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DEPARTMENT OF PSYCHOLOGY

Topic: The Experiences of NGO-Employed HIV Caregivers in Peri-Urban Informal Settlements, South Africa

By

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Declaration

I declare that this Research Report is my own original, unaided work. It is being submitted for the award of the degree of Masters by coursework and research report in the field of Research Psychology (MA) at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other university.

Candidate: Veronica Kemble

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Date……………………………

Date: ……………………………

Dedication

To all HIV infected and affected people in the world,

And to those who work tirelessly to care for them

Acknowledgements

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Abstract

Caregivers comprise a unique population of people who devote much of their time to the ill people whom they serve. This study aimed to examine the complex experiences of NGO-employed HIV caregivers in peri-urban informal settlements. This study provides an overview of the literature pertaining to NGO-employed HIV caregivers. Due to the fact that the caregivers who participated in this study worked for a faith-based organisation, this study examined the possible role of religiosity in influencing the experiences of the caregivers. Twelve in depth, semi-structured interviews were conducted with NGO-employed HIV caregivers who worked for a faith-based (Christian) organisation. Thematic content analysis was used to analyse data generated by the interviews. Religiosity is common to the majority of the themes identified, and seems to play an important role in the way in which the caregivers cope with stress, the way that they treat their patients, the way that caregivers perveive people in informal settlements to think about HIV, as well as the way in which they feel that communities within informal settlements think about and deal with HIV. The results of this study have various implications for future research, theory and policy regarding HIV caregivers, home-based care in South Africa, as well as the possible role of faith-based organisations in assisting with the HIV pandemic.

Abbreviation List

DOH	Department of Health
HBC	Home-Based Care
HIV/AIDS	Human Immunodeficiency Virus (HIV) / Acquired Immune Deficiency Syndrome
NGO	Non-Government Organisation
PLWH	People Living With HIV

Chapter 1: Introduction & Literature Review

1.1. Introduction

This study aimed to examine the experiences of NGO-employed HIV caregivers in peri-urban informal settlements. There is an impressive body of literature surrounding the Human Immunodeficiency Virus (HIV) / Acquired Immune Deficiency Syndrome (AIDS) pandemic. The majority of this literature is focused on the prevention and medical treatment of the disease, and not on the experiences of HIV caregivers. It is thought that HIV caregivers are faced with a unique caregiving situation which has implications for their mental and physical health. In South Africa, many people do not have access to adequate health care (Russel & Schneider, 2000). As a result, family members of individuals living with HIV, as well as caregivers from Non-Governmental Organisations (NGOs) are often the primary providers of care. In South Africa, there are a large number of NGOs that provide various support services to people affected by HIV and AIDS (Russel & Schneider, 2000). Clearly, care provided by these institutions constitutes a critical component of the health care system (Wight, 2000), however research on the experiences of HIV caregivers from NGOs is lacking. Consequently, understanding the experiences of these caregivers is pertinent.

To date, the majority of the literature in caregivers that *has* been conducted has not focused on the specific concerns of HIV caregivers in peri-urban informal settlements in developing countries; most studies have been done in developed countries such as the USA, Great Britain and Australia. These countries have significantly lower levels of unemployment, better social support and healthcare systems and lower HIV infection rates than South Africa (Kingdon & Knight, 2004). In South Africa, 40% of the population is affected by poverty, most of whom live in rural areas and peri-urban informal settlements which have limited access to even the basic living essentials of safe drinking water, food and sanitation. ‘Poverty’ is defined here in accordance with the World Bank definition which states that an individual is deemed ‘poor’ if they have less than $1.25 per day (Chen & Ravallion, 2008). Given that a large number of PLWH in South Africa are affected by poverty, research examining the experiences of caregivers within this context is important.

Furthermore, it is thought that the guiding theories of previous studies may not be appropriate for use in contexts affected by poverty as the premises on which they are based are too narrow. For example, Folkman (1997) analyses the results of her study using a comprehensive coping model to frame the experiences of HIV caregivers. It is argued that highly specific theoretical models are inappropriate in the current study in that they only allow for a one-dimensional view of the caregiving experience (for example, examining the caregiving experience from a psychological perspective using stress and coping as key focal points). Additionally, such theories tend to ignore the complex, transactional relationships between HIV caregivers and the numerous factors which could possibly impact on their experiences. Thus it would be useful to conduct a study which is guided by a more holistic, social-epidemiological theoretical framework. Within this framework, it is thought that the ecosocial theory would be most appropriate in the present study in that it allows for the possibility of numerous factors at multiple influencing levels that may impact on the experiences of HIV caregivers.

This study provides an overview of the literature pertaining to NGO-employed HIV caregivers (Chapter 1). This study aimed to examine the factors which impact on the experiences of NGO-employed HIV caregivers who work in peri-urban infornal settlements. Due to the fact that the caregivers who participated in this study worked for a faith-based organisation, this study examined the possible role of religiosity in influencing the experiences of the caregivers. Twelve in depth, semi-structured interviews were conducted with NGO-employed HIV caregivers who worked for a faith-based, Christian organisation (Chapter 2). The results of the study (Chapter 3) reveal themes related to various factors which are involved in impacting on the experiences of the caregivers. Religiosity is common to the majority of the sub-themes identified in this study, and seems to play an important role in numerous aspects of the caregivers' lives, as well as the way in which religiosity is perceived to impact on the lives of those living with HIV. The results of this study have various implications for future research, theory and policy regarding HIV caregivers, home-based care in South Africa, as well as the possible role of faith-based organisations in assisting with the HIV pandemic (this is discussed in more detail in Chapter 4).

1.2. Literature Review

This section provides an overview of the HIV/AIDS pandemic in South Africa, as well as what is being done in terms of home-based care for those who are HIV positive in the country. It then looks at the unique role of NGO-employed HIV caregivers in contexts of poverty, as well as the possible role of religiosity in these contexts. Lastly, ecosocial theory is discussed with relevance to the current study.

1.2.1. The HIV/AIDS Pandemic: An overview

The number of people living with HIV worldwide is increasing. Everyday "more than 6800 people become infected with HIV, and more than 5700 die" (WHO, 2009, p. 1). HIV is the most serious infectious disease in the world, and is an enormous challenge to global public health (WHO, 2009). Particularly at risk are: sex workers, men who have sex with men, injecting drug users as well as migrant populations (WHO, 2009). In addition, it affects females disproportionately, with women accounting for about 60% of all HIV infections in sub-Saharan Africa (UNAIDS & WHO, 2009).

The high infection and death rates due to HIV are indicative of people's lack of access to effective intervention programmes, and to treatment and care services, all of which are necessary to form a comprehensive system for managing the disease (WHO, 2009). Despite the fact that infection rates remain high, there has been considerable progress in the treatment of HIV, and more and more people are able to access antiretroviral therapy (ART); which has led to an increasing number of PLWH (Scovdal & Ogutu, 2009). South Africa has the largest population of people living with HIV in the world, with 5.7 million people living with the disease (UNAIDS & WHO, 2009). The extended lives of PLWH have implications for the potential need for caregivers. Typically, individuals who become infected with HIV go through 4 clinical stages. As the virus progresses, the individual's CD4 count decreases, making individuals more likely to contract opportunistic infections (especially if they are not on Anti-retroviral treatment – ART) (WHO, 2007). The first stage is often asymptomatic (although it can be associated with high fever and persistent swelling of the lymph nodes); stage 2 is characterised by moderate symptoms (for example, unexplained weight loss, recurrent oral ulcers, and respiratory tract infections). Stages 3 and 4 mark the individual's progression into AIDS, where the individuals' CD4 count decreases to 200 or less (WHO, 2007). Each stage of HIV/AIDS, encompasses new challenges to those who provide care.

In the advanced stages of HIV, the individual experiences more severe symptoms and opportunistic infections (for example, severe weight loss, chronic diarrhoea, persistent fever, HIV wasting syndrome, and tuberculosis), and they can be said to have AIDS (WHO, 2007). The final two stages in the progression of HIV place a significant burden on public health systems to provide care to PLWH, the needs of whom are often unable to be met by health professionals due to a lack of resources as well as the large number of PLWH who require assistance. Additionally, people in developing countries often cannot afford to pay for the transport to get to hospitals to collect Anti-Retroviral medication if this is available (Maskew et al, 2007). The lack of resources, along with various other factors (such as stigma) has meant that many PLWH in developing countries rely on the assistance of informal caregivers (such as family members and friends) as well as caregivers from NGOs for assistance in managing their illness (Knowlton, 2003, Freeman & Nkomo, 2006).

Informal caregivers are defined as family members of an individual living with HIV, or individuals who choose to look after the PLWH (such as friends) who care for the person at home (Brown & Powell-Cope, 1993). NGO caregivers comprise a unique caregiving population in that they are not regarded as informal caregivers (in that they are not family members or friends of the PLWH), nor are they formal caregivers in the sense that they are not health care professionals (such as qualified nurses or doctors).

The South African government has been unable to provide adequate care to the large number of PLWH in South Africa; terminally ill people are discharged from hospitals to free up space for those who can be cured. The argument is that terminally ill patients will then be able to die at home, surrounded by friends and family (Cullinan, 2000). Often, however, the families of PLWH do not have the resources available to provide adequate home-based care (HBC) to their loved ones. Additionally, the role of the state in this regard is not well defined, thus placing the burden of HIV epidemic on the shoulders of South Africa's poorest communities.

Numerous NGOs have formed in an attempt to assist the millions of people affected by the HIV/AIDS.

1.2.2. HIV/AIDS: The Unique Caregiving Experience

The term ‘caregiver’ implies an individual’s provision of “some type of assistance to another person” (Wight, 2000, p. 760). While there is a large body of literature which examines the caregiving experiences of chronic illnesses such as Alzheimer’s disease and cancer (see for example, Covinsky, Newcomer, Fox et al, 2003; Grant et al, 2002; Nijboer et al, 1999; Raveis, Karus & Siegel, 1998), there has been a lack of attention paid to the experiences of HIV caregivers (Wight, 2000, Carlisle, 2000). Additionally, the literature regarding HIV/AIDS has been largely focused on the prevention and treatment of the disease, and most studies have focused on the symptoms and experiences of the person living with HIV (Silverman, 1993) – rather than the experiences of the caregivers.

A study by Ward and Brown (1994) found that informal HIV caregivers spent large amounts of time caring for the PLWH (8.5 hours a day for personal care of the patient, and about 5 hours a week doing house work for the patient). Similarly, caregivers from NGOs may be under a large amount of pressure to provide care for numerous patients, especially in peri-urban informal settlements where there are high levels of poverty. The current research will focus on the experiences of HIV caregivers from an NGO (‘Refilwe Life for All’) which cares for people in peri-urban informal settlements; such as Zandspruit, Thabo Mbeki, Malatji, Joe Slovo, Rhinos and Video; situated in and around Lanseria, north of Johannesburg. Understanding the experiences of HIV caregivers is pertinent, in that they constitute a “critical component of the health care system” (Wight, 2000, p. 760). Given that the DOH has stipulated that PLWH need to be taken care of at home, caregivers from NGOs play a vital role in supporting the needs of PLWH by taking care of them when they are ill in the absence (or unwillingness) of family members and friends.

For many persons infected with HIV, the normal channels of social support are not available, and may not have been available for some time (for example, in homosexual individuals) –

this is often due to stigma as the family of the PLWH may assume that he/she contracted the disease due to promiscuity. Alternatively, the family of the PLWH may be afraid to acknowledge their HIV diagnosis. Thus, many PLWH are alienated from their families who would traditionally be viewed as “a source of social, emotional and physical support when a member has an illness” (Carlisle, 2000, p. 751). While many, if not most, caregivers in developing countries are family relatives of the PLWH (Freeman & Nkomo, 2006), this is not always the case in that people who have HIV/AIDS often redefine their concept of ‘family’, and extend this understanding to include their “chosen kin” (Carlisle, 2000, p. 751). A collaboration of various caregivers may therefore be involved in supporting the PLWH throughout their illness; family members, friends, NGO caregivers as well as health care professionals all play important roles in caring for the PLWH (Panchaud & Cattacin, 1997).

Although the current research will focus on NGO caregivers, it should be noted that due to the increasing number of people living with HIV, it is not uncommon to find caregivers who are children under the age of 18. Often, one or both parents become infected with HIV, and the children (often the girls) are forced to drop out of school to care for their parents (Freeman & Nkomo, 2006; Keigher, Zabler, Robinson, Fernandez & Stevens, 2005; Skovdal & Ogutu, 2009). This transfer of parental roles leads to the phenomenon of the ‘parentified child’ (Keigher et al, 2005) who assumes responsibility for other siblings, and for the care of the parents.

Caregiving is thought to be a highly stressful process, especially if one is providing care to a spouse or partner who eventually dies (Akintola, 2004, Folkman, 1997). A large body of literature consistently associates caregiving with psychological distress. It has been found that HIV caregivers often suffer from psychological distress, depression, and general ill mental and physical health (See for example: Keigher, 2005; Knowlton, 2003; Pirraglia et al, 2004; Silverman, 1993; Wacharasin & Homchampa, 2008; Wight, 2000). This may be partially due to the stress associated with being a caregiver of a PLWH, which can be highly demanding especially in terms of the opportunistic infections and diseases (for example Tuberculosis, Hepatitis, Malaria and other STD’s) which are characteristic of advanced HIV (Guberski, 2007). Notably, the majority of the literature pertaining to the HIV caregiving experience has focused on the stress experienced by family caregivers. Since there are so many NGO caregivers in South Africa, research on their experiences is pertinent.

