EXPERIENCES OF FAMILY CAREGIVERS OF HIV POSITIVE ZIMBABWEANS
IN MASVINGO URBAN: HIGHLIGHTING THE
SIGNIFICANCE OF CAREGIVING WORK

BY

CHIKUKWA HERBERT TICHAUYA

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ABSTRACT

The study examined the experiences of family caregivers of HIV positive people in Masvingo urban. The qualitative methodology was used in the study. The study adopted the psycho ethnographic research design as the operational framework for data gathering. In-depth interviews, focus group discussions and observations were the main techniques for data collection. A sample of forty-three (43) participants, both males and females took part in the study. These were drawn from Mucheke and Rujeko suburbs of Masvingo City, using the respondent driven sampling, a form of non-probability technique almost similar to chain-referral or snowballing sampling. Data were analysed using the thematic content analysis. The results of the participants’ experiences and coping strategies consisted of four themes, which contained the essential meanings of participants’ accounts. These were challenges of caring, the caring experiences, burdens and rewards of caregiving, and coping with the role of caring. The results of the study also revealed that caring for an HIV infected individual is emotionally, psychologically, physically, socially and financially taxing during the period of caring as well as in grief and bereavement. Families and communities were also observed by carers to be emotionally strained by the HIV diagnoses of their loved ones. The family caregivers’ conceptions of care were also identified in the research study. These included: nourishing the people living with HIV and AIDS (PLWA) while struggling with poverty, maintenance of cleanliness and hygiene of the person and surroundings, comforting the PLWA, and sacrificing self to sustain the PLWA. It is evident that families play a major role of support for HIV and AIDS patients in Zimbabwean society, but this goes unnoticed and with very little support, if any at all, from the government and other responsible authorities in the health fraternity. This research has shown that the demands on family caregivers of the HIV and AIDS patients are enormous and need to be addressed by the policy makers and implementors. I recommended that advanced training for HIV and AIDS formal caregivers is needed to enable them to help the infected persons to cope with their situation and live a normal life. Primary caregivers need systematic counselling and assessments for caregiver burden and other stressors like coming to terms with death. Primary caregivers need to be helped in order for them to recognize and build on aspects of their lives that contribute to their physical, psychological, and social well-being. Health professionals need to develop partnership with informal caregivers and assess both the caregiver and the patient periodically. I further recommended that advanced training for HIV and AIDS formal caregivers is also needed to enable them to assess stress among the informal caregivers for them to be able to help the primary caregivers. Hence, there is great need to highlight the significance of caregiving work so as to bring into focus the carers of HIV positive Zimbabweans and give them a helping hand in their noble work of caring for the HIV and AIDS infected Zimbabweans.
ACKNOWLEDGEMENT

Firstly I wish to thank all caregivers who agreed to participate in this study, for sharing their experiences, which can be a very difficult part of their lives. My greatest sympathy goes to those that have lost their loved ones from this dreaded pandemic; may their souls rest in eternal peace.

I would also like to thank Batanai HIV & AIDS Support Organisation (BHASO), District AIDS Committee (DAC) Masvingo and the Red Cross Society Masvingo for allowing me to carry out this research within their organisations and for being so accommodating with their time and resources. Not forgetting also all the support groups in Mucheke and Rujeko suburbs of Masvingo for their unwavering support during the same period of this research.

I wish also to thank my supervisor Dr Ellen Gwaradzimba for her feedback and ongoing encouragement. Without you Doc (Auntie Gwa), this could not have been possible.

To my family, especially my wife, I thank you greatly for your constant support and encouragement as well as understanding.
DEDICATION

This research is dedicated to my wife Millicent, my son Elvis and my three daughters Maryjane, Nyaradzo and Nyashadzashe.
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<tr>
<td>AIDS</td>
<td>Acquired Immune Deficiency Syndrome</td>
</tr>
<tr>
<td>ARV</td>
<td>Anti Retro Viral</td>
</tr>
<tr>
<td>BAECS</td>
<td>Bachelor of Arts in English and Communications</td>
</tr>
<tr>
<td>BAMS</td>
<td>Bachelor of Arts in Media Studies</td>
</tr>
<tr>
<td>BHASO</td>
<td>Batanai HIV &amp; AIDS Support Organisation</td>
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<tr>
<td>DAC</td>
<td>District AIDS Committee</td>
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<tr>
<td>DSM-IV</td>
<td>Diagnostic and Statistical Manual of Mental Disorders</td>
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<tr>
<td>FGD</td>
<td>Focus Group Discussion</td>
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<tr>
<td>GZU</td>
<td>Great Zimbabwe University</td>
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<tr>
<td>HAART</td>
<td>Highly Active Antiretroviral Therapy</td>
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<tr>
<td>HBC</td>
<td>Home Based Care</td>
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<td>KII</td>
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<td>NAC</td>
<td>National AIDS Council</td>
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<tr>
<td>NGO</td>
<td>Non Governmental Organisation</td>
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<tr>
<td>PCA</td>
<td>Personal Care Assistant</td>
</tr>
<tr>
<td>PLWA</td>
<td>People Living With HIV and AIDS</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organisation</td>
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<tr>
<td>UNAIDS</td>
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<tr>
<td>UNGASS</td>
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<td>UNICEF</td>
<td>United Nations International Children’s Education Fund</td>
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<td>ZOU</td>
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1.1 Introduction

This chapter serves to put the problem of family caregivers into context. It provides the background information that helps the reader to appreciate the problem under investigation and the theoretical framework within which the study is guided. The main purpose and objectives of the study, its importance and pertinence, and the delimitation and assumptions of the study are highlighted, with study limitations and the definition of key terms concluding the chapter.

1.2 Background to the Study

In the early 1980s, scientists discovered the Human Immunodeficiency Virus (HIV) and with it the question: ‘what is Acquired Immune Deficiency Syndrome (AIDS)’? was answered. According to Jackson (2002), HIV is a virus that is transmitted from person to person through the exchange of body fluids such as blood, semen, breast milk, vaginal secretions and sharp instruments like razor blades. Sexual contact is the most common way to spread HIV and AIDS, but it can also be transmitted by sharing needles when injecting drugs, or during childbirth and breastfeeding. It is the virus that can lead to Acquired Immune Deficiency Syndrome, or AIDS. There are two types of HIV, HIV-1 and HIV-2. In the United States, unless otherwise noted, the term “HIV” primarily refers to HIV-1. Both types of HIV damage a person’s body by destroying specific blood cells, called CD4+ T cells, which are crucial to helping the body fight diseases (http://www.cdc.gov/hiv/topics/basic/).
As the HIV virus reproduces, it damages the body’s immune system and the body becomes susceptible to illness and infection. Since its discovery in the early 1980s, there has been no cure for HIV infection (http://aids.about.com/od/aidsfactsheets/a/whathiv.htm).

AIDS is a condition that describes an advanced state of HIV infection. With AIDS, the virus has progressed, causing significant loss of white blood cells (CD4 cells) or any of the cancers or infections that result from immune system damage (Jackson, 2002:5). Those illnesses and infections are said to be "AIDS-defining" because they mark the onset of AIDS. Like HIV, there is no known cure for AIDS, (http://aids.about.com/od/aidsfactsheets/a/whathiv.htm).

Soon after the emergence of the AIDS pandemic, it became evident that HIV was much more than just a disease. Because of its magnitude, HIV not only touches the lives of those infected, but it also impacts on the lives of virtually all human beings. It is very rare to find a family that has not been affected by the HIV pandemic in some way the world over. Simply put, it is clearly one of the most challenging public health issues in the history of mankind.

According to 2011 estimates from UNAIDS, WHO and UNICEF, around 30.6 million adults and 3.4 million children were living with HIV at the end of 2010 (WHO/UNAIDS/UNICEF, 2011). In a number of African countries the adult HIV prevalence rate is over 15%, with the number of infected people as high as 5.6 million in South Africa, 1.4 million in Mozambique, 3.3 million in Nigeria and more than 1.7 million in Zimbabwe (UNAIDS 2010). Typically, countries with high prevalence have overstretched health systems; they lack resources and are among the lowest levels of hospital beds and health workers per person. The AIDS pandemic itself contributes to the overburdened health sector. In one study in Kenya, for example, 50-
60% of public hospital beds were found to be occupied by HIV patients (Opiyo, Takashi and Jayne, 2008).

The diminished capacity of many countries’ health sectors means having people with HIV cared for at home. Home based care, became more appealing to governments than treating them at hospital. It is also important to note that, being cared for at home, a person with HIV may be in a more ready position to work or look after family members for short periods of time while the primary earners work. The time the family would otherwise use travelling to and from hospital can instead be spent on house work and looking after other family members. Expenditure on transport and hospital costs is also reduced (Ogden, Esim and Grown, 2006).

Providing care for people with HIV and AIDS in the home has many potential benefits for both HIV infected and affected people, yet there are many failings in the support given to carers. It has been estimated that up to 90 percent of illness care may be provided in the home by untrained family members and associates, and up to 80 percent of AIDS related deaths occur in the home (Ogden, et al 2006).

Home based care often results from necessity as mentioned earlier, health facilities may not be able to cope. Furthermore, fear of stigma and discrimination from doctors and nurses directed towards people living with HIV could deter people from seeking care in a medical setting (Ogden, et al, 2006). The costs, both direct (i.e. paying for transport) and indirect (i.e. time lost from work) associated with going to hospital regularly also mean that being cared for at home is often an inevitability rather than a choice.
Though Zimbabwe has, in recent times, recorded a decrease in new cases of HIV infection (from 32.1% in 2000 to 23.9% in 2004 and 18.1% in 2008) and even down to 14.26% (The Sunday Mail, September 7-13, 2008), UNGASS (2010) Zimbabwe National Aids Estimates (2009), a substantial number of persons are still living with HIV and AIDS. Because AIDS is a fatal illness, supportive care continues to be a crucial issue, influencing the government’s attempt to develop appropriate policies to address the care needs of patients with HIV and AIDS (USAID Health Profile 2005). With a high number of PLWAs, the demands of family caregivers who take responsibility for the care of AIDS patients at home are escalating (UNAIDS Report, 2004).

The primary caregivers provide practical support (e.g. shopping, housekeeping, bathing, feeding, etc.) and as symptoms worsen they are likely to take on more clinical roles such as keeping track of medication, giving injections, inserting catheters and cleaning wounds (Folkman et al., 1994). In many cases the caregiver finds him/herself caring for more than one person. Unlike formal caregivers and volunteers, these people are on call 24 hours a day, thus they are faced with many challenges.

Caring not only increases the financial burden on these carers (Ala, 2001), but it also produces the additional strain of stigmatisation (Powell-Cope & Brown, 1992; Turner, Catania & Gagnon, 1994), as well as distressing emotions, relationship difficulties, somatic symptoms and grief (Pakenham, Dadds & Terry, 1995). Limited research has been conducted on the experiences of primary caregivers of HIV and AIDS patients. Moreover, the focus of the past research has been primarily on the role and experiences of formal caregivers, that is; doctors, nurses, volunteers, etcetera (Karasz, Dysche & Selwyn, 2003) and experiences of
people living with HIV and AIDS (Hsiung & Thomas, 2001) as well as on behaviour change. Little attention has been given to the experiences of primary caregivers.

1.3 Theoretical Framework

The study is located in a phenomenological theoretical approach. Phenomenology is defined as “the name for a philosophical movement whose primary objective is the direct investigation and description of phenomena as consciously experienced, without theories about their causal explanation and as free as possible from unexamined preconceptions and presuppositions” (Spiegelberg, 1970: 810). Wagner (1983 in Speziale & Carpenter, 2003) defines phenomenology as “a system of interpretation that helps us perceive and conceive ourselves, our contacts and interchanges with others, and everything else in the realm of our experiences in a variety of ways, including to describe a method as well as a philosophy or way of thinking” (p. 52). It also provides “a way of exploring lived experiences, the actuality of experiences, from the inside” (Osborne, 1994: 167). This theory allowed the research to explore how people experienced, described and interpreted a phenomenon: In this case, living with and caring for PLWA. Phenomenological research has been applied to several studies looking at caregivers caring for people with chronic diseases. Phenomenology allows researchers to describe an individual’s total sphere of experiences, which is bound by the objects, persons, and events encountered in the quest of realistic objectives of living. By exploring their experiences as well as their coping strategies, a description of the world as experienced by these participants was given in order to discover the common meanings underlying the phenomena.
1.4 Rationale for the Study

The problem of primary caregiving has seriously impacted on the Zimbabwean communities where most primary caregivers have no or little knowledge of HIV and AIDS caregiving. The care of persons with HIV and AIDS can place a significant burden on primary family caregivers. Little attention has been given to the experiences of primary caregivers.

The limited research sourced on informal caregivers was mostly based on researches carried abroad (Bor, 1990; Flaskerud & Tabora, 1998; Folkman, 1997; Mullan, 1998:712; Pakenham, Dadds & Terry, 1995; Powell-Cope & Brown, 1992; Rose & Clark-Alexander, 1999; Turner, Catania & Gagnon, 1994; Turner & Catania, 1997) with some of these studies looking at a specific group of people, for example; caregivers of HIV positive children or gay communities (Folkman, 1997). Research undertaken so far in Zimbabwe has addressed the burden of caring and the coping strategies of volunteers and home-based care workers (Melnick, 2002; Van Wyk, 2002), thus leaving out the primary caregivers undertaken in this study.

The experiences of primary caregivers of HIV positive Zimbabweans have been given little attention and as such, the knowledge of their experiences in HIV and AIDS caregiving work can help the government develop specific intervention strategies for family caregiving in order to enhance quality of life for the carers.

1.5 Statement of the Problem

This present study intended to highlight the significance and experiences of primary caregivers of HIV and AIDS infected persons in Masvingo in order for them to be recognised
and be understood by the general public. Relatives and friends providing care to HIV positive Zimbabweans experience many challenges during the period of care, as well as in grief and bereavement and lack emotional and cognitive support from their communities which is mostly directed towards the care recipient instead.

1.6 Purpose of the Study

The study sought to critically examine the experiences of primary family caregivers of HIV positive persons in Zimbabwean societies with the view of highlighting the significance of caregiving work. It examined how primary caregivers of HIV positive persons in Masvingo go about in caring for their infected relatives. The research explored and tried to establish the challenges, experiences, advantages and disadvantages of caregiving work as well as the possible coping strategies employed during this period and in times of grief and bereavement.

1.7 Objectives of the Study

The specific objectives of the study were:

1. To establish the challenges faced by primary family caregivers of HIV positive and AIDS patients in Masvingo Urban.
2. To establish the psychological, emotional, physical, economic and social experiences of family caregivers of HIV positive and AIDS patients.
3. To determine the negative consequences of HIV and AIDS caregiving work.
4. To evaluate the positive consequences of HIV and AIDS caregiving work.
5. To explore the coping strategies used by primary family caregivers during the care and in bereavement of their departed HIV positive loved ones.
1.8 Research Questions
1. What are the challenges faced by primary family caregivers of HIV positive and AIDS infected Zimbabweans in Masvingo?
2. Outline the personal and psychological experiences of Zimbabwean primary family caregivers in caring for their relative HIV positive and AIDS patients?
3. State the advantages of HIV and AIDS caregiving work?
4. Give the disadvantages of HIV and AIDS caregiving work?
5. How do primary family caregivers cope with HIV and AIDS caregiving and in bereavement of their departed HIV positive loved ones?

1.9 Significance of the Study
This study is of great importance in that:

a) The findings of this research may be useful particularly to policy makers in health institutions and government as it highlights the significance of primary family caregivers of HIV positive Zimbabweans.

b) Research on primary caregivers in Zimbabwe is limited. The study provides detailed and comprehensive understanding on the work experiences and significance of primary family caregivers of HIV positive and AIDS infected Zimbabwean

c) The research also serves as reliable sources of empirical data as well as a methodological yard stick for future researches on the topic of HIV and AIDS primary caregiving.

1.10 Delimitation of the Study
The study was mainly concerned with the experiences of family caregivers of HIV positive and AIDS patients in Masvingo Urban and the services that may be rendered to them to make their caregiving work a success and manageable. Information was sourced from informal and
formal caregivers based in the high density suburbs of Masvingo. I chose to do this research project in the city of Masvingo because the provincial capital has a high HIV and AIDS prevalence rate of around 16% according to the December 2010 Masvingo District AIDS Committee report (NAC Masvingo 2010 report) as compared to 14.26%, Zimbabwe’s national prevalence rate. Primary Caregivers of the infected persons in this city were of particular interest to the study, as the demands placed upon them escalate and compound during the last stages of the illness due to the decreased functionality of the infected.

I also managed to establish good relationships with organisations in the city offering home-based care and hence it was easy for me to access the affected communities with limited suspicion from the participants. Participants consisting of 36 informal and 7 formal caregivers for persons living with HIV and AIDS were drawn from Masvingo suburbs where there are established home-based care (HBC) programs for persons living with HIV and AIDS.

1.11 Limitations of the Study

The issue of HIV and AIDS is still very sensitive to most Zimbabweans. Due to the stigma associated with HIV and AIDS, many people, both the affected and infected were at first very reluctant to openly talk about the phenomenon and more so to a stranger. However, since I was accompanied by formal caregivers and members of Non Governmental Organizations (NGOs) working with the target group, it made easy to gain entry into their communities and gather the needed data. Also because of some ethical reasons, participants felt not obliged to divulge their personal, psychological experiences in as far as caregiving of the infected person was concerned. It is also important to note that the results of this study cannot be generalised to the whole population.
Notwithstanding the above constraints that the researcher encountered, the limitations were overcome by guaranteeing the participants confidentiality and anonymity and to use information gathered for the purposes of this study only.

1.12 Research Methodology

This research was a qualitative study conducted using the psycho ethnographic research design. Data was gathered using face to face interviews and focus group discussions as well as participant observations. Participants totalling 43 were drawn from formal and informal HIV and AIDS caregivers in the suburbs of Masvingo urban. Data was analysed using thematic and interpretive phenomenological analysis. Details of the research methodology were fully discussed in Chapter 3

1.13 Ethical and legal considerations

Denscombe (2002) defines ethics as “the system of moral principles by which individuals can judge their actions as right or wrong, good or bad”. Researchers are expected to operate ethically in the creation of knowledge as determined by the larger society as a matter of professional integrity. Since the research on experiences of family caregiving of HIV positive people involved obtaining a lot of personal and intimate data from the respondents, much consideration was given to ethical requirements. Where the respondents showed reluctance to elaborate on sensitive information, the researcher respected such decisions.

Even though various ethical problems were encountered during the conduct of this research, no misplaced promises were made to caregivers since this would have been unethical. The Government prohibits that yet compensating participants for the time devoted to answering
research questions was an important consideration, no money was paid to research participants serve for some refreshments during the in-depth interviews. Participation was voluntary. Permission from institutional gatekeepers NAC and DAC Masvingo Regional offices, BHASO and Red Cross Masvingo Province were sought.

The participants participated on an informed consent basis. The purposes of the research and potential reparations to the participants were made explicit to them in addition; people were told that they reserved the right to choose whether or not to participate. Anonymity, confidentiality and right to withdraw from the study were spelt out. I made sure that the individual study participants did not experience any harm as a result of their participation in the research. I also ensured the participants that the resulting research and publications will not be used in such a way that they may bring harm to the participants as a group. There were no traumatised respondents as a result of the study and therefore no referrals were made for psychological help.

In the case of participant observation situations in which I interacted with people in more public settings, I made the objectives clear, respected individual’s wish not to participate, and left the scene where necessary.

1.14 Definition of Terms

While some unfamiliar and technical terms that are unique to this study are defined in the text, to give their operational and contextual meanings, there are some words that need immediate clarification. The following words are, in this study, defined as follows:

1. **Persons living with HIV and AIDS**: These are persons infected with the AIDS virus who need to be looked after. These have a weakened immune system that any disease
can infect. They also have a very low CD4 count, (Maartens, 1999). The sufferer is bedridden for more than 50% of the day, during the last months of the illness. The infected person presents with symptoms like wasting, chronic persistent diarrhoea for more than a month, affected brain functioning leading to confusion, with signs of mental disorder (Maartens, 1999). Other symptoms include opportunistic infections like tuberculosis, in other parts of the body, pneumonia, herpes, fungal and parasitic infections throughout the body, infections in the brain and infections being carried around the body by the blood.

2. **Caregiver or carer** are words normally used to refer to unpaid relatives or friends of a disabled individual who help that individual with his or her activities of daily living ([http://en.wikipedia.org/wiki/Caregiver](http://en.wikipedia.org/wiki/Caregiver)). The words may be prefixed with "family" "spousal", "child", "parent", "young" or "adult" to distinguish between different care situations, and also to distinguish them definitively from the paid version of a caregiver, a Personal Care Assistant or Personal Care Attendant (PCA). In this study, caregivers therefore referred to paid and unpaid persons who help an HIV positive individual with his or her activities of daily living. They can be health personnel, counsellors, and relatives of the infected like wife, husband, children or parents and friends.

3. **Family caregiving** refers to the caring for or looking after persons who are HIV positive, either formally or informally, by either paid or unpaid personnel. Family caregivers provide a wide variety of services to care recipients such as administering medications and physical therapy, assisting with daily tasks, meeting with healthcare providers, coordinating treatment regimens and schedules, helping with financial and
administrative aspects of medical care, health insurance and more. They can also provide emotional support for coping with the disease (http://en.wikipedia.org/wiki/Family_caregivers accessed 28/02/2012).

4. **Formal/secondary caregivers:** These include health professionals, behavioural health specialists, and social workers who are trained and compensated for their care giving activities. The trained volunteers and spiritual counsellors associated with AIDS service organizations, AIDS care teams, and hospice programs also fall in this definitional category.

5. **Informal/primary caregivers:** These include relatives, spouses/partners, and friends who provide in-home care – usually on an unpaid basis. These caregivers vary in the types of tasks performed, the amount of time devoted to care giving, and living arrangements (i.e., same or separate household).

6. **Caregiver burden** is ‘the extent to which caregivers perceive their emotional or physical, social life, and financial status as suffering as a result of caring for their relative, or the consequences of the activities involved with providing necessary direct care to an ill relative or friend that result in observable and perceived costs to the caregiver’.

7. **Palliative care** is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (https://apps.who.int/dsa/justpub/cpl.htm). Palliative care provides relief
from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends either to hasten or postpone death; integrates the psychological and spiritual aspects of patient care and offers a support system to help patients live as actively as possible until death.

In this study palliative care refers to the active and total care of patients at a time when their disease is no longer responsive to curative measures and when other symptoms of psychological and social problems are of great importance.

1.15 Summary

Chapter one looked at the background to the study. It contained a detailed and clear statement of the problem to be solved. The rationale or motivation of the study was clearly spelt out. The purpose of the study and what it seeks to accomplish was clarified. The chapter also highlighted the moral principles guiding the conduct of the study and constraints that were inherent in the study were also stressed. The study delimitations made clear the boundaries of this research. The researcher rounded up the chapter by identifying those words that required defining in order to avoid any misrepresentations.

1.16 Organisation of Thesis

Chapter two mainly constituted of literature related to this research. It touched broadly on the the Review of Related literature on HIV and AIDS caregiving work and the challenges involved. It also highlighted on the clinical stages of HIV and AIDS which are critical to the study. This helped to limit my research problem or research questions and to clarify and define concepts of the study. It helped me to avoid unintentional replication of previous studies.
Chapter three involved a clear and concise description of how the study was carried out. It is a description of all the activities and procedures undertaken during the course of the research. It includes the Thesis’ methodology, research design, instruments, data collection procedures, data presentation and analysis plans and the chapter summary.

Chapter four focused on data presentation techniques, discussion and interpretation of research findings. The discussion and interpretation of findings were equally focused to ensure that all the results of the sub problems/ sub questions were discussed.

The last and final chapter included the summary of the research report, the research conclusions and the recommendations. It also informs of the research problem tackled, the research methodology used and its limitations, major findings of the study and their implication for practice.
CHAPTER II

REVIEW OF RELATED LITERATURE

2.1 Introduction

People living with HIV and AIDS often constitute a large proportion, if not the majority of people seeking medical treatment at hospitals these days. Many hospitals do not have adequate resources to care for HIV patients (Olagoke Akintola, 2004). With the high rate of HIV infection in African countries and hospitals unable to accommodate the resulting large number of sick people, discharging patients for home care has become one way to cope. When AIDS enters the household, women and girls provide most of the care to the ill, as expected by society and this requires high personal cost of caring for the primary family caregiver. How then did this pandemic came to be?

2.2 HIV and AIDS and its Origins

HIV and AIDS pandemic is a health and developing crisis throughout the world. Despite extensive research, the origins of HIV itself remain incompletely understood. According to Jackson (2002), HIV belongs to an unusual group of viruses called retroviruses found in humans, cats, cattle and some other animals. More specifically, HIV is related to simian (monkey) immunodeficiency viruses (SIVs) (Jackson, 2002). Viruses easily mutate and it is probable that HIV mutated from viruses found in monkeys and apes.

Exactly when, where and how SIV crossed over into humans is according to Jackson (2002) unclear. According to Schoofs (1999) and Essx (2002), cited by Jackson (2002), evidence
suggests that the crossing over of SIV into humans has happened several times. Several SIVs have been identified, and it is believed that most of these viruses do not cause ill health or death in their host species but, if injected into other monkey species, can cause an AIDS like condition of immune deficiency. Evidence also suggests that the immune system of monkeys and apes that frequently have SIV have adapted to cope (Jackson 2002). That the human immune system is eventually overcome by HIV suggests that HIV is fairly new to the human species. SIV may have crossed into humans about 60 to 70 years ago according to Jackson (2002), and would take many generations for human populations to evolve sufficient immunity to survive infection.

Debates continue as to how, where, when and even why HIV first infected humans. Some have attributed AIDS to God, according to Jackson (2002), as punishment for sexual promiscuity. Others have blamed biological warfare experiments by developed nations that released the virus into the global population, either deliberately or accidentally (Jackson 2002). Another line of thought is that polio vaccines, widely given in central Africa in the 1950s and 1960s using monkey serum, could have been contaminated with SIVs. According to Jackson (2005), these viruses could not be detected at the time but could have been rapidly passed on to thousands of humans through vaccination.

In Africa, and as sub-Saharan Africa reels under a series of apparently chronic illnesses and health crises such as AIDS, witchcraft and witchcraft accusations appear to be on the rise. In Zimbabwe for example, it is believed that a man who suspects that his wife is being unfaithful may go to an n'anga (traditional healer) and get a type of medicine to place in her drink or her food that will bring on a type of affliction locally known as runyoka. Any man that she has sexual relations with, other than her husband, will begin to 'waste' away, the
husband being unaffected. Not surprisingly, runyoka is often conflated with HIV and AIDS. Runyoka is, however, curable with a traditional healer's intervention HIV and AIDS is not.

HIV and AIDS presents itself in many ways, and as the disease progresses through stages particular symptoms are normatively experienced by the infected at each stage. The World Health Organisation (hereafter referred to as WHO) classifies the progression of HIV and AIDS into four (4) clinical stages (Maartens, 1999). According to Maartens (1999) this presents a clear guide to the way this disease progresses. During Stage I, known as the early stage of the infection, the main symptom is swollen glands which persist. The infected person also presents with fever, headaches, tiredness, sore muscles and diarrhoea that occur for a few weeks to a few months after the infection (Maartens, 1999). Although the infected is experiencing these symptoms, these are actually minimal to the extent that the person appears asymptomatic. They are able to perform normal activities.

During Stage II of the infection, the infected person experiences repeated infections of the upper airways as well as mouth ulcers and less than 10% of unintentional body weight loss. Other concurrent infections include shingles, rashes, skin diseases, fungal infections in the nail and severe cracks of the mouth. During this stage symptoms may be observable, but the individual can still perform normal daily activities.

The clinical features observable during Stage III are more than 10% of body weight loss, diarrhoea or fever that persist for longer than a month, thrush in the mouth, back of the throat and sometimes the female genitals, oral hairy leukoplakia, tuberculosis and pneumonia (Maartens, 1999). The sufferer is bedridden for less than 50% of the day, during the last
month of the illness. All these indicate that AIDS will occur within a year or two (Maartens, 1999).

During Stage IV, also known as the AIDS-defining conditions, the infected presents with symptoms like wasting, chronic persistent diarrhoea for more than a month, affected brain functioning leading to confusion, with signs of mental disorder (Maartens, 1999). Other symptoms include opportunistic infections like tuberculosis in other parts of the body, pneumonia, herpes, fungal and parasitic infections throughout the body, infections in the brain and infections being carried around the body by the blood. Kaposi sarcoma, which is a certain type of skin cancer, may also occur at this stage. The infected will be bedridden for more than 50% of the day during the last month of the illness thus requiring 100% nursing care. This stage can endure from anything from one (1) month to six (6) months so it may require more than short, acute periods of care.

