

**PSYCHOLOGICAL AND SOCIAL NEEDS AND  
TYPES OF INFORMATION NEEDED  
AMONGST PRIMARY CAREGIVERS OF  
FAMILY MEMBERS LIVING WITH AIDS IN  
MANSA DISTRICT, ZAMBIA.**



A mini-thesis submitted in partial fulfillment of the requirements for the degree of Master  
of Public Health, School of Public Health, University of the Western Cape.

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## ABSTRACT

### Background

The Zambia Demographic Health Survey reports that 81% of the population of Mansa District, Zambia lives in extreme poverty. Eleven percent (11%) of this population is estimated to be HIV positive. Many of this HIV positive population were the primary breadwinners in their households prior to the onset of AIDS. The majority of them are cared for by family members (PCGs) with limited training. Home Based Care programmes provide care and support to patients at their homes. However, this support does not extend to the caregivers.

This explorative study investigated the psychological, social and informational needs of primary caregivers of AIDS patients in Mansa District, Zambia. It was envisaged that the findings of the study would assist home-based care organizations to provide comprehensive support and care to the primary caregivers, in addition to patients.

### Methods

A qualitative research approach was chosen to gain an in-depth understanding of health-related experiences of caregivers while taking into consideration the context within which this phenomenon takes place. Twenty-six caregivers who provide basic care and support to family members who had advanced HIV-disease were recruited into the study. All AIDS patients in the study were former breadwinners of their households. Purposive, maximum variation sampling was used to select non-homogeneous cases of family caregivers, who provided services to AIDS patients within their homes. It was envisaged

that such a heterogeneous sample would provide wide variations in experiences, and this would contribute to the range of issues pertaining to caregiver needs being covered.

Three Focus group discussions were conducted, audio-tape recorded and transcribed.

## **Findings**

The findings of the study highlight that caregivers have the following psychological needs: reciprocated sympathy and appreciation from society and their patients, stress coping mechanisms, and the capacity to display patience despite unreasonable demands made by the patients for whom they are caring. The study highlights that caregivers face numerous challenges in dealing with conflicting relationships and in handling stigma and discrimination, and that they are in need of a strong social support network. It also emphasizes that many of the primary caregivers lack adequate information about social services organizations that can assist them with training. The training will enable those (PCGs) to provide care in a manner that does not compromise the safety of the patients or themselves, as well as give them opportunities for education and skills development for income generation that will make it possible for them to provide for the upkeep of the family.

## **Conclusions**

Home-based care workers are best placed to support PCGs at home. The training of such home-based workers should be extended to take in consideration the specific needs of these caregivers. In addition, the role of primary caregivers should be acknowledged in national HIV/AIDS strategies.

## **KEY WORDS**

Primary care giver

Psychological needs

Social needs

Informational needs

HIV and Aids

Sick family member

Home based care workers

Palliative care

Stigmatization

Poverty



## **ABBREVIATIONS**

ART = Antiretroviral Therapy

ARV = Antiretroviral Drugs

HBC = Home Based Care

HBCW = Home Based Care Workers

MD = Medical Doctor

MoH = Ministry of Health

NGO = Non-Governmental Organization

OVC = Orphans and Vulnerable Children

PCG = Primary Caregivers

PLWHA = People Living With AIDS

STI = Sexually Transmitted Infections

TB = Tuberculosis

UNAIDS = United Nations Programme on HIV/AIDS

VCT = Voluntary Counseling and Testing

WHO = World Health Organization

ZCSO = Zambia Central Statistical Office

ZDHS = Zambia Demographic Health Survey

ZHMIS = Zambia Health Management Information System

ZNAC = Zambia National AIDS Council

ZSBS = Zambia Sexual Behavioral Survey



## DECLARATION

I hereby declare that this thesis, *Psychological and social needs and types of information needed for primary care givers of family members living with AIDS in the Mansa District Zambia*, is my own work; that all sources have been acknowledged and that it has not been previously submitted for any degree or examination in any other University.

Moses Zulu

November 2008

Signed: .....



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# Chapter 1

## Introduction

The Global HIV/AIDS Report estimates that 38.6 million people worldwide were living with HIV/AIDS in 2005 (UNAIDS, 2006). Sub-Saharan Africa has the largest burden of the global AIDS pandemic with an estimated 25.4 million people living with HIV/AIDS in 2006 (Michael, Margaret & Fiona, 2006). In 2003, in response to the AIDS pandemic, the African sub-Saharan countries of Malawi, South Africa, Zambia and Zimbabwe introduced antiretroviral therapy (ART) programmes into their public health services so that HIV-infected patients could receive treatment at no cost to the patient (Makwiza, Nyirenda, Goma, Hassan, Chingombe, Bongololo, *et al.*, 2006). ART, when administered properly, has been shown to prolong the lives of HIV-infected patients. In a study conducted in South Africa, the antiretroviral therapy (ART) services were associated with slowed disease progression and reduced HIV-related mortality (Badri, Maartens, Mandalia, Bekker, Penrod, Platt, *et al.*, 2006). AIDS patients continue being economically productive when they experience reduced morbidity as a result of ART.

In 2005, a WHO and UNAIDS combined report pointed out that significant number of people was able to access ART services in Africa and Asia (WHO & UNAIDS, 2005). For instance, one in ten persons in Africa and one in seven in Asia accessed the needed ART services. However, AIDS patients are unable to receive comprehensive services due to overburdened health facilities. Even where ART programmes were introduced, people in low income countries find it difficult to access these services due to distance.

This means that in many settings in low income countries AIDS patients have to be cared for at home. This places an increased burden on affected communities to provide care and support.

### **HIV/AIDS epidemic in Zambia**

Zambia has a population of 10.4 million and an annual growth rate of 2.9%. Zambia is among the countries most affected by the HIV/AIDS pandemic with an estimated HIV prevalence rate of 16% (MoH, 2006). According to the Zambia Sexual Behavioral Survey (ZSBS) youth under 20 years are the most vulnerable group to HIV infection (Zambia Sexual Behavioral Survey, 2003). The ZSBS further indicates that 7.7% of youth aged 15-24 years are HIV infected and 18% of all children under the age of 15 orphaned due HIV/AIDS (ibid) The Economic Impact of AIDS in Zambia Report indicates that 37% of all households were caring for one or more orphans whilst 25% were headed by widows (Bollinger & Stover, 1999). The loss of human lives in their productive age impacts negatively on communities and places an increased burden on old people to care for orphans. Zambia has 600,000 orphans (UNICEF, 2006).

## **National Response to HIV/AIDS**

The vision of the government of Zambia is to control and prevent the spread of HIV, to promote care for those infected and affected, and to reduce the personal, social and economic impact of the epidemic. The National AIDS Council (NAC) was established in 2002 to strengthen the coordination and implementation of the National HIV/AIDS/STI/TB strategy (Zambia National AIDS Council [ZNAC], 2005). In 2005, the Zambian government finalized the National HIV/AIDS/STI/TB policy. Included in this policy is the provision of Antiretroviral Therapy (ART) to all Zambians in need of this treatment, at no cost to the patient, at public health facilities nation-wide. The Ministry of Health, in collaboration with its cooperating partners, began to scale up ART programmes through expansion of voluntary counseling and testing (VCT) and ART centers countrywide. Since the emergence of the National HIV/AIDS/STI/TB policy, there has been an increase in the number of AIDS clients accessing ART: from 24,000 in 2004 to 51,764 in November 2005 (MoH, 2006).

In caring for those affected by HIV/AIDS, the government has focused on supporting vulnerable citizens; especially orphans in school (Ministry of Finance and National Planning, 2006). The programme is administered through the Ministry of Community Development and Social Welfare and the Ministry of Education. The two ministries have grass roots committees that link the orphans to the bursaries section in the districts. The district committees allocate funds to the schools where the orphans have been identified. Home-based care programmes are provided by the Ministry of Health (MoH) and its partner's i.e non-governmental, community based and faith-based organizations.

Mansa Catholic Diocese Home-based Care is the active structures that identifies orphans in need of educational and food support.

### **Remaining Challenges in HIV/AIDS Control, Prevention and Care**

Despite government efforts to date, many challenges in response to the AIDS epidemic remain. The major challenges the government is facing in responding to the AIDS epidemic are:

- the increase in number of orphans and vulnerable children (OVC),
- inadequate support for the needs of primary caregivers,
- increased poverty,
- inadequate material supplies to health facilities for ART services,
- client difficulties in accessing ART services,
- increases in the default rate from ART programmes and
- difficulty in expanding ART services to rural areas.

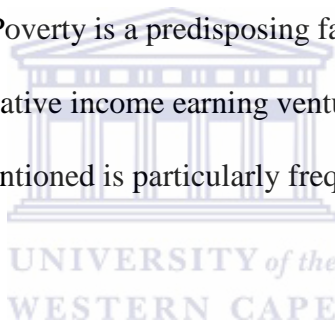
The above mentioned challenges are similar to what has been reported in international AIDS conferences in Durban (2000), Barcelona (2002), Bangkok (2004) and Toronto (2006) (Makwiza, Nyirenda, Goma, Hassan, Chingombe, Bongololo, *et al.*, 2006).

### **Primary caregivers**

Although the government promotes care for those affected by HIV and AIDS, PCGs have not been included in the National HIV/AIDS care programmes. The PCGs are not recognized as being in need of assistance, although government recognizes them as partners for home based care (Ministry of Finance and National Planning, 2006).

### **Poverty**

The spread of HIV has significantly contributed to increasing poverty in Zambia (ZCSO, 2004). ZDHS (2002) reports that 81% of the people living in rural areas of Zambia, live below the poverty datum line. Poverty is a predisposing factor to HIV-infection, because it leads to people seeking alternative income earning ventures that include transactional sex (ZDHS, 2002). The last-mentioned is particularly frequent in the rural parts of Zambia .



### **Health services challenges**

While the government is committed to roll out the ART programme, the logistical support for this expansion is lacking (Makwiza, *et al.*, 2006). Laboratory equipment such as CD4 count machines is limited to a few centers in each district. Since the introduction of antiretroviral drugs treatment in Zambia only medical doctors (MD) are allowed to prescribe. Medical doctors are only found in the town centers. This makes it difficult for patients in need of ARV drugs to be initiated on treatment in the rural parts of Zambia because most Rural Health Centers are staffed by nurses or non-medical personnel.

### **Access to health care**

While some clients who live far from the health facilities may initiate treatment, they often discontinue treatment due to difficulties in accessing health care (Makwiza, *et al.*, 2006). This is particularly true in the rainy season (October through April) when many roads become inaccessible, even by bicycle.

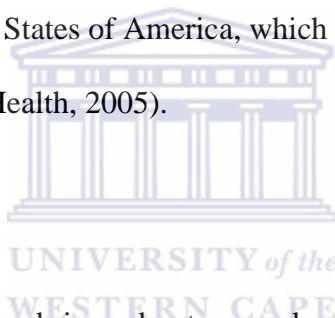
### **Treatment defaulting**

AIDS patients defaulting on HIV treatment risk their health, because this can lead to the development of a virus that is resistant to first-line ART regimes (Makwiza, *et al.*, 2006). People who are HIV positive and receiving ART often do not receive back-up services to treatment such as information on the benefits and advantages of adhering to treatment, common side-effects of antiretroviral drugs. For instance, some patients stop ART when they are no longer bedridden, whilst others stop when they experience side effects such as numbness of feet and arms.

### **Expansion of ART services to rural areas**

The challenges faced by the Zambian Government in response to the need for HIV treatment are greater in the rural areas (Ministry of Finance and National Planning, 2006). ART is available only in scattered mission hospitals and general hospitals located at the centre of the districts. People in the rural areas who are able to access the services necessary for ART generally live within a radius of 12 kilometers of the treatment centers. Counseling and testing services, however, are currently being offered by mobile testing centers in many areas of the country. The mobile testing programmes are a

response by the government of Zambia and its implementing partners to provide services to people, obtain accurate information about the extent of the HIV infection rate in the country, and to approximate the need and cost of other services. The mobile HIV testing programmes, however, are challenged by people's demand for ART services. The government effort to provide mobile ART services is hampered by lack of human and materials resources. In response to this shortage of medical doctors, the government reaction has been to train clinical officers and nurses to provide for the needs of the patients. This effort is hindered, however, by the increasing number of Zambian nurses leaving the country in response to aggressive recruitment from developed countries such as United Kingdom and United States of America, which offer higher salaries and better living conditions (Ministry of Health, 2005).



### **Research problem**

Caring for AIDS patients at home brings about new roles and responsibilities that PCGs do not necessarily expect to take on at that stage of their lives. The future plans of younger PCGs are often disrupted when they are forced to leave school to care for an infected parent. Lack of basic essentials becomes more pronounced in households where the breadwinners are infected with HIV. Studies on caregivers for AIDS patients in Southern Africa and South Australia indicate that strain, physical burden, insufficient household income and food supplies are commonly experienced (Fereire, 2004; Grimmer, Moss & Falco, 2004). PCGs may be affected both psychologically and socially. Consequently, the exploration of psychological and social needs of the PCGs as well as access to relevant and appropriate information to cope with their new roles is



important. This study set out to describe the psychological and social needs as well as types of information needed by PCGs of AIDS patients in Mansa District, Zambia.

### **Description of the Research Setting**

Mansa is the administrative capital of Luapula Province. The province consists of seven districts: Mansa, Samfya, Mwense, Milenge, Nchelenge, Kawambwa and Chiengi (Figure 1). Mansa District is vast and shares borders with Democratic Republic of Congo (DRC) in the west. The district is well centered for connections to other provincial districts in the north and south, as well as other provinces in the country.

Mansa District is predominantly rural. In 2002, poverty levels in rural Zambia were reported as high as 81% in the survey (ZDHS, 2002). The Zambia Demographic Health Survey (ZDHS) carried out in 2000, indicates that the HIV prevalence in Zambia was 16% among the 15-49 year age group. In 2000, the Central Statistics Office estimated the Mansa District population was 223,737 with an annual growth rate of 2.62%. The estimated HIV prevalence for the district in 2000, was 11% (ZDHS, 2002). The latest ZDHS carried out in 2006-2007, show an increase in prevalence to 13.9% in Luapula Province (ZDHS, 2007). It is unclear if this is a true increase in prevalence, or simply a more accurate figure made possible by the increase in counseling and testing services. Latest indications also show that the population is declining.

