EXPERIENCES OF INFORMAL WOMEN CAREGIVERS IN CARING FOR PEOPLE LIVING WITH HIV AND AIDS IN DAR ES SALAAM, TANZANIA

DISSERTATION

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DECLARATION

I, Eunice Pallangyo, hereby declare that the work on which this dissertation is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

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DEFINITION OF TERMS AND ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
EPA	Environmental Protection Agency, Tanzania
HIV	Human Immunodeficiency Virus
MEASURE	USAID funded MEASURE programme (began its second phase in 2003) which was designed to provide and promote the use of accurate and timely information on population, health and nutrition in developing countries.
NACP	National AIDS Control Programme (Tanzania)
NBS	National Bureau of Statistics (Tanzania)
ORC Macro	Opinion Research Company (research management consulting and information technology firm with headquarters in Washington DC
PASADA	Pastoral Activities and Services for people with AIDS, Dar es Salaam Archdiocese
RUHISWE	Rural and Urban HIV Social Welfare Group in the Dar es Salaam area
TACAIDS	Tanzania Commission for AIDS
TASAF	Tanzania Social Action Fund
UNAIDS	Joint United Nations Programme on HIV/AIDS
VSO	Voluntary Services Overseas
WHO	World Health Organization

ABSTRACT

Aim of the study

The aim of this study was to explore and describe the experiences of informal women caregivers of people living with HIV and AIDS at home in Dar es Salaam, Tanzania. The study took place in Temeke district in the Dar es Salaam region through the auspices of Pastoral Activities and Services for people with AIDS, Dar es Salaam Archdiocese (PASADA), a non-governmental organization that provides home-based care services.

Research design and method

The research design was a qualitative, descriptive and exploratory study based on the interpretive paradigm. The study population was informal women caregivers looking after spouses or relatives at home who were living with HIV and AIDS (staged at World Health Organization clinical stages III and IV), some on antiretroviral therapy and others not. Purposive sampling was used to select participants who were attending PASADA's community centre.

Data were collected using semi-structured interviews which were audio-recorded. Eight participants were interviewed in order to explore their individual experiences of caring for people living with HIV and AIDS. Data collection continued until data saturation was achieved. The recorded data were transcribed verbatim and analysed using thematic analysis. Anonymity and confidentiality of the study participants was maintained throughout.

Findings

Themes which emerged from the data were as follows: social and economic situation; HIV-related stigma and discrimination; stress and burn-out; treatment and support system; care burden and the challenges. Financial problems made an impact on food security, and the caregivers also had to cope with multiple illnesses in the people under their care. The lack of support for the caregivers increases their vulnerability to stress and burn-out.

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CHAPTER 1: INTRODUCTION

1.0 Background

The HIV and AIDS epidemic has brought with it a challenge in caring for and supporting people living with HIV and AIDS. Hospitals have been overwhelmed, especially in countries where the prevalence is high; hence it is difficult to continue nursing all patients in hospitals (Uys and Cameron, 2003:3). Hospital care by professionals has been replaced with informal caregivers, who may be household members, neighbours or friends. Care at home is provided mostly by women, who are generally more vulnerable to the consequences of AIDS both in terms of morbidity and mortality, whether themselves HIV-positive or living with and caring for others within the family who are HIV-positive (World Health Organization (WHO), 2003:9). Although Uys and Cameron (2003:3) suggest that care will be both comprehensive and cost-effective if provided at home, this might not be true for many African countries.

Caring for persons with HIV and AIDS is a demanding task, and in most developing countries is compounded by difficult social circumstances as a result of extreme poverty. The high cost of care and burials falls onto already overburdened households, leaving orphans and dependants in difficult situations (Tanzania Commission for AIDS (TACAIDS), National Bureau of Statistics (NBS) and ORC Macro, 2005:13). The home-caring role is associated with multiple stressors relating to socio-economic status, a lack of knowledge of the disease, demanding and exhausting tasks, the sadness of observing a loved one suffering, stigma and discrimination (Brandt, 2005:10). Caring involves a large amount of work, and caregivers are at risk of suffering from adverse health, psychosocial and financial effects because of their role (Randy and Richard, 2006:1175). The burden of care should be assessed, stress levels and mental health monitored and appropriate steps taken to prevent caregivers from becoming overwhelmed (Brandt, 2005:11).

1.1 Overview of the current situation

HIV and AIDS has remained a major problem world wide, despite many efforts to reduce the incidence of the disease. About 40 million people were estimated to be living with HIV and AIDS in 2006 (UNAIDS, 2006b:14). Of these, 37 million were adults and over 2 million were children under 5 years of age; 17.7 million women were living with HIV and AIDS and

over 4 million people were newly infected with HIV in 2006 (UNAIDS, 2006b:14). According to UNAIDS (2006b:14) there were 2.9 million AIDS-related deaths in 2006.

The 2007 UNAIDS report shows a slight reduction in statistics compared to 2006, with an estimated 33.2 million people living with HIV and AIDS in 2007 globally (a reduction of 16% from 2006) (UNAIDS, 2007:2). Of these, 30.8 million were adults. Women, the most affected group, were estimated to number 15.4 million, children under 15 years 2.5 million and the newly infected 2.5 million (2.1 million adults and 420 000 children). The number of deaths related to AIDS in 2007 was 2.1 million (2.1 million adults and 330 000 children). The UNAIDS report (2007:11) state that "the analysis in the 2007 report cannot specifically measure the opposing influences on HIV prevalence of prevention efforts that reduce new infections and treatment scale up that reduces deaths among people with HIV" This report cautions, however, that the major cause of the differences between 2006 and 2007 is the methodological advancement in data collection and the extensive revision of estimates published in 2006, rather than trends in the pandemic itself. According to UNAIDS (2007:4) the global prevalence rate remains the same, although the number of people living with HIV is increasing because of accumulation of new infections with longer survival times due to the use of antiretroviral drugs (ARVs).

Sub-Saharan Africa is the most affected region in the world. The report on the global AIDS epidemic (UNAIDS, 2006b:15) indicates that almost 64% of the global total of HIV-positive persons and persons living with AIDS live here. The report further states that three-quarters of all women (15 years and older) living with HIV are in sub-Saharan Africa. Moreover, about 43% of children living with HIV and AIDS in the world are concentrated in this region. In countries such as Zimbabwe, Botswana, Swaziland and Lesotho, it was estimated that one in every three adults is infected by HIV (Parry, 2005:82). Although the 2007 UNAIDS report indicates that HIV prevalence in some countries in this region (such as Zimbabwe) has shown signs of decline, it still remains the most affected region in the world. This report indicates that more than two out of three adults and nearly 90% of children infected with HIV live in sub-Saharan countries.

Tanzania is one of the sub-Saharan countries heavily impacted by HIV and AIDS. Three AIDS cases were first described in 1983 in the Kagera region, followed by rapid spread across the country; by 1986 all regions of Tanzania mainland had reported AIDS cases

(Tanzania Commission for AIDS (TACAIDS), 2003:13; TACAIDS *et al.*, 2005:17). The HIV/AIDS Indicator Survey (TACAIDS *et al.*, 2005:1) reports that the epidemic has affected the most productive sector of the population, specifically adults (both women and men) between the ages of 20 and 49 years. As a result, there is a remarkable increase in AIDS-related absenteeism from work, deaths, suffering and grief. A total of 144 498 AIDS cases were passively reported through the health services between 1983 and 2001, and under-reporting may be as high as 80% (TACAIDS, 2004:13). According to TACAIDS (2003:13) only about 150 000 AIDS cases have been reported officially since identification of the first cases.

The hospitals are overwhelmed; in Tanzania it is estimated that 50-60% of adult patients in medical wards are admitted due to HIV-related causes (National Aids Control Programme (NACP), 2005a:17). This is an indication that home/community-based care in Tanzania is needed in all regions. Families are the central focus of care and form the basis of community home-based care (NACP, 2005a:17).

1.2 Researcher's interest

The researcher developed her interest in this area after observing and witnessing the problems that face the caregivers of people living with HIV and AIDS in the community in which she lives. Through talking to some caregivers and members of the community, the researcher felt that caregivers of people living with HIV and AIDS experience problems which might not be clearly understood. This stimulated her interest in exploring the experiences of caregivers in caring for people living with HIV and AIDS at home in the Temeke district of Dar es Salaam region.

1.3 Problem statement

People living with and households affected by HIV and AIDS have psychological, social, nutritional, legal, clinical and nursing care needs which change over time as the HIV infection progresses to AIDS (NACP, 2005:18). Although efforts have been made by both Government and non-governmental agencies in Tanzania to strengthen and develop HIV and AIDS home-based care services, the focus to date has been more on patient care. Although

caregivers are to be included as partners when dealing with the issue of HIV and AIDS (Sison, 2002:1), little has been done to address their needs.

With the progress of the epidemic, there are many indications that communities, families and individuals hardest hit by HIV and AIDS face enormous difficulties in securing their survival (TACAIDS, 2003:48). This suggests that much more needs to be known and done to enable affected families and communities to survive in a world shaken by AIDS (Ogden, Simel and Caren, 2004:24).

In Tanzania, where home-based care and support programmes are still unable to respond to many of the social support needs of people living with HIV and AIDS (TACAIDS, 2007:19), there is limited information concerning the experiences of women caring for people living with HIV and AIDS at home. It is anticipated that as more information about the experiences of the caregivers becomes available, the appropriate support can be provided; in turn this will impact on the quality and extent of home-based care for people living with HIV and AIDS.

1.4 Research question

What are the experiences of informal women caregivers in Dar es Salaam, Tanzania, in caring for persons with HIV and AIDS at home?

1.5 Aim of the study

The aim of this study was to explore and describe the experiences of informal women caregivers in Dar es Salaam, Tanzania, in caring for persons living with HIV and AIDS at home.

1.6 Objectives of the study

1. To explore and describe the experiences of women informal caregivers in Dar es Salaam, Tanzania, in caring for HIV and AIDS patients at home.
2. To identify the common activities carried out during caring for HIV and AIDS patients at home.
3. To determine the main psychosocial and economic problems that women informal caregivers experience in caring for HIV/AIDS patients at home.

4. To explore their reflections on their coping strategies.

1.7 Significance of the study

AIDS is a leading cause of adult mortality in Tanzania (TACAIDS, 2003:13), and from this it can be deduced that there is a high demand for care. Community- and home-based care programmes have been established (although still at their infancy) in response to the burden of care on hospitals resulting from AIDS-related conditions. Providing care at home has been described as cost-effective by many governments and communities; Voluntary Services Overseas (VSO) (2006:5) argues that it is based on the unrecognised, undervalued and frequently unpaid work of women and girls. Informal caregivers face challenges linked to their caring roles which may affect their own health as well as the effectiveness of the care that they provide. The caring role can evoke strong emotional feelings, that can take time to get used to (Battison, 2002:134) – especially in informal (untrained) caregivers. Exploring and describing the experiences of informal women caregivers in caring for people living with HIV and AIDS at home will provide information which may be supportive of effective home care. The findings of the study may be used to provide appropriate support services to informal caregivers.

CHAPTER 2: LITERATURE REVIEW

2.0 Introduction

The literature review is limited to the following areas relating to the aim of the study: the concept of care, women and HIV and AIDS, HIV and AIDS treatment, women burden of care, HIV-related stigma and discrimination, and poverty in Tanzania. The literature search was conducted using computerised database searching, citation-index searches, hand searching and internet searching. Databases searched were EBSCO and PubMed, which included Academic Search Premier, Cinahl, Medline and Health Source: Nursing/Academic Edition. The key words used to search the literature were: women and HIV, care, carer, caregivers of HIV and care burden.

2.1 Concept of care

Leininger (1988:4) defines caring as the direct or indirect nurturing and skilful activities, processes and decisions that people need to grow, remain well, avoid illnesses and survive or face death. She states that caring is provided in a manner that reflects behavioural attributes which are empathetic, supportive, compassionate, protective, educational and others depending on the needs, problems, values and goals of the individual or group being assisted, and that care and support are needed most when people fall sick (Leininger, 1988:4). According to Leininger, "caring is the essence of and unifying intellectual and practical dimension of professional nursing" (2001:5). Professional nurses have traditionally exhibited caring behaviours such as compassion, support and comfort which are important to client recovery (Leininger, 1988:4); therefore, caring is the heart and soul of nursing, which people seek most from professional nurses and health care services (Leininger, 2001:5).

While Leininger's definition of care provides a good understanding of the concept, it is centred primarily on clinical care by trained people. Ogden *et al.* (2004:3) present a definition of care that extends beyond clinical care by professionals. They state that "care and support are terminologies used interchangeably to reflect both clinical and non-clinical care, treatment focused activities, emotional and spiritual support, counselling and other activities that are health oriented such as income generating projects" (Ogden *et al.*, 2004:3). Ogden *et al.* (2004:3) further argue that care encompasses more than daily nursing activities and involves any activities that contribute to the welfare of others, including visiting others,

sharing money and food, providing labour and attending funerals - demonstrating that care and support are necessary even in the absence of disease.

Kyle (1995:512) reviewed literature on the concept of care and concluded that caring is a complex phenomenon that involves more than a set of caring behaviours. It is a process that entails physical, moral, cognitive and emotional components which are culturally derived (Kyle, 1995:512). Caregivers can be affected physically, morally, cognitively and emotionally in the process of care provision.

A carer is defined as a person who spends time and energy to care for another person who needs extra attention because of his/her age, illness, physical or other disability (Battison, 2002:134). Studies indicate that when care is given at home it is always provided by the informal caregiver, mainly close relatives (Akintola, 2004:22; Battison, 2002:134). Prior to the HIV epidemic, care of sick people was often provided in hospitals; however, the HIV and AIDS epidemic has elevated the importance of home care.

Van Dyk (2005:323) states that home-based care is any form of care provided to chronically ill people in their homes. According to Uys and Cameron (2003:3), home care programmes started in North America and Europe in the 1980s when hospital care became too expensive. There are developed home care systems in most African countries, although coverage and access is still not universal (Uys and Cameron, 2003:3). Uys and Cameron (2003:4) describe home-based care as involving the provision of necessary health care by a primary caregiver to a patient or family at home, often supported by a community caregiver. They described systems that have been developed to offer home-based care: integrated home-based care, single-service home-based care and informal-based care (2003:5). The integrated home-based care model links all the service providers (families, community caregivers, clinics, hospitals, support groups, non-governmental organisations (NGOs) and community-based organisations) with patients and their families in a continuum of care. In the single-service home-based care system, one service component (a hospital, clinic, NGO or church) organises home-based care by recruiting volunteers, training them and linking them with patients and their families at home. In the informal home-based care system families care for their members at home with the informal assistance of their own social networks, with no specific training or external support (unlinked care).

Although Uys and Cameron (2003:7) suggest that it would be ideal if all home-based care could be delivered through an integrated model, because the patients and the family get all the help they need throughout the period of illness, this is often not the case. Ogden *et al.* (2004:3-4) and VSO (2006:4) argue that care is mostly provided by untrained and unpaid family members (mostly females), friends and neighbours of the patient, and it is not linked to any formal care and support system.

The World Health Organization (WHO) has classified caregivers of persons living with HIV and AIDS as health professionals; children, volunteers, elders, social workers, priests and other people are involved in that role (1993:10). Many people who are living with HIV and AIDS, especially when in clinical stages III and IV of the disease, are nursed at home. Among other reasons, this is a response to an HIV and AIDS epidemic that has led to an overflow of patients in many hospitals.

2.2 Women and HIV/AIDS

The global report on the AIDS epidemic describes how women and girls are affected by the HIV and AIDS epidemic differently to men and boys, due to their unequal biological and socio-economic status (UNAIDS, 2006a:42). Gender inequality not only underlies women's vulnerability, it also limits efforts to protect themselves and their families (Baylies and Bujra, 2000:3).

A high prevalence of HIV in women has been reported from different countries, particularly in sub-Saharan Africa. The global report on AIDS indicated that in 1997, four out of ten people living with HIV and AIDS worldwide were women. By 2004 women made up almost 50% of people living with HIV and AIDS (UNAIDS, 2005b:4). In recent years it has been noted that about 60% of adults living with HIV and AIDS in sub-Saharan Africa are women, and almost 75% of young people living with HIV in Southern Africa are females (Kleintjes, Prince, Cloete and Davis, 2005:72). The UNAIDS report for 2007 indicates that women are the most affected group (2007:8). This report estimates that about 61% of adults living with HIV and AIDS in the sub-Saharan region are women.

In South Africa HIV prevalence among persons aged 2 years and older has been estimated to be 10.8%, with a higher prevalence in females (13.3%) than in males (8.2%) (Shisana *et al.*,

2005:34). They reported that the prevalence was high (16%) among the group aged 15-49 years; in this group too the prevalence among females (33.3%) was much higher than among males (23.3%) (2005:34).

In Tanzania almost all population-based studies indicate higher HIV prevalence among women than men (MEASURE, NACP and NBS, 2001:67). A survey conducted in Tanzania by TACAIDS *et al.* (2005:1) indicates that 7% of the adults aged 15-49 years are infected with HIV, the prevalence in women (8%) being higher than in men (6%). Further, it was reported that HIV prevalence among young women is higher than among young men in almost all regions of Tanzania.

The WHO states that social-cultural norms which involve systems of oppression have increased women's vulnerability to HIV infection (WHO, 2003:9). Women's marginalised status indicates that they have less power to negotiate safe sex and reproductive health matters, less economic independence, less education and less access to health care, all of which exposes them to infection (WHO 2003:9). Women's vulnerability to HIV infection and the cultural norms of females being the carers have a significant impact on the burden of care on them.

Women are subjected to different misfortunes. Girls are the first to be removed from school when poverty forces families to prioritise the educational needs of their children (Bond, 2005:5). This increases their vulnerability to traditional practices found in African countries, such as early marriages which parents force in order to receive 'bride price' from the family of the groom (Bond, 2005:5). Additionally, polygamy, which is practiced in these countries, negatively affects women and increases their risk of contracting HIV and AIDS (Bond, 2005:5). As a consequence, women in Africa are the group most affected by the epidemic.

2.3 HIV/AIDS care and treatment

ARV treatment has been successful in reducing the rate of virus replication, hence lowering the viral load in the body of the affected individual. The drugs cannot cure the disease, but slow its progression (Castleman, Seumo-Fosso and Cogill, 2004:3; Evian, 2003:81).

The ARVs commonly used in low-resource settings are divided into two classes: reverse transcriptase inhibitors and protease inhibitors, which act at different stages of virus replication (Castleman *et al*, 2004:4; Evian, 2003:81). The third class of fusion inhibitors has not yet been included in the WHO recommendations for low-resource settings (Castleman *et al.*, 2004:3). Reverse transcriptase inhibitors consist of non-nucleoside reverse transcriptase inhibitors (NNRTIs) and nucleoside reverse transcriptase inhibitors (NRTIs). NNRTIs (Efavirenz and Nevirapine) bind on the reverse transcriptase and prevent HIV RNA from converting into DNA, while NRTIs (Lamivudine, Stavudine, Zidovudine, etc.) prevent viral DNA from producing copies of the virus (Castleman *et al.*, 2004:3). Protease inhibitors (Indinavir, Ritonavir, etc.) act on the protease enzyme to prevent the assembly of new HIV material which is released to infect other cells. The drugs from these classes are combined and used together to reduce the chances of resistance. In Tanzania the Ministry of Health recommends four different combinations of drugs for adults and adolescents (NACP, 2005b:94). All patients commence therapy on: Stavudine + Lamivudine + Nevirapine. However, patients can be prescribed:

- Zidovudine + Lamivudine + Nevirapine if there is peripheral neuropathy
- Stavudine + Lamivudine + Efavirenz if there is tuberculosis (TB) and anaemia (< 7.5 g/dl)
- Zidovudine + Lamivudine + Efavirenz if there is TB and no anaemia.

The combinations of ARVs are used according to indications and contraindications to minimise side-effects and drug interactions.

