission, I will be disciplined. So, that is the main thing that I hate…Is something that I cannot change, is how we should work. It is an instruction from our authorities. Sometimes you would find that we are distributing food parcels and you would meet a patient that you feel deserve more than one and once you give more than one you will be in trouble"*.

Dineo's sentiments mirror Cameron-Taylor's (2012:94) assertion that sometimes HBCGs feel as if they are in a battle against the wider health care system for the patients' goodness. This is particularly understandable when HBCGs have to follow a prescribed bureaucratic process. Frustrations around the protocol to be observed by HBCGs were one of the experiences found in the South African study on occupational stress among the HBCGs (Van Dyk, 2007:58). Participants were frustrated by the bureaucratic process which made it difficult for them to address some of their patients' needs. A similar challenge was also voiced by HBCGs in Zulu et al.'s (2014) study that explored the motivations of volunteers to engage in voluntary work in which the issue of following protocol was highlighted as one of their challenges. They were particularly concerned about the delayed communication of important information by their seniors whose actions ended up demoralising them.

- **HBCGs' challenges with the way their organisations were managed**

Selinah, Mpshe, and Segwagwa experienced the way their HBC organisation was managed as a particular concern.

Selinah expressed some concerns about management's attitude towards the care workers and their lack of support*: "Friday was supposed to be day of the caregivers but it is not happening. We would just stay here and talk about our own issues until we knock off at 14:00 … It was supposed to have a representative from management who would ask us about our weekly challenges and how did we overcome them and offer some necessary support. So, there is no one who would come and ask how our work throughout the week was. So, they don't care about what we are going through. There was supposed to be a debriefing day where we would go out and get some counselling but that as well is not happening. You just come to work and knock off every day without any support system… I think is management. I am not sure why I am saying that but I think is them. They do not inform us with anything. Previously they would say, the Department of Health says it does not have funding for that but as you hear from other organisations, they get funding for that. So, we get confused because we are funded by one Department of Health. That is why I am saying is because our management does not care".*

She later in the interview referred to another frustration with management when stating: *"For example, our stipend is very low and it happened that during December we were working through skeleton staff and only to find that only caregivers were here. There was not management and I think is wrong for employees to be at work while part of management is not here. When we try to find the reasons for that in January we were told that management was not supposed to be here and there were no reasons provided to you. Then we just kept quiet and left it there".*

Mpshe expressed her dissatisfaction regarding the way the organisation was managed: *"We don't reach their goals as a company and they expected to achieve certain things. But we are still delivering the same service that we were delivering to the communities …They are busy asking us what we want and what we need through questionnaires. They do communicate with us but through questionnaires*

and we write and we don't get feedback from those questionnaires. I have spoken about debriefing for two years now [as] *the kind of debriefing that they are giving us is not working. Always when I leave that room* [the debriefing room] *I come out having invited everything in my life because that debriefing asks you about your personal life, the experiences that you meet along the field in the community as we do our work. So, once I integrate my personal life and the work that I am doing, I feel overloaded. So, I did explain this several times in the meetings and I feel that they do not meet our needs"*.

Segwagwa, for instance, found management's attitude towards the caregivers as disheartening: *"is about the team that you are working with. Especially people who are on top of you...Management yes, they are the ones who exerts pressure on us and to work under pressure is not nice while a lot of work is being done by you the carers...Is like once you do a mistake, they oppress you and when you do a good thing you are not appreciated. Once you come up with some suggestions to improve service, they only get happy when it comes through them. You are nothing you are just a mere caregiver"*.

The challenge in connection with the organisation's management, their attitudes to and lack of support of their HBCGs is confirmed in the literature consulted (Zulu et al., 2014; Wringe et al., 2010:5; Kang'ethe 2008:361; Dieleman, Biemba, Mphuka, Sichinga-Sichali, Sissolak, Van der Kwaak and Van der Wilt 2007:145). Wringe et al. (2010:5) found in their literature review on existing HBC programmes and the possibility for their expansion in the context of ART, that HBCGs did not receive any supervision and that resources and time were insufficiently allocated for regular meetings. Hermann et al. (2009) too point to neglect of managerial support and supervision to HBCGs, and underscore the fact that good supervision and necessary support are imperative for the success of any HBC operation. However, and on the flipside, Kang'ethe (2008:361) and Dieleman et al. (2007:145) report that HBCGs are favoured by their management team who even ensure that they receive the required support.

The work-related challenges mentioned by the participants with reference to their employer organisations and working conditions impede on the aspects of self-care

and role support known to be enablers to help the caregiver cope with the caregiver-receiver dyad put forward in the middle range theory of caregiving (Williams 2014:311). Specific issues are low stipends, lack of resources, supplies and transport. Self-care is, amongst other benefits, facilitated through the provision of resources and supplies to both the caregiver and the patient, to enhance the relationship between the HBCG and the patient.

In Chapter One (sub-section 1.2.1), I indicated that role support can be realised through competent and compassionate care that ensures that financial obligations for both the caregiver and the patient are met. In this context, the participants' concerns about their low stipends and the need for training is a cry for good role support to enable them to be better equipped.

- **A HBCG's challenge with racial segregation in her organisation and its resultant effect on her**

This category is reflected in **Segwagwa** sharing of her storyline: *"I feel like, we are all working here as blacks and the whites remain in their offices and they don't see what we are going through. The white caregivers work in the white communities and they are very supportive to their white fellows. We as blacks we are trying but we cannot do things ourselves. We still have to come back to them and seek help for what we get out there. We get hurt almost every day because of what we encounter in the field. But when it comes to support they would say we are troublesome. So, we end up sitting with our own problems…They must mix us. Maybe if we go out with the whites, our management will hear their complaints and assist us":*

Racial segregation in the HIV and AIDS context has been well documented particularly among PLWHA themselves (Bharat, 2002:1). Despite some evidence of the existing racial segregation within the HIV and AIDS context, Segwagwa's experiences could not be confirmed or contrasted as relevant literature on racial segregation particularly among HBCGs within their respective organisations was not available. Among some sections of the literature consulted in relation to this category was Ukocki's unpublished dissertation (2007) which considered caregivers' decision making, experiences and perspectives in which he cited Bregal and Song who argue

that when caregivers caring for people with chronic and mental illnesses did not have access to any forms of support, the barrier experienced was not necessarily due to race (Ukokhi, 2007:36). In another study focusing on vulnerabilities and caregiving in an ethnically diverse HIV-population in Manhattan, US by Moody, Morgello, Gerrits and Byrd (2009:8), they report that white caregivers receive wider support networks as opposed to their black counterparts.

3.4   CHAPTER SUMMARY

This chapter introduced the reader to some of the research findings of this study. The demographic characteristics of twenty-five HBCGs who took part in this study were presented in Table 3.1. The chapter revealed that HBCGs who took part in this study were mainly black women between twenty-four and fifty-eight years of age and therefore supported by some of the findings already in the body of literature of this field of study. HBCGs were reported to be mainly those with a poor economic background and affiliated to various forms of groupings like the church and different support groups.

This was followed by a discussion of such characteristics to compare and contrast them against examples from existing literature. An overview of all the nine themes, thirty-one sub-themes and fifty-five categories is presented as Table 3.2.
In this chapter, the first two themes were presented.

Theme One addressed the HBCCs' accounts of their motivation to care for PLWHA and was presented under three sub-themes: HBCGs' desire to help people as their motivation; HBCGs' personal experiences as their motivation; and opening up a career path as their motivation along with its five categories.

In Theme Two, the focus was on HBCGs' work-related challenges in caring for PLWHA. Theme Two was presented along with its seven sub-themes that addressed the HBCGs' experiences in relation to the challenge of negative attitudes held by some community members; the patient-related challenges experienced; challenges in relation to the patients' relatives; challenges in relation to working in unsafe

conditions; challenges concerning colleagues; the attitudes of other role players; and the HBCGs' challenges in relation to their own organisations.

All these themes, sub-themes and categories were substantiated by direct quotations taken from the transcribed interviews conducted with the participants and discussed in detail using some existing literature as a form of literature control. What emerged varied in that, in some instances, the findings confirmed what had already been found by other researchers; while in other instances it emerged that the findings were rather contrary. The points covered in this chapter were summarised in a form of a chapter summary which served as a chapter conclusion.

In the next chapter I present the second part of the research findings with specific attention being placed on the experiences, coping strategies and suggestions made by HBCGs in caring for PLWHA.

CHAPTER FOUR

RESEARCH FINDINGS (PART TWO): THE EXPERIENCES, COPING STRATEGIES AND SUGGESTIONS FOR SOCIAL WORK SUPPORT

4.1 INTRODUCTION

As indicated in Chapter One (Section 1.11, format of the research report), in this chapter the remainder of the research findings are presented and the focus is on the caregivers' feelings and emotional reactions to their care work and its related identified challenges. Their experiences, resulting from the attitudes of their friends, families and members of their communities, and the participants' suggestions on how these work-related challenges of HBCGs can be addressed, are also presented. Before concluding the chapter, the findings related to how the HBCGs coped with their work-related challenges, and suggestions for Social Work support are discussed.

4.2 A CONTINUATION OF THEMES, SUB-THEMES AND CATEGORIES THAT EMERGED FROM DATA ANALYSIS

In the next sub-sections, I present the remaining seven themes that emerged from the process of data analysis along with their sub-themes and categories.

4.2.1 Theme three: HBCGs' accounts of their feelings and emotional reactions to their care work and its challenges

Caring for PLWHA is, by nature, an emotionally, physically and socially stressful exercise (Koto & Maharaj, 2016:55; Abasiubong, Bassey, Ogunsemi & Udobang, 2011:494; Land 2010:312; Makoae, 2009:21). Whereas the strength-based perspective regard emotions and physical scars as testimony to difficulties through which human beings have to go, it also acknowledge that these tribulations are necessary for caregivers to have a few life lessons which, in turn, will help them proceed with their lives (Saleebey, 2013:15; Saleebey, 2006:13; Saleebey, 2002:11).

It is out of these difficulties that caregivers grow, become capacitated, knowledgeable, insightful and stimulated to address their communities' demands (Saleebey 2013:15; Saleebey, 2006:13-14; Saleebey, 2002:11). This essentially means that, for researchers who explore any phenomenon from the strength-based perspective, the participant's expressed emotions should be understood as some form of the aftermath of their stressful experiences that somehow gives them strength to continue with their lives and enables them to overcome future similar challenges.

Unlike the strength-based perspective, the coping theory regards expression of emotions as a form of coping, or a coping strategy (Lazarus & Folkman, 1984:150). One of the premises on which coping theory is founded is that hardships are dealt with through an appraisal process which aims to change the meaning of the situation (Frydenberg, 2014:83; Ntoumanis, Edmunds & Duda, 2009:249; Laux & Weber, 1991; Lazarus & Folkman, 1984:150). Thus caregivers, out of their agonies, still express positive emotions like happiness which enables them to see their daily tribulations as an opportunity to be empowered so that they can conquer future challenges.

By focusing on the aspect of participants' feelings towards their care work and its challenges, I noticed that the emotional return for this investment of caring for PLWHA, and the work-related challenges experienced were predominantly expressed as negative feelings and emotional reactions. This led me to present the findings related to this theme under the following two sub-themes:
- HBCGs' negative feelings and emotions associated with caring for PLWHA and their work-related challenges
- HBCGs' positive feelings and emotional reactions associated with caring for PLWHA and their work-related challenges

4.2.1.1 Sub-theme: HBCGs' negative feelings and emotions associated with caring for PLWHA and their work-related challenges

From the participants' responses to the question on the feelings experienced in relation to caring for PLWHA, this sub-theme focuses on the aspect of HBCGs' negative feelings and the emotion associated with caring for PLWHA and their work-related challenges. The seven categories into which this theme is divided are presented next.

- **HBCGs' feeling of sadness about their care work and its challenges**

To care for PLWHA saddened Kgomo, Pekwa and Malume. The following extracts reflect this:

From **Kgomo:** *"Even now I have a patient that I cared for since around 2011 or 2012, whom I bathe daily and she has been on bed since then... she is very thin now… I don't feel good at all… So, I feel sad. Most of the times when I leave my home to work, she is the first person that I start with. I must change the nappies and everything and sometimes I also get tired. Last time I was sharing with colleagues that if I skip a day or two, the day on which I will go there she would be worse. The worse thing is that her children are still small … So, I always feel sad about her and whenever I look at her I feel like she cannot make it any longer"*.

Later **Kgomo** reiterated the feeling of sadness*: "They* [referring to patients] *are many; some I would be wondering about them thinking about how we had a good relationship before she became ignorant and ended up having unsafe sex. Some were most intelligent and understood the programme very well. I feel very sad…".*

From **Pekwa**: *"It is sad because this person* [referring to the patient] *does not want to stand up* [Meaning she does not want to recover], *she doesn't want to see herself/himself one day caring for other people like I am doing"*.

From **Malume:** *"…there will be a time where you will do some visits and you would see that here is the patient and when you ask, they would say, 'I will call you when I'm bad'* [meaning the patient will only call them when their condition deteriorates]*. But we* [referring to the caregivers] *do not give up; we would come until we find a funeral tent and be told that the person has died…It's very sad. We would just come and report it"*.

This same feeling of sadness Kgomo, Pekwa and Malume experienced when caring for PLWHA is confirmed in other studies (Makoae, 2009:21; Van Dyk, 2007:54; Koto & Maharaj, 2016:55-56). It is also reported that seeing a patient's deteriorating health was a sad experience and even tended to erode caregivers' courage to continue to care for PLWHA. Makoae's (2009:22-23) participants were saddened by the clearly visible bones and veins exposed on their patients when they were in a critical stage of AIDS. The study reported on the experiences of HBCGs caring for the bodily care of PLWHA before the introduction of ART in Lesotho. From a South African study (Van Dyk, 2007:54) on occupational stress among caregivers of PLWHA, the participants mentioned that they were saddened by the pain and suffering their patients had to endure, and they wanted to salvage or save them. Koto and Maharaj's (2016:55) caregiver participants were saddened by the fact that they were caring for people living with a condition for which there was no cure. Their study in Lesotho explored the difficulties caregivers faced; some of them were discouraged when they had to witness the deterioration of their patients (Koto & Maharaj, 2016:56).

- **HBCGs' feelings and emotions of discouragement because of caring for PLWHA and their work-related challenges**

Apart from the feeling of sadness reported, Cassie, Selinah and Lenyalo mentioned feeling discouraged from caring for PLWHA and the work-related challenges they experienced.

Cassie explained how discouraged she was after witnessing some of her patients dying: "*You take care of this person and when you come back you find that the person is passed on. 'Can you imagine the pain?' And yet your goal is to heal this*

people. The moment they do not get healed and die, your heart feels pain. My brother you feel very discouraged the whole day to an extent that you do not want anything".

Selinah shared her feeling of discouragement that arose because of a lack of equipment: *"It* [referring to a lack of equipment] *destroys your morale because even when you visit patients you do not go with that passion. You just go and work. We no longer have patience with our clients, where we would sit and ask them how they feel and things like that. I just go and look at him and write report. I do not do my job the way is supposed to be done because I am discouraged".*

Lenyalo, felt discouraged when her good work simply went unrecognised: *"Your spirit goes down and you become discouraged because you try to do a good thing but is* [referring to her effort to do good] *not getting any recognition. I want to help but I do not get the necessary support".*

Gleaning from the literature consulted, to feel discouraged does not seem to be uncommon amongst caregivers caring for PLWHA (Koto & Maharaj, 2016:56; Greenspan et al., 2013:8; Naidu et al., 2012:123; Van Dyk, 2007:58; Pallangyo & Mayers, 2009:487; Mathauer & Imhof, 2009:11; Russel & Schneider, 2000:16; Turner, Pearlin & Mullan, 1998:140). In her South African study focusing on occupational stress among caregivers caring for PLWHA, Van Dyk (2007:58) found that experiencing feelings of discouragement was one of the signs of burnout among the caregivers.

In another South African study conducted in all provinces except the Northern Cape to appraise community-based HIV and AIDS care and support programmes, Russel and Schneider (2000:16) found that caregivers were discouraged by the reality of orphaned children who were unable to access social grants. Reasons given were a lack of documents like birth certificates that were not available and HBCGS' work-related challenge of lack of transport to travel to Home Affairs offices to negotiate on behalf of these children. In a study conducted in Benin and Kenya among health care workers, Mathauer and Imhof (2009:11) found that one of the participants was discouraged by receiving training which was purely theoretical and the inclusion of a

practical component applying a relevant skill was missing. Moreover, a lack of equipment to demonstrate the lessons to learn was a major problem. Although Koto and Maharaj's (2016:56) study in Lesotho focused on the difficulties of health care workers' in the era of AIDS treatment in Lesotho, they too were discouraged when witnessing their patients' health deteriorating.

- **HBCGs experiencing feelings and emotions of failure due to their work-related challenges**

Cassie, Mokete and Xhathula's accounts quoted below, in particular gave rise to this category of HBCGs' experiencing feelings of failures due to their work-related challenges.

Cassie, in explaining her feelings of guilt as a result of failing in her efforts to help patients stated: *"It* [referring to her inability to assist the patient] *will end up haunting you as you could see that that person needs your help. You would feel like you have failed to help him/her although I am not supposed to force him/her to receive my help"*.

Mokete ascribed his feelings of failure to limited resources available while caring for PLWHA: *"I feel very bad because that means I have failed to help that person because the resources are not enough and they are limited. I can even see that there is nothing I can do"*.

Xhathula, in referring to a very specific experience of failed efforts to help the patient confessed: *"You feel like you are a failure. That person if you were in there you could have helped him to accept himself* [Meaning her inability to help the patient come to terms with the fact that she is living with HIV makes her feel like a failure]"*.

The utterances made by Cassie, Mokete and Xhathula correlate with the findings in the literature consulted (Chow, 2011; Clark in Bennett et al., 1996:151; Van Dyk, 2007:60). In her study done at the South African institution, UNISA that looked into occupational stress experienced by caregivers working in the HIV and AIDS field, Van Dyk (2007:60) records that her participants experienced feelings of failure and

hopelessness when most of their patients died. In addition, a feeling of failure was a common experience amongst the caregivers in this study especially when things did not turn out the way they expected. Chow (2011:99), in a study entitled "Prevention of burnout and compassion fatigue through education and training: the project ENABLE", mentions that the inability of HBCGs to cure the terminally ill caused them to feel useless - like a failure. Similarly, "a feeling of non-achievement" was reported by the caregiver-participants in the study of Bennett et al. (1996:151) who looked into the relationship between recognition, rewards and burnout in AIDS caring conducted in Texas. The feelings of non-achievement were experienced due to a high death rate among their patients.

- **HBCGs feeling sorry for or having pity on their patients**

Ching and Martin, in particular, mentioned feeling sorry for their patients and took pity on them.

Ching felt sorry for her patient when she realised that she really did not understand that she was there to help her and not to be an intruder. *"I felt sorry but not sorry for me; sorry for her* [referring to the patient] *because there are things she doesn't understand. She doesn't understand that we came to her to help her not to be an intruder so I wish she could have listened to us and understand what we talking about"*.

Martin mentioned feeling sorry for a patient who defaulted on his treatment. *"I don't feel good; I feel pity for him* [referring to the patient] *because a person lives once on this planet. So, if you decide to stop taking a treatment which will heal you and wait for someone to do it for you while you can do it yourself, that concerns me because your life is my life. In other words, if you live, you can share some ideas with me so that I can also grow in my life...I feel bad because if he doesn't take treatment, he will eventually die and as a human being your body needs to be free from pain"*.

This feeling of sorry for or having pity for their patients, Van Dyk (2007:22) also found to be the case with HBCGs who participated in her study. Her participants became so concerned that they wished they could do something to ease the pain

whenever the patient was in pain. They were also caregivers caring for PLWHA in South Africa at UNISA who were experiencing occupational stress. In the Lesotho study conducted by Koto and Maharaj (2016:55) in Maseru that focused on the difficulties faced by health care workers, the participants reported feeling sorry, especially, for their patients who were critically ill and had no one to care for them in their homes. In some instances, the compassion the carers felt for their patients led to some of the health care workers breaking the rule of not giving handouts to patients, as they felt that they could not turn a blind eye to the appalling conditions of their patients (Koto & Maharaj, 2016:57).

- **HBCGs feeling pain due to the nature of their care work when witnessing the pain and suffering their patients experienced**

This category focusing on HBCGs feeling pain due to the nature of their care work and when witnessing the pain and sufferings experienced by their patients was also deduced from the recollections of Cassie, Martin, Kgomo, Jini, Dineo, and Nakedi during their interviews.

Cassie admitted: *"This type of work is very difficult as we ourselves ended up being traumatised. Seeing people dying is very painful, my brother. You take care of this person and when you come back you find that the person is passed on. 'Can you imagine the pain?' And yet your goal is to heal this people. The moment they do not get healed and die, your heart feels pain"*.

Martin explained the pain experienced when hearing that a patient had passed on: *"My heart becomes very painful because when the message reaches others, it will be as if I have just neglected him, the family and the community in general who used to see us walking down the streets and conducting door to door campaigns telling them that we are here to care for the patients…It is very painful, especially when you remember the efforts that you have made to advise him/her to take responsibility. There is a time where some people would give themselves up and say, 'if I die, let it be'"*.

Kgomo expressed the pain she experienced when witnessing a patient's health condition deteriorating: *"It is painful because one day you will meet such person in the streets and see some changes and you would get worried that this person is slowly being eaten by the illness. Just like the woman…she doesn't look the same like when I met her earlier. She has changed and she is even thin. Last time when I meet her I even felt like challenging her and asked what the problem was and she said is because she is getting old. But I could see that she is not well and is not because of age. And she even said she once had diarrhoea. So, because I know the signs and symptoms, sometimes I feel like just going straight to her, but it's difficult".*

What filled **Jini** with feelings of pain and sadness was not the patients' pain and suffering, but rather the fact that they did not want to accept the treatment that was available. She spoke about this as follows: *"Is painful because you know very well that it helps and I have seen it. For me because I am HIV-positive myself. It makes me feel sad because they also have rights and the moment he/she says no, you don't have to force him/her. It is his/her right".*

Dineo experienced pain when seeing patients who do not comply with prescribed treatment: *"It is painful because you will find the patients suffering in silence. What we are doing is huge because unlike the clinics that only dish out treatment, we go all out to monitor if they are taking it as per prescription. You will find that they complain about being dizzy and the moment we check their treatment, they do not take it as required".*

For Nakedi, a variety of realities and challenges confronted her as a care worker caring for PLWHA. She spoke about this along the following lines: *"Some of the challenges are that you would find a woman who is a single parent with little children and she has been left alone because children went to school. You will get there and find that she has since been left on a bed. You will start by opening the curtains, windows and prepare some food and water to bath her… It is painful as you would end up seeing that this person needs a hospice as we realise that during the day we will be there but late in the night we are not there".*

She described other circumstances that pained her: *"It is painful* [referring to her experiences with households that do not welcome caregivers]. *As you leave that household you will feel discouraged although you would console yourself that you are here to work and people are not the same. So we would not lose courage, we would go to the next house because we are here to work and we are here to help the community. We don't care about those who don't want us, one day they will need us. Many of them used to chase us away from their houses but eventually they would come referred to our offices seeking help by those who were our patients before. When you get there, you realise that you were once informed about that patient but could not assist because you were chased away. As you leave a household where you are chased away, you would feel pain because you would be thinking about that patient who is hidden, without food, not bathed and often left alone. It is very painful because we are there for such kinds of patients. Some would come to report that they are working and the patient is alone the whole day until she returns from work".*

The participants' accounts as shared correspond to what other scholars have found among PLWHA caregivers they consulted who too were affected negatively, saddened and pained by witnessing the painful experiences which their patients were going through (Hlengwa, 2011:84; Kasimbazi & Sliep, 2011:105; Dada & Sliep, 2011:138; Mashau & Davhana-Maselesele, 2009:44; Makoae, 2009:22; Van, Dyk, 2009:51; Akintola, 2008; Nesbitt, Ross, Sunderland & Shelp, 1996).

During the process of caring, the HBCG develops a personal relationship or bond with the patient and it becomes an emotionally devastating experience when the HBCG loses their patients (Akintola, 2008; Nesbitt et al., 1996). Although the caregiver's closeness with the patient is a crucial form of support, Van Dyk (2007:51) argues that over-involvement and intense relationship between the HBCG and the patient may have adverse consequences for the caregiver. In latching onto this train of thought, Mashau and Davhana-Maselesele (2009:44) in a study on the experiences of HBCGs caring for PLWHA in Vhembe district, Limpopo, South Africa, for example, reported incidences where HBCGs became so attached to their patients that when the patients suffered, they would also suffer to the same extent. In a study conducted in Lesotho by Makoae (2009:22) that tapped into the experiences of HBCGs with bodily care of PLWHA before ART, two of the caregivers reported that it

became painful for them to see a patient's' health deteriorating. Some of the participants in Hlengwa's (2011:138) South African study outside Durban, which looked at the perceived support of informal caregivers who are saddened when witnessing that their patients' pain was actually exacerbated by poverty. Another study in KZN, South Africa that demonstrates the pain of caregivers of PLWHA is the one which investigated the obstacles that unpaid volunteers experience when ensuring care and support for their patients. The consistent worry about their pain and suffering caused them nightmares and sleepless nights (Kasimbazi and Sliep, 2011:105).

- **HBCGs' feelings and emotions of fear of getting infected with HIV and fear of doing wrong things**

Nakedi, Mamadee and Mpshe, in particular made reference to the fact of experiencing feelings of fear which manifested as a result of being afraid of doing wrong things during their care work and being afraid of contracting the HI-virus and getting cancer.