In addition to the above-mentioned stressors, HIV caregivers are faced with the added stress of stigma (Zelnick & O'Donnel, 2005). More so than other chronic illnesses, HIV/AIDS is shrouded in stigma. Negative social attitudes such as stigma and discrimination against people who are HIV positive are often prevalent, and impede treatment and intervention programmes (Zelnick & O'Donnell, 2005; Holzemer et al, 2006).

Stigmatisation "devalues people because of their traits, behaviours or illnesses, and it is often followed by unfair and unjust treatment" (WHO, 2009, p. 66). Stigma also makes individuals more reluctant to go for HIV testing – and to disclose their HIV status to their loved ones – this is seen in a study done by Chimwaza and Watkins (2004) in rural Malawi where many of the caregivers were reluctant to name HIV/AIDS as their patient's disease and offered alternative diagnoses. It is thought that this reluctance to name AIDS as the disease is "due to its association with promiscuity, an association emphasised in the AIDS prevention messages of the government and international donors" (Chimwaza & Watkins, 2004, p. 805). In South Africa, stigma around HIV/AIDS is a major cause for concern in prevention and treatment programmes. It would be interesting to examine how caregivers from NGOs deal with stigma regarding HIV/AIDS in the communities which they serve.

HIV caregivers are therefore often faced with large amounts of stress in assisting PLWH. Since this study focuses on HIV caregivers who provide care in peri-urban informal settlements which are often resource poor (Akintola, 2004), the effects of poverty on PLWH and their caregivers will now be discussed.

1.2.3. Home-Based Care and South African Policy

In South Africa, approximately 46.2% of patients seeking care at public hospitals are HIV positive (Akintola, 2006). In response to the increasing demands on health care, as well as the limited health care resources in South Africa (there is a shortage of hospital beds, there are not enough qualified health professionals, and hospitals are often overcrowded) the South

African government and Department of Health (DOH, 2001) have begun to promote home-based care (HBC) for PLWH.

In 2001, the South African Department of Health (DOH) published the National Guidelines on Home-Based Care/ Community-Based Care (2001); these guidelines were intended to facilitate the implementation of HBC. It is stipulated within this document that "no single entity is able to meet the requirements and challenges of home-based care" (p. 1), and that multiple stakeholders including the formal healthcare system (i.e. healthcare professionals), family members, caregivers from the non-formal sector (i.e. NGOs), as well as caregivers from the informal sector (for example community volunteers and church members) need to work together in order to provide adequate care to those who are living with HIV (DOH, 2001). By involving numerous stakeholders, the aim of HBC is to provide a 'continuum of care' to PLWH which "addresses the range of needs of PLWHAs, from diagnosis through to death and bereavement; and creating effective referral linkages between all actors in meeting these needs" (Russel & Schneider, 2000, p. 8).

Despite the recognition by the DOH that a wide range of stakeholders needs to be involved if HBC is to be successful, the responsibility for implementing HBC has largely been placed in the hands of communities and the family members of the ill (Russel & Schneider, 2000), while the efforts of government are still largely focused on awareness and prevention campaigns (Stachan, 2000). Various NGOs have been formed to improve the situation, however often they do not have enough resources to deal with the various challenges associated with caring for PLWH over time (such as the need for child care services whose parents are sick, provision of material support for the families of the ill individual, as well as services which care for orphans) (Akintola, 2004). Additionally, many NGO programmes rely on volunteers from the community who are often not paid, or are paid a small stipend. Therefore, the burden of HBC falls largely on the families affected by HIV/AIDS, as well as communities. Caregiving is highly gendered; the majority of caregivers are women and girls, for example, 68% of primary caregivers were women in a study conducted by Steinberg et al (2002). Akintola (2006) argues that the gendered nature of caregiving reinforces gender inequalities in South Africa, and defies the Millenium Development Goal of gender equality in that women are often not paid for the critical role they play in providing HBC to PLWH.

One of the major advantages of HBC which is stipulated in the guidelines published by the DOH (2001) is that it will reduce the cost of care within the formal health care system. However, whether or not HBC is a ‘cheaper’ option has been fiercely debated. Home-based care programmes are often viewed as the most cost effective manner in which to deal with the challenges associated with providing care to PLWH in that it is cheaper than hospital care, saves hospitals money, and “frees beds for patients who can be cured” (Cullinan, 2000, p. 3). However, this view has been challenged.

Home-based care may be cheaper than hospital care in monetary terms, however, the burden that it places on communities and family members (including children) to provide care to PLWH encompasses various hidden costs; including the decreased mental and physical health of the caregivers, the costs to society involved in removing children from school to assist in caring, and the further entrenchment of gender inequalities as women often fill the role of unpaid caregivers. Additionally, HBC requires large-scale training programmes to ensure that family members and volunteers are prepared to handle the numerous medical challenges that they may be faced with in providing care to PLWH. Cullinan (2000) argues that “if state health facilities are simply going to discharge AIDS patients and assume they will be cared for ‘at home’, HBC will simply be a brutal form of privatisation where the poorest communities are expected to bear the greatest burden of the epidemic” (p. 3). Thus, tension exists as to who is responsible for providing home-based care to PLWH, how various stakeholders will work together to provide adequate care, as well as who will pay for this care if PLWH are to be taken care of at home instead of at state-funded hospitals. There is thus a need for research which focused on the experiences of home-based HIV caregivers in order to inform policy regarding home-based care in South Africa.

1.2.4. Poverty and HIV Caregiving

The reciprocal relationship between HIV and poverty is well documented (For example, Guberski, 2007; Hughes, 2007; Manase, Nkuna & Ngorima, 2009; Poku, 2002). However, very few studies have examined the experiences of HIV caregivers in settings of extreme poverty. Poverty in South Africa is high, affecting approximately 40% of the population (Manase, Nkuna & Ngorima, 2009).

The impact of poverty on the lives of PLWH also has implications for the HIV caregivers. Although there has been a great improvement in the availability of ART, many people are still going without this life-saving medication because they cannot afford the cost of transport to attend at hospitals and clinics distributing the medication. Thus, they are unable to adhere to the strict treatment routine. In addition, PLWH who are poor may not have access to enough supplementary food which is needed in conjunction with the ART medication (Poku, 2002; Skovdal & Ogutu, 2009). This struggle to provide enough food for the PLWH causes frustration and feelings of hopelessness for caregivers in peri-urban informal settlements. This is illustrated in the study done in rural Malawi by Chimwaza and Watkins (2004), where caregivers said that their patients crave “special foods – fish, meat and sodas” (p. 803), and that it pained them when they couldn’t afford this food which they believed would prolong their patients’ lives, “Sometimes when my son tells me ‘I want such and such a thing’, I cry after I fail to think how I can find the things he wants” (p. 803). While the study done by Chimwaza and Watkins (2004) was done in a rural area in Malawi which is characterised by extreme levels of poverty, the situation may be similar for PLWH in peri-urban informal settlements in South Africa, as these areas are also characterised by high levels of unemployment and low monthly incomes (de Wet et al, 2001).

Caregivers from NGOs who work in informal settlements in South Africa may feel frustrated in that they may not have access to adequate resources with which to help the people whom they serve. Many informal settlements in South Africa are highly overcrowded and have inadequate infrastructure to support the numbers of residents, thus resulting in poor access to safe drinking water and sanitation facilities (such as flushable toilets) (de Wet et al, 2001). Additionally, NGOs rely on financial support from various donors, and receive little or no support from the government. Thus, ensuring that there are enough resources to meet the needs of PLWH may be a difficult task, and may limit the amount and quality of care that NGO caregivers are able to provide. Therefore, HIV represents a major challenge, particularly in informal settlements where there are a large number of individuals who require assistance in dealing with the repercussions of HIV and AIDS (Thomas, 2002).

1.2.5. Caregiving and Religiosity

Due to the severity of the HIV epidemic in South Africa, it is important for research to focus on various possible interventions which may have a positive impact on the lives of PLWH. Due to the fact that the caregivers who participated in this study worked for a faith-based organisation, the role of religiosity on the experiences of both PLWH, as well as the caregivers who assist them was examined. The definition of religiosity for the purposes of this study includes, but is not limited to attendance or involvement in a church, the individual's sense of spirituality, their perceived support from a church or members thereof, as well as the influence of religion or religious beliefs in everyday life (Bennet, Deluca & Allen, 1995; Elifson, Klein & Sterk, 2003). It is argued that faith-based organisations may have a vital role to play in assisting people living with, and affected by HIV; these organisations often have access to a wide audience, are an integral focal point of many communities. Additionally, the leaders of faith-based organisations are often highly respected (Francis & Liverpool, 2009). Faith-based organisations could therefore play an important role in disseminating HIV prevention messages, as well as other HIV-related information to communities (Francis & Liverpool, 2009).

Not only could faith-based organisations play a role in HIV prevention interventions, religious communities could be a crucial source of social support to PLWH and their families; in a study done by McIntosh, Silver and Wortman (1993), religious participation was shown to be "related to increased perception of social support" (p. 812). The value of religious faith and spirituality in assisting individuals who are recovering from problems such as post-traumatic stress disorder, substance abuse, and in coping with negative life events is well documented (see for example Carter, 1998; George et al, 2000; Mcintosh et al, 1993 & Pardini et al, 2000). Additionally, religion has been related to greater optimism, less alcohol use, as well as a greater sense of self worth (Cotton et al, 2006). Various recovery interventions incorporate spirituality and religion – one of the most well-known is the 12-step recovery programme, advocated by the Alcoholics Anonymous organisation (Steigerwald & Stone, 1998). Additionally, faith-based intervention programmes have been found to have positive results in reducing tobacco addiction, in assisting individuals to participate in regular excercise, have proper nutrition and go for routine check-ups (such as mammographies); and have even been shown to reduce the perpetration of domestic violence (Elifson, Klein &

Sterk, 2003). However, despite findings of the positive role of religiosity on health behaviours, as well as in assisting people to cope with negative life events, very little research exists which examines the role of religion in assisting those living with and affected by HIV. It has been suggested that this could be due, in part, to a reluctance of researchers to involve spiritual leaders in HIV prevention and intervention activities for fear that these leaders would communicate negative, or conservative messages regarding condom use and safe sexual behaviours (Elifson, Klein & Sterk, 2003).

Despite these concerns, studies have found that spiritual leaders *do* consider HIV as a serious health concern facing their congregations, and acknowledge the need for education in this regard (see for example Coyne-Beasley & Schoenbach, 2000). Therefore, although there may be barriers present in involving faith-based organisations in the prevention and intervention of HIV (such as a reluctance to discuss condom use or safe sex practices), more research is needed on the possible role of these organisations in assisting with the HIV pandemic, as well as providing support to caregivers and PLWH.

1.2.6. Social-Epidemiology: The Ecosocial Theory

In order to gain a more holistic understanding of the experiences of HIV caregivers in peri-urban informal settlements, a social-epidemiological framework was employed to guide the present research. Social epidemiology is a multidisciplinary approach which is concerned with the social determinants of health (Kawachi, 2002). In other words, social epidemiology attempts to incorporate theories and explanations from a wide variety of social science perspectives in order to gain a more holistic sense of the numerous influencing factors which may impact on the health of individuals and populations (Kawachi, 2002). For example, social epidemiology may incorporate psychological perspectives (such as stress and coping variables); sociological perspectives (such as culture and stigma); economic variables as well as political science theories.

For the purposes of the current study, it is thought that a broad social-epidemiological framework would be more useful in guiding the examination of the experiences of HIV caregivers than the theories which have been used in previous studies (as discussed previously). In particular, the ecosocial theory was used to guide the current research in terms of the focus of the interview questions (i.e. in the data-gathering procedure – see methods section) in that questions were developed and structured around the various possible dimensions, or levels, of factors which could impact on the experiences of NGO-employed HIV caregivers.

There are three main theories within the social-epidemiological perspective, all of which attempt to provide an explanation of the social determinants of health (Krieger, 2001). Firstly, the psychosocial theory highlights the importance of individual agency in living a healthy lifestyle, while also arguing that individuals need to be seen as part of a larger environment, or society, which plays a role in determining their health. Secondly, the theory of the social production of disease and the political economy of health offers a materialist analysis of health by focusing less on individual lifestyles and more on the economic and political determinants of health - such as “structural barriers to people living healthy lives” (Krieger, 2001, p. 670). The final, and most relevant theory for the current study is the ecosocial theory. The ecosocial theory argues for a multidimensional, dynamic view of the determinants of health. From this perspective, an individual’s health is determined by numerous, dynamic factors which are not independent, but are “intertwined at every scale, micro to macro” (Krieger, 2001, p. 671).

It is thought that the ecosocial theory was useful in guiding the current research in that it allowed for the inclusion of multiple possible influencing factors, operating at various levels which could impact on the experiences of HIV caregivers. For example, from a psychological perspective, there are numerous factors identified in the literature which could possibly have an impact on the experiences of caregivers in peri-urban informal settlements: the burden experienced by the caregiver – defined as “the negative impact of caregiving on the caregiver’s life” (Pirraglia et al, 2004, p. 510); the caregivers’ cognitive appraisal (the way in which the caregivers subjectively cope with the disruptions in their lives which are caused by providing care to a PLWH); the caregivers’ coping resources (for example, available social support); coping strategies (such as problem-solving skills); and the caregivers’ ability to make meaning out of their experiences.

