

AN INVESTIGATION OF THE CHALLENGES AND COPING MECHANISMS OF
HOME-BASED CAREGIVERS FOR PATIENTS LIVING WITH HIV IN MAMELODI

by

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DECLARATION

I, Mmalesiba Dorothea Mabusela, declare that **“AN INVESTIGATION OF THE CHALLENGES AND COPING MECHANISMS OF HOME-BASED CAREGIVERS FOR PATIENTS LIVING WITH HIV/AIDS IN MAMELODI”** is my own independent work, that it has not been submitted for any degree or examination at any other university, and that all the sources I have used or quoted have been indicated and acknowledged by means of complete references.

.....

Signature

(Ms M D Mabusela)

.....

Date

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DEDICATION

This dissertation is dedicated to my dearly departed father, Mr Elijah Malose Mabusela, who was an advocate for education, my pillar of strength and my source of inspiration. I have reached this milestone inspired by your teachings, which I will behold throughout my life to achieve more.

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LIST OF ACRONYMS AND ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
CHBC	Community Home-Based Care
CHBCGs	Community Home-Based Caregivers
CBOs	Community-Based organisations
FBOs	Faith-Based organisations
HBC	Home-Based Care
HBCC	Home-Based Care Centre
HBCGs	Home-Based Caregivers
ICBC	Integrated Community-Based Care
HIV	Human Immunodeficiency virus
NGOs	Non- Governmental organisations
PALHIV	Patients living with HIV
TASO	The AIDS Support Organisation
UNAIDS	United Nations Programme on HIV/ AIDS
WHO	World Health Organization

ABSTRACT

HIV/AIDS is a global challenge and its impact is evident. This places a burden on hospitals and health professionals. To ease this burden there are home-based care programmes which, through home-based caregivers, provide patients living with HIV/AIDS with physical and palliative care.

However, these HBCGs face various challenges such as poverty, discrimination and stigma when caring for PALHIV, and their own emotional strain, which becomes burdensome without sufficient support from the home-based care centre.

The qualitative study undertaken investigates the challenges and coping mechanisms of the HBCGs. Thirteen research participants were drawn from a centre in Mamelodi.

Data was gathered through interviews and observations, categorised into themes and analysed. Major findings revealed that social challenges faced by HBCGs include poverty, stigmatisation and discrimination. Emotions experienced by HBCGs include guilt, anger, hopelessness, but they have spiritual reliance through prayer as one of their coping mechanisms.

Keywords

Acquired Immune Deficiency Syndrome; challenges; caring; coping; emotions; Home-based caregivers; Human Immunodeficiency Virus; social support; workload

CHAPTER ONE: INTRODUCTION OF THE STUDY

1.1 Background

The impact of the Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome (HIV/AIDS) globally has not yet reached its peak but already it has hit Africa harder than any other continent. A United Nations Programme on HIV/AIDS (UNAIDS 2006:81) projection indicates that by 2015, African countries highly affected by HIV/AIDS will have a population reduction of 115 million as a result of the HIV/AIDS epidemic. Contributing factors to the spread of HIV include poverty, social instability, high levels of sexually transmitted infections, to name a few (AIDS Foundation South Africa 2005).

South Africa is one of the countries hardest hit by HIV/AIDS in the Sub-Saharan region, with the national prevalence rate estimated at 18,1% in 2007 and 17,5% in 2008 in the general population, and 29,3% in the antenatal population in 2008. In South Africa's Gauteng province the HIV prevalence rate amongst antenatal women has decreased by 0,6% from 30,5% in 2007 to 29,9% in 2008, contrary to provinces such as Free State where there has been an increase from 31,5% to 32,9%, and Western Cape from 15,3% to 16,1%. Western Cape Province however remains one of the provinces in South Africa with the lowest prevalence rate of 16,1% in 2008 (National Department of Health 2009).

The impact of HIV/AIDS can also be seen through an increase in the number of Patients living with HIV (PALHIV), which has put pressure on hospital staff who are already struggling to cope with their workload. This gave rise to Home-based Care Centres (HBCCs) with Home-based caregivers (HBCGs) to care for the PALHIV. However, due to the high prevalence rate, HBCGs are as overburdened as hospital staff (Uys & Cameron 2003:3).

According to Uys and Cameron (2003:3), the system of AIDS care is described in three components, each with different functions. The *first* component is hospitals, and their main function is diagnosis and in-patient therapy. They further have a discharge plan which begins in hospital when a patient is discharged. This plan brings patients discharged from hospital in contact with the out-patient and community agencies through effective referral, for example to HBCGs in communities and back to relevant health services. The *second* component is out-patient services which focus mainly on the medical management of PALHIV, which is ideally delivered through dedicated AIDS programmes in clinics such as counselling and health education. The *final* component is community-based care, which provides care for PALHIV at a patient's residence or a centre to supplement or replace hospital-based care. Community-based care includes services such as medication management, palliative care and social support. This latter type of care is the focus of this study.

The theoretical orientation of Lazarus and Folkman's (1984:31) cognitive appraisal which focuses on coping is adopted in support of this study. This theory sees coping as a process that consists of step. It further highlights the coping strategies which can be adopted to deal with demands in a taxing environment such as working with PALHIV some of whom are terminally ill.

This research was conducted in the community of Mamelodi, a township¹ in Gauteng, South Africa, situated east of the city of Pretoria, with a diverse set of living standards ranging from well-built houses to small informal structures such as shacks (Wireless Africa 2008).

¹ Township: an urban area which was set aside for African people under the *apartheid* regime. *Apartheid* is an Afrikaans word which means the policy of keeping people of different races apart (*South African Oxford SchoolDictionary* 2004: 479).

1.2 Problem statement

According to Dageid, Sedumedi and Duckert (2007:3), there is a shortage of qualified health workers such as nurses and doctors, leading to, amongst other things, increased workloads. To reduce the workload, lay staff and volunteers are hired and trained under supervision of a professional. The formal health care system also has partnerships with HBCCs to deal with issues of caring for PALHIV. Thus, in order to alleviate the enormous workload on the formal health care system, community care and support personnel such as HBCGs are employed (as explained above), but they are also suffering similar and additional challenges such as lack of resources, support and training, large numbers of patients, low wages, heavy and unpredictable workload as well as the inevitable death of patients (Dageid *et al.* 2007:4). The Community Home-Based Caregivers (CHBCGs) in a study by Makoae and Jubber (2008:44) were reported to be experiencing frustration, anger, helplessness and disillusionment in their area of work. HBCGs have difficulty in dealing with all the challenges, which makes them feel emotionally as well as socially weak and hamper their performance. In general they face challenges that are emotional, financial, physical and social in nature (Pendukeni 2004:3; Shebi 2006:3; Uys & Cameron 2003:28).

In view of the above challenges, the question that is directing this research is: **How do HBCGs deal with the challenges they are faced with when providing care to PALHIV?** In addressing this main question, the following subsidiary questions are posed:

- What kind of challenges do HBCGs face when caring for PALHIV?
- How do they deal with such challenges?
- What are the coping mechanisms of HBCGs?
- What kind of support do they receive in dealing with these challenges?

1.3 Rationale of the study

The South African health sector is experiencing a human resource crisis due to various challenges. One such challenge is the increased workload experienced by health personnel as a result of an increase in demand for health services, with 28% of the patients being HIV-positive in 2002. Laboratory services in hospitals are also under pressure – not only as a result of HIV testing but also for diagnosis of opportunistic infections which are too complex for poorly trained microscopists (Jorge & Cabral 1993:158). The result is an unmanageable number of patients, leading to a high staff turnover as more and more qualified health workers cross borders in search of greener pastures (Kohler 2008:3). These types of challenges contribute to PALHIV being discharged too early, hence the need arises for HBCCs to take over with the caring for PALHIV since hospitals cannot cope with the pressure alone. According to Makoae & Jubber (2008:37), HBCCs are encouraged to share this burden with the communities so as to reduce the economic and human resource pressure faced by hospitals.

The study by Naidu (2005:8) implies that the incentives for HBCGs are not enough. This issue is elaborated on by Uys and Cameron (2003:12) when they explain that most HBCGs are volunteers and impoverished, posing an ethical and economic dilemma. The inevitable need to earn a living may also contribute to the strain on their coping strategies. Naidu's (2005:7-8) study revealed that for every two staff members paid, there are on average eight unpaid staff members. There is virtually no part-time paid staff, with the exception of a small proportion (5%) by a few HBC organisations. Most of the HBCGs are working on a voluntary basis under strenuous conditions with little support, and they do not receive sufficient remuneration or incentives because most NGOs are donor-dependent and are unsustainable.

According to Dageid *et al.* (2007:5), previous research on HIV/AIDS care and support has primarily focused on HIV patients, children, health care workers in hospitals, the burnout experience as a result of the high workload and the low incentives they receive, given the amount of work they do.

In the SADC region, studies on HIV health workers have focused on their perceptions and confidentiality and not coping. In South Africa, studies have addressed the burden of caring and coping strategies, targeting primary caregivers (in this study referred to as CHBCGs) and volunteers in different provinces such as the Western Cape and Gauteng provinces, and not specifically HBCGs in Mamelodi.

There is a general need for research in specific communities such as Mamelodi, which has not received much attention, especially in the context of HIV/AIDS and HBCGs' coping mechanisms, something this research seeks to address.

1.4 Purpose of the study

Research on the experiences of HBCGs in communities and how they cope with working with PALHIV, is limited. The purpose of this study is to increase the limited knowledge about HBCGs, especially in a HBCC based in the community of Mamelodi.

This study further seeks to provide more insight on the dynamics and struggles faced by HBCGs caring for PALHIV in a specific HBCC, and to investigate how they cope with such challenges, at the same time attempting to test the feasibility of conducting a more intensive study in future.

The results of this study will be used to draw attention to the specific HBCC and to highlight the need for intervention, as well as recommend possible strategies

to assist HBCGs in coping with their work. The recommendations of the study may also be used by policy makers in the specific HBCC in reviewing the current policies and legislation to improve the working environment of their centre. This information can also be shared with other organisations in the same position and field as the centre under study, such as NGOs and CBOs working with HBCGs that provide similar services to PALHIV.

1.5 Objectives of the study

This study is about understanding the coping mechanisms of HBCGs in a HBCC with a view to explore the possible emotions that they experience as they strive to cope.

The following are the objectives of the study:

- Investigate the psychological challenges experienced by HBCGs in giving HBC to PALHIV;
- Investigate the social challenges experienced by HBCGs in giving HBC to PALHIV;
- Investigate the coping mechanisms used by HBCGs in giving HBC to PALHIV;
- Investigate the types of support provided to HBCGs in giving HBC to PALHIV;
- Investigate interventions necessary to support HBCGs in giving HBC to PALHIV as perceived by HBCGs.

This study looks at reflective experiences expressed by participants and their emotional reactions in their trying to work with PALHIV.

1.6 Research design

A qualitative approach to conducting research was adopted for the purpose of this study. This approach was chosen to gain a better understanding of the coping mechanisms of HBCGs in a HBCC in Mamelodi.

1.6.1 Method of collecting data

Data was collected through interaction with HBCGs, using observation and in-depth interviews. Participants were interviewed individually and requested to volunteer their participation by signing a consent form (see Appendix C, in English and Northern Sotho). The interview schedule (see Appendix D, in English and Northern Sotho) was used to guide the interviews.

1.6.2 Data analysis

Data gathered was analysed and coded. Themes were developed through clustering data into similar themes. This helped the researcher to discover meaning in what she observed and heard through the interviews.

1.6.3 Research participants

The population of this study was the HBCGs in the chosen HBCC in Mamelodi.

The criteria set included:

- Employment with the centre for three or more months; and
- Involvement in daily duties of the centre.

The sample consisted of 13 research participants, who were approached through purposive sampling.

1.6.4 Ethical consideration

Ethics were considered in this study where the researcher ensured that participants were not exposed to danger. The researcher further obtained

consent from participants to take part in the study with parameters of confidentiality assured. The participants signed consent form in Appendix C (in English and Northern Sotho) as an agreement to take part in the study. Unisa Ethical committee provided ethical clearance before fieldwork was undertaken.

1.7 Operational definitions

HBCGs: Home-based caregivers are persons who are associated with a HBCC and who care for people who are living with HIV.

PALHIV: Patients living with HIV are people who have tested positive for HIV and are living with the virus. In this study PALHIV are in different phases of HIV infection. Some are taking treatment because of the decline of their CD4 count whereas some are still recovering and others are fully recovered and self reliant.

CD4 count: In this study CD4 count is understood in accordance with ACASA (2003) namely that it is a blood test that measures the number of T4 (CD4 cells) in one's blood. It tells one how the immune system is and how much damage the HIV virus has done to the immune system. As the disease progresses T4 count becomes lower. When CD4 count is somewhere between 350 and 200, PALHIV must start taking treatment. These are the PALHIV that this study focuses on.

HIV: In this study HIV is understood in accordance with Van Dyk (2001:423), namely that it is the human immunodeficiency virus, the virus that causes AIDS.

AIDS: In this study AIDS is understood in accordance with Van Dyk (2001:423), namely that it refers to the Acquired Immune Deficiency Syndrome, emphasising that the disease is acquired and not inherited. It is caused by a virus that invades the body, attacks the immune system and makes the body weak and ineffectual

to the extent that it is unable to protect itself from serious and common infections and pathogens.

CHBC: Community Home-Based Care is understood in accordance with WHO (2002:8), namely that it is any form of care given to the sick people in their homes including physical, psycho-social, palliative and spiritual care. Home care draws on two strengths that exist throughout the world: families and communities. Families are a central focus of care and form the basis of the CHBC.

Social Grant: Social Grant is understood in accordance with South African Social Security Agency (2010:1), namely adult grant that is a disability grant for the aged and war veterans.

Grant in Aid is understood in accordance with South African Social Security Agency (2010:1) namely that social grant is intended to provide for the basic needs of adults who are unable to care for themselves and is certified by a medical officer. This is the grant that is received by PALHIV in this study.

1.8 Structure of the dissertation

The *second* chapter focuses on a review of the relevant literature. It begins with a theoretical perspective of coping and further gives background on home-based care and issues relating to coping, including challenges experienced by HBCGs, coping strategies and support necessary to help them cope.

The *third* chapter describes the research methodology, namely the research design, sampling, the process of data collection and analysis, data interpretation, and the limitations as well as ethical considerations of this study.

In *Chapter 4* the research findings of this study are presented and discussed.

Chapter 5 closes with conclusions and recommendations.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

According to Van Dyk (2001:3), the AIDS epidemic impacts on the medical, psychological, social, spiritual, educational and economic life of the infected person and the community at large. The HBCGs who are the central focus of this research, form part of the community resources available to PALHIV.

This chapter will begin by outlining the theoretical framework of cognitive appraisal by Lazarus and Folkman (1984). This theoretical framework centres on coping, which is a central concept in this study. Thereafter an overview of home-based care, home-based caregivers, their roles and responsibilities and motivation as well as the kind of support needed when working with PALHIV will be highlighted.

In the process of caring for PALHIV, HBCGs experience challenges such as high levels of stress, burnout and anxiety as a result of the emotional intensity of this helping profession. Detailed discussions from the literature of these challenges and how they influence the coping abilities of HBCGs will be presented to investigate how HBCGs deal with challenges they are faced with when providing care for PALHIV, as well as the kind of support available for them at work to enable them to continue giving quality service.

2.2 Theoretical orientation

This research attempts to extensively investigate the challenges HBCGs face in a HBCC and their coping mechanisms. In order to understand coping mechanisms it is important to define coping. Coping can be 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 a person (Lazarus & Folkman 1984:141). These demands are appraised by individuals engaging in them and by the people around them. In the case of this study, appraisal is done by HBCGs themselves as they engage in caring for PALHIV (Lazarus 1991). Working with PALHIV can be appraised as taxing since it is difficult for the HBCGs to manage the internal and external demands that come with the job. According to Gottlieb (1997:58), demands facing HBCGs include overload, which defines the nature of stress: the person feels torn between multiple independent, immediate, and uncontrollable demands that cannot be put aside. To be able to manage these demands it would be necessary for HBCGs to learn a variety of coping mechanisms. They further need to assess the situation in order to determine which strategy might work best in different situations (Hood & Carruthers 2002). The demands placed upon HBCGs who care for PALHIV will be discussed in more detail below (section 2.10).

2.2.1 Coping process

Coping is a process that is characterised by functions of continuous appraisal and reappraisals of the shifting person-environment relationship, as mentioned in Lazarus and Folkman (1984:142). Appraisal is thus seen as a fundamental component of the coping process. According to Aldwin (2007:115), how a person copes with a problem is largely dependent upon his or her own appraisal of the situation. Appraisal is considered to be a conscious evaluation of whether a situation is benign, threatening, involves harm or loss, or constitutes a challenge.

Lazarus and Folkman (1984) see coping as a process which consists of four steps. The first step involves determining the meaning of an event or situation and its implication for one's well being. The second step is assessing one's coping resources and the likelihood of the effectiveness of various coping strategies. Selecting a coping strategy concludes this step. The third step involves carrying

out the selected coping strategy. Finally, the fourth step involves evaluating one's coping efforts with regard to the effectiveness in eliminating or reducing the stressors or managing one's response to the stressful event.

The meaning of coping as a process that encompasses the steps above can be seen, for example, with grieving people and the changes that take place over time, beginning with the moment of loss. Initially, in the loss of a loved one, there may be shock and disbelief, or efforts to deny the death. There may also be frantic activities, tearfulness, or brave struggles to carry on socially or at work. Later stages often involve temporary disengagement and depression, followed ultimately by acceptance of loss and re-engagement (Lazarus & Folkman 1984:143). This example reflects more of the first and last step of the process of coping. When working with PALHIV it is inevitable to deal with death and grief and it will therefore be interesting to note how HBCGs follow the abovementioned steps in order to cope with their own grief and that of their patients therefore having to adopt some or all of these steps. This study will also allude to bereavement counselling that HBCGs provide therefore witnessing the process of coping their patients and their families undergo.

Chapter 4, which covers the research findings of this study, will clearly articulate the extent to which the research participants followed these steps in an attempt to cope.

2.2.2 Coping strategies

There are two widely accepted models of coping strategies, which are seen by Lazarus and Folkman (1984) as major categories of coping responses, namely emotion-focused and problem-focused forms of coping:

Emotion-focused forms of coping are more likely to occur when there has been an appraisal that nothing can be done to modify harmful, threatening or challenging environmental conditions. It consists of cognitive processes directed at lessening emotional distress and includes strategies such as avoidance, minimisation, distancing, selective attention and positive comparisons from negative events. However, there are also cognitive strategies that increase emotional distress, such as self-blame which comes in a form of self-punishment.

Problem-focused forms of coping are more probable when such conditions are appraised as amenable to change. Its strategies are similar to those used for problem-solving, and are directed at defining the problem, generating alternative solutions, weighing alternatives in terms of their cost and benefits, choosing amongst them, and then acting. Problem-focused coping also include strategies directed at the environment and those directed at the self (Lazarus & Folkman 1984:153).

These coping responses are interconnected and necessary for effective coping. They emphasise managing responses to various problems and incorporate a reactive perspective to the situation; they are not mutually exclusive and may even occur simultaneously. Women are seen to be more comfortable with emotion-focused strategies (Hood & Carruthers 2002:4).

Lazarus and Folkman (1984:119) identified various coping strategies, which are referred to as coping devices, and which include self-control, humour, crying, swearing, weeping, boasting, talking it out, thinking it through, and working off energy. They are regarded as normal or, at worst, distinctive characteristics. Hood and Carruthers (2002, citing Overholser 1992) indicate that humour is an important psychological resource for coping and is associated with experiencing lower levels of loneliness and depression and higher levels of self-esteem. If these

characteristics are used inappropriately or to an extreme, for example, when a person talks too much, laughs too easily, loses his or her temper frequently or seems erratic, they lose their status as coping devices and become symptoms which indicate a degree of dysfunction and threatened disequilibrium.

This theoretical framework has provided understanding in the way HBCGs reflect on what is happening and their own emotional reactions to situations in relation to coping, and how it affects the physical and societal environment. It further highlights the strategies that the HBCGs implement to solve problems. There is a striking similarity in the different types of coping strategies that this framework encompasses and those implemented by HBGCs in this study.

2.3 Studies on coping

According to Aldwin (2007:117), coping is an organisational construct that describes “how people regulate their own behaviour, emotion, and motivational orientation under conditions of psychological distress and contains peoples’ struggle to maintain, restore, replenish, and repair fulfilment of these needs”.