The development and approval of ARVs in 1996 is considered a great success story of modern medicine in many developed countries, changing the previously fatal HIV and AIDS into a chronic disease (Wyllie, Strike, Antoniou and Bayoumi, 2007:1). It is estimated that ARVs have reduced HIV-related deaths by about 80% in these countries (Koenig *et al.*, 2006:602). However, this is not the case in developing countries where extreme poverty complicates efforts towards roll-out of ARVs. In addition, critical concerns regarding toxicity, adherence and widespread development of viral resistance have been reported from these countries (Curran *et al.*, 2005:1-2).

The accessibility and cost of ARVs to people living with HIV and AIDS in low-resource settings have significantly affected efforts to reach all the people in need of these drugs.

Although the number of people on ARVs has increased in Africa (for example, in South Africa the number has increased from fewer than 5000 at the beginning of 2004 to 190 000 by the end of 2005), about 80% of those in clinical need of ARVs are not receiving them due to barriers such as lack of infrastructure, poor transportation, shortages of trained workers, stigma and discrimination (UNAIDS, 2006b:155). Consequently, UNAIDS estimates that over 5700 people die from AIDS every day, mostly due to inadequate access to HIV prevention and treatment services (2007:4).

In Tanzania, as in other countries, international development has at least opened up the possibility of a limited number of people living with HIV and AIDS having access to life-prolonging treatment (TACAIDS, 2003:46). Tanzania receives various sources of funding from organisations such as Global Fund to Fight AIDS, the Clinton Foundation, the Swedish International Development Agency and the US President's Emergency Plan for AIDS Relief (PEPFAR) (WHO, 2006:177). In line with this, the Tanzanian government has developed the HIV and AIDS Policy, that emphasises disease prevention, care and treatment (The United Republic of Tanzania, 2006:22). The government provides free ARVs through public hospitals and NGOs (The United Republic of Tanzania, 2006:22). It has brought on board non-State actors, including faith-based organisations, in the fight against the disease. Moreover, the Government of Tanzania has developed a Strategic Plan for HIV and AIDS which aims at scaling up the availability of supplies including ARVs and other commodities such as condoms, and ensuring access to all (The United Republic of Tanzania, 2006:22).

Although the government is making efforts to implement comprehensive care and treatment, NACP (2005:18) states that "there is still a long way to go to achieve equity and reach all of those in need". There are a number of challenges that hinder implementation of plans, such as unavailability of drugs, increased costs of drugs, resistant strains of HIV which necessitate the use of expensive combination therapies, rapidly changing medical technology, and lack of adequate human resources (The United Republic of Tanzania, 2006:17). Moreover, the health systems are weak and unable to support the growing demands brought about by the HIV epidemic. For instance, health facilities in Tanzania lack laboratory facilities to conduct CD4 cell counts, which are needed to monitor the efficacy of the treatment and to decide when to start drugs (WHO, 2006:14). As a result of this, people have to wait for some time before they can be put onto ARVs. The success of the ARV programme in developing countries such as Tanzania is questionable.

Studies conducted in Tanzania, Botswana and Uganda to determine adherence levels reported that although patients are highly motivated to take ARVs as prescribed, constraints such as lack of food, transport costs, user fees, long waiting times, hunger, stigma, side-effects and lack of appropriate counselling limit them from doing so (WHO, 2006:7). All three countries provide ARVs free of charge, but transport costs are reported to be an obstacle for visiting the health facilities for follow-up and refill (2006:7).

Food insecurity was also reported in all three countries. Unlike in Tanzania and Uganda, ARV users in Botswana who have been assessed and found to meet certain criteria receive food baskets (WHO, 2006:10). In Uganda and Tanzania some people receive food support from non-governmental AIDS support organisations. This is unreliable and insufficient to meet food requirements that go along with taking certain drugs. Castleman *et·al.* (2004:5) state that food affects drug absorption, metabolism, distribution and excretion. The antiretroviral drugs affect food absorption, metabolism, distribution and excretion. Side-effects caused by drugs can affect food consumption and nutrient absorption.

The study conducted in Botswana, Uganda and Tanzania noted that in Tanzania the distance that people living with HIV and AIDS travel to obtain ARVs ranged from 1 km to 246 km. The travel costs to clinics are significant, ranging from about 20 US cents to US $30.00 per month. Patients in Uganda and Tanzania have to pay the registration and user fees in private facilities. The study further reported that in Tanzania, the private facilities charge user fees (range: US $1.50 to $3.00 per visit) and an additional US $15.00 for laboratory investigations.

Long waiting times are reported to be a major challenge to adherence. The average number of hours spent at the clinic is 6 in Tanzania and 4 in Uganda, the longest wait being 12 hours. Moreover, counselling support provided to people living with HIV and AIDS was not adequate. They were not taught about the side-effects which could be experienced in the early weeks of drug initiation and that disappear thereafter. This decreases their ability to cope with side-effects and increases the possibility of dropping out of the treatment programme. The proportion of people on ARVs that see counsellors was only 21%.

People living with HIV and AIDS and their caregivers may have problems despite the availability and effectiveness of ARVs. A study conducted in Toronto on the adverse quality

of life consequences of ARVs pointed out that patients on these drugs reported side-effects and toxicities, loss of self-esteem, declining mental and sexual health, and increased stigmatisation (Wyllie *et al.*, 2007:256). It is apparent that caregivers are affected when their patients face difficulties with their drugs, and sometimes they also suffer from the consequences such as stigma and discrimination. The effects of these consequences are deteriorating social interactions and interpersonal relationships (Wyllie *et al.*, 2007:256), rendering care at home difficult.

The development of ARVs for people living with HIV and AIDS has brought with it new challenges (including those to do with drug adherence) that need attention. The studies discussed pointed out some causes of non-adherence, such as unavailability of food, long distance to clinic centres, stigma and discrimination, and long waiting times for consultations. Caregivers of people living with HIV and AIDS who are on ARV are supposed to ensure appropriate administration of drugs, availability of drugs, and monitoring of side-effects - stressful activities in addition to their other responsibilities.

2.4 Women's burden of care

All over the world women are expected to take the lead in domestic work and in providing care to family members (UNAIDS, 2006a:7). The HIV and AIDS epidemic has increased the burden of the domestic role. According to UNAIDS (2006b:61), "poverty and poor public services have also combined with AIDS to turn the care burden for women into a crisis with far-reaching social, health and economic consequences". Caring for a sick individual - in this case a person with AIDS - over a lengthy period may lead to stress and burn-out.

VSO noted that more than 6.5 million people living with AIDS currently need ARVs and many more need treatment for opportunistic infections, palliative care, general nursing care and emotional support (VSO), 2006:4). However, the public health systems in most developing countries do not have the capacity to provide the necessary care and support; as a result, most people living with HIV and AIDS turn to family, neighbours and friends for care (VSO, 2006:4). It is mostly women and girl children who bear the burden of caring (UNAIDS, 2006a:15; WHO, 2003:17).

Despite the existence of excellent laws and sound policies, many communities have failed to protect women and girls from HIV infection and the social consequences of AIDS (UNAIDS,

2004: 12). It is apparent that the gender inequality which exists in society and the socio-cultural norms that define the roles and responsibilities of men and women account for women's burden of care of people living with HIV and AIDS. Typically, men are expected to be responsible for the productive activities outside the home, while women are expected to be responsible for reproduction and productive activities within the home (WHO, 2003:17; UNAIDS, 2006a:15). Therefore, women and girls more than men and boys are likely to assume responsibilities for those who are sick and in need of care such as orphans and HIV/AIDS patients (UNAIDS, 2005:9).

A study conducted in Ottawa, Canada, on the burden on caregivers of breast cancer patients reported that the caregiver's depression and perceived burden increases as the patient's functional status declines (Grunfeld *et al.*, 2004:1795). The study found that caregivers were more anxious than patients and were more likely to be depressed, especially when patients approach the terminal stage of illness. In this study, 75% of working caregivers reported that they had to miss work because of their caregiving responsibilities. The researchers suggested that strategies are needed to help reduce the psychosocial, occupational and economic burden associated with caregiving.

The report on the global AIDS epidemic by UNAIDS (2006b:18) referred to a recent study conducted in Northern Zambia that explored the dynamics of the impact of HIV on families and communities. This study compared five household categories: female-headed households with orphans; male-headed households with orphans; female-headed households taking care of people with HIV-related illness; male-headed households taking care of people with HIV-related illness; and non-affected households. The study reported that female-headed households taking care of people living with HIV supported an average of 3.6 orphans each, far more than male-headed households; again, these households were less able to participate in community-based organisations and had fewer assets such as radios and bicycles. Again, this demonstrates the burden of care on women.

A recent study on the psycho-social impact on caregivers of people living with AIDS conducted in South Africa reported that care-giving placed considerable demands on caregivers. This was exacerbated by insufficient support, poverty, and the added responsibility of caring for other family members. According to Orner (2006: 236), lack of basic resources was reported to be common and chronic. It was further reported that care-

giving impacted negatively on employment and social life Stigma and discrimination towards caregivers were reported to be common, and this exacerbated their stress levels.

In Tanzania it is common for women to take on the main responsibility for caring for their families. Activities include fetching water, cooking, bearing children and taking care of them, agricultural activities and taking care of cattle. They are also involved in activities that earn money for the family, such as art, crafts and gardening (Thompson, 2007:2). According to Thompson (2007:2), women are the major producers and preparers of food; they generate income to facilitate access to food; they ensure that household nutritional requirements are met, and by doing this protect the health of children and other members of the family. When a family member falls sick, his/her care means more responsibilities in addition to the existing normal burden of care experienced by women (Niranart, 2006:125). The need to maintain this highly valued caring role sometimes leads to women's silence about their HIV status (WHO, 2003:9). Therefore a woman who is also HIV-positive continues to care for others in her family who are in need of care. This is likely to pose challenges to the woman's psychological and physical well-being (Brandt, 2005:11).

Caring for a sick member of the family drains family income, and if the sick person is a family breadwinner the situation worsens. The time spent on caring for people living with HIV and AIDS could be time used by women for food production. The burden of care becomes heavy and enduring, particularly when public and private support services are lacking or unable to cope with demand (UNAIDS, 2005:4). Caring that takes place in extreme poverty with lack of support has a big impact on the health of a woman. Brandt (2005:11) argues that "the multiple stressors associated with poverty, HIV and AIDS care-giving quite clearly put women caregivers at increased risk for mental health problems".

A cross-sectional study conducted in Bumbu district, Kinshasa, Democratic Republic of Congo, on 80 women caregivers of HIV-infected spouses revealed that their caring role was conducted in difficult situations (Kipp, Nkosi, Laing and Jhangri, 2006:695); 94% of participants reported that caring was difficult. Only 25% of these women received support from relatives, friends, in-laws and husbands' employers. Those who did not receive support believed that this was due to stigma and discrimination. Almost all of the participants reported that they frequently faced lack of food and an irregular drug supply. Lack of food was sometimes due to lack of money and availability. Of these women, 89% reported that

care-giving was stressful, and 90% women reported having experienced stigma and ostracism and having been subjected to negative reactions from relatives, friends, neighbours and their husbands' employers. The caring responsibilities reported by these women included buying food, cooking and feeding, seeking resources, moving the patients, giving medications, staying with the patient, and communicating with health care professionals, relatives and husbands' employers. The burden of care documented in this study went hand in hand with high levels of social isolation, low self-reported health status, high stress levels and deep unhappiness (Kipp, Nkosi, Laing and Jhangri, 2006:695).

Caregivers experience many problems due to the overwhelming burden of caring for their relatives, spouses, children and loved ones who are infected by HIV. There are emotional, cultural, sexual, religious, and legal issues that, if not managed, may lead to stress and burnout. Bellani *et al.* (1996:209) give reasons for stress and burn-out as close interaction with clients, excessive demands, time pressure and job stress. Stress and burn-out affect the caring role (Miller *et al.*, 2006:126) and also undermine caregivers' ability to give compassionate care (Uys and Cameron, 2003:5). This suggests a high-priority need for support to caregivers, and that new home-based care arrangements should respond flexibly and sensitively to the carers' needs.

2.5 HIV-related stigma and discrimination

Stigma is a Greek name which was given to visible marks that resulted from tattoos marked on people who broke society's laws (Holzemer and Uys, 2004:166; Mills, 2006:499). Parker and Aggleton (2003:14) argue that society conceptualises stigma as a negative attribute that causes undesirable differences, leading to a spoilt identity. As a result, people who have those attributes are ostracised and blamed for their social deviance. HIV and AIDS is sexually transmitted and thus is associated with deviant sexual behaviour. In addition, HIV and AIDS is a lethal and contagious disease. Stigma in this case therefore comprises fears such as fear of death, fear of contracting a disease and fear of isolation. The clinical manifestations such as wasting syndrome experienced by persons suffering from HIV and AIDS mark them as AIDS sufferers. Discrimination occurs as a result of stigma, and consists of actions that are deduced from stigma and directed towards those individuals who are stigmatised (UNAIDS, 2005a:5).

Stigma can occur at different levels. It can be direct discrimination against a person by family or community members (enacted stigma) (UNAIDS, 2005a:5); at this level an individual may be rejected and devalued by other people. Gossiping about and sometimes blaming people living with HIV and AIDS results in discrimination. Discrimination can also be at the institutional level (structural discrimination), such as in workplaces, health care services, prisons and educational settings (Holzemer and Uys, 2004:167; UNAIDS, 2005a:5). At this level a person living with HIV and AIDS may be denied important requirements such as adequate health care and employment. Stigma can also be internalised (self-stigmatisation), where persons living with HIV and AIDS apply labels to themselves, believe these labels and live accordingly (Holzemer and Uys, 2004:167; UNAIDS, 2005a:5). This emanates from the shame associated with AIDS, which has a powerful psychological influence on how people living with HIV and AIDS view themselves. The consequences of this are isolation and lack of engagement with support and care services.

UNAIDS (2005a: 4) states that stigmatisation is underpinned by different factors such as lack of understanding of the illness, misconceptions about how HIV is transmitted, lack of access to treatment, and incurability of the disease. Although discrimination on the grounds of one's HIV status is considered a violation of human rights (UNAIDS, 2005a:4), nevertheless the problem remains unchallenged (Parker and Aggleton, 2003:14). Parker and Aggleton (2003:17) argue that strategies that have been used to mitigate stigma are focusing on stigma as an individual rather than a social process, thus ignoring the important aspect of social context, culture and differences that exist. These authors argue that stigma and discrimination function at the point of intersection between culture, difference and power (2003:17). The power difference is well demonstrated by the fact that the stigmatised group accepts and internalises the stigma and discrimination they are subjected to, following the negative evaluation of an attribute caused by the disease. This suggests that approaches to combating stigma should focus beyond the psychological and biomedical model and address social, cultural and other forces in the social context that structure it.

Studies in various places have reported that HIV-related stigma is a huge problem that has been interfering with efforts in respect of prevention, care and treatment, HIV testing and disclosure (Akintola, 2004:30; D'Cruz, 2002:1; Holzemer and Uys, 2004:166; Mills, 2006:501; Poindexter, 2002:65; UNAIDS, 2005a:4). In Tanzania the level of acceptance of people living with HIV and AIDS is low. It is estimated that less than 50% of Tanzanians

have attitudes of acceptance towards people with HIV (TACAIDS *et al.*, 2005:25), which indicates high levels of discrimination. Consequently, less than one in ten adults nationwide has taken an HIV test and received the results (TACAIDS *et al.*, 2005:25). According to TACAIDS et al. (2005:26), people who have requested and received an HIV test and the results in Dar es Salaam region, Tanga, Kilwa and Arusha represent only 12-24% of the population.

A WHO study conducted in Tanzania, Uganda and Botswana showed that some people living with HIV and AIDS who disclosed their HIV status lost their employment, were abandoned or badly treated by their partners and were isolated by community members after disclosure (WHO, 2006:10). People living with HIV and AIDS develop fear about disclosing their status to colleagues, friends and relatives. This has negatively impacted on their care, adherence to treatment and support of people living with HIV and AIDS.

In South Africa studies indicate that home-based care providers have had problems in finding people willing to receive care through these services due to stigma and discrimination (Akintola, 2004:30; Holzemer and Uys, 2004:166; Mills, 2006:501). Rabbets and Edwards (2001:6) conducted a study in KwaZulu-Natal to examine needs experienced during the late stages of AIDS, and noticed that people living with HIV and AIDS experienced social isolation after disclosure and therefore refrain from disclosing their status for fear of such isolation by relatives (2001:6). This might also have had an influence on their access to ARVs.

In Ethiopia and Zimbabwe studies on stigma found that women attending antenatal clinics were not ready for HIV testing due to fear of stigma and discrimination (Holzemer and Uys, 2004:169). Another study in Zimbabwe found that stigmatisation results in silence, secrecy and denial, which affect care and treatment and have serious implications for prevention of the disease (Duffy, 2005:16). Failure to use the available services effectively and timeously due to stigma and discrimination has negative implications on disease progression in people living with HIV and AIDS.

Caregivers of people living with HIV and AIDS are also stigmatised. A study in India on family caregivers showed that they faced difficulties due to high levels of stigma and discrimination (D'Cruz, 2002:1). In this study caregivers reported that soliciting support was

accompanied by feelings that the HIV status of the patient might become known and communicated further. To minimise discrimination they sought help only at critical points when there were no other options (D'Cruz, 2002:1). Similar findings were found in a study conducted in South Africa by Mills (2006:501), which indicated that caregivers discouraged their patients from disclosing their HIV status and from accepting food parcels provided by home-based care centres for fear of discrimination (instead they travel to distant areas where they are not known to seek care and treatment). This affects caregivers' and patients' emotional, physical and mental health. Moreover, it can contribute to poor management, rapid progression of the disease and a high burden of care.

2.6 Poverty in Tanzania

Tanzania is a country with 25 regions and a population of about 35 million. Poverty throughout the regions is profound and pervasive. It is estimated that 17.74% of the Tanzanian population live in households with total expenditures insufficient to obtain enough food to meet nutritional requirements (The United Republic of Tanzania, 2006:4). The Millennium Development Goals progress report indicates that poor people are concentrated in rural areas, but urban poverty is also widespread and growing (The United Republic of Tanzania, 2006:4). This report states that in 2001 about 35.6% of households were unable to meet their food and non-food basic requirements.

Although the government is making efforts to reduce poverty, this is challenged by a number of factors. There is a high illiteracy level. The HIV indicator survey shows that about 58% of adults have primary education only (TACAIDS *et al.*, 2005:2), and the literacy level is lower in women. The survey indicated that 22% of women and 11% of men have never been to school. Consequently there are high levels of unemployment. These and other factors account for slow progress in economic growth and limited success in combating the HIV epidemic.

In some countries such as South Africa there are grants available to vulnerable groups such as children and those with ill health and/or disability. This provides a level of economic and social protection (Hosegood, Preston-White, Busza, Moitse and Timaeus, 2007:1255). In Tanzania there is no social security system in place.

Although the gross domestic product rose from 4.8% in 2000 to 6.8% in 2005, it is not enough to address the poverty in Tanzania (The United Republic of Tanzania, 2006:8). The general socio-economic status of people in Tanzania is poor. The Millennium Development Goals progress report indicates that the roofing materials used for rural houses are mainly grasses, and that only 11% of households are connected to electricity (The United Republic of Tanzania, 2006:4). About 75% of households were found to be within 6 km of a primary health facility. Those who do not have access to piped water obtain water from unprotected sources such as rivers, lakes and uncovered wells.

2.7 Conclusion

The literature review indicated that women are more affected by the consequences of HIV and AIDS, especially in the sub-Saharan region of Africa. Informal women caregivers of people living with HIV and AIDS experience a number of problems which threaten home care. Although there are existing social support systems for individuals living with HIV and AIDS, the literature highlights the fact that more needs to be done to address caregivers' needs. It was seen that stigma and discrimination are huge problems that affect both the patients and their caregivers. In Tanzania there is limited information on informal women caregivers of people living with HIV and AIDS at home. In the light of this, this study sought to explore and describe the experiences of informal women caregivers who are caring for people living with HIV and AIDS at home in Dar es Salaam, Tanzania.

CHAPTER 3: METHODOLOGY

3.0 Introduction

This chapter presents the study design and describes the study setting, population, sampling method and process followed to gain access to the study population. Ethical issues, the researcher's preparation, data generation, rigour of the study, and data management and analysis are presented.