## MAP OF ZAMBIA

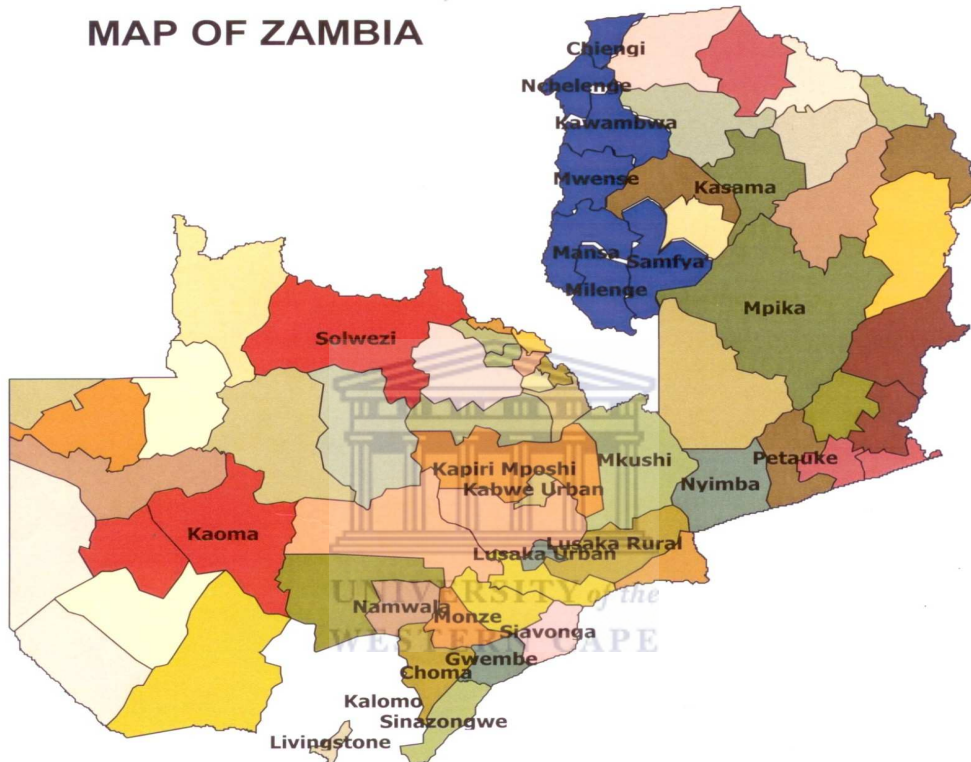


Figure 1: Source: (ZDHS, 2002)

The commercial activities attract settlers to Mansa District centre. In recent years the district has experienced growth, evidenced by the increase in number of residential houses and commercial buildings. The growth of the district has also contributed to an increase in the population of the district.

This growth in the town has enticed many OVC living in the rural villages to travel to Mansa town in search of education sponsors and one-time (casual) jobs. Some non-governmental organizations (NGOs) such as Luapula Foundation and Mansa Diocese HBC, offer assistance to OVC. Both public and private organizations support OVC in schools. For instance, Luapula Foundation pays school fees and provides needed school supplies such as books, uniforms and mathematics sets. Luapula Foundation reports that it is currently (2008) supporting 2,934 OVC in basic and high schools, and is providing 150 out-of-school youth with livelihood activities (Luapula Foundation, 2008). The livelihood activities include supporting the out of school male-youth with materials such as carpentry equipment and other materials so that the youth can start their own businesses. Female youth who have skills in designing and tailoring clothes are supported with fabric materials so that they can produce school uniforms for selling at area schools. The income youth generate from these activities assists them to pay for their education and other basic needs in life.

The number of OVC in the district has increased. The increase of orphans is directly related to AIDS epidemic that has affected the community (ZNAC, 2005). When primary caregivers take over the responsibility of food provision and making family decisions from the AIDS patients, they also 'inherit' the responsibility of educating, through payment of school fees and providing of books and uniforms, the OVC in the family. Primary caregivers find it difficult to sufficiently provide for the dependants such as OVC (Armstrong, 2000).

### **Home-based care**

Mansa District has several home based care programmes providing care for AIDS patients. The Mansa Catholic Diocese home based care program, as well as other churches in the district provide support for people living with AIDS (PLWHA) in the form of donations of food and medical supplies for treatment of minor ailments. The home based care organizations have a cadre of home based care workers (HBCWs) whom they have trained in provision of the basic needs of AIDS patients. Most of these organizations operate within a radius of 10 kilometers from their office of administration.

### **HIV/AIDS health services**

The government general hospital in Mansa District was the first place (in 2005) where the Zambian government rolled out the ART programme. Mansa General Hospital provides ART services to the surrounding communities. However, the hospital has no reliable mobile ART services for the communities that live far away from the hospital. AIDS mortality rate in the hospital was reported to be very high-175 per 1000 patients in 2006 (Zambia Health Management Information System [HMIS], 2006). Mansa General Hospital also provides HIV counseling and testing and conducts CD4 counts. Two percent of the AIDS patients in the district were reported to be receiving ART at the provincial hospital in 2005 (Ministry of Health, 2005). To complement the services offered by the government hospital, there are several NGOs in Mansa District that provide mobile counseling and testing services to the communities beyond the ten kilometer radius from the town centre.

Mansa District HIV prevalence is not higher than other districts in the province. The factors that led to choice of the study district were the minimal research resources available during the study and availability of the study population. Mansa District is the provincial headquarters for Luapula province. These services led to an increase of primary caregivers (PCGs) with their AIDS patients in Mansa District. In addition, there are a considerable number of other service organizations that provided continuity of care to AIDS patients. These organizations have contributed to reduced stigma such that both the infected and the affected easily disclose AIDS patient status. This was very important in the study since the study target population were the PCGs who needed to freely express their personal experiences.



### **Rationale for the study**

Understanding the challenges that PCGs experience in the district could inform training programmes for HBCWs as well as provide other interventions. Generally HBCWs visit the AIDS patients one time per month, in order to supervise the care that is provided on a daily basis by the PCGs. HBCWs are equipped with skills to assist AIDS patients. The skills are important because the HBCWs acquire safety skills that protect both themselves as attendants and the clients. HBCWs care for clients at various stages of the illness. In the late AIDS stage, patients may have skin lesions that produce a liquid discharge. The HBCWs receive adequate training so that they understand the transmission of HIV and how to protect themselves when caring for patients with discharge of infected body fluids. Such knowledge is also important for PCGs because they share the same challenges in caring for AIDS patients in their homes.

In Mansa District PCGs are regarded as partners in the care for and support of AIDS patients. The PCGs are always present and continue caring for patient till death. With little or no knowledge and training, the PCGs face many challenges in caring for and supporting their family member infected with AIDS. It is believed that an exploratory study design using qualitative research techniques (focus groups) will provide sufficient in-depth information to provide useful information about the challenges and experiences of PCGs in this district. It is envisaged that such information will articulate the needs of PCGs and provide necessary understanding to improve training programs for HBCWs.

### **Outline of the thesis**

In the Chapter that follows (Chapter 2), a review of caregiving in the context of the HIV/AIDS epidemic is provided.

Chapter 3 contains a description of the research methodology for this study. The argument is put forward that a qualitative research approach is most appropriate for this type of study. This Chapter details the plan and execution of data collection and analysis.

In Chapter 4 the results of the study are presented and discussed.

In the discussion (Chapter 5), the results of the thematic analysis of information obtained during the focus group discussions are presented.

The final Chapter (6) provides some conclusions and recommendations based on the finding of this research. In addition, Chapter 6 suggests some possible future research directions.

## Chapter 2

### Literature Review/Theoretical Framework

#### Introduction

An overview of recent publications on HIV/AIDS caregiving practices was conducted to identify knowledge gaps with respect to the needs of primary caregivers for AIDS patients. The reviewed material included journals, publications and the grey (unpublished) literature studies using qualitative research conducted in this area in sub-Saharan Africa and Zambia. Social science textbooks were reviewed to identify theories that were relevant. This chapter starts with a conceptualization of caregiving and home-based care, and placing these within the context of the HIV epidemic.



#### Caregiving

Caregiving is argued to be the longest serving informal social network in the world (Littlewood, 1992). Caregivers are people who provide care and support to terminally ill patients in their home setting. Caregivers in communities play an instrumental role in buffering misfortune and painful experiences faced by close relations and neighbours in times of illness. In the past, caregiving in communities was not considered to be a burden because the members of the community regarded this as an opportunity for the young to learn the art of caring. Caring is regarded as an action of dedication to another human being. This altruistic act inspired and energized people (Leininger, 1988). People were taught to offer care in times of painful situations, without any sense of obligation or compensation. Through caring a person learnt how to reciprocate in life, and thereby

becomes an active participant in societal life. Human fulfillment was achieved through unfolding the human capacity to provide care (Roach, 1992). The reciprocated social support has been observed across generations. This means that community members will passionately support the family taking care of the ill person. The care offered had little or no stigma attached to it.

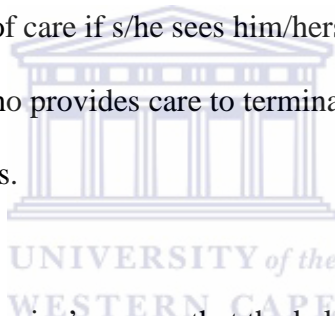
The term 'primary care givers (PCGs)' is defined in the current thesis as adults and/or children living in close contact with and offering support to the family member suffering from terminal illness. The term PCG is used synonymously and interchangeably with the word 'caregiver.' Traditionally, caregiving had been linked to elderly people who fed and nurtured the ill persons. People in communities invested themselves in others by demonstrating commitment to something that matters in the society. In contrast, in AIDS caregiving times, elders and young alike gather to provide psychological and social support to the terminally ill persons and, after death, to the bereaved members. The terminally ill person's relation to the caregiver varied from child, sibling, spouse, other close relation, and, in some cases, simply a neighbor.

Littlewood (1992) regards social support in the society as a life stress moderator. Caregivers undergo different challenges during provision of care for people with stressful events such as illness, funerals and loss of property due to, for instance, fire. However, in these times of the AIDS pandemic, care and support provision has dramatically increased the already existing demand for traditional care and support responsibilities in communities. AIDS has increased pressure on people caring for the terminally ill in the



past 25 years in addition to the existing cross-cutting issues such as poverty, gender inequality and social exclusion (UNAIDS 2006). The pressure created due to care and support provided for AIDS patients can have devastating effects such as stress and unstable emotions on the PCGs.

Higgins' Self Discrepancy Theory (1989) describes the two influencing standpoints that affect confidence in oneself. Two types of standpoints on the individual self were: (1) one's own personal standpoint and (2) the standpoint of a significant other (e. g., mother, father, and close friend). In the first standpoint, the theory postulates that an individual would participate in provision of care if s/he sees him/herself as an investment to others in the society. The caregiver who provides care to terminally ill person because s/he feels s/he should reciprocate to others.



From the second standpoint, Higgins's argues that the beliefs about how performance can be improved are dependant on the standpoint of the significant other involved. Elders are communities' significant others in executing tasks such as caregiving in their community. Significant others such as elders and caregivers were successful in care and compassion tasks stimulated the young in performance of caring roles. Higgins theory links possible factors that influence caregivers' perceptions towards caregiving in their societies.

## **Home based care**

Home Based Care Workers (HBCWs) are defined as volunteers who have been trained and employed by organizations to provide occasional care and support for patients in their (the patient's) home. The HBCWs provide palliative care to AIDS patients. The term 'palliative care' is defined as care the AIDS patients receive from HBCWS to relieve both physical and emotional pain. Palliative care techniques assist in relieving pain.

## **Caregiving in an HIV Epidemic**

AIDS patients may live for many years with the disease (Makwiza, Nyirenda, Goma, Hassan, Chingombe & Bongololo, *et al.*, 2006). In the epicenter of HIV/AIDS epidemics, caring for and supporting AIDS patients at home poses great challenges for PCGs. This could be due to inadequate information about HIV/AIDS and available support services, as well as lack of psychological and social support for PCGs. Since the AIDS pandemic emergence, human beings have suffered devastating impacts (UNAIDS, 2006). Issues arising from poverty, gender inequality and social exclusion have been exacerbated by the pandemic. In order to handle the impact of AIDS, household members have undertaken the challenge of providing care and support services to the AIDS patients. Although care in traditional context has been regarded as females' activity, men providing care has increased (Armstrong, 2000). PCGs, regardless of gender, age and status, undertake care and support responsibilities.

Poverty is one of the emerging effects of AIDS in society (UNAIDS, 2006). The term 'poverty' here is defined as lack of essential needs such as food, clothing, shelter, and

land for farming, money to support children at school, or insurmountable debt. Poverty deepens in the households as HIV infection in the breadwinner progresses to the AIDS stage. In the AIDS stage, breadwinners cannot continue to provide for their households. Children cannot continue with their education especially in high schools. Close relatives such as brothers and uncles often grab their land, rendering the household members unproductive in the rural areas.

Primary care givers have been the serving social networks of the world from time immemorial (Littlewood, 1992). Care and support responsibilities are carried out by caregivers regardless of gender, age and status. Both adults and children are burdened with the task of being PCGs to family members suffering from AIDS (Armstrong, 2000). Social networks are critical in alleviating physical and psychological strain experienced by PCGs of AIDS patients. A social network is defined as a social tie that enables an individual to interact with the rest of the members in the society in which they live. Social ties encompass shared values and norms such as sexual relationships, kinship and friendship. These social ties enable individuals or groups to interact with and find support from the rest of the community. In these social ties, significant others have already set standards on what good care is and is not. Caregivers are often stretched beyond their capabilities in trying to meet the standards for caring set by societal expectations.

Gurr's Relative Deprivation Theory (Gurr, 1970) describes how people become discontent after recognizing what they cannot do and what society expects them to do. Gurr argues that if people recognize that they have no ability to perform as society

expects them to, they are affected negatively. The theory seeks to illustrate the linkage between social networks and ties that caregivers have in their communities and how these (social networks and ties) affect caregivers when they are unable to perform tasks expected by society.

According to UNAIDS (2006), PCGs may suffer significant financial hardship. They may also have feelings of insecurity and inadequacy resulting from inadequate training for the caring tasks that they are now obliged to provide and lack of materials to use to caring for and support of patients. In an attempt to save the life of the breadwinner, caregivers try both traditional and western medicine for the patient. They take long and expensive trips to wherever they have heard rumors of effective treatment. In an effort to materially support the patients, caregivers often liquidate household assets. The impact is felt on the household, as it is not easy to replace liquidated assets.

In the midst of caregiving, caregivers become physically and emotionally challenged. In a study conducted in Uganda, it was observed that caregivers were physically and emotionally disturbed (Horwood, 2003). These disturbances manifested as inability to sleep, bowel disturbances, feelings of helplessness, a sense of guilt and withdrawal from other people. These symptoms compromised their ability to adequately care for and support patients and also strained their social relationships.

Another study, carried out in South Australia among thirty-four unpaid caregivers looking after elderly persons, showed that after hospital discharge the caregivers were

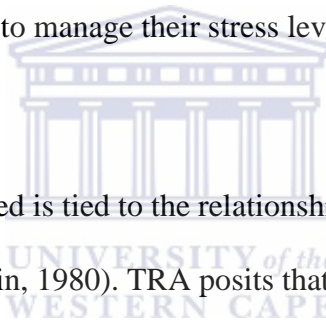
physically and emotionally strained (Grimmer, Moss & Falco, 2004). Grimmer *et al.* report that caregivers' lives were characterized by anger, anxiety, sadness and depression.

Another study conducted in rural Zambia found that AIDS patients were generally considered to be a long-term burden. Caring for AIDS patients was associated with increased vulnerability at household levels because it stretched the available resources and introduced extra responsibilities due to the nursing care required (Drinkwater, *et al.*, 2006).

### **Psychological needs**

Psychological needs refer to basic human needs that bring satisfaction in one's life in specific areas (Deci & Ryan, 2000). According to these authors, the general psychological needs of life relate to concerns for competence, autonomy and relatedness. Caregiver experiences such as reduced mutuality of relationships, feelings of dissatisfaction, withdrawal and lack of concentration indicate the need for psychological support. Hilgard and Atkinson (1992) observed that the emotional state of an individual is important as it affects (positively or negatively) the way s/he adjusts to life's demands. Caregivers undertake new roles and responsibilities in caregiving which affect their interaction with other society members. The caregivers' lives oscillate between household tasks and caregiving responsibilities. These caregiving experiences affect the caregivers' emotional state because of the anxiety produced by the newly assumed role.

Caregivers suffer emotional instability such as feeling low and insomnia that may actually lead to illness. According to a study carried out in Canada, caregivers for advanced cancer patients experienced emotional distress in response to changes (taking responsibility of providing counseling, changing linen, turning the patients) in their lives that resulted in their assuming new caregiving roles (Cameron, Franche, Cheung & Stewart, 2002). In another study, Armstrong (2000), reports that stress and burnout affect caregivers due to disruption of personal plans and anxiety about the future. He further points out that the stress occurs as a result of performing a caring task without being mentally prepared for it. He also discovered that the stress usually builds up gradually until caregivers completely fail to manage their stress levels.