Aldwin (2007:124) looks at other aspects of coping, namely those that relate to what Lazarus and Folkman (1984) refer to as coping devices (section 2.2.2 above), such as problem focused strategies and emotion focused strategies. Aldwin (2007:125) highlighted self-efficacy as an important aspect of coping. He further mentioned that research has shown that there was a relationship between self-efficacy and problem-focused strategies (problem-focused strategy is well explained in section 2.2 above). Individuals who used few coping strategies but thought that they had solved the problem they were encountering, were psychologically the least distressed. Those who used relatively few problem-focused strategies but thought they had mishandled the problem, were most

stressed. The choice of a specific coping strategy may be less important than how well one executes that strategy.

According to Gueritault-Chalvin, Kilicham, Demi and Peterson (2000:150) studies that investigate the impact of coping styles on the intensity of burnout showed that individual coping strategies may be an important buffer against perceived stress. In one study, it was found that coping style was a major determinant of burnout. External and internal coping strategies all predicted burnout. The following coping dimensions, which were internal and external coping, were present in studies on AIDS carers. External coping includes pessimistic strategies (negative expectations) and denial (avoidance of difficult situations). Internal coping included positive coping strategies (positive and optimistic attitude and outcomes), self-expressive strategies (expression of feelings and emotions), vigilant strategies (patience, persistence and waiting) and time out (escapist and self-preserving coping techniques).

According to Gueritault-Chalvin *et al* (2000:151), a study by Bennet found that the use of external coping mechanisms led to higher levels of burnout among HIV/AIDS caregivers. Coping skills play a very important role in the prevention or exacerbation of burnout. In the same study it was reported that older nurses used more internal coping strategies than the younger ones, who used external coping strategies (Gueritaul-Chalvin *et al.* 2000:151).

Aldwin (2007: 124) further looked at religion as one of the coping devices. Religious coping is seen as consisting of five key functions: meaning, control, comfort/spirituality, intimacy and life transformation. Religion can provide a sense of relief and peace – even in extremely stressful circumstances. For example a study by Folkman, Chesney, Cooke, Boccelari, Richards, Moskowitz *et al* (2000:1) on stress and coping of gay male caregivers reported spirituality as a

coping strategy, especially at the death of a partner – an experience similar to what the sexual partner is going through. On the contrary it was also found that there is at times a negative aspect to religious coping such as feelings of abandonment, punishment, or judgement by others, which can intensify stress instead of alleviating it (Aldwin 2007:124).

2.4 Home-based care

Home-based care is defined by Gumbi (2001:10) as any form of nursing care given to sick people (including PALHIV) at home by a family member, a friend, a HBCG or a volunteer from the community through regular visits. Home-based care offers health care services to support the overall care in the home environment of the patient.

HBC includes physical, psycho-social, palliative and spiritual support and ensures continuity of care as well as encourages participation by the family and community in taking care of their own health and the health of their loved ones. Seventy (70) to 90% of illness care takes place within the home, as most people prefer to be taken care of at home. It is an effective way of involving families and community in the care and support of PALHIV (Naidu 2005:1; National Department of Health 2001:1; WHO 2002:9).

South Africa has an Integrated Community-Based Care (ICHC) programme with important elements such as treatment support for disease-specific care, for example antiretroviral treatment, early identification and treatment of opportunistic infections, management of distressing symptoms, emotional support and social support including facilitating access to social grants, economic empowerment programmes and care of orphans and vulnerable children (Gwyther 2008:517).

According to Uys and Cameron (2003:5), ICHC links all service providers with patients and their families in a continuum of care and enhances collaboration with different stakeholders in this model, e.g. families, clinics, hospitals, support groups, nongovernmental organisations (NGOs) and community-based organisations (CBOs), donor agencies and governments. This system allows for referral between all partners and develops capacity in all partners involved (WHO 2002:9).

2.4.1 Why home-based care

Home-based care is an indispensable part of the health continuum due to the ever-increasing number of PALHIV globally. It promotes a holistic approach to care and ensures that physical, social, emotional, economic and spiritual health needs of PALHIV are met (Naidu 2005:1). HBC came into existence as a response to the increasing need for care by PALHIV who are unable to afford hospitalisation. Overcrowding in hospitals, lack of resources, an inadequate number of medical, nursing and allied health professionals in the public sector, and the high cost of institutional care are examples that signify the inability of the health system to provide hospital care for those who are living with HIV/AIDS. This has intensified the demand for the provision of home-based care by family members or volunteers on such programmes and of centres in the form of hospices (Joubert 2005:29; UNAIDS [sa]:1).

In Africa there has been a gradual shift from hospital-based care of PALHIV to HBC, since PALHIV constitute a large majority of people seeking medical attention at hospitals, and hospitals do not have adequate capacity to take care of them. PALHIV admitted in hospitals are usually discharged after a short period of admission or are not admitted at all due to shortage of beds. One South African hospital reported that patients' average stay in hospital has decreased from 14 to 3,5 days, when they were referred to a HBC organisation - a clear

indication that HBC relieves the burden of caring for PALHIV and that the system is effective in that regard (Akintola 2004:2; Leake 2009; Uys & Cameron 2003).

The benefits of home-based care compared to hospital care include that sick people can spend their final moments at home, surrounded by people they love and are familiar with, who will provide flexible and nurturing care, therefore reducing stress, time spent on hospital visits and transport costs for the family. It also allows the patient and his/her family time to come to terms with the illness and the impending death. The PALHIV will also not be exposed to hospital-based infectious diseases. PALHIV get an opportunity to spend their final days at home. Family and relatives can take care of the PALHIV while attending to other chores. In addition, many people prefer HBC to a hospital, as can be deduced from a study in the UK where 56%-74% of critically ill patients who were dying in hospital indicated that they would have preferred to die at home (Leake 2009; Uys & Cameron 2003:5).

According to Sepulveda, Marlin, Yoshida and Ullrich (2002:93), situations in various countries differ as far as HBC programmes are concerned. Traditions and cultures also differ as far as home-based care is concerned, and so does the framework of the existing health care services into which home-based care should fit.

2.4.2 Historical and geographical overview of Home-based care

HBC has a long history and has changed in the last 200 years in various countries. In New York, where it is called 'home health nursing', it dates back to 1813 with the first organised visiting nursing work provided by the Ladies Benevolent Society of Charleston, South Carolina. In 1909 the Metropolitan Life insurance company began offering nursing services to its policy holders in the

USA and Canada. Nursing care was regulated by Medicare in 1966, and reimbursement mechanisms were established for the services. In 1967 there were 1 753 home health agencies in the United States. By 1980 there was a dramatic increase in the patients needing home health services. By 1994 the 7 521 Medicare certified home health agencies were reported signified a 429% growth in 28 years (Grindel-Waggoner 1999:1).

In developing countries HBC programmes were initiated and implemented by churches and other faith-based organisations (FBOs). In Uganda it started in 1997 when an AIDS Supply organisation was founded and assisted in developing its community-based treatment. In recent years there are organisations such as The AIDS Support Organisation (TASO), which have trained volunteers who provide a range of services such as HBC and the management of opportunistic diseases (Bharat & Mahendra 2007:94). In South Africa, prior to 1990, HBC programmes were largely nonexistent - which means that the majority of HBC programmes in existence have emerged since 1990 (Naidu 2005:6).

Initially, most HBCs programmes were established through unsystematic, need-based efforts. In recent years they have become more structured and in most countries that remain in the forefront of service delivery, some of their activities include delivery of treatment, care and support to PALHIV (UNAIDS 2006:215). Consideration of expansion and scaling up such programmes is underway to cater for the ever-increasing needs of PALHIV (WHO 2002:8). In recent years HBC has broadened and provides many services that vary from country to country worldwide (UNAIDS [sa]:2), as the following examples demonstrate.

In India the HIV/AIDS Alliance supports NGOs to provide community-based care for PALHIV, as well as for children affected by AIDS. The programme

provides psycho-social support, health care, voluntary counselling and testing, economic and food support, as well as skills training (UNAIDS [sa]:2).

In Guinea there is a network of volunteers providing community home-based counselling and support for PALHIV. At any given time, between 50 and 60 volunteers are visiting people with HIV/AIDS in their home villages and providing counselling as well as practical care and support. Volunteers undergo two weeks of training, followed by follow-up workshops (WHO 2002:41).

In Vietnam there is the Vietnam Women's Union which is involved with women caregivers affected by AIDS. It is an organisation that encourages and supports older women caregivers in their communities. The organisation has improved the lives of those providing care and of their families (UNAIDS [sa]:2).

Partners in Health and the Haitian Study Group on Kaposi's Sarcoma and Opportunistic Infections were the first organisations in Haiti to offer antiretroviral therapy, and NGOs still care for the majority of the people on antiretroviral drugs (UNAIDS 2006:210).

In Kenya there is an AIDS support organisation called Women Fighting AIDS (WOFAK), which consists of some 3 000 women, and supports caregivers who are providing home-based care. The caregivers offer nursing care, nutritional support, counselling, and education for family members and communities. This organisation is largely run by women living with HIV (UNAIDS [sa]:2).

In Mozambique older women have established support groups, called Older People's Committees, to reduce the cost of care and increase their income. Money raised from small businesses is placed into a social fund which is run by such Older People's Committees (UNAIDS [sa]:2).

In Ethiopia, the Integrated Service for AIDS Prevention and Support Organisation has helped minimise the risk of HIV infection amongst commercial sex workers. In 2006 more than 1000 women have been reached through activities such as awareness raising and behavioural change, and more than 200 of them had left sex work to run small business (UNAIDS 2006:211).

The government of Swaziland, through the grant from the Global Fund to Fight AIDS, pays a minimal stipend to caregivers, largely women, who provide support to people living with TB, malaria and HIV (UNAIDS [sa]:2).

In a review of 26 palliative care service organisations in sub-Saharan Africa, UNAIDS (2006:176) found that hospital-based palliative care is virtually nonexistent in the region because of the high costs and the low priority it is accorded in the overall health system. Most HBC programmes have proven to be excellent sources of palliative support for PALHIV, but unfortunately access to such care is difficult – especially in rural areas, although this varies from one area to another.

According to Joubert (2005:29), the White Paper for Social Welfare in South Africa states that home-based, family oriented and community care strategies are the preferred options for coping with the need for care and the psycho-social consequences of HIV/AIDS. The South African government has funded the development of home- and community-based care, the training of caregivers, and the provision of home-based care kits to caregivers. All these are also included in the official strategies to improve HIV/AIDS care and reduce the burden experienced by the hospitals, and form a way of prioritising care of PALHIV at home.

Home-based care has made a positive impact over the years in the HIV/AIDS arena, especially in South Africa. Without home-based care, hospitals would be vulnerable and overburdened, thereby compromising the health of PALHIV. There is however, a need to strengthen the home-based programmes for even better results through provision of the necessary resources.

2.5 Caregivers

Greene (2008:1) defines a caregiver as anyone who provides help to another person in need. There are various descriptions given of various types of caregivers, which differ from country to country and from institution to institution. Different scholars use different names to define them such as carers, caregivers, community caregivers, health workers and home-based caregivers. All these different names in essence carry the same description as the one mentioned by Greene. The difference may only be the location of the patient, for example, at home or at a hospice. Some of the caregivers are unpaid, unaccounted for and undervalued, despite their contribution. Many caregivers are poor, have large families or are living with HIV themselves and are thereby increasing their susceptibility to the virus, which contributes to their difficulties in coping with their work. Donors provide financial contributions towards communities, who are the implementers of home-based programmes through HBCGs who provide care to PALHIV to mitigate the impact of HIV/AIDS (France 2008:1; Jackson 2002:250).

A distinction between two main types of caregivers should be highlighted for the purposes of this study, namely formal and informal caregivers (Primo 2007:20).

Formal caregivers include professionals and specialists such as physicians, pharmacists, medical social workers, occupational and speech therapists, doctors and nurses. This category of caregivers also include trained volunteers, spiritual

volunteers, spiritual counsellors associated with AIDS service organisations, AIDS care teams and hospice programmes.

Informal caregivers comprise relatives, spouses or partners and friends who provide at-home care on an unpaid basis. They are in some cases not trained at all, or have received very little training. Respected traditional healers in various communities, especially in sub-Saharan Africa, also provide care for PALHIV. This study, which focuses on CHBCGs, refers to the former category, namely formal caregivers.

2.6 Dominance of women in the caring role

Throughout the world it is mostly women who carry the burden of caring for sick people, including PALHIV. According to Mohammad and Gikonyo (2005:4), the burden of caring for PALHIV rests disproportionately with women, including girls and grandmothers, as primary caregivers and volunteers. This is evident in cases where PALHIV are released from hospitals; they are then normally cared for by women in the communities or at home.

According to Ankitola (2004:1), caregiving tasks are often delegated to children, particularly girls, or, in the case of single-parent households, a child or a girl has to be the primary caregiver (informal caregivers). Studies on caring for PALHIV such as the one conducted by Bharat and Mahendra (2007:94) reported that in under-resourced countries hardest hit by HIV/AIDS, 90% of the care for PALHIV is provided by young girls and women – and they receive no financial compensation for the services provided. These women are at times depressed, sexually exploited and physically abused. According to Leake (2009:2), a study conducted in South Africa reported that over two thirds of family caregivers (in this study referred to as informal caregivers) in households affected by HIV/AIDS were women and girls – which confirms the dominance of women in

caring for the sick. Another study by Homan, Searle, Esu-Williams, Aquirre, Mafata, Meidany *et al.* (2005:4) showed that the vast majority of the respondents (formal caregivers in this case) were reported to be women, with 20% of these caregivers over 55 years of age and 43% 26-45 years of age. This indicates that caregiving for PALHIV includes adult women of all ages.

This gendered nature of the caring role was well captured by Nelson Mandela in this statement, “Women don’t only bear the burden of HIV/AIDS infections; they also bear the burden of HIV care. Grandmothers are looking after their children. Women are caring for their dying husbands. Children are looking after dying parents and surviving siblings” (Mandela 2005).

With this dominance of women in caregiving, it is important that men should be encouraged to become members of home-based caregiving teams. This gender balance is very important in providing care, especially to men who are very ill. According to Leake (2009), caregivers may risk their physical health – for example, when they are assisting a patient who is heavier than themselves with simple tasks such as getting out of bed, moving around and so on.

2.7 Roles and responsibilities of HBCGs

HBCGs see the reality of HIV/AIDS in their area of work and yet strive to ensure that infected and affected people can live with hope and dignity to face the challenge of living with the epidemic, from the time of infection to their eventual death. This is done through provision of medical, emotional and physical support to PALHIV and their families, including sustainable relations in the community. They also provide psycho-social support to the families of PALHIV (France 2008:1; Sardiwalla 2004:2).

2.7.1 Physical care

HBCGs provide basic nursing care and comfort measures such as symptom recognition, diagnosis, treatment, symptom management, referral and follow up. Basic nursing care include positioning and mobility, bathing, wound cleaning, skin care, oral hygiene, adequate ventilation, and guidance and support for adequate nutrition. They furthermore identify situations where adequate caregiving such as basic needs of shelter, food, bedding and clothes is not provided (WHO 2002:35).

2.7.2 Palliative care

HBCGs also provide palliative care, which involves a combination of active and compassionate long-term therapies intended to comfort and support individuals and families living with a life threatening illness. The HBCGs strive to meet the physical, psychological, social and spiritual needs of PALHIV, a task that requires a team approach and that includes the patient, family, health and social welfare workers as well as the HBCG (WHO 2002:36).

They also assist PALHIV with running of errands, recreational services, companionship, transportation, in-patient services, clerical work, conference participation, public speaking, and counselling among other duties, to lighten the burden of the disease on the client and family. They also accompany the patient to the hospital to obtain medical treatment and negotiate for what they perceive as appropriate treatment based on their experience (France 2008:1; Jackson 2007:22; Makoae & Jubber 2008:41; Sardiwalla 2004:3; WHO 2002).

In a survey of home-based care patients in Malawi, about 15% of PALHIV were healthy and not showing visible signs of HIV. More than one third needed help bathing and walking, and about 28% needed help going to the toilet. In another study in South Africa about 16-17% of PALHIV could not control their bladder or

bowels, and needed help getting on and off the toilet. A similar proportion required help in bathing themselves. Given the debilitating effect of HIV/AIDS, a certain percentage of PALHIV may need assistance performing the simple tasks that most of us take for granted, and they are often assisted by HBCGs. These are some of the roles and responsibilities HBCGs have to perform under dire circumstances, for example, where there is poor sanitation. In a South African survey it was found that less than half of the households had a tap and only 20% of rural homes had access to a flush toilet, with a quarter having no access to any form of toilet or latrine (Leake 2009:2), which does not make roles and responsibilities any easier. All these factors make it difficult for the HBCGs to optimally fulfil their roles and responsibilities.

According to Jackson (2002:249), the role of caring for PALHIV is very difficult, even to the point where a caregiver may end up feeling a sense of failure, inadequacy, resentment and anger, which will be discussed under section 2.10 below. The care role is made more difficult by the fact that PALHIV may get sick, recover, become ill with something else, again recover, and so on. This could be an endless, confusing circle which can be emotionally exhausting to both the caregiver and the patient.

In summary, the roles and responsibilities of HBCGs are to provide basic care and assistance deemed necessary by the conditions of the client. The support HBCGs provide varies widely and depends on the needs and availability of resources.

2.8 Motivation of caring for PALHIV

HBCGs have various motivating factors that keep them providing services to PALHIV, despite various challenges that they come across within this profession. It is important that organisations that depend on HBCGs understand their

motivation and expectations as this can assist these organisations to make adjustments that would allow them to sustain a stronger and longer serving staff base.

2.8.1 Pure altruism

According to Jackson (2002: 211) community work has become a culture which is well instilled in most African communities and the impact of HIV/AIDS shows effectiveness of this culture. As more people are dying in the communities, some compassionate community members find it difficult to turn a blind eye to ailing fellow community members in need of help, therefore they volunteer to provide assistance, although this is not a consistent practice but rather a personal choice on the part of the volunteer. Most caregivers in a study by Akintola (2004) mentioned that their primary reason for providing services to those who are in need, is their love and empathy for the sick.

2.8.2 Unemployment

Unemployment is often one of the reasons for volunteering in caregiving, as people often have enough time to spare and they feel they would rather spend their time engaging in something productive and meaningful such as caregiving. According to Akintola (2004), the caregivers find themselves so absorbed in their work of caregiving and they enjoy it so much that they find it difficult to quit, even if other job opportunities are a possibility.

2.8.3 Hope for reward and reciprocity

HBCGs hope that they will be cared for if they were to have similar needs in future. Some hope that the government might recognise the kind of difference they are making and reward them financially, especially in a case where HBCGs receive no financial reward at all (Akintola 2004).

2.8.4 Religious considerations

Some HBCGs feel that it is noble to volunteer, more synonymous with doing God's work. They see their role as HBCGs as an enactment on the image of God, therefore giving them a closer link to Him. "There are days when I praise Him, and I can keep going. I know this is what He wants. This is what I must do," as is said in one of the case studies mentioned in WHO (2002:71) – which clearly indicates that HBCGs view this service as a religious obligation.

2.8.5 Experience of HIV/AIDS in the family

Many HBCGs have experienced HIV/AIDS in their own household and therefore feel the need to acquire the skills to deal with the situation. Some of the people who enrol as HBCGs recognise the need to give adequate supportive care to PALHIV, because of the chronic nature of the disease and the complex nature of the activities that are required to care properly for the sick (Akintola 2004).

2.8.6 Hope of securing employment

Some HBCGs who volunteer their services to caring for PALHIV, do so in the hope of securing a job, even though this is not explicitly expressed. Some of them receive a stipend to cover some of their expenses, and some do not as this depends on the availability of funds for the programme. In situations where funding is minimal, volunteers receive incentives such as biscuits, soap, or cosmetics, which have been donated by the programme (Akintola 2004).

A HBCG can thus be motivated by a number of reasons to take up the challenges of caring for PALHIV that ensures the provision of these much needed services.

2.9 Challenges faced by HBCGs

HBCGs are faced by many challenges emanating from caring for PALHIV. Caring for PALHIV is associated with high levels of stress, burnout, anxiety, and

financial burden, and can be very draining – physically, emotionally and psychologically as well as socially. Both caregivers and PALHIV are faced with challenges such as continuous physical and psychological deterioration, their own mortality and the fear of contagion and death. This can challenge a caregiver’s ability to cope. If they do not learn how to care for themselves, they will not survive the onslaught of the HIV pandemic (Akintola 2004; Van Dyk 2001:282).

