

**CHALLENGES FACED BY WOMEN PROVIDING HOME-BASED
CARE IN MZIMBA, MALAWI: A QUALITATIVE STUDY**

by

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I declare that CHALLENGES FACED BY WOMEN PROVIDING HOME-BASED CARE IN MZIMBA, MALAWI: A QUALITATIVE STUDY is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.

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Supervisor

Date

DEDICATION

I dedicate this body of work to all women who lost the battle of life to HIV and AIDS, to those whose life was cut short because of this scourge that has baffled even the most brilliant of the scientific world. I also dedicate this work to all the orphaned children who have had to live a life of misery, a life of love lost due to the death of their beloved parents. In my mother tongue (Tumbuka), I say, *mwafwa twafwa...* (i.e. ...Your loss is mine too....or... I share your pain...).

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I thank God Almighty for the graces received. It has been possible only because God willed it so. This work would have not even taken shape if the Almighty God did not bless it. Thank you, Lord. Amen.

A special word of thanks goes to the women of Mzimba who gave their time to sit for the interviews and shared their stories, some of which were very personal and emotional. I also want to appreciate the three key informants who accepted to be interviewed although they had very busy and hectic work schedules.

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ABSTRACT

The aim of this research was to explore the challenges faced by women providing home-based care to those infected and affected by HIV and AIDS. The specific objectives of the study were to explore the gender-related, sociocultural and socioeconomic challenges faced by these women; and to investigate best practices in home-based care.

An exploration of the challenges women experience in their communities as they provide care for the HIV and AIDS infected and affected is located within a gender and power framework. Feminist theories are also used to try and explain the reasons behind the differences and inequalities that exist in the community, particularly as regards the women who provide home-based care.

A qualitative study, which used both qualitative and participatory methods of data gathering, was undertaken in 2014 in Mzimba, Malawi.

Data was collected from 26 women participants by means of Critical Incident Narrative interviews (5), Individual In-Depth Interviews (5), and two Focus Group Discussions (6 and 10 participants respectively). Three Key Informant Interviews were conducted with a Ministry of Local Government official, another with a Nursing sister at the Mzimba District Hospital Tuberculosis Ward, and the Mzimba District Hospital Home-based care Coordinator. Purposive and snowballing sampling techniques were used to recruit the research participants. A topic guide was used in critical incident narrative interviews. An interview schedule consisting open-ended questions and face interviews were used for the Individual In-depth Interviews. A topic guide was used for the Focus Group Discussions. All the data collection instruments were guided by the themes of social, economic, cultural, psychological challenges; food security, and coping mechanisms. An interview schedule consisting of open-ended questions were used for the Key Informant Interviews. A Check List of WHO minimum package for home-based care programmes was used to assess the actual program best practices.

The methodology of this study was guided by the WHO framework on home-based care. In this framework, the home-based care programme includes the following

elements which make up the minimum package of care: provision of care, continuum of care, education, supplies and equipment, staffing, finance and sustainability, and monitoring and evaluation.

Very few studies have been concluded to understand the sociological issues that affect women who provide care to the HIV and AIDS infected and affected in households and communities. It is hoped that this study will in some way address this gap, and that the information and recommendations contained in this thesis will guide policy recommendations in Malawi that will incorporate the lived experiences of those who provide this care.

The study revealed that women providing home-based care to the HIV and AIDS infected and affected experience harsh challenges. Women carry the burden of care as traditionally men do not provide care. Women experience extreme deprivation which manifests itself through a number of socio-economic difficulties and these include been shown in their inability to provide for their basic necessities such as food, and other household needs. For most of the women carers, the deprivation is a direct consequence of their low levels of education which rendered them unable to find employment or engage in successful business ownership. The women carers also lack social security in the sense that they do not have access to land for example which could ensure that they have some level of food security. When the main income earner died the women carers and their dependants were left to fend for themselves. Women carers also experienced various psychological problems and these included nightmares, insomnia, depression and these affected their physical health such a few reported lack of appetite for food as a major issue.

Women carers and in particular the young women reported that they had to drop of school to marry when their parents or guardians died. The other dimension to this issue was that the older women carers reported that during their young years, it was common place to find girls who did not attend school or were pressurised to get married because their parents did not believe in educating girls. The background is currently affecting the women carers as they find that they cannot get involved in profitable business or even look for employment. They lack the basic literacy levels that would allow them to be become more productive and ensure financial security.

Women carers experienced a number of gender related challenges as they provided care and these included the burden of care being almost solely borne by the women.

Women revealed that they have had to use various coping strategies in the face of the overwhelming challenges that they continue to experience. Elderly women have found ways to cope by selling the property such as land and household goods, conducting small scale informal business, and sending the children away to relatives to be fostered. The young women on the other hand have sometimes reverted to some dangerous strategies for coping such as getting a boyfriend to provide for their financial needs, engaged in transactional sex, and some got married very early. The other coping strategies that the young women employed were to conduct small businesses, depended on family and relatives to provide for their various needs. The women volunteers revealed that they used their group as a therapy group, they shared the work, and that they were involved in small scale businesses.

The study has also revealed that there is a home-based care programme that is functioning fairly well. However, there are indications that as much as the various players are trying to assist those who are infected and affected by HIV and AIDS, there are severe gaps in the effectiveness of the programme. There is need for a review of the programme so that it answers to the needs of those who are caring for those who are on home-based care i.e. a more rigorous implementation of HBC programme is required.

The overall findings of the study indicate that the poverty trap in which the women are caught impacts on every aspect of their existence, with little hope of them ever improving their conditions. There is need for the Malawi government to come up with strategic interventions that would alleviate of women in general but in particular those who are left to provide care at home. Such interventions could include poverty alleviation strategies for women who are providing care to ensure that their situation does not deteriorate once they begin to provide care.

Since Malawi is a signatory to the UN Millennium Development Goals, it is important that the plight of women is revisited and find lasting solutions to the challenges that they experience. Women are still lagging behind in education for example. There is need to improve girls and women access to education. The health of women has

been affected by HIV and AIDS. The Government of Malawi also needs to review the policies that are in place which address women's health. Essentially the status of women is need of a major change in order for the country to achieve some level of development which is at par with other countries in the sub-Saharan African region.

KEY TERMS

Continuum of care; Home-based care; Palliative care; Primary care giver

LIST OF ACRONYMS

AIDS	Acquired Immunodeficiency Syndrome
ARV	Anti-Retroviral
ART	Anti-Retroviral Therapy
CBO	Community Based Organization
CSO	Civil Society Organisation
CAC	Community Action Committee
CHBC	Community Home-Based Care
DACC	District AIDS Coordinating Committee
DHO	District Health Office
FBO	Faith Based Organization
GDI	Gender Development Index
GII	Gender Inequality Index
HBC	Home-Based Care
HIV	Human Immunodeficiency Virus
HSA	Health Surveillance Assistant
MOH	Ministry of Health
NAC	National AIDS Commission
NGO	Non-Governmental Organizations
NSO	National Statistical Office
OPC	Office of the President and Cabinet
PLWHA	People Living with HIV and AIDS
TB	Tuberculosis
TFR	Total Fertility Rate

UN	United Nations
UNAIDS	United Nations Joint Program for HIV and AIDS
UNDP	United Nations Development Programme
UNESCO	United Nations Educational, Scientific and Cultural Organization
UNFPA	United Nations Population Fund
UNGASS	UN General Assembly Special Session
UNIFEM	United Nations Development Fund for Women
VAC	Village AIDS Committee
VCT	Voluntary Counselling and Testing
WHO	World Health Organisation

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CHAPTER ONE

INTRODUCTION

1.1 Introduction

The objective of this research was to explore the challenges faced by women providing home-based care in Mzimba, Malawi. Home-based care is widely viewed as an alternative and viable form of care for those who are chronically ill with HIV. In Malawi, as in most other countries, the burden of care falls predominantly on women, who face multiple challenges resulting from gender-based disparities.

1.2 Background to the study

Home-based care has become the most widely used care model for looking after for the chronically ill in the field of HIV and AIDS (Young & Busgeeth, 2010; Ogden, Esim & Grown, 2006; Lindsey, Hirschfeld, Tlou, & Ncube, 2003). It involves comprehensive management and control strategies for HIV and AIDS which may include prevention, treatment, care and support (Lindsey, Hirschfeld, Tlou, & Ncube, 2003; Ogden, Esim & Grown, 2006). Home-based care has become a means of alleviating the strain on overburdened and under-resourced hospitals whilst providing better and more holistic care to chronically ill, especially those infected with HIV (Mahilall, 2009; Akintola, 2006).

Home-based care services are provided for at either family or community level. The model of home-based care has long been part of African traditional social and care systems and existed before western models for an allopathic health care system were introduced. In African traditional healthcare, all care activities are integrated into a way of life (Kwasi, 2008). In the western biomedical system, "cooperation" is the basis of care, and while the western biomedical system is highly specialised, it has been unable to meet the numerous medical, psychological, social and economic needs that have emerged with the AIDS pandemic (ibid). With the advent of HIV and AIDS, the traditional African healthcare system has become more relevant to caring for those suffering from chronic illnesses because, as Kwasi (2008) explains, it is holistic in nature. That is, it encompasses all the needs of those who are ill.

Families and communities are increasingly being called upon to care for people who are suffering from long-term illness as a result of overstretched and overburdened health care systems which also function with very few qualified health personnel. Baylies (2002a) observes that where state welfare provision is minimal and the capacity of the government limited, the role of the household in dealing with illness and death becomes critical by default. Essentially, in many countries, home-based care is being provided out of necessity (Baylies, 2003; Akintola, 2004).

Within the home-based care system, families experience a number of challenges, which impede caring activities. They often take on the burden of caring for the sick with minimal resources, knowledge, and skills. As has always been traditionally the case, women take the leading role in caring for the various needs of the chronically ill.

Another model of home-based care is community home-based care which is a community response to the HIV and AIDS epidemic and its effects. It is mainly provided for by a number of agencies. In Malawi, such agencies include government, non-governmental organisations (NGOs), community-based organisations (CBOs), faith-based organisations (FBOs) and other community support groups in various parts of the country (Munthali, 2002; Fairley & Gallagher, 2006). The activities carried out by the community home-based care groups, most of whom are volunteers, include caring for the chronically ill, training people who are providing care for the chronically ill in their own homes, caring for orphans and other vulnerable children, and spreading messages of prevention to their respective communities (Fairley & Gallagher, 2006; Omoto & Malsch, 2005; Munthali, 2002).

1.3 Burden of care

Home-based care work is carried out mostly by women. Various studies reveal that when there is sickness in the family or community, it is usually women who automatically carry out the caring duties (Akintola, 2004; Urdang, 2006; Ogden, Esim, & Grown, 2006). Urdang (2006: 166) observes that almost all people living with HIV “whether male or female, [were] cared for by a woman – a mother, a grandmother, a sister, a daughter, [a] female neighbour, a female home-care attendant – regardless of where they lived”.

HIV and AIDS have exacerbated an already precarious situation for women who are already overburdened by many other responsibilities within the home as most of them also carry out household work, agricultural activities, caring activities, and community-related activities in Malawi (Munthali, 2002; Pindani, 2006).

In Malawi, women experience many challenges due prevailing gender-based disparities: low education levels which limit their life chances; unfair socio-cultural impediments which reduce their empowerment; and lack of access to land which affects their food and nutritional security.

1.4 Gender disparities in Malawi

This research study has a special emphasis on gender and its related disparities. Caring for those who are ill in the family has always been a woman's job. This care work is consistently carried out in addition to all the other duties that women perform in their homes. With the advent of HIV and AIDS the caregiver's role has become significantly more burdensome. Women in Malawi have now been tasked with becoming more than just caregivers. Women are currently performing multiple roles in providing care for those who are chronically ill with HIV. The challenges that come with these roles are enormous and are exacerbated by the social inequalities and power imbalances that prevail in Malawian society (Nolan, 2009). This scenario is common in most African societies; women are usually disadvantaged in terms of access to education, to agricultural resources and to health services (Semu, Ngwira & Kamchedzera, 2003; Ngwira & Mkandawire, 2003; Bernbaum, 1999; Castro-Leal, 1996; Ngalande-Banda, 1995).

1.4.1 Low education levels

Low education levels define the life chances of a person. As is the case in most sub-Saharan Africa countries, the status of women remains especially low due to poor education levels which subsequently limits their ability to earn a living (Semu, Ngwira & Kamchedzera, 2003). Most women do not attain high education levels in the majority of sub-Saharan countries for a number of reasons. For example, preferential treatment of males at home limits female access to schooling as male children are sent to school instead of female. In a study conducted in Ghana, Bradley (2000) observes that childhood poverty, together with established gender roles and

traditional cultural beliefs favouring the education of boys over girls leads to young girls' life chances being disadvantaged from an early age. Gender disparities continue to exist in most sub-Saharan African countries not only in terms of access to but also in participation in the learning process (UNESCO)¹. Sub-Saharan Africa is the region with the highest class repetition rate, (more than fifteen percent in half the countries with data,) and in this region girls also tend to repeat classes more than boys (ibid). Furthermore, school survival rates up to Grade 5 in sub-Saharan Africa are also lower than elsewhere in the world, and this more notable in Guinea-Bissau, Malawi and Mozambique (ibid).

These gender and economic impediments have affected women's access to education leading to a lifetime of chronic levels of deprivation. A number of studies have shown the link between low education levels and poverty among women (Mbirimtengerenji, 2007; Masanjala, 2007; Lloyd & Hewett, 2009). Similarly, a study conducted in Malawi by Kathewera-Banda, Kamanga-Njikho, Malera, Mauluka, Kamwano Mazinga and Ndhlovu (2011) found that women in Malawi continue to experience the pervasive effects of poverty due to low levels of education.

In Malawi the adult literacy levels of women versus those of men are generally extremely low. According to the Malawi Integrated Household Survey 2010-2011 (NSO, 2012: 21), the national average literacy rate for both men and women was at sixty-five percent. The national male literacy average rate was seventy-four percent while that of females was fifty-seven percent. However, the adult literacy levels of men and women in Mzimba are higher than the national levels whereby ninety-two percent of men are literate while about eighty-three percent of the women are literate (NSO, 2008). It is generally clear from these figures that women still lag behind in terms of acquiring literacy and are being left behind in a number of social-economic areas, leading to low income levels and productivity (Gregg, 2008; Ngwira 2001). Other reports also point to the fact that the disadvantages faced by women tend to create socio-economic inequalities resulting in discrimination in the health

¹ UNESCO [O] Available at: <http://www.uis.unesco.org/Education/Documents/unesco-world-atlas-gender-education-2012.pdf> Accessed on 04/11/2014

sector, education, and labour market. (UNDP, 2002; Wrapson, Mewse & Lea, 2008; Ashford, 2002).

The next section briefly outlines the way in which the organisation of society predetermines the status of women in Malawi.

1.4.2 Socio-cultural disparities

In Malawi, the status of men and women is considered non-negotiable because the socio-cultural systems that determine such status are well entrenched. Two cultural systems – matriarchal and patriarchal - exist in Malawi. In the matriarchal cultural system a man marries into his wife's family, while in the patriarchal system a man brings a wife into his family and community after paying a bride price (Phiri, 1983). In both cultural systems the status of women is lower than that of the men but the status of women living in a patriarchal system is the lowest (ibid).

In a matriarchal cultural system a woman is dependent on her brother or uncle (her mother's brother) to make decisions that in the patriarchal culture would be made by her husband. In both cultural systems, a woman is, for example, not allowed to own land which ultimately can affect her household food security (Kishindo, 2004). Other restrictions include those related to sexual relationships. Here, a woman does not have the power to make decisions concerning her own sexual health. As can be seen in the next section, in relation to a great many issues women, in Malawi, experience a marked lack of empowerment.

1.4.3 Obstacles to women's empowerment

In terms of issues of empowerment, women are prevented from accessing sexual health information and services because they are expected to be innocent and submissive when it comes to sex (Kathewera-Banda, Gomile-Chidyaonga, Hendriks, Kachika, Mitole & White, 2005; Sternberg & Hublely, 2004). Ngwira et al (2001), found that rural women who were poor and economically dependent had limited influence on the conditions under which sex occurred, including the use of condoms in a Malawi.

Behavioural Surveillance Survey of 2004 (FHI 360, 2004), it was also found that without the autonomy to act in a male-dominated culture, knowledge among women regarding the HIV and AIDS epidemic to avoid infection was insufficient.

The Ngoni² (i.e. the tribe found in Mzimba), for example, are patriarchal in nature. Women are married and taken to their husbands' families after *lobola* (dowry), which may be in the form of cattle and/or money, has been paid to the bride's family (Kathewera-Banda, Kamanga- Njikhoh, Malera, Mauluka, Kamwano, Mazinga & Ndhlovu, 2011). Culturally, people from Mzimba are polygamous (ibid). According to the 2004 Malawi Demographic Health Survey (MDHS), sixteen percent of the men in Mzimba reported that they had two or more wives (National Statistical Office, 2011). In a polygamous marriage, and even in monogamous marital systems, men's decisions in terms of women's fertility tend to dominate as norms of masculinity prize the man's fathering numerous children (Baschieri, Cleland, Floyd, Dube, Msona, Molesworth, Glynn & French, 2013; Sternberg & Hubley, 2004). If a man is infected with HIV, he would in turn infect his wives or wife, and the control of women's fertility renders them vulnerable to HIV infection.

1.4.4 Lack of access to agricultural resources

Having access to agricultural land can enhance an individual's socio-economic status. Socio-economically, the position of women is lower than men's in Malawi due to a lack of access to agricultural resources, such as land. Matchaya (2009: 5) describes the two customary systems of inheritance in Malawi, the matrilineal and the patrilineal. In a matrilineal system, chieftaincy is handed down through the female line, as is land. In practice, however, it has been observed that land cultivation decisions are made by the women's husbands or brothers (Kishindo 2004; Ngwira 2001). Land tenure in a matrilineal system is complex. In this system of marriage, a man's rightful heirs to his land are his sister's children (Pachai, 1978; Ngwira, 2001; Kishindo, 2004). In a patrilineal system, on the other hand, land ownership and use is transferred from fathers to sons (Matchaya, 2009: 2). In both systems, however, women do not own land. The use of land is determined by men, be it their brothers

² The **Ngoni people** are an ethnic group living in Malawi, Mozambique, Tanzania, and Zambia in east-central Africa. The Ngoni trace their origins to the Zulu people of Kwa-Zulu Natal in South Africa. Rangeley (1966).

and uncles as is the case of the matrilineal system, or by their husbands or sons as is in the patrilineal cultural system. This is a source of confusion, especially when a man dies leaving behind orphans. In the matrilineal culture, the orphans can be dispossessed by their cousins, who within this tradition are the rightful owners of the land. In the patrilineal culture, the orphans can be disposed by the deceased man's brothers as they lay claim to their brother's land.

Essentially, the low literacy levels of women, socio-cultural disparities, lack of empowerment, and lack of access to agricultural land exacerbate women's burden of care as well as their own ability to cope with the burden.

1.5 Challenges faced by women providing home-based care

As HIV and AIDS have impacted severely on all aspects of Malawian society, the researcher was particularly interested in understanding the challenges that women face as caregivers for those who are chronically ill with HIV. In order to do so, it was important to look at two aspects of the challenges they face: their gender-related HIV infection vulnerabilities, and the socio-cultural and economic challenges they face when providing care.

1.5.1 Gender and vulnerability to HIV-infection

Women who provide home-based care are women first and carers second, so it was essential to look at the issue of women's vulnerability to HIV-infection through the lens of gender. Women are not only more vulnerable to HIV-infection, i.e. due to physiological vulnerability, but they also suffer as a result of social, economic, cultural inequalities, i.e. 'social vulnerability' or 'societal vulnerability' (Cannon, Twigg & Rowell, 2002; Ashford, 2002; Enarson, 2007). Men act as 'gatekeepers', restricting women and children's access to health services and through abuse or neglect men's actions have a direct bearing on the health of their partners and their children (Sternberg & Hubley, 2004: 389). Women's vulnerability to HIV infection and access to health services are described in the following sub-sections.

Biological or physiological vulnerabilities

Around sixty percent of adults living with HIV in Malawi are female (UNAIDS, 2008). The reason for this high prevalence lies in the biological differences between men

and women which make transmission of HIV through sexual contact more efficient from men to women than vice versa (Ashford, 2002). During sexual intercourse, a woman has a larger surface area of her genital tract exposed to her partner's sexual secretions than a man (ibid). The immature reproductive tracts of young women make them even more susceptible to infection than adult women, which makes younger females, aged 15–24, about four to six times higher in infection rates than their male counterparts (UNAIDS, 2000; UNDP, 2001a).

Another factor which puts women at risk of becoming infected with HIV is the practice of dry sex. 'Dry' has several meanings. For the purposes of this study, dry sex is the drying and/or tightening of the vagina using various methods of douching and/or the application of caustic leaf concoctions, powders, or household detergent to absorb vaginal lubrication (Runganga, Pitts & McMaster, 1992).

Many studies have been conducted to understand this phenomenon (Brown, Ayowa, & Brown, 1993; Runganga and Kasule, 1995; Dallabetta, Miotti, Chipangwi, Liomba, Canner, Saah, 1995; Sandala, Lurie, Sunkutu, Chani, Hudes & Hearst, 1995; Civic & Wilson 1996; Gresenguet, Kreiss,; Foxman, Aral & Holmes, 1998; Baleta, 1998; La Ruche, Messou, and Ali-Napo, 1999; Beksinska, Rees, Kleinschmidt & McIntyre, 1999; Myer, Denny, de Souza, Wright & Kuhn, 2006). These studies explain that the main purpose of dry sex is to increase friction during intercourse, enhancing the male's experience. Such practices prove to be destructive and costly in terms of women's health (Foxman, Aral & Holmes, 1998). The destruction of the vagina's natural flora facilitates the proliferation of other potentially harmful microorganisms. The lack of lubrication results in lacerations of the epithelial lining of the vagina, creating a portal for HIV entry (Beksinska, Rees, Kleinschmidt & McIntyre, 1999). In addition, condoms break easily due to the increased friction, exposing the woman to sexually transmitted diseases (STDs), including HIV. In a study of 329 women ages 15-50 attending an STD clinic in Lusaka, Sandala, Lurie, Sunkutu et al. (1995) found that fifty percent of the women had engaged in at least one dry sex practice and about fifty-eight percent of those women were HIV-positive. The most common methods of dry sex were drinking "porridge," a suspension believed to cause drying of the vagina (twenty-eight percent); removing vaginal secretions with a cloth (twenty-two percent); and placing caustic leaves in the vagina (eleven percent) (ibid).

Women tend to endanger their lives in order to please men sexually and this is directly linked to the status and empowerment of women in their societies. It is out an engrained need to ensure a man provides for their needs that the women to take such extreme measures to the detriment of their own health.

Social, economic, and cultural vulnerabilities leading to HIV-infection

As has been described in the previous sections, women's socio-economic and cultural status is very low and as a result of this they are left with few life chances. In Malawi many women are vulnerable to HIV-infection because they live in conditions of severe socio-economic deprivation. This deprivation leads to extreme desperation often compelling them to offer sex in exchange for money, or gifts, as they struggle to feed themselves and their families/dependents (Chersich & Rees, 2008). The lack of economic empowerment means that affected women find themselves in dire situations where the exigencies of providing for their families outweigh all other considerations (Chersich & Rees, 2008). Other studies have also found that such women tended to engage in transactional sex with men whose lifestyle rendered them high risk (MacPherson, Sadalaki, Njoloma, Nyongopa Nkhwazi, Mwapasa, Lalloo, Desmond, Seeley & Theobald, 2012; Moore, Biddlecom, Zulu, 2007; Hunter, 2002; FHI 360, 2004). Men tended to have multiple and concurrent partners, and/or did not use condoms consistently in every sexual encounter (FHI 360, 2004). In a second round of the behavioural surveillance survey conducted in Malawi (NAC, 2009), it was found that only twelve percent of male and female participants (6,274 being the study population) consistently used condoms with commercial partners. It also found that only about five percent of the women in the study consistently used condoms with their regular partners (ibid). This suggests that most women who engaged in commercial sex did not use condoms, putting themselves at risk of being infected with HIV. It was further reported in the same study that the reason most women did not use condoms with their partners (commercial, casual or regular) was that they lacked the socio-economic power to negotiate condom use with their partners (NAC, 2009; United Nations Systems in Malawi, 2001).

Other cultural practices found in Malawi which also endanger the lives of women include widow inheritance, widow cleansing, dry sex. Practices such as sexual

initiation rites expose young women to HIV (United Nations Development Programme/Malawi Government 2002; UNDP 2001; UN, 2002).

In Malawi, as in many sub-Saharan African countries, a man's property, including his wife, passes to his adult sons or brothers after his death (Luke [sa]; Widow's Rights International; Von Streunsse, 2005). The fate of African widows ranges from disinheritance and forceful deprivation/dispossession of property to the mandatory observance of harmful rituals, such as widow cleansing (Von Streunsse 2005; UNDP 2001). A dangerous traditional practice is widow inheritance, a ritual whereby a widow is forced, or is under immense duress to agree to, marry her husband's younger or older brother to continue as a member of the family and ensure her children are "cared for". In case of refusal, she is expelled and left to care for the children on her own (Luke [sa]; Widow's Rights International [sa]). Such customs have continued to put women at a great risk of HIV-infection among women in sub-Saharan Africa.

1.5.2 Socio-cultural challenges when providing care

Women who provide care to those infected and affected with HIV experience a number of challenges related to their gender roles as producers of food, carers of family and children, and also resulting from their roles in the community in general.

Gender roles and the gendered burden of care

The role of caring for the sick and dying is primarily a household and familial responsibility. Although this role can be shared between men and women, the burden falls heaviest on women. With the advent of AIDS, this has become even more acute, particularly for young and elderly women (Akintola, 2004; Urdang, 2001).

In a household in which both parents are ill from AIDS, the responsibility for household management and of the main carer is taken on by a daughter (Esplen, 2007; VSO, 2006; UNAIDS, 2008) Because of this burden of care, the daughter is often forced to miss school or drop out (ibid). This has led to an increase in the number of girls dropping out of (ibid). In Malawi it was found that grandmothers have also been forced to take on the responsibility of caring for chronically ill children (Ngwira & Kalulu, 2000; OXFAM, 2001; Mtika, 2001). They are also providers

and procurers of food and other household necessities. Women play a leading role in securing food for the home even at the expense of their own welfare and health. Hyder, Maman, Nyoni, Khasiani, Teoh, Premji & Sohani (2005) conducted a study in East Africa in which they reported that worldwide and in Africa in particular women traditionally play a critical role in securing food for their families. Despite major constraints women are expected to meet the basic survival needs of their families (ibid). Among poor women of the world, rural women farmers of Africa are among the lowest in social status and they are often expected to support themselves and their families virtually independently (ibid). In a household which is caring for an HIV-infected person, the burden of caring for such a person simply adds to the existing challenges.

Hyder et al (2005) found that the vicious cycle of increasing work, lack of time and lack of independent decision-making for women who were responsible for food production and the health of their families had adverse health and social consequences. They found that food securing activities had negative health consequences for women and these were further exacerbated by issues of gender inequality (ibid).

1.5.3 Socio-economic and psychological challenges

Usually the women who provide care for those who are infected with HIV in the household and in the community at large are volunteers. This means that the activities related to home-based care are unremunerated and this entails its own socio-economic challenges, including its effects on the household, or community, and the work's inherent stresses.

Socio-economic effects of home-based care on women and their households

Home-based care activities consist largely of unremunerated care work and in some cases women may be forced to leave paid jobs to tend to a relative. Opiyo, Yamano and Jayne (2008), in their East African study, found that caring for ill parents, children or husbands is usually unpaid in the case of relatives who are ill and can increase a person's workload by up to a third and that this care work displaces other health producing activities. While caring for sick family members, women also have to reduce the time they spend on other activities, such as non-farm self-employment,

and for young women, attending school (Ogden, Simel & Caren, 2004; UNAIDS, 2008). As Ogden, Esim & Grown (2006: 333) state "...when there is a sick or dying person in the house, someone quite literally has to care, whether out of love, duty or simply a lack of options".

Ogden, Esim & Grown (2006: 333) refer to this as the 'care economy' and in relation to the HIV and AIDS pandemic this conceptualisation illuminates the increased labour time required along with other demands placed upon households, and particularly upon women. As women are increasingly asked to perform caring duties and fewer economic activities, their economic status continues to be eroded. In their weakened position, women continue to struggle to bring an income home while they are caring for the chronically ill and resultantly experience an increase in poverty (Akintola, 2004).

In some countries in sub-Saharan Africa, like Malawi, where a family's livelihood relies on growing and maintaining crops, the withdrawal of human labour due to illness or death of the economically productive men and women in the family can lead to food insecurity and limited social and economic support (Munthali, 2000). When there is an illness in the household, women automatically take up the caring role leaving the production of food in the gardens to the younger members of the family (Hyder et al 2005; Munthali, 2000). Since women are primary food producers in most households, such survival strategies tend to reduce their socio-economic status as their households are unable to produce adequate food or generate enough income. Consequently, female-headed households are often reported as being more dependant-heavy and as having low socio-economic status (Chant, 2007; Posel, 2001).

Studies in Malawi at the turn of the century also revealed that if a woman were suffering from AIDS-related illnesses she would have to rely on female relatives to care for her (Ngwira, Bota & Loevinsohn, 2001; OXFAM, 2001:2; Mtika, 2001). As a result, if a married or adult woman fell ill, it was likely that another household would be affected because an adult woman's labour would be withdrawn to provide nursing care to the chronically ill person (ibid). Consequently, these local safety nets were put under great strain as AIDS took hold in a community.

As a result of frequent chronic illness and death due to AIDS, households are pushed into a downward spiral of impoverishment. These consequences are influenced significantly by systems of marriage in Malawi. In matrilineal systems, which are predominant in most parts of the country, the illness and death of a husband leaves a wife with children with some security of land tenure (Kathewera-Banda, Kamanga-Njikho, Malera, Mauluka, Kamwano, Mazinga & Ndhlovu, 2011). However, if in the matrilineal system, the wife dies, the man is sent away and the children have no direct parental care (OXFAM, 2001; Bota, Loevinsohn, Ngwira, 2001). Other studies have revealed that the death of a man also has serious consequences for those households that are urban-based and in patrilineal marriage systems because of biased and insecure property and inheritance rights which tend to favour the deceased husband's family (Ngwira, Bota, Loevinsohn, 2001; OXFAM, 2001). Consequently, women are more likely to be left without the means to care for themselves, such as land and other capital goods.

Psychosocial effects of coping while providing home-based care

Women providing care for the HIV-infected also tend to experience problems of a psychosocial nature. This may become manifest through outbursts of anger, nightmares, insomnia, worry, anxiety, fears about imminent death, and despondency due to frequent deaths in the family or community (Quinlan, [sa]). Socially, women tend to experience stress as they feel stigmatised and alienated from friends and social activities. These women also suffer from economic stress as the majority of these women are also heads of their families and are the breadwinners (ibid). Because of their low levels of economic activity, and in some instances having lost their jobs or job opportunities, they tend to suffer from diminished incomes. As a result they often have insufficient money to attend a health facility when the patient's condition deteriorates. Eventually, they do not have sufficient money even for funeral and burial costs (ibid).

1.6 Overview of the HIV and AIDS epidemic³ in Malawi

Malawi is characterised epidemiologically by high prevalence rates of communicable diseases which include malaria, tuberculosis, HIV and AIDS which account for most of the bed occupancy in hospital admissions (Manthalu, Nkhoma & Kuyeli, 2010). There is also an increasing burden of non-communicable diseases such as cancer, diabetes, hypertension, cardiovascular diseases, mental illnesses, and high incidence of maternal and child health problems (ibid). This huge burden of disease exerts pressure on an already fragile health system leading to women taking on the caring role of those who are chronically ill.

In order to understand the increasing demands on women as caregivers to the affected and infected in Malawi, it is necessary to provide an overview of the HIV and AIDS epidemic in Malawi and the mitigation measures put in place by the government and the community.

The HIV prevalence rate (i.e. total percentage of population aged between 15 and 49) in Malawi, among both men and women, is reported to be approximately eleven percent (World Bank, 2011; Pindani, Maluwa, Nkondo, Nyasulu & Chilemba, 2013). There are more than 92,000 adults and children living with HIV ((UNAIDS, 2011). Women account for about fifty-three percent of the adult HIV-infected population (UNAIDS, 2012; NAC, 2003).

1.6.1 Malawi estimated adult HIV prevalence (15-49 Year Olds), 1990-2009

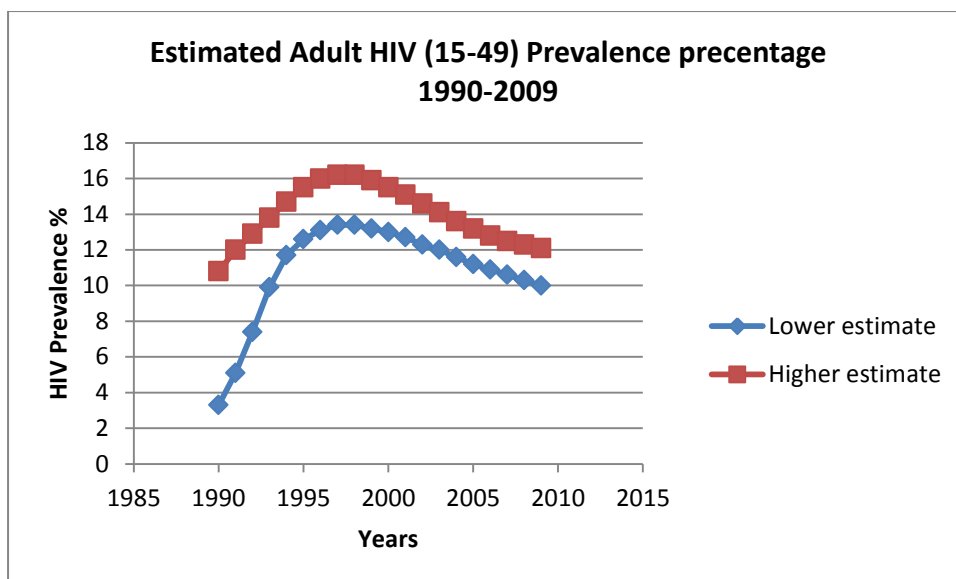
The prevalence of HIV among adults progressively increased over a period of almost twenty years. However, the past ten years have seen a decline in the rate of increase of new infections in the population, as seen in **Figure 1.1**.

Fig 1.1: HIV prevalence estimates (1990-2009) in Malawi

³ **HIV and AIDS**

In this study, the terminologies 'HIV' and 'AIDS epidemic' are used as proposed by the UNAIDS.[O] Available at:

http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2011/JC2118_terminology-guidelines_en.pdf (Accessed on 12/11/2013)



Malawi has seen a steady decline in the total number of people who have died due to AIDS-related illnesses over time. For example, the number of people who died of AIDS-related illnesses by mid-2008 was reported to be more than 68,000 and, in 2011, the number of people reported to have died of AIDS-related illnesses was 43,000 (UNAIDS, 2010; UNAIDS, 2012).

Although there has been a decline in AIDS-related deaths, the number of people who living HIV remains high. As a result of the high rates of people living with HIV, fifty percent of all medical-ward beds are usually occupied by people who are suffering from AIDS-related illnesses (UNAIDS, 2010).

One of the major causes of morbidity among HIV-infected people is tuberculosis. Several studies show that an estimated seventy percent of all pulmonary tuberculosis patients are infected with HIV in Malawi (National AIDS Commission, 2003; Harries, Kwanjana, Hargreaves, Van Gorkom, & Salaniponi, 1998), resulting in an increasing of the bed occupancy rate to more than hundred in all hospitals with patients sleeping on the hospital floors.

HIV-infected persons also suffer from a variety of opportunistic infections. Harries et al (1998) reported that due to the frequency of opportunistic infections, all HIV-infected patients tended to remain in hospitals longer than other patients which impacted enormously on the workload of hospital health care providers.

1.6.2 The national response to the HIV and AIDS epidemic

The national response to the HIV and AIDS epidemic in Malawi emerged through the development in 2005 of the National HIV and AIDS Policy⁴ and the HIV and AIDS Strategic Framework or the National HIV/AIDS Action Framework (i.e. NAF for short) (NAC, 2005). One of the priority areas of this response was the provision of equitable treatment for people living with HIV, such as making available antiretroviral drugs for those who required them to ensure that they remained socially and economically active (NAC, 2005). The NAF was extended to continue up to 2012 and it covers: prevention and behaviour change; treatment, care and support; impact mitigation; mainstreaming and decentralisation of care; research, monitoring and evaluation; resource mobilisation and utilisation; and policy and partnerships (UNAIDS, 2010). Within these key areas, the government developed a policy to support the provision of community home-based care services (UNAIDS, 2008).

Ideally, home-based care services are meant to be sustained by government. Women who care for those infected and affected by HIV are meant to be provided with support from the government through the Ministry of Health. However, as has been discussed in brief above, women carers in fact experience many difficulties and , moreover, few studies have been conducted to understand these challenges experienced by women as they provide care.

1.6.3 Anti-Retroviral Treatment (ART)

One of the major responses to mitigate the effects of HIV and AIDS in Malawi has been the introduction of anti-retroviral treatment (ART). ART was introduced in 2003 in Malawi and has been gradually scaled-up since to treat more AIDS patients (UNAIDS, 2012). As a result, people infected with HIV are living longer. According to Ministry of Health programme reports, by the end of the first quarter of 2011, there were 264,512 people taking ARVs (UNAIDS, 2010) and by the end of 2011, there were

⁴ National AIDS Commission 2005. National HIV/AIDS Action Framework (NAF) 2005 to 2009. [O]. Available at: http://www.ilo.org/wcmsp5/groups/public/---ed_protect/---protrav/---ilo_aids/documents/legaldocument/wcms_125537.pdf (Accessed on 07/01/2013).