During all stages of HIV infection, the caregiver requires physical, psychological and social delivery of care, and especially during Stages III and IV of the disease as the infected are physically as well as mentally affected by the disease leading to decreased functionality and independence (Maartens, 1999). Knowledge of the experiences and the coping strategies of the primary caregivers living with and caring for HIV positive persons at all stages and especially Stages III and IV, HIV and AIDS infected persons at home is of great importance to the carers themselves and the nation at large.

Although scientists have not yet discovered a drug combination that can completely eradicate the virus, it is important to note that major advances in highly active antiretroviral therapy (HAART) have dramatically altered the nature and duration of HIV and AIDS caregiving in
the world. The new HAART regimens are helping many HIV-positive individuals to live longer and enjoy a better quality of life. Marked declines in rates of opportunistic infections and deaths have brought the hope that HIV can be managed in the home as a chronic disease. The populations that require HIV management also are changing. Growing numbers of HIV positive Zimbabweans are poor, marginalized, and uninsured or publicly insured (O’Neill, Marconi, Surapruik, Blum, 2000).

2.3 The Personal Costs of Caring
2.3.1 Stress
The term stress refers to the physical and emotional response to situations in which environmental challenges or threats are greater than a human being’s capacity to respond (Sapolsky, 2004). Such challenges often include changing life circumstances, such as moving house, changing or losing jobs, relationship difficulties, particularly conflict and emotionally abusive interactions, financial and legal challenges, commonly debt. Work related challenges including demanding work situations, long hours, and few breaks in the workday, few opportunities for leave, conflict with co-workers and clients, and so on are a growing cause of stress (Sapolsky, 2004). The work of a family caregiver involves many stressors relating to personal work context; personal relationships with family and other colleagues, and of course issues in caregivers’ personal lives such as relationship and financial problems.

At a physical level, according to Sapolsky (2004), stress is characterized by the release of stress related neurotransmitters and hormones, sometimes called the adrenal response because of the central role played by the adrenal glands. These chemical changes engage the sympathetic nervous system which initiates physiological changes, sometimes referred to as the “fight-or-flight response”. Heart and breathing rates become accelerated; blood flow is increased to the brain and muscle group related to running, climbing or fighting, and
decreased to the skin and the digestive and reproductive systems; and hearing and vision becomes more focused.

At a psychological level, it is the appraisal of the environmental challenge that in fact triggers the physiological stress response described above. Thus changes to the way in which a person appraises challenges in his or her environment can change the stress response and the resultant health and mental health consequences. This is a key component of stress management (Lazarus and Folkman, 1984). Stress also has psychological consequences including feelings of anxiety, hopelessness, helplessness, irritation and exhaustion.

While the stress response is a healthy consequence of the mammalian evolutionary past, excessive chronic stimulation of the sympathetic nervous system has grave health and mental health implications. Stress related health conditions include blood pressure and heart problems, compromised immune system, and constant headaches. Mental health problems include anxiety disorders, mood disorders, insomnia, substance abuse and burnout (Friedman and Silver, 2007).

2.3.2 Traumatic stress.

This is the second important foundation concept where stress is typically understood as the accumulation of multiple, chronic life and environmental challenges, traumatic-stress is the response to a sudden event that is perceived to be life threatening. The Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) (American Psychiatric Association, 2000:379) describes a traumatised person as

One who experienced, witnessed, or was confronted with an event or events that involved actual or threatened death or serious injury, or a threat to the physical integrity of self or other. The person’s response involved intense fear, helplessness, or horror.
As such, the emphasis is on events characterized by serious danger or threat or injury. Implicit in the work itself, is the witnessing or confronting of death, and some deaths may be particularly horrific. In this case horror refers to situations which involve extreme physical suffering and graphic injury and pain. Traumatic stress responses also develop from the operation of the sympathetic nervous system and the “fight-or-flight” response and have some of the same health consequences of stress.

However, the likelihood of a post-traumatic stress response and the possibility of a person developing acute stress disorder (ASD) or post-traumatic stress disorder (PTSD) differentiates traumatic-stress (American Psychiatric Association, 2000). Post-traumatic stress responses are characterized by three symptom clusters. The first of these are the intrusive symptoms which involve a sufferer re-experiencing the traumatic event in different ways. Examples of intrusive symptoms include constantly thinking about or remembering the traumatic event, nightmares, and dissociative flashbacks.

The second set of symptoms associated with traumatic stress is avoidance symptoms which involve the sufferer avoiding aspects of their life associated with the traumatic events. This category includes avoidance of people, places and activities associated with the event, avoiding talking or thinking about the event, as well as traumatic amnesia and psychic numbing.

The final category of trauma related symptoms is referred to as the arousal symptoms and includes not being able to concentrate, sleep problems, and hyper-vigilance (Friedman, 2006). Research conducted in the United States of America shows that although more than
half of Americans will experience a traumatic event in their lives, only 8% will develop PTSD (Kessler, Sonnega, Bromet, Hughes and Nelson, 1995). Recently, a parallel study conducted in South Africa found that approximately 75% of South Africans have experienced at least one traumatic event, with 38% reporting three or more traumatic events. Criminal victimization, partner abuse, child abuse, threat to life, traumas of loved ones, and disasters all contribute to high distress and the experience of multiple traumatic events increasing risk of stress and distress exponentially (Williams, Williams, Stein, Seedat, Jackson, and Moomal, 2007).

The theory of secondary traumatic stress also links the experience of carers to existing knowledge of traumatic stress. The theory predicts that suffering carers will experience and demonstrate many of the same symptoms as those suffering from PTSD. This turns out to be true with many carers reporting on-going rumination about their clients (intrusion), avoidance of particular clients due to feelings of horror or helplessness (avoidance), as well as sleep disturbances and irritability (arousal). The theory of secondary traumatic stress also links carers’ primary experience of trauma and loss and the secondary experiences derived from their work. Of particular interest to home-based care is the shared background of client and carer. Part of the rationale for home-based care programmes is the argument that people who come from the same community as the client are better positioned to understand the client’s position and so will be more acceptable and successful as a helper.

A further stream of thinking and theory building in relation to the impact of caring, produced the concept of ‘vicarious traumatisation.’ This concept was originally proposed by McCann and Pearlman (1990) and enhanced by Pearlman and Saakvitne (1995). At the heart of vicarious traumatisation are the relationship dynamics between the client and the carer. In
particular, these authors focus on the special role of transference and counter-transference on
carers’ health and wellbeing. In some cases, clients become overly dependent upon carers and
expect carers to provide for all their needs, at all times, and without appropriate boundaries.
In other cases, clients may express their multiple frustrations and sense of loss through anger
and accusations of abandonment, poor service delivery against carers. Similarly, the carer
may derive feelings of powerfullness and being needed by keeping the client in a helpless and
dependent position, or in fact may displace their own frustrations and disappointments on to
their clients. Carers require a high level of self-reflection as well as skilful and close
supervision in order to remain healthy and effective in their work.

2.3.3 Grief

A third foundation concept of importance to this study is that of grief. Grief is the healthy,
human response to loss, and most commonly refers to the loss of a significant person in the
sufferer’s life. It is characterized by emotion numbness, disbelief, social withdrawal, anxiety,
despair, sadness, and loneliness. Several stage models of the healthy grieving process have
been proposed, of which the most well known is that of Kübler-Ross. Kübler-Ross’ model
proposed five stages of grieving: denial, bargaining, anger, depression and acceptance
through which a grieving individual passes, although not necessarily in sequence (Kübler
Ross, 1997). While the Kübler-Ross and other stage models of grief are not without their
detractors they do provide a containing structure for both sufferers and those who work to
support them.

Although grief is a healthy response to loss, a minority of bereaved people develop a
condition described as complicated or prolonged grief. In these cases the natural grief
response described above does not ameliorate with time and the condition may develop into a
psychiatric disorder. Although usually associated with major depressive disorder, many believe that complicated grief should represent a separate diagnostic category. Horowitz, Siegel, Holen, Bonanno, Milbrath, and Stinson (2003) suggest that this category would be characterized by intensive intrusive thoughts, waves of severe distress, distressing yearnings, feeling alone and empty, avoidance of activities that remind the sufferer of the deceased, sleep disturbances, and loss of interest in significant personal activities. The similarities to the PTSD diagnosis described above are compelling.

Family caregivers deal with stress, traumatic stress and grief on a daily basis in their personal lives and in their work. Incorporating such distressing experiences into the routine of one’s working life presents challenges not adequately described by these foundational concepts. The next section outlines various theoretical perspectives designed to understand the experience of professional carers and support them in their work.

2.3.4 Resilience and negative resilience

While a great deal of work has been done in relation to general adversity, especially in children, for example the work of Rutter (2000), much less has been done in terms of resilience in potential traumatic situations. Resilience is broadly understood as the capacity to withstand or “bounce back” from significant adversity with limited distress and no long-term negative consequences. Herman (1992) also provides a useful definition of resilience in the face of traumatic exposure. Resilience is the capacity to preserve social connection and active coping strategies, even in the face of extremity, which seems to protect people to some degree against the later development of post-traumatic syndromes. Resilient people remain consciously focused on preserving their calm, their judgment, their connection with others,
their moral values, and their sense of meaning, even in the most chaotic battlefield conditions.

Herman (1992) suggests that approximately 10% of the population is naturally resilient in the face of traumatic stress. Strumpfer (1995) argues that social scientists need to pay attention to the questions they ask. Rather than researching the origins of traumatic stress (pathogenic questions), or even the origins of health in the face of traumatic stress (salutogenic questions), social scientists should be investigating the origins of strength (fortigenic questions). This perspective is important because it reminds us that the demands of some occupations require extraordinary psychological strength, and that failing to remain healthy should not be seen as a personal failing but as an injury in the workplace.

While little work has been done on understanding the characteristics of the resilient family caregiver, some concepts from Friedman and Higson-Smith’s (2003) work with police are relevant. These authors use the term negative resilience to describe a particular and common response to repeated traumatic exposure in the line of duty over many years. They argue that when healthy people begin a career that involves repeated exposure to traumatic stressors they experience a healthy acute traumatic stress response equivalent to that of people in other professions exposed to danger. When this happens, however, they are explicitly or implicitly informed that they will not be successful in their line of work if they respond in this way. In essence, the organisational culture requires that they suppress their natural and healthy response to threat. This is described as disenfranchised distress.

Messages that refer to “professional behaviour”, “professional distance”, “toughening up” and so forth all contribute to this particular dynamic of many professions that involve
increased exposure to threat. Friedman and Higson-Smith (2003) argue that workers respond to these messages by developing a negatively resilient position characterized by dissociation, psychic numbing, and denial. This is related to the earlier and simpler point about reduced empathy. Negative resilience may also be supported by substance abuse using illegal, legal, or even prescribed substances.

Negative resilience is explicitly differentiated from positive resilience for several reasons. Firstly, negative resilience involves a loss of emotional and empathic capacity with predictable long-term implications for personal and professional relationships, wellbeing and health, (Herman 1992). Secondly, this form of resilience represents a reduced range of response to threat and it is likely that this strategy will eventually prove ineffectual at which point severe, possibly fatal, results are predicted. Thirdly, negative resilience is associated with a loss of professionalism. The associated loss in meaning of the work, and loss of deep compassion for care recipient can lead to abscondment, negligence, corruption and other forms of unethical conduct, (Herman 1992).

According to Herman (1992), the resilient family caregiver is the person who is able to tolerate high levels of exposure to suffering, trauma and grief, and yet remain healthy, happy, connected and professional. This is the prize that researchers and practitioners are seeking and the long-term goal of the intervention and research that comprise this project. With this in mind, the care for the carers programme was developed. In conclusion it is important to note, that although separated out in this theoretical overview, the effects of stress, traumatic stress, grief, and compassion fatigue are cumulative and very difficult to disentangle in the lives of carers. All these different psychological challenges work on the same neurological and hormonal systems within the individual. Stressors and dangers at home and at work all join
together in affecting the health and wellbeing of carers. As such it is not possible to design care for the carer programmes that target only the effects of work related challenges (Herman 1992).

2.4 Prevalence rate of HIV and AIDS infection in Zimbabwe

The first case of AIDS in Zimbabwe was reported in September 1985, and the AIDS pandemic had increased dramatically by the mid-1990s (http://www.kff.org/hivaids/upload/7370.pdf). Estimates show that between 1.6 to 1.7 million people are living with the disease in Zimbabwe. Sentinel surveillance data for Zimbabwe shows adult HIV prevalence increased from >1% in 1993 to over 30% in 2001 and dropped to about 18% in 2006 (UNAIDS Global Report, 2006) and even down to 15% according to The Sunday Mail, September 7-13, 2008. Though being the case, the disease is still quite prevalent and those infected need to be taken care of.

Considering the long incubation period of HIV and AIDS, many HIV-infected persons are not yet symptomatic. These numbers represent only a portion of those who will need care in the near future. Although the prevalence rate of the adult HIV infection has dropped significantly as compared with the previous years, Zimbabwe is still placed among the countries with the highest infection in the world. Heterosexual intercourse has been the dominant route of HIV transmission in Zimbabwe and other developing countries (UNAIDS Report, 2004). Unlike young adult deaths that occur suddenly, like those due to accidents or violence, PLWAs often require extensive care and other resources as they become ill. The demands and outcomes on the family caregivers of these patients are enormous and need to be addressed in terms of public health policy, health economics and patient-care perspectives (World Health Organisation, 2006).
The provision of family care for HIV positive persons in Zimbabwe faces numerous obstacles. The context in which the provision of care occurs is vital in understanding the challenges faced by family caregivers in Zimbabwe. The fact that HIV and Aids epidemic occurs in conjunction with the severe shortages of health carers means that the provision of care in Zimbabwe is critically over-burdened (http://www.kff.org/hivaids/upload/7370.pdf). In addition to this, poverty and lack of infrastructure, as well as high incidence of tuberculosis are complicating factors in the provision of care. In response to the Zimbabwean government policy and given the increased demands on the health-care system, as well as the shortage of nursing staff, the role of integrated community based home carers plays a pivotal role in the provision of health care and especially palliative care in Zimbabwe. HIV and Aids carers are faced with many challenges in their provision of palliative care. These challenges relate to lack of resources; lack of support, training and supervision; unsafe working practices, fear of infection and possible exposure to illness; risks to physical safety; and the stigma of being associated with HIV and AIDS and death among others (http://www.kff.org/hivaids/upload/7370.pdf).

There is no cure for HIV and AIDS and as such, societies will continue to endure the challenges of caring for the infected. The personal cost of caring is a key issue facing service providers who offer critical services to individuals and families suffering as a result of terminal illness in the developing world. By drawing on the work and experiences of carers in Masvingo urban and associated organisations it is hoped that this study will offer insight into the development of more effective care for the carer programmes in Zimbabwe and beyond.
2.5 Prevalence of HIV and AIDS Care

A lot of people are now involved in some form of informal caregiving in one way or another. More than 54 million people – 27% of the adult U.S. population – served as informal caregivers for people with chronic illnesses or disabilities between August 1999 and September 2000 (http://www.ncbi.nlm.nih.gov/pubmed/8036534). Fifty-six percent of these caregivers were female, and 37% lived in the same household as the care recipient.

No current data are available on the proportion of U.S. adults providing in-home care to people with HIV and AIDS. However, telephone interviews conducted with a probability sample of U.S. adults between June 1990 and February 1991 found that 3% of all adults and six percent of central-city residents were caring for HIV-positive relatives or friends. Nationally, 59% of these caregivers were female, and 22% were people of colour, other Americans not white Americans. The vast majority were under age 40 (74%) and heterosexual (90%), (UNAIDS, Report of the Global AIDS Epidemic, 2004).

Findings from the HIV Cost and Services Utilization Study (HCSUS), a nationally representative sample of U.S., according to the UNAIDS, Report of the Global AIDS Epidemic (2004), adults receiving medical care for HIV disease, indicate that 21% of the infected used in home nursing and supportive services during early 1996. AIDS-diagnosed individuals were much more likely to use home care services than people in earlier stages of disease (40% vs. 10%). Of the home care users with AIDS, 42% used unpaid (informal) care only, 35% used paid (formal) care only, and 23% used both types of care. The most common sources of unpaid care were family members other than a spouse or partner (38%) and friends (27%). While most AIDS-diagnosed individuals relied upon relatives and friends
for help with household tasks and personal care, 22 % received in-home nursing services (e.g., injections, infusion therapy, and parenteral nutrition) from informal caregivers (Kaiser Family Foundation, 2001).

In Zimbabwe, AIDS has contributed to the loss of youths and older adults, which has become a more common event than it was previously. Between 8% and 13% of the Zimbabwe older cohort, aged ≥ 50 years in 1995, will experience the death of an adult youth due to AIDS before their own death (UNAIDS Global Report, 2006). As such, first Zimbabwe’s National Primary Health Care Policy promotes the concept of self care and the community-centred system. The family members are assumed to play a collaborative role with health-care providers instead of a dependent role in the health-care arena.

A project on prevention and control of AIDS by communities adopted by the Zimbabwean government is of the notion that AIDS prevention must be the responsibility of both health-care provider and everyone in the community (Kaiser Family Foundation, 2012). As a result of implementing the policy of decentralization of care for HIV and AIDS patients, families are the key persons to take care of HIV-infected members in their homes.

McCann and Wadsworth (1992) found that the majority of caregivers were friends and spouses of PLWA. Caregivers were performing tasks like personal and household chores, giving advice about health and welfare, providing psychological reassurance, and transporting and accompanying to appointments. Primary caregivers are on call 24-hours a day. This is in contrast to nurses who are shift workers, thus having time off from patients. This in itself places great demands on the well being of the caregiver. Thorough research is
therefore needed to advise on the needs of caregivers in order to develop interventions and support structures.

2.6 Caregiving Work

The world over, caring for a sick person is a challenging task, and often the caregiver feels tremendous stress because of the nature of the illness and attitude of the patient toward both the illness and the caregiver. The caregiver may also feel isolated when relatives refuse to help, and may become angry with the sick person, especially if he or she is a spouse. The caregiver may also lack the necessary resources including gloves, essential drugs and food. In some cases the high death rate associated with AIDS has forced the sick to care for the sick.

That being the case, the researcher feels compelled to carry out a research of this magnitude. Home-based care programmes were started in North America and Europe when it was found that families had difficulty coping on their own with the demands of caring for people living with HIV and AIDS (PLWA) (Spier & Edwards, (1990) in Uys, 2003). During the late 1980s and early 1990s this type of service was introduced in a number of African countries (Sims & Moss, (1995) in Uys, 2001). In Zimbabwe, community-based care organizations have been designed to take care of those that are infected with as well as affected by HIV-related illnesses. Home-based care entails the provision of necessary health care by a volunteer caregiver to a patient or family at home, often with the support of a Community Caregiver. These support services are offered by Community-Based Organizations and include home visits, where assistance is given with physical, medical, and emotional care.

In African countries the home-based care approach was developed mainly because of AIDS. The Zimbabwean government, along with other NGOs, understood that AIDS is more than an
illness; hence home-based care is the best kind of care an individual can hope for. At home, patients and their relatives spend as much time together as they want (http://www.tandfonline.com/doi/abs/10.1080/). Patients are free to come and go, and they can take on responsibilities and not feel helpless. Their diet can be monitored easily, home-cooked food is usually better for their health, and home-based care is much cheaper for the family.

In a study conducted by Uys (2001), community caregivers from seven sites that participated in the study had been trained for three months in the theory and practice of home-based HIV and AIDS care. Unlike family/primary caregivers, community-based caregivers receive emotional care support from the institutions that employ them.

Although the services of community-based caregivers are available, it is the informal caregivers who provide most of the care for the sufferers. Thus they experience a lot of emotional, financial, physical and social difficulty. These people are typically the lovers, spouses, children, friends or family of someone diagnosed with HIV and AIDS. They usually have little or no training in the home-based care which is offered to them by community caregivers during visits, which would enable them to cope on their own when these professionals are not present.

AIDS is the late stage of HIV infection, when a person’s immune system is severely damaged and has difficulty fighting diseases and certain cancers. Before the development of certain medications, people with HIV could progress to AIDS in just a few years. Currently, people can live much longer - even decades - with HIV before they develop AIDS. This is because of “highly active” combinations of medications that were introduced in the mid 1990s.
However, because of it being a debilitating and fatal illness, AIDS leads to dependency on others for care giving and other forms of support. While persons living with AIDS (PLWA) are often able to continue to work and care for themselves initially, most require demanding care giving during the final stages. Moreover, the virtual certainty of death, at least for most infected persons living in developing countries, and the potential stigmatisation associated with the disease are likely to lead PLWA to seek an emotionally supportive environment in which to live after their symptoms become obvious to themselves and others. These aspects of the disease often prompt changes in living and care giving arrangements during the course of the illness.

Previous research in Thailand reveals that the most common place for adult PLWA to spend the terminal stage of the illness is in the parental home and the most common caregiver at this stage is a parent, particularly a mother (Knodel & Mark Vanlandingham, 2001). Two-thirds of adults who died of AIDS either core sided with or lived next door to their parents. For those cases with a parent alive at the time of illness, more than three fourths received some care from a parent and for almost 60%; a parent was a main caregiver. The vast majority of AIDS parents were at least aged 50 and more than half were 60 or over. Parents are also likely to be important as caregivers to adult children with AIDS in many other settings in the developing world where the epidemic has spread. A series of surveys in Uganda found similar levels of parental involvement as primary care givers (Ntozi and Nakayiwa, 1999). Likewise, studies in Zimbabwe also stress the important role of parents in caring for AIDS-afflicted adult children (Mupedziswa (1997); Williams and Tumwekwase (1999); WHO 2001).
One South African hospital reported patients’ average stay decreased from 14 days to 3.5 days when referred to a home-based care organisation (http://www.avert.org/aids-home-care.htm). According to the same source, a potential benefit of home-based care is that sick people are surrounded by people they love and are familiar with, so they can also receive more flexible and nurturing care. They will also not be exposed to hospital-based infectious diseases. As people with terminal illness generally spend their final moments at home, improving the quality of their care at home also removes the cost and distress of travelling to and from the hospital when they are weakest.

In Zimbabwe, the impact of HIV and AIDS on health services is emerging at a rapid pace, overburdening the system and leaving households and communities with the responsibility of care. Though they seem to be a decline in the rate of new HIV and AIDS infections in Zimbabwe (from 32.1% in 2000 to 23.9% in 2004, 18.1% in 2008 and down to 14.26% by end 2009 according to National AIDS Estimates, 2010), there is still urgent need to address the issue of caring for those already infected.

People living with HIV and AIDS need assistance performing basic household tasks. These include washing, cooking, feeding, cleaning, purchasing household essentials, going to the toilet and other needs not necessarily specific to HIV and AIDS. More HIV related tasks include purchasing, administering and supporting adherence to ARV drugs and medication for HIV related pain if the infected person is receiving treatment, as well as helping with nutrition, as the person’s diet may differ from other members of the household. Monitoring and recording progress, making notes of events such as toilet visits, fluid intake and symptom occurrence are other tasks that can be undertaken by family and home based care workers and volunteers, (HIV & AIDS Treatment in Practice 2003). These very practical measures are in
addition to seeing to the person’s social, psychological and emotional needs – often termed ‘psychosocial’ needs – which everyone has but which are often broader and more severe if living with HIV (HIV & AIDS Treatment in Practice 2003).

Family members and friends provide the majority of home based care for people with HIV and AIDS. Among this group, however, the provision of care falls disproportionately to women and older people. In one South African study, over two-thirds of family caregivers in households affected by HIV and AIDS were women or girls (Steinberg, et al 2002). It is estimated that half of all older people in areas severely affected by AIDS are involved in caring for older children with HIV and/or AIDS orphans, (Help-Age International 2005, November). This burden of care assumed by women and the elderly has been recognised at the highest levels. The United Nations’ 2006 Political Declaration on HIV/AIDS advocates "providing support and rehabilitation to these children and their families, women and the elderly, particularly in their role as caregivers" (United Nations 2006). At an awareness raising concert former South African president, Nelson Mandela, specifically mentioned these carers as deserving of more attention.

“Women don’t only bear the burden of HIV infection; they also bear the burden of HIV care. Grandmothers are looking after their children. Women are caring for their dying husbands. Children are looking after dying parents and surviving siblings” (Nelson Mandela VSO, 2006).

In Zimbabwe, knowledge about family caregiving of PLWAs is sparse and research in family caregiving is in the infant stages. Prior studies in Zimbabwe also indicate that the most common place for adult AIDS persons to spend the advanced stage of their illness is in their parents’ home and the most common caregiver is a parent—particularly mother—providing care for almost two-thirds of the Zimbabwe adults who died of AIDS (Medecins Sans
Frontieres, 2009). For married PLWAs, the spouses, especially wives, often play a major role. As more complex care is offered at home, mothers and wives will continue to be the main caregivers of PLWAs.

The changing demographics of the HIV epidemic, along with the growing complexity of medical care, have created major challenges for the health professionals who provide curative and palliative care and the informal caregivers who provide emotional and practical support to relatives and friends living with the disease. As mentioned earlier on, it is estimated that between 1.6 and 1.7 million Zimbabweans are living with HIV with 300,000 of these in urgent need of antiretroviral (ARVs) drugs. Only about one-third is receiving regular medical care in the form of ARVs (The Sunday Mail of September 7-13, 2008). For those who are in care, decisions must be made on when to start antiretroviral therapy, which drug combinations to use, and how to manage viral resistance and drug-specific toxicities.

As treatment options have expanded, so have the stresses experienced by caregivers. The prolongation of the disease course, uncertainty about overall prognosis, and a “roller coaster” pattern of repeated exacerbations and remissions in later stages of HIV disease have intensified the emotional and physical demands of care giving (Mupedziswa, 2002). In-home caregivers increasingly are being asked to help patients manage sizable pill burdens, frequent and complicated dosing schedules, and therapy-related side effects. According to Mupedziswa (2002), many of these caregivers face the added burdens of poverty, inadequate housing, and lack of knowledge about available resources. Some are themselves HIV-positive. These developments underscore the importance of recognizing and meeting the needs of HIV and AIDS caregivers over the long term, both for their benefit and for the well-being of people in their care.
The HIV pandemic is overwhelming public hospital capacities. A serious consequence of this being that other patients’ care is compromised due to premature discharges from hospitals. The increased demands placed on medical budgets, combined with the prolonging of patients’ lives through antiretroviral therapy treatment, has led to HIV being classified as a chronic disease best suited for home based care (Hickey, 2001). Many countries proposed that family members and others willing to care for the HIV and AIDS patients be given the opportunity to minimise the financial costs of the disease as well as to let the infected die comfortably among their loved ones (http://www.cdc.gov/hiv/topics/basic/). This could also provide HIV infected persons with improved social support.

With the high rate of HIV infection in African countries and hospitals unable to accommodate the resulting large number of sick people, discharging patients for home care has become one way to cope. Many people in Africa and in Zimbabwe in particular, believe that a person discharged for home-based care has been sent home to die. But that is not true. Individuals can actually be helped to reclaim their lives and return to work.

2.7 Experiences and Challenges of Family Caregiving

Caregiving is a demanding responsibility. Research in caregiving seems to be an accumulation of diverse points of views. Over the past decade, many studies have emphasized the negative consequences of caregiving, generally referred to as caregiver burden, caregiver stress and caregiver strain. Some studies used positive terms such as caregiver esteem, caregiver satisfaction and uplifts of caregiving (http://www.neurology.org/content/51/1_Suppl_1/S53.short). Other research used neutral
terms including health, mental-health outcomes, caregiver appraisal, caregiver well-being and quality of life.

Most of the HIV and AIDS home care is carried out by family members who have no contact with professional help and suffer through lack of support (Wringe, Cataldo, Stevenson, & Fakoya, 2010). This means that infected people may be inadequately looked after despite the best efforts of their carers and families. Also of importance are the challenges faced by these primary caregivers that include among many others inadequate help from home-based care organisations, limited resources, risks faced by carers, economic burden on the family and bereavement issues (http://www.avert.org/aids-home-care.htm).

There are two types of caregivers who provide clinical care and supportive services to people with HIV and AIDS. Formal caregivers include health professionals, behavioural health specialists, and social workers, who are trained and compensated for their caregiving activities (USAIDS, Health Profile: 2005). The trained volunteers and spiritual counsellors associated with AIDS service organizations, AIDS care teams, and hospice programs also fall in this definitional category. Informal caregivers include relatives, spouses/partners, and friends who provide in-home care – usually on an unpaid basis. These caregivers vary in the types of tasks performed, the amount of time devoted to caregiving, and living arrangements (i.e., same or separate household) (USAIDS, Health Profile: 2005). The concerns of this research are on informal caregiving.