Nakedi refer to how scary it was in the beginning to care for people with full-blown AIDS. *"At the beginning it was difficult. There were lot of people* [referring to patients with full-blown AIDS] *who were bedridden and it was scary when you get there* [i.e. during home visits] *and find a very thin person. I have never seen such thin people in the private hospitals. They were scary and as we bathe them you could see some holes you could clearly see some bones, in the armpits as you bath her, the washing cloth goes deeper. That was my first time seeing such people especially during my first week".*

Mamadee told me how scared she was of breaking some of the rules of caring as prescribed by her seniors: *"I would be scared. I remember there was this case of child and I wanted to finish it but I was scared for things that would go wrong. I was thinking about the consequences thereof…I was scared of doing some mistakes because as we work, we are expected to follow certain rules. So, I was scared to violate such rules".*

Mpshe explained how, as a result of her care work there was a stage when she developed a personal fear of contracting the HIV-virus and getting cancer, which subsequently did affect her personal life. *"There was a period where I even got frightened because when I enrolled for nursing, the only life threatening disease that I knew of was HIV and AIDS, so here comes again cancer. So, I was scared of HIV. I was very scared of it because of its cruelty to people. The way it was eating on people, the way in which all these opportunistic diseases invade the human being. So to me it was a very dangerous illness and I was always scared. It then made me to stop getting involved in* [passionate] *relationships with men…Then here comes cancer again, seeing that woman who had a hole, seeing people with strange things coming out of their bodies, and a person suddenly dies, then I said to myself "I thought HIV was a threatening disease but I was wrong." So, cancer became the most threatening disease. Even today it still threatens me. If I feel any strange thing on my body I feel scared. With HIV I am no longer scared because I even know my status* (referring to her HIV status]*. But with cancer I am scared because there are so many things that expose me to cancer you see. So it is threatening"*.

What the participants did express under this category partly supports the work of Makoae (2009:22) and Van Dyk (2007:58). Caregivers from the South African and Lesotho studies respectively were found to be afraid of patients whose conditions were deteriorating, while some, just like Mamadee, were afraid of hurting their clients during the caring process.

The fear of being infected by the HIV-virus as Nakedi and Mpshe mentioned also appears in the study Koto and Maharaj (2016:55) did in Lesotho concerning the difficulties health care workers faced. They reported that HCWs would go to the extreme of referring the critically ill patients with open wounds to their colleagues to avoid tending to them for the fear of contracting the HIV-virus. Being confronted with the deteriorating state of their patients' health when executing care activities such as bathing and changing patients' nappies worsened the fear and emotional stress the caregivers experienced (Kasimbazi & Sliep, 2011:105). Makoae (2007:22) believes that response of HBCGs being filled with fear for not hurting the patients as well as the fear for contracting the virus is not surprising because by touching their patients, caregivers do get closer to the source of their real suffering.

4.2.1.2 Sub-theme: HBCGs' accounts of feelings and emotions of happiness associated with care work

While the HBCGs' mostly mentioned negative feelings associated with caring for PLWHA and their work-related challenges, Wendy and Jini spoke of the happiness they get from their care work.

Wendy felt happy about her care work as it was a source of help and support for them: *"I am happy because they need love as well; many people isolate them so I want to be close to them so that they can experience that love, encouraging them and telling them that they will be fine, such things"*.

Jini implied that she feels happiness in caring for PLWHA: "*It feels good because I help someone to be healed and end up having a good life…*"

Wendy and Jini's feelings of happiness associated with caring for PLWHA is underscored in the literature consulted. Despite witnessing patients dying of AIDS-related diseases, HBCGs still derived a sense of pleasure and pride from their care work and said it renewed their inner strength, spirituality and strong belief (Valjee & Van Dyk, 2014; Stajduhar & Davies[43] in Prachakul & Grant, 2003:60; Uys, 2002:10). Some of the participants from the South African study of Valjee and Van Dyk (2014) on the impact of caring for people living with HIV on the psychosocial well-being of palliative caregivers working in KZN, reported that patient care resulted in a sense of accomplishment which, in turn, gave them a sense of happiness. Similar sentiments were expressed by some participant caregivers as quoted in the study of Warlaw[44] in Prachakul and Grant (2003:57) indicating that they derived meaning and fulfilment through their care work.

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[43] Stajduhar & Davies' study addressed the "day-to-day caregiving experiences for the dying loved ones with HIV/AIDS (Prachakul & Grant, 2003:60).

4.2.2 Theme four: HBCGs' accounts of community members' positive attitudes and perceptions towards them because of their work of caring for PLWHA

Caring for PLWHA is not all gloom and doom. As, interspersed in the responses of the participants, I found accounts that pointed to the community members' positive perceptions of and attitudes to the HBCGs and the work they do. These positive accounts are presented next as two sub-themes.

4.2.2.1 Sub-theme: Community members welcomed and appreciated the HBCGs

Cassie, Dineo, Lenyalo, Mamadee, Pekwa, Wendy and Zulu mentioned the fact that that HBCGs generally felt most welcome and appreciated by members of the communities they served and referred to this along the following lines:

"Now, my brother I can say, people are well informed. We are so welcomed to help PLWHA. People are now free and they can be able to talk openly about it. I think the campaigns and workshops which are conducted have improved people's attitudes. They can accept their status. There are those who would welcome us and who even like our job". **[Dineo]**

"Community members are different. You find those who will welcome you with some smiles and who will even buy you some cold drinks or give you some cold water…appreciate your work and even give you some best wishes in your work for the future". **[Lenyalo]**

"Some are thinking good about us because they even tell us about the good work that we are doing and even call us social workers. So I think we are blessed because we are called social workers from Mnaka[45] HBC But for some you will find that whenever they see you they will greet you, saying you are a social worker". "I think the community appreciates my work…Sometimes I would be doing my visits to the

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[45] Mnaka is the pseudonym for an organisation from which Mamadee was recruited.

patients and a woman would just call me and say I see you are wearing black and white [referring to the HBC-uniform]*, there is a patient in so and so address but you must not say we have sent you there. It must appear as if you were just doing your random rounds. That to me shows that the people are realising the importance of our work".* **[Mamadee]**

"When we walk in they welcome us we greet and tell them we from Tanzania HBC and we work with patients, we ask if there is a patient at home those who needs help. So they become open with us tell us more if they have a patient and if they need our help, sometimes they say they have a patient she can't go to the hospital so they ask us to fetch the medication for her". **[Wendy]**

"People know what our uniform looks like. I have already explained that many people know about the work of Tsatsawani[46]. People are free with me. They give me respect and they have accepted me. Sometimes people treat me like a fully-fledged nurse. They respect me and they give me dignity. Some even ask me health-related questions. They respect me. I think many community members are proud of our work. You know that we work with the community. Our patients are from this township". **[Zulu]**

"I remember even a day before... They were calling us the healers. We were at one of our patient's gate and one woman passed across us and said 'greetings to you healers. You really heal people'. Then she just passed. So we often get those kinds of words. Yes even the concerned neighbours they know. Some would say my other cousin was helped by caregivers and when she realise that there is a patient, she would go and advise them to contact us". **[Mpshe]**

"I think they have [referring to members of the community] *improved because the TV talks about HIV every day, newspapers talks about HIV every day, there are some awareness all over and the clinics also talks about it".* **[Segwagwa]**

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[46] An organisation where Zulu was working as a HBCG.

From the participants' accounts, it is clear that some of them were generally satisfied with the way in which members of the community treated, appreciated and welcomed them. In the literature consulted (Valjee & Van Dyk, 2014; Campbell, Nair, Maimane & Gibbs, 2008; Ama & Seloilwe, 2011; Rödlach, 2009:429) similar reports are found testifying to the fact that HBCGs are appreciated and supported by members of the community in executing their care work duties. Rödlach (2009:429), in an investigation exploring HBCGs' motivations and concerns in rendering HBC to people living with AIDS in Zimbabwe, found that some gestures of recognition from members of the community during the memorial service boosted the caregivers' commitment to the deceased. This appreciating of the caregivers' work by communities, according to Bennett et al. (1996:148) contributes to experiencing a feeling of work satisfaction amongst the caregivers. However, and contrary to this, several studies (Schneider et al., 2008; Akintola, 2011; Ama & Seloilwe, 2011; Valjee & Van Dyk, 2014) reveal that HBCGs are generally shunned at by community members and make their lack of appreciation clear despite evidence of their good and hard work.

4.2.2.2 Sub-theme: A perception that community members think a HBCG is brave to care for PLWHA

Mamadee stated that members perceive her as a brave person as she works with people who suffer from AIDS, an illness that most people fear. *"I think they see me as a strong person because I am working with something that is feared by people"*.

Mamadee's view that the community perceived her as brave when caring for PLWHA, in a sense, corresponds with reference in the US study of Ngazimbi, Hagedorn and Shillingford's (2014:321) conducted in Florida on the topic of counselling caregivers of families affected by HIV and AIDS. A caregiver form this study mentioned that her grandmother would think of her as someone who has man-like qualities of bravery and determination because of her involvement in caregiving. A South African study conducted by Akintola (2008:361) which focused on the challenges related to volunteer caregiving for PLWHA in KZN, remarked that to be a competent caregiver, one has to be brave, have hope and love for voluntary care work.

The theme, HBCGs' accounts of community members' positive attitudes and perceptions towards them because of their work of caring for PLWHA reflects both aspects of the strength-based perspective and the middle range theory of caregiving dynamics. Providing role support is identified as one of the dynamic forces that drive the caregiving dyad according to Williams' middle range theory of caregiving dynamics (Williams, 2014:316). Role support in this context is experienced in the HBCGs' knowing that members of the community care about what they are doing as they welcome them in their houses and demonstrate appreciation of their work. Moreover, they go as far as providing helpful information referring some patients to other relevant professional people.

This belief in HBCGs' bravery to care for PLWHA ties in with the strength-based perspective, in that this perspective appreciates the ability human beings have to keep going despite these difficulties, challenges and adversities (Saleebey, 2013:15; Early & GlenMaye, 2000:123; Song & Shih, 2010:24).

4.2.3 Theme five: HBCGs' accounts of the attitudes of their families and friends towards them because of their work of caring for PLWHA

Participants were questioned about the attitudes of their family and friends towards them for being engaged in care work caring for PLWHA. Their responses were clustered around a number of sub-themes to be presented next.

4.2.3.1 Sub-theme: Family members and friends understand and appreciate the HBCGs' work

Amongst all the participants interviewed, Lenyalo, Vanessa, Amelia, Mamadee, Pekwa and Martin were the ones who spoke out about how the members of their own families and friends understood and appreciated the care work they did in caring for PLWHA.

Lenyalo described how her mother who was initially sceptical about her decision to care for PLWHA but later on decided to give her support: *"In my family, the first time I told them that I want to work with PLWHA, my mother was curious about that and*

wondered how am I going to care for the PLWHA if I do not have experience. And as I began to work, people would see my work and tell her and she started giving me courage. Most of my family members do appreciate it".

Vanessa told me how her immediate family understood and accepted her work as a HBCG: *"… my immediate family, my children, and my partner at home, they're interested in what I'm doing. They accept what I'm doing. They accept and they understand. They are the ones affected, directly affected by anything I do, so they are important to me".*

Amelia also expressed how she shared what she learnt from her work with her family that resulted in a positive response: *"They did not have a problem. I explained everything to them. I also educate them about the different illnesses and diseases such as cancer and so on. I share information with them so that they can know what to do if there is something that worries them".*

Mamadee shared her experience of friends whom she said were also understanding and supportive: *"My friends are generally good people and since I started this kind of work, I realised that they are much welcoming and caring and they understand that I am very passionate about caring for people".*

In **Pekwa**'s situation, it became easy for friends to understand and accept her work because they were mostly HIV-positive themselves: *"To be honest with you, most of my friends are HIV-positive and they understand what I am going through very well to an extent that I can remind them about the treatment dates".*

In the case of **Martin**, his friends and family members supported him immediately after he started working as a HBCG: *"Since I started working here, I receive a lot of support from friends and relatives. I can now chat with them, I can visit them but before I come here, even friends did not want to be close to me….I think maybe is because they could not gain anything from me….maybe they could not (get) any inspiration from me so that they can lead their lives productively, that is why they were retreating".*

What the participants shared in this study corroborates with what Naidu, et al. (2012:121) found in their South African study focusing on the social identity of HBCGs caring for PLWHA in Durban wherein some of their caregiver participants acknowledged the support received from family members. As far as the recognition from friends is concerned, Bennett et al's (1996:146) participants mentioned that their friends regarded their care work as important.

In addition to the literature quoted in support of this theme on "family members and friends understand and appreciate the HBCGs work", literature testifying to family members and friends' lack of understanding and appreciation for care work done in relation to caring for PLWHA, is also found (Valjee and Van Dyk, 2014:6; Ama & Seloilwe, 2011:6; Land, 2010:313; Van Dyk, 2007:66; Kipp, Tindyebwa, Rubaak, Karamagi & Najenja, 2007:866). In their Botswana study looking into the burden of caregivers providing care to PLWHA in Kweneng East, Selibe Phikwe and Bobirwa districts, Ama and Seloilwe (2011) document that some of the caregiver-participants' family members and social networks were unable to provide the required support due to insufficient resources to support the caregivers. Similarly, Valjee and Van Dyk (2014:6) reveal that some of the caregivers in their study focusing on the impact of caring for PLWHA on the psychosocial well-being of palliative caregivers from South Africa's KwaZulu-Natal were unable to share their caregiving experiences with friends and members of the family. Their anticipated lack of understanding and fear of burdening them with their complicated work-related problems explains this. In the South African study of Van Dyk (2007:57) focusing on occupational stress among caregivers caring for PLWHA, one participant shared her experience of how some of her best friends refused to come for tea at her place because of her involvement with PLWHA.

4.2.3.2 Sub-theme: Family members and friends reacted negatively to the HBCGs caring for PLWHA

Amelia and Pekwa's accounts bear testimony to the fact that family and friends reacted negatively to them for being caregivers caring for PLWHA.

Amelia explained her experience of friends' negative attitudes towards her: *"Some [referring to friends] stopped being friendly towards me. People know that the employees of Tsatsawani HBC[47] are HIV-positive. So, some friendships just fade away. People that I thought were my friends, begin to avoid making contact with me...It is not good to lose friends. But sometimes, it is necessary to let go of relations that do not add value to your life. I accept things as they are. I can't force relationships on people who are no longer interested in being friends with me…We just greet each other and that's that. If they were really concerned, they would have asked me about my condition. Friends should be able to everything. I don't worry about their attitude because I understand their situation".*

Pekwa also explained how her family and friends are put off by her work as a HBCG: *"They would ask me whether how I manage to put a nappy on someone who is HIV-positive and then eat when you get home. In my heart I would say, 'you can because you were once in that situation and if you have told yourself that you want to do it you will do it because as human beings we can do things that we feel comfortable doing. And if you don't want to do it you can't do it'. What is interesting in my case is that I was once a patient myself, so maybe if I have never been a patient I would have never been a caregiver at all…When I was at home* [referring to not being a caregiver] *it was nice, I did not receive any bad treatment. Things changed when I started to work here. The moment I told people that I am now working as a caregiver, they reacted with shock and asked me if I can make it. Then I said yes I can make it because I do not have any income and I have children. So from thereon there was no cooperation between us but now things are back to normal because they have realised that we serve a purpose in the communities".*

Amelia and Pekwa's disclosure that family and friends reacted negatively towards them for being caregivers caring for PLWHA is underscored in the literature consulted (Singh, Chadoir, Escobar & Kalichman, 2011; Kipp et al., 2007; Van Dyk, 2007:57; Prachakul & Grant, 2003; Uys 2002). In her study of occupational stress among the South African HIV and AIDS caregivers, Van Dyk (2007:57) found that

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[47]The pseudonym Tsatsawani is a substitute name for an organisation where the HBCG works to assure anonymity.

some of the husbands of her study's participants harassed them; even pressurising them to resign from their jobs and even refused to have a sexual relationship with them because of their fear of being infected.

Contrary to Amelia and Pekwa's experiences and the literature quoted in support of this sub-theme, several authors point to friends and family members' support for the caregivers caring for PLWHA. Chimwaza and Watkins (2004:805-806) in their study that investigated the caregivers' perspectives on giving care to people with AIDS symptoms in rural areas in the Balaka District in Malawi, learnt of the support the caregivers enjoyed from family and friends. Another study which revealed that friends and members of the family provided support to the caregivers was the one focusing on "giving care to people with symptoms of AIDS in rural sub-Saharan Africa" conducted in Balaka district of Malawi. In their review and analysis of studies on caregivers of PLWHA, Prachakul and Grant (2003) found that some of the HBCG participants quoted their families as being part of their group that offers support.

Fynn (2011:116, in her South African study on social support among volunteer caregivers of PLWHA, arrived at the conclusion that HBCGs received reassurance and encouragement from their own family members in relation to the work they were doing which motivated them to continue to care for PLWHA in KZN. To conclude the literature support for this sub-theme under discussion, reference is made to observation made by Olwit, Musisi, Leshabari and Sanyu[48] (in Mashau, Netshandama & Mudau, 2015:70) illuminating the trend of how HBCG who were caring for PLWHA relied on support from the family and friends whenever they were under stress.

While some of the HBCGs in a study by Kipp et al. (2006:695) revealed that caregivers receive the necessary support from their families and friends, some reported that families, friends and relatives were among the most stigmatising and rejecting groups due to their involvement in HIV and AIDS work. One of the findings

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[48] Olwit, Musisi, Leshabari and Sanyu's study addressed the lived experiences of caregivers of patients disagnosed with schizophrenia in Butika hospital, Kampala in Uganda (Mashau, Netshandama & Mudau, 2015:71).

from Olang'o et al's (2010) Western Kenyan study which examined the trends and causes of attrition among HBCGs caring for PLWHA was that some of the HBCG participants' mentioned that their children were dismissive of their work for the fact they could not afford to give them pocket money or school fees from the money they earned as caregivers. Singh, et al.'s (2011) South African study of stigma, burden, social support and willingness to care among HBCGs caring for PLWHA in KZN did not specifically report that the caregivers were rejected by friends and families; but highlighted that caregivers did not receive the necessary support from their families and friends.

4.2.3.3 Sub-theme: Family members and friends lack understanding for HBCGs' involvement in caring for PLWHA

The accounts of Vanessa, Paul and Yena, gave rise to this sub-theme.

Vanessa explained how her former best friend and her brother did not approve of her work of caring for PLWHA: *"Well, I had a best friend. We are no longer friends, not at all. She works in the Police. We're no longer friends, not at all. My one brother doesn't really visit me at all… He is a bit of a tough somebody. He's totally, just living in the city, catering for the needs of the city. Sick people and all the other work that we do, he just doesn't understand. And again my status has dropped from having everything to coming down to the minimum or just enough. It doesn't go by him. That doesn't fit by him. So, he doesn't want to know what I do. He doesn't care what I do. It's not up for discussion with him. It's just that you went down; you're supposed to go up, not go down…he told me that he doesn't like what I'm doing, where I live, so he would rather stay away from me. So, it's like he won't accept it. I cannot change to suit him"*.

Paul explained how some family members and church members do not understand his role a HBCG*: "The younger family members have accepted but my sister would for instance be jealous with you walking in here visiting me and she find another person who is HIV-positive* [meaning that her sister is the only person who does not appreciate his involvement with PLWHA]. *Or if would say, 'I have got an appointment, I will not see you I will see you tomorrow', she would say, 'yeah, but*

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they always come first…' This makes me feel sad because I feel that they must understand me as a person and accept what I am doing. It feels like they don't accept what I am doing. My mother was very supportive 'til she passed away in 1999. She did understand quite well. Also they don't talk to me about it. You know, it is easy for them to talk about all other things but not HIV…In this stage of my life I feel like I am living my own life and I don't care what they feel. If I feel like I want to care for another person why not? I have had some reactions before from them over the years. I will just do my own things… At our church is only few people who are HIV-positive that approached me privately. I think they accept me at the church because they know what I am doing. But I think there are few people there that do not want to be associated with HIV-positive people that just don't talk to me".

Yena explained the attitudes of family and friends towards her as a HBCG as being very negative: "*Sometimes they* [people in the community] *do not show any smile and others do not want to greet but not all of them, some can welcome us and wish if you can help, but in general they react in a bad way like my family members, they like to be visible and …no they* [referring to her family] *do not know that I am HIV-positive because if I can tell them it will kill me so that is why I kept quiet, I live with them but they do not know for my safety*".

Mamadee referred to her family's lack of understanding regarding her decision to get involved in care work: "*The treatment in my family is generally good. Is just that they do not understand why I decided to resign from the store to join the caregivers*".

While friends and family members can be a very important sources of support for the HBCGs, the participants' accounts provided above demonstrate friends and family members' lack understanding for their care work in caring for PLWHA. In substantiating this sub-theme, findings from two studies by Akintola (2005 and 2008) are quoted. In his study on community responses to HIV and AIDS in relation to the role of volunteers in HBC for PLWHA in South Africa, conducted in KwaZulu-Natal province it was revealed that the friends of the male caregivers did not understand why they were involved in what they called "women's job" (Akintola, 2005:6). In another study conducted in Durban, South Africa, reported under the title, "Defying all odds: coping with challenges of volunteer caregiving for patients with AIDS in

South Africa", Akintola (2008:362) documents that some of the HBCGs' family members did not understand why they were involved in caring for PLWHA without any remuneration.

Contrary to friends and family members' lack of understanding for HBCGs engagement in caring for PLWHA as some of my participants revealed and the literature referred to, some of the caregiver-participants in Bennett et al.'s (1996:146) study on "the relationship between recognition, rewards and burnout in AIDS caring" reports that friends understand that their work is a valuable contribution to society. Huynh, Winefield, Xanhopoulou and Metzer (2011:5) whose Australian research examines the role of burnout and connectedness between job demands and resources amongst palliative care volunteers and their families, reveals that friends and family members of the palliative care volunteers do care about how they feel about their work pointing to the fact that they understand what they are going through in their work.

4.2.3.4 Sub-theme: Family members and friends are concerned about a HBCG's low remuneration

Vanessa, in giving rise to this sub-theme, explained that although her children understand and accept her care work, they are concerned about the low remuneration. *"They ask me and they asked me a few times, stop what you're doing, Mummy, but not because of sick people, because of salary. They don't ask me to stop because of sick people; they'll ask me to stop because of salary. And the amount of hours we spend without compensation to those hours, and sometimes extra time that is your own, so yes, I understand when they ask me to stop. But they also know my heart; they also understand why I do what I do. So, it's difficult for them to see Mummy with this less money and Mummy can't buy us the iPhone and what my friends have".*

The issue of low remuneration brought up by Vanessa is also highlighted by Fynn (2011:117) when stating that low remuneration affected caregivers' families in a negative way. Olang'o et al. (2010:234), in their study on the topic of "staff attrition among community health workers in HBC for people living with HIV and AIDS in

Western Kenya", found that some of the HBCGs resigned from their caregiving duties as a result of being conditioned by their husbands who believed that they were wasting their time by caring for PLWHA without a stable salary. Furthermore, these researchers report that some of the children of HIV and AIDS caregivers dismiss their parents' care work as the salaries earned do not even provide pocket money nor pay school fees (Olang'o et al., 2010:234).

4.2.4 Theme six: the coping strategies used by HBCGs to manage the work-related challenges experienced in caring for PLWHA

One of the elements of the strength-based perspective is that life goes on and people move forward even if there is pain, discomfort, despair and humiliation (Blundo, 2013:41). This relates to what Saleebey (2013:14; Saleebey, 2006:13; Saleebey, 2002:11) calls resilience, which basically means that, as people, we have the innate capacity to recover and overcome our misfortunes.

This tie in with coping theory (Lazarus & Folkman, 1984:150) that asserts that human beings cope with environmental stressors by adopting either of the two strategies: the emotion-focused coping strategy or the problem-focused coping strategy (Padden et al., 2011:25; Haux & Weber, 2007:235; Grambling et al., 1998:1083; Lazarus & Folkman, 1984:150-153). By adopting an emotion-focussed coping strategy, the aim is to respond to environmental stressors by regulating, controlling our emotions, and changing our attitude to cope better with the stressful encounter (Padden et al., 2011:251). Once our attitudes to the stressful event have changed, the way we think and feel about the stressful event will change (Lazarus, 1995:33). In other words, we now begin to see the stressful encounter in a different light. Rezenbrink (2007:247) explains this strategy better through an example of caregivers who undergo difficulties in caring for the terminally ill. They display what he calls "chronic niceness" in which they portray themselves as carrying on as if nothing bad is really happening. The person is emotionally developing a positive attitude out of agony.

In terms of the problem-focused coping, efforts to cope are directed to taking action against the source of stress and the environment that gives rise to the problems

(Padden et al., 2011:251; Lazarus, 1993:238; Folkman, 1984:845). The problem-focused coping strategy involves acting to prevent problems before they happen, getting professional help and then modifying the stressful environment (Barbosa et al., 2011:494).

Coping is a process which is an outcome of appraisal and reappraisal of an event and the decision making that follows it (see sub-section 1.2.2). It takes place around the use of available resources which are either in our surroundings or are part of our personality. From the accounts provided by the participants on how they cope with the work-related challenges encountered in caring for PLWHA, it became clear that they use a variety of coping strategies that prevail. The sub-themes around which they cluster are presented next.

4.2.4.1 Sub-theme: HBCGs cope through support from their employers

Eleven of my participants reported that their employers' support assisted them in coping with their work-related challenges.

For **Dine**o, her manager was her source of support. *"Our manager is the one who supports us. She is the one who says we should be there for the patient. So, if we go into the house and greet people and find that they are not responding, we go straight to the patient's room and attend him/her. She says we must just let it go"*.