3.1 Study design

The study is a qualitative, descriptive, exploratory study based on an interpretive paradigm. According to Holloway and Wheeler (1996:2), qualitative nursing research adopts a person-centred and holistic perspective. The qualitative approach develops an in-depth understanding of human experiences, which is important for health professionals who focus on caring, communication and interaction (Holloway and Wheeler, 1996:2). These authors argue (1996:3) that through the interpretive paradigm approach, nurse and midwife researchers gain rich knowledge and insight about human beings as well as focusing on their social and cultural context and not just on specific conditions.

Bowling (1997:103) states that "each branch of scientific enquiry is based on a set of theoretical perspectives or paradigms which consist of a set of assumptions on which the research questions are based". Theoretical perspectives are important because they direct attention and provide frameworks for interpreting observations (Bowling, 1997:103). Researchers are encouraged to be aware of their own theoretical perspectives and assumptions about the research topic.

According to Holloway and Wheeler (1996:12), contemporary interpretivists claim that the experiences of people are context-bound; therefore they cannot be free from time and location or the mind of the human actor. It is the researcher's belief that factors such as socio-cultural norms contribute to women's experience of caring for people living with HIV and AIDS. This research focused not only on the objectively verifiable facts, but also on other subjective meanings that informal women caregivers attach to them (Ulin, Robinson and Tolley, 2005:19). According to Ulin *et al.* (2005:19), identifying, sorting and analysing

meanings in relation to objective behaviour (decisions, actions and practices) are the methodological substance of the interpretive framework. Holloway and Wheeler (1996:12) argue that researchers must understand the socially constructed nature of the world and realise that values and interests become part of the research process. Holloway and Wheeler (1996:189) further explain that the researcher in qualitative research is the main research tool, and that the identities of researchers infringe upon their work as they record what they hear, feel and see. In this regard the researcher documented and clearly identified what she knows about the experience of caring for HIV and AIDS patients before the interviews. This process provided a guide around potential researcher bias, to represent the study participants fully and more credibly (Ulin *et al.*, 2005:166).

The study focused on exploring and describing the experiences of informal women caregivers from Temeke district in Dar es Salaam region in caring for persons living with HIV and AIDS at home. According to Ulin *et al.* (2005:18), the type of research questions that arise in an interpretive framework address the "how" and "why". The researcher used these types of questions, which allowed the participants to give in-depth information concerning their experiences in caring for people living with HIV and AIDS.

3.1.1 The study setting

The study was conducted in the Temeke district, which is one of the three municipalities of the Dar es Salaam region. This region is densely populated, with about 3 million people. It is estimated that 50% of Dar es Salaam's population live in the Temeke district (Environmental Protection Agency, 2003:1). The district is organised into 24 wards and 97 streets. Approximately 19% of households in the Dar es Salaam region live below the poverty line. The area is unplanned, with overcrowded dwellings and informal roads. Housing varies from brick dwellings roofed with iron sheets to moulded houses roofed with grasses. As in other regions of Tanzania, electricity is available to some houses and is only used on a limited basis due to high power costs. It is estimated that more than 65% of households in urban areas use charcoal as source of energy for cooking (TACAIDS *et al.*, 2005:2). In some parts of Dar es Salaam access to water is a big problem, hence women and girls spend considerable time searching for water and walk for more than 1 km to water sources (The United Republic of Tanzania, 2006:4). Some people have access to water from local wells.

The study was conducted through PASADA, a church organisation located in the Temeke District, Dar es Salaam. PASADA was started in 1992 to serve people in the Dar es Salaam region who are affected by HIV and AIDS, with particular attention to the poorest (Maas, 2003:4). According to Maas (2003:4), PASADA provides spiritual, social, medical and material relief to all individuals without any kind of discrimination. Medical assistance (TB diagnosis, ARV therapy and routine laboratory tests), counselling services, home-based care programmes (general care and medication, support to family caregivers, pain control) and other services are provided. PASADA provides counselling, support services and visits to extended families raising children whose parents have died from HIV and AIDS. Maas (2003:4) states that the organisation has provided school fees and other requirements enabling over 700 children to continue with their education. More than 1300 children and 8000 clients have received support services from PASADA (Maas, 2003:4). It is estimated that there are over 1000 patient visits each month, and the medical clinics follow up over 500 children with HIV (Maas, 2003:4).

3.1.2 Study population

The study population was informal women caregivers caring for spouses or relatives living with HIV and AIDS at WHO clinical stages III and IV, whether or not on ARVs. The researcher relied on health professionals working in PASADA to identify persons in stages III and IV of the disease. The carers of such HIV and AIDS-affected persons were approached when bringing them to the centre. Participants selected were between 18 and 50 years of age; it is the researcher's belief that this is the stage at which women's productive activities are at a peak. It is also the period of fertility and child-raising, which can impact on the burden of care that women experience when there is a sick family member at home.

3.1.3 Sampling

In the qualitative paradigm the selection of participants is determined by the information-richness of the sample (Miles and Huberman, 1994:8). Using a purposive sampling strategy, the researcher continued sampling until data saturation occurred (or no new information was obtained). Purposive sampling is defined as non-probability sampling that is based on the judgement of the researcher regarding subjects or objects that are typical or representative of the study phenomena (Brink, van der Walt and van Rensburg, 2006:133). The researcher interviewed eight participants in all. The selection was conducted as informal women

caregivers escorted their patients to PASADA community centre to seek services such as drugs for opportunistic infections and other consultations. Only those who showed interest in participating were recruited into the study. The researcher asked health professionals to identify caregivers whose spouses/relatives live with HIV and AIDS, who met the WHO criteria for stages III and IV; no personal information of the individual patient was accessed.

The inclusion criteria were as follows:

- Informal women caregivers from Temeke district.
- Women caregivers caring for one or more family members or relatives in WHO clinical stages III and IV at home.
- Informal women caregivers who have provided care for two months or more (this was considered sufficient caring experience).
- Caregivers between the ages of 18 and 50 years.

The exclusion criterion was:

- Informal women caregivers who, although meeting the above criteria, were not interested in participation.

3.1.4 Gaining access to the study population

The researcher requested permission from PASADA management to conduct the study by writing a letter (see Appendix 1), and the proposed study was introduced to them. Since stigma and discrimination related to HIV and AIDS is a considerable problem in Tanzania (TACAIDS, 2003:48), the researcher requested that staff at the centre mediate access to the caregivers. The researcher introduced the study to the staff, who then explained it to the patients in private, without the researcher present. Women who met the above inclusion criteria and were interested in participation were introduced to the researcher. The researcher explained the study to each interested person individually in a private setting. Should the woman still wish to participate, written informed consent was negotiated. All the participants who were introduced to the researcher were interested in participating in the study. Once the woman had consented to participate, a suitable time and venue were negotiated for the interview.

3.2 Ethical considerations

Approval for the study was obtained from the University of Cape Town, Faculty of Health Sciences Research Ethics Committee and the Aga Khan University, Tanzania (the researcher is a staff member at this university). After approval of the study, permission was sought from PASADA to allow the researcher to conduct the study. The researcher conducted interviews after permission was granted by the PASADA management.

The researcher was guided by fundamental ethical principles when conducting this study: that of respect for persons, beneficence, non-maleficence and justice. These ethical principles are based on the human rights that need to be protected in research, and include the right to self-determination, to privacy, anonymity and confidentiality, to fair treatment, and to being protected from discomfort and harm (Brink *et al.*, 2006:133).

3.2.1 Principle of respect for persons

Respect for persons implies a respect for autonomy or the right of people who are capable of making decisions to make those for themselves (Trevor, 1999:6). The researcher addressed this principle by obtaining individual informed consent that ensured participants' understanding of the purpose of the study, the risks and benefits of participation, and that their participation was voluntary (see Appendices 2 and 3). The researcher treated participants as autonomous agents, observing their rights to self-determination and protection. The participants were free to ask questions and the researcher provided information.

3.2.1.1 Confidentiality

Confidentiality is an important aspect of respect for persons. The participant's name is not listed in any research report. The participant was offered the opportunity to use a pseudonym of her own choice for the interview if she so desired. The participants were informed that any information provided to the researcher was confidential and would not be shared with anybody without prior consent. The study was conducted in a room with privacy observed.

Numerical codes were used instead of real names for the purpose of identification (e.g. P1). These codes were used to label the recorded interviews. Audio interviews, the list of names

of participants and any other identifying documents were kept locked away and accessed by the researcher only. The personal particulars of the participants were not provided to a colleague who in ensuring the researcher's accuracy reviewed the translated interviews: this colleague was also informed about managing data confidentially.

The data will be destroyed after completion of the study and write up. The researcher will inform the participants when the data will be published for the benefit of other researchers.

3.2.1.2 Voluntary participation

The full understanding of the research by the participants was emphasised to allow them to make an informed choice. The participants were informed that they had a right to choose to participate or not, and to withdraw from the interview at any time, and that this would not in any way affect the services that they received from PASADA. The researcher embarked on the study only after the participants had adequate information about the research and had voluntarily given their informed consent.

3.2.1.3 Informed consent

The informed consent form had been designed in English and translated in Kiswahili, which is the local area language (see Appendices 2 and 3). The form included the researcher's title and position, description of the nature of the study, description of risks and harm from the study, description of the benefits expected from the study, and the contact details of the researcher. Anonymity, confidentiality and voluntary participation were emphasised.

3.2.2 Principle of beneficence

This principle requires the researcher to do good and maximise the benefits of research, and that research should justify the expected risks or harm. The risks and benefits of the study were clearly shared. The participants were informed that there would be no immediate benefit from the study. For example, no payment would be provided for participation, but the findings may provide information which will be useful to the organisations which provide support.

3.2.3 Principle of non-maleficence

This principle requires the researcher to conduct a study that will minimise any harm to the participant. The study involved sharing experiences that might have provoked pain and powerful emotional reactions. In this regard the researcher allowed time for the participant to reflect and share her experiences. The researcher prepared the counsellor from PASADA prior to interview for participants who might have required further support and counselling. Although the participants showed high levels of stress (such as crying) during interviews, no participant required further support from the counsellor. They recovered and continued with the interview. Should a participant have become unduly distressed during the interview, the researcher would have offered to terminate the interview or have allowed time for the participant to recover. There was no pressure on any participant to provide information which was not volunteered.

3.2.4 Principle of justice

This principle requires fair distribution of benefits and burden as well as fair treatment. As far as possible the researcher will ensure that findings are made available to PASADA and the Ministry of Health and assist in implementing any changes on her return to Tanzania. The researcher selected participants who met the study inclusion criteria and treated them fairly throughout the study.

3.3 Researcher preparation

The study involved a sensitive topic which required the participants to reflect on personal feelings. This could provoke powerful emotional reactions in participants and the researcher. Oskowitz and Meulenberg-Buskens (1997:83) suggest that the researcher be prepared to handle interpersonal aspects of qualitative research with sensitivity and skills. They further state that researcher preparation is required for the research to be trustworthy The process of preparing the researcher involves reflecting on the research topic, research situation and on the suitable method, and training in the capacity and skills needed in conducting the study (Oskowitz and Meulenberg-Buskens, 1997:83). The researcher was aware of the sensitivity of the topic. She attended a workshop on interviewing skills before conducting the interviews, and also arranged for debriefing sessions to be available after interviews if

required, with an experienced counsellor at PASADA (Oskowitz and Meulenberg-Buskens, 1997:83).

3.4 Data generation

Semi-structured interviews were used to collect data which allowed the researcher to ask specific questions, and also to pose additional probes (Brink *et al.*, 2006:152). The participants were offered a choice of venue for interview. The researcher believed that the choice of venue would be influenced by the level of stigma and discrimination, and disclosure of the disease. Three of the eight participants preferred to be interviewed at their homes because they could not leave their patients. Five participants chose to be interviewed at RUHISWE (an office for HIV and AIDS community volunteers), which was closer to their homes than PASADA. All interviews took place in a quiet room, at a time convenient for each participant. Interviews were conducted in Kiswahili, the national language spoken by most Tanzanians. The interviews were conducted for approximately 45-60 minutes and recorded using an MP3 player. Interviews took place until no new information was obtained (data saturation).

3.4.1 The qualitative research interview

According to Kvale (1996:70), the qualitative interview is a uniquely sensitive and powerful method for capturing the experiences and lived meanings of the subject's everyday world. However, researchers using this method are cautioned to be careful due to its risk of exploitation, especially in a situation where there is prolonged contact between researcher and participants (Clarke, 2006:19). The researcher in this study conducted individual semi-structured interviews which had a structure similar to ordinary conversation but involved a specific approach and technique of questioning (Kvale, 1996:70). The researcher used the structured questions to guide the interview towards the area of study (Ulin *et al.*, 2005:83). Probes were used which encouraged depth and details (Ulin *et al.*, 2005:82) and allowed for expression of feelings and concerns. Open-ended questions and probes were used to encourage participants to interpret questions themselves (Ulin *et al.*, 2005:82) and to lessen the possibility of exploitation by the researcher (Clarke, 2006:27).

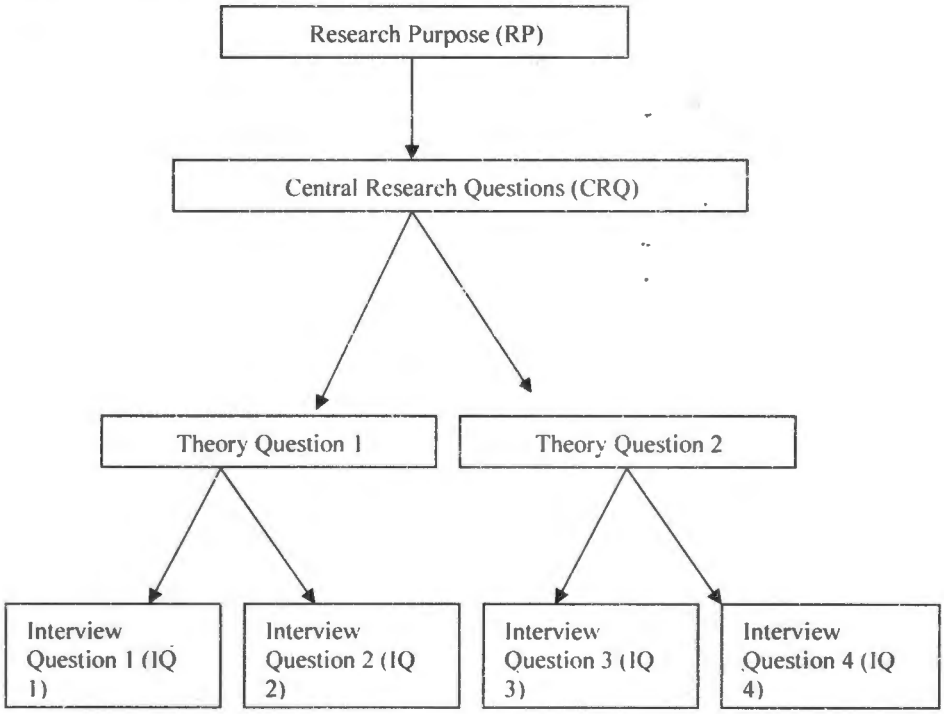
The interviews were conducted in Kiswahili, and translated into English. The researcher is fluent in both languages. This facilitated engagement with the data. Familiarity with the

participant's language enabled the researcher to use the experience of translation to discuss points in the text where she could reflect on the meaning (Temple and Young, 2004:168).

3.4.2 Formulating the questions

The questions were developed using the CRQ-TRQ-IQ pyramid model discussed by Wengraf (2001:38). According to Wengraf (2001:38), research questions are called "theory questions" and need to be clearly distinguished from interview questions or prompts that the researcher might design. Wengraf suggests that researchers use theory questions to guide the production of interview questions (see below) which are asked of participants to produce the interview material relevant to a particular theory question.

Figure 1: CRQ-TQ-IQ Pyramid Model

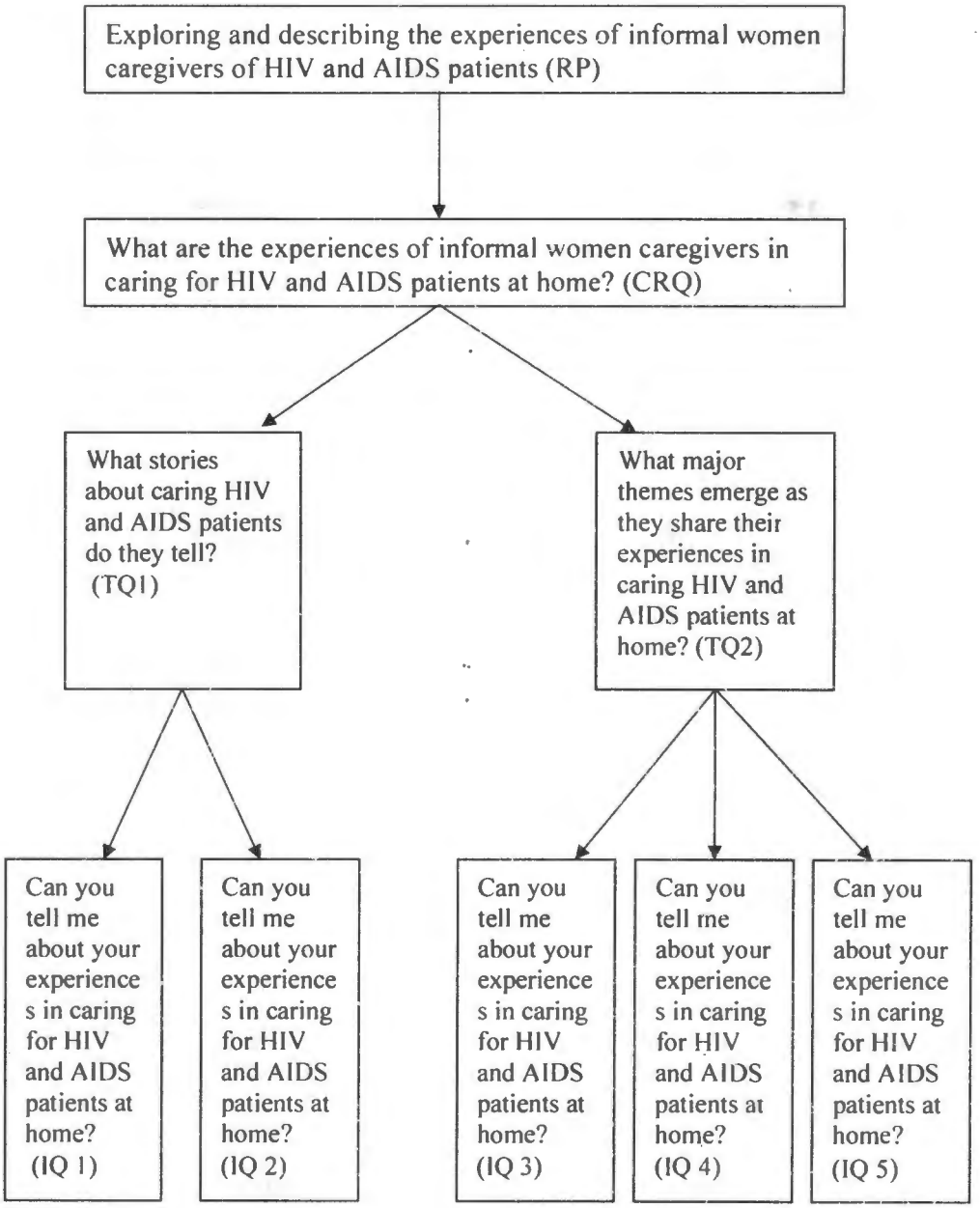


Key

RP----- Purpose of the Research
CRQ---Central Research Question
TQ----- Theory Questions
IQ-------Interview Questions

The researcher, having identified the purpose and the central research questions, used these to develop theory questions. Theory questions were used to develop questions which guided the interviews. The following diagram illustrates this process.