From a sociological viewpoint, it is important to account for the local understandings of the caregivers, in that some cultures may view caregiving as a duty and service that is not something which is viewed as a ‘burden’. For example, a study done in Thailand (Wacharasin & Homchampa, 2008) emphasised the impact of the Thai culture of mutual support in the experiences of HIV caregivers. In addition, a study done in Western Kenya (Skovdal & Ogutu, 2009) shows how child caregivers are able to construct positive identities around the meanings associated with caregiving in their culture. Culture may also determine the level of social cohesion in communities, thus impacting on the level of social support available to HIV caregivers. The social context may also impact on the way in which HIV has redefined the concept of ‘family’; stigma related to the disease may prevent family members from caring for a relative with HIV and may also limit the amount of support that an HIV caregiver from an NGO feels he/she has access to (Holzemer et al, 2006).

Furthermore, caregivers of NGOs will need to work together to provide care to the individuals whom they serve, and may be a source of support for one another in stressful situations. Importantly, caregivers who work for the NGO of interest in this study (Refilwe for Life) live within the communities which they serve. This has implications for the numerous roles which they may play; for example: as NGO caregivers, neighbours, mothers/fathers, or community leaders. Due to the fact that the HIV prevalence rates in South Africa are so high (and affect women disproportionately), there is also the possibility that the caregivers may be HIV positive themselves. Thus, the multiple challenges faced and roles played by the NGO caregivers need to be considered.

Financial variables also influence the experiences of caregivers. The reciprocal relationship between poverty and HIV, as well as the impact of caring for a PLWH on caregivers has already been discussed. There are several factors associated with poverty which may impact on the experiences of HIV caregivers – for example, unemployment, lack of adequate drinking water and sanitation, lack of food security and lack of access to healthcare for PLWH. Additionally, the financial resources available to the NGO may impact on the amount and quality of care which the caregivers are able to provide to PLWH. This too may influence the caregiving experience.

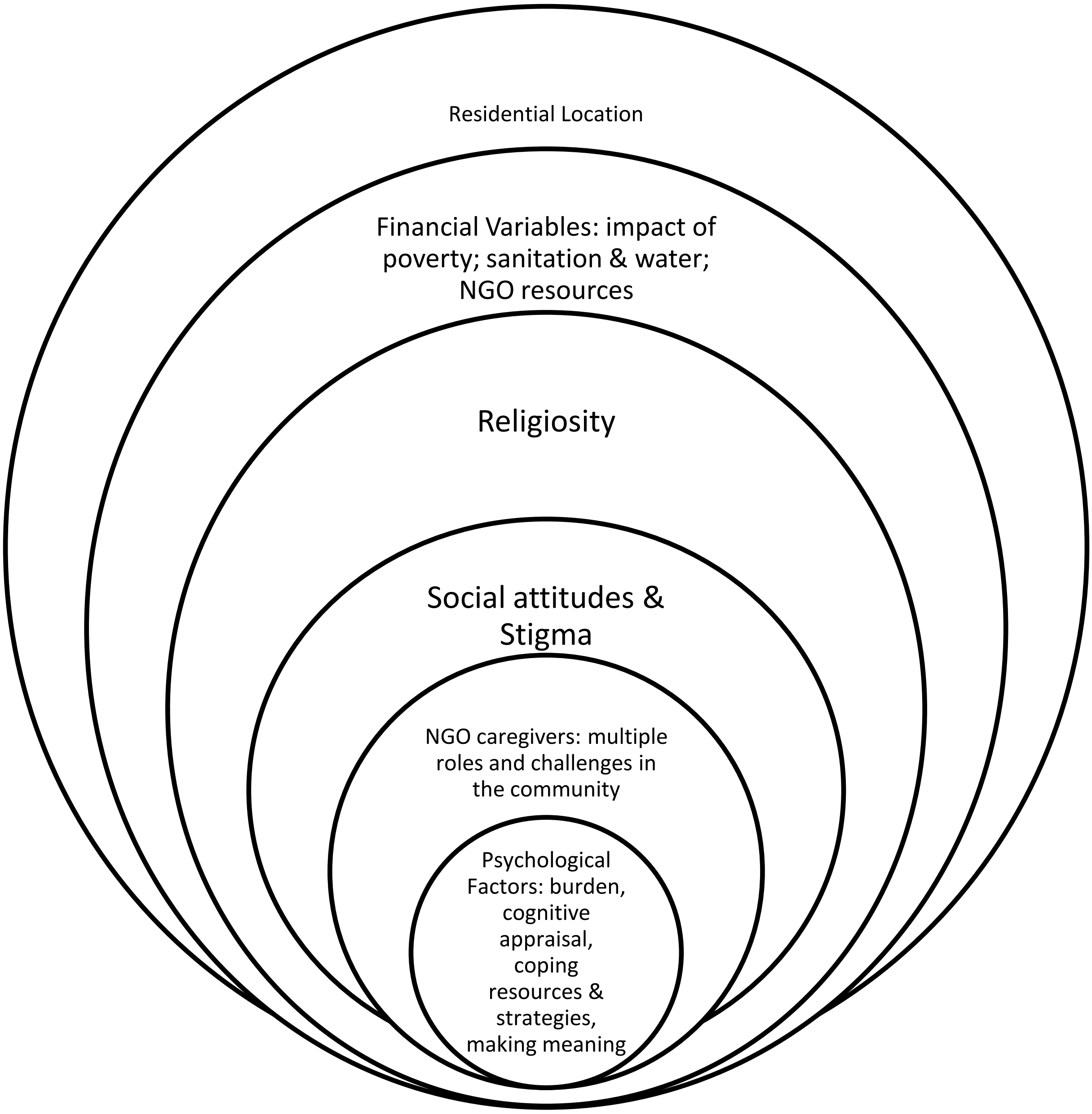
Furthermore, the religious beliefs of the caregivers may impact on their experiences. Folkman (1997) points to the importance of spiritual practices and beliefs in helping HIV caregivers to cope with their situations. It is argued that the religious practices of the caregivers may present a source of social support for them. Additionally, religion may be an important form of social support for PLWH, and may assist them with dealing with negative life events. This study will examine the role of religiosity in the lives of NGO-employed HIV caregivers and their patients. As discussed previously, faith-based organisations may have an important role to play in HIV prevention and intervention strategies.

Of particular relevance to this study is the impact of the residential location of the PLWH, as this may influence the experiences of NGO caregivers. This study will examine the experiences of HIV caregivers who care for people in informal settlements in and around Lanseria, Johannesburg. Informal settlements represent a “radically different social context than the suburbs” (Myer et al, 2003, p. 116), in that they are often highly overcrowded, and lack the basic infrastructure to provide residents with adequate drinking water and sanitation such as access to flushable toilets, individuals living in these areas may not have access to adequate nutrition – yet another health risk for PLWH. This lack of adequate sanitation and resources has implications for PLWH in that it puts them at greater risk of opportunistic infections. Therefore, informal settlements in South Africa display many of the inequalities of Apartheid with households experiencing inadequate access to water, sanitation and electricity. Additionally, informal settlements are often characterised by high levels of unemployment and low monthly incomes (de Wet et al, 2001). HIV represents a major challenge, particularly in informal settlements - according to Thomas (2002), people living in informal settlements are “the most vulnerable, often marginalised and unable to mobilise resources” (p. 116).

The residential location of PLWH, and the contexts in which care is provided is a function of South Africa’s legacy of apartheid. According to Krieger (2001), “it is fairly obvious that population patterns of good and bad health mirror population distributions of deprivation and privilege” (p. 668), and South Africa is no exception. The impact of the political environment on the experiences of HIV caregivers is particularly important in the South African context, The effects of the previous legacy of political, social and economic discrimination are enduring, and continue to have an impact on the lives of large population groups in South Africa – “Extreme disparities in wealth and income persist; the national Gini coefficient for income inequality (0.58) demonstrates the second-highest level of inequality among all countries worldwide” (Myer et al, 2003, p. 114).

1.3. Conceptual Framework

While various factors which could impact on the experiences of HIV caregivers in peri-urban informal settlements have been discussed, it is important to note that this is not a ‘neat’, definitive model. Therefore, while the following conceptual framework will guide the current research, it allows for new ideas and factors to be identified in the data-gathering and analysis procedure.



1.4. Research Questions

- What factors influence the experiences of NGO-employed HIV caregivers in peri-urban informal settlements?

- How important is religiosity in the experiences of NGO-employed caregivers?

- What are the implications of the experiences of NGO-employed HIV caregivers in peri-urban informal settlements for theory, future research and policy?

Chapter 2: Methodology

2.1. Research Design

This was a qualitative study which aimed to form the basis of understanding for future studies on the experiences of NGO-employed HIV caregivers, working in peri-urban informal settlements in South Africa. This study made use of a cross-sectional design, with one group of HIV caregivers. Qualitative methods of obtaining and analysing data were employed in order to gain a detailed, in-depth understanding of the unique experiences of these caregivers.

2.2. Sample

A purposive, criterion sample of 12 caregivers of PLWH was obtained for this study. The sample was located from the NGO 'Refilwe Life for All', a small organisation which employs about 14 home-based caregivers (who provide care to PLWH in informal settlements), as well as 8 house parents (who manage the childrens' home facility). Refilwe Life for All provides home-based care for PLWH in peri-urban informal settlements North of Johannesburg (such as Zandspruit, Thabo Mbeki, Malatji, Joe Slovo, Rhinos and Video); as well as a home for vulnerable or orphaned children. These areas are characterised by poverty, unemployment and overcrowding, and are home to over 120 000 people. This study did not focus on child caregivers, thus the age of the participants is 18 years or older. HIV caregivers who work for 'Refilwe Life for All' are paid a stipend, and live in the communities which they serve. Refilwe life for all is a faith-based organisation and was chosen for this study in order to examine the possible role of religiosity in addressing the HIV/AIDS pandemic, since this topic is highly under-researched. Additionally, while invitations to participate in the research were extended to four other faith-based NGOs providing home-based care to PLWH in Gauteng, Refilwe Life for All was the only organisation that responded in time for field work to commence. The organisation was founded in 1981 as a Christian based community development initiative, focused in resource-poor areas in and around Lanseria, Johannesburg. While the organisation is not aligned to any specific church, its values, ethos, vision and mission are strongly tied to Christian beliefs.

Initially, an invitation to participate in the study was sent to the organisation and was conveyed to the caregivers by their area managers (Appendix A). The researcher was then informed that there were interested participants, and times were set up for interviews to be conducted. It was decided that interviews would be conducted over a period of three days in order for the researcher to be able to travel to as many of the areas as possible. The organisation kindly offered to drive the researcher from the organisation to each area. Given that most of the caregivers live in the areas that they serve, eight of the interviews were conducted in their homes. Four of the caregivers preferred not to hold the interviews in their homes, and as such interviews took place in the organisation's vehicle while the driver waited outside.

Being both an HIV patient as well as an HIV caregiver presents a 'dual challenge' to these individuals (Hackl et al, 1997), in that they need to manage their own illness as well as provide care for others. Although the researcher did not ask the participants about their HIV status, 4 participants voluntarily disclosed this information during the interview. As a result, the dual challenge of being an HIV patient and an HIV caregiver was explored in these interviews.

Demographic characteristics of the sample

The following table provides an overview of the demographic characteristics of the sample of participants in this study. Four of the participants revealed that they were HIV positive.

Table 2.1: Demographic characteristics of the sample

Participant	Sex	Length of Employment at NGO	Length of time providing care to PLWH
1	Female	1 year	1 year
2	Female	2 months	1 year
3	Female	1 year	9 years
4	Female	3 months	3 months
5	Female	1 year	6 years

6	Female	2 years	2 years
7	Female	2 years	2 years
8	Male	2 years	2 years
9	Female	2 years	3 years
10	Female	1 year	1 year
11	Female	1.5 years	1.5 years
12	Female	3 months	1 year

All but one of the participants was female. The length of time spent working as an HIV caregiver for the NGO ranged from 2 months to 3 years. Most of the participants indicated that they had been providing care to PLWH for a longer period of time than they had been employed by the NGO. This may be an indication of the DOH’s move towards HBC, where community members often take responsibility for PLWH.

2.3. Instruments

Semi-structured interviews were conducted (Appendix G). Interviews were used in order to gain a detailed understanding of the participants’ experiences of caring for PLWH. The use of interviews allowed the researcher to explore the experiences, feelings, and coping strategies of the respondents in relation to being a caregiver of PLWH. Semi-structured interviews were chosen for this study to allow the researcher to be flexible when questioning the participants; more questions could be asked in order to ‘probe’ the participants for more detailed answers. While semi-structured interviews allow flexibility they also provided some structure in the interview process to keep the conversation focused on key areas of interest in the study. The sections in the interview schedule are guided by the social-epidemiological framework in that they ask questions pertaining to the various possible influencing factors (outlined earlier) which may impact on the experiences of the caregivers.

The interview schedule examined the psychological factors which impact on the caregiving experience as well as the possible ways in which the residential location of the PLWH influences caregiving. It asked questions pertaining to the possible influence of religiosity, as well as impact of economic variables on the caregiving experience.

2.4. Procedure

Permission was obtained from the NGO ‘Refilwe Life for All’ for the researcher to interview the caregivers of the organisation (Appendix G), and ethical clearance was obtained from the University of the Witwatersrand (Appendix I). The researcher sent an invitation to participate in the research via e-mail to the area supervisors of the various communities which ‘Refilwe Life for All’ serves, explaining what the research is about and why it is important (Appendix A). The area supervisors then conveyed the invitation to participate in the research to the caregivers, and informed the researcher if caregivers were willing to participate in the study. Following this, times were set up, and the interviews were conducted.