322,209 people receiving ART (Masanjala & Kajumi, 2013: 11). The following table and figure illustrate the trend in expanded ART provision.

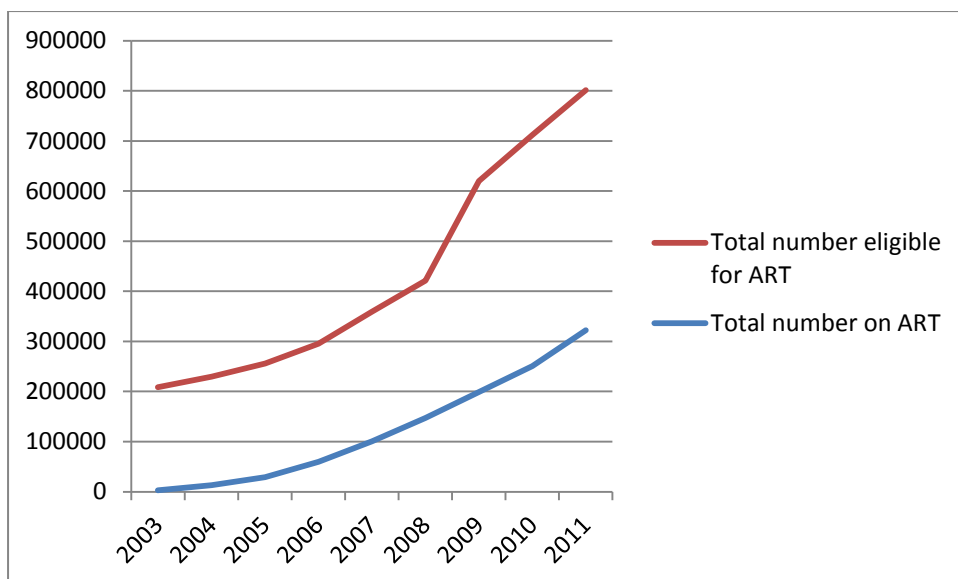
Table 1.1 ART coverage and enrolment figures for Malawi, 2003–2011⁵

Year	Total number on ART	Total number eligible for ART	Total ART coverage (percentage)
2003	3,100	205,295	2
2004	13,183	216,531	6
2005	29,087	226,512	13
2006	59,980	235,715	25
2007	100,649	258,829	39
2008	147,497	273,499	54
2009	198,846	420,895	47
2010	250,987	461,158	54
2011	322,209	478,904	67

Figure 1. 2: ART coverage in Malawi (eligible and actual Malawians) 2003-2011⁶

⁵ Data presented in Table 1.1 was found from a number of sources which included: UNAIDS (2007, 2008, 2009); UNAIDS, 2010. Malawi HIV and AIDS Monitoring and Evaluation Report: 2008-2009 UNGASS Country Progress Report; 2012 Global AIDS Response Progress Report: Malawi Country Report for 2010 and 2011; National AIDS Commission. (2003 & 2005).

⁶ Figure 1.2 was generated from Table 1.1



There are, however, many more people who are HIV-infected and who are not on ART. According to the 2010 Malawi Demographic Health Survey and the 2010 UNGASS Country Progress Report, there were 930,000 people living with HIV and AIDS in Malawi and only about forty-seven percent of these were on ART (NSO MDHS 2010; UNAIDS, 2011).

In consequence, many people living with HIV face the possibility of being chronically ill and in need of home-based care services.

1.7 Best practices in home-based care

In order to understand the context in which the best practices in home based care are found, it is necessary to understand the organisation and arrangement of health care system of Malawi.

The Ministry of Health is made up of central directorates which include: nursing, clinical, preventive, health technical support services, planning, finance and administration, HIV and AIDS, reproductive health, and health education (MoH, 2012: 14). The administrative responsibilities for public health are devolved to the zonal level, with each zone comprising a cluster of districts (ibid). District and Christian Health Association of Malawi (CHAM) hospitals provide the district level health services, both secondary and primary health care (ibid). However, primary health care is provided through health centres, which are generally located at the community and village levels. The public health hospital system in Malawi is structured in a

three-tiered network of interlocking medical facilities (ibid). There are several providers of health care services in Malawi and these include government central and district hospitals, Christian Health Association of Malawi (CHAM) institutions, and private hospitals (ibid). All these providers of health care are involved in providing HIV and AIDS care services.

Hirschfeld and Lindsey (2002: 34) argue that a properly functioning community home-based care programme should consist of the following elements: provision of care; continuum of care; education; supplies and equipment; staffing; financing and sustainability; and monitoring and evaluation.

It was also the objective of this study to determine whether the home-based care programmes in Malawi contain all these elements. The study has also sought to identify home-based care best practices existing in Malawi.

Looking at the literature available regarding the situation of women in the context of HIV and AIDS, it is apparent that a gap in information exists concerning the challenges facing women as they provide home-based care to the HIV- and AIDS-infected and -affected. This study is then a timely attempt to provide information to address this gap in Malawi.

1.8 Setting and statement of the research problem

1.8.1 Setting of the study

Mzimba District, which has a vibrant home-based programme supported by the local government hospital and National AIDS Commission, was the site of the study. A local NGO, named Towwirane AIDS Organisation⁷ also works with those infected and affected by HIV and AIDS in the area. It was formed in 1993 to mainly offer services to the HIV and AIDS infected and affected people in and around Mzimba town. Its programmes include: HIV counselling and testing, care for the chronically ill using the home based care approach, provide psychosocial support to orphans and

⁷ Towwirane AIDS Organisation is a local NGO, which was founded in 1993 to HIV/AIDS prevention, advocacy, quality care and support services including livelihoods, health and education to the community, those infected and affected by HIV and AIDS in Mzimba with love, accountability, and professionalism. <http://www.globalgiving.org/donate/25335/towwirane-hiv-aids-organisation/info/>

vulnerable children, and people living with HIV and AIDS, adolescent sexual reproductive health and rights, and training of volunteers who provide early childhood development, psychosocial support, home based care, stigma and discrimination services.

The research participants, i.e. women who provided home-based care, were recruited from two villages with help of Group Village Headmen, Alick Chisi and Mbale. These are two villages which are close to the Mzimba town; Alick Chisi village is located about four kilometres south of Mzimba town, while Mbale village is located about three kilometres south-west of Mzimba town.

1.8.2 Statement of the problem

The health care system in Malawi is under significant strain, principally as a result of inadequate budget allocation and a shortage of health care workers. The average annual health care expenditure by the Malawian government is \$31 USD per person per year (Hoffman, Mofolo, Salima, Hoffman, Zadrozny, Martinson & Van Der Horst, 2012: 74). The health care worker: patient ratio remains one of the highest in the world with an estimated sixty-four to seventy-seven percent of available health care positions in Malawi remaining unfilled (ibid). As early as 2008, the health care provider to patient ratio was 1:2,771 and the physician to patient ratio was 1:50,000 (ibid). The ratio of nurse to patient in particular is at 1: 3,500 (Phiri, 2007: 8). With such a shortage of nurses, physicians and clinical officers, hospitals are severely understaffed and ill-equipped to provide adequate patient care (Hoffman et al, 2012: 74). As a result, most gravely ill people are discharged from hospital prematurely and have to be cared for at home. The creation of home-based care is a specialised community response to the care needs of those who are chronically ill and have been discharged from hospital. Over time, home-based care has become more of a necessity than a care option for all concerned, that is, for the government, the sufferers themselves, and their carers (UNAIDS, 2008).

While both men and women take on the role of carers, women tend to be burdened with a larger share of caring for the ill than men. There is a body of evidence which shows that unequal AIDS-related care work responsibilities are assumed disproportionately by girls and women of all ages when compared to boys and men

(UNAIDS, 2008; UNAIDS/UNFPA/UNIFEM, 2004; Steinberg, Johnson, & Schierhout, 2002; Tumwine, 2007). In Southern Africa, two-thirds of primary care givers are female (Steinberg, Johnson, Schierhout, 2002).

Women in Malawi are responsible for domestic chores; the care and feeding of their families; and the cultivation, exchange and commercialisation of household gardens (Vivas, 2011). They have also been consistently charged with the roles of reproduction, production and caring for the community which creates a “triple burden of care” (ibid). HIV-care has exacerbated this burden of care (UNAIDS, 2008).

Older women and married women have taken on the major part of the caring responsibilities associated with the HIV and AIDS epidemic because a substantial proportion of those living with HIV and AIDS move back to their communities of origin to be cared for by their parents. Older women often take responsibility for their grandchildren if and when it becomes necessary (Knodel, Saengtienchai, Im-em & Van Landingham, 2001). The care role itself encompasses many activities, including: fetching water, lifting patients to assist them with using the toilet, washing patients, cooking, cleaning, and farming (ibid). Younger women, however, are also called on to carry out caring roles primarily when one or both of their parents or guardians become infected with HIV (VSO-RAISA, 2007a).

A shortage of qualified health care workers has created a huge burden of caring for those who are infected with HIV. Caring duties fall largely on women who are already overwhelmed by other duties and chores in the family and community. Despite the fact that the burden of care falls largely on women, there are few social science research studies which have studied the plight of the women they provide care. The study was therefore guided by the overarching research question: what challenges do women who provide home-based care in Mzimba, Malawi experience?

1.9 Rationale for the study

The rationale for the study is grounded in the vulnerability of women in Malawi and in the challenges they face when providing home-based care in their communities.

Home-based care is a model of caring for the chronically ill which differs from age traditionally-observed community-based care. The advent of the HIV and AIDS

epidemic has drastically changed the nature of community-based care. It has become a form of care notably more demanding and requiring specialised skills. This is because HIV and AIDS are relatively new illnesses which have unique demands and require unique knowledge. While a number of studies have been conducted in the area of home-based care in Malawi, most have concentrated on biomedical issues relating to the continuum of care for HIV and AIDS patients and health care workers. Sociological studies relating to home-based care are few and the findings of this study are intended to provide some complementary insight into the issue of home-based care, particularly with regard to the improvement of policy and programmes intended to mitigate the challenges presented by HIV and AIDS. The challenges that have been identified in this study will provide the impetus on addressing the difficulties that women face especially in providing home-based care.

1.10 Main aim and specific objectives of the study

The main aim of this study was to determine the challenges faced by women providing home-based care in Mzimba, Malawi.

Specifically, the study was conducted to:

- determine the gender-related challenges which render women who provide home-based care vulnerable to HIV-infection;
- determine the socio-cultural challenges women who provide home-based care experience;
- investigate the socio-economic challenges which women who provide home-based care experience;
- investigate best practices in home-based care.

1.11 Methodological approach

A combination of methods to collect data with the aim of producing both exploratory and descriptive data was used in this study. The use of both qualitative and participatory methods allowed for the generation of data that would provide an in-depth and detailed understanding of home-based care issues. A primary aim of using qualitative methodologies has been to generate in-depth (“thick”) and rich descriptions, and understanding, of actions and events (Babbie, 2010). Participatory

methods such as Pairwise Ranking and Time-Activity Profiles were used to obtain data that would augment the qualitative data. Pairwise ranking was also employed because it allows for comparison of two items at a time, participants are asked which is preferred, why it is preferred and what is good or bad about each choice (Kapila & Lyon 1994: 30). In this study it was adapted to gather data on the different activities that women caregivers are involved in addition to home-based care and ranking the ones that they found to be the most challenging. Time-Activity profiling was a tool that was adopted from a tool called Daily Activity Programmes (Kapila & Lyon 1994: 31). In this study, the participants were asked to identify all the activities that they carry out from the moment they wake up in the morning to the time they go back to bed, giving an estimation of time each activity takes. This method was used to gather data on the challenges which women caregivers faced in trying to carry out all the relevant home-based care activities and at the same time cater for their own needs.

The use of qualitative and participatory methods allowed, too, for triangulation of the data. The data gathered in order to produce a complete and detailed description of the challenges faced by women providing home-based care in Malawi. The research methods used to collect data were in-depth individual interviews, focus group discussions, pairwise ranking activities, and time-activity profiles.

1.11.1 Sampling strategies

Purposive and snowball sampling procedures were used in this study. Purposive sampling entailed using pre-selected participants. Snowball sampling was employed to complement purposive sampling. Snowball sampling is a particular non-probability method of sampling used when the desired sample characteristic is rare. Snowball sampling was used because it relies on referrals from initial subjects to generate additional subjects (Russell, 2006).

1.12 Relevance and contribution of the study

Home-based care as an alternative to caring for the HIV-infected in hospital emerged in Malawi once it became clear that the crisis of AIDS was becoming too overwhelming for hospitals to cope with, due, inter alia, to inadequate material and human resources. Despite this implementation of home-based care, very few studies have been conducted into home-based care as an alternative form of care, and little

is known, moreover, concerning the difficulties experienced by women caring for the chronically ill.

The bulk of research conducted in Malawi concerning care for HIV and AIDS patients has concentrated on the patients and their health needs (Zimba & McInerney, 2001; NAC, 2003). Some studies have focused on the needs of primary caregivers when it was found that primary caregivers felt stressed, overburdened and unable to meet the demands of their caseloads with increasing numbers of people ill with AIDS and escalating referrals. The wellbeing of children who were affected by HIV and AIDS was also found to have suffered; the assumption of care roles at an early age had it appeared negatively impacted their development (Zimba & McInerney, 2001; Kamphinda, 2004).

The few studies carried out in Malawi concerning caregivers of HIV and AIDS patients show that caregivers do indeed experience a number of emotional (such as stigma and discrimination, anxiety, worries and fears of death); physical, and financial strains (Nkhandwe, 2001; Pindani, 2009).

While, it is clear that some studies have been carried out in the country, most of these studies have looked home-based care from the patients' point of view. This study, on the other hand, took a different approach i.e. to look at home-based care and its challenges from the point of the caregivers.

1.12.1 Relevance for society

The effects of HIV and AIDS have taken a heavy toll on Malawi, which is a low-income country. Current programmes to mitigate the epidemic at both micro- and macro-levels have been in operation for some time. Arguably, the HIV and AIDS pandemic has been successfully contained if one refers to the statistics showing the declining levels of people being infected annually (UNAIDS, 2013). The number of people living with the virus has gradually declined (ibid). The introduction of ART has meant that many people who are infected with HIV and who had previously given up hope are now able to live productive and relatively health lives (ibid).

AIDS mortality rates have also drastically reduced. However, not everyone who is HIV positive is receives ART. Even when a patient receives ART, this does not free them

entirely from ill-health. Many people who are HIV positive are constantly ill due to opportunistic infections which often affect those with the disease as such they are frequently admitted to hospital, and are those most in need of home-based care (UNAIDS, 2013) This study's relevance for society is the understanding it may foster concerning the life of carers as they take on the roles of care providers, counsellors and a multiplicity of other roles needed by the patient.

Women have taken on these roles in addition to the other roles they play in their households and communities. This study has examined the challenges that women have experienced and continue to experience as they care for those in need of home-based care. Understanding these challenges will assist those who are interested in improving the wellbeing of women and, at the same time, improving the home-based care programme.

1.12.2 Relevance for the home-based care programme in Malawi

Home-based care in Malawi has evolved a great deal over the last twenty years, having emerged as an emergency response to Malawi's overwhelmed hospital system at a time when large numbers of very ill people who were hospitalised in vastly overcrowded facilities.

In 2001, after many years of informal home-based care provision provided by community members and relatives of HIV-infected people, the National AIDS Commission, in collaboration with the Ministry of Health and other stakeholders, established a formal community- and home-based care programme. The burden of caring for those who were HIV-positive had grown tremendously and as a result the NAC formed the community home-based care programme to spearhead the national response to the pandemic (Malawi National AIDS Commission, 2003).

Under this programme, the chronically ill would be cared for at home by relatives and volunteers. This led to the proliferation of various community home-based care projects set up to mitigate the effects of HIV with the aim of providing best quality of life for those infected and affected (NAC, 2005).

1.12.3 Contribution of the study

In order to understand the specific issues relating to caring for the chronically ill at home, home-based care has been studied using various approaches and disciplines. Medical studies have concentrated principally on providing evidence-based research into health care, clinical practice, and medication (Cochrane 1972; Gray 1997; Sackett, Rosenberg, Gray, Haynes & Richardson, 1996). Economic studies have looked at the care giving process as a 'care economy', focusing on care work in terms of unpaid work. Ogden et al. (2006) and Urdang (2001) have both looked at home-based care from an economic perspective. Anthropological studies have looked at the problem of HIV and AIDS and its effects on traditional and extended family systems, and looked at people's coping mechanisms in the face of the epidemic (Munthali, 2002: 6-7). Anthropological perspectives have also been used to understand community home-based care in Malawi by applying phenomenological methods to examine subjective human experiences (Pindani, 2008: 41). Sociological studies have been conducted examining at community home-based care with some seeking to understand the contexts in which family members and communities try to provide care for the HIV-infected. Kimani, Mwanthi & Olenja (2001), for example, conducted a study in Kenya using sociological methods and paradigms to determine the priority needs and interventions necessary to assess, plan, develop, and implement an effective community home-based care programme. Campbell and Foulis (2004), on the other hand, studied the context of the HIV and AIDS epidemic with a view to creating environments for effective home-based care. Scholars have for a long time agreed that the social and personal impact of HIV and AIDS requires the use of sociological theories, such as feminist theories, functionalist theories, or even social action theories.

Feminist theories are employed in this study to account for the fact that most care givers are women and that the bulk of the care and household work is also done by women (Noble, 2000). Functionalist theories elucidate the way in which everyone has a role to play in society to ensure its smooth operation. In relation to caring for the chronically ill, society's division of labour results in women carrying out the duties of caring. In terms of social action theories, a rational point of view is proposed, in the sense that caring for those infected with HIV is a rational action rather than

behaviour. In other words, there is a social need for someone to carry out the caring duties for the chronically ill. This study contributes to the emergence of research concerning the issues surrounding HIV and AIDS and their consequences on both individuals and the collective.

The home-based care approach to providing care for the HIV-infected and -affected has been studied by a number of scholars in Malawi. However, very few have used sociological methodologies to understand the myriad aspects associated with this care, such as HIV patients' quality of life and the effects of home-based care on the patients and others. In this study, the use of both qualitative and participatory methods was appropriate and vital for gaining a detailed picture of the daily lives of the participants. The use of participatory methods allowed for the capturing of those subtle but vital experiences that quantitative methods alone would not have revealed. Interview schedules were used to collect qualitative data by allowing the participants to open up and express ideas, to express these clearly and to explain and elaborate on those ideas, while allowing the researcher to focus on the question at hand. This form of listening and questioning is an art that the researcher must master (de Vos, Strydom, Fouche, Delpont 2011: 350). Pairwise ranking activities and time-activity profiles were used to collect data which would show the complex nature of caring for the HIV-infected and -affected while performing a myriad of other duties. This study was consequently exploratory and descriptive in nature.

Feminist theories are used in this study to explain the challenges that women experience as women while providing care for the HIV-infected and -affected in their homes or community. Theories of inequality and oppression, and of difference, are used in this study to explain why women find themselves in a less privileged position in society, and why these women have to bear the burden of care. These women live in an unequal and oppressive society. In this study, the researcher made the following assumptions: firstly, that society is a social construct which operates as a complete well-functioning entity with the roles ascribed to men and women essential for maintaining a cohesive the social structure; and secondly, that the home-based care programme and the challenges it presents to women carers can be approached using feminist theories.

The researcher looked at society as a social construct with roles and responsibilities. Such society constructionism assumes that understanding, significance and meaning are developed not separately within an individual but in coordination with other human beings in society. In other words, human beings rationalise their experience by creating a model of the social world. A social structure is created using social action and social institutions, which are henceforth associated with the social structure. In describing social institutions, it is also important to bear in mind that they are organised patterns of social behaviour. This is what functionalists refer to as the elements of social structure (Giddens, 2011). Social structure also refers to the enduring orderly and patterned relationships between the elements of a society. In the study of social structure, the concrete reality with which we are concerned is the set of actually existing relations at a given time.

1.13 Delimitation of the research area

This study was carried out in Mzimba, Malawi.

1.14 Limitations of the study

The pool of potential participants for the study was affected by two factors. Firstly, the time of data collection coincided with general elections, and secondly, it was harvest time. Even with these limitations, the researcher was able to find a sufficient number of participants to sit for data collection until the level of saturation of was achieved.

The study was confined to a single area in Mzimba, Malawi and while the findings of the study cannot be generalised to the whole country they may be used to provide a stepping stone for policy review of home-based care programmes.

The methodology used for this study was only meant to generate explorative data which may not be enough to explain all the challenges that women and their communities in this area experience.

1.15 Definition of key concepts

The key concepts used in this study are defined as follows:

Home-based care is a form of providing care to the chronically ill in their own home by family members or/and volunteers (WHO, 2000).

HIV stands for Human immune-Deficiency Viruses, the virus that caused AIDS. (Scott & Marshall, 2009).

AIDS stands for acquired immunodeficiency disease syndrome. It is a complex of symptoms and ultimately deadly infections caused by Human Immune-Deficiency Viruses (HIV) (Scott & Marshall, 2009).

Lobola refers to a bride price, typically of cattle, paid to a bride's father among Bantu-speaking people of southern Africa (Scott & Marshall, 2009).

Matriarchal system is a social system whereby a woman rules a family, clan, or tribe (Scott & Marshall, 2009).

Matrilineal system is a social system whereby one inherits or determines descent through the female line (Scott & Marshall, 2009).

Matrilocal system is a societal system relating to a housing pattern or custom in which a married couple lives with or near the wife's parents (Scott & Marshall, 2009).

Patriarchal system is a social system in which the role of the male as the primary authority figure is central to social organization, and where fathers hold ultimate authority (Scott & Marshall, 2009).

Patrilineal system is a social system whereby one inherits or determines descent through the male line (Scott & Marshall, 2009).

Patrilocal system is a societal system relating to a housing pattern or custom in which a married couple lives with or near the husband's parents (Dictionary.com).

Continuum of care is a term used to define care that is provided to those who are infected HIV throughout all stages of HIV and AIDS through a health care delivery approach which links health, medical and social support services within a clearly stipulated geographical space to comprehensively meet a wide and evolving range of needs over time (WHO, 2002; Jackson, 2002).

Home-based care is a form of assistance given to a patient, within the home environment (Jackson, 2002; Ludwig & Chittenden, 2008). Home-based care services involve prevention and care and support provided beyond the health institution that aims at meeting the overall needs of people suffering from chronic illnesses and their family members, including those taking life-long medications such as ARV drugs (WHO, 2002; Urdang, 2006). Palliative care is usually provided by the patient's family, friends, volunteers and members of the community that are trained and supported by skilled health care workers (Urdang, 2006; Akintola, 2004). The care given may include physical, psycho-social, spiritual and material support and should adapt to the patient's needs (Ludwig & Chittenden, 2008; Akintola, 2004).

Palliative care is a set of supportive interventions that improve the quality of life of patients and their families who face problems associated with a chronic disease or life-threatening illness (WHO, 2002; Jackson 2002). This can be done through the prevention and relief of the broad spectrum of suffering which could either be physical, psychological or spiritual (Sachs, 2005; Akintola, 2006).

Primary caregiver is an informal caregiver who may be the biological mother or father, grandparent, or friend, etc., and who provides most of the care to HIV and AIDS patients in the home (Zimba & McInerney 2001:84).

1.16 Organisation of the thesis

The subsequent chapters of the study are organised as follows:

In *Chapter Two* background information on the study area and its characteristics are outlined. The following background characteristics are discussed in greater detail: population structure; national poverty incidence; agriculture, food security and livelihood sources; literacy levels, health indicators; and cultural traits of the people.

In *Chapter Three*, literature on home-based care and its definitions; models of home-based care; and existing information relating to best practices in home-based care are presented. Available literature relating to gendered aspects of home-based care in terms of roles, burden of care, and vulnerabilities of women who provide home-

based care is also reviewed. Gaps are identified in terms of information relating to home-based care and women who provide care to the infected and affected.

Chapter Four presents and defines the theories which guided the research study. These theories include those of social structure, gender and power, and *cathexis* (social norms and affective attachments). The concept of gender is first defined; the relationship between gender and power is explained while linking these concepts and relationships to factors that define women's roles and vulnerability.

Chapter Five describes the methodology used in the study, ethical considerations taken into account, and the procedures followed during data collection and analysis.

In *Chapter Six*, the findings of the study are presented. First, the profiles of the research participants are explained while the second part of the chapter includes the results of the study according to the specific objectives set.

In *Chapter Seven*, the findings of the critical incident narrative interviews with young women are presented. These are presented in the form of life stories given by the young women who were providing home-based care to parents or guardians infected with HIV. These are the personal stories of young women trying to cope with challenges of caring for the chronically ill while at the same time coming of age.

In *Chapter Eight*, findings from the Key Informant interviews with Key informants are presented.

Chapter Nine, guided by the aims and objectives of the study, presents a discussion and summary of the study's findings, and goes on to draw its final conclusions and present the recommendations of the study.

CHAPTER TWO

SOCIO-ECONOMIC AND CULTURAL PROFILE OF THE STUDY SITE

2.1 Introduction

This chapter discusses the research site, the population structure of Malawi, and the national poverty incidence, fertility levels, health indicators, agriculture, food security, livelihood sources, literacy rates and cultural traits, as they pertain to Malawi, in order to contextualise the socioeconomic challenges that Malawian women face in providing home-based care to the chronically ill, and then focuses more specifically on Mzimba.

2.2 Research study site

The study was conducted in Mzimba, a district in the northern region of Malawi. Malawi is a small, landlocked, densely populated country in southern Africa. It is bordered to the north and northeast by the United Republic of Tanzania; to the east, south and southwest by the People's Republic of Mozambique; and to the west and northwest by the Republic of Zambia (Malawi DHS, 2011; Minot, 2009). The country is 901 kilometres long and 80 to 161 kilometres wide with a total area of approximately 118 484 square kilometres of which 94 276 square kilometres are land and the rest is lakes and rivers (Malawi DHS, 2011; Benson, 2002). Mzimba district is the largest district with a land size of 10,382⁸ square kilometres.

The following figures (Figure 2.1 and Figure 2.2) show the Maps of Malawi and Mzimba district.

Figure 2.1: Map of Malawi ⁹

⁸ Knoema. World Data Atlas. [O] Available at: <http://knoema.com/atlas/Malawi/Mzimba/sources> (Accessed on 28-07-2015)

⁹ Map of Malawi showing the country with international borders, provincial boundaries, the national capital Lilongwe, regional capitals, district capitals, cities and towns, and major airports. [O] Available at: <http://www.nationsonline.org/oneworld/map/malawi-administrative-map.htm> (Accessed on 28-07-2015)

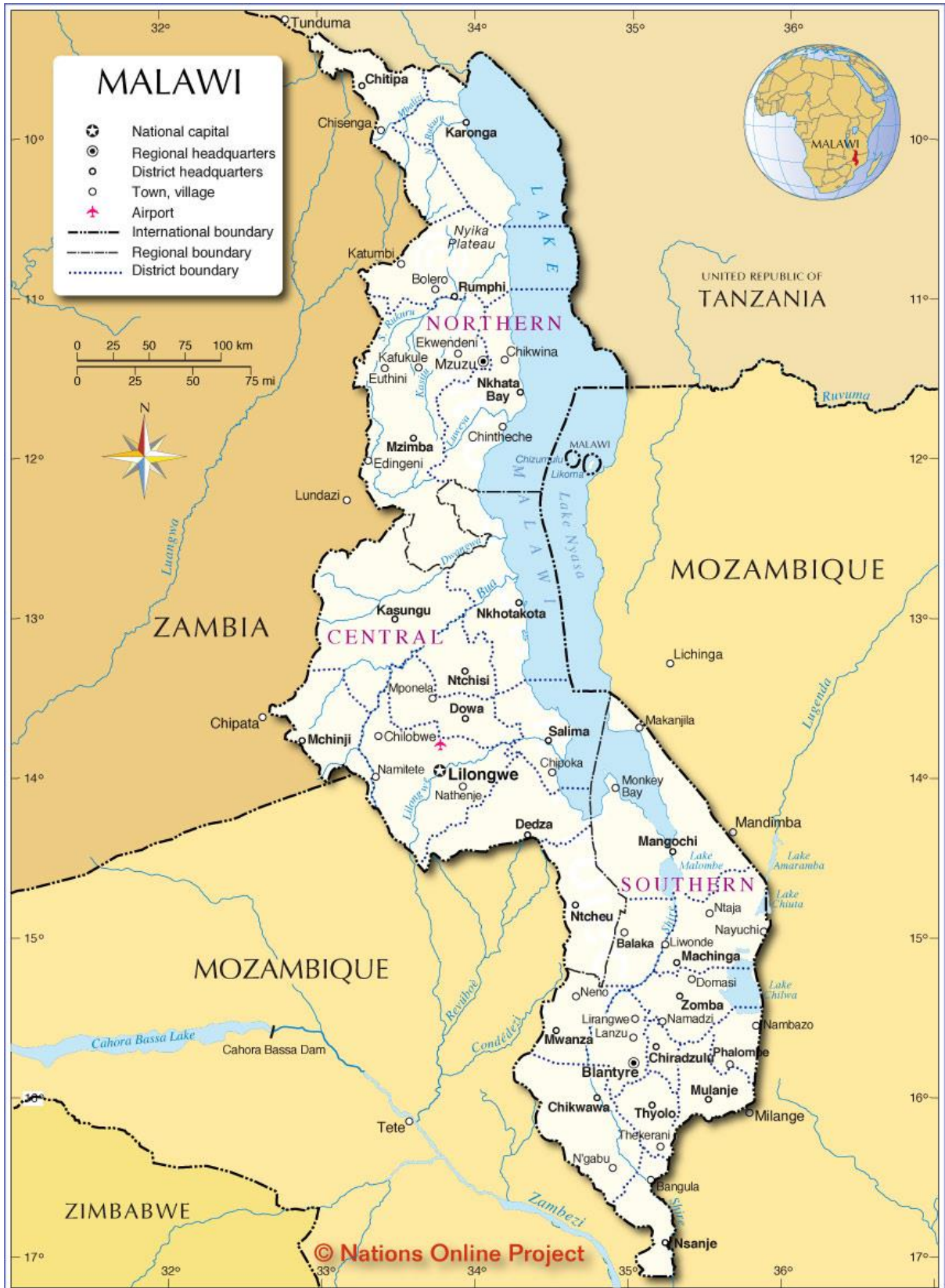


Figure 2.2: Map of the Mzimba District¹⁰



2.3 Population structure

The last population census conducted in Malawi in 2008 revealed that there were 13 077 160 people living in the country, with an annual growth rate of approximately three percent (National Statistical Office, 2009; Minot, 2009). There are slightly more women than men, with a national gender ratio of 99 males per 100 females (NSO, 2009). Mzimba had a population of 724,873—approximately six percent of the total population of the country (NSO, 2009: 3). There are 349,150 men and 375,723 women (ibid).

Malawi has a young population with forty-seven percent of the population being below fifteen years of age (NSO, 2012). The life expectancy at birth in Malawi has been declining over time and is currently estimated to be at just over fifty-four years (UNDP, 2012). One of reasons why the population structure in terms of age has become skewed is the devastating effects of the HIV and AIDS pandemic which has led to the death of numerous people in their prime, resulting in turn in significant numbers of orphaned children. The under twenty orphaned population accounts for

¹⁰ Mzimba location guide [0] Available at: <https://www.google.co.za/search?q=map+of+mzimba+district+in+malawi> (Accessed on 28-07-2015)

thirteen percent of the country's population (ibid.). There is also a slight gender disparity in life expectancy with women living longer than men. The life expectancy of women is almost fifty-seven years and that of men fifty-six years (UNdata, 2012).

2.4 The national poverty incidence

The levels of national poverty incidence in the country are extremely high and Malawi is one of the least developed countries in the world. The national poverty rate is about fifty-one percent and in Mzimba, the poverty incidence is at about sixty-one percent (NSO, 2011: 204- 206). The incidence of poverty is higher in the rural areas as compared to the urban areas with about seventeen percent of the population in urban areas living in poverty compared to fifty-seven percent of the rural poor population (NSO, 2011: 205). In addition, there is a distinct gender dimension to poverty in Malawi whereby about forty-nine percent of the people in male-headed households are poor while fifty-seven percent of people in female-headed households are poor (NSO, 2011: 219). Furthermore, in the rural areas, fifty-five percent of male-headed households are poor while sixty-three percent of female-headed households are poor (NSO, 2011: 219).

There are a number of reasons why Malawi, as a country, continues to remain in the poverty trap. These reasons include women continuing to bear children (this increases monetary poverty but reduces subjective poverty); lack of ownership of productive assets; lack of access to wage employment; and limited participation in agriculture and livelihood activities (Mussa & Pauw, 2011: 2–3). Subjective poverty is different from monetary poverty because consumption level does not corresponds to poverty as the 'experts' say thereby 'objectively' fixing a poverty line but rather defines poverty through the eyes of those who live it Van Praag & Ferrer-i-Carbonell, 2006: 5). Thus household poverty is by no means clearly classified as 'poor' or 'non-poor' according to the objective definition of poverty (ibid.). Subjective poverty scholars maintain that the household's wellbeing does not exclusively depend on money income, but also on leisure time, health, etc. (Van Praag & Ferrer-i-Carbonell, 2006; Massoumi, 1986).

In addition, the country is subject to periodic severe weather shocks and these tend both to drag vulnerable households below the poverty line and to limit the extent to

which such households are able to invest in inputs for the next production cycle (ibid.). Malawi is also heavily dependent on the importing of goods and services and this high import intensity in turn means that fluctuations in the real exchange rate and/or international price shocks have a significant impact on the domestic economy (ibid.).

As a consequence of the abovementioned factors the country has remained one of the lowest ranking countries in terms of the human development index. According to the UNDP Human Development Report of 2013, Malawi was ranked one hundred and seventieth out of one hundred and eighty-seven countries and territories (UNDP, 2013). In 2007, the United Nations estimated that the gross domestic product (GDP) per capita for Malawi was US\$ 256.6 (UNdata, 2011).

The poverty line is the minimum level of income deemed adequate in a particular country and is also known as the welfare indicator (Ravallion, 1992; NSO, 2005). The common international poverty line has for some time been calculated at approximately one US dollar a day. However, in developing countries such as Malawi, the consumption and expenditure of the majority of households is less than one US dollar per day (equivalent to just over 400.00 Malawi kwacha at the time of the study and as quoted by the National Bank of Malawi¹¹) (Sachs, 2005; NSO, 2005). Those households in respect of which the welfare indicator is below the poverty line are defined as poor (Van Praag & Ferrer-i-Carbonell, 2006; Laderchi, Saith, & Stewart, 2006; NSO, 2011). In Malawi, the ultra-poverty line was set arbitrarily at sixty percent of the poverty line: MK 4.17 (US \$0.17) (NSO, 2005).

There is also a gender dimension to poverty and this is reflected in gender-based inequalities relating to these factors: reproductive health, empowerment and economic activity (UNDP, 2013). High gender inequalities often lead to a lack of human development as a result of the inequality between female and male achievements in terms of these factors (ibid.). Malawi ranks one hundred and twenty-fourth out of one hundred and forty-eight countries in the Human Development Index of 2012 (ibid.).

¹¹ The National Bank of Malawi is one of the big commercial banks in Malawi. Available at <http://natbank.co.mw/index.php/2013-01-10-09-18-18/foreign-exchange-rates-nbm> (Accessed on 20/06/2014).

For the purposes of this study the concept of poverty incidence was deemed to be of great importance as it relates to the HIV infection vulnerability among women as they try to mitigate the effects of poverty. Poverty increases both gender inequality and a susceptibility to contracting HIV as a result of sexual exploitation (IDRC, 2006).

2.5 Fertility levels

Fertility levels are also an indicator of wellbeing insofar as they affect the socioeconomic status of women. High fertility levels affect the household socioeconomic levels of both people and countries.

Despite the declining life expectancy in Malawi, the Malawian population continues to grow as a result of the high fertility rate in the country – currently an average of approximately six children per woman (Malawi Population Data Sheet, 2012; NSO & UNICEF, 2006). The total fertility rate in Mzimba is about six (NSO, 2011). The total fertility rate (TFR) in Malawi is significantly higher in the rural areas compared to the urban areas, with an average total fertility in the rural areas of almost seven children, as opposed to almost five in the urban areas (4.5) (Population Data Sheet, 2012). Despite the fact that the United Nations estimates that the TFR has dropped to five children per woman, this figure continues to remain relatively high when compared to neighbouring countries in the region such as Mozambique with a birth rate of approximately five and Zimbabwe with a birth rate of three (UNdata, 2012, World Bank, 2011). Nevertheless, Malawi's TFRs are comparable to other neighbouring countries such as Tanzania, at approximately six, and Zambia at just over six (World Bank, 2011). The high TFR levels in Malawi have been ascribed to a number of social factors such as early child bearing, a low contraceptive prevalence rate, high female illiteracy rates, and a desire for large families (NSO, 2009). High TFR leads to high household sizes. The average household size in Malawi is at about five people while in Mzimba, the household size is just over five people (NSO, 2011).