2.9.1 Stress and burnout

According to Van Dyk (2001:283), burnout can be defined as a syndrome of physical and emotional exhaustion involving the development of a negative self-concept, negative job attitudes, and loss of concern and feeling for clients.

According to Gueritault-Chalvin *et al.* (2000:149), occupational burnout may occur where work demands – especially those of an interpersonal nature – lead to chronic emotional exhaustion, depersonalisation and a reduced sense of personal accomplishment, such as may happen when caring for PALHIV.

HBCGs work very closely with PALHIV who are dying and this can leave them emotionally and physically drained. According to Ross, Greenfield and Bennet, (1999:729), emotional overload brings unhappiness, over-involvement, exposure to others’ grief, death of a client and a feeling of helplessness on the part of the caregiver. When HBCGs feel emotionally stressed they therefore face work-related stress, which leaves them very susceptible to symptoms of burnout such as loss of interest in and commitment to work, a lack of job satisfaction, not being punctual and neglecting duties, a loss of sensitivity in dealing with clients or patients, referring to clients in a dehumanised or purely impersonal way, avoidance of clients to limit the time spent with them and frequently but unnecessarily referring clients to other health care professionals, deteriorating

relationships with colleagues and friends, tension and distress in their personal life as well as difficulties in getting on with people. These symptoms can lead to a high level of turnover, absenteeism, and reduced productivity, which impact on the general running of the organisation (Jackson 2002:253; Pendukeni 2004:14; WHO 2002:420).

When HBCGs begin to feel that they are not supported, it often leads to burnout. If burnout is not controlled it may lead to depression, which will make them feel despondent and will affect the caregiver's ability to provide optimal care to PALHIV. Depression in the context of HIV is caused by many factors including a feeling of a lack of control over one's fate, changes in a person's self-image, and exposure to stigma. (Simpson 2006:8; Uys & Cameron 2003; WHO 2002:40).

A study by Demmer (2004:524) provided evidence that younger caregivers for PALHIV are more likely to experience burnout than older workers. This may be due to lack of experience as well as to being over-involved in the job. There is no significant difference in burnout based on marital status and sexual orientation in HIV caregiving or a person's occupational role.

The following has been found in different African countries: a study in Zambia reported that, despite the fact that health workers were still relatively motivated, emotional exhaustion occurred among 62% of the respondents who took part in the study (Dieleman, Biemba, Mphuka, Schinga-Sichali, Sissolak, Van der Kwaak *et al.* 2007:1). In one Namibian study, mentioned in Pendukeni (2004:14), it was found that nurses were not prepared to deal with PALHIV, and as a result looked for reasons to stay away from work – clearly confirming that stress leads to absenteeism.

Workload also contributes to burnout. According to the study conducted by Dieleman *et al.* (2007:1) in Zambia, HIV/AIDS has had a negative impact on the workload of carers and has considerably changed or added tasks to an already overburdened health sector. Gueritault-Chalvin *et al.*'s (2000:158) research reported that the perceived workload was positively correlated to burnout, and even significantly predicted burnout.

Stress leads to frustration as a result of HBCGs' lack of knowledge and skills in dealing with patients, work demand, lack of competence, and as a result also of their hiding their true feelings, emotions and fear. This could be as a result of a lack of training or understanding in respect of professional conduct and accountability, indicating a need to strengthen monitoring and supervision of the HBCGs (Jackson 2007:76; Pendukeni 2004:14).

According to WHO (2002:71), a HBCG from Namibia, described the stress they undergo as carers and their ways of dealing with such stress in the following manner, "I think of our work like holding up a candle of hope to other people. But unless we protect that candle, it will burn out." This shows that certain HBCGs recognise that they need to care for themselves lest they burn out.

According to Primo (2007:22), caregiver stress can be divided into primary and secondary stress. Primary stress comes from the everyday duties of a caregiver such as assisting a patient with bathing, toileting and managing the patient's difficult behaviour as well as the planning of daily care. Secondary stress emanates from the caregiver's conflict with other family members (own family or the family of the patient).

Stress and burnout affect caregivers providing care to patients suffering from various chronic diseases such as cancer and dementia. When considering

whether AIDS caregivers experience more burnout than those caring for patients with other chronic diseases, contradictory results are reported. According to Gueritault-Chalvin *et al.* (2000:150), research on cancer showed that other caregivers experienced similar stress-producing activities as AIDS caregivers. There was no difference in the level of burnout experienced by both cancer and AIDS caregivers. On the contrary, Demmer (2004) highlighted that in countries such as Germany and Italy, the caregivers of PALHIV were more prone to burnout than caregivers working in fields such as oncology.

According to Gueritault-Chalvin *et al.* (2000:158), more research on burnout indicated that health workers who have more concentrated exposure to HIV/AIDS may be more likely to experience burnout.

2.9.2 Physical effects

According to Primo (2007:22), caregiving is burdensome and may compromise a caregiver's health. Symptoms of poor physical health are markedly present among AIDS caregivers and are associated with care-related demands and stressors.

The level of depression among caregivers strongly correlates with different physical ailments. The multiple tasks they perform often result in neglecting their own self-care, such as nutrition, exercise, socialising and sleep. They develop detrimental health behaviour such as overeating, smoking, not exercising and disturbed sleep patterns (they sleep less than non-caregivers). Consequent to detrimental health behaviour, certain caregivers, especially women, gain weight, their immune system weakens and the healing of their wounds are often affected. One study mentioned by Leake (2009) found that most caregivers suffered physically as a result of caring and experience headaches, body aches, backaches and exhaustion as common problems.

2.9.3 Financial aspects

In a study by Jackson (2007:76), finance was one of the challenges experienced by HBCGs as their stipend included transport to see a doctor, and transporting patients to hospital, for example. Some therefore leave caregiving after having received training, as they often do not receive any stipend or it is not sufficient to cover their needs and those of their patients. This challenge can be categorised as secondary stressors (economic hardships), which may include loss of employment and income, as highlighted in Primo (2007:22).

2.9.4 Stigma and discrimination

According to Van Dyk (2001:284), and Friedland, Renwick and McColl (1996:16), both infected and uninfected HBCGs working in the HIV/AIDS arena are stigmatised. According to WHO (2002:40), for PALHIV and their family members, the stigma, fear and discrimination often associated with the illness can create barriers to effective care. This was reported in a study mentioned in a WHO report, which revealed isolation, fear and discrimination as common themes that were related to HIV/AIDS. The study also acknowledged that teaching health and social service personnel about universal precautions is not sufficient to reduce stigma behaviour (WHO 2002:49). HBCGs on the other hand are at times avoided or ostracised because they work with PALHIV, and therefore they are deprived of much needed support.

Stigmatisation amongst colleagues working with PALHIV is another challenge faced by HBCGs. Research indicates that employers and employees often discriminate against workers who are suspected to be or confirmed to be HIV-positive. This behaviour emanates from ignorance about the facts around HIV transmission and the progression of the disease, fear by employers or superiors of reduction in productivity and profits, as well as fear of stigmatisation of the organisation in the event that clients get to know workers are positive

(Pendukeni 2004:17). There is still a lot to do to change the attitudes of people towards PALHIV.

2.9.5 Attachment

According to Bennett, Ross and Sunderland (1996:145), many HIV carers expressed fear of getting too involved or attached to their patients and forming close relationships with them. They try to avoid closeness because of the imminent death of the PALHIV.

2.9.6 Risk of contracting the disease

Many studies, such as Primo (2007), Pendukeni (2004) and Dieleman *et al.* (2007), have identified contagion as one of the serious concerns among HBGC. One major stress-producing concern shared by many AIDS workers is anxiety over safety practices and fear of occupational contagion, rooted in occupational exposures to HIV. According to a study conducted by Pendukeni (2004), the nurses in her study expressed fear of contagion not only from the PALHIV but also from their colleagues, as is well described by one the respondents: "I am scared of getting the HIV virus not only from the patients but from colleagues as well. I know I cannot contract it from sharing cups, and so on, but some colleagues have open wounds and some oozing rushes from the lips and all over the face."

This fear is exacerbated by the difficulties experienced in maintaining consistent and appropriate infection control precautions. HBCGs may also harbour irrational fears of contagion taking place through casual contact, or touching utensils used by a PALHIV, despite their knowledge of the facts about HIV/AIDS. This fear can consequently cause physical or empathetic withdrawal from persons with HIV/AIDS, resulting in deprivation of physical and emotional contact with the PALHIV, which is the most valuable intervention. In

another study of caregivers in Zambia, more than 75% of the respondents expressed fear of infection in the workplace, despite the fact that there are protective measures in place (Dieleman *et al.* 2007:1). According to Leake (2009:5), close contact with patients' faeces, vomit and other bodily fluids create the risk of HIV and tuberculosis infection for the caregiver. The risk is exacerbated by not taking precautionary measures such as wearing rubber gloves. However, even though there are anecdotal reports of caregivers becoming infected with HIV in this manner, there is little documented evidence of this (Gueritault-Chalvin *et al.* 2000:150; Pendukeni 2004:18; Primo 2007:25). In a study by Demmer (2004:526) it was found that there was a higher score on burnout among the HBCGs who experienced fear of contagion as well as those feeling discomfort in dealing with injection drug users and PALHIV (unfortunately this article by Demmer does not state clearly as to where the study was conducted).

2.9.7 Confidentiality and autonomy

Confidentiality is one of the challenges faced by HBCGs. According to Makoe and Jubber (2008:37), confidentiality has mainly been considered from the perspective of protection of PALHIV from stigmatisation; however, this contradicts the fundamental values of shared responsibility in informing other sexual partner/s so that they can practise safe sex (WHO 2002:48). WHO (2002:42) mentions that some PALHIV do not want their families, including their spouses or sexual partners, to know their diagnosis and the HBCGs should agree to this as it is the human rights of the patient/s. This is evident in the study by Primo (2007:25), which reported that HBCGs are often designated as the "keepers of secrets". The keeping of secrets not only depletes emotional energy and causes inner conflict and isolation, but also affects the ability to provide a professional relationship.

Some patients cared for by HBCGs present obvious symptoms of opportunistic infections but refuse to test for HIV, and the HBCGs cannot force them. All these ethical dilemmas, together with a lack of appropriate community resources and facilities, can make a HBCG in the field of HIV/AIDS experience a sense of inadequacy and exacerbate their difficulty in coping with their work (Primo 2007:26).

2.9.8 Human sexuality

According to Primo (2007:24), HBGCs struggle with discussions on issues of sexuality with PALHIV, especially because HIV/AIDS is contracted sexually. This discomfort that HBCGs suffer can lead to inadequate sexual history recording, which is necessary for diagnosis and treatment of the PALHIV. The lack of information makes it difficult for the caregiver to respond adequately to the needs of the patient, thereby compromising the quality of care that the patient can receive.

2.9.9 Workload

Health professionals can no longer provide adequate care to patients in public hospitals due to the workload, which is exacerbated by staff absenteeism, attrition resulting from resignations and HIV/AIDS-related deaths. At a time when the efficient staffing levels of the workforce are compromised by HIV, the demand for HBCGs' services continues to rise, especially from PALHIV.

This section has highlighted different types of challenges that HBCGs go through as they provide care to PALHIV. Delays and difficulty in dealing with these challenges can affect the quality of care that they provide to PALHIV.

2.10 Social support of HBCGs

Caregiving takes an enormous physical, psychological and economic toll on its providers, for they have to deal with multiple deaths of their patients, as mentioned in Uys and Cameron (2003). They therefore need more access to psycho-social support and economic assistance to help them sustain this physically and emotionally draining, yet vitally important service (UNAIDS [sa]). However, providing emotional support is very difficult for HBCGs if they do not feel supported themselves (WHO 2002:40). Without support they may experience burnout and it will be difficult for them to give compassionate care (Uys & Cameron 2003:28). It is therefore important that caregivers should become proactive and try to guard against potential stressors that could lead to difficulty in coping with work. According to Jackson (2002:250), caregivers need to know when to seek professional help, and to have access to spiritual and counselling support to help them and the patient cope emotionally. A professional relationship in the workplace is also documented to reduce stress at work, therefore enabling coping (Pendukeni 2004:16). Primo (2007:29) points out that through talking, sharing feelings or releasing them through crying, laughing, dancing together with other caregivers as they have the same work demands, can help one to cope better with feelings such as isolation, anger, sadness or grief. Social workers are able to connect to caregivers so that they can form spiritual and counselling support groups. The caregiver's mental and physical health is vital to the PALHIV, making it critical that the caregiver must be able to strike a balance between taking care of him-/herself first, so as to be able to take care of other people. This can be done through rest and exercise, enough sleep and eating well.

According to WHO (2002:49), the HBCGs need to be provided with an opportunity to express their fear, uncertainties and prejudices provided by the organisation they work for. The organisation must ensure that the environment

is conducive for the HBCGs to express themselves. In this way they can overcome negative emotions and learn more about the experiences and challenges facing PALHIV.

A study by Dieleman *et al.* (2007:1) reported that organisational support for caregivers to deal with HIV/AIDS was either haphazardly employed or not in place at all. Demmer (2004:525), in his article on health care workers, mentions that it is important for the caregivers to feel that their organisation or institution is supportive, that it values their contributions and cares about their well-being, listens to their complaints, helps them with their work-related problems and treats them fairly. Less organisational support, including a lack of support from supervisors and colleagues, is linked to burnout. Support can be in the form of clear policy guidelines, standards and regulations to govern the HBCGs (Jackson 2007:23), and which are well understood by the HBCGs. These can be well understood if the HBCGs themselves become part of the process of their development. Adequate resources such as staff, education, equipment and finance need to be made available to ensure successful implementation of such policies and guidelines (Uys & Cameron 2003). This emphasises that staff support by the employer may reduce the stress and burnout experienced by caregivers for PALHIV (Pendukeni 2004:16). The more support gained, the more PALHIV begin to open up to others and thereby learn to cope more efficiently and gain more strength and wisdom through the support of others. Recognition and reward from supervisors are known to act as buffers against stressors.

2.11 Summary

This chapter has covered the theoretical orientation by Lazarus and Folkman on coping; coping was discussed as a process, as well as coping strategies, complemented by previous research on coping.

There is ample research that indicates that caregivers experience many challenges, particularly stress and burnout. Their reactions include emotional exhaustion, despair, depression and helplessness. Many studies on stress and burnout of caregivers have focused more on the negative and difficult aspects of work done by HBCGs, and reward of care and motivating factors that keep HBCGs doing this work are not fully considered. The literature however, acknowledges that caregiving is demanding but rewarding and is dominated by women – hence the presence of challenges and the motivation to care for PALHIV. There is acknowledgement and recognition of what organisations need to do to support and help HBCGs with their work.

It is clear that most studies on coping regard stress and burnout as major challenges that influence the choice of strategies the HBCGs opt for to deal with the challenges they encounter during the course of their work. Mostly studies focus on coping strategies of health workers in hospitals, or of HIV/AIDS patients, but seldom on HBCGs in a HBCC, especially in townships. In light of the above, this study will focus specifically on the Mamelodi township.

The next chapter will cover the research methodology employed in this study.

CHAPTER THREE: METHODOLOGY

3.1 Introduction

This chapter will present the research methodology employed in this study. It focuses on the research design, which is qualitative in nature, and provides information about the sampling method used. The process of data collection through observation and interviews as methods of collecting data are discussed. This chapter further gives a detailed discussion of the data analysis and the relevant themes that emerged during this process.

The last sections of this chapter cover the limitations of the study and relevant ethical considerations pertaining to the study, as well as the rights of the research participants during the study.

3.2 Research design

This study follows a qualitative research paradigm, which is considered the most suitable method as it may provide explanations on how HBCGs deal with challenges they are faced with when providing care for PALHIV, by conducting detailed examinations of their challenging work experience that arises in a natural flow of social life. It further has the potential to capture and discover meaning once the researcher becomes immersed in the data (Neuman 2000:123). According to Terre Blanche and Durrheim (1999:42), a qualitative approach collects data in a written or spoken format. In this qualitative investigation, the researcher attempted through observation and in-depth interviews to determine how HBCGs cope with their work, and identified themes with the aim of building a detailed, coherent and consistent picture of their experiences emerging through the data analysis.

3.3 Population and sampling

The particular HBCC (which will not be named to protect the identity of the research participants) in Mamelodi was chosen for a number of reasons. Apart from accessibility to the researcher, the HBCC in Mamelodi has been in existence since 1995 and has expanded its services over the years responding to the needs of the community of Mamelodi. At the centre more than 540 caregivers have been trained and the establishment of other community-based home care groups have been facilitated from here. The variety and depth of services as well as having an established track record made this centre an ideal site for the research. The choice of this setting was also influenced by the suitability of the population.

According to Arkava and Lane (in De Vos, Strydom, Fouché & Delpont 2002:198), 'population' refers to all the potential subjects who have the specific characteristics related to the study. For the purpose of this study, the population was the 35 HBCGs employed in the HBCC in Mamelodi, which is described in the above paragraph. The sample consisted of 13 HBCGs currently in the employment of the HBCC in Mamelodi. This sample was reached by applying the criteria, namely that the participants be caregivers working with PALHIV for three months or longer at this HBCC, and they must be involved in other daily activities of the centre. It was appropriate to use purposive sampling in this study as it is concerned with the construction of a sample which is meaningful, and since the researcher knew the type of characteristics she was looking for in the sample. Purposive sampling is often appropriate to select unique cases that are informative, thus the selection of a specific HBCC for an informative investigation (Mason 2002:124; Neuman 2000:198).

The researcher visited the centre to engage the centre's management regarding the intentions of conducting research at their centre. The centre management accepted the letter of request to conduct research, which is included in Appendix

A (in English and Northern Sotho) as authorisation for the researcher to conduct research at the centre. The researcher was allocated a contact person to assist in coordinating the process of collecting basic information and gaining access to the participants.

Initially the researcher wanted to interview half of the population, which amounted to about 17 HBCGs, but saturation of information was reached earlier, which refers to hearing the same information, repeatedly being reported and no longer learning anything new (De Vos *et al.* 2002:301). In this study, by the time the researcher reached the tenth participant, the pattern of the answers was the same and little new information was shared. Mason (2002:138) argues that the researcher must work out not only when to make sampling decisions but also when to stop sampling. The sample also depended on the willingness of the HBCGs to participate in the study. Only 13 of the 35 HBCGs consented to participate in this study, and nothing new was coming from the interviews. Furthermore, according to Mason (2002: 134), when using purposive sampling, whether or not the sample is large enough to be statistically representative, is insignificant.

3.4 Data collection

Interviews and observation are the two methods of data collection that were used in this study, signifying triangulation to increase the amount of research data and hence increase knowledge (Sarantakas 2005:146), as well as to overcome deficiencies that flow from using one method only (Babbie & Mouton 2001:275-288). Triangulation enhances rigour and generalisation within a qualitative approach.

Qualitative research aims to achieve validity which is considered to be strength of research since it frees data from interference and contamination or variable

manipulation through construction of appropriate method of data collection, which in this study is observation and interviews. Validity of this study was seen through communicative validation which entails the involvement of participants by checking accurate data by using triangulation in order to achieve multiple perspectives and confirm authenticity (Sarantakas 2005:86).

According to Rolfe (2004:305), validity in qualitative studies should be linked to trustworthiness. A study is trustworthy if the reader judges it to be so by validating its credibility and dependability, some of the elements of trustworthiness. Credibility is demonstrated by ensuring that the subjects were accurately identified and described. In this study the identified participants met the identified criteria set by the researcher and have lived the described experiences. Dependability is demonstrated in this study by attempting to account for changing conditions in the coping mechanisms of HBCGs chosen for the study as the setting will always be constructed and difficult to replicate (Marshall & Rossman 1995:143-145).

In-depth interviews were used in this study to allow participants to express their views freely, giving the interviewer an opportunity to probe and request clarity.

3.4.1 In-depth interviews

According to Marshall and Rossman (1995:81), an interview is a useful way of obtaining large amounts of data quickly. In this study, individual interviews were conducted. Babbie and Mouton (2001:289) define an open interview as a data collection method that allows the respondent to speak for him- or herself. Furthermore, immediate follow-up and clarifications are possible with open interviews (Marshall & Rossman 1995:81). An interview guide listing all the key questions asked during the interview is attached as Appendix D (in English and Northern Sotho). The interviews were conducted in an informal manner, which

allowed the researcher to probe and ask for clarification as needed (Babbie & Mouton 2001:326).