Twelve caregivers participated in this study. Participants were given an information sheet to inform them of the study (Appendix B). Once they had received the information sheet, participants were asked to sign the consent form for the interview (Appendix C), and for the recording of the interviews (Appendix D). One interview, lasting approximately 45 minutes to an hour, was conducted with each participant. A translator was not needed in conducting or transcribing the interviews because the caregivers could speak English. Interviews were either conducted in the caregiver’s homes, or alternatively in the vehicle which was provided by the organisation while the driver waited outside.

In addition to conducting interviews, field notes were kept by the researcher in order to contextualise the interviews within the context of the informal settlements – the field notes served as a record of the circumstances under which the caregivers were providing care to the PLWH. Care was taken to ensure the confidentiality of the participants in that while the area supervisors and co-workers of the caregivers may have been aware of which caregivers volunteered to participate in the study, they will not be able to link the responses in the research report to any particular individual as the participants are from different communities, and all details which may be used to identify the caregivers have been omitted in the research report – such as the participants' names. Additionally, the director of Refilwe Life for All will not know who participated in the interviews. All audio tapes and transcriptions have been stored in a safe place for the duration of the study, and will be destroyed after the research report has been examined and passed.

2.5. Data Analysis

The data obtained in this study was analysed from a constructivist paradigm in that it was assumed that individuals construct and interpret their *own* realities. The constructivist paradigm assumes that there is no external, essential Truth, but that individuals are part of a social world and use symbols and language to construct meaning, a sense of self, as well as a sense of their own realities (Phillips, 1995; Taylor & Ussher, 2001). Therefore, this study did not attempt to portray a single reality of HIV caregivers, but attempted to generate themes in order to identify some of the common ways in which the caregivers in this study think about, construct and talk about their lives.

Thematic content analysis (Braun & Clarke, 2006) was used in order to analyse the data obtained from the interviews, in order determine whether there are common themes present in the experiences of the caregivers. The thematic content analysis conducted is consistent with the constructivist paradigm in that one is able to conduct the analysis from within the constructivist paradigm (Braun & Clarke, 2006). Constructivist thematic content analysis was useful in the current study in that it allowed the researcher to identify the main factors which impact on the experiences of HIV caregivers in peri-urban informal settlements, and whether or not these fit into the various factors outlined earlier in terms of the ecosocial theory; while allowing for the realities of the caregivers and the ways in which these are constructed to emerge. The analysis thus allowed for the inclusion of the underlying ideas, assumptions, conceptualisations and ideologies of the caregivers to surface. This was important in the current study in that the participants were working for a faith-based organisation. In carrying out the thematic content analysis, the present research followed the steps outlined by Braun and Clarke (2006). In short these are: transcribing the interviews and becoming familiar with the data; searching for themes; reviewing themes; defining and naming themes; and finally, producing the report (Braun & Clarke, 2006).

From listening to the recorded interviews, the researcher identified initial themes which were coded. Initially, ten themes were identified. These were then grouped together in terms of whether they applied to the caregiver, the patients, or to the community. The final themes were checked by reading and re-reading transcripts, as well as re-listening to recordings. This also aided the researcher in interpreting the themes which were identified. Importantly, once the themes were identified, the underlying assumptions and ideologies of the themes were analysed. This led to the identification of two main themes (religiosity and socio-cultural factors), under which the previously identified themes fell under as sub-themes.

2.6. Self-Reflexivity

Numerous authors who have conducted qualitative research highlight the importance of self-reflexivity as a methodological tool which is used to "legitimise, validate, and question research practices and representations (Pillow, 2003, p. 175). The concept of self-reflexivity posits that qualitative researchers should not overlook the role and impact that their subjective identity may have on the procedures and findings of their research. For example, socially constructed assumptions of gender and ethnicity are part of the research process and need to be acknowledged by the researcher – the researcher therefore needs to be conscious of the fact that "who I am, who I have been, who I think I am and how I feel affect data collection and analysis" (Pillow, 2003, p. 176). To be self-reflexive, the researcher needs to be cognisant of his/her socially constructed position and ideological assumptions, as well as the ways in which he/she is perceived by the participants in the study. In the current study, the researcher is a white, middle-class female, and conducted interviews in a cross-cultural context, situated within a history of colonialism and apartheid – therefore, care was taken to ensure that the participants were given the authority and space to voice their experiences, which are the primary focus of this study (Pillow, 2003).

2.7. Ethical Considerations

An ethical clearance certificate was obtained from the University of the Witwatersrand Human Research Ethics committee (non-medical); clearance certificate protocol number H100 610 (Appendix I). Participation in this study was voluntary, and participants were free to withdraw from the research without penalty. Participants were given a participant information sheet before they participated in an interview (Appendix B), and were also asked to sign informed consent forms for the interview (Appendix C) as well as for the recording of the interviews (Appendix D).

Confidentiality of the data and the participants' personal information was guaranteed. No names were recorded; and the tape recordings as well as the transcriptions will be kept in a safe place and destroyed after the research has been accepted. There were no expected adverse effects or dangers to the participants in this study; however, participants were provided with information about the resources available to them should they wish to attend counselling – the information sheet provided participants with information about the Emthonjeni Centre; as well as information about the South African Depression and Anxiety Group. Participants were told that a short summary of the results of the study will be sent to their organisation, should they wish to be informed of the results.

Chapter 3: Results

3.1. Introduction

A thematic content analysis was conducted in order to discover themes that might provide an overview of the complex factors which impact on the experiences of NGO-employed HIV caregivers in peri-urban informal settlements. The analysis was conducted from a constructivist standpoint in order to allow for the interpretation of the underlying assumptions and ideologies of the themes. The following chapter will discuss the results of this study in relation to two predominant themes which were identified; namely religiosity (which includes the following sub-themes: caregiver motivation, caregiver stress and coping, patients' sense of self worth and religion), and socio-cultural factors (which includes sub-themes regarding the resources available to caregivers and patients, tension between cultural beliefs, Western medicine and religion, as well as stigma in communities). Although the two main themes are outlined separately for the purposes of this chapter, they are not independent, but highly inter-related and dynamic in that tension exists between religion, cultural beliefs and stigma in the communities involved in this research. Many of the sub-themes identified in this study confirm and substantiate findings of other research, however, numerous sub-themes were also found to be unique to the context of peri-urban informal settlements in South Africa (for example; language barriers, the absence of family and the impact of traditional medicine). Interestingly, religiosity was found to play a major role in almost all of the themes identified in this study.

3.2. Religiosity

In many of the initial themes identified from the thematic content analysis, the religiosity of both the caregivers as well as their patients was emphasised as being an important influencing factor. As a result, the underlying ideology of religiosity is the first main theme which is identified by this study.

3.2.1. Caregiver Motivation

Caregiving as a calling

Religion played a major role in motivating the participants to provide care to PLWH. Many of the caregivers indicated that they felt that they had been ‘called’ by God to assist PLWH, and that this was their purpose in life. Additionally, many of the participants indicated that they felt privileged to be able to provide care for PLWH, and that to them it was a ‘blessing’ to be able to help their communities.

> Extract 1: Participant 1
>
> *God has got a purpose for me and now I’m very happy because I can do something, I can make a difference and I can encourage others... People with HIV must not have fear because you are the light, you know? I didn’t expect that by this time I would still be alive. But you know, when you’re doing this, I am doing it for God, because I am encouraged, I feel like I have been treated.... Sometimes, especially when I get my salary...the first month I got my salary I thank God. God bless me by giving me this job, serious!*

> Extract 2: Participant 5
>
> *I honestly believe this is a calling... It’s easy to get your initial compassion, but to carry on is a calling, and it’s something that God says you have to do, and it’s something that you know you have to do, and it’s something that...that keeps you alive, it makes me fulfilled that I can help AIDS* [sic] *people...*

Caregiving is seen as a good opportunity to help PLWH, and to ‘be the light’ within the communities. In this study, the caregivers were very positive about their role in the community, and about their work. This differs from findings in previous literature, in which caregivers have indicated negative attitudes towards their work, and have often suffered from depression and high levels of stress. For the caregivers in this study, being a caregiver has offered them employment, purpose in life, and is seen as a blessing from God. This was especially the case for the caregivers who had indicated that they were HIV positive, in that they felt that they had been given a purpose in life, to be the example to others who have HIV, and to show them that even with HIV, one can live a healthy and fulfilled life. The importance of religion in motivating the caregivers to assist PLWH was emphasised by the participants in this study. Not only has religion influenced the participants to become caregivers, it motivated them to continue to provide care to those who need their help. The caregivers' belief in God has enabled them to conceptualise their role in society in a positive way.

> Extract 3: Participant 2
>
> *I can encourage people who are like me. When I talk to them I tell them about myself and I tell them when I was tested until now, look at me, I am fresh and happy. Since 1998 until now, I am fresh and happy and I am still alive, I am not dead because I take my tablets every day.*

Being HIV positive and able to lead a happy and fulfilled life has inspired these caregivers to be an example in their communities, to try and show people that HIV is not a death sentence. Furthermore, their religiosity seems to motivate them to continue to provide care, and to see their lives in a positive way in that they view themselves as having a purpose in life that has been offered to them by God.

Caregiving as a means to relieve stress and guilt

Importantly, most of the caregivers who participated in this study live within the communities that they serve. This has meant that they are well aware of the circumstances faced by PLWH in these communities, and have witnessed the large numbers of people who are sick, who are fighting HIV all alone, and who are suffering. The PLWH often do not have family nearby (or if they do their family may be unwilling to assist them). Additionally stigma, and cultural beliefs held by many people in the communities prevents them from assisting PLWH (this will be explained in more detail later). For many of the participants, being exposed to this suffering combined with the realisation that PLWH are often alone has caused them to feel that if they did not help PLWH they would feel guilty and stressed.

Extract 4: Participant 12

> *I decided to become a caregiver because I see the people are suffering from pain, others I see they don't have a person who stays to care, take care of her or him. So that's why I decided to take this position, to help the community... It's hard to see people in pain you know... or to see people who have nothing to wear, or nothing to eat in the house. I feel very, very guilty in this situation...*

Extract 5: Participant 7

> *I am helping the people in the communities, at least I am doing something about the problems I see. So ya, it can be difficult but it's not so stressful because it is more stressful to be doing nothing.*

From the above extracts it can be seen that the caregivers do not find it easy to live in their communities where they can see that people are suffering, it is stressful for them to witness this on a daily basis. Therefore, providing care to PLWH is a means for them to alleviate these feelings of stress and guilt, by actively doing something to improve the quality of life for the PLWH. In addition, this sub-theme may be related to the participants' perception of caregiving as a calling from a higher power, in that they may feel that it is God's purpose for them to provide care to PLWH.

3.2.2. The Multiple Roles of the Caregivers

The participants in this study play a major role as caregivers of PLWH in their communities. Their work has been pertinent in improving the quality of life for many of their patients, especially those who do not have any family nearby who are willing to support them during their illness.

Extract 6: Participant 5

> *You know that there's nobody out there for them, because they've got such stigma, so they... they're nobody's nothing.*

When the family members of the PLWH are not nearby, or are unwilling to help, the caregivers take on full responsibility for their patients. This includes making food for the patient, cleaning the house, bathing the patient if they are unable to do so themselves, checking that the patient takes his or her medication properly and so on. The patients' families are often far away, and are difficult to contact. In these situations, the caregivers take on the role of a family member for their patients:

> Extract 7: Participant 9
>
> *You'll find that some of them they are Zimbabweans, so they... most, most are Zimbabweans. So they don't have anyone around. So we will go through this situation with them until the end, you know, it's difficult to find their families, sometimes we don't even know where to start to find them, because some came here by themselves, they don't even have documents and it's... it's tough.*

> Extract 8: Participant 10
>
> [If the family is not available to help] *Then we become your family. Um, ya like if you are in that stage like you are in a bed-bound, we have to check you more often to see that you are ok. To cook for you, to check on your medication – like your sister.*

Living with HIV in peri-urban informal settlements can be a very lonely experience, especially for those who do not have family members or friends to help them. The participants who indicated that they were HIV recall this sense of loneliness:

> Extract 9: Participant 1
>
> *Before, I didn't even have one friend who could talk to me, except maybe Prudence*[1]*, and I have found that love, you know, love is very important... I was very stressed, but*

---

[1] Prudence (name changed) was the caregiver who helped the above participant when she was ill

> *when Prudence came to visit me I felt comfortable because I could tell her what's inside of me. When we would talk I would feel like I'm here, you know.*

> Extract 10: Participant 1
>
> *Sometimes it is stressful to not have friends when you're lonely, you know? So I think as caregivers we need to encourage, and we must have that love as caregivers.*

The participants noted that when the patient *does* have family nearby, the caregivers often need to act as mediators between the PLWH and their family, in that the patient may find it difficult to reveal their status to their family members. This is especially the case for young teenagers who may find it frightening to disclose this information to their parents. While the caregivers do keep the HIV status of their patients confidential, they encourage them to tell their families, so that they can receive support from their family members. If the patient feels ready to reveal their illness, the caregivers are often the ones who speak to the family members about it for the patient. They offer counselling for the family, and education about how they can help the patient.

Caregivers who are HIV positive themselves have insight into the experiences of the PLWH in their communities, their role is therefore also one of a fellow patient who is able to understand the pain and loneliness that is being experienced by the PLWH, and to provide the care and friendship that they know would have been helpful in their own situations, before they started taking ARV's, when they were ill. The participants who indicated that they were HIV positive highlighted the importance of providing more than just care to the PLWH, by offering their patients their friendship, and motivating them to take care of themselves, and encouraging them when the PLWH are feeling lonely or distressed. Thus, caregivers are also given the role of motivational speakers, and counsellors for the PLWH as well as their families in the communities. In addition to the absence of family members, stigma in the communities has meant that often the neighbours or friends of the PLWH are often unwilling to help them.