Thus, as a result of the low life expectancy and the high fertility rate, the population of Malawi is both young and dependent (UNdata, 2012). According to the Welfare Monitoring Survey of 2011, the dependency ratio (population aged under fifteen added to population aged sixty-five and over as a proportion of the population aged 15 to 64) was estimated to be 1.09 (NSO, 2012: 2). The dependency ratio of 1.37 in

female-headed households is higher as compared to the 1.02 in male-headed households (ibid.). This higher dependency ratio in female-headed households is relevant to this study as most of the women who care for the chronically ill tend to have a number of dependents, possibly as a result of the effects of HIV and AIDS.

The 2011 Welfare Monitoring Survey estimated that female-headed households comprised twenty-four percent of all households (NSO, 2012), with twenty-six percent of the rural households being female-headed as compared to sixteen percent of the urban households (NSO, 2009). At the time of the Survey, the dependency ratio in the rural areas was measured at 1.12, and 0.78 in the urban areas (NSO, 2009). Mzimba, as a predominantly rural district, typifies this phenomenon.

The high dependency ratios have a negative effect on the welfare of poor households, particularly as poor households also tend to have large families and their dependency ratios are higher than those of non-poor households (Mussa & Pauw, 2011: 2). There is a vicious cycle of poverty in households with high dependency ratios. The household heads of poor household tend to have had little education and this leads to a lower likelihood of finding salaried employment or engaging in a profitable business enterprise, thus resulting in greater poverty (Mussa & Pauw, 2011: 2).

2.6 Health indicators

The health and development indicators in Malawi are those typical of other low-income countries in sub-Saharan Africa ([Zere](#), [Moeti](#), [Kirigia](#), [Mwase](#) & [Kataika](#), 2007). According to the World Health Organisation (2012: 56), the average life expectancy at birth for both men and women is forty-seven years with men have a life expectancy of forty-four and women fifty-one. In Mzimba district the life expectancy for men is just over fifty years and for women, it is fifty-four years (NSO, 2011; Knoema¹²). Life expectancy at birth indicates the number of years a new born infant would live if the prevailing patterns of mortality at the time of the infant's birth were

¹² Knoema. World Atlas. [O] Available at: <http://knoema.com/atlas/Malawi/Mzimba/sources> (Accessed on 28-07-2015).

to stay the same throughout the infant's life (ibid.). The major health problems that beset Malawi include HIV and AIDS, tuberculosis and malaria.

The HIV prevalence rate (i.e. total percentage of population aged between 15 and 49) in Malawi, among both men and women, is reported to be approximately eleven percent (World Bank 2011; Pindani, Maluwa, Nkondo, Nyasulu, Chilemba 2013). This does, however, represent a decline in the HIV prevalence from over sixteen percent in 2000 to the current level (see Fig 1.1).

Mzimba, which is the study research site, is considered to be a high prevalence area for both HIV and AIDS and tuberculosis. Geubbels and Bowie (2006) reported HIV prevalence rates of fifteen percent in the rural parts of Mzimba as compared to the approximately twenty-one percent in the urban areas in 2006. Zere et al. (2007) reported a tuberculosis prevalence rate of 551 per 100 000 in 2003 and a malaria prevalence rate of 240 per 1 000 in 2002.

According to a World Bank (2010) report, Malawi's public health expenditure comprised just over twelve percent of government expenditure in 2009, while in April 2011 the World Bank reported that the percentage of total health expenditure in Malawi was just over sixty percent (ibid.). The total health expenditure is defined as the sum of public and private health expenditure (World Bank, 2011) and includes the provision of health services (preventive and curative), family planning activities, nutrition activities, and emergency aid designated for health, but not the provision of water and sanitation (ibid.). Furthermore, the country spent approximately seven percent of GDP on health (ibid.). In other words, the country's health expenditure per capita (current US\$) in 2011 was US\$ 26. Studies have also shown that Malawi has the lowest health worker to population ratio in sub Saharan Africa, with approximately two physicians and fifty-nine nurses per 100 000 people (Liese & Dussault, 2004; Zere et al., 2007)

Low health and development indicators reflect the poor status of health of any country. Banda et al. (2006) reported that poor health outcomes in Malawi are affected primarily by HIV and AIDS, insufficient access to public sector health services as a result of the low public financing available for health, and a huge shortage of health workers. In addition, several studies conducted in Malawi have pointed to the

fact that women in Malawi are significantly affected by the country's poor health indicators (Munthali, 2002; Ngwira & Mkandawire, 2003; Makwiza, Nyirenda, Goma, Hassan, Chingombe, Bongololo, Theobald, 2006; Theobald, Tolhurst, Eley & Standing, 2005).

In this research study health indicators were used to draw inferences on the status of women's health in order to understand the challenges faced by women providing home-based care.

2.7 Agriculture: food security and livelihood sources

In Malawi, agriculture comprises ninety percent of the export revenue and approximately thirty-four percent of the GDP. Maize is the most important food crop in the country and it accounts for ninety percent of all caloric intake, followed by cassava, sweet potatoes and sorghum (Minot, 2009:1). The dominant export crop is tobacco which is grown by both small-scale farmers and on large estates (Minot, 2009; FAO, IFAD & WFP, 2014). Other important cash crops are sugarcane, tea, cotton and coffee – all of which are produced mainly by estates (Minot, 2009:1).

Agriculture is the main economic activity of the majority of people who live in the rural areas and who are essentially subsistence farmers. As such, agriculture provides a livelihood for more than eighty percent of the rural population (ActionAid, 2006; FAO, IFAD & WFP, 2014). In the past these farmers ensured food security in the country. However, food security has slowly declined over time, partly as a result of inadequate and erratic rainfall, as more than ninety percent of the farmers rely on rain-fed subsistence farming in order to survive (ActionAid, 2006; Minot, 2009; FAO, IFAD & WFP, 2014).

Food self-sufficiency is a critical issue in Malawi as the majority of households in the country experience chronic food shortages on an annual basis. Food security in Malawi implies the availability of maize or "*nsima*" – the staple food in the country (ActionAid, 2006; Minot, 2009). Maize is by far the most important food staple with the per capita consumption of maize of 133 kilograms accounting for fifty-four percent of the caloric intake of Malawian households (Minot, 2009:1).

The production of maize is affected by a number of factors which, ultimately, affect household food security. These factors include the availability and affordability of fertilizers. Although there is some form of fertilizer subsidy programme in Malawi, not all the farmers are able to afford to buy these subsidised fertilizers and which are necessary to ensure good harvests. In view of the fact that most farmers could not afford even the subsidised fertilizers, the government of Malawi first introduced a targeted input programme in August 2005 to provide a package of twenty-six kilograms of fertiliser and five kilograms of seed to approximately three million beneficiaries throughout the country (Chinsinga, 2008:2). However, the programme, is fraught with corruption and bias and, as a result, not everyone is able to access the crucial inputs (Jayne, Mather, Mason, & Ricker-Gilbert 2013; Minot 2009; Bryceson & Fonsenca, 2005). Jayne et al. (2013) found that the subsidised fertilizer was being diverted and sold on the secondary market (for example through theft and/or corruption). The other main cause of the food crisis in Malawi has been the persistent adverse climatic patterns which have affected the amount of annual rainfall which is required for most food crops. Simukonda (1992) explained that Malawi's rainy season, which extends from November/December to March/April, is long enough for a complete crop production cycle. However, the rain is not always evenly distributed in the country while, at times, it tends to be either too much or too little, leading to serious crop failures. Climatic changes have also led to changes in the amount of rain which falls and changes in the growing seasons (ActionAid, 2006). Consequently, most of the smallholder farmers, who are responsible for the bulk of the food production in Malawi, have experienced dwindling crop yields which have, in turn, led to food shortages at the household level (Minot 2009; Bryceson & Fonsenca, 2005; ActionAid, 2006).

Households that, in the past, grew their own food have been forced either to buy food in order to supplement shortfalls or to borrow food and money from members of the extended family, neighbours and friends (Chilowa, 1991: 13-15). Approximately sixty percent of all households experience food shortages, especially between the months of December and February when the previous year's harvest usually runs out (ActionAid, 2006). Female-headed households are the most affected by the food shortages during this period, as are children, as they tend to be the most

vulnerable to the adverse effects of poverty (UNDP, 2005). In addition, HIV and AIDS have triggered food insecurity on a much wider scale as compared to the seasonal food shortages (ibid.). HIV and AIDS have effectively diminished the workforce available to cultivated crops for food with this, in turn, leading to reduced agricultural productivity (Oramasionwu, Daniels, Labreche & Frei, 2011).

For the purposes of this study the ways in which women try to cope with the effects of food shortages were of interest to the researcher. Several studies have reported that, in order to cope with the effects of food shortages, many women tend to engage in casual labour activities, known as "*ganyu*", in the fields of others so as to earn extra income (FHII 360, 2004; Bryceson & Fonsenca, 2005; Simukonda 1992; ActionAid, 2006; Ngwira et al, 2001). Women rely heavily on the "*ganyu*" work in order to buy food (Bryceson & Fonsenca 2004; Ngwira et al, 2001). In some cases, women sell sex or are forced into selling sex in order to survive. This renders them vulnerable to HIV and AIDS infection (FHI 360, 2004).

The gender of the head of a household is an important factor in Malawi, particularly as regards to the relationship between income and poverty. The results of the Malawi Integrated Household Survey conducted by the National Statistical Office (NSO, 2005) revealed that the gender of the household head is a statistically significant explanatory variable for poverty, even when poverty is measured using consumption expenditure. This implies is that, to a large extent, the gender of the household head determines the level of poverty of a household.

United Nations and other reports on Malawi have indicated that approximately thirty-four percent of all households in Malawi are female-headed (UNDP, 2001a; UNIFEM 2005; Krogh, Hansen, Wendt, Elkjaer. 2009). The majority of these female-headed households tend to be poorer than the male-headed households as a result of gender disparities in access to resources and opportunities (Gillespie, Kadiyala & Greener 2007; Anema, Vogenthaler, Frongillo, Kadiyala & Weiser, 2009; Binswanger, Gillespie & Kadiyala, 2006). It would appear that these disparities stem from the fact that most of the women are less educated than men; they have limited recourse to productive resources; they enjoy a narrower range of formal sector labour market

opportunities; and they tend to receive lower wages than men (Chipande, 1987; National Statistical Office of Malawi & UNICEF, 2006).

In this study the researcher investigated the socio-economic status of women in relation to their poverty levels. It emerged from the literature reviewed that the socio-economic status of female-headed households in Malawi is extremely low, and that such households are in the bottom range as far as poverty levels are concerned.

2.8 Literacy levels

The literacy levels of women were an important factor in this study in view of the fact that education is the main determining factor with regard to life chances and decision-making processes in Malawi. According to the 2008 Malawi Population Census (NSO 2009), the national average literacy rate at the time was sixty-four percent. The literacy rates among women tend to lag behind those of men. There were 5.2 million males, of whom sixty-nine percent were literate compared to 5.5 million females of whom fifty-nine percent were literate (ibid.).

This trend is also evident at the district level in Mzimba. According to the Malawi Demographic and Health Survey (MDHS, 2011), three percent of men only were not able to read either a complete sentence or part of a sentence (i.e. completely illiterate) as compared to eight percent of women.

There are various reasons why women tend to lag behind in educational achievement in Malawi. These reasons include negative attitudes towards the education of women in some communities; early pregnancies; and a lack of food and clothes in households (UNDP, 2001a). In addition, girls are often subjected to sexual harassment from male teachers and male students, which often lead to unwanted pregnancies (Robb & Kaunda, 1998; Leach, Fiscian, Kadzamira, Lemani, & Machakanja, 2003; UNICEF 2002; United Nations Integrated Regional Information Networks 2002). Another factor that causes girls to drop out of school entirely is the fact that in Malawi pupils tend to repeat classes if they do not do well at the end of the year. The World Bank (2011) reported that nineteen percent of female and male students in Malawi in 2010 were repeaters. However, as the students become older, that is, as they reach puberty, they start to drop out. In 2010 it was reported

that in Malawi the ratio of female to male secondary enrolment, expressed as a percentage of girls to boys enrolled at secondary level in public and private schools, was ninety one percent (World Bank, 2011d). Repeating a class is meant to ensure that the students have gained sufficient knowledge to enable them to proceed to the next class. However, a study conducted by the Ministry of Education, in conjunction with the USAID/Malawi (1990), revealed that girls did not often benefit from repeating classes because this delayed their educational progress and the onset of adolescence placed them at risk of early pregnancy with the intense concomitant pressure to marry. In addition to repeating classes, in some cultures girls undergo initiation rituals which precipitate their leaving school before completing their education (USAID/Malawi, 1990).

Education is an independent and important predictor of health behaviour (Lindau, Tomori, McCarville & Bennett, 2001). If women have a low literacy rate or are illiterate they are less likely to know how to prevent disease infection and make informed choices than their more literate counterparts (ibid.).

2.9 Cultural traits

Malawi has a socially diverse culture in terms of both religion and ethnicity. According to the 2008 census (NSO 2009), Christians made up more than eighty-two percent of the population, thirteen percent of the population was Muslim, and approximately two percent followed other religious beliefs, while about three percent did not follow any religion at all. In terms of ethnicity, there are eight major tribes in Malawi, namely, the Chewa, Yao, Tumbuka, Lomwe, Sena, Tonga, Ngoni and Ngonde (Malawi High Commission in Zambia [sa]). These tribes speak their own ethnic languages and dialects, and have distinct cultures (ibid.).

People from Mzimba are mainly Christian and are of either Tumbuka or Ngoni (Ngoni) descent. Morris (2000) states that those of Ngoni origin are descendants of the Zulu from South Africa and the Tumbuka were already settled in Malawi (formerly Nyasaland) when the Ngoni arrived in the country. The Ngoni are patrilineal and pastoral in nature (ibid.). In this culture, a woman is married and taken to her husband's families after *lobola* (dowry), which may be in the form of cattle and/or money, has been paid to the bride's family (ibid.). In terms of culture, the people

from Mzimba are polygynous in nature (ibid.). Sixteen percent of the men in Mzimba were reported to have two or more wives (ibid). Women have no autonomy after the bridal price has been paid for them (MDHS, 20011).

The social dynamics in polygynous marriages are unique to such marriages, especially as regards the prevention of HIV infection. Polygynous relationships are often regarded as a cultural practice that facilitates the spread of HIV (Reniers & Tfaily, 2008; Gausset 2001; Oppong & Kalipeni, 2004). Included in the reasons for the spread of HIV in polygynous marriages is the fact that such marriages involve multiple partners, each of whom may introduce HIV to the other partners in the union. Once one of the spouses has become infected with HIV, the others are also exposed to it (Reniers & Tfaily, 2008). Biomedical studies have found that the simultaneous nature of partnerships in polygynous unions is likely to have an independent effect on the spread of the virus (net of the quantum of partnerships) (Morris & Kretzschmar, 1997). In addition, concurrent partnerships are considered to be particularly relevant to the spread of HIV because the probability of transmitting the virus is highest in the period immediately following seroconversion¹³ (Morris & Kretzschmar, 1997; Wawer, Gray, Sewankambo, Serwadda, Li, Laeyendecker, Kiwanuka, Kigozi, Kiddugavu, Lutalo, Nalugoda, Wabwire-Mangen, Meehan, & Quinn , 2005). Anthropological studies have found that polygynous marriages are often characterised by high rates of marital dissolution and the ease with which widows and divorcees remarry (Goldman, Pebley & Lesthaeghe, 1989; Halton, Ratcliffe, Morison, West, Shaw, Bailey, & Walraven, 2003; Van de Walle, 1968). This may lead to an increase in the total number of sexual partners over a man's or a woman's lifetime, thus increasing the risk of contracting HIV. These cultural practices were all found to be prevalent in the study area and were the focus of the study insofar as they impacted on the challenges faced by women carers.

¹³ Seroconversion refers to the change from HIV-negative to HIV-positive status during blood testing. Gale Encyclopaedia of Medicine. 2008. The Gale Group, Inc. [O] Available at: <http://medical-dictionary.thefreedictionary.com/seroconversion> (Accessed on 2014/12/28).

2.10 Summary

After discussing the contextual issues of Malawi in relation to the research site, the population structure of Malawi, the national poverty incidence and fertility levels, health indicators, agriculture, food security and livelihood sources, literacy rates, and cultural traits in Malawi were described. This background information highlighted the socio-economic and cultural context in which the study population live.

CHAPTER THREE

"Caregivers are truly the unsung heroes

as they take care of every need of their loved ones....."

Judith L. London (PhD)¹⁴

REVIEW OF RELATED LITERATURE AND THERORETICAL FRAMEWORK

3.1 Introduction

This chapter has two sections: first, existing literature on home-based care, specifically exploring the concept and definition of home-based care and the rationale for home-based care is presented. Existing models of home-based care are also described. The components and best practices of home-based care as an intervention are outlined. In order to put into context the issue of home-based care in Malawi, existing literature on HIV and AIDS, and home-based care is also reviewed. Information on women and home-based care is also presented by examining the gendered burden and roles involved in home-based care and also the subsequent challenges that women face when they provide care to those infected and affected by HIV and AIDS. The vulnerability of women to HIV infection is discussed, focusing particularly on women who provide care for the HIV and AIDS infected and affected. In addition, available information on the socio-economic and socio-cultural challenges that women face as they provide care and how they meet such challenges is also discussed.

The second section presents the theories which guided the study. This includes the theories of gender and power, and feminist theories which are explained so that the role and vulnerability of women who provide home-based care to the chronically ill who are infected with HIV is explained. These theories fall within the social structural theory which is based on existing philosophical writings on sexual inequality, gender and power imbalances (Wingood & DiClemente, 2000: 539). The chapter defines the term gender and also discusses theories of gender and power; the sexual division of

¹⁴ London, JL. "Support for Alzheimer's Caregivers: The Unsung Heroes" (2013) and "Connecting the Dots: Breakthroughs in Communication as Alzheimer's" (2009). [O] Available at: <http://www.prweb.com/releases/2014/02/prweb11603316.htm> Accessed on 02/12/2014

labour; the sexual division of power and the theories of cathexis (social norms and affective attachments). These theories are all relevant to the purpose of the study.

3.2 Home-based care

Home-based care exists as a variety of typologies, each representing a different delivery scheme, mix of services, staff and reach (Mohammad & Gikonyo, 2005: 12). There are a variety of definitions of the term 'home-based care'. This chapter discusses these definitions in an effort to illustrate how home-based care is defined by different researchers.

The World Health Organisation study group first defined long-term care as an integral aspect of health and social systems and as including activities undertaken on behalf of people requiring care by both informal caregivers (family, friends and neighbours) and traditional caregivers and volunteers (WHO, 2002: 1). In a later document the World Health Organisation defined home-based care as the provision of health services by both formal and informal care providers in the home in order to promote, restore and maintain a person's maximal level of comfort, function and health, including care towards a dignified death (WHO, 2002: 15). The UN Womenwatch defined community and home-based care as any form of care given to people within their homes and including physical, psychological, palliative and spiritual interventions (United Nations Division for the Advancement of Women, United Nations Division for the Advancement of Women, 2008: 2).

Ludwig and Chittenden (2008: 42-43) define home-based care as a form of palliative care. According to them, palliative care is an interdisciplinary process which is initiated in order to relieve the suffering and improve the quality of life for the recipients and their loved ones. Gibbs & Campbell, (2012: 4) defines home-based care as the provision of care by non-formal health care workers, primarily in the patient's home, while Akintola (2004) defines home-based care as the care given to people living with HIV and AIDS at their respective homes after their having been discharged from hospitals after a short admission period.

All aspects of the above-mentioned definitions are evident in the home-based care system in Malawi and in terms of which home-based care patients include those who

are bedridden, as well as those who have been discharged from hospital care into ambulatory care and are strong, healthy and are leading a relatively normal life (Ogden, Esim & Grown, 2006: 334). As Bowie, Kalilane, Cleary, and Bowie (2006: 1-7) found in a survey of home-based care AIDS patients in Malawi, individuals in the groups of people who are suffering from HIV and AIDS may experience a wide range of AIDS and HIV symptoms that affect their day-to-day life and for which they require care and assistance. Bowie et al (2006) found, for example, that only one in seven patients was able to live as though they did not have the disease while approximately a third required assistance with washing, walking and using the toilet.

For the purpose of this study, the inclusive definition of Jackson (2002: 17), who defines home-based care, as it applies to HIV and AIDS patients, as a holistic concept that incorporates the full needs of the HIV and AIDS patients, and also addresses the needs of family carers and the children who will be orphaned by AIDS, is adopted.

3.2.1 Rationale for home-based care

Home-based care plays a vital role in the care of people with chronic or terminal illnesses. It has been practised worldwide for many centuries from the advent of already known traditional societies (Ankrah, 2007; Airhihenbuwa & Webster, 2004). Many countries have opted for home-based care as a result of the overwhelming demand for care for those infected with HIV. The overarching rationale for providing home-based care to HIV and AIDS patients has, therefore, been to provide care for people living with HIV and AIDS (PLWHA) at their respective homes as a result of the lack of ability on the part of hospitals to cope because of both inadequate numbers of trained staff and insufficient space in which to care for HIV and AIDS patients (Jackson, 2002; Ogden, Esim & Grown, 2004). When a person is either sick or dying in a household, someone has to provide care either out of love, duty or simply a lack of options (Ogden et al, 2004; Urdang, 2006). In view of the chronic nature of HIV and AIDS home-based care for HIV and AIDS patients is, in the majority of instances, long term. It is in light of this that the World Health Organisation instituted a study in 2002 to investigate the nature of HIV and AIDS and also the needs of those infected with the virus. In their report, the WHO Study Group (2002: 1) argued that there is need for long-term care and also that such care is influenced primarily by the

changing physical, mental and/or cognitive functional capacities that may alter over the course of the individual's life.

Studies have indicated that up to ninety percent of illness care is provided in the home (Ogden et al, 2004; Bowie et al, 2006). This is also in response to the growing problem of care for PLWHAs with chronically ill patients being in need of care and support being cared for at home (Pindani, 2008; Stanhope & Lancaster 2004; Pindani, Maluwa, Nkondo, Nyasulu & Chilemba, 2013). There are a number of advantages for all concerned if a person living with HIV is cared for at home with home-based care having a positive impact on the social, economic, psychological and physical well-being of the patient, the family, the community and the general health care system (Van Acker, 2007; United Nations Division for the Advancement of Women, 2008; WHO 2002).

However, this traditional type of care has changed, resulting in the inception of formalised models of home-based care in order to deal with the adverse consequences of and meet the complex demands created by chronic diseases such as HIV and AIDS (Fox, Fawcett, Kelly & Ntlabati, 2002: 6).

Jackson quotes King Mswati III of Swaziland who, in 2002, made a speech in which he sought to capture the national spirit relating to home-based care. The King said, "The notion of a caring, sympathetic national family has never been as badly needed as at this time of crisis. Let us give those who have the disease the support and confidence to carry on living useful lives and to help spread the message of hope among our people" (Jackson, 2002: 278).

Home-based carers are called upon to provide nursing, counselling, family support and resources to infected family members and neighbours (Wood 2009: 2). However, care-giving in the context of the family encompasses more than just the practical concerns of ensuring that the infected individual is comfortable (Klaitis, 2002; Livingston, 2003). In their writing about the Tswana culture Ogden et al (2004: 3) argue that this broad ranging system of care is applicable to many people and societies. Essentially, care-giving may include preventative, promotive, therapeutic, rehabilitative, long-term maintenance and palliative care (Fox et al 2002: 6). Care involves performing practical duties and tasks. However, it also entails providing

positive healing sentiments, moral negotiations and the love (*lerato*) which is, in fact, closely synonymous with care (Ogden et al, 2004: 3). In addition, the acts through which people demonstrate care and love extend well beyond the daily nursing tasks and include any activity that contributes to the welfare of others (ibid).

Studies on home-based care also show that sharing money and food, providing labour and time, attending funerals and visiting those who are in need of comfort and assistance are all acts of care while it is through such activities that people mobilise sentiment in order to strengthen or heal relationships (Ogden et al, 2004; United Nations Division for the Advancement of Women 2008; VSO, 2006; Urdang, 2006; Akintola, 2004). Nevertheless, challenges are experienced by those who offer care to the HIV-infected and affected. This study focuses specifically on the challenges faced by women who provide home-based care in, Malawi.

3.2.2 Models of home-based care for HIV and AIDS

Various models of home-based care for HIV and AIDS are used in the many countries in which HIV and AIDS are rife. A number of these models are discussed in this section.

It emerged from a review conducted by Fox et al (2002: 6-7) that, in 2001, the Department of Health in South Africa had recommended five models of community-based home care. These models included the community-driven model; formal government sector model; integrated home/community-based care centre model; NGO home/community based care model; and the hospice integrated community home-based care model (IHC) (ibid). It is, thus, clear that, as in the case in South Africa, several different models of home-based care may be found in one country. Akintola (2004: 3) identified the following six models of home-based for PLWHA, namely, care organisations set up by religious groups and hospitals to assist the overextended health facilities; concerned individuals; families; groups of people, some of whom may have been infected with HIV or retired health professionals; and religious and international organisations. These six models operate in different ways. There are those that are volunteer community based while others provide home-based care through and from hospitals. In addition, there are models which are set up specifically to provide step-down care (i.e. another form of palliative care).

Tertiary, out-patient care programmes may also be set up to provide comprehensive rehabilitative and palliative outpatient care to the chronically ill. Another model provides semi-comprehensive care programmes while one model has been set up to provide a comprehensive care programme in terms of which services, that include HIV and AIDS prevention, voluntary counselling and HIV and AIDS testing as well as treatment, care and support to PLWHA, were provided by trained personnel. The latter model is usually hospital based (ibid).

In other parts of sub-Saharan Africa, such as Uganda and Zambia, it would appear that two models of home-based care only exist (Eburn, Aceng, Tindyedwa, Nabyonga, Ogwang, & Kiiza, 2005). These are institutional-based and community-based programmes which are often supported by churches and local non-governmental organisations (ibid). It has been recognised that the involvement of faith-based organisations in the fight against the HIV and AIDS pandemic has resulted in the introduction of programmes which have succeeded in reducing the HIV prevalence and mitigating the effects of the AIDS pandemic. At the UN Special General Assembly on HIV and AIDS on 25–27 June 2001, Benn¹⁵ explained that faith-based organisations were acutely aware of the complex nature of the infection as well as the root causes which have fuelled the pandemic, including global socio-economic inequalities, marginalisation of vulnerable people, poverty and gender issues. The involvement of faith-based organisations constitutes a response to the problems that have come as a result of the increased prevalence of HIV and AIDS (Benn, 2001). Faith-based organisations have extensive networks of people, institutions, and infrastructure which allow for successful interventions because they have direct access to and impact on the people (Liebowitz, 2002: 1-2).

Three models of community and home-based care only have been identified in Malawi (Phiri, Weigel, Housseinipour, Boxshall & Neuhann, 2004; Pindani, 2008). These models include the outreach, the integrated and the integrated community home-based care models. In the outreach model of care, the responsibility of caring for the chronically ill lies with professional health care workers. On the other hand, in the integrated model a network of community care givers is consistently supported

¹⁵ Christoph Benn was the Coordinator of the Ecumenical Team facilitated by the World Council of Churches Commission of the Churches on International Affairs of the World Council of Churches

by formal health care workers, while in the integrated community home-based care model the care responsibility falls on community volunteers with very little involvement on the part of health care workers (Phiri et al, 2004; Pindani, 2008;). The integrated community home-based care model comprises the majority of home-based care programmes in Malawi. In terms of this model, the patients are cared for at home until, when the illness becomes unmanageable at home, they are taken to a hospital or clinic near to their homes (MoH, 2012: 3). Home-based care for the HIV infected is clearly a necessity and includes various components to ensure that the care needs of HIV and AIDS patients are adequately provided for.

3.3 Home-based care as a response to HIV and AIDS

Home-based care for HIV and AIDS patients may be regarded as a social-medical response to mitigating the effects of HIV and AIDS in both the home and the community as most of the HIV and AIDS patients spend most their illness at home after having been discharged from hospitals while continuing to access medical support as out-patients (Jackson & Kerkoven, 1995). This modus operandi represents the continuum of care which was developed by the World Health Organisation and it combines two key principles, namely, addressing the range of needs of PLWHAs, from diagnosis through to death and bereavement; and creating effective referral linkages between all actors as regards meeting these needs (Van Praag, 1995; Russel & Schneider, 2000).

Home-based care as an intervention has emerged in many resource-poor countries as a means of alleviating the strain faced by the overextended, overburdened health care systems (Mahilall, 2009; Ogden et al, 2006). At the same time, home-based care enables the provision of better and more holistic care to chronically ill HIV and AIDS patients (ibid). The majority of the care provided to people infected with HIV takes place at home and is provided by family, friends or local home-based organisations. There are several reasons why this method of care continues, including the lack of a coordinated public policy addressing care needs, inadequate health infrastructure and human resources, and patient preference (Ogden et al, 2006; Urdang 2006; Mahilall, 2009; VSO, 2006). Ideally, home-based care, as a response to the epidemic, should function as a support mechanism for the hospital system as well as for

PLWHAs and their families. In addition, it should also empower the communities themselves to respond to the impact of HIV and AIDS by providing the skills required to offer physical, psychosocial, palliative and spiritual care (Mahilall, 2009; Malale, 2011). However, the majority of these skills are not provided to communities and/or the affected families, primarily as a result of, inter alia, insufficient funding (Urdang, 2006:166). Thus, the burden of caring is borne by the households and individuals who are most in need of home-based care, or by volunteers and unpaid caregivers in the home (United Nations Division for the Advancement of Women 2008: 2). This situation poses serious challenges to caregivers.

3.4 Home-based care components and best practices

This section discusses existing information on home-based care components. This is, in turn, followed by a review of the literature on the home-based care best practices which was set out by WHO (2002) for the care of those infected with HIV.

3.4.1 Home-based care components

A report of the WHO (2002), namely, *Community home-based care in resource-limited settings: A framework for action* contains the following quote by the Hon. Joy Phumaphi, Minister of Health in Botswana: "Home-based care is taking us back to the root of human coexistence. It reminds us that we all have the responsibility to one another. If we hold hands through this tragedy [...] we will be able to retain our humanity and will come out of this epidemic as a stronger community" (WHO, 2002: 9). This quote captures the spirit of home-based care, especially in resource constrained countries such as Malawi. The World Health Organisation has spearheaded the work that is being done to ensure that there is uniformity in the components of home-based care. In general, the World Health Organisation argues that a community home-based care (CHBC) programme may be defined as any form of care given to ill people in their homes and includes physical, psychosocial, palliative and spiritual activities (WHO, 2002: 7). Community home-based care involves ill people, family caregivers, health and social welfare personnel, community health workers and community volunteers (ibid). Other key stakeholders such as community and spiritual leaders, traditional healers, pharmacists, community health committees, neighbours, other community agencies or organisations and community

groups (including groups of people with HIV and AIDS, orphans, young people and women) are sometimes included in the community home-based care team (ibid). A number of significant individuals such as business and union leaders, journalists and other mass media personalities also support the practice of home-based care (ibid).

3.4.2 Best practices

In terms of best practices, a properly functioning community home-based care programme may comprise the following elements, namely, provision of care; continuum of care; education; supplies and equipment, staffing, financing and sustainability; and monitoring and evaluation (WHO, 2002: 33-74).

Provision of care

According to the World Health Organisation guidelines, the provision of care should be guided by health professionals who should make certain that the care offered is complete by ensuring that basic physical care, palliative care, psychosocial support and counselling, and the care of affected and infected children are all provided in the home (WHO, 2002: 35). When people begin to experience poor health as a result of HIV infection, they usually retreat to their respective homes (Urdang, 2006; Ogden et al, 2006; Uys, 2003). In the main, the burden of caring for these people rests heavily on women who may be mothers, grandmothers, sisters, daughters, female neighbours, or female home care attendants (Urdang 2006: 166). This care includes, but is not limited to: collecting water, washing clothes, cleaning, food preparation, feeding, child rearing, provision of emotional and spiritual support, and other tasks to ensure the comfort of the ill person (ibid).

A properly functioning home-based care programme should ensure that the provision of care is linked to a health facility. In this study, the researcher examined the link between the local health facility and the home-based programme that was in operation in the study area.

Continuum of care and support

According to World Health Organisation (2002), home-based care should ensure that there is accessibility, continuity of care, knowledge of community resources, access to other forms of community care, community coordination, record-keeping for ill

people, case-finding, and case management (2002: 35). Jackson (2002: 289) maintains that home-based care forms part of the continuum of care in terms of which patients are referred to different levels of care as the need dictates. In contrast, Ogden et al (2004: 12) take a broader view of home-based care when they refer to the continuum of care as including the full range of activities undertaken by family members in the home, including psychosocial support (emotional and spiritual), custodial care (cooking, cleaning, feeding, helping with toilet needs, etc.), and the ministrations of remedies and treatments as well as the more subtle elements such as love and healing.

The care which is provided for at home is usually without expectations of being paid and is, thus, referred to as "unlinked care" (Ogden et al, 2006: 1). Uys (2003: 99-108) defines such unlinked care as the care that is provided in the home by unpaid and untrained family members, friends, and neighbours all of whom are female. The women carers are usually related to or personally know those living with HIV and AIDS and the care may not be linked with any formal care and support service (Ogden et al 2004: 13). In countries where the burden of HIV and AIDS is high, up to 90 percent of illness care is provided in the home by the unlinked system of home care and consequently up to eighty percent of AIDS-related deaths occur in the home (ibid). One of the aims of this study was to critically examine the phenomenon of unlinked care because home-based care in Malawi is essentially unlinked care. . In the main the continuum of care is performed by women who also fulfil the day-to-day roles and responsibilities within the household (Urdang 2006: 167). This is also known as "unpaid care work" (Ogden et al 2006: 16-17). This unremunerated work undertaken within the home, and which ensures the physical, social and psychological maintenance and development of family members, as well as the 'volunteer' activities performed in the community and that keep the social fabric in good order, are referred to in the literature on economics as the 'care economy' (Ogden et al 2006:17; Waring, 1990; Elson, 1991, 1998. These unpaid health providers (i.e. volunteers) are usually linked to the home-based care services but care (generally non-clinical) is sometimes provided by family members who are not linked to these home-based care services (ibid). Home care includes the day-to-day support which a chronically ill person receives within the community, either from family

members, neighbours or agencies from outside the community (Blinkhoff et al, 2001; Gilks et al, 1998; Jackson, 2002; Russel & Schneider, 2000).

The figure below depicts all the elements in the continuum of care and in terms of which chronically ill patients may access various services.

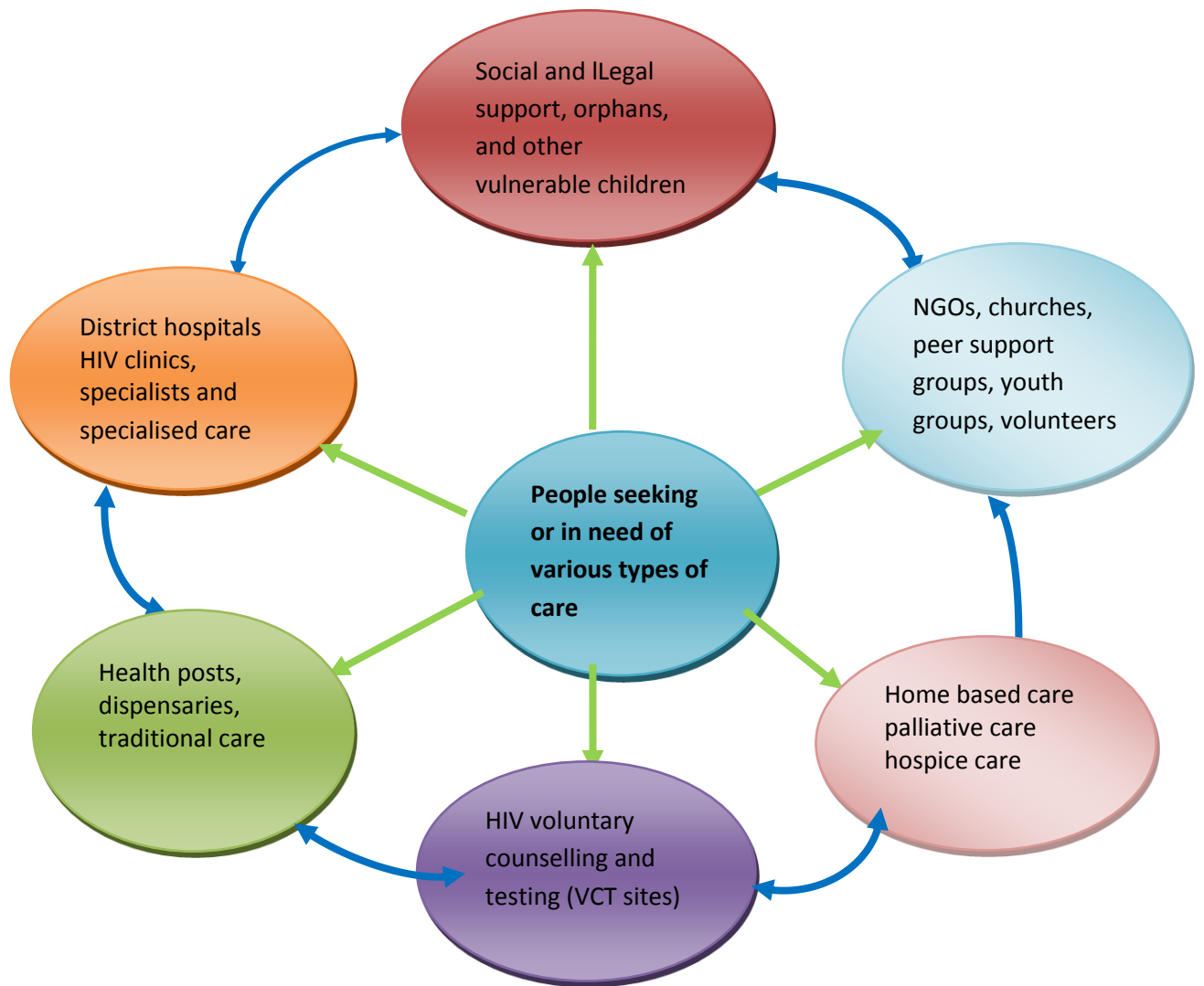


Figure 3.1: Van Praag’s Model of Home-based Care Components (undated), adopted from Jackson (2002)

Education

According to the World Health Organisation guidelines, those who are offering technical support to home-based care to HIV and AIDS patients should make certain that the carers are properly educated about the disease. This should be done by ensuring that there is a proper curriculum developed; the education is effectively managed to ensure an efficient curriculum delivery; proper outreach services; education to reduce the stigma associated with the disease; mass media involvement and that the education provided is evaluated (WHO, 2002: 35).