Informal caregivers perform a variety of roles that help people with HIV and AIDS adhere to treatment regimens, avoid unnecessary hospital admissions, reduce reliance on formal caregivers, remain at home longer, and maintain quality of life. Traditionally, family
members have served as the primary caregivers for seriously ill individuals. Because HIV care involves more diverse social networks, many HIV-positive individuals have redefined family boundaries to include lovers, friends, and other “chosen kin.” (Mpedziswa, 2002)

Findings from a 1997 national survey according to CIA Factbook ‘USA’ (2010) indicate that the typical caregiver devotes more than 20 hours per week to caregiving tasks. These tasks may include emotional support (e.g., comforting, empathizing, and providing encouragement), help with activities of daily living (e.g., feeding, bathing, dressing, and toileting), help with instrumental activities of daily living (e.g., cleaning the house, running errands, providing transportation) and management of financial and legal matters. Health care advocacy (e.g., linking the care recipient with formal and informal services, communicating with health professionals) and nursing care (e.g., dispensing medications and monitoring use, administering injections, inserting catheters) are tasks that primary caregivers undertake.

Informal caregivers are increasingly being asked to administer pain medications, manage epidural catheters and home infusions, and provide wound care, but relatively few studies have examined their contributions to palliative care. Informal caregivers can play an important role in identifying and managing symptoms and side effects, yet most are thrust into these roles with little or no training. PLWAs that are single (or non-partnered) often have no one on whom they can depend for care and support other than their parents, siblings or other relatives. Hence, many PLWAs who live away from their place of origin are likely to return to their family home when they can no longer earn a living or when they need extensive care because the symptoms worsen (UNAIDS Report, 2004).
The recent findings in Zimbabwe, in a qualitative study of caregivers using focus group, reported that caregivers took responsibilities for caring for PLWAs including providing physical care; assisting with activities of daily living (ADLs); cooking; giving medicine; physical exercise; wound care; providing basic care for general symptoms such as fever, headache, oral thrush, cough, diarrhoea and skin infection; and giving emotional support (UNAIDS, 2006). Data from the study have also shown that family caregivers felt overwhelmed with the caregiving demands in the care of their family members.

Burden is one of the most commonly used variables in caregiving research both as a predictor and as an outcome. However, much published research has identified the determinants in the effort to predict or explain caregiver burden. Several definitions of caregiver burden have been defined in the literature. Zarit, Reever and Bach-Peterson (1995:649), defined caregiver burden, an outcome measure, as ‘the extent to which caregivers perceive their emotional or physical, social life, and financial status as suffering as a result of caring for their relative’. Caregiver burden might be defined as a predictor such as ‘an external demand or potential threat that has been appraised as stressor’, continues Zarit et al (1995:649). Caregiver burden is a multidimensional phenomenon reflecting the physical, psycho emotional, social and financial consequences of caring for an impaired family member.

Burden of care of PLWAs can be linked to an outcome of care. Structure of care, related to non-clinical influences on outcomes is composed of two categories: (i) characteristics of the caregiver; and (ii) characteristics of the patient. The latter are being the stronger predictor of caregiver outcomes. The process of care is patient self-care and self-care burden. The outcome of care is caregiver burden and quality of life of caregivers. Caregiver characteristics
that might influence caregiver outcomes include age, gender, socioeconomic status, duration of caregiving and family relationship between the patient and the caregiver.

The caregivers’ ability to tolerate problem behaviours increased with time as disease progressed in caregivers of dementia patient. Conversely, Gaynor (2000) found feelings of perceived burden to be higher among women who had been involved in caregiving for an extended time. Patient characteristics that have been cited in the literature as having an influence on caregiver outcome include patient’s age, activity of instrumental tasks and stigma.

In contrast, Riedel (2001) found that patient’s age was not associated with caregiver burden. No studies were found in the relation of patient characteristics and burden of HIV and AIDS caregivers in Zimbabwe. In the studies of caregivers for HIV and AIDS patients including in Thailand, instrumental tasks are a major source of caregiver burden. Similar to the care for the elderly, caregivers who assist care receivers with care for persons with behavioural problems exhibit greater burden than caregivers who assist with other care needs (USAIDS. Health Profile: Thailand HIV/AIDS, 2004). The effects of societal stigmatization, as well as the degree of caregiving demands, might become overwhelming for the caregivers.

Stigma attached to HIV and AIDS and the association of HIV infection with sexual practices, with injection drug use and with death have placed the disease in societal taboos. In Zimbabwean culture according to Mushonga (2000), the perception of AIDS as a frightful contagious disease, resulting from immoral behaviour, leads to the view that HIV and AIDS patients are ‘bad people’ especially among the ‘religious people’. As such family caregivers are shunned by people around them, including their family members, relatives, friends and
health-care providers, as well as society. Caregivers of HIV and AIDS patients share some of the burdens related to a stigmatized person. Mushonga (2000) found that stigma was associated with perceived burden in HIV and AIDS caregivers in Zimbabwe.

According to the USAIDS Health Profile Thailand HIV/AIDS (2004), multiple factors contribute to caregiver burden. First, caregiving usually comes as an unexpected role, one for which people are neither socialized nor prepared. To assume this new role, caregivers must restructure pre-existing role obligations and social activities and the ways in which they relate to the care recipient. Interpersonal strains may intensify as the caregiver and care recipient attempt to resolve issues of autonomy and reciprocity within the context of an increasingly asymmetrical relationship. Progressive enlargement of the caregiver’s role over the course of illness may require further adjustments in family, work, and social commitments (USAIDS. Health Profile: Thailand HIV/AIDS, 2004).

The physical demands of informal caregiving also contribute to burden. Unlike formal caregivers, the relatives and friends providing in-home care often are “on call” 24 hours a day. While working this 24-hour shift, caregivers may be required to perform multiple, and sometimes conflicting roles. UNAIDS (2010) Report on Global AIDS epidemic, stated that, those who have never cared for a seriously ill person must learn basic nursing skills, often under extremely stressful circumstances. They must also find ways to oversee complex medication schedules while meeting their own home and work obligations. Some have the added burden of caring for entire families infected/affected by HIV disease.

The emotional issues surrounding caregiving are a third source of burden. Because HIV is most prevalent among people under age 40, the caregivers also tend to be relatively young.
The non-normative experience of caring for someone with a terminal illness can be a major source of stress for these young adults. For people of all ages, HIV and AIDS caregiving creates the emotional strain of dealing with an unpredictable and currently incurable disease, (UNGASS 2010). Some caregivers are burdened by fears of contracting HIV even when they know there is little basis for concern. Those who are already infected may worry that no one will be around to care for them when they become ill. Adjusting to disease progression can be especially difficult for caregivers who have experienced multiple losses and the attenuation of social support networks.

2.7.1 Economic challenges

In Zimbabwe, as compared to the total U.S. population, informal caregivers are more likely to have annual household incomes of less than $3000.00, making it highly challenging to care for the infected (UNAIDS, Report of the Global AIDS Epidemic, 2004).

The care for HIV and AIDS patients is provided through general and infectious disease hospitals in Zimbabwe. As a result of the economic crisis in Zimbabwe, in previous years, it has been very difficult for the government hospitals to accommodate the ballooning numbers of the HIV and AIDS infected numbers (http://www.avert.org/aids-zimbabwe.htm). The care for HIV and AIDS was limited particularly in the area of medical interventions. These medical treatments, such as the use of antiretroviral drugs and opportunistic infection drugs, could not effectively match the potential demand for curative services. For example, hospitals developed the guidelines for HIV and AIDS patients who needed treatment for opportunistic infections, provided supportive and palliative care instead of specific treatment for some cases and motivated the use of alternative medicine such as herbal treatment and medications.
In addition, in response to the crisis, the treatment focuses more on social and psychosocial services.

The HIV and AIDS pandemic has created a significant burden on the Zimbabwean hospital system (Mupedziswa, 2002). The opportunistic infection of HIV and AID disease is the leading cause of admission to the hospital. Nevertheless, only 15% of the patients can be hospitalized because of the hospital bed limitations. Because the hospitals are unable to care for the majority of HIV and AIDS patients and because of the trend of shorter hospital stays and home-based care, HIV and AIDS patients receive care at home. As a result of the economic crisis, the change of treatment of HIV and AIDS patients focused on palliative care instead of curative care.

Studies have shown that HIV and AIDS patients would rather stay with their families at home than in a hospital. It is reported in some studies that 96.4% of the HIV and AIDS patients preferred home-based care services because they feel safe, happy and comfortable with their close relatives (Olagoke Akintola, 2004). The necessary emphasis on family caregiving is even more significant because the family member is given the responsibility of the care of PLWAs.

Primary caregivers are those individuals who provide practical help and nursing to PLWA at home. Typically these primary caregivers are parents, siblings, a partner or friend of the patient. These primary caregivers have no formal training in caring for the terminally ill, yet they provide physical and emotional nursing and financial assistance to PLWHA. In extreme cases, as is the case with Stages III and IV of the illness, these caregivers find themselves
delivering services like bathing the patient, doing shopping for them, preparing meals, administering medication, and taking them for regular check-ups (Maartens 1999).

Turner, Catania and Gagnon (1994) conducted a study to identify the prevalence of informal AIDS caregivers in the United States, their social and demographic characteristics and the type of tasks they perform. He found out that caregiving imposes disruptions in task development on caregivers, which might have detrimental long-term economic and psychosocial consequences. Turner et al. (1994) also found that those with the poorest financial resources are more likely to perform the most labour intensive care giving tasks due to their inability to pay for the professional services.

As the researcher, I am not aware of any data available on the proportion of Zimbabweans providing in-home care to people with HIV and AIDS. However according to a survey done by this researcher, DAC Masvingo claims there are over 26000 people infected by the HIV and on ARVs in Masvingo as a province. The prevalence rate of the city is around 16%, which is more than the national prevalence rate (DAC Report for NAC Masvingo, December 2010). This prevalence gave the researcher an estimate of how much caregiving activity is going on in the city. DAC Masvingo also estimates that there are on average 56 support groups only in the whole province for HIV and AIDS infected persons from different Non-Governmental Organisations, Ministry of Health and the Red Cross Society. These support groups are composed of formal caregivers in the form of HBC facilitators amounting to more than 200 members. According to Red Cross Society, Masvingo office, each of the HBC facilitator under their supervision cares for six households infected with the pandemic on average, giving us about 1200 under formal care out of the 26000 infected.
If these statistics are anything to go by, at least 26000 people infected are being cared for by someone and the question is, ‘who then is caring for these carers?’ How many of these carers are under DAC’s spotlight or else the majority suffers silently? From the above, it can be estimated that more than 20000 are under informal care. What is even more surprising and of great concern is the recent report in the local newspaper The Mirror of 18-24 May 2012. According to Elizabeth Mashiri, a reporter for this paper, ‘five people are infected with STIs in Masvingo every hour’. This aggravates the prevalence of HIV infection and as such the caregiving activities for the infected in the city of Masvingo. It is important therefore that this study brings into focus all those involved in caregiving work in Masvingo urban and the country at large, as well as explore their experiences and help put in place intervention strategies in order to enhance the quality of life for both the affected and infected.

The financial impact of caregiving can be a major source of burden. Many families suffer severe economic hardships when a key wage earner is forced to reduce work hours or leave paid employment to care for a sick partner or relative. As bills accumulate, the family’s most basic needs may go unmet. The loss of income also makes it difficult for caregivers to access formal resources, such as home health and respite care, which could make their tasks more manageable.

This is unlike most home based care (HBC) programmes in South Africa which rely on unemployed (mainly female) volunteers from affected communities (Child_Gauge_2005). In a few cases, these are paid a small stipend. Many caregivers share food and other material goods with the patients they visit, spending long days working free of charge instead of looking for paid employment (Plusnews, 2005.)
According to Olagoke Akintola (2004), a three-province survey in South Africa found that almost three quarters of AIDS affected households were female-headed, a significant proportion of whom were also battling AIDS-related illnesses themselves. Poverty and faltering public services in many areas are combining with AIDS to turn the care burden for women into a crisis that has far-reaching social, health and economic consequences. In a four-province research study of Home Based Care organizations conducted by the Population Council, qualitative data from focus group discussions with beneficiaries of funding similarly revealed that care-givers within the family tend to be female. Respondents felt that fathers and brothers do not provide support.

According to a female respondent in that study, “Fathers can’t take care of the sick; they only help out with money once in a while.” Another woman from a different province commented: “You know males they are not that sensitive. Mothers can take care of so many things. Most males don’t like taking care of sick people... women are patient and caring. Men can’t be like that” (Olagoke Akintola, 2004).

A final source of burden is the stigma surrounding HIV disease. Community rejection of HIV-positive individuals because of their disease or the mode of transmission often extends to the relatives and friends who provide care. Rather than face stigmatization, some caregivers try to conceal their caregiving activities by withdrawing from social relationships. Those who do acknowledge their caregiving status may find it difficult to obtain support from familial or social networks.

HIV positive parents face additional challenges that increase their sense of burden. These challenges include arranging for guardianship of the children, balancing the needs of “sick”
and “healthy” family members, and helping their children cope with the disease and possible discrimination. If a child is HIV positive, the mother’s guilt about transmitting the virus can be overwhelming. HIV-positive parents also may have unmet needs for social support. For example, in one multi-city study, only 30 percent of the HIV positive mothers were aware of childcare services, and only 8 percent had used these services. In another study of African-American and Latino families with HIV positive children, seropositive parents reported more isolation and fewer financial and support resources than uninfected caregivers.

It is important to note that many of the burdens experienced by formal and informal caregivers are the same. For example, fear of exposure is a major source of stress for some health professionals. Formal caregivers may experience a lack of support from their families and professional colleagues due to concerns about contagion or “stigma by association.” They also may share the informal caregiver’s emotional distress about not being able to “cure” the disease.

The unpredictable course of HIV disease and the wide range of potential complications can create significant burden, particularly for clinicians with limited HIV management experience. While attempting to control chronic symptoms and conditions, clinicians also must be prepared to treat episodes of acute illness and therapy-related side effects. Additional sources of burden include repeated exposure to the death of young patients, ethical dilemmas, and finding the time to counsel and support informal caregivers. Formal caregivers also may be burdened by workplace-related stressors, such as work overload, unrealistic expectations of what can be accomplished, lack of decision making autonomy, communication problems and role conflicts, and inadequate medical resources and referral arrangements (USAIDS. Health Profile: Thailand HIV/AIDS, 2005).
AIDS-related grief and bereavement experiences impact a lot on the primary caregivers in a number of ways (Kain, 1997). First, many people who die of AIDS do so at a relatively young age. Walker (1991) notes that although survivors may have anticipated an HIV-positive person's death, it still remains out of synchrony with the expected life-cycle of someone young. Second, HIV-related bereavement is also distinguished from other types of grief by the stigma associated with AIDS. This stigma may prevent those who survive from freely mourning or acknowledging the cause of a friend or loved-one's death. Third, AIDS bereavement can become complicated when the grieving person has served as primary caregiver to the deceased (Kain, 1997). This is especially the case for caregivers who had a difficult time feeling entitled to respite from attending to the needs of the dying person to see to their own personal affairs. For many people, survivor guilt may prevent them from fully engaging in the bereavement process. Particularly in the gay community, survivors may feel guilty about being HIV-negative in light of the suffering of their peers. Kain (1997), went on to say children may also experience survival guilt in response to the death of a parent or sibling. Fourth, when survivors are themselves HIV-positive, worry about their own health status may confound bereavement. Clinical and counselling psychologists as well as the health personnel need to address some or all of these issues in helping primary caregivers especially to come to terms with a friend or loved one's death.

For many people, the time needed to grieve the loss of one person to AIDS-related complications becomes interrupted by the demands of caring for or mourning the death of another person. Thus, multiple loss, the overwhelming task of living in a situation where continual loss has become commonplace, has become a very important issue that distinguishes HIV-related bereavement from other types of grief. The phenomenon of
multiple losses owes its recognition to psychological studies of war-time survivors (Lifton, 1980). The AIDS crisis marks the first time in modern history that widespread multiple losses have occurred in an atmosphere of non-violence (Walker, 1991).

Lifton (1980) identifies five common psychological responses which make up the experience of multiple losses. First, people suffer from indelible mental images of death and dying, stemming from the enormity of the loss. Second, people suffer from survivor guilt rooted in the randomness of the situation. In the context of multiple losses, survivor guilt is rarely the sole property of HIV-negative people. Third, people with multiple losses often experience a diminished capacity to feel, known as psychic numbing. Fourth, Lifton reports they also often experience a suspicion of "counterfeit nurturance." People who have survived multiple losses often crave special nutrition however; the identity of "victim" is often highly defended against. Therefore, nurturance given in response to a survivor's multiple losses is often not seen as "real" and is rejected according to Schwartzberg (1992), because it unconsciously reinforces a feeling of victimization. Finally, people with multiple loss syndromes actively search for meaning. Schwartzberg (1992) maintains that multiple loss syndrome is extremely relevant to grief in an HIV-immersed subculture. For example, he writes, "it can be an overwhelming experience to be simultaneously mourning a recent loss, remembering several past losses, and anticipating still others to come, yet this is the reality of grieving for many primary caregivers" (p 243)

2.8 Disadvantages of Caregiving
Caring for the infected has its own advantages and disadvantages. Caring for an individual with a chronic disease, such as HIV and AIDS, leaves little time or energy for self-care. The multiple tasks performed by caregivers may cause them to neglect nutrition, exercise,
socialization, and sleep (The Independent, 17th November 2006). One study of women caring for people with physical or mental disabilities according to Women and Caregiving (2004), found that caregivers with high levels of subjective burden were less likely to eat balanced diets, exercise, and participate in stress management and health-promoting activities. Another study of women caring for HIV-positive relatives and friends found that almost two-thirds had experienced at least one chronic physical symptom (Women and Caregiving: Confronting the Crisis, 2004). A third study of Latinas caring for family members with HIV and AIDS documented high levels of physical health problems and affective disorders (Women and Caregiving: Confronting the Crisis, 2004).

The extent to which caregivers experience these and many other symptoms depends on their personalities, belief systems, health and energy levels, and coping skills. Additional factors affecting caregivers’ response to stress include the severity of the care recipient’s illness, the duration of caregiving, and the accessibility of social support and financial resources (O’Neill, Marconi, Suraprui, Blum, 2000:244)

2.9 Advantages of caregiving

Although caregiving work tends to have a lot of burden in caring, there also are many rewards. According to Olagoke Akintola (2004), when asked about the positive aspects of providing HIV and AIDS care, informal caregivers cited opportunities to bring mission and purpose to one’s life, they develop empathy and self-knowledge. Primary caregivers felt they gained a sense of personal effectiveness by demonstrating competence under very difficult circumstances as well as experience the positive feelings associated with loving, caring, and feeling needed. One study suggested that helping caregivers define the meaningful and
valued aspects of their roles and become more attuned to “brief human moments” that create positive feelings can enhance both their physical and psychological well-being.

However, finding rewards in caregiving does not necessarily make these activities less stressful. A high degree of involvement, whether positive or negative, can produce stress. The term “burnout” is used to describe the process in which everyday stressors that are not addressed gradually undermine the caregiver’s mental and physical health.

Psychologists define burnout in terms of three components: emotional exhaustion, depersonalization, and reduced personal accomplishment. Emotional exhaustion represents the basic stress dimension of burnout (Myers, 2002). This condition is characterized by feelings of being emotionally overextended and lacking enough energy to face another day. Depersonalization represents the interpersonal dimension of burnout. Feeling drained and “used up,” the caregiver develops an emotional buffer of detached concern and interacts with others in a negative and callous manner. Reduced personal accomplishment represents the self-evaluation dimension of burnout. This dimension is characterized by a growing sense of inadequacy and may result in a self-imposed verdict of failure.

The literature on caregiving suggests that both individual and situational factors increase the risk of burnout. The individual factors include among others, age (younger caregivers more subject to burnout), high expectation of oneself and others, high levels of commitment, dedication and idealism. Other individual factors include the need to work hard, improve oneself and a strong goal orientation. Difficulty delegating responsibility to others, propensity towards self-sacrifice and tendency to be a ‘giver’ rather than a ‘receiver’ completes the list of individual factors (Scott, Palliative Care 2000).
On the other hand situational factors include among others; role ambiguity (i.e., lack of clarity about what the caregiver is supposed to do), conflict between role demands and work overload. Job tension, interpersonal conflict (with care recipient, family members, colleagues, or supervisors), inadequate preparation for caregiving and inadequate social support are other factors. Lack of recognition for the caregiving functions performed, workplace-related factors (e.g., unrealistic work targets, lack of decision-making autonomy, inadequate referral arrangements), complete the list.

Empirical research suggests that situational factors are more strongly predictive of burnout than individual characteristics (Scott, Palliative Care 2000). Caregivers experiencing work overload and interpersonal conflict over an extended period of time are particularly vulnerable to burnout.

Caregiver burnout has serious consequences for the caregiver, care recipient, and health care system. Caregivers typically experience burnout in stages. Early warning signs may include feeling less motivated, putting in more hours with poorer results, and/or voicing complaints about the caregiving role. During later stages, caregivers develop many of the physical, psychological, and behavioural problems. Because burnout occurs gradually, caregivers tend to keep working until the downward spiral goes too far and the costs in performance and well-being become unacceptably high (UNAIDS, 2004).

Care recipients suffer when burnout leads to lower-quality care. Caregivers struggling with emotional exhaustion often become less sensitive to the care recipient’s feelings and needs. This “compassion fatigue” increases the likelihood that the care recipient will be neglected;
treated in a detached, mechanical fashion; or even subjected to mental/physical abuse. Burnout symptoms, such as decreased judgmental ability and difficulty focusing on tasks, make it more difficult for caregivers to competently perform clinical roles. As these changes occur, care recipients may be at increased risk for disrupted care or placement in a long-term care facility.

The health care system is negatively affected when burnout depletes the supply of experienced caregivers and creates a need for continual training of replacements. Burnout among caregivers who remain in the system may require greater commitments of resources for their physical and mental health care. The health care system incurs additional costs when relatives and family members become too exhausted to provide in-home care and responsibility shifts to formal service providers (UNAIDS, 2010).

2.10 Psychosocial needs of caregiving

Caregivers of HIV positive persons require comprehensive assessments of emotional burden and social support. Six psychosocial needs were identified in one study Turner (1998) and these were:

- Need to Maintain Physical Integrity (i.e., desire to be knowledgeable about the modes of HIV transmission and ways of protecting the infected child from opportunistic infections)
- Need to Learn (i.e., desire to know the different roles of the health professionals with whom they interact, to receive information on new HIV/AIDS treatments, to have their questions answered honestly, and to learn how to deal with stress)
- Need to Act According to a Set of Beliefs and Values (i.e., desire to have health professionals respect them for doing what they believe is “right”)
[Need to Communicate](i.e., desire to be kept informed on the condition of the child and to be able to express their feelings. Desire for greater support from their informal social networks)

[Need to Feel Worthwhile and Useful](i.e., desire to be supported by health professionals throughout the course of disease)

[Need for Continuity of Care](i.e., desire to develop and maintain relationships with the same group of health professionals)

Caregivers experiencing guilt, hopelessness, or spiritual distress may need to be referred for religious or spiritual counselling. Discussions with clergy, hospital/hospice chaplains, or other spiritual counsellors can help caregivers find comfort and peace even in the absence of strong religious or philosophical belief systems. Caregivers with affective disorders or high levels of burden should be referred to mental health professionals for assessment and counselling.

It seems as if Health professionals sometimes overlook the importance of extending counselling into the bereavement period. Bereavement counselling can help caregivers mourn appropriately, cope with the changes resulting from their loss, and plan for the future.

### 2.11 Summary

This Chapter mainly constituted review of literature related to the key concepts in this study. It touched broadly on the origins and prevalence of HIV and AIDS, on the caregiving work, experiences and challenges involved in caregiving. It also highlighted on the clinical stages of
HIV and AIDS which are critical to the study as well as the advantages and disadvantages of caregiving.

There has been a growing interest over the past twenty years in exploring the caregiving experience. Over the course of the AIDS pandemic, family caregivers have provided an essential source of care to PLWAs. The assessment of burden has become a challenging task for most researchers. The literature suggests that the characteristics of the caregiver, the characteristics of the patient, stigma, the nature of the caregiving relationship and finance among others are the determinants of caregiver burden. Formal caregivers are in an excellent position to minimize the burden of care experienced by informal family members through their intervention.

There is generally limited research on primary family caregiving in Zimbabwe while most such researches are based abroad. In Zimbabwe, research undertaken so far mainly focused on the caring and home based care volunteer coping strategies and the welfare of those infected with HIV and AIDS leaving out the experiences and significance of HIV and AIDS caregiving work by the primary family caregivers. This study’s emphasis was on highlighting the significance of the primary family caregivers’ work.

Chapter three will focus on how the study was carried out. It is a description of all the activities and procedures undertaken during the course of the research. It includes the methodological framework, research design, instruments, data collection procedures, data presentation and analysis plans.
CHAPTER III

RESEARCH METHODOLOGY

3.1 Introduction

This chapter presents and justifies the research methodology used and the philosophical assumptions underlying the methodology. This is followed by a description of the research design and the justification for its use. Also included are details of the population, sampling techniques, data collection instruments, measures taken to optimize validity, reliability and generalisability of findings. The actual data collection process is explained in the final part of the chapter which focuses on data analysis, presentation and interpretation. Ethical considerations will round off the chapter.

3.2 Methodological Framework

A research philosophy is the way in which data about a phenomenon should be gathered, analysed and used (http://www.docstoc.com/docs/8558617/Research-Philosophy). The term epistemology (what is known to be true) as opposed to doxology (what is believed to be true) encompasses the various philosophies of research approach. The purpose of science, then, is the process of transforming things believed into things known: doxa to episteme. Two major research philosophies have been identified in the Western tradition of science, namely positivist (sometimes called scientific) and interpretivist (also known as anti-positivist) (Galliers, 1991).
Interpretivists contend that only through the subjective interpretation of and intervention in reality can that reality be fully understood. Interpretivism emphasises that life is constructed from a subjective point of view and that social research should seek to elicit the meaning of events and phenomena from the point of view of participants (Johnson 1994). The study of phenomena in their natural environment is key to the interpretivist philosophy, together with the acknowledgement that scientists cannot avoid affecting those phenomena they study. The theory acknowledges that humans have feelings and cannot be treated like objects in research. These are some of the positive aspects that the researcher considered when conducting this study on the psychological experiences of primary caregivers of HIV positive Zimbabweans, which involved eliciting information of a very sensitive and personal nature from respondents. Interpretivists admit that there may be many interpretations of reality according to Johnson (1994), but maintain that these interpretations are in themselves a part of the scientific knowledge they are pursuing. Interpretivism has a tradition that is no less glorious than that of positivism, nor is it shorter.

On the other hand, the researcher noticed that positivism emphasizes the importance of an objective scientific method. These researchers see their role as collecting facts and then studying the relationship of one set of facts to another. They analyse quantitative data using statistically valid techniques and produce quantifiable and generalisable conclusions. Positivism stresses the importance of studying social and organizational realities in a scientific way that mirrors the research processes used in the natural sciences (http://zh-hk.facebook.com/note.php?note_id=399218525897&comments).

I was however convinced that interpretivism was a more reputable approach to a study of this nature. This is so because interpretivism is concerned with understanding of human’s
perceptions of the world. Interpretivists see facts as the product of human interactions – they are the product of shared understandings and meanings and are not always predictable. The less quantifiable and the subjective interpretations, reasoning, and feelings of humans are seen as a more relevant line of enquiry in order to understand and explain the phenomena. Therefore, the focus of interpretivism is not numbers but on words.

In any scientific research, the study can either be quantitative, qualitative or both. Quantitative research as a measurement must be objective, quantitative and statistically valid. It is about numbers and objective data (Denzin, 1978). On the other hand qualitative research is much more subjective than quantitative research and uses very different methods of collecting information, mainly individual, in-depth interviews and focus groups. The nature of this type of research is exploratory and open ended. Small numbers of people are interviewed in-depth and/or a relatively small number of focus groups are conducted.