Extract 11: Participant 6

> *If the family is not there then we have to go there every day to go and check how is the patient...because we had another client who passed away in his room. So that week we didn't go there for one week so he passed away, he was alone, nobody even knows that. So they started to see the...the flies on the door, the next door neighbours. When they tried to open they found that this man is dead.*

As seen in the above extract, the isolation of people living with HIV is exacerbated in communities in which there is a high level of stigma. People in the communities are often unwilling to assist the PLWH for various reasons (which will be discussed later). This makes the experience of living with HIV a lonely one, in which the caregiver is often the patient's only friend and contact with the outside world. Additionally, the above extract highlights the fact that the caregivers may be unable to assist all of the PLWH all the time; most of the caregivers have children that they need to care for, the caregivers also have lives, and things come up. Additionally, caregivers who are HIV positive themselves are faced with the dual challenge of being a patient, and looking after others who are HIV positive.

Extract 12: Participant 1

> *Before I started at Refilwe, I couldn't leave my home because by that time I was very, very ill. Ya, so I was sick for a long time... I was scared that if I would die, what about my children... I took up most of my time sleeping, just sleeping all day, but not really sleeping – just feeling pain. I was not working so I was thinking of my children – who will support them, who will take care of them?*

Extract 13: Participant 4

> *One of my kids usually cries, I don't know but I think he is feeling maybe mommy is gonna die, and before I was also feeling that maybe I'm gonna die. But now I know that one day I'm gonna die, but I'm praying to God that He will extend my days so that I can see the weddings of my children.*

Thus, at the same time that these caregivers are trying to assist others in their community who are living with HIV, they also have their own lives to think about, as well as the ways in which their HIV status has affected the lives of their children. They indicated that they worry about their children and have made arrangements with other family members to take care of their kids if they become unable to do so. Thus, while they are providing care to PLWH in their communities, they are also faced with the challenges associated with living with HIV in their own lives. The caregivers who indicated that they were HIV positive also highlighted their role in the communities as role models to others who are living with HIV.

> Extract 14: Participant 7
>
> *I can be sort of a role model for others because I'm also HIV positive, and I'm normal...and I can, I can advise to the people that they can also do like me. To show them you can survive with HIV... especially from the experience that I have had you know, say I meet a person with HIV, I know how to deal with that person because I'm also like him.*

The participants in this study play a major role as teachers, or educators, in their communities. The caregivers often have to teach their patients about HIV, to dispel any misconceptions which they may have about the disease. For example, the caregivers have to tell their patients that they can live healthy and fulfilled lives even though they have HIV, as long as they take their medication. Many of the participants indicated their frustration at the fact that many of their patients, and people in the community subscribe to religious and cultural beliefs about HIV that, according to the caregivers, are inaccurate, and cause harm to PLWH (for example, the patient will refuse to take ARV's and will use traditional medicine instead), this tension between Western medicine (which is supported by the caregivers who subscribe to Christianity), and traditional medicine will be discussed in more detail later. They also educate their patients about the side effects that they may experience for the first few weeks of taking the ARV's, and that they cannot drink alcohol with this medication. The caregivers educate the PLWH about cross-infection, and the importance of using condoms even if both partners know that they are HIV positive. Additionally, the caregivers teach their patients about healthy eating practices, as well as how to maintain good hygiene by washing their hands after going to the toilet and by using a toilet instead of defecating in the sand. As seen in Extract 16, the participants in this study also indicated their role as religious mentors to their patients:

> Extract 15: Participant 8
>
> *We try to teach them about God, sometimes we can even leave a Bible there. This way maybe they will see that their life is not meaningless...*

While the participants said that they would never turn somebody away because they do not have the same religious beliefs, the do try and educate their patients about God and Christianity. The participants in this study see themselves as leaders in their communities. If there is somebody who is sick, people in the community will point this out to the caregivers. Since the caregivers live within the communities they serve, people know that if they are experiencing problems they can go to see the caregivers at their houses.

3.2.3. Caregiver Stress and Coping

A number of stressors were highlighted by the caregivers. Various factors related to the patients as well as their communities impact on the stress experienced by the caregivers. Due to the fact that the caregivers in this study live within the communities they serve, many of them mentioned that caring for PLWH in these communities could be stressful because sometimes they would find somebody in need of help, and it would be a friend of theirs, or someone they grew up with or went to school with.

> Extract 16: Participant 9
>
> *When I go back home and I sleep in my house, and I start to reflect back to everything, it makes me sad. Because I know a lot of people are dying out there. And it's a lot... some of them I went to school with them, and when I go out there and they*

> *see me, I see them and then we start talking about this... it's a challenge, and also it makes me sad.*

The caregivers face different difficulties at each stage of their patient's illness. Initially, when they get diagnosed with HIV, the patients often go through a period of denial, which can be long-lasting. This is often a significant cause of stress for the caregivers because they know that the individual needs to start taking medication.

> <u>Extract 17: Participant 6</u>
>
> *Some people are tested HIV positive but they keep on in denial, saying that 'no, I am not positive'. Then maybe that person can go for a test 3 times or 4 times, and each time the results will be saying positive, but still she will be saying 'no, they have made a mistake'.*

Once the patients eventually accept the fact that they are HIV positive, they may go onto ARV's (if they don't go onto traditional medicine, which will be discussed later). Encouraging the patient to keep on taking their medication every day, despite the side effects is stressful to the caregivers, because the PLWH often do not adhere to the strict medication procedure which they need to follow. Often the PLWH will stop taking to medication because of the side effects, or once the ARV's begin to work the patients feel better and think that they can stop taking them. Additionally, some of the patients become distressed when they learn that they are HIV positive, and they go out and drink alcohol. The caregivers indicated that often their patients will drink heavily over the weekend, and as a result they will forget to take their medication for three or four days.

> <u>Extract 18: Participant 9</u>
>
> *You know, some of these people they are ignorant, you go to them, you still monitor their situations and you want them to take their medication because it will help a bit, and they just ignore the situation. They go out, they drink, they do all these funny*

> *things, and you ask yourself questions whether these people they gonna look after themselves or they just gonna spoil their lives like that.*

The fact that the PLWH often drink has severe consequences for their health, due to the fact that ARVs should not be taken with alcohol. Additionally, the PLWH then default on their treatment schedules. The caregivers indicated that the incessant drinking habits of PLWH in their communities also increased the chance that their patients would have unprotected sex. This was a major source of stress for the caregivers, in that it went against all of their efforts as caregivers.

> <u>Extract 19: Participant 3</u>
>
> *Finding those mammas who are HIV positive and they still have sex without protection, and they fall pregnant again. Just saying this, really, saying this* makes me ANGRY!!! *It makes me angry because it happened to two ladies that I know and I was like, 'but you knew! You knew that you have this but then you still go and you sleep with someone without protection... why?* Why? *And they still not going for check-ups for their pregnancy, they just give birth and those babies also, they come HIV positive. It really makes me angry. It stresses me so much.*

The confidentiality of the patients' HIV status which is maintained by the caregiver was often pointed out as a cause of stress for the participants in this study, not only because they were unable to disclose this information to individuals who may be at risk for having unprotected sex with the PLWH, but also because often the PLWH (especially those in their teens) did not want their family members to know about their illness, and as such refused treatment from the caregivers.

> <u>Extract 20: Participant 2</u>
>
> *Sometimes I find very sick people like this one girl who passed away, because she was too scared to tell her mother, she didn't tell her mother 'I'm HIV positive'. She was*

> *scared. So I found her, she was lying on the bed, and I talked to her but she didn't wanna know... And you see others like her and you see that she is gonna die...*

For some of the caregivers, the most stressful thing that they had to deal with was language barriers when they were trying to explain to people who had been tested positive for HIV what they had to do in terms of treatment. Language barriers were a major concern for the caregivers in that they have been unable to provide explanation and care to some of the PLWH, especially those who come from other African countries who are unable to speak English, Zulu, Xhosa, or any of the languages spoken by the caregivers:

> Extract 21: Participant 3
>
> *People are coming from other countries, and they do not understand my language that i am speaking. So they can't understand English or Zulu, or Tswana. Then it's stressful to make them to understand what you are saying to them.*

Due to the fact that the caregivers often offer their friendship to the PLWH, and often spend a lot of time and effort caring for them, the death of a patient can be highly stressful for the caregivers.

> Extract 22: Participant 7
>
> *It can be hard sometimes, like when you give care sometimes the patients...you become close with them – like a friend. So it can be tough if they get very sick, or even die... then you miss them a lot, and sometimes it's you who finds that they have died. So it can be hard.*

Extract 23: Participant 10

> *Um, when I lose a patient ya I get really stressed, I feel that I haven't done enough, even though I have tried* hard*. Ya so it's very stressful when that happens.*

In the advanced stages of HIV, the caregivers have to deal with severe symptoms such as chronic diarrhoea. When the PLWH are severely sick, many of the caregivers indicated that it was stressful them to try and keep their patients clean, due to the fact that it takes a lot of physical strength to carry enough water to constantly clean the PLWH, which not easy to do, especially since the majority of the caregivers were women. Additionally, most of the caregivers in this study expressed concern about the fact that often they do not have access to gloves, which makes caring for people who are in the late stages of HIV difficult.

Extract 24: Participant 6

> *Some people are not maybe able to wake up by themselves, even to wash themselves. So that's hard because then as a caregiver we need to go and do these things for the patients and it is hard sometimes, because, especially as a woman, we must carry the water, clean the patient, and it's hard work.*

The majority of the participants in this study indicated that their religious beliefs play a major role in enabling them to cope with the stressful situations that they are faced with on a daily basis. Their Christian faith is seen as a source of strength for the caregivers in that they believe that they can do anything through God. Additionally, the participants indicated that the act of prayer is a stress reliever in that it enables them to 'offload' their problems and 'give them' to God.

Extract 25: Participant 8

> *I cope with stress by reading the word – the Bible. My verse, I call it my verse because it really gives me strength, is in Philippians chapter 4 verse 13 where Paul*

> *says 'I can do all through Christ who empowers me'. That makes me to go on because I know I am able to do things through Him. He alone strengthens me and empowers me.*

Religion played a major role in assisting the caregivers in this sample to cope with the stress associated with caring for PLWH. Additionally, some of the participants mentioned that they go and speak to the counsellor who works at their NGO.

> <u>Extract 26: Participant 11</u>
>
> *Since we have a counsellor at Refilwe, sometimes I can set up an appointment with that counsellor, because we need that, we become burnt-out. So to off-load we have someone like our counsellor, and that helps.*

Importantly, all of the participants in this study highlighted the importance of the support that they receive from the caregivers who they work with in helping them to cope with stress. If one caregiver is experiencing difficulties in dealing with a particular situation, they can ask their colleagues for ideas or help in assisting their patients.

> <u>Extract 27: Participant 5</u>
>
> *We work together, I work with my area manager and another caregiver. So it's very nice to be connected in this, because the other caregivers will give you another way to help the people, they will give you another mind. So we come together as one and then you conquer the situation.*

The caregivers not only support and encourage each other when they are facing difficult situations, they can also come together and work as a team, thereby alleviating the stress of facing problems all alone. They therefore form a strong support system for each other. This means that if one caregiver becomes highly stressed, that individual is able to go home and take a few days off, in the knowledge that her colleagues will attend to her patients on those days.

> Extract 28: Participant 10
>
> *We support each other, if someone feels that, you know what I'm burnt out, take 2 days or one day off and try to relax and calm yourself down. Especially sometimes, you really need a space, we really need our own space because the challenge that we get, sometimes you'll find that the client he even comes to us after hours... and sometimes you know, we also have our own problems. So giving someone that space or chance to take 2 days off, it's good for us.*

The participants who indicated that they were HIV positive acknowledged the fact that they are often faced with difficult situations in their daily lives, however these participants emphasised the importance of not allowing these difficulties to become stressful, due to the fact that being stressed lowered their CD4 counts, and made them ill.

> Extract 29: Participant 3
>
> *I try by all means to not get stressed because of when you are... especially because of my situation, if I get very stressed I will be getting sick, and my CD4 count will be dropping a lot, and so, emotionally if I feel that I am getting stressed I try to take 15 to 30 minutes and just try to ignore what is stressing me.*

This highlights the dual challenge of being both an HIV patient, as well as an HIV caregiver. Stressful caregiving situations have the potential to have a negative impact not only on the mental and emotional well-being of these caregivers, but also on their physical well-being.

As seen in the themes discussed above, the caregivers highlighted the importance of individual factors which motivated them to provide care, and persist in their efforts to assist

PLWH. This section also highlighted the importance of the caregivers to their communities not just as caregivers, but as role models, teachers, friends and family members. Additionally some of the factors which are potential stressors for the caregivers as well as how they cope with this stress has been outlined in this section. The caregivers emphasised the important role that their religion played in motivating them to provide care as well as in assisting them to cope with stress associated with PLWH. Various other factors were also noted as pertinent in influencing the experiences of the caregivers. Factors related to the patients will now be discussed.