The stress caregivers experienced is tied to the relationship theory, Theory of Reasoned Action [TRA] (Ajzen & Fishbein, 1980). TRA posits that an individual's performance of any given behaviour is determined by two major factors:

- (1) the person's attitude toward the behaviour and the normative beliefs regarding other peoples' views of the behaviour and,
- (2) the person's willingness to conform to the views of others.

Attitudes are formed by perceptions in the society in which an individual lives. Beliefs influence how an individual judges and acts in a given situation. When beliefs are normative in a particular setting, they energize an individual to perform as the society expects them to perform. Caregivers' behaviour, to a large extent, is linked to attitudes and beliefs in the given society. Performance of an individual is driven by exercising the commitment an individual makes in life. Caregivers predispose themselves to stress that

in turn may cause burn-out. In sub-Saharan Africa, several researchers observed that caregivers suffered some aspects of physical, emotional and mental stress (Harding, Stewart, Marconi, O'Neill & Higginson, 2003). The caregivers reported experiencing abdominal discomfort and had difficulties to sleep as result of stress. Theory of Reasoned Action links possible predisposing factors to stress and burn-out caregivers encountered in other studies conducted in other parts of the world.

### **Social needs**

The AIDS pandemic has negatively impacted society due to the stigma and discrimination associated with the disease (Armstrong, 2000). PCGs continue to suffer from the social effects of courtesy stigma in the form of isolation, while providing care and support to their loved ones (Grimmer, *et al.*, 2004). In a study conducted among the primary caregivers of mentally ill family members in Canada, it was found that both family members and mental health professionals suffered courtesy stigma and discrimination in society because they (caregivers) were close to the mentally ill patients (Stuart, 2005). Caregivers seemed to have been affected with isolation from the society members. In turn, the mentally ill patients were observed to be receiving diminished quality of attention in both treatment and care. This was similar to findings in other studies (Goffman, 1963; Stoltzman, 1994; Falk, 2001 & Smith, 2002).

Caregivers of AIDS patients assume many new tasks for which they are neither prepared nor trained.. For example, the caregivers assume tasks of dressing wounds, positioning patients to prevent pressure ulcers, providing food for the households and negotiating

family matters. These new roles challenge the caregivers because they are not socially competent in providing caring services, managing households' matters and are often not aware of existing social support systems of the society. Caregivers' need for social support systems during this time of stress becomes clearly evident.

According to Mallinckrodt and Wei (2000), social competencies are defined as the skills needed to recruit and maintain satisfying supportive relationships. PCGs, because of social stigma attached to caring for AIDS patients, are unable to negotiate for these needed support systems. In the context of social support, the "Stress-Buffering" model underpins the fact that a person's social support system may help to moderate or reduce the effects of stressful life events on the psychosocial well being (Littlewood, 1992).

Although the occurrence of many major life events cannot be prevented, social support can, to some extent, mitigate their adverse effects. Although the previously mentioned model has its own limitations, it can be applied to the needs of PCGs. Caregivers experience enormous challenges when the breadwinner in the home becomes ill and is unable to fulfill his/her role. Fraley (2004) argues that the Infants-Caregivers Attachment Theory can be applied to the PCGs and patients relationship as well. The Attachment Theory emphasizes that infants become anxious when their caregiver is either not within reach or when the infant cannot hear the caregiver's voice. He demonstrates how features of this theory can be applied to adult romantic relationships: adults in such relationships may feel insecure and expect prompt responses from their lover when dealing with stressful life events. In the case of the caregivers, as their tasks increase, the family roles



change. The PCGs no longer share close moments with the sick person on whom they formerly depended. This distance affects the PCG/patient relationship.

The 'Stress Buffering Model' argues that the concept of social support is associated with the type, source and structure of support, and not necessarily the amount of support received. Littlewood (1992) pointed out that the emotional, practical and cognitive components of any relationship have four types of supportive behaviors. These are emotional, instrumental, informational and appraisal support. Emotional support involves caring, trust and empathy. Instrumental support involves practical help with tasks. Informational support involves keeping people informed about relevant developments. Appraisal support entails encouraging and sustaining the participation of an individual in various activities. Caregivers are in need of all four types of supportive behaviours. They need trust and care from society and patients in their communities. In case of instrumental support, caregivers are in need of significant others to help them with tasks. If significant others helped, the caregivers would acquire caregiving skills and develop experiences in provision of care for and support to patients.

### **Lack of information**

In HBCWs training programs, information provided to HBCWs is largely concentrated on aspects related to care and support for AIDS patients and the needs of PCGs are not included in any way. The PCGs were considered as partners in providing care and support to their family members and AIDS patients (O. Chansa, Personal communication, 27 March 2007). The monthly data collection from the Mansa Diocese HBC showed that

the needs or challenges faced by PCGs in caring for AIDS patients were not documented and it was clear that there was inadequate information regarding support, psychological and social needs of PCGs.

The Education Officer at the Luapula Foundation, a local organization that provides support to in-school orphans and vulnerable children (OVC), revealed that OVC had dropped out of school in the previous year because they did not know where to obtain educational support (Luapula Foundation, 2008). He reported that PCGs usually lack information about the skills required to provide care to the patients. They often do not have knowledge about the availability of social service organizations for material assistance. Lack of information has grim consequences for PCGs. Many spend their productive time providing care and support to sick relatives rather than going to school, raising crops for food security or pursuing their careers. Caregivers often delay or cancel other essential day-to-day activities in order to take care of family members suffering from AIDS.

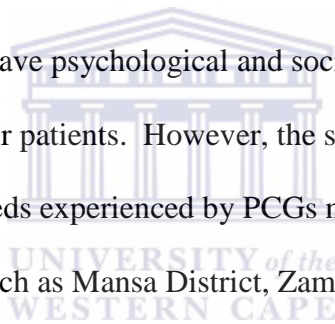
The lack of information revealed above was consistent with the Health Belief Model developed in the 1950s (Rosenstock, Strecher & Becker, 1994). The HBM describes health seeking behaviour in individuals with emphasis on how behaviour is affected by attitudes and beliefs of individuals. The HBM key variables are perceived threat (susceptibility and severity), perceived benefits, perceived barriers and cues to action. An individual takes into account how he could be affected if exposed to infection. The model encourages information exchange that ultimately affects the individual's behaviour. The

model illustrates how information seeking is significant in the life of caregivers of AIDS patients. The caregivers' perceptions will be affected if they gain knowledge in how to care for and support patients whilst safety measures are put into practice.

Grimmer *et al.* (2004) report that caregivers who were not well equipped with caregiving skills eventually become physically and psychologically distressed. In addition, caregivers who are not equipped with skills do not observe safety rules that are designed to protect both the caregiver and the patient from transmission of infection.

### **Summary**

This review shows that PCGs have psychological and social needs, and may lack vital information needed in caring for patients. However, the studies reviewed did not consider the whole range of needs experienced by PCGs nor did they investigate the plight of PCGs in rural areas such as Mansa District, Zambia.



## Chapter 3

### METHODOLOGY

#### Study Design

A qualitative approach was used to investigate the context and needs of PCGs of AIDS patients. The approach is particularly useful when seeking to gain an in-depth understanding of health-related behaviour of participants (Gephart, 1999). The qualitative approach takes into consideration the context within which such behaviour takes place. Patton (2002) stated that the qualitative approach tolerates researcher's personal and close contact with respondents and the situation under study. Qualitative researchers labour to seek answers to questions of individual or group experiences. The researchers emphasize the socially constructed nature of reality, the intimate relationship between the researcher and what is being studied, and the situational constraints which shape the inquiry (Denzin & Lincoln, 2003). The researcher then interprets experiences by attaching meaning in a particular context. Critics (quantitative researchers) argue that the qualitative approach is too subjective because the researcher is instrumental during data collection and data interpretation. However, this researcher chose to undertake a descriptive study using qualitative methodology, because qualitative research allows the development of an in-depth and detailed understanding of sensitive issues. This understanding is reached by uncovering the cultural meaning of society and the life experiences of primary caregivers.

Qualitative inquiry is conducive to exploration, discovery and inductive logic. Using qualitative inquiry, information is received and uncovers the respondents' experiences. When experiences are uncovered, the researcher and respondents discover issues that people attach meaning to during interpretation. The inductive inquiry phase then ensues when the findings are interpreted and the theory adjusted to fit the newly discovered facts (Terre Blanche, Durrheim & Painter, 1999). Inductive analysis contrasts with the hypothetical-deductive approach of experimental and other quantitative designs that require the specification of main variables and the declaration of research hypotheses prior to data collection (Patton, 2002).

Qualitative research is concerned with the meanings people attach to their experiences of the social world and how people make sense of that world. This type of research therefore purposes to interpret social phenomena in terms of the meanings people attach to these phenomena. To acquire information that could aid formulation of the above mentioned interpretation, the researcher must ask probing questions about the natural phenomena as these play out in the social world of the participants. Qualitative research lends itself to describing the natural setting unlike quantitative descriptive studies (Pope & Mays, 2000).

Qualitative research was undoubtedly the most appropriate methodology for researching the psychological and social needs and the type of information needed by the caregivers in Mansa District. This methodology allowed questions about the extent of the challenges faced and what was experienced by the caregivers in Mansa District. The qualitative

methodology of inquiry also allowed for the exploration of the lived experiences of the primary caregivers to family members suffering from AIDS.

### **Aim**

The study aims to explore the psychological and social needs and types of information needed by primary care givers of AIDS patients in the Mansa District.

**Objectives** of the research are:

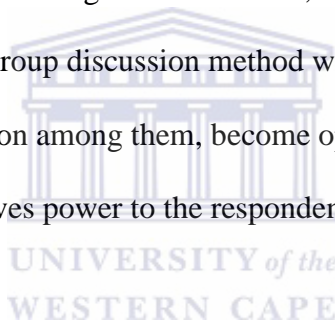
- To describe the household context in which caring for family members with AIDS takes place in Mansa district.
- To explore psychological needs of Primary Care Givers (PCGS) of AIDS patients.
- To explore social needs of PCGs.
- To explore the types of information that PCGs need.
- To formulate recommendations for training of HBCWs in providing and support to the primary caregivers.

### **Data collection methods**

The researcher used the focus group discussion method to explore caregivers' psychological and social needs and the type of information needed. The focus group discussion had two distinct advantages in this study. The first advantage is that focus group discussion produced qualitative data which is of high quality (Legard, Keegan &

Ward, 2003). Quality data is defined as the product of the data collection process and management.

To improve on quality of data, in qualitative research, the researcher triangulated the sources of data collection methods. The researcher interviewed the participants in focus group discussions and he also observed their non-verbal language. The researcher behaved as expected by the participants because he was aware of traditions and customs of the Aushi ethnic group. The researcher has lived in Mansa District for the past nine years. Secondly, focus group discussion encouraged group interaction among respondents who become the source of data. During the interactions, respondents exchanged ideas among themselves. The focus group discussion method was appropriate because respondents find what is common among them, become open to discussing sensitive issues and the researcher devolves power to the respondents.



### **Sampling**

Purposive sampling was used in the study. Purposive sampling means that sampling depends not only on availability and willingness to participants but that cases are typical of the population is selected (Terre Blanche, *et al.*, 1999). Purposive sampling facilitates collecting information-rich cases for in-depth study of the phenomenon of interest (Patton, 1999; Kuzel, 1992). Participants in the study were primary caregivers of family members who were breadwinners of their households prior to developing AIDS.

To be eligible for inclusion participants must have been:

- Caring for and supporting an HIV infected family member;
- Caring for a family member with AIDS who was formerly the primary breadwinner for the family.
- Caring for a family member with AIDS who was also under the care of a Home Based Care Worker from Mansa Diocese HBC.
- Fulfilling the above mentioned three criteria for at least one month.

Thirty (30) PCGs from Mansa District were invited to take part in the study. Twenty-six (26) PCGs were successfully recruited into the study. Maximum variation sampling was used to select the 30 non-homogeneous cases that provided wide variations in experiences. Maximum variation sampling is a technique employed in the study to seek to obtain the broadest range of information and perspective on the subject of study by focusing on a diversity of participants with different circumstances such as age, social class and relationship status and experiences (Terre Blanche, Durrheim & Painter, 2006).

### **Description of participants**

The participants in the study were residents of Mansa District. They were all members of the Aushi speaking ethnic group, which is the dominant ethnic group in Mansa District,. There were seventeen females and nine males. The participants had diverse personal experiences in life. Some participants had formal or informal employment. Informal employment in this context means an individual who has not worked for a registered private company or public sector. Educational levels ranged from low primary to middle



basic (grade 9) school education. Some participants had dropped out of school to care for their sick family member. The age ranges for the participants were as follows (Table 1):

**Table 1: Age Ranges for Study Participants in Mansa District**

<b>Age Ranges in Years</b>	<b>Number of Respondents in Each Range</b>
10-19	5
20-29	3
30-39	5
40-49	6
50-59	2
60-69	3
70-79	2
<b>Total</b>	<b>26</b>

The patients for whom the PCGs were providing care came from all walks of life. The patients included one trained primary health care (PHC) nurse, a former banker, electrical company supervisor and twenty-two (22) subsistence farmers.

## **Sampling Procedure**

The key informants included the AIDS Coordinator, Site Coordinators and village volunteers from Mansa Diocese HBC. The gatekeepers/informants visited the caregivers' houses and inquired if the AIDS patients were agreeable to participate in the research study. Verbal consent was obtained from AIDS patients.

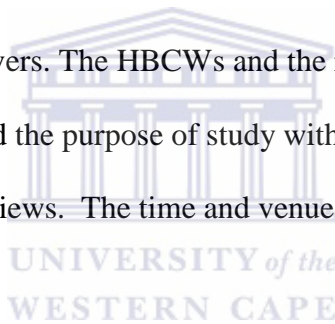
The information sheet providing the relevant information about the study was given to primary caregivers so that they would become aware of the study objectives (Appendix 2).

Mansa Diocese HBC is a local NGO that was formed in 1999 by the Catholic Church in Mansa, Zambia. Mansa Dioceses HBC works with grass roots people in care of and support for chronically ill community members, primarily AIDS and tuberculosis patients, in Luapula Province. The HBC has branches in all parishes found in the districts in Luapula Province. The HBC collaborates with Ministry of Health in terms of logistics and skills. The trained health staff work for the home based care programme in their own time as care supporters. The caregivers, who normally are community members, are drawn from all parishes and they are trained in the care and support of the AIDS patients as HBCWs. The caregivers identify chronically ill people in the communities and refer them to the HBC where they undergo voluntary counseling and testing for HIV. The HIV positive patients are then referred to the centrally located hospitals for further evaluations and for CD4 count before being initiated on ART. Therefore, Mansa Diocese HBC was an appropriate organization for entry to data collection because all participants were first in contact with key informants who established the link between the researcher and the PCG.

The researcher visited the Mansa Diocese Home Based Care (HBC) to introduce himself, explain the purpose of the visit and ask for permission to review HBC records by zones.

The researcher then reviewed the records to identify cases that complied with the eligibility criteria for participation in the study as earlier described.

The compiled list of cases was used to identify the HBCWS assigned to each patient. The researcher visited the HBCWs and explained why he wanted to invite the selected PCGs for an interview. In order to establish a venue and time that was appropriate to conduct the interview, the researcher relied on the HBCWs advice about suitable times to conduct interviews with primary caregivers. The HBCWs and the researcher then visited the homes of the patients, discussed the purpose of study with the caregivers, and invited them to participate in the interviews. The time and venue were communicated to those who agreed to participate.