Figure 2: CRQ-TQ-IQ Pyramid Model – developing questions



Key

PR------Purpose of Research
CRQ---Central Research Question
TQ-----Theory Questions
IQ------Interview Questions

3.5 Pilot study

The researcher conducted a pilot study in order to pre-test the interview questions and interviewing technique. In qualitative research pilot studies are not always conducted, but they are particularly useful for refining a research question and for enabling the researcher to determine biases or improve questioning (Sampson, 2004:383). The pilot interviews for the pilot study involved two informal women caregivers who were accessed through PASADA. The findings of the pilot study were not included in the study, but were used to improve the interview questions.

3.6 Scientific rigour of the study

Bowling (1997:321) states that qualitative research requires that attempts be made to reduce bias and errors throughout the research process. Credibility, dependability, confirmability and transferability are the foundations for demonstrating trustworthiness and identifying the decision trail in qualitative research (Holloway and Wheeler, 1996: 162). According to Ulin *et al.* (2005:166), the researcher needs to immerse herself in the process of reading and rereading, labelling, dissecting, questioning and synthesising to determine the trustworthiness of the data.

3.6.1 Credibility

Credibility, also called the "truth value" (Ulin *et al.*, 2005:25), focuses on confidence in the truth of the findings, including an accurate understanding of the context. Ulin *et al.* (2005:166) further explain that credible interpretations of qualitative data offer explanations that are consistent with the data collected and are understandable to people in the study population.

The researcher moved back and forth between the design and implementation to ensure congruency between question formulation, literature, data collection strategies and analysis (Morse, Barrett, Mayan, Olson and Spiers, 2002:10) to ensure the credibility of the study. This process indicates that qualitative research is iterative rather than linear (Fereday and Muir-Cochrane, 2006:4; Morse *et al.*, 2002:10).

Prolonged engagement, persistent observation, triangulation, peer debriefing, negative case analysis and member checks increase the credibility of the findings and interpretations (Miles

and Huberman. 1994:314). Prolonged involvement means spending enough time to learn about the culture and build trust with participants in the study, because they can only be understood well when the researcher has spent enough time in the setting (Holloway and Wheeler, 1996: 164). Being an assistant lecturer at the Aga Khan University in Tanzania, the researcher has an understanding of the culture and the environments from which the participants were drawn following interaction with the community during student supervision at community sites. The time identified for the interview allowed the researcher to interact with and build a trustful relationship with the participant. In this study the researcher conducted individual recorded interviews and also took field notes. The findings from the field notes were then compared with the recorded interviews.

Holloway and Wheeler (2005:165) state that peer debriefing involves presenting data analysis and conclusions for peer evaluation, and that supervisors who have skills in the particular research approach are necessary for this role. In this regard the researcher of this study regularly met with the supervisor and other students for discussion and feedback.

Member checks, as explained by Lincoln and Guba (1985:314), allow for the participants to be consulted, ensuring that what the researcher has written is true to their experience. Due to time constraints (field work had to be conducted during the university vacation) the researcher did not conduct member checks.

3.6.2 Transferability

This refers to whether the findings can be generalised or transferred from a representative sample of a population to the whole group (Holloway and Wheeler, 1996:166). Lincoln and Guba (1985:316) state that in qualitative studies the researcher is not expected to provide an index of transferability; his/her responsibility is to provide the data base that makes transferability judgements possible. The researcher has clearly described the decision trail and an account of the theoretical framework has been provided. The researcher has given a thick description of data and the conclusions have been drawn with support from the data to enable the reader interested in making transfer to do so.

3.6.7 Dependability

Ulin *et al.* (2005:168) state that in quantitative study reliability is well tested by the extent to which the findings can be replicated, while in a qualitative study if the data are dependable, logically consistent patterns of response will be found that remain reasonably stable over time. To increase the dependability of qualitative findings the researcher in this study analysed the data and the results were given to the supervisor who reviewed them.

An audit trail is an important component of trustworthiness in a qualitative study (Lincoln and Guba, 1985:314). Lincoln and Guba (1985:314) describe an audit trail as a report (journal) of organised notes related to the background of the data, methodology used, findings and researcher's orientation to the data. The audit trail provided a report that described activities throughout the study.

3.6.8 Confirmability

Ulin *et al.* (2005:168) point out that in qualitative research the researchers check whether they have sufficiently maintained the distinction between their own and the subjects' ideas by opening the study process to outside inspection and verification. In line with this, the researcher transcribed the data and results were shared with her supervisor for verification.

3.7 Data management and analysis

Miles and Huberman (1994:50) recommend that researchers interweave data collection and analysis from the start. They argue that early analysis helps the researcher to cycle back and forth when thinking about the existing data, thus generating new strategies to collect better data. Data analysis took place from the time of data collection. This enabled the researcher to identify and fill the gaps from early interviews in order to obtain improved quality data in subsequent interviews. A contact summary sheet was used (see Appendix 4) to guide planning for the next interview, suggest new or revised codes, reorient the researcher to the contact when returning to the write up, and help with further data analysis (Miles and Huberman, 1994:52). According to Miles and Huberman (1994:51) a contact summary sheet is a single sheet with some focusing or summarising questions about a particular field contact. The questions were arranged on a single page and space left for the researcher's answers. The researcher completed the form after the raw data had been written up.

The raw data from field notes and audio recordings were processed (transcribed) within 24 hours of interview. The audio recordings were transcribed verbatim into text with verbal and non-verbal communication accurately connected. The field notes were written (typed) and made clearer; this also added back some of the missing content because when reviewed the raw data stimulated the researcher to remember things said at the time of the interview (Miles and Huberman, 1994:50). The researcher translated data from Kiswahili to English. This was given to a colleague who is fluent in English and Kiswahili to be checked for accuracy.

3.7.1 Methods and stages of analysis

Traditionally the analysis of qualitative data has been conducted manually. The data were recorded on small notes, coded and filed (Burns and Grove, 2001:591). The need to cross-check data with a bulk of paperwork can result in data loss. Computerised qualitative analysis assists researchers in processing, storage, cataloguing and sorting data programmes (Burns and Grove, 2001:592).

Data analysis was done systematically and rigorously to ensure trustworthiness of the study. Miles and Huberman (1994:65) describe systematic data analysis as a process in which a researcher works with and manages the data methodically before coming to conclusions. The approaches to data analysis described by Miles and Huberman (1994:65) were used. The researcher followed a sequence of interrelated steps in analysing the qualitative data: reading, coding, displaying, reducing and interpreting them.

The researcher used NVivo computer software that facilitated coding and systematic organisation of the data. Using this program codes were identified which were subsequently collapsed into themes. Although it has been debated by some qualitative researchers that a computer program keeps the researcher away from the data and may interfere with accuracy, nevertheless it is widely accepted that using computer-assisted programs helps to code much faster and to use more codes in a short period (de Wet and Erasmus, 2005:3; Marshall, 2002:58). The computer program assisted the researcher in managing documents and concepts more systematically and made retrieval of the information easier (Ulin *et al.*, 2005:163), allowing the researcher more time to engage with the data.

3.7.2 A close reading of data

The transcripts were reviewed and repeatedly read to help the researcher become familiar with the content and to identify the key themes and patterns arising from the data. Reading included the field notes. The non-verbal communication noted during interviews provided necessary information in conceptualising the emerging ideas. This process facilitated immersion in the data and the development of themes. Morse *et al.* (2002:81) encourage researchers to be responsive. As such, they have to remain open, use sensitivity, creativity and insight and be willing to relinquish ideas despite their excitement. They argue that researchers should listen to the data rather than adhering to instructions, be able to develop abstracts, and synthesise and step beyond the technicalities of data coding. The researcher carefully listened to the data from the initial step of analysis. As suggested by Morse *et al.*, this process helped the researcher to avoid working deductively from previous assumptions or theoretical frameworks, which threatens trustworthiness (Morse *et al.*, 2002:81).

3.7.3 First-level coding

The NVivo program requires the electronic document to be in a rich text format (rtf). Therefore the transcripts were saved as rich texts and imported into the program for coding. Miles and Huberman (1994:69) state that coding is a process that involves reviewing a set of transcripts and field notes and dissecting and keeping the relations between them meaningful. In this study the reading of transcripts was followed by the first-level coding. Codes were attached to different sizes of information, such as words, sentences, paragraphs and phrases that represented the identified themes. This helped to summarise data, make them more simplified, and place similar data together for review and interpretation.

Miles and Huberman (1994:56) state that at this level codes are descriptive and interpretive. Drawing on that information, the process of attaching codes to texts (words, sentences, paragraphs) continued through all the transcripts. The researcher explored and linked various segments of unstructured data to a certain meaningful concept. For instance, when a participant described the CD4 cell counts her patient had, the researcher linked that to the knowledge on HIV, and hence coded it under '*Caregiver's knowledge of HIV/AIDS*'. The researcher worked through each transcript and completed this before moving to the next According to de Wet and Erasmus (2005:10), this process maintains the integrity of each respondent, and prevents the voice of one from flowing into that of another. The data were

categorised, and all codes attached were described to ensure validation of the data. The description could be accessed to verify and remind the researcher about what was defined under the concept. This allowed the initial code descriptions to be refined for clarity.

In qualitative studies verification is important in ensuring rigour of the study. Morse *et al.* (2002:9) define verification as a process of checking, confirming, making sure and being certain. The researcher continually verified the data, thus ensuring a rigorous analysis. The electronic search facility in NVivo showed how many respondents were put under a certain code. The constant checking of data allowed the researcher to verify the findings. Combining codes/categories into larger groupings is recognized as data reduction (Fielding and Lee, 1998:41). This allowed visibility of the most essential concepts, and made the researcher even more familiar with the data.

3.7.4 Second-level coding

Miles and Huberman (1994:102) describe the second-level coding, also called pattern coding, as the way of grouping the summarised data into a smaller number of sets, themes or constructs. They regard a second-level coding as a meta-coding process. At this stage the researcher explored and related categories developed above to find key linkages. The software provides options to record descriptions of ideas and possible explanations with categories developed. At each stage the researcher described the concepts and attached a memo, within which she clarified the interpretation. This process stimulated deeper understanding of the data, ordering of ideas and development of relationships between the concepts.

The second-level coding was divided into two phases. In the first, clusters and hierarchies of information with some similarities were identified from the codes allotted in the first-level coding, grouped thematically and assigned new names. For example, the following free nodes (codes in the first level): *death or illness of bread earner, lack of support (no support from relatives, no support from government), unreliable income (future worries about caring expenses and income generation activities deterioration), caregiver's lifestyle changes and children assuming adult roles* were coded under the "challenges accompanying caring" tree node. Thus these free nodes became 'children' of this tree. The researcher found that some free nodes in that tree were linked. These were grouped and assigned names: *lack of support*

and unreliable income (the free nodes are in brackets). Phase two of the second-level coding involved a more detailed level of analysis. Categories developed in phase one were further reduced to sub-themes, and from further analysis of these, five major themes emerged.

The stages outlined above are defined as hierarchical categories. Richards and Richards (1995:114) state that it is common to call the categories linked to a category from immediately below it, its children. All the children under those categories are called siblings. Hierarchies are called trees because of their branching nature, although they are not oriented upwards and the category developed at the top is called a root (Richards and Richards, 1995:114).

Figure 3: Hierarchical categories

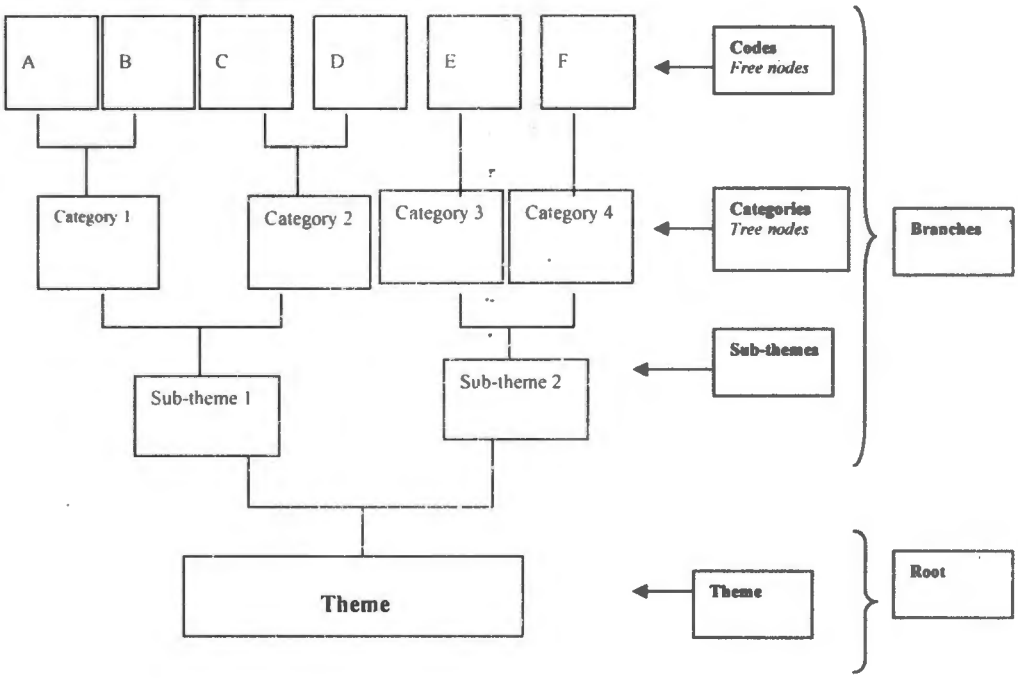


Figure 3 presents the process of analysis that produces a tree which consists of codes, categories, sub-themes and themes. Codes at the top of the tree are developed from first-level coding. Further analysis of the codes produces categories. The analysis of categories produces sub-themes. From these sub-themes the major theme is developed, as shown at the bottom of the tree. Codes, categories and sub-themes form branches of the tree while the theme developed forms a root.

The researcher mapped flow charts using Microsoft Word. The charts demonstrate the hierarchical category described above (trees with branches and roots). The trees clarify,

display and enhance interpretation of data. The researcher further used the NVivo program to create a model that mapped the codes. displaying how they related to each other. De Wet and Erasmus (2005: 20) regard this visual illustration as data display that helps the researcher in organising and seeing the full range of data when developing its interpretation. They argue that data displays prove for both verification relationships between data and making procedures and decisions transparent. According to Ulin *et al.* (2005:157), displaying data means giving an inventory of what the researcher understands in relation to a theme, capturing the variation of richness of each theme, and noting differences between individuals. The process of data display is regarded as integral to data analysis (de Wet and Erasmus, 2005:20) and it demonstrates a rigorous analysis.

After computer-aided analysis the list of all of the codes and their descriptions, the document with all memos and the codes model was printed. This was useful when writing up the findings of the study.

3.8 Conclusion

Women who were caring for their relatives or spouses provided information that reflected their experiences in caring for people living with HIV and AIDS. The study design used enabled the generation of information that reflected experiences of caring for a person living with HIV and AIDS at home. Data collection and analysis were interwoven from the beginning of interviews. A computer-assisted program (NVivo) was used to facilitate analysis of the data. The systematic analysis of data and thorough description of the process enabled themes to emerge. These are presented in the following chapter.

CHAPTER 4: PRESENTATION OF FINDINGS

4.0 Introduction

This chapter presents the findings of the study. Five themes emerged from the data analysis, which reflect the experiences of informal women caregivers of people living with HIV and AIDS at home in the Temeke district of Dar es Salaam. These themes are: caring costs and social issues; HIV-related stigma and discrimination; stress and burn-out; treatment and support system; and care burden and challenges.

4.1 Description of participants

Eight persons participated in the study, of whom four were themselves living with HIV. Two of the HIV-positive caregivers were caring for their husbands; one was caring for her child and the other caring for a cousin. All had suffered from AIDS-defining illnesses over the previous few months, but their health had improved after they had begun taking ARVs. The other four caregivers were caring for a sister, a brother, a neighbour and a cousin.

4.2 Theme 1: Caring costs and social issues

This theme refers to costs and social issues associated with caring for people living with HIV and AIDS at home. Three sub-themes emerged: caring costs; care and culture; and extreme poverty; which are described and illustrated in Figure 4.

Figure 4: Theme 1

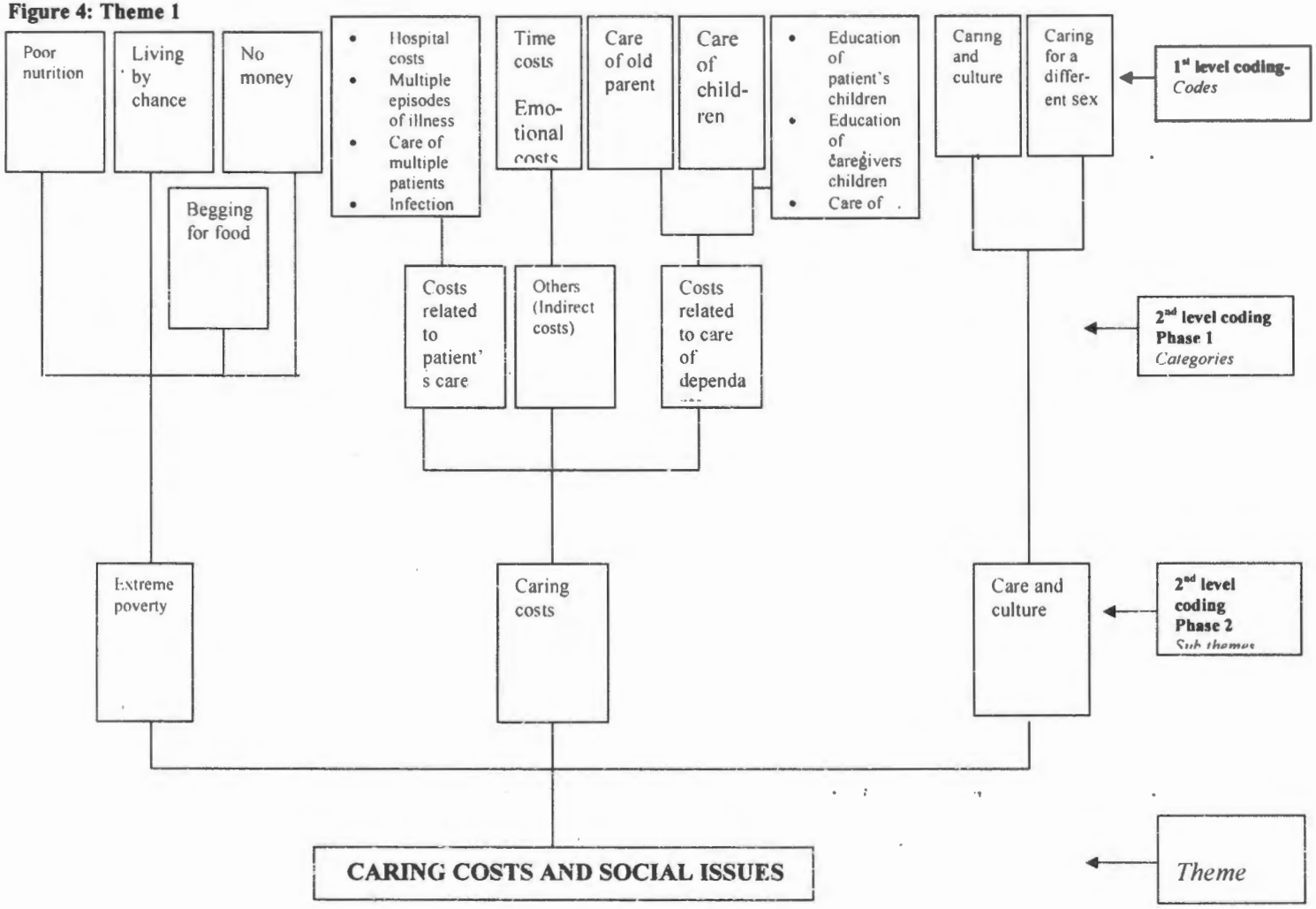


Figure 4 presents the process of analysis that produced the theme: caring costs and social issues. Themes at the top of the tree were developed from first-level coding. Further analysis of those themes (second-level coding phase 1) produced three categories. The analysis of categories (second-level coding phase 2) produced sub-themes. From these sub- themes the major theme was developed, as shown at the bottom of the tree.