3.2.4. The Patients’ Sense of self worth

The caregivers highlighted the importance of the patients’ attitude towards life, and towards themselves as a person living with HIV in impacting on their experience of providing care to them. Additionally, participants emphasised the importance of the religion of the patients not only in aiding (or inhibiting in the case of traditional medicine) their health; but also in determining the amount of support available to patients from their religious communities. The patients’ education about HIV, good hygiene and healthy eating habits was also thought to play an important role. Lastly, the participants in this study highlighted the fact that in many cases, they have to deal with PLWH who have are quite dependent on them, and often do not want to do anything for themselves. These themes will be discussed in detail in this section.

The participants in this study emphasised the difficulties that they face in trying to convince some of their patients that their lives are worthwhile, and that they are important. Many of the PLWH live alone, and do not have friends or family around who are willing to help them; their partners have often passed away, or have left them, and their living circumstances are destitute. Many turn to alcohol, and many simply do not see the point in taking their medication to prolong their own lives. As one caregiver pointed out, many of the PLWH in her community used to hang themselves - now they just stop taking their medication. The caregivers highlighted the sense of hopelessness felt by their patients, and emphasised their patients’ lack of self-worth. Many of the caregivers felt that it would be helpful for them to receive training in building the self esteem of their patients, to motivate them to look after themselves, to take their medication, and to fight for their lives.

> Extract 30: Participant 8
>
> *Some of the people will just say 'I'm unemployed, 'I'm not married' or 'my partner left me 3, 4 years ago so what is my life? So there's no need for me to live'. And I try to really turn that back and say you are really so important, and God plans on you that you can keep on living. You don't have to give up, this is not time to give up, go on with life!*
>
> Extract 31: Participant 9
>
> *They need to be reminded that look, you still have a life, you can do it if you are looking after yourself.*

The participants felt that their patients do not care about themselves, and that the PLWH feel as if it would not make a difference if they were to die. Additionally, the caregivers noted that many of their patients are ashamed of themselves, and feel that the world has abandoned them because they are HIV positive. This was not only one of the explanations that was offered by the caregivers for the high number of patients who default on their treatment schedules, but was a major source of stress for the caregivers in that they were trying to provide care to an individual who no longer sees the point in living. Additionally, the caregivers have received training about HIV and AIDS, as well as how to treat this disease, they know all about how to educate their communities about how to prevent and stop the spread of the disease, but they have not received any training on how to improve the self esteem of their patients, to make them feel important enough to take their medication, and go on living their lives. Many of the participants in this study were making use of their religious beliefs to try and make their patients feel important. This points to the importance of religiosity in assisting PLWH to gain a feeling of self worth in order to motivate them to look after themselves.

> Extract 32: Participant 8
>
> *I say to them, even if the world doesn't love you, God loves you... God loves me despite what I am doing, or the type of life I am living at this present time.*

The religiosity of the PLWH was emphasised by the caregivers as important in motivating their patients to take their medication, and to feel worthwhile enough to take care of themselves.

3.2.7. Patient Dependency

Although the education of PLWH does impact on their ability to care for themselves in terms of taking their medication correctly, the caregivers emphasised the fact that many of the people who they care for have a sense of dependency in which they do not want to do things for themselves – they want others to give, and do things for them.

> Extract 33: Participant 10
>
> *In informal settlements there is a lot to be done because these people they always need to be dependent, they don't want to do for themselves, they always want others to give to them and do for them rather than do for themselves – even like their medication.*

This attitude of their patients was a cause of frustration for the caregivers, because they wanted their patients to become independent again, and to start doing things for themselves, to improve their own lives. This relates to what the caregivers said earlier about the self esteem of their patients, in that they want the PLWH to feel worthwhile enough for them to take care of themselves, to take their medication for themselves, to cook for themselves and so on.

> Extract 34: Participant 9
>
> *So far I've kicked their butts and said move! Stand up! Do things for yourself! I can start doing it for you, you know, I can teach you how to fish but I will never feed you every day, but I can teach you how to start fishing for yourself.*

In an attempt to start motivating their patients to do things for themselves, the caregivers had started planting food gardens for the PLWH. As seen in the above extract, this sub-theme also encompasses underlying religious connotations – for example, the caregiver's comment of teaching her patient to fish. This picks up on the comment made by a participant earlier that caregivers are 'the light' in communities in that they see themselves as doing God's work.

The religiosity of the caregivers in this study is thus the major, underpinning ideology to all of the sub-themes identified above; as it influences various facets of their lives, as well as the way in which the caregivers perceive their role in the communities that they serve. In answering God's calling to provide care to PLWH, the caregivers in this study seem to perceive themselves as 'the light', as leaders in their communities who, through Christianity, are able to educate and assist those who are living with HIV/AIDS.

3.3. Socio-cultural factors

The Christian religion of the caregivers in this study, as well as their support for Western medicine exist in tension with the cultural beliefs held by many people in the communities which they serve.

3.3.1. Tension between Cultural Beliefs and Western Medicine

The religion of the PLWH has important implications for the type of treatment that they choose to use, as well as the amount of support that they have. The caregivers mentioned that many of the people in their communities come from the Zionist church. They also said that, from their perspective, many of the people who follow the Zionist belief system also believe in ancestral worship. From this perspective, the caregivers in this study said that the use of traditional medicine is often favoured, because it deals with the spiritual beliefs held by many people in this community that if you are sick it is because you are bewitched, or because you have upset the ancestors.

> Extract 35: Participant 5
>
> *The Zionist church believes that you're bewitched if you have HIV, so those people get very little support from the community. So what they would do, they would baptise that person, or try to take the demons out of that person, and they also use a lot of traditional medicine, and they've done a lot of harm in this community, the Zionist church, because of this traditional medicine. The traditional medicine they sell for R600 in a coke bottle that smells like battery acid, and people are dying. But they believe they're doing it for the right reason, and it's terrible.*

Therefore, according to the caregivers in this study, people who subscribe to the Zionist belief system may not want to be treated with ARVs. Additionally, because of the belief system perceived to be held by this church, PLWH receive very little support from their religious community, in that it is believed that the PLWH is bewitched, and that this individual can give their 'demon' to those who go near their place of residence.

On the other hand, the caregivers said that sometimes the PLWH do have good friends from their religious communities, who do take care of them when they are ill. It was noted that patients who had been at a Christian church before falling ill often get support from these communities in that members from the church would go and visit the patient, and try to assist them while they were ill. Additionally, there is more support available for the caregivers from other Christian members of the communities.

Extract 36: Participant 5

> *Some people have very good friends, like sisters in Christ – you know, sisters like that, but not family sisters...*[When the patient's family is not available to help] *you do it yourself with your other caregiver and you try to pick up people from the community, or other Christians to help you.*

The choice to use traditional medicine instead of ARVs was stressful for the caregivers in this study, in that they would watch the PLWH get sicker over time. Additionally, the lack of support of the PLWH would make the work of the caregivers more difficult because they would be alone in their struggle to help their patient when he/she became ill, with no support from the community. The religiosity of the PLWH may thus be an important source of social support; however according to the caregivers in this study this is not the case if one subscribes to the Zionist church.

The caregivers in this study emphasised their frustration at the way in which people in the communities stick to their beliefs despite what they tell them about HIV. Many of the people in the communities believe that if you are HIV positive, you are bewitched, and can pass the 'demon' onto others who come near you. As such, the person infected with HIV often does not use ARV's, but would rather use traditional medicine. The cultural beliefs of HIV as a bewitchment are therefore problematic in a number of ways; they prevent people from seeking Western treatment, they isolate PLWH, and they make the task of caregiving more difficult because people in the community do not want to help the caregivers. In addition, the PLWH may feel that they do not need to use condoms because their illness is 'cultural' (in that it is thought that the ancestors are angry with the individual and the illness is a punishment) rather than biological:

Extract 37: Participant 3

> *They've got wrong ideas that if I touch an HIV woman who's dying, I can give them HIV, or I've taken their demon on and I can give it to them.*

> Extract 38: Participant 6
>
> *When they get diagnosed, you have a problem, they don't accept it, or they deny they're in it, and they believe they don't have it or they believe they're bewitched. So they don't go for treatment and they'll carry on not using condoms.*

The residential location of both the PLWH as well as the caregivers impacts on the resources which are available to assist people who are ill:

> Extract 39: Participant 5
>
> *The lack of proper facilities is just* terrible*. You've got to have a lot of people to help you because you clean a bottom, then you've got to put the cloth back into the water then you clean it again and then more diarrhoea comes and you've got to go and get the water changed and the diarrhoea is coming... So yes, it's a huge problem, but you've* got *to make a plan.*

> Extract 40: Participant 11
>
> *People also need money to get to clinics, some people are so poor they can't get to the clinics.*

This lack of resources exacerbates tension between cultural beliefs (and the use of traditional medicine) and Western medicine, in that people often do not even have enough money to pay for transport to go and collect ARVs from clinics. On the other hand, traditional healers are usually present within communities, and are also often more trusted by community members to cure illnesses – traditional healers often play an active role in communities, and tend to involve community and families in treating illnesses (Gilbert, Selikow & Walker, 1996). Additionally, the caregivers in this study noted that many of the PLWH whom they care for are unable to read or write. This makes it difficult for PLWH to know which pills to take at which times – there may not even be a time piece available for the PLWH to take the ARVs at the correct time. In these situations, where traditional medicine is more easily available and is part of the cultural beliefs of a community, it becomes difficult for caregivers to convince PLWH to use Western medicine instead.

3.3.2. Stigma

The cultural beliefs mentioned above lead to high levels of stigma in which people in the communities will not go near someone who they know is HIV positive. Being HIV positive in these communities can be a highly lonely experience for PLWH because of this stigma. In addition to the cultural beliefs of many of the people living in peri-urban informal settlements, PLWH may feel ashamed of themselves for having HIV. This is because they feel that many people in the communities (especially their parents if they are teenagers) would think that they became HIV positive from being sexually promiscuous. Additionally, many people in the communities still believe that HIV is a death sentence, thus adding to the stigma of PLWH.

> Extract 41: Participant 12
>
> *There is a lot of stigma in the communities, people don't want to be known, people pretend to be fine especially when they know that they are somehow positive, they will never come out. They are ashamed and don't want to tell their relatives sometimes... Stigma is killing our people because they don't want to get tested. If they have been tested and others know they are sick, they won't help. Some just want to go to these herbal doctors thinking that things will change.*

> Extract 42: Participant 4
>
> *Communities are not helping. You know these people, there are a lot of people that are suffering, and they won't go and clean their houses or try to share food with them, even if they have cooked something and that person doesn't have food, they won't dish up for them.*

The above extracts illustrate how stigma impacts the lives of PLWH Being known as HIV positive can lead to isolation from their families, and from the community. Stigma surrounding HIV in the communities also affects the work of the HIV caregivers, in that they become known as ‘the HIV people’. In one way this has assisted the caregivers because people who are affected by HIV know who they are and come and speak to them. However, it has also hindered their work in that people do not want to be seen talking to the caregivers because everyone in the community knows that those are the ‘HIV people’.

Chapter 4: Discussion

This study aimed to qualitatively examine the unique and complex experiences of NGO-employed HIV caregivers, working in peri-urban informal settlements. This chapter will discuss the results of this study in relation to previous studies on this topic; and will discuss the theoretical and practical implications of the results.

According to Akintola (2004, 2006), home-based care programmes in South Africa entrench gender inequalities in that the majority of caregivers are women due to the traditional roles of women and girls. Unsurprisingly, eleven of the twelve caregivers in this study were female; and all were being paid a small stipend from the NGO. Due to the fact that these caregivers live within the communities they serve, they too are affected by poverty and were unemployed before deciding to become caregivers. In providing care to their communities, the caregivers do not seek other employment, and remain poor because they are paid very little even though the work that they do is so critical in assisting people living with, and affected by HIV and AIDS. This issue has been pointed out by other researchers (for example, Akintola, 2004), who highlight the need for organisations that offer home-based care to design their programmes in such a way as to allow for career development and formal job employment. This would not only address gender inequalities, but would make HIV caregiving a more attractive form of employment (Akintola, 2004). Increased state funding for HIV home-based care is important in this regard.

The thematic content analysis which was conducted revealed two main themes – religiosity, and socio-cultural factors; within which various sub-themes exist which impact on the experiences of NGO-employed HIV caregivers. The first sub-theme which was found was the caregivers' motivation to provide, and to continue to provide care to PLWH. In this study, most of the caregivers viewed their role as caregivers as a calling from God. Having being previously unemployed, many of the participants (particularly those who indicated that they were HIV positive) felt that caregiving has been a good opportunity for them in that it has offered them employment, as well as a sense of purpose in their lives. This supports the findings of a study undertaken by Russel and Schneider (2000) which indicates that employment offers individuals a sense of purpose in life, "Jobs are seen as very important, as they make people feel validated and useful" (p. 14). This is especially the case for the caregivers who are HIV positive in that they have often lost their jobs due to recurrent illness.

Due to the fact that they reside within the communities that they serve, the caregivers had witnessed the suffering and isolation of PLWH in these communities. As a result, they had become caregivers in order to alleviate their feelings of stress and guilt brought about by seeing individuals in their communities suffering from HIV/AIDS. This finding relates back to the gender inequalities mentioned earlier; the majority of home-based caregivers in communities are female. This is an indication of the ongoing gender inequalities whereby the burden of caregiving is placed on the females in communities (Akintola, 2004). Interestingly, the caregivers in this study noted that actively providing care to PLWH in their communities has alleviated some of the stress associated with seeing people who are suffering from HIV and who do not have anyone to help them. Thus, while caregiving was still noted by the caregivers as being a stressful process, the caregivers said that they would feel far more stressed, guilty and anxious if they were not doing anything to help the PLWH in their communities.