Although this study was primarily intended to investigate the challenges that women face in providing care, it was also deemed important to examine the knowledge with which the women were provided in order to address effectively the challenges that they faced when offering home-based care services to the chronically ill patients in their households or community.

Supplies and equipment

The World Health Organisation guidelines stipulate that it is essential that home-based care carers are provided with the requisite supplies and equipment to enable them to carry out their work effectively (WHO 2002: 35). In addition, where there is proper functioning community home-based care, the volunteers must be supported by a team that is situated in the area, has access to health centre supplies, is well managed and monitored and has in place proper record-keeping procedures, including home-based care kits (WHO 2002: 35).

In this study it was deemed important to ascertain whether the women who were providing care to the HIV infected and those suffering from AIDS-related illnesses were provided with sufficient supplies and equipment to enable them to offer effective home-based care services.

Staffing

The World Health Organisation (2002:35) also stipulates that the community home-based care team that offers technical assistance to the women who are caring for the chronically ill should be properly supervised and coordinated. In addition, there

should be proper recruitment and staff retention procedures as these would ensure the effective and efficient running of the home-based care is.

In Malawi the National AIDS Commission and other NGOs provide technical support to home-based care volunteers. In order to understand the challenges involved in the burden of care, it was vital to find out whether there was sufficient trained staff in Mzimba and who would offer ongoing technical support to the women who were providing the home-based care services.

Financing and sustainability

It is essential that an effectively functioning home-based care programme has a proper budget and that there is effective finance management of the programme (WHO, 2002: 35). The home-based care programme should also enjoy sound technical support and continuous or sustained funding (ibid). The programme should institute place activities which encourage other people to join as volunteers and ensure that there is a pooling of resources (ibid). As regards the issue of the sustainability of the programme, ongoing volunteering is dependent on a number of factors including whether or not volunteers should receive stipends. There is currently a debate regarding the out-of-pocket payments given to volunteers as a token of appreciation. There are those who consider that it is unethical to pay volunteers of any kind. Largent, Grady, Miller, and Wertheimer (2012) conducted a study in which they investigated ethical issues relating to the recruiting of research subjects. Although the study focused on the recruiting of research subjects, the findings may also apply to volunteers who provide care for the HIV infected and affected. Largent et al (2012) found the practice of paying research subjects raises ethical concerns of coercion and undue inducement (ibid). However, in countries in which paid work is scarce, stipends may be the only means of income for the families of the volunteers. For some volunteers such money may be their only intrinsic and tangible reward (Hunter & Ross, 2013: 745). Other researchers argue that payment of a stipend is important to maintain the volunteer spirit of volunteers their time to carry out caring activities (Friedman et al, 2007: 24).

In order to understand the motivation of the women who volunteered their time and money to care for those whose required their assistance, it was important to find out

whether the home-based care volunteers were being given any sort of material compensation for their work or not.

Monitoring and evaluation

Home-based care programmes which support patients in their respective homes are required to maintain high levels of quality assurance mechanisms (WHO 2002: 35). It is, thus, essential that indicators for the quality of the care provided should be developed with the programme should being consistently monitored and supervised (ibid). There should regular informal evaluations and, at the end of each cycle, a formal evaluation (ibid). However, there is also need for flexibility to ensure that the programme is able to accommodate the needs of patients and their carers (ibid). The researcher investigated the record keeping of the home-based care programme in Mzimba in order to determine how the programme was keeping track of progress and whether there was room for improvement.

3.5 Malawi, HIV and AIDS, and home-based care

Malawi has a comprehensive health provision system in terms of which people who are infected with HIV are able to access medical care through a number of health services, including maternity units, dispensaries, health centres as well as district and central hospitals, all of which are linked through a well-defined, referral system (Dippenaar, Chinula & Selaledi, 2011: 23). However, although the country has a comprehensive health care system, the quality and extent of the care provided is currently under huge strain. This is primarily as a result of the enormous burden imposed by HIV and AIDS on the health care system in Malawi. The prevalence rate of HIV and AIDS is eleven percent, making the country one of the worst affected in the world (NSO, 2010; Pindani et al, 2013). The disease burden as a result of HIV infection is, thus, extremely high, accounting for sixty percent of all hospital in-patient admission (Pindani et al, 2013: 1). In view of the structural, financial and human resource deficiencies in the health care system, the majority of chronically ill patients are discharged earlier than they should be and are placed under ambulatory care (Jackson, 2002; Ogden et al, 2004; Urdang, 2006).

Home-based services in Malawi were initiated by the National AIDS Commission in 2001 as a result of the increasing numbers of people living with HIV and AIDS in the

country (Stanhope & Lancaster 2004). Home-based care in Malawi is provided for by communities which have mobilised themselves and which are providing care for PLWHA using their own resources in their homes (Kamphinda, 2004; Pindani et al, 2013).

3.6 Women and home-based care

In a position paper written by the Networking HIV and AIDS Community of South Africa (NACOSA, 2013), it reported that there is a cadre of people, primarily women, who are providing home-based care in communities and who are not being recognised for their work.

During the illness it is incumbent on someone in either the family or the community to take care of the sick person. This carer is usually a female member of either the family or the community (Barnett & Blaikie, 1992; Ogden et al, 2004). As regards HIV and AIDS sphere, it is usually women who ensure that the patient adheres to treatment regimes, keeps appointment dates and goes to the hospital for the referral issues to be taken care of (Akintola, 2006: 237).

Although providing home-based care to people infected and affected with HIV and AIDS may be rewarding for both the provider and the patient, there are often numerous challenges involved (Browning, 2008; Pindani et al, 2013; Akintola, 2004). However, information on the challenges which women in Malawi face when providing care to the HIV infected and affected is scanty.

Women bear the triple burden of HIV and AIDS as women are often the primary caregivers, providers and mothers (Health24, 2006:1). A number of studies have shown that, as a result of poverty, women have tried to find ways in which to cater for their families and which have, ultimately, influenced both their livelihood choices and their sexual behaviours (Akintola, 2004; Munthali, 2002; Munthali & Ali, 2000).

Another dimension to volunteerism in home-based care is related both to the nature of the work itself and what people derive from it. A survey conducted on caregivers (Wade, Ganzekaufer, Hayes, Vanvadharan, & Prayog, 2007: 1-54) highlights the fact that, although, in the main, home-based care work is conducted on a volunteer basis, it is not voluntary and those who are providing the major response to AIDS are

sacrificing their sparse income and their energy in service to their communities (ibid). This invisibility of women's work is symptomatic of gender and class as well as the marginalisation and impoverishment which often lead them to engage in risky sexual behaviours in order to survive (ibid).

3.7 Gender burden, roles, and physiological vulnerabilities to HIV infection

This study used a gender lens to understand the challenges that women face when caring for those who are infected and affected by HIV. The study described the gender burden of care. In addition, a gender lens was also used to investigate the gender roles that apply to women in their caring for the HIV infected and affected. Women are also physiologically vulnerable to HIV infection and it was, thus, important to examine such vulnerability on the part of women who provide care to the HIV infected and affected.

3.7.1 Gendered burden of care for the HIV infected and affected

The burden of care for women, also referred to as the "triple burden" has been described as a condition which women are "...triplely burdened by their status as widows, their role as caregivers, and their obligation to care for young children at a time in their lives when they had imagined they were through raising children..." (Wade, Ganzekauer, Hayes, Vanvadharan, & Prayog, 2007: 16).

Akintola (2006:238) points out that the women who provide care to people living with HIV and AIDS experience both physical and psychosocial stress. In an earlier report, Akintola (2004: 24) indicated that the physical consequences of providing care include sudden and recurring head and body aches, fatigue, and muscle strain from lifting patients and carryout out other chores associated with care-giving were common among women care givers. The caregivers often tended to downplay these physical impacts and delayed seeking health care, prioritising instead of their own needs the needs of the person for whom they were caring (ibid). Emotional stress, feelings of despair, and impotence were also experienced, particularly when a patient's health deteriorated dramatically (ibid). Psychologically such feelings may be compounded for those caregivers who are, or who suspect they are, also living with HIV and observe and cope with the severe, sometimes horrific, symptoms of AIDS, anticipating as they must their own eventual illness and death (ibid).

Women who provided care to patients who are infected with HIV and are on home-based care also experience moments of anguish as the patient's health declines. Makoae (2011) describes the perceptions of caregivers when it comes to food and medical efficacy. In a study conducted on "Food meanings in HIV and AIDS caregiving trajectories: ritual, optimism and anguish among care givers in Lesotho", Makoae found that caregivers experienced moments of optimism and anguish as their patients' health progressed or declined especially as they ensured that the patients consumed food. Caregivers experienced hope when the patients' health improved and guilt when the latter's health deteriorated as their care giving role was intricately linked to "the caregivers' identity" (ibid). Furthermore, when giving care, the women caregivers touch the bodies of the patients and there is significant meaning attached to the action. The social meanings and boundaries attached to the touching and accessing others' bodies and bodily matter tends to contribute to the caregivers' stress (Makoae, 2009).

Women also care for the children who are affected and sometimes infected by HIV. In this nurturing role, women experience a number of challenges. A study by Berman, Kendall and Bhattacharyya (1994: 205-15) reveals that, in the main, women play a vital social role in many countries as they usually determine the state of household health. The study also showed that women often experienced improved self-esteem and approval from society for their care-providing skills. However, this finding may be perceived as a challenge in the face of HIV as the material and psychological demands placed on women in the context of this epidemic differ dramatically from the demands imposed under normal or pre-epidemic circumstances (ibid).

3.7.2 Gender roles in providing home-based care

The health care that is provided by women in their homes is not well defined as such although it is regarded as an integral aspect of their caring role in the family (Abbott, Wallace & Tyler, 2005: 171-172). Abbott et al (2005) argue that the discourse on health tends to assume that women will care for the members of their family when they are unwell and that it is often taken for granted that women are responsible for the health care work in the domestic sphere.

Ogden et al (2004: 7-8) further argue that, while many women embrace their care-giving roles, they are being increasingly being expected to fulfil these roles in conditions of ever deteriorating poverty and constraint. With fewer resources at their disposal, women are being expected to do more (ibid). Furthermore, Ogden et al (2004: 7-8) argue that, where women were once able to divide their time between a wide range of tasks, they now have to make impossible choices between, for example, spending the necessary time and money on agriculture in order to produce food for the family or carrying a spouse to a pit latrine. In addition, as volunteers in home-based care programmes, women take on additional care work, even beyond what they are expected to do in their own households (Akinintola, 2004; Ogden et al, 2004).

Whenever there is a household crisis such as an illness, the amount of time and energy required to deal with such illness (unpaid work) increases exponentially (Abbot & Wallace, 2005: 17). Depending on the nature of the crisis or illness, the duration of this increased workload may be either short- or long-term (ibid). HIV and AIDS are chronic, long-term illnesses or what Barnett terms a "long-wave disaster" (Barnett & Blaikie, 1992; Barnett, Blas, & Whiteside,1996; Barnett & Whiteside, 2002). However, there are numerous, significant differences between AIDS and other human disasters and these may be seen in the way in which people respond to AIDS (Barnett & Blaikie, 1992: 2). People have had to be creative to counter the effects of the epidemic in their lives. This is also because AIDS does not assume the form of a discrete event with recognisable stages and responses (ibid) and, thus, caring for the HIV and AIDS patients may be of either long or short duration depending on the length of illness and the subsequent death of the person (ibid).

Caring for the chronically ill in their homes takes up most of the productive time which women have at their disposal. Abbott and Wallace (2005: 171-172) argue that this work takes up much of their time and that many of them end up giving up paid employment or, at least, some part of their earning capacity in order to be carers. Women also have multiple roles which they play in their homes and all these roles tend to affect both their physical and their mental well-being (ibid). This point is also expanded upon by Akintola (2006) who conducted studies in South Africa. Akintola (2006: 239) found that, almost everywhere, the extra burdens of care and support are

borne by women and that the implications for their own health and well-being are often enormous, not least when those providing this care are themselves living with HIV. The amount and quality of the work done in the home is often not appreciated in the formal economic sector. Ogden et al (2004: 3) report that the care work carried out by women and girls in the household includes the services associated with the physical, social and psychological development of family members, as well as the volunteer activities in the community that help to keep the social fabric in good order. These largely unpaid activities sustain families, enable children to go to school and free up the time of other household members, allowing them to generate income.

In a study conducted in South Africa, Akintola (2004: 3) also found that care giving was usually carried out by family members, especially women, who served as the primary caregivers and also by community members who were recruited and trained to provide services as volunteer caregivers. These care giving activities included the provision of physical and emotional support to chronically ill people, and work such as the carrying, lifting and bathing of patients, staying awake at night to attend to those who were in the terminal stages of their illness, and cleaning those who suffered frequent bouts of diarrhoea among other debilitations (ibid).

Lindsey, Hirschfeld, Tlou and Ncube, (2003: 486-501) found in a study they conducted in Botswana that most of the care-giving activities were conducted primarily by older women and girls. The activities included, and were not limited to, cooking, feeding the sick, bathing them, water collection, cleaning, washing clothes, child-bearing and rearing, caring for the elderly and the sick, providing emotional support, passing on social values as well as providing informal education (Urdang, 2006: 166).

3.7.3 Physiological vulnerabilities of women to HIV infection

UNAIDS (2013) reported that, at the end of 2012, it was estimated that there were 35.3 million [32.2 million–38.8 million] people living with HIV and, of this estimate, more than half were women (ibid). It was suggested that 98 percent of these women live in developing countries (UNAIDS Factsheet 2013). Michel Sidibé, Executive

Director of UNAIDS aptly summed it when he stated that this epidemic, unfortunately, remains an epidemic of women (UNAIDS, 2011).

As an epidemic AIDS has had a unique impact on women with this impact being exacerbated by the biological vulnerability of women to HIV infection as a result of the larger surface area of their genital tract being exposed to their partners' sexual secretions during sexual intercourse as compared to men (Higgins, Hoffman & Dworkin, 2010; Chersich, & Rees, 2008;). Women, especially young women, are also particularly vulnerable to the heterosexual transmission of HIV as a result of the substantial mucosal exposure to seminal fluids (Chersich, & Rees. 2008; Higgins, Hoffman & Dworkin, 2010). In other words, the physiological differences between men and women mean that it is easier to transmit HIV from men to women through sexual contact than vice versa (Ashford, 2006; Higgins et al, 2010).

Women who care for those who are infected with HIV are also vulnerable to HIV infection due to lack of knowledge about infection and materials to protect themselves. Akintola and Hangulu (2014) found that volunteers had insufficient training on infection control and the materials necessary for the maintenance of hygiene and protective equipment were also insufficient and of poor quality.

The social and cultural status of women also plays a role in the physiological vulnerability of women in developing countries. In many developing countries the status of women is extremely low and this, in turn, increases their vulnerability to HIV infection. A lack of education also contributes to the low status of women and plays a role in the fact that they are not sufficiently empowered to negotiate the use of condoms to prevent the transmission of HIV. This, in turn, amplifies the risk of HIV transmission – a risk which is exacerbated by the high prevalence of non-consensual sex, sex without condom use, and the unknown or high-risk behaviours of male partners (; Ashford, 2006; Chersich, & Rees. 2008.

3.8 Challenges faced by women providing home-based care in Malawi

The primary objective of this study was to investigate the challenges that women face as they provide home-based care in Malawi. The socio-economic and socio-cultural challenges they face were deemed to be particularly important.

3.8.1 Socio-economic challenges of women who provide home-based care

In the study they conducted in Malawi, Ghosh and Kalipeni (2005: 320-332) found that gender inequalities play a role in the spread of HIV as women are both physiologically and socially more vulnerable to HIV infection than men. Ghosh and Kalipeni further argued women often have less access to education, training and productive resources such as land and credit as compared to men (ibid), thus often remaining dependant on men for most of their financial needs (ibid). This, in turn, tends to lead to a situation of survival at all costs. One such survival tactic is selling sex for money or in kind.

Other studies in Malawi (Ngwira, Bota & Loevinsohn, 2001; Loevinsohn & Gillespie; 2003) found that poor women with few other subsistence options tended to resort to selling sex for gifts or money on an occasional or even an ongoing basis. The researchers further argued that "commercial sex work" is an inadequate concept to cover the range of situations in which sex was either bartered or sold. In another study conducted in Malawi Ghosh and Kalipeni (2005: 320-332) also found that men were often dominant within relationships, rendering women dependent on their financial support. In Malawian society men are viewed as responsible for both the family and for income generation (ibid) while women are valued as mothers but with limited economic responsibility. Ghosh and Kalipeni (2005: 320-332) further found that, in when circumstances changed for the worse, women tended to be forced to engage in commercial sex work to supplement their incomes.

In two behavioural surveillance surveys conducted among vulnerable and at risk groups in Malawi, it was found that commercial sex work was common among poor women and female workers earning minimum wages, for example, farm workers, teachers and police officers (NAC/ NSO 2006).

The major reasons for women engaging in commercial sex have been reported in a number of studies to be poverty and deprivation (Ngwira et al 2001; Ghosh & Kalipeni, 2005; NAC/ NSO 2006). However, in such sexual encounters, women tend to be vulnerable because they are not always in a position to negotiate for condom use (NAC/ NSO 2006). Rural women, in particular, and who are poor and economically dependent, tend to have limited influence in the conditions under which sex occurs,

including the use of condoms (Ngwira et al, 2001:7-8). In a male-dominated culture, poverty worsens the status of women and their ability to assert their needs (ibid). In their study in the peri-urban townships in Lilongwe, Malawi, Ghosh and Kalipeni (2005: 320-332) also found that, in situations in which women live in poverty and have limited resources, sex is often used as a means of survival. It is apparent, therefore, that poverty exacerbates women's vulnerability to HIV infection.

The socio-economic status of women is also affected by their literacy levels, thus impacting on their ability to ensure socio-economic independency and, hence, placing in a vulnerable position as they have to depend on men for their livelihood. The literacy levels among women are usually low in most of the developing countries and Malawi is no exception. Malawi is characterised by some of the lowest literacy levels among women in the world. According to UNESCO, in 2011 the literacy rates, in Malawi, were seventy-two percent for men and fifty-one percent for women (UNESCO Institute for Statistics, 2013.). This, in turn, implies that the majority of women are unable to engage in wage labour and this affects their socio-economic status. As a consequence of this scenario women rely on men to provide for all their social and economic needs. With the advent of HIV and AIDS, women have been the most severely affected as many have lost the male breadwinners (husbands, brothers, fathers, uncles) upon whom they depended for their survival.

Another source of social inequality is to be found in the way in which the social system in Malawi is constructed. Women in Malawi tend to have limited entitlements; they generally earn low wages, they are less likely to own land as compared to men, they do not receive any government assistance and nor do not benefit from international aid programmes (Gosh & Kalipeni, 2005: 331). Gosh and Lalipeni also point to the fact that, as compared to men, women in general have less access to education beyond the primary school levels and this, in turn, restricts them in their choices of occupation, formal sector employment and access to a sustainable income (ibid).

The inequality which is inherent in the social fabric between men and women also influences power structures and vulnerability to HIV. In Malawian society, men are viewed as responsible for the family and for income generation (Ngwira et al, 2001:

7-8). This tends to exacerbate dependency on men because men are perceived to be the primary and, in some cases, the sole providers for their immediate and extended families.. Thus, when the primary income generator dies, his family is left to fend for itself and this may which render the women vulnerable to HIV infection as they try to make a living on their own by selling sex (ibid).

The toll of providing care to those infected and affected by HIV and AIDS has been extremely severe in the affected households. AIDS has stripped families of their assets and income earners, further impoverishing the poor (Bota, Loevinsohn & Ngwira, 2001: 7). Providing care for those who are infected and affected by HIV and AIDS has also strained these families socio-economically with families experiencing the effects of deprivation at the household level. The major effects on households as a result of providing care to those infected and affected with HIV and AIDS include dwindling household income; reduction of basic necessities; food insecurity; and increased healthcare and other related expenses.

Household income

Household income tends to be negatively affected by the illness and death of productive adults but also as a result of the medical and funeral costs incurred by family members and the time lost caring for new dependants as a result of HIV and AIDS (Mussa & Pauw, 2011: 2).

In Botswana, for example, it was estimated that, on average, every income earner was likely to acquire one additional dependant as a result of the AIDS epidemic (Bota et al, 2001: 8). A dramatic increase in the number of destitute households – those with no income earners – is expected (ibid). Other countries in the southern African region are experiencing the same problem as individuals who would, otherwise, provide a household with income are prevented from working – either because they are ill with AIDS themselves or because they are caring for other sick family members (ibid). Such a situation has repercussions for every member of the family, especially for the women and girls who have to care for the sick members of the family. Research also shows that, in such cases, the girl children are often forced to abandon their education while, in some cases, women are forced to resort to sex work ('prostitution') (Munthali, 2002: 5). In terms of female vulnerability, such a scenario

then leads to a higher risk of HIV transmission as than would otherwise have been the case and this may further exacerbate the already dire situation.

Basic necessities

Research studies indicate that, when a household is caring for those infected and affected by HIV and AIDS, the household tends to reduce on its spending levels on basic necessities in order to cope. The most likely expenses to be cut were clothing (21%), electricity (16%) and other services (9%) (Akintola, 2004). In addition, diminishing incomes forced about six percent of households to reduce the amount they spent on food with almost half of the households reporting having insufficient food at times (Akintola 2004; Akintola, 2008).

Food is a vital necessity in all homes but, with dwindling incomes levels in HIV and AIDS affected homes, the food supply in such homes becomes affected. In Kenya, inadequate food was ranked by as the most pressing problem among older caregivers and was attributed to the fact that they lacked sufficient income to purchase food (Juma, Okeyo & Kidenda, 2004; Datta & Njuguna, 2009).

Food production

Food security is described as year-round access to sufficient food of appropriate nutritional value (Interagency Coalition on AIDS and Development, 2006). Food security is a basic need and is dependent on a number of factors which include availability and stability of food stocks, through either home production or from readily accessible markets; accessibility of food stocks; and equal distribution of food among members of the community especially marginalised members such as the elderly, children and women (ibid).

Food production and, ultimately, food security in the households tends to be affected by marginal landholdings, labour shortages, low agricultural yield, lack of opportunities for the commercialisation of the surplus result in low incomes and insecure livelihoods (Haslwimmer, 1994; Barnett, [sa]; Du Guerny [sa]; Topouzis & Du Guerny, 1999). In Malawi, food production is affected by a number of factors. A World Bank study in 2006 listed the following major shocks that affect food production and food security at household level, namely, climatic shocks which affect

the amount of rain the country receives annually; animal and plant diseases which lead to major crop and livestock losses; the price volatility of crops such as maize and tobacco; and the availability and affordability of fertiliser and, finally, health shocks, in particular as a result of the HIV and AIDS, malaria, tuberculosis, and anaemia which are pervasive in Malawi (Mussa & Pauw, 2011: 2).

Studies have also shown that the AIDS epidemic exacerbates the food insecurity in many areas as agricultural work is either neglected or abandoned due to household illness. A study in Kenya demonstrated that the food production in households in which the head of the family had died of AIDS had been affected in different ways depending on the sex of the deceased (Opiyo, Yamano & Jayne, 2008: 1-4). As in other sub-Saharan African countries, it was generally found that the death of a male reduced the production of 'cash crops' such as coffee, tea and sugar, while the death of a female reduced the production of the grain and other crops necessary for household survival (ibid).

AIDS has taken a toll on the ability of families to grow their own food as it has killed the majority of the productive members of a population. A senior government official in Malawi stated, "Our fields are idle because there is nobody to work them. We don't have machinery for farming, we only have manpower – if we are sick, or spend our time looking after family members who are sick, [...] we have no time to spend working in the fields"(USA TODAY, 2005, 18 October).

In Malawi, where food shortages have had a devastating effect, it has been recognised that HIV and AIDS have had diminishing effects on the country's agricultural output (Ngwira et al, 2004; Gillespie, 2006). It is thought that, by 2020, Malawi's agricultural workforce will be fourteen percent smaller than it would have been without HIV and AIDS (Ngwira et al 2004: 7-8). In other countries, such as Mozambique, Botswana, Namibia and Zimbabwe, the reduction in the workforce is likely to be over 20 percent (ibid).

Healthcare expenses

Taking care of a person sick with AIDS is not only an emotional strain for the household members but it also constitutes a major strain on the household

resources. Studies have shown that the loss of income, additional care-related expenses, the reduced ability of caregivers to work, and mounting medical fees drive affected households deeper into poverty (United Nations Division for the Advancement of Women, United Nations Division for the Advancement of Women 2008/WHO, 2002). It is estimated that, on average, HIV-related care may absorb one-third of a household's monthly income with the loss of household income arising mainly from the illness and the death of the patient (UN Women, 2001: 4).

Studies have also shown that, in addition to from the financial burden, providing home-based care can impose demands on the physical, mental and general health of the carers – usually female family members and friends of the sick person. Such risks are amplified if the carers are untrained or unsupported by a home-based care organisation. Moreover, the loss of household income often forces older women and adolescent girls to re-enter or enter the productive sector with adolescent girls leaving school to help the family or to supplement the household income (United Nations Division for the Advancement of Women, United Nations Division for the Advancement of Women 2008:).

3.8.2 Socio-cultural challenges for women who provide home-based care

The social inequality that exists in most of sub-Saharan Africa relates primarily to property rights. In most of the cultures in sub-Saharan Africa, when a husband dies, the widow and her children are dispossessed of their land and property. In a study conducted in Kenya, Datta and Njuguna (2009: 170-178) found that vulnerable groups such as widows and orphans were dispossessed of land by greedy relatives and, as a result, were not able to engage in meaningful farming. There have been similar incidences occurring elsewhere in countries such as Ethiopia, Rwanda, and Malawi with studies conducted in these countries indicating that widowhood is the single, biggest factor which renders women vulnerable to HIV infection as a result of the impoverishment in which the widows and children find themselves (Merso [sa]; Ziktato JP. 2008; Ngwira et al, 2001).

In Malawi, the effects of widowhood are influenced primarily by the cultural systems of marriage. There are two marriage systems in Malawi i.e. matrilineal and patrilineal. In terms of the matrilineal system the man leaves his ancestral home to live in his

wife's home (Koratayev, 2003: 335-372) while, in terms of the patrilocal system, the married woman is brought into her husband's ancestral home (ibid).

However, in Malawi, a new law has been passed and which protects the rights of women and children when property and inheritance issues arise. The new Deceased Estates Act protects the spouse's and the children's share in the estate (Ezer, 2011). Before this act was promulgated, women had to contend with loss of their homes as well as property such as land, household goods, and cars (ibid). However, although a new law has been passed to protect the women and children from greedy in-laws, the law is yet to be taken seriously by all concerned. In Malawi and in many other societies in which patriarchy is entrenched women are the victims of the system when their husbands die. Researchers have shown that the majority of societies do exhibit at least some degree of patriarchy and that even in most matrilineal groups the brothers (or mother's brothers) are the authority figures and not the wives or mothers themselves (Koratayev, 2003; Green, 2010; Hughes & Knox, 2011).

Several studies conducted in Malawi have also shown that, in the matrilineal marriage system which is predominant in almost two thirds of the country, the death of a husband leaves the wife with the children and some security of land tenure. On the other hand, if the wife dies, the man is sent away and the children are left with no direct parental care (OXFAM MALAWI, 2001; Ngwira, 2001). The death of a man also has serious consequences for households which are based in an urban setting.

In terms of a patrilocal marriage system there is bias against the widows which shows that the insecure property and inheritance rights tend to favour the family of the deceased husband (Ngwira et al, 2001, OXFAM MALAWI, 2001). Widows and orphans are usually dispossessed of all their property and land. This, in turn, renders the women helpless and increases the risk of her becoming infected with HIV. Jackson (2002: 366) reports that women such as these are at high risk of being infected with HIV and that there is evidence to show that AIDS increases the number of women living in poverty as they lose an income due to their husbands becoming ill and die from complications of AIDS. Widowhood is, thus, a common reason for women to enter into sex work (ibid).

Socially and culturally both men and women fulfil gender roles which tend to influence and affect their role expectations. The social constructions of gender roles also involve power relations between men and women with these power relations playing a significant role in sexual relationships (Nzewi, 2009: 6-7) and having significant implications as regards the transmission of HIV. For example, in many societies women are expected to be innocent and submissive when it comes to sex and this, in turn, prevents them from accessing sexual health information and sexual health services (ibid). As for many men, masculinity is linked with taking risks and being tough and this may, in turn, increase their vulnerability to HIV infection and also discourage them from seeking testing and treatment (Nzewi 2009: 8). A number of studies have shown that men are as vulnerable as women to HIV and AIDS although to a lesser degree (Peacock & Levack 2004; Mutonyi & Greig, 2003; Gupta 2000;). Traditionally, the norms of masculinity which are prevalent in most sub-Saharan Africa expect men to be well informed, knowledgeable, and experienced in matters of sex and risky sexual behaviour (Nzewi, 2009: 9). As a result, men either do not or they delay in seeking health services and information relating to harmful sexual behaviour (ibid). When men do not seek testing and treatment, they increase their female partners' vulnerability to HIV infection.

Gupta et al (1994: 5) also revealed that there are some traditional norms and beliefs that encourage men to have multiple sex partners as a sign of manhood. These gender norms create social pressure for men to take risks, be self-reliant, and prove their manhood. When men have numerous sexual partners the practice of abstaining from as a prevention method against HIV and AIDS is severely undermined.

HIV is also spread where gender based violence is prevalent. A decade of research in HIV and gender based violence has shown that women who have experienced partner violence are more likely to be infected with HIV as compared to those women who have not experienced sexual violence (; Straten, King, Grinstead, Vittinghoff, Serufilira, & Allen, 1998; Maman, et al, 2002; Dunkle, Jewkes, Brown, Gray, McIntyre & Harlow, 2004; Decker et al, 2009). The sexual domination of women and, in some instances, sexual aggression, coercion and violence are sometimes considered attributes of men's power and control (UNAIDS, 1999; **Jewkes & Morrell, 2010**).

3.9 Coping mechanisms in the face of the burden of care of women who provide home-based care

One of the major coping mechanisms available to families affected by and infected with HIV and AIDS is the extended family. This is particularly true of Africa with Ogden et al (2004: 7-8) arguing that the strength of the African extended family has been used as a safety net to support families in crisis. This is supported by the following quote: "In rural Africa, the extended family and clan assume the responsibility for all services for their members, whether social or economic. People live in closely organized groups, and willingly accept communal obligations for mutual support. The sick, aged and children are all cared for by the extended family" (Seeley, Kajura, Bachengana, Okongo, Wagner & Mulder, 2007: 117). The role of traditional family support systems has been well documented (Ogden et al, 2004:9). Foster (2002a: 4) reports on the extraordinary resilience of families in Zimbabwe, their ability to survive crises and the fact that they continue to find ways to effectively support, console and nurture their sick members and to absorb children orphaned by the epidemic.

However, Carballo and Carael (1988: 81-94) note that this social safety net has been overexploited. It is the purpose of this research study to determine whether the extended family continues to offer the social safety net in as far as home-based care is concerned. Ogden et al (2004: 10) argue that the extended family as a safety net may be more of a myth than a reality. Observational studies have been conducted to investigate the extended family as a safety net, for example, Taylor et al (1996: 55) report observing relatives and friends offering valuable resources in times of need. Thus, it would appear that the extended family provides the best coping mechanism that is available (Mirimo, 2008; Akintola, 2004). In addition, coping strategies that are adopted by affected households include, for example, using the families' savings, selling household assets and, as a final resort, sending children out of the house to be fostered by friends and relatives or the girls dropping out of school.

Older women are also severely affected by the epidemic as many of them have to provide care for their sick children and are then often left to look after their orphaned grandchildren (Foster, 2002a; Urdang, 2006; Akintola, 2006). These older women also face the burden of providing financial, emotional and psychological

support at a time when they would usually be expecting to receive increased support themselves as their energy levels drop with old age (Akintola 2006: 237-247). In addition, as a result of the amount of time they spend caring for their dependents, these older women tend to become isolated from their peers as they no longer have the time available to dedicate to the social networks which help to prevent isolation and loneliness (ibid). There have, however, been few studies conducted to ascertain how older women cope with loneliness and isolation as well as the socio-economic factors within their households.

In their study of the Masaka women of Botswana, Barnett and Blaikie (1992: 157) observed that women caregivers are not necessarily isolated in their caring roles. They document a wide-range of ways in which such women helped each other. For example, they found out that neighbouring women tended to support each other in their care-giving roles, including giving each other breaks and providing emotional support. The women also reported that they offered one another various informal counselling sessions. They also provided support for each other in the course of everyday life (for example, when collecting water or fuel or sharing a cup of tea). This support was vital for both their well-being and their ability to continue caring for the sick in their homes (ibid).

Another coping mechanism that the women providing home-based care tended to use was to tap into their life savings if they had (Barnett & Blaikie, 1992: 157). It was reported that these women either tapped into their savings, if available, or that they took on more debt. These were usually the first options chosen by households struggling to pay for medical treatment and other needs (ibid). Once they had depleted their savings, they tended to accumulate debts. Then, as the debts mounted, precious assets such as bicycles, livestock and even land were sold. Thus, once the households had been stripped of their productive assets, the chances of the women recovering and rebuilding their livelihoods became even less likely (ibid) and, hence, their vulnerability.

A more drastic form of coping mechanisms used in the case of chronic illness or a death in the poorer households is the removal of the children (especially girls) from school (Akintola, 2004: 239). Often the school uniforms and fees become

unaffordable for the families as they struggle to survive while the child's labour and income-generating potential are necessary to enable the household to survive (Ogden et al, 2006; Urdang, 2006; Pindani, 2008).

The study was guided by theories of gender, power and feminism which framed the exploration of the challenges that women experienced.

3.10 Gender and power, and feminist theories

The term gender draws attention to the socially constructed aspects of differences between women and men (Scott & Marshall, 2009; Delphy, 1993). Gender may be defined as the expectations regarding the social, cultural and psychological traits and behaviour which are regarded as appropriate for members of a particular society (Giddens & Sutton, 2014: 94). The distinction between sex and gender is explained by Oakley (1972:16) who defines sex as a word that refers to the biological differences between male and female: the visible difference in their genitalia and the related difference in their procreative functions while gender is a matter of culture and refers to the social classification into "masculine" and "feminine". Gender, therefore, is a term that is used to describe a wide set of characteristics that are seen to distinguish between female and male entities, extending from biological sex to, as in the case of humans, social role or gender identity (Giddens & Sutton, 2014) Thus, gender differences are as a result of gender socialisation (Ritzer, 1992; Giddens, 1984). Gender identity may, thus, be regarded as the gender with which a person self-identifies, for example, man or woman. It is, therefore, a social construction and may or may not also change over time (Giddens & Sutton, 2014). The term gender is used in this study in its broadest sense to refer to concerns regarding what it means to be either male or female and also how gender defines a person's opportunities, roles, responsibilities and relationships. It has been argued that being a woman exposes the person concerned to more challenges than does being a man, not only as a result of society viewing women as a social category but also, in personal terms of self-perception, as a felt sense of self, a culturally conditioned or constructed subjective identity (Delphy, 1993; Trepte, 2006). In terms of gender stratification, women occupy lower levels as compared to men and this, in turn, excludes them from life chances (Abbott, Tyler & Wallace 2006; England 1993). The identity of a

person is derived from the social group with which the person identifies (Tajfel & Turner 1986; Trepte, 2006). Social identity, therefore, is that part of an individual's self-concept which derives from his/her knowledge of his/her membership of a social group or groups together with the value and emotional significance attached to such membership (Tajfel, 1978: 63). Ashforth and Mael (1989) also define social identity as a common identification with a collectivity or a social category which creates a common culture among the participants concerned. Thus, social identification is a perception of oneness with a group of persons (ibid).

Social identity theory was applied in this study to describe the women who provide home-based care to the HIV infected and their motivations for continuing to do so. These women may be identified as a group which shares common life experiences and challenges. Social identity theory suggests a fundamental individual motivation for self-esteem in terms of which self-esteem is the prime mover of an individual's behaviour within a group (Tajfel & Turner, 1986; Turner, 1982). Social scientists such as Turner (1987) and Hogg & Abrams (1988) argue that human beings have a basic need for positive self-esteem. It was, therefore, theorised that the women who provide home-based care also have a need for positive self-esteem and this, in turn, enables them to continue even if they are experiencing enormous challenges.