3.4.2 Observation

In this study, simple observation was one of the methods used to generate qualitative data. Three days were chosen by the researcher for observation, in consultation with the centre administrator allocated to assist in this study. The following formed part of the factors observed during visits to PALHIV, as recommended by Babbie and Mouton (2001:293):

- Non-verbal behaviour, such as expressive movements which include eye movement/contact, facial expressions, bodily movements, posture, behaviour;
- Surroundings of the household where the patient resides;
- Language used and topics engaged in;
- Duration of engagement in all activities undertaken at the centre; and
- Interaction between staff and patients.

Notes were taken soon after observation took place. Babbie and Mouton (2001:275) highlighted the importance of notes being kept by the researcher to describe the environment under study as well as other relevant observations.

One of the strengths of observation is that social interactions are witnessed first-hand, as it occurs, rather than relying on other people's retrospective account. In this study the data gathered from interviews was verified through observation. It was evident how observation and interview methods can complement each other. Observation produces great rigour when combined with other methods. These are especially valuable as an alternate source of data for enhancing cross-checking, or for triangulation against information gathered through other means, such as interviewing in this study. Observation, when added to other research

yielding depth and breadth, enhances the consistency and validity of a study (Denzin & Lincoln 1994:382). According to Mason (2002:85), the situational dynamics of a setting are never fully reportable by people participating in them, therefore making observation an integral method of gathering data in exploratory studies is recommended.

According to Babbie and Mouton (2001:293), the reasons for using observation as a method is because it forces the observer/researcher to be familiar with the subject under study; he or she is able to notice things that he or she would not have noticed if observation had not been one of the methods of collecting data.

3.4.3 Process of data collection

The first step for the researcher was to arrange a meeting with the centre manager to request permission to do a study at their centre, prior to the actual data collection beginning. The centre manager granted permission by accepting the letter of request to conduct research (see Appendix A, in English and Northern Sotho), and assigned the centre administrator to assist in the coordination of data collection.

The second step was to brief the centre administrator about the purpose of this study, and she expressed and demonstrated eagerness to provide assistance. She arranged a meeting for the researcher where all the caregivers (35) who worked at the HBCC in Mamelodi were present. The researcher explained the purpose of the research and the need for their participating in the study. The research process was explained to them and they were assured that their participation in this research was voluntary, and those who were interested in participating in this research were requested to stay behind and collect the consent forms (see Appendix C, in English and Northern Sotho) and the letter to the participant (see Appendix B, in English and Northern Sotho). The latter gives an overview of

what would be expected of the participants. They were requested to take home, read, sign and return the documents. Then the interviews were conducted. The confidentiality of all information shared with the researcher and the fact that they could withdraw their participation at any point if they felt they could not continue was emphasised.

The centre administrator scheduled appointments over a period of three days with the HBCGs who volunteered to participate in the study, and the researcher conducted the interviews at the Mamelodi HBCC in the meeting room.

All the participants were informed of their ethical rights before commencement of the interview. The interview guide in Appendix D (in English and Northern Sotho) was the research instrument used to conduct the interviews. The average duration of an interview was 40 minutes. All the interviews were audio-taped and recorded to ensure that the data was of good quality and also for the purpose of reference.

During the interviews the researcher mentioned to the participants the need for observation and requested them to take her along to visit their patients if they were comfortable with the idea, and provided their *patients had granted them their consent* to bring someone along. Once all the participants were interviewed, the researcher held another meeting with them to check those who were prepared to assist with observation. Confidentiality was once more emphasised.

Three days were put aside, during which the researcher went to visit patients as an observer accompanied by some of the participants. Seven of the 13 research participants took part in observation. The researcher chose days on which the HBCGs were doing minor activities (e.g. bathing a patient is too intimate for observation), so as to avoid awkwardness between the patient and the HBCG, as

most HBCGs emphasised how self-conscious PALHIV were and how they mostly do not appreciate strangers.

The researcher made notes after every observation activity before proceeding to the next patient. During observation the researcher was introduced to the patients and observed the interaction between the patient and the HBCG. The visits lasted 20 minutes on average.

3.5 Data analysis

According to Marshall and Rossman (1995:111), qualitative data analysis is a process of bringing order, structure and meaning to the mass of collected data. In this study, the data gathered from both interviews and observation was transcribed from tape recordings, views and actions were analysed through various stages of coding, and later categorised into various themes.

3.5.1 Coding

In a qualitative approach, coding helps to organise raw data into categories. It further prevents data from deviating from the original intent, but allows categories to be generated and at the same time allows the researcher to make sense and create meaning from the data. The three types of qualitative coding, which are incremental in nature, were used in this research, namely open, axial and selective coding (Neuman 2000:420).

3.5.1.1 Open coding

According to Neuman (2000:421), when using open coding the researcher reads the field notes repeatedly and look for themes which will be noted and labelled on a note card and highlighted in various colours. In this study, the researcher listened to the audiotaped interviews and typed them, making notes as she progressed. She further read the field notes repeatedly in an attempt to identify

themes; different colours were used to shade various themes, with the same ideas being coded in the same colour.

3.5.1.2 Axial coding

According to Neuman (2000:423), with axial coding the researcher will focus more on the coded themes that were created in open coding. In this study the researcher read through the colour-coded information to check for any misplaced data, thus continuing to organise information into meaningful segments by clustering common factors together, identifying and creating new themes, recording data that was consistent in all the themes, and deleting data that did not add any value.

3.5.1.3 Selective coding

During this last stage the major themes were clearly identified. In this stage the researcher began to analyse the data by comparing and contrasting the themes. For example, the researcher read through the notes to establish the relationship between themes (Neuman 2000:421-423).

3.5.2 Themes

According to Mouton (2005:111), we analyse data by identifying patterns and themes in the data and drawing certain conclusions from them. Themes were developed through the three types of coding found in Neuman (2000), as mentioned above, which assisted the researcher in drawing conclusions based on the findings.

3.6 Data interpretation

The above-mentioned themes were compiled and analysed in the three coding steps explained in section 3.5. The transcribed information was read to identify weak points in the gathered data such as contradictions, prejudices, biases,

underlying meaning, and interpretations were dealt with in the interest of the study (Terre Blanche & Durrheim 1999:144).

According to Mouton (2005:109), the interpretation of data also include that the results and findings of the study be related to the existing theory, which in this study will be the theory by Lazarus and Folkman (1984) on cognitive appraisal, covering the change that occurs as a result of a person having time to reflect on what is happening as well as their own emotional reaction.

3.7 Limitations of the study

This section will be focusing on the limitations of the study found in this dissertation.

3.7.1 Qualitative study

The results of a qualitative approach cannot easily be generalised to other contexts. Yet it creates a deeper understanding of a particular context, as in the interpretation of this study. The qualitative approach further enriches an investigation of this nature by building a detailed, coherent and consistent picture of the experiences of the research participants.

3.7.2 Researcher's bias

It is important for the researcher to try and view the world through the eyes of the participants, although there are disadvantages. The role of the researcher as an outsider is important, but may contain bias, especially when there are differences between the researcher and participants in terms of language, race, culture, beliefs, sex, geographical location, religion, education, professional background and political affiliation, as these may introduce barriers between the researcher and participants (Babbie & Mouton 2001:271; Ritchie, Zwi, Blignault, Bunde-Birouste & Silove 2009:108).

The researcher has an insider and an outsider status and at times it may be difficult to remain neutral and not to impose his/her own ideas/perceptions. If the researcher establishes too strong a relationship as an insider, this will lead to bias and non-credible findings. In the case of this study the researcher did her best to remain neutral by *listening* to the responses of the research participants and probing where needed. She did her best to keep her relationship with the research participants on a professional footing, by contacting them only through the designated coordinator.

Seniority may also affect the responses from the interviewees and may pose a threat to objectivity. In the African culture, for example, a young female researcher cannot speak to an older adult male about sex and related matters, let alone sexually transmitted diseases. This also touches on cultural values and gender, which could make it difficult to gather data. The fact that the researcher was a female was an advantage in this study, as the respondents were all women, and she therefore did not have to deal with cultural issues that are normally present when interviewing African men.

In this research the researcher also played the role of an outsider, because she does not work at the centre, she does not live in Mamelodi, and she has a higher level of formal education than the research participants. There could have been misunderstandings between the researcher and her participants, especially as they might have assumed that she understood things based on a shared racial category, language and knowledge, but she might not have understood certain things and might have made incorrect assumptions. However, it is believed that this type of qualitative research journey will make the researcher more of an insider, as the status of an insider and outsider is fluid (Rabe 2003).

According to Neuman (2000:279), the following can lead to researcher's bias. Firstly the researcher can alter answers, omit or reword questions where answers he or she is looking for are not understood or answered according to expectation. Secondly, failure to probe properly can also lead to researcher's biasness. Thirdly, the interviewer's expectations of a respondent's answers may be influenced by the respondent's appearance, living conditions or other answers. Finally, the interviewer's appearance, tone, attitude, reaction to answers, or comments made outside of the interview schedule, may influence the interviewee's answers. In this study, the researcher did her best to guard against any bias that might compromise the quality of the data.

In this study therefore the tension between being both an insider and an outsider was carefully monitored by trying to present an in-depth perspective, whilst not being biased or partial to singular views. Where there was potential for assumptions, the researcher always clarified by asking more probing questions in person.

3.7.3 Language of interview and translation

The HBCC is situated in a predominantly black township. Northern Sotho was used as a language in communication (it is an African language predominantly used in Mamelodi, therefore mutually intelligible) during the process of data collection, so that the research participants could best express themselves. The language was translated during coding into English. It is acknowledged that translation has pitfalls such as misconstruing meaning. A specialised translator who has a sound knowledge of both English and Northern Sotho was asked to help with the translations. The translation was done together with the researcher, who is also conversant with both languages.

3.7.4 Age category

The targeted HBCGs were limited to adult caregivers working in a HBCC. The HBCGs in the HBCC in Mamelodi were mostly in the 25-45 age category. This age category was relevant for this study because of the maturity and experience of the HBCGs and their ability to articulate coherently.

3.7.5 Time

The data collection process was limited to the period between September 2009 and January 2010, as the researcher had to switch between her office work and collecting data. Only events that took place during this period form part of this study. This time was appropriate for this study as there were few events or trainings from the HBCC, and the HBCGs were able to set time aside to assist the researcher without long delays.

3.7.6 Access

The participants were only accessed after permission was granted by the management of the HBCC in Mamelodi through their centre administrator. Appointments were scheduled to interview participants.

The researcher was aware of the limitations of this study and did her best to deal with them in a responsible manner through consultation with the centre and the research participants wherever needed. The limitations were considered in conjunction with the ethics below to avoid bias on the side of the researcher.

3.8 Ethical considerations

Researchers need to be aware of ethical issues before entering the field (Neuman 2000), especially when dealing with sensitive topics such as those that are HIV/AIDS-related and touch on the emotional and psychological aspects of all human spheres in society. The following ethical issues were considered in this study:

3.8.1 Consent and voluntary participation

The researcher obtained consent from each one of the participants who participated in the study. According to Terre Blanche and Durrheim (1999:66), participants need to receive a full non-technical and clear explanation of what is expected of them so that they can make informed choices to participate voluntarily, or not. An information session was arranged by the centre administrator for the researcher to meet potential participants, where she explained what was expected of them, including all the steps to be followed during the research, and informed them of their right to discontinue their participation at any time despite giving initial consent. They were therefore granted the opportunity to accept or decline their participation in the study, rendering consent on a voluntary and informed basis. Consent forms (in English and Northern Sotho, see Appendix C) were given to all the volunteering participants to fill in and return during interviews. All the participants who were interviewed handed their signed consent forms to the researcher prior to the commencement of the interview.

The participants were also informed that the researcher would always be available if they should need further clarity.

Prior to observation, the participants were requested by the researcher to seek consent from the PALHIV to bring her along during visits.

According to Babbie and Mouton (2001:520), participants must be informed that they should not expect any special rewards in participating in the study. Clarity on that was also provided during the information session, to avoid creating any possible expectations of being rewarded.

3.8.2 No harm to participants

According to Babbie and Mouton (2001:522), social research should never harm or injure people participating in a study. The researcher ensured that the participants were not exposed to any danger. Interviews were held at the centre, an environment they are familiar with and which is also safe. During observations the researcher drove the participants in her car to visit patients, thereby minimising any potential danger they might have been exposed to.

3.8.3 Confidentiality

According to Terre Blanche and Durrheim (1999:68), in the consent form that the participants sign, they must be assured of the parameters of confidentiality of the information they will supply and that will be shared with them during the information session. Part of the information shared with participants during the information session included the confidentiality parameters relevant for this study, which were also included in the consent form in Appendix C (in English and Northern Sotho). In this study no names and addresses are used, HBCGs participating in this study are addressed only as research participants, and pseudonyms are used when referring to them.

3.8.4 UNISA Ethical Committee

This research proposal served before the UNISA Ethical Committee and was given ethical clearance by this committee (see Appendix E), prior to any fieldwork being undertaken.

3.9 Summary

This chapter described the research design and methodology of the study, including the population, sample, data collection, data analysis and ethical considerations.

Chapter 4 discusses the findings of this study.

CHAPTER 4: FINDINGS

4.1 Introduction

This chapter gives a detailed account of the results of the fieldwork of which the methodology was explained in the previous chapter. It presents the study's findings with the following themes: caring experience of HBCGs, their coping mechanisms, their emotional reaction to caring, psycho-social support and challenges experienced in the workplace. The discussion starts with a general orientation to the HBCC that coordinates the activities of the research participants.

4.2 Background of the centre under study

The HBCC under study is a non-profit organisation located in Mamelodi, northeast of Pretoria. It was founded in 1995 by a professional sister and was conceived as a response to the growing need to provide health and home care nursing services to the increasing number of HIV/AIDS patients who were discharged from hospitals due to a lack of facilities and resources. It currently provides home-based care services to PALHIV, HIV-affected families and terminally ill people and their families which include orphans and vulnerable children. This HBCC consists of two sections: one is for HBC specifically, which is the focus of this study, and the other is for Orphans and Vulnerable Children (OVC). It also provides home-based care training services accredited by the Health and Welfare Sector Education and Training Authority. The HBCC in Mamelodi provides support to the Mamelodi community through the help of HBCGs, who first have to undergo training - which is also provided at the centre.

4.3 Services provided by the centre

The following are the services provided by the centre:

4.3.1 Home-based care and support for the chronically and terminally ill

This include regular visits and nursing care for the patients at their homes, counselling to family members in coping with and caring for patients, a referral system for advisory and rehabilitative services (medical services, psycho-social services, the availability of rehabilitation and community care workers, religious groups and peer support groups), and supply of food parcels for those in dire need, linked to a food garden project. The HBCC in Mamelodi also provides bereavement counselling and support to families and assist with the establishment of palliative care support groups within the community.

4.3.2 Social care and support for HIV/AIDS orphans and vulnerable children

This involves assistance with the establishment of child support groups, parental support and guidance for child-headed families, referrals for child support grants, supply of food parcels to those waiting for support grants, and a drop-in centre for orphans and vulnerable children, i.e. those parents who are too ill or, for various other reasons, not capable of looking after their children.

4.3.3 Training and Home-based Care

Vocational training is provided by the centre on home-based care with the aim of building capacity for individuals, families and community support groups in caregiving for sick people. This includes training in nutrition, gardening, first aid and other life skills. All the HBCGs working at the centre have to undergo this training before they are employed, as it is a prerequisite to do this kind of work.

4.3.4 The patients that HBCGs visit

The patients that HBCGs provide care for, live in the community of Mamelodi with their families and do not have anyone else to care for them during the day. Others live with their families who have no interest in their well-being despite their desperate state of health. Their patients include the old and frail, PALHIV of various ages as well as orphans infected and affected by HIV/AIDS.

4.4 Demographic profile of the research participants

HBCGs working for the HBCC in Mamelodi all reside in Mamelodi township and have all undergone training in HBC; some hold a certificate and some do not yet as they have not finished paying for their training. Their daily routine includes meeting every morning at the centre to clock in, pray and then disperse to see their patients in various sections of Mamelodi. They later come back to sign out and report any pressing challenges experienced during the day that needs immediate attention of senior staff members. They receive a monthly stipend of R1100 and R100 for transport.

In Table 1 below is a summary of certain demographic characteristics of the group of the research participants.

Table 1: Demographic and occupational profiles of research participants

Pseudonym	Gender	Age	Years of experience	Previous work experience	Highest std passed	Number of patients
1. Abigail	Female	32	10 years	Petrol attendant for a year	Grade 12	13
2. Ephenia	Female	40	10 years	N/A	Grade 12	10

3. Andronicca	Female	33	10 years	N/A	Grade 11	09
4. Valentino	Female	44	18 months	Post office, mail room as mail distributor	Grade 12	10
5. Raphaela	Female	35	3 months	Fashion design (still does it)	Grade 12	08
6. Cindy	Female	35	1 year	Cleaner and cook for the centre	Grade 12	10
7. Kgaugelo	Female	25	1 year 3 months	N/A	Grade 12	10
8. Jino	Female	25	18 months	Child care for 18 months	Grade 12	09
9. Mamito	Female	37	10 years	Was a volunteer	Grade 12	10
10. May	Female	42	9 months	N/A	Grade 11	08
11. Patience	Female	39	8 years	N/A	Grade 11	10
12. Asnath	Female	35	18 months	Plumbing	Grade 12	10
13. Tamara	Female	32	2 years	child care for 2 years	Grade 11	07

In this study 13 research participants were interviewed and all of them were female. Overall, the HBCC in Mamelodi has 35 female HBCGs in their employment and only one male HBCG. This reflects the overall female

domination of the caring role in the caring profession in South Africa, as it is worldwide. Home-based programmes in South Africa are deemed by Akintola (2004:2) to entrench gender stereotypes due to the traditional roles of women, which explains why caregivers are usually women and young girls.

The majority of the research participants (eight) were in the 30-39 age category, while three were in the 40-49 age category and two in the 20-29 age category. Nine of the research participants have obtained their matric (Grade 12) certificate and the remaining four have passed Grade 11. Five of the research participants have been employed as a HBCG at this particular centre for more than four years, while four of them have been with the centre for more than nine years. Two research participants have been working there for less than a year.

The majority of research participants, namely nine, gave on average care to nine or ten patients per week. Three research participants gave care to five to eight patients, and one research participant gave care to 13 patients- the maximum number of patients in the sample that was interviewed.

Patients registered at the centre to be cared for by the HBCGs are shared among the available HBCGs employed at the centre. If one HBCG resigns, takes maternity leave or is absent for any other reason, his or her patients are shared among the remaining HBCGs.

One of the research participants highlighted the fact that the number of patients that they are providing care for, impacts on the quality of care they can provide. The higher the number of patients they have to provide care for, the higher the chances of quality being compromised. This is in line with certain studies which reported that shortage of staff compromises quality as HBCGs have to adjust to role expansion and bear added responsibilities. This increases the workload

which in return increases the frustration levels of the carer and hence compromises the quality of care (Bharat & Mahendra 2007:103; Pendukeni 2004:53).

Most of the research participants were not employed in any other work before their current position, but if they were, their jobs were most likely related to home-based care. Five of the research participants have not had any previous work experience, three of them are the longest serving HBCGs at the HBCC in Mamelodi with their years of service between 8 and 10 years. Two of the research participants have child care experience, which is another wing within the centre, and the rest of the research participants have had experience unrelated to home-based care, e.g. petrol attendant, cleaner and mail distributor.

It is important to note that three of the research participants had moved from working in the centre kitchen to being a HBCG within the centre. This seems to be an unexpected change since HBC is perceived as offering little opportunities for occupational growth or promotion. It is also interesting to note that there is one research participant who does fashion designing which she pursues on a part-time basis, reflecting that she is not only relying on one job.

4.5 Roles and responsibilities of research participants

The HBGC have various roles and responsibilities that they have to fulfil as they provide service to their patients. In the case of the HBCC in Mamelodi the research participants in this study highlighted the following:

4.5.1 Home-based care

HBC for chronically ill patients is one of their main functions and it includes regular visits and nursing care for patients in their homes, with the HBCG providing services such as:

- bathing and grooming (cutting nails, mouthwash etc);
- 'dotting' (directly observed treatment) for TB patients;
- counselling patients (giving them moral support, encouraging them to go to the clinic);
- assessment of patients' condition;
- massaging and rubbing of patients;
- helping them exercise;
- dressing of wounds;
- educating the patients and families about HIV and caring for the PALHIV.

4.5.2 Referral system

If the centre does not have capacity to assist patients who need additional care, they refer them to other agencies for advisory and rehabilitative services. When the HBCGs identify such patients, they consult the senior staff members who will visit the family for verification and then make a recommendation for referral, based on the incapacity to provide services to that patient. The HBCG will discuss that with the patient first and then the process will follow. Patients needing critical care and hospitalisation are included in this.