This study highlighted the numerous roles that NGO-employed caregivers play in the communities that they serve. Apart from providing care to their patients in terms of ensuring that they take their medication correctly, bathing the patient, cleaning and cooking for the patient; the caregivers in this study play various other roles in their communities. They are seen as leaders in their communities, and as role models to their patients (especially the caregivers who divulge that they are also HIV positive); they offer their friendship to the patients, and often see themselves as a member of their patients' family in that often the patient does not have any family nearby who can care for him/her. In South Africa, international immigration, especially from neighbouring African countries, is common; South Africa "has become both a magnet and a notable springboard for migrants" (The National Population Unit, 2000). Consequently, many people have been separated from their support networks in that they have migrated to South Africa alone. Their families are often far away, and are difficult to contact. In these situations, the caregivers take on the role of a family member for their patients. This supports the argument made by Carlisle (2000) that PLWH often redefine the boundaries of what is traditionally understood as 'family'.

When the family is available, the caregivers often need to act as mediators between the patient and his/her family members both in terms of trying to contact family members, as well as in helping the patient to tell his/her family members about their HIV status. Additionally, the caregivers have a crucial role to play as educators in their communities, in that they inform people about HIV, and tell the family members of the patients how to care for an individual who is HIV positive. Four of the caregivers in this study indicated that they were HIV positive, and reflected on the dual challenge of being an HIV patient, as well as an HIV caregiver. These caregivers expressed concern regarding the lives of their children should they be unable to take care of them in the future, and mentioned that it is imperative to them not to get too stressed in their jobs, as this could cause their CD4 count to drop.

Due to the fact that the home based caregivers in this study operate without help from the professional healthcare sector, they carry the full burden of caring for PLWH physically (for example, ensuring that their medication is taken correctly); emotionally (for example, the caregivers provide their patients with emotional support and counselling); as well as socially (in that the caregivers often attempt to dispel myths surrounding HIV/AIDS, and are also involved in accessing basic resources for their patients where these are lacking – such as food and water). In taking on full responsibility for the home-based care of PLWH, the caregivers are often under a lot of stress.

With regard to providing care to PLWH, it has been reported that a ‘continuum of care’ for HIV/AIDS (Van Praag, 1995) is most useful in that it addresses the needs of PLWH from the time they are diagnosed through to their eventual death; a continuum of care includes emotional support services (counselling, family support and education); social support (such as the facilitation of access to basic resources), medical care and treatment (both in-hospital treatment as well as home-based care) as well as bereavement services (such as the follow-up of orphans, and offering bereavement counselling) (Russel & Schneider, 2000). The continuum of care would ideally involve medical health professionals, home-based caregivers, members of the community, qualified counsellors, and family members of the PLWH. The situation for the caregivers in this study, however, does not reflect this ideal. Often it is up to the caregivers alone to ensure that the PLWH is cared for at all stages of his/her illness.

The stressful nature of caregiving has been widely researched (see for example Folkman, 1997; Keigher, 2005; Pirraglia et al, 2004); HIV caregiving is commonly associated with psychological distress, depression, and general ill mental and physical health. According to Akintola (2004), there are four major kinds of stress experienced by home-based caregivers; physical stress (in that caregiving is a physically demanding task); emotional stress (in that caregivers may feel anxious and worried about their patients); social stress (caregiving is often very time consuming, and caregivers often give up their own social activities in order to care for their patients) and economic stress (in that caregivers are usually the breadwinners in their households, and are paid very little to provide care to PLWH). This study confirmed and substantiated the above results. Physically, the caregivers noted that as a patient progresses into the later stages of their illness, water is often needed to bath them (especially if the PLWH has diarrhoea); the caregivers in this study felt that fetching enough water, as well as changing and bathing their patients is a physically challenging task, especially if they cannot get anyone in the community to assist them. Additionally, the caregivers often take on household chores, visit the patients several times a day, and work for long hours.

Emotionally, the caregivers in this study felt anxious and worried about their patients, especially when they were aware that the PLWH was defaulting on their treatment schedules, or drinking heavily. The caregivers were providing care to people in difficult circumstances, in which often their patients do not have access to even the most basic resources. Furthermore, the language barriers brought about by the large number of people who have moved to South Africa from other African countries was noted as highly stressful to the caregivers. The caregivers in this study noted that in giving home-based care to PLWH, they would often form a close bond with their patients; the death of a patient is thus a highly stressful, often devastating event for the caregivers. Maintaining confidentiality of a patient's HIV status was pointed out as a cause of stress for the caregivers, in that at times the caregivers are aware that the PLWH is having unprotected sex, yet they are unable to warn individuals who are being placed at risk for contracting the disease. This frustration with regard to confidentiality was also found in a study done by Russel and Schneider (2000), "I understand the reasoning for confidentiality but it is very difficult to accept morally and ethically when you see someone you know, who is HIV+ having active sexual relations with many different young women" (p. 34).

Socially and economically, the caregivers in this study indicated that they often need to go and fetch water for their clients, as well as food (which is provided by the NGO). Additionally, at times the caregivers need to arrange transport for the PLWH to go and collect medication from the nearest clinic. The caregivers noted that often PLWH, or concerned family members or neighbours would come to their place of residence after hours for help. This makes it difficult at times in that the caregivers also have children and difficulties of their own. Additionally, most of the caregivers in this study were single parents, and were the sole breadwinners for themselves and their children. This places a large amount of pressure on them financially to provide enough finances. In addition, tension exists in people's choice of treatment in that it often appears to be more convenient to use traditional medicine, since there are often traditional healers who work within communities – thus PLWH do not need to pay for transport to get to them. Furthermore, traditional healing often falls within peoples' cultural beliefs; and traditional healers are seen as leaders in their communities (Gilbert et al, 1996). With traditional medicine, the focus is not just on the individual, but rather on the individual as part of the community. This underlying collectivist perception of life may be more accepted within communities. This has important implications for policy in that it may be highly beneficial to involve all facets of the healthcare system in attempting to assist those who are living with HIV - not just Western doctors, but also traditional healers.

The caregivers reported coping with the stress that they experience in three major ways. Firstly, religious beliefs were pointed out as a major coping strategy by the caregivers in this study ('I can do all through Christ who empowers me'). This finding confirms Folkman's (1997) emphasis on the importance of spiritual practices and beliefs in coping with stress. Secondly, the counsellors noted that speaking to the counsellor who works at their NGO aided them in dealing with the stressful situations which they are faced with. Lastly, the social support which they receive from other caregivers working with them was highlighted as an important coping strategy. Importantly, caregivers who work for an NGO have more support, both financially and socially, than informal caregivers (such as the family members of the PLWH) have access to. Thus, they are better able to cope with the numerous challenges associated with caring for many PLWH. Financially, the NGO enabled the caregivers to offer food to patients who have none. Additionally, the NGO distributed seeds so that the caregivers could assist PLWH to plant a food garden. The caregivers in this study also receive a small stipend which assists them in providing food for their own families. The importance of social support in dealing with difficult or stressful situations is well documented (see for example Cohen & McKay, 1984). The caregivers in this study highlighted the importance of the support that they receive from their colleagues in coping with stress. Working together allows the caregivers to take time off if they are feeling stressed, and allows them to help one another in difficult circumstances.

The experiences of the caregivers in this study were also influenced by the sense of self worth of their patients. The caregivers reported concern over the fact that their patients often feel that their lives are of no value to society. Similarly, in a study done by Russel and Schneider (2000), PLWH were found to feel that their lives were worthless. People who are living with HIV/AIDS have often lost their jobs, do not have any family nearby, and live in circumstances of desperate poverty. This has led them to feel a sense of abandonment, isolation and hopelessness, all of which have contributed to the low self esteem of PLWH in that they feel that their lives are simply not worth living, and that it wouldn’t make a difference if they were dead or alive. The sense of isolation felt by many PLWH living in peri-urban informal settlements in South Africa may be exacerbated by the fact that these areas have been sites of xenophobic attacks in the past; South Africans are often intolerant of immigrants (Crush, 2001). Since the caregivers reported that many of their patients are from Zimbabwe, these PLWH may feel isolated from their communities due to the fact that they are immigrants and may feel vulnerable living within a community which may feel hostile towards them. The caregivers in this study noted that it was a constant struggle for them to encourage their patients to keep on taking their medication, and to convince their patients that their lives have value. This has implications for policy in that it may be of use for home-based caregivers to receive training on boosting the self-esteem of their patients. Religiosity may have an important role to play here; the caregivers in this study said that they tried to use religiosity to instil a sense of worth and purpose in their patients.

The caregivers in this study reported that their patients often do not want to do things for themselves, and show a high level of dependency on the caregivers. They felt that many PLWH in their communities expect other people to do everything for them – even when they begin to be well enough to do these tasks for themselves. This attitude was also reported in the study done by Russel and Schneider (2000) in which one programme manager, when reflecting on the lack of volunteers in the programme, said “people don’t want to volunteer, perhaps it is because of Apartheid. They feel they’ve already been exploited and now they’re owed something” (p. 32). Although this example is referring to potential volunteer caregivers, it may provide insight into the way in which the caregivers in this study experience their patients’ lack of willingness to do things for themselves. On the other hand, it could be linked to the low sense of self worth of the PLWH, they may not feel worthwhile enough to take care of themselves. The theme of religiosity was picked up here in that caregivers felt that they needed to ‘teach their patients how to fish’. Interestingly, religiosity plays a role in many facets of the care provided by the caregivers in this study.

The second main theme of this work refers to socio-cultural factors, and the tension which exists between the cultural beliefs of PLWH and Western medicine. The religion of the PLWH was pointed out as an important factor by the caregivers in this study both in influencing the type of treatment that is sought by individuals, as well as in determining the amount of support that is available to them. Tension was highlighted between Western medicine, and the cultural beliefs of PLWH. Many people in the caregivers’ communities are from the Zionist church, in which the use of traditional medicine is favoured in that it is believed that illness is caused by bewitchment, or upset ancestors. This was of great concern to the caregivers in that they watch PLWH get sicker the longer they refuse to be treated with ARVs. Additionally, PLWH who are from the Zionist church often receive very little support from their religious community because it is believed that ill individuals are ‘cursed’ and can pass their ‘demon’ on to those who go near them. On the other hand it was pointed out that individuals who are from a Christian church often receive more support from their religious communities in that members of the church would come and visit the PLWH and would offer their assistance to them in times of illness.

Support and care were being provided to PLWH in an environment where resources are limited. Often, patients lack access to the basic necessities of life, such as water, food, as well as adequate housing. This makes it difficult for PLWH to sustain the treatment that they receive from the caregivers; not having enough food to be able to take ARVs was noted as a major problem. Similar results were reported in the study done by Russel and Schneider (2000). The lack of resources exacerbates the tension between Western medicine and the choice to use traditional medicine, as traditional medicine is often more easily available to PLWH in peri-urban informal settlements.

Stigma surrounding HIV/AIDS has a negative impact on both prevention and treatment efforts (WHO, 2009). In addition, this study found that it also impacts negatively on efforts to provide home-based care to PLWH. In conjunction with the challenges discussed above, the caregivers in this study are faced with cultural beliefs and stigma surrounding HIV and AIDS which further complicate and problematise efforts to provide care to PLWH in their communities. Such beliefs prevent people from utilising western treatment in that their illness is perceived as being ‘cultural’ rather than biological (often this also leads people to believe that they do not need to use condoms). Stigma within communities further isolates PLWH, and makes the caregiving process more difficult in that people in the communities do not want to assist the caregivers in their efforts.

NGO-employed caregivers working in peri-urban informal settlements are thus faced with numerous challenges. In circumstances characterised by unemployment, inadequate resources, deepening poverty, as well as the overarching stigma and cultural beliefs surrounding HIV/AIDS, PLWH are often experience feelings of worthlessness, isolation and hopelessness. Within these contexts, tension exists between Western medicine, cultural beliefs and traditional medicine. The caregivers in this study were seen to play a crucial role in their communities by assisting those suffering with and affected by HIV and AIDS.

Strengths and Limitations of the research

The present study had certain strengths. Since this study made use of a qualitative methodology, and made use of a holistic theoretical framework, the researcher was able to obtain rich detail about the experiences of NGO-employed HIV caregivers. This research focused on examining the unique and complex experiences of HIV caregivers working in peri-urban informal settlements. Since very little research has been done on this area of focus in South Africa, this study may provide an important starting point for future research on this topic. Additionally, the results of this study may contribute to informing policy regarding home-based care for PLWH in South Africa, as well as possible recommendations for future caregiver training programmes. In particular, the findings related to the role of religiosity, as well as traditional medicine may have important implications for the role of religion in future home-based care interventions in South Africa.

The present study also had certain limitations. Of concern is the fact that the research relied exclusively on self-report; this is problematic in that it is dependent on the subjective experiences of the respondents – therefore, what one individual reports as stressful or anxiety-provoking, another may not. Furthermore, the sample of this study was acquired from one NGO, situated north of Johannesburg, Gauteng. This may limit the possibility of the generalisability of the findings to all NGO-employed caregivers working in peri-urban informal settlements in South Africa.

Directions for future research

Future research should focus on the financial implications of promoting HBC for NGOs, and should provide firm evidence that informs policy concerning state funding for HBC. The consequences of HBC on families and NGO-employed caregivers should be examined more closely in future studies in order to gain an in-depth understanding of the hidden costs of HBC. Additionally, future research should seek to gain a better understanding of how well prepared community members, families and volunteers at NGOs are to care for PLWH in terms of the training that they are provided with. Comprehensive formative and summative monitoring and evaluation systems are needed in order to provide information regarding home-based care programmes, the extent to which they are meeting the goals set out by the DOH, as well as the ways in which they can be improved.