According to Mead (2003), the majority of societies divide the universe of human characteristics into two i.e. men and women. In society, the members are socialised to take up their various social roles as ascribed to them and these, then, become gender roles (Delphy, 1993). Mead (2003) considers sex roles as natural to the culture of a people and maintains that, in most societies; social roles are usually clearly defined. For example, women are assigned the reproductive roles while men are responsible for the productive roles. Despite the fact that male and female roles vary from culture to culture there is ample evidence to suggest that women's roles are universally less valued than those of men (Delphy, 1993; Giddens 2006). This, in turn, tends to create gender inequality.

The Gender Inequality Index (GII) (previously known as the Gender-related Development Index (GDI) reflects the gender-based inequalities between men and women which are manifested in three dimensions, namely, reproductive health,

empowerment and economic activity (UNDP, 2013). Reproductive health is measured by maternal mortality and adolescent fertility rates while empowerment is measured by the share of parliamentary seats held by each gender and the attainment of secondary and higher education by each gender. On the other hand, economic activity is measured by the labour market participation rate for each gender (ibid). As may be derived by the country development reports that UNDP and other development agencies produce on a regular basis women are faring poorly in respect of all these factors.

Gender inequality has a significant impact on women and their ability to meet the basic needs of the family. There is a growing realisation throughout the world that poverty has become increasingly feminised. In 1992 the UN produced a report which clearly showed how this phenomenon has become widespread (Moghadam, 2005: 2). The UN report revealed that the number of rural women living in poverty in the developing countries had increased by almost fifty percent from 1972 to an incredible 565 million in 1992 – 374 million of them living in Asia, and 129 million in sub-Saharan Africa (Power, 1993: 5). Thus, on the African and the Asian continents, it is more likely that men will have more opportunities as regards earning an income as compared to women while they also have greater political and social rights than women (Moghadam, 2005). Women, on other hand, are systematically denied the resources, information and freedom of action they need in order to meet the basic needs of their families and, as a result, they experience more poverty than men do because of gender discrimination (ibid). In addition, there are also major inequalities between men and women in terms of the ownership, control of and access to land and this, in turn, also affects women's livelihood outcomes (Tsikata, 2009: 13).

3.10.1 Gender and power theories

In order to understand the framework in which the women in this study operated, it is important to understand the roles played by gender and power in their everyday lives. Connell (1987) produced a collection of writings on the theories of sexual inequality, gender and power imbalances. In these writings Connell explains the issue gender, integrating both patriarchy and masculinity into a theory of gender relations (Giddens & Sutton, 2014: 95). Connell argues that labour, power and cathexis

(personal/sexual relationships) are distinct but interrelated components of society that work together and change in relation one another.

Connell (1987) identified the critical components of existing theories and developed an integrative theory of gender and power. According to him, the following three major structures characterise the gendered relationships between men and women, namely, the sexual division of labour, the sexual division of power and the structure of cathexis. Social scientists have identified both the sexual division of labour and the sexual division of power as two fundamental structures that partially explain gender relations. However, Connell devised a third structure, namely, the structure of cathexis, to address the affective component of relationships. These three overlapping but distinct structures serve to explain the cultural-bound gender roles assumed by men and women. Wingood and DiClemente (2000: 542) used these theories of gender and power to examine the exposures, social/behavioural risk factors and biological properties that increase the risk of women contracting HIV.

Sexual division of labour

The division of labour has long occupied a prominent position in both sociology and anthropology as the foundation of the processes of economic specialisation and exchange in human society. In 1893 Emile Durkheim argued that the division of labour is an essential moral value in a fractionated, unequal world which is already divided along the lines of "human solidarity" (Noble 2000; Tajfel & Turner, 1986). Giddens and Sutton (2014: 95) regard the sexual division of labour as occurring within both the home and in the labour market. Murdock and Provost (1973a: 203) refer to the sexual division of labour as the "most fundamental basis of marriage and the family and, hence, the ultimate source of all forms of kinship organization". Other theorists such as Parsons have emphasised the importance of the sexual division of labour and, ultimately, its link to the status of women (Parsons, 1975). Parsons argued that "for the family to function effectively there must be a sexual division of labour in which adult males and females play very different roles" (Ritzer, 1992:317). Ritzer (1992: 317) also states that men, whose "role is to tie the family unit into the wider social system, must be "instrumental" in orientation, manifesting qualities of drive, ambition, and self-control; whereas women whose task is the

internal functioning of the family, supportive of both children and adult males, must be "expressive", that is, gentle, nurturing, loving, and emotionally open". Thus, a family operates as a functional unit and, according to functionalist theory, each member of the family plays the role ascribed to them, for example, the woman plays a role of carer of the family and the community at large (Giddens & Sutton, 2014: 210).

Researchers subscribing to Emile Durkheim's functionalism such as Tajfel and Turner (1986: 45) argue that society should be viewed as an entity in itself and one that may be distinguished from other natural entities that are not reducible to their constituent parts but that these constituent parts (system parts) fulfil basic functional needs in the society. According to Durkheim, the division of labour was a moral obligation aimed at restoring social order in a society which has become highly competitive as a result of the specialisation of tasks (p 46). It would, thus, appear that it is the threat to social order that ushers in the division of labour (p 47).

Wingood et al (2000: 542) argue that a fundamental structure in the gender and power theory is the sexual division of labour. At the societal level, the sexual division of labour refers to the allocation of women and men to certain occupations with women often being assigned different and unequal positions relative to men. At the institutional level the sexual division of labour is maintained by social mechanisms such as the segregation of "unpaid nurturing work" in respect of women, namely, child care, caring for the sick and elderly, and housework. However, in view of the fact that, in the main, there is no remuneration for this work, an economic imbalance occurs in which women are often forced to rely on men financially (Abbott, Tyler & Wallace, 2006). Other social mechanisms that occur in the context of the sexual division of labour include practices that favour male educational attainment and the allocation of "income-generating work" to men, thus allowing men to control the family income. While women do participate in the paid labour force, their participation is often less than that of males and remains highly sex segregated. Abbott, Tyler & Wallace (2006) contend that, whereas "men's work" is often valued either directly through paid remuneration or indirectly through its high status, women's work often fails to be recognised as work and has less value than men's work.

Sexual division of power

Another fundamental structure is that of the sexual division of power. At the societal level, inequalities in power between the sexes form the basis for the sexual division of power. Power has been conceptualised in various ways by several different disciplines. Sociological literature defines power as possessing the capacity to influence the action of others, thus conceptualising power in terms of power over others. According to Giddens and Sutton (2014: 209), power is the ability of individual or groups to achieve their aims or further their interests, even despite opposition or resistance.

It is vital to understand that power is not exercised in a vacuum and that there have to be social structures in terms of which power may be exercised. These social structures include the family, community, or institutions. As regards the women who are involved in home-based care, social structures have often influenced these women to assume such responsibilities.

Cathexis (social norms and affective attachments)

Gender and power theories also include the structure of cathexis. This is sometimes referred to as the structure of affective attachments and social norms (Connell, 1987). At the societal level, the structure of cathexis dictates appropriate sexual behaviour for women and this is characterised by the emotional and sexual attachments of women to men (ibid). This structure constrains the expectations of society about women with regard to their sexuality and, as a consequence, shapes women's perceptions of both themselves and others and limits their experiences of reality (ibid). In addition, this structure describes how women's sexuality is attached to other social concerns such as those related to impurity and immorality (Wingood et al, 2000: 544).

3.10.2 Feminist theories

Theories of difference and inequality were the main feminist theories which the study used to explain the situation of women.

Theories of difference

The major focus of the theories of difference is that women's location in, and experience of most situations, is different as compared to that of men in the same situation (Ritzer 1992: 319) with Ritzer (1992: 318) arguing that women's location is not only different from but less privileged than or unequal to that of men. Using these theories in this study was useful in order to understand how women carers were treated.

Theories of inequality

Theories of inequality argue that it is essential that the situation of women be understood in terms of a direct power relationship between men and women (Ritzer 1992: 318). Women are oppressed, that is, restrained, subordinated, moulded, used and abused by men.

3.11 Summary

Literature reviewed has shown that there are many advantages to home -based care as an intervention in mitigating the effects of HIV and AIDS and it is often seen as the only way in which to assist those who are infected and affected to lead a "normal" life and, when the time comes, to have a dignified death in their own families and communities. Home-based care is beneficial to both the person living with HIV and AIDS and family members because it affords the person who is sick the comforts of home and care in a familiar environment while also affording the whole family an opportunity to prepare for eventual demise of the patient in dignity and at home (Akintola, 2004: 2). However, home-based care may also be burdensome in countries with high levels of poverty and in which resources are scarce.

Nevertheless, home-based care is not a simple, straightforward, and less costly way of caring for the HIV infected and affected people in their homes and communities. The literature review has revealed that home-based care work is, in most countries, heavily dependent on women labour.

Coping with caring for the HIV infected and affected was of interest to this study. The complex nature of HIV and AIDS creates a myriad of challenges with the literature showing that women in many societies have had to cope with the challenges they face.

This chapter also discussed the theories that the study used to understand women and the challenges they face in terms of gender and power and, in particular, feminist theories. Gender as a concept was defined. Gender and power theories were discussed in order to understand the structural issues that surround the use of power in society in order to dominate others. The chapter also discussed the sexual division of power and labour, focusing on the way in which labour is divided in society as well as the way in which power is divided or apportioned in society to ensure the proper functioning of society.

Feminist theories were also discussed, particularly in terms of how women as a gender are treated differently and unequally from men. Women tend to be treated differently from men (even within the same household). Women also tend to experience unequal treatment from society even if both men and women are experiencing the same social event. These theories were used in order to understand the challenges that women face as they provide care to those who are infected and affected by HIV and AIDS.

It may, thus, be argued that the challenges that women face as they provide care to those who are affected and infected with HIV stem from the gender and power and may be explained by feminist theories, particularly theories of difference and inequality. As compared to men women are treated differently, they are usually subordinated and, at times, they are subjugated to the power which men exercise over them.

CHAPTER FOUR

RESEARCH DESIGN AND METHODOLOGY

4.1 Introduction

This chapter commences with a discussion of the research design and methodological approach used in the study. This is followed by an outline of the research methodology used, including sampling techniques, study populations, data collection instruments, accessing gate keepers, building rapport, obtaining consent, building trust, data capturing process, data analysis, and data interpretation. In addition, the chapter discusses the ethical considerations that were applied in the study.

The fieldwork for the study was conducted between 29 April 2014 and 10 May 2014.

4.2 Research design

A research design is a clear plan or blueprint for conducting research (Babbie & Mouton 2001: 55). The aim of the study was to determine the challenges faced by women providing home-based care in Mzimba, Malawi. A combination of qualitative and participatory methodological approaches was selected for the purposes of this explorative study. The qualitative methodological approach gave the participants the opportunity to speak freely about the challenges they face when providing home-based care to HIV infected and affected people.

Qualitative research is guided by the way in which the researcher would like the reality to be viewed, that is, the researcher's ontology (De Vos, Strydom, Fouche & Delpont, 2011: 309). There are two ways in which this reality may be created. As suggested in the literature, the first way is based on the belief that reality should be approached objectively as an external reality 'out there', thus requiring the researcher to maintain a detached, aloof position when studying such a reality. The second way is based on the notion that there is no truth 'out there' and that reality is subjective and may be constructed through an empathetic understanding of the meaning the research participants attribute to their world (ibid.). In other words, as Kvale (1996: 41) observes, "the conception of knowledge as a 'mirror of reality' is

replaced by the conception of the 'social construction of reality' where the focus is on the interpretation and negotiation of the meaning of the social world".

The qualitative methodology enables the researcher to collect 'thick' data which, in turn, provides both descriptions and a thorough understanding of actions and events. Babbie and Mouton (2001: 53) refer to this methodology as studying "human action from the insiders' perspective". This approach may, thus, be regarded as a naturalistic approach to social inquiry. According to Patton (2002: 39), "the researcher does not attempt to manipulate the phenomenon of interest" but, instead, as Golafshani (2003: 600) argues, the researcher uses a naturalistic approach that seeks to understand phenomena in context-specific settings, such as "real world setting". Ultimately, the use of qualitative methodology enables the gathering of information which is derived from real-world settings and the "phenomenon of interest unfolds naturally" (Patton, 2001: 39).

While the study was able to collect "rich" and "thick" data that provided an in-depth understanding of the challenges that the women who provide home-based care face, the underlying philosophical nature of the study also allowed for detailed interviewing (Babbie & Mouton, 2001; Golafshani, 2003). Thus, the study was able to use the various qualitative methods in which the researcher's involvement is crucial. According to Patton (2001: 14), "the researcher is the instrument".

A qualitative study attempts to understand people's perceptions, perspectives and understanding of a particular situation (Leedy & Ormrod, 2001; Marshall, 2006). Qualitative research typically relies on four methods for gathering information: (i) participation in the research setting, (ii) direct observation, (iii) in-depth interviewing, and (iv) analysing documents and material culture (Marshall, 2006: 97). These methods form the core of social science inquiry (ibid.). A qualitative research design is also able to provide complex textual descriptions of the way in which people experience a specific issue (FHI, [sa]). While the biomedical aspect of the problem of HIV and AIDS has been studied extensively, there is, however, also need to study the "human" aspect of the HIV and AIDS problem within the home-based care context (ibid). The use of the qualitative study design for the purposes of this study allowed

for the identification of intangible factors such as social norms, socioeconomic status, gender roles, and the ethnicity of the women involved in the study.

While there are many advantages to using qualitative data collection methods, the researcher was aware of the inherent biases that can be introduced due to the subjective nature of the research design and from the methods of data collection. Lincoln & Guba (1985:290) recommend that qualitative research requires that the "biases, motivations, interests or perspectives of the inquirer" are explicitly identified throughout the study and addressed. Other disadvantages of using qualitative research include: unreliable sources or subjects, research subjects being influenced by previous studies or may suffer from research fatigue, and missing background information (ibid).

Participatory research methodology can be defined as a research paradigm in terms of which the researcher's function is to serve as a resource to those groups being studied – usually disadvantaged groups – in order to empower them to act effectively in their own interests (Babbie, 2010; Babbie & Mouton, 2001.). Thus, participatory research aims at empowering disadvantaged members of society by giving them the opportunity to define their problems and find solutions to these problems (De Vos et al 2011: 494). In other words, participatory research endeavours to improve the well-being of people and their communities (Cornwall & Jewkes 1995: 1667-1676). In addition, it also aims to ensure that, after the research has been conducted, the people or community in question becomes more self-reliant (ibid). The cultivation of self-reliance and [the] energising of the community may be "the driving force for creative activity that requires an awareness of one's creative assets, confidence in one's ability to solve life's problems [and challenges] (Rahman, 1995; Rahman 1985). By using the participatory approach to the data collection process, the researcher was able to collect data while ensuring that the participants felt as if they were being empowered to define the challenges they were facing and that they were beginning to find solutions to their problems themselves.

The socio-cultural aspects of the Ngoni tribe to which the women providing home-based care belonged were studied using a combination of both qualitative and participatory methods. The women were given the opportunity to describe their

cultural traits in relation to the challenges they faced as they provided care for the chronically ill. This enabled the researcher to understand the context and setting of the study population and, thus, to gain a deeper understanding of the reality in which the women existed than was previously the case.

The use of two approaches to the data collection process allowed for the gathering of information that was more comprehensive than would otherwise have been the case and while at the same time allowing the research participants to define their own problems and find solutions that would empower and enabled them to become self-reliant than they had been before the commencement of the study.

4.3 Research paradigm

A qualitative research methodology is based on different theories of knowledge and different perceptions of the social world. Accordingly, a qualitative researcher endeavours to uncover an understanding of, rather than an explanation of, the social world.

A research paradigm refers to an all-encompassing system of interrelated practice and thinking that define the nature of enquiry along the three major dimensions of ontology, epistemology and methodology (TerreBlanche & Durkheim 1999). Paradigms refer to a pattern, structure and framework or system of scientific and academic ideas, values and assumptions and inherently reflect our beliefs about the world we live in and want to live in (Olsen, Lodwick, & Dunlop, 1992; Lather, 1986).

Ontology and epistemology, on the other hand, concern what is commonly referred to as a person's worldview which has significant influence on the perceived relative importance of the aspects of reality (Weber, 1990).

There are a number of possible research perspectives, each with its own ontology, epistemology and methodology (De Vos et al., 2011: 310). Recognising this enables the researcher to understand his/her own philosophy of social research (ibid). In other words, it is essential that a researcher understands his/her own ontology in order to design a research study that reflects his/her own belief of social reality.

Interpretive paradigm, on the other hand, is concerned with understanding social phenomena through the subjective experiences of individuals by the use of meaning oriented methodologies such as interviewing and participant observation which rely on a subjective relationship between the researcher and the subjects (Reeves & Hedberg, 2003). Critical postmodernism is a combination of two different paradigms and these are critical theory and postmodernism. Although slightly different, they both form part of the contemporary social semiotic analysis. Critical scholars agree that although people are aware of their socio-economic circumstance, their ability to change for the better are constrained by a number of prevailing social, cultural, and political factors. Ultimately critical postmodernism strives to bring about an understanding that the taken-for-granted beliefs, values, and social structures need to be made visible by encouraging self-conscious criticism and by developing emancipatory consciousness (Kincheloe & McLaren, 1994).

The choice of a qualitative methodological approach for the purposes of this study implied that the researcher believed that the social reality may best be explained subjectively and without losing the true meaning of that reality. This study used an interpretive paradigm which allowed the researcher to collect data which would be explained to provide subjective reasons and meanings to the social action. In other words, the study used an anti-positivist paradigm which emphasizes that social reality is viewed and interpreted by the individual herself according to the ideological positions she possesses (Dash, 1993: 2).

4.4 Research methodology

While the research design may be regarded as the research plan, the research methodology is the procedure that the researcher follows in order to find a solution to the research problem (Babbie, 2010: 4). This section includes a description of; sampling techniques used in the study; study population; data collection process; accessing gate keepers and the pilot study conducted.

4.4.1 Sampling techniques

Where there is an existing list of potential research participants, random sampling is possible and because there was no existing list of possible participants which the researcher could draw from, a purposive sampling strategy was used initially. This

was followed by snowball sampling. These are both convenience forms of sampling and serve to identify participants for the purposes of data collection (De Vos et al., 2011: 232–233).

Purposive sampling is one of the most popular sampling strategies in qualitative research because it enables researchers to group their participants according to pre-selected criteria which are relevant to a particular research question (Denzin & Lincoln, 2007 Pope & Mays, 2000). In this study the researcher used purposive sampling, also known as judgemental sampling. Accordingly, the selection of the sample was based purely on her own judgement in that, in line with purposive sampling, the sample selected was composed of the elements that contained the most characteristic, representative or typical attributes of the population that served the purpose of the study best (Babbie & Mouton, 2001; Grinnel & Unrau (eds) 2010; De Vos et al., 2011). In accordance with the principles of purposive sampling the population was non-randomly selected based on a particular characteristic (Babbie, 1990; Frey, Botan & Kreps, 2000), while the individual characteristics were specifically selected to ensure that answers would be found to the research questions about a “certain matter or product” (MacNealy, 1999; Latham, 2007). Thus, the researcher was able to select participants based on their internal knowledge of the relevant characteristics (Latham, 2007: 10).

In most cases snowball sampling (also known as chain referral sampling) is used to find and recruit “hidden populations”, that is, groups that are not easily accessible to researchers through other sampling strategies (FHI [sa]: 6). Thus, snowball sampling is a method which is used “in those rare cases when the population of interest cannot be identified other than by someone who knows that a certain person has the necessary experience or characteristics to be included” (MacNealy, 1999: 157). Snowball sampling may also be used to identify and recruit participants by relying on previously identified group members to identify others who may share the same characteristics as the group already in place (Henry, 1990: 21). Patton (2002: 234–244) explains that snowball sampling is often used to complement purposive sampling because it is the only non-probability method which unveils the rare desired sample characteristic. In addition, it is also an extremely cost effective way in which to locate participants as it depends on referrals from the initial participants

who already have social networks in place and who assist the researcher by referring or generating additional, potential participants for the study (Russell, 2012; FHI, [sa]).

4.4.2 Study site

The study site was Mzimba district which was chosen due to the extensive home based care programme that exists there. The research participants were recruited from two villages with help of Group Village Headmen, Alick Chisi and Mbale. These two villages are close to the Mzimba town; Alick Chisi village is located about five kilometres south of Mzimba town, while Mbale village is located about three kilometres south-west of Mzimba town. These two villages which are close to Mzimba district hospital have very vibrant home-based care programme.

4.4.3 Study population and rationale for the selection of the population

Data was collected from a total of twenty-nine participants which included: five elderly women, five young women, sixteen women volunteers, and three government officials.

The study population of women was stratified into three sub-populations of: women volunteers, young women, elderly women. The three groups of women were taken as distinct sub-populations due to their unique lived life experiences. These women sub-populations were selected because they had different standpoint of life experiences as far as home-based care is concerned.

The first group of participants which the researcher purposively selected included the women volunteers. These participants took part in the focus group discussions. The rationale behind selecting these women was the researcher felt that they would enable her to collect data that would explain the challenges the women faced as volunteers when they perform caring duties for those who were HIV-infected. The women volunteers were identified through their work at the Mzimba district hospital. The first "seed" was identified through the hospital. She was able to lead the researcher to the other volunteers. The volunteer women were aged between 39 and 65 years old.

The second group comprised the young women carers who were aged between 18 and 25 years old. These participants were also purposively selected. The researcher used the narrative technique with this group in order to collect detailed data. Thus, this technique was used to enable the researcher to obtain information that would lead to a deeper understanding of the young women's life stories than was previously the case and, in particular, of those stories relating to events during their parents'/guardians' illnesses, by examining these incidents from the perspective of the participants and taking into account cognitive, affective, and behavioural elements (Wilson, 1997: 209—224). The researcher requested the women volunteers to assist her in finding young women in both villages, that is, Mbale and Alick Chisi, who would be able to contribute to the study as the women volunteers were aware of people who were chronically ill in their respective villages. Two of the young women participants were from Mbale village and three from Alick Chisi village.

The third group, which was also purposively selected, comprised elderly women carers. The requisite data was obtained from this group by means of individual in-depth interviews. The group was selected because the participants all had personal experience of the challenges they had faced in caring both for their own HIV-infected children, relatives or spouses and also for the children in the home who had also been affected by the illness. The main reason for using this method of data collection was to understand the experiences of these women as they provided care and to understand the meaning they derived from these experience (De Vos et al., 2011: 348). Their age range was 67-79 years old.

The final group comprised the key informants with whom interviews were conducted. They were aged between 34 and 59 years old. These participants were also purposively selected as they were able to provide first-hand and specialised knowledge on home-based care. For example, they were able to provide, from a professional point of view, insights into the nature of the problems or challenges experienced by women providing home-based care. These key informants were conversant with the home-based care policies and programmes being implemented by the government of Malawi. In addition, they had also received formal training on how to provide support to care givers. Key informant interviews are qualitative, in-depth interviews that are conducted with people who are both expert and up-to-

date with regard to their particular field of work or sphere of influence (UCLA Center for Health Policy Research Health DATA Program – Data, Advocacy and Technical Assistance [sa]). As already stated these key informants were conversant with government policies, programmes and the specific support given to carers. The key informant interviews were used to gather information from a home-based care coordinator from the Mzimba district hospital and who was working with women carers of HIV-infected patients; a tuberculosis ward registered nurse who was working with patients who were infected with TB and those co-infected with TB and HIV; and an official from the Mzimba district assembly who was working in the Ministry of Local Government in the district assembly offices. From a technical point of view, both the home-based care coordinator and the registered nurse were involved in the daily treatment of a variety of illnesses relating to people infected with HIV. In addition, they were involved in providing guidance and support to the home-based care caregivers and volunteers. The Mzimba district assembly official was interviewed because he was responsible for assisting with the implementation of the home-based care programme in the district by articulating government policy. This official was also able to provide an insight into the way in which the home-based care programme works in collaboration with the district health care personnel, women volunteers and other grassroots level stakeholders.

Biographical profiles of research participants

The five elderly women included widowed grandmothers whose children were infected with HIV. Four of these elderly women had children who were infected with HIV and who had also transmitted the infection to their children, thus, essentially, the grandchildren born had been infected with HIV. The fifth elderly woman was caring for two HIV infected women; the first one was her own daughter who contracted the infection from her lover. The second patient was the elderly woman's granddaughter who was born HIV positive.

The five young women had cared for their parents or guardians who had been infected with HIV. These young women had lost either one or both parents. Three of these women were also infected with HIV and were on anti-retroviral treatment (ART). Four of the young women were also young mothers who had married at a very

young age (less than 15 years) while one was still unmarried and had dropped out of school to care for her ailing mother and siblings.

The sixteen women volunteers were caring for community members who were home-based care patients. These were members of the villages where the home-based care patients also came from.

The three government officials were working in the home-based care programme which provided care and support to the women caregivers.

Age range of the participants

The age range of the participants was extremely wide with the youngest participant being 18 years old and the oldest 79 years old. Data was collected from elderly women whose ages ranged between 67 and 79 years old while the young women were aged between 18 and 25 years old. The volunteer women were aged between 39 and 65 years old while the key informants were aged between 34 and 59 years.

Marital status

The majority of the participants had been widowed. All the elderly women who were providing home-based care for their children were widowed. Two of the women volunteers were married. All the other young women caregivers were single. The young women who were caring for their ill parents were all single although three of them had been married and their husbands had since died. One young woman had been widowed twice. One of the young women was not married although she was in a stable relationship. The last one was single and abstaining from sexual relationships.

Level of education

All the women participants, with the exception of one participant who was completely illiterate, could read and write. The literate women had had varying levels of education with most them having finished eight years of primary school. The key informants were all university graduates with degrees relating to their field of work.

4.4.4 Data collection process

The data collection methods and data collection instruments used in the study are graphically presented in Table 1 below:

Table 1: Data collection methods and instruments

Method	Category of participants	No of participants	Data collection instruments
Focus group discussions	Women volunteers	Group 1 (6) Group 2 (10)	Pairwise ranking activities Topic guide
Critical incident narratives	Young women carers	5	Interview schedule Time activity profiles
Individual in-depth interviews	Elderly women carers	5	Topic guide Time activity profiles
Key informant interviews	Registered nurse (Mzimba district hospital – TB ward) Home-based care coordinator (Mzimba district hospital) District AIDS Coordinator (Mzimba District Assembly).	3	Key informant interview schedule Checklist

The requisite data for the study was collected by means of (i) focus group discussions, (ii) critical incident narratives, (iii) individual in-depth interviews (IIs), and (iv) key informant interviews.

The data collection instruments included a focus group discussion topic guide, an individual in-depth interview schedule, a critical incident narratives interview schedule, and a key informant interview schedule. The researcher also used a checklist in conjunction with the key informant interviews to obtain information which would show whether the home-based care programme included best practices as stipulated by the World Health Organisation.

Two forms of participatory research techniques, namely, Pairwise Ranking Activities (PRAs) and Time Activity Profiles (TAPs) were also used. The participatory research techniques were used to augment the data collection process and also to facilitate the triangulation of the data which had been collected. In addition, the use of participatory research techniques also facilitated rapport building with the participants. In view of the nature of the study, it was anticipated that building a good rapport with the participants at the outset of the study would assure the researcher of high quality data.

4.4.5 Accessing gatekeepers and participants

In order to gain access to the participants for the study, the researcher first paid a courtesy visit to the group village headmen (and Chiefs) of both Mbale village and Alick Chisi village. During these visits the researcher introduced the topic of the proposed study. These chiefs were each given a letter from UNISA explaining the project and requesting permission for the researcher to conduct the study in their villages (see Appendix 2). In order to meet the chiefs the researcher had first to make appointments with them and visit them on days which were most convenient to them.

The researcher explained that she was interested in “chatting” (i.e. direct translation from the Tumbuka word *kuchezya* as there is no word to effectively explain the art of interviewing) with women who were caring for those infected with HIV in their homes. The researcher was advised to contact the Mzimba district hospital in order to access the home-based care volunteers as they would be able to introduce the researcher to the women who were caring for the chronically ill in their homes in the two villages.

4.4.6 Pilot study

All the data collection tools were pre-tested in Chimkusa village in Mzimba. This village was not one of the final study sites but shared all the social, cultural and economic characteristics of the two intended research sites. Permission to work in Chimkusa village was obtained from the group village headman, Mr Jambasi Sambo. Although no problems were experienced with the data collection instruments, the two participatory research techniques, which were used in conjunction with the other qualitative data collection instruments, proved to be problematic as they took longer to administer than anticipated. Nevertheless, the researcher opted to continue to use these two research techniques and the participants in the main study were informed about the length of the exercise.

Before the commencement of data collection process, it was important to ensure that the participants felt comfortable with the researcher. The researcher took care to establish rapport between the participants and herself; that the participants had consented to taking part in the data collection process; and that there was also trust between researcher and the participants.

Building rapport

When conducting qualitative research it is essential that the researcher bear in mind that the participants are trying to understand him/her and that their perception of the researcher will affect their interaction. For example, the participants will try to find out information about the researcher's personal characteristics such as ethnicity, status, gender and social distance (Brikci & Green, 2007: 14). In order to achieve optimal rapport with the participants, the researcher must appear modest and non-intimidating. For the purposes of this study the researcher also dressed in the traditional dress in an attempt to close the distance between the participants and herself. In order to create a relaxed atmosphere, the researcher introduced herself and then asked the participants to introduce themselves and say something about themselves. She then introduced the subject under discussion and explained what would be expected from the interviews. The participants were encouraged to express themselves without reserve.

Consent

Before the researcher commenced the data collection process, the participants were asked for their consent to tape record the data collection process. Informed consent may be obtained either orally or by means of a signed, written consent form. A written consent form was provided for those participants who were able to read and write and they were requested to sign the form. The consent of those participants who were not able to read or write was obtained orally. The form of consent (written or oral) was documented for each participant (see Appendix 4: Consent form). Consent would not be obtained using finger prints as this would have introduced identifiers and ultimately jeopardise the data collected at the same time compromising the anonymity of the research participants.

Trust

The fact that the researcher was native to the area and her family well known in the community helped to create an environment of trust. Most of the elderly women knew the researcher because she had grown up in the area, and had been to school with some of their children. It was also an advantage that she spoke the same language as the participants and shared the same culture. This also helped them to trust her. On a personal level, the researcher has lost friends and relatives to HIV and AIDS and this helped her to understand their plight. The participants felt that the researcher was on their side. Throughout the data collection process, the researcher responded both truthfully and empathetically to the challenges experienced by the participants and to their personal queries.

The next section describes the data collection methods which were used to gather data according to the objectives of the study.

4.5 Data collection methods

This section discusses the various data collection methods which were used in the study. They include focus group discussions, pairwise ranking activities, time-activity profiles, critical incident narratives, individual in-depth interviews, key informant interviews, and a checklist.

4.5.1 Focus group discussions

Two focus group discussions were conducted with two groups of women volunteers (comprising six and ten participants respectively) who were providing home-based care to HIV-infected people in their villages. The first group of women volunteers met at the house of one of the volunteers in Mbale village. The second group met at the premises of their food security project called Walusngu Project at Kamsombeni in Alick Chisi village.

The main reason for using focus group discussions was to allow the women the opportunity to discuss the challenges that they faced in caring for those infected with HIV, to create meaning for themselves and to find the synergy of insights and solutions during their discussions (Wilson, 1997: 209–224). This would not have happened if the women had been interviewed separately. Focus group discussions are an extremely popular data collection method, especially in HIV and AIDS research, and have been used extensively in order to understand the social-cultural issues that either lead or render people vulnerable to HIV infection as well as other sexual behaviour and health-related issues (Akwara, Madise & Hinde, 2003; Morgan, 1993).

Before holding the focus group discussions with the women volunteers, pairwise ranking activities¹⁶ were conducted with the participants in order to acquire information about their daily work activities. Ranking activities may take any form of ranking – from wealth ranking in social science research to physics. Pairwise ranking compares two items at a time and the participants are asked which item they prefer, why they prefer that item and what is either good or bad about each choice (Kapila & Lyon, 1994: 30). In this study pairwise ranking was used to document the activities in which the women caregivers were involved and rank these activities in order of priority.

The participants were asked to list all the activities that they performed in a day, from the time they woke up until the time they went to bed at night. They were then

¹⁶ The process by which pairwise ranking activities were conducted is contained in Appendix 1.

asked to rank all these activities according to which they believed were the most challenging. This method was used to augment the focus group discussions. Each participant came up with her own pairwise ranking activity and these pairwise ranking activities then formed part of the group activity as a whole. All the activities were then discussed at the end of the discussion to form a group picture i.e. a social activity profile. For the purpose of the focus group discussions a topic guide with standard topics was used to guide the data collection process. Topic guides are used primarily in focus group discussions in order to obtain information from the participants from their own perspectives or worldviews. As a data collection tool, a topic guide consists of a list of the key questions which the interviewer asks in order to gather the data which is required for the study while also providing useful prompts to encourage the interviewees to talk about specific issues if they do not spontaneously refer to such issues (Brikci & Green, 2007: 13). For the purposes of this study the researcher used the topic guides to collect data that could be compared across groups and individuals while ensuring that there was a consistent coverage of the theoretical concerns and that the data collected was both reliable and valid (Lunt & Livingstone, 1996; Fern, 2001; Silverman, 1998). In addition, the topic guides used in focus group discussions provide a standardised format for the simultaneous and systematic collection of data from a number of participants (Babbie, 20010: 308) (see Appendix 6e).

During the focus group discussions the women were also able to reflect on the questions or topics of discussion asked or presented by the researcher. They were able to listen to one another's responses and make additional responses according to the way in which the discussion was progressing. There were no right or wrong answers and it was not necessary to reach a group consensus because the aim was to accumulate the individual experiences of the participants (Patton, 2002; Neuman, 2007).

In view of the time constraints imposed on the participants by domestic and other duties, there was not sufficient time to go into great detail on all the issues under discussion. However, saturation point was achieved by conducting the two focus group discussion sessions.

4.5.2 Pairwise ranking activities

Pairwise ranking activities were conducted with the women volunteers who had come together for a focus group discussion. Before conducting the focus group discussions, the researcher wanted to gather information on the daily work activities carried out by the women volunteers. Ranking activities may take any form ranking from wealth ranking in social science research to physics. Pairwise ranking compares two items at a time and the participants are asked which is item they prefer, why they prefer the item and what is good or bad about each choice (Kapila & Lyon, 1994: 30). For the purposes of this study the method was used to document the activities in which the women caregivers were involved and rank these activities in order of priority.

The participants were asked to list all the activities that they performed in a day from the time they woke up until the time they went to bed at night. They were then asked to rank all these activities according to what they believed were the most challenging. This method was used to augment the focus group discussions. Each participant came up with an individual pairwise ranking activity and these then formed part of the group activity as a whole. All the activities were discussed at the end of the interview in order to form a group picture i.e. a social activity profile (see Appendix 6a).

4.5.3 Time-activity profiles

Time-activity profiles were used before conducting the individual in-depth interviews with the elderly women participants and the critical incident narratives with the younger women participants.

The researcher used time-activity profiles to determine the amount of time dedicated to home-based care work as compared to all the other household activities. In addition, this tool was also used to augment the individual in-depth interviews and critical incident narratives with the both older and the young women who were caring for their HIV infected family members and guardians/parents. By conducting these activities prior to conducting the individual in-depth interviews and the critical incident narratives, the researcher was able to gather data which could be used to triangulate the other data which she would collect at a later date

using the aforementioned data collection methods such as individual in-depth interviews

Time-activity profiling was a tool that was adapted from a tool known as daily activity programmes (Kapila & Lyon 1994: 31). Kapila and Lyon (1994) reported that, in daily activity programmes, the information gathered on the daily activities of community members is analysed and compared to provide a profile of such activities. The time-activity profiling enabled the researcher to identify the challenges which women faced in trying to carry out all the relevant home-based care activities and, at the same time, cater for their own needs.

The participants were asked to list all the activities that they performed from the time they woke up until the time they went to bed at night and to record the amount of time spent on each activity (see Appendix 6b).

4.5.4 Critical incident narratives

Five young women carers were interviewed using the critical incident narrative method. These young women carers were taking care of either their parents or guardians. The critical incident narrative/technique is a method of qualitative data collection that "relies on a set of procedures to collect, content analyse, and classify observations of human behaviour and can be defined as one that makes a significant contribution, either positively or negatively to an activity or phenomenon" (Gremler 2004: 66). It is, thus, an interview technique which "facilitates the investigation of significant occurrences (events, incidents, processes, or issues) identified by the participant, the way they are managed, and the outcomes in terms of perceived effects" (Chell, 2004: 56). This technique was used to obtain information which would lead to better understanding of the young women's life stories than may otherwise have been the case, especially as regards the events of their parents'/guardians' illness by examining the incidents from the perspectives of the participants and taking into account their cognitive, affective, and behavioural elements (ibid.). This method also enabled the researcher to collect data on complex issues, particularly those events which had had either a strong positive or strong negative impact on the participants' lives. In the study participants were able to narrate all the critical events of their lives and relate how these events had affected their lives and their futures.

Critical incidents are, in essence, the life stories of those who have lived these incidents. Thus, the researcher, may use critical incident narratives as a method of collecting data that may be considered potentially sensitive or emotional to the participants. A topic guide was developed based on the research objectives of the study and was used to collect the requisite data (see Appendix 6d).

The data collected was documented as life stories and, this, it also allowed for the gathering of retrospective data. This method does have certain drawbacks, including the fact that it is retrospective in nature and, thus, there is a potential for recall bias (Gremler, 2004: 67). Where the participants experienced problems recalling some facts of their life stories, the researcher gave them time to remember these. When it became too painful for the participants to continue, the researcher allowed them to take time and decide whether they wanted to continue with the interviews. The interviews were sufficiently flexible to give the participants the opportunity to express their deepest feelings and fears about their experiences. Another advantage of using this data collection method is that the researcher is able to collect data which is both rich and concrete because the participants are able to determine which incidents are relevant to them in relation to the issues in which the researcher is interested. In addition, the participants also have the opportunity to provide a detailed account of their own experiences (Gremler, 2004: 66).