This research is a qualitative study that was conducted using the psycho ethnographic research design. According to Denzin, Norman, Lincoln, and Yvonna (2005), qualitative research is a methodology of inquiry employed in many different academic disciplines, traditionally in the social sciences, but also in market research and other contexts. Qualitative researchers aim to gather an in-depth understanding of human behaviour and the reasons that govern such behaviour (Denzin et al 2005). The qualitative methodology investigates the why and how of decision making, not just what, where, when. Hence, smaller but focused samples are more often needed than large samples. In the conventional view, qualitative methods produce information only on the particular cases studied, and any more general conclusions are only propositions.
Qualitative researchers typically rely on the following methods for gathering information: participant observation, non-participant observation, field notes, reflexive journals, structured interview, semi-structured interview, unstructured interview, and analysis of documents and materials (Marshall, Catherine & Rossman, Gretchen. 1998). Some distinctive qualitative methods of gathering data are the use of focus groups and key informant interviews. In the academic social sciences the most frequently used qualitative research methods include the ethnographic research, critical social research, ethical inquiry, grounded theory, phenomenology and philosophical research. In this research, the researcher used the psycho ethnographic research design (http://en.wikipedia.org/wiki/Qualitative_research).

3.3 Research Design

Ethnographic research design was used in this study. The choice of the psycho ethnographic research design was influenced by various considerations which include the nature of the problem, the population under study, the resources available and the philosophical underpinnings or research orientation, guiding the research itself in as far as its epistemology (the way humans create knowledge) and ontology (the nature of social reality) is concerned (http://zh-hk.facebook.com/). This research has a strong bias towards the interpretivist paradigm.

In this research, the approach used involved entrance into the participants’ environment in order to collect psychological data in the contexts within which the participants live. In psycho ethnographic research, the researcher completes the study through asking questions, listening and observing. The word ‘ethnography’ has been borrowed from the synthetic Greek word which basically means ‘a portrait of people’ (Harris and Johnson, 2000). Having said that, ethnography has been characterized by Gummesson (2003) to be an in-depth
research methodological approach, as well as regarded to be by researchers such as Fetterman (1998) and Dey (2002), both the art and science of understanding, interpreting and describing a group or culture. Ethnography has been used if research focus on the human side was desired and as such, this researcher chose this method because of its power to study in depth an intact group. Data collection and analysis are intertwined to reveal areas that may have been missed and shape subsequent data collection. Psycho ethnography basically involves combining psychological and ethnographic data collection methods in collecting psychological data, (http://www.incommunityresearch.org/).

Ethnographic methods are a means of tapping local points of view, households and community "funds of knowledge" (Moll & Greenberg, 1990), a means of identifying significant categories of human experience up close and personal. Ethnography enhances and widens top down views and enriches the inquiry process, taps both bottom-up insights and perspectives of powerful policy-makers "at the top." It also generates new analytic insights by engaging in interactive, team exploration of often subtle arenas of human difference and similarity. Through such findings ethnographers may inform others of their findings with an attempt to derive, for example, policy decisions or instructional innovations from such an analysis.

The advantages of using a qualitative design are that it generates detailed, valid and unbiased data. Psycho ethnography is based on ethnography, and by their nature ethnographic paradigms accumulate knowledge about people by, watching [them] in their own territory and interacting with them in their own language according to Kirk and Miller (1986). This is made possible by the fact that data is collected in the natural contexts within which the participants live. This psycho ethnographic research involves systematic description and
analysis of a people’s culture (symbolic meanings, beliefs, attitudes, and behaviours) that is oriented by a particular research problem.

Psycho ethnographic research design is justifiable in this context since it offers rich, detailed, thick, multifaceted and holistic data (Geertz, 1973). Psycho ethnography, since it is embedded in the ethnographic paradigm, is ideal for hidden populations like HIV positive persons. Hidden populations are the disadvantaged and disenfranchised populations often omitted from national studies since they want to keep their status a secret (protect their identity) and are less likely to agree to an interview (Lambert and Wiebel, 1990).

Ethnographic methods are ideal for topics about which little is known, primarily because they are fundamental and exploratory, preparing the way for more rigorous studies that strive for precision and quantification. In Zimbabwe there is dearth in literature on caregiving of HIV positive persons. Furthermore, caregivers of HIV positive patients have a tendency to be very secretive about their situation due to stigma and other issues associated with the pandemic, hence give untrue data (Lucchini, 1996a:131), which can be offset by use of ethnographic methods (Dube, 1999).

3.4 Population

According to Myers (1991), research population is generally a large collection of individuals or objects that is the main focus of a scientific study. However due to large sizes of populations, researchers often cannot test every individual in the population because it is too expensive and time consuming among other things. This is the reason why researchers rely on sampling techniques. Myers (1991), goes on to say it is a well defined collection of
individuals or objects known to have similar characteristics. All individuals or objects within a certain population usually have a common, binding characteristic or trait.

In this study the population was all Zimbabwean caregivers who look after persons infected and suffering from HIV and AIDS. These include both informal/primary caregivers e.g. spouses, relatives and friends of the infected and formal/secondary caregivers like the HBC facilitators, health personnel and NGO official who are into caregiving of HIV and AIDS infected Zimbabweans.

3.5 Target Population

Target population refers to the entire group of individuals or objects to which the researcher is interested in generalising the conclusions (Myers, 1991). The target population usually has varying characteristics and it is only known as the theoretical population. The target population of the study were caregivers of HIV positive persons in the City of Masvingo. These comprised of primary caregivers who were in constant touch with the care recipients 24 hours a day and secondary caregivers who included trained HBC facilitators who would come in to help the primary caregivers periodically.

3.6 Study Population

There is often confusion on the usage of the terms ‘target’ and ‘study’ populations. The terms are often interchangeably used yet in actual fact they are different. Study population is referred to as the accessible population in research to which the researcher can apply his or her conclusions (Myers, 1991). This population is a subset of the target population. It is from the study population that researchers draw their sample.
The study population is the group of people which the researcher is interested in gaining information and drawing conclusions from (Johnson 1994). Due to logistical constraints, I collected data mainly from primary caregivers and some secondary caregivers of HIV positive Zimbabweans living in Mucheke and Rujeko, two high density suburbs in the city of Masvingo, Zimbabwe. A few secondary caregivers were consulted for their professional opinion on the subject matter under study.

3.7 Sample Size

Sampling is when researchers reduce the amount of data they need to collect by considering only from a subgroup rather than all possible cases (Saunders et al, 1997). Sampling eliminates the need for testing everyone in a population. Sample size is critical in research. Without an appropriate sample size, data may not be reliable, and conclusions may be based on misinformation. Sample size is an important part of establishing the validity of the study. In general the larger the sample size, the more likely the research is to be accurate. As mentioned previously, this sample is drawn from the study population.

A sample size of forty-three (43) participants took part in the study. A total of thirty-eight (36) informal caregivers took part in Focus Group Discussions. The participants for Focus Group Discussions consisted of sixteen (16) female and twelve (12) male caregivers. Another eight (8) informal caregivers took part in In-Depth Interviews. A total of seven (7) Home Based Care facilitators, Non Governmental Organisations (NGOs) officials involved in caring for the infected and other such health personnel were consulted for information. All the participants in the study were drawn from the suburbs of Masvingo urban. It is also important to note that the study participants were also used for participant observation.
3.8 Sampling Techniques

Sampling techniques are classified as either probability or non-probability (Saunders et al. 1997). A probability sampling scheme is one in which every unit in the population has a chance (greater than zero) of being selected in the sample, and this probability can be accurately determined. Random sampling, systematic sampling and stratified sampling are examples of Probability sampling (Saunders et al. 1997).

Saunders et al. (1997) defined non-probability sampling as any sampling method where some elements of the population have no chance of selection. These are sometimes referred to as 'out of coverage'/undercovered', or where the probability of selection can't be accurately determined. It involves the selection of elements based on assumptions regarding the population of interest, which forms the criteria for selection. Accidental/convenience sampling, quota sampling, snowball/respondent driven sampling and purposive sampling are some examples of non-probability sampling methods.

Snowballing in social science research is a technique where existing study participants are used to recruit more participants into the sample, (Saunders et al. 1997). Some variants of snowball sampling, such as respondent driven sampling, allow calculation of selection probabilities and are probability sampling methods under certain conditions. Respondent-driven/snowball sampling is a special non probability sampling technique used when the desired sample characteristic is rare. It may be difficult or cost prohibitive to locate respondents in these situations.

Respondent-driven sampling according to Myers (1991) is a new form of sampling of chain-referral sampling/ snowball sampling. It is ideal where no sampling frame exists. It reduces
biases like volunteerism and masking which means over-recruitment of especially cooperative participants and under-recruitment of less cooperative participants respectively. In essence, respondents recruit their peers, as in network-based samples, and researchers keep track of who recruited whom and their numbers of social contacts.

Respondent Driven Sampling incorporates a method for removing sampling bias introduced by typically arbitrary selection of initial respondents. The selection of initial respondents introduces a bias compounded by each additional recruitment wave; affiliation patterns that are friendship occur among persons similar in levels of education, ethnicity and interests termed homophily. However, this bias was weakened by having large number of waves making it reach equilibrium independent of the characteristic of the seeds.

This study employed respondent driven sampling to recruit informal family caregiver participants for Focus Group Discussions, and In-Depth Interviews. This is a sampling procedure in which respondents recruit their peers to be studied on and is applicable for hard-to-get samples like family caregivers for HIV positive patients.

The traditional sampling methods were found to be unsuitable for family caregivers for HIV positive individuals as response rates are low and also because the responses lack condor. The sampling begins with initial respondents who serve as “seeds” and expands in waves, where first wave consists of respondents referred to by the seeds. The second wave in turn consists of respondents referred to by the first wave respondents, and so, each recruitment is linked in the recruitment chain.
A purposive sample is a sample selected in a deliberate and non-random fashion to achieve a certain goal. In a focus group, for example, you may want to consciously seek out respondents at both ends of a spectrum (as well as some in the middle) to insure that all viewpoints are adequately represented. You might also preferentially recruit participants who have the best knowledge and experience in an area, (http://www.childrensmercy.org/stats/definitions/purposive.htm)

Purposive sampling, a variant of snowball sampling, allows calculation of selection of a study sample. According to Saunders et al (1997), purposive or judgemental sampling enables the researcher to select cases which will best enable them to answer research question(s) and meet objectives. This form of sampling is often used when working with small samples, and when you wish to select cases that are particularly informative (Neuman, 1991).

The sampling technique was used in the study to recruit participants for key informant interviews and participant observation and non-participant observation. Theoretical sampling was employed to ensure the inclusion of such a sample. Theoretical sampling necessitates building interpretative theories from the emerging data and selecting a new sample to examine and elaborate on this theory. It is the principal strategy for the grounded theoretical approach, according to Glaser and Strauss (1998), but will be used in some form in most qualitative investigations necessitating interpretation.

As I learnt more about the primary family caregivers, relevant distinctions between the family caregiver categories emerged. Using this theoretical knowledge, sampling decisions were made to ensure the inclusion of a broad representation of family caregivers. Eligibility was
restricted to those family caregivers (both male and female) who were involved in the caregiving of HIV positive Zimbabweans.

Caregivers were approached in their organisations or places of work, introduced to the study, and asked to participate in an interview that was to take place in a nearby setting that was part of the caregivers’ own natural setting but also provided ample opportunity to conduct the interview in a coherent and relatively private manner, such as an office. Most participants however were interviewed during meeting times with other members from the different support groups at the two established field stations of Mucheke and Rujeko Community Halls of Masvingo. After the interview was completed, the interviewer asked the respondent to recommend other caregivers for potential participation in interview. Chain referrals were limited to one per respondent.

3.9 Data Generation Instruments

Qualitative research involves generating information on what people say and do and create in their natural settings to discover the world as the people themselves see and experience it. Data generating instruments used in this study included observations schedules, interview guides focus group discussion schedules, video/audio recorders and myself as the researcher.

An interview guide, based upon prior ethnographic research done among some family caregivers was prepared for use in these interviews. The content and focus of this schedule was designed using conclusions from key informant interviews, focus group discussions, initial participant observation and the research objectives. It comprised open-ended questions on family caregiving of HIV positive persons and questions on demographic data on the in-depth interview respondents.
Key informant interview schedule was used to tap information from key informants interviews. The content and focus of this schedule was designed using conclusions from ethnographic mapping, initial participant observation and the research objectives. It was comprised of open-ended questions on family caregiving of HIV positive people and questions on demographic data on the key informants.

Focus Group Discussion Guide was designed to tap information on focus group discussions. The content and focus of this guide was designed using conclusions from key informant interviews, initial participant observation and the research objectives. The guide included open-ended questions on family caregiving of HIV positive persons and questions on demographic data on the focus group participants.

3.10 Data Generation Techniques

In this study, I as the researcher was the main instrument for data generation. My role was to conduct interviews, facilitate in focus group discussions and taking note of my observations of primary caregivers doing their daily chores of caregiving work.

However I used a number of techniques to help me generate the needed data. The techniques I used included Focus Group Discussions (FGDs), Participant Observations (POs), and In-Depth Interviews (IDIs) as detailed below:

3.10.1 In-Depth Interviews

In-depth interviews are loosely structured and informally conducted interviews that may commence with one or more themes to explore and then narrowed down to the research
questions of the study. Qualitative researchers rely quite extensively on in-depth interviewing. Kahn and Cannell (1957) describe interviewing as “a conversation with a purpose” (p. 149).

In-depth interviews helped to explain some of the apparent differences in the family caregiving population that had been tentatively formulated on the basis of other data collection methods. Thus, in-depth interviews data allowed the researcher to put the information from other methods in a temporal perspective and to acquire an understanding of how family caregiving function psychologically.

In-depth interviews were conducted with eight (8) informal caregivers most of whom resided in the areas targeted in the ethnographic mapping. Initially I had intended to use ten participants, however, due to commitments of caregiving work, only eight availed themselves for the interviews. In-depth interviews were used to establish the challenges; psychological experiences faced by family caregivers and identify coping strategies they employ in caring for the HIV-positive persons. In-depth interviews were also used to validate results from other data collection methods. As I became more familiar with the family caregivers, I developed better rapport with the participants and began to ask more in-depth questions. A series of in-depth interviews were conducted in which, over a period of several sessions, caregivers were invited to tell me their life stories in their own terms, in their own way, and with an emphasis on what they felt was important for me to understand about their caregiving activities and self-image.
3.10.2 Key Informant Interviews

Key informants are experts or people with experience on the population under study. These may be current or former, formal caregivers in the form of health personnel, NGO officials, Home Based Care (HBC) Facilitators and other such personnel.

In this study key informants were used as another technique of acquiring data. As the researcher, I had key informant interviews with seven secondary caregivers. These Key informant interviews were carried out to establish key informants’ psychological experiences on caregiving for the infected persons and what could be the possible copying strategies for caregivers. These key informants were also used as neighbourhood guides, showing me the affected persons, gaining access to them and explaining to the targeted group the purposes of carrying out this research. Using key informants added the credibility and legitimacy of me on the informal caregivers. Key informants also played a critical role in the recruitment of research participants. This was especially true when I sought a particular sort of person, e.g., male or child caregiver.

3.10.3 Focus Group Discussions

Focus group discussions are interactive events guided by a researcher who stimulates participation, guides discussion, and probes for further answers to meet research objectives on a focused research topic. These interviews may be conducted several times with different individuals so that the researcher can identify trends in the perceptions and opinions expressed, which are revealed through careful, systematic analysis (Krueger, 1988).
I conducted four focus group discussions involving twenty-eight informal caregivers. These focus group discussions comprised of seven participants of mixed gender and each discussion took on average 30 minutes. Focus group discussion participants’ ages ranged from 17 years to 61 years. These discussions were carried out at Mucheke, Rujeko and Batanai community halls where the primary caregivers met with members from different support groups every Wednesday and Friday. Focus group discussions were used to establish the psychological experiences of informal caregivers, the coping strategies they use in caring for the infected persons and the challenges they face in doing so.

Focus group discussions were also used to validate results from key informant interviews, in-depth interviews and participant observation. The purpose of focus groups was to solicit from the caregivers, recommendations for possible family caregivers coping and government intervention strategies for caring for the infected population in Zimbabwe. These focus group discussions provided insights into the meaning of family caregiving and the challenges encountered in caring for the infected persons.

The sharing of personal experiences, feelings, and opinions by members of the group interacting together provided for a clearer understanding of the range of these experiences, feelings, and perceptions of these family caregivers. These experiences were useful at all stages of data analysis as they provided explanation, depth, and detail and served as another resource for cross-validation of data collected by other methods. Focus group data were generally in the form of audiotapes, notes, and transcripts of the sessions.
3.10.4 Participant Observations

Adler (1990) noted that in conducting participant observation, ethnographers attempt to gain a “quasi-membership role” that permits them “to participate in routine practices.” One of the initial tasks given to the ethnographers is that of mapping the geography of the family caregivers, which is, identifying where family caregivers spend most of their time. Participant Observations were used to validate data obtained from Focus Group Discussions and In-Depth Interviews with key Informants. Participant observation is a dialectic process cycling back and forth between assuming the role of a participant and the role of an observer.

As the researcher, I accompanied members of the different support groups in the two suburbs when they went to visit HIV and AIDS patients in Stages III and IV of the infections in their communities. During these visits, I observed the activities of these caregivers, took pictures and helped where I could.

Data from observations and conversations were recorded as field notes from recall and recorded information after I had left the social gatherings or visits. Developing rapport by myself as the researcher meant creating and maintaining complementary relationships with people. Building relationships can contribute to the execution of qualitative interviews in more controlled settings.

3.11 Validity and Reliability

Ethnographic research was evaluated in terms of its reliability and validity. Validity and reliability in qualitative research can be achieved through trustworthiness between the researcher and participants. I used triangulation and member checking to find if I had
captured data correctly. I compared data gathered using the different techniques employed in order to check for consistances and irregularities. I would also revisit the members interviewed to cross check with them whether the data I had was what they had initially supplied me with and if there were any additions they felt compelled to inform me.

The prolonged engagement that I had with the participants helped in moulding trustworthiness, and I was able, as a result, to capture the participants’ emic view points that I recorded for transcription. As such, data generated was presented from both the emic and etic view points of the participants and the researcher thereby validating the data.

It is also important to note that I reviewed each interview immediately following each session, analyse, reflect and interpret the data that emerged from these sessions. This ensured validity and reliability of the study findings. Reliable data are accurate, consistent, and dependable. Triangulation of data and prolonged stay in the natural settings of the participants ensured reliability.

### 3.12 Procedure

A data collection process is necessary as it ensures that the data gathered are both defined and accurate and that subsequent decisions are based on arguments embodied in the findings are valid (Weller & Romney, 1988). The process or procedure provides both a baseline from which to measure from and in certain cases a target on what to improve.

#### 3.12.1 Ethnographic Mapping (Site Mapping)

Ethnographic mapping is the drawing and showing of the geographic distribution of, and spatial relationships between the phenomena and objects of study of ethnography. The main
goals of the ethnographic mapping were to identify geographical areas where primary family caregivers spent their time in each of the selected geographic area and to highlight or make clear to me the geographical boundaries of the ethnography study.

Ethnographic mapping involved entrance into the field of study for site mapping which involved, looking for common places where caregivers met for the purposes of social interaction. It was also important for me to identify the residence of these caregivers in order to contact them for the personal interviews. The main reason for doing this was to identify places where family caregivers spent their time in each of the selected suburbs. I noted these places of interactions, the days and times that the members met as well as the groups’ leadership. The whole exercise was done through the facilitation of the formal caregivers, participant observation, formal and informal conversations. Participant observation was a major component of ethnographic mapping and became more important as I progressed. As knowledge and understanding increased, the observations became more focused.

3.12.2 Gaining Trust

As a researcher, one needs to come up with ways of gaining access both of the environment and participation of the respondents. Initially entering any group, gaining trusts, especially with informal caregivers, would be slow and difficult. Unless one has been formally introduced to the participants, each individual would form his or her own judgment about whether the new person(s) can be admitted into their confidence. The key informants played an important role in connecting me to the participants. I met participants at different times and at different levels and as such developed relationships with them. However, I was trusted more by some people than by others, in part because of their greater familiarity with me.
although knowing someone or even liking him or her does not automatically guarantee that trust will be extended to them.

Exit is a negotiated process of leaving the field after saturation of data and some debriefing to both key informants and other family caregiver respondents and to do final data analysis. It must be stressed that the above stages were not followed strictly as there were overlaps and some data analysis was done in-between.

3.12.3 Ethnographic Field Station

Functionally, an ethnographic field station is a research “outpost” in a community of interest to the researcher. The field station served as a base of operations for me, providing an environment in which research participants and I interacted most during the period of the research. In this study there were two ethnographic field stations established, one at Mucheke Community Hall and the other at Rujeko Community Hall where participants normally met for other social gatherings or meetings.

3.13 Data Analysis and Presentation

Data analysis involves breaking up the data into manageable themes, patterns and trends. The aim of analysis is to determine whether any pattern or trends can be identified or isolated, or to establish themes in the data (Mouton, 2001). Thematic and Interpretive phenomenological analysis (IPA) was used to analyse data. As a first step of the data analysis process all audio-recordings were transcribed on a daily basis soon after the recordings were done. This ensured that the richness of the text was not lost. Transcripts were then translated from Shona into English with the assistance of a Doctor of Linguistics Lecturer who is fluent in both languages and working for the Zimbabwe Open University (ZOU), Department of Bachelor of Arts, English and Communications (BAECS) and Bachelors Arts and Media Studies.
(BAMS), Masvingo Regional Campus. Verbatim transcripts were then analysed by means of thematic content analysis.

Thematic content analysis is a process of breaking down the text into themes and categorising the patterns in the data (Terre Blanche & Durrheim, 2002). The steps for the method followed are those outlined by Terre Blanche and Durrheim (2002, p.140):

♦ Familiarising and immersing in the data,
♦ Inferring themes that arise naturally from the data but also relating to the research question,
♦ Coding, (breaking up the data into analytically relevant ways),
♦ Exploring themes in greater detail and
♦ Checking for omissions and consistence before the final interpretation.

All themes emerging concerning the caregivers’ experiences were considered important.

It is important to note that, data analysis in qualitative research is interpretive in the sense that it is verbal. Its focus is on reading and giving meaning to observed behaviour, reports of conversations, diary reports and research notes, among others (Chisaka & Mukabeta, 2011). Generally, the process of analyzing empirical material (data) in qualitative research takes an inductive or formative angle. As I generated data through interviews and focus group discussions, conversational observations and audio taping, I checked on patterns, behaviour images, themes or sub themes in the evidence that would be unfolded. This I achieved through entry of evidence in personal journals, coding data identified from emerging themes, summarizing my observations, taking notes of allegory and metaphors, and looking out for new questions or challenges that emerged from the data forms and essence. This was a continuous process and as such helped validate the data generated.
3.14 Summary

The foregoing chapter began by looking at the methodological framework, and the philosophical underpinnings guiding this study. I then have detailed the research methodology used in this study. The research was based on a psycho ethnographic design. I unearthed rich data from family caregivers for HIV positive Zimbabweans. Noteworthy however were the difficulties associated with carrying out the research where participants would be asked to talk about personal experiences on this sensitive topic of HIV and AIDS. The following chapter reveals the results emergent from the research. Chapter four focused on data presentation techniques, discussion and interpretation of research findings. The discussion and interpretation of findings will be equally focused to ensure that all the results of the research study are discussed.
4.1 Introduction

This Chapter focuses on data presentation, discussion and interpretation of the research findings. The Chapter looks at the findings of the research based on the thematic content analysis of the recorded transcriptions and notes from the interviews and focus group discussions as well as the observations I made. The research tried to answer research questions to deal with the challenges faced by the caregivers, their experiences, the rewards and burdens of caregivers and how caregivers are managing to cope with this phenomenon among other things. Several recurring themes and subthemes emerged across the data generation processes.

Dominant themes that emerged included:

- Challenges of caring
- The caring experiences
- Burdens and rewards of caregiving
- Coping with the role of caring

These themes dominating in the results outcomes depict the psychological experiences and coping strategies used by family caregivers of HIV and AIDS sufferers in Masvingo and especially to those patients who have progressed to Stages 111 and 1V of the disease. The themes were continually compared to previous research in order to elicit how they guide the
depth and insights into the previous findings on the psychological experiences and coping strategies of HIV and AIDS family caregivers and in the process highlighting the significance of caregiving work.

4.2 Information on Participants

Forty-three participants were interviewed and also took part in focus group discussions. Thirty-six of these participants were informal or primary caregivers. Twenty eight participated in focus group discussions while the other eight took part in in-depth interviews. Seven secondary caregivers were the study’s key informants who took part in key informant interviews.

NB: It is important to note that the names used in this study are not the real names of the participants. I used pseudo-names in this study to uphold ethical considerations to conceal the participants’ real names. They are only pseudo-names used specifically for the purposes of this study.

4.2.1 Information on Informal/Primary Caregiver Participants

Table 4.1 below shows the demographic data in terms of the characteristic values and percentages of the thirty-six primary caregivers who participated in the study.
### Table 4.1 Demographic Data for Informal/Primary caregivers

<table>
<thead>
<tr>
<th>Characteristic variable</th>
<th>Participants ( n=36)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender: male</td>
<td>13 (36, 1 %)</td>
</tr>
<tr>
<td>Female</td>
<td>23 (63, 9 %)</td>
</tr>
<tr>
<td>Age: Below 20 years</td>
<td>5 (13, 9 %)</td>
</tr>
<tr>
<td>20-29 years</td>
<td>6 (16, 7 %)</td>
</tr>
<tr>
<td>30-39 years</td>
<td>9 (25 %)</td>
</tr>
<tr>
<td>40-49 years</td>
<td>11 (30, 6 %)</td>
</tr>
<tr>
<td>50 and above</td>
<td>5 (13, 9 %)</td>
</tr>
<tr>
<td>Marital status: Married</td>
<td>17 (47, 2 %)</td>
</tr>
<tr>
<td>Not married</td>
<td>8 (22, 2 %)</td>
</tr>
<tr>
<td>Lost spouse through death</td>
<td>8 (22, 2 %)</td>
</tr>
<tr>
<td>Separated</td>
<td>3 (0, 08 %)</td>
</tr>
<tr>
<td>HIV and AIDS Status: positive</td>
<td>22 (61, 1 %)</td>
</tr>
<tr>
<td>Negative</td>
<td>6 (16, 7 %)</td>
</tr>
<tr>
<td>Not known</td>
<td>8 (22, 2 %)</td>
</tr>
<tr>
<td>No. of care recipients: Self</td>
<td>2 (0, 06 %)</td>
</tr>
<tr>
<td>1-2</td>
<td>23 (63, 9 %)</td>
</tr>
<tr>
<td>3-4</td>
<td>10 (27, 8 %)</td>
</tr>
<tr>
<td>5 and above</td>
<td>1 (0, 03 %)</td>
</tr>
<tr>
<td>Co-resident with care recipient: Yes</td>
<td>33 (91, 7 %)</td>
</tr>
<tr>
<td>No</td>
<td>3 (0, 08 %)</td>
</tr>
<tr>
<td>Level of Education: Primary</td>
<td>11 (30, 6 %)</td>
</tr>
<tr>
<td>Secondary</td>
<td>18 (50 %)</td>
</tr>
<tr>
<td>Tertiary</td>
<td>5 (13, 9 %)</td>
</tr>
<tr>
<td>Other</td>
<td>2 (0, 06 %)</td>
</tr>
<tr>
<td>Employment status: Self</td>
<td>5 (13, 9 %)</td>
</tr>
<tr>
<td>Not Employed</td>
<td>24 (66, 7 %)</td>
</tr>
<tr>
<td>Employed</td>
<td>7 (19, 4 %)</td>
</tr>
<tr>
<td>Relationship with care recipient: Spouse</td>
<td>17 (47, 2 %)</td>
</tr>
<tr>
<td>Child</td>
<td>5 (13, 9 %)</td>
</tr>
<tr>
<td>Parent</td>
<td>4 (0, 1 %)</td>
</tr>
<tr>
<td>In-laws</td>
<td>1 (0, 03 %)</td>
</tr>
<tr>
<td>Friend</td>
<td>3 (0, 08 %)</td>
</tr>
<tr>
<td>Other Relative</td>
<td>5 (13, 9 %)</td>
</tr>
<tr>
<td>Period in caregiving work: 1-4</td>
<td>10 (27, 8 %)</td>
</tr>
<tr>
<td>5-10</td>
<td>19 (52, 8 %)</td>
</tr>
<tr>
<td>More than 10 years</td>
<td>7 (19, 4 %)</td>
</tr>
</tbody>
</table>
Thirty six primary care givers participated in the study; twenty-three were females while thirteen were males. There were also five children below the age of twenty in the study constituting two boys and three girls. The majority of the primary caregivers were in the 40-49 age group, while nine were aged between 30 and 39 and only five were above 50 years of age.