Furthermore, the role of religiosity in assisting PLWH has been highly under researched. Due to the increasing number of PLWH in South Africa, and the focus of the DOH on home-based care, various possible interventions should be explored in greater detail in order to improve the quality of life for those living with HIV. The findings of this study imply that religion may have a positive impact on the lives of those living with HIV in that it may offer these individuals a feeling of self-worth and purpose in life; and may motivate them to look after themselves despite their difficult circumstances. More research is needed on the role of religion in assisting those living with HIV, as well as the role of religion and faith-based organisations (including traditional healers) in future HIV prevention and intervention programmes. Furthermore, research in needed on possible ways of reconciling Western and traditional healthcare systems, in order to be beneficial to PLWH.

Implications for Theory

In this study, the ecosocial theory was useful in guiding the research at both the data collection and analysis stages. The theory allowed for the inclusion of multiple possible influencing factors, operating at various levels which could impact on the experiences of HIV caregivers. The current research has highlighted the highly complex nature of HBC within communities characterised by poverty. Within these contexts, NGO-employed caregivers are faced with numerous challenges, many of which go beyond providing care for ill individuals. The multiple roles played by the caregivers in this study indicates that more effort is required to achieve a HBC model which implements the use of a continuum of care, in which multiple stakeholders are involved in the caregiving process – including traditional healers. Not only would this alleviate some of the stress experienced by NGO-employed caregivers, it would also ensure an improved quality of life for PLWH. In terms of the eco-social theory, this study also highlighted the role of religiosity and the complex ways in which religiosity impacts on the experiences of both caregivers and PLWH in peri-urban informal settlements. This study has provided a foundation for understanding the roles of NGO-employed caregivers in providing HBC to PLWH in the South African context, as well as the shortcomings that exist in the practical implementation of HBC in the country. It has also highlighted the need for more of a focus on religion, and the role that religiosity and various faith-based organisations may be able to play in future HIV prevention and care strategies. In terms of theory, this study has shown how the experiences of NGO-employed HIV caregivers cannot be defined by a neat, definitive theory, and that research focusing on this topic needs to allow for the multi-faceted nature of their work to be examined.

Implications for Policy

This study has highlighted the immense burden that is placed on NGO-employed caregivers in peri-urban informal settlements. If the South African government is going to promote HBC programmes, more needs to be done to ensure that caregivers who are not part of the formal healthcare sector are provided with adequate training in order to better equip them with the numerous challenges that they are faced with. In particular, this study highlighted the need for caregivers to receive more training on counselling, especially with regard to improving the sense of self-worth of their patients; PLWH who are unemployed, isolated from their communities and living in situations of extreme poverty often feel that their lives are of no value to society, and stop taking their medication. This is highly problematic, and a major source of stress for caregivers who are not adequately equipped to deal with the challenge of increasing the self-worth of their patients. Importantly, the caregivers in this study emphasised the importance of religiosity in helping their patients to feel a sense of purpose in their lives, and to feel of enough value to take care of themselves. It is suggested that more research needs to be done on the value of including religiosity in future HIV intervention programmes; as has been implemented in various other intervention strategies (such as the 12-step programme implemented by the Alcoholics Anonymous group). Furthermore, the value of integrating Western and traditional medicine needs to be looked at in greater detail.

Furthermore, funding is needed in order to ensure that caregivers are provided with adequate resources to deal with their patients' illness – such as gloves and anti-septic solutions. More funding is also required for NGOs to be able to offer structured job placements for the caregivers, this should be done in an attempt to curb the entrenchment of gender inequalities brought about by the gendered nature of caregiving, and to strive for the Millennium Development Goal of gender equality in South Africa. Additionally, HBC in South Africa needs to include stakeholders from all healthcare sectors, and the role of the state should be better defined in the provision of HBC to PLWH.

Conclusion

In conclusion, this study confirmed and substantiated a number of findings regarding the stressors experienced by home-based caregivers, the factors which contribute to these stressors, as well as how stress is coped with. The experiences of NGO-employed caregivers are multi-faceted, interlinked and dynamic. Importantly, this study highlighted the possible role of religiosity and faith-based organisations in assisting with the HIV pandemic. It highlighted the multiple roles of NGO-employed caregivers who live and work in peri-urban informal settlements; within these communities the burden of providing home-based care to PLWH is the sole responsibility of NGO caregivers and family members, and there is a lack of interaction and collaboration between different healthcare sectors, as well as between Western and traditional medicine. Although home-based care is being promoted by the South African government and the DOH, it should not be seen as an alternative to the care offered by the formal healthcare sector, but rather as one aspect of an ongoing continuum of care, in which multiple stakeholders work together to ensure that the needs of PLWH are addressed at all stages of illness. Further research is required on the value of religiosity in HIV prevention and care strategies in order to inform policy regarding home-based care in South Africa.

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Appendix A: Invitation to Caregivers

UMTHOMBO WOPHUHLISO LOLUNTU
School of Human &
Community Development

Hello,

My name is Veronica, and I would like to invite you to take part in my study. I am conducting research for the purposes of obtaining a Masters degree in Research Psychology at the University of the Witwatersrand. My area of focus is that of the experiences of caregivers of people living with HIV. This research aims to examine the various factors which impact on your caregiving experience.

More specifically, I would like you to take part in an interview which will take between 45 minutes to 1 hour. Your participation in the interview process would be greatly appreciated as it will provide in-depth, detailed information about your unique experiences of caregiving. Your participation in this study is purely voluntary – you do not have to take part if you do not want to. If you choose not to participate, no negative consequences would result. This research is important as it will contribute to a better understanding of the experiences of HIV caregivers in South Africa.

Thank you for your time in considering your participation in my study.

Kind Regards

Veronica Kemble

Appendix B: Participant Information Sheet

Good day,

My name is Veronica, and I would like to invite you to take part in my study. I am conducting research for the purposes of obtaining a Masters degree in Research Psychology at the University of the Witwatersrand. My area of focus is that of the experiences of caregivers of people living with HIV. This research aims to examine the various factors which impact on your caregiving experience.

More specifically, I would like you to take part in an interview which will take between 45 minutes to 1 hour. Your participation in the interview process is greatly appreciated as it will provide in-depth, detailed information about your unique experiences of caregiving. With your permission this interview will be audio taped to make sure that I collect accurate information about your experiences; the tapes will be destroyed once the research report has been completed.

Your participation in this study is purely voluntary – you do not have to take part if you do not want to. If you choose not to participate, no negative consequences would result. If you feel uncomfortable at any time, you are free to stop your participation in the study without prejudice. No one will know who you are except me and the translator. The translator has signed a document which ensures that he will keep your identity secret. I will write your responses in my research report, but I will give you a different name so that no one will be able to identify you. This research will contribute to a better understanding of the experiences of HIV caregivers in South Africa. Once the study is finished, a short summary of what was found will be sent to your organisation. If you want to contact the researcher regarding any questions about the research, you may use the following contact details:

Veronica Kemble (Tel): (011) 476 7545 (E-mail): veronicabopeep@gmail.com

Dr Brendon Barnes (Tel): (011) 717 8333 (E-mail): Brendon.Barnes@wits.ac.za

Additionally, if you feel that you would like to receive counselling with regard to your experiences as an HIV caregiver, you can contact the Emthonjeni centre at the University of the Witwatersrand: **(011) 717 4513**. Alternatively, you can contact the South African Depression and Anxiety Group (SADAG) on: **(011) 262 6396**

Appendix C: Participant Consent Form: Interview

I______________________________ hereby consent to being interviewed by Veronica Kemble for her study on the experiences of HIV caregivers.

I understand that:

-Participation in this interview is voluntary.

-That I may refuse to answer any questions I would prefer not to.

-I may withdraw from the study at any time.

-No information that may identify me will be included in the research report, and my responses will remain confidential.

-Direct quotes from this interview may be used in the research report

-There are no direct risks or benefits involved in my participation

Signed_________________________

Date___________________________

Appendix D: Participant consent form - Recording

I ____ consent to my interview with Veronica Kemble for her study on the experiences of HIV caregivers being tape recorded. I understand that:

- The tapes and transcripts will not be seen or heard by any person in this organisation at any time, and will only be processed by the researcher.
- All tape recordings will be stored in a secure place after the research is complete, and will be destroyed when they are no longer needed.
- No identifying information will be used in the transcripts or the research report.

Signed__________________________

Date____________________________

Appendix E: Organisational Permission Letter

UMTHOMBO WOPHUHLISO LOLUNTU
School of Human &
Community Development

Dear Sir/Madam,

My name is Veronica Kemble, and I am conducting research for the purposes of obtaining a Masters degree in Psychology at the University of the Witwatersrand. My area of focus is that of the experiences of caregivers of people living with HIV. This research aims to examine the various factors which impact on the caregiving experience. Research in this area is highly lacking. Since the experiences of HIV caregivers are thought to be highly unique, it is important to gain a detailed understanding of these experiences in order to inform theories around caregiving, as well as health policies regarding HIV caregivers.

I would like to invite your organisation to participate in this study. Participation involves allowing the researcher (myself) to conduct interviews with 15 of your staff members who provide care to people living with HIV. Interviews will take between 45 minutes to an hour to conduct, and will be held over the months of June and July 2010.

Your participation in this study would be highly appreciated. The name of your organisation will remain confidential if you wish, as will the names of the staff members who participate (their real names will not be mentioned in the research report). Therefore, your organisation is invited to take part in this research, which will contribute to a better understanding of the experiences of HIV caregivers in South Africa.

Thank you for your time in considering your participation in this study.

Yours Sincerely

Veronica Kemble

Cell: 074 181 9922 ; E-mail: veronicabopeep@gmail.com

The above letter was sent to the CEO of 'Refilwe Life For All', Claire Said. Her reply follows:

Appendix F: Permission Granted by NGO:

Permission has been granted by Refilwe Life For All:

from **Claire Said** <claire.said@refilwe.org> 5:05 PM
to veronicabopeep@gmail.com

date Mon, Apr 19, 2010 at 5:05 PM
subject RE: HIV Research

Dear Veronica
We would gladly participate in this research. Please provide details closer to the time.
Thank you

Take care and G-d bless
Claire
Refilwe Community Project
083 401 1376

Appendix G: Interview schedule

The interviews will start with a brief introduction:

Thank you so much for agreeing to take part in an interview, by doing so you are contributing to a better understanding of the experiences of HIV caregivers in South Africa. Just a reminder that our conversation will be tape recorded, and the interview will take about 45 minutes to an hour. The interview will be informal – please feel free to interrupt me or ask questions during the interview. If you do not want to answer any of the questions that I ask, feel free to say so, and we can move on.

Interview Questions:

- How long have you been associated with Refilwe Life for All?
- What is your involvement with them
    - Full time employee? Volunteer? etc
- How long have you been providing care to PLWH?
- What factors led to you becoming an HIV caregiver?
    - *If participants reveal that they are HIV+*
        - *What are the challenges you face in managing your own illness and that of the people you care for?*
        - *How has being HIV+ influenced the way in which you care for those you serve?*
- How many hours per day would you say you spend providing care?
- Typically, what do you do for the patient(s) on a daily basis – what are your daily activities? Does this vary? If so, why?
- How does it feel to be a caregiver of a PLWH?
- What is good about being a caregiver? / has caregiving had any positive impact on you personally, or on your life?
- What could be better? / What are the disadvantages of being a caregiver?
- In terms of the different stages that people with HIV go through, what difficulties do you face in each stage?
- What struggles have you faced / are you facing in terms of providing care to the patient?

- In your experiences, what are the most stressful things that you have to deal with?
- How do you cope with stress? / stressful situations?
- What motivates you to continue to provide care to PLWH?
- Could you describe the locations in which you provide care?
- What is it like providing care to people in informal settlements / townships?
- How do you determine who needs your help or not? (probe in detail)
- In terms of access to good drinking water and sanitation (such as clean toilets), are these available to the people who you serve?
- How does the lack of these facilities impact on caregiving?
    - In terms of the later stages of HIV (e.g. diarrhoea), hand washing, cleaning up after diarrhoea, clean drinking water, getting bed-ridden people to a toilet etc
- What are the biggest stressors for the PLWH? And for their loved ones?
    - How do you deal with these issues?
- How do you think this community supports the PLWH?
- What do the communities think about the people you care for?
- How does stigma around HIV affect the PLWH / their loved ones?
- Does stigma surrounding HIV impact on your job?
- Do you have any help with the caregiving responsibilities? / Does the PLWH's community support you in your efforts?
- In terms of the NGO that you work for, what is it like working together with other caregivers to help PLWH?
- How closely do you work with relatives/family members of the PLWH?
- What happens when the family is not available to help the PLWH?
- Are there resources available to you to help you deal with the stress that you deal with in your job?
- Do you feel that your religion plays a role in your caregiving / the way in which you make meaning of your experiences?
- How do you feel that religion plays a role in your job as an HIV caregiver?
- Does the religion of the PLWH play a role in the help that they receive in their communities?
- What resources (personal and material) do you have that aid you in your ability to provide care??
- What don't you have that impedes your ability to provide care?

- How does your access to resources impact on your experiences as a caregiver?
- How does your patients' level of access to resources(e.g. water, sanitation, food) impact on your experiences?
- How well equipped do you feel you are in providing care to the person
    - In terms of the resources available to you (e.g. water, medication etc)?
    - In terms of your personal capabilities?