4.5.3 Food supplies

The HBCGs supply food parcels for patients who are poor and do not have food at home. The food parcels are made available through donations from various sponsors as well as vegetables from the centre's garden. The vegetable garden is managed by the centre management and taken care of by gardeners employed by the centre; HBCGs have to get approval from centre management before taking the food and vegetables to a patient.

4.5.4 Bereavement counselling and support to family members

HBCGs prepare families for the eventual death of their loved ones, and advise them on steps they could take once that happens. After the death of the patient, the HBCG visits the bereaved family to give them counselling on how to deal with the death of a loved one.

The roles and responsibilities of HBCGs vary from one institution to another and the availability of some HBC services depends on the availability of funds for the programme – and this is often fraught with various challenges. The HBCC in Mamelodi had a hospice which was closed down due to financial constraints, which forced the centre to decentralise some of the services it provides, thereby changing some of the roles and responsibilities of the HBCGs. Similar cases were reported by Akintola (2004:3), who found that most care organisations do not have resources to take on some services and that few care organisations in South Africa have taken into account the need to accommodate the changing needs and demands of their services over time, often because of lack of financial resources.

The HBCC in Mamelodi plays an important role in the battle against HIV/AIDS, which is demonstrated by the successful running of the HBC programme. According to research conducted by Kohler (2008:2), the health sector has been receiving a declining portion of total government expenditure, with the sector's share having fallen from 11,5% in 2000/1 to an estimated 10,5% in 2008/9, although it is set to increase to 10,7% by 2011. Considering the increase in the number of PALHIV, this budgeted increase may not be enough to help the sustainability of NGOs such as this HBCC in Mamelodi.

4.6 Motivation for caregiving

Various reasons have been given for doing this job, ranging from practical financial considerations to expressing enjoyment and love for the work, and many have stated different reasons why they continue caring for PALHIV.

Earning a living is one of the motivations to caregiving, as there is a high unemployment rate and few job opportunities in Mamelodi, with an unemployment rate of 65% (Squidoo 2010:2). This is how a research participant described earning a living to get out of poverty and hunger: *Re hloka mošomo gobane ga re nyake go bolawa ke tlala. "We need to work because we do not want to go hungry"* (May).

Compassion and a desire to help patients who do not have family members to assist them, makes Kgaugelo wake up in the morning and go to work. She feels concern for the patients she provides services to, as she realises that some of them will not survive this battle without her help. These words were said by Kgaugelo: *Ke kwela balwetši bohloko, ntle le rena ba ka se kgone. "I feel sorry for my patients; without us they won't survive."*

A study by Dageid *et al.* (2007:9) found that carers acknowledged that PALHIV need their support and they believe they can make a difference in their lives, as also implied by Jino (one of the research participants). Most of the research participants indicated that they viewed their job as meaningful and important because they were helping community members who were ailing. In a study by Dieleman *et al.* (2007) on HBCGs, research participants reported that their motivation for working with PALHIV was linked to the type of work they did and that they enjoyed taking care of the ailing.

Acquiring skills and experience about health matters is another attraction to this type of work. Tamara indicated that she was compelled to this type of job in home-based care as some of her family members had died from HIV/AIDS, and she felt that she could have helped them better if she had had the expertise during that period of need. That is how she ended up training in HBC. There is, however, the frustration of minimal opportunities for growth at work, especially for the research participants who have worked there for many years. The latter expressed a need to improve their skills and getting better paying jobs in future.

4.7 Caring experience

HBCGs experience many challenges as they provide care to their patients on a daily basis. Some of those experiences are highlighted below.

4.7.1 Disclosure, stigmatisation of PALHIV and confidentiality

PALHIV are facing a challenge of disclosing their status, even to the HBCGs who are caring for them, as it is often conceived as a taboo to be HIV-positive in certain communities and one runs a risk of being stigmatised. A study by Molefe (2009:29) on stigma also reported that few patients reveal their status to their caregivers.

Some PALHIV cared for by research participants do not want the HBCG in uniform visiting them as they do not want neighbours to ask questions and talk about them, but the HBCGs are not allowed to see patients without wearing a uniform. A study by Ehlers (2006) similarly reported that families visited by HBCG might be socially ostracised and stigmatised as “AIDS families”, especially in the cases where HBCGs wear uniforms or T-shirts with AIDS slogans.

Research participants further reported that the neighbours at times interrogate the HBCGs to find out about the purpose of their visits, which most families do not appreciate as it makes them uncomfortable. Some families go to the extent of hiding their patients from curious neighbours and community members. Tamara mentioned that the hospital sometimes allocates HBCGs to new patients whom they have to visit at designated addresses. When the HBCGs visit them, some patients claim that there is no one by that name as they do not want to be associated with HIV/AIDS. They are ashamed of HIV/AIDS and this is stressful for the HBCG as the PALHIV cannot get quality care because of this stigmatisation. This is an indication that PALHIV and their families are subject to prejudice, discrimination and hostility related to the stigma associated with HIV. PALHIV fear being mistreated by their neighbours or community at large, as also reported by Makoae, Greeff, Phetlhu, Uys, Naidoo, Kohi *et al.* (2008:137). However, the HBCGs always have to allow them their right to exercise confidentiality, and provide help where they can. The HBCGs continue to give them counselling and encourage them to take treatment.

It is common practice that PALHIV at times request HBCGs to keep their status a secret and at times they die without disclosing their status, which leaves the HBCG to face the questions raised by the family - and she is bound to still maintain confidentiality. "Keeping secrets is part of my job" (Tamara). This was also found by Ross in Primo (2007), who viewed HBCGs as "keepers of secrets".

As was mentioned in a WHO (2002:42) report and also found in this study, some PALHIV neither want their families to know their diagnosis nor warn their spouses or sexual partners about their status. Such non-disclosure is the right of any person, but it disadvantages other affected people who can benefit from the information to change their behaviour and give the person support. Some patients present symptoms of opportunistic infections but refuse to test for HIV,

and that has to be respected as well. In the case of this study the research participants reported that PALHIV hide their status, despite the visible physical symptoms of the disease and the type of medication they take. *Molwetši yo a nago le HIV a ka se go botše ka diARV, o tla go botša ka kalafo ya TB.* “It is easier for PALHIV to say they are suffering from TB but never from HIV/AIDS – even when they are taking ARVs” (Mamito). PALHIV feel ashamed and do not want to be judged, and therefore they refuse to collect treatment from the clinic or hospital for fear of being seen there by members of the community or neighbours.

This non-disclosure of certain people poses an ethical dilemma for the HBCG as it is also the right of the partner of the patient to know his/her status in order to have the option of starting treatment if they have a positive status. In this case the patient who is exercising his/her own right is violating the partner’s rights. All these ethical dilemmas, together with the lack of appropriate community resources and facilities, are delaying progress in the realisation of comprehensive reproductive health.

The research participants reported that they counsel PALHIV to disclose their status without putting them under pressure. They rather wait for the patient to trust them enough to disclose their status. In all relationships personal or professional discrimination counteracts trust, as mentioned by Molefe (2009:12) and also recorded in this study: *Balwetši ba thoma ba sa re tshepe.* “In the beginning the patients do not trust us” (Tamara).

According to Makoae and Jubber (2008:43), where the status of the patient was shared with the caregiver, the available support from hospitals, community and family was discussed and the patient was encouraged to use the services. Carers who are not given an honest statement by patients of their HIV status have a

very chaotic caregiving experience. Research participants expressed that they feel frustrated and stressed when patients lie about their status and are in denial, as it makes it difficult for the HBCG to help them.

Valentino related how one of her patients, who was bedridden when she began caring for her, was seeking advice on whether she could begin having sex as she was now feeling better and felt that she would have liked to have sex. However, the patient did not know whether to tell the partner or whether to just insist on a condom without disclosing her status. This shows how the issue of disclosure of one's status gives the patient an opportunity to share his or her anxieties with the HBCG and discuss sensitive issues. Had she not disclosed her status, she would not have been able to share this with her carer.

Stigmatisation is still a huge problem since it prevents open statements about HIV status. This in turn poses a problem for caregiving as there are cases where HBCGs are not even given an honest account by their patients of their status. In other cases, the HBCG is asked to keep their status confidential, which can be detrimental to the rights of other people. Universal tolerance of HIV/AIDS needs to be advocated for, through awareness programmes in an attempt to reduce stigmatisation and discrimination.

4.7.2 Dealing with the death of patients

Research participants expressed difficulty in nursing patients whom they knew would neither fully recover nor be cured from their ailments, and would eventually die. They struggled to accept the sufferer's condition. This made certain research participants often feel stressed, although others mentioned that they accepted the condition of their patients.

Research participants experienced conflicting feelings about the death of their patients. Patience mentioned that she did not feel well when one of the patients she was nursing died; she felt stressed and could not cope.

Asnath described the effect of the death of a patient on herself: *Letšatši le lengwe ke ile go mmona, ke humane a ile boyabatho. Taba ye ya dira gore ke se je tše di welago. Ke hlokometše molwetši yo lebakanyana. Ke be ke holofetše gore o tlo mpha nako ya go mo hlokomela pele a ntlogela, mogongwe nkabe a phedile.* “One day I went to see her and found that she had died. This never sat well with me. I treated the patient for a short period of time and felt strongly that the patient could have afforded me a chance to treat and care for her before departing, maybe she would have survived.” Asnath seems to feel guilty and blames herself for the death of her patient.

On the other hand, Cindy mentioned that when a patient dies, life goes on, as she felt that they were relieved from pain.

All these feelings depend on various factors such as the level of attachment between the HBCG and the patient and how they deal with their emotions in relation to their work.

Ke hlokofoletšwe ke molwetši wa HIV a tshwenyegile ka ge a be a tlogetšwe ke mosadi ka lebaka la HIV, o be a ipea molato ka la gore o mo feteditše bolwetši bjo. O be a palelwa ke go amogela maemo a a lego go ona, a fela pelo, a enwa kudu, a sa nwe dihlarare eupša ka lebaka la dikeletšo, o ile a thoma go ntheetša, gomme mafelelong a amogela seo se diragetšego. O be a phela a le bolaong a gateletšwe, ka morago ga go ba kaone, a ba bokoa ka lebaka la go se nwe dihlarare. Lehu la gagwe le ile la ntshwenya kudu moyeng fela go homotša, go kgothatša le go thuša ba lapa la gagwe go ile gwa mpha maatla. “I lost an HIV positive patient who was troubled as he lost his wife to HIV and blamed himself for having infected her. He could not accept his situation; he was moody,

drank a lot and was not taking treatment, but through counselling he started cooperating. He started as a bedridden patient who had various symptoms of HIV/AIDS, but eventually improved, and deteriorated later on as he stopped taking treatment. His death really affected me, but giving his family bereavement counselling and support made me stronger as I was able to deal with my grief" (Valentino).

Most research participants demonstrated a struggle with emotions when it came to dealing with the death of a patient. These emotions include a high level of guilt, self-blame and a feeling that they could have done more for the patients despite admitting that they are aware that their patients will eventually pass on. Related results were found in the study by Primo (2007:26) where carers expressed feelings of anger, depression, frustration and powerlessness for not being able to influence the course of the disease.

4.7.3 Supportive families

The research participants in this study stated that there are families that are very understanding and give full support to their patients. These supportive families get accustomed to having a patient around and want to know more about providing assistance to the patient. They share their feelings and thoughts, and the HBCGs get attached to them as they make their job easier and lighter. The HBCGs then educate and counsel them on giving care to the patient. Some of the research participants indicated that they were well accepted by the patients' families and this gave them a platform to discuss confidential issues such as the cause of the illness, status in life as well as issues affecting the family when caring for a PALHIV. There are some families and patients who would love to see the HBCGs every day and who appreciate their help and always invite them to stay longer. This was also evident during observation when some of the

patients would offer the HBCG tea and complain that their stay is too short. Some family members also write moving letters of gratitude to HBCGs.

According to Makoae *et al.* (2008:144), PALHIV who experienced supportive environments, such as the support of their families, and services provided by non-governmental organisations, such as AIDS training and counselling centres, had success in overcoming the stigma. Counselling and health information has been reported to empower PALHIV to change their risky behaviour and adopt a healthier lifestyle, as was also found in this study.

4.7.4 Patient neglect or abuse by family members

Some of the families of PALHIV view HBCGs as outsiders and refuse to help them in any way. A study by Ehlers (2006) viewed HBCGs as adding value to community but they are also subject to exploitation by patients and their families, as reflected in this section.

There are families who are neither there for the PALHIV nor care for their well-being and are therefore not helpful in ensuring their full recovery. In such cases patients tell the HBCG that they are often the only people to dress their wounds, they bath themselves, and their families do not assist them with anything. This is evident when the HBCGs go for their next visit to find the patients in the same clothes, soiled and in a much worse condition, thereby increasing her workload and the time spent with the particular patient. The following quotes illustrate some of the HBCGs' difficulties when dealing with unsupportive families:

Asnath said: *Ga ba re thuše.* "They do not help us."

Re hwetša balwetši ba robotše, ba palelwa, ra ba hlapiša mmele le meno, re ba retolla ntle le thušo ya ba lelapa. "We find patients asleep and bedridden, bath them entirely, brush their teeth, and turn them over without the assistance of the family" (May).

The following is the image of a patient, as painted by May: *Ke be ke na le molwetši yo a bego a dula ntlongtheikišo ya bjala (ke lefelo la morwagwe). Bana ba gagwe ba be ba amogela tšhelete ya gagwe ya mphiwafela eupša ba be ba sa nyake go mo rekela maleiri le disepa. Ka Mošupologo ge ke etla go ba etela ke humane ba šomiša dipampiri sebakeng sa maleiri. Ke be ke tšwafa go ba etela ge nako ya go ba bona e fihla. Ge a ile boyabatho ke bona a ikhuditše gobane ba lapa ba be ba sa mo fe tlhokomelo ye e swanetšego. Ditaba tša balwetši di gagola pelo, di dira gore o dule o nyamile.* “I had a patient who lived in a shebeen² (her son owned the shebeen). The children were receiving a grant on her behalf but could hardly buy her nappies or any detergents. On Monday when I came to see the patient, I found that the family had used newspapers in the place of nappies. I dreaded going there when the time came. When she died I thought at least she was at peace now, as she had not been treated well by her family. These kinds of things are stressful and make me feel distressed.”

The senior members of staff at the centre tried to intervene, but realised there was little they could do to change the mind-set of the family. In this type of situation the HBCGs can only be encouraged to continue doing their supportive work. They would try their best to cater for the needs of the patient, by for example washing the blankets as the family did not want to wash them, and they just continue with their work without expecting much from the family.

4.7.5 Challenging interactions between HBCGs and patients

This section will highlight some experiences of research participants with difficult patients.

² Shebeen: a place that sells home-brewed and other alcoholic drinks to the public. This term is commonly used in townships in South Africa (*South African Oxford Dictionary* 2004: 412).

HBCGs find that some of the patients are extremely difficult and hard to please and they even have disagreements with them, as Mamito puts it: Balwetši ba AIDS ga ba bonolo go šoma le bona. "PALHIV are difficult."

It has been argued that PALHIV who are in denial may have avoidance tactics that may manifest in behaviour such as social withdrawal, increase in alcohol consumption, or risky behaviour (Dageid *et al.* 2007). This kind of behaviour keeps them from directly dealing with their status. In this study, Raphaela reported how PALHIV struggle to deal with their status and therefore overindulge in alcohol and non-nutritious food such as chocolates, sweets, and high cholesterol food. Such behaviour among PALHIV is believed to be indicative of their battling to accept this disease.

The research participants find some of the patients to be very destructive as they cause conflict between them and the senior staff members by making false claims. Such false claims include complaining and mentioning to management that the HBCG had not come to see them in months, whereas the HBCG prioritises those who are badly in need of their help. HBCGs believe that they do this in the hope to cause conflict, so that the HBCG will stop seeing them. This could be because of the stigma associated with HIV/AIDS and that the neighbours are now beginning to talk, and because the patient is now feeling stronger she/he feels that the HBCG can stop assisting her/him, but does not want to say so directly.

Some PALHIV absolutely refuse to take their medication, saying that they feel worse off and vomit after taking treatment (this is often a side effect when they begin taking ARVs). Others postpone collecting their medication from the clinic, while some miss their regular doses or postpone taking their medication. For

example, one of the PALHIV told the HBCG that she was tired of taking medication and wanted to stop.

There are patients who are moody and not cooperative, even if they are not very critical, and they do not have the willingness to live and help themselves. They just become hopeless and helpless and counselling by HBCGs is to no avail.

Some patients display anger towards the HBCGs by verbally abusing them and chasing them away. Some of these patients are never satisfied with anything given to them. Often this happens if the HBCG does not bring any food for the patient/s. The following is what different research participants had to say about difficult patients: *Ge ke ya go bona ke sa swara dijo ga ba nnyake gomme taba ye e dira gore moya wa ka o ye fase.* “If I do not bring anything to eat they do not want me and this makes me feel down” (Asnath). She often delays going to see such patients until she finds something to take to them.

Balwetši ba bangwe ga ba kgotsofale, ge o ba tlišetša bupi bja batho ba ba lwalang, ba nyaka merogo goba dihlare. Ge o di tliša ba nyaka maleiri, ba phela ba balabala ka se sengwe le se sengwe. “Some of the patients are never satisfied; when you bring them e ‘pap’³, they want vegetables as well, when you bring them ointment, they want nappies and often complain about everything” (Tamara).

Some patients at times do not like it when HBCGs use gloves, as highlighted by Cindy when she said: *Ba re re a ba šišingwa.* “They say we find them disgusting.” Yet HBCGs always use gloves despite such complaints.

³ E’pap: it is precooked fortified food that uses state of the art nutritional chemistry and delivers a food portion with 28 nutrients in a bio-available form. It is a nutritional food supplement and an important support tool for malnourished people to boost their immune system against opportunistic diseases (Cherscot Agencies [sa]).

Balwetši ba bangwe ga ba rate go hlapa, kudu ba ba tšofetšeng le ba ba lwalago kudu. Re gapeletšega go boledišana le bona pele. Ge ba dumela go hlapa, ka nako ba gana go apara diaparo tše di hlwekilego, lebaka la bona ke gore ga ba ye felo. "Other patients do not want to bath, especially the old and frail. We always have to negotiate with them. At times they would bath but want to wear dirty clothes, saying they are not going anywhere so why should they bother to dress in clean clothes" (Cindy).

Jino stated that when the patients are being "difficult", for example when they refuse to take treatment, shout at the HBCG for no reason, or refuse to take a bath, the HBCG coaches and counsels them. In most cases they eventually change their attitude and their condition improves.

Cindy mentioned that she persuades and counsels patients to do what they have to do, for example take medication, by telling them of the benefits of that and how much better they will feel if they take medication consistently. *Balwetši ba ka nako ba gana dihlang ebile ba lwa le wena ge o ba gapeletša. Bao ba ganang go hlapa, ga ke ba gapeletše, ge ba sa rate, ketelong ya ka ye e latelang ba a dumela.* "The patients do not want to take medication at times and they fight you if you force them to ... Those who refuse to bath, I do not force them, they often oblige during the following visit" (Cindy).

There are situations when HBCGs visit a patient and find that most of the family members are bedridden, and it is difficult for them to give care to all of them. The HBCC usually refers them to hospitals, hospices or other agents that can be of assistance in improving their living conditions since they cannot take care of each other. This is often done in consultation with senior staff members at the centre.

It is evident that PALHIV need help from family and HBCGs, but some of them are difficult to handle and /or have indifferent families, which makes caregiving a difficult experience, to their own detriment. This compromises the quality of the care that they can receive.

4.7.6 Use of traditional medicine by PALHIV

In many African settings, traditional healers play an important role in people's health, including in the lives of those affected by HIV/AIDS. Some PALHIV visit traditional healers prior to or concurrently with formal health care. The HBCGs at the HBCC in Mamelodi are at times requested to administer traditional medication.

According to Cindy, a patient once asked her to use traditional medication. Since she was uncomfortable with that, she went to ask her supervisor. The supervisor recommended that she should not become involved in this and accompanied her the following day to see the family and inform them that it is not part of the responsibilities of a HBCG to administer traditional medicine. The family accepted this since they were not agreeing amongst themselves about the use of traditional medication.

Some of the PALHIV seek traditional explanations and treatments for their symptoms as they do not want to be associated with HIV and are willing to try any conceivable approach such as an alternative type of medicine. This is to a great extent influenced by a strong belief in traditional medication, hence the reason for the request by some PALHIV for HBCGs to assist in administering such medicine.