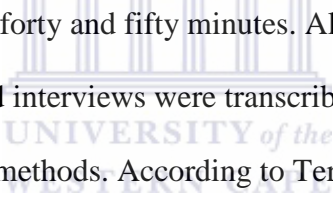
### **Data collection**

Primary data was collected by conducting three focus group discussions (FGDs) consisting of 6 to 10 participants each. A focus group guideline was used (Appendix 1). The guideline consists of typical questions used to facilitate the flow of the FGDs, and to ensure that all relevant topics are covered in the discussions. Using a guideline ensures that focus group discussions are conducted uniformly (Patton, 1990).

The researcher moderated the focus group discussions. The site coordinator from Mansa Diocese HBC attended the sessions. Interviews were scheduled between 10 AM and 12

PM Zambian time. This was the time most caregivers were free from their caregiving schedules. The discussions were held in community built structures. It was important to interview the participants in a place where they felt comfortable.

The notion of selecting a familiar place to conduct interviews has been presented by Green and Thorogood (2004). Green and Thorogood argue that conducting data collection in a place that is familiar to participants would lessen anxiety during discussion. The environment needs to be conducive (private, quiet and physically comfortable) for the respondents to concentrate and be open enough to talk about their experiences (Legard, *et al.*, 2003).



The discussions lasted between forty and fifty minutes. All three interviews were audio-taped. The audio-taped recorded interviews were transcribed verbatim. There was triangulation of data collection methods. According to Terre Blanche and Durrheim (1999) triangulation involves collecting materials in as many different ways and from as many diverse sources as possible. This helps researchers to focus on the correct understanding of a phenomenon by approaching it from several different angles. The researcher audio-taped the focus group discussions and made observations to respondents as they were discussing. For instance, respondents shed tears and were heard to say that their experiences were regarded as ‘normal’ because they had been living with them for such a long time. As the researcher collected data, he also noted and recorded non-verbal body language among participants. For example, one of the caregivers, a single orphan, shed tears when she described how she imagined her mother dying.

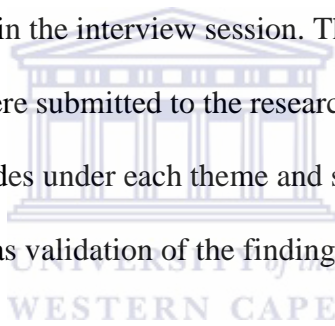
## Analysis

Thematic analysis of the transcripts was done. *A priori* categories (need for information, psychological and social support of the PCGs) were formulated. The following process was followed in data analysis:

- Interviews were conducted in Cibemba, the local language used in Mansa District, tape-recorded, and then transcribed verbatim.
- Cibemba was translated to English by the researcher who is intimately familiar with the language.
- Each line of the participants' responses was numbered for easy referencing of extractions from transcripts typed in matrix in Microsoft Word.
- Data was coded after transcription from each session of FGD for the three interviews conducted.
- Codes were categorized under themes of the research as follows: psychological needs, social challenges for caregiving and information needed by caregivers.
- The ordered excerpts were grouped and coded. These coded categories were related to prior categories where appropriate. New categories were formulated to accommodate new information derived from the data.
- The themes were formulated to denote the relationship between various coded categories.

Thick descriptions (in form of field notes) that captured the context (household and socioeconomic conditions) of caregiving in the district were made.

Verbatim transcription of focus group discussions was done by the researcher to ensure that all information was captured. The audio-taped interviews were transcribed by the researcher so that he should include all non-verbal expressions he saw during the focus group discussion sessions. To increase self-awareness, the researcher documented his perceptions and opinions throughout the process of data collection and analysis by keeping a research diary. Verbatim transcriptions facilitated a check on data reliability because researcher could read the transcripts while listening to the recording (Terre Blanche, *et al*, 1999). The reading of transcribed verbatim while listening to audio-tape recorded interview helped the researcher to correct what was transcribed wrongly and note other omitted expressions in the interview session. The themes for the three FGDs conducted in Mansa District were submitted to the research supervisor to validate the categories and placement of codes under each theme and sub-theme. The confirmation of the research supervisor served as validation of the findings.



### **Ethical considerations**

The researcher obtained permission from the HBC coordinator to access the records of AIDS patients after explaining the purpose of the study to the coordinator. A HBCW accompanied the researcher to the residences of AIDS patients to make contact with the PCGs. The researcher explained the purpose and rationale of the research to each PCG and invited her/him to participate in the study. The PCGs were asked to sign a consent form if s/he agreed to participate. PCGs were informed of their ethical rights pertaining to the study.

In particular, they were informed that their participation was completely voluntary; that they were free to withdraw from the research even after initial consent, without having to explain reasons for withdrawal. The respondents were further informed that their participation would be treated with complete confidentiality. Participants were assured that the researcher would maintain anonymity with respect to the information shared in the focus group discussion (See Appendices 2 & 3).



## Chapter 4

### RESULTS

#### Introduction

In this chapter the main findings (themes) from the focus group discussions with primary caregivers (PCG), translated from 'Chibemba' to English are reported. The main themes and sub-themes are organized to correspond to the objectives of the study (p. 33) (Table 2):

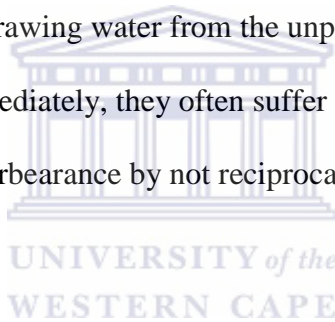
Objective	Theme	Sub-themes
Psychological needs of PCGs	Psychological requirements of caregiving	<ul style="list-style-type: none"><li>• Forbearance</li><li>• Burden of care</li><li>• Emotional distress</li></ul>
Social needs of PCGs	Social challenges of caregiving	<ul style="list-style-type: none"><li>• Responsiveness to patient's needs</li><li>• Challenges of caregiving</li><li>• Need for social support</li><li>• Dealing with conflicting relationships</li><li>• Handling stigma and discrimination</li></ul>
Needs for information	Lack of information	<ul style="list-style-type: none"><li>• Awareness of patient needs</li><li>• Nature of caring tasks</li><li>• Training for caring</li><li>• Opportunities for education</li></ul>



## **I. Psychological requirements of caregiving**

### **Forbearance**

Forbearance is the act of an individual exercising patience, self-control, tolerance, and charity in the face of challenging situations. Caregivers reported that they were often insulted, frustrated and provoked to anger by the AIDS patients they are caring for. The patients might call them in an angry tone when they (the caregivers) delay in responding to the patient's needs. This often happens when the caregiver is busy with other chores such as cleaning the house or drawing water from the unprotected wells. When caregivers do not provide their meals immediately, they often suffer verbal abuse from their patients. Caregivers exercise forbearance by not reciprocating in anger out of fear of offending their patients.



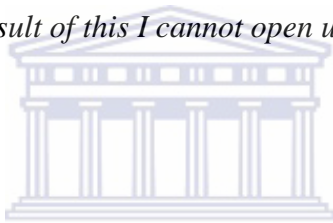
*[“When my patient is in pain and I take time to respond to her call, she becomes angry with me and she talks to me in an angry tone. When this happens I do not usually reciprocate but instead I just apologize for the delay and assist her with whatever she needs and quietly attend to that. I do this because I have come to understand that the patient’s anger simply comes as a result of the pain they are going through.”]*

### **Burden of care**

Caregivers reported that caring for the sick was burdensome because they were forced to assume this role without being adequately prepared.

Some of their new responsibilities involved having to find food and clothing for the patient as well as other household members. In addition, the caregivers represent the patients in most community meetings such as village meetings where the headmen give rules of the village. Most caregivers felt that their daily workload has doubled since taking up the primary caregiving role.

*[“To me, the caregiving task has been very difficult because apart from the patient, I also care for my young sister... I also have to think about myself and what the future holds for me. Neighbours and some of her relatives say a lot of bad things and this has been a major challenge to me. As a result of this I cannot open up to them about how I feel so I am always feeling stressed.”]*



It was evident that the patients were the first priority in the lives of the caregivers. The caregiving responsibilities seemed endless and most of the caregivers said that they seldom found time to rest or attend to their own personal needs. One of the caregivers stated that she could only do other household duties after the AIDS patient had been fully attended to.

*[“I always start my day with a session of prayer together with my patient. We first sing a hymn that he likes most and then we pray. I then prepare warm bath and food before he takes some medication. My day then goes like any other village woman’s. For example going to the fields, fetching firewood and water as well as doing other household chores.”]*

Caregivers reported being pre-occupied with activities related to caring for and supporting their patients and other family members to the point of disrupting their previous lifestyle. One of the caregivers stated that her personal freedom was restricted since taking up the caregiving role. She no longer had time to interact with friends or to attend to her personal needs.

*[“I cannot buy what I want as a young girl who is growing up. I do not have enough clothes because all the money that I make from my small business, I now have to use to buy food. Sometimes I just end up crying because of too much pressure. But my friends are very encouraging and that strengthens me.”]*

*[“My mother expresses to me how bad she feels because I have been admitted in the college but I am unable to attend because there are no funds to pay for tuition. She recalls how well we used to live in the old days. In sadness, she urges me to depend on God; He will create a way for me.”]*

It was clear that the caregivers had to put in a lot of effort to have a healthy relationship with their patients. They reported that they had to be very careful about the way they discussed certain matters with their patients. Most caregivers encountered difficulties when trying to explain to their patients that they could not obtain the particular food items that the patient requested and that they therefore were not able to prepare those meals as requested. The caregivers suffered psychologically as a result of the constant insults and ill-treatment at the hands of their patients.

*[“My son is very provoking. I have to exercise patience not to pick a quarrel with him. I have problems in providing some of the food that he asks for because of financial constraints. Each time I fail to provide him with what he wants, he becomes very angry and insults me using very strong language.”]*

### ***Emotional distress***

Caregivers pointed out that they were distressed because of their inability to satisfy the needs of their patients. They were always worried about whether they were doing enough to meet the expected standard of quality in caring for and supporting the patients.

Caregivers said it was not easy to know what was right and wrong about aspects of patients' care, because they did not receive any guidance and/or support. They reported feeling as if they were left to their own devices. Caregivers stated that they often experienced a sense of helplessness because the disease is incurable and terminal.

*“[Everyday is challenging to me because it is so difficult for me to find food for my father. I have to also think of my siblings and be able to meet their daily needs. All the people that were close to him have now deserted him. Each day that passes I feel more confused because under these circumstances I do not know what the future has in store for me.”]*

Seeing other patients die of AIDS was traumatizing to the caregivers. Some of the caregivers witnessed the death of close family members such as a father or a mother, which was even more traumatizing. This greatly added to caregivers' distress.

It was clear (from the non-verbal messages) that there was a lot of anxiety among those caregivers who had gone through such experiences. Caregivers reported that they found it difficult to imagine how they would survive when the breadwinner is ill. There were also instances where caregivers feared that the patient might die during the night while they were sleeping. Fears such as these exacerbated caregiver distress and feelings of helplessness.

*[“To be honest with you, I am always afraid. It’s not very long ago when I lost my father and the thought of losing my mother again makes me very scared.”]*

According to the caregivers, most patients acted in ways that showed no gratitude. Patients were not considerate of the feelings and increased responsibilities and roles of the caregivers. The married female caregivers reflected on their past experiences in life. Their husbands took care of them and their entire households. Caregivers’ reflections, coupled with inadequacy in provision of husbands’ needs, were so strong that the caregivers suffered feelings of guilt. One caregiver expressed feelings of guilt and a sense of obligation to repay.

*[“I feel guilty because sometimes he says things like I do not pay attention to him now that he can no longer provide for me. He even looks confused because of his sickness.”]*

Some caregivers however, still regarded their patients as a source of encouragement to them and other family members. Despite their helpless state, some caregivers said that the patients still played a vital role in decision making as they sometimes gave valuable ideas or suggestions. All respondents reported that there are times when they felt encouraged by the mere presence of the patients although they could not do much to resolve the caregivers' situation. One caregiver expressed it as follows:

*["I know she is helpless and cannot provide anything for me but her presence gives me the strength to carry on. At times I do consult her about certain things; she gives me sound advice, so there are other ways that I still rely on my patient."]*

The caregivers acknowledged that they were not satisfied with level of care that they offered to patients. They stated that they were unable to provide adequate food to their patients. The caregiver said that sometimes they lacked the necessary skills and resources required to fully perform their caregiving tasks. These problems affected them emotionally as it created a sense of guilt, which, in turn, led to feelings of depression.

*["I get very disturbed about having to take care of the patient with HIV because of the risk of contracting the infection in the process. I am not sure how I could reduce the risk of contracting it. The patient demands many different things, most of which I cannot provide. This makes me feel more of a failure than a caregiver to my patient."]*

In summary, caregiving roles expose the caregivers to various stressful episodes. The caregivers had many distressing experiences as a result of having to meet the daily needs of the patient. The caregivers lacked adequate preparation to undertake the caregiving roles.

## **II. Social challenges of caregiving**

### ***Responsiveness to patient's needs***

Most caregivers reported that they tried as far as possible to attend to all the patient's requests without delay. Even though the patient may be rude when making their requests, the caregivers stated that they would endeavor to respond to the patient's requests. The caregivers believed that responding promptly relieved the pain or discomfort of the patient in some way. One of the caregivers stated:

*[“Sometimes the patient demands things because of pain or discomfort. If the patient needs to go to the toilet I escort her without delay. When you delay to take the patients to the toilet, they can mess on the bed because they are too weak to walk on their own.”]*

The previous relationship between patients and caregivers determined what kind of treatment patients expected. Traditionally in Mansa, marriage is valued as a lifelong relationship and husbands and wives are expected to stay together. In times of trouble or sufferings, the patient expects the closest person to be the spouse. In this context, it was evident that caregivers caring for their husbands felt obliged to meet all the demands of the patient.

This is because failure to do so would be interpreted by the patient (husband) as lack of love. Therefore, this particular group of caregivers made every effort to attend to the patient's demands promptly.

*[“My husband always wants me to respond promptly when he calls for my help and if I happen to delay he thinks that I do not care for him because he is ill. I end up feeling guilty when he says I do not pay attention to his needs because he can no longer provide for the family as he used to do. He now looks very confused all the time and I think he is losing his mind because of his sickness.”]*

It was clear that the caregivers showed a lot of sympathy and patience when providing care to someone to whom they were very close, or to someone who had contributed much to their life. In the Mansa District, the way care was provided by the caregivers was consistent with cultural expectations. This is illustrated by the Cibemba proverb “*Mayo mpapa naine kakumpapa*” which means that the help that someone gives is an investment that an individual can use in future times of difficulties when they need the help too. The caregivers sympathized with the patient especially when the patient was in pain.

*[“Sometimes it is very difficult to help the patient because of their unreasonable demands. Because one moment the patient says they want rice and the next they say don't want it and they want potatoes and so on. This make it very difficult because I spend most of my time attending to their demands which are constantly changing; and it makes time management very difficult. However, I realize that the reason they do that is because they are in pain. So I try to be there for them and do as much help as I can”.]*



### ***Challenges of caregiving***

Caring for the sick affects caregivers socially and economically. Caregiving is even more difficult if the caregiver was previously a dependent of the patient and experiences a reversal of roles where the caregiver becomes the breadwinner. For instance, many caregivers report that the workload becomes more than they can handle. Caregivers assume caregiving roles for which they are unprepared and untrained. In the Mansa District, caregivers stated that they faced challenges such as lack of consistent food supply, insufficient financial resources and also physical limitations in caring for AIDS patients. These physical limitations included age (too old or too young to move the patient around) and disability.