Cassie also referred to the practical support her manage provided. *"Eventually our manager decided to redeploy us. She made sure that we do not serve areas where we are staying so that patients can be open with us. The day on which you visit the houses without a caregiver who stays in that area, the patients started opening up and began to even tell us that they were scared to talk the presence of so and so who stays in that area. So, it became easy to an extent that when we get to patients who are very sick they would eventually stand up and walk. Now, when I count my statistics, most of my patients are now back to their work"*.

Lenyalo mentioned a nurse's support: *"There is a professional nurse who tries to support us. Most of the time when we encounter these problems* [referring to their

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work and its challenges] *we share them with her and she would go out with us and as we enter the households, she would explain to them nicely that we are working with PLWHA and if we work with this people it does not mean that we are also infected on that we are going to search if you are infected or what"*.

Martin made mentioned of a whole convoy of support that assisted them to cope in their care work: *"Normally we are helped by the sister, who gives us some lessons and encourage us to remain strong as the work that we are doing is not easy… Another thing is unity between us as caregivers, between us and our patients and our principals who supports and guides us to address these problems"*.

Nakedi indicated her supervisor as her pillar of strength: *"We normally give feedback report every afternoon and that is when we share our challenges with the supervisor. But for me when I feel uncomfortable, I do not wait for reporting time. I simply tell her and she even knows very well. She would provide some counselling and the next day I would feel much better"*.

Zulu mentioned the support from their management as coping strategy: *"We have superiors. Like today, is the day for lectures. We don't do home visits. At 4* [referring to 4 pm in the afternoon]*, we attend the MGM[49] meeting. We discuss challenges that we encounter when we do home visits. It is where we tell our superiors about the challenges that we encounter our superiors give us guidance on how to react to different situations...it is useful"*.

Pekwa obtains counselling within the organisation: *"She* [Referring to the sister] *provides some counselling and advises. When we share our challenges with her, she would tell us that it is not easy to work with a human being. It requires patience and perseverance"*.

Amelia explained that meetings are held in her organisation but not all their challenges are addressed in these meetings: *"We have monthly meetings where we*

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[49] By MGM meeting, Zulu refers to the Monday General Meetings wherein caregivers are provided with an opportunity to share their challenges with their seniors.

table these challenges but they are not being addressed. In other cases, we are told that a particular issue is supposed to be addressed by the department and not by the organisation".

Mokete indicated her co-workers as a valuable source to help her cope*: "So when we meet as a team we normally share the events and they are turned into jokes. So we become motivated and relieved so that we can face another day with courage".*

Mamadee copes through support within the organisation*: "We do get support from management in this regard. For example after working very hard we would go somewhere where we would relax at places like cinemas to watch movies so that you can simply forget the bad things that may have happened or sometimes they will organise a braai for us. There is also a psychologist at this centre. So if we feel that we need to talk to someone, we would go to her for one-on-one session".*

Letsatsi explained how the organisation arranged counselling for her: *"I think there is enough support because when I started here within a week I wanted to quit and they sat me down and provided some counselling. They explained to me why they wanted me to come and be part of them; they saw my work and they were happy as I was working hard".*

This sub-theme and the participants' storylines substantiate how use is made of the problem-focused coping strategy mentioned by Lazarus and Folkman (1984:152). The HBCGs in this study were mostly able to draw on many colleagues within their organisations for support to help them negotiate and cope with the work-related challenges experienced, specifically employers, management personnel, supervisors and fellow workers.

The significance of organisational support to cope with their work-related challenges when caring for PLWHA, as these participants reported is confirmed in the work of Van Dyk (2007:62). Her South African study of occupational stress among HBCGs caring for PLWHA as caregivers whose employers supported them on various levels through supervision; training and debriefing coped better than those who just received one form of support. In the case of Valjee and Van Dyk's (2014:7) South

African study on the impact of caring for palliative PLWHA caregivers in Durban regarding their psychological well-being, some participants coped by sharing their challenges with the nursing sister.

The support the HBCGs received from their employers fits in with the aspect of self-care identified as a force that moves the caregiving trajectory forward, according to the middle range theory of caregiving dynamics Williams (2014:312) developed. Through self-care, caregivers reach out to someone with whom they can share their frustrations, like a nurse or manager. Getting away from it is another way of self-care (Williams, 2104:312). Employers, as Cassie explained, assisted HBCGs in "getting away from it" in that they redeployed them from uncooperative site to areas where they were more welcomed. This assisted them in retaining their usual composure which is necessary in this profession.

4.2.4.2 Sub-theme: HBCGs cope through counselling and support groups

Making use of counselling and joining a group for support can be regarded as problem-focused coping strategies as they help a person to manage the environmental stressors they experience by providing the skills and capacities to do so (Padden et al., 2011:251; Outten & Schmitt, 2009:149; Grambling et al., 1998:1083; Lazarus & Folkman, 1984:158). Through counselling, the HBCG can develop inner strength and the capacity to use their innate potential to overcome their challenges (Thompson & Thompson, 2016:191).

Cassie, Kgomo, Nakedi and Wendy referred to how they use counselling and support groups to help them cope with their work-related challenges, as deduced from the quotations provided below.

"We had some ministers of religion who would provide us with counselling because truly this type of work is very difficult as we ourselves ended up being traumatised. Seeing people dying is very painful my brother. You take care of this person and when you come back you find that the person is passed on, can you imagine the pain? And yet your goal is to heal this people. The moment they do not get healed and die, your heart feels pain". **[Cassie]**

"So, in our case our bosses realised that we encounter lots of challenges and they ended up arranging a woman to come and provide us with some counselling. So this helped us to cope with some painful experiences that we had". **[Kgomo]**

"Most of the time we [referring to the caregivers] *just gather together as a team and share among ourselves. We would sit under a tree and share and that I think is working for us. And even our manager would sit with us and provide some support. I think sharing is a good method of addressing this"*. **[Nakedi]**

"We have a support group so we do meet and talk about our problems". **[Wendy]**

This strategy of going for counselling and joining support groups to cope with their work-related challenges, as indicated by some of my participants, is also recorded in Van Dyk's (2007:62) study as one of a number of the strategies for preventing occupational stress and burnout among PLWHA caregivers. One participant in Van Dyk's (2007:62) work mentioned that she calls Lifeline (a telephonic counselling service that respects calls anonymously) to receive counselling. Providing counselling to caregivers in a home-based HIV and AIDS project with the aim of preparing them to execute their duties is also reported in the study by Uys (2002:107). It implemented the integrated HBC model to prepare HBCGs to execute their duties at the seven sites of the South African Hospice Association. In another South African study of "Psychosocial experiences and coping among caregivers of PLWHA in South Africa's North West province", Amoateng, Kalule-Sabiti and Oladipo (2015:137) state that thirty-four percent of their participants preferred professional counselling as a coping strategy to address their challenges.

With reference to support groups as a strategy to address work-related challenges and provide support, Uebel, Nash and Avalos (2007:502) underscore the significance of providing support groups to address the emotional burden of nurses who render care to dying patients. For some of the participants from my study it is a familiar practice. The advantage of using a support group to cope with caregiving-related challenges is its ability to enrich the caregiver by enabling them to develop personal friendships among themselves. It also decreases feelings of loneliness and

isolation among the caregivers and mitigates the impact of caregiving on caregivers (Orner, 2006:39; Prachakul, 2009:70; Turner et al., 1998:148).

4.2.4.3 Sub-theme: HBCGs cope by networking with other organisations and by referring cases

Vanessa, Zulu, Segwagwa, Mamadee and Mpshe, in particular mentioned that included within their repertoire of coping was the skill to network and to refer cases to assist them in coping with their work and its work-related challenges of caring for PLWHA. They spoke about this along the following lines.

Vanessa told me that she coped by knowing her scope of operation and when she needs to network and refer cases to others: *"Many caregivers are not doing what they are supposed to be doing. They're also just doing anything they feel like doing. And then when we started to work together and learn each other, we find strength in each other. So in that aspect what we did in this area, I have my strength in confrontation, in making a phone call professionally and saying, look, we need one-two-three. Look, we're sending one-two-three patients in. What we've done in the process – networking. We've started building relationships, so sometimes we only have one or two nurses that we deal with, that we send patients to. What we do is we use each other's strengths to cope and to help cope. So if you're good at something, I don't give you what you're not good at. I don't take on what I'm not good at. So, if I know there's a dying patient, I try my best to stay away because I know I can't handle it. I'll walk to a certain point and then do a referral…When it comes to them needing to do referrals they come to me. That's my strength again. Then I'll be phoning whichever department to say, look, we need one-two-three. We need to call SASSA[50] in, social workers phone, maybe it's a supervisor, to send someone. So, we help each other to cope, but still the pressures of this job don't, they don't end there"*.

Zulu copes by referring patients when necessary: *"We refer patients to social workers so that they can discuss their situation with them. The assistance that they*

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[50] SASSA is a South African social security agency which provides social grants to the poor.

receive from their interaction with social workers is that the patient is able to apply and receive food parcels. The others are assisted with grant applications. That way, there won't be any excuse to default on treatment…they end up getting help. That's why I say I am proud to be doing this work. I see that I am important in helping a person to feel better".

Segwagwa also refers patients to appropriate sources according to their needs: *"We try to refer for psychosocial counselling or spiritual counselling because counselling types are not the same. For instances you might send a social worker and only to find that the patient will be comfortable if he/she can get counselling from the minister of church who can quote some verses from the bible and if is a woman he can be linked with other women who can come and pray for her, invite her for the church services so that she can be healed spiritually".*

Mamadee refers to the social auxiliary worker*: "…there would be a case of a mother who does not have an ID and does not earn grant. You will then have to refer her to the social auxiliary worker who would take it further and eventually get what she needs. Or you would find someone who needs counselling and you would also refer the matter to the social auxiliary worker for further intervention".*

Mpshe refers cases to the social worker within the organisation*: "Yes, we have a social worker in the institution and we refer patients to her, so she could assist us in certain matters. Now we do not delve much in to uniting families, we refer such cases to her. We talk to the patients and address the clinical issues which are our primary responsibility and after that they come and relate the social problems to the social worker and the social worker would make an appointment with the family and conduct her counselling. Previously it was a challenge because there was no social worker. We would take everything to ourselves like in taking the patient and advocate her at the clinic. We are not allowed to take patients with our vehicles to the clinic but sometimes circumstances compel us to do go out of the way and take her to the clinic and leave one of us with her on queue until he or she receives treatment".*

The strategy of referring brings benefits for the HBCGs and their patients and it comes through collaboration and networking between organisations. Kwait Valente and Celento (2001:469) agree and emphasise that networking and referral not only strengthens the capacity of the caregivers, but also ensures that clients have access to the right and necessary services.

This sub-theme on HBCGs' way of coping with work-related challenges by networking with other organisations and by referring cases as well as the participants' accounts is confirmed in the literature consulted. (Duckert & Vaagte, 2011:58; Kaleeba, Kalibala, Kaseje, Ssebbanja, Anderson, Van Plang, Tembo & Katabira, 2010:22; Ncama, MInerney, Bhengu, Corless, Wantland, Nicholas, McGibbon & Davis, 2008:1761; Uys, 2002:101; Leserman, Parkins & Evans, 1992; 1514). HBCGs who took part in their studies called for social support networks and referral systems to assist them with caring for PLWHA. In their Ugandan participatory study to evaluate counselling, medical and social services offered by The AIDS organisation(TASO), to PLWHA and their families, Kaleeba, Kalibala, Kaaseje, Ssebbanja, Anderson, Van Plang, Tembo & Katabira (2010:22) recommend that appropriate referral systems and greater community involvement in the care of PLWHA is necessary.

By networking with organisations and referring cases, HBCGs practices what Williams (2014:316) calls "finding support for other responsibilities" in the middle range theory of caregiving dynamics. This is one of the dimensions for ensuring role support. In the context of this study, HBCGs source support for responsibilities which may be beyond their capacity by simply networking and referring cases.

This coping strategy of networking and referring the cases resonates with one of the principles of the strength-based perspective stating that: "every environment is full of resources". This basically suggests that, even if HBCGs experience some difficulties, there are always resources around them to help them to cope better. In this context, peer organisations appear to be some of those resources that help them relieve their workload.

4.2.4.4 Sub-theme: HBCGs use self-help or self-motivation to cope with their work and its related challenges

Mokete, Paul, Letsatsi, Wendy, Cassie and Jenny, pointed to the fact that the use of self-help or self-motivation as another of the strategies that helped them to cope with their work-related challenges. They spoke about this along the following lines:

For Mokete to remain hopeful in view of finding another job keeps her going*: "Is just a matter of having hope that one day things will turn out to be better and another thing is that maybe tomorrow I won't be here. So, that is one of the things that motivate me and I end up saying, maybe I am here for temporary and I am just waiting for another opportunity from somewhere where I can be given an opportunity to develop and move forward. That is some of the things that motivate me to remain patient because they will pass and once they pass I will get a better opportunity. You will find that sometimes when I see some vacancies somewhere I will start to apply with a hope that they will take me somewhere and I will leave this place"*.

Paul involved himself in other activities that help him cope*: "You have asked me how I deal with some things…I told you before that I am involved with the theatre where I can be a little bit creative. So, it takes me away from the negatives, so I think is important to do some other things besides that* [referring to caring for PLWHA]*, that are more relaxing and creative…I do the lights, I set the stage … and clean up and enjoy the show"*.

Letsatsi has taught herself, practising self-help, to treat patients like her own family: *"Previously I was feeling small* [Meaning she did not really know how to deal with patients]*. But now I feel like let me treat him* [referring to the patients] *like my younger brother or my younger sister. I feel is important to treat them like my own family because they are here and they need that love and support"*.

Wendy motivated herself by thinking that no matter what patients said she would be strengthened. *"I told myself that the more they speak the more they will make me strong and I must stand tall".* And she strengthens herself further: *"You have to get rid of them in your mind and when you have to tell yourself that I am going to do this*

and there is no one who is going to let me down, I am a person I have feelings as well but it will pass".

Cassie used her patience and perseverance to cope. *"The difficulty is that a patient needs someone who is very patient and if you do not have such patience, you cannot cope. Patients can do things that would irritate you; not because he/she wants to, but because of the illness. And if you are not called* [referring to caring for PLWHA as a calling]*, you would be impatient and begin to maltreat the patient while he/she is not doing that deliberately but because of illness. Some would "itshenyetsa"* [referring to relief themselves] *if you can allow me to use that word…So, if you have been called you won't be disgusted by such things. The moment they defecated themselves up, you simply take your kid and clean them up. I still remember one patient with some bedsores that were so bad to such an extent that they were even smelly. You could not even sit next to him without courage and patience to work with patients. She even had some worms and we had to clean them so that we can bring life to that person. And if you did not have that patience and perseverance, you would vomit".*

Jini also spoke of self-motivation helping her to be patient with her patients: "*So I would ask myself why the person decided to study midwifery if she/he does not have patience for it. Working with HIV and AIDS needs patience because you handle many things and sometimes a patient will come very dirty and you have to dress her and leave her smelling nice. So others are disgusted. You can't force to do something that you have not called for. With me I can say is my calling. Even when my seniors send me to go and dress a wound, I do not go there feeling disgusted, no. I want to see the patient being healed". I do those things. I listen to motivational speakers, spiritual motivational, professional motivational speakers, sometimes if I found a relationship which I had to build with you is difficult; I look for somebody else in your department. If something becomes too difficult to handle ask for advice from other professionals. You look for different things. Think out of the box, just don't think yourself within the box. That's all. Just think out of the box".*

Emotion-focused and/or the problem-focused coping (Lazarus and Folkman, 1984:150-164) is evident in the participants' accounts as resort to cognitive

reappraisal which is thinking differently that makes them change the meaning of the distressing situation to enable them to cope better (Lazarus & Folkman, 1984:150). Mokete's hope and belief in the fact that a better work-opportunity will eventually arise means that he does not believe things will stay as they are forever, pointing to the fact that he adopted emotion-focused coping. He changed the meaning of the difficulty through positive reappraisal. We also see the possibility of problem-focused coping in Mokete through the possibility of leaving his current stressful environment should an opportunity arise. In Letsatsi's case we see some evidence of emotion-focused coping as she decided to treat her patients like her brother and sister to minimise the stressful experience. She adopted a different frame of reference, enabling her to cope with this reality.

Paul's involvement in theatre work, when not engaged in care work points to the adoption of an emotion-focused coping strategy in order to defocus his mind, feelings and attitudes from the stressful caring work he was experiencing. In Wendy we see strong evidence of emotional coping through her resistance to back-down regardless of the difficulties. She instead believed that the difficulties will strengthen her further. Emotion-focused coping was also found to be the case in Cassie and Jini's situation wherein they believed patience made them cope better. In other words, through patience they could understand why patients behave in a certain way, and therefore gained some strength to continue to care for them. By believing in themselves and their ability to make a difference in their patients' lives, caregivers found themselves coping better with their challenges (Lazarus and Folkman, 1984:158)

In further explaining the emotion-focused coping, Lazarus and Folkman (1984:150) state that for some people to cope better, they expose themselves to the difficulty so that they can have worse experiences of it. Cassie displays this strategy by being passionate about difficult situations.

The sub-theme, "HBCGs use self-help or self-motivation to cope with their work and its related challenges" relates to the aspect of "expectation management" as one of the dynamic forces that keep the caregiving relationship moving forward (Williams, 2014:313; Williams, 2007:382; Williams, 2003:681) in line with the middle range

theory of caregiving dynamics. Expectation management as indicated in Chapter One: sub-section 1.2.1 is realised through, among others, reconciling the twists and turns of treatments the caregiver administers. They come to terms with the difficulties they face in their caregiving dyad. From the participants' expressions, it is apparent that they found ways to manage their difficulties themselves.

Furthermore, the sub-theme had some elements of the strength-based perspective which generally posits that, within every person, there are some strengths and capacities that enable them to prosper through their difficulties (Saleebey, 2013:10; Song & Shih, 2008:24-25). This is evident from the utterances made by the participants who acknowledge having difficulties which they managed using their inner strengths that do not deter them from continuing to care.

4.2.4.4 Sub-theme: HBCGs cope with their work-related challenges by having faith in God

In substantiating this sub-theme on HBCGS faith in God to help them cope, the accounts of the participants below are provided.

Vanessa shared how she finds strength through prayer: *"Personally, I have to offload every night. I have to go on my knees, I go and talk to God and say, 'Lord, I'm full'. Sometimes I've got to fight with God and ask, 'God why do you allow these people to get sick?' Sometimes I've got to cry before God and plead for somebody, but it helps me because then I've off-loaded. Off-loading in a family setup, I can't. I just can't because then you put the burden into your family"*.

Letsatsi also prays: *"I tried hard to pray and asked please God help me to deal with this thing,* [Referring to her work of caring for PLWHA] *and now God helped me and I am enjoying it"*.

Paul believes that God is his stronghold as if it was not for God he would have left care work: *"It was not for God, I would have quitted long time ago, is because God is good for me… Because I still got a place to stay and I still got food and my house is okay"*.

Nakedi: *"But I told myself that God is there, I am going to help them and I did this course because I like it"*.

Dineo believed that God called her to be a caregiver and He will determine her destiny**:** *"I say this is my field and I am here to help people. God have chosen this job for me and if I not here to stay, he will take me somewhere at his own time. So, as time goes on they will get used to me and continue to ask 'are you still here'?"*

Cassie*: "You console yourself by saying even if she closed the door for me, she is sick and one day I will come for her. And because God is there with us, you would even find that they would call you for the same patient"*.

Mpshe believes that God will reward her: *"Yes, because that person who feels happy and comfortable because of my deeds make me happy as well and the only person who can reward me is God. From that person I did not expect anything"*.

The strategy of faith in God and heeding His Word during tough times as practised by the participant caregivers of this study, is also interspersed in the literature consulted (Campbell et al, 2008:5; D Cruz, 2004:14; Chimwaza & Watkins, 2004:804; Amoateng et al., 2015:137; Akintola, 2010:7). In a study conducted by D'Cruz (2004:14) in Mumbai, India the experiences of families caring for PLWHA are documented. One of her participants is a family caregiver who reported that only God knew how she survived the financial difficulties associated with care work. In another study focusing on giving care to rural Malawian people with symptoms of AIDS by Chimwaza and Watkins (2004:804), one participant reported that she asked God day and night to help her with her patient. Amoateng et al.'s (2015:137) South African study looking into the psychosocial experiences and coping among caregivers of PLWHA in North West, also found that believing in God was one of the coping strategies adopted by thirty-nine percent of their participants to overcome their challenges.

4.2.5 Theme seven: HBCGs' suggestions to management on how their work and working conditions could be improved

Improving the caregivers' working conditions and resolving their work-related challenges relates to the aspect of self-care, as proposed in the theory of caregiving dynamics (Williams, 2014:312). The reader can refer to Chapter One, sub-section 1.2.1 for a detailed discussion of this theory. Self-care is a prerequisite for the caregiving dyad to be healthy and to proceed smoothly. It is founded on four pillars: a supportive environment which may include provision of material resources like accommodation, food and other equipment that nurture the caregiving relationship (Williams, 2014:312). The second pillar is cultivating healthy habits, which basically means that the HBCG and the patient ensure that they support each other to remain in this healthy caring relationship (Williams, 2014:312). This support can take a form of the caregiver's mere presence in the patients' life to listen to their challenges and offer material and any form of support.

Third, it involves "letting it out" which is explained by Williams (2014:312) as creating a conducive and confidential environment or space where both the HBCG and the patient are afforded opportunities to ventilate feelings and express their frustrations freely. The fourth pillar is described as getting away from it (Williams, 2014:312). This is where the HBCG and/or the patient are afforded a space in which they can temporarily dissociate themselves from each other - the patient from the HBCG and the caregiver from their usual caring environment. By asking the participants how they would like management staff and social workers to support them, I invited suggestions from them in view of my intention to offer recommendations for ensuring self-care throughout the caring trajectory as part of the work (see Chapter Five, Section 5.3)

Some elements of the strength-based perspective are also found in a central assumption that every individual has ideas that can be expanded and renewed (Saleebey, 2013:13; Saleebey, 2006:12; Saleebey, 2002:10). In view of this assumption, I invited the HBCGs to suggest what they thought could be done to improve their working conditions. Their responses to these questions posed to them

about how they would like be supported by management and social workers were clustered into three sub-themes presented next.

4.2.5.1 Sub-theme: HBCGs' suggestions to management to visit patients

Dineo, Amelia and Segwagwa suggested that management and other officials should go and see for themselves what they are going through to understand their challenges better. The quotations below testify to this:

"[Mothokwa[51]] *(the manager) come once a week and deal with a specific challenge that we point out to her and yet we are having a lot of challenges in many households. What she would do is to go to that specific household and address that particular challenge and leave. So I think given the volume of challenges that we encounter, if I was Nelly* [The manager] *I would extend the number of days and come three days so that I can see all the challenges that caregivers are going through because some of them we just deal with them and tell her afterwards".* **[Dineo]**

"When these people from the Department [referring to the DoH *come around, they read the reports that we have submitted and they say that we are not doing a good job. I wish they could walk around and do the work that we are doing. Maybe they will see how difficult it is to work under these conditions. Working with people is not easy. I want them to experience what we are going through. Sometimes, we send the patient to the clinic and the patient's health does not improve. We also run around looking for forms and getting information from social workers".* **[Amelia]**

"I think management should sometimes leave the offices and conduct the door to doors with us so that they can see all our challenges. If possible for them to solve them, they must help us. I am not saying they must leave their work, but they must make time to go out to see what is happening outside because sometimes we find a patient who is staying in a one room shack, she stays with four or five children who are still small, she can't do anything by herself, the children must not go to school

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[51] Mothokwa is a pseudonym used to substitute the manager's real name to ensure anonymity.

and bath her, there is no food, there is nothing. So it becomes a problem, our problem because sometimes we even take our last monies and give them. So I think if it's possible for them to go out and identify the problems that we are facing specifically to the patients who are struggling so that they can understand what we are going through". **[Segwagwa]**

The suggestions of the caregivers stating that their management team should visit their patients to witness their challenges, as caregivers were not found in the literature consulted. However, Uys (2002:106) recommended that registered nurses should conduct visits with the HBCGs so that they could attend to matters that might be beyond the HBCGs' scope of practice. He does not highlight the need for management to visit the patients.

4.2.5.2 Sub-theme: HBCGs' suggestions to management to provide resources

Contrary to a general suggestion Van Dyk (2007:64) makes about management staff and employers making an effort to reduce the stress level among caregivers caring for PLWHA, the participants in my study were very articulate and specific in their suggestion that management should provide resources to support them in their care work. The provision of the necessary resources to execute their care work relates to creating a supportive and enabling environment for the caregiving dyad to be healthy and to proceed smoothly in accord with the middle range theory of caregiving dynamics (Williams, 2014:312). The HBCGs' suggestions for management to supply resources are clustered as four categories presented next.

- **HBCGs' suggestions to management to provide transport**

Cassie, Malume, Wendy and Lenyalo, were the participants who suggested that management should assist them with transport to do their care work when stating:

"…first thing, I would arrange a transport for them so that it can ferry them to the field because the one [referring to the transport available] *that we are having now is only for patients. They find themselves walking long distances in the sun to reach out the patients and come back. So, it is very difficult. So, if we had a transport that could*

drop them off and later on go can collect them it would be better because we even walk with umbrellas and rain coats during rainy weathers. This kind of a job is not affected by wind or rain, the patients are always waiting…". **[Cassie]**

" … And she can also help us get a transport like a quantum [referring to a taxi] *to avoid walking in the sun"*. **[Malume]**

"I would assist them with transport when they go to check the patients because they walk for a distance in sunny weather even if they cannot deliver us everywhere we go, maybe if we work at [Angola[52]], *they just drop us at the entrance and when we come back we find that transport there and drop us where we stay"*. **[Wendy]**

Lenyalo: *"maybe to raise funds so that when they visit their patients they can have resources like transport"*.