The researcher focused on the young women's experiences by tracking the course of the parents' or guardians' illness by using simple language probing methods, for example, asking "What happened next?" This helped to researcher to uncover the reasons why they had been forced to make the decisions they had had to make, for example dropping out of school.

4.5.5 Individual in-depth interviews

Five individual in-depth interviews were conducted with elderly women carers who were taking care of their HIV infected and affected children after they had completed the time activity profiles. Marshall and Rossman (2006: 101) describe interviewing as "a conversation with a purpose". An individual in-depth interview is a one-to-one interview which uses the unstructured interviewing technique of a formalised conversation (De Vos et al., 2011: 348).

Individual in-depth interviews were conducted in order to generate detailed explanations of the challenges that the participants were experiencing as they provided home-based care rather than evaluating the home-based care programme per se (De Vos et al., 2011; Russell, 2006; Patton, 2002). Individual in-depth interviewing effectively allows the participants to describe their experiences and the meaning they have derived from these experience (De Vos et al., 2011: 348). Individual perceptions and experiences are documented and this, in turn, also generates specific quotations for the report to be compiled (Russell, 2006; Patton 2002).

An interview guide was used in order to collect the data during these interviews. An interview guide or schedule is a written questionnaire which provides the researcher with "a set of predetermined questions that might be used as an appropriate instrument to engage the participant and designate the narrative terrain" (Holstein & Gubrium, 1995; Monette, Sullivan & DeJong, 2005; De Vos et al., 2011). In addition, an interview schedule or guide also assists the researcher to think carefully about the type of data he/she hopes to obtain and the possible difficulties that may be encountered during the data collection process (De Vos et al., 2011: 352) (see Appendix 6c).

4.5.6 Key informant interviews

Three key informants were interviewed using key informant interview schedule. All these key informants were interviewed at their places of work. It was, thus, important not to disturb their work. Interviewing these three key informants enabled the researcher to validate the data she had already collected from the women in the community.

Key informant interviews are characterised by certain inherent information biases and, hence, distortions that the key informant interviewees tend to introduce into the data gathered. In order to counter the effects of such biases in this study, data was collected from the key informants first before data was collected from the women carers (see Appendix 6f).

4.5.7 Checklist

A checklist was used to collect the data from the key informants. The information that was collected using the Check list was required to answer the questions on the home-based care best practices (see Appendix 6g).

An in-depth account on how data was captured during the data collection process is given in the following section.

4.6 Data capturing

Tumbuka was the language that used for interviews with the women caregivers. This is the language commonly spoken in Mzimba. English was only used with the Key Informants. The researcher conducted all the interviews as she is fluent in both languages.

All the interviews were tape recorded. According to Smith, Harre and Van Langehoven (1995: 17), the tape recording of interviews allows the researcher to collect "a much fuller record than notes taken during the interview". Taping the interviews allowed the researcher to concentrate on the interview questions, how they were proceeding, what to pursue next or how to probe or ask follow-up questions (De Vos et al., 2011: 359). The researcher also took notes to capture the non-verbal cues, for example, the expressions and gestures of the participants.

A detailed explanation on how data was analysed and interpreted so as to answer the research question is given in the next section.

4.7 Data analysis and interpretation

Being qualitative and participatory in nature, the study begun by collecting data which was relevant to understanding the challenges women who provided home-based care experience. This is known as inductive approach to research (Patton, 2002). The data analysis was conducted using a thematic framework of analysis which had been developed using the objectives and issues that had been identified in the initial problem analysis. The framework of analysis was revised when additional themes and sub-issues emerged from the data. The data was coded and sorted into different themes and sub-issues and then summarised, extracting general

common quotes and rare/common themes. Similarities and differences between the responses were also analysed. The data interpretation was conducted immediately after the analysis had been completed.

The data analysis of qualitative and participatory data may be both challenging and time consuming. However, once patterns begin to emerge, the researcher realises that the exercise was not in vain and, in fact, the process becomes quite enjoyable as meaningful conclusions are drawn from the discussions and interviews. For the purposes of this study, the qualitative data which had been collected was analysed by coding the data sets. Coding was used because, as an interpretive technique, it both organises the data and provides a means with which to introduce the interpretations derived from the data into certain qualitative methods (Saladana, 2012; De Vos et al., 2011). In addition, the data was further analysed by using a thematic approach in terms of the researcher looked through all the data in order to identify common issues which were occurring and to identify the main themes which summarised all the views of the participants (Neuman, 2000; Green & Thorogood, 2013). The researcher went through the following steps in order to analyse the data using a thematic approach.

4.7.1 Reading and annotating of transcripts

Reading and annotating the transcripts is the first and most basic stage in the data analysis of qualitative data. For the purposes of this study the researcher did not provide an overview of the data but made preliminary observations on a few of the transcripts. This proved extremely useful as it provided the researcher with an initial sense of the data. In addition, the researcher took time to make short notes which would guide the data analysis process.

4.7.2 Identifying themes

The second stage involved examining the data in great detail in order to enable the researcher to begin to identify the themes which were emerging. First the researcher summarised the data set in order to obtain a better understanding than previously of the narratives and perspectives that had emerged during the interviews and discussions. The researcher printed out the transcripts and, in the margins of each transcript or set of notes, she made notes on what the various interviewees had been

referring to. It was important to ensure that these notes were as abstract as possible. This process did not merely involve summarising the text but also trying to ascertain what the text was referring to or giving an example of unique quotes from the data. Each segment in the transcript was numbered to assist in the coding of the data. As the researcher went through the data she made a list of the themes which had emerged.

4.7.3 Developing a coding scheme

The initial themes were collected together in order to develop a coding scheme. A coding scheme is a list of the themes that emerged and the codes that were assigned to the data. Each code also included sub-codes. The researcher began developing the coding scheme as soon as she had collected the first set of data. This early analysis helped in giving direction to the data collection process, in particular, by directing the researcher to ask the right questions and ensuring that the appropriate people were recruited as participants. The early analysis acted as a feedback mechanism for the researcher.

4.7.4 Coding the data

The next step involved coding all the data which had been collected by writing either codes or notes in the margins of transcripts. Some lines of text were coded more than once and in several different ways, ranging from the basic codes to categories that reflected the broader analytic themes that had emerged. As the researcher started going through/assessing/studying the data in detail, it was also possible to amend the coding schemes. The entire data set was coded to ensure that the analysis did not concentrate solely on the atypical or "exotic" extracts of data. The researcher ensured that the coding was done in such a way so as to render the data analysis truly comprehensive.

4.7.5 Cutting and pasting

When all the data had been coded, the data extracts were taken from the original context, for example from the interviews or focus group discussions, and put together with other examples of the data on the same topic in order to reveal patterns and relationships across the data. These patterns and relationships were

then used as the basis for the research findings. The chapter on the research findings contains certain quotes from the data set and which represented both major and minor issues relating to the main objective of the study.

4.7.6 Narrative analysis

As well as the themes that cut across the data, the research also sought to look at each case in order to guard against the "story" of a woman's challenges being lost. As a method of data analysis cutting and pasting may, at times, lose aspects of the narrative context. It was regarded as particularly important to avoid such losses in the analysis of data from the critical incident narratives of the young women. The researcher examined these narratives in great detail in order to assess how to present these stories in tandem with the other results from the data analysis.

4.7.7 Data interpretation

As the categories and themes were developed and the coding underway, the researcher began the process of the integrative interpretation of what she had learned (Marshall & Gretchen, 2011: 219). Data interpretation, often referred to as "telling the story", brings meaning and coherence to the themes, patterns and categories, developing linkages and a story line that makes sense and is engaging to read (ibid). Patton (2002: 480) defined data interpretation as "attaching significance to what was found, making sense of the findings, offering explanations, drawing conclusions, extrapolating lessons, making inference, considering meaning, and otherwise imposing order". Marshall and Gretchen (2011: 219) argue that this phase includes evaluating the data segments in order to support the emerging story, illuminate the questions that were explored and decide in what way the questions are central to the story that is unfolding concerning the social phenomenon being studied. The data interpretation in this study was based on three factors that influenced the emphasis accorded to all the topics, namely, how many groups of participants mentioned the topic in question; how many participants in each of these groups mentioned the topic in question; and the degree of energy and enthusiasm which the topic had generated in the participants. This is known as "group-to-group validation" (Patton, 2002; Green & Thorogood, 2013). In view of the unstructured nature of qualitative study, there is need, when interpreting the data, to ensure that

both the validity and reliability of the data. Thus, in order to interpret the data, the researcher was guided by the following four questions: What is important in the data? Why is it important? What may be learnt from it? So what?

The researcher then tried to contextualise the findings from the study by examining the convergence of the evidence and then referring to the theoretical framework guiding the study. In addition, in order to ensure that the research study was both complete and credible, the researcher used the following strategies, namely, triangulation, audit trail and theoretical sufficiency (Marshall & Gretchen, 2011: 221). Triangulation, alluded to earlier in this chapter, was built into the structure of the data collection. As a strategy, this assisted the researcher to asserting that her data interpretations were credible (ibid). In addition, this strategy also attempted to illustrate that the participants' views were real and their behaviour authentic (ibid). Audit trails enabled the researcher to demonstrate that both the data collection and the management process had been transparent (ibid.). The audit trails also helped the researcher to account for all the data collected and also for all design decisions made in the field so as to enable anyone to trace the logic used (ibid). Theoretical saturation is the ideal in terms of data collection and refers to the researcher continuing to collect data until any additional data collection would only result in more of the same findings. Dey (1999: 257) terms theoretical saturation an "unfortunate metaphor", suggesting that we should be speaking about theoretical sufficiency. As regards theoretical sufficiency, Marshall and Gretchen (2011: 221), defined it as a process in terms of which the categories defined have been sufficiently described and they fit with the data, while acknowledging the fact that it is not possible ever to know everything and that there is never one complete "truth".

4.8 Debriefing and counselling

The nature of the study made it essential that the participants did not feel they were under interrogation but, instead, that the researcher was empathetic to their challenges and their plight. In order to ensure this happened, the researcher made contact with the relevant professionals who could assist should the need for intervention arise, for example, the provision of extra counselling, care and support services. Thus, the researcher ensured that the participants were assisted in their

respective situations and also that all the ethical precepts of research were adhered to.

The ethical considerations informing the study are described in the following section.

4.9 Ethical considerations

Ethics may be defined as “a set of widely accepted moral principles that offer rules, and behavioural expectations of the most correct conduct towards experimental subjects and participants, employers, sponsors, other researchers, assistants and students” (De Vos et al., 2011: 129).

According to the Belmont Report (National Institutes of Health, 1972), the core principles that make up the universally accepted basis for research ethics include respect for persons, beneficence, justice and, others add, respect for communities. In this study all researcher ensured adherence to all these core principles by employing measures such as maintaining confidentiality; obtaining the informed consent of the participants; and make certain that the participating individuals, groups, and communities were not harmed in any way.

In order to maintain confidentiality the participants were assured that the data collection process would be conducted anonymously and that their names would not be included in the transcripts. Each potential participant was provided with complete information about the study and its objectives. Only after the participants had indicated that they had clearly understood the objectives of the study and the type of information required, was their consent to participate in the study obtained.

Babbie and Mouton (2001: 522) have argued that social science research should not injure the people who are being studied, regardless of whether the participants volunteered to participate in the study or not. However, injury may not be merely physical and may also imply revealing embarrassing information about a participant (ibid.). No identifying biological data was collected from the participants in the study and nor were any of the participants paid to participate in the study.

Before commencing the data collection, the researcher sought formal ethical approval from the Department of Sociology at the University of South Africa to allow

her to conduct the study in Malawi. The research review board reviewed the research proposal to ensure that it had addressed all the issues relating to safeguarding the dignity, rights, safety and well-being of all actual or potential research participants (Brikci & Green, 2007: 6) (see Appendix 1: Sociology Department Ethical Clearance Letter). At the time of obtaining ethical clearance from the University of South Africa the researcher made enquiries at the Ministry of Health on the regulations regarding obtaining an ethical clearance letter from the Ministry in Malawi. She was advised that because the study was not a biomedical but a social science one, she did not require ethical clearance from the Ministry of Health.

All ethical issues were strongly adhered to such that issues of autonomy (respect of the right of the individual); beneficence (doing good); non-maleficence; (not doing harm) and justice (particularly equity) were taken into account at all times (Brikci & Green, 2007: 5). Brikci and Green (2007: 5) also remind all researchers that asking a person to talk about experiences that were frightening, humiliating and/or painful may either cause or increase anxiety. This was certainly the case with regard to this particular study. Brikci and Green (2007: 5) quote WHO (2003) which goes further to argue that distress may not only be created during an interview but that it may also emerge after an interview. Accordingly, the researcher ensured that care was taken regarding how the questions were posed and also at what point she chose to ask and probe for further information (Brikci & Green, 2007: 5). It is essential that the two key issues of consent and confidentiality be considered at all times and this was done throughout this study.

4.9.1 Obtaining the consent of the participants

Mack, Woodsong, MacQueen, Guest and Namey (2005) define informed consent as a mechanism for ensuring that people understand what it means to participate in a particular research study in order that they may decide in a conscious, deliberate way whether they want to participate in the study in question. As such informed consent is one way in which to ensure respect for persons during a research study. Informed consent may be obtained either orally or by means of a signed written consent form. A written consent form was given to those participants who were able to read and write and they were requested to sign the form. The consent of those participants

who were not able to read or write was obtained orally. The form of consent (written or oral) was documented for each participant (see Appendix 4: Consent form).

The researcher visited the relevant gate keepers such as the village headmen or district home-based care coordinator in order to ask for permission to access the potential participants. Once the participants had been accessed, the researcher asked the individual participants for their consent to participate in the study. This consent was obtained either orally and in written form. The participants were also informed that they were free to stop the researcher at any stage during the data collection process and they would be free to leave. The participants were neither coerced into participating in the data collection process nor were they paid for their participation.

4.9.2 Maintaining confidentiality and anonymity

Confidentiality and anonymity are the cornerstones of ethics in research. It is important, therefore, to ensure that the information which the participants provide in response to the research questions does not either compromise or injure them in anyway. Adherence to confidentiality and anonymity should be a norm when conducting a research study and is of paramount importance, thus ensuring that participants feel that they will be protected in the case of any potential repercussions arising from the responses they have given (Babbie & Mouton, 2001; Mack et al., 2005). Although it is not always easy or even possible to measure the dangers of a certain context to a given population, let alone to individuals, researchers are always reminded that it is vital to protect the identity of the persons from whom they gather information (Brikci & Green, 2007: 5). In addition, if the researcher has information about the identities of the participants, such information must be protected at all times. This includes not leaving notebooks or unprotected computer files lying around so that others may easily access them (ibid.).

In order to ensure that the data collection process was conducted in a strictly confidential way, the participants were given numbers with which to identify them. No names were kept by the researcher for the purpose of identifying the participants. However, in view of the fact that qualitative research is conversational in nature, there is always a possibility of the researcher becoming familiar with the participants. In order to ensure that the information obtained from the participants

could not be made public, the researcher created a master identification file with links to the numbers assigned to each participant (Babbie & Mouton, 2001: 523–524). The researcher had established a good rapport with participants and there was undoubtedly trust between the two sides. The researcher was aware that it was important to gain the trust of the participants because, without such trust, the quality of data collected may have been compromised.

4.10 Summary

This chapter discussed the methodological approach which was used to gather the information required to attain the research objectives. The study was exploratory in design and both qualitative and participatory methods were used to collect the requisite data. In addition, the chapter described the specific data collection methods which were used in the study, including focus group discussions, individual in-depth interviews, critical incident narratives as well as participatory methods such as pairwise ranking activities and time-activity profiles. The process of data gathering was presented, together with reasons for each step in the process. The chapter discussed the ethical considerations which were adhered to in order to ensure that the anonymity and confidentiality of the participants were protected. The chapter also highlighted that the participants had given their informed consent to participate in the study. In view of the fact that the study was both qualitative and participatory in nature, the methodological approach discussed in this chapter was deemed appropriate for gathering data which was, at times, both personal and emotional.

CHAPTER FIVE

FINDINGS, ANALYSIS AND INTERPRETATION: WOMEN VOLUNTEERS AND ELDERLY WOMEN

5.1 Introduction

This chapter presents the data that was collected from the women volunteers and elderly women. The study findings are presented according to the specific objectives which guided the study; the gender-related, socio-cultural and socio-economic challenges faced by the women caregivers and the coping mechanisms that the women use.

5.2 Pairwise Ranking Activities

Pairwise Ranking Activities were conducted in the two FGDs with the women volunteers. Before conducting the focus group discussion, it was deemed important to gather information relating to the daily work activities of the women volunteers. Pairwise ranking compares two items at a time, thus the participants were requested to rank the items in order of preference while also providing reasons as to why an item was preferred over another and what was good or bad about each choice (Kapila & Lyon 1994:30). The method was used to document the activities in which the women caregivers were involved and to rank these activities according to order of priority.

The participants were asked to list all the activities they performed in a day, from the time they woke up to the time they went to bed at night. They were then asked to rank all these activities according to what they believed were the most challenging. This method was used to augment the narratives from the FGDs. Each participant came up with an individual pairwise ranking activity which then formed part of the entire group activity. All the activities were discussed at the end of the session in order to compile a group picture of the activities. (The process in terms of which the Pairwise Ranking Activities were conducted is presented in Appendix 6a.)

The activities listed included the following:

- 1) business activities
- 2) gardening activities

- 3) home-based activities
- 4) church activities
- 5) household chores
- 6) child caring activities

5.2.1. Pair-wise matrix

First level Pairwise Ranking:

1	Business activities	Home-based care activities	Household chores
2	Gardening activities	Church related activities	Child caring activities

Second level Pairwise Ranking:

1	Business activities	Gardening activities	Church related activities
2	Home-based care activities	Household chores	Child caring activities

Third level Pairwise Ranking:

1	Business activities	Household chores	Church activities
2	Home-based care activities	Gardening activities	Child caring activities

After a series of activities had been cited by each participant, all the participants discussed their rankings and decided on the following ranking:

Final ranking exercise:

- 1 business activities
- 2 home-based activities
- 3 household chores
- 4 gardening activities
- 5 church activities
- 6 child caring activities

There was an intense debate in both the FGDs on the ranking of first two activities as they appeared to be equally important to the women. However, the women finally decided on the ranking as presented above.

The significance of the Pairwise Ranking Activities becomes apparent in relation to the findings from the FGDs.

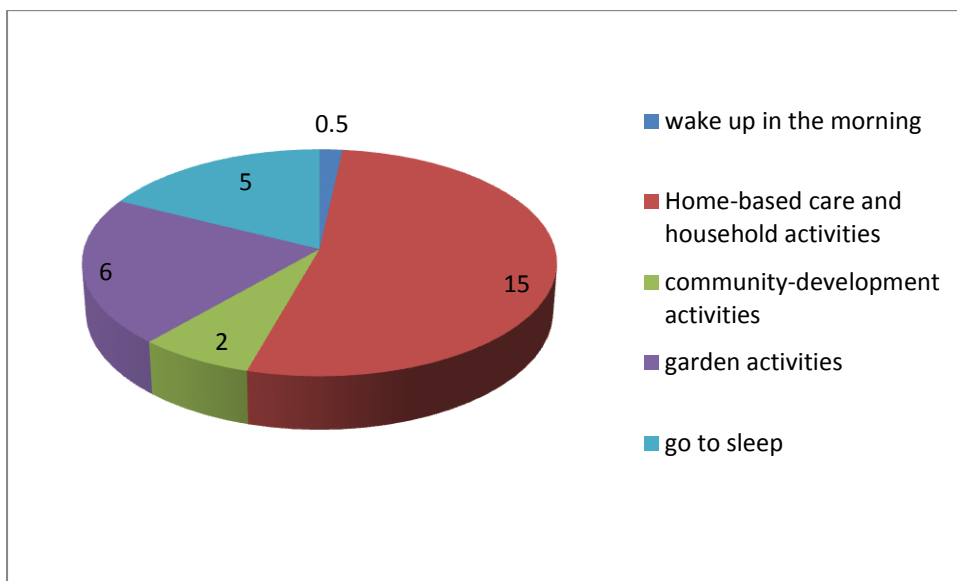
5.3 Time-Activity Profiles

Five Time-Activity Profiles were conducted with the group of elderly women. These Time-Activity Profiles were conducted in order to determine which activity took more time to complete as compared to all the competing activities in the household (see Appendix 6b). Figure 5.1 comprises an amalgamation of all five Time-Activity Profiles. It emerged that the second most time consuming activity was the garden activities. At the time of collecting the data, the women were busy harvesting their crops. This involved travelling a few kilometres to their gardens to harvest the maize, groundnuts and beans which they had cultivated. In addition, they also had to transport the harvest home. This work is extremely labour intensive and three of the elderly women were receiving help from their relatives and grandchildren. The other two indicated they did not have anybody to assist them and that they had to transport the harvest home on their own.

Table 5.1: Table of time spent on an activity by the elderly women

Activities	Hours
Wake up in the morning	0.5
Home-based care and household activities	15
Community-development activities	2
Garden activities	6
Go to sleep	5

Figure 5.1: Time-Activity Profiles for the elderly women



It is clear from the amalgamated Time-Activity Profiles that the elderly women spend most of their time carrying out household activities. These include the caring activities for the chronically ill in the home. All the women reported that the caring activities were merely part of the activities that they carried out at home. For example, when they prepared a meal, the meal was prepared for the whole family and the patient would receive a portion of the meal. If the patient were not able to feed him/herself, the elderly women would feed the patient. In addition, they drew water or collected firewood for the whole family and not just for the patient. However, the elderly women reported that the caring activities had increased their already heavy workload.

5.3.1 Opportunity costs

The Time-Activity Profiles conducted with the elderly women provided information about the opportunity costs that these women had given up in order to provide care for the chronically ill people in their families.

The responses revealed that the elderly women spent the majority of their waking hours carrying out home based care and household activities (see Figure 4). When asked what they had had to give up so that these activities were done, they all said they had had to sacrifice their sleep. They have to wake up very early in the morning to ensure that the patients have been given their morning baths, have been fed and have taken their medicines before the women were able to continue with the other household chores. The women also reported that they went to bed after everyone has retired to bed for the same reasons. In other words, they had to ensure that the patients had had an evening meal, taken their medicines and were comfortably sleeping before they could retire to bed. Most of them said they went to bed after eleven o'clock at night.

The elderly women also reported that they had to give up some of the time they had spent participating in community activities such as the village development activities in which everyone is supposed to be involved in order to give all their attention to the patients. One woman explained her difficulties in participating in community activities as follows:

I do not have much time between the patient, house and the harvesting activities [...] there is not much time to be involved assisting in building a bridge near the school... there simply is no time for me [...] so, I excuse myself or I send my grandchildren to go and help [...] out. (Elderly woman 1).

The women caregivers also reported that there were occasions when they did not have the time to sit down and have a proper meal with their families while family meal times were sometimes shortened in order to cater for the needs of the patient. This often happened when the patient was totally bedridden.

5.4 Gender-related challenges

The first specific research objective was to understand the gender-related challenges that the women faced. The data collected provided insights into HIV prevention and

the problems that the women experienced as they tried to find a life partner (husband) or someone who would assist them financially.

5.4.1 Gender and vulnerability to HIV– the challenge of protecting themselves

The women participants reported having faced the dilemma of protecting themselves against HIV infection while, at the same time, engaging in sexual relations with men who were spouses, boyfriends or casual acquaintances. The majority of the women reported that they found it difficult to negotiate the use of condom during sexual encounters with the men who were supposed to assist them in some way. This, in turn, had led to some becoming mothers at a young age and some even becoming infected with HIV.

The women caregivers explained that they felt vulnerable to HIV infection when their partners did not use condoms, particularly if they were aware that their partners had sexual relationships outside the marriage/or stable relationship. However, it also emerged that, as compared to the young women, the older women were more knowledgeable about the disease and that they were more empowered and assertive in demanding that their sexual partners use condoms.

Vulnerability to HIV infection was considered as a major challenge for the women caregivers as a result of their low socio-economic status in society. In other words, the women were unable to protect themselves from HIV infection because of their lack of negotiating skills, their dire economic circumstances, and their low socio-cultural status which made them feel less empowered to demand protection than would otherwise have been the case.

In their role as caregivers, women reported that they were encouraged to improvise when they had run out of protective materials such as gloves. The quality of these improvised materials was not always good and tended to render the women vulnerable to infections including HIV.

5.4.2 Burden of care of home-based care

The burden of caring for those who were infected with HIV and were chronically ill was another gender related challenge that the women experienced with this burden

falling squarely on the shoulders of the women in the community in question. This finding was common to all three groups of women.

During the FGDs, the women volunteers reported that they carried out most of the caring activities with the men occasionally assisting where there was a need for male participation. These caring activities included cleaning the patients' houses, washing the bedding, drawing water, cooking meals, feeding the patients, giving bed baths to the patients, treating the pressure sores with the medications provided by the hospital, collecting firewood and counselling the patients and their families.

The volunteers maintained that these activities were carried out at every house in the village where there was an HIV patient and that these activities were in addition to their own household chores. The women explained that they had sometimes felt overwhelmed and, thus, they had devised a plan to divide up the work and responsibilities. For example, when going to visit the patients in one village, they shared the responsibilities with some bringing firewood and others bringing water in buckets from their homes. When they arrived at the home of the patient, they would also divide up the workload. Some who would be responsible for cleaning the house, others would boil water for the bed bath while others would prepare food for the patient and, sometimes, the whole family. Thus, all the work that had to be done was shared among the volunteers to enable them to finish more quickly than would otherwise have been the case and then return to their respective homes to carry out their daily household chores.

It emerged from the individual, in-depth interviews with elderly women that caring for the chronically ill in the home was regarded as the woman's responsibility. It was explained that this was the way things were in their community and that it was even more evident if the patient were female. Men were rarely considered as carers. An elderly woman recounted how she had been left alone to care for her chronically ill daughter until she had died:

[...] I had been looking after my daughter myself [...] until the day she died. It was not even considered that my husband would look after her [...] (Elderly woman 4).

All the elderly women reported that they have had to care for children whose parents were suffering from AIDS, some of whom had subsequently died. The challenges of caring for these children are linked to the challenges that these elderly women were experiencing when caring for own HIV infected children. One participant expressed the difficulties of caring for such children as follows:

[...] children who have parents who are ill become very difficult to care for [...] They are always anxious [...] I tried to calm their fears but the older one kept saying 'mama is dying' [...] there was very little I could do to quell his fears because I knew he was right [...] (Elderly woman 2).

The elderly women also reported that caring for a person suffering from a chronic condition such as HIV infected was extremely exhausting and that dealing with the problems that came with the condition was tiring:

I have to be alert and mostly awake when she is very ill and bedridden [...] her needs are many... she may need to go to use the toilet [...] I must be there to assist her, she may feel like vomiting, I need to be there with a bucket [...] there are so many things that she needs[...] (Elderly woman 1).

The lack of medical knowledge was also cited as a challenge. The home-based care programme assumed that the caregivers would be familiar with the medicines that the patients were taking and the proper dosage. However, their understanding of pharmaceutical products was very limited and this, in turn, affected how they assisted the patients. If the patients were not very sick they were able to administer the correct dosages on their own. However, when the patients became too ill to follow the drug regime, their caregivers had to take over this responsibility.

It is very difficult to follow all these drug regimes as she is on tuberculosis drugs as well. She takes her ARVs in the morning after her breakfast and then she must take her TB drugs a few hours later [...] Sometimes I forget which is which [...] (Elderly woman 2).

There was also a gender dimension to the burden of care. In the main, it is women who provide almost all the care for those who are chronically ill. This gender dimension has its origin in the socio-cultural set up of this particular society. It is regarded as the role of women to provide care for all those who are ill in both the home and the community. Women are socialised to carry out these roles and these roles are not negotiable. However, with the high prevalence rate of HIV infection in Mzimba, the burden of care has increased tremendously. The study findings revealed

that the women caregivers are facing enormous challenges and that many of these challenges are psychological, socio-economic and socio-cultural in nature.

5.5 Psychological challenges

It emerged that, as they cared for the chronically ill, all three groups of women were suffering from a range of psychological problems which included extreme worry, anxiety, mental exhaustion, nightmares and depression. For example, a woman volunteer reported that she sometimes felt totally overwhelmed by the responsibility of having to care for several people, especially the patients. Another reported feeling so mentally exhausted that she found it difficult to concentrate at times. A few of the women said that before they had started working as volunteers they had felt extremely depressed as a result of the sickness and subsequent deaths of their loved ones. However, when they had started their volunteer work, they had met other women who had experienced the same trials or worse and this, in turn, had made them stronger. Relinquishing their duties as volunteers was not an option for these women because there were people in their community who depended on them. One of the women volunteers expressed this as follows:

[...] looking at our friends here and listening to their struggles made me stronger [...] I stopped having self-pity by just seeing the resilience of my friends [...] (Woman in FGD 1).

The elderly women also reported experiencing a number of psychological challenges and that there were many times when they felt so anxious, worried and mentally stressed that that they could not sleep at all.

There have been many days that I did not sleep at all. I was very worried about everything [...] I could not eat well [...] My daughter was too ill to even talk to me. I did not know whether she would wake up in the morning [...] It was a very difficult time. (Elderly woman 4).

Some of the elderly women also reported that they suffered from nightmares. One reported that the nightmares were so real that there were many times when she awoke and realised that she had been crying in her sleep.

[...] My child was lying in her bed and I was sitting on the mat just watching over her. Then I dozed off. Suddenly, I dreamt that my daughter had died and I was trying to find my brother to go and buy a burial cloth [...]. It was very vivid. It was terrible. My sick daughter woke me up [...] asking what was

wrong. I could not tell her.[...] How do you tell a patient about such a dream?
(Elderly woman 5).

The majority of the elderly women also mentioned a lack of interest in food and even taking care of their general body hygiene and grooming as consequences of their negative psychological state of mind.

I just did not want to eat at all [...] looking my children dying slowly was enough to kill my appetite for food. I just did not care about myself anymore. There were days I did not have a bath and wore the same clothes for a while [...] (Elderly woman 3).

It was apparent that these women caregivers were depressed, traumatised and mentally exhausted. Certainly, their psychological challenges were sufficiently serious to merit professional assistance.

5.6 Socio-cultural challenges

The second specific objective of the study was to determine the socio-cultural challenges that women face when caring for those who are HIV infected and affected. Gender roles in Malawi, in general, and in Mzimba, in particular, are socio-culturally prescribed and there is little, if any, room for negotiation. The roles of caring for the HIV infected and affected, providing for their families and ensuring that all household chores are carried out are left to the women.

5.6.1 Providing for family needs

All the participants reported that they were the sole providers for their families, even those who were married and whose husbands were supposed to provide material goods for the families. However, in all instances it was the women who took the leading role in providing for their families. All were engaged in some small business venture or another in order to raise money for the needs of the families.

In order to ensure that there was enough food in the family they grew food crops. Maize is the main food crop in Malawi and also among the people of Mzimba. However, as a result of financial constraints, the participants were not able to afford to buy agricultural inputs such as maize seeds and fertilizers and this, in turn, meant that most of them do not produce sufficient crops for their needs. As a result, food

security in their homes was always a problem. In the first FGD a woman summed up the situation as follows,

[...] we are constantly on the road looking for food to ensure the children do not sleep hungry [...] (Woman in FGD 2).

In other words, the women had to carry out some businesses to ensure that they could buy food.

In this society, as in many others, raising children is regarded as the mother's role. However, the women participants reported that they had to raise their own children as well as the orphaned children who had been left behind after their parents had died. One elderly woman summed up the situation thus:

These children depend on me to care for them [...] their parents are both dead. Just as I raised their mother, I am doing the same for them. But now, I find that I do not have the strength and energy to be as vigilant as I was with their mother...that is why you see that some of them have become unruly...one is even smoking marijuana [...] (Elderly woman 5).

5.6.2 Household chores

The women also reported that they carried out almost all the household chores, including caring for the chronically ill patients. The women participants reported that they did not receive much help from their male relatives while the elderly women, in particular, did not have any male relative to assist them. Household chores are closely linked to the gender roles of people in this society. The elderly women also added that, even when their husbands had been alive, they had not assist to any great extent in caring for the sick in the family or carrying out the other household chores. These roles remain as the responsibility of the women.

[...] I tell you now, even when he was alive, he would not lift a finger to assist me with my ailing daughter [...] there were times I just needed him to come and assist me lift her to put her on the bed after I had given her food [...]. He would not. I had to ask my co-wife to assist [...] I am not saying this because he is not here [...] no [...] it is the true and my co-wife can agree with me [...] (Elderly woman 2).

The gender roles encompassed everything that is required to be done at home. The women explained that, in their culture, it is the woman's responsibility to ensure that the family is taken care of on a day to day basis. One of the major challenges faced

was to provide food for the family. One elderly woman spoke at length of the difficulties she experienced in providing for the family.

I have struggled to raise these children as both their parents died. I have had to scarp for food. Sometimes well-wishers would invite the children for a meal [...]. Sometimes, they slept hungry [...] it has been a real struggle to raise them. (Elderly woman 3).

All the elderly women mentioned providing food as an immense challenge as they did not have at their disposal the finances required to ensure food security in the home. All the women were not employed nor did they have any source of regular income.

[...] I do not have enough money to buy fertilisers [...]. Although, I do have seeds which I use every year [...] it is the fertiliser that we need for the crop to do well in the garden [...] (Elderly woman 4).

5.6.3 Providing care for the sick in the home and community

Women also felt compelled to provide care for those who were HIV infected because the men would not do it. Women are culturally considered to be the care givers in this society and, thus, when there is a person who is chronically ill in the community, the women organise themselves to go and assist the family who are caring for this person. This, indeed, was the origin of the started home-based care groups in this society. The women started getting together in the communities to care for those who were suffering from AIDS because the families were becoming overwhelmed. A common response was:

[...] we just had to come and help [...] our neighbour and relatives were becoming helpless in the caring for the sick and the dying [...].

The women in the FGDs reported that they were also responsible for meeting the health needs for their immediate families. This included ensuring that, when a family member was sick, the women in the home took care of the sick person until he/she was well again. This care activity is considered as the woman's job unless there are no women in the family or the women are not well themselves. Thus, the primary care giver in the home is the mother, sister, or grandmother. However, all the activities which home-based care entailed left the women with little time to become involved in community and cultural activities.

There was, nevertheless, a positive aspect of acting as volunteers for those who were HIV infected and affected with the women volunteers reporting that there were some positive things that came out of being involved in home-based care. One woman volunteer articulated it in this way:

[...] our social status in the community had been elevated. We are considered sources of knowledge as far as issues of HIV and AIDS are concerned [...] We are stopped by the roadside to explain issues of AIDS to people who sometimes more educated than us [...] (they all laughed) (Woman in FGD 2).

The socio-cultural challenges which were discussed in this section are all linked to the burden of care. In view of the fact that it is a woman's role to provide for the needs of both her family and the community by performing out the household chores and providing health care, the burden of care continues to increase, especially when there are people who are HIV infected and who are in need of long term care for their chronic illness. It may be appreciated that the challenges noted in this section are making it extremely difficult for women and their families to cope with the burden that have to bear.

5.7 Socio-economic challenges

The third specific objective of the study was to determine the socio-economic challenges that the women face as they provide care for the HIV infected and affected. All the women reported that they faced several socio-economic challenges as they cared for the HIV infected and affected. These included economic hardships, food insecurity and high dependency ratios.

5.7.1 Economic hardships

All of the women expressed feelings of helplessness as regards their socio-economic situation at home. Their economic and financial needs may differ according to their individual situations but, nevertheless, they all felt that they were experiencing extreme hardships and that their personal circumstances had become worse as a result of the illness in the home or their giving their time as volunteers who were caring for others. The major socio-economic challenges that the women faced included a lack of money with which to buy basic necessities such as food, toiletries, clothes, and farm inputs. In addition, they also did not have enough money for other

expenses such school fees as well as health care expenses, and transport when the condition of the patient deteriorated.

All the women reported that the major challenge socio-economically was the fact that they did not have enough money in the house to meet all their needs. For most of the women the person who was ill had been the bread-winner. During the illness it was reported that the household income usually dwindled as most of the money was spent on buying medicines and paying for transport to the hospitals or clinics. As a home based care patient the patient had to be made comfortable in the home but all the comforts cost money. For example, the patient needed to sleep in a clean, comfortable and warm bed. The household income was used primarily to ensure that such comforts were provided such as special body creams to apply on the sores of the patients.

The women also reported that, once the patient had become totally reliant on home-based care, the household usually suffered from a lack of the basic necessities. The women also said that the money which could have been used for buying basic commodities such as sugar, tea, bread, soap, paraffin, matches, maize flour, meat, beans and other food stuffs was now being used to buy the patient's medicines and everything that was required to ensure that patient had a better quality of life.

An elderly woman narrated how the family had been left destitute when her daughter had become ill as she had been brought in money from her business.

The women volunteers all reported that caring for those who are HIV infected and affected was extremely costly and they had had to raise the money to assist the affected families while they, themselves, were also struggling financially. These women reported that, as a result of their lack of education, they lacked employable skills and this, in turn, led to extreme hardships. All of them are involved in informal, small scale businesses buying and selling anything that the people in their communities needed. The goods they sold included firewood, charcoal, maize for popcorn making, timber, food stuff, second-hand clothes, soaps, salt, matches etc. However, their lack of financial security also affected their food security as they were not able to afford to buy farming inputs such as fertilisers.