*["I hardly have enough food for my patient. I spend a lot of time looking for food. Sometimes, I can only afford to provide a single meal to the family. We normally have the single meal at 15:00 in the afternoon. I know my patient needs to eat but I cannot provide enough for him. I also have another responsibility of providing clothes for my own children and my brother's children."]*

Younger children and other older caregivers said they experienced difficulties performing physical tasks such as lifting patients, bathing them, washing the bedding and other manual tasks.

*[“My daughter gets very angry with me if I give her food that she doesn’t like. She would then refuse to eat the food and that means I have to try and find a substitute. This is very stressful and traumatizing to me because I am old and I am not physically fit. My legs are very swollen as you can see.”]*

*[“I feel much troubled when my patient is very sick. I am too weak to carry her and take her to hospital. The last time I had to ask the neighbours to help me to take her to hospital.”]*

### ***Need for social support***

The caregivers reported that they received little social support from either the family or the community. Material and/or emotional support for the caregivers is often necessary in order for the caregiver to provide adequate care for the patient.

### ***Support from family***

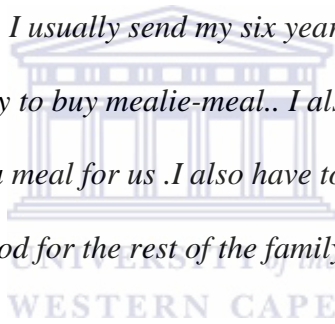
The caregivers stated that they received help from their younger sisters who do baby sitting or stand in for them to sell goods they were trading at the local market. The baby sitting relieves the pressure on the caregiver so that they are more available for the patient.

*[“I gave birth to baby boy almost the same time my mother started feeling sick and it has been difficult for me to care for the patient and at the same time look after my baby.”]*

*The only fortunate thing is that my young sister helps me with baby sitting and this makes the load lighter.”]*

Family members of the caregivers helped to sell goods at the local market. When family members helped with above mentioned in-come generating activities, the caregivers found time to rest, to do other caregiving tasks for the patient, or to take care of their own personal needs. This helped the caregiver to take a breather from the demands of caregiving.

*[“When my mother is very sick, I usually send my six year old sister to sell vegetables at the market. I then use the money to buy mealie-meal.. I also use some of the left over stock of vegetables to prepare a meal for us .I also have to continue going to my field to cultivate in order to produce food for the rest of the family members.”]*



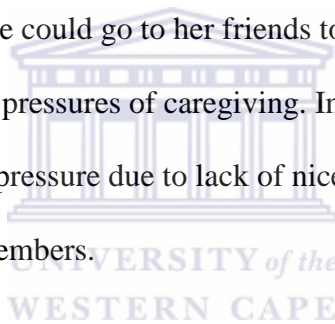
### ***Support from community***

Some caregivers stated that they received help from neighbours when bathing patients. In Mansa District, it is against the norm for the sister to bathe the brother, if he is above 15 years old. In such instances the caregivers need to obtain help from other community members. The help requested from the neighbours posed a challenge because sometimes the neighbours would pretend to be busy with their own activities as way of avoiding giving help to the person with AIDS.

*[“You know it’s not accepted in our culture to bath an opposite sex person who is not your husband, so in order to bath my brother, I have to depend on my neighbours.”]*

The caregivers also received help in the form of casual jobs from neighbours, so that they could earn some money. The jobs involved cleaning the neighbours’ premises, washing dishes and laundry and fetching water and firewood. These earnings helped them to be able to provide in the patient’s needs.

One of the caregivers stated that her friends were very supportive and sympathized with her when she felt depressed. She could go to her friends to talk about her situation and this helped to relieve her of the pressures of caregiving. In addition, friends gave her clothes. The caregiver felt less pressure due to lack of nice clothes. The caregiver felt free to interact with other society members.



*[“My daddy died a long time ago and now my mother is also sick. I am worried when my mother deteriorates. The small business that I run at the local market, does not give me much profit. So I cannot buy what I want as a young girl. I do not have enough clothes to wear. All money that I make from the small business I use it for patient’s requirements. My friends, however, are very helpful and supportive”]*

The caregivers reported that they felt comforted with the home-based care workers’ (HBCWs) visits, although these only occurred once a month. The HBCWs are trained caregivers who work with Mansa Diocese Home Based Care for AIDS patients in the

designated zones. In their home visits, they attend to the patient by dressing the sores, and giving supplementary nutrition such as HEPS. HBCWs also discussed the patients' antiretroviral therapy, and any difficulties they may be having with the therapy with caregivers.

### ***Dealing with conflicting relationships***

As much as the caregivers benefited from relationships with family members, community members and organizations, caregiving roles conflicted with their private lives at these (family and community) levels.

Caregivers stated that the caring role had intruded in their personal privacy. For instance, a caregiver reported that he felt uncomfortable spending nights with the patient (his son) following the collapse of the patient's shelter due to heavy rains. Since there was only one bedroom available, they had to share it. In the setting where the research was conducted, it is against the community norms for a woman to share a bedroom with an older son (above six years of age). One of the married male caregivers said that his relationship with his wife had been affected because he had to share a bedroom with the patient. The caregiver said he could not have sexual relations with his wife because of the continual presence of the patient. In accordance with caregiver's tradition (Bemba) his wife could customarily divorce him because of failure to meet her sexual needs.

*[“The house for my son collapsed due to heavy rains this season and we are sharing a single bedroom with my son who is above the age of six. It is traumatizing for such*

*sleeping. MZ you understand our culture that once you are grown up you do not sleep in your parents' house, worse still a single room.”]*

Caregiving roles are not performed in specially designated or isolated places in the community. The roles are performed in the household of the patient. All the household members and the patient continue living together despite the illness. The caregivers reported that they had additional responsibilities of caring for other family members in the households but they were forced to prioritize the patients' needs each day when providing care.

*[“My day is always very challenging because I cannot find food for my father. In the morning, I have to prepare food for my father so that he eats before he takes his medication if there is food. I have to think also of my siblings and be able to supply their daily needs to them also. At the end of each day, I am very exhausted and confused about what the next day's challenges will be.”]*

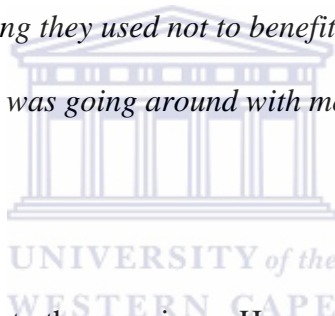
Another caregiver said that he used to go to the market place where he sold eggs before he started caring for the patient and this was the only way he would raise money to buy clothes. Caring for the patient therefore meant that he had to abandon this income-generating opportunity and stay at home.

*[“I am always worried. Clothes have finished. It has not been a good thing to me. I used to spend time selling eggs at the market.”]*

### ***Handling stigma and discrimination***

Stigma is the disgrace and inequity people with AIDS and their caregivers suffer in the community. AIDS patients are looked upon as people who cannot do any form of work in order to contribute to society. Caregivers feel ashamed when society members talk rudely about the patients. Caregivers stated that some of the neighbours were reluctant to assist them because they accused their patient of having been reckless. Some community members associated the illness with risky behaviour that the patients practiced in their lives.

*["I have heard neighbours saying they used not to benefit from the things my grandmother brought when she was going around with men who infected her. She now has to pay for her behaviour".]*



Some neighbours provided help to the caregivers. However, caregivers were not happy with the same neighbours gossiping when they (neighbours) provided any sort of help. Neighbours provided help such as food, clothes and transport to take the patient to hospital

*["It has not been easy for me caring for my mother. It is difficult at home. I hear people stigmatize her, they talk badly about her, and especially that at one time she lost her mind. She was taken to mental annex but later on she was discharged on ARV.*

*Neighbours and some of her relations say all sorts of bad things and this poses a challenge to me although I cannot tell to them how I feel. I am depressed all the time."]*

### III. Lack of information

#### *Awareness of patient needs*

All the respondents stated that they pay particular attention to the patients' needs in their homes. They reported that everything the caregivers did was programmed around time schedules of their patients. In the morning, they have to bathe the patient and supply food before they can give ARV medication as prescribed by the doctor.

*[“Every morning I start by preparing bath water and then wake her up for a bath. At around 08:00hrs, I give her food and when she is eating I always sit by her side to continue encouraging her to eat her food if she is struggling.”]*

ART patients are supposed to adhere to the medication. This means that the patient needs to follow prescribed treatment dosages and time regimens for taking the drug. Failure to adhere to the drug regime caused treatment resistance among patients. Caregivers had to manage the time schedule for the patients. They reported that treatment was administered at 12 hour intervals. Caregivers stated that they had the responsibility of encouraging the patient to eat as much food as possible before taking treatment. Caregivers have noticed improvement when AIDS patients are put on treatment and eat adequate food.

*[“In my case, every morning I have to prepare porridge for my daughter. I then give medication according to the instructions. If the food is not ready I cannot give medication*



*because the last time I forced her to take the ARV before eating, her condition became worse.”].*

*[“When she is struggling to eat, I sit by her side encouraging her to eat more and more. Every day I want to show that I still love her and that I will always be by her side. I do not want to care for my mother like I have seen other caregivers do. The patient dies from feeling bad because of bad treatment.”]*

### ***Nature of caring tasks***

The physical chores that caregivers perform in the household include food preparation (for the patient and other household members), cleaning the room where the patient spends much of his/her time, washing utensils, providing and washing clothes for the patient and other household members, bathing the patient, and giving medication. Some caregivers stated that they were involved in generating income so that they could buy food for the patient as required.

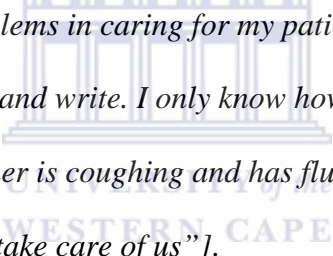
*[“I always try to maintain a high level of cleanliness especially for the pillows and beddings. Since many people come to visit the patient, therefore, I should keep everything clean.”]*

Addressing lack of information about tasks the caregivers undertake when caring for and supporting the patients will be helpful to caregivers. Information on the preparation of

nutritious foods, for instance, is needed by the caregivers when patients are in terminal stage.

### ***Training for caring***

The caregivers were afraid that they may be infected through patient's coughing and bodily discharge. They also felt they had insufficient knowledge of how HIV was transmitted from one person to another. Caregivers reported that it was a burden for them to take care of the patients, because they lacked skills to protect themselves against infections.



*[“I sometimes think I have problems in caring for my patient (grandmother) because I am not educated. I cannot read and write. I only know how to write my name. I become very afraid when my grandmother is coughing and has flu. I always get worried that if I fall sick there will be no one to take care of us”].*

*[“I have been caring for AIDS patients in my family for a long time. My son is the third AIDS patient I am caring for now. I feel I have a challenge. I now know that AIDS has come to stay in my family but at the same time, I do not know much about the disease.”]*

*[“My mother feels uncomfortable when I put on gloves for my own safety. The other day when the HBCWS brought gloves, she complained. I would need to know how to prevent diseases but without offending the patient.”]*

Caregivers experienced difficulties in mobilizing resources to meet all the patient's needs. They have to work in the field, uproot cassava (Cassava is plant transplanted using stem. The plant produces tubers or roots that are used to make flour for preparing porridge. Cassava is a traditional food in Northern part of Zambia. ) and process it to prepare a thick porridge for patient. They also have to sell these traditional foods to get money to buy soap and other foods.

*["I used to sell vegetables at the local market but now I cannot go there because I have no capital anymore. That makes it difficult for me to provide food for my husband. The food my patient needs is not always available at home."].*

The caregivers lack information that is vital in the performance of tasks. Caregivers, if not provided with training, can contract HIV infection. In addition, they need information on how to mobilize resources to use in care and support of the patients.

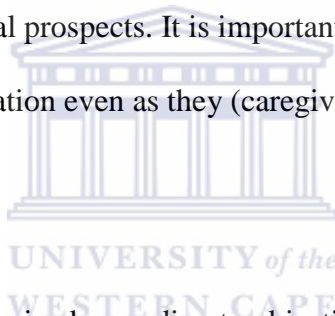
### ***Opportunities for education***

Young caregivers expressed concern about missed opportunities for education. The caregivers were aware of how education could improve their lives. But sometimes they had to miss this opportunity in order to provide care to the patients. Only one caregiver was supported by Catholic nuns in her lower basic education (grade 6). Those that had a chance to proceed to middle basic (grades 8-9) and high school or tertiary level reported that they were not receiving any kind of support.

*["I feel bad because my young sister has stopped going to school. My mother used to make money because she was a dressmaker. The young girl shall never have a chance to go to school."].*

*["I need to go to college or to University. I think this is what worsens my mother's condition. She is always worried about the fact that I can't proceed with my tertiary education."].*

Caregivers' lack of information on how to access educational support prohibits them from furthering their educational prospects. It is important for the caregivers to have access to social welfare information even as they (caregivers) concentrate on the patients.



### **Summary**

In summary, the results are organized according to objectives, themes and sub-themes.

Under objective, *psychological needs of PCGs*, the caregivers' psychological requirements of caregiving are forbearance, burden of care and ways to address emotional distress. Under the objective, *social needs of PCGs*, social challenges of caregiving included that caregivers be responsive to patient's needs, need of social support, dealing with conflicting relationships and handling stigma and discrimination.

Finally, under objective, *need for information*, the following gaps were identified: awareness of patient's needs, nature of caring tasks, training for caring and missing opportunities for education.

## Chapter 5

# DISCUSSION

### Overview

The current study aimed to explore the psychological and social needs, and types of information needed by caregivers in Mansa District, with the intention of providing such valuable information to organizations involved in providing home based care workers to AIDS patients in this district. It was envisaged at the outset of this study that these findings would help humanitarian organizations to structure the training of home-based care workers (HBCWs) so that they are more sensitive to the primary caregivers' needs. The discussion will follow the format used in the reporting of results in chapter 4. In the first section, the psychological requirements of caregiving are discussed with particular themes in Mansa cultural context drawing on three theories, namely the *Relative Deprivation Theory*, *Theory of Reasoned Action* and *Self-Discrepancy Theory*. In the second section, the social challenges of caregiving are discussed with particular themes in Mansa cultural context drawing on the '*Stress Buffering*' model and *Attachment Theory*. In the third section, the lack of information for caregiving is discussed with particular themes in Mansa cultural context drawing on the *Health Belief Model (HBM)*.

## Psychological needs

The findings from this study suggest that forbearance is one of the most critical qualities required by caregivers in order for them to cope with all the caregiving roles at home. In this context, *forbearance* means an individual shows patience, self-control, tolerance, charity and determination to do something for others, in the face of various adversities and challenging situations. Challenges at home included insults and provoking language and behaviour from their AIDS patients. In this study caregivers reported being verbally abused (insulted) when they failed to meet the demands of the patients such as providing food, bedpans and other requests immediately. Most caregivers reported that the patient was infuriated if s/he did not react promptly to the patient's needs. Although most delays were due to commitments to other household activities, the findings showed that some of the patients understood this kind of burden on the caregivers. Most caregivers reported that having forbearance with their demanding patients was challenging in the face of lack of appreciation and/or gratitude from their patients. These last-mentioned displays affected them in a psychologically adverse manner.