Concerns about transport for caregivers who care for PLWHA has been raised in various studies (Duckert & Vaagte, 2011:65; Fynn, 2011:119; Akintola, 2006:244; UNAIDS, 2008:3; Kipp et al., 2006:9; WHO, 2000:28). In a South African study by Duckert and Vaagte (2011:65) conducted in KZN looking into the organisational challenges in creating care and support services for HIV-positive individuals in rural South Africa, the lack of transport was highlighted as the main concern for a team of participating caregivers. In their paper, which was presented at the AIDS impact conference in Gaborone, Botswana, under the title, "Community home-based carers: voicing their needs, voicing their challenges", Davids et al.' (2009) recommended that organisations should make arrangements for transport for HBCGs who travel distances to visit their patients. Although Tsheboeng's (2015:79) recommendation was directed specifically to the North West Provincial Departments of Health and Social Development, she also called for the provision of transport for caregivers, especially HBCGs. In Valjee and Van Dyk's (2014:6) South African study focusing on the impact of caring for PLWHA regarding the psychosocial well-being of palliative caregivers in KZN, caregivers made their stance clear in suggesting that their organisations should provide transport for them.

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[52] By Angola, Wendy refers to the name of the community that she serves as a HBCG.

- **HBCGs' suggestions to management to provide more equipment and supplies**

The suggestion for management to provide more equipment and supplies for caregivers to help them to execute their care work properly was mentioned by a number of participants as evidenced in the following storylines.

Ching recommended: *"…now we need… the complete uniform including shoes because we have to look presentable"*. He added more: *"…supply them with uniform, education, backpacks, and umbrellas… Because when we visit patients we take files with us and we put them in bags and also those files can be protected when rain is falling and also we need umbrellas to protect us from the sun"*.

Kgomo said: *"I would like us to have some protective equipment because sometimes as time goes by, you may be infected by illnesses like TB. Others maybe the* Multi-drug resistant *TB …So I know some who have been infected by such kind of illnesses, so even us we may find ourselves in that situation because we work with patients"*.

Amelia's suggestion was*: "Our superiors need to consider the difficult weather conditions under which care workers work. So, they should provide us with protective clothing like raincoats and umbrellas. Sometimes we work outside while it is windy. That contradicts what we teach our patients… We teach patients that some of the viruses are air-borne. Now, we lose credibility when we continue to work under the weather conditions that are likely to cause us to get sick…They should ensure that we all have raincoats and umbrellas so that we can protect ourselves"*.

Letsatsi recommended: *"to buy new equipment to supplement old ones. I will try to adapt to the changes and development within the caring fraternity. With the BP machine for example we are using the one which you must first punch before you can get the temperature and when you go to other organisations they use the electric ones which you just plug on a socket and it tells you the temperature"*.

Malume stated**:** *"I think I would expand this organisation and do a hospice because you find those patients that we care for during the day and during the night they are alone. In other words, there are those that we feel like we can be with them 24 hours".*

Viola had a number of suggestions about equipment and she spoke about it along the following lines: *"... make them* [referring to caregivers] *visible by giving them uniform even if we can buy them ourselves but having uniform and nametags, that is very important to us… we want uniforms and name tags so that they can see, at least when you have a name tag saying you coming from* [Segopje[53]] *they can listen unlike when you don't have a nametag they will say, 'ah these ones are fooling us they just want our grants'. Also to get material from the government* [referring to equipment] *so that we can be visible. Also cell phones so that if we are outside the field maybe there is a patient who is bedridden, we can get the ambulance very fast or maybe be provided by a car, or maybe a government provide each NGO with a car or a bus so that they can take a patient to a clinic and at the moment we have a feeding scheme at the centre and there are suffering kids who are going to school with bare feet they don't have uniform and food, our manager is then one who is buying them food from her pocket because there is no any funds for it".*

Zulu explained what he would do for caregivers who needed equipment. *"I would try my best to buy things like umbrellas for the care workers. Care workers work in the sun and they need some kind of protection. We also need schoolbags in which to put in the documents and the particulars that they are using. They buy shoes on a monthly basis…It is not everyone who stays in the centre. The care workers, who stay here, don't pay rent. So, they are able to buy shoes that can last them for a longer period. For care workers who don't stay in the premises, they have many expenses. They walk in the sun all day long. Walking long distances every day, has its toll on the care worker's shoes… salaries are low, people cannot afford to buy durable shoes… We buy cheap shoes from Chinese dealers. That is why they have to include costs for a new pair of shoes every month".*

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[53] Segopje is a pseudonym for the name of the community Viola serves.

Martin stated**:** *"The other thing would be to ensure that they have a uniform so that they can be clearly visible that they belong to a particular organisation. Currently we are not provided with any uniform…Uniform is important because it can distinguish you from other people as belonging to a particular organisation".*

Mokete emphasised that HBCGs should have equal access to resources: *"We expect that the treatment that we get must be the same. No matter the time that one has joined the organisation, people should have equal access to resources. Some of the caregivers are not given certain things because they are told that they are not that long in the organisation. So you find that you cannot access these things and is not like you do not want them. You want them so that they can motivate and inspire you to like your job so that you can continue with your job. So you will find that they say you are new stay behind, your turn will come. So you will feel that you are left out and the older ones are the ones who are taken seriously. And another is that say for example I am off today and someone came and donated some food parcels for caregivers, the next day when I come they will tell me that I won't get anything because I was not there".*

The suggestions made by some of the participants in relation to the provision of equipment by management to assist them in executing their caregiver duties are confirmed in the literature consulted (Ngazimbi et al., 2014:318; Dil, Stratchan, Cairncross, Korkor & Hill, 2012:1192; Campbell & Foulis, 2004:11; Adebajo, Bamgabla and Oyediran, 2003:111). Dil et al. (2012:1198) report that the lack of equipment to assist caregivers to perform their duty results in a low morale amongst them. From Adebajo et al.'s (2003:111) perspective, provision of protective equipment for caregivers who are caring for PLWHA is believed to be a buffer against exposure to infections. Therefore, the need to provide HBCGs with equipment in a form of protective and safety, materials like gloves, gowns, masks and sterilising equipment emerged as one of the important recommendations Davids et al. (2009:5) put forward. Campbell and Foulis (2004:11) are of the opinion that employers or local businesses can play a role in the provision of equipment for caregivers. Some of the participants in Ngazimbi et al.'s (2014:318) study focusing on the topic "counselling caregivers of families affected by HIV/AIDS: the use of narrative therapy" who did not work under the auspices of any organisation, like their

counterparts who were linked to organisations, made reference to the lack of equipment to care for their beloved. In some instance they had even to improvise to provide care.

The need to increase human resources by increasing staff was one of the suggestions made by the HBCGs as highlighted by the next presented categories.

- **A HBCG's suggestion to management to appoint more male HBCGs**

Jini suggested that management appoint more male HBCGs to assist in cases where female HBCGs experienced difficulties due to their gender. "I *wish that as we could have enough male caregivers so that they can help us with our male patients. Sometimes you will find a male patient who is staying alone and is not easy to bathe a male patient. It is difficult, because a male patient will not allow a female who is not his wife to bathe him and you will find that he does not have a family and he stays where I am staying. As caregivers we are supposed to work in areas where we are staying so that whenever there are problems you can quickly address them. Let's say his family is in Vaal and he is here. So, I must quickly look for a male person to assist. So we need male caregivers, not only female ones…They are concerned that as a female you will see his private parts. They don't realise that it is going to remain between me and him".*

Jini's need for the appointment of more male HBCGs corresponds with the findings Tsheboeng (2015:59) makes in her South African study conducted in Mafikeng, North West. It considers the effects of HBC on PLWHA in which the HBCG has male patients who refuse to be bathed by female caregivers as they believe that female caregivers would gossip about their genitals. In another instance, Leclerc-Madlala[54] (quoted in Akintola, 2005:6) cites men who would avoid touching any female's private parts as they believed women are contaminated and bearers of disease. Akintola (2006:238) admits that there are very few men who are involved in caregiving and postulates that those who are involved in caring are selective about

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[54] Leclerc-Madlala's study addresses the relationship between cultural construction of HIV and AIDS and femininity (Akintola, 2005:6).

their caring responsibilities. For example, in his South African study which investigated the informal caregivers' experiences in caring for PLWHA in Marian Hill, KZN, Akintola (2006:241) found that when men get involved in caring, they usually cook and do other chores but would not touch a sick woman or bathe her. Moreover, he found that most of the men who get involved in caring quit once they do home visits due to their inability to cope with the chronic nature of the patient's condition (Akintola, 2006:242).

Although Jini singularly advocated the appointment of more male HBCGs, Morgan (2009:9) is of the view that males, as caregivers, are sometimes pushed aside by females who allege that they do not know how to support the sick and PLWHA. Morgan's viewpoint is endorsed by Homan and Esu-Williams (2005:4), who postulate that women caregivers of PLWHA have come to accept the lack of male caregivers in caring for PLWHA and believe that males do not have passion to care.

- **HBCGs' suggestions to management to appoint other professionals to assist in caring for PLWHA**

Amelia and Letsatsi accounts quoted below are provided to substantiate this category.

Amelia felt that a social worker or a nurse who will be dedicated to them would be very helpful: *"Maybe if the people from government could dedicate a social worker or a nurse to us, it will help us a great deal"*.

Letsatsi explained what she would do if she was a manager of her organisation would be *"...first of all I will bring two doctors who deal with palliative care because as it stands now we don't have a Doctor for all patients. We rely on Tshwane District Hospital and Steve Biko[55] Academic's doctors. I will introduce this as it will cut off all this trips of going to Tshwane and Steve Biko. I think it will also be cost-effective because it will cut off the expenditure on petrol"*.

6[55] Steve Biko is the name of an Academic Hospital in Pretoria, South Africa.

The suggestions forwarded by Amelia and Letsatsi for management to appoint other professionals to assist in caring for PLWHA is supported by Schietinger (2005:39) and Goeren (2011:360). They are of the view that, given the number of HIV and AIDS patients, effective palliative care requires a team of medical personnel, social workers, psychotherapists, case management experts, dieticians and pastoral counsellors to give the necessary comprehensive care and support. Van Dyk (2007:64) too has the same opinion and recommends that management considers involving a multi-disciplinary team to protect staff from stress.

The suggestions from HBCGs to management to provide resources corresponds with the concept of role negotiation propounded in the middle range theory of caregiving dynamics in that the caring responsibility should be shared (Williams, 2014:315), if the caregiving trajectory is to proceed forward smoothly. Suggestions by HBCGs for management to appoint other professionals and male HBCGs in this context appears to be an appeal to ensure that the caregiving dyad progresses by ensuring that some responsibilities are allocated to such professionals and male HBCGs. In some instances, one sees the role of management as that of being an enabler for HBCGs' self-care through their creation of a supportive environment also proposed by the middle range theory of caregiving dynamics (Williams, 2014:312). The work of HBCGs is easier if role support is considered. It can be achieved through the provision of transport to access their patients; appointing male HBCGs and other professionals to ease their load of responsibilities; and for them to have adequate and proper equipment.

4.2.5.3 Sub-theme: HBCGs' suggestions to management to provide training

This suggestion that training should be provided was highlighted by several participants as their storylines suggest.

Ching believed that training would help her to answer some of the difficult questions her patients often ask. *"To teach patients about diseases, sometimes when we went to see patients they trust us more than nurses and doctors so they ask us about some things that we don't know because of lack of knowledge, so when we have this knowledge we can teach them more, now we need a training…".*

Lenong felt that carers must be supported to further their studies so that they can be more knowledgeable and even earn better salaries: *"I think they* [referring to management] *must give some bursaries, they can improve our opinions, take us to school to learn more and more, to be part of the community and because of our experience we know we can do those challenges…Because while we are here we lack finances. We are not getting improved and all what is happening is that they employ more and more qualified people and give more and more money and for the carers they don't care".*

Lenyalo shared the same sentiments when asked what she would do if she was the manager of her organisation: *"First thing I would raise funds for those who need to further their studies if possible".*

Letsatsi held a similar train of thought: *"Maybe to give them an opportunity to study further and not be caregivers for a long, long time. Maybe we must have our own school until auxiliary level…Is like when you are a person, you can't stay in the same position for a long time. Maybe if there were other stages like auxiliary, staff nurse and professional nurse".*

For **Selinah** equal treatment and training were the main things she would address as a manager*: "I would treat caregivers equally regardless of the qualifications because they are doing the same thing. And I would support them to go and study auxiliary nursing so that they can move from the levels of being caregivers to auxiliary nursing which is quite better".*

In **Yena's case**, lack of comprehensive training and education restricts them from accessing available opportunities and this important concern, she believed, could be addressed by lobbying for funds for their further education and training*: "... if we can receive more information to advance our skills and know how to help these people". I would get them funds because we can't get money from one place to help this whole society but if there were funds to help these care workers… Many carers are not educated and most have not matriculated so that is our problem, and we cannot open other doors* [meaning access to other available opportunities] *because you do not have matric, so if we could get some allowance so that we can study and get*

more information because I don't think we have to be caregivers who do not have matric or maybe not be accepted anywhere because of not being educated…you may have been a volunteer for some time, you've got an experience but you are not educated, at least if we can be given a learnership and be given a chance to study maybe on Saturdays or after work, we want to see ourselves somewhere even if we help people but we want more knowledge".

Zulu was very specific on her need for training on counselling and how to avoid infections: *"I believe that it would be good to receive additional training. We want to be trained in counselling so that we can be able to help our patients with confidence and with no fear of contracting any disease".*

In the case of **Mamadee**, she thought that training caregivers on how to be passionate is crucial: *"I would offer training because some do not understand what people are going through and some do not have passion for working with people. I think I would train them along those lines. I will equip them of things like linking the children's behaviour to their respective developmental stages and on issues relating to confidentiality".*

The caregivers' need for training fits into the middle range theory of caregiving as Williams (2014:314) proposes and which was adopted as one of the theoretical frameworks for this study (see Chapter One: sub-section 1.2.1). According to the middle range theory of caregiving dynamics, the caregiving trajectory is characterised by uncertainties and occurrences and they respond to order (Williams, 2014:313; Williams, 2007:380; Williams, 2003:681). For the care relationship between the HBCG and/or the patient to continually proceed efficiently, immediate action is essential especially when unanticipated eventualities take place. For these sudden events to be managed proficiently, the HBCG must engage in what is called expectation management. Mastering this skill of expectation management comes with personal and professional growth, and it is for this reason that Martson (2003:117) proposes that HBCGs should have the necessary theoretical and practical training. The need for training, as the participants from my study propose, was also expressed by the palliative caregivers who took part in Valjee and Van Dyk's (2014:6) South African study that focused on the impact of caring for PLWHA

on palliative caregivers' psychosocial well-being in KZN. For the caregiver-participants in Akintola's (2005:22) South African study concerning the role volunteers caring for PLWHA play in mitigating the burden of care in households and communities, training is more than acquiring skills to execute their duties properly. In addition, proper training was rather associated with status as they felt more elevated than other community members.

4.2.5.4 Sub-theme: HBCGs' suggestions to management to provide better or increase stipends

Among the suggestions regarding how management could improve their working conditions, Zulu, Ching, Jini, Kgomo and Yena highlighted the need to provide a better or increase stipend.

Zulu told me that some people would like to become caregivers caring for PLWHA but they are mainly turned off by the salary: *"The others, who would like to work where I am working now, give up early due to the salary … if the salary was good, they would be able to look after their families. Many people, who work here, end up resigning because the salary is too low. They can't pay for their needs with the money we are earning currently. That makes people to lose interest in the work because they don't earn enough money. The low salaries make it difficult for people to pay their rent and cover other living expenses. It would be good if people could earn a living wage so that they can take care of their families. It would be great if we could earn better salaries so that employees can be able to take care of the needs of their loved ones because they are doing the work that they like"*.

For **Ching**, a higher regular income would motivate her and assist her in addressing some of her basic needs: *"if they can increase the allowance, because the more you earn the more you do your job and you can do your work with a good heart, you can buy new shoes, buy toiletries, coming to work, and when you going to work you know that you going to work hard because at the end of the month you know you get something"*.

Jini was very brief in highlighting her need for caregivers to be remunerated like others for their hard work: *"I would ensure that they receive stipend like other caregivers because their work is strenuous too"*.

Kgomo thought that her age and experience would somehow be considered when being paid but this was not the case: *"they must pay us. Yes, this work is challenging. And this ones* [referring to her employer] *they are not paying. We have spoken to them until we get tired and we have just surrendered. You cannot believe me when I say I have worked here for the past ten years but I earn less than R1 500. I feel like there is no other work that I can do and I am too old to go around looking for another work and besides I like this kind of work that is why I am still here. It is not such a difficult work. The only time it gets difficult is when patients begin to be critical"*.

In **Yena**'s situation, management should consider the HBCGs' very low income background when it comes to remuneration: *"... and be given some stipend and food because sometimes at home is difficult as we come from different families with different challenges so we will be happy if we can be helped as care workers"*.

My participants' suggestion for management to improve or increase salaries/stipends is confirmed in the literature consulted. Akintola (2010:8) is of the opinion that for caregivers, receiving a stipend is a significant motivator and should never be taken lightly. Ama and Seloilwe (2011:7) did an analysis of the costs incurred in providing care to PLWHA in four districts in Gaborone, Kweneng East, Selibe Phikwe and Bobirwa. They are also very vocal about the fact that financial and material supplies are some of the motivators that can lift a caregiver's morale.

For Campbell et al.'s (2008:170) participants from their study on the social landscape of child adherence to ART in Zimbabwe, a stipend was regarded and described as the caregivers' source of pride. Just as was the case with some of my participants quoted above, the participants in Alam, Tasneem and Oliveras' (2012:513) Bangladesh study conducted in Dhaka to assess the factors that influence the activity of community health workers recommended that their respective organisations increase their stipends. Similarly, Kasimbazi and Sliep's (2011:106)

South African caregivers who took part in their study with the topic "Unpaid volunteers and perceived obstacles in ensuring care and support for people living with HIV/AIDS" in KZN proposed that the stipend be standardised to enable them have a regular constant monthly salary. Although Akintola's (2005:21) South African participants who took part in his study of the role of volunteers in mitigating the burden of HIV and AIDS in the households and communities in KZN highlighted the need to be paid a stipend, they believed that this should be more of a token of appreciation than a payment for their service. In addition to paying adequate salaries, Van Dyk's (2007:64) recommendation to management is also for personnel to have adequate vacation leave.

This suggestion from HBCGs to management to provide better or increased stipends relates to the aspect of role support in the middle range theory of caregiving dynamics (Williams, 2014:316) in that decent stipends are likely to serve as a motivate for them to be more committed in their caring duties and inspire them to acquire better skills.

4.2.5.5 Sub-theme: HBCGs' suggestions to management to provide them with psychosocial support

The need for management to provide HBCGs with psychosocial support became evident when HBCGs raised the question about the need for counselling, debriefing and teambuilding.

- **HBCGs' suggestions to management to arrange for counselling and debriefing support**

The comments (quoted below) show that Jini, Paul, Selinah, Viola, Wendy and Yena spoke up about aspects associated with this category.

Jini explained how she, if she was a manager would assist caregivers to have counselling sessions. *"The first thing that I would do is to encourage them to talk and be open because you cannot help someone who is not open about his problems. Secondly, I would ensure that they receive some counselling because their work is*

tiring. Truly speaking the caregiving work is tiring. You are just like sister even though they undermine us the workload is just the same. So, they also need some counselling, they need people who can debrief them".

Paul alluded to the fact that he will arrange for debriefing based on his experiences of having patients with whom he had close relationships who passed on: *"I will arrange that there be somebody to make sure that they get debriefing after a very bad experience and counselling. I think lots of organisations don't have a qualified person to do debriefing. Like when I was with Lifeline where we were doing online telephone counselling, a person who was dealing with someone who wanted to commit suicide will afterwards phone a backup person to debrief a little bit so you can continue with your work. That is what I would do here".*

Paul explained further: *"What I have experienced in the past especially in the beginning years, when I support somebody for a long time and that person passed away, is like that person becomes a friend and your friend passed away. So, you get so involved with the person's life and suddenly that person passes away… I think the family doesn't think that way. They will mourn but in the meantime the caregiver who was supporting that person for a long time also needs to go through the mourning process…when you really get involved with a person, is not like that person goes to the Doctor for fifteen minutes, or go to a psychologist of go to a counsellor and see that person once or twice. When you are really involved as a caregiver, you become part of that person's life …".*

For **Selinah**, having quarterly debriefing sessions would enable those HBCGs who attended them to overcome some of their challenges*: "I would have the quarterly debriefing sessions where I would sit down with them and interview them…so that we can talk about our challenges. I think it would help because currently we just talk amongst ourselves as caregivers and this does not make some sense because we are experiencing the same thing. But if we give it to a neutral person he/she will know how to deal with it because she/he has been trained for that".*

Wendy held a similar view to what Viola expressed. *"…if maybe they* [referring to the management] *can get us some professional helpers, psychologist maybe going for*

counselling…So that we can heal and then also they help us to accept the situations we encounter so that we can face them…Besides counselling and support group you have to help yourself".

Yena implied the need for support groups that had monthly gatherings when caregivers met with their managers exchange ideas: *"… if there can be something for us maybe once in a month where we can meet and exchange thoughts and advices and also have leaders who can advise us more and to strengthen us to carry on with what we do, and as we sometimes got stumbled we need to help each other, we do love this work and we need to be strengthened to carry on".*

This suggestions made by some of my participants for management to arrange for counselling, debriefing and support corroborates with similar recommendations made in the literature consulted (Kang'ethe, 2009:77; Abasiubong et al., 2011:495; Campbell & Foulis, 2004:5). Akintola (2005:19) is of the opinion that providing counselling and debriefing to caregivers caring for PLWHA is of paramount importance as the irony is that they experience grief, suffer psychologically and emotionally and follow or observe the passing of their patients. Yet it is expected of them to continue as though nothing had happened. It is for this reason that recommendations are made to improve the caregiver's psychological well-being through the provision of support (Abasiubong et al., 2011:495; Campbell & Foulis, 2004:5), counselling, support groups and debriefing (Kang'ethe, 2009:77). Regarding debriefing, Kang'ethe (2i09:86) suggests that formal meetings be conducted individually or in small groups, usually after stressful incidents, to address the emotional residual a caregiver is left with after such an incident.

- **HBCGs' suggestions for management to arrange for team building**

From my interview with Mpshe and Letsatsi, team building and support appeared to be a common need to address some of their challenges, as is evident from this record of their accounts.

Mpshe was of the opinion that team building would enable them to socialise and forget about their challenges for a while. *"There is a need for team building. To socialise as colleagues. Not in a work context, outside the work environment …"*

Letsatsi was very brief when highlighting the need for team building: *"To make them one team and understand each other"*.

This lack of and need for teambuilding referred to by Mpshe and Letsatsi correspond with those of the hospice caregivers who took part in Hillard's (2006:400) study aiming to evaluate the effects music therapy and team building have on compassion fatigue experienced by professional hospice workers. They expressed the need for teambuilding and teamwork as they felt lonely and experienced that a team spirit amongst them were lacking. It is on the basis of this need experienced that Van Dyk (2007:64) urges management of HBCs to create a supportive environment for caregivers to avoid burnout and team building is one of the ways of providing an antidote for this. Through team building, by way of an outdoor experiential activities and indoor group discussions, a sense of unity and cohesiveness is promoted, enabling the team to function together more smoothly and effectively in accomplishing tasks and addressing work-related challenges (Senecal, Loughead and Bloom, 2008:187; Klein, DiazGranados, Salas, Le, Burke, Lyons and Goodwin, 2009:2).

The call by HBCGs for management to provide psychosocial support relates to role support in view of self-care as an enabler and dynamic force that moves the caregiving relationship forward, as found in the middle range theory of caregiving. According to Williams (2014:312), self-care is realised when there is, amongst other issues, cultivation of a healthy habit whereby the caregiver will remain healthy and be both physically and psychologically fit to continue with their caring duties. By providing HCBGs with counselling and debriefing support and arranging for team building, management offers role support which in turn would be nurturing self-care, as an enabler contributing to moving caregiver-receiver trajectories forward.

4.2.6 Theme eight: HBCGs' suggestions on what they, as HBCGs, could do to manage their work-related challenges

The theme, HBCGs' suggestions attribute on what they as HBCGs could do to manage their work-related challenges, was filtered through and f gave rise to theme.

To substantiate this theme, Lenyalo and Pekwa thought that a HBCG has to exercise patience when engaging in care work and it is a crucial attribute to have.

Lenyalo appealed for patience among the HBCGs. *"I would like us to have patience. So that even if these patients do not welcome us, we must not be impatient …This will give us some courage and even when we go to these patients, they will start welcoming us"*.

Pekwa shared the same sentiments as Lenyalo, as quoted above, and highlighted the importance of training HBCGs to be patient: *"I would bring in patience, so that they can persevere… I would help them to get some training on how to be patient…"*.

Working with vulnerable and helpless people requires some form of tolerance and compassion on part of the caregiver. The call for tolerance was also made by the United States Ambassador to Ghana, Cretz (2014) when sharing his thoughts about the International Day of Tolerance (which is held on annually on November the 16th) through the Embassy's Facebook page. According to WHO (2000:15), broadmindedness, tolerance and acceptance of diversity are particularly important when it comes to caring for PLWHA. When tolerance diminishes, it may lead to depersonalisation – a change in a caregiver's personality which is characterised by coldness and impersonal contact with patients; it is the same as having sinister attitudes, irony and indifference to others (Van Dyk, 2014:2). In other words, caregivers who run out of patience when caring for PLWHA will be more likely to disrespect their patients and therefore only perform their caring duties for sake of doing them and out of routine and not really caring.