4.1.1 Caring costs

Costs of caring for people living with HIV and AIDS are extremely high. There are different types of costs, such as financial, time and emotional costs. Financial constraints were common and all had experienced these after the loss of income of the patients, who were mainly the breadwinners. Financial costs included direct care of the patient as well as the care of other members of the family. The households' economic problems began immediately after the patients started to suffer from frequent AIDS-related illnesses. Caregivers were unable to generate an income since the care of the patient took up so much time, which further reduced financial security.

4.2.1.1 Costs related to care of the patient

Costs experienced directly in respect of patient care were expenditure for medical care, transport, food and infection prevention. These costs were particularly challenging for the caregivers living with HIV and AIDS. The costs increase when patients have to be admitted, due to hospital and transport expenses. Patients suffer from multiple episodes of illness, which place enormous financial strain on the household. A caregiver who was very stressed because of her sister's severe illness and pain expressed her worries about death and about the hospital costs. When asked if she was planning to take the patient to hospital, she responded:

> *"Yes, but who is going to give us 20,000/= Tshs (100 rand) for transport, 20,000/=Tshs (100 rand) for a unit of blood because she looks pale; they will ask us to pay for blood .Just few weeks back I paid the same amount. Now I do not have a single cent. My father has nothing. I'm so confused."*

Caregivers may provide care to more than one patient at a time or to a number of patients in quick succession. Costs incurred by one caregiver for multiple patients are high, as illustrated by this participant:

> *"There is her brother who sometimes gives some little money for food. Surprisingly, last month there was one of her friends who is also living with HIV and AIDS who moved to this house. They are now staying together. She has been chased away from their house by her husband immediately after she started falling sick. Now because they were friends before sickness, she came here. They are two of them in the same room. Although the friend is walking, she is weak and needs assistance. I don't know what will happen because every little I get and what PASADA and the brother are bringing, they have to share."*

A caregiver stated that she has cared for three people in succession: first her older brother and his wife, both of whom had already died of AIDS illnesses, and at the time of interview she was caring for her younger brother. Financial costs of drugs and food for multiple patients as well as costs for funerals negatively impact on the economic situation of the household. The permanent loss of income of the deceased occurs together with increased household expenditure in respect of care of the deceased's dependants. The care of a new patient by the same caregiver in quick succession is stressful:

> *"I had a brother who has already died of the same disease. The current patient is another brother younger than the one who died. Immediately after the older brother's burial, we started noting that the current patient's health was changing day after day. He lost weight. He had frequently episodes of tuberculosis. He is on TB drugs now, the fourth episode."*

Prevention of infection is expensive. Two methods are used to protect themselves from contracting infection: boiling water and antiseptic. Caregivers mentioned that they boil water which is used to wash the patient's clothes, which required them to buy fuel (charcoal or firewood) and soap. Antiseptics were rarely used due to the costs. The nature of the illness [frequent diarrhoea and vomiting] generates large amounts of laundry:

> *"The task is heavy because when she is bedridden I have to assume all the responsibilities like washing frequently as a result of stool and urine she passes on bed. I have to boil water, take the clothes and put them in. If I have Dettol* [liquid antiseptic] *I also add it but this happens rarely."*

4.2.1.2 Costs related to care of dependants

Apart from the costs related to care of the patients, caregivers have other people who depend on them. All of them were caring for their own children, the patient's children, or both. Only one caregiver did not have children.

Childcare costs include education (school fees, uniforms and stationery which, are expensive, especially for secondary schools), medical costs, food, clothing and transport. One HIV-positive caregiver who is caring for her sick husband reflects on the education-related costs:

> *"Yes. First born is studying at Kigamboni Secondary School. She is in form three. The school is a bit far from home; second born is studying at Vijibweni Primary School; third born at one primary school close to home, and the last born is five years old. She is in pre-school."*

The pre-existing poverty in households is exaggerated by the costs relating to HIV and AIDS. Consequently families struggle to manage the normal household living expenses. In this situation it becomes difficult to have savings for emergencies, and this creates further stress for caregivers when health care is required:

> *"My children need to eat, dress and live like other children. You see! They also admire some other things like toys, playing kits and bicycles just like other children. There are so many things; for example, my child got a fracture on the hand during plays. It was difficult to do an X-ray which I was asked to pay for. I could not afford to pay 15,000/= Tshs (75 rand)."*

Costs of caring for a newborn are particularly high. A caregiver provided care to a newborn whose mother died of AIDS-related illnesses three months after birth. At the time of this child's birth she was also caring for a brother (father of the newborn), who subsequently died of the same illness. They had hospitalisation costs due to frequent illnesses over a long period, and the cost of feeding a newborn infant:

> *"And the baby I told you; since day one. Do you understand? I cared for this baby in a very difficult situation. I don't know how to explain this! He was getting diseases frequently. Diarrhoeas ended after he was 9 months. I thought he was also sick... It is expensive because you can't breast-feed. I needed milk for porridge but this was difficult to get"*

4.2.1.3 Emotional costs

Caregivers witness their loved ones suffering. Caregivers who are living with HIV and AIDS are affected because they observe the effects of the illness which they themselves might suffer. One caregiver had cared for her daughter and granddaughter, both of whom had died in quick succession of AIDS-related illnesses:

> *"Yes. I first cared for my daughter. My daughter conceived when she was in school... She died of AIDS two years ago. My granddaughter would have been 22 years now. My grand-daughter as well died of AIDS a year after her mother. My first experience in caring for people living with HIV and AIDS was from these daughters. This task was not easy to me. Caring for a daughter, observing her suffering, was a very bad experience to me."*

Children are sent to grandparents as one way of reducing living expenses and coping with the loss of income caused by the illness of a breadwinner. Although forced to choose this option,

caregivers were severely affected and concerned by separation from their children. It is difficult to send children to grandparents who themselves are poor and have few resources to meet food and school expenses of their grandchildren. One caregiver expressed her difficulties as follows:

> *"I am planning to take the older daughter to Iringa to her grandparents where she might get a cheaper school and also get help from there because I have no other means. I spoke to them and they agreed. Also the child accepted to go. When my husband will be better, I will get time to go to school to inform teachers about the transfer."*

Another caregiver:

> *"When I was very sick, my mother took my son... She said she will stay with him so that I can take care of my health. I was very sick so I agreed with my mother. This decision was good, but now it is disturbing me. My parents are old and that boy is an adolescent. He can just play with school. If I was with him here, I could at least talk to him and see how he is doing. I know the financial situation there. It is bad. My son could be getting lots of problems. I hate watching the TV and seeing children who are projected there that have no food. It reminds me of my son. It reminds me of the time I will die. Who will take care of him? He might become among these children who do not get proper care. I have nothing to do since my husband is in bed. He is no longer producing."*

4.2.2 Extreme poverty

The high cost of care of the patients together with loss of income by both patient and caregiver impoverishes the affected household, and consequently life becomes very difficult. Children who need adequate nutrition for their growth are affected by the poor economic situation:

> *"Children need to eat, the house rent to be paid; children fall sick like any other children in the world and therefore need medical treatment. If the business is small the life becomes very difficult. If you have rented the house, the owner doesn't care that you are sick. If you don't have money for the house the owner can just take your properties out because really, she /he needs money. So sometimes you use the capital for your small business and pay the rent. Life becomes new and challenging every day."*

Inability to afford daily meals is a sign of extreme poverty. The financial hardship faced by households leads to food insecurity, and meals are missed. When available, the food is insufficient, and this is source of great distress to the caregivers. Caregivers in this study

struggled to provide food on a daily basis and they often went without. Begging is sometimes the only option. Caregivers said that "they live by chance". This means that they are not certain of food availability and other life demands:

> *"Sometimes I don't drink even tea. I normally say 'I'm living by chance'. I just live by chance. When you get for today, you give thanks to God. You are not sure of tomorrow but we see days passing... When children come back from school they expect to find food, fruits and request other things from me The sick child requires nice food. I know things like fruits, eggs are all required but sometimes I fail to manage the costs."*

Caregivers ask for assistance from others in their community and children are sent to neighbours and friends. One caregiver said:

> *"When children come from school, I ask them to go to people who know that I am sick like those people at church and ask them to give anything like food. They help me, some might give even 3 kg of flour, and some give vegetables from their gardens so when they bring, I cook, we eat and the day passes. I give the patient whatever I get. But this is very unreliable. Sometimes I don't have anything to give the children and even the patient. Even now as I'm speaking, I have no food because although I'm much better, to get the money is very difficult. I do what I can. Sometimes I wish to give my patient what she prefers or can take. I feel sorry when I fail to do so. For example, the patient may ask for something you cannot afford such as milk. She might need fruits. All those to me are dreams."*

Although HIV-positive caregivers are happy that they have access to ARVs and are knowledgeable about drug requirements, the inadequate food supplies impacts on drug efficacy. Coping with the drug regimen without an adequate food intake is a challenge. One caregiver expressed her dilemma:

> *"I have no option. I take my drugs properly and I give the patient hers at the right time as well. Then we eat when we get. We are told that, as we start drugs we don't have to stop and not even delay. So whether you have food or not, we have to comply with the drugs. The drugs are very strong, my cousin is not responding well because she started drugs two months ago but is still in bed. Therefore my dear, about food...mh! But we are surviving just like that. God is so merciful. I have forgotten about the breakfast. I cannot afford to buy sugar for tea and other things such as bread for breakfast. The little money I get, instead of buying sugar which is 1200/= Tshs (6 rand), it is better if I buy maize flour and cook stiff porridge which the whole family will eat, and save some money for soap and other expenses ... Sometimes I admire fruits but I cannot buy. Fruits are expensive ... Therefore to me, breakfast is a luxury."*

4.2.3 Care and culture

Caring is a culturally female role, and HIV and AIDS have exacerbated this role. Caregivers require assistance from relatives, but very few people are willing to support them. Caregivers had expected to receive help from other women in the family, and this may be an obstacle for men who are willing to provide care. A caregiver whose brother helped her to wash the patient's clothes defines that situation as a shame of all women in the family (sisters, aunts, cousins). Although she needed the help and expressed her appreciation, nevertheless she complained that care should have been provided by the women:

> *"It is a shame that sisters and aunts haven't helped me but this man felt sorry for me. It is a big shame."*

Culturally women provide all the care required, such as cooking, washing and feeding of the patients, except for bathing of men. This is particularly difficult when a patient is a close relative such as a brother. With other diseases, women ask men to assist with that role; however, the stigma of HIV and AIDS has compounded the discrimination and therefore the willingness of men to assist with personal hygiene. As a result of that, caregivers have to assume all the roles. Caregivers in this study reported that providing care to a patient of a different sex is frustrating to both the patient and the caregiver. One caregiver stated:

> *"Although it was difficult to do some of the things like bathing, and it was also culturally unacceptable, I had no choice, I did it ... It was extremely difficult for me and for the patient as well."*

4.3 Theme 2: HIV-related stigma and discrimination

Stigma and discrimination is a serious problem for caregivers and their patients and further complicates the problems associated with caregiving. Stigma is more challenging for the caregivers who are HIV-positive, who require more physical, material and emotional support from relatives but are isolated by them. Relationships between the caregivers and their patients and the families of the patients become strained, which in turn affects the care-giving and the psychological and emotional health of caregivers and patients.

This theme comprised three sub-themes: reaction to the illness, reasons for reaction to the illness, and response to the relative's reaction.

4.3.1 Reaction to the illness

Partners, relatives and friends react in different ways once a person displays the signs of AIDS. This results in a burden for the few caregivers who have no option but to provide care. For instance, one caregiver is caring for two patients: a cousin and her friend. The cousin's friend had been chased from her home by a husband after several episodes of illness. Isolation from close relatives can provoke powerful emotional and physical feelings: One caregiver expressed the following:

> *"The big problem I face is that relatives and friends isolate me and my family They don't come, talk and see the patient...This causes patients to become more depressed and difficult to care for. I get sad to see my close relatives doing this to me."*

Relatives blame the patients and feel that they deserve their suffering because of what they did in the past. This is evidenced by the marks (names) that are attached to people living with HIV and AIDS. This also demonstrates lack of support for caregivers. As one caregiver put it: *" These relatives have not accepted her. They still call her a 'dog', which means prostitute."*

Stigma and discrimination cause people to fear disclosing their HIV status, and they keep quiet when they discover that they are HIV-positive. Living with HIV and AIDS as a secret has negative implications, such as inability to access available services leading to poor prognosis of the disease and high burden of care, as demonstrated by this participant:

> *"I shared the results with my husband. It is our secret. It is not good to say this because people might isolate us. Is better to keep quiet and let them suspect "*

Caregivers and patients who disclose to close relatives regret doing so because of the response they get from them.

> *"We were neighbours living very close but she never knocked at my home to ask the progress. I felt so sad. I'm actually regretting why I told her. There was no need for that."*

Figure 5: Theme 2

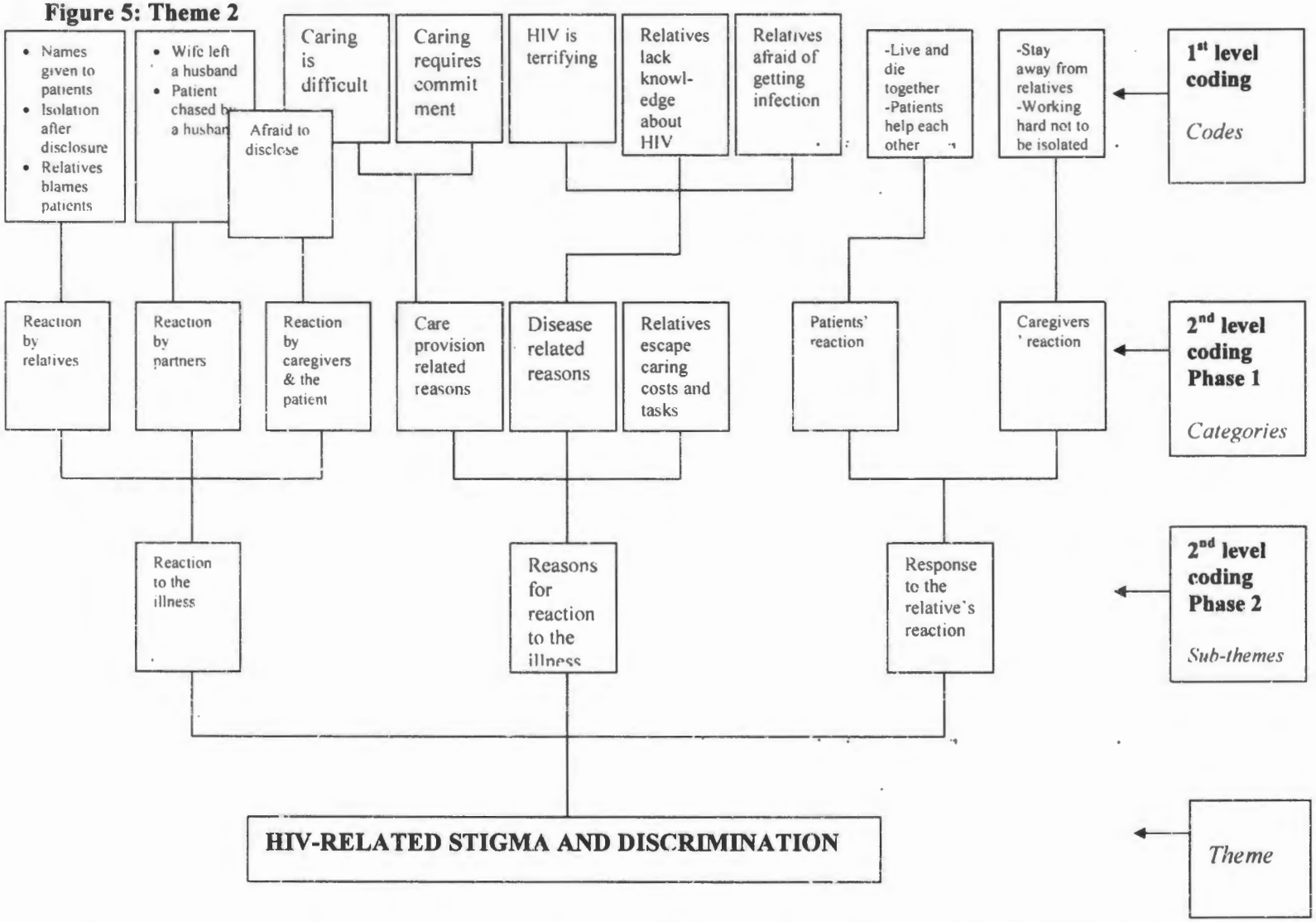


Figure 5 presents the process of analysis that produced the major theme: HIV-related stigma and discrimination. Themes at the top of the tree were developed from first-level coding. Further analysis (second-level coding phase 1) produced three categories. The analysis of categories (second-level coding phase 2) produced three sub-themes. From these sub-themes the major theme was developed, as shown at the bottom of the tree.

4.3.2 Reasons for reaction to the illness

The provision of care to a person living with a potentially fatal, contagious and sexually transmitted disease requires commitment. The demands associated with care of such patients increase the avoidance behaviour of relatives. They are unwilling or unable to cope with the financial demands:

> *"The caring role is difficult and needs a serious commitment and I'm responsible since I decided to care. You see! You know someone who is not committed will not manage to help the patient."*

Lack of knowledge about the disease, its transmission and the care needed may also affect people's willingness to care. Participants thought that their relatives lacked knowledge about HIV and AIDS:

> *"I think lack of knowledge could be one of the reason that some people don't understand the difference between HIV and AIDS. They think when you have the virus, you might die the following day. This is not true. It is very different. Some of us have knowledge that you may find someone already in bed, but you care and he/she gets well and walks and continues with his/her activities."*

Caring for a patient who is expected to die means that the caregiver will be responsible for other expenses, such as caring for the patient's children. An HIV-positive caregiver whose husband had died and who is caring for her child with AIDS said:

> *"Sometimes some relatives are escaping from a burden of caring. They think that if they will come and care for me, they might incur expenses or even carry the whole burden of my family."*

4.3.3 Response to the relative's reaction

When rejected and isolated, patients and caregivers are forced to find means of coping. In this study it was found that caregivers have developed a network among themselves to help each other (described in a later section). Caregivers and their patients distance themselves from their relatives by moving to a new place or avoid communicating with relatives. They find this painful, and the loss of family and loved one causes further emotional stress, which negatively affects their mental and physical health. One HIV-positive caregiver who is caring for a child and has been rejected by her sister, father and other relatives described her experience:

> *"I decided to move from that place because I felt better to stay away from her. It is more painful when you know that there is a person close to you who is supposed to help you but not willing to do so. I went to a place where nobody knew me. During this time I was so depressed. The blood pressure was very high."*

Caregivers attempt to minimise the barriers that they perceive may prevent relatives from visiting. They work very hard to ensure that the patient and the home environment remain clean. They feel that a dirty environment and odours may stop relatives from visiting. This also acts as an increased stress to caregivers:

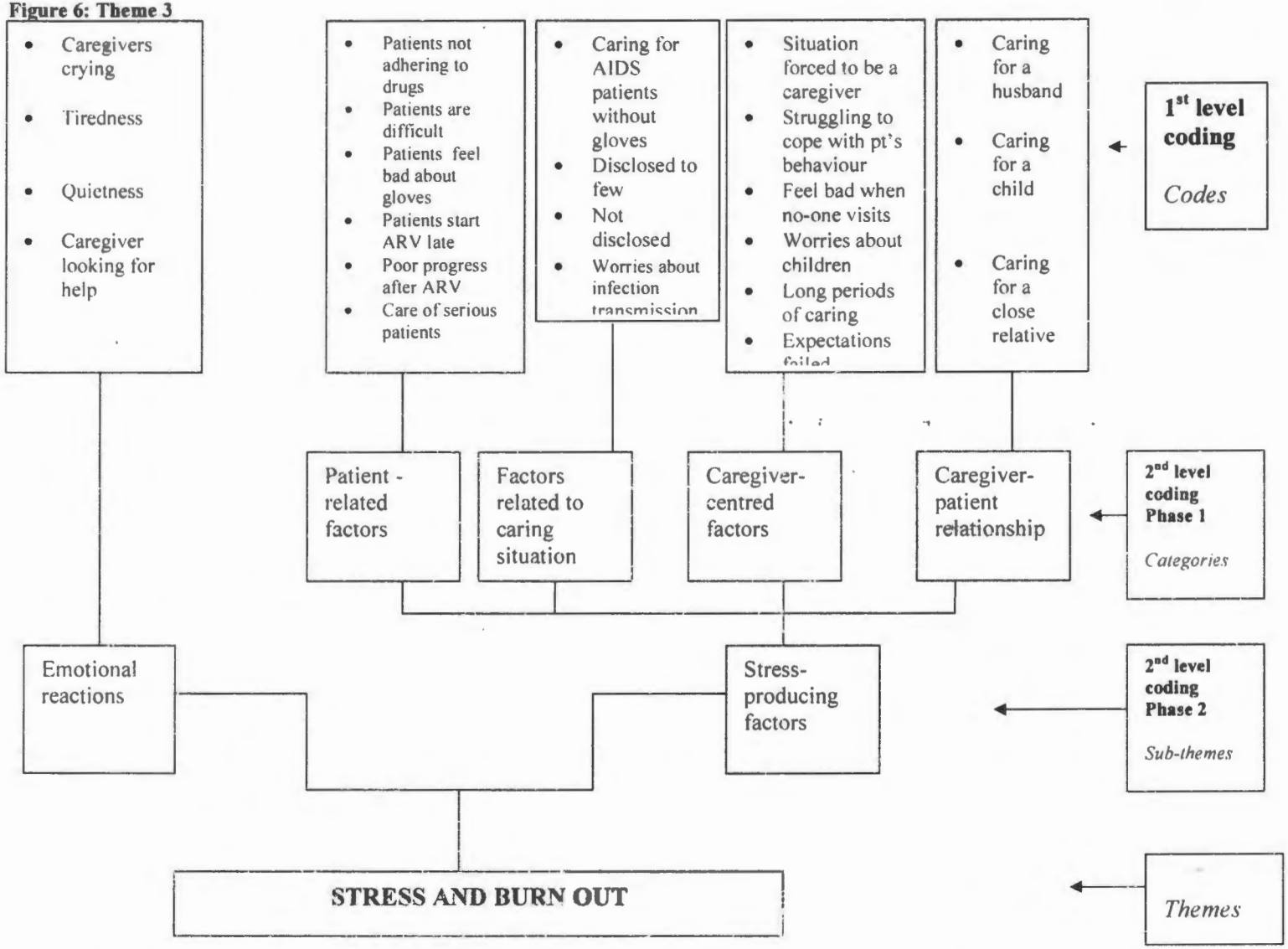
> *"I can't stop making this environment clean because she is wetting the bed every time... I don't want visitors to stop coming because of bad smell. They might isolate us more. Even myself, I'm trying to be smart and just show them, is a normal task."*

4.4 Theme 3: Stress and burn-out

Caregivers in this study were highly stressed, which was aggravated by a lack of support from relatives and the government. Fear of the stigma and discrimination makes them stay quiet about the disease. As a result of their extended long-term caring and dealing with unresolved and recurring problems, there is a feeling of helplessness, tearfulness, body pain and loss of courage.

This theme comprises two sub-themes: stress-producing factors and emotional reactions. Figure 6 outlines the emergence of this theme.

Figure 6: Theme 3



The tree above presents the process of analysis that produced the theme: stress and burn-out. First-level coding produced themes placed at the top of the tree. Further analysis (second-level coding phase 1) produced four categories. The analysis of categories (second-level coding phase 2) produced two sub-themes. From these sub-themes, the major theme was developed, as shown at the bottom of the tree.

4.4.1 Patient-related factors

People living with HIV and AIDS may become angry and depressed, which has an effect on caregivers. Caregivers who were providing care to their husbands bitterly expressed their concerns, particularly as it seemed to them that people who are HIV-positive delay testing, and only go to be tested after a long process of persuasion by the caregiver. This stressed the caregivers and has an impact on the severity of the illness at the point of diagnosis, and possibly on the patient's response to medication. Caregivers also feel that this may be the cause of poor response to drugs and poor adherence. As caregivers they have to take on the responsibility of administering the medications. An HIV-positive caregiver caring for her husband stated:

> *"I informed my husband about this but as you know, Tanzanian men are very rigid. I'm on antiretrovirals since January last year. He reminds me time for drugs but he does not want to go for the HIV test. In February he got herpes zoster. I continued to insist on the need for the test and even asked him to see how I'm getting better because I know my status. Sometimes I get angry. Last time I said to him: look here, once you will fall sick, I will run away. Don't expect that I will care for you. In April 2007 he asked me to look at his body. There were rashes like a starting herpes zoster . .. The following day he went to work and came back with herpes zoster. I continued caring for him because this kind of people need to be cared for politely. He is also smoking and drinking. I have continued caring but I'm getting tired. I went to his brother and told him that I'm HIV-positive but his brother doesn't want to go for the test. During this time he was very sick. His brother promised to talk to him. He did so but failed."*

Another caregiver stated:

> *"I was expecting that after she gets ARVs, like two months later, I thought I would get a relief. I thought she could take care of herself with only minimal support from me. What I expected is not what is happening. She is not showing any improvement. I have lost hope."*

Caregivers experience the consequences of the effects of the disease on the patient's mental health. Patients are aggressive and subject to mood changes. This can be exhausting, thankless and demoralising to caregivers. In elaborating on this, one caregiver stated:

> *"For example, the patient may ask you to cook a certain food. When you give the food to him, he becomes so furious. He can look at the food and say to you: who said I need this food? Take it away. He can throw the food and the plate away and sometimes break whatever is around. The current patient is very bad. He has frequent mood swings. He sometimes fills his mouth with food and blows it at me!"*

4.4.2 Factors related to the caring situation

Caregivers are afraid of contracting HIV, particularly when the patient has not disclosed his/her status, making it difficult to take adequate protective measures and get support from other people. Providing care to a patient who is not ready to disclose the disease causes uncertainty. The caregiver below described her concerns:

> *"The problem is that I can't say anywhere that I need help because I cannot share to other people that I have a sick husband. He does not want me to do so. Otherwise I could get help from my friends and other people living with HIV in our group. I don't want to force or go against his wishes. Even now that I know his status, I cannot do anything."*

Patients feel bad when caregivers use gloves and caregivers often provide care without them. This makes them nervous and afraid for their safety, but they hope that God will protect them. One of them stated:

> *"The problem is that it is difficult to wear the gloves. If the patient sees me using the gloves he feels that he is near to death. Sometimes I feel that I don't have to use the gloves. God will protect me... Now this one is even worse. He's got so many wounds. His brother did not get all these wounds. Haaa! God will protect me."*

4.4.3 Emotional and physical exhaustion

Caregivers experience extreme fatigue, especially because caring takes place with high levels of stress and without support. During the interviews participants were tearful, and there were periods of silence as they reflected on their painful experiences. Caregivers become exhausted by their caring responsibilities. The unwillingness of other relatives to become involved makes it impossible to abdicate their caring role:

> *"It comes the time when I say mh! Honestly speaking I am tired, but I make sure the patient doesn't hear me. Even though the work is still there and I have to do it. As a human being the body becomes exhausted. Sometimes I can't eat. I even say even if it is caring for a brother, mh!, it is too much."*

Another caregiver:

> *"I am very tired but anyway, I am continuing. If I won't assist her, who else do you think will take care of her? No-one "*

An HIV-positive caregiver said:

> *"Remember that I also have the virus. Drugs exhaust me. Sometimes I get extremely exhausted because I do the activities while crying. I just do them because I have no option ..* [crying]."

4.5 Theme 4: Care burden and the challenges

Caregivers assume different, often overwhelming, responsibilities. It is difficult to detail all the caring activities to others, and these are therefore unrecognised and undervalued. However, these activities are heavy, very demanding, and affect the physical, psychological and emotional health of an individual.

This theme consists of four sub-themes: caregivers' health challenges, caregivers' roles, challenges accompanying care giving, and efforts to cope. The tree below presents the stages of analysis that produced this theme.

Figure 7: Theme 4

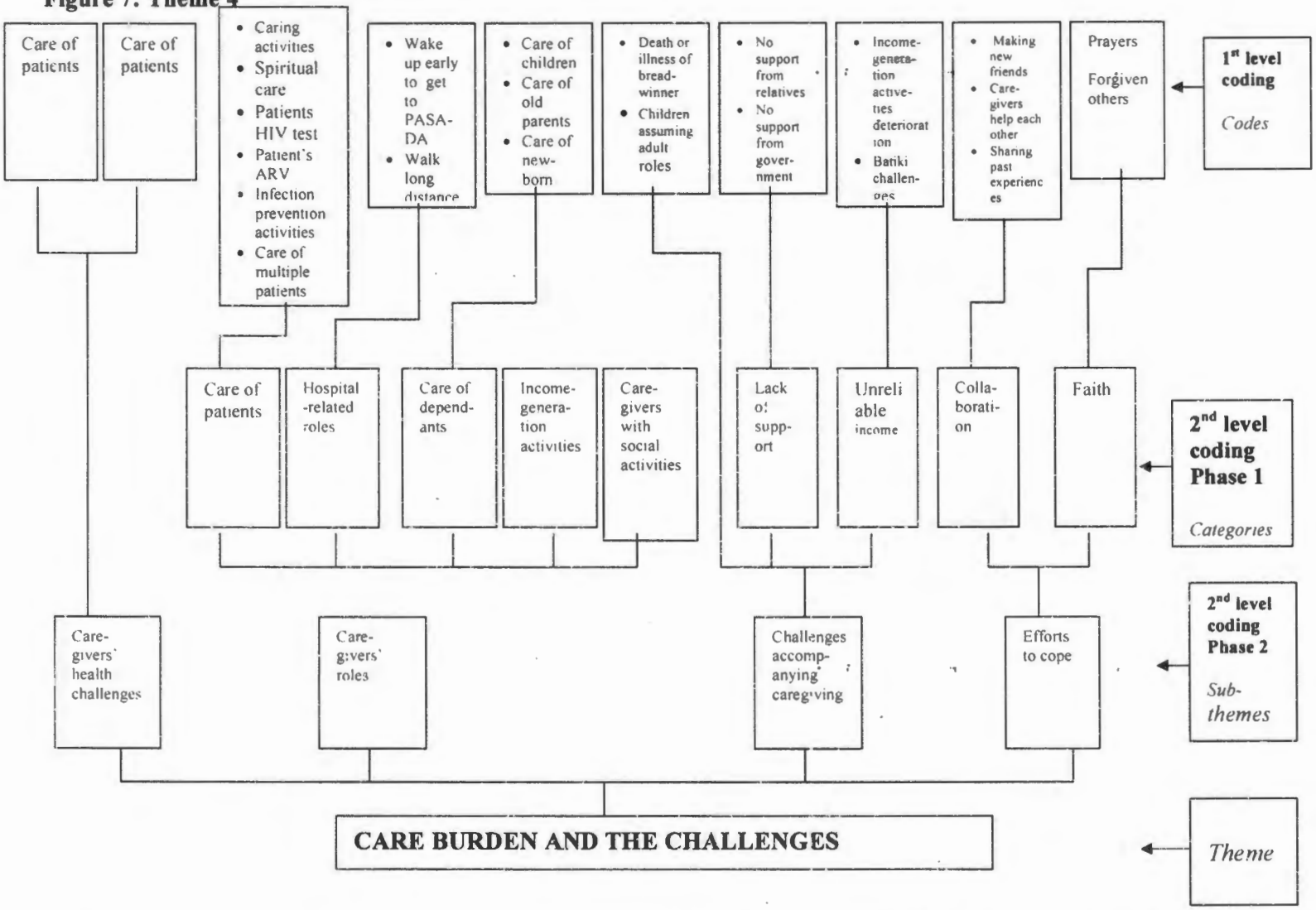


Figure 7 presents the process of analysis that produced the theme: care burden and the challenges The themes at the top of the tree were developed from first-level coding. They were further analysed and (second-level coding phase 1) produce three categories. The analysis of categories (second-level coding phase 2) produced sub-themes. From these sub- themes the major theme was developed, as shown at the bottom of the tree.

4.5.1 Caregivers' roles

Caregivers assume multiple roles. Apart from the roles that relate to care of the patients, there are many other responsibilities, such as care of dependants, activities to generate income and social-related activities such as involvement in funerals and weddings. Patient care is very demanding and affects other roles. This provokes powerful emotions. The following example reflects some of roles related to patient care that are performed every day:

> *"When I wake up, I find the dirty clothes. I normally wake up early in the morning, and look for firewood or charcoal if have money. I boil water and wash the clothes to make the environment look clean. I have to bath the patient and change the bedding because they get soiled easily. At around 8.00am, I give her breakfast and thereafter drugs. After giving drugs, I stay with her because the drugs are strong and therefore need close monitoring. She rests a bit, at around 10.00am; I normally go to the market to buy food, fruits and other things.. At around 12.00 noon, I have to cook soft foods like banana and soup, which she can eat. I also have to cook for other family members. My parents are old. They can't do anything, they depend on me.*

> *"While doing this, I pay attention to the patient because she may need any help. I have to assist her. I also have to assist her to do some exercises. Therefore I really don't have time because after lunch, she rests a bit and I have to give the afternoon drugs. You see! I stay with the patient. At around 4.00pm, I cook and give some porridge to the patient. If I get some juices, I give them to her at around 6 p.m. After that I prepare dinner. At the end of the day, I find myself exhausted; the day ends just like that."*

Caregivers reported other activities, such as taking patients to different preachers for prayers. They believe that the patient can be healed or die peacefully through the use of prayer. Moreover, caregivers stated that monitoring of drugs and support was necessary to all patients because the drugs are very strong.

Caregivers whose patients were not on ARVs because they did not know their status had an extra-difficult task of convincing their patients to test. They had to find an older person respected by the patient who could assist them to convince the patient to go for the test. This process sometimes involved disclosing the HIV status of the patient and the caregiver to these relatives, which was stressful and a further burden of care, as described by a caregiver:

> *"My husband has been sick for the last three months. He is now in bed very sick but he has refused to go for the HIV test. I decided to go to his elder brother two days ago and explained to him how his brother has refused to go to the hospital. He said he will come on Sunday to talk to him."*

Another caregiver said:

> *"I went to his brother and told him that I'm HIV-positive but his brother doesn't want to go for the test. During this time he was very sick. His brother promised to talk to him. He did so but failed."*

Having to boil water to prevent infection when washing patients' clothes adds to the high burden of care. Walking long distances to health centres is particularly challenging for the HIV-positive caregivers, who take patients while themselves sick. Long waiting times at health centres make caregivers exhausted. Caregivers rise early on days when they have to collect drugs from PASADA because of the large numbers of patients at the clinic.

4.5.2 Caregivers' health challenges

The caregivers' health is challenged by different issues associated with the disease. Caregivers become exhausted and lose their appetite. Failure to use gloves puts them at risk of contracting infection. They struggle to get enough rest and sleep due to the demands made by the patient. They have to cope with the patient's pain, fear of death, and worrying about the care of the children. One caregiver said:

> *"Oh! I don't sleep, sometimes the whole night passes without getting any sleep. Sometimes I sleep for the first two hours and that's it. How could I? I can't! The husband is sick and I am also sick. If we die, who will take care of our children? If the situation is unexplainable now, how will it be in future?.. Mmh!* [looking down and crying]"

4.5.3 Challenges accompanying caregiving

Caregivers face many challenges. Death or illness of a person who is supporting the affected family causes further stress. One caregiver (HIV-positive) who is caring for a husband (the breadwinner) explained that her brother who was supporting her had died one month before the interview. Explaining the challenges that she experiences, she reflected:

> *"This has been worse after the death of my brother. Before he died he helped us a lot. I did not experience what I do now. When I started drugs, my brother was alive and my husband was not in bed. Now it is like this. I don't understand completely what to do"*

The death of a breadwinner or illness in members of the household affected by HIV and AIDS provokes fear and anxiety, especially when it is anticipated that other members of the family will also get sick or die. Coping with life changes caused by loss of income is very distressing. One caregiver who is caring for a child after the death of the husband expressed the following:

"I did not experience all these when my husband was alive. My small money was for clothing and small needs. Now everything is upon me. Life without support is very difficult."

Income-generation activities are limited due to time spent on caring. Caregivers in this study were unemployed since they had limited education, which aggravates suffering and economic difficulties when their breadwinners fall sick. The informal employment in which caregivers have engaged is challenging and produces limited income. They sell clothing material which they get from RUHISWE (a community volunteers association which supports people living with HIV to have a source of income). Although that employment has given them hope, it is tiring. One caregiver explained:

"Yes we are very thankful to them. But it is also challenging because you have to go to people's houses and knock, and ask them to buy the material. Sometimes they take and say they will pay at the end of the month. When you go at the end of the month, they again ask you to go the following day or even after 3 days. So it is not easy. I walk too much and sometimes I get exhausted to the extent of not continuing with that business. But since I have nothing else to do, I encourage myself to just go on."

Children assume some activities that can negatively affect their health and education, such as fetching water early in the morning before going to school and walking long distances to school due to lack of taxi fare. This is particularly an issue for the HIV-positive caregivers who themselves are weak and sick and whose children have to assist in caring. Some children of participants had interrupted their schooling so that that they could assist with caring for sick parents and/or cut down on the education costs. One caregiver reflects on this problem:

"I wake up my children early in the morning so that they can fetch water from the well before the bigger one goes to school. In fact, my child stopped school when I was very sick But now she has started going again. She has to fetch water before she goes to school because I cannot carry the bucket from that far well. So it helps a lot."

Children get involved in income-generation activities. The caregiver whose income is generated from selling *batiki* reflects on the situation:

"At this time the children are back from school so they escort me, and also learn the places because I sometimes ask them to go back another day to collect money. I ask those people to recognise my children so that they give them money. That way I reduce the distance that I have to walk because I also cannot leave my cousin alone for so long and I'm also sick."

Children are not excluded from the experiences of physical and emotional stress. They witness their parents suffering. However, they are not informed about the HIV status of their parents. When asked if

she was planning to tell her children about their [the parents] HIV status, the caregiver described her dilemma:

> *Yes...mmh! It is very difficult. She is educated. Even radios talk about this disease. She must know from there. She sees her father sick and bedridden and she knows that I got TB. Moreover, she is intelligent at school, therefore she knows. But me to talk to her? No! No! No! To tell my daughter? Completely no. I wish I could tell her, but I find it difficult. The situation will tell her. Probably in many days to come."*

4.5.4 Efforts to cope

Caregivers have developed informal networking as one of the strategies to survive and face the challenges. They collaborate and help each other regardless of their relationship. This kind of networking is useful, particularly for HIV-positive caregivers who when they fall sick have nobody to help their patients and themselves. Caregivers make new friends who are also living with HIV and AIDS. Their relationships start slowly at the clinic where they meet, suspect each other's problem and then share and get to know each other. A participant reflects on her experience:

> *"One day I prayed for God to help me. I was very sick but I had to go to the clinic. At the clinic I met friends who are also living with HIV but they just went for drugs. They saw me coming towards them. They recognised that I was sick, trembling and breathing with difficulty. They felt sorry for me and started to ask me questions such as 'why did you come alone?'. I openly shared my story to them because I suspected that they were also positive They were very helpful to me. They supported me and after the service, they escorted me home. They contributed some money for food. They cooked and served my children. Thereafter they frequently visited me and continued to help me with so many things. God did not throw me aside. When I prayed, he answered my prayers. We are friends to date."*

Faith is an important coping mechanism which gives courage to caregivers. Being a caregiver is difficult, but God is great and gives them energy to continue. As the situation becomes worse, they pray for the patients and themselves. One caregiver described how she prays before giving food to her patient so that he won't throw it away as he normally does. One caregiver explained that "*the disease is within us so we have to find means to live with it*". Prayer helps them to cope:

> *"Prayers are powerful. I pray a lot. I have a small radio that I use to put on the station with different preachers and leave the patient to listen. They also pray for different diseases. He likes that radio these days. I'm very happy about that."*

Faith enables caregivers to cope with negative issues associated with caring, as discussed previously. For example, an HIV-positive caregiver who had strong faith and was isolated by relatives after the

illness forgave them despite their rejection, as she believed that God wants people to forgive each other and live in harmony. This is very useful in reducing levels of anxiety which affect their emotional well being:

> *"God wants us to forgive. Although they have not asked for forgiveness, I have forgiven them."*

Caregivers have the strong hope that God is there with them and will help them to address the challenges that they experience during caring. Prayers become an important part of the solution-seeking process.