Seventeen of the primary caregivers were married; eight were not married while another eight had lost their spouses through death. Only three had recently separated due to misunderstandings associated with the caregiving work commitments. Twenty-two of the participants that took place in the study indicated that they were also HIV positive; six said they were negative and eight did not disclose their status. The majority of the primary caregivers, twenty-three have at least two care recipients under their care, ten have between three and four care recipients under their care while only one has at least five care recipients to look after. Two of the primary caregivers claimed to be looking after themselves since they also are infected and have no one to look after them.

Most of the primary caregivers who participated in the study, thirty-three co-reside with the care recipient(s) and only three do not. The level of education for the participants is reasonably good with eighteen having gone as far as the secondary level, and five) reaching tertiary education level. Most primary caregiver participants were unemployed, five were self employed as vendors and only seven were permanently employed. Those unemployed and those vending depended mostly on Non Governmental Organisations (NGO) hand-outs to help in looking after the care recipients.
Five cared for their children and other relatives while seventeen cared for their spouses. Only one cared for their in-laws and four cared for their parents. Only three cared for their friends. The study had the majority of the caregivers as spouses and relatives. The majority of the participants had been in caregiving work for a period spanning between five and ten years while only seven participants had been in the caregiving work for more than ten years. This helps to inform you on the composition and demography of the primary caregiver participants of this research.
4.2.2 Information on Formal/Secondary Caregivers

The table 4.2 below shows the demographic data of the formal (secondary) caregivers who participated in the study.

Table 4.2 Demographic Data for Formal/Secondary caregivers

<table>
<thead>
<tr>
<th>Characteristic variable</th>
<th>Participants (n=7)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender:</td>
<td></td>
</tr>
<tr>
<td>male</td>
<td>3 (42.9%)</td>
</tr>
<tr>
<td>Female</td>
<td>4 (57.1%)</td>
</tr>
<tr>
<td>Organisation:</td>
<td></td>
</tr>
<tr>
<td>NAC/DAC</td>
<td>1 (14.3%)</td>
</tr>
<tr>
<td>BHASO</td>
<td>1 (14.3%)</td>
</tr>
<tr>
<td>RED Cross</td>
<td>2 (28.6%)</td>
</tr>
<tr>
<td>HIV and AIDS Support Group</td>
<td>3 (42.9%)</td>
</tr>
<tr>
<td>Position Held:</td>
<td></td>
</tr>
<tr>
<td>Home Based Care Facilitator</td>
<td>4 (57.1%)</td>
</tr>
<tr>
<td>Counsellor</td>
<td>1 (14.3%)</td>
</tr>
<tr>
<td>Coordinator</td>
<td>2 (28.6%)</td>
</tr>
<tr>
<td>Age:</td>
<td></td>
</tr>
<tr>
<td>20-29 years</td>
<td>2 (28.6%)</td>
</tr>
<tr>
<td>30-39 years</td>
<td>3 (42.9%)</td>
</tr>
<tr>
<td>40-49 years</td>
<td>1 (14.3%)</td>
</tr>
<tr>
<td>50 and above</td>
<td>1 (14.3%)</td>
</tr>
<tr>
<td>HIV and AIDS Status:</td>
<td></td>
</tr>
<tr>
<td>Positive</td>
<td>5 (71.4%)</td>
</tr>
<tr>
<td>Negative</td>
<td>2 (28.6%)</td>
</tr>
<tr>
<td>Not aware</td>
<td>0</td>
</tr>
<tr>
<td>Level of Education:</td>
<td></td>
</tr>
<tr>
<td>Secondary</td>
<td>4 (57.1%)</td>
</tr>
<tr>
<td>Tertiary</td>
<td>2 (28.6%)</td>
</tr>
<tr>
<td>Other</td>
<td>1 (14.3%)</td>
</tr>
<tr>
<td>Period in caregiving work:</td>
<td></td>
</tr>
<tr>
<td>1-4 years</td>
<td>1 (14.3%)</td>
</tr>
<tr>
<td>5-10 years</td>
<td>3 (42.9%)</td>
</tr>
<tr>
<td>More than 10 years</td>
<td>3 (42.9%)</td>
</tr>
</tbody>
</table>

Seven formal (secondary caregivers) participated in this study, four were female and three male. From these participants, four were home based care facilitators while one was an HIV
and AIDS counsellor from one of the support groups and two were HIV and AIDS coordinators one from District AIDS Committee (DAC) and another from a NGO, Batanai HIV and AIDS Support Organisation (BHASO).

Five of the secondary caregivers in the study were HIV positive while the other two were negative. Six of them had some education up to at least secondary level with two of them having reached the tertiary level of education. Majority of the formal caregivers in the study had been in the caregiving work for more than five years.

4.2.3 The Living Conditions of the Primary (Informal) Caregivers

Regarding the number of people within the household, it was found that the number ranged between three and five. Most of the families were staying in rented houses where they would occupy one or two rooms with only a few owning their own houses. This proved challenging for the caregivers as some were constantly moving houses because their ‘Land Lords’ i.e. the owners of the houses did not approve of the infected staying with them and the increased volumes of people visiting to see the infected.

With regard to the period the caregivers had spent caring for the care recipients, the response varied from a minimum of a year to more than ten years for some caregivers. Most of them did not really know exactly how long it had been, although they could say it had been for a lengthy period. Regarding the caregivers’ knowledge of what was wrong with the infected, most of the caregivers first knew the infected as having tuberculosis (TB), cancer or meningitis; other co-morbid diseases included sugar diabetes. Knowledge of the HIV diagnosis happened after they had been providing care for some time. Some caregivers knew
the diagnosis before the onset of the illness as the care recipients were diagnosed during the antenatal period (i.e. during their pregnancy).

4.3 Emerging Themes

4.3.1 Theme 1: Challenges of Caring

Four questions were asked to the family caregivers based on this theme. The questions were:

a) In general, what challenges are you facing in life these days as Zimbabweans?

b) From your own experiences, what are the health challenges currently faced by most Zimbabweans?

c) What challenges are you facing as caregivers for HIV positive Zimbabweans?

d) Do you feel you are currently under a lot of stress?

Responses of the family caregivers revealed some commonalities showing challenges that include changing one’s life circumstances. Most respondents did not own houses and as a result of caring for the infected that most house owners, popularly known as Land (Lords) seemed not to approve, moving houses was very common.

The family caregivers’ work involves many stressors which also relate to personal work context. This is supported by Sapolsky (2004), who said relationships at work, with family and other colleagues are savoured as a result of caregiving work. Family income is also eroded due to medication, travelling expenses, funeral expenses and food expenses for the care recipient.
Challenges that most family caregivers revealed were of a psychological nature. These included the feelings of anxiety, hopelessness, irritation and sometimes exhaustion. This is what Mrs. Tamburai said:

“…mwanangu, pamwe unoti iwe uchifirira kubatsira murwere kuti aite zviri nani, iye anenge achiwedzera kurwara kwacho. Unobva wangopererwa…”

‘..My son, it is disheartening to see that the effort of caring you put on the patient is not helping to improving their health…’

The resultant death of the care recipient after all the effort of caring by the caregivers is another challenge that was highlighted on. Although research says grief is a healthy, human response to loss and especially the loss of a significant person to the caregiver, is a major challenge and it comes as a shock to the caregiver regardless of the known condition of the care recipient. One of the respondents, Mr. Tatenda had this to say regarding the death of a grandson due to HIV and AIDS:

“…hapana kwandisina kusvika nechizukuru changu ndichizama kumurapisa, kuzvipatara, kumaporofita zvese nekun’anga ndakapotedza asi mudairo wekutambudzika kwangu kwese uku rufu rwachizukuru changu…”

“I went to various hospitals, prophets and even traditional healers trying to save my grandson but all my efforts were rewarded by his death.”

The theme is supported by Sapolsky (2004) who reports that there are foundational psychological concepts to the study of caregiving which are stress, traumatic stress and grief. Stress refers to emotional and physical response to situations in which environmental challenges or threats are greater than human beings’ capacity to respond. The challenges
could include changing life circumstances, relationship difficulties, financial and legal challenges among others.

At a psychological level, stress can cause feelings of anxiety, hopelessness, helplessness, irritation and exhaustion. It also has some physical effects on the caregiver. While grief may be viewed as a healthy response to loss of a loved one, there is the danger of some bereaved caregivers developing prolonged grief which may lead to psychiatric disorders. Family caregivers deal with these stresses and grief daily in their lives as carers of infected persons.

4.3.1.1 The Economic Challenges

Most of the caregivers were not working, with the majority depending on pension funds/social grants, and hand-outs from Non Governmental Organisations (NGO) and informal vegetable markets, causing an adverse financial impact. Caring for a terminally ill individual can be financially demanding, due to medical costs and a need to feed the ill-person healthy food. Some of the caregivers were burdened by financial constraints, leading to stress and frustration. These were views expressed by different caregivers:

Mr. Tatenda had this to say:


“...Sometimes it’s really difficult to care for the infected, last Wednesday I called for the ambulance around 1800hrs and only arrived around 10pm. If we had money I could have hired someone. Early morning the next day, he passed away. This broke
my heart because of my financial constraints; my grandson was put on drip late resulting in his death...”

This also increased feelings of helplessness, as the individual could not meet the medical requirements of the care recipient. Participants expressed feeling helpless when they could not maintain the medical and physical care of the PLWHA because of financial constraints. This resulted in the inability of caregivers to take sufferers for regular medical check-ups, as well as not being able to meet their basic daily needs, like providing a nutritious diet. Chenai said:

“Mwedzi wega wega sisi vangu vanoenda kuMorgenster saka mari yangu ndiyo inoshanda kuvatakurisa. Hapana umwe anga zviita nokuti ndini ndega mumhuri anoshanda...ndakatombomira zvidzidzo zvangu zvepamusoro ne ZOU”

“My sister has to go for treatment every month at Morgenster Mission Hospital so all the money I get is used on transport hire to take her to hospital. This is impacting on me since she needs to go for treatment and I am the only one working...I cannot even go further with my education at ZOU where I enrolled for a degree”

This placed a greater impact on the family, and resulted in her being unable to continue with her studies. As the only one working in this particular household she needed to sustain the family by doing part-time jobs. Helplessness not only distresses caregivers when they are unable to meet the medical and physical needs of the care recipient due to financial difficulties, but also when it is a result of emotional difficulties.
Brouwer et al. (2000) and Flaskerud and Tabora (1998) in their studies also noted that poverty increases the worries of caregivers, as they might not have enough money for a balanced diet and regular medical check-ups - especially when the person is bedridden, as there is a need for transportation to medical facilities. In the present study, it is noted that most of the caregivers and care recipients are unemployed, thus are dependent on social grants e.g. the Child Support Grant or the Disability Grant. Uys (2002) also found out that community caregivers reported economic constraints as a challenge to their work. The care facilities were also far from the caregivers’ and care recipients’ living areas. Due to the physically weakened situation of the care recipients as a result of the disease, to avoid embarrassment, discomfort and feelings of shame, they needed to use special hired transport. Government Medical services in Zimbabwe are still poor, leading to long waiting periods for ambulances. The emergency facilities use a rating scale (triage) to determine the severity of the condition and how urgent the case is. At times, the sufferer might not be rated as a first priority emergency case, which can be frustrating for the carers who have no medical training. This also increased feelings of distress, as uttered by Mr Tatenda as he waited for the ambulance for almost 4 hours.

Turner, Catania and Gagnon (1994) reported that young adults suffer from opportunity costs of care giving, as these individuals are striving to establish careers and economic security. It was also observed in this study that Ms Chenai had to be a part time worker as well as a caregiver to a sister in need of care. Because she was unable to continue with studies, there were disruptions for her in task development. This will literally result in long-term detrimental economic and psychosocial consequences. This also denotes the burden of caring, as it impacts on the caregiver’s functionality and productivity at work. This is further supported by Turner et al. (1994), who found that those with the poorest financial resources
are more likely to perform the physical care activities, as they do not have the ways and means of getting assistance from others.

Helplessness, due to emotional difficulties, is supported in the research of Brouwer et al. (2000), who found that caregivers experience feelings of helplessness, denial and despair. Unlike in their study, where it was noted to happen mostly when the sufferer does not want to eat, in the present study it occurred as a result of the sufferer having cognitive impairment, as sufferers present with mental impairment during the fourth stage. Being challenged with a younger individual who is suffering from memory loss, confusion, and disorientation makes the carer’s life extra difficult and too demanding. Other challenges were around relationship issues. Edelman (2000) also states that the relationship of the carer and the recipient aggravates the emotional experience of the caregiver. Feelings of helplessness are more intense when the caregiver is a spouse of the care recipient and has been with the care recipient for a long time. Being intimate with and knowing the care recipient as an independent individual by the caregiver, increases the emotional intensity.

4.3.1.2 The Physical Challenges
Some of the carers reported experiencing physical symptoms as a result of dealing with the HIV diagnosis. One carer expressed having lost weight as a result of not knowing how to deal with the news that his partner is HIV positive.

This is what Mr Hama had to say:

“Ugwere uhu unohushaiwira zano, zvandipedza chero nemuviri...hausiwo muviri wangu uyu”

“I did not know how to deal with it. I even lost weight. ...This is not the way I used to be”.
Another carer expressed staying awake at night, thinking a lot about this situation that she is in and how she can enable things to look different. Ms. Fadzai said:

“...Sometimes I don't sleep because I am thinking the whole night about how I am going to feed these children. I also have sugar diabetes and blood pressure”.

Caring for an HIV and AIDS victim brings up conflicting feelings in the carers. One of those feelings is fear of becoming infected with the virus, thus making the caring process difficult. This fear becomes increasingly overwhelming when an individual is not well informed about how one becomes infected with the virus. Misconceptions about infection are misleading. During Stage III and IV, infected people can have skin problems, leading to open wounds. In this situation, fear was caused by doubts regarding the skin integrity of the sufferer, especially when having to bath them, but not using or having available protective measures, (i.e. gloves). One out of eight carers expressed fears about bathing the sufferer, specially in the presence of open wounds when they don’t have gloves to wear - and also when it’s not known whether the sufferer has any skin lesions that they might not be aware of.

Ms. Elizabeth had this to say:

“I at times had fears when bathing him especially when I did not see a dent on him but when I know that he has a wound or I have one then I would not feel so terrified, then I will use gloves”.

Others felt that they never kept the diagnosis in mind even when dealing with blood, but were rather concerned about the well-being of the individual. They never even used gloves. This is what Ms. Grace said:
“I never had thoughts of her infecting me. I just think of helping her so that she can get better and do things for herself. Last time at the hospital her drip came out and there was blood flowing out of her arm, I just wanted to stop the bleeding and when I was about to touch her the sister (Nurse) arrived and said I must stop doing that, I must always use a glove when touching blood”.

The theme of physical challenges is supported by Flaskerud and Tabora (1998), who noted that caregivers experienced health problems associated with depression, anger and the number of care recipient’s illness symptoms. Being stricken by poverty also increases the symptoms experienced, as the carer also worries about what to feed the sick and vulnerable children under his/her care. Ms. Fadzai was suffering from loss of sleep, as that was her time to think through her problems, when there were moments of quietness. This theme is further supported by Leblanc, London and Aneshensel (1997), who noted that caregivers reported symptoms of poor physical health that were associated with care related demands and stressors. In this situation the demands of care associated with economic constraints aggravated loss of sleep experienced by Ms Fadzai.

Care workers in many studies have reported fear of infection. In a study done by Horsman and Sheeran (1995:1535), results revealed that HIV and AIDS care workers reported fearing of infection. Melnick (2002) also found that caregivers expressed concerns regarding being infected. Contrary to this, the present study revealed the fact that some caregivers never thought of being infected, even when dealing with blood. These individuals were eager to assist their loved ones, hoping for improvement in their health status.
4.3.2 Theme 2: The Caring Experience

Four questions were asked to the caregivers on their caring experiences. The questions asked were:

a) What are the caregiving activities that you are engaged in as carers of HIV positive Zimbabweans?

b) How does it feel to be a caregiver? (Your personal experiences in caring for HIV positive Zimbabweans)

c) What do you do to relieve your stress and tension?

d) What are the caregiving experiences at death and during bereavement/grief of the care recipient?

From these questions there were commonalities in the participants’ responses, primarily revealing among other things, issues of emotional ambivalence, physical challenges and the economic constraints, throughout the caring process. These will be discussed together with their sub-themes, as expressed by caregivers.

4.3.2.1 Emotional Ambivalence

Ambivalence refers to the coexistence of opposing feelings. What emerged from the interviews and focus group discussion is that the caring experience is an intensely emotional process. Respondents reported different aspects of this emotional process, which were called upon in being a carer. The following thus emerged:

a) Emotional Roller Coaster

A lot of emotional issues were revealed by the participants, which were uncontrollable and unstable. One of the carers, due to her knowledge about the disease, described anticipating a
positive diagnosis while she was caring for the sufferer. This is what Mrs. Tamburai had to say:

“... kubva parwara murume wangu, ndaiowona kuperezeka kwake muviri ndikabva ndazvigadzirira kugamuchira zvese. Pandakaenda kunowongororwa, ndakawanikwa ndiri positive...”

This was to say, “... as I was caring for my sick husband, I became aware of the signs and symptoms as I observed him, so I prepared myself to be emotionally ready for anything. When I was tested, I was also found to be positive...”

Although she anticipated the diagnosis, she expressed a lot of conflicting feelings when her suspicion was confirmed. Just like Mrs. Tamburai, carers expressed their wide range of feelings when they first heard about their loved ones’ HIV diagnosis. Carers expressed being shocked, feeling sad and hurt, as well as being disturbed by the HIV diagnosis. Some caregivers had this to say:

Mrs Zvichanaka

“... pamwe unomboti varume imbwa, unosara wakachengeta musha nevana iye achitosasana hake nekutivigira zvigwere...”

“...sometimes you feel husbands behave like dogs and not respectful. They leave you to look after the home and children while they go out with other women only to come and infect us with HIV and AIDS...”

On the other hand, Mrs. Chengetai had to say this,

“I feel so bad, don’t know what to do or say. I feel so sad when my son is very sick but when he is better, I feel well too.”

Ms Rutendo:
“... I always ask myself the questions; why me..., how did I come to be in this situation..., what wrong did I do to deserve this?”

According to Keene Reder (2003) caregivers and PLWHA experience what is termed anticipatory grief, which is associated with the development of symptoms that people perceive as life-threatening. Caring increases distressing emotions (Pakenham, Dadds and Terry, 1995:189). The study also revealed that caregivers experienced a lot of emotions ranging from shock, hurt, sadness, and feeling very terrible - as expressed by Ms. Rutendo. Caregivers did not only utter these words, but it could also be observed from their body posture and the way they expressed themselves. Some of them were very tearful when remembering some moments. As similarly stated by Edelman (2000:23), it was also observed in the present study that emotional experiences were aggravated by the relationship of the caregiver to the care recipient, as noted in Mrs. Zvichanaka’s comment that husbands are like dogs and not respectful.

b) Emotional Confusion

Participants expressed feeling grateful for knowing the status of the care recipient, however, a feeling of confusion followed. Living with and being intimate with the sufferer brings up questions as regards the carer’s status. This becomes a very difficult situation, as the carer is divided between having to care and having to establish what it all means as an individual and as an intimate partner. This is how Mrs. Tumai felt;

“When my husband tested positive for TB, he was advised to be tested for HIV and AIDS of which he also tested positive. As husband and wife, we were intimate naturally all the time. Now I am so...so...confused, I don’t know whether I have it too. If it comes out that I am also positive, then who will look after the other...?”
Edelman (2000) found that caregivers experience feelings of low morale, stress, fatigue and anxiety, as well as hopelessness about the future. In this context, confusion can lead to anxiety and hopelessness about the future, as it isn’t known what it is the carer is faced with. It can also lead to poor self-esteem, which might result in secrecy and isolation. Edelman (2000) also states that the relationship of the carer and the recipient aggravates the emotional experience of the caregiver. This was the case for Mrs. Tumai, where confusion was created and intensified by the fact that this was someone that she was intimate with, aggravating her emotional distress at the possibility of she also being positive. This can later bring difficulty in caring, as the caregiver is intimately related to the care recipient.

c) Fear of Death

Knowing the HIV status of someone raises a lot of questions in one’s mind, especially when one is family and depends on that individual for support. Being attached to each other and being supportive of each other as siblings enables one to deeply explore what a positive HIV result could mean. Most people regard an HIV diagnosis as a death sentence, and thus being diagnosed with the disease means losing the loved one to death. Carers expressed having a fear of death for their loved ones, and this was even severe when multiple deaths have been observed in the family, as stated by Mr. Tonde:


“AIDS is a killer disease. We buried my son in 2002, in 2004 his wife. Now I am scared for their child who was only four years when the mother died. ARVs have helped to sustain her life this far (Shaking his head), its scarring!”
Grace said:

“... my mother is not worried about her illness but I sometimes worry about what if... if something could happen to her. I don’t want her to die now. I wish she could see me graduate next year”

According to Mullan (1998), caregivers experience a lot of difficulties that have to do with patient comfort, especially when patients are acutely ill or cognitively impaired. The fear of death of those they care for is a constant threat. It has been noted that fear of death in this study was also a constant threat to caregivers. Several caregivers expressed their fears of losing their loved ones as a result of being positive. This is due to the fact that the positive result (or being known as HIV positive) automatically is associated with death. Although there are ARVs and positive lifestyle habits that can prolong an individual’s life, it was noted that poor lifestyle, lack of knowledge and poverty increased fear of death on the caregivers and sufferers. In other instances, it (death) became a threat when an individual had experienced multiple losses; therefore being faced with an HIV positive family member brought up issues around future implications for the caregiver, the family at large, and to the sufferer.

**d) Suffering Multiple Losses**

Fearing the death of a loved one causes an individual to become worried about what that will really mean to him/her. Although most of the participants were worried about the sufferer’s well-being, some of the caregivers’ main worry was around the sufferers’ children. Having a child within the African culture carries a great meaning, like being an heir within the family or having to keep the family name in existence. Others were worried that the sufferer was childless, as the child would have served as a reminder should the person pass on. This led to
suffering a string of losses: the loss of having the recipients’ children as a remembrance, and the loss of bringing up their children, caring for and nurturing them. Other carers indicated that they resorted to a lot of crying, which denotes grief among the caregivers. These were noted from these carers: Mrs Chengetai said:

“What worries me most is that she does not even have children. The husband died when they didn’t have a child. This could have been better if she had children of her own that were going to remind us of her. Should she die there will be nothing at all”.

Ms Rutendo on the other hand said:

“Chinondishungurudza nekushaisa mufaro mwana wake achiri mudokosa”

“What worries me most is her child; the kid is still too young”

Ms Grace said:

“When she is worse I become very worried. My sister has four children and I have three, my main worry is these children should anything happen, I really do not know”

Loss did not only include worrying about having children or caring for the children of the infected. For others it included a *loss of intimacy*, as one of the caregivers said:

“My husband is no longer interested in sex especially now that we have to use condoms…. But I am fine with it. I respect his decision and I do support his feelings, I cannot do anything…..”

Other caregivers experienced the *loss of support* accompanied by the *loss of income*. According to one formal caregiver, a husband abandoned his wife whom he was caring for and the recipient wife suffered stroke as a result. The case is now with the magistrate’s court. One of the caregivers also stated that only the two of them were surviving; the sufferer was taking care of the household chores, and he (the caregiver) depended on her for everything.
Not only this, but the infected also lost her job, as her employers were afraid she might infect them with TB. They advised her rather to stay at home, and to bring someone to stand in for her until she is fully recovered. This family was depending on the money that the caregiver made through ‘maricho’ referring to piece jobs. Mr.Taura a home based care facilitator had this to say:

“It is so painful to notice how some of these caregivers do difficult piece jobs so as to supplement for the general family upkeep and particularly for the care recipient. Remember the majority of these caregivers are also positive.”

Experiencing a sense of loss prior to the actual death of the care recipient has been supported by Mullan (1998), who sees this as a primary source of the stress of caregiving. Mullan (1998) states that caregivers respond to primary stressors with subjective stressors, such as “feelings of loss, overload and being a captive to caregiving demands”. Suffering losses can be overwhelming for both the caregiver and the care recipient. Anticipatory grief takes its toll as the caregivers are making assumptions about what the future holds for them, e.g. more challenges, dealing with the financial burden, demands of bringing up children and the pain of bereavement. Flaskerud and Tabora (1998) also found in their study that carers experience loss.

4.3.3 Theme 3: Burdens and Rewards of Caregiving

4.3.3.1 Burdens of Caregiving

Psychologists use the term “caregiver burden” to describe the physical, emotional, financial, and social problems associated with caregiving (Pakenham, Dadds and Terry, 1995). Burden can be assessed in terms of objective or subjective impact. Objective burden assesses the extent to which caregiving disrupts daily routines and social relationships and negatively
affects resources. Examples include forced changes in household routines, missed days of work, family frictions, reduced social contacts, loss of income, and/or reduced energy. This is what Mrs Fungisai had to say:

“... Pakatanga murume wangu kunyanyisa kurwara, ndakabva ndatora leave kuti ndimupepe. Murungu andinoshandira akabva ati anondibhadhara chidimu chemari yandinotambira pamwedzi asi ndikaita mwedzi miviri ndisiri pabasa anobva atsvaka mumwe.”

“... When my husband worse, I took leave from work so that I can care for him. My employer then said I will be paid half my salary and if I exceed two months, he will look for someone to replace me”

Subjective burden assesses the caregiver’s perceptions of and reactions to caregiving demands. Caregivers with high levels of subjective burden may report “feeling trapped,” “feeling nervous or depressed about their relationship with the care recipient,” or “resenting caregiving tasks” even when their objective burden is relatively low. Mr. Tonde:

“... kurwara kwemudzimai wangu kwandishaisa zano. Zvinondigozhera kuti ini ndimugezese saka ndakakumbira mai vake kuti vazogara pano”

“...the illness of my wife left me with no plan. It’s difficult for me to bath her and as such I asked her mother to come and stay with us”

A number of factors contribute to caregiver burden. Caregiving usually comes as an unexpected role, one for which people are neither socialized nor prepared. To assume this new role, caregivers must restructure pre-existing role obligations and social activities and the ways in which they relate to the care recipient.
The physical demands of informal (primary) caregiving also contribute to burden. Unlike formal caregivers, the relatives and friends providing in-home care often are “on call” 24 hours a day. While working this 24-hour shift, caregivers may be required to perform multiple, and sometimes conflicting roles. Some have the added burden of caring for entire families infected/affected by HIV disease (Mullan, 1998).

The emotional issues surrounding caregiving are also a source of burden. HIV and AIDS caregiving creates the emotional strain of dealing with an unpredictable and currently incurable disease. Some caregivers were burdened by fears of contracting HIV even when they know there is little basis for concern.

The financial impact of caregiving can be a major source of burden. Many families suffer severe economic hardships when a key wage earner is forced to reduce work hours or leave paid employment to care for a sick partner or relative. The loss of income also makes it difficult for caregivers to access formal resources, such as home health and respite care, which could make their tasks more manageable.

A final source of burden can be stigma surrounding HIV disease. Community rejection of HIV positive individuals because of their disease or the mode of transmission often extends to the relatives and friends who provide care. However, it is important to note that the communities that this research was carried were very supportive of those in caregiving work. Caregiver burden has its consequences; it often produces high levels of chronic stress. The second chapter highlighted some of the common signs of stresses that can be a result of caregiver burden.
4.3.3.2 Rewards of Caregiving

When asked about the positive aspects of providing HIV and AIDS care, informal caregivers in focus group discussions cited opportunities to:

- Make the care recipient see the purpose to life and never to give up
- Give a helping hand to the care recipient
- Develop empathy and self-knowledge
- Gain a sense of personal effectiveness by demonstrating competence under very difficult circumstances and
- Experience the positive feelings associated with loving, caring, and feeling needed

Some member of the Varaidzo focus group participants had to say this about caregiving work,

“... zinosunungura mwanwangu kuvona munhu anga asingagoni kana kudya oga ava kukwanisa kudya, kufamba pamwe nekuzvigeza oga. Unobva wawona kuti zvokwadi Mwari ariko”

“It brings joy my son to see the care recipients, who couldn’t eat on their own, eating, walking and even bathing on their own”

Helping caregivers define the meaningful and valued aspects of their roles and become more attuned to “brief human moments” that create positive feelings can enhance both physical and psychological well-being.