In addition, caregivers faced challenges from the community in the form of discrimination and stigmatization from neighbours. In this study, it was reported that neighbours frequently talked about how immoral the AIDS patients were and how that led to their contracting of HIV. This gossip was frequently conducted in the presence of the caregivers. In Mansa District, it is culturally inappropriate for younger members of

society to express their views and feelings about a matter under discussion when in the company of elderly people, especially when their views are contrary. In such a scenario, the younger person would be regarded as being disobedient. If the younger person offered a disproof to or contested an elder's view on his family member with AIDS, s/he would be considered to be rude. In turn the caregiver may not receive support from members of the society. As a result of this, the caregivers frequently felt upset and distressed.

Stress is harmful to the health of caregivers because it narrows their ability to think clearly, function effectively, and enjoy life (Smith, Jaffe-Gill, Segal & Segal, 2007). In this regard, if the trainers of HBCWs become aware of risk factors of stress in caregivers' lives, they could train HBCWs staff on how to assess and respond to caregivers' stress.

The study also identified that in some cases the patients exhibited a degree of understanding of the caregiver's situation - a form of 'reciprocated' sympathy. In one example a young woman had completed high school three years before and was now caring for her mother who had AIDS. The caregiver was eager to pursue tertiary education but she could not afford to pay fees for tertiary course. In Mansa District, most girls get married upon completion of high school education. Thus, achieving a tertiary education qualification is not highly regarded by themselves or their community. In this particular case however, the patient (the girl's mother) strongly supported the idea of her daughter attending college. Such reciprocated sympathy from the patient was interpreted by the caregiver as a sign of appreciation for the work she was doing in caring for her mother and other siblings. In a matrilineal society such as is present in Mansa District,

seeing a daughter through college and then placed in gainful employment is considered a benefit for all the members of the clan. In this case, the psychological support given by the mother (patient) encouraged the caregiver as she laboured to provide for the family. The caregiver reported that her mother's concern for her future relieved her even though the mother was not able to provide any material support for her to continue with her education. Identifying and supporting the caregivers' priority needs could help to moderate the caregivers' stress.

Some caregivers received emotional support from the home based care workers (HBCWs) during their monthly visits. The HBCWs encouraged the caregivers to discuss the patient's condition and commended the caregivers for the care that they were giving to their patients. The commendation from the HBCWs encouraged caregivers in their work, and provided an emotional buffer against the hardships and challenges they faced, thus relieving them of the distress caused by their caregiving roles.

Caregivers experienced two forms of transition challenges; the disruption of their usual lifestyles and the assumption of new roles. Concerning disruption of their usual lifestyles, caregivers reported that the quality and quantity of food available to them and their families had been greatly reduced because of reduced income levels. They also reported that their style of clothing had deteriorated, and they were distressed that they were unable to keep up with latest fashions as their friends did. This was consistent with the study in Canada among the caregivers for advanced cancer patients (Cameron, Franche, Cheung & Stewart, 2002). The findings were that caregivers experienced



emotional distress when reacting to the changes in their lives caused by assuming caregiving roles. The caregivers' experiences are akin to the tenets of Relative Deprivation Theory (Gurr, 1970), which argues that people become discontent if they recognize an unfavourable discrepancy between 'value expectations' and 'value capabilities'. The caregivers' reflection on their lives before the breadwinners fell sick indicates that they were unable to meet the expectations of society because of the diminishing of the patients (former breadwinners) resources. It has now become difficult because they have no capacity to provide for the household. For instance, the caregivers noticed reduced quality and quantity of food, lack of clothes and 'turning into beggars.'

Prior to the assumption of caregiving roles, the caregivers could afford adequate food of good quality and also they could keep up with latest fashions of clothing. This transition from one lifestyle to another resulted in depression among the caregivers, as most of them were concerned about the society's perception of the changes that had occurred in their lives. The emergence of these new caregiving tasks hindered them from taking on income-generating projects that would ensure that they had enough food and fashionable clothing. Instances where caregivers felt they had less than what they thought they rightly deserved led, to feelings of anger, moral outrage or resentment.

In most cases, it was evident that caregivers took on these new caring roles involuntarily and their consent was not sought about whether they were willing to take up these roles or not. The illness of the patient, often the breadwinner in the family, forced the caregivers to take over tasks such as caring for the entire household.

The involuntary nature of their position as caregivers was influenced by their relationship to the patients. This is consistent with relationship theories such as Theory of Reasoned Action (TRA) and Self-Discrepancy Theory (SDT) (Ajzen & Fishbein, 1980; Higgins, 1987). The Theory of Reasoned Actions states that an individual's performance of a given behaviour is determined by two major factors:

- (2) the person's attitude toward behaviour and normative beliefs regarding other people's views of behaviour and,
- (2) the person's willingness to conform to the views.

Attitudes are a result of perceptions in the society in which an individual lives. Beliefs influence how an individual judges and acts in a given situation. When beliefs are normative in a particular setting, they energize an individual to perform as the society expects them to perform. Individual caregivers expressed that they exercised tolerance and charity toward the patients in their homes. They were also empathetic to the patients as evidenced by an example of a young caregiver who often cried when her mother's condition became worse or when her mother was experiencing pain.

Caregivers' behaviour, to a large extent, is linked to attitudes and beliefs in the given society. The performance of an individual is driven by exercising the commitment an individual makes in life. The caregiver's performance of tasks related to caring for AIDS patients is believed to be influenced by and to conform to what the caregiver perceives to be the expectations of the society in Mansa District, as well as the life commitments the caregiver has made. In Mansa District, the society expects that caring for relatives is a

primary responsibility of any individual who is close to the sick person. In most cases the person in the household is expected to automatically take over the caring responsibilities and to immediately function at the same level as the former breadwinner (usually the patient). This is because of the general perception that such a person understands the habits, attitudes, and other personality characteristics of the patient.

It is common to find a young girl taking care of the mother because she is the one who was closest to patient prior to the illness. Society's expectations however do not take into account the age of the prospective caregivers. Caregivers responded to the societal expectations by sacrificially taking up all these responsibilities - even those that they know that they may not manage on their own, such as turning the patient in bed without asking for assistance. Members of the community also create distance from the caregivers and the caregivers suffer loneliness. Loneliness, coupled with knowledge of what is expected by society caused psychological pressure on caregivers' in the form of emotional distress. The most affected were the very young and the very old caregivers who were often not capable of providing what was expected by the community.

In summary, the relationship between caregivers' attitude towards the performance of caring roles supports the tenets of the Theory of Reasoned Actions. Caregivers were influenced by the perceptions of how the society looked at them during execution of caregiving tasks and the caregivers' innate drive to perform what they viewed as fulfillment of societies expectations.

According to the Self-Discrepancy Theory (Higgins 1987), beliefs about how performance could be improved are dependant on significant others (persons who have influence in an individual's life). Significant others such as those who had successfully cared for their AIDS relatives till death were influential in caregivers' lives in Mansa District. In addition, caregivers were influenced by the Mansa societal expectations that caring for the relatives is a primary responsibility of any individual in the community regardless of their age and gender. Those people who were close to the sick before the illness are expected to take primary responsibility for the care of the AIDS patients. In addition, the society considers responding well to traumatic situations as a passage to maturity and the development of wisdom. Therefore, regardless of their age, the caregivers took the responsibility of caring for and supporting the AIDS patient, as was demanded by the community in which they were living. Taking on these responsibilities in order to be regarded as capable and blameless in the society of Mansa District, however, precipitated stress and burn out in their lives.

Assuming caregiving roles in the society of Mansa poses great challenges to caregivers. Taking on societal expectations often traumatized the caregivers, especially the young caregivers. Avoidance behaviour adopted by caregivers in the Mansa District study included isolation and suspicion of scorning friends, and these coping mechanisms resulted in stressful reactions among caregivers. Stress commonly affects people who experience traumatic events. In the case of the youthful caregivers, the stress of a parent's illness was often increased by the societal expectations such as taking over responsibilities of care involuntarily. Caregivers reported changes in behaviour such as

enjoying being alone at home. When alone at home, caregivers said they experienced a measure of peace - away from other people's comments that affected them negatively. One of the caregiver's said she had lost trust in her friends because whenever she saw them laughing, she always thought that the friends were laughing at her. Avoidance behaviours precipitated stress however, because it meant that the caregivers had no one with whom they could express feelings.

Caregivers sometimes behaved in what is considered to be a bizarre manner in the Mansa District study. For instance, when discussing how the patients' condition changed every day, the caregivers may be laughing and within the blink of an eye, look sad again. The inconsistency of the moods and the dramatic mood changes are unusual in the culture, as the people believe that once an individual is sick, it is considered to be a sorrowful situation, and laughing is inappropriate. The rapid mood changes, along with the societal expectations, were important in the study, and enhanced the finding that it is essential for the caregivers to have a trusted person with whom they can express emotions without judgment. Stress is harmful to the health of caregivers because it narrows their ability to think clearly, function effectively, and enjoy life (Smith, Jaffe-Gill, Segal & Segal, 2007). Such study findings can facilitate the development of awareness campaigns among instructors of HBCWs to include stress management strategies in their caregiver training programmes.

## Social needs

The findings of this study elucidate the fact that caregivers faced severe challenges in relation to responsiveness to AIDS patients. In this context, *responsiveness* means that an individual shows sensitivity, openness and receptiveness to the patient's needs. In the study conducted in Mansa District, caregivers were less sensitive to the patients' needs such as position changes when the bedridden patient is in discomfort. Caregivers reported that when a patient needed escorting to the toilet, the caregivers could not promptly give assistance, which resulted in patients soiling the bed linen. This meant that caregivers thus had to wash laundry more often than they had planned. In such cases, caregivers said the relationship between them (caregivers) and the patients often became unpleasant. This was important in the Mansa District study because relationship between patients and caregivers has direct bearing on the care and support the patients receive.

Moreover, this study revealed that caregivers were less sincere (open) with themselves and their patients, because they were not able to fully express how they (caregivers) felt. For example, even when the caregiver had prepared food for which the patient had asked, and then the patient refused to eat but demanded another meal, the caregivers seldom felt free to express their frustrations.

Caregivers caring for patients who were previously financially independent, expressed difficulties in meeting their patients' particular food demands in the same manner that the patient was accustomed to when the patient was the breadwinners.

Such situations further deteriorated when caregivers had difficulties discussing illness progression with the patient, as this would exacerbate the patient's anxiety. However, one of the caregivers said that she discussed the patient's (her brother) illness with him and advised him not be anxious about his illness. The caregiver cites examples of other diseases that kill people, such as malaria and diarrhea. Malaria and diarrhea diseases are commonly known as diseases with high mortality in the communities of Mansa District because the area has swarms of mosquitoes and has unsafe and unclean water supply from unprotected wells and streams. .

In Mansa District, people are generally not open to each other with respect to discussing personal feelings. For instance when an individual experiences hurt, he cannot express himself out of fear of exposing himself as being emotionally weak. In the cases of caregivers, society expects them to be strong and provide continuous care to the patients in their homes. When caregivers express that they feel challenged in providing care for and supporting their patients, they could be misinterpreted as being unable to take care of the patients by fellow community members.

Responding to challenges of caring for the patients was one of society's expectations regardless of inaccessibility to resources such as food, linen and manpower. Caregivers felt challenged because at times they were compelled to always respond to both the patients and the society in which they live. Instructors for home-based care workers (HBCWs) therefore need to be aware of these challenges when they conduct training.

The caregivers in the study in Mansa District highlighted that they faced many challenges in caregiving. Caregivers said that they had difficulties in obtaining assistance for food, and performing other tasks like working in the field (a place where food crops are cultivated). Considerable time is spent looking for food and performing other caregiving tasks. In some cases, caregivers could only afford to provide a single meal despite being aware that the patient needed to eat more frequently than once a day.

In Mansa District, most people earn a living from subsistence farming. During planting season people spend time cultivating their fields and everyone is expected to have adequate food at all times of the year. Caregivers find it difficult to become highly productive since they spend much time caring for and supporting patients at the expense of working in their fields. Not being productive predisposes the caregivers to lack of basic household supplies such as food and clothes. As a result, the caregivers are further marginalized in the community. Becoming marginalized in the society affects the caregivers' position in the community and caregivers are predisposed to social stress because caregivers had all they needed before the breadwinners fell sick. It is important for HBCWs' instructors to understand the causes of social stress amongst caregivers and to equip HBCWs with skills to provide counseling to caregivers as they carry out their monthly visits to AIDS patients.

The findings in this study revealed that caregivers need social support from their immediate family and community members. In this context, *social support* means enjoying close relationships and being helped with physical tasks.



Most caregivers said that they worked closely with siblings of their immediate families and neighbours in the community. The caregivers could receive support from the neighbours when they (caregivers) encountered physical limitations. This is consistent with the “stress buffering” model that underpins the fact that an individual’s social support system may help to moderate or reduce the effects of stressful life events on psychosocial well being (Littlewood, 1992). In Mansa District, people relate in clans (grouping of similar names). The clan visits individuals and comforts them when they experience stressful events such as funerals. In this setting of the study, caregivers received support such as food supplements from these clan members.

Another caregiver said she had difficulties in helping her father as his illness worsened. In Mansa District, daughters are not allowed to be close to their fathers especially when they reach puberty. Daughters are regarded as a second ‘mother’ to their father and hence they receive more respect than sons. Daughter caregivers felt great discomfort when bathing the patient (Father) in bed and frequently turning him. These tasks conflicted with cultural norms and she found these relationship conflicts difficult to handle.

This study also revealed that married caregivers encountered numerous challenges in their relationship with their spouses. Caregivers caring for their spouses said that their spouses needed them either to be close or to respond promptly when called for help. Caregivers said it seemed that their ill spouses now needed them to be closer than before. The caregivers’ experiences in their relationship with spouses were similar to *Attachment*

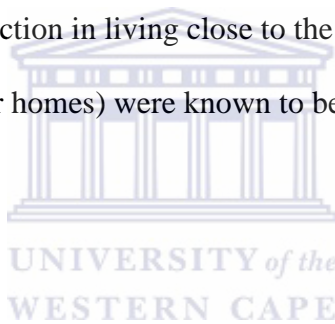
*Theory* (Fraley, 2004). This theory describes the infant-caregiver attachment and it fine points the bond that develops between infant and the caregiver (infant sitter). The infant feels secure in the presence of the caregiver and expects immediate response from the caregiver and also that the caregiver should be available all times. If the caregiver is not available the infant becomes anxious. In his research, Fraley discussed similarities in adult romantic relationships and infant-caregiver attachments (Fraley, 2004). The theory argues that adult romantic relationships exhibit three features similar to infant-caregiver relationship in the attachment theory:

- 1) The partner needs to feel secure in their relationship and to feel confident that their partner will be there for them when in need,
- 2) The partner is expecting that caregiver will be responsive and that the caregiver is available at all times and,
- 3) The partner's behaviour and thinking are influenced by the individual's expectations and beliefs that the other shall be there for him.

The theory affirms that an adult who had lived in a romantic relationship with a partner (patient) found it difficult to detach and live independently from the spouse (caregiver). In line with the above mentioned features, if an individual becomes insecure he worries, and easily gets frustrated or angered when his attachment goes unmet. Since an individual in an adult romantic relationship expects the partner to be responsive and available; these feelings of confidence are necessary to secure him in the relationship. A caregiver, for instance, said that her spouse accused her of not responding promptly because he (former breadwinner) had nothing to provide now.

This affected the caregiver-patient relationship. The caregivers became frustrated and this affected their closeness to the patients, which promoted further detachment.

The study also showed that caregivers faced challenges in handling stigma and discrimination. In this context, the stigma and discrimination suffered by caregivers was a result of being closely associated with an AIDS patient. The stigma and discrimination affected caregivers when they needed assistance during execution of caregiving tasks. For instance, when the patient was bedridden, the caregiver could not bathe the patient alone but instead required assistance that was often denied them. In another instance, neighbours expressed dissatisfaction in living close to the home of caregivers of AIDS patient because these (caregiver homes) were known to be lacking most basic needs.