The majority of the elderly women reported that they did not have the means with which to earn a living and, thus, they had to depend on charity from family and friends who could assist them once in a while as these well-wishers were also not well off. One woman said,

[...] my brother sometimes comes with some groceries for the children but he, too, is struggling because he has a large family [...] (Elderly woman 1).

For the women who were caring for orphaned and vulnerable children, the lack of money was reported to be a major challenge if the children were to continue with their education. One woman said,

[...] as you can see, these children are supposed to be in school but I do not have money to buy school uniforms and notebooks and pencils. So they just hang around here with me [...] (Elderly woman 5).

5.7.2 Health care expenses

Home-based care also has an effect on household finances because of the health care expenses involved. The young women reported that caring for their parents or guardians had left them without any money as most of the money had to be spent on ensuring that the patient's health care expenses were paid for. It was also found that, in addition to seeking the health care services at the government hospitals and which were free of charge, the patients on home-based care also went to see other health care givers such as traditional healers while they also sometimes they visited private doctors when they required urgent health care. Except for one young woman whose mother would not access any health care because of her religious beliefs, the other four participants emphasised that health care expenses had impacted negatively on household expenses.

These women also had to contribute money in order to assist those in the community who were on home-based care and this is what they had agreed to do. Those who did not have ready cash would give in kind, for example, flour, salt, matches, soap, etc. with these items going to assist the patients and their families. The women reported that sometimes they would find that they did not have either money or goods to contribute to the common fund and that this affected their morale.

It is hard to find the money but we do try to ensure that those whom we assist are provided for [...] sometimes we have to conduct some fund raising activities such as selling vegetables [...] sometimes we grow the vegetables ourselves [...] we have a common garden here [...] we are running a permaculture project as well [...] (Woman in FGD 2).

. The women reported that patients had to eat well balanced and healthy foods but that this costs money. The women emphasised that having to care for the patient at home stretched their household income.

[...]The doctor said that the patient needed to eat well so that she can get her strength back [...] This meant that we should buy milk, eggs, meat, cooking oil, and all these nice foods [...] it cost us a lot to ensure she had what the doctor ordered [...] (Elderly woman 4).

The women also mentioned that, because of the overextended household, they had to trim their basic necessities in order to cater for the needs of the patients.

We have to make do with fewer items than we used to as most of the money goes to paying for the needs of the patient, for example, we no longer buy bread for the family [...] we buy sweet potatoes when they are in season or cassava[...] for our tea [...] (Elderly woman 2).

As was reported earlier, the women also reiterated that food production had been hampered because they had so little time to do everything, especially when they were caring for the patients in their homes.

The last effect of home-based care reported by the elderly women was the high cost of health care medications and treatment. Although these are provided for free in the government facilities, the women reported that they incurred considerable costs when accessing the health services, particularly as they often had to take the patients to either the health care centre or the hospital by bus while they sometimes had to hire an ox-cart or bicycle. One woman, whose daughter had died a few months before this study was undertaken, stated:

When she became very ill, I had to take her back to the hospital but I did not have enough money to hire a car, so I asked a neighbour, who had an ox-cart to assist me to take her to the hospital. He agreed but he said I should pay him upfront a sum of MK 15, 000.00 (equivalent to USD 33.33 at that time) (Elderly woman 4).

Nevertheless, these elderly women had learnt to cope with challenges and effects of providing home-based care to the chronically patients at home..

5.7.3 Food insecurity

All the women mentioned food insecurity as the most taxing challenge they faced with all of them reporting that they had to buy food as the food they obtained from their harvests was not always sufficient. These women indicated that they often found their families could not produce enough food from their gardens as they did not have sufficient money to buy the fertilisers and seeds required to ensure good harvests.

As a family we are always looking for food. It is not enough [...] Throughout the year, we continually have to buy bags or buckets of maize to ensure that there food in the house [...] but it is never enough [...] (Woman in FGD 1).

They also mentioned that they did not have enough time and strength to cultivate their gardens. This fact was also expressed in the Time-Activity Profiles which indicated that home-based care and household activities absorbed considerable time and energy. One woman fittingly summed up this issue as follows:

[...] at my age (she is over seventy years of age) I do not have the strength to cultivate my garden and produce a good harvest [...] as you can see, this is harvesting time and this is all I have managed to produce this year [...]. (She said this while pointing to a small pile of maize on her veranda) (Elderly woman 4).

Thus, food insecurity was clearly a major problem for families whose main provider had become infected with HIV and was bedridden. This was particularly prevalent in the homes where the young women were caregivers. The young women all reported that, as soon as their parents or guardians had become too ill to work in the garden, food production had suffered. One of the young women said.

My mother was too ill to go to the garden and I was too young to cultivate the garden on my own. So, I just managed to plant maize on a small portion of the garden. We did not have the money to hire anyone to assist us in the garden. We did not produce enough to carry us through the whole year. (Young woman 5).

A few of the participants reported they had other family members who assisted in cultivating the fields and that it was the lack of money with which to buy fertilisers and seeds which affected their food production. This was aptly expressed by one woman, who said,

[...] it is not the fact that we do not have time to go to the garden that affects our food production and security, it is the fact that we do not have enough money to buy fertilisers or seeds for the garden that affects us [...] we are always trying but every year the situation is the same [...] empty barns [...] (Woman in FGD 1).

The issue of food insecurity is also affected by the lack of land ownership and tenure of land for women. All the women reported that they did not own the land on which they cultivated their food crops. When their husbands or fathers, who had owned the land had died, their access to and use of the land had become problematic. In an FDG one widowed woman stated:

[...] when my husband died, my late husband's relatives told me to go back to my maternal home because I did not have any land on which to grow my food crops such as maize, potatoes and beans[...] (Woman in FGD1).

All these women reported that the food insecurity was also a result of the high number of dependents in the home.

5.7.4 High dependency levels

The high prevalence of HIV in Mzimba has resulted in an increase in the numbers of orphaned and vulnerable children. All the women caregivers were also caring for children who had been orphaned by AIDS with the high dependency ratios in society being cited as a major challenge by the women caregivers.

Almost all of the women volunteers were caring for their own children, or members of their extended family such as brothers, sisters, cousins, and their own grandchildren. In addition, they were also caring for the orphans of their deceased relatives. Most of these women had also lost their own children, relatives or siblings to AIDS. The responsibility of caring for the children of the deceased fell directly on them. The study population comprised widows, orphaned young women and two married women.

One woman volunteer revealed that she had lost her husband, four children, two brothers and three sisters to AIDS. She was responsible for sixteen orphans who lived in her home.

My children left me with seven grandchildren [...] my brothers left five children [...] and my sisters left four children. In total I care for sixteen orphaned children who must eat, be clothed, and be sent to school [...] I do not have much but what can I do [...]? (Woman in FGD 1).

The high dependency ratio also increased the amount of work that these women had to do in and around their own homes with the situation often leaving the women feeling overwhelmed.

The women all mentioned the high dependency ratio as a social challenge they had to confront. The women explained that, as their children and relatives fell ill and some died, they left behind children who needed to be cared for. They were the natural choice as these children were part of the family. One of the women was caring for sixteen children orphaned by the deaths of children and her extended family members.

[...] You cannot chase these children away. Where will they go to? You cannot wish them away. They are my family. They are my children too. They will care for me someday [...] (Elderly woman 5).

However, the dependents had needs that had to be met and these women reported that they were struggling to care for these many children. All the women mentioned how exhausted they became by ensuring that the children's needs were met.

5.7.5 Low literacy levels

Extremely low literacy levels were a feature of all the women caregivers while a few were illiterate and, thus, unable to find gainful employment. They were extremely limited in their ability to engage in proper and profitable businesses.

All the women reported that the major source of their extreme poverty and other hardships was the fact that they were unable to attain economic security as a result of their low levels of education. The main reason for their dropping out of school had been a lack of school fees as their parents had been unable to afford to continue paying for their education. One woman stated:

As soon as I reached puberty my father said he did not have money for me to continue with school. I had just passed to go to secondary school [...] I had to stop going to school and waited to get married [...] that is how my dreams of becoming a nurse ended [...] (Woman in FGD 1).

This sentiment was shared by most of the women volunteers during the two FGDs. One woman had even been told that her father would rather pay for her brother's school fees than invest in her.

I was brighter than my brother and used to get good grades [...] but my father chose him over me because he was a boy and he was going to carry the family name [...] for him investing in my brother's education was a better thing to do since my brother would care for him when my parents are old [...]. This did not happen as my brother did not even finish school. (Woman in FGD 2).

The elderly women had also experienced similar challenges as a result of their lack of education. Four of the five elderly women had basic literacy while one could neither read nor write. However, not one of possessed the skills that would have enabled them to seek employment and, as a result; they depended on relatives and friends to assist them to meet their financial needs. These women reported that, when they were growing up, their parents had preferred to send their brothers to school as opposed to sending the girls. One woman articulated her sentiments as follows:

My father said that I was too old to continue with school [...] I should get married. I was only twelve years old that time [...] so he stopped paying for my school fees. I had to drop out. I got married soon after. I think I was about thirteen or fourteen (Elderly woman 3).

These women also mentioned that, because they were barely literate, it was difficult for them to run a successful business.

5.7.6 Financial security

The women volunteers reported that their household financial security depended on their going out to sell their goods. Although they had reported that they depended on one another as regards sharing the work involved they also indicated that sometimes the assistance they received was not enough. One woman volunteer who was involved in selling second-hand clothes explained how anxious she was to keep her business going while providing care.

I am always worried that my business will suffer if am not putting in much time [...] I cannot leave it to my grandchildren to sell for me [...] It is too much work for them [...] Besides they do not understand how I do the pricing [...] there is a lot haggling that goes on when you are selling second-hand clothes [...] (Woman in FGD 2).

The socio-economic challenges that were discussed in this section are linked to both gender vulnerability to HIV infection and the burden of care. Economic difficulties, health care expenses, food insecurity and even the high dependency ratios in the home have often resulted in the women trying to earn money by engaging in unsafe

sexual relationships. The burden of care has also increased because of the lack of or diminished household finances. In addition, the socio-economic challenges were exacerbated by the low literacy levels of the women caregivers which meant that they were not able to find gainful employment nor could they run successful businesses.

However, all the women caregivers have learnt to cope with the challenges and effects of providing home-based care to chronically patients. The next section discusses these coping mechanisms are presented.

5.8 Coping mechanisms

The women in the study reported that they employed a number of coping strategies which alleviated the problems that they were experiencing in caring for the HIV and AIDS infected and affected. These coping mechanisms included obtaining assistance from family and friends, relying on the support of the extended family, finding a boyfriend, conducting a business, participating in volunteer group therapy sessions, the extended family fostering children who have been left vulnerable or orphaned by HIV and AIDS, division of labour and selling family possessions and/or land. 56.8.1 Assistance from family and friends

The majority of the women depended on the goodwill of both the immediate and the extended family to enable them to cope with the challenges that they were experiencing while caring those who were HIV infected and affected.

Women volunteers expressed feelings of gratitude that they had family and friends on whom they could rely from time to time for assistance in various ways, especially as regards their work as volunteers for home-based care patients. When asked to elaborate on the assistance they received from others, one woman stated:

[...] the work we do is good but there are times when we need a bit of support so that we can effectively assist others [...] for example, we do get tired and sometimes sick [...] that is when our families come in and assist us [...] by taking on some of the responsibilities that we have [...] (Woman in FGD 2).

The women volunteers also mentioned that they received material and financial support from family and friends. They also assisted each other in their volunteer group when one is in need either financially and materially or both.

[...] In this group we are all friends... and, so, when one is in need, we come together and assist that person [...] We also have a common fund to which we contribute money monthly so that we can assist each other in time of need [...] .(Woman in FGD 2).

It emerged that the assistance they received also took the form of psychological support from family and friends. Most of the women volunteers had lost someone close to them to AIDS and they indicated that, from time to time, they experienced some low moments when they felt emotionally drained. A woman in the first FGD offered an insight into the psychological difficulties that she experienced and how her colleagues assisted her.

[...] I sometimes feel very sad when I remember all those who have lost the battle to AIDS [...] especially four of my children who died of AIDS... At these moments, I just want to hear some encouraging words [...] and so my family and these friends of mine help to remain hopeful and grateful [...] AIDS has visited all of us [...] am not an exceptional [...] (Woman in FGD 1).

The elderly women reported that they had extended family members who usually came to assist at crucial times, for example, when patients became extremely ill or when a patient died. This was the social safety net on which these women depended. However, the women also reported that, in view of the fact that most families were experiencing problems of their own as regards the HIV and AIDS epidemic, such assistance was not always readily available especially when the family members had to care for their own patients.

My sisters used to come to assist me care for my daughter. She had to travel for a day to come here... but then her son fell ill and they brought him home from Lilongwe [...] My sister had to care for her son. (Elderly woman 1).

Members of the extended family would sometimes come and work in the garden when the women could not do so. A few of the women reported that their brothers and other family members had assisted them to ensure that their crops did not die because of overgrown weeds.

The women also reported they received both financial and material support from their relatives and that this enabled them to continue to provide for their families and, especially, for the HIV infected patients. However, one woman also mentioned that, in view of the financial hardships they all were facing, such material and financial help was not always regular.

A few of the women mentioned the support they received in the form of financial assistance to help to pay the school fees of the orphans and vulnerable children.

My younger son took the two sons of his ailing sister and sent them to boarding schools. This alleviated so much pressure for me and the children's mother. They have now finished their secondary school and one is doing some course in Mzuzu¹⁷.(Elderly woman 5).

In addition to the support they received from their extended family members, the elderly women also reported that they received support from their friends and peers. This coping mechanism was mentioned by two women who revealed that they had reached a point at which they were failing to cope with the demands of caring for the patients and, at the same time, caring for children. They explained how their families had assisted them:

My son came and took the children and he sent them to a boarding school. (Elderly woman 5).

and

My younger sister took the youngest ones and lived with them while I was caring for their ailing mother. She still has them. (Elderly woman 3).

However, as a result of the overwhelming demands imposed by home-based care activities, this support was diminishing as the friends and peers are also involved in providing care in their communities. Furthermore, the women said that most of their friends and peers have either died or they are experiencing similar problems in their homes or extended families. One woman stated:

We all are in the same boat and the best thing we do for each other is to be there when your friends need your help. This problem is too big to be alone [...]. My friend is the one whom you already visited. She too is struggling like I am doing. (Elderly woman 2).

5.8.1 Informal businesses

Another way in which the women carers coped with the difficulties at home involved conducting an informal business in order to raise money for the family. One of the young women sells charcoal and clay pots to raise money for her family while another

¹⁷ Mzuzu is the capital of [Malawi's Northern Region](http://www.commonwealthofnations.org/country/malawi/) and is the third largest city, by population, in Malawi. It is situated in the [Mzimba District](http://www.commonwealthofnations.org/country/malawi/) [O] Available at: <http://www.commonwealthofnations.org/country/malawi/> (Accessed on 08/01/2015)

young woman who had trained as a tin-smith runs a small business making tin buckets and basins to sell. She explained:

[...] I had to find something to do when my mother became sick so that we had food every day [...].(Young woman 2).

However, because of the extreme hardships in which they live in, the young women all mentioned that it was extremely difficult to start and sustain a business as they did not have money.

The women volunteers reported that they used several coping mechanisms to address the challenges that they experienced while providing home-based care to the HIV infected in their communities. These coping mechanisms included obtaining assistance from family and friends and doing volunteer work as it offered them an opportunity to deal with personal issues and to share the tasks that had to be performed.

5.8.2 Volunteer group therapy

The women volunteers reported that they found being part of the volunteer group gave them the opportunity to unwind and talk about their personal challenges, particularly in view of the fact that volunteer group provided them with an opportunity to talk about things that the group would understand because of their shared experiences. For example, one woman had lost her son a few months before the researcher arrived in the community. This woman was not coping well with the loss. Her son had been a mental patient who was also HIV positive and had died tragically. In fact, it was suspected that he may have been poisoned. The group helped her to mourn the loss and deal with the pain without losing hope. At the time of the data collection, the woman said,

[...] if it was not for this group of brave women [...] I would have died [...] I am a high blood pressure (hypertension) patient and, during this time, my blood pressure kept going up [...]. I also died [...] but these women made sure I was not alone to deal with all the loss [...] (Woman in FGD 2).

In addition, the women found that sharing with those who understood their circumstances also enabled them to feel useful as they were able to assist others who had experienced the same life events. The women indicated that they understood and were more empathetic to the pain of others, especially those that

were involved in home-based care and also in their group of volunteers, than may otherwise have been the case.

[...] you have to walk this journey for you to understand what the other is feeling or going through [...] (Woman in FGD 1).

This sentiment was more pronounced for those women who were also living positively with HIV. Five of the women in the volunteer group were HIV positive. These women told the researcher that it helped them to assist others who were HIV positive because they knew how it felt to be HIV positive.

5.8.3 Division of labour

The women volunteers reported that another way of coping with everything they had to do, especially as regards the home-based care activities, was to divide the work between them. This, in turn, enabled them to manage their personal, community, and home-based care activities. One woman explained how they divided the chores:

[...] we divide the work among us and see who does what or brings what this week and the next [...] and so on. So, if I bring fire wood this week, I may be drawing watering from the well next week [...] in this way we all plan in advance. If I am not available, I ask my friends in the group to cover for me (Woman in FGD 2).

The elderly women reported that they used certain coping mechanisms that assisted them to survive all the challenges that they have experienced and continue to do. These coping mechanisms included relying on the extended family system and friends; selling family property and sending the children to live with relatives.

5.8.4 Selling of family possessions and property

An extreme coping mechanism, especially as regards financial matters, involves selling off whatever the family owns, for example, household goods and property. Some of the women had had to sell off some of the family land and other saleable items that the family had owned in order to meet the financial needs of the family.

I have just sold some part of the family land in order to raise enough money to buy food and pay for the children's education. (Elderly woman 1).

Another woman revealed that she had sold some furniture in order to buy food for the patient and also other household necessities.

As discussed in this chapter coping in the face of such immense challenges requires a number of strategies. The women caregivers revealed that their coping mechanisms were within the bounds of what was possible and available to them. For example, obtaining assistance from family and friends is possible only because in the society in question, the extended family systems are the safety net that people use when there is a problem that one person is not able to solve. For example, the extended family system is used to foster children when their parents have succumbed to AIDS.

Some of the women caregivers cited engaging in a sexual relationship in return for financial assistance as the only option available to them. The young women, in particular, had used this strategy when the financial situation of their households was in dire straits. On the other hand, those women who were able to raise financial capital had started small scale, informal businesses. However, this strategy was possible only if the family had excess income to spare and, in most cases, the women caregivers did not have much to spare. Financial problems had often led to caregivers having to sell family possessions and property. However, in most cases, this coping mechanism plunged the households into further poverty.

The women volunteers mentioned two more strategies that they used in order to cope with the challenges they experienced, namely, volunteer group therapy and the division of labour. The women made effective use of these strategies in order to cope, in particular, with the psychological, socio-cultural and economic challenges they faced. By sharing their experiences the women experienced relief in realising that they were not alone. On the other hand, by dividing the activities and covering for each other when someone needed time off to carry out other activities at home, the women were able to provide the safety net which they all needed from time to time.

5.9 Summary

The findings revealed that women who provide home-based care to the HIV and AIDS infected and affected experience a wide range of challenges. One of the greatest challenges was the vulnerability to HIV infection, while other challenges

included the gender burden of care and the psychological challenges which are a direct consequence of caring for those who are chronically ill.

These women also experience severe socio-economic and socio-cultural challenges, primarily as a result of the extreme deprivation in which they live. In addition, women who are caregivers experience financial difficulties as a result of their low social status. The majority of them have basic education only and this, in turn, does not allow them either to find gainful employment or to run successful businesses. Their financial hurdles affect their food security as they are not able to afford to buy agricultural inputs such as fertilisers and seeds to ensure a good harvest. The lack of a reliable income affects their ability to provide for their household needs, the needs of the patients, and the needs of the orphaned children for whom these women are caring.

Socio-culturally the women who provide home-based care in Mzimba experience a number of challenges which stem from their low socio-cultural status. The findings revealed that, in the main, these women have to provide for their families on their own and without the assistance of their spouses or other male members of their families. They also have to perform all the household chores, including agricultural activities. In addition, they have to provide for the chronically ill in their homes and their communities. A recurring theme that emerged in the findings was that the gender roles in the society in question are not negotiable. Culturally it is expected of the women that they will fulfil all these roles without either questioning or negotiating.

However, the findings also revealed that, despite the everyday challenges faced by the women who provide care to the HIV and AID infected and affected, they have developed a number of coping mechanisms which they use in order to survive. These include assistance from family and friends (both material and financial assistance), conducting informal businesses, dividing up the various home-based care activities between themselves (mainly found among the volunteers) and selling family property or goods in order to raise funds.

CHAPTER SIX

FINDINGS, ANALYSIS AND INTERPRETATION: YOUNG WOMEN'S LIFE STORIES

6.1 Introduction

This chapter presents the data which was collected from five young women caregivers. This data was collected using critical incident narrative narratives and is presented in short life-story form. In addition, the results of the time-activity profile exercises which were conducted with the five young women are presented in the form of a pie chart.

6.2 Life stories

The motivation for collecting the life stories of the young women was to gather data from these young women who were caring for chronically ill parents or guardians. Four of these life stories are retrospective in nature in that the events described had already happened. Only one participant was still caring for her ailing mother at the time of the study. Her story is thus most recent.

Temwa's¹⁸ story

Temwa is a young mother of 28 and has been widowed twice. She cared for her older sister who was her guardian. Her sister had contracted HIV from her husband. When Temwa was 10, her sister took her to live with her in the city. The plan was that she would go to school while assisting her sister to raise the sister's children. Her sister then became ill and Temwa was forced to stop attending school so that she could care for her sister's children as well as her ailing sister. Although she did not know the nature of her sibling's illness, she believed that her sister had had AIDS.

[...] you know it was the time when we did not know much about the disease
[...] so I am talking about the symptoms that I saw [...] They looked like
someone who was HIV positive.

Temwa used to bath her sister, cook for her and feed her. It was then that her brother-in-law also became ill. The work of caring for both of them became too much for Temwa, especially when it came to caring for her brother-in-law and, so, a male relative came to live with them so that he could take care of the her brother-in-

¹⁸ The name has been changed to preserve the anonymity of the respondent.

law. Her sister suffered from a number of illnesses, including tuberculosis, but Temwa continued to care for her. She reported that this experience had made her become extremely responsible and more mature than was previously the case. Her sister's health then started to deteriorate as a result of the side effects of the medical treatment she was receiving for both the tuberculosis and the HIV. Temwa suffered psychologically as she witnessed her sister's slow death. In addition, she also suffered from extreme exhaustion, insomnia and a lack of appetite. She said she grieved for her sister while she was still alive.

I was so sad to see my sister slowly dying [...] I could not eat, could not sleep, and, sometimes, I just cried.

Her sister died while being treated for tuberculosis when Temwa was only 15 years old. She then had to return home to the village where she had been born and start her schooling again. She was, however, too old to go back to class while her sister's children also needed her care as her brother-in-law had also died. Her mother encouraged her to marry as, according to her, a husband would take care of Temwa and her sister's family. She married when she turned 16 years old. She had borne four children when she started feeling unwell. She went to be tested for HIV and was diagnosed as HIV positive. Her husband then died after five years of marriage. In view of the extreme deprivation which her family was experiencing she remarried. She had a child from this marriage but her second husband also died. Temwa had, thus, been widowed for a second time. She had five of her own children to raise in addition to her sister's children.

In order to care for the children, Temwa has chosen to live with her mother and works as a maid. The main challenges this family faces include a lack of food, clothing, school fees, and bedding. The family is forced to buy food because, although the family has a garden, the garden does not produce enough food because of a lack of fertiliser.

Temwa receives some assistance from her brother who is employed. He assists whenever he can, particularly as regards the purchase of foodstuffs such as maize. However, he also has his own children who he is responsible for. Temwa has in total fourteen children who she is raising in her household. Her first husband's relatives

assist in paying the school fees for her first born son and he was finishing high school at the time of the study.

Temwa reported that the orphaned children had become unruly and troublesome. They had become disillusioned with their status as orphans. These orphans did not get any assistance from government. As a result of their frustrations, they started to engage in petty crime and selling and illegal drugs.

Modesta's¹⁹ story

Modesta is a young mother of one. Her story is typical of a young girl who had lost both parents to AIDS and was forced to marry at a young age. At the age of 14 she had married a man who practised polygamy and he had infected her with HIV. At the time of the study she was living with HIV.

Modesta had two brothers and the family had lived in a village near Mzimba town. Her father had been involved in informal trade and this had taken him away from home for long periods at a time. Her mother had been a housewife who had occasionally sold second-hand clothes at the local market near their home village.

When Modesta turned 13 her father and mother were both diagnosed with tuberculosis. They were both put on treatment. Her mother responded well and was cured of the disease. However, her father had not adhered to the treatment regimen because of the frequency with which he was away on business and he would forget to take his medication. As a result he became extremely ill. He was admitted to hospital and appeared to respond well to the medication he received in hospital. He was then discharged to continue the rest of the treatment as an out-patient. However, as he had done previously, he did not adhere to the treatment regimen and he became very weak and ill. The doctors counselled both him and his wife. They both took the HIV test and were both found to be positive.

Modesta, who was at secondary school in Form 2 at the time, was forced to drop out of school to assist with the household chores as her mother was no longer able to cope. Modesta was 15 when her father died. The death of her father affected her

¹⁹ The name has been changed to preserve the anonymity of the respondent.

mother badly as she was left to care for the children on her own. The family suffered greatly as it had lost its main breadwinner. The extended family met and it was decided that Modesta should marry. There was a businessman in her village who was already married but who agreed to marry her as his second wife. She was not happy about the situation but was forced to agree in order to lessen the burden on her sickly mother. However, she remained with her mother to take care of her. Her mother suffered from a variety of diseases and she finally succumbed to a bout of malaria.

After the death of her mother Modesta joined her husband in Lilongwe where he sold spare car parts. She became pregnant and gave birth to a daughter. Her child was sickly as a baby and she spent several days in hospital. The doctors at the hospital in Lilongwe advised Modesta to be tested for HIV because they felt that it was possible that her daughter was constantly ill because the child may have contracted the infection from her mother. When she went to the hospital for the test, the health care worker enquired whether she was comfortable taking the test and whether she understood what it entailed. They counselled her about the nature and effects of HIV and AIDS and drew blood from both Modesta and her daughter. Modesta related the following about her experience of being informed of the results:

When the results came, it was found that I have HIV and my daughter, too, was HIV positive. They explained to me that I had the virus and my child also got it either from me or from the blood transfusion which she got from the hospital.

This was before blood was screened for HIV in hospitals. Modesta recounts being both shocked and sad but said she had accepted the results. The health care worker gave her a letter that contained all the information required to enable her to continue her medical care at Mzimba hospital. When she reached home she explained the situation to her husband. He did not say much although he was not happy that she had taken the HIV test. She then went to Mzimba hospital to show them the letter which she had received from the doctors in Lilongwe. They read the letter and decided to investigate whether she could start ARV treatment. However, they found that her immune system was extremely strong and instructed to go home

and take care of herself. The doctors advised her to return every six months to have her CD4²⁰ count checked. She describes the subsequent events:

I would only start taking ARVs when my immunity has gone down [...] so I started taking ARVs in 2006. It was in April. From that time in 2006 I became chronically ill. I would spend weeks, even months in hospital [...]. After that, I became well again [...]. My hands turned black but, after that, my hands became normal [...] even when my husband was dying, I was well enough to be there at his funeral in 2008.

When she had been told that she was HIV positive she had explained the situation to her husband and told him that they had to use condoms to avoid her being re-infected. He did not, however, want to use the condoms she had brought home from the hospital. She had, thus, informed him that she would abstain from engaging in sexual intercourse with him. She had told him to go to his first wife when he wanted to have sex. This had not pleased him but Modesta had been adamant. Her husband had refused to be tested for HIV. He had then become ill but had thought he had malaria. He had been taken to hospital where he was tested for malaria. However, the results showed that he did not have malaria but, because he was never tested for HIV, he never received the correct treatment. Modesta had told him to be tested so that he would know his status but he had refused to do so:

He was very much in denial. He did not believe that he could be infected. So, when he fell ill, he was not given the proper diagnosis [...] that is what I think.

She even suggested that they go somewhere far away from their village, for example, to Lilongwe, to be tested where nobody knew him. If he were diagnosed as HIV

²⁰ CD4 cell" and "T-cell" both refer to the same type of cell – a *CD4 T lymphocyte* – and often are used interchangeably. CD4 cells or T-cells are a type of white blood cell that plays a major role in protecting the human body from infection. Once a person is infected with HIV, the virus begins to attack and destroy the CD4 cells of the person's immune system. HIV uses the mechanism of the CD4 cells to multiply and spread throughout the body. A CD4 count is a laboratory test that measures the number of CD4 cells in a sample of blood and it is an important indicator of how well a person's immune system is working. A CD4 count is also used to help the patient and the HIV care provider to decide when to start antiretroviral therapy (ART). AIDS.gov. HIV/AIDS Basics. 2014. [O] Available at <https://www.aids.gov/hiv-aids-basics/just-diagnosed-with-hiv-aids/understand-your-test-results/cd4-count/> (Accessed on 06/01/2015).

positive, she offered to collect his medicine when she collected hers but he refused. She explained:

But all this was like speaking to a rock [...] he did not want anything to do with this disease [...] you know how men are [...] *kuti wajimasule pakuwa pakusuzga* (i.e. they are stubborn [...] to become humble is a very difficult thing to do for them) [...] especially that I was his junior wife [...] he did not take me seriously [...] and I gave up and he died in 2008.

His older brother had also tried to convince him to be tested but he had refused despite the fact that the brother had been insistent:

Look at your wife! She has had time to reflect on this and she is now at peace with her diagnosis [...] so you look at your daughter, she, too, is at peace [...] why can't you do the same?

Most people had been convinced that Modesta was going to die because she was so emaciated and weak.

I was already a dead person to people's eyes [...] but, look at me now. I am still alive and my husband is dead [...] because he did not want to humble himself and listen to what I was telling him. *Wakufwa wakumanyika yayi* (i.e. nobody knows who will die first).

A year after her husband's death, Modesta went to Karonga (a district on the border of Malawi and Tanzania) to order to sell goods and, on her way back, she became very ill. She was chronically ill for the whole year and was unable even to grow crops that year. She went to hospital because she was felt a painful constriction in her chest. The doctors changed her treatment regime but this made her feel worse. She explained her difficulties as follows:

I could not even get out of my bed [...] I complained to the doctor, he said my illness will take a long time to go away [...] so I must just persevere. I could feel that my face was hot like I was sitting next to an open fire [...] my feet and hands had a tingling sensation [...] something like pins and needles [...] it was terrible.. I asked the doctor again and he said that these things will slowly go away [...] I never understood what this was [...] and [...] why [...] But now I feel that these things have gone away and the doctor was right [...] it took a while but now I feel better [...] I do not fall ill as frequently as before. I am feeling better now and still taking my medication.

Since that time she had been living in her home with her daughter and her co-wife in the same compound. After the death of her husband, her co-wife had been tested for HIV. She tested positive and was taking ARVs at the time of the study. At the time of the interview the co-wife was active and selling goods at the local nearby market.

Modesta was struggling financially as she spent all her money on paying her daughter's school fees and the household bills. There were times when she had to obtain a loan in order to do set up a business, for example, sawing and selling timber. In 2014 (i.e. the year in which this interview was conducted) she had also grown popcorn maize for sale. She was hoping that, by selling the maize, she would make approximately MK5000 (i.e. about USD12 at the time of the study) which would assist her and her daughter.

When they had relocated from Lilongwe, Modesta's husband had started up his business again but this time selling various types of goods, including fertilisers. However, the business had closed when he died. Modesta described his last days:

He did not suffer for a long time [...] it was not even 5 weeks [...] something like 2 weeks [...]. What killed him was the fact that he was suffering from denial [...] he was hiding in the house [...] he did not allow anybody to come and visit him while he was sick.

After his death there were some fertiliser bags left and which were sold to pay off all his outstanding debts. The money that was left over was shared between Modesta and her co-wife.

At the time of the study Modesta was struggling financially. She has no one to assist her, not even her church. Her late husband's niece, whom Modesta and her husband had raised when her father had died, was the only relative on whom she could depend to provide for her. Modesta had been a newly married woman when her husband had brought the young, orphaned niece into their home and she had been raised as their own child. The child's father had been Modesta's husband's brother. Since that time the niece had always been extremely close to Modesta, coming to assist whenever Modesta was unwell. Her husband is a migrant worker in South Africa. In addition, Modesta received assistance from her brother-in-law (i.e. her late husband's remaining brother).

In terms of her health, Modesta reported that she felt quite strong. She even worked in her garden. When she felt low she had friends who would come to her house to give her comfort and courage. These friends were also all HIV positive.

I try to remain optimistic [...] Always [...] even when am really down [...] for the sake of my daughter.

Her real concern, however, was that she was struggling to obtain fertiliser for her garden and this, in turn, affected her household food security. Ultimately, she aspired to becoming financially independent.

If I had a chance to get money and to start a real business, I would be very grateful. I do not like to continue begging for assistance when I can actually do things for myself.

Catherine's²¹ story

Catherine is the first born daughter in a family of seven children. Both her parents died of AIDS. Her mother died first and then her father, leaving seven orphans, the youngest of whom was only eight months old. Catherine was 15 when her mother died. She had already been married at 14 and she had a baby of her own.

When her mother fell ill and was no longer able to care for her children, Catherine had come back from her marital home to care for her mother and her siblings. Her mother was HIV positive. In those days when many people had not known much about the 'new disease'. Catherine's mother was bedridden for weeks at a time and Catherine had to feed, bath and clothe her, and take her to the toilet. Although Catherine was not strong enough to do all this she had had to try and do her best. Catherine had suffered much during that time. She reported that she had suffered from psychological stress, fearing the day when her mother would no longer be alive. She spoke of her nightmares:

I was constantly bombarded with dreams of my mother's funeral [...] I was so scared [...]. (She cried and the interview had to stop for a while to allow her to calm down and compose herself).

After suffering for two years, her mother succumbed to AIDS. One morning her mother just did not wake up. She was so emaciated at the time that Catherine was able to lift her up. After her mother was buried, Catherine became responsible for all her siblings and her own child. She had taken all the children back to her marital home. Her husband had not been very pleased but she had not had a choice. However, this had taken a toll on her marriage and her husband left her and went to Zimbabwe to look for work.

²¹ The name has been changed to preserve the anonymity of the respondent.

Subsequently, her mother-in-law died of AIDS, leaving four orphans for whom she had been caring. Catherine now had twelve children in her care. Her child and her baby sister were still toddlers and had particular needs. In order to care for all the children she conducted a small business making clay flower pots. She used to sell these pots locally but the money was never enough for all of them to survive on.

By the time her husband left she had four children of her own. She had stayed in her marital home for a year after he had left her but life had been extremely difficult. She was forced to relocate to her parents' home in Mzimba town. The decision to relocate back to her father's home had been helped by the fact that he had fallen ill and was bedridden. He had required constant care which she had provided until his death. However, she was not able to stay in her father's house as her father's relatives did not want to assume such a huge responsibility. Catherine and her siblings were also dispossessed of their land and they were left with nothing. She had had to rent a house and look for employment in order to earn a living.

Catherine had tried to send the children to school but she had not had enough money to pay the school fees and other school-related expenses. Consequently, all of them had had to drop out of school.

All these kids I was caring for, I tried to send them to school but some children did not finish school due to problems with school fees. Others did not continue because we were experiencing extreme problems.

When her financial situation improved she had sent some of them back to school, which they were still attending at the time of the interview. Her youngest sister had been fostered by a local NGO known as the Tovwirane AIDS organisation and the organisation paid for her education and all her needs. However, she had also dropped out of school as a result of the poverty at home which exerted significant pressure on her to become independent. Catherine and the children received milk and soya beans from the Tovwirane AIDS organisation and they also received help from the Catholic nuns and the government. This help was, however, not enough. Although it did provide some relief it was not enough to cater for her and the children's circumstances

Catherine had continued to raise the children but with a great deal of hardship. Two of her younger sisters married at the age of 14. They married young in order to relieve her of the responsibility of caring for them. She explained:

So the girls decided to get married as soon as they were old enough. They both got married when they were 14 years old. It is because of hardships which we were experiencing that drove these girls to get married in order to alleviate me of the responsibilities of caring for them.

One of the young women in her care had contracted HIV and died at 17 years of age, leaving behind two orphans whom Catherine had to raise. Her one sister had died when Catherine was 20 years old. Another sister had also died of AIDS and left two orphans whom Catherine had to raise. Her sister's husband had also died. By this time Catherine had been left to raise fifteen children without any assistance from her relatives. She tried to encourage her own children to work hard in school and finish their studies but, as a result of lack of resources, her children had also dropped out of school. Her first-born daughter dropped out of high school in Form 2. Her son had tried to stay on and had Form 4. Her second-born daughter had become pregnant and had left school. Once she had delivered her baby, she had returned to school. Catherine's youngest daughter also has a daughter whom she had left behind when she left for South Africa to join her husband who worked there.