In certain other African countries nurses serve as a bridge between the traditional and the formal (Western) health care system, because nurses are familiar with both these systems. In the case of the HBCC in Mamelodi, the HBCGs are not equipped to deal with such cases because traditional medicine is not integrated in their health practices (Bharat & Mahendra 2007:107; Dageid *et al.* 2008:16; Ehlers 2006:3; Makoae *et al.* 2008). The HBCC in Mamelodi needs to consider integrating the use of traditional medication in caring for PALHIV. This should be done in conjunction with training in that regard.

4.7.7 Fear of contagion

There are clear indications that some of the HBCGs fear contagion and are traumatised by their experiences, but they are not open about it:

Ke a šišingwa, ka nako tše dingwe ge ke nagana ka ditiragalo tša letšatši la ka, gomme ke hlape ka Dettol ge ke fihla gae. “Sometimes when I get home I think of all those things that happened during the day. I take a bath when I get home and use Dettol disinfectant to cleanse myself in case I have contracted some germs” (Cindy).

Apart from the above research participant, the other research participants did not want to discuss this and little openness could be found in this regard.

Fear of contagion is one of the major concerns among HBCGs working in the field of HIV/AIDS. Although it was not explicitly mentioned in this study, it was implied and has been confirmed by studies such as Primo’s (2007:56), where some of the research participants feared that wearing gloves may not provide sufficient protection to prevent infection by HIV/AIDS. Despite the knowledge that HBCGs have about HIV transmission, they still have an irrational fear of contagion which can compromise the quality of care that PALHIV might need,

and which explains why a HBCG can think of using disinfectant when taking a bath after caring for a PALHIV – as mentioned in the paragraph above.

4.7.8 Lack of knowledge

Some research participants expressed difficulty in dealing with complex clinical aspects of the health of their patients such as septic wounds which included bedsores, which do not form part of their training in HBC. This makes it hard for them to give full quality care to the patient. More intensive training about the clinical aspects of caregiving can equip her better to provide a better service and, as they mentioned during the interviews, auxiliary nursing can assist in dealing with some of the clinical problems they encounter.

Ba bangwe ba balwetši ba HIV ba ba swerwego ke bolwetši bja swikiri, maoto a bona a swanelwa ke go ripša, morago ba tšwa dintho mo mmeleng ka lebaka la go phela ba robetše, tšeo di epegago ka morago ga nako, ka ge ba sa hlapišwe le go fetolwa mahlakore nako le nako. Ga ke na tsebo ya go hlapiša, go tlotša le go bofa dintho tše bjalo le go fa molwetši tlhokomelo. Ke bona gore ba hloka tlhokomelo ye e tseneletšego ya dingaka. “PALHIV who have diabetes, some of them their feet have to be cut, and they develop bed sores, which become septic as a result of not being turned regularly. I feel inexperienced to dress such wounds and give full care to the patient, and feel they need more intensive medical attention” (Valentino).

Similarly, in a study by Pendukeni (2004), nurses expressed their frustration from the lack of knowledge in the management of HIV/AIDS patients, and felt that they did not receive enough training to deal with this particular aspect of their work. In this study and the study by Pendukeni, frustration about different aspects of the caring experience is expressed, which indicates a need to close the gaps that seems to be hampering complete care of PALHIV.

Continuous capacity building is vital for HBCGs to refresh their current skills and be equipped with new skills so that they can be able to provide the necessary quality care to their patients. If they are not equipped with the knowledge and skills they need, they will not be able to function too well and the HBC programme will also not succeed (Uys & Cameron 2003). The HBCC in Mamelodi provides regular capacity building refresher courses to keep up with the dynamics of HIV care, but these are not clinical in nature. Where the patient requires clinical intervention they are referred by the HBCG to the hospital or clinic as they are not capacitated to deal with the intensive, clinical aspects of this work.

It is important to note that courses that carers can undergo depend on availability of funds and are at times not as regular as the centre would like them to be.

4.7.9 Poverty

Most PALHIV cared for by HBCGs are unemployed, have poor housing, lack nutritious food and experience many family problems. Some PALHIV do not receive grants, and therefore cannot afford food, making it difficult for them to take medication which must be taken with meals.

4.7.9.1 Effects of poverty on providing care for PALHIV

Hlabyago and Ogunbanjo (2009:509) reported that families in their study with PALHIV and orphans lived in dilapidated, unkept and overcrowded shacks. Although this may not be true universally, as there are those who can afford all they need and do not need financial help, it was certainly true of most of the PALHIV in this study. Often, their family members were unemployed or inexperienced and did not know how to access a social grant. This was also reported in this study by Raphaela: *Malapa a mangwe a re a etelago a tsene ka gare ga*

bodiidi ka hlogo, ga ba kgone go reka dijo gore ba kgone go nwa dihlarere. Ke beakanya le senthara ka ga maemo a tlhokego ya dijo, gomme ke ba išetše bogobe bjoo nka se ba išetšego bjona ketelong ye nngwe le ye nngwe ka ge bo swanetše go abelwa balwetši ka go lekana. E' pap ke ya batho ba PALHIV fela e sego maloko a malapa a bona, ka ge e phagamiša tsela ya go šireletša mebele ya bona kgahlanong le phetetšo ya malwetši.

“Some families that we visit are trapped in poverty and cannot afford food to be able to take medication. I liaise with the centre about the situation and bring them e ‘pap, which I cannot take during every visit as it has to be evenly distributed and is therefore dependent on availability. The e ‘pap is only for PALHIV and not their families, as it boosts their immune system.”

Sometimes, PALHIV do not have toiletries or bathing facilities, because they cannot afford them. The HBCGs make requests from neighbours, if they do not have supplies in their kit. When the centre has received donations to that effect, the HBCGs make requests on behalf of the PALHIV in need and take those along when they visit their patients.

The HBCG encourages the PALHIV and their families to have gardens in their backyards; however, not all PALHIV and their families are willing to take part in this endeavour. There are also companies that come and sponsor the gardens, e.g. SABC gave patients seeds for their gardens.

4.7.9.2 Access to grants

Social grants for PALHIV are problematic as they are stopped once the CD4 count of the PALHIV has picked up, and it is a lengthy process to reinstate it. This leaves the PALHIV poor and unable to afford basic necessities such as food. *Go kgaolela balwetši tšhelete ya mphiwafela ka morago ga kgwedi tše tshela go dira gore mošomo wa ka o be boima ka ge molwetši a ka se fiwe dihlarere a se a je selo. Gantši ke lemoga gore balwetši bao tšhelete ya bona ya mphiwafela e emišitšwego ga ba na le dijo*

tše di lekanetšego ka ntlong. Ge ke na le tšhelete ke fela ke ba rekela borotho. “The cutting of grants for patients after six months makes the work difficult, as a patient cannot be given treatment when hungry. I normally find that those patients whose grants have been cut do not even have food in the house. If I have money I sometimes buy bread for the patient” (Abigail). This problem applies to both adults and children.

Some families collect the grant on behalf of PALHIV but do not buy anything that serves the interest of the PALHIV.

Poverty is observed in most studies on HIV/AIDS, especially in Africa, as many families have become poorer owing to the HIV/AIDS pandemic, as family members are often financially and physically depended on the support of the ailing family member. Such families do not have the knowledge on how to apply for social grants. The research participants in this study reported assisting families and PALHIV with social grant applications. The research participants described below how the lack of grants impacts on their job:

Asnath and Abigail expressed frustration in accessing grants for the PALHIV as such grants are stopped as soon as the PALHIV’s CD4 count picks up – leaving the family in dire poverty unable to afford food. This was also evident during observation when some of the family caregivers expressed their need for the grant because they could not afford electricity and food.

The study by Hlabyago and Ogunbanjo (2009:510) reported that the application for social grants at times takes as long as two years for a submission to be processed. The poorest families rely on social grants and families that are unable to access these grants are the poorest of the poor, who seldom receive financial assistance from other members of the extended family. This was evident during

observation as some of the families we visited indicated that they were waiting for the grant and do not know how long this would take, and it seemed as if they really needed the money. This shows that financial support, whether formal or informal, is an important buffer for the family caregivers of PALHIV.

Poverty remains one of the main challenges faced by HBCGs when they provide care to PALHIV. Unless poverty is reduced there will be little progress in achieving more in caring for PALHIV as the quality of the care given to PALHIV will be compromised for they would not be able to afford basic essentials including food, which they need to be able to take their medication. The cutting of the social grant makes PALHIV more vulnerable to succumb to full-blown AIDS.

4.8 Emotional reactions to the caregiving experience

The caring experience as reported by the research participants proved to be an intense process, and different emotions were triggered by different circumstances.

4.8.1 Over-compensation/attachment

HBCGs at times overstep the bounds of duty to assist patients, and it becomes hard for them to draw the line between work and personal life – especially if they get too close to their patients. The following quote exemplifies how HBC work can demand almost a caregiver's entire life: *Ke kwetše molwetši yo mongwe bohloko ka ba ka dula le yena go mo hlokomela ka sekgauswi go fihlela a ya badimong. Lehu la gagwe le nkamile kudu ka ba ka idibala ke le mošomong, ka išwa bookelong. Pelo ya ka e be e amegile ka ge ke se na batswadi. Molwetši yo o be a le bjalo ka mma go nna. Ke ile ka fīwa keletšo gomme bjale ke ikwa ke le motho gape.* "I felt so sorry for the patient that I moved in with her to take care of her at close range until she died. Her death affected me so much that I collapsed at work and was taken to

hospital. My heart was sore as I did not have parents and the late patient was like a mother to me. I received counselling and recovered” (Ephenia).

Another participant, Abigail, relates constant worry about one of her patients: *Ke na le molwetši wa mengwaga ye 23 yo a nago le bana ba babedi, ba mengwaga ya 3 le 4. Yo mongwe wa bona e be e le molwetši wa HIV. Bana bao ba be ba swerwe ke bolwetši ba mafahla ka bobedi. Gonabjale yo mogolo o fodile empa yo monnyane o na le twatši ya HIV. Mme o dula jarateng ya tatagwe ka mokhukung le bana ba gagwe. O lwala kudu ka nako ye nngwe, bana ba gapeletšega go ikapeela. Se se boifišang ke gore mokhukhu o ka swa. Ke be ke nagana gore molwetši a ka dumela gore bana ba išwe lefelong la bana bao ba nyakago tlhokomelo gomme ka kgopela thušo ya modirelaleago fela molwetši a gana go ahlogana le bana ba gagwe etšwe go bonala gore ga ba bolokega.* “I have a 23-year-old patient who has two children aged three and four, and one of the children is HIV positive. The children were both TB-positive but now the older one is okay and the younger one is HIV-positive. She lives in her father’s yard but at the back in a shack with the children. She is at times so sick that the children have to cook for themselves which is very risky as the shack can catch fire. I thought it best that the children be fostered and requested help of a social worker, but the patient refused to let go of her children and it is not safe.”

Abigail visits this particular family outside working hours, even over the weekend as they live near her home; she is especially worried about the children. The father of the patient plays no role whatsoever in the life of this girl. This behaviour of the research participant demonstrates the struggle of becoming too close to a particular PALHIV and having genuine concern and compassion for others.

According to Miller (1995:17), caregivers must be able to maintain a balance as he or she cares for others. The caregiver can become immersed in the patient’s life

by feeling his or her feelings, even fears. A good caregiver must be able to maintain his or her separateness, which seems to be hard for Ephenia who have developed a close bond with her patient, as reflected above. Setting boundaries is a way of protecting the self. The inability to practise professional detachment can be a source of high stress as the HBCG can experience a sense of failure and guilt when the patient dies, or when there is deterioration in the patient's health (Bharat & Mahendra 2007:104).

4.8.2 Stressful events accompanied by intense emotions

The following are emotions experienced by HBCGs through caring for PALHIV. Intense emotions were evident when research participants spoke about the deterioration and death of a patient; this seems to leave HBCGs in serious emotional turmoil. The following is what the research participants had to say about their emotional experiences: *Molwetši wa HIV a ka go kgaola pelo ge o bona seemo sa gagwe koafala. Ke ipea mo maemong a bona ka gore le nna ga ke ronwe ke go bolawa ke bolwetši bjo. Ba kwa bohloko gohle mmeleng wa bona, se se ntira gore ke hloke thušo, ke fele ke dio ba kwela bohloko.* "A patient who is HIV positive can break your heart as they deteriorate in front of you, I put myself in their shoes and feel that I might die like that. They just feel pain everywhere and this makes me feel helpless and I can only feel sorry for them" (Andronicca).

This is what May said about neglected patients: *Ke kwa bohloko kudu ge ba lapa la molwetši ba sa mo kgathalele, gagolo ge ba ba tlogela ba le ditšhila. Yo mongwe wa balwetši ba bjalo o bile a ikela badimong, ka kwa bohloko, eupša ka fetša ka gore o ikhuditše.* "It makes me sad when a patient is neglected by their family, especially if they leave them soiled. One such patient died. I was sad but I felt she has found peace."

The following are the feelings of Ephenia and Raphaela on the death of their patients: *Pelo ya ka e bohloko ge ke lahlegelwa ke molwetši. Ke fela ke bolela le molekodi gomme ke homotšege.* "I have a heavy heart when I lose a patient but I discuss the matter with a supervisor, which helps" (Ephenia).

Ke a nyama gomme ke bona e ke ga ke šome ka tšhwanelo ge maemo a bophelo bja molwetši a theogela fase, ke ipona molato ka seo. "I get so disappointment that I am not doing my job properly when the health of a patient deteriorates and I blame myself" (Raphaela).

Strong emotions are consistently expressed in studies involving PALHIV such as confusion, disappointment and helplessness. In general, HBCGs working in the field of HIV/AIDS face greater emotional strain than most people ever do (Ntsunswana 2006:56).

4.8.3 Reactions to these emotions

Research participants mentioned crying when feeling emotional, which makes some of them feel better. Patience said: *Ke fela ke ikwa ke na le tshepo ka morago ga go lla.* "I often feel hopeful after crying." Most of the research participants confirmed that they felt better after crying. However, most research participants mentioned that they try to avoid crying in the presence of patients and only do it in private if they feel like it, because they have to be stronger than their patient to be able to give them support. The following is how Ephenia and Kagugelo expressed the circumstances that make them cry: *Ke lla kgafetša ge molwetši a hlokafala, a tlogela masea ao a ka se itireleng selo gore a iphediše.* "I often cry, especially when a patient dies and leave young helpless children to fend for themselves" (Ephenia).

Ke kwa ke tlelwa ke meokgo ge ke theeditše dikgang tsa balwetši, kudu bao ba iponago molato ka go fetetša bana ba bona bolwetši bjo. "I feel like crying when I listen to the stories of my patients, especially those who feel guilty about infecting their children, who will eventually die on their account" (Kgagelo).

In contrast, May mentioned that she used to cry a lot when she started working with PALHIV, but she is now used to this job and she does not cry anymore.

Most research participants acknowledged often feeling emotionally drained by the job but were always able to pull through. This is what Kgagelo said in this regard: *Ke ikhumana ke nolegile moko, ke fedile pelo ke hloka mafolofolo a go yo bona balwetši ge ke gopola gore ba sepela bothateng bjo bo bjang goba ba mpitlagantšha bjang. Ke ikwa ka dinako tše dingwe ke nyaka go tlogela mošomo wo, eupša ke gopole bana ba ka. Ba ikantše nna ka moputso w ke o humanang mošomong, ke humana maatla le mafolofolo a go tšwela pele. "I find myself feeling depressed, short-tempered, lacking enthusiasm to see patients when I think of what they go through or what they put me through (referring especially to difficult patients). At times I feel like abandoning this job but then I think about my children and the fact that they are dependent on the income derived from this job, so I get motivated to carry on."*

Those who are affected by the disease, including the research participants as carers, are often shocked, angry, feeling guilt, depressed, afraid and confused or have a mixture of emotions at once, especially where the death of a patient is involved (Ntsunswana 2006:75). These emotions are also described in a study by Dageid *et al.* (2007), where carers expressed similar feelings including hopelessness, sadness as well as disappointment.

Emotional exhaustion has been linked to over-involvement with clients and constant contact with emotionally demanding, often critically ill patients (Held

& Brann 2007). In this study it is not explicit but implied, that some of the research participants often have second thoughts about going to work.

4.9 Coping mechanisms

Experiences that research participants have shared, described in the previous section/s, clearly indicate that they require support in order to cope with their work and to continue giving PALHIV the much needed care. Below is their experience of how they cope, the amount of support at their disposal and how that support adds value.

There are various support structures available for the HBCGs at the HBCC in Mamelodi.

4.9.1 Debriefing

At the HBCC in Mamelodi there is empathy with the intensity of the emotions that come with caring for PALHIV and there is an awareness of the need for sufficient support for HBCGs. To ensure that HBCGs get such support there is a counsellor/psychologist available for debriefing services every three months. The purpose of the debriefing sessions is to provide HBCGs with a platform to explore their emotions and frustrations in order to cope with the challenges that they face in their daily duties as they care for PALHIV.

The research participants Mamito, Asnath, Kgaugelo, Cindy, Tamara, Ephenia and Abigail are amongst those who expressed gratitude in having the psychologist around as the sessions assist them in coping with their work.

Ke kwa ke imologile kudu ge ke fešja go bolela le mosaekholotši. "I feel really better, as if a burden has been lifted off my shoulders after interaction with the psychologist, who comes quarterly" (Ephenia).

As much as debriefing is appreciated, the caregivers raised some disadvantages to it, such as: *Ke mo go botse go ba le mosaekholotši go tlo bolela le rena eupša ditlamorago tša seo ke gore o begela ba bagolo mošomong tšeo re di ahlaahlilego le yena gobane le bona ba re emela ka maoto. Tše re di bolelang e swanetše go ba khupamarama.* “It is good to have the psychologist for debriefing but the greatest disadvantage is that she reports back to the senior staff members, who in turn get upset about what was discussed and the HBCG get reprimanded for that, whereas everything they discuss should be confidential” (Asnath).

All research participants felt that the psychologist/counsellor must maintain confidentiality as the lack of confidentiality causes or contributes to conflict at work.

Some of the research participants would have liked to have had more debriefing sessions, as mentioned by Tamara, Ephenia, Cindy, Jino, whereas Asnath and Kgaugelo felt that the sessions were sufficient. This could be as a result of the fact that they are offended by the breach of confidentiality on the part of the psychologist, as mentioned above.

4.9.2 Consultation with senior staff members

At times, HBCGs have problems with patients which they cannot resolve on their own, and which they then refer to the senior staff members, such as an immediate supervisor. If it is beyond the capacity of the centre they recommend referral of the patient. This happens when the severity of the disease intensifies, when the patient experiences severe pain and life-threatening symptoms such as chest pains, difficult breathing, coughing, diarrhoea, nausea and vomiting.

The ability to solve problems through consultation and referral is associated with positive experiences on the part of the HBCG (Makoae & Jubber 2008:42). If the

unresolved issue is something that can be resolved by the HBCC, a senior staff member will intervene by accompanying the HBCG to help settle any difficult issues between the HBCGs and their patients (examples in section 4.7.5 above). This alleviates potential stressors and is an option that seems to work for most HBCGs.

4.9.3 Informal support groups

Most research participants seemed to resort to sharing their fears, anxieties and most work-related challenges with fellow HBGCs. Even if they know that sometimes not much can be done by fellow HBCGs, simply sharing their experiences provides some comfort, as they have similar experiences and they know confidentiality will be maintained. There is no formal time set aside for such sharing of experiences; it happens informally and spontaneously.

Kgaugelo mentioned that she shared her patients' challenges with nurses at the clinic, especially because HBCGs provide care to PALHIV who were referred to the centre by the sisters at the clinic. The research participants appreciated these informal conversations with each other to such an extent that they wished this could be formalised.

Go botšiša dipotšišo go thuša ge a šomana le ditaba tše di sepelelanago le tšohle tša mošomo. Ge mosaekolotši a se gona ke abelana tsebo le bao ke šomago le bona. Ke hloka go fiwa nako ye ntši mošomong mmogo le bašomikanna, kudu ka gore mosaekolotši o tla morago ga sebaka. "Debriefing helps in dealing with work-related issues, which I share with the fellow carers in the absence of the psychologist. I feel a need to be given more time at work to talk about work-related issues alone as carers, especially since the psychologist comes only once in a while" (Asnath).

Patience and Kgaugelo saw speaking to some of the senior management as a good compromise in sharing problems in the absence of the psychologist; for others it was safer to speak to fellow workers.