4.2.7 Theme nine: HBCGs' suggestions on how social workers could support them to improve their work-related challenges

Social Work is regarded as a major psychosocial contributor to the comprehensive palliative care provided to PLWHA (Goeren, 2011:365; Qalinge, 2011:53; Hall, 2008:55; Rutledge, Siebert & Wilke, 2008:51). Participants were asked about the services they would like a social worker to provide for them; what social workers would do to support HBCGs; and also what advice they would give a social worker working with them. Their responses are presented (below) in two sub-themes, namely: HBCGs' suggestions for social workers to provide them with Social Work services and HBCGs' suggestions for social workers to provide Social Work services to patients, families and communities.

4.2.7.1. Sub-theme: HBCGs' suggestions to social workers to provide them with Social Work services

The role of a social worker in caregiving is primarily to coordinate the HBCGs' services by providing ongoing supervision and to educate volunteers on interpersonal and service boundaries, train them in communication skills, family systems, how they should take care of themselves and to deal with grief where necessary (Walters and Watts, 2011:509).

Paul held a very critical view of social workers in the arena of HBC and caring for PLWHA. He expressed himself as follows about this: "*As I told you before, I don't like social workers (laughing). I don't think they have studied enough or they may have studied but haven't got the practical experience to tell someone that have been working for twenty years supporting PLWHA what to do and over write them…But they have got a role to play in the community I think. Is not only me who don't like social workers...because they always interfere. And sometimes they interfere without having the proper background or knowledge of the person or the situation...A training course where that person can be taught to listen to a person without saying something. Social workers are the same as ministers in the church. They qualified theologically, but they have never done a counselling course. Same with the social workers they want to tell a person what to do. So, I think they need to be taught how*

to listen to a person properly". Paul added further: "*I think social workers need to be trained more specifically in caring and about the AIDS field. They must specialise in that field. I think so and I base that on my experience with them in the past…*"

Paul's suggestion for social workers to receive specialised training in the field of AIDS research is echoed by the social workers' AIDS Network (SWAN) (in Parry, 2001:72) which is of the view that social workers who are working with PLWHA require a specialised kind of training (Parry, 2001:72). Support for specialised training is called for in view of Nelson-Becker, O'Mahony and Baron's (2016) assertion that many social workers do not have specialised education on end-of-life care, palliative care and ethical dilemmas which they face when working in these areas of hospice and palliative care which, according to Walsh (2003:1) is "highly specialised and constantly changing".

Despite Paul's critical view of social workers, the HBCGs' had various suggestions for social workers on services they required from them. This is presented next as categories.

- **HBCGs' suggestions for social workers to provide them with counselling, support, debriefing and team building**

In substantiation of this category, the accounts of the participants who had this suggestion for social workers to provide them with counselling, support, debriefing and team building are presented.

Dineo suggested that a social worker must provide them with counselling on how to cope with the treatment they receive from members of the community*: "I think she* [referring to a social worker] *must provide counselling with regard to the way in which the community members are treating us. She must try to help us how to deal with such treatment and give us support. Maybe there is much that we can do than to simply 'let it go' as our manager says".*

Ching explained how social workers could support them: *"…help by giving a support… because sometimes when they come here they only concentrate to the patients, and forget us"*.

Lenong explained how social workers should counsel and encourage HBCGs: *"And as a social worker you have to tell the care workers that...as long as you do good, there will be opposition. As long as you are fine, those real people who are seeing you fine, they still gonna say bad* [things about you] *and there is no way that you gonna be good to everyone, to everybody, to whoever, no"*.

In addition, **Lenyalo** was of the view that having a social worker around to support them will help them to cope better: *"…I think to consistently provide them with counselling and encourage them and support them on what they do. Just to show them that they are not alone in what they are doing. I think that will help in dealing with the challenges"*.

Mokete felt that an open environment in which caregivers can openly share their challenges and experiences should be coordinated by a social worker: *"There was once an organisation called SAOPA[56], which had social workers and they were dealing strictly with debriefing of caregivers. That would also work and it is part of the social worker's duties to arrange that so that we can just sit and share. And I think if she can also arrange a day in a week or so that we can talk about our internal challenges that affect us from within the organisation so that we can talk freely and people can be able to say 'I do not like this, I do not like that.' So, people should feel free, I must not be targeted simply because I said I do not like this and that. So, the social worker should create such a friendly environment where management can understand that whatever frustrations that we share with them are the causes of our pain and they need to be addressed"*.

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[56] By SAOPA, Mokete refers to an organisation which was dedicated to offering them counselling and debriefing sessions.

Mpshe felt that if she was a social worker, the first thing she would arrange would be counselling*: "As a social worker the first thing I would do is to do counselling with caregivers… I would have spoken to them so that they can offload their challenges".*

Nakedi provided some motivated reasoning for why a social worker is required to provide them counselling: *"I think I would like him/her* [referring to a social worker] *to provide us with counselling because we need it a lot. We do sit and provide one another with some counselling but we were not trained for that. So because he/she would has been trained. I think that would assist us…I think she must come on Fridays so that we can share all the problems that we encountered throughout the week and receive the necessary support for the next week but given the fact that sometimes we face very difficult challenges, she may even come twice a week. Sometimes you would find yourself being reluctant to go to the field as you would be overwhelmed by these challenges. Your mind would be very tired and as your mind becomes tired so does your body. You would then just force yourself to go to work even if you are not ready".*

In **Paul**'s case and if he was a social worker, debriefing sessions will be the first he will conduct, followed by some relaxation activities: *"I will firstly provide a debriefing session and then I also think that relaxation things. I will provide an opportunity where they can really be themselves and not in that role of caregiver. That they can be valued as a person in total not only in what that caregiving is* doing…*Because they also get stressed and have personal problems that they must deal with and how do you deal with those problems before you can deal with somebody else's problems".*

Segwagwa had much to say to contribute to support/counselling/debriefing if she was a social worker working with caregivers: *"If I was a social worker, I would make sure that every week I sit with the caregivers and look at the priorities. I would explore the challenges and stresses which are faced by caregivers and then set aside certain periods on which caregivers go out (even if they don't go all at once, they can alternate), so that they can refresh and forget a bit about their work...Or even if is not an outing, but there should be some sessions which could take them out of the work context. Things like the swimming pools, having some discussions*

with other organisations so that they can share. If there is anyone who feels like crying they should do so. It must be something like counselling, caring for the carers. I would make sure that every term they go out. Then I would provide some counselling until they recover. I would also consider giving those who are overwhelmed some half days. Maybe I would also get some chocolates although I know that some companies cannot afford. A small chocolate Chomp with a ribbon, send a small message just to give them some courage." "I don't remember the year but there was a social worker who was taking good care of us. She would arrange an outing for the entire group that does field work. She would organise a place where we would refresh and sleep. We would have some discussions and later we sleep and the next day we wake up is breakfast and sometimes we would go out with our patients. That one was our own suggestion as caregivers when we left on Thursday for Durban and returned on Monday."

In **Vanessa**'s view, social workers should conduct individual counselling and group therapy with some form of activities: *"On the care side they* [referring to the caregivers] *need more one-on-one counselling. They need more group therapy. When I'm saying group therapy, I mean learning to play games, because sometimes we're more serious and then you don't know how to relax. They need to be taught how to relax, how to let go of the day, every day, every single day. And they need to be taught to take care of themselves first before they even go out there and give care, because when you give care you forget how to care for yourself".*

Viola was of the view that a social worker should help them solve their own personal problems*: "I would like her* [referring to the social worker] *come to help us with our problems. Some of us have problems and angers so we don't know what is happening. So if they could provide us with someone who will talk to us …some of us we are struggling from home like coming here you struggle so if they can provide us with something maybe food parcels…Sometimes one has her own challenges at home, her children doesn't have food to eat, when you try to chat with her she is not concentrating thinking about the situation she left at home so if we can have a social worker whom we can tell our problems that would be nice… We need people whom we can talk to because some of us we are emotional we need someone to listen to our problems because I'm afraid to tell someone here, they may spread them out so*

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if there is a social worker to talk to or someone else whom we can explain our problems to and give advice".

Letsatsi believed that social workers should use their competencies to assess caregivers' needs and intervene where necessary: "I *think I will tell him to arrange for some counselling sessions for new care workers and ensure that those that are here for some time are also provided with counselling. I think he/she will use her own experience and skills as someone who works with people and develop an understanding of the situation and provide the necessary interventions".*

Mpshe had the following suggestions, should she be a social worker: "*As a social worker the first thing I would do is to do counselling with caregivers. I would talk to them and from there I would facilitate the team building process so that they can forget about the patients. I would also take them out for camping. I think that would assist. I would have spoken to them so that they can offload their challenges and from there I would take them out as a group for team building. Because you will find that they are carrying a burden and this will be an opportunity for them to relieve themselves".*

Without the necessary support, caregivers' constant exposure to their patients' sufferings and loss can lead to burnout and once burnout occurs, the risk of becoming despondent kicks in along with the possibility of a compromised compassion to care (Defilippi, 2003:28). The need for counselling, support, debriefing and team building for caregivers cannot be overemphasised enough. Uys (2002:102) recommends that both caregivers and PLWHA need bereavement counselling as they are struggling with grief from deaths of family members. In some studies, about caregivers caring for PLWHA (Singh et al., 2012:2; Van Dyk, 2007:63; Akintola, 2008:133; Akintola, 2005:17), it was reported that HBCGs had emotional and psychological problems resulting from the death of some of their patients and the shock associated with the deteriorating health conditions of their patients. For example, in her South African study of occupational stress among caregivers caring for PLWHA at UNISA, Van Dyk (2007:59) found that only twenty-seven percent of her participants reported that they received debriefing. It is therefore on this note that researchers like Akintola (2005:23) call for psychosocial support for services for

HBCGs and that Primo (2007:iv) in a South African study that explored the effects of caregiving on physical and mental health of HBCGs in AIDS caring for PLWHA conducted in Nigel, recommends that debriefing should be provided to caregivers who care for PLWHA. Whereas Defilippi (2003:28) and the WHO (2000:7) encourage teamwork and communication as some supporting strategies for HBCGs, Dow and McDonald (2003:201) in particular, call for social workers to counsel caregivers and their families to adopt more effective coping strategies in dealing with their challenges.

The HBCGs' suggestions for social workers to provide them with counselling, support, debriefing and team building ties in with the aspect of role support in view of self-care as an enabler aiming to assist the caregivers to cope with their caring duties as highlighted in the middle range theory of caregiving dynamics developed by Williams (2014). The suggested service to be offered by the social workers would create a supportive environment in which they can cultivate healthy habits to maintain psychological and physical well-being, as well as their motivation and commitment.

In addition, the suggested services will provide a space for 'letting it out' as a means of self-care (Williams, 2014:318) towards someone in whom they confide. In this milieu of support and team building, new insights may develop and opportunities created for further growth and the acquisition of new knowledge and skills.

- **HBCGs' suggestions for social workers to motivate them**

Cassie, Jini, Amelia and Selinah expressed the need for social workers to motivate them and therefore forwarded this as a suggestion as deduced from their accounts as presented in the next page.

Cassie, if she were a manager, "… *would at least ensure that once or twice a year there is someone* [referring to a social worker] *who will come to give you some motivation, to strengthen us so that we do not get tired in our journey".*

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Jini believed that a social worker would provide motivation when demotivated*: "I would love her to give us some motivation because sometimes we are demotivated'.* For **Amelia,** the social worker's motivation would be her fuel to continue serving the community: *"I would like the social worker to motivate us so that we can be able to continue serving the community".*

Selinah was of the view that a social worker would give them courage by appreciating their contribution*: "She* [referring to a social worker] *could also encourage us because we lack someone who can give us some courage by simply appreciating our work. We need words such as 'guys you are doing a very good job' from social workers".*

The suggestion by the caregivers that the social worker should provide motivation falls within the sphere of motivational interviewing as one of the strategies adopted by social workers during the counselling process. Rollnick and Miller (1995:326) define motivational interviewing as a "directive, client-centred counselling style for eliciting behaviour change by helping clients to explore and resolve ambivalence". In other words, the main aim of motivational interviewing as a counselling approach is to help the caregivers realise their uncertainties, and inconsistencies and help them develop some strategies to resolve them. The aim is to trigger the caregivers' motivations and resources for change which serves to improve their conditions (Miller & Rollnick, 2012:16). Coupled with this is the concept of "empowerment" which is one of the pillars on which the strength-based perspective (adopted as one of the theoretical approaches for this study) is founded (Saleebey, 2013:7; 2006:7; 2002:7). Empowerment aims to enable individuals to believe in themselves and realise that they have within them all the resources they need to liberate themselves from their challenges (Benard & Truebridge, 2013:208). In this context, the motivation provided by a social worker should as suggested by some of my participants serve as an empowerment and liberation strategy to enable caregivers to revive their courage and continue with their caring tasks.

- **HBCGs' suggestions for social workers to provide them with training**

Ching and Vanessa's suggestion was for social workers to provide them with training. They referred to this along the following lines:

"I would like him [referring to the social worker] *to offer us training … For us to have more knowledge so that he know what to do when we visit the patients and also to answer the questions they ask because it is embarrassing when a patient ask a question and you don't know what to say because they think we know everything since we wear uniform"*. **[Ching]**

Vanessa felt that as a social worker, she would offer caregivers some basic training related to caregiving, counselling and HIV and AIDS and its related factors*: "Then, now you just came to deal with HIV/ADS. You have no cooking clue how to deal with the others that coming with that, and the way it started. It started somewhere and that's how it ended up HIV/AIDS. And then you don't have any cooking idea what to do with that. And counselling, I teach them, I would make sure they go on the courses for counselling. Counselling, I wouldn't take an in-depth medical, but just foundation medical on the disease and related diseases to HIV/AIDS; social aspects, abuse, alcohol, drug abuse, just foundation. I wouldn't take them in-depth but give them, equip them, just equip them to be able to better do what they do"*.

Without proper training, caregivers will not function as part of the health care system and if they do, they run the risk of failing the HBC programme (Cameron, 2003:33). Tsheboeng (2015:75), in her South African study of the effects of HBC for PLWHA on HBCGs conducted in Mafikeng, North West, observed the significance of addressing the HBCGs' challenges through the provision of training.

- **HBCGs' suggestions for social workers to liaise and negotiate with management for better salaries for the HBCGs**

Malume, Selinah and Vanessa voiced the suggestion that social workers must liaise and negotiate with management for better salaries for HBCGs. They spoke about it as follows:

Malume said: *"I would expect him/her* [referring to the social worker] *to help us to be well recognised, to be appreciated so that people can see how big our contribution is… Although is not about money, I would also say she/he* [referring to the social worker] *can help us with money. Caregivers are earning a very low salary"*.

Selinah lamented the fact of the low salaries they received and suggested that a social worker could be instrumental in the process of lobbying for better salaries at management level: *"I would advise you to you start at the management level … the issue of money is the main problem here. It is this issue that makes us to feel discouraged. R800 is a very little money for one to survive. I would suggest that the social worker work closer with management to represent the interests of caregivers. But I think if a social worker is closer to them, they would start doing the right thing. As it stands now we do not know anything about the budget. The social worker would then confirm things like whether is true that the Department of Health says they must give us R800. So, if there is someone like a social worker who represents the caregivers at their meetings, they would now begin to do things the right way and the social worker would take part in the decision-making process on behalf of the caregivers"*.

For Vanessa, and if she were a social worker, it would be crucial for her to play an advocatory role in lobbying for better salaries for HBCGs: *"I would advocate or look into how they can together advocate better salaries, more benefits on their side; education and with that more salary and benefits, which they can qualify in something"*.

The suggestion voiced by the participants for social workers to liaise and negotiate with management for better salaries for the caregivers, seems not to be too farfetched especially in light of Parry's (2001:24) view that social workers working in a health care setting can use their liaison skills to benefit the interdisciplinary teams so that they can provide more comprehensive services to dying patients and their families, for example, by lobbying for better remuneration for HBCGs.

- **A HBCG's suggestion for social workers to undertake home visits**

For **Amelia**, and if she were the a social worker, she would accompany HBCGs to home visits as this would enable the social worker to easily address problems that were within their scope of practice: *"I would accompany the care workers to home visits so that I can understand their challenges. Where I see that there are problems, I would try to help"*.

The home visit as described by Martson (2003:115) "is central to the concept of home-based care". Home visits offer various advantages such as enabling the HBCGs to observe family dynamics and assess their needs in the comfort of their own homes (Martson, 2003:115). Given their encounter with problems that could require the expertise of a social worker, it is therefore crucial to have a social worker with them during their visits so that they could witness what is going on. Although some of the caregivers who took part in Duckert and Vaagte's (2011:56) South African study of the organisational challenges in creating care and support services for HIV-positive individuals in KZN, were able to address some of the Social Work-related cases like guiding and supporting orphans to apply for foster care grants, they were not necessarily able to identify and address the underlying psychosocial issues that would be purely within the Social Work scope of practice, due to their lack of training, skill and legitimacy of the Social Work domain.

Homan and Esu-Williams (2005:2) are of the view that social workers and health educators should make home visits when the patients' needs exceed the caregivers' capacity (Homan & Esu-Williams, 2005:2). By visiting the patients with the HBCGs, the social worker will ensure success of the programme in handling cases that might fall beyond the HBCGs scope of practice and this may even ease their pressure of

work. Rowe et al. (2005:266) demonstrated the success in adherence to TB treatment in Thailand, Uganda and Brazil in which the social workers conducted visits to trace the patients who had defaulted their treatment. Although Rowe et al. (2005:266) could not directly link these successes to the social workers' visits, Thailand reported sixty-nine percent adherence, Uganda reported sixty-two percent and Brazil reported sixty-one percent. In the South African case no evidence of social workers' visits was found and only forty-seven percent reported adherence (Rowe et al., 2005:266).

4.2.7.2   Sub-theme: HBCGs' suggestions to social workers to provide Social Work services to patients, their families and communities

Participants saw a need for a social worker to assist them in addressing the Social Work-related challenges their patients encountered. Participants' suggestions for social workers to assist their patients in rendering services to their patients are therefore not likely to be questioned, particularly given Van Dyk's (2007:56) South African revelations from her study of occupational stress among caregivers caring for PLWHA in which some of the nurses who took part in her study reported that they sometimes felt like they were doing the duties of social workers. Below I present the responses of the participants divided in three categories related to this sub-theme.

- **HBCGs' suggestions for social workers to assist in resolving patients and family Social Work-related problems**

Some of the caregivers felt the need for social workers to render counselling and Social Work-related assistance to the patients and their families as given below.

Kgomo was of the view that social workers could assist by intervening in cases where patients are resisting care and support: *"I think she* [referring to the social worker] *must help us with these patients who close doors and chase us away and those families that do not take care of their patients. I wish social workers could provide them with some necessary counselling so that they can take responsibility for their patients"*.

For **Pekwa,** social workers could be of assistance in cases where patients could not take treatment for poverty-related issues*: "I would advise her [*referring to the social worker] *to look into families that do not have income and whose patients cannot take medication due to lack of food and to those that do not receive any grant"*.

For **Dineo,** an in-house social worker, could assist in addressing problems which are beyond the HBCG's scope of practice*: "I wish each home-based care organisation can have a social worker so that they can help us with families that have some social problems like those with children who are without the birth certificates, children from foreign countries and so on…Sometimes you find families that do not have any income and there is nothing that we can offer apart from a small food parcel. So, I wish we could have a social worker"*.

Mokete believed that, as HBCGs, they should only address the health-related problems of their patients and leave social problems to the social worker: *"For example, if we go out to the field we encounter a lot of social problems then we would refer them to her* [referring to the social worker] *so that she can intervene from her level. So, next time when I visit the patient I would only deal with the health part of it… I should not look at the social and health problems like for instance when you get into the household you find that the patient has some children and they do not receive any grant and they do not have birth certificates. So, you will be running to connect to Home Affairs and from Home Affairs to SASSA and all these things. So, I think if we have a social worker, we would be relieved and reduce a burden of work because she may address other things easily through her networks. At least she is a professional and when she gets to those offices, they will understand that she is talking from their level. But if you go as a caregiver and not a professional, it becomes much difficult"*.

For **Lenyalo**, a social worker could liaise with doctors in the interests of the patients. *"She may liaise with the doctors to help them get grant that can assist them".* Lenyalo later in the interview explained how she would go about helping caregivers if she were a social worker: "*Like when we encounter patients from households where there is no income, I would find ways of raising funds for such families help them get some food and others. I think that would help … So, if a social worker can come in*

and try to raise funds so that we can help this kind of families…given the social worker's involvement with children, they would help such children with school uniforms and food".

Jini also expressed the need for a social worker to attend to the social problems encountered: *"I just wish we could have a social worker who is always with us because as we visit the patients we find some of the difficult cases that needs a social worker. So we need a social worker who can always make sure that she assists us whenever there are social problems"*.

Nakedi told me how social workers could help them address social problems in some of the families: *"…there are those families where you would find that there is a woman who is sick and she stays with children and she would say, she can't look after the children, they are still small and she wish that they could be taken to the children's home. I think those kind of cases need a social worker. Just like the friend whom I told you earlier that she eventually died and left the children, she also needed a social worker"*.

Viola believed that social workers could coordinate material like helping with providing food parcels*: "…and also those people who are living with HIV here in the centre can get something like food parcels or something"*.

HBC as described by Defilippi (2003:22) involves, among other things, the provision of social support through welfare services, aspects of legal advice, referrals to certain service providers, bereavement care and poverty alleviation. Some of these aspects can be addressed immediately by the HBCGs while others could require the professional expertise of a social worker. Whereas Berkman (1996:543) states that the social workers should play a role throughout the caring process, Ama and Seloilwe (2010:1) have particularly called for skilled welfare officers to support family members in addressing their psychosocial needs. For Connor, Lycan and Schumacher (2006:203), the social worker in hospice care generally arranges community resources and provides support when decisions are made around treatment choices, life support and funeral and estate planning. Arno (1986:1327) describes the role of a social worker as that of a liaison between the patient and

relevant government departments and service providers for the patient's benefit. In addition, Parry (2001:72) states that the social worker should work with PLWHA to help their significant others make peace and come to terms with the reality of their condition.

The participants' above-quoted suggestions for social workers to provide assistance with Social Work services to patients, their families and communities point to the roles highlighted by Zastrow, (2014:44-46) and Berkman (1996:544) that the social worker can fulfil. These particularly relevant to the suggestions made by my participants in are introduced below.

- o *Enabler:* as an enabler, the social worker will create a conducive environment within which the patient or the family is helped to express their needs, clarify and identify their problems, explore resolution strategies and get capacitated to face their problems (Zastrow, 2014:44). In her role as an enabler, the social worker could, for instance, create time to listen to the patients and families as highlighted by Kgomo with the aim of capacitating them to realise their problems and develop strategies to address them.

- o *Broker:* In their role as brokers, the social workers link the patients and their families to relevant service providers from within the community (Zastrow, 2014:44). In other words, the social worker will get involved in the issues raised by Dineo regarding liaising with the Department of Home Affairs for these children to access the birth certificates that will eventually enable them to apply for child support grant.

- o *Advocate:* As an advocate, the social worker becomes a representative of the family and the patients and fight for the interests of the patients and the community (Zastrow, 2014:44). Lenyalo's suggestion for Social Work intervention points to fulfilling an advocate's role in that the social worker will be the advocate for the family in the patient's interests regarding communicating with the funding institutions and organisations.

o *Empowerer:* Zastrow (2014:44) states that, in the role of empowerer, the social worker strives to help the patient and their families develop a better understanding of their environment, make choices, influence their choices by organising themselves to advocate for what is best for them. As an empowerer, a social worker, could, in the case of all the participants' suggestions, help them to identify their main problems, organise themselves and form some committees which could then address all their highlighted issues.

o *Mediator:* The mediatory role of a social worker mainly aims to assist parties that are in dispute to reach a mutually satisfactory agreement (Zastrow, 2014:45). This role is particularly relevant to Kgomo's situation. In this case the social worker would step in and assist both Kgomo and her patients to understand each other and their roles better, which may eventually culminate in a resolution of their difficulties.

o *Negotiator:* A negotiator, who also relates to the function of a mediator as described by Zastrow (2014:45), aims to bring people together who might be in a conflict situation so that they could reach a compromise and a mutually acceptable agreement. In this case, the social worker would play the negotiator role where there is conflict, either between the patient and their families or between the patient and the caregiver.

o *Educator:* When assuming the role of an educator, the social worker provides information and skills to families and the patients on how to cope (Zastrow, 2014:45). The suggestions Nakedi and Kgomo made for Social Work intervention boils down to the fact that the social worker will, amongst other roles, also fulfil the role of an educator.

o *Coordinator:* The role of a social worker as a coordinator is to mobilise help from various service organisations for the patient or the family (Zastrow, 2014:45). The coordinator's role could be particularly relevant to Nakedi's situation where the social worker would coordinate services by linking the sick woman to appropriate caregivers, the children with drop-in

centres or child care workers, and even lobby the ordinary community members to step in to assist the family in addressing their problem.

o *Public speaker:* In coordinating help for the patients and the families, social workers could find themselves addressing board meetings and community meetings.

- **A HBCG's suggestion for social workers to educate and involve the community**

Lenong believed that the social worker can play an important role in educating the community and therefore had this suggestion: *"I think the social workers must educate the community"* [meaning to educate the community to take a part in caring].

What Lenong calls for has also been noted by some researchers and documented in existing literature. The significance of the educational role of a social worker in the fight against HIV and AIDS is noted by Hall (2008:58) who wrote: "prevention and behaviour change is crucial and, as social workers, we recognise how important education and awareness is in combating AIDS". As described by Harnett (in All, Fried, Roberto, Shaw, Richter, 1997:46), education is an important component of intervention since it promotes understanding. This means communities that are empowered through education and prevention awareness will be more informed to make responsible decisions that would not leave them in venerable situations. Furthermore, Hall (2008:63) cites the SHAZ (Shaping Health of Adolescents in Zimbabwe) project which was initiated with the Zimbabwean social workers to provide young women with HIV prevention programmes, training and education on reproductive health.