4.3.3.3 Caregiver Burnout

Rewards in caregiving do not necessarily make these activities less stressful. There is a high degree of involvement, whether positive or negative, which can produce stress. “Burnout” is
a term used to describe the process in which everyday stressors that are not addressed gradually undermine the caregiver’s mental and physical health. Focus group discussions revealed the following that:

_Caregivers get emotionally exhausted and will come to fear facing a new day of the same or even worse caregiving activities as a result the caregiver becomes cocooned in their own activities and avoid mixing with others in the social sphere_ according to one of the members of the Paradise focus group.

Some of the members of Kuzvipira focus group highlighted that:

_Because of the expectations that the caregivers have in wishing to see their care recipient up and doing their things on their own, they tend to overwork themselves too much._

“… nedzimwe dzenguva unoshaya kuti murwere ungamuita sei kuti afare nokuti chero ukabika zvakanaka sei anozviramba. Anodya kana uchinge watoita zvekumunyengerera apa ndinenge ndichida kuenda kumadiscussion nevamwe”

“It is demotivating when the recipient refuses to eat even a well prepared meal. You have to be patient with him to eat when at the same time I am supposed to have discussions with other students.” Mr. Tawanda’s sentiments, a student at Great Zimbabwe University (GZU)

According to Myers (2002), caregivers of HIV positive persons experience a lot of psychological impact in their caregiving work including burnout. Burnout is defined by Psychologists in terms of three components: emotional exhaustion, depersonalization, and reduced personal accomplishment. Emotional exhaustion represents the basic stress dimension of burnout (Myers, 2002). This condition is characterized by feelings of being
emotionally overextended and lacking enough energy to face another day. Depersonalization represents the interpersonal dimension of burnout. Feeling drained and “used up,” the caregiver develops an emotional buffer of detached concern and interacts with others in a negative and callous manner. Reduced personal accomplishment represents the self-evaluation dimension of burnout. This dimension is characterized by a growing sense of inadequacy and may result in a self-imposed verdict of failure.

There are serious consequences of caregiver burnout for the caregiver, care recipient, and health care system. Because burnout occurs gradually, caregivers tend to keep working until the downward spiral goes too far and the costs in performance and well-being become unacceptably high (UNAIDS, 2004). Care recipients suffer when burnout leads to lower-quality care. Caregivers struggling with emotional exhaustion often become less sensitive to the care recipient’s feelings and needs.

As a result of caregiver burnout, care recipients suffer and receive low quality care. It increases the likelihood that the care recipient will be neglected. Mr Farai a care facilitator said:

“The Kushinga Support group of Rujeko experienced a situation of the effects of serious consequences of burnout when a husband left his ill wife for another. The abandoned wife suffered stroke as a result and the case is now with the magistrate’s court”

The health care system is negatively affected when burnout depletes the supply of experienced caregivers and creates a need for continual training of replacements. Health professionals historically have been trained to focus on the clinician-patient relationship, with
little attention to the needs of the informal caregiver. Newer educational models encourage health professionals to develop “partnerships” with informal caregivers that include periodic assessment of the caregiver and the patient.

Caregiving burnout is a result of many factors which when identified might help the health care professionals in the fight to reduce burnout and increase the quality of life for the care recipients suffering from HIV and AIDS.

4.3.4 Theme 4: Coping with the Role of Caring

The questions based on this category theme revealed commonalities among the caregivers, and these will be discussed based on the sub-themes of controlling emotions, integrating HIV and AIDS into their lives, turning to spirituality, acquiring feelings of hope and gathering support from family and society.

4.3.4.1 Controlling Emotions

Caregivers expressed having to make themselves strong, especially when in company of the care recipient. Most caregivers believed that showing real feelings of distress could affect the PLWA, worsening their condition. As such caregivers most of the time, put the care recipient’s well being first, and by controlling their feelings they were protecting themselves from extra stress, which might negatively affect their caregiving work and the care recipient state as well.

Ms. Elizabeth said:

“...ndaishungurudzika neurwere rwababa zvokuti ndapota ndichichema ndakavanda kuti asandiwona sezvo ndaitya kuti aizogona kunyanyisa kurwara”
“I felt so bad, such that I used to cry, but hid myself so that he couldn’t see me because he was going to be worse”.

Ms. Rutendo on the other hand said:

“...ndiri kuramba ndakashinga nekuzvishingisa kuti asawona kushungurudzika kwangu”

“I am holding on, strengthening myself so that she cannot see that this thing does not feel well for me”.

Several researchers have observed the issue of self-control in care giving. Melnick (2002) found that family caregivers were trying to control feelings as a way of coping. According to Lazarus and Folkman (1989), one factor that influences an individual’s coping strategy is self-control. Putting on a brave face and concealing their hurt, anger, disappointment or anxiety helps them to function best. Being in control helped the care recipients to have hope and courage to persevere under difficult circumstances and to have hope about the future. Also of importance was the use of ARVs. These have helped many care recipients who were bed ridden to be up and about.

4.3.4.2 Integrating HIV and AIDS into their Lives

Caregivers have come to accept the illness of the care recipient as part of their daily living and to completely resort to assisting the sufferer to deal effectively with the diagnosis. Some of the caregivers felt that encouraging and supporting the care recipient to correctly and regularly take their medication was fulfilling for them. However the caregivers sometimes felt sorry for the care recipient when experiencing side effects from the medications, thus being tempted to stop the treatment to minimise their misery. Some caregivers felt that being
the “treatment buddy” to encourage adherence was rewarding. Improvement in the sufferer’s condition brought fulfilment to the caregivers.

Mr. Tonde said:

“Ndinogara ndakamutarisa...ndinomukurudzira kuti amwe mapiritsi zuva roga roga. Dzimwe dzenguva ndino munzwira tsitsi...asi ndowedzera kumukurudzira...ava kunzwa zviri nani manje”

“To be in her company...I then encouraged her to take her treatment everyday. At times it was difficult, I used to feel sorry for her....I then became strict to her...she is much better now”.

Knowing what they were dealing with was also fulfilling for caregivers. This helped to minimise the caregivers’ fears. Accompanying the care recipient for regular check-ups, supporting the infected emotionally, physically and socially made caregivers become emotionally stronger for the care recipients, and able to learn from the situation. Some of the caregivers found it difficult to accept the care recipient’s condition, and to learn to live with the challenges of the diagnosis, as well as the physical debilitation of the care recipients when they first heard about them having the HIV virus.

Feeling sad, hurt, and confused, as well as being tearful and helpless were feelings that clouded caregivers’ attitudes when they first heard of the HIV diagnosis. The caregivers expressed being able to accept the disease when the care recipient had accepted it. This led to feeling free to talk about what they were dealing with, as the care recipients were being open about their disease. This resulted in feelings of relief and acceptance for both the care recipient and the caregiver.
Mr. Tatenda said:

“She is telling them about her sickness and that made me free to also talk about it to others”.

Ms. Grace on the other hand said:

“kugamuchira kwakaita murwere urwere kwakaita kuti ini ndizvinzwisise...murwere akasununguka kutaura nezveurwere”

“She has accepted it, so I also just have to accept it... She talks about it too”.

In cases where the care recipient had not yet disclosed their status, caregivers were encouraging them to live openly with the virus in order to reduce the burden. It would also keep them from being overwhelmed by the knowledge of their status without being able to deal with it openly.

For some caregivers, caring came as no choice to them but they felt that they were committed to their loved ones thus had to show respect and give care. Mr. Hama said:

“Mudzimai wangu uye ndakazvipira kuva naye upenyu hwese, naizvozo ndichamuchengeta”

“She is my wife; I have committed myself to be with her for life so I just have to care for her”

For some, caring was offered as a way to return the favour to the recipient, as he/she has done so much in the caregiver’s life. Ms. Elizabeth said:

“Ndakazvigamuchira kuti anorwara...zvakawedzera kundisunungura kutsigira kwaanondita kwakasiyana siyana”
“I told myself that he’s got it...What made me feel OK was that he was always by my side, helped me in many ways.”

Despite the distress and demands, some of the caregivers, with their family members and the care recipient, created joyful times together to create an atmosphere of understanding and acceptance for both the caregivers and recipients. This was aimed at making the recipients feel accepted and cared for by the family and to understand the dos and don’ts of the disease.

Ms. Elizabeth said:

“Taisitora murwere kuenda naye kwakasununguka, tichimukurudzira kudya nekuita zvaanoda”

“Like we (caregiver and husband) used to take him out, show him how he is supposed to eat and let him do funny things that he enjoys”

Ms. Rutendo also said with an ecstatic face:

“Nedzimwe dzenguva murwere anotisekesa kwazvo...anoti kana azvitarisa mumirror unonzwa oti ‘Inga ndangosara mabhozo ega’ ”

“She is sometimes so funny you know we used to laugh about it...she would look at herself on a mirror and say ‘I am only bones, shoo I look terrible, don’t I?’ She is a very funny person.”

I also was impressed during his data gathering exercise when, while talking to one of the caregivers, a passer-by came and sat with us openly talking about how the ARVs were giving them hope for a long life.

Several researchers have supported integrating the situation into an individual’s daily life. Folkman (1997) found that caregivers experience positive psychological states during
caregiving and bereavement, with positive reappraisal being one of the coping strategies employed by them. A positive psychological state is associated with searching for and finding positive meaning. In this study, commitment to caring was associated with commitment in marriage, that is the vows that two individuals made, which meant having to provide care irrespective of the nature of the illness. This involved the activation of beliefs, values or goals that help define the positive significance of the events. It is noted that in the study Mr. Hama felt that as a married man he vowed to care for his partner irrespective of the situation, and therefore had to stay committed to his vows.

Dorz et al. (2003) found that using denial and humour were associated with emotional exhaustion and depersonalisation. Humour was seen to be an inadequate coping strategy, as it made use of ridiculing, laughing, trifling, and joking about the situation. This was the case with Ms. Rutendo and her care recipient; although they both experienced humour in a positive way, as a way to ease their minds and to accept the situation, the care recipient depersonalised herself with regard to the way she appeared. Caregivers also filled ordinary events with positive meaning by creating joyful moments with their loved ones. Caregivers in the study pursued and attained important goals by encouraging recipients to take their treatment, as well as advising them to seek medical advice. Caregiver studies have also revealed that positive effects are related to the use of positive reappraisal, deriving satisfaction from caregiving and problem-focused coping according to Dorz et al. (2003).

4.3.4.3 Spirituality

The caregivers expressed spiritual beliefs and practices either negatively or positively. In a positive way, it was expressed in the form of praying as an individual or with members of the
church and/or community, and going to church for spiritual support and giving praises that God has heard their prayers.

Ms. Fadzi said:

“When I worry a lot I go to church...sometimes I pray by myself”.

Ms. Chenai said:

“I used to pray to God that she must get better”.

In a negative way, it was noted that caregivers felt that for their loved ones being diagnosed with HIV was God’s way of testing their faith. Caregivers even asked themselves questions like, “Why me, God?” Which implied the diagnoses were a punishment from God.

Ms. Grace said:

“I wonder what is God doing or maybe He is testing my faith in him”.

Mr. Hama said:

“I asked myself why me God?...why is this happening to me?”

The use of faith as a coping mechanism has been supported by several studies. Folkman (1997), in her study of gay caregivers’ coping processes, identified spiritual beliefs and practices, which intensified after the partner has passed on. In the present study, spirituality was observed either positively, in the sense that the caregivers were praying for their care recipients’ well being, or negatively, by having thoughts of their faith being tested or it being a punishment from God - hence the question, “Why me, God?” Melnick (2002), in her study of voluntary caregivers, also identified faith as one of the coping mechanisms employed in the arena of HIV and AIDS caregiving. Catalan et al. (1996), in their study to determine coping mechanisms used by AIDS and oncology nurses and doctors, identified religion as a coping mechanism. It is also important to note that Religious groups these days include a lot of palliative support to those infected by HIV and AIDS.
4.3.4.4 Feelings of Hope

Although caregivers feared death, feeling helpless and having feelings of confusion, there were times when they were hoping for the best; hoping that things will be fine for the care recipients; hoping that one day they will recover and be able to do things for themselves. With the supply of ARVs, most of the caregivers felt a sense of relief that the suffering of their loved ones will be over. For those primary caregivers who were fearful of their families’ and society’s response towards the care recipient, the coming to terms with the diagnoses of the care recipients and their opening up, gave a sense of hope for the best to the caregivers. These were noted from the following:

Ms Elizabeth said:

“Ndinonzwa kusununguka nokuti ndinoziva kuti achaita nani nekuda kwemapiritsi aari kunwa. Zvinonyevenutsa nokutikana iye pachake ava kukwanisa kutaura nezvechirwere chake aka sununguka”

“I am now feeling better; I told myself that he is going to be fine. He’s going to have nothing now because he is getting treated and he is also talking about it now”

Mr. Farai, a care facilitator said:

“The use of ARVs has brought high hopes for the primary caregiver because some of the care recipient who were bed ridden can now do things on their own giving much hope to the caregivers”

Contrary to the study of Brouwer et al (2000), who found that caregivers experienced feelings of helplessness, denial and despair, in this study it was found that caregivers experienced this at the beginning when they first heard about the HIV diagnoses. When sufferers openly talked about the disease and were on anti-retroviral treatment, they had hope for the future.
For others, observing HIV activists successfully living with the virus gave them hope that their loved ones could also succeed. Rose and Clark (1999) see maintaining hope and optimism as an emotive-focused coping mechanism used to avoid the problem and to deny the facts and implications.

### 4.3.4.5 Gathering Support

‘Gathering support’ describes the process by which the caregivers sought information regarding HIV and AIDS and care, as well as sought economic, physical, and psychosocial support from family, friends, health care workers and community members. Some of the caregivers disclosed to family, friends and community members so that they could be assisted when in dire need. Others needed practical help that involved cleaning, washing, bathing and cooking; requesting their friends and neighbours to assist them minimised the burden. Some of the caregivers joined the home-based care organisation by requesting referrals from the clinic staff so that they could be assisted with care, transport and food parcels for the recipient and the families.

Mr. Hama said:

“Pakutanga ndaisaziva kuti vanhu vachivamuchira sei...Asi nekuda kwekutaura nezvechirwere ichi, ndava kuwana rubatsiro rwakasiyana siyana zvava kurerutsa kuchengeta murwere”

“In the beginning I was afraid how people will react... Since I am speaking about it, I’m feeling much better they are supportive... They bring her medication and also advise me on what to do”.

Ms. Fadzai said:

“Musikana atakavakidzana naye anombopota achibatsira nemabasa apamba kana kubika apo ndinenge ndichiendesa mumwe murwere kuchipatara”
“There is a girl in the house behind us whom I always ask to give me help like bathing them, cleaning or even cooking for us when I maybe have to take one of them to the doctor or hospital”.

Mr. Tatenda said:

“Madzimai ehome based care anobatsira chose, anoti dzidzisa kuchengeta zvakanaka varwere vakadai”

“The home-based caregivers are very good people to get help from as they are trained in working with people like her…”

However, there were some caregivers who felt too much family interference sometimes stressed them in their caregiving work. Ms. Grace said:

“Dzimwe hama pane kukubatsira kuchengetedza murwere vanotouya kuzokushungurudza vachiita kunge vari kuda kubatsira ivo vachimhura”

“Some family members come to give you stress pretending to be helping the care recipient when they will actually trying to look for faults in my caregiving work”.

Mrs. Fungisai said:

“Nekuti vazhinji vava kutaura nezve chirwere ichi pachena, tava kukwanisa kuenda revarwere vedu kumapoka anobatsira takasununguka”

“Now that people are openly talking about HIV and AIDS, we can now join support groups free of stigmatisation and discrimination and discuss on how to overcome stresses so as to improve on our care for the care recipients”

It was also noted among the caregivers that men were also actively participating in the caregiving activities as indicated by the male caregivers who participated in this research. Men were playing an increasing role in adopting tasks and responsibilities within the
household that are culturally perceived to be ‘women’s work’. In Zimbabwe, the Red Cross reported in 2002 that of the 1042 home based caregivers, there were 104 males and 938 females, a ratio of 1:10. Male caregivers in Masvingo had this to say:

“Takawona kuti varume havadi kana kuti vanonyara kuita mabasa ekuchengetedza varwere veHIV saka tiri kuita macompaigns ekuti vazine. Tiri kuronga boka reMan’s Forum iro rinosangana Mugovera wekutanga wemwedzi umwe neumwe tichitaurirana nezve denda iri nekuchengeta kwevarwere”

“Men are reluctant or ashamed to be associated with the caring of HIV infected persons and as such a Man’s Forum group was formed which meets every first Saturday of the month to discuss on HIV and AIDS and how to assist in the caring of those infected by the epidemic.”

It was echoed amongst the participants that the major challenge still lies on how males were socialized. This is why you find males asking female relatives to come and help in the caregiving of a wife or child.

It is noted that caregivers in the study used what Lazarus and Folkman (1980) termed a ‘problem-focused coping strategy’. Research found that individuals, when faced with a stressful situation, are inclined to use problem-focused coping rather than emotive-focused coping (Rose & Clark-Alexander, (1999); Lazarus & Folkman, 1980). Individuals in the study bargained and sought social support to be able to cope effectively. Caregivers in the study, as noted especially by Mr. Hama, said that the caring were overwhelming at first, because they were not openly talking about what they were dealing with; rather, they saw it as their problem, and were ashamed of what people were saying about them. By openly
talking to people, letting them to know and understand what they were dealing with, enabled them to access assistance from others.

As men (Mr. Tatenda & Mr. Hama) with less knowledge about caring, they accessed help and advice in order to be able to deal effectively with the burden of caring. This led to instrumental support from family members and their neighbours in the form of labour work (e.g. bathing, cleaning and cooking) or financial assistance (e.g. assisting with applications for grants), which enabled them to cope effectively. It is also important to note that there are other family members who fail to appreciate the good work being done by these caregivers who always criticize and yet they have nothing to offer the care recipient.

4.4 Discussion of Findings

The relationship between the aforementioned themes will now be explored. It is worth mentioning that the dominant themes together with supporting themes are interconnected. These themes are not remote, but rather each theme enriches the reader’s understanding of the other themes. Caregivers in the study experienced the caring process as challenging and emotionally taxing, although later were able to see it in a positive way. In the beginning, when they first heard of the HIV diagnosis, caregivers went through a series of emotional experiences. Caregivers experienced emotional ambivalence clouded by feelings of sadness, hurt, shock, unease and emotional confusion. This was later followed by fear of death for their loved ones, resulting in them experiencing multiple losses as a result of HIV and AIDS.

Turner and Catania (1997) in their study also found that family members experienced greater subjective strain associated with caring. Unlike the Turner and Catania (1997) findings which found that heterosexual friends were experiencing lesser subjective strain, it is noted that in
the present study the care recipients’ partners experienced fear for their own status, which led to emotional confusion. The existence of emotional confusion is supported by Edelman (2000), who construed that caregiving brings feelings of low morale, stress and fatigue. The caregivers found themselves being preoccupied with the possibility of being positive, which caused fear and negligence of the care recipient.

A study by Mullan (1998) further confirms the fear of death experienced by caregivers as a constant threat leading to feelings of overload, loss and feeling captive to caregiving demands. Some of the caregivers in the study also expressed having the fear of death of their loved ones. Mullan (1997) further reports feelings of guilt associated with caring, whereas caregivers in the present study expressed this less; rather, they expressed feelings of incompetence as they carried on with caring. Grieving before the actual death has also been supported by research. Caregivers in the study also experienced what is termed by Keene Reder (2003) as “anticipatory grief”. In the present study, the caregivers’ anticipation was based on knowledge of the disease symptoms and progress. The relationship they had with the infected influenced the feelings. It is noted that the majority of the caregivers were partners of the infected, with the minority being other relatives, children or parents revealing a strong bond between infected and caregiver. Several researchers supported the notion of emotional demands and experiences with regard to caring in the arena of HIV and AIDS (Pakkenham, Dadds & Tarry, 1995; Mullan, 1998).

Participants in the study experienced more than just emotional strain as a result of knowing the infected individual’s actual diagnosis. It was noted that financial demands of caring brought feelings of helplessness. Brouwer et al (2000) and Flaskerud and Tabora (1998) also found in their study that poverty increased the worries of caregivers, as they could not reach
their care recipients’ health needs. The result of this study correlated with these findings, as the participants expressed their financial challenges. A study by Turner and Catania (1997) further confirms these experiences, as they found that lower income caregivers were more burdened. Experiencing physical constraints as a result of caregiving demands have already been researched (Leblanc, London & Aneshel, 1997).

The results of this study also suggested that the demands and stressors of caregiving led to poor physical health. Emotional difficulty associated with knowing that your loved one is living with the virus were observed not to be experienced by the caregivers only. Participants in the study reported different emotional experiences of the family and the community when they knew about the care recipient’s diagnosis. Bor et al. (1993) also found that families may respond to the news of the diagnosis with disbelief, shock and confusion. The present results also supported the notion that these feelings impacted not only on the caregivers, but also on the entire family structures. Difficulties associated with whether to disclose or not to disclose when dealing with HIV and AIDS have been observed by several researchers (Powell-Cope & Brown, 1992; True Love, May 2002). Participants in the study reported experiencing rejection, prejudice, and discrimination, mostly directed at the care recipients by their families following the disclosure (Katz, 1981). Other participants in the study resorted to blaming the opportunistic infections as the causes of illness in order to avoid humiliation and rejection (Powell-Cope & Brown, 1992). Although caregivers used opportunistic infection explanations as a way of minimising negative responses, participants in the study observed the family and community responses as positive.

The families and the communities offered support to the caregivers as well as the care recipients. The results correlate to Owens’ (2003) findings, which reported that families of
HIV positive women gave emotional and concrete support. This study found that support was mostly offered to the care recipients, and not so much to the caregivers. A study by McCann and Wadsworth (1992) also found that support from care team members was mostly directed towards care recipients, and less so to caregivers.

This study elicited the coping strategies employed by caregivers in the arena of HIV and AIDS. Participants in the study reported controlling their emotions as a way of coping with their knowledge of the disease and the caring demands.

Self-control as a coping mechanism was also supported by Lazarus and Folkman (1989) and Melnick (2002). As a buffer, this improved caregivers’ self-esteem, which in turn boosted the care recipients’ courage and hope for the future. Other coping mechanisms employed by caregivers included integrating HIV and AIDS into their lives, spirituality, having feelings of hope, as well as gathering support from other members in the same predicament through discussions and support group facilitations. These coping mechanisms entail what is termed “problem-focused coping mechanisms” (Folkman & Lazarus, 1989; Folkman, 1997; Melnick, 2002). Poor coping mechanisms used by caregivers in the study included denial and inappropriate humour.

4.5 Summary

The participants’ psychological experiences and coping strategies have been described and presented under five dominant themes, namely challenges of caring, The caring experiences, burdens and rewards of caregiving, caregiver burnout, and coping with the role of caring. The supporting sub-themes under each category were also detailed; lend more meaning and clarity to the participants’ experiences and strategies. These themes were chosen from the data and
reflect the essential meanings shared by participants. Direct quotes from participants’ accounts were incorporated to provide qualitative descriptions of these themes. The themes were compared to previous research on HIV and AIDS caregivers’ experiences and coping mechanisms, and were found to corroborate the majority of the previous research findings. The following chapter summarises the key findings of this thesis and make conclusions. It also further explores their implications for further research, policy formulation and training in the arena of HIV and AIDS. Lastly, recommendations for future research will be addressed.
CHAPTER V

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

5.1 Introduction
This chapter concludes the study by summarising the key research findings. The aim of the study was to provide an overview of the psychological experiences of HIV and AIDS primary caregivers in Masvingo Urban, and to understand the coping strategies employed by these caregivers to deal with their own feelings as well as the responses of the public towards them. It has been argued throughout this thesis that the lived experience and coping strategies of caregivers, specifically informal caregivers, is of primary significance. Their study is of great importance if one is to gain an in-depth and broad understanding of the caring of sufferers in the arena of advanced HIV conditions and AIDS disease. Previous research findings can be seen as relevant in that they reveal the psychosocial experiences of caregivers, but they do not address the lived experiences and coping strategies of HIV and AIDS primary caregivers.

5.2 Summary of Findings
A thematic content analysis was used to describe the psychological experiences and coping strategies of HIV and AIDS primary caregivers in Zimbabwe. These findings were presented as five main themes namely challenges of caring, the caring experiences, burdens and rewards of caregiving, caregiver burnout, and coping with the role of caring. Participants described caring as a challenging process, experienced in both positive and negative ways. The caring experience was found to be an emotionally ambivalent situation, where participants experienced feelings of shock, hurt, confusion, sadness and helplessness, as well
as suffering multiple losses. Participants further expressed experiencing financial challenges as a result of caring demands, because they were not employed, thus depending on grants. As a result of the strains experienced by caregivers, some of the participants expressed experiencing physical symptoms due to caring demands.

With regard to family and societal responses, caregivers also observed that families and society experienced emotional turmoil when first hearing about the diagnosis. Although these feelings were apparent, some of the caregivers had found it difficult to disclose what they were dealing with as a result of being ashamed of what the responses could be towards them and especially towards the infected. Some of the participants expressed using opportunistic infections that the care recipient was suffering from, like TB, meningitis, pneumonia, and strokes as the causes of illness. Those caregivers that disclosed to their families experienced rejection and hostility from family members, which was mostly directed towards the sufferers. This resulted in feelings of discrimination and isolation for both the care recipient and the caregiver.

Furthermore, participants told of being offered support by family members and society in the form of “instrumental support” i.e. bathing, feeding and supplying transport for the care recipient, together with emotional support, which was mostly directed towards the recipients. The study further reveals that participants experienced little or no emotive and cognitive support from family, society, nor the community health workers who were visiting the sufferers at home. This led them to feel more helpless, leading to the use of poor coping mechanisms. Regarding the participants’ way of managing their own experiences and feelings, as well as the way society and families responded to them, some of the caregivers spoke of controlling their emotions, especially when in company of the care recipient, in
order to protect the care recipients so that they can cope better with their conditions or disease. Caregivers further expressed integrating the disease into their daily lives by accepting the care recipients’ condition as being real and existing, and by creating joyful meaning for the care recipient and other family members, and by fulfilling their commitments to the care recipients.

Use of spirituality, in either a negative or positive way, was also experienced. Some of the caregivers expressed going to church, and praying with other family members and the community for the well being of the sufferers. Others expressed questioning God with regard to their loved ones being affected by HIV and infected with the AIDS disease, and saw the disease as a punishment for them from God. Participants also expressed having feelings of hope, especially with the introduction of anti-retroviral therapy as part of the disease management for their loved ones. They hoped for better results from the treatment for the sake of the care recipient, as well as for the benefit of the infected people’s children. Caregivers further expressed gathering support from other family members and health care workers to be able to deal with the disease’s demands actively.

The findings of this research are relevant as they supplement previous research on the demands of HIV and AIDS on informal caregivers, providing the experiences and coping strategies of primary HIV and AIDS caregivers within the Zimbabwean context. It is suggested that caring within the HIV and AIDS arena can be emotionally challenging, and that caregivers within this context still experience HIV related stigma, leading to nondisclosure. And where the HIV condition and AIDS disease are disclosed, caregivers and care recipients experience discrimination, resulting in isolation, which later results in the use of poor coping mechanisms. The results further suggest that although there was emotional
and cognitive support, it was mostly directed towards the care recipients, with minimal support for the caregivers. In summary, the participants’ experiences and coping strategies were found to support and supplement the findings from previous research on HIV and AIDS primary caregivers’ subjective and objective experience, thereby adding new insight and meaning.

5.3 Conclusion

From the findings of this research, the following conclusions were reached. The study results revealed that primary caregivers of HIV and AIDS patients in Masvingo Urban experienced a number of challenges in caring for the infected. The results suggest that caring for an HIV positive individual can be emotionally and physically draining, but later can be fit into one’s daily lifestyle. The negative consequences of caregiving work included the fact that it left the carer with little time or energy to care for themselves. It can lead to prejudice and stigma from those that could potentially offer support to the sufferer as well as the carer, causing strain. There were also advantages of caring for the infected as alluded to by the primary caregivers. Primary caregivers felt that providing care for the infected brought purpose to their lives as it developed in them empathy and self-knowledge. To cope with their situations, most primary caregivers mentioned faith and also taking the whole phenomenon as part of their daily lives. Support from other members in similar situations gave them hope. The findings of this research strongly support previous research and sheds light on issues that were observed positively as being negatively observed. The study adds to the body of knowledge, which can inform policies and training in the HIV and AIDS arena.
5.4 Recommendations

The thesis results substantiate previous research by providing rich, in-depth descriptions of how previous findings are subjectively experienced by HIV and AIDS primary caregivers. This has important implications for future research on HIV and AIDS primary caregivers. This study shows that caring for an HIV and AIDS individual can be emotionally, physically, socially and economically demanding. The study further sheds light on the minimal support structures available to caregivers, resulting in poor coping mechanisms, which can lead to increased stress and can result in physical and emotional burnout. It is therefore recommended that future research explore these caring demands to provide additional insight and understanding of the primary caregivers of HIV and AIDS, specifically among young adults.