HBCGs explained their coping mechanisms in relation to caring for their patients and none of them mentioned their own status and how that affects their work. Emotional coping at work was difficult and the debriefing helps, but more long-term intervention is necessary.

4.9.4 Emotional understanding

Some research participants have positive coping mechanisms that keep them optimistic as they provide care to PALHIV.

The following are some of the positive aspects mentioned by research participants that helped them to cope with their work:

Ke lebelela dilo ka pono ya go kgolwa, bjale ka ge ke sa rate go di tlogela di sa hlokomelwa lebaka le le telele. "I look at things in a positive light as I do not want to leave them unattended for a long time" (Mamito).

Ke leka go se befelwe. Ke rata go dira meswaso, go opela kudu go tloša maikutlo a go befelwa. "I try not to be angry, I like to joke and sing a lot to release emotion of anger" (Asnath).

Bjale ka ge ke bona balwetši ba e ba kaone ke tia matla, ke thušega go kwešiša. "Seeing that patients are getting better keeps me motivated and that enables me to cope" (Valentino).

Ke amogela maemo a balwetši, ga ke ba dumelele gore ba dire gore ke se iketle maikutlong. "I accept the condition of patients and do not allow them to unsettle me emotionally" (Kgaugele).

These are some of the research participants who displayed emotional self-reliance as they were able to depend on themselves to deal with their emotions in a positive manner, and this should be encouraged as it reduces the emotional burden that comes with a caring profession.

Lazarus and Folkman (1984:119) view self-control, humour, crying, weeping, and boasting as coping devices which are normal. Humour is viewed as an important coping resource as it lowers loneliness and depression and boosts self-esteem. The coping mechanisms found in this study are thus similar to coping devices highlighted in Lazarus and Folkman's theory.

4.9.5 Spirituality

Some of the research participants believe in God and prayer to cope with their work. They believe that through God anything is possible. They pray as a group every morning when they get to work before they start with their daily routine, and other research participants mentioned that they do it on their own as it is part of their spirituality.

Ke rapella nna le balwetši ba ka pele ke ya mošomong, mošomong le gona ke fihla ke bea thapelo le bašomikanna pele re thomoša mošomo. "I pray before going to work, for myself and the patients and when I get to work we pray as a group before starting with work" (Patience).

Ke a rapela, ke fa Modimo mathata a ka. "I pray and give my problems to God" (May).

Ge dilo di senyegile ke rapela Modimo, ka morago ke ipotša gore se sengwe le se sengwe se se diregago ke thato ya Modimo. O na le lebaka la tšohle, bjale ka lebaka la go šoma ga ka mo, go tseba Yena. “When things are tough I pray to God and feel that anything that happens is God’s will, and He knows why everything is happening the way it does. Everything has a purpose with Him, as there is a reason why I work at the HBCC in Mamelodi” (Tamara).

Being spiritual and close to God help research participants deal with their emotions better and soothe their pain. Singing gospel music seems to be another emotional outlet, and hoping that God will assist in solving problems.

According to Makoae *et al.* (2008: 144), deriving comfort through religion is one of the most common coping strategies. Religion plays an important role in the HIV/AIDS arena. In this study spirituality and hope in God emerged as a coping strategy that was manifested through prayer, alone or as a group.

Studies involving caregivers also suggest that certain coping strategies are consistently associated with particular mental health outcomes. Active strategies, such as offering encouragement to the patient, relaxation and seeking social support were associated with less distress and better emotional adjustment amongst caregivers of people with dementia (Gottlieb 1997:88).

4.10 Workplace challenges/ working conditions

Research participants expressed several challenges they experienced in the workplace that related to working conditions and benefits.

4.10.1 Communication problems between HBCGs and senior staff members

There is evidence that there is a lack of communication between senior staff members and the HBCGs, and this causes a lot of confusion and

misunderstanding. The HBCGs reported that they were not listened to and were often accused of going astray during the course of duty – which was not based on facts. They felt that they were not given a chance to argue their cases during such confrontations and felt vulnerable and disrespected. They expressed extreme unhappiness about the way they were spoken to, and were afraid of sharing their exact feelings.

This is what May mentioned: *Ke ikgethela go homola mabapi le dipolelo tše bohlokwa tša mošomo tše di ka hlolago thulano. Ga ke rate go rogwa.* “I prefer keeping quiet about burning work-related issues that might cause conflict. I do not want to be scolded.”

May felt that there were some HBCGs that senior staff members listened to when they had something to say: *Go na le ba sekegelwang tsebe ge ba bolela, ke lebaka leo re kgetha go homola.* “Some of us are not listened to, so we prefer to keep quiet.”

As mentioned the psychologist who facilitates debriefing sessions breaches the code of confidentiality by sharing their problems with management – something which contributes to the conflict.

There exists opposing feelings about how the HBCGs at the HBCC in Mamelodi are treated by senior staff members. Some of the research participants mentioned that they were treated well, but there are those who felt that they were not respected and said that senior staff members treated them harshly.

Re swerwe gabotse. Ke leka go ikokobetša, le go hlompha ba bagolo go nna mošomong. Ba ba bangwe ba rena ga ba kgethe mantšu ge ba bolela le ba bagolo go bona. “We are

treated well. I try to humble myself and respect my superiors. Other people do not choose their words when they speak with superiors” (Tamara).

Ke befelwa kudu ge mo re šomelago gona, batho ba kgetha go bolela le nna ba sa laetše tlhompho, ka bošaedi, le go gwaba. “I feel a lot of anger when at the centre, especially when people talk to me without respect, carelessly, rudely” (Ephenia).

There is obviously a problem of misunderstanding and communication between the HBCGs and the senior staff members and it needs to be addressed as it causes animosity. The communication problems have nothing to do with patient-related problems but have more to do with interpersonal relations in the centre. The challenge that senior staff members face is that of dealing with different personalities, hence the need to exercise some tact to make sure that colleagues do not feel that they are ignored or that there is favouritism.

4.10.2 Transport

The HBCC in Mamelodi has a car which sometimes drops HBCGs off to visit their patients but is often parked at the centre. Most of the time research participants reported walking long distances to visit their patients and at the same time having to come back and clock out, which they find strenuous. They are given an allowance of R100 for transport to see patients, which they feel is not sufficient.

Re fiwa tšhelete ya go namela eupša ke ye nnyane ge re lebelela bokgole bjo re bo sepelang. “We are given a transport allowance of R100, which is not enough given the distances we travel to and from the centre” (May).

Dinamelwa ke bothata, re tshepišitšwe senamelwa sa mošomong fela ga se re nametše ka mehla, ebile balwetši ba rena ba dula kgole. “Transport is a problem. We are

promised that it will take us every day but it takes us sometimes and our patients live very far and we receive only R100 for transport per month” (Mamito).

Re swanetše go fiwa senamelwa sa go re iša go bona balwetši. Seo se tlo re thuša go etela balwetši le go bega go tla le go sepela ga rena mošomong. Ka letšatši la Morena ke lakalela go ya mošomong ge ke nagana tsela ye telele yeo ke tlogo e sepela. “We should be provided with transport to take us on our visits to our patients, which will make it easy for us to clock in and out ... On Sundays I find myself dreading to go to work as we walk a long distance” (May).

Ge ke nagana botelele bja leeto le ke le sepelago go ya go bona balwetši, bo dira gore moya wa ka o ye tlase. “When I think of the distance I have to walk to the patients, it really kills my spirit” (Tamara).

Transport problems have a bearing on the job of the HBCG as their place of work is far from the patients, and by the time they get to the patient/s they are too tired to work properly or to give a desired or satisfactory service.

4.10.3 Incentives

All the researchers felt that they were not earning enough. They could not afford to enrol for courses on their own to empower themselves and have to depend on the availability of what the centre can offer. They will be happy if they could receive at least R2000 per month compared to the current stipend of R1100. Moreover, Patience reported that the salary is not enough given the number of years she has been with the centre.

Asnath said: Mogolo ke wo monnyane. Ke dula mekhukung ebile ke somiša setimela go ya mošomong. A mangwe matšatši ke fihla morago ga nako ka lebaka la setimela se fihlile morago ga nako. Ge go le bjalo ke swanela go sepela ka senamelwa sa batho bohle seo

mašeleng a sona a bitšago. “The stipend is too little; I live in the squatter area and use the train to get to work, and at times I am late for work due to train delays and have to take a taxi, which is more expensive.”

It is important to note that most NGOs such as the HBCC under study are donor-dependent; however, it should be taken into consideration that HBCGs are taking great responsibility in providing care for PALHIV and should be provided with reasonable financial incentives in order to boost their morale, given the emotional conditions they work under (Ntsunswana 2006:74).

4.10.4 Training

All HBCGs employed at the HBCC in Mamelodi have to undergo training, as mentioned in the beginning of this chapter (see section 4.3.3), and they continuously have capacity building workshops which are dependent on common needs and the availability of funds.

The research participants felt that there were minimal opportunities for growth despite their years of service. The training they undergo does not equip them for some of the clinical challenges they encounter (as mentioned above in section 4.7.8). “This cannot be a lifetime job in the absence of training to empower us” (Raphaela).

Kgaugelo, Asnath and Mamito mentioned that available opportunities are not equally shared according to fair and transparent procedures. They would like to develop their skills to become auxiliary nurses, if possible, or to maximise their chances of accessing other job opportunities. Research participants believe that the centre has the potential of sourcing more training programmes for the HBCGs, but that this is done too slowly.

4.10.5 Safety on the job

HBCGs fear for their safety on the job, as they walk long distances to see their patients on a daily basis.

Mamito shared an experience that she felt threatened her safety: *Ke be ke na le molwetši o beng a dula ko bonwelo ba bjalwa. Ke ile ka re ke yo go mmona ka hwetša banna ba lebeletše di DVD, ka tšhaba go boelela gobane ke sa tsebe go re ba ka ntira eng gobane ba be ba sa lebelege bjalo ka ba batho ba go ba le botho.* "I had a patient whose home was a shebeen. I went there and found men watching DVDs, and I never went back again for fear of not knowing what these men are capable of doing to me as they did not look friendly at all."

Ka nako dingwe ga ke sepela mo motseng go ya go etela balwetši ke kopana le bašimanyana ba go kgoga direthebatši, seo se dira gore ke tšhabe go šwarwa poo. Go go le bjale nna le badirammogo baka re sepela ka sehlophana go leka go itšhireletša. "At times as I walk in the township to visit my patients I come across young boys who smoke dagga and I fear that I might get mugged. Under such circumstances I tell my other colleagues who will be going in the same direction and we walk in a group of about four. This is our way of trying to take some safety measures" (Valentino).

According to Avert (2010:5), carers fear sexual abuse and rape, especially where men live alone – as reflected above by Mamito. She did not spell it out as fear of being sexually assaulted, but it is implied in what she has said.

4.11 Conclusion

This chapter presented and discussed the findings of this study. It gave a detailed account of the background of the centre under study, the gender-based profiles of the research participants, as well as the core services of the centre based in Mamelodi.

The findings highlighted the challenges that HBCGs face on a daily basis as they give support to PALHIV which encompasses the rewarding experiences as well as difficult ones that require intervention of the centre supervisor. Coping mechanisms adopted by HBCGs as a way of coping with the emotional and physical strain of the job are also mentioned. It is noted that there is support from the centre although it is not always seen to be sufficient. It is clearly articulated that caregiving is rewarding, yet very emotional for the HBCGs as they experienced negative and positive emotions.

The following chapter concludes this study. It further gives recommendations based on the findings of the study which are directed to the HBCC in Mamelodi and government departments involved with HBC.

CHAPTER 5: Conclusion and recommendations

5.1 Introduction

In this chapter the researcher will present this study's conclusion and recommendations for interventions and future research. This study has shed some light to better understand the strategies that HBCGs in a HBCC use to deal with the daily psychological and social challenges they experience during their caregiving, and the type of social support available to HBCGs from the HBCC to assist them in coping with their work. The study has further identified possible remedies to some of the challenges experienced by HBCGs, which could complement the already existing support available at the centre.

5.2 Objectives of the study

As set out in Chapter 1, this study set out to investigate *How do HBCGs deal with challenges they are faced with when providing care to PALHIV?* This question was approached by focusing on the following:

- Investigate the psychological challenges experienced by HBCGs in giving HBC to PALHIV;
- Investigate the social challenges experienced by HBCGs in giving HBC to PALHIV;
- Investigate the coping mechanisms used by HBCGs in giving HBC to PALHIV;
- Investigate the types of support provided to HBCGs in giving HBC to PALHIV;
- Investigate intervention necessary to support HBCGs in giving HBC to PALHIV, as perceived by HBCGs.

The objectives of the study were addressed by a literature review being conducted to gain more insight into the key concepts, and exploring the available body of knowledge relating to the topic under study. To be able to understand the psychological and social challenges experienced by HBCGs it was important to gain insight into the history of HBC (Chapter 2) and give detailed information of the HBCC under study (Chapter 4), before looking at what motivates HBCGs to care for PALHIV.

The HBCGs do their best to meet the needs of the PALHIV, but they experience psychological and social challenges during the course of their duties, such as poverty and dealing with the death of a patient. In Chapter 2, attachment, risk of contracting the disease, stigma and discrimination were some of the challenges highlighted. The HBCGs are doing their best to deal with the challenges they experience and involve their supervisor where they experience difficulties, which is another way that they cope with their work. HBCGs have proved to have various methods of coping when working with PALHIV, such as religion and social support. Some are also reflected in Chapter 2 and formed part of the findings. Coping mechanisms adopted by HBCGs reflected in the findings such as avoidance, self-blame, humour, and crying, are similar to those mentioned in the theory of coping by Lazarus and Folkman (1984), which shows the relevance of this theory to this study. Support for HBCGs was also highlighted as an integral part of the coping during the caring experience, and needs to be available in any way possible and be improved continuously.

In the context of caring for PALHIV – the context in which this study was conducted – coping appears to be self-taught, and the debriefing intervention makes the work-related problems bearable. The involvement of supervisors in dealing with difficult situations of patients alleviates the potential stressors that

can be very destructive and can compromise the quality of the care that HBCGs can give to their patients.

5.3 Major findings of the study

In this section the following conclusions were drawn, based on the major findings categorised into these main themes, namely research participants, psychological and social challenges faced by HBCGs, coping mechanisms, and support provided for HBCGs.

5.3.1 Characteristics of research participants

One of the most salient findings to emerge from this study is that almost the entire research population consisted of women, with only very few men being carers. A conclusion drawn on this fact is that caregiving seems to attract more women than men – a view that authors such as Leake (2009), Homan *et al.* (2005), as well as Bharat and Mahendra (2007) support in their studies.

The study further showed that the research participants are motivated to work with PALHIV by various aspects of their work, including compassion, earning a living and personal accomplishment of skills and experience. Yet the latter is hard to fully achieve, given the limited opportunities of growth that they are exposed to; nonetheless, they are aspiring to better their skills and improve their productivity.

5.3.2 Psychological and social challenges

This section covers the conclusions drawn on psychological and social challenges faced by HBCGs.

5.3.2.1 Safety

The findings showed that the HBCGs did not feel safe as they walked in the streets of Mamelodi to visit their patients – a critical factor that needs more attention from the senior staff members at the centre. The centre could buy the HBCGs safety sprays and if there is funding, could send them for self-defence classes.

5.3.2.2 Stigmatisation

The findings revealed stigma as slowing the provision of care to PALHIV. Most PALHIV and their families still fear the abuse and stigmatisation by their community associated with HIV/AIDS, especially in cases where the HBCGs wear uniforms. Disclosure is key to good relations between the HBCG and the PALHIV and better care that may impact on the general well-being of the patient, thereby improving the general health status of the patient. PALHIV should be encouraged to share their status so that they can be cared for effectively, and so that HBCGs can also ensure protection of both the patient and themselves.

5.3.2.3 Poverty

The findings revealed that poverty is one of the socio-economic factors that make the caring experience difficult and thus impedes the overall recovery of the patients, as they cannot take their medication without eating. Although the HBCGs at times bring them food, this is not sufficient to cater for all their needs, especially in cases where the social grant has been stopped.

5.3.2.4 Low pay

The HBCGs in general contribute substantially to the health of fellow community members which indirectly translates as savings for the national health budget, as

they are not well remunerated – an essential economic factor raised by all the research participants in this study.

5.3.2.5 Communication

The findings in this study further highlighted poor communication between the HBCGs and the employer, creating mixed emotions, confusion and twisted information, and also a feeling that there was favouritism and to a certain extent lack of respect between senior staff members and HBCGs. There was confusion about opportunities for growth, especially with regard to training and to a certain extent an insinuation of nepotism.

5.3.3 Coping mechanisms

It was found that attachment to patients affect the emotional status of the HBCGs where there is evidence of being too close to the patient and more so when a patient dies. In the theory of Lazarus and Folkman (1984), which focuses on coping, coping is seen as a process which is common in situations where individuals (in the case of this study HBCGs) have been working with grieving people over a long period.

This study has shown that the research participants were often overwhelmed by emotions when caring for PALHIV. They suffered high levels of guilt, anger, hopelessness as well as disappointment and at times found it difficult to manage the demands that come with the job. The HBCGs shared their pain amongst themselves or with nurses they worked with at the local clinic. It further emerged that there was a psychologist who came to the HBCC to counsel the HBCGs so that they could deal with their emotions; however, this support was deemed insufficient. Dealing with their emotions also confirms the third and fourth steps of Lazarus and Folkman's (1984) coping process where coping strategies are implemented to eliminate the sources of stress. Although the HBCGs expressed

their appreciation for the positive contribution of a psychologist and the need for more frequent visits, they also revealed being unhappy about the breach of confidentiality when she shared issues with the senior members of staff that caused victimisation and conflict between the two parties. This led to withdrawal and prevented HBCGs from being completely free and honest about what they went through; it also negatively impacted the quality of their service.

It transpired that some of the coping mechanisms HBCGs identified include spiritual reliance through individual prayer and as a group. Singing, joking and keeping a positive attitude are other coping mechanisms that seemed to work for some of the research participants. These were some of the self-taught coping mechanisms used by research participants. Crying is another way of coping and was reported by most research participants to be easing their pain. These coping strategies are named coping devices in the theory of Lazarus and Folkman (1984).

It further emerged that avoiding confrontation is another way of coping with emotions – an approach adopted by some participants especially with work-related issues pertaining to senior staff members and not patients. According to Makoae *et al.* (2008), coping by letting it be or avoiding confrontation is a passive way of protecting one's self, which was the case with most research participants in this study.

5.4 Recommendations for intervention

This section covers recommendations for intervention by government, HBCCs and other stakeholders.

5.4.1 Home-based care in Mamelodi

The HBCC in Mamelodi needs to expand their HBC programmes to find ways to assist households with income generation as most households served by the HBCGs are poor. Linking HBC programmes with income-generating activities may alleviate some of the financial burdens they face that delays recovery of patients. As much as patients and their families are encouraged to have vegetable gardens, the HBCGs need to be capacitated on how to assist PALHIV and their families to continuously maintain such a garden.

Lack of or minimal support from the senior staff members can cause the HBCGs to suffer emotional fatigue to the extent that they are unable to render quality care for PALHIV. HBCGs also need to support each other and make their voices heard at decision-making level concerning the allocation of resources and manpower and opportunities for growth (Ehlers 2006). They can do so by selecting a spokesperson who will communicate their interests and complaints to management to avoid confrontations in the presence of everyone.

HBCGs need to be supported with adequate supplies and infrastructure, relevant information and guidelines to be able to carry out their duties to full capacity. The HBCC in Mamelodi can try to have team building expeditions, annually if possible, to review and recreate synergy.

Support groups need to be formalised with time allocation periodically where HBCGs can share their caring experiences with each other. Peer networks can also help; HBCGs from the HBCC in Mamelodi could interact with others in the same field to share their caring experiences.

Communication between the senior management and the HBCGs needs to be improved to create an open environment so that any subject can be discussed

and addressed. It is important to note that injuries on duty are possible. Under the current circumstances it will be difficult for HBCGs to communicate sensitive issues to senior management, such as a HBCG being exposed to HIV, because of the culture of silence that they have adopted – for they fear being victimised or patronised.

The HBCC in Mamelodi has relevant support necessary for carers working with PALHIV, but the planning and management thereof needs more attention. The psychologist's breach of confidentiality has to be re-evaluated as it has been shown to contribute to unnecessary conflict. Some of the HBCGs have lost their trust in the system, good as it may be; they would rather stick to the safest route of silence than expressing feelings, which can lead to the centre losing some of its HBCGs, not by leaving but by silence. The relationship between the senior staff members and HBCGs can be restored through more open and honest communication.