Suggestions made by HBCGs in relation to the provision of Social Work services to patients, their families and the communities will provide the necessary role support to HBCGs in caring for PLWHA. Such role support is labelled by Williams in her middle range theory of caregiving (Williams, 2014:316) as an enabler assisting caregivers to cope in the caregiver-receiver dyad, and it also facilitates the smooth progression of the caregiving trajectory.

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4.3 CHAPTER SUMMARY

This chapter, as it was the case with the previous chapter (Chapter Three) was dedicated to the presentation of the research findings. In the previous chapter the findings on two themes were presented: first, the HBCGs' accounts of their motivation to care for PLWHA; and, second, caregivers' work-related challenges in caring for PLWHA.

In this chapter, the remaining seven themes of the research findings were presented.

The reader was introduced to Theme three of the research findings that highlights the HBCGs' accounts of their feelings and emotional reactions to their care work and its related challenges along with its two sub-themes: first, the HBCGs' negative feelings and emotions associated with caring for PLWHA and their work-related challenges; and, second, the HBCGs' accounts of feelings and emotions of happiness associated with care work.

The fourth theme with its focus on the HBCGs' accounts of community members' positive attitudes and perceptions towards them because of their work of caring for PLWHA was presented under two sub-themes, community members welcome and appreciate the HBCGs; and a perception that community members think a HBCG is brave to care for PLWHA.

Flowing from Theme four was the fifth theme. Theme five addressed the HBCGs' accounts of the attitudes of families and friends towards them because of their work of caring for PLWHA. These were presented under four sub-themes: first, family members and friends understand and appreciate the HBCGs' work, and second, family members and friends reacted negatively to the HBCGs caring for PLWHA; third, family members and friends lack understanding for HBCGs' engagement in caring for PLWHA and, fourth, family members and friends are concerned about the HBCGs' low remuneration.

Theme six addressed the coping strategies adopted by HBCGs to manage the work-related challenges experienced in caring for PLWHA. The coping strategies

mentioned were clustered in five sub-themes: first, HBCGs cope through support from their employers; second, HBCGs cope through counselling and support groups; third, HBCGs cope by networking with other organisations and by referring cases; fourth, a HBCG uses self-help or self-motivation to cope with the work and work-related challenges; and fifth, HBCGs cope by having faith in God.

In the seventh theme the focus was on the HBCGs' suggestions to management on how the work-related challenges experienced by HBCGs caring for PLWHA could be improved. The suggestions forwarded were presented under five sub-themes: first, HBCGs' suggestions to management to visit patients; second, HBCGs' suggestions to management to provide resources; third, HBCGs' suggestions to management to provide training; fourth, HBCGs' suggestions to management to provide better or increase stipends; and fifth, HBCGs' suggestions to management to provide them with psychosocial support. Of the information provided under some of the sub-themes was presented further as categories.

Theme eight, Theme eight addressed the HBCGs' suggestions on what they, as HBCGs, could do to manage their work-related challenges.

Finally, in Theme nine, the chapter highlighted the HBCGs' suggestions on how social workers could support them to improve their work-related challenges. This theme was filtered into two sub-themes: first, HBCGs' suggestions for social workers to provide them with Social Work services; and second, HBCGs' suggestions for social workers to provide Social Work services to patients, their families and communities. The sub-theme HBCGs' suggestions for social workers to provide them with Social Work services, had five categories, the sub-theme, HBCGs' suggestions for social workers to provide Social Work services to patients, their families and communities was presented along with its two categories.

In the next chapter, I address the conclusions and recommendations based on the findings.

CHAPTER FIVE

SUMMARIES, CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS

5.1   INTRODUCTION

As indicated in Chapter One, the primary aim of this study was to develop an in-depth understanding of experiences of HBCGs, in caring for people living with HIV and AIDS (PLWHA), their work-related challenges, the coping strategies they employ to negotiate these challenges and suggestions on how they would like to be supported by social workers in their care service provided. To address this aim, a research plan, which was subsequently included as part of Chapter One of this report, was drafted with five research questions posed along with the research objectives (see Chapter One sub-sections 1.3.1; 1.3.2 and 1.3.3) and submitted to the UNISA's Social Work Departmental Research and Ethics Committee for approval and ethical clearance. Once ethical clearance and permission to conduct the research was granted, the plan was operationalised and in Chapter Two of this report an account is provided of how this operationalisation happened. The data obtained from the sample of purposively recruited participants were analysed and presented under various themes, sub-themes and categories in in Chapters Three and Four of this report.

In this chapter, the information presented in relation to the general introduction and orientation to the study; the applied description of qualitative research process as the approach adopted for this study; and the research findings based on the themes, sub-themes and categories that emerged from the process of data analysis of the data collected, will be summarised. Conclusions arrived at on this journey will be presented. Prior to complementing the conclusions with recommendations, the limitations inherent in the study will be mentioned. The recommendations will focus on guidelines for Social Work support to HBCGs caring for PLWHA focusing on practice, programmes and policy; guidelines for education and training; and an agenda for further research will be suggested. As in all the preceding chapters of this

report, this chapter will be concluded by a chapter summary which succinctly ties together all aspects that were addressed in this chapter.

5.2   SUMMARY AND CONCLUSIONS

In the following section, I present the summary and conclusions in respect of the general introduction and orientation to the study, and the applied description of the qualitative research process as the approach that guided this study. In addition, I will also, in this section, present a summary of and conclusions related to the research findings presented in two parts in Chapters Three and Four of this thesis. Chapter Three covered the motivations of HBCGs in caring for PLWHA and their work-related challenges experienced in this regard. In Chapter Four the HBCGS experiences in caring for PLWHA, their coping strategies adopted to manage the work-related challenges, and suggestions for social work support were reported.

5.2.1   Summary and conclusions based on the general introduction and orientation to the study (Chapter One)

In laying the foundation for this study, a general introduction and orientation to the study was provided in Chapter One. In the introduction I provided a back drop for and set the scene (Creswell, 1994:42) for the study by introducing the nature and scope of HBC and trace its origins to as far back as the 16th century among French charity groups (Tshabalala, 2008:1&3; Ginzberg et al., 1984:18). The evolution of HBC was followed through its proliferation in Africa in which the scourge of HIV and AIDS compelled it to be an alternative for relieving the overcrowded and incapacitated public health care institutions through the provision of HBC services to patients and their loved ones in their households (Caregiver Action Network, 2013:9; Wright et al., 2006:12; Qalinge, 2011:51; Friedman et al., 2010:14; WHO, 2010:15; Tshabalala, 2008:1; DoH, 2001:3). In Africa, the emergence of HBCs was more of a formalisation of the already existing practice of Ubuntu which propagated caring for one another (Martson, 2015:424; Sarpong et al., 2016:17).

The emergence of the HBC phenomenon in the South African context was also highlighted with attention being placed on its recognition as a viable strategy to fight

HIV and AIDS through a concerted effort from the MDT (Friedman et al., 2010:20; Tsheboeng, 2015:23; DSD, 2006:6) along with acknowledgement of the HBC-related challenges coming from the South African government (DSD, 2006:4; DoH, 2001:1&10-11). These challenges were among others, a lack of support and inadequate training and these concerns were also prominent in some of the existing literature consulted around this phenomenon (Akintola, 2008:358; DSD, 2006:4; Mieh et al., n.d.:189; Marincowitz et al., 2004:29). What was generally revealed, however, was that, despite its long period of existence and clear evidence of its instrumental role in health care, HBC had not received adequate research attention. My engagement with the literature around the phenomenon of HBC in the HIV and AIDS context revealed a gap in literature (Vaijee & Van Dyk, 2014; Van Dyk, 2007; Akintola, 2005) particularly from the Social Work perspective.

Although few studies (Tsheboeng, 2015; Qalinge, 2011; Primo, 2009) were found to have considered the phenomenon of HBC and HIV and AIDS from a Social Work perspective, it was found that they did not specifically address the experiences and work-related challenges of HBCGs in working with PLWHA, nor how they managed such challenges or how their suggestions on how social workers could assist them in managing such challenges. This scarcity of literature and knowledge base on this topic was accompanied by clearly documented evidence of a lack of support among the HBCGs who care for PLWHA (Akintola, 2008:358; DSD, 2006:4; Mieh et al., n.d.:189). Lack of literature along with its concomitant lack of support for HBCGs justified the relevance of this research study. From these spotted gaps, the problem statement and the rationale of the study were formulated with the aim of bridging the knowledge gap by adding to the knowledge base, particularly in the field of Social Work HIV and AIDS HBC.

The three theories identified to guide this study were introduced (see Chapter One, Section 1.2). Loretta Williams' middle range theory of caregiving dynamics (Williams 2014; Williams, 2007; Williams, 2003) positioned caregiving on an illness trajectory with the caregiver-receiver dyad being enabled and/or hampered by various forces, including the caregiver, the patient and other role players involved in this caregiving trajectory. The coping theory of Lazarus and Folkman (Lazarus & Folkman, 1984; Barbosa et al., 2011:491; Folkman & Moskowitz, 2004; 1984; Folkman, 1984) was

adopted to explain and anchor how HBCGs, like any other human being, encountered various stressors from their working environments and resorted to the process of appraisal and reappraisal, which eventually led to the adoption of either emotion-focused coping or problem-focused coping to manage their difficulties. The strength-based perspective (Saleebey, 2013; Bernard, 2006; Saleebey, 2006; Saleebey 2002; Weick et al., 1989), which is widely accepted in Social Work was adopted as part of the theoretical framework for this study. Narratives of the HBCGs bore testimony to the fact that wisdoms and capacities, both within and around them were present. Despite encountering challenges such as the lack of recognition, lack of support, low remuneration and other issues, the HBCGs had, and demonstrated, inner strength and resilience to manage their difficulties.

On reflecting on how I approached the general introduction and orientation to the study, I was reminded of a familiar saying that claimed that to go forward, you need to first look back. By tracing the origins of the HBCG phenomenon as far back as the 16th Century and to track its evolution, enabled me to get a broader perspective on this phenomenon, which further enhanced my understanding of its manifestation in the South African context.

I came to the conclusion that the middle range theory of caregiving dynamics, the coping theory and the strength perspective adopted as the theoretical framework for this study, were particularly suitable. These theories and perspective became the proverbial coat closets, according to Maxwell's (2013:49) analogy that a theory and a perspective could serve as a coat closet in which to display the research findings in an orderly manner. The constructs and concepts that underpin the theory adopted by the researcher become what Maxwell (2013:49) calls the coat hooks in the closet upon which the researcher hangs their data to enhance their meaning. In addition, the middle theory of caregiving dynamics enhanced my understanding of caregiving as a process, driven by various forces which either enhance or diminish its success. These therefore enabled me to develop an in-depth understanding of the relational and work-related experiences caregivers face during the caring process. The strength-based perspective provided insight into what motivates HBCGs to keep going despite difficulties, and provided the hooks on which to hang the data that bore witness to the HBCGs' well of inner wisdoms and strengths which they draw upon to

manage their work-related challenges. Coping theory enabled me to arrange the HBCGs coping strategies in an orderly manner for them to manage their work-related challenges under the emotion-focused coping strategy and/or the problem-focused coping strategy.

At the outset of the study, I developed five research questions (see Chapter One: sub-section 1.3.1) to serve as signposts to guide this investigation. By way of summary, I will now present each question and, in a summarising fashion, present the answers to these questions based on the accounts of the participants interviewed. The conclusions of the research findings will be elaborated on in Sections 5, 5.24 and 5.2.5 further on in the chapter.

- **What prompted/motivated HBCGs to involve themselves in caring for PLWHA?**

Various factors motivated the HBCGs to become involved in caring for PLWHA. For some, it was not a single motivation, but multiple forces had acted together prompting them to become engaged in caregiving. In this regard, they revealed that their general desire to help people, their personal experiences of caring for or witnessing a sick member of their family being cared for, and their need to develop a career path in nursing, served as an impetus to care for PLWHA.

- **How is it for HBCGs to care for people living with HIV and AIDS?**

The answers the participants provided on this question as presented under the theme of HBCGs' accounts of their feelings and emotional reactions to their work and its related challenges, revealed that most HBCGs experienced negative feelings in relation to their care work and the work-related challenges hitherto, along with, and in minor instances of feelings of happiness derived from their caregiving for PLWHA.

- **What are the work-related challenges experienced by HBCGs whilst caring for PLWHA?**

What emerged from the participants' answers was that in caring for PLWHA, they face a variety of work-related challenges. On a community level, caregivers were faced with the challenges related to community members' negative attitudes, hostility and stigma, fuelled by ignorance, fear and misinformation. Patient-related challenges encountered included the moodiness of patients, non-compliance with treatment; patients' substance abuse, patients' losing hope and cultural practices hindering them in executing their care duties. The participants also reported challenges in relation to the patient's families who, as relatives of the patients were uncooperative and neglected the patients. In addition, unsafe working conditions, namely, the HBCGs' own vulnerability to rape and TB and HIV infections; work-related challenges with fellow caregivers and other role players involved with patients in the context of HBC and from within the HBC organisations themselves were mentioned as problems. For instance, their own colleagues would disclose the patients' HIV-positive status; clinic staff and other professionals would undermine them; and the HBC organisations that were under-resourced and poorly managed too were obstacles to face in the execution of their responsibilities.

- **How do HBCGs caring for PLWHA cope with their work-related challenges experienced?**

Among the strategies that were found to have been adopted by HBCGs in managing their difficulties, was management support in a form of redeployment; and the availability of a professional nurse who would intervene in cases that were beyond the scope of HBCGs. It also emerged that HBCGs coped through going for counselling and joining support groups; by networking with other organisations and referring cases; by motivating themselves and having faith in God.

- **How and with what would HBCGs caring for PLWHA like to be supported by social workers in managing their work-related challenges?**

Apart from suggestions on how social workers can support the HBCGs in managing their work-related challenges, they forwarded suggestions on how the management of their organisations and they themselves could tackle the work-related challenges experienced. Suggestions directed to social workers were that, as professionals, the social workers could provide Social Work services to them as HBCGs, to their patients, their patients' families and the community. These services, as the HBCGs suggested, should include, among other things, providing HBCGs with motivating initiatives, providing their patients and patients' families with counselling and support, offering HBCGs training, liaising with management for the betterment of their stipends and educating the community about the importance of HBCGs in the communities.

<u>In conclusion</u>: The summary of the answers obtained from the participants in relation to the overarching research questions formulated at the outset of this study to steer this endeavour, point to the fact that I managed to answer all the research questions.

In addition, the answers to the research questions presented as research findings in Chapters Three and Four of this report, bear testimony to the fact that realised the goal formulated at the outset of the study, which was to *"develop an in-depth understanding of South African HBCGs' work-related challenges and experiences in caring for PLWHA, their coping strategies and suggestions on how they could be supported by social workers in overcoming their challenges"* (See Chapter One, sub-section 1.3.2). By studying the phenomenon under investigation closely and broadly from its origins historically whilst tracing its evolution; and by assessing the current state of the knowledge on the topic of HBCGs caring for PLWHA with specific reference to work-related challenges experienced; its management and need for social work support, had indicated a lacuna in the body of knowledge and research on the topic, hence the need for such an investigation in this field was clearly warranted. In responding to this through engaging in a research project, I conducted my study by deliberately choosing a qualitative approach and purposively selecting participants to interview on the topic being investigated. I succeeded in gaining

insight into the experiences of being a HBCG caring for PLWHA from the in-depth enquiry I undertook and became aware of their work-related challenges and coping strategies used to address their challenges. In addition, I also managed to gather suggestions on how social workers could improve the work-related challenges the HBCGs experienced in caring for PLWHA.

From the research aim and research purpose, tasks and research objectives were formulated (See Chapter One, sub-section 1.3.3). These objectives are revisited and presented below with a view to determining whether this study achieved them or not.

- **Obtaining a sample of HBCGs who care for PLWHA within the municipal boundaries of Region 1 of the City of Tshwane Metropolitan Municipality (CTMM)**

As mentioned in Chapter Two (see sub-section 2.5.1), my initial plan of drawing a sample from the HBCGs from the CTMM had to be amended once the processes of participant recruitment and data collection unfolded. Soon after entering the field I realised that the actual number of possible participants in Region 1 of the CTMM were not adequate enough to provide for rich data saturated information around the phenomenon and I had to extend the boundaries of the population. This became a possibility after receiving funding from the National Research Foundation (NRF). The population and sample in this case were therefore expanded to include HBCGs from Gauteng, North West and Limpopo and I managed to recruit a sample of participants I could interview until data saturation materialised, as was verified by my supervisor and the independent coder employed to independently code the data set.

- **Conducting the individual face-to-face semi-structured interviews facilitated by open-ended questions with the view of exploring –**

  - *the motivations of HBCGs' that prompted them to become involved in caring for PLWHA*
  - *HBCGs' experience in relation to caring for PLWHA*
  - *the work-related challenges experienced by HBCGs whilst caring for PLWHA*

○ *the coping strategies employed by HBCGs to manage the work-related challenges experienced whilst caring for PLWHA*

○ *how and with what would HBCGs caring for PLWHA like to supported by social workers in the managing their work-related challenges*

Once a sample was drawn and all protocols such as obtaining informed consent observed regarding the study, I managed to realise this objective in that individual face-to-face semi-structured interviews were conducted with twenty-five participants I purposively selected according to a criteria of inclusion (See Chapter One: sub-section 1.6.1) from twelve HBC organisations which were located from Gauteng, Limpopo and the North West with the view of exploring the research questions formulated for the study.

- **Sifting, sorting and analysing the data using Tesch's eight steps for qualitative data analysis as cited in Creswell (2014:198)**

As reported in Chapter Two (Section 2.8) once data was collected, it was analysed taking the step-wise format Tesch (in Creswell, 2014:198) proposes to facilitate the process of developing themes, sub-themes and categories which formed part of the research findings.

- **On the objective of describing –**

  ○ *the motivations of HBCGs' that prompted them to become involved in caring for PLWHA:* In confirming the realisation of this objective, under Theme one (see Chapter Three) a detailed description of the motivations for HBCGs to become involved in HBCGs is provided.

  ○ *HBCGs' experiences in relation to caring for PLWHA* are reported under Theme one in Chapter Four, the second part of the research findings. The feelings and emotional reactions participants had regarding their care work as some their experiences are dealt with here.

- o *the work-related challenges experienced by HBCGs whilst caring for PLWHA*: A descriptive account of the work-related challenges experienced by HBCGs is provided as part of Chapter Three as a view to materialising this objective.

- o *the coping strategies employed by HBCGs to manage the work-related challenges and their experiences whilst caring for PLWHA*: This research objective was realised in that a theme was dedicated to the description of the coping strategies adopted by HBCGs in managing their work-related challenges (see Chapter Four: sub-section 4.2.4).

- o *how and with what would HBCGs caring for PLWHA like to be supported by social workers in managing their work-related challenges*: A description of the suggestions on how social workers could support HBCGs was addressed under a theme dedicated to this objective (see Chapter Four: sub-section 4.2.7). In addition to the suggestions directed to social workers, suggestions were directed to HBCGs themselves as well as to the management of the HBC organisations on how their conditions could be improved (see Chapter Four: sub-sections: 4.2.5 and 4.2.6).

- **Conducting a literature control in order to verify the research findings**

In addressing this objective, each theme was presented in this thesis together with its related sub-themes and categories where applicable. Whereas storylines were used to substantiate the themes, the literature was sourced to compare and contrast what the participants described with extant source material. In some cases, the research findings supported the documented literature while in other cases they were in contrast with the literature.

- **Drawing conclusions on HBCGs experiences in relation to caring for people living with HIV and AIDS, the work-related challenges they experience in this regard; coping strategies they employ to address these challenges; and their suggestions on how they would like to be supported by social workers in overcoming their challenges**

In addressing this objective, the preceding sections of this chapter drew some conclusions that related to the general introduction and the orientation to the study; the research questions, goal and objectives. Some conclusions will be drawn further in the next section regarding the applied description of qualitative research, the demographic features of the research participants and the research findings.

- **Forwarding some recommendations as guidelines for social work support, specifically on how social workers can support HBCG's in their duties as caregivers caring for PLWHA, and the managing of the work-related challenges they experience in this regard**

In relation to this objective, the current chapter, with its focus on summaries, conclusions and recommendations is designed to address this particular objective. As indicated in the introduction of this chapter, the conclusions will be based on the summary of the research findings which will, in turn, inform the recommendations that are further presented in the next section (see Section 5.4 of this chapter).

To sum up: The foregone discussion on the objectives for the study and its realisation showed that the research objectives had all been addressed, hence the conclusion that the study's objectives had been carried out.

5.2.2 Summary and conclusions on the applied description of qualitative research process (Chapter Two)

To attain the stated aim and objectives of this study and obtain answers for the research questions formulated, I decided to investigate the topic from a qualitative research approach due to its ability to provide detailed understanding of human

experiences as they happen from within their natural settings (Shelton et al., 2014:271; Hays et al, 2012:6; Yin 2011:138; Creswell, 2016:6; Marshall & Rossman, 2016:2; Ritchie 2003:34). In this sub-section, I present a summary and conclusions drawn from the qualitative research process adopted for this study, and how its application was explained in Chapter Two.

Qualitative research is, among other things, particularly relevant when the researchers embark on a sensitive study especially when very little is known about the phenomenon under investigation (Creswell, 2016:8; Marshall & Rossman, 2016:2; Richard & Morse, 2013:14; Thomas & Magilvy 2011:152). It is also described as a suitable research approach for researchers who are interested in people's experiences as they happen in a natural setting like their homes, their neighbourhoods, their schools and workplaces (Creswell, 2016:6; Marshall & Rossman, 2016:2; Shelton et al., 2014:270; Edmonds & Kennedy, 2013:112; Yin 2011:138). As indicated in the general introduction and orientation to the study (See Chapter One: Section 1.1 and sub-section 5.2.1 in this chapter), I realised through the review of existing literature that there is a gap in the knowledge concerning the experiences of HBCGs in caring for PLWHA, their associated work-related challenges, how they manage them and how they wish to be assisted by the social workers. Moreover, by opting for the job as a caregiver for PLWHA, they encounter experiences and challenges in their day-to-day caring duties that are, and have become in themselves, personal issues that can well touch on a range of sensitive and painful issues. In view of this, I can deduce that adopting a qualitative research approach for this study was indeed a good fit as it allowed for the development of an understanding of this phenomenon as experienced by the participants in a personal way through constructive and deeply meaningful exploration. In addition, qualitative research is conducive to investigating a phenomenon that has not, to date, been adequately researched (Nieuwenhuis, 2016:55; Creswell, 2014:420; Hays & Singh, 2012:4), which strengthens the case of the adoption of the qualitative research approach even further.

Given my desire for a detailed understanding of the experiences and challenges that face HBCGs when caring for PLWHA, how they manage such challenges and how they wish to be supported by social workers, a phenomenological research design,

as one of the qualitative research designs (Bevan, 2014:136; Finlay, 2012:190; Hays & Singh, 2012:429) with its centrality on the meanings participants attach to their lived experiences in relation to a particular phenomenon (Marshall & Rossman, 2016:17; Nieuwenhuis, 2016:5; Finlay, 2012:173; Hays & Singh, 2012:50) was chosen. Hence, I arrived at the conclusion that the phenomenological research design enabled me in my quest to develop an in-depth understanding of how it was for HBCGS to care for PLWHA, the work-related challenges they experienced in this regard and how they had negotiated (coped) with these challenges and the meaning they attached to this. In essence, phenomenological research seeks to "explore, describe and analyse the meaning of individual lived experiences" (Marshall and Rossman, 2016:17).

Gaining a comprehensive understanding of the phenomenon under investigation, not only required an in-depth exploration, but also necessitated taking into consideration the context in which the HBCGs executed their caregiving duties to allow for a detailed description of their lived reality and the meaning they attach to it.

Incorporating the explorative, descriptive and contextual strategies of enquiry, in addition to the phenomenological research design was, upon reflection, and by way of conclusion, a befitting decision to address the research questions and attain the research aim. These research designs were found to be effectively instrumental in affording me an opportunity to explore the life-world the participants' caring for PLWHA while they shared and described their daily and context-situated experiences as they related to caring for PLWHA and their work-related challenges encountered in this regard; and to find out how they managed the challenges. It was through these selected research designs that I felt privileged to be taken on an exploratory tour through words that represented these considered aspects that are characteristics of the world of this group of HBCGs. In addition, the descriptive research design afforded them an opportunity to describe their realities, and me the opportunity to report comprehensively on the topic being investigated.

In Chapter Two the concept of an emergent design as characteristic of the nature of qualitative research was highlighted. This boils down to the fact that research plans are not fixed. Researchers can at any time during the research process review and

amend some elements of the plan where they deem it necessary, based on their quest to develop an understanding of the phenomenon from the participants' frame of reference dictates and that the process is led by the direction in which the participants take it (Creswell, 2014:186; Maxwell, 2013:2; Mathani, 2004:58). In view of this feature, I had to make some amendments to the plan which initially targeted HBCGs from Region 1 of the CTMM by extending the geographical boundaries for the study to include participants from the other provinces that then included Gauteng, Limpopo and the North West. These amendments as mentioned earlier (see Chapter Two: sub-section 2.4.2) were made due to availability of funding from the NRF and the lack of a sufficient pool of participants who could provide rich information on the phenomenon being researched. This latitude could be allowed in view of the choice of an emergent design which is generally characteristic of qualitative research and was well-suited as it made provision for unexpected events such as the one highlighted above. Clearly should I have adopted a more rigid approach for this study, however, I would never have had the leeway to make the required amendments as the process unfolded as I could do had I not allowed for flexibility to proceed with this alternative.