> *"As women we are facing problems because men are very difficult. I'm so touched; my heart is full and painful. I have prayed for so long for God to change him .I have special time for prayers. I want God to change my husband. He is my husband. I would not like to see myself doing well and my husband deteriorating."*

4.6 Theme 5: Treatment and support system

Treatment with ARVs has brought hope that a person can live longer with the disease if he/she is adherent to the ARV treatment programme. In this study impoverished households affected with HIV and AIDS are struggling to make sure that they also benefit from the drugs. However, there are a number of challenges which may contribute to poor drug outcome. This theme consists of two sub-themes. treatment outcome, and encouragement to continue caring. Figure 8 shows the steps followed to develop this theme.

Figure 8: Theme 5

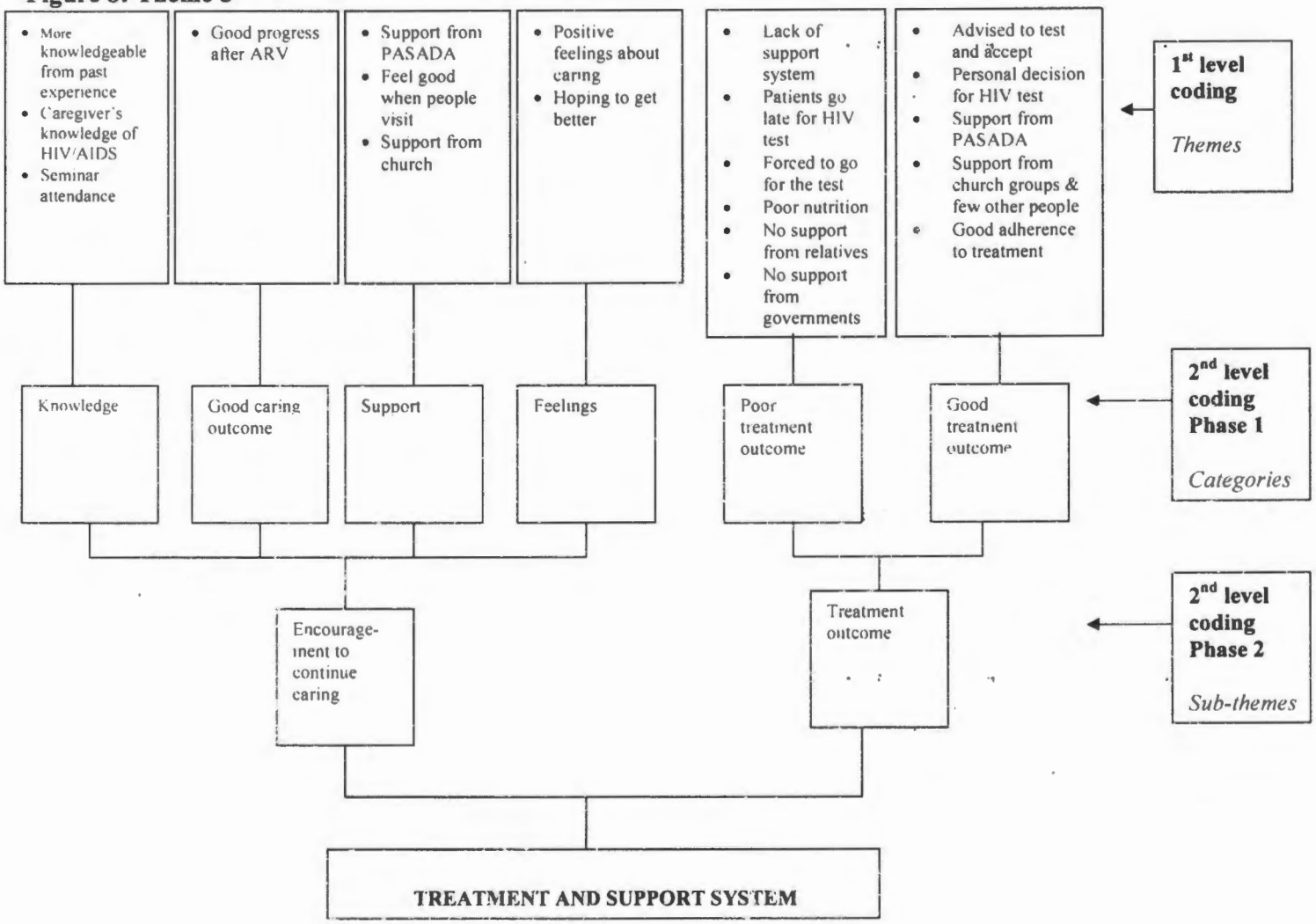


Figure 8 presents the process of analysis that produced the theme: treatment and support system. The themes at the top of the tree were developed from first-level coding. They were further analysed and (second-level coding phase 1) produced three categories. The analysis of categories (second-level cod ng phase 2) produced sub-themes. From these sub- themes the major theme was developed, as shown at the bottom of the tree.

4.6.1 Treatment outcome

Caregivers start caring with the great hope that once the patient starts ARVs, he/she will respond positively and continue with life. This is not always the case, and there are a number of obstacles that accompany the use of ARVs that affect a patient's response to the drug. These include the poor economic status of the affected families, which is exacerbated by inadequate support of affected households and people on drugs by the government and relatives.

Patients receive drugs free of charge from the public hospitals and PASADA. Nutritional support (such as flour, sugar and butter) is provided by PASADA once a month. The government programme TASAF (Tanzania Social Action Fund) aims to support the community-initiated activities and projects to mitigate poverty and create wealth. Although TASAF is well known to the caregivers, they get little or no support from this source:

> *"Last year there are people who came from TASAF and we were asked to list our names. We thought they will give us the loans. Nothing! They never came back."*

A caregiver who received support from TASAF complained that the loan she was given to start a casual business was very small (about 250 rand):

> *" Mmmh! A big problem, we are still not supported enough by our government because if we are given a loan of 50,000/= Tshs what kind of a business will you run?"*

Lack of support from partners and relatives of the patient can affect drug compliance. The complications and side-effects of the drugs call for a supportive environment for a person on ARVs. Food and material support are also important to enable the person living with HIV and AIDS to cope with drugs effectively, but this is minimal. One caregiver, when asked about the support she receives, responded that she has "no A or Z". When asked to explain this, she described her situation as follows:

> *"I mean that. I am helpless. As I am talking here, I don't have a husband. I don't have any relative to care for me. The same for the patient. I have young children who depend on me. So it is just too difficult to carry on. At the same time, I'm sick. I just completed the second dose for TB on 25/05/2007 ... Honestly, we are suffering. If I had any way to send this disease back to where it came from, I would do it as soon as possible."*

PASADA provides comprehensive support to families affected by HIV and AIDS. Caregivers who were HIV-positive had shown improvements in their health status after drug, financial and food support from

this NGO. Although caregivers said that the support they get is not enough, nevertheless they strongly appreciate the contribution of PASADA. Home visits conducted by PASADA are also highly appreciated. One caregiver reflected on the help she received:

> *"The help is there but very small, sometimes 2 kg of millet flour; 2 kg for a month is not enough. Sometimes we are given beans and sugar. The help is not enough, therefore care- givers bear the burden. PASADA helps a lot but patients are many. I think government has to help too. They visit us when we are helpless and give us hope. God will bless them."*

Another caregiver said:

> *"I get assistance from PASADA and the friends I told you about only. At the end of the month PASADA gives children stationery. At least my children have been registered there so they get treatment for free. I thank God for that. On the clinic day, I wake them up very early in the morning to go earlier to be in the queue because there so many people who go there."*

Informal church groups (e.g. women's groups) visit the patients and help them with some activities and sometimes financial support. Caregivers stated that they depend on this help for their survival:

> *"I just depend on people from church who come on Thursdays. They give me some money. Sometimes I get other visitors who can also give some money. I have to budget and be careful until the following Thursday. Now this is not enough to take care of the children, myself and the patient."*

4.6.2 Encouragement to continue caring

Caregivers who have knowledge about HIV and AIDS are encouraged to continue with their caring role, and they experience less stress. Moreover, caregivers who had previous experience in caring were more knowledgeable and had more strategies to deal with patients than those who undertaking caring for the first time. A caregiver stated as follows:

> *"Some of us have knowledge that you may find someone already in bed, but you care and he/she gets well and walks and continues with his/her activities."*

Another caregiver said:

> *You know, the bad thing is that this disease is not cured. I was not aware before and this was the cause that we went to hospital late, so drugs did not help. So I'm now aware of the disease. If I see anybody, I can advise them to go earlier to get drugs so that they won't die ... They won't be cured but they will have more days to live. Probably if one goes earlier they will not experience problems I experienced with my patients."*

Caregivers who attended a 2-day seminar conducted by PASADA were more courageous and energised to continue caring:

> *"I have attended some seminars where we were told to care for the patients and show her love because one day we might also fall sick...They taught us how to protect ourselves. This encouraged us to continue caring with love."*

Caregivers who had cared for or seen patients who progressed well after the use of ARV drugs had hope that continuing to care for their patients would have better results. The kind of support received from PASADA and people from the church encourages caregivers to continue with their caring role. One caregiver described the support she received:

> *"PASADA helps a lot. When the patient is very sick, I take her to PASADA. Sometimes I inform health care workers at PASADA to come and visit her at her place because it is difficult to walk with her and I do not have money for the taxi."*

4.7 Summary and concluding comments

The findings of this study show that caregivers experience a multitude of problems. Caregivers who themselves are living with HIV provide care while coping with their own illness, pain, and ARV regimen. The participants have to deal with the pain of witnessing the suffering of their loved ones. There is no clearly defined support that caregivers receive from relatives and government. The only source of support mentioned is PASADA and groups of people from churches.

Caregivers have developed a network among themselves in which they share different experiences that each face and their coping strategies. Learning takes place through sharing of experiences. Helping each other financially and materially reduces the anxiety that caregivers experience when they are left alone. Although some caregivers are caring because they have no option, they stated that HIV is within us therefore we have to provide care to those who are sick. Caregivers who had cared for a person with AIDS before had developed strong coping strategies, and were more able to continue in the role. A strong faith helps them to have a positive outlook and be less stressed in a very negative situation.

CHAPTER 5: DISCUSSION OF FINDINGS

5.0 Introduction

This chapter presents a discussion of the study findings on the experiences of informal women caregivers of people living with stages III and IV HIV and AIDS at home. The findings will be discussed in relation to other studies reported in the literature under the following headings: caregivers' health; economic circumstances; stigma and discrimination; women's perception of caregiving; psychological and emotional stress; care burden; support system; and coping mechanisms Conclusions drawn from the data analysis and discussion, recommendations and further research options will be presented.

5.1 Caregivers' health

The health of the caregivers is often compromised by emotional and physical stresses. The high burden of caregiving and the nature of caring tasks required, financial stringencies, social isolation and work overload put the health of caregivers at risk. Caring for persons in the late stages of HIV and AIDS exacerbates the stresses, since in addition to the normal stresses of caregiving, the caregiver has to cope with stigma and discrimination towards the person with HIV and herself as the caregiver

Caregiving for persons who themselves are living with HIV further compromises the caregivers' health. In a study on trauma and growth within the context of HIV in Canada conducted by Cadell (2003:639), it was found that 44% of 176 caregivers involved in the study were themselves HIV-positive. As a result of the multiple stresses related to care- giving, 86.4% of the HIV-positive caregivers in this study exhibited symptoms of post-traumatic stress disorder (Cadell, 2003:639).

The present study demonstrates that caregivers themselves are vulnerable to HIV infection because they don't use protective equipment such as gloves. This is due to unavailability or because the patients perceive the use of gloves as a sign of impending death. Some caregivers do not use gloves because they provide care without being certain of the HIV status of their patients, and this increases their vulnerability to infection transmission. A study conducted by Akintola (2004:24) on the gendered analysis of the burden of care on family and volunteer caregivers in Uganda and South Africa revealed similar findings. This study indicated that caregivers were exposed to TB infection due to close contact when bathing and lifting the patients. Caregivers in this study did not use gloves because they felt it would imply that they did not love the sick person.

5.2 Economic circumstances

Pre-existing poverty is a significant contributor to the financial crisis reported by caregivers in the study. Like other African countries, Tanzania is a poor country, with its people living on less than US $1 per day (Sanders, Todd and Chopra, 2005:755). Households affected by HIV and AIDS struggle to survive and to cope with the disease and the increased financial demands. The existing poverty in these families is exaggerated and onerous.

Caregivers face financial challenges when the patient was a breadwinner prior to his/her illness. Caregivers were unemployed due to their low levels of education, and hence have no reliable source of income. They engage in informal employment, such as selling fruit and *batiki*. The time taken in care provision negatively impacts on caregivers' opportunities and abilities to generate an income. Studies undertaken elsewhere indicate similar findings (Akintola, 2004:24; Hosegood, Preston-White, Busza, Moitse and Timaeus, 2007:696). The study conducted in South Africa (Hosegood *et al.*, 2007:696) found that there was a loss of income for both the caregiver and the ill breadwinner, and that this occurred concurrently with increased expenditure due to illnesses. A study in Uganda and South Africa reported that the economic stresses were mainly caused by a reduction in household income due to people living with HIV and AIDS not being able to work and the caregiver losing his/her job due to the demands of the caring role (Akintola, 2004:24).

Caregivers are responsible for different costs attached to caring for the patient and other members of the family: medical and transport costs, costs related to patient care (e.g. food, soap), care of the patient's children, care of the caregiver's children, and care of ageing parents. Other living expenses, such as house rental, food and medical costs for other members of the family place a great amount of stress on the caregivers. Meeting these costs is extremely difficult. Children are transferred to live with grandparents in the village to reduce costs; however, the caregivers experience emotional distress following separation from their children. Caring costs at home were found to be similar in other studies (Ogden *et al.*, 2004:8; Akintola, 2004:22-23). A study in South Africa reported that illness or deaths in one household result in people moving to another household for care and financial assistance, and this changes the composition and dependency ratio of both households (Hosegood *et al*, 2007:1255).

One of the consequences of limited/irregular income is food insecurity. Families in this study were unable to afford adequate nutrition and sometimes missed meals. This is a big challenge, particularly with patients and caregivers who are on ARVs. Caregivers reported that they (and their patients) have to take their medication without food and eat when food is available. Food insecurity and other problems

due to loss of income by families affected by HIV and AIDS have been reported by other studies conducted in Africa (Hosegood *et al.*, 2007:698; Kipp *et al.*, 2006:698; Parry, 2005:81). A Zambian study to measure the burden on family caregivers reported that 98% of the 80 women respondents experienced lack of food and/or lack of special nutritious food for AIDS patients, and this increased the dependency rate and negatively affected their health (Kipp *et al.*, 2006:698).

Food insecurity is also reported by a study conducted to assess adherence to ARVs in parts of Tanzania, Uganda and Botswana (WHO, 2006:9). This study reported that lack of adequate nutrition for affected households in these countries was one of the causes of poor adherence to treatment. The study reported that people living with HIV and AIDS who were on ARVs complained of an inability to afford the food needed to satisfy their increased appetite (especially during the initial stages when the body needs extra nutrition for drug consumption and to regain weight) (WHO, 2006:9). Some people who are living with HIV and AIDS in Tanzania were taking drugs only in the evening because this was the only time that food was available, and because drugs have to be taken with food (2006:11). This study also noted that some people living with HIV and AIDS were selling drugs which they obtained free of charge from public hospitals in order to buy food. However, this did not emerge in the present study.

People living with HIV and AIDS require proper nutrition to strengthen their immune systems. The lack of food security found in the present study and in previous studies is a serious problem. Moreover, Castleman *et al.* noted that the interaction between ARVs and food/nutrition can significantly influence medication efficacy, nutritional status and adherence to drug regimens (Castleman *et al.*, 2004:1). While some drugs impose food restrictions others, particularly protease inhibitors, must be taken with food to improve absorption rates (Castleman *et al.*, 2004:1). The sustainability and success of the treatment for persons without adequate food is questionable.

5.3 Stigma and discrimination

Stigma and discrimination were described by all participants as an ongoing problem which compounded the stress of caring. Stigma is experienced in a number of ways - but in particular as a lack of support from close relatives. An HIV-positive caregiver was stigmatised by her father and sister immediately after she had informed them of her HIV- positive status. They stopped visiting her home or the hospital to which she was admitted. Her children had to stay by themselves during this hospitalisation. Because of the stigma and discrimination, the participants in this study tended to remain quiet about their status. These findings are consistent with those of previous studies (Hosegood *et al.*, 2007:698; Kipp *et al.*, 2006:698; Parry, 2005:81). Hosegood *et al.* (2007:1252) and Akintola (2004: 30) have reported that

stigma and discrimination remain high in Southern Africa. Hosegood *et al.* (2007:1252) state that as families became more impoverished by the disease, they experience more stigma and discrimination. In contrast, Akintola's study in Uganda reported that stigma and discrimination were subtle, and many people with HIV were attending HIV health centres without hiding their status, as had been the norm in previous years. This may be due to particular efforts to address the problem in this country.

Stigma and discrimination in the communities lead caregivers and patients to hide their HIV status. Caregivers are reluctant to request help from anybody since their patients have not disclosed their status. Hosegood *et al.* (2007:1256), Akintola (2004:22) and Ogden *et al.* (2004:17-19) all reported similar findings. In Switzerland, a study on HIV family caregiving revealed that care of a person living with HIV and AIDS was provided by family members in the context of silence to avoid stigma and discrimination (Spiriq, 2001:377). Stigma and discrimination by relatives were reported in a survey which measured the burden on caregivers in Zambia and Zimbabwe (Kipp *et al.*, 2006:696).

HIV and AIDS is a sexually transmitted disease which if untreated has fatal consequences. This study found that care of a person living with HIV and AIDS is compounded by difficult tasks that require commitment. Due to the nature of the disease and the tasks involved, only a few people are prepared to take on the caring role. Similarly, a study in Zambia showed that 94% of 80 women respondents described that care is a difficult task. Another study in Namibia reported that care is provided by a few, who do so out of love or when no other option is available (Thomas, 2006:1374).

Stigma and discrimination by relatives was compounded by the costs that associate with caring. Moreover, caregivers stated that relatives lack knowledge about HIV and that they think they might become infected during caring; therefore they avoid the caring role for their safety. Studies elsewhere present the same findings (Hong, Anh and Ogden, 2004:23; Nyblade, Pande, Mathur, MacQuarrie, Kidd, Banteyerga *et al*, 2003:16). A study conducted in Ethiopia, Tanzania and Zambia indicates that an incomplete understanding of HIV and AIDS feeds fears about casual transmission. The respondents in this study do not understand that there is a difference between HIV and AIDS, how the disease progress and longevity of a person with HIV. The study shows that a person who is living with HIV is seen as already dead.

5.4 Women's perception of caregiving

Women perceive caregiving as a role that should be performed by them. They regard this role as culturally based; thus they have no option but to take it on. However, caregivers find it difficult to

provide care to a close relative, especially one of the opposite sex. Caregivers in Uganda reported that bathing family members was often psychologically and physically stressful, and they preferred to ask assistance from friends who were not related to them or the sick person (Akintola, 2004:24). This personal/cultural preference may interfere with the delivery of care to the patient.