Health professionals historically have been trained to focus on the clinician-patient relationship, with little attention to the needs of the informal caregiver. Newer educational models should encourage health professionals to develop “partnerships” with informal caregivers that include periodic assessment of the caregiver and the patient. By assessing the causes and levels of stress in informal caregivers, health professionals can more effectively tailor interventions to meet their needs.

Therefore I further recommend that trained caregivers working within the area of HIV and AIDS caregiving be equipped to be able to apply the Triad Model, whereby the care recipient and his/her caregiver are emotionally and physically assessed in order to combat burnout. Home-based caregivers must be able to define for themselves what is personally meaningful and of value to the caregivers, facilitate intimacy and conversations between caregivers and their care recipients to be able to disclose to other family members.
Some informal caregivers accompany HIV positive patients to medical appointments and can be easily identified. If a patient’s sources of emotional and practical support are not known, this question should be asked when taking the family and social history. Once informal caregivers are identified, their level of perceived burden and the presence of affective disorders, such as depression and anxiety, should be assessed. The availability, accessibility, and appropriateness of social support resources also should be evaluated. Because caregiver burden tends to intensify over time, particularly among caregivers with the fewest personal and material resources, health professionals should periodically reassess each caregiver’s problems and needs. The early detection of caregiver burden conserves resources by preventing or reducing medical visits for psychosomatic complaints. In many cases, health professionals can assess the degree of burden by asking just a few questions, according to Medecins Sans Frontieres (2009).

As such, other recommendations include training home-based caregivers to be able to assess stress-related symptoms among caregivers and to refer accordingly. Future policies must also be developed to accommodate this group that is not well understood. Identifying difficulties and the resources that impact in the individual experiences of caregiving, both in the families themselves as well as in the larger socio-cultural context, is valuable as a guide for the development of family interventions tailored to the specific needs of the different family subgroups.

Counselling Caregivers is another important recommendation by this researcher. Information gained from the systematic assessment of caregiver burden places health professionals in a stronger position to help informal caregivers cope with stressors. Time should be set aside
during each medical appointment to discuss what is happening in caregivers’ lives and to give them a chance to express their feelings. In addition to serving as empathic listeners, clinicians may be able to offer practical suggestions for eliminating or better managing stressors. They also can help caregivers recognize and build on aspects of their lives that contribute to physical, psychological, and social well-being (American Psychiatric Association, 2000).

Caregivers experiencing guilt, hopelessness, or spiritual distress may need to be referred for religious or spiritual counselling. Discussions with clergy, hospital/hospice chaplains, or other spiritual counsellors can help caregivers find comfort and peace even in the absence of strong religious or philosophical belief systems. Caregivers with affective disorders or high levels of burden should be referred to mental health professionals for assessment and counselling.

Health professionals may sometimes overlook the importance of extending counselling into the bereavement period. Bereavement counselling can help caregivers mourn appropriately, cope with the changes resulting from their loss, and plan for the future. These interventions could support the diversity of families living with HIV and AIDS, and also help sustain families in their important and challenging caregiving task.

Making the carers visible, and highlighting the significance of their work to national and international HIV and AIDS policies, will enable these policies to provide a truly holistic continuum of care for those living with HIV and AIDS, their families and communities.
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Appendix 1: Letter Giving Permission to Carry Out the Research

ZIMBABWE RED CROSS SOCIETY
Patron: H. E. The President of Zimbabwe
The Geneva Convention Act (No. 36) 1981

WO 52/67

MASVINGO
P.O. Box M 20
Chikato
Masvingo

Tel: 039 - 262970
Fax: 039 - 264962
E-Mail: masvingo@redcrosszim.org.zw

27th June 2012

TO WHOM IT MAY CONCERN

This letter serves to acknowledge that Chikukwa Herbet Tichanya I.D. 22 – 125916 H 22 carried a research study for his Masters Degree with our Institution.

He made use of the Zimbabwe Red Cross Society Masvingo Urban HIV and AIDS Support Groups to enquire on the experience of primary care giving of People Living with HIV AIDS (PLHIV) in Zimbabwe. His research was carried from October 2011 to January 2012.

Regards,

[Signature]

M. PHIRI
PROVINCIAL PROGRAMMES OFFICER
Appendix 2: Informed Consent Agreement Form

Name of Researcher : Herbert Tichauya Chikukwa
Institute : Zimbabwe Open University
Degree : Master of Philosophy in Educational Psychology
Research Topic : Experiences of Family Caregivers of HIV Positive Zimbabweans in Masvingo Urban: Bringing the Carers Into Focus

Purpose of the Study : To critically examine the experiences of family caregivers of HIV positive persons in Masvingo Urban

Description
You are being asked to participate in a study that is looking at the experiences of family caregivers of HIV persons in Zimbabwe. The interviewer will ask you questions about your lifestyle and living conditions, things like employment, family, physical health, housing and food. There are also more personal questions about your personal experiences as primary caregivers of HIV positive persons in Masvingo. The study will be conducted using the ethnographic research design. Data will be collected from primary caregivers in Masvingo’s Mucheke and Rujeko suburbs. Participants will be engaged in face-to-face interviews and focus group discussions with the researcher where data will be recorded on an audio recorder and some pictures taken.

Research Ethics
Persons who are willing to participate in this research should read or listen to the following information very carefully so that they can make an informed decision about their participation.

Conditions of participation
Participation in this research is voluntary and participants should do so out of their own free will. The participant is free to withhold any information that they may decide not to share with the researcher or withdraw from the interview at any point if they feel like doing so for whatever reasons. If the interviewer asks you a question that you do not wish to answer, just say “pass” and the interview will skip that question.

Published results will only report aggregate information so your identity cannot be determined from these results. The computer data file that contains the interview responses as well as all other research materials will be kept in a locked, secure facility that is accessible only to the Principal Investigator.

Benefits
There are no direct benefits to any participants other than that, it is hoped the results from this research will further the understanding of the experiences of family caregivers of HIV positive Zimbabweans and bring them and their plight into focus. Also as a citizen you would have contributed to valuable information that helps the nation and police makers to understand the experiences of primary caregivers of HIV positive Zimbabweans with the view of assisting them to formulate well conceived policies on this issue.

Risks
Some of the questions that you will be asked during the interview are of a personal nature, particularly those dealing with your personal experiences in caring for your loved ones who
are HIV positive and how you cope with grief and bereavement. It is possible that you might find these questions upsetting. If you should become upset the interview will be stopped immediately. There are no other known risks associated with participation in this study.

Use of data collected
The end product of this study will be a Master of Philosophy in Educational Psychology dissertation. The researched information will be available for inspection by the Research Supervisor, the Higher Degrees Committee and Internal Examiners at the Zimbabwe Open University, and appointed External Examiners from other institutions.

INFORMED CONSENT
Your signature on this consent form indicates that you fully understand the above study, what is being asked of you in this study, and that you are signing this voluntarily. If you have any questions about this study, please feel free to ask them now or at any time throughout the study.

Signature of volunteer participant..........................................................................................................................................
Date .........................................................................................................................................................................................
Signature of researcher ............................................................................................................................................................
Date .........................................................................................................................................................................................

Contact Details
If you have any questions about this research, please contact the Principal Investigator at cell +263 773 901 184 or email address: hchikukwa@gmail.com or contact DR Ellen Gwaradzimba, Dean of students Africa University. Cell: +263 772351625; +263 777991187 or e-mail address: gwaradzimaellen@yahoo.com

Thank you.
Appendix 3: Shona Version of the Research Data Gathering Instruments

INSTRUMENTS FOR EXPERIENCES OF FAMILY CAREGIVERS OF HIV POSITIVE ZIMBABWEANS IN MASVINGO URBAN-BRINGING THE CARERS INTO FOCUS: THE SHONA VERSIONS

KEY INFORMANT INTERVIEW GUIDE (HBC Facilitators and Health Personnel)
This interview guide is designed to collect information on psychological experiences of family caregiving for HIV positive Zimbabweans based in the suburbs of Masvingo and how the caregivers are coping. It is made up of three sections; A, B, and C. All information gathered will be treated in strict confidence and shall be used for the purpose of this research only.

DEMOGRAPHIC DATA
Name.........................................................................................................................................................
Organisation...................................................................................................................................................
Gender...............................................................................................................................................................
Position held.....................................................................................................................................................
Age.................................................................................................................................................................
Period with Organisation (complete yrs).....................................................................................................
Period in caregiving activities (complete yrs).............................................................................................
Number of care receivers................................................................................................................................
Education: Primary/Secondary/Tertiary/University/Other (specify)..............................................................

PERSONAL EXPERIENCE AS CAREGIVER
1. Semunhu anoita mabasa ekuchengetedza vanorwara nedenda reHIV and AIDS, ndeapi mabasa anotarisirwa kuitwa mukuchengetedzwa kwevarwere ava?
2. Munonzwa sei kuva mumwe wevanochengetedza varwere vedenda?
3. Ndezvipe zvigozhero zvinosanganwa nazvo mukuchengetedzwa kwevarwere vedenda iri?
4. Munombonzwa kushungurudzika nekuchengeta varwere ava here?
5. Munobata/shanda zvakadii nevamwewo vanoita mabasa akafanana neamunoina aya?
6. Ndevapi vanhu mumaruwa umu vanonyanya kuita mabasa ekuchengeta kwevarwere ava (Varume, vakadzi kana vana)?
7. Zvingaitwa sei kuti vanhu vese vape rubatsiro rwakafanira kune varwere vedu ava?
8. Mune rubatsiro here rwamunowana kubva kumwe pakuchengetedza kwenyu varwere?
9. Mukuchema nekusurukirwa panofa murwere, ndezvipi zvinosanganwa nazvo nevanga vachimuchengeta?

RECOMMENDATIONS
• Semawonero enyu uye ruzivo rwenyu, ndezvipi zvanunofunga kuti zvingaitwa kubatsira avo vanogara vachichengeta varwere mumaruwa umu?
• Munezvimwe here zvanungadz kutura kana kuzivisa vanwe nemaererano ekuchengetwa kwevarwere vedenda iri?

TINOTENDA
IN-DEPTH INTERVIEW GUIDE (Informal caregivers: spouses, friends and relatives)

DEMOGRAPHY DATA

Name...........................................................................................................................................
Employment Status..........................................................................................................................
Gender..........................................................................................................................................
HIV & AIDS Status (If willing to disclose)..................................................................................
Age............................................................................................................................................... 
Relationships with care receiver(s)................................................................................................
Number of care receivers.............................................................................................................
Co-residence with care receiver(s) Yes....................................................................No..........................
Period in caregiving activities (complete yrs).............................................................................
Education: Primary/Secondary/Tertiary/University/Other (specify)............................................

PERSONAL EXPERIENCE AS CAREGIVER

1. Mungataura nezvamakasangana nazvo muupenyu semuchengeti wemurwere
2. Munonzwa muchishungurudzwa here nekuchengeta kwamunoita murwere?
3. Ndeapi mabasa ekuchengeta murwere amunoita?
4. Ndezvipi zvamungati zvigozhero mubasa rekuchengeta murwere?
5. Mukati mezuva, ndezvipi zvinyanya kukushungurudzai pakuchengeta murwere?
6. Munobata pamwe here nevezvipatara kana mamwe mapato/organisations?
7. Pane hama neshamwari dzinombopota dzichikuzorodzai mubasa iri here uye vanofungei nebasa renyu?
8. Mukuchema nekusurukirwa panofa murwere, ndezvipi zvinosanganwa nazvo nevanga vachimuchengeta?

RECOMMENDATIONS

 o Nderwupi rubatsiro rwamungada kuona rwuchipiwa vanhu vakaita semi vanochengeta varwere muZimbabwe?
 o Kuti vanochengeta varwere vasa shhungurudzika nebasa iri vangaita sei uye imi munoitavo sei?
 o Pano zvimwe zvamungada kutaura kwatiri kana kune vamwe vanochengeta varwere semi?

TINOTENDA
FOCUS GROUP DISCUSSION SCHEDULE

DEMORGRAPHIC DATA

No. in Group.................................................................................................................................
Gender of Group.............................................................................................................................
Age Range of Group.........................................................................................................................
Education: Primary/Secondary/Tertiary/University/Other (specify)....................................................

CAREGIVING EXPERIENCES

1. Zvigozhero zvinosanganwa nazvo mukuchengeta varwere veShuramatongo
   a. Ndezviipi zvigozhero zveupenyu zvinowanikwa mazuvano?
   b. Ndezviipi zvigozhero zveutano zvinosangana nevazhinji muZimbabwe
   c. Ndezviipi zvigozhero zvamunosangana nazvo mukuchengeta kwamunointa varwere veshuramatongo?
   d. Munonzwa muchishungurudzika neupenyu hwamuri kurarama mazuvano here?

CAREGIVER ACTIVITIES

a. Ndeapi mabasa amunoita sevachengeti vevarwere?
b. Munonzwa sei sevachengeti vevarwere ava?
c. Ndezviipi zvinonyaya kukushungurudzai mukati mezuva pakuchengeta kwenyu murwere
d. Munoita sei kopedza kushungurudzika kwenyu nebasa ramunoita?
e. Mukuchema nekusurukirwa panofa murwere, ndezviipi zvinosanganwa nazvo nevanga vachimuchengereta?

RELATIONSHIPS/UKAMA

a. Ukama hwenyu hwakamira sei nemamwe mapoka anoita mabasa ekuchengeta varwere vakadai?
b. Ukama hwenyu hwakamira sei nevamunogara nvo muraini maererano nebasa ramunoita?
c. Hama neshamwari vanombo kuzorodzaiwo here mubasa iri?
d. Nderwupi rubatsiro rwamunowana kubva kunze?

ATTRACTING MORE CAREGIVERS

a. Nderwupi rudzi runonyanya kuita mabasa ekuchengeta varwere (varume, vakadzi, vana) uye sei zvakamira saizvozvo?
b. Ndeipi hurudziro ingapiwa kuti vanhu vese vabatsirane kuchengetedza vanorwara?
c. Vanhu vangaita sei kubatsira kubvisa kushungurudzwa kwavangaitwa nekuchengeta murwere?
d. Ndezviipi zvimwe zvamungada kuzivisa pamusoro pekuchengeta varwere vedenda iri?

TINOTENDA
Appendix 4: English Version of the Research Data Gathering Instruments

INSTRUMENTS FOR EXPERIENCES OF FAMILY CAREGIVERS OF HIV POSITIVE ZIMBABWEANS IN MASVINGO URBAN-BRINGING THE CARERS INTO FOCUS: ENGLISH VERSION

KEY INFORMANT INTERVIEW GUIDE (HBC Facilitators and Health Personnel)
This interview guide is designed to collect information on experiences of family caregivers for HIV positive Zimbabweans based in the suburbs of Masvingo and how the caregivers are coping. It is made up of three sections; A, B, and C. All information gathered will be treated in strict confidence and shall be used for the purpose of this research only.

DEMORGRAPHIC DATA
Name...........................................................................................................................................
Organisation......................................................................................................................................
Gender..............................................................................................................................................
Position held....................................................................................................................................
Age....................................................................................................................................................
Period with Organisation (complete yrs)..........................................................................................
Period in caregiving activities (complete yrs)..................................................................................
Number of care receivers..............................................................................................................
Education: Primary/Secondary/Tertiary/University/Other (specify)..................................................

PERSONAL EXPERIENCE AS CAREGIVER
1. In your own personal/professional opinion, what would you say are the caregiver activities?
2. What are your own and professional experiences as a caregiver for HIV positive Zimbabweans?
3. Do you feel you are currently under a lot of stress?
4. What would you say are the challenges of being a caregiver in your own personal/professional opinion?
5. Have you been feeling more anxious or irritable lately as a result of caregiving?
6. What are the relationships (of caregivers) like with the stakeholders?
7. From your personal/professional experience, who are mostly involved in caregiving activities (males, females or children)?
8. What do you think should be done to attract more (of the less involved) to be active caregivers?
9. Do you have any outside help?
10. What are the caregiving experiences at death and during bereavement/grief of the care recipient?

RECOMMENDATIONS
 o In your personal/professional opinion, what would you say is the way forward in caring for HIV positive patients? (Suggestion for the copying strategies)
 o Any other personal/professional recommendations you would want to make on caring for the HIV positive Zimbabweans.

Thank you
IN-DEPTH INTERVIEW GUIDE (Informal caregivers: spouses, friends and relatives)

DEMOGRAPHY DATA

Name..............................................................................................................................................
Employment Status...........................................................................................................................
Gender...............................................................................................................................................
HIV & AIDS Status (If willing to disclose).......................................................................................
Age...................................................................................................................................................
Relationships with care receiver(s)..................................................................................................
Number of care receivers..................................................................................................................
Co-residence with care receiver(s) Yes.........................................................................................No..........................................................................................................................
Period in caregiving activities (complete yrs)..................................................................................
Education: Primary/Secondary/Tertiary/University/Other (specify).....................................................

PERSONAL EXPERIENCE AS CAREGIVER

- Briefly tell us your personal experience as a caregiver
- Do you feel you are currently under a lot of stress as a result of caregiving activity
- What caregiving activities are you undertaking in caring for the infected?
- What challenges are you facing in caring for the infected?
- What aspects of your day are the most stressful?
- What is your relationship like with other stakeholders e.g. health personnel, NGOs etc.
- Do your friends and family watch the care recipient for you so that you have time for yourself?
- How do others (in the family, community and the like) view your situation?
- What are the caregiving experiences at death and during bereavement/grief of the care recipient?

RECOMMENDATIONS

a. In your opinion, what do you think should be done as a way forward to assist caregivers in caring for HIV positive Zimbabweans?
b. What would you recommend as the possible copying strategies of caring for the HIV positive patients (to other informal caregivers)?
c. Anything else you would want the researcher or fellow HIV and AIDS caregivers to know on caregiving for the HIV positive Zimbabweans?
d. What do you do to relieve your stress and tension?

THANK YOU FOR YOUR TIME AND COOPERATION.
FOCUS GROUP DISCUSSION SCHEDULE

DEMORGRAPHIC DATA
No. in Group.................................................................................................................................
Gender of Group..............................................................................................................................
Age Range of Group.........................................................................................................................
Education: Primary/Secondary/Tertiary/University/Other (specify).................................................

CAREGIVING EXPERIENCES
Challenges faced in caregiving activities
1. In general, what challenges are you facing in life these days as Zimbabweans?
2. From your own experiences, what are the health challenges currently faced by most Zimbabweans?
3. What challenges are you facing as caregivers for HIV positive Zimbabweans?
4. Do you feel you are currently under a lot of stress?

CAREGIVER ACTIVITIES
a. What are the caregiving activities that you are engaged in as carers of HIV positive Zimbabweans?
b. How does it feel to be a caregiver? (Your personal experiences in caring for HIV positive Zimbabweans)
c. What aspects of your day are the most stressful?
d. What do you do to relieve your stress and tension?
e. What are the caregiving experiences at death and during bereavement/grief of the care recipient?

RELATIONSHIPS
f. As caregivers, what are your relationships like with the stakeholders?
g. As caregivers, what are your relationships like with the other relatives of the infected and members of the communities that you come from?
h. Do your friends and family watch the care recipient for you so that you have time to yourself
i. Do you have any outside help?

ATTRACTING MORE CAREGIVERS
j. From your experiences, which gender is mostly involved in caregiving activities?
k. What could be the reason for this trend from your opinion?
l. How can the least involved be attracted to take part in caregiving activities for HIV positive Zimbabweans?

WAY FORWARD
- What would you say are the possible copying strategies in caring for the infected Zimbabweans?
- Any other issues you would want the researcher to know in caring for HIV positive Zimbabweans?

THANK YOU FOR YOUR TIME AND COOPERATION
Appendix 5: Verbatim Report on Focus Group Discussions.

NB. No names are used in this write-up, however, pseudo names are used in the main report

Paradise focus group discussion

Introduction
Tsvakiridzo yandiri kuita ndeyekuda kuona zvamunosangana nazvo mukuchengeta varwere vanorwara ne HIV and AIDS semaprimary care givers. Ndizvo zvatinoda kuti tibatsirane kwonesana tichipanana zivo yezvatinosangana nazvo zvakasiyana siyana.
I am carrying out a research on the experiences of primary caregivers of HIV positive persons in Masvingo. I want us to share our experiences as primary caregivers on the work that we do.

Question: Ndezvipi zvigozhero zvamunosangana nazvo mukurarama zvisiri zvekurwara asi zvakasiyana siyana?
In general, what challenges are you facing in life these days as Zimbabweans?
Answer: Zvigozhero zvatinosangana nazvo chikafu, murwere anoda kudya makuseni, mari hakuna, mabasa hakuna, zvinhu zvatinokurudzirwa muzvipatara kuti tinge tichipa murwere chikafu chakanaka, mafruits newhite meat. Mari inonetsa kwana
Food is the main challenge, the sick want to feed early morning but we don’t have the money to buy the food needed like fruits and white meat.

Question: Zvimwewo?
What else?
Answer: Mari ndiyo inonyanya kunetsa
Cash is the main problem.

Question: Zvigozhero zveutano zvamunosangana nazvo kana zvinosangana nevanhu vazhinji muzimbabwe?
From your own experiences, what are the health challenges currently faced by most Zimbabweans?
Answer: Zvinhu zvekushandisa kana tichibata murwere...hatina magloves, sipo nezvimwewo.
Health apparatus to use when handling the infected person, we don’t have gloves, soaps and so on.

Question: Zvimwe zvatinosangana nazvo (in general). Pamwe hamuna kusangana nazvo asi tinoziva kuti idambudziko ririko kana kuti zvinonyanya kugoza?
What other challenges are being experienced?
Answer: Chinonyanyo kugoza kachinji kunyaya iyemari ndezvekuti munhu anozotanga nemaARV kunodiwa kuti kuitwe matests saka anobhadharwa. Saka apa the average HIV person haana mari yacho.
The main challenge is that for a person to be on ARVs you must go for some tests first and these need to be paid for. An average person cannot get the money they ask for in order to do the tests.

Question: Vana mai zvimwewo zvigozhero zveutano?
Ladies what other health challenges?
Answer: Tinoramba tichingotenderera panhu pamwechete ipapo. Kana munhu ave HIV positive anezvimwe zvirwere zvinoramba zvichingotora mukana eg. Thrush inogona kutanga iri mumukanwa ichidzika kuzasi uku, saka ukaenda kuhospital mishonga yekurapa mathrush iwayo unotenga nemari yako.

The issues remain the same. When one is HIV positive, one is continuously affected by infectious diseases such as thrush which can start in the mouth and even spread to the genitals. If you go to hospital you will be asked to buy the medication using your own cash.

Question: Ndanga ndichida zviri kunyanya kugozha nenyan azeutano muno munyika. Zve HIV tichataura nezvazvo, ndinoda zvimwewo?

What are the other main health challenges in this country? We will talk about HIV later.

Answer: Mishonga iri kushaikwa muzvipatara saka unenge wotoenda kunotenga. Drugs are not available in hospitals and so one has to buy.

Answer: Kuhospital manesi haachaiti zvaiita kudhara. Kudhara manesi aivako aiva nemoyo wekumuzwira, izvyino vari kungoda mari. Havachine nezvapatara, they are rude, havasiswa kana tsitsi, that calling yaiva nemanurse aivako kudhara.

Nurses of today are unlike the nurses of yester-year. Long ago nurses used to have empathy but now they only want money. They nolonger care for the patients, they are rude, they nolonger have sympathy, that calling which nurses long ago used to have.

Answer: Vana chiremba vashoma nekuti vazhinji varikubuda vachinoshanda kune dzimwe nyika.

Doctors are now few as most of them have migrated to other countries for greener pastures.

Question: Zvamunowanawo zviri zvigozhero zvamunosangana nazvo pakuchengeta murwere anorwara neHIV and AIDS. Ndezvipi zvigozhero zvamakasangana nazvo imi an individual muchichengeta mwanu weumwe?

What would you say are the challenges of being a caregiver in your own personal opinion?

Answer: Zvigozhero zvamunosangana nazvo unenge uchida kumubatsira, kumuchinja nekumupa mushonga asi anoramba.

The challenges are that you would want to help the infected, changing their clothes and administering them their medication, but they sometimes refuse.

Answer: Vamwe unoedza kuti umugezese asi anoramba.

Others don’t want to be bathed.

Answer: Kana une murwere kumba unogona kuvungwa nevamwe vanhu vanenge vachida kubatsira kungnda mumwe wako asi iye anenge asingadi kuwendekwe nevanhu. Saka pakatouya vanhu anotoshatirwa achitai wasudanira vanhu kuti vazoono kuti ane HIV and AIDS.

When you have a patient home, people can visit you to see the patient. The patient will get angry sying you have invited outsiders to come and see that l am suffering from HIV and AIDS.

Question: Munonzwa muchishungurudzika here nehupenyu hwamuri kurarama nekuchengeta munhu anorwara nechirwere cheHIV and AIDS?

Do you feel you are currently under a lot of stress as a result of caring for the HIV and AIDS infected person?

Answer: Hazvishungurudzai nekuti tinochengeta murwere anenge achirwara. Kuwana tigare naye tatozipira kuchengeta'. Saka tinenge tichida kuti pakumuchengeta angowona kuti zvaingoiita paya paya ndizvo zvaunofanirwa kungonzwa achita.
It doesn’t stress us because we will be doing a noble job. We will be trying to provide the patient with help so they can return to their normal way of life.

**Question: Saka munonzwa zvichigutsa kuti muri kuita chimwe chinhu chakanaka muupenyu? Hapanawo zvinoshungurudza here?**

Are you satisfied by being a caregiver? Anything that is stressful?

**Answer:** Chimwe chiripo ndechekuti murwere mwana mudiki. Ini ndakazvigamuchira kumuchengeta. Pamwe zvinonetsa kuti tinzwisisane kuti inwa nguva dzakati kana kuti idya nguva dzakati.

The problem is the patient is very young. I accepted to look after him. There are some issues that we fail to agree especially the times to take drugs and to eat food.

**Answer:** Ini ndine murwere andinogara naye. Ndakazama asi zvinonetsa kuti tinzwisisane ndikati shandisa zvakati, inwa zvakati, dai dai.

I have a patient that I stay with. I have tried but we get on well especially when I instruct him on what to use, when to take medicine and other such issues.

**(Probe)**

**Answer:** Vanwe vanotokava ndiro yechikafu pamunovapa zvekudya.

Others will kick away the plat of food when you feed them.

**Answer:** Pane mumwe murwere anogona kuti akadya chikafu chinobva changobuda chakadaro chero rikava apple unozongwana patsvina kuti ringori apple. Iwe uchirimukubvisa tsvina pamwe anenge achikanzwira tsitsi (kunyanya murwere ari mukuru iwe uri mudiki). Anorwadziwa kuti mwana wangu wangu avu kutambudzika. Next moment yandinomupa chikafu anoramba achiti chikafu chinongobuda futi, nekuda kweizvozvo anongopedzisira oramba chikafu. Saka izvozvo zvinoshungurudza.

Some patients will have running stomach as soon as you give them some food even fruits like apples. When you try to them up, they will feel pity for you (especially when the patient is elderly). They feel that they are stressing you and so next time you give them food they will refuse afraid to repeat the same. As such they will always refuse to eat and that stresses a lot.

**Question:** Ndeapi mabasa amunoita pakuchengeta varwere vanorwara neHIV and AIDS?

What are the caregiving activities that you are engaged in as carers of HIV positive Zimbabweans?

**Answer:** Tinoita zvakasiyana siyana, kumugezesa nekumubikira zvekudya, nekuwacha nhumbi dzake.

We do different activities, such as bathing the patient

**Answer:** Tinoenda kuchipatara kunomutorera mishonga yake nekumupa mishonga yacho.

We go to hospital to collect their medication and administer them.

**(Probe)**

**Answer:** Kubatsira kuchengeta utsanana hwake, kuwona kuti mumba maari mune mhepo here, paakavata hapana kunyorova here.

To help maintain a hygienic environment where the patient is kept.

**(Probe)**

**Answer:** Chimwe kupa murwere chikafu

Giving the infected food

**Answer:** Murwere anofanirwavo kutaurwa naye nguva dzose kuti asanyanyofunga nezveurwere hwake, saka tinotaura naye zvimastory
The infected person must be talked to all the time to help him/her to forget about his/her condition

**Question:** *Imi pachenyu munoita sei kuti mubvise kushungurudzika kwamunowana mukuchengeta murwere, ndezvipi zvamunoita/zvamunoiwanzoita?*

What do you normally do to relieve your stress and tension as a caregiver?