Details around how the adopted research methods were enacted also took centre stage in the discussions provided in Chapter Two (Section 2.5) with explanation of how the population group, the population parameters and the target population were established; how the participants were recruited and eventually interviewed using individual face-to-face semi-structured interviews. The research questions posed at the outset of the study, clearly indicated the unit of analysis pointing to 'who' the population and the target population of this study had to be, namely, HBCGs who were caring for PLWHA and nobody else. It is therefore on this note that a conclusion is made that the research population and the targeted population were particularly suitable for the study in that they were information-rich enough to provide a detailed account of the topic under investigation.

With reference to the method of data collection employed, I arrived at the following conclusion: the individual face-to-face semi-structured interviews along with the interviewing skills employed were well-suited to this study in that it enabled me to manage the process of data collection in an orderly but flexible manner. The semi-

structured nature of the interviewing was advantageous in that it allowed the participants, in their own way and at their own pace, and with minimum guidance from my side to respond to the topical questions posed to them in as much detail as they wished. Yet I could further enrich their answers through the skill of probing.

A further deduction made is that the open-ended questions in an interview-guide made it a useful aid, especially in that it helped me to explore all the facets related to the topic under investigation with all the participants. I decided to follow this route in spite the stance taken against predetermined questions by proponents working from a phenomenological frame of reference (Chan et al., 2013:4-5; Englander, 2012:26). Whilst the purist phenomenological researcher advocates for only one central question to be posed to the participants and the answers provided further explored by the researcher, Chan et al (2013:4-5) and Englander (2012:26), propose that allowance should be made for preparing open-ended questions and probes in advance to steer and guide the individual face-to-face semi-structured interviews in phenomenological studies. This, they (Chan et al., 2013:4) contend must be regarded as a precautionary measure to prevent the researcher from posting leading questions. In addition, such questions must be viewed merely as a guide, with the expectation that the interviewer should probe further after the participant has shared a response (Chan et al., 2013:4).

In reflecting on my decision to adopt and use the eight steps of Tesch (in Creswell, 2014:198) for analysing the qualitative data collected, I realised these steps had assisted me in a systematic and focused fashion to immerse myself in the massive volume of data collected. In addition, they helped me extract word-pictures from the data that display the depth and the breadth of the topic being researched.

Finally, and in reflection on the ethical principles of obtaining informed consent, maintaining confidentiality and anonymity, avoiding harm, debriefing participants and the management of the data obtained, I arrived at the following conclusions: due to the sensitive nature of the topic investigated, I found the ethical considerations used to be a good fit as I had to get the buy-in from the individuals approached to participate in the study. I therefore had to inform them comprehensively about the aim of the study and what their participation would entail; the risks and benefits and how I would protect their identities and manage the information shared in a

responsible and ethical manner. Through adhering to these adopted ethical principles, I displayed the fact that the research was legitimate, I was trustworthy as the researcher, which, in turn, enabled the HBCG participants to freely express their thoughts and feelings about their experiences, challenges, coping strategies and needs for social work support in caring for PLWHA.

5.2.3 Summary and conclusions: the demographic particulars of the research participants (Chapter Three)

This sub-section provides a summary and conclusions about the demographic particulars of the research participants that formed part of the research findings presented in Chapter Three (see Section 3.2).

Twenty-five HBCGs (twenty-two females and three males) aged between twenty-seven and fifty-eight were identified, found eligible to participate in the study and were recruited so that I could gain insight into their experiences regarding caring for PLWHA; their work-related challenges in caring for PLWHA; how they managed these challenges; and how they wished that social workers would assist them. Of these participants, the majority (twenty-one) were blacks with one white, one Indian and two coloureds. The picture painted by the demographic details of the participants was that they were from poor socio-economic backgrounds with a total average of R3780.00 in family income and lower educational qualifications with highest qualification being either a certificate in counselling or first aid.

On this note: it is concluded that the caregivers who took part in this study were mainly black women from poor family backgrounds, with lower levels of education which correspond with similar the demographic features on HBCGs reported by other researchers (Maes & Kalofonos, 2013:57; Akintola, 2005:6; Takasugi & Lee, 2012:840).

5.2.4 Summary and conclusions: the research findings on the motivations and challenges of HBCGs in caring for PLWHA (Chapter Three)

The findings of this study were divided into two parts with part one focusing on the motivations and challenges of HBCGs in caring for PLWHA (presented in Chapter Three) and part two focusing on the experiences, coping strategies and suggestions by HBCGs on how their challenges could be managed in caring for PLWHA (presented in Chapter Four). In the next section the focus will be on the summary of and conclusions derived and presented as two themes in Chapter Three, namely:

- HBCGs accounts of their motivation to care for PLWHA
- Caregivers' work-related challenges in caring for PLWHA

- **Theme one: HBCGs' accounts of their motivations to care for PLWHA**

From the participants' accounts of what prompted them to become involved in caring for PLWHA, I concluded that for some it was a mix of factors that provided the impetus for embarking on the journey of becoming caregivers caring for PLWHA, whilst for others only a single reason served as motivation. The desire to help people emerged as one of the motivators in which HBCGs saw their caring work as being motivated by both a calling and a passion and love for caring for PLWHA. In other instances, having had a personal experience of caring voluntarily for a sick member of the family, or being recipients of care themselves, had led them along this path of becoming a caregiver. This declared motivation ties in with the assertion Williams (2014:310) makes the "middle range theory of caregiving dynamics" which was adopted as a theoretical framework for this study. Getting involved in caregiving and how they approached and operated within this caregiver-care receiver dyad was shaped and influenced by their past experiences (i.e. caregiving relationships).

I also arrived at the conclusion that following a career path through caregiving served as motivation for becoming involved in caring for PLWHA, as was the need for employment. This motivation resonates with what Saleebey (2013:8) in the strength-based perspective refers to as "heroism", which is "the desire to transcend circumstances, to develop one's own powers" (Smith, 2006:27; Rhee et al., 2001:7).

Those who used this avenue of informal caregiving to open up an avenue as an occupation or a voluntary service to ultimately increase their prospects for being qualified as nurses, admitted that they had chosen this route to travel to acquire skills that would further their career aspirations.

The second theme addressed the work-related challenges encountered by HCBGs in caring for PLWHA as presented below.

- **Theme two: HBCGs' work-related challenges in caring for PLWHA**

From the participants' responses to a question around their challenges in caring for PLWHA, I came to the conclusion that they experienced multiple challenges as forces that impeded the caregiver-receiver dyad process and these challenges were also noticed as being multi-levelled.

At the level of the community, they encountered challenges fired by the negative attitudes of members of the community, such as the misconception that HBCGs themselves were infected with HI-virus (Fyn 2011:122), leaving them stigmatised on the basis of their association with PLWHA (Harber et al., 2011:541; Van Dyk, 2010:412; Bennett et al., 1996:145). In addition, HBCGs' work was further complicated by community members who were afraid of the stigma attached to being a person living with HIV and AIDS to such an extent that they would even deny or refuse to accept their own HIV-positive status (Lawson et al., 2008:26; Ben-Zur et al., 2000:160). Due to fear of being stigmatised, other members of the community (Akintola, 2005:15; Waithera, 2011; Olenja, 1999), would refuse HBCGs access to their houses (Campbell et al. 2012:127; Akintola, 2005:13) and become judgemental and even avoid them (Kasimbazi & Sliep, 2011:104; Fyn, 2011:116-117). In view of this I concluded that, in the eyes of some community members, individuals caring for PLWHA were seen as useless and offered a lower standard of work (Zulu et al., 2014:12; Campbell & Foulis, 2004:8; Akintola, 2005:13), hence not being taken serious by members of the community in their attempt to disseminate crucial information (Hlengwa, 2011:77; Chimwaza & Watkins, 2004).

On the level of their encounter with the patients themselves I came to the conclusion that the care work a HBCG does can be challenged by a patient's moodiness, their involvement in drugs as well as their non-compliance with the prescribed treatment (Van Dyk, 2014:5; Cataldo et al., 2015:7; Guerra et al., 2012:71; Chesney et al. in Hinkin et al., 2004; Cheever & Wu in Wang et al., 2009:381; Van Dyk, 2009:381; Van Dyk, 2007:58; Muhammad & Gikonyo, 2005). It also emerged that patients who were losing hope concerned HBCGs. It is now known from existing evidence that, in order to survive HIV and AIDS and other infectious diseases, particularly for PLWHA, remaining hopeful is one of the crucial aspects that must be maintained and sustained (Grönlie et al., 2011:167; Rödlach, 2009:427). I also reached the conclusion that cultural traditions, especially within the African culture complicate the work of caregivers in executing their duties. An example is that male and older patients sometimes refuse to be bathed by younger caregivers and female patients respectively (Tshabalala, 2008:16; Makoae, 2009:21), as it is believed to be a cultural shock for young HBCGs to see the naked body of an older patient. A result of socialisation that it is a taboo for a female to see a male's genitals unless it is that of her own partner (Tshabalala, 2008:8; Chingandu et al., 2010; Leclerc-Madlala, 2001:41).

In addition to the challenges experienced at a community level and with the patients themselves, it became evident that the HBCGs in caring for PLWHA also encountered challenges with patients' relatives. Some of them had received a poor reception from the relatives when they visited the household's residence to care for the patient. The fear of stigma can explain this situation (Campbell et al., 2012:127; Campbell et al., 2008:10; Akintola, 2005:13). In addition, some relatives did not even demonstrate any level of appreciation of their services. In some instances, relatives were reported to be negligent of their sick relatives' condition (Guerra et al., 2012:72; Thabethe, 2011:790; Rödlach, 2009:426; Akintola, 2008:360; Akintola, 2005:14-15; Campbell, et al., 2005:809), and surrendered the care of the relatives to the HBCGs who were not always around. Whilst meanwhile some relatives were receiving the patient's social grant and not using it for the patient's benefit (Pindani et al., 2013:2; Mashau & Davhana-Maselesele, 2009; Rödlach, 2009:426; Motswasele & Peu, 2008:29; Van Dyk, 2009:58; Dada & Sliep, 2011:135).

I also became acutely aware of the fact that the HBCGs had to perform their duties in unsafe working conditions and the challenges that they had to contend with in this regard was their vulnerability to getting raped (Gilson et al., 1989:525; Carrol, 2008) and being infected with TB with the HIV-virus (Smart, 2009:10; Davids et al., 2009; Koto & Maharaj, 2016:54; Okeke, 2016:37) and the effect of the AIDS odour on them (Rödlach, 2009:425; Makoae, 2009:23; Parry, 2001:70).

I also arrived at the conclusion that the HBCGs experienced challenges at a collegial level with their fellow HBCGs as some colleagues disclosed the patient's HIV-positive status breaching confidentiality, while others did not want to associate with them due to their involvement in care work with PLWHA (Maslanka, 2010:196; Fynn, 2011:115-116; Makoae & Jubber, 2008:37).

As far as the HBCGs' relationships with other role players in providing care and services to PLWHA were concerned, both positive and negative experiences were reported. Challenges experienced on this point were around the negative attitudes some of the clinic staff members displayed towards HBCGs (Schneider et al., 2008; Akintola, 2005:21; Rödlach, 2009:426; Uys, 2002:102; Hermann et al., 2009:3). Some professionals devalued the contribution the HBCGs make in caring for their patients and their role in the community (Bennett et al., 1996:149; Cameron-Taylor, 2012:15; Akintola, 2008:362; Gwyther et al., 2008:88; Kang'ethe, 2008), while other HBCGs even experienced the challenge where professionals dumped their workload of caring for PLWHA on them.

In addition to all the challenges mentioned in this summary and conclusion (Section 5.2.4), I also became aware of the challenges the HBCGs had to encounter on an organisational level. The challenge that took centre stage was the lack of transport to go and conduct home visits and access patients who resided in remote areas (Valjee & Van Dyk, 2014:6; Takasugi & Lee, 2012:842; Campbell et al., 2008:510). Other challenges were obtaining transport for patients to get to clinics and health care centres; lack of training, low stipends being paid (Cataldo et al., 2015:6; Valjee & Van Dyk, 2014:6; Takasugi & Lee, 2012:842; Wringe et al., 2010:5&6; Glenton et al., 2010; Mohammad & Gikonyo, 2005:14); and limited resources such as gloves and other equipment (Wringe et al., 2010; Pallangyo & Mayers, 2009:486; Rödlach,

2009; Ama & Seloiwe, 2011:57). Other organisational challenges that the HBCGs encountered were the protocols which they had to observe; the manner in which the HBCGs organisations were managed; and racial segregation among the HBCGs.

When mirroring challenges against the ways of providing role support (see Chapter One: sub-section 1.2.1), as suggested in the middle range theory of caregiving dynamics of Williams, (2014:318), as an enabler for caregivers to cope within the caregiving dyad, I realised that providing the necessary support to fulfil the role of caregiver in caring for PLWHA (Chapter One: sub-section 1.2.1) was, to a greater or lesser degree lacking. From the participants accounts it became clear that as HBCGs caring for PLWHA they did not continuously have:

- o *competent, compassionate care available for the patient's benefit and use*
- o *support for other responsibilities, like relatives who would, for example, take the responsibility for providing basic needs of the patient*
- o *a convoy of support such as community members, relatives of the patients, fellow caregivers and other professional) to assist them in their caregiving duties*
- o *the financial and other resources and/or supplies available to execute their care duties optimally and for the patients to adhere to their prescribed treatment*
- o *a wealth of helpful information on which to draw to assist them in the caregiving-receiver dyad.*

To sum up: The challenges the HBCGs face in caring for PLWHA, instead of facilitating the necessary support and care to their patients, hinder and complicate their efforts.

In the next sub-section, I present the summary and conclusions related to the research findings around the experiences, coping strategies and suggestions from HBCGs in caring for PLWHA on how their challenges could be addressed as presented in Chapter Four of the report.

5.2.5 Summary and conclusions on the research findings: the experiences, work-related challenges, coping strategies and guidelines suggested for social work support in managing their challenges (Chapter Four)

The focus of this section is to present a summary and conclusions with regard to the six themes that followed from the first two themes presented in the previous sub-section (see sub-section 5.2.4).

- **Theme three: HBCGs' accounts of their feelings and emotional reactions to their care work and its challenges**

In reflecting on the accounts of feelings and emotional reactions to their care work and its challenges, I came to the conclusion that caring for PLWHA is a demanding duty that evokes more demands and an array of negative feelings (Koto & Maharaj, 2016:55; Abasiubong et al., 2011:494; Land, 2010:312; Makoae, 2009:21). Some of the HBCGs were saddened when witnessing a patient and their relatives, sometimes small children, being left helpless in the face of an incurable disease (Koto & Maharaj, 2016:55-56; Makoae, 2009:21; Van Dyk, 2007:54). It pained them to see the extent of some of their patients' suffering. This pain was intense in the case where relatives and members of the community accused a HBCG (Martin) of being responsible for a patient's death after his dedicated care for the patient. For some, the death of their patients resulted in feelings of discouragement as their care efforts came to nothing when patients simply passed on (Koto & Maharaj, 2016:565; Greenspan et al., 2013:8; Naidu et al., 2012:123; Van Dyk, 2007:58; Pallangyo & Mayers, 2009:487; Mathauer & Imhof, 2009:11; Russel & Schneider, 2000:16; Turner et al., 1998:140.

Feelings of discouragement was also evident in cases where HBCGs found themselves committed to caring for their patients, whilst not receiving any support from their organisation's management to supply the resources they needed to perform their care duties, as well as the lack of recognition of their caring efforts from members of the community. In addition, some HBCGs felt like failures due to their inability to help the patient because of their work-related challenges. These feelings experienced as result of organisational and management dynamics once again

corroborate with an earlier stated conclusion, namely that the lack of support as an enabler for caregivers to fulfil their caregiving role and to cope within the caregiving dyad as highlighted in the middle range theory of caregiving dynamics (Williams, 2014:318), is a problem.

Feelings of fear were also mentioned in relation to the fear of being raped and being infected with the HI-virus and TB (Koto & Maharaj, 2016:55; Kasimbazi & Sliep, 2011:105; Makoae, 2009:22; Van Dyk, 2009:58), as well as the fear of not being in line with rules as stipulated in organisational caregiving protocols.

Alongside, the predominantly negative feelings expressed by HBCGs in reacting to their care work and work-related challenges in caring for PLWHA, traces were also found of feelings of happiness as some of the participants were particularly happy about the contribution they made in the patients' lives regarding the provision of the care and support they needed (Valjee & Van Dyk, 2014: Stajduhar & Davies in Prachakul & Grant, 2003:60; Uys, 2002:10). This feeling of pleasure was traced back to those HBCGs who viewed caregiving as a calling and who therefore had a passion and love to care for PLWHA.

- **Theme four: HBCGs' accounts of community members' positive attitudes and perceptions towards them because of their work of caring for PLWHA**

At an earlier stage of this study, I arrived at the conclusion that some members of the community, as reported in Theme two of the research findings, harboured negative attitudes towards the HBCGs and were hostile towards them and their work. Subsequently, I also arrived at the conclusion, based on the accounts the participants presented under Theme Four in the research findings (Chapter Four: sub-section 4.2.2) that some members of the community displayed a positive, welcoming and appreciative attitude towards them by being friendly and treating them with respect and dignity (Valjee & Van Dyk, 2014; Campbell et al., 2008; Ama & Seloilwe, 2011; Naidu et al., 2012:121; Bennett et al., 1996:148; Rödlach, 2009). Some members of the community regarded HBCGs as being brave – something the caregivers took much pride in.

To sum up: I finally came to the conclusion that HBCGs, in caring for PLWHA, encounter both positive and negative attitudes from members of the communities in which they operate.

- **Theme five: HBCGs' accounts of the attitudes of their families and friends towards them because of their work of caring for PLWHA**

From the participants' responses to a question relating to their experiences of the attitudes and treatment from their friends and members of their own families as a result of their work of caring for PLWHA, I concluded that family members and friends had either a negative and/or positive attitude towards the participants because of their care work involvement with PLWHA. Some of the participants' relatives understood the reason why they were doing this work and showed their support and appreciation. For one participant (Pekwa), it became easier for her friends to understand and appreciate her involvement in caring for PLWHA because most of them were HIV-positive themselves. Having support from community members, relatives of the patients and fellow caregivers and other professionals to assist them in their caregiving duties is one way of enabling caregivers to properly fulfil their caregiving role and to cope within the caregiving dyad (Williams, 2014:318).

Contrary to the positive attitudes displayed by some of the HBCGs families and friend, others shared how some members of their family and friends who reacted negatively to the HCBGs either by simply cutting off the friendship ties or by asking offensive questions about their work. Furthermore, there were reports of those families and friends who demonstrated lack of understanding in HBCGs' work with some wondering how they out of all other jobs could opt to care for PLWHA. Concerns around low remuneration were also raised by one HBCG as an issue bothering her family members about the HBCGs' involvement in caring for PLWHA with children continuously asking her to stop her caring work because remuneration was low and could not address their needs

- **Theme six: The coping strategies used by HBCGs to manage the work-related challenges experienced in caring for PLWHA**

From the answers on the question posed to the participants on how they manage the work-related challenges experienced in relation to caring for PLWHA, I arrived at the conclusion that a variety of coping strategies were employed to negotiate these challenges. It became evident that the participants in terms of, and as part of the strategies they employed to cope with the work-related challenges experienced that they drew on what Lazarus and Folkman (1984:159) in their coping theory refer to as "available resources". The concept of available resources is further distinguished in terms of primary assets possessed by the person and the environmental resources available (Lazarus & Folkman, 1984:159).

In addition, I also arrived at the conclusion that they have adopted a problem-focused coping strategy in that they executed some actions or behaviours to modify their relationship with the environment which is the source of stress by either modifying the environment itself or by modifying their own behaviour towards such an environment (Padden et al., 2011:251-252; Lazarus, 1995:33; Lazarus, 1993:238). It became evident that they used their social skills as personal asset to enlist a convoy of support both in and outside of their organisations to help them cope with their respective work-related challenges. They used the platforms (i.e. counselling services and support groups) for sharing challenges and receiving support from colleagues and management provided by their respective employers, and also formed their own support group for this purpose. Some of them were even redeployed to render care services in areas other than the ones they were staying to enable patients to open up for HBCGs who are not known to them.

In other instances, they resorted to manage their work-related challenges by networking with other organisations and refer cases which fell beyond their scope of practice. This enabled HBCGs to build relationship with these organisations and relieved them from the burden of going beyond their scope of practice in handling cases which could be resolved by people like social workers. Self-help or self-motivation, falling within the category of emotion-focused coping (Lazarus, 1995:33) emerged as another strategy adopted to manage the challenges encountered by

these HBCGs where they would be very patient and tolerant to these challenges, remaining hopeful that their circumstances will eventually change for the better. To recapitulate, emotion-focused implies dealing with ones attitudes towards the appraised meaning of the stressor (Padden et al., 2011:251; Grambling et al., 2007:1083). Once one has successfully changed ones attitude towards the meaning of the stressor by reframing it, it becomes bearable even though the realities of the stressor have not changed (Lazarus, 1995:33). I also learnt of some participants' faith in God being one of the forces that kept them going.

I came to realise that the HBCGs are not deterred from continuing to care for PLWHA in the face of the work-related challenges and adversities they encountered, they rather display a sense of tenacity and adopting strategies which enable them to acclimatise to these challenging working conditions and/or address these difficulties whenever they emerge so that they could perform their duties smoothly. This in essence underscores the philosophy underpinning the strength-based perspective which places the emphasis on the strengths and capacities that we as human beings (Weick et al., 1989:352) possess and appreciates human beings' ability to keep going despite these difficulties, challenges and adversities.

- **Theme seven: HBCGs' suggestions to management on how their work and working conditions could be improved**

In terms of the suggestions on how the HBCGs' work and working conditions could be improved, I arrived at the conclusion that HBCGs had some experience based suggestions for the management of the organisations they are employed at. What became evident was the fact that suggestions forwarded related to the aspect of role support as an enabler for caregivers to cope with and optimally perform within the caregiving dyad suggested in the middle range theory of caregiving dynamics of Williams, (2014:318) referred to earlier in this chapter. They had the suggestion for management to physically go and visit their patients so that they can have a clear understanding of what they were going through so that they can make informed decisions in attempting to address their work-related challenges. It was also suggested that management provide adequate material and human resources in the form of transport, equipment and supplies (Tsheboeng, 2015:79; Valjee & Van Dyk,

2014:6; Duckert & Vaagte, 2011:65; Fynn, 2011:119; Akintola, 2006:244; UNAIDS, 2008:3; Kipp et al., 2006:9; WHO, 2000:28), and to appoint more male HBCGs to assist with caring for male patients (Akintola, 2006:238; Homan & Esu-Williams, 2005:4), as well as the appointment of other professionals who would address issues which fell outside the scope of HBC practice. The need for in-service training (Martson, 2003:117; Vaijee & Van Dyk, 2014:6; Akintola, 2005:22) and to increase their stipend (Ama & Seloiwe, 2012; Kasimbazi & Sliep, 2011:106; Tasneem & Oliveras, 2012:513; Akintola, 2010:8; Campbell et al., 2008:170; Van Dyk, 2007:64) also emerged as suggestions which HBCGs believed would ease their pressure in caring for PLWHA. Furthermore, HBCGs suggested that management should offer them with the psychosocial support in a form of counselling and debriefing support and teambuilding (Abasiubong et al., 2011:495; Kang'ethe, 2009:77; Klein et al., 2009:2; Senecal et al., 2008:187; Van Dyk, 2007:64; Hillard, 2006:400; Akintola, 2005:19; Campbell & Foulis, 2004:5).

- **Theme eight: HBCGs' suggestions on what they, as HBCGs, could do to manage their work-related challenges**

I arrived at the conclusion that the HBCGs not only had suggestions for management on how to improve their working conditions and address their work-related experiences, but through introspection had a suggestion for themselves and their fellow HBCGs: They called for patience among HBCGs in their care and support for PLWHA and their loved ones; and to persevere as this would eventually lead to a greater understanding of what they do within communities and an attitude change would follow.

- **Theme nine: HBCGs' suggestions on how social workers could support them to improve their work-related challenges**

In responding to a question of how social workers could support them in managing their work-related challenges in caring for PLWHA, the HBCGs came up with several suggestions. They would like social workers to provide them with counselling, debriefing and team building services as a way of supporting them in their caregiving

role and enabling them to cope with the difficult work and its challenges (WHO, 2000:7; Van Dyk, 2007:59; Primo, 2007:iv; Akintola, 2005:17; Defilippi, 2003:28; Dow & McDonald, 2003:201; Uys, 2002:102). They believed that their lack of courage could be reignited by social workers through motivation which would enable them to fall in love with their work again (Bernard & Truebridge, 2013:208; Millner & Rollnick, 2012:16). Furthermore, the HBCGs suggested that social workers could assist them with training with a view to equipping them with correct information and additional knowledge on the topic of HIV and AIDS so that they could inform the communities they were serving better (Tsheboeng, 2015:75; Cameron, 2003:33). The HBCGs also suggested that social workers could actively liaise with management and advocate for better remuneration (Parry, 2001:24. It was also suggested by some of the HBCGs that social workers should accompany them when conducting home visits as this would enable the social workers to understand what the HCBGs' realities and work-related challenges involved, which, in turn, would inform the interventions to support them in this regard (Homan & Esu-Williams, 2005:2; Rowe et al., 2005:266)

Another suggestion forwarded by some of the HBCGs was for social workers to provide social work services to the patients, their families and the communities they were servicing with the view to addressing social work-related problems which were outside the HBCGs scope of services (Ama & Seloiwe, 2010:1; Defilippi, 2003:22; Parry, 2001:72; Berkman, 1996:543; Arno, 1986:1327). Furthermore, it was found that HBCGs believed social workers could play a crucial role in educating the community on the significant role played by HBCGs and encourage them to take part in this initiative of caring and supporting PLWHA (Hall, 2008:58; Harnett in All et al., 1997:46).