5.5 Psychological and emotional stress

Caregivers experience anxiety, insomnia, hopelessness and helplessness and are frequently tearful. Factors which generate these symptoms include the inability to cope with the HIV diagnosis of a loved one and/or of themselves, worries associated with lifestyle changes following loss of income, worries about children (particularly if the caregiver herself is HIV- positive), and witnessing the pain and suffering of their patients. Multiple episodes of illness, care of multiple patients and deaths of relatives who were supporting caregivers were found to be stressors associated with strong emotional responses. Studies on caregivers in different countries present similar findings (Akintola, 2004:24; Thomas, 2006:78; Ogden *et al.*, 2004:14). A study in Namibia revealed that HIV-positive caregivers experience fears and anxieties concerning the current (while sick) and future security and well-being of their children (Thomas, 2006:78).

Caregivers in this study reported a lack of cooperation and outbursts of anger from their patients, also reported by Akintola (2004:26). A study conducted in Kinshasa reported that patients had episodes of depression, agitation and verbal and physical aggression to which caregivers were exposed (Kipp *et al.*, 2006:696). This makes caring difficult and personally threatening.

The present study found that HIV-positive caregivers experience anxiety and worries related to the future of their children after their own deaths, and are afraid that no-one will be prepared to care for the children. Similar findings were reported in studies conducted in Namibia (Thomas, 2006:78-79) and KwaZulu-Natal (South Africa) (Akintola, 2004:34). The latter study reported that HIV-positive caregivers wished that their HIV-positive children would die before them; yet when this did occur, they found great difficulty in coping and coming to terms with their death.

This study revealed that children experience physical and emotional stresses when a member of the family (parent) falls sick. They are involved in provision of care for the people living with HIV and AIDS, and therefore witness the suffering that their loved ones go through, and this affects their emotional health. Similar findings were reported by a study in Uganda and South Africa (Akintola, 2004:28), which reported that children in the HIV and AIDS-affected households were providing care to

terminally ill patients and experience a myriad of difficulties. This study also indicated that children have difficulty in managing physical activities (such as in turning bedridden patients into different positions to avoid pressure sores) due to their size. This affects them physically and psychologically (Akintola, 2004:28).

Children are not informed about the HIV status of their parents. Parents find it difficult to tell their children about the disease because of its nature as a sexually transmitted and fatal disease. Similar findings have been reported in other studies (Thomas, 2006:78; Akintola, 2004:28). A study in Uganda and South Africa indicated that children are not considered as caregivers and are therefore not prepared for the caring role, while in reality they are very involved in caring. They are sent out of the house when community volunteers train adults on caring (Akintola, 2004: 28); hence, children provide care without any training. This study further reported that some children had been found sitting near their deceased mothers without knowing that they were dead.

5.6 Care burden

Caring is a very demanding task involving multiple activities. Caregivers rise early in the morning to have enough time to accomplish these tasks, and get little or no time to rest. When their patients are in severe pain, the caregivers have to cope with sleepless nights, even after a very tiring day. The overwhelming nature of the caregiving activities has also been reported by other studies in Africa (Kipp *et al.*, 2006:696; Thomas, 2006:78, Akintola, 2004: 24). However, unlike other studies, the present study found that in addition to the multiple caring roles already described, caregivers who were caring for AIDS patients who had not tested had to try to convince their patients to go for the test in order to be able to get ARVs. This task was particularly challenging and very distressing, and required the involvement of older family members (brothers) to try to persuade the patient. These findings reflect the complexity of the care burden.

5.7 Support system

Caregivers in this study received treatment and material support from PASADA (a religious organisation) and church groups. Support may be material, financial or emotional. Elsewhere religious organisations are recognised for their contribution to social and the national responses (Parry, 2005:89). A study in Los Angeles, USA, on social service providers found that faith-based organisations offer more services on average (2.5) than their secular counterparts, which ranged from 1.1 (for-profit providers) to 1.7 (secular non-profit providers) (Graddy, 2006:330). In Philadelphia, USA, religious congregations supply different services to low-income families; if these services were supplied by the

government they would cost a quarter of a billion dollars a year (John. 2007:3) In South Africa the Treatment Action Campaign is widely supported by faith-based organisations (Parry, 2005:94). Like PASADA, it has been the norm for these organisations to support HIV- positive people and help them to respond to and survive crises.

Caregivers in this study bitterly expressed the fact that they receive no support from the government. There had been promises of support from government which had not materialised A loan of 50,000/= Tshs. (R250) by government was insufficient to embark on any kind of informal employment. Lack of adequate support by government has also been reported by other studies in African countries (Hosegood *et al.*, 2007: 1252; Akintola, 2004: 26). Although the Tanzanian Government has done much to ensure that drugs are made available at no cost, without adequate food and support the ARV regimen is hard to follow.

5.8 Coping mechanisms

Caregivers have developed an informal network among themselves which facilitates their ability to cope. They visit, help each other and share different experiences and coping strategies. Caregivers living with HIV network with other people living with HIV and AIDS (whether caregivers or not). This enables them to gain control and cope with the situation. Caregiver networking has been reported by other studies in other countries (Akintola, 2004:37; D'Cruz, 2002:6). A study in India indicated that due to limited formal support, caregivers rely on informal networks. These networks provide emotional, material, financial, medical, information and physical support in the execution of caregiving tasks (D'Cruz, 2002:6).

Caregivers saw themselves as spiritual and this seemed to be an important coping mechanism. This spirituality also influenced the patient, who became more positive in outlook. Spirituality has been reported to be an important coping mechanism of caregivers and people living with HIV and AIDS (Simoni, Martone and Kerwin, 2002:139; Jacobson, Luckhaupt, Delaney and Tsevat, 2006:53). A study on spirituality and psychological adaptation among HIV-positive women found that spirituality helped caregivers to reappraise their situation and gain greater control, thus aiding in psychological adaptation (Simoni, Martone and Kerwin, 2002:139).

6: CONCLUSION AND RECOMMENDATIONS

6.0 Relevance of the study and its findings

The findings of this study provide information on the experiences of women caregivers of people living with HIV and AIDS in the Temeke region, Dar es Salaam. The use of semi-structured qualitative interviews to explore the participants' experiences provides an insight into the reality of their day-to-day lives, the challenges that they face, and the coping strategies that they have developed.

Little is known about the experiences of caregivers of people living with HIV and AIDS at home in Tanzania. This study therefore offers an understanding of the experiences and the contexts in which care is being provided. This information can be used by policy makers and other social service agents to develop care and support services that focus not only on the patients, but also on the caregivers.

6.1 Limitations of the study

This study is a small qualitative exploration of a particular group of carers and cannot be considered representative of carers in the region. The study participants were women caregivers of people living with HIV and AIDS who had support from PASADA; thus their experiences do not reflect those of other caregivers in different settings.

Due to time constraints in conducting the interviews, which were limited to the university mid-year vacation, the researcher was not able to return to participants to further explore their experiences. This is a limitation since it may have been possible to explore certain issues in more depth.

Translation of interviews posed the challenge of remaining true to the original words as expressed by participants. Some of the essence of the meaning may have been lost in the translation. Every effort to minimise this was undertaken, as outlined in the methodology.

6.2 Recommendations

On the basis of the findings of this study, the following recommendations should be considered:

- Policy makers in the Dar es Salaam region should consider the hefty burden of care incurred by caregivers, and appropriate grants should be instituted.

- There is considerable psychological and emotional stress associated with caregiving - and therefore a need for counselling services that address the emotional and psychological needs of caregivers.
- Educational support for children from affected families would be very helpful for their future and the future of the nation. This relief will address the concerns raised by caregivers about the impact of HIV on the well-being and future of children in HIV-affected families.
- Caregivers are overwhelmed, which is exacerbated by stigma and discrimination, particularly from relatives. A programme to assist families to deal with HIV in the family could be considered.
- Food security may impact on adherence to ARVs and coping with the disease. It is apparent that food and material support is required for low-income households affected by HIV and AIDS.
- The informal networks that have been formed by caregivers can be strengthened and become structured and supported by the health and welfare sectors. This should alleviate the burden of care.

6.3 Suggestions for further research

- A larger representative study on informal women caregivers could be carried out to further explore their experiences in caring for people living with HIV and AIDS at home.
- A study could be conducted to develop an understanding of the support needs of informal caregivers in caring for people living with HIV and AIDS at home.

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Appendix 1: Letter of request for permission to conduct study at PASADA

Aga Khan University-TIHE
P.O BOX 38129
DAR ES SALAAM
TANZANIA

The Director
PASADA
PO BOX 38129
DAR ES SALAAM.

Dear Sir/Madam.

Ref: REQUEST TO CONDUCT A STUDY ON EXPERIENCES OF INFORMAL WOMEN CARE GIVERS IN DAR ES SALAAM, TANZANIA IN CARING FOR HIV/AIDS PATIENTS

The reference is made to the above. I am a student at University of Cape Town registered for Master of Science in Nursing (student number PLLEUN001).

I kindly request permission to conduct a study with informal women caregivers of HIV and AIDS patients who attend the clinic as they escort their family members for whom they care. I also request your staff to be the mediators for accessing these women.

The study aims at exploring and describing the experiences of informal caregivers of HIV and AIDS patients who attend the PASADA clinic services in Dar es Salaam. Tanzania. The findings will enable health care professionals and organizations to better understand the needs of caregivers.

If given permission 7 to 8 women will be interviewed individually either at your centre or caregivers' home; this will depend on the women's preference. Written consent will be given by each caregiver. The researcher will provide the participant with information to understand the nature of the study, the right for voluntary participation, confidentiality and to withdraw at any stage (see Appendix 2).

Please use the contact below for communication regarding the above requests.

Yours sincerely.

Eunice Pallangyo
Phone: (0754) 371 374
Email: esiaity@yahoo.com
Name of supervisor: Mrs Pat Mayers
Phone: +27214066464
E-mail: Pat.Mayers@uct.ac.za

Appendix 2: Participant Consent form - English version

University of Cape Town
Faculty of Health Sciences
Division of Nursing and Midwifery
Anzio Road
Observatory 7925

RESEARCH: EXPERIENCES OF INFORMAL WOMEN CAREGIVERS IN DAR ES SALAAM, TANZANIA IN CARING FOR HIV/AIDS PATIENTS

Researcher: Eunice Pallangyo (BSc. N).

I kindly request you to participate in a study that aims to explore and describe the experiences of informal women caregivers of HIV and AIDS patients. Being a caregiver for two months or more, I believe you have experiences which could be of value to the understanding of the needs of caregivers.

Participation

The participation in this study is voluntary. You can also withdraw from this study at any stage, your patient's right and that of yourself to services will not be affected by any decision that you will make. This interview will either be in a quiet room at PASADA or at your home, as you prefer, to ensure confidentiality.

Nature of the study

The researcher will conduct the interview if you will agree to participate for about 45 minutes to one hour. The interview will require sharing of your experiences on caring for people living with HIV and AIDS (stage III or IV) in your home and demographic data such as age and place If you will agree the researcher will present the interpretation of data to you to ensure that its meaning is the same as what you presented. All information from you is confidential, will not be shared with anybody without your consent. Data will be stored in a secure place and after use the researcher will destroy them.

Benefits and risks

This study will have no immediate benefits, but the findings will be useful in helping organisations to identify issues relating to caregiving. There are no major risks expected. Perceived discomfort that may develop due to interview will be managed according to your needs.

I welcome any question if you have any about the study and your participation. Should the need to contact me arise, please use the contact details below.

The above information has been clearly discussed with the participant. I believe that the participant is aware of the nature of the study, their right to voluntary participation and confidentiality, benefits and risks.

Name of researcher

--- ---

Signature of the researcher Date

I understand the nature of the study, risks and benefit, my right to voluntary participation, confidentiality and withdrawal from the study without any penalty. I have had the opportunity to ask questions and have had these answered.

I hereby freely consent to take part in this study.

Name of participant

--- ---

Signature of the participant Date

Researcher:
Eunice Pallangyo
Phone: 0754 371 374
Email: esiaity@yahoo.com

Supervisor:
Mrs Pat Mayers
Phone: +27214066464
E-mail: Pat.Mayers@uct.ac.za

Appendix 3: Consent form - Kiswahili

Chuo Kikuu Cha Cape Town
Kitengo Cha Sayansi ya Afya
Idara ya Uuguzi na Ukunga
Anzio Road
Observatory 7925

FOMU YA KIBALI

UZOEFU WA AKINA MAMA WA DAR ES SALAAM, TANZANIA KATIKA KUUGUZA WAGONJWA WANAOISHI NA VIRUSI VYA UKIMWI MAJUMBANI

MTAFITI: Eunice Pallangyo (BSc. N).

Nawaombeni ushiriki wenu katika utafiti utakaolenga kuchunguza mambo/uzoefu wanayokutana nayo akina mama wanauguza wagonjwa wanaoishi na virusi vya UKIMWI. Kwa kuwa umeuguza kwa muda wa miezi miwili au zaidi, naamini kuwa utakuwa umepitia kwenye mambo mengi.

Kushiriki

Kushiriki kwenye utafiti huu ni hiari. Una haki ya kuhifadhiwa siri, kukatisha kushiriki wakati wowote bila kuingilia haki yako na mgonjwa ya kupata huduma. Mahojiano haya yatafanyika kwenye chumba cha siri na ambacho kiko kimya PASADA kama utapenda au nyumbani kwako kama utakavyochagua.

Aina ya utafiti

Mtafiti atafanya mahojiano kama tu utakubali kushiriki kwa muda wa dakika arobaini na tano au lisaa limoja. Mahojiano yatahusisha kushirikiana uzoefu wakati wa kuuguza maelezo mengine kama umri na mahali unapoishi. Wakati wa mahojiano kutakuwa na chombo cha kurekodi.Taarifa yeyote utakayotoa ni siri, haitatolewa kwa mtu yeyote bila idhini yako. Taarifa zote zitahifadhiwa sehemu ya siri na baada ya kutumia zitateketezwa.

Faida na hatari za utafiti

Utafiti huu hautakuwa na faida za hapo kwa hapo, lakini matokeo yatakayo patikana yatatumika kutafutia jinsi ya kusaidiwa.Hakuna hatari zozote kubwa zinazotegemewa kwenye huu utafiti. Hali yeyote ya kiafya itakayoashiria kutokana na mahojiano itashuhulikiwa ipasavyo.

Nakaribisha maswali kama yapo yanayohusiana na utafiti au ushiriki wako. Ikitokea haja yeyote ya kuwasiliana na mimi, tafadhali tumia namba zilizotolewa hapo juu.

Mshiriki ameelezwa barabara kuhusiana na maelezo hapo juu. Naamini kwamba mshiriki ameelewa aina ya utafiti utakaofanyika haki ya ushiriki wa hiari, haki ya kuhifadhiwa siri pamoja na faida na hatari za utafiti.

Jina la mtafiti

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Sahihi ya mtafiti Tarehe

Naelewa aina ya utafiti, faida na hatari zake, haki yangu ya ushiriki wa hiari, kuhifadhiwa siri na pia kukatiza ushiriki wakati wowote bila haki zangu kudhurika. Nimepewa nafasi ya kuuliza maswali na yamejibiwa.
Na hapa natoa kibali changu cha kushiriki kwenye utafiti.

Jina la mshiriki

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Sahihi ya mshiriki Tarehe

Mtafiti
Eunice Pallangyo
Simu: 0754 371 374
Anwani ya barua pepe: esiaity@yahoo.com

Jina la Mhadhiri msimamizi wa mwanafunzi:
Mrs Pat Mayers
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Appendix 4: Contact summary form

Contact type. ---------- Site: ----------

Contact date: ----------

Researcher: ----------

What situation was involved during interview? (such as participant reaction)

What were the main themes in the contact?

Which research questions that you had were addressed in the contact? Summarise both the information obtained and that which you failed to get.

Anything else important from the contact?

Which new suggestions about the research arise from the contact?

Appendix 5: Interview questions

1.--Can you tell me about your experiences in caring for HIV and AIDS patients at home?

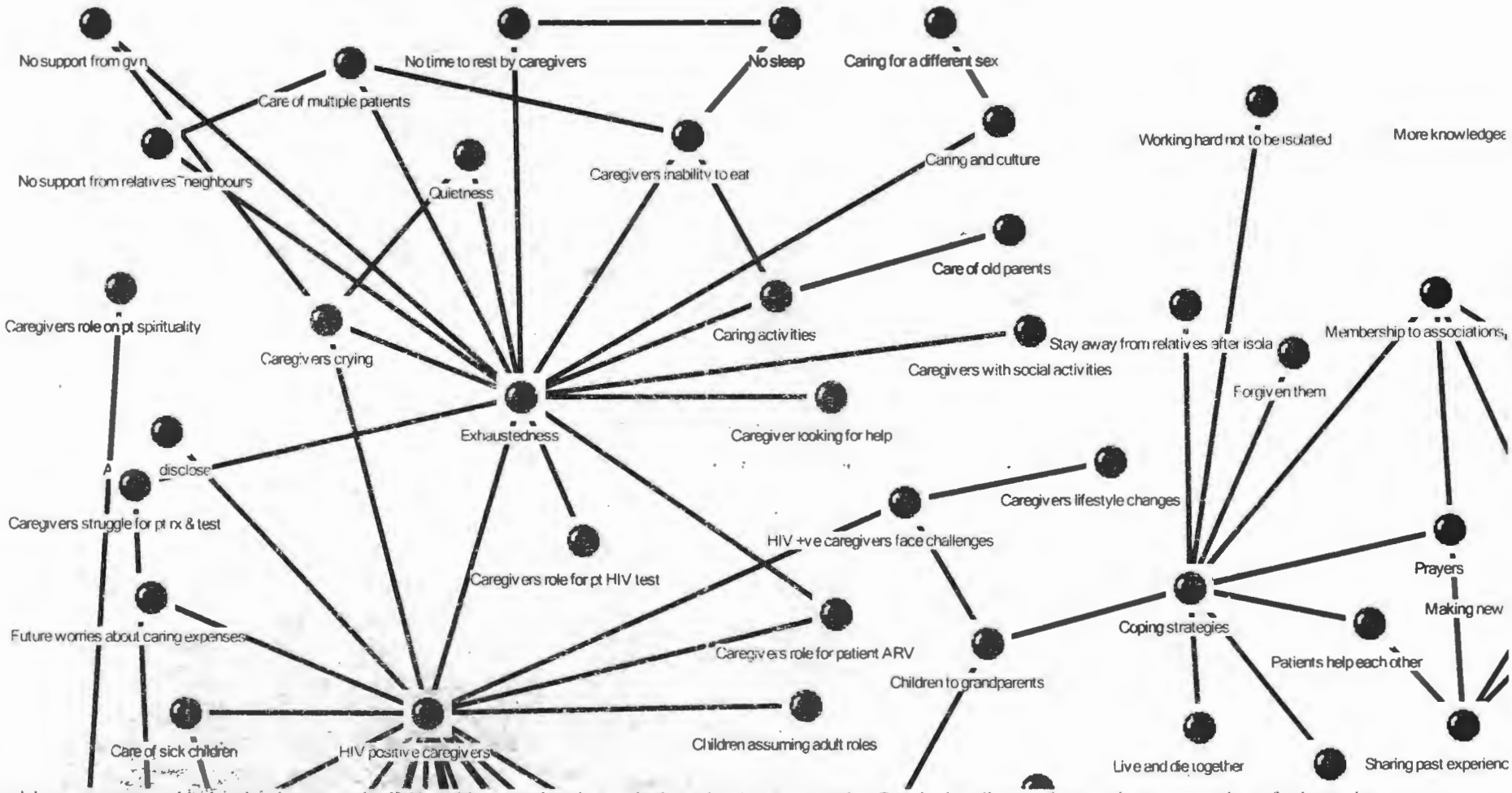
2.--Can you give a more detailed description of what you experience?

3.--Which activities do you normally pursue during caring?

4.--What kind of support do you get in caring for your patient?

5.--Can you explain if you have at any time felt exhausted?

Appendix 6: Model displaying code relationship



The model presents some related codes. For example, HIV-positive caregiver is a code that related to many codes. Despite her disease the caregiver assumes lots of roles such as nursing care of the patient, monitoring patient's antiretroviral, convincing patient to go for the HIV test and many more. Therefore she becomes very exhausted, highly stressed and experiences different worries. The caregiver gets no time to rest because of the large burden of care and lack of support. This causes strong emotional feelings that are sometimes presented by crying or quietness.