**Answer:** *Zvinoda moyo murefu*

It requires patience

**Answer:** * Ini pachangu ndinonzana kutaura naMwari kungovaudza zvandinoda, kutovaudza kuti vandipindire*

I pray to God to intervene

**Answer:** *Iyezvino kune vanokanzela (counselling) saka unoenda kunocounselewa. We now have counselors, so you can go for counselling.*

**Answer:** *Kushungurudzika kwangu zvinoreva kuti ndangofanana nemurwere uya wemumba, nekuti iwego wavakutorwara nepfungwa saka unofanirwa kuenda kunotsvaga mazano kune vanwe kuti kana munhu achidai anorwara zvakadai nezvakadai, ndingabatsirike sei? Kana wobva ikoko vakubatsira unobva warerukirwa wogona kuramba uchienderera mberi nebasa rako.*

When you get stressed, you are like the care recipient, so you must seek assistance from other support group members by sharing your experiences. Only after that will you feel relieved and continue with your responsibilities.

**Answer:** *Ndingati sezvatiri zvinoizvi tichichengeta murwere ari HIV positive tarekowanikwa tinechirwere tikatozvimuchira, unomucousellor uchimupa maexamples ako, pawakambopinda napo kuti kana wakambodzidzera kufambira unotomutu iwe unotori pari nani pane ini ndakadzidzira kufambira kuti oni...unopora.*

We are carers who are also HIV positive. So you counsel the care recipient by giving him/her examples of your own experiences, how you were once in an even worse situation and assure them that they will do very well if they do what they are told by the health professionals.

**Question:** *(Probe).* *Ndehupi hukama hwamunahwo nemamwe mapoka anoita zvekuchengeta vanorwara nechirwere. Pane zvamunowana kune mamwe mapoka zvekushandisa pamurwere, munonzwisana here uye ndeapi mapoka acho eg. Hospital, organisation etc. pane vanwe vanunodyidzana nabo here?*

As caregivers, what are your relationships like with other stakeholders and those organisations that care for the infected?

**Answer:** *Mazuvaano tinonyanyodyidzana nechipatara kana clinic iri pedyo, kuti kana arwara ndoenda naye kuclinic kana kuchipatara kana kunomutorera mishonga yake. Kana ari mamwe maorganisations, ikozvino hakuna.*

Currently we rely on the nearest clinic for assistatance. We take the infected to the clinic or hospital when they are not feeling well and we also get their medication from there. As for other organisations, there are currently not there.

**Answer:** *Kwaimbova neRedCross ndivo viita program yeHBC but iyezvino izvi program yacho yakapera.*

Red Cross used to to have some HBC programs but these have since stopped.

**(Probes)**

**Answer:** *KuBHASO, HBC program muno mutown haisati yanyatsopinda, haisati yavamo. Vanonyanyoita kumarural areas.*
BHASO have HBC programs running in the rural areas mainly, in town they are not very active.

(Probes): DAC, NAC etc Havana zvavanotira here kubetsera especially imi munochengeta varwere kana kuti vanenge vakangonangana nevanorwara?
Does DAC, NAC give you help in caring for the infected or they are mainly concerned with the welfare of the infected people themselves?
**Answer:** Kubatsira hapana
They don’t help!

**Question:** Mukugarisana kwatinenge takaita mamasuburb edu, kwaMucheke kana kungava kuRujeko kuTichiroja, ukama hwakamira sei, vanhu vanokutorai sei kana vachiziva kuti mumba uma umunure kana kuti iye murewere anochengeta murewere? Vanokuyurai kana kuti vaanokusema, vanokudii?
How is your relationship with other people in your suburbs, how do the public view you as primary caregivers?
**Answer:** Iyezvino hakusisina zvekusemana, munhu wese akutongoziva kuti munhu anogona kurarama nechirwere, kana asati aziva hake ndiye one one.
People are now aware that they can also live with the virus, so they appreciate us.

(Probes): Asi vazhinji vanotsigira mabasa enyu amunoita?
Do they support what you do?
**Answer:** Vamwe vanotoyemura kuti madii henyu makatoraramisa. Vamwe vanotodemba kuti vakaregerera hama dzavo.
Some actually envy us because we are giving back life to our infected relatives. They even regret not having done that to their late relatives.

(Probes)
**Answer:** Dzimwe nguva zvinosiyana nepauri kugara. Unogona kunge uri kuroja, vanwe havadi, vanogona kuti hatidi kuti mushandise toilet yedu. Endai zvenyu munotsvaga pamwe pekugara, vanwewo Havana basa nazvo…..
It also differs with where one is lodging. Some ‘landlords’, house owners will not be comfortable using the same toilet with you so they will ask you to go and lodge somewhere else.

**Probe:** Tichiri ipapo ngatitarisei kungogarisana kwedu mukati medhorobha. Ngatitii mumusha wenyu, paukama hwenyu. Mune murume, mudzimai, mvana muine munhu wamuri kunchengeta anorwara. Ko hama dzenyu chaidzo chaidzo dzinozvitora sei, dzine kubatsira kwadzinoita here kana kuti vanongoti ndezvako?
What is you relationship with your other relatives in town, how do they view your caregiving situation?
**Answer:** Vazhinji vanongoti ndezvake. Vamwe vanoti ngayavengeretane
The majority don’t care. They like you to look after the infected on your own.

(Probes)
**Answer:** Hanzi chikonzero ndechekuti vaivigirwa shuga vachidya vega. Vamwe vanenge vatowana nyaya, vanotoseva neve.
They say you used to enjoy alone the groceries that you were given by the infected. They laugh at you and talk behind your back.
**Probes:** Munoreva kuti vagari vemumadhorobha unu vanokutsigirai kudarika hama chaidzo?

Do you mean that you get more help from your neighbours in town than from your relatives?

**Answer:** Kwazvo. Munorudhoro tinosangana vanorwara vese tovaka hukama hwedu hwakakura. Saizvozvi tiri muno musupport group kana chandinetsa tinobatsira. Manje kana kuri kumusha pamwe kana ndikaenda kumunin ina wangu anobva andipa maexcuses.

Very correct! In town we meet as HIV positive people and build our relationship on that and assist each other. With your relatives, they always make excuses.

**Probes:** Akaita mwana sikana hanzi magrocery maitambira maiti anobvepi?

If it it a daughter who gets sick, they say where did you think the groceries she brought you came from?

**Question:** Chirwere cheHIV and AIDS tinoziva kuti mhedzisiro yacho munhu watinochengeretaanoshaika, pamwe vanwe vakatoshaika uye zvinhu zvatinoziva zvinoitika, saka mukushaika ndofunga ndeimwe nguva yakaoma zvikuru mukuchengeta murwere. Ndezvipo zvamakasangana nazvo pamakamboshaikirwa nemunhu wamaichengeta? Imi pachenyu kushungurudzika kwamakawana kozoti zvaaiita kunze uku zvichinangana nekushaikirwa kwenyu nehama yenyu.

Normally the end result for an HIV and AIDS infected person is death. What challenges do you encounter in the event of death of your care recipient? Also how do you, as the caregiver cope with death especially of your care recipient?

**Answer:** Takashungurudzika nekushaiva mari yekutenga coffin uye mari yekezvi nditakure maiguru vangu. Vana vange vasipapo vakanga vachisevenza kwaMutare, saka chokwadi ndakangotakurana navo vakadaro kuenda kumusha tikukudzika kwemunhu wako kuchinetsa. Coffin takazonotsvaga tasvika kumusha.

We failed to secure money to buy a coffin for my sister in-law. So we took her to the rural areas wrapped in a blanket. We got the coffin when we were home.

**Answer:** Ini ndaithoshungurudzika nekuti munhu wacho ashaika anga aramba kugamuchira status yake achipihwa matabets achiviga. Of which takateauzona matabets munhu atoshaika kuri munhu anga akapihwa matabets nhai kudhara. Mucoffin macho kanga kungova kumwana kadikidiki and ugonzwa kumazezuru kana onemera masahwira, votaura kuti aah masoja vaitionakirwa muri musango mavakuuya muchitintesha nekuti siyisa mabasa eu emumunda. Saka zvimpwe zvezvinhu zvinoshungurudza.

The deceased had defaulted taking the pills and had grown so small when he died. It was stressful. The friends from the Zezuru clan would joke at the funeral talking of how the deceased died as a result of loose moral.

**Probe:** Saka pane kuti vanhu vacheme newe vanotentse vokuseka. Mhai manga muchida kutaura zvimpwe.

So instead of sympathizing with you, people would mock you. Mother, you wanted to say something.

**Answer:** Zvinotishungurudza chaizvo zvekushaikirwa newamunochengeta kazhinji kacho kana umaye mumba unenge uchidza kuti ngatimwi mapiritsi vachiramba. Kazhinji kacho varume vanenge vachimwa vakatanga kare asi vakavanda, saka pawanozorwara ndipo pavanobuda pachena kuti ndozyavari, saka izvi zvinoshungurudza iwewe wozogumikidza wamushaya futi.

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It’s very stressfull for a care recipient to die in your care because they will be refusing to take their tablets. Most of the time the husbands will be secretly taking ARVs and come in the open when they are ill. This is so stressfull because you will lose them in the end.

**Question:** Madzimai pane dambudziko ramunowanwanzowana kana murume wenyu wamunochengeta afa, hama dzopindira. Hapana zvamunosangana nazvo zvakadaro?

Ladies, when your husbands pass on, what are the main challenges that you encounter?

**Answer:** Kana arī murume ashaika, hama kazhinji kacho vanouya vachiti iweve ndiwe wauraya uyu afa uyu. Koita kana iri pfuma vanouya vokutorera wosara usisina chaunacho. Pamwe pamusha ipapo unobva wadzingwa nokuti wakauraya hama yedu. Kana pane vanoziva kuti iwe uri positive unonzwa wonzi ndiwe wakuya nechirwere chacho chibuda unofira kumusha kwako.

Usually if it’s the husband who has passed on, his relatives would blame you for his death. They will take away the wealth and ask you to leave the family. If they are aware of your HIV status, they tell you to go to your family and die there.

**Probe:** Wotodzingwa, pane kuti vacheme newe.

Instead of sympathizing with you, they chase you away.

**Answer:** Ehee vanotenge vachikushungurudza kana mari yaunenge uinayo yekuti unenge wakachengetawo unonzwa voti iwe hapana usavi vanenge vava kutobvunza kwandiri inini wacho arī kuchema zvekare.

Yes they will stress you. Even the cash you have they will ask you to give it to them to buy meat for the funeral when I am the grieving wife.

**Probe:** Ko kuvmwewo, hakuna here zvinonetsa here kana kusangana nazvo kana wafirwa? Ndeapi matambudziko amunowanwanzosangana navo pakufirwa apa?

What about others? What are the challenges that you face when your care recipient passes on?

**Answer:** Kuti waahirwa nemukadzi, matambudziko anowanwogona kuwanikwa ukaahirwa nemukadzi, vekumhuri yemukadzi vanogona kuti hatisi kuzoviga mwana wedu kana asati apedza kuroora.

When your wife passes on, your inlaws sometimes will refuse to bury her until you pay the lobola balance.

**Probes:** Ndakatarisa muno, ndaona kuti pane murume one arī muno. Kuti tingati isu vanochengeta vanorwara vazhinji vanhukadzi here kana kuti vanhirume kana kuti zvakangofanana?

It looks like there is only one man in this FGD, can we therefore conclude that most primary caregivers are females or males?

**Answer:** Vazhinji vanhukadzi vanochengeta asi vanhirume vavakovo.

Most primary caregivers are female however we also have males who are primary caregivers.

**Question:** Zvino tingaita seiko kuti tikurudzire especially vechirume nokuti pamwe variwe vakwouna kuti mukadzi ndiye abatwa nechirwere pamwe vanotiza mumba kana kuti zviri kose?

What must be done therefore to encourage more men to be caregivers? Some men will leave their wives if they discover that are HIV positive?

**(Chorus):** Ehee hapana apa, variwe vanotoenda kunotsvaka vanwe vakadzi. Variwe vashoma vanobvuma kugara vachichengeta
Most men will remarry if they discover that their wives are positive. Very few men will stay and care for their wives.

**Question:** Saka tingaita sei kukurudzira especially sevarume kuti vaanye vagonewo kuva vanochengeta varwere kana vaita murwere mumba?

What encouragement can we give men to care for someone positive in their homes?

**Answer:** Vanotofani rwukuva vaendewo kumagroups akaita seano awa

Men must also go to support groups like these ones

**Answer:** Semuno muMasvingo takatotanga Men’s forum kwatinosangana tiri varume chete. Saka ikoko ndiko kwatinenge tichitaura as boys to man. Tine vakomana nevarume.

We have started a men’s forum in Masvingo where we meet as men. It is there that we talk about HIV and AIDS issues as men.

**Probe:** Inoitirwepi iyoyo?

Where do you hold such meetings?

**Answer:** Mangwana kwaYeukai kuna Tongogara street.

We meet at Yeukai, Tongogara street.

**Question:** Ndezvipo zvamunenge muchitaura ipapa apa?

What issues will you be discussing?

**Answer:** Maissues akaita seiwavo nekutrier kuti tipewo message kune vanwe varume. Tinomboenda sepaYeukai shopping centre tonoitawo braai nevarume vanenge vachinhu kudhaurwa dii ipapo tichita nyaya navo varume, tichitaura maissues eHIV tichiudzana magariro emumba nemhuri.

We talk about HIV and AIDS care giving trying to relay the message to every men. We can go and have a braai, say at a shopping centre likeYyeukai where men will be drinking beer and we talk about HIV and AIDS and how to live positively in home.

**Question:** Kana pane mumwe anezvaanonzwa kuti angada kutaura zvingabatsira especially pakushungurudzia kunogona kusanganikwa nako nemunhu anochengeta murwere weHIV/AIDS. Angangova nezvimwe zvaangada kushare wokuti dai zvadai, zvingaitwa kana rubatsiro rwamusungumungu kana rungaphwa vanhu vanochengeta varwere ava?

Is there anyone with something to say on caring for the infected who have no one to care for them. They can be housed somewhere were medication can be administered to them.

**Answer:** Dai hurumende yakwanisa kumunhu vanhu HBC munzvimbo yavanoisa vaya vanenge vasina vanovachengete uchipo mubone nechikafu, vochengetwa vari panzvimbo iyoyo.

The government should train HBC facilitators to look after the infected who have no one to care for them. They can be housed somewhere were medication can be administered to them.

**Probes:** Ko vanwewo? Vanochengeta havasi kuzikanwa ava, chinozikanwa murwere saka kuti vachengeti vaziikanwe ndezvipo zvingaitwa?

What else? The carers are not known. What needs to be done to bring them into focus?

**Answer:** Kudawo masangano akaita saana NAC votsvagawo mestructures kana kuti a way yekuti ma HBC givers azikanwe kana pane kasmall bit tekuti vatengewo zvingavabatsira pakuita mabasa iwaya.

Dzidziso kumunhu wese! Ndinotenda vana mai nababa tatabura.

Organisations such as NAC should find a way to help HB care givers be known. They can give them some stipends, for example, to help them to buy healthy apparatus to use in their daily care giving work.
Education for all.

Thank you.
Appendix 6: A Verbatim Report on Interviews with Primary Caregivers

The verbatim reports on the interviews between the researcher and the participants/respondents

NB. No names are used in this write-up, however, pseudo names are used in the main report

Interview 1

Introductions

Question: Makadiiko amai?
How are you mother?
Answer: Tiripo hedu makadii.
I am fine.

Question: Ndauya ini kubva kuZOU ndichiita tsvagiridzo yevanochengeta vanorwara nechirwere cheHIV and AIDS. Vzandinoda kutsvaga apa ndinoda kuti ndiwane kuziva kuti mukuchengeta uku ndezvipi zvamunosangana nazvo uye kuti pazvigozhero izvi munoita sei kuti mukunde zvigozhero izvi. Ndichatsvagazve kuti hapana here zvimwe zvamungada kubatsirwa kuti musava nekushungurudzika mukuchengeta murwere, makambochengetawo here murwere muupenyu?
I am from ZOU doing a research on the experiences of primary caregiver of HIV and AIDS patients. The challenges you face and how you counter these challenges I would also want to find from you what you would recommend to make this noble job of yours manageable.

Question: Makambochengeta kana kuti mune murwere we HIV wamunochengeta here?
Are you a caregiver or have you cared for a patient in your life?
Answer: Ndakambochengeta tete vangu.
Yes, I cared for my aunt.

Question: Pamakachengeta tete, tete vacho vakazodii?
What happened to your aunt?
Answer: Vazoshaika, vakamboti rwarei ndobva vapora ndobva vambogara kwemakore ndobva vazotanga futi gore rapera iro kubva November we gore rapera museri vakazoshaika muna April we gore ratapedza iro.
She passed away. She got sick for some time, got well and then got sick again last year from November two years ago and passed away April last year.

Question: Imimi mune makore mangani okuberekwa
How old are you?
Answer: Iyezvino ndave ne41.
I am now 41.

Question: Wamaichengeta nditete hanzvadzi yababa... maigara navo here kana kuti?
The aunt you were caring for, were you staying together
Answer: Ehe ndingangoti ndaingopota ndichienda kumba kwavo nekuti ini ndairoja pangu ndega, vaiva nemba yavo vega.
Yes, I would frequently go to her house to assist as I was lodging somewhere else.
Question: Makagara navo muchivachengeta kwenguva yakareba zvakadii
How long did you care for her?
Answer: Ndingangoti pavakozonyanya kuita serious vakaita serious kwe3 months.
When she got serious it was for 3 months.

Question: Mukadzidza chikoro kusvika pakadii?
You are educated up to what level?
Answer: Ndakagumira grade 7 zvikanzi vandoenda kuchikoro noutofo hwanga huripowo.
Up to Grade 7 and we were told to school. I was also a slow learner anyway.

Question: Ndinoda kuti munditaurirewo kuti zvamakasangana nazvo muupenyu semuchengezi wemurwere, muchichengeta murwere uyu?
Tell me your experience as a primary caregiver of someone suffering from HIV and AIDS?
Answer: Ndingati dambudziko guru rimwe raivapo nderekuti paya paunenge uchiti unoda kuenda kuchipatara nemurwere mari yainetsa, ndakamboenda kwacouncillor ndichiti nditsvage tsamba yesocial welfare, tsamba yesocial welfare yacho iyo vakanga vakaviga chitupa chavo saka handina kukwanisa kuiwana kusvikira tatoita zvechikwereti ikoko. Inini semunhu anotengesa ndinenenge ndichiti apa nguva dzandinofamba dziya idzi kuti ugone kuwana nguva yekutengeswa uwane mari chero neyekumba kwangwane ndiripwo nevina idambudziko rinenge riripo, saka zvinenge zvoita kuti mushaye mari yekutengera murwere zvinodiwa.
My main challenges were cash to take the patient to hospital. I even went to the counsellor seeking for assistance from social welfare. I failed to get the social welfare letter as the care recipient had hidden his I.D card, so I got into debts as a result. As a vendor I am supposed to be selling something but I don’t get the time since I will be caring for my patient. As such, it reduces my income even to cook after the patient.

Question: Pamaichengeta murwere mainzwa imimi muchishungurudzwa here?
When you were caring for a care recipient, did you feel stressed or challenged by doing so?
Answer: Murwere anotoshungurudza.
The care recipient is naturally stressful.

Question: Ndezvipi zvainyanya kukushungurudzai pakuchengeta murwere?
What stressed you most in your care giving activities?

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Ndopandakaona kuti ipapo maitiro acho agozha, ndipo ndakazopihwa mota serubatsiro nevechechi ndobva ndavasenga tondovasiya mumusha ndikoko kwavakazoshai kira.

What stressed me most was failure to get nutritious food. After cooking she would refuse to eat. I took her to the hospital where she was given some tablets and as a result developed diarrhoea. So she would always say you want to kill me so that you can get my house. I grew up with her because she was barren and didn’t have her own children. So I was so stressed that I gave up caring for her because other relatives didn’t want to visit her. I was however counselled by others. What stressed me most is what she was saying all the time. She was hallucinating but we didn’t listen to some of her utterances. She got serious and I got a truck as assistance from the church and took her to the rural areas where she later passed on.

**Question:** Ndeapi mabasa amunowanzoita kana muchichengeta murwere?

What daily activities do you do caring for the infected person?

**Answer:** Kudya pavaikwanisa kudyapo kwevingove kuvabikira chete.ukavabvunza kuti munodei vakati mapotatoes kungubikira chete uchivapa.pavakange vasingachakwanisi chaiko kudyapo zvokuvafidha vakazofidha neyanhu vakuru, vakazotadza kubata spoon vega takavasimudza voenda mumusha, chero kusimuka kuno vakanga vasichagoni, tiri pakuzovapakazvongedzidza vakanga vava kupakwa vari mumusha. Ini ndakangokwanisa kuenda kugenerali navo, nekukwetorera mupfizwa ndovap.

When she could eat alone I just cooked for her. When she couldn’t feed no her own, the elders fed her. She was later taken to the rural areas. I was taking her to the General Hospital to collect her medication and making sure she takes her medication.

**Probe:** Konyaya yekugeza?

What about bathing?

**Answer:** Zvimwe zvese zvakaitwa vava mumusha, pavakangoita 2 days chete vasingagoni kusimuka, vechechi vakabva vakuromudza kupindinda nekuti ini ndakangokwanisa kudya kugenerali navo, nekukwetorera mupfizwa ndovap.

All other things were done when she was now in the rural areas, where she just spent 2 days only not being able to stand on her own. Members of the church had to interview quickly because I couldn’t lift her on my own.

**Question:** Mukati mezuva pamaivachengeta zvainyanya kukushunguridzai kana zvaikunakudzai pamaivachengeta ndezviiped?

What caregiving activity do you find challenging or interesting in caring for the infected?

**Answer:** Aah ini hapana chinhu chake chakafamburesi kana kusungunakikadzika chero nguva.

Nothing was good for me at all because she was my guardian and I expected a lot from her. I was stressed all the time.

**Question:** Pamaivachengeta maibatsirana nezvipatara here kana mamwe mango, ndevapi vanhu vamaishanda navo? Vaiuya kumba nekubatsira mukurwara ikoko?

Did you get any help from the health facilities or other NGOs? If so, which groups assisted you? Did they come home to help?

**Answer:** Kubva pavakanyatsorwara chaiko chaiko, ahh kudhara kwaimbova neRedCross yakauya. RedCross ndobva yazomira. Gore ravashaika kwanga kusimuka reRedcross, vakamboendo kuchipatara ndokugobudiswa tichivotera mupfizwa kusvika vazoshaika.

From the time she really got sick, aah Red Cross used to visit sometime back but it has since stopped. When she passed away, Red Cross had stopped giving assistance. She was once admitted then discharged and was getting her medication from home.
Probes: General Hospital yeMasvingo iyoyi? Ko hama dzaimbouyawo here?
Masvingo General Hospital? How about relatives, did they come to see her?
Answer: Pane hanzvadzi yangu yaimbouyawo nokuti vekumusha vairamba vaitakati isu ngaanye agare kumusha saka kana iye achida kugara ikoko ini ndii ndichagona kuvachengeta, saka vairamba kuuya vana hanzvadzi dzavo dziriko. Saka ini nehanzvadzi yangu tusi taitopota tichivabatsira
My brother used to come but those from the rural areas had refused saying she was supposed to stay in the rural areas. I and my brother would help her since her own brother had refused.

Question: Saka pavakazoshaika tete makanzwa sei?
When your aunt passed away how you did feel?
Answer: Ndakarwadziwa zvekuti nanhasi ndichiri kungoshungurudzika nekuti nhumbi dzavo dzichakangozara mumba, mari yekudzisengesa hapana saka nanhasi hazvisati zvapera
I was pained and even up until now; I’m still stressed. Her clothes are still in the house. I don’t have the money to transport them to the rural areas so there are still challenges.

Question: Nderwupi rubatsiro rwamungada kuona rwuchipihwa vanoita mabasa amanga muchiita? Akaita sekuchengeta varwere ava muno muzimbabwe
What assistance would you want to see being given to primary caregivers in Zimbabwe.
Answer: Rubatsiro rungadiwa pakuchengeta murwere unoti munhu aarwara akaenda kuchipatara vanomupa mubhedha chero achipihwa mapiritsi mahara, saka panguva yekurwara iy iwe ndiwe unowana mari uchitengesa panguva dzaunenge uchiwana, kuudza murwere kuti hapana anenge achatengesa hapana anokupa mari. Saka mapiritsi aunenge uchinzi utenge umwe haukwanisi kumatenga nokuva unenge wamira basa asi kana wakasimba unogona kukwanisa.
When the infected get sick they go to hospital and get admitted. They sometimes ask you to buy tablets when you don’t have the money because most of the time you will be cooking after the sick and not working.

Question: Saka rubatsiro rwamunoda nderwei?
So what assistance would you want in caring for the infected
Answer: Zvose zvinotongodiwa nekuti pane anenge achikubatsira here paunenge uchirwara. Apa unenge unemwana anenda kuchikorp anodawo kudyda iwe usina Mari yekubhadhara mubhedha, kana uri mutano unogona uchitengesa tsamba yesocial welfare, KO zvino ukarwara manje unodzifambira sei, unowanepi mari yacho?
Everything is needed because it depends on whether you have someone helping you. Kids must go to school, they need food yet you don’t have the money to even pay for her admission into hospital. If you are healthy you can seek the assistance of Social Welfare. What about if you are also ailing, how will you do that or where will you get the money from?

Question: Imi makabatwa TB riini?
When were you diagnosed for TB?
Answer: 2009.

Probes: Pakuzvichengeta moga zvigozhero zvamunosangana nazvo ndezvipi?
What challenges do you face cooking after yourself?
Answer: Zvigozhero ndingati zvukungoshaiwa mari yekakwana nechikafu chakakwana.
The main challenge was enough cash for food.
Probes: Ko kushungurudzikawo pfungwa?
What about psychological stress?
Answer: Ehe unogonawo kushungurudzika mupfungwa nekuti murwere unogona rice woti handiridi wokukavira woti ndoda drink, woti drink waya naro woti iri handiridi ndoda coke, fanta kana mamwe. Woti ndoda mazai everyday handidyi chimwe chinhu, ndoda rice ,ndoda spaghetti. Iwe hauna mari yekumutengera chero nyama. Uripo murwere anogona kukurova nendiro achiti handidi zvawabika woti enda unotenga fish iwe mari usina, ndiro rimwe dambudziko rinonyanya kuwaniwka
Yes, you can be psychologically stressed because you can cook rice for the patient and he/she would refuse or even kick the plate away. The care recipient will change and say I want coke, fanta or something else. The patient may demand eggs everyday. Without money to buy these things, it becomes a challenge and very painful. The care recipient can even throw a plate of food at you asking for something else. These are the major challenges.

Question: Rumwe rubatsiro rusiri rwemari rwekudzikamisa pfungwa rungapihwa vanhu vakadai kana pamunousangana nevamwe apo?
What other assistance, other than cash, like psychological assistance would primary caregivers need?
Answer: Patinosangana kuhall hapana rubatsiro rwandinowana nekuti munenge muchingovaraidza pfungwa nekuti mese munenge muchingovaraidzana muchipoanana mazano kuti vasikana muchiona zvakadai munodai, saka mazano kune vamwe anenge akanaka.
When we meet at the Hall, there is no assistance there except keeping each other company, and sharing experiences.

Probe: Saka uyu musika ndiwo umwe unotobatsira kuti murera musika?
So this vendor stall contributes to your income earnings for survival?
Answer: Ehe ndipo pane murume wangu patinowanira mwana wangu mari yechikoro kana ndisina kuwana unongodzingawo, kudhara ndiko kwataikwanisa kuita misika chaiyo yatipa mari
Yes, this is where my husband is, where I get money to send my child to school. If I fail to get the money here, the child will be send home. The vending business used to flourish some time ago.

Question: Mune vana vangani vari kuenda kuchikoro
How many children do you have?
Answer: Iyezvino ndasara ne one.
I am now left with one.

Question: Iye mwana iyeyu haanawo chirwere here?
What is the child’s HIV status?
Answer: Pandakamuzvara ndichienda kumatesa ndaibatwa negative, saka kubva pandakamuzvara handisai ndamboita problem naye
When I gave birth to my child I was negative, so I haven’t had any problems with him ever since.

Ndatenda/Thank you.