Based on the research findings and the conclusions arrived at, recommendations were formulated and are presented after the limitations inherent in this research study are dealt with next.

5.3   LIMITATIONS INHERENT IN THIS STUDY

The following limitations inherent to this study are:

- **Non-generalisation of findings as a limitation**: the qualitative research approach followed offered context-bound information and this does not allow for generalisation of the findings to broader contexts.

- **Limitations in relation to the demographic profile of the participants:** the fact that the majority of the participants were black and female must be highlighted as a limitation.

- **Limitations resulting from the cultural background of the researcher**: in my culture, as a Northern Sotho, and being in my mid-thirties, in some instances hindered me to further probe statements made by some of the older participants, as I was socialised not to question my seniors.

5.4   RECOMMENDATIONS

The recommendations formulated are presented as guidelines for Social Work support focusing on practice, programmes and policy, Social Work education and training and continuous professional development (CPD), and pointers and an agenda for further research.

5.4.1 Recommendations: Guidelines for Social Work support focusing on practice, programmes and policy

The recommendations are specifically based on the informed suggestions from the participants on how they would like social workers to support them in their role as HBCGs caring for PLWHA based on the research findings related to their experiences of caring for PLWHA; and their work-related challenges in this regard. The following recommendations are directed as guidelines to HBC organisations and social workers involved in or practising in the field of HIV and AIDS.

It is recommended that social workers:

- be employed in HBC organisations, or the ones already in the employ of such organisations be tasked with the job-description of providing training, counselling, debriefing and psychosocial support to the full body of HBCGs through training sessions that use case and/or group work. In addition, to render Social Work services to their patients and their families. In view of providing Social Work services to the HBCGs, it is recommended that the social workers conduct a needs-assessment to familiarise themselves with the needs of the HBCGs to be addressed through Social Work interventions and develop dove-tailed, needs-based wellness programmes. It is recommended that such interventions be offered through individual counselling, group work with a therapeutic and supportive focus, and even excursions, workshops and break-away sessions to support HBCGs whose task it is to care for PLWHA to enable them to cope with psychosocial difficulties relating to their work and to foster their commitment to HBC.

- develop user-friendly and culture-sensitive educational material and programmes to create awareness in communities and educate them about the role and function of HBCGs in the context of providing care service to PLWHA. The aim of such endeavours would be to eradicate the myths and the misinformation not only around HIV and AIDS, but also around HBC and the caregivers caring for PLWHA.

- negotiate entry for HBCGs into communities by way of establishing relationships and getting the goodwill and support of these communities for HBCGs and their care work.

- develop and conduct educational and awareness programmes in communities to educate them about becoming involved with and care for PLWHA and support the HBCGs rendering care services to PLWHA, and overall, to foster and strengthen the spirit of Ubuntu.

- play a leading role in initiating a consultative process involving all relevant stakeholders to assist HBCG organisations in the designing and development of internal policies, service agreements and job descriptions for HBCGs that is just and humane in order to promote their commitment and their health and wellness as well as their career advancement.

- liaise and advocate with all relevant stakeholders, from both within and outside the HBC organisations, for the betterment of the HBCGs working contracts and working conditions.

- convene and lead multi-forum stakeholder meetings with various role players like clinic nursing staff, church leaders, patients' family members, HBCGs themselves and patients with the aim of promoting support for HBCGs caring for PLWHA and addressing the hindrances of HBC.

- conduct meetings and workshops with the managers and the management of HBCG organisations to make them aware of the realities and work-related challenges experienced by HBCGs in caring for PLWHA in an attempt to help management understand the impact of these challenges on the morale and the role performance HBCGs; and to encourage and assist them to put support strategies and interventions in place to address the challenges experienced.

- take the lead in lobbying at organisational, regional and governmental levels and at the Departments of Health and Social Development for and mobilising resources; recognising and standardising HBC as a career; career path advancement prospects for those already in the field of home-based caregiving and those who want to venture into it career-wise, and for better working conditions for HBCGs caring for PLWHA.

- develop the MDT policies and programmes which encourage teamwork and stakeholder relations to address all hindrances that prevent HBCGs from rendering effective care for PLWHA.

5.4.2 Recommendations for Social Work education and training and continuous professional development (CPD)

The following recommendations are directed towards Social Work education and training and CPD based on the research findings:

- It is recommended that information on the aspect of HBC in caring for PLWHA be included by institutions of higher learning in their undergraduate Social Work[57], syllabi of modules focusing on or covering the topic of HIV and AIDS. The nature and scope of HBC in caring for PLWHA; the realities and work-related challenges as highlighted in this study, as well as the role of the social worker in this regard are some of the aspects to be included in this module. It is suggested that the information on middle range theory of caregiving dynamics of Williams (2014) as adopted as one of the theoretical frameworks for this study also be included in the syllabi in view of orientating students on the nature of this caregiving dyad and how they provide role support to the caregivers in such dyads. They also need to be given knowledge and skills on how to provide Social Work services and support to HBCGs, patients, patients' families and the communities when they enter in this area of practice after qualifying.

- Continuous professional development (CPD) training programmes should be developed and training activities such as workshops; seminars and conferences should be presented to educate social workers on the topic home-based care in the context of HIV and AIDS and in so doing to keep social workers updated with issues within the field of HIV and AIDS HBC to further enhance the mainstreaming efforts connected to HIV and AIDS.

- In-service and CPD-training needs to be provided by social workers and other experts in the field of HIV and AIDS as part of the MDT to further equip the HBCGs for their work of caring for PLWHA.

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[57] The aspects could also be covered in relevant modules in the disciplines of Nnursing Sscience, Psychology, Development Studies.

5.4.3   Pointers and an agenda for further research – Recommendations

Since this research project focused only on a sample of HBCGs in Gauteng, Limpopo, and North West, I would like to recommend that this research project be replicated on a national level. In view of good fit of the qualitative approach and the phenomenological, explorative, descriptive and contextual research design, together with the individual face-to-face semi-structured interviews, I would like to recommend that this approach and design and method of data collection be used in other follow-up studies.

As this study was prompted by a lacuna in the knowledge base within the ambit of Social Work on this topic, both nationally and internationally, more research projects focusing on the topic of HBC in caring for PLWHA is recommended.

Flowing from the conclusions derived from this research project undertaken that most of the participants in this study and the literature consulted (Cataldo et al., 2015; Kohli, et al., 2012; Takasugi & Lee, 2012:840; O'lango et al., 2010:233-234; Akintola, 2010:3; Orner, 2006:237; Akintola, 2005:22; Claxton-Oldfield et al., 2004:80-81) is that HBCGs caring for PLWHA are mainly black women from poor economic conditions with low levels of education, it is recommended that further studies be conducted to determine the recognition of gender, race and economic background of the HBCGs as factors in caring for PLWHA.

An agenda for further research from a Social Work perspective on the following topics is recommended:

- An investigation into the current career prospects of HBCGs caring for PLWHA

- An exploration into personal experiences of HBCGs caring for PLWHA as motivating or contributing factors to becoming involved in caring for PLWHA

- The factors contributing to the positive and negative relationships between HBCGs caring for PLWHA and members of the community

- Caregivers caring for PLWHA perceptions and experiences of associated stigmas

- Managing uncooperative patients and families in the context of caring for PLWHA: HBCGs' experiences and coping strategies

- An exploration into home-based HIV and AIDS care and gender dynamics within the African context

- An investigation into the HBCGs' experiences in working in unsafe working conditions

- HBCGs' perceptions and experiences on the nature of their relationship with members of staff from the local clinics

- The experiences and perceptions of HBCGs caring for PLWHA during their interaction with HBCGs caring for patients with other illnesses

- The perceptions of health and welfare professionals like nurses and social workers on the role, role performance and contribution of HBCGs caring for PLWHA

- The impact of HBC-organisations on the role and function of HBCGs caring for PLWHA

- The influence of caring for PLWHA on the HBCGs primary relationships

- An investigation into the resiliency of HBCGs caring for PLWHA
- Perceptions by friends and family members on HBCGs caring for PLWHA and their work

- An investigation into organisational forces that facilitate and/or hinder the HBCGs' role performance in the caregiver-receiver dyad

- The role of HBC organisational management in addressing the challenges faced by HBCGs in caring for PLWHA

- The nature of Social Work support for HBCGs caring for PLWHA and the role of the social worker in this regard

5.5   CHAPTER SUMMARY

The main aim of this chapter was to present a summary of the study, to draw conclusions and forward some recommendations. This was done by first introducing the chapter to the reader. A summary of the general introduction and orientation to the study was then presented by revisiting the research aim, goal and objectives and research questions as the basis on which this study was conducted. A conclusion was then drawn on the basis of this general introduction.

A summary of the applied description of the qualitative research process was also highlighted where conclusions were drawn based on qualitative research as an approach which guided this study as well as the research methods adopted. This was followed by a summary of the research findings which addressed the demographic particulars of the research participants and the nine themes that emerged from the data analysis process, each with its own set of conclusions. Finally, recommendations were made with a specific focus being on guidelines for support directed at Social Work practice, programmes and policy development, education and training, the research process and future and further research.

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LIST OF ADDENDA

ADDENDUM A

A PREAMBLE TO AN INFORMATION AND INFORMED CONSENT DOCUMENT

Dear Ms Pekwa (Pseudonym)

I Maditobane Robert Lekganyane, the undersigned, am a Lecturer at the University of South Africa in the Department of Social Work and a part-time doctorate student in the same University Department. In fulfilment of requirements for the doctoral degree, I have to undertake a research project and have consequently decided to focus on the following research topic: ***Experiencing and managing work-related challenges by home based Home-based caregivers caring for people living with HIV and AIDS: guidelines for support from a Social work perspective.***

In view of the fact that you are well-informed about the topic, I hereby approach you with the request to participate in the study. To help you decide whether or not to participate in this research project, I am going to give you information that will help you to understand the study (i.e. what the aims of the study are and why there is a need for this particular study). Furthermore, you will be informed about what your involvement in this study will entail (i.e. what you will be asked/or what you will be requested to do during the study, the risks and benefits involved by participating in this research project, and your rights as a participant in this study).

This research project originated as a result of an identified gap in the knowledge and practice in the area of Social Work and HIV and AIDS HBC and the aim is: *to develop an in-depth understanding of HBGCs experiences in relation to caring for PLHWA, the work-related challenges they experience in this regard and their coping strategies they employ to address these challenges and to proffer suggestions on how they could like to be supported by social workers in overcoming their challenges.*

The information gathered from this study will provide an insight into the experiences of work-related challenges HBCGs, how they manage such challenges and how they wish to be supported by workers and therefore further intensify the fight against HIV and AIDS and its related challenges.

Should you agree to participate, you would be requested to participate in four individual face-to-face semi-structured interviews that will be conducted at your nearest City of Tshwane offices from 16:00 to 17:00 It is estimated that the interview(s) will last approximately one hour. The questions which will be directed to you during the interviews are attached as (Annexure F). As the research proceeds, you may be required to do the following activities:

1) Complete the schedule focusing on biographical information
2) Share your expectations regarding the whole project.
3) Evaluate the value of every interview to check if expectations are being addressed and by sharing the experiences gained.
3) Read through the verbatim transcriptions of interviews to verify if they are indeed a true reflection of the conversation

With your permission, the interviews will be audiotaped. The recorded interviews will be transcribed word-for-word. Your responses to the interview (both the taped and transcribed versions) will be kept strictly confidential. The audiotapes will be coded to disguise any identifying information. The tapes will be stored in a locked safe at my private house and only I will have access to them. The transcripts (without any identifying information) will be made available to my research supervisor, translator and an independent coder with the sole purpose of assisting and guiding me with this research undertaking. My research supervisor, the translator and the independent coder will each sign an undertaking to treat the information shared by you in a confidential manner.

The independent coder is someone who is well versed and experienced in analysing information collected by means of interviews and is appointed to analyse the transcripts of the interviews independently of the researcher to ensure that the researcher will report the participants' accounts of what has been researched. The audiotapes and the transcripts of the interviews will be destroyed upon the

completion of the study. Identifying information will be deleted or disguised in any subsequent publication and/or presentation of the research findings.

Please note that participation in the research is completely voluntary. You are not obliged to take part in the research. Your decision to participate, or not to participate, will not affect you in any way now or in the future and you will incur no penalty and/or loss of which you may otherwise be entitled. Should you agree to participate and sign the information and informed consent document herewith, as proof of your willingness to participate, please note that you are not signing your rights away. If you agree to take part, you have the right to change your mind at any time during the study. You are free to withdraw this consent and discontinue participating without any loss of benefits. However, if you do withdraw from the study, you would be requested to grant me an opportunity to engage in informal discussion with you so that the research partnership that was established can be terminated in an orderly manner. As the researcher, I also have the right to dismiss you from the study without regard to your consent if you fail to follow the instructions or if the information you have to divulge is emotionally sensitive and upset you to such an extent that it hinders you from functioning physically and emotionally in a proper manner. Furthermore, if participating in the study at any time jeopardises your safety in any way, you will be dismissed.

Should I conclude that the information you have shared left you feeling emotionally upset, or perturbed, I am obliged to refer you to a counsellor for debriefing or counselling (should you agree). You have the right to ask questions concerning the study at any time. Should you have any questions or concerns about the study, please dial this number: 071-493 5017.

Please note that this study has been approved by the DR& EC. Without the approval of this committee, the study cannot be conducted. Should you have any questions and queries not sufficiently addressed by me as the researcher, you are more than welcome to contact the Chairperson of the Research and Ethics Committee of the Department of Social Work at UNISA. His contact details are as follows: Prof AH (Nicky) Alpaslan, telephone number: 012 429 6739, or email alpasah@unisa.ac.za.

If, after you have consulted the researcher and the Research and Ethics Committee in the Department of Social Work at UNISA, their answers have not satisfied you, you might direct your question/concerns/queries to the Chairperson, Human Ethics Committee, College of Human Science, PO Box 392, UNISA, 0003.

Based upon all the information provided to you above, and being aware of your rights, you are asked to give your written consent should you want to participate in this research study by signing and dating the information and consent form provided herewith and initialling each section to indicate that you understand and agree to the conditions.

Thank you for your participation.

Kind regards,

_____

Robert Lekganyane
Researcher
Cell No: 071 493 5017/082 757 3575
Fax: 086 268 4614
Email: robertlekganyane@yahoo.com

ADDENDUM B

INFORMATION AND INFORMED CONSENT DOCUMENT

Title of research project: *Experiencing and managing work-related challenges by home-based caregivers caring for people living with HIV and AIDS: guidelines for support from a Social Work perspective*

Address: 12111 Block X Ext

Mabopane

0190

Contact telephone Number: (012) 429 2926

Cell Number: 0714935017 or 0827573575

Email: lekgamr@unisa.ac.za

DECLARATION BY THE PARTICIPANT: I, the undersigned,_____ (name), [ID No: _____] the participant of _____ _____ _____ _____(address) **A. HEREBY CONFIRM AS FOLLOWS:** 1. I was invited to participate in the above research project which is being undertaken by Mr Robert Lekganyane of the Department of Social Work in the School of Social Science and Humanities at the University of South Africa.	
	Initial

2. The following aspects have been explained to me: 2.1 Aim: In studying the *Experiences and management of work-related challenges by home-based caregivers caring for people living with HIV and AIDS, I aim to develop an in-depth understanding of HBGCs experiences in relation to caring for PLHWA, the work-related challenges they experience in this regard and their coping strategies they employ to address these challenges and to proffer suggestions which will serve as guidelines on how they could like to be supported by social workers in overcoming their challenges.*	Initial
2.2 I understand that I am participating in this research project without any expectation of payment of whatsoever and that I will be interviewed on my experiences of stigma in caring for PLWHA.	Initial
2.3 Risks: As the research proceeds I may be emotionally too overwhelmed to handle some of the experiences that I will be sharing and the researcher will in this regard refer me for debriefing.	Initial
A possible benefit: As a result of my participation in this study, I will be afforded an opportunity to share my experiences and work-related challenges in caring for PLWHA, and therefore I would be playing a huge role in making the voices of HBCGs caring for PLWHA to be heard.	Initial
Confidentiality: My identity will not be revealed in any discussion, description or scientific publications by the researcher.	Initial
Digital recording of interviews: I also understand that the interviews will be digitally recorded through a digital voice recorder in order for the researcher not to miss important data during analysis and this process will not result in my identity being revealed.	Initial
Possible follow-up interviews: I am also aware that the researcher may come to do some follow-ups on the interviews in order to get clarity on issues which may not be clear.	
Access to findings: Any new information/benefit that develops during the course of the study will be shared with me	Initial
Voluntary participation/refusal/discontinuation: My participation is voluntary. My decision whether or not to participate will in no way	Initial

affect me now or in the future.	
3. The information above was explained to me by Mr Robert Lekganyane in both English and I am in command of these languages. I was given the opportunity to ask questions and all these questions were answered satisfactorily.	Initial
4. No pressure was exerted on me to consent to participate and I understand that I may withdraw from the study at any stage without any penalty.	Initial
5 Participation in this study will not result in any additional cost to me.	Initial
B. I HEREBY CONSENT VOLUNTARILY TO PARTICIPATE IN THE ABOVE PROJECT. Signed at _____on_____2015 _____ _____ Signature or right thumbprint of participant Signature of witness	

ADDENDUM C

CONSENT FORM REQUESTING PERMISSION TO PUBLISH AUDIOTAPES OR VERBATIM TRANSCRIPTS OF AUDIOTAPE RECORDINGS

As part of this project, I have made, audio recording of you. I would like you to indicate (with ticks in the appropriate blocks next to each statement below) which uses of these records are you willing to consent to. This is completely up to you. I will use the records only in ways that you agree to. In any of these.	Place a tick [☐] next to the use of the record you consent to
1. The records can be studied by the research team and quotations from the transcripts made of the recordings can be used in the research report.	
2. The records (i.e. quotations from the transcripts made of the recordings) can be used for scientific publications and/or meetings.	
3. The quotations from the transcripts can be used by other researchers.	
_____ Signature of participant	_____ Date

ADDENDUM D

STATEMENTS AND DECLARATIONS

<table>
<tr><td>

STATEMENT BY RESEARCHER

I, Maditobane Robert Lekganyane, declare that I have explained the information given in this document

to_____ (name of participant. He/she was encouraged and given ample time to ask me any questions; this conversation was conducted in Setswana and it was translated into English by Mr Lekganyane.

Signed at _____ on _____20___

(place) (date)

_____ _____

Signature of investigator   Signature of witness

</td><td></td></tr>
<tr><td>

IMPORTANT MESSAGE TO PARTICIPANT

</td><td></td></tr>
<tr><td>

Dear Participant

Thank you for your participation in this study. Should at any time

during the study an emergency arise as a result of the research, or

you require any further information with regard to the study, or

the following occur :

- You suffer any harm as a result of the researcher process, kindly contact Robert Lekganyane on 0714935017 (name) at telephone number.

</td><td></td></tr>
</table>

ADDENDUM E

Date: 05 March 2015

REQUEST FOR PERMISSION TO CONDUCT RESEARCH
AMONG GIVERS CARING FOR PEOPLE LIVING WITH HIV AND AIDS

Greetings,

My name is Maditobane Robert Lekganyane, a Lecturer in service of the Department of Social Work University of South Africa, Muckleneuk ridge campus in Pretoria. I am also a part-time doctoral candidate in the same department at the same University. In the fulfilment of the requirements for my doctoral qualification, I have to undertake a research project and I have consequently decided to focus on the following research topic: ***Experiencing and managing work-related challenges by HBCGs in caring for people living with HIV and AIDS: guidelines for support from a Social work perspective.*** This research project originated as a result of an identified gap in the knowledge and practice in the area of HIV and AIDS home-based care and Social Work and its primary aim is to *develop an in-depth understanding of HBGCs experiences in relation to caring for PLHWA, the work-related challenges they experience in this regard and their coping strategies they employ to address these challenges and to proffer suggestions on how they could like to be supported by social workers in overcoming their challenges.*

In view of the fact that HBCGs are well-informed about the topic, I hereby approach you with the request of your permission to conduct a study among HBCGs in your organisation. The data gathered from this study will provide an insight into the experiences and challenges faced by HBCGs, their support preferences from social workers and further intensify the fight against HIV and AIDS and its related factors by shedding light to decision makers when designing and developing policies and programmes. The study will take a form of some interviews which will last for about 1 hour with the HBCGs. As part of my ethical responsibility, I am obliged to treat the participants with respect, ensure that they are protected from any form of harm, not forced to participate in the study, that they are informed about the practical details of

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the study and that any information provided to me by them is treated as confidential. Participants will sign a consent form through which they will be informed about the study in detail and through which as a researcher I will be committing myself to the ethical principles. It is therefore my conviction that granting permission to conduct this study will contribute towards bridging the gap of knowledge in the field of HIV and AIDS home-based care while on the other hand raising the voices of HBCGs in relation to the challenges which they face and their preferences for support from social workers.

A blessed day ahead of you,

…………………..
MR Lekganyane
Principal Researcher

ADDENDUM F

THE INTERVIEW-GUIDE

1. Tell me what motivated you to become involved in caring for PLWHA

2. How is it for you to care for PLWHA?

3. What are the work-related challenges that you face when caring for PLWHA?

4. How do you cope with such challenges? …

5. How and with what would you like social workers to assist you as caregivers caring for PLWHA?

ADDENDUM G

PROOF OF ETHICAL CLEARANCE FROM THE DEPARTMENTAL RESEARCH AND ETHICS COMMITEE

PROOF OF ETHICAL CLEARANCE

DEPARTMENT OF SOCIAL WORK

UNIVERSITY OF SOUTH AFRICA

Declaration

We, the undersigned, hereby declare that the research proposal for the proposed doctoral studies with supportive documentation (i.e. the letter with detailed information about the research directed at prospective participants, the informed consent forms and the instruments of data collection) of the student named below was approved at the Research and Ethics Committee of the Department of Social Work at their meeting conducted on 5 June 2013

Title of the approved proposal: EXPERIENCING AND MANAGING WORK-RELATED CHALLENGES BY HOME-BASED CAREGIVERS CARING FOR PEOPLE LIVING WITH HIV AND AIDS: GUIDELINES FOR SUPPORT FORM A SOCIAL WORK PERSPECTIVE

Student Name: Mr MR Lekganyane   Signature:

Student Number: 33197083   Date: 5 June 2013

Supervisor Name: Prof AH Alpaslan   Signature:

Staff Number: 90160355   Date: 5 June 2013

Name of Chair: Prof AH Alpaslan   Signature:

Departmental Research and Ethics Committee   Date: 5 June 2013

Ethical Clearance Reference Number: DR&EC_05/06/13_33197083

ADDENDUM H

AN EXAMPLE OF A RESEARCH JOURNAL: AN EXCERPT

Date: 19th March 2016

Purpose and objective of the day	*To prepare Paul* (one of the participants)*
Preparation, activities and the process	*Information and informed consent forms, my declaration as a researcher (i.e. addendum D) consent document for publishing verbatim transcripts all put together with some extra copies for the participants. I took time to explain the purpose of the study; the risks and benefits involved and answered questions where necessary.*
Challenges encountered during preparation and implementation of the process	*Challenges that I encountered were in relation to the cats that were running all over the house as we talk. This interrupted the flow of our conversation. Another challenge was that Paul was an Afrikaans speaking white man who battled to express some of the words in English and this also made our conversation flow to have some hiccups.*
Solutions implemented to resolve challenges encountered	*Paul was asked if he can't make a plan to restrain the cats until we finalise the interview and he did restrain them. In terms of the language problem, I asked Paul to feel free to express himself in Afrikaans whenever he experiences some difficulties with some English words.*
Results achieved for the day	*Paul was eventually prepared and demonstrated an understanding of the entire process of the study. Another appointment for follow-up preparation was made just to make sure he is well informed before he could make a decision on whether to participate or not.*

Reflection on the process (i.e. feelings, experiences, roles, values, etc. which played a role)	*Having been raised form a family were cats are frowned at mainly due to their association with witchcraft, I found my interaction with Paul to be very uncomfortable. I think I was more concerned about the kind of life that this man is living with these cats than the main purpose of my visit. I questioned his sanity and wondered if he really is a normal person. The fact that he was just staying alone with cats escalated my concern about his sanity. Despite this, I have managed to restrain myself and forced myself to remain focused on the process.*

ADDENDUM I

DEBRIEFING LETTER

Catholic Women's League
DIOCESAN COUNCIL · ARCHDIOCESE PRETORIA

Katolieke Vrouebond
RAAD VAN DIE AARTSBISDOM · PRETORIA

REGISTERED WELFARE ORGANISATION
REGISTRATION NUMBER · DXI-679 NPO

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Pretoria
0002

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012-343 0112
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086-620-0094
e-mail: cwlpretoria@vol.co.za

09 February 2015

Sir/Madam,

RE: Confirmation to assist with providing Counselling to Research Participants

I Refilwe Matsimbi am a qualified Social Worker (Reg No: 10- 26389) who is practicing under the auspices of Catholic Women's League. I hereby confirm that I have offered to provide counselling and debriefing to participants who are involved in a PhD research project.

The project is conducted by Mr Lekganyane under the topic: Experiencing and managing courtesy stigma by Home-Based Care Givers Caring for People Living with HIV&AIDS: Guidelines for Support from a Social Work Perspective.

Yours Faithfully,

RM Matsimbi
Social Worker
SACSSP Ref: 10- 26389