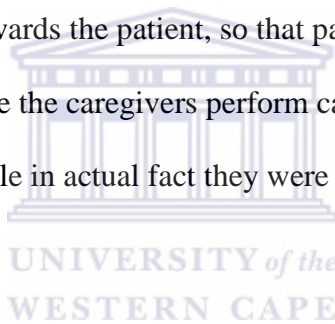


### **Information needs**

The findings of the study clearly illustrate that caregivers are aware of the physical needs of the patients. Caregivers said they arranged their time schedules around caring for the AIDS patient. They prepared meals and warm baths, and supervised the patients taking their antiretroviral drugs and other prescribed medications. Management of the patient's personal hygiene and cleaning the household environment were some of the additional tasks that caregivers performed. These findings were consistent with the studies carried out in Zambia in which caregivers spent much of their time doing home chores such as food preparations, washing clothes and bathing patients (Esu-Williams, Schenk, Motsepe, Geigel & Zulu, 2004 ; Grimmer, *et al.*, 2004; Drinkwater, *et al.*, 2004).

These physical chores occupied much of their time, so that they had little time to access social service organizations for help for themselves and other household members.

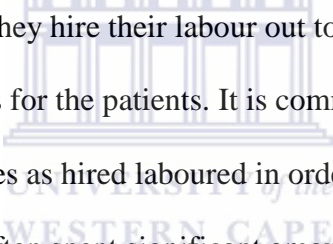
This study also showed that patients needed to be shown affection. People in Mansa District believe that showing love and affection is very important and expected of everyone who is caring for the sick. It is not expected that the affection shown be “genuine” all the time but that caregivers display a pleasant smiling face to the patients and speaking nicely and encouragingly to them. Most people in the community felt that showing “real” love is paramount. The caregivers reported that sometimes they just pretended to be affectionate towards the patient, so that patients would feel accepted and loved. This is important because the caregivers perform caregiving roles for the sake of making patients feel loved; while in actual fact they were often severely distressed at having to play this role.



In order for HBCWs instructors to develop relevant teaching materials, it is important for them to be aware of the physical tasks performed by caregivers, the time spent on these tasks, as well as the emotional needs of both the patients and the caregivers. This will ensure that appropriate interventions are being developed for implementation by HBCWs.

In this study caregivers were involved in numerous tasks to ensure that the patients’ physical needs were met. These tasks often included attempts to generate income to purchase what the patients needed. Most caregivers reported that they engaged in selling

of some crops grown on small pieces of lands in order to raise money. In rural parts of Mansa District the people depend on subsistence farming as a source of livelihood and the most commonly grown crops are cassava, millet, sorghum, groundnuts and maize. Most of the caregivers, however, were unable to cultivate adequate crops for selling and family consumption. Those interviewed mentioned several factors contributing to their inability to cultivate enough to feed the family. Among these was the fact they spent inordinate amounts of time caring for the sick, that they did not have enough time to do the work in their fields. The caregivers were often either too young or too old to manage the strenuous activities required in the cultivation of large plots of land.



Some caregivers also said that they hire their labour out to the neighbors in order to earn enough money to provide meals for the patients. It is common in Mansa District for young people to offer themselves as hired labourers in order to earn extra money for the family. The young caregivers often spent significant amounts of time working in the homes of the neighbours as well as caring for the patients. This means that they do not have time to work in their own fields. The young caregivers could benefit from access to information that would improve their entrepreneurial and marketing skills. Trainers of the HBCWs should explore with the HBCWs to design methods of various skills development in the primary caregiver in order to improve their ability to support the family and thus provide for the needs of the patients.

The study reveals that caregivers had inadequate or no skills to improve safety precautions while performing caregiving roles. Caregivers said that they did not feel

comfortable negotiating for their own safety even when safety items such as gloves were readily available in the home. They said that they were concerned about taking safety precautions for fear that the patients would feel stigmatized. In Mansa District society, using precautionary measures was misinterpreted as sign that someone is not willing to care for the patients because safety measures such as putting on gloves are thought to create barriers.

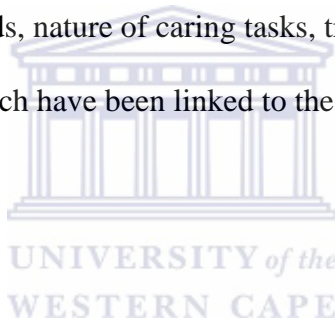
The caregivers' experiences are similar to the principles of the Health Belief Model (HBM) (Rosenstock, Strecher & Becker, 1994). The HBM attempts to explain and predict health behaviors by focusing on the attitudes and beliefs of individuals. The model's key variables include perceived threat (susceptibility and severity), perceived benefits, perceived barriers, cues to action and self-efficacy. An individual becomes aware of how he can contract the infection if exposed to it. He then looks at how he can benefit if he avoids the infection while taking into account possible barriers. The above are influenced by individual attitudes and beliefs. In Mansa District, society concludes that caregiver is not interested in caring if he uses the precautionary measures such as gloves. Caregivers' attitudes need to be influenced positively. Caregivers' attitudes to seek safety precautions when imparted with knowledge on how HIV is transmitted, regardless of what the society expects of them, could improve the caregivers' practice of safety measures. For instance, caregivers should know that the virus is found in most body fluids of patients such as blood and discharge from wounds. Adequate knowledge on safety measures as well as self-efficacy to deal with community attitudes and beliefs will improve caregivers' ability to successfully execute their roles as well as ensuring that

they take certain measures required to prevent them contracting the infection. It is also important for the caregivers to know which body fluids contain the virus, and to avoid contact with these fluids as they provide care for the patients. HBCWs must therefore educate both the caregivers and patients about safety measures necessary to prevent transmission of infection through contact with infected fluids. The instructors need to understand and therefore address challenges that caregivers face during implementation of caregiving roles in their homes.

This study highlighted that many youthful caregivers missed opportunities for themselves and their siblings which are vital to a brighter future. Caregivers frequently said that they could not continue with their academic education because they not only did not have the funds required, but they also were not aware of assistance available from government and non-governmental organizations. One of caregivers cited difficulty in accessing support for studies after high school. Orphans and Vulnerable Children (OVC) affected by HIV/AIDS can be sponsored by service organizations such as Luapula Foundation (NGO) and Government Social Welfare Department, but must be registered with the organization in order to be assisted. HBCWs instructors should gather accurate information about the status of the caregivers and other children in the household and then provide information about services available in the province so that the caregivers can access them.

## Summary

In summary, caregivers encountered psychological requirements such as need for forbearance, burden of care and emotional distress that related to the theories namely *Relative Deprivation Theory*, *Theory of Reasoned Action* and *Self-Discrepancy Theory*. Caregivers also faced social challenges of caregiving such as being responsive to patient's needs, challenges of caregiving, need for social support, dealing with conflicting relationships and handling stigma and discrimination which related to '*Stress Buffering Model and Attachment Theory*'. Caregivers were in need of information, in particular being awareness of patient needs, nature of caring tasks, training for caregiving and opportunities for education which have been linked to the *Health Belief Model (HBM)*.





## Chapter 6

### CONCLUSIONS AND RECOMMENDATIONS

#### Overview

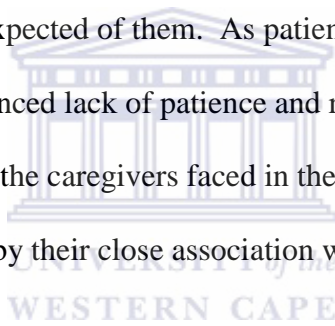
The purpose of the study was to explore and gain an in-depth understanding of the experiences and challenges faced by caregivers in providing for the needs of patients in their homes. These findings were intended for communication to the instructors of the home based care workers (HBCWs) to equip the HBCWs with skills necessary to respond to the identified needs of the caregivers. Analysis of data collected throughout the study in Mansa District, Zambia revealed three main themes:

1. Caregivers have unmet psychological needs
2. Caregivers face many social challenges in caregiving,
3. Caregivers lack the necessary information.

The study clearly demonstrated that caregivers were in need of psychological support as they must demonstrate a high degree of patience and tolerance in order to perform the caregiving roles. It is difficult for them to develop these qualities unless the patient demonstrates an understanding of the stresses faced by the caregiver. In addition, it is essential that the members of the surrounding community show a degree of understanding of the challenges faced by the caregiver, and that these community members offer emotional support to the caregivers.

It was shown to be important that the community members realize that in many cases the caregivers are going through a colossal life style change, and that at this time they need a trusted individual in their lives to whom they are able to express their emotions.

It was found that caregivers encountered many social challenges; lack of social support and the ability to deal with conflicting relationships were social challenges the caregivers faced in the Mansa District on a daily basis. One such challenge was the need for the caregivers to remain responsive to the needs of the patient. This was often difficult as the patient-caregiver relationship became strained as the roles of each changed, and both struggled to fill the new role expected of them. As patients became more and more demanding, caregivers experienced lack of patience and respect towards for the patient. An additional social challenge the caregivers faced in the study was stigma and discrimination, brought about by their close association with a person with AIDS.



The study found that the caregivers lacked essential information in several areas: availability of social services that could meet the material needs of caregivers and their families, support for small scale income-generating activities, safety information concerning the management of bodily waste of AIDS patients, and other opportunities that the caregivers missed in life due to their caregiving role.

## **Study limitations**

A limiting factor of this study is that the researcher's own experiences and the views and the experiences of the caregivers (PCGs) may have influenced the interpretations and inferences of the data. However, subjective interpretations and inferences are considered to be vital components of qualitative research (Patton, 2002). The researcher makes contextual meaning of what the interviewee says and insinuates for the particular target he is interviewing in a particular area. In this case experiences of the caregivers influence the research conclusion. However, the study makes a contribution to the gaps identified during the review of literature concerning needs of primary caregivers to AIDS patients.



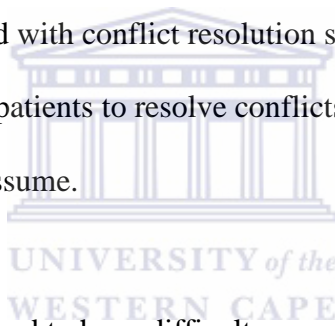
## **Recommendations**

The following recommendations are targeted for the instructors of conventional home based care organizations such as Mansa Catholic Diocese. The study findings demonstrate the importance of incorporating these recommendations into the training curriculum used to equip the HBCWs with skills to care for and provide support for AIDS patients in their homes, as well as to meet the needs of their primary caregivers.

- Primary caregivers often suffer disruption of life style as they assume the caregiving role unprepared. In addition, the expectation of the society is that these primary caregivers should successfully take on the role of caregiver despite their lack of experience and knowledge and their often tender age. These factors create

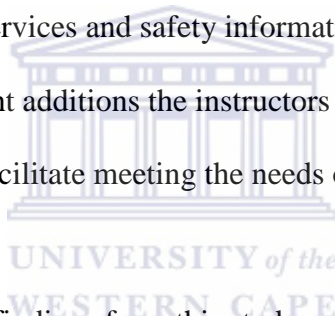
psychological pressure in the form of stress. The study therefore recommends that instructors should incorporate stress indicators as well as stress management strategies in the HBCWs training so that HBCWs can identify and help to mitigate the impact of stress suffered by the primary caregivers.

- Instructors should also build the capacity in HBCWs to continually update the social service directory so that, as they make their monthly visits, they can inform the primary caregivers about the social services that are available.
- HBCWs should be equipped with conflict resolution skills in order to assist the primary caregivers and the patients to resolve conflicts that emerge due to the changing roles each must assume.
- Primary caregivers were found to have difficulty expressing sincere feelings especially in regard to the changing roles in their lives and their frequent inability to meet the needs of the patient. HBCWs should be trained in effective listening skills, and in giving productive feedback in order to buffer the emotional distress experienced by the primary caregivers.



## Conclusions

The study aimed to explore the psychological and social needs and types of information needed by primary caregivers of AIDS patients in Mansa District. The study identified the psychological needs of caregivers such as the need for forbearance, need for stress reduction and emotional buffering, and the need to associate with trusted confidants. Social needs identified were support from others, methods of dealing with relationship changes, ineffective feedback from society and patients, and ways to reduce stigma and discrimination. Finally the study identified types of information needed by the caregivers such as availability of social services and safety information for prevention from HIV infection. These needs highlight additions the instructors for HBCWs should incorporate in the curriculum in order to facilitate meeting the needs of the primary caregiver.



It is therefore possible that the findings from this study may be applicable to other districts in Zambia. During literature review in this study (Mansa District), studies conducted in other parts of the world, for instance, Uganda, Canada and Australia had similar findings. It is therefore probable that the findings of this study may also be applicable to rural areas of sub-Saharan Africa.

## REFERENCES

- Ajzen, I., & Fishbein, M. (1980). *Understanding Attitudes and Predicting Social Behaviour*. Englewood Cliffs, NJ: Prentice-Hall.
- Armstrong, S. (2000). *Caring for Caregivers: Managing Stress in those who Care for People with HIV/AIDS*. Geneva, Switzerland: UNAIDS.
- Badri, M., Maaetens, G., Mandalia, S., Bekker, L., Penrod, J., Platt, R., Wood, R. & Beck, E. (2006). Cost Effectiveness of Highly Active ART in South Africa. *PLoS Medicine*, 3.
- Bengtsson, E. & Bengtsson, I. (2005). *Where We Can't Cure, We Can Care. A Participatory Evaluation of A HBC Project in Zambia*. Sweden: Vaxjo University.
- Bollinger, L. & Stover, J (1999). *The Economic Impact of AIDS in Zambia*. The Future Group International & Research Triangle Institute (RTI) the Centre for Development and Population Activities (CEDPA). Lusaka, Zambia: Government Printers.
- Cameron, J., Franche, R., Cheung, A., & Stewart, D. (2002). Lifestyle Interference and Emotional Distress in Family Caregivers of Advanced Cancer Patients. *Cancer*, 94: 521-527.
- Central Statistical Office [CSO] (2000). *2000 Census of Population and Housing Census of Zambia*. Lusaka, Zambia: Zambia Central Statistical Office.
- Chopra, M. (2005). ARV Treatment and Health Systems: Avoiding the Pitfalls. *AIDS Bulletin – March 2005*, 14 (1): 5-9.
- Deci, E. L., & Ryan, R.M. (2000). The “What” and “Why” of Goal Pursuits: Human Needs and the Self-determination of Behaviour. *Psychological Inquiry*. 11: 227-268.
- Denzin, N., K. & Lincon, Y., S. (2005). The Discipline and Practice of Qualitative Research. In N. K. Denzin, & Y.S. Lincon (eds). *The Sage Handbook of Qualitative Research*. (3<sup>rd</sup> ed). Thousand Oaks, California: Sage Publications: 1-32.
- Drinkwater, D., McEwan, M. & Samuels, F. (2006). *The Effects of HIV/AIDS on Agricultural Production System in Mpongwe Zambia: A Restudy 1993-2005 Analytical Report*. United Kingdom: London School of Economics. .
- Esu-Williams, E., Schenk, K., Motsepe, J., Geigel, S., & Zulu, A. (2004). *Involving Young People in the Care and Support of People Living With HIV and AIDS in Zambia: Final Report of an Operational Research Study in Luapula and Northern Provinces*. Horizons Final Report. Washington, DC: Population Council.

Familydoctor.org. (2007) *Understanding Stress: Signs, Symptoms, Causes, and Effects*: [Online], Available. [http://www.helpguide.org/mental/stress\\_signs.htm](http://www.helpguide.org/mental/stress_signs.htm). [27/06.08 14:30 PM].