5.4.2 Training

The HBCC in Mamelodi needs to consider integrating the use of traditional medication into caring for PALHIV. The HBCGs need to also be coached repetitively to avoid establishing boundaries so that they do not get too attached to patients so that they are able to maintain separateness for their own self-protection. This could be done in conjunction with training and benchmarking with institutions with similar programmes, and liaison with provincial and local government who work closely with HBCCs, on how to implement this successfully.

The provincial and local government should regularly provide funds to HBCCs to ensure continuous capacity building to refresh their knowledge and skills.

5.4.3 Funding and fundraising

The Department of Health and Social Development, and external funders must prioritise and invest in HBC programmes to improve the working conditions of HBCGs by increasing benefits such as salaries and other resources necessary to assist them in carrying out these valuable activities of caring for PALHIV. Monitoring and evaluation of HBC programmes should also be given priority as that will highlight the impact that these programmes are making in communities and identify areas that need more intervention. This can be done by increasing the overall budget for HBC by government given the reliance that hospitals have on HBC (Bharat & Mahendra 2007:101).

The HBCC must also consider sourcing funding from external donors, and if all fails, to employ a fundraiser who would raise funds for the organisation and could be paid a percentage of what he or she brings in. This could alleviate some of the financial burdens found in this study.

5.5 Limitations of the study

The findings of this study have identified and recognised the following as limitations:

- The sample size in this study was small; the results cannot be generalised to other situations and the findings can only be suggestive.
- Time was too limited for the researcher to be able to gain enough trust of the research participants, which made it difficult to obtain more in-depth information.

5.6 Recommendations for future research

It is recommended that further research be undertaken to investigate coping mechanisms of HBCGs who care for PALHIV in various HBC programmes in Mamelodi. Such a study will enable the researcher to draw a more generalised conclusion about HBCGs in Mamelodi and can suggest a community-based approach to support the HBCGs. This would therefore address the first limitation of this study.

More research should be considered on the impact of the withdrawal of social grants received by PALHIV on their recovery and survival. This kind of research will enable HBCGs to have a better understanding of what leads to withdrawal of social grants and they will be able to make informed choices on how to ensure that grants are not stopped, thereby improving the financial capacity and well-being of their patients and enhancing the quality of their care.

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7. APPENDICES

APPENDIX A: LETTER REQUESTING PERMISSION TO CONDUCT RESEARCH IN A HOME-BASED CARE CENTRE - ENGLISH VERSION

13 Hartedief Place

Elandspoort

Pretoria

0183

Tel no: 082 551 2974

Fax no: mabusmd@unisa.ac.za

The Director

Name of the Home-Based Care Centre

Address

Re: Permission to conduct research

I, Ms Mmalesiba Dorothea Khomotso Mabusela, am a registered student studying for a Master's degree in Social Behaviour (HIV/AIDS), with the University of South Africa, and hereby request permission to conduct research in the above Home-Based Care Centre.

The title of my research is "*An investigation of the challenges and coping mechanisms of Home-based caregivers in a Home-Based Care Centre*". This study is a mini-dissertation for the partial fulfilment of the requirements for the Master's degree in Social Behaviour (HIV/AIDS).

I hereby request permission to use this home-based care centre to conduct my research. I would like to interview 15 of the caregivers in this centre with their consent, which they will grant by signing a consent form.

My research will consist of the following phases:

Phase 1

In the first phase I would like to be an observer to get an idea of how activities at the centre are carried out, and will take notes of what will be relevant for my research. This will be done over 8 different days in one month. Dates will be communicated in advance.

Phase 2

After observation, I will further arrange to conduct interviews with 15 of the home-based caregivers (HBCGs) over a period of two months. Appointments will be scheduled according to the availability of the HBCGs in that period. Each interview is estimated to take between 45 minutes and 1 hour.

Confidentiality will be strictly adhered to and the participants will remain anonymous.

Thanking you in advance.

Yours sincerely

Mmalesiba Mabusela

Researcher

**KOKETŠO YA A: LENGWALO LA TUMELELO YA GO DIRA NYAKIŠIŠO
SENTHARENG YA TLHOKOMELO YA BALWETŠI YA SEGAE- KA
NORTHERN SOTHO**

13 Hartedief Place

Elandspoort

Pretoria

0183

Tel no: 082 551 2974

Fax no: mabusmd@unisa.ac.za

The Director

Name of the Home-Based Care Centre

Address

Ka ga: Tumelelo ya go dira nyakišišo

Nna, Mtšna Mmalesiba Dorothea Khomotso Mabusela, ke moithuti Yunibesithing ya Afrika Borwa (Unisa) gomme ke ithutela grata ya Master's ka ga Boitshwaro bja batho malebana le HIV/AIDS gomme ke kgopela tumelelo go dira nyakišišo Senthareng ye ya tlhokomelo ya balwetši ya Segae.

Hlogo ya dinyakišišo tšeo ke di dirago ke *An investigation into the challenges and coping mechanisms of Home-based caregivers in a Home-Based Care Centre* (Phatišišo ka ga ditlhohlo le maano a katano tša bahlokamedi Senthareng ya Tlhokomelo ya Balwetši ya Segae ka la Mamelodi. Thutelo ye ke sengwalo se sekopana seo e lego senyakwa go dithuto tša grata ya *Master's* ka ga boitshwaro bja batho mabapi le HIV/AIDS.

Ka gorealo ke kgopela go šomiša senthara ye ya tlhokomelo ya balwetši ya segae go phethagatša nyakišišo ya ka. Ke rata go rerišana le bahlokamedi ba 15 ba senthara ye ka tumelelo ya bona, yeo ba tla e fago ka go saena foromo ya tumelelo.

Nyakišišo ya ka e tla latela magato a a latelago:

Kgato ya 1

Sa pele ke rata go ba molebeledi/mmogi gore ke hwetše tsebo ka ga ka moo dilo di sepetšwago ka gona senthareng gomme ke ngwale dintlha ka seo se tla sepelelanago le nyakišišo ya ka. Se se tla dirwa lebakeng la matšatši a 8 a go fapana kgwedding e tee, gomme le tla tsebišwa ka matšatšikgwedi nako e sa le gona.

Kgato ya 2

Ka morago ga go lebelela, ke tla dira peelano ya go rerišana le bahlokamedi ba 15 ba lagaeng (HBCGs) lebakeng la dikgwedi tše pedi. Dipeelano di tla beakanywa go ya ka go ba gona ga bahlokamedi nakong yeo. Therišano ye nngwe le ye nngwe e ka tšea botelele bja metsotso ye e ka bago ye 45.

Tshepedišo e tla ba ya sephiri gomme batšeakarolo ba ka se tsebagatšwe.

Ke a leboga.

Wa lena

Mtšna Mmalesiba Mabusela

Monyakišiši

APPENDIX B: LETTER TO PARTICIPANTS - ENGLISH VERSION

13 Hartedief Place

Elandspoort

Pretoria

0183

Tel no: 082 551 2974

Fax no: mabusmd@unisa.ac.za

Name of Home-Based Care Centre

Address

I am a registered student of the University of South Africa studying towards a Master's degree in Social Behaviour (HIV/AIDS), and am currently conducting a study with the title *"An investigation of the challenges and coping mechanisms of home-based caregivers (HBCGs) in a home-based care centre in Mamelodi"*. In this study I would like to conduct an interview with you to gain more understanding of the type of work you do as a HBCG, the challenges you face in your daily activities including how you cope with working with PALHIV, and what you do when they come across a stressful situation.

I will highly appreciate it if you can assist me with my research by allowing me to interview you on the topic above, and hereby request your consent. Please note that you are free to stop the interview or stop participating at any point during the process of consenting to participate in the interview. You are also not obliged to answer any questions you are not comfortable with. Anonymity and confidentiality will be maintained at all times. The interview will take 45 minutes to an hour. An appointment will be scheduled according to your availability.

I also seek your consent for using a tape recorder during the interview, on the attached form. The recording will be used when preparing the dissertation on condition that your name or identity is not revealed and that my supervisor can have access to the tape if need be. Once I have successfully completed my dissertation I will destroy all the tapes.

Kindly receive my gratitude for your agreeing to participate in this study in advance.

Ms Mmalesiba Mabusela

Researcher

KOKETŠO YA B: LENGWALO GO BATŠEAKAROLO - KA NORTHERN SOTHO

13 Hartedief Place

Elandspoort

Pretoria

0183

Tel no: 082 551 2974

Fax no: mabusmd@unisa.ac.za

Name of Home-Based Care Centre

Address

Ke moithuti yunibesithing ya Afrika Borwa gomme ke dira dithuto tša grata ya *Master's* ka boitshwaro bja batho malebana le HIV/AIDS, gomme gabjale ke dira thutelo ka ga “(Phatišišo ka ga ditlhohlo le maano a katano tša bahlokamedi Senthareng ya Tlhokomelo ya Balwetši ya Segae ka la Mamelodi.” Thutelong ye ke rata gorerišana le wena gore ke kwešiše mohuta wa modiro wo o o dirago bjalo ka HBCG, ditlhohlo tše o lebanago natšo mošomong wa gago wa letšatši ka letšatši go akaretšwa le ka moo o katanago ge o šoma le PALHIV, le seo o se dirago ge ba lebane le maemo ao a hlagišago kgatelelo.

Nka leboga kudu ge o ka nthuša nyakišišong ya ka, ka go ntumelela go rerišana le wena ka ga hlogo ye e filwego ka mo godimo. O lokologile go ka emiša therišano goba go emiša go ba motšeakarolo nako efe goba efe. Ga o gapeletšege go araba potšišo efe goba efe ye o sa lokologago go ka e araba. Leina la gago le ka se utollwe gomme tšohle di tla bolokwa e le sephiri nakong ka moka. Therišano e tla tšea metsotso ye 45 go iša go iri. Peano e tla bewa go ya ka go ba gona ga gago.

Foromong yeo e mamareditšwego, ke kgopela gape tumelelo ya gago gore ke šomiše setšeamantšu nakong ya ditherišano. Dikgatišo di tlo šomišwa ge ke lokiša sengwalwa, le gore mohlapetši wa ka a kgone go ka hwetša segatišamantšu ge go hlokega gomme leina le boitsebišo bja gago di ka se utollwe.. Ge ke feditše go dira sengwalwa sa ka ke tla phumola dikgatišo ka moka.

Ka boikokobetšo amogela tebogo go tšwa go nna ya go dumela go tšea karolo thutelong ye.

Mtšna Mmalesiba Mabusela

Monyakišiši

APPENDIX C: PARTICIPANTS' CONSENT FORM - ENGLISH VERSION

I.....hereby agree to participate in a study with the title “An investigation of the challenges and coping mechanisms of home-based caregivers in a home-based care centre”. I hereby acknowledge that I am participating in this research voluntarily, am aware that I can stop the interview at any time, and am not obliged to answer questions that I am not comfortable with. I agree that the interview be recorded on condition that anonymity and confidentiality be maintained.

Consent granted by:

Signature

Date

Witness

Signature

Date

KOKETŠO YA C: FOROMO YA BATŠEAKAROLO YA TUMELELO -KA NORTHERN SOTHO

Nnake dumela go tšea karolo thutelong ye yeo sehlogo sa yona e lego “An investigation on coping mechanisms of home-based caregivers in a.....home-based care centre “(Phatišišo ka go maano a katano a bahlokomedi ba balwetši Senthareng ya Tlhokomelo ya Balwetši ya Segae Senthareng ya ya tlhokomelo ya Segae). Ke dumela gore ke ithaopa go tšea karolo nyakišišong gomme ke lemoga gore nka emiša therišano nakong efe goba efe gape ga ke gapeletšege go araba dipotšišo tšeo di sa nkgotsofatšego. Ke a dumela gore ditherišano di gatišwe ge fela leina la ka le ka se utollwe le gore di tšewe bjalo ka sephiri.

Tumelelo e filwe ke :

Mosaeno

Letšatšikgwedi

Hlatse

Mosaeno

Letšatšikgwedi

APPENDIX_D: INTERVIEW GUIDE - ENGLISH VERSION

Preamble to interview schedule

Thank you very much for your participation in this research. Be assured that all the information conveyed during the interview will be treated with confidentiality and your anonymity will be protected by using a pseudonym, so as to ensure that your personal identifying details will not be revealed at any stage. This interview is conducted with your full consent and you have the right to withdraw from it at any given point when you feel that you do not want to continue.

This interview is conducted to try to gain more understanding of the type of work you do as a home-based caregiver (HBCGs), the challenges you come across and, how you cope with working with Patients living with HIV/AIDS (PALHIV); also what you do when they come across a stressful situation.

The interview process will comprise of only one interview per participant, which will last between 45 and 60 minutes. The interview will be tape-recorded and notes will also be taken by the researcher. The main idea is to explore your experiences, feelings, thoughts, ideas and maybe questions. Please note that there is no wrong and right answer.

Demographic details

Respondent no

Age

Male

Female

Current Position:

Years in position

Duties

Other positions held in the centre

Years employed in the centre

Are you a full-time employee or part-time?

Do you get paid?

Training-related questions

What type of training have you received?

How long was the training?

Where did you train?

Did you obtain any certificate? If yes, in which field?

Previous work with PALHIV

Have you worked with PALHIV before elsewhere?

If yes, where and for how long?

What was your reason to leave?

What were your duties?

Problems in the workplace

Do you work with PALHIV?

What do you do?

Do you like your job?

What gives you a reason to wake up in the morning and go to work?

What type of challenges do you experience when you work with PALHIV?

How often do you experience them?

How do you resolve such challenges that you experience?

Coping

Do you always do whatever possible to resolve the problem?

Give an example.

Do you do any of the following on the scale of: very often – often--sometimes--seldom--never:

1. Think hard about how best you can handle the problem?
2. Do you wait a bit and think it through?
3. Do you try to get advice from a friend?
4. Do you talk to your colleagues/superiors?
5. Do you try seeing things in a more positive light?

Recall a challenge, threat or loss that you have experienced within the last six months?

What was it and how did it make you feel?

How did you deal with it?

What type of emotion do you experience when you are struggling to deal with challenges? For example, anger, despair, desperation, crying, sense of hopelessness or a sense of loss.

How do you overcome such emotion/s?

What do you do if you cannot cope? Do you do any of the following:

1. Do you become hostile?
2. Distant?
3. Self-controlling?
4. Seek social support?
5. Accept responsibility?
6. Avoid the problem and pretend it does not exist?
7. Come up with a plan to resolve it?

What type of issues do you find most difficult to cope with?

Do you have a personal attachment to some of your patients?

If yes? Are you always able to deal with seeing their condition deteriorating? If yes, how?

How does that make you feel?

Possible Strategies

How does the centre assist in helping you deal with issues pertaining to your work to help you cope?

What would you recommend should be done to deal with the problems mentioned above?

What new strategies would you recommend to be developed to assist you to cope with your work?

What old strategies need to be kept in assisting you to cope?

What old strategies need to be changed?

What changes would you recommend?

KOKETŠO YA D: TLHAHLO YA DITHERIŠANO - KA NORTHERN SOTHO

Matseno go lenaneo la ditherišano

Ke leboga kudu ge o tšeere karolo nyakišišong ye. Ke go tshepiša gore tsebo ka moka ye e hweditšwego nakong ya therišano e tla bolokwa e le sephiri gomme boitsebišo bja gago bo tla šireletšwa ka go šomiša leina la go iphihla go netefatša gore ditshedimošo tša go šupa boitsebišo bja gago di se utollwe le ka mohla o tee. Therišano ye e phethagatšwa ka tumelelo ye e tletšego ya gago gomme o na le tokelo ya go ikgogela morago nakong efe goba efe ge o ikwa gore ga o sa nyaka go tšwela pele.

Therišano ye e dirwa gore ke be le tsebo ya mošomo wo o o dirago bjalo ka mohlokamedi wa balwetši bao ba dulago lefelong la tlhokomelo ye e lego ya segae (HBCG), ditlhohlo tše o lebanago natšo, le ka moo o katanago ge o šoma le balwetši bao ba nago le HIV/AIDS (PALHIV) le seo o se dirago ge ba lebane le maemo ao a hlagišago kgatelelo.

Tshepetšo ya therišano e tla ba ka mokgwa wa therišano e tee le motšeakarolo o tee, yeo e tla tšeago nako ya metsotso ya gare ga ye 45 le ye 90. Ditherišano di tlo gatišwa ka segatišamantšu gomme go tlo ba le dintlha tše monyakišiši a tlo di ngwalago. Tabakgolo ke go utolla maitemogelo, maikutlo, se o se naganago, kgopolo ya gago mo gongwe le ge go ka ba le dipotšišo. Lemoga gore ga go karabo yeo e nepagetšego goba yeo e fošagetšego.

Dintlha ka ga dipalopalo mabapi le go belegwa, mahu bjalobjalo setšhabeng

Nomoro ya mofetodi

Mengwaga

Monna

Tshadi

Maemo a bjale:

Mengwaga maemong a

Mošomo

Maemo a mangwe senthareng

Mengwaga ya go šoma senthareng

Na o mošomi wa ka mehla goba wa nakwana?

Na o a lefša?

Dipotšišo tše di amago tlhahlo

Na ke mohuta ofe wa tlhahlo wo o o hweditšego?

Na tlhahlo e be e le ya nako ye kaakang?

O hlahlilwe kae?

Na o hweditše setifikeiti? Ge go le bjalo ka ga eng?

Mediro ya nako ye e fetilego ka PALHIV

Na o kile wa šoma le PALHIV pele go gongwe?

Ge go le bjalo kae le gona nako ye kaakang?

Lebaka la go tloga fao e be e le lefe?

Mošomo wa gago o be o le wa go dira eng?

Mathata lefelong la modiro

Na o šoma ka PALHIV?

Na o dira eng?

Na o rata modiro wa gago ?

Ke eng seo se go fago lebaka la go tsoga mesong gomme o ye mošomong?

Ke ditlhohlo dife tšeo o itemogelago tšona ge o šoma ka PALHIV?

Na o itemogela tšona gaka?

Na o rarolla ditlhohlo tše o itemogelago tšona bjang?

Go katana /rarolla bothata

Na o leka ka mo o ka kgonago go rarolla bothata?

Efa mohlala.

Na o dira se sengwe sa tše di latelago?

6. O nagana kudu ka ga ka moo o ka rarollago bothata?
7. O ipha nako gomme o naganišiše?
8. O leka go hwetša keletšo go mogwera wa gago?
9. O bolela le bašomimmogo/balaodi ba gago?
10. O leka go lebelela dilo ka leihlo la gore go tla loka?

Gopola tlhohlo, tšhošetšo goba tahlegelo tše o kilego wa itemogela tšona dikgweding tše tshela tša go feta?

Yona ke efe gomme e dirile gore o ikwe bjang?

Na o ile wa katana le yona bjang?

Ke maikutlo afe ao o itemogelago ona ge o katana le go lwantšha ditlhohlo?

1. O a befelwa?
2. O a itlhoboga?
3. O ba tlalelong?
4. O a lla?
5. O ba le tshepo?
6. O ikwa o le tahlegong?

Na o fenya maikutlo a mabjalo bjang?

Na o dira eng ge o palelwa ke go fenya bothata? Na o dira se sengwe sa tše di latelago?

8. Na o ba le lehloyo?
9. O ikgogela morago?
10. O ba le boitaolo?
11. O nyaka thekgo bathong?
12. O ba le boikarabelo?
13. O hlokomologa bothata wa dira o ka re ga bo gona?
14. O loga leano la go bo rarolla?

Ke mathata afe ao o hwetšago go le boima go a lwantšha?

Na o na le tswalano ye e tseneletšego le ba bangwe ba balwetši ba gago?

Ge go le bjalo? Na o kgona go itshwara ge o bona seemo sa bona sa bolwetši se ya fase? Ge go le bjalo, bjang?

Seo se dira gore o ikwe bjang?

Maano ao a ka kgonegago

Senthara e le thuša bjang gore le katane le mathata ao le kopanang le ona modirong wa lena gore le tle le thušege twantšhong ya ona?

O eletša gore go dirwe eng go thuša go lwantšha mathata ao a boletšwego ka godimo?

Ke maano afe a maswa ao o eletšago gore a latelwe go le thuša gore le tšwele pele gabotse ka mošomo wa lena?

Ke maano afe a kgale ao a swanetšego go se tlogelwe go le thuša go katana le mathata modirong wa lena?

Ke maano afe a kgale ao a swanetšego go fetolwa?

Ke diphetogo dife tše o ka eletšago go re di dirwe?

APPENDIX: E LETTER OF ETHICAL CLEARANCE FROM UNISA