Fereire, M. (2004). *HIV/AIDS and Family Well Being in Southern Africa; Towards an Analysis of Policy and Responsiveness*. Windhoek, Namibia: United Nations Department of Economics and Social Affairs Division for Social Policy and Development Policy.

Finch, H. & Lewis, J. (2003). Focus Groups. In J. Ritchie & J. Lewis. (eds). *Qualitative Research Practice*. London.: Sage Publications: 170-198.

Falk, G. (2001). *Stigma: How We Treat Outsiders*. New York: Prometheus Books.

Fraley, R. C. (2004). *A Brief Overview of Adult Attachment Theory and Research/ R. Chris Fraley*: [Online], Available. <http://www.psych.uiuc.edu/> [03/06/2008 14:00 PM.].

Gephart, R. (1999). *Paradigms and Research Methods*. Research Methods Forum. Edmonton, Canada: University of Alberta.

Goffman, E. (1963). *Stigma: Notes on the Management of Spoiled Identity*. Englewood Cliffs, NJ: Prentice-Hall.

Green, J. & Thorogood, N. (2004). *Qualitative Methods for Health Research*. London: Sage Publications: 3-26.

Grimmer, K., Moss, J. & Falco, J. (2004). Becoming a Carer for an Elderly Person after Discharge from an Acute Hospital Admission. *Allied Health Sciences and Practice*, 2 (4): 9-21.

Gurr, T.R. (1970). *Why Men Rebel?* Princeton, NJ: Princeton University Press.

Harding, R., Stewart, K., Marconi, K., F O'Neill, J. & Higginson, I.J. (2003). *Current HIV/AIDS End of Life Care in Sub-Saharan Africa*. Department of Palliative Care & Policy. London, United Kingdom: King's College.

Harding, R., Stewart, K., Marconi, K., O'Neill, J.F. & Higginson, I.J. (2003). A Survey of Model, Services, Challenges and Priorities. *Current HIV/AIDS End of Life Care in Sub-Saharan Africa. Public Health*: 3-33.

Higgins, E.T. (1989). Self-Discrepancy Theory: What Patterns of Self-Beliefs Cause People to Suffer? *Advances in Experimental Social Psychology*, 22 (6): 93-136.

Hilgard, E.R. & Atkinson, R.C. (1992). *Introduction to Psychology*; (4<sup>th</sup> ed). New York: Harcourt Brace Jovanovich.

Horwood, C., Liebeschuetz, S., Blaauw, D., Cassol, S. & Qazi, S. (2003). Diagnosis of Paediatric HIV Infection in A Primary Health Care Setting with a Clinical Algorithm. *World Health Organization*, 81 (12): 858-866.

Kuzel, A.J. (1992). Sampling in Qualitative Inquiry. Crabtree B.F Miller, W.L (eds.), *Doing Qualitative Research*. London: Sage Publications.

Legard, R., Keegan, J. & Ward, K. (2003). In-depth Interviews. In J. Ritchie & J. Lewis. (eds). *Qualitative Research Practice*. London: Sage Publications: 138-169.

Leininger, M.M. (1988). *Care, the Essence of Nursing and Health*. Detroit: Wayne State University Press.

Littlewood, J. (1992). *Aspect of Grief: "Bereavement in Adult Life"*. London: Routledge.

Luapula Foundation. (2008). *Mid-Term Evaluation Report on Effectiveness and Efficiency of NPI Programmes: Mansa District, Zambia*. Unpublished Report: Department of Monitoring and Evaluation.

Mallinckrodt, B. & Wei, M (2005). Social Competencies, Social Support and Interpersonal Process in Psychotherapy. *Counseling Psychology*. Columbia: University Of Missouri: 239-266.

Makwiza, I., Nyirenda, L., Goma, F., Hassan, F., Chingombe, I., Bongololo, G., Theobald, S. (2006). *Equity and Health System Strengthening ART Roll Out: Analysis from Literature Review of Experiences from East and Southern Africa*. The REACH Trust, Malawi Commissioned by Regional Network for Equity in Health in East and Southern Africa (EQUINET).

Ministry Of Health-Zambia [MoH]. (2006). *2005 Annual Report*. Lusaka, Zambia. Ministry of Health.

Mwanamwenge, M.T., Chilopa, B., Chewe, P.M., Banda, R., & Burkner, B. (2003). *Zambia Sexual Behavioral Survey: MEASURE Evaluation*, 2004 Mar. North Carolina, Chapel Hill, USA : University Of North Carolina: 136

Patton, M, Q. (2002). *Qualitative Research & Evaluation Methods (3<sup>rd</sup> ed)*. Thousand Oaks, California: Sage Publications.

Patton, M, Q. (1990). *Qualitative Research & Evaluation Methods (2<sup>nd</sup> ed)*. London: Sage Publications.

Pope, C., & Mays, N. (2000). *Qualitative Research in Health Care (2<sup>nd</sup> ed.)*. London BMJ Publishing Group.



Reed, J. C. (2005). *HIV/AIDS Workplace Interventions in South Africa and United States*. Florida, USA: University of South Florida.

Rosenstock, I., Strecher, V., & Becker, M. (1994). The Health Belief Model and HIV Risk Behavior Change. In R.J. DiClemente, and J.L. Peterson (Eds.), *Preventing AIDS: Theories and Methods of Behavioral Interventions*: New York: Plenum Press.

Roach, M. (1992). *The Human Act of Caring*. Ontario: Canadian Hospital Association Press.

Smith, M. (2002). Stigma. *Advances in Psychiatric Treatment*, 8: 317-325.

Smith, M., Jaffe-Gill, E., Segal, J., & Segal, R. (2007). [Online], Available. ([http://www.helpguide.org/mental/stress\\_signs.htm](http://www.helpguide.org/mental/stress_signs.htm)). [27/06.08 16:31 PM].

Stoltzman, J.D. (1994). The Distribution and Treatment of Mental Disorders by Social Class: Review of the Research and Theoretical Interpretations, in B.S. Bolaria and H.D. Dickson (2<sup>nd</sup> eds.). In *Health, Illness, and Health Care in Canada*: Toronto: Harcourt Brace Canada.

Stuart, H., (2005). *Fighting Stigma and Discrimination is Fighting for Mental Health*. Canadian Public Policy-31 Supplement/Numero Special 2005. Ontario, Canada: Queen's University Kingston.

Terre Blanche, M., & Durrheim, K., & Painter, D. (2006). *Research in Practice. Applied Methods for the Social Sciences*. Cape Town, South Africa: University of Cape Town Press.

Terre Blanche, M., & Durrheim, K. (Eds.). (1999). *Research in practice: Applied Methods for the Social Sciences*. Cape Town: University of Cape Town Press.

Theis, S. L., Biordi, D.L., Coeling, H., Nalepka, N., & Miller, B. (2003). Spirituality in Caregiving and Care Receiving. *Holistic Nursing Practice*, 17: 48-55.

UNICEF. (2006). *Africa's Orphaned and Vulnerable Generations: Children Affected by AIDS*. Geneva, Switzerland: UNICEF.

United Nations Joint Programme On HIV/AIDS [UNAIDS]. (2004). *2004 Report On Global AIDS Epidemic*. Geneva, Switzerland: UNAIDS.

United Nations Joint Programmes On HIV/AIDS [UNAIDS]. (2006). *2006 Report on the Global AIDS Epidemic*. Geneva, Switzerland: UNAIDS.

Wagner, B.M, Compas, B.E & Howell, D.C., (1988). Dairy and Major Life Events: A Test of an Integrative Model of Psychology Stress. *American Journal of Community Psychology*, 16 (2): 189-205.

Wennman-Larsen, A. & Tishelman, C. (2002). *Advanced Home Care for Cancer Patients at The End of Life: A Qualitative Study of Hopes And Expectations of Family Caregivers*. Stockholm, Sweden: Department Of Nursing, Karolinska Institutet, Unit/Palliative Care, at Stockholm Sjukhem Foundation.

Zambia Central Statistic Office [ZCSO]. (2004). *2004 Census of Population and Housing Census of Zambia*. Lusaka, Zambia: Zambia Central Statistical Office.

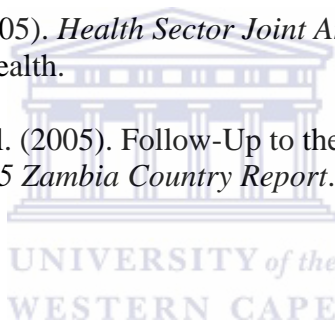
Zambia Demographic Health Survey [ZDHS]. (2001-2002). *2001-2002 Demographic Health Survey*. Maryland, USA: ORC Macro.

Zambia Health Management Information System [ZHMIS]. (2006). *Draft Annual Report 2006*. Mansa, Zambia: Luapula Provincial Health Office.

Zambia Ministry of Health. (2005). *Annual HMIS Report for 2005*. Lusaka, Zambia: Ministry Of Health.

Zambia Ministry of Health. (2005). *Health Sector Joint Annual Review Report 2005*. Lusaka, Zambia: Ministry of Health.

Zambia National AIDS Council. (2005). Follow-Up to the Declaration of Commitment on HIV/AIDS (UNGASS). *2005 Zambia Country Report*. Lusaka, Zambia: National HIV/AIDS/STI/TB Council.

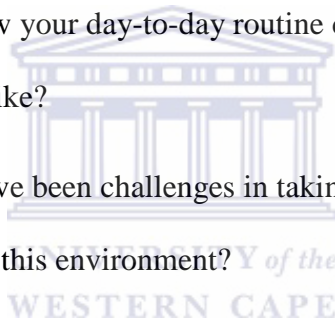


## APPENDICES

### Appendix 1

#### Guide to conducting FDGs with PCGS

- What have been your experiences during caring for and supporting the breadwinner within your home?
- Could you describe how your day-to-day routine caring and supporting for AIDS sick family member is like?
- What would you say have been challenges in taking care of family member suffering from AIDS in this environment?
- What help do you need in caring for and supporting family member suffering from AIDS?





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**Appendix 2**

**SR1**

**INFORMATION SHEET**

**Psychological and social needs and types of information needed for primary care givers of family members living with AIDS in the Mansa District Zambia.**

Dear .....

My name is Moses Zulu. I am a student doing a Masters Degree in Public Health in the faculty of community health sciences at the University of the Western Cape, School of Public Health in South Africa. I am collecting information related to the *needs of primary care givers of AIDS patients and* I would like you to participate in this study.

The reason for this research is because Aid has increased the burden of care on their family members. We call the family member that is tasked to take care of the AIDS patients in the house the primary care giver (PCG). The current study aims to explore the psychological and social needs as well as needs for information experienced by such primary care givers. The identified needs shall be used to inform Home-Based Care Workers training programmes so that they in turn could further support primary care givers.

The study therefore seek to recruit as participants primary care givers who are providing care to family members with AIDS in Mansa district. You will be asked to participate in the focus group discussion with 6 to 10 other persons who are also caring for AIDS patients in their households. I will facilitate the discussion and record the proceedings on

an audiotape. The focus group discussion will include both males and females regardless of age. I will facilitate the discussion about your experiences, day to day routine caring for and supporting AIDS patients, challenges you have encountered to provide care in home environment and help that you need in caring for and supporting AIDS family members. The discussion will last approximately 60 to 90 minutes.

The audiotapes will strictly be locked in the safe box and only played in closed room where I (researcher) shall listen alone. After the purpose for which your discussion has been completed, the tapes will be destroyed by fire. To further ensure anonymity, during the recording, you will use false name so that your identity is disguised completely. The result of the study will be presented to the conventional non-governmental organizations so that they can develop training programmes for the home based care workers to support you as primary care givers of AIDS patients.

The study is voluntary and you will not be harmed in any way should you choose not to participate. You are free to refuse or withdraw at any time during the discussion without having to explain your reason for doing so. Should you have further questions or wish to know more, I can be contacted as follows:

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Mansa, Zambia.  
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Email: [bvanwyk@uwc.ac.za](mailto:bvanwyk@uwc.ac.za)

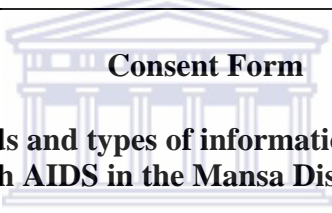
If you agree to participate in this study, please read and complete the consent form below.



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**Appendix 3**

**SR1**

  
**Consent Form**  
**Psychological and social needs and types of information needed by primary care givers of family members living with AIDS in the Mansa District Zambia.**

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I have been informed the purpose of the research I am participating in as a respondent. I have asked questions and I am satisfied with the answers I have been given. I have understood and what my participation involves. I know that I participate as a volunteer and any information that I will give shall be maintained in confidentiality.

Signature: ..... Date: .....

Witness: ..... Date: .....

## Appendix: 4

### Field Diary

#### *Volunteer recruitment*

The research project began with a visit to the Project Coordinator as well as the Site Coordinator for the Mansa Diocese HBC. The purpose of the visit was to inform the Mansa Diocese coordinators of the scope of the up-coming research project and how the project would involve the HBCW from Mansa Diocese HBC. Written information clearly delineating the scope of the project as well as the fact that I am a student from the University of the Western Cape was made available to the coordinators. The coordinators expressed understanding of the materials presented and both signed the consent forms.

With the consent and assistance of the Site Coordinator, I reviewed client records from six zones. Three zones were identified as appropriate for the study due to availability of clients; these were Chitamba, Kaole and Sumbu. . The Site Coordinator (SC) agreed to contact HBCW Zone Coordinators and to explain to them the purpose of the upcoming study. In the first meeting with Zone Coordinators, I was surprised to be introduced by the SC as an outsider rather than as a local student; the introduction, in my view, created fear and mistrust in the Zone Coordinators. It was clear to me that it would be necessary for me to re-introduce myself, to explain why I wanted to meet with them, and to gain their trust. This was quickly accomplished when the site coordinator invited me to speak. After a discussion with the Zone Coordinators, they each expressed understanding of the purpose of my visit and agreed to cooperate fully in the study. This was followed up in

two days by a visit to the Zone Coordinators at the office of the Site Coordinator. Again the Zone Coordinators expressed understanding and interest in the project, and subsequently signed consent forms for the study. Each agreed to visit potential research subjects (primary caregivers of AIDS patients in their zones) and to invite them to meet with me at a set date and time. The zone coordinators expressed understanding that they would only facilitate the meeting between me and the primary caregivers, and that they would not participate in the interviews.

Within each zone, I visited the homes of each primary caregiver (potential research subject), explained the purpose of the study, and obtained written agreement of each to participate in the study. Participants chose a suitable venue for the focus group discussion which was to be held the following day. In one case, the patient was present during the invitation of the primary caregiver, and I was concerned that the patient would object to her family member participating; however, she strongly encouraged the caregiver to participate.

The venue for the FGD was in shelter built by Mansa Diocese HBC for the treatment of the AIDS patients' opportunistic infections. The shelters are community owned and the community members maintain these structures. Each day, I was at the venue for interviews at 09:30 hours. The interviewees were very cooperative and they attended interviews on time.



The Site Coordinator for HBC attended the interviews. Prior to the interview he had expressed understanding of his role, which was to hold the tape recorder but not to participate. However, sometimes he attempted to clarify my questions to the participants. FGD were conducted in “Cibemba”, the local language of the area among members of the Aushi ethnic group.

I dressed casually for the FGD; this was appropriate as the discussions were held in rural villages among very poor people. . The interviews proceeded well although participants expressed expectations that they would be given supplies which they needed for the care of the patients despite it having been made clear to them in initial interviews that this was not the case.