None of Catherine's children or her siblings has ever had a home of their own. The house that Catherine's parents had built had since collapsed. Since that time they had rented a house. At the time of the study they were living in the house of a relative and he was threatening to evict them on the grounds that he needed his house back. Thus, Catherine was struggling to find a home for herself, her children and her sisters' children. She had no garden and she rented a piece of land on which she grew maize for food. She had lost her harvest the previous season as she had been ill and people had set her crop on fire. The year in which the study was conducted (2014) Catherine had asked a neighbour for a piece of land on which she grew some maize but the crop had not done well as she had not used fertiliser as she had had no money for fertiliser. Had she been living in her ancestral home her chief would have included her in the list of beneficiaries but, as this was not the case, she was not given free fertiliser.

Catherine also ran a small business selling charcoal near her house. She is assisted by her younger brother who conducts some informal business but he, too, is overwhelmed by his family's needs. Other than her brother there is no-one who assists them. She does not receive any assistance from her relatives and expressed a sense of abandonment:

I feel abandoned to deal with huge responsibility.

Catherine herself has been diagnosed as HIV positive. She stated that, when she was divorced, she had had several partners and had had unprotected sex with them. She contracted HIV in 2008 from a man whom she had befriended, believing that he could assist her financially after her divorce. She did not initially know that she had been infected. She had not gone for a test immediately because she had feared being stigmatised. She was, however, tested later, in 2010, and discovered she was HIV positive. When she had told her employer she was HIV-positive she had been fired and had since been fired a number of times as a result of her HIV-positive status.

She was put on ARVs immediately after she had been diagnosed positive. However, she became very ill and spent two years going in and out of hospital. In 2012, she started feeling healthier and stronger. At the time of the study she was feeling better although she suffered from hunger because she did not have enough food at home. In addition, she also had no money with which to buy food, bedding and clothes, pay for school fees for the children, or even to pay her house rent. The family did not own land on which to grow food. Catherine was practising complete abstinence from sexual relations. Her family, especially her children and her siblings, were supportive of her situation and did not stigmatise her.

Rachel's²² story

Rachel is 18 years old and lives with her ailing mother and brother. Her father had died more than five years previously. She belongs to a religious sect which does not allow its followers to use allopathic medicine. They believe in the healing power of prayer. Consequently, Rachel does not know from what disease her mother is

²² The name has been changed to preserve the anonymity of the respondent.

suffering from but, in view of her mother's symptoms and signs, she presumes it must be AIDS. She said that her father had experienced similar symptoms to those experienced by her mother. At the time of the data collection in May 2014, her mother was in bed and was extremely ill. Rachel had had to drop out of school when her mother became very ill. It appears that, when her father was alive, life was much better than it was at the time of the study. However, Rachel was the only one caring for her mother. She had not taken her mother to hospital as it is contrary to their faith to take sick people to hospital. She stated,

We do not take any medicines even when we are gravely ill. Even those who are HIV positive do not take any medication [...]. We hear that there are ARVs now but they do not get those [...] we just pray for them and they get well.

Rachel reported that since her mother became very ill, the family experienced extreme hardship and that they lacked food, school fees, decent clothing. Rachel had had to leave school to care for her mother

I always envy my friends who have decent and beautiful colourful clothes to wear [...] every day [...] I am dressed in these rags every day.

Rachel felt that caring for her mother had robbed her of her childhood as she was unable to go anywhere to play or chat with her friends. She had to be at home to ensure her mother had all she needed. Rachel performed all the household chores and gardening and also worked to raise money for the family.

Rachel had trained as a tailor and is a qualified dressmaker. However, at the time of the study her sewing machine was broken and she did not have the money for repairs. She did *ganyu* (piece work or casual work) anywhere in the village and relied on this casual work:

I do go around looking for "*ganyu*" work [...] and when I have been paid some money [...] I buy some sweet potatoes to boil and give my mother and brother to eat [...] otherwise we sleep hungry.

She sometimes went to collect firewood to sell in town in order to earn money with which to buy the basic essentials such as paraffin for the lamp, matches, sugar, salt, etc. Her family's relatives were too poor to assist the family and the government was not providing assistance. She had heard that there were organisations which assisted people in their situation. However, even the NGOs operating in the district or other

philanthropic organisations such as local faith-based organisations did not assist them. Rachel did not know why they were being offered no assistance. The lack of assistance was disastrous:

Many times we sleep hungry [...] even those who are near us are equally poor [...]. Yesterday we slept on an empty stomach [...] we cannot find any help from anyone [...].

As a young woman she was aware of her looks. She would like to have had new clothes and the other necessities that young women require to look nice:

I do not even have any decent clothes [...] as you can see [...] my clothes are dirty and in tatters [...] I cannot afford to buy some washing soap [...] we are extremely poor [...] I need help [...] my clothes are in shreds [...] *wanyithu wakuvala makora* [...] *nkhukumbira umo wanyane wakuvwalira* (i.e. my friends dress very well and I envy the way they dress) [...] at my age, I should be looking better than this but I cannot afford any new clothes.

She explained that, because they did not have any money, they slept in a dark house as they were not able to afford paraffin for the lamp. She had been looking for permanent or regular work but had not been able to find any form of employment.

Rachel did not have a boyfriend because her religion did not allow girls to have boyfriends until the elders had found suitable partners for the young women. They were raised in accordance with very strict codes and are encouraged to marry only within their faith.

Wezi's²³ story

Wezi is a young woman of 22 who was orphaned at the age of 15. Both her parents had suffered from AIDS and she had cared for both parents while they were ill. She would wake up in the morning to give her mother a bath and feed her before she left for school. Her father, who was stronger, had been able to bath himself. Life had become extremely difficult financially as her father was not able to work. The family had relied on donations from friends and neighbours.

Wezi had been stigmatised at school as a child of AIDS patients. She had left school because of the stigma and also because her parents' health, especially her father's health, had deteriorated and she was needed at home. Her father had died soon

²³ The name has been changed to preserve the anonymity of the respondent..

after and, two years later, her mother also died. She had immediately taken charge of running the household to ensure that her 4 siblings continued with their schooling. When her father had died, she had been forced to leave school as no relative had offered to take them in and support them. Wezi had become both the bread winner and the parent overnight.

I grew up within a short time [...] I become a mother and father to my siblings.

Once the burial rituals of her parents were completed in their rural home, Wezi took her siblings and returned to Mzimba town where their parents had settled so that Wezi could try to find employment. However, this had not been easy as Wezi did not have any formal qualifications. She then went to a local NGO, Towwirane, which was taking in orphans and teaching them skills such as tinsmithing and tailoring. She was taught tinsmithing and became a good tinsmith. However, the money she was making from her tinsmithing was insufficient and she was forced to seek other employment. While at Towwirane, she had also trained as a youth counsellor for HIV and AIDS. Accordingly, she used these skills to find employment at the government hospital which provided voluntary counselling and testing (VCT).

Wezi met a young man and fell in love with him. However, she soon fell pregnant. The young man did not honour his commitment to Wezi and left her with a young baby to care for. She was only 19 years old.

6.3 Time-activity profiles

Time-activity profiles were used to collect data on all the daily activities which the young women performed. This information revealed which activities required the most time. Five time-activity profiles were conducted with the young women participants (see Appendix 6b). The figure 6.1 below presents all five time-activity profiles. The activities that were included in the time-activity profiles were home-based and household activities, community development activities, gardening activities, sleeping and waking up. Home-based and household activities included the actual caring activities for HIV-infected and -affected people such as drawing water, collecting firewood, cooking for the patients and the family, feeding the patients, doing the laundry, keeping the house and the surroundings clean, and caring for the children.

The community development activities included the activities involved in providing time and labour to community projects such as clearing a road; building a bridge or classroom; and even working in a communal garden to raise funds for other projects from the sale of produce. These activities are usually organised and managed by community leaders, such as village headmen, and under the auspices of village development committees. Garden activities included those activities which take place at the household level to produce food for household consumption and, perhaps, to sell. In other words, these activities are aimed at ensuring food security.

The time-activity profiles start when the person wakes up. The participants reported that the waking up activity involved a number of activities such as starting a fire to boil water for quick ablutions before beginning the day's activities. These activities may include bathing the children and the patients before the women embarked on other activities. As regards the going to bed activity, the participants reported that this included several activities such as preparing the sleeping area, mat, or bed. Generally, in view of the size of the family and the available sleeping area, the women have to pack the bedding and mats or beds up after everyone has woken up while, in the evening, they have to ensure there is sufficient room for the family to sleep. Thus, the participants reported that, when evening came they would unpack everything and make the beds for everyone to sleep in.

It emerged that the activities which took up the most time were household and home-based care-related activities. The bulk of the daily chores involved drawing sufficient water and chopping firewood to use for bathing, cooking and washing; food preparation for everyone, especially for the patient; and cleaning the house and its surroundings. Other activities included ensuring that the children were both fed and clean. There was so much work to be done in the home such that all these young women had had to leave school to care for their ailing parents or guardians and run the household. The young women reported that the workload became heavier as the severity of the illness increased when the patient's condition deteriorated and that aspects of the household work suffered as they often failed to cope. One of the participants explained the toll it was taking on her as follows:

I became so exhausted caring for my mother [...] ensuring that she was comfortable and had taken her medications [...] such that I could forget to give the children their baths (she sobs).

The participants reported that they were unable to take care of themselves because of their heavy workload such that often they did not have sufficient time and energy to bath themselves properly.

The second most time consuming activities were the garden activities. At the time of the data collection, the young women were harvesting crops from the gardens. However, as a result of the financial problems arising from the effects of HIV and AIDS, the families often did not have much to harvest as they would have been unable to use fertiliser to increase the harvest. In addition, they often had to travel a distance of kilometres to their gardens to harvest the maize, groundnuts and beans they had cultivated and to transport the harvest to their homes.

Table 6.1: Activity and time taken to accomplish each activity by the young women

Activities	Hours
Wake up in the morning	0.5
Home-based care and household activities	12
Community-development activities	2
Garden activities	6
Go to sleep	7

Figure 6.1: Time-activity profiles for the young women

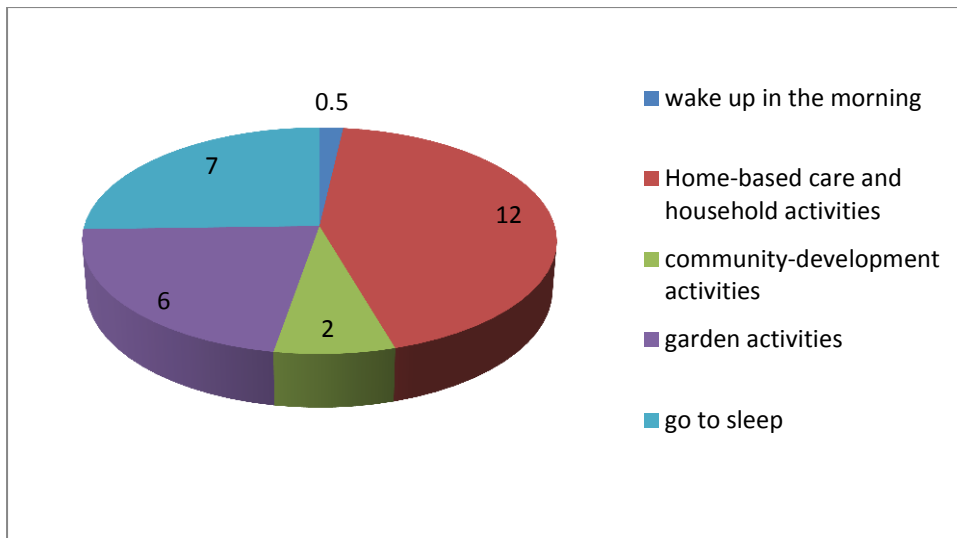


Figure 6.2: A house belonging to one of the young women participants

A house such as the one depicted in the photograph above is a typical dwelling structure of most of the members of the society in the research site. A house such as this one would, on average, accommodate no fewer than five people.

6.4 Challenges facing the young women

Common themes arising from the life stories of the young women providing care to those infected and affected by HIV and AIDS were: gender and HIV vulnerability; psychological challenges, and socio-economic challenges.

6.4.1 Gender and HIV vulnerability

Three of the five participants were infected with HIV and were on anti-retroviral drugs. These infected young women shared their life stories in the critical incident narratives.

In terms of HIV vulnerability, these young women explained that they had been orphaned at a young age and had been left without someone to care for them. This, in turn, had resulted either in their marrying at early age or finding an older man to provide for them and their households. One of the young women explained what had happened to her:

I was married at the age of 14 and, by the time my mother died, I already had a child. I was 15 years [...] I had four more children from my husband [...] my husband divorced me [...] and I had to come home [...] I was caring for my children and my siblings [...] I was desperate [...] A man came along and promised to assist me financially [...] We had a sexual relationship [...] for a few months ... then he disappeared [...] then I got sick [...] I went to get tested at the hospital and the health care worker told me I was HIV positive (Young woman 3).

Another young woman reported that, when her mother had died, she had, at an early age, married a polygamous man who had infected her with HIV:

He had a wife [...] and I am sure other women (girlfriends). He never used any protection [...] so, when my daughter got sick several times [...] the health care worker advised me to get tested because the child may have been infected by me [...] They found that I was HIV positive (Young woman 2).

The third woman related a similar story. She had been widowed twice.

I got married as soon as my sister, who used to pay for my school fees, died of AIDS [...]. I was forced to get married due to hardships at home [...]. My first husband may have infected me [...]. But I am not sure [...]. He died before I knew that I was infected [...]. My second husband also died. After his death, I went to get tested [...]. That is when I was told I am HIV positive [...] So, I am not sure who infected me [...] but the fact is I am living with a virus and I am on ART (Young woman 3).

The other two young women did not know their HIV status. The young, unmarried woman believed she was HIV negative because she had never had sexual relationship while the other young women reported that she had been tested twice and, both times, the results had shown that she was HIV negative.

6.4.2 Psychological challenges

All the young women participants reported that, while caring for their ailing parents or guardians, they had experienced psychological problems such as extreme worry, anxiety, mental exhaustion, nightmares and depression and that they had been exposed to stigma. One young woman explained the psychological challenges which she had experienced when her mother was bedridden as follows.

I could not sleep as I saw my mother's condition getting worse [...] I had nightmares of her funeral [...] I was just mentally exhausted.

The psychological problems which they had reported had not disappeared after the deaths of their parents/guardians and the young women stated that they had continued to feel haunted by their experiences. One young woman explained the trauma she had experienced and which had left her feeling haunted by her mother's illness and subsequent death.

I am haunted by the whole experience although my mother has been deceased for over five years now [...] It is like yesterday when she was here [...] I still cry.

The young woman whose mother was ill at the time of the study reported that she continued to feel anxious and worried.

I am always worried that I will wake up and find that my mother has died while I'm in my sleep [...] I do not know whether this feeling will stop.

Stigma was another major challenge that the young women faced. This stigma manifested in various ways. One young woman had been forced to leave school because her schoolmates had made fun of her about her parents' illness while another had been fired from her work as soon as she had disclosed her positive HIV status to her employer.

6.4.3 Socio-economic challenges

The young women reported experiencing extreme hardships while caring for their parents or guardians who were chronically ill. The major socio-economic challenges that the young women faced included insufficient money with which to buy basic necessities such as food, toiletries, clothes, farm inputs for food production, and health-related supplies for the patients.

Household income

The young women reported that, during the illness of their parents and guardians, the household income and savings had dwindled as most of the money was spent on buying medicines and paying for transport to hospitals or clinics. As home-based care patients it was essential that the patients be made comfortable in their homes. However, the comforts required cost money. For example, the patients needed to sleep in clean, comfortable and warm beds. Accordingly, the bulk of the household income was used to ensure that such comforts were provided.

My mother developed bed sores and we were advised to ensure that her beddings were clean always and that we needed to buy special creams to apply on her sores.

Basic necessities

A lack of basic necessities as a result of the illness of the breadwinners also presented a major challenge. When the breadwinners had become bedridden, no-one had taken their places and provided for the family's needs. The young women also reported that the money which could have been used to buy basic supplies, such as sugar, tea, bread, soap, paraffin, matches, maize flour, meat, beans, and other foodstuffs, was being used to buy the patient's medicines and those things required to ensure a better quality of life for the patient than would otherwise have been the case.

The young women also explained that, because of the illness of their parents or guardians, the general quality of life in the home had declined/deteriorated. They could not afford adequate, good food. The lack of money with which to buy even the most basic essentials, such as food, was experienced in all the households in which these young women lived.

I could not afford to buy meat and so we only made a vegetable stew every day [...] once in a while our neighbours would give us beans [...] I would then make a bean stew for the family [...] it was like a Christmas meal [...] (she laughed but with sadness in her eyes).

The purchase of household cleaning products and personal toiletries presented yet another difficulty for these young women. As a result of the illness of their parents or guardians and the consequent lack of money, they could not afford such necessities as bathing and washing soap, body lotions, or even toothpaste. For young women, in particular, such things are extremely important, helping them look and smell good in order to feel socially comfortable and boost their self-esteem.

One young woman aptly expressed this problem as follows:

I do like to go and chat with my friends [...] but I do not smell really good. We cannot afford soap [...] my teeth have not had a decent brushing for a while [...]. I feel very self-conscious about my body odour [...] I do not have money to buy nice clothes [...] we are so poor. All the little money I make from doing casual work [...] I buy food for my brother, mother and myself [...] I envy my friends who have nice clothes to wear [...] at my age, I should look nice [...] but no! We have nothing (she sighed) (Young woman 5).

Sustainable food production

The young women interviewed explained that, as soon as their parents or guardians had become too ill to work in the garden, food production had suffered:

My mother was too ill to go to the garden and I was too young to cultivate the garden on my own, so I just managed to plant maize on a small portion of the garden. We did not have the money to hire anyone to assist us in the garden. We did not produce enough to carry us the whole year.

The lack of money with which to buy farming inputs, such as the fertilisers and good seeds required to ensure a good harvest, was a major impediment to sustainable food production and self-sufficiency.

Health care expenses

Health care expenses also constituted a drain on the household finances. Caring for their parents or guardians left these young women without any money as most of the money was spent paying the patient's health care expenses. Apart from seeking the health care services at government hospitals and which are free of charge, the patients receiving home-based care also often consulted other health care givers

such as traditional healers. In addition, they sometimes also visited private doctors for urgent health care.

6.5 Coping mechanisms

In the main the young women carers had to try to cope with the illness of their parents or guardians on their own. Their coping strategies often involved asking for assistance from family members and friends of their parents, finding boyfriends who would assist or marrying in order to alleviate the difficulties at home. Some also started up business.

6.5.1 Assistance from family and friends

The young women reported occasional help from immediate family members. However, as a result of the widespread poverty in this community, the extended family members were usually also in financial difficulty. Two of the young women reported that they had not received any assistance from family members i.e. relatives on their mothers' and fathers' sides. In essence, both had been disowned by their relatives because of conflicts over property and inheritance and which had resulted in rifts in the families.

[...] as soon as they buried my father, we were told to go back to where we were living before and never to come back. My father died after the death of my mother. By that time, they had taken everything that my father owned. We did not have anything. We were on our own (Young woman 1).

[...] my father died earlier than my mother [...] so mama continued to care for us [...] but when she died, we were dispossessed of all that we had [...] Mother taught me how to make clay pots. That is all I could do, make pots for sale. We were left with nothing [...] We do not have a home or even a garden to grow food for ourselves (Young woman 2).

The other three participants reported that they had received occasional assistance from relatives and some of the friends of their deceased parents but that such assistance had not been sufficient:

They, too, are struggling to ensure that their families are provided for. As you can see we are all struggling here.

6.5.2 Finding a boyfriend or marrying young

Many of the participants believed that finding a boyfriend would solve their problems. This was primarily the view of those who had already started dating or who had children. One participant only who had never had a boyfriend stated:

I do not know whether finding a boyfriend would help as I am not allowed to find a man to date or marry because our religious belief do not allow young women to find suitors for themselves (Young woman 3).

The other participants had all been married by the age of 14. One young participant explained her decision to marry:

I saw my ailing mother suffering trying to care for all of us and I decided to get married so that, at least, I could relieve some of the burden on her [...]. I got married at 14 and, by the age 15, I was a mother (Young woman 4).

Another participant had been in a similar situation:

I was basically left with little choice as my sister, who was my guardian, had died, leaving behind her children to be cared for by my elderly mother and I [...] It was not easy to survive. After a few years, my husband died [...] I went through the same problems and I had to get remarried [...] He, too, died after a few years [...] I am now single (Young woman 2).

One young woman reported that, when her marriage collapsed, she had decided to find a man to assist her financially as she had several dependents that she had to raise.

[When] I came back home, I had thirteen orphans [...] that is my children, my siblings, and my deceased siblings' children [...] Then I met a man who said he loved me and was willing to assist me to raise the children. He was with me for a while but then left (Young woman 5).

6.5.3 Operating an informal business

Another coping strategy involved engaging in informal businesses in order to raise money for the family. One of the young women sold charcoal and clay pots in her village while another young woman, who had trained as a tinsmith, ran a small business making tin buckets and basins to sell. However, because of the extreme hardships they faced, the young women all reported that it was exceedingly difficult to start and sustain a business as they had almost no money.

6.6 Summary

The life stories of the participants painted a picture of extreme hardship and suffering. These women had been deprived of a normal childhood when they had become the primary caregivers of their chronically ill parents or guardians.

The time-activity profiles revealed that the young women spent most of their time performing home-based care and household activities, running the households, caring for the home-based care patients and growing crops for food and, thus, they had little time for anything else. These young women had had to leave school; some had married at a very young age; some had become mothers at a young age while some had even become infected with HIV. In addition, they had lost their parents or guardians at an age when they had needed them the most.

Caring for their parents or guardians as home-based care patients meant that these young women often faced financial, social, cultural and psychological challenges and they had been forced to adapt to their circumstances to ensure that they survived. In so doing, they had often made life changing decisions which had had dire consequences. Some had found men who had married them while others had found men who had promised to provide for their daily needs. This, in turn, had often meant that they had become mothers at a young age while others had become infected with HIV because of unprotected sex with their partners.

In addition, these young women also experienced hardships at home, including a lack of money with which to buy household necessities and fertiliser and seeds for the garden; a diminished ability to produce food; and health care expenses that escalated as a result of the chronic illness of their parents or guardians.

The young women all adopted various strategies in order to cope, including obtaining assistance from friends and relatives and starting informal businesses. However, as discussed in this chapter, these young women were not able to raise enough money to start viable business ventures. As a result some tried to find boyfriends who would assist them financially although this often entailed their making themselves vulnerable to HIV infection.

CHAPTER SEVEN

FINDINGS, ANALYSIS AND INTERPRETATION: HOME-BASED CARE COMPONENTS AND BEST PRACTICES

7.1 Introduction

This chapter, which comprises the third segment of the findings section of the study, presents the data that was collected from the key informants. This data includes the views which were expressed by women caregivers on home-based care.

In order to compare the perspectives of the two study populations, this section presents the findings from the interviews which were conducted with the key informants on home-based care best practices. Accordingly, this section contains the views of the female caregivers (i.e. young women, elderly women and women volunteers) who participated in the study. The section also presents information on the separate components of home-based care in order to illustrate who provides home-based care and the manner in which such home-based care is provided. In addition, this section discusses the best practices of the home-based care which is provided in the study area.

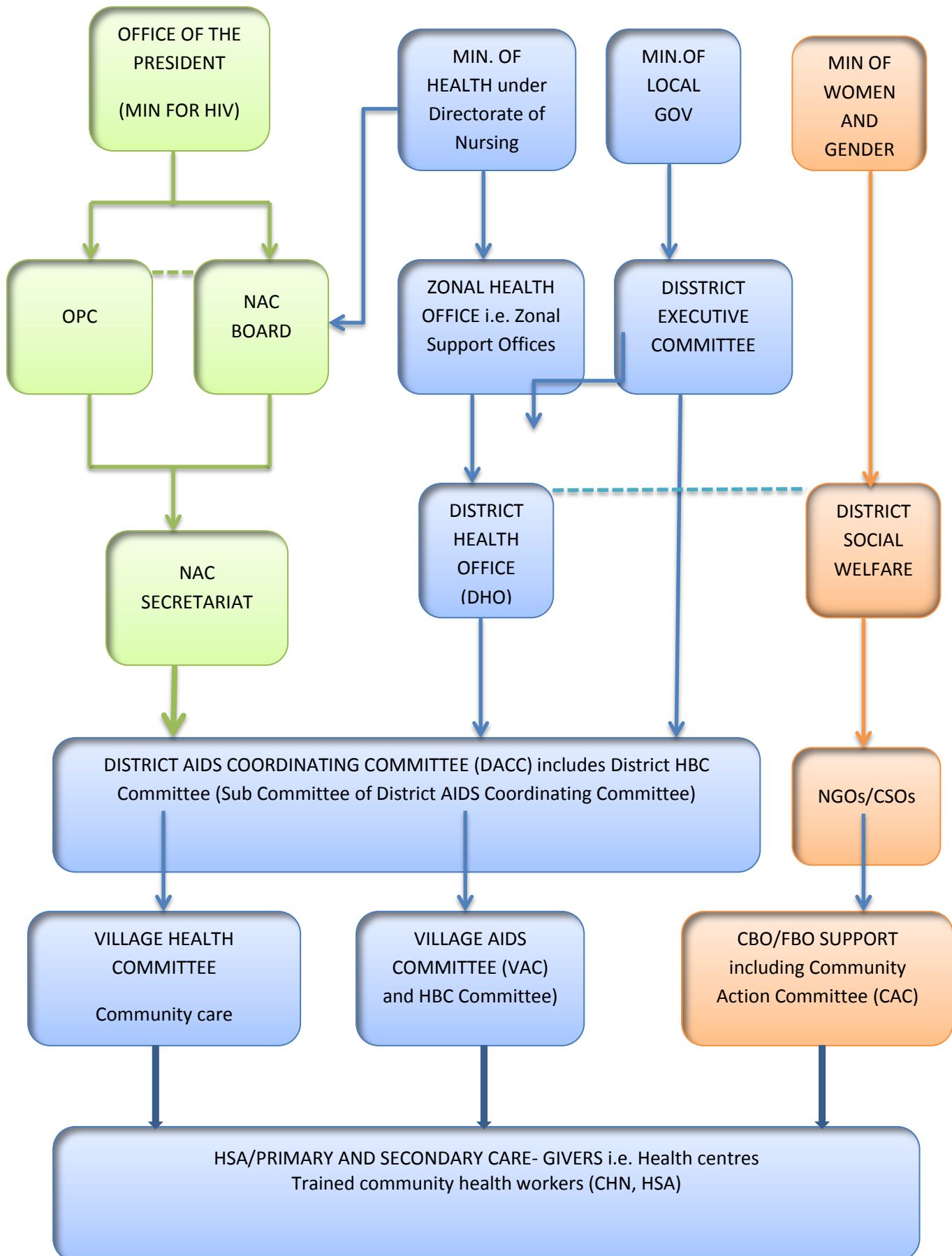
7.2 Home-based care components

The interviews with the three key informants provided relevant technical information on the phenomenon of home-based care. The structure of home-based care in Malawi is depicted in Figure 7.1.

Malawi's home-based care programme falls under the Directorate of Nursing in the Ministry of Health. This home-based care office works closely with the district health officers (DHOs) who are primarily medical doctors. The DHOs work with health centres that train community health workers – community health nurses and health surveillance assistants. These community health workers work closely with village agriculture committees and home-based care committees on issues of nutrition, and food security and also on HIV and AIDS. The community care providers/volunteers from the various villages are nominated to work with the health care workers.

According to the government's official home-based care programme policy, the Ministry of Health is responsible for training master trainers, trainers and caregivers in home-based care. The findings of this study confirmed that the ministry organises training workshops on a regular basis to ensure that new information on HIV and AIDS is shared and disseminated rapidly. In addition, the Ministry also designs strategies for the implementation of home-based care throughout the country. These strategies are then rolled out in the various districts and adapted to suit the specific locality. The health ministry is also responsible for developing and reviewing policies and manuals on the implementation of home-based care. Officials from the Ministry of Health conduct supervisory visits to health centres in order to monitor and evaluate the functioning of the home-based care programme. Such officials are also responsible for supporting those care givers who provide home-based care at home or in the community by providing them with the requisite drugs and supplies.

Figure 7.1: Components of home-based care in Malawi



There is also the district assembly level at which ministry departments and the local assembly work together in order to address relevant issues in the district concerned.

According to the local government worker who was one of the key informants and is based at the Mzimba district assembly offices, the district assembly appoints zonal support offices which work directly with the Ministry of Health. He explained the role of the zonal officers as follows:

These zonal officers work with the District Home-Based Care Committee which is a Sub Committee of the District AIDS Coordinating Committee (DACC). They also support health care officers (from the Ministry of Health) who are also responsible for the supervision, monitoring, and evaluation of home-based care services. They collect and analyse data for the district assembly (Key Informant 1).

Thus, the DACC works with the community-based organisations (CBOs) which, in turn, work closely with Village Health Committees (VHC). The district assembly also works closely with Ministry of Health as regards the home-based care programme.

7.3 Home-based care providers and institutions linked to the home-based care programme in Mzimba

Home-based care providers in Malawi may include family members, community members, health workers, for example health workers who have retired; teachers, church groups, social workers and expert clients, that is, people living with HIV (PLHIV). Other institutions which are also involved in the home-based care programmes include religious groups, the general community, faith-based organisations (FBOs), community-based organisations (CBOs) and international and local non-governmental organisations (NGOs). One such NGO is Tovwirane AIDS Organisation which also trains home-based care workers.

Thus, a number of interlinked players who offer various services are involved in the home-based care programme in Mzimba. The key informant who worked for the Ministry of Local Government explained:

There are a number of institutions who work with those who are chronically and terminally ill and vulnerable people. These include religious groups, general community, FBOs, CBOs, NGOs, Ministry of Health, zonal support health offices, political parties and other influential leaders (Key Informant 1).

According to this key informant, there were a number of religious groups in Mzimba who assisted in providing support services to the home-based care programme and who were, in turn, supported by the district assembly. These religious groups provided care in the form of spiritual counselling, moral support and the provision of resources such as food, soap and clothes. They also provided education to people on HIV and AIDS as well as on other health issues and diseases. The members of these religious groups also often assisted with household chores. In addition, they sometimes assisted affected families by raising money for their needs. There were also times when they assisted in/by providing food and promoting food security programmes. These groups were also sometimes involved in training caregivers, identifying individuals who could be trained as volunteers and raising finances to facilitate home-based care training.

The women participants who provided care gave various responses to the key informant's description of religious groups and their role. The majority of the women were not aware of any religious group in their community which was involved in the activities mentioned by the key informant. One of the young women referred to the lack of assistance from FBOs as follows:

I don't know whether this is true [...]. If they did this, I should not be struggling to care for my mother (Young woman 4).

Another woman mentioned that she knew that, once in a while, her church would give out free maize to families with home-based care patients or who had been affected by HIV and AIDS:

They once in a while invite me to go and get a bucket of maize for us [...] but this not regular [...] Sometimes once a year after the harvest season (Woman in FGD 2).

A few of the participants indicated some of the activities mentioned had been carried out by FBOs a few years previously but not at the time of the study. The key informant in the district assembly office reported that members of the villages carried out auxiliary duties in respect of home-based care.

These duties included assisting the sick with household chores such as gardening, smearing the house, fetching water and firewood, digging refuse pits and latrines (Key Informant 2).

According to this key informant, ordinary village members also assisted both household caregivers and volunteer caregivers to provide the types of care that could not be provided by the household primary caregiver groups. These included generating income by maintaining communal gardens, and promoting food security. The ordinary members of the villages would be elected to the village community organisations, such as the Village Health Committee, and which referred patients to health care facilities. The key informant further explained that these people often provided moral support to those infected and affected by HIV and AIDS while, at the same time, promoting non-discriminatory practices. In addition, they often actively participated in community discussions on home-based care activities because of their involvement in all the activities related to home-based care

When the women in the study were asked about the support they received from members of the general community, almost all were in agreement that they did receive some degree of assistance from the other members of the community. However, a few reported that they had not found the general community helpful to their plight.

I never get any assistance from anyone. We are virtually on our own. We feel abandoned [...]. I have to care for my mother on my own [...] we sleep hungry. No community member has ever assisted us on any of the issues you are talking about (Young woman 4).

However, the majority of the women indicated that they did receive moral support when they were struggling and also when they had been bereaved, with assistance from the general community to bury the dead.

When my mother died, some of the village members came to find out what we required for the funeral and they went and organised everything to bury her ... I was too young and too helpless to do anything (Young woman 2).

One key informant from the district assembly explained that there were some faith-based organisations and community-based organisations which were involved in supporting the home-based care programme through the provision of training to caregivers. These groups also assisted in educating people about other chronic or terminal diseases, such as hypertension and diabetes, as well as other issues related to family health. In addition, these faith- and community-based groups were also involved in counselling both family members and members of the general

community on issues relating to HIV and AIDS. The work of caring for those who are chronically or terminally ill is a community issue and these groups also provided physical care to those who were chronically and terminally ill, particularly with AIDS.

The members of these FBOs and CBOs also assisted households with chronically ill patients to raise money for their needs, at times they helped to provide food for these families, and they were also involved in promoting food security programmes in the villages. In a focus group discussion a member of a women volunteer group reported that the group actually operated as a local CBO and worked with families with chronically ill family members:

We assist families who have HIV infected patients who are on home-based care by ensuring that they have everything they require. We provide physical care, emotional care, food and other needs. We also provide information relating to HIV and AIDS and other disease on how to prevent them and how to positively live with them. We even do fundraising for the families who are affected by HIV and AIDS. We have a garden here at Walusungu Project at Kamsombeni²⁴ where we grow vegetables and fruits which we share with families in need (Woman in FGD 2).

The key informants also mentioned non-governmental organisations as playing a central role in assisting families who were caring for HIV-infected people. Although these organisations did not work in all areas of the district they did operate in some areas. The male key informant reported that, in the areas in which they operated, they assisted in providing support for home-based care and to those caring for the chronically and/or terminally ill.

They assisted particularly in building the capacity of the carers by providing training. They also initiated projects for the affected families. They assisted in training CBOs on issues of monitoring, and evaluating community home-based care programmes. They also provided resources for the CBOs, such as computers, bicycle ambulances and other resources. They were also involved in carrying out advocacy campaigns for changes in behaviour (Key Informant 1).

The male key informant also reported that there were times when certain political parties and other influential leaders had provided assistance:

Such assistance has been in the form of mobilising and providing resources [...]. Sometimes they would call for a community meeting and educate people

²⁴ Kamsombeni is a place in the Alick Chisi village where the women volunteers meet. They also have a vegetable garden.

on HIV and AIDS, and other related health issues. They also occasionally conducted advocacy campaigns on HIV and AIDS issues [...] and by just being good role models in the society, especially for the youth in the community (Key Informant 1).

7.4 Home-based care best practices

The study also sought to determine whether the home-based care programme adhered to the guidelines stipulated by the World Health Organisation for best practice in home-based care. It emerged that, in general, the home-based care programme in Mzimba in Malawi was adhering to the following best practices to ensure both the provision of care as well as a continuum of care and support to the chronically ill. However, as discussed in the following sections, the study also revealed gaps in the extent and consistency of the care provided.

7.4.1 Provision of care

As regards the provision of care, the best practices which were observed included the provision of basic physical nursing care and the management of common health ailments in both the home and the community. However, both young and elderly women who cared for the HIV-infected at home were less likely to have had formal training in providing the basic physical care as compared to the women volunteers. The provision of physical care for the chronically or terminally ill at home involved giving bed baths, feeding the patients and ensuring that they had taken their medicine.

The type of physical care that the patients get includes having a bed bath, mouth washing care, caring for pressure sores ... all these are given to the patient in his bedroom. They also get nutritional care whereby the patient gets a warm meal such as porridge. The patients are fed [...] (Key Informant 2).

It was clear that the immediate relatives worked closely with the volunteers to provide care to those who were chronically or terminally ill in their homes.

Other types of care offered to home-based care patients included assistance with writing a will, spiritual care as well as care and support for orphans and vulnerable children. One key informant explained that the trained volunteers worked closely with other stakeholders to offer these services:

When there is need for a will to be written the volunteers assist the patient to do this. They have been trained to assist in this issue. The church also assists in providing spiritual care. Any other problem which the patient is experiencing, the volunteers go out and bring the required help to the patient. It could be that the patient is in need of spiritual care; the volunteers go to that patient's religious denomination and bring a religious leader to come and counsel or pray with the patient. This is done through the priests, pastors or any church leader. The Ministry of Gender and Social Welfare assists in providing others services to those who are affected by HIV and AIDS in the communities (Key Informant 2).

The women carers were asked whether they received support in the provision of care. The women volunteers indicated that they had been trained in providing care to home-based care patients. However, such training was no longer conducted on a regular basis as a result of changes in the way in which the programme operated and was implemented. The programme was now run by the DHO office as opposed to the previous arrangement in terms of which the women volunteers had worked under a local NGO known as the Towwirane AIDS Organisation. However, Towwirane had since ceased to provide most of the HIV and AIDS services it had provided. The volunteers in both FGDs explained that they used the knowledge they had acquired a few years previously through Towwirane to provide care.

Both the young and the elderly women indicated that, in the main, they were left to provide care on their own without much support from the hospitals unless the patient was a registered ART patient.

Before my daughter was put on the anti-retroviral treatment, I was providing all the home-based care on my own, without much support from the hospital. As soon as she was put on ART, then I saw that there was much improvement in the guidance that we received from the hospital on what we should do or not do while she is on this treatment [...] (Elderly woman 4).

A young woman who was caring for her chronically ill mother stated:

All this you are asking me, I cannot give you an answer [...] as I have never received any provision of care or guidance from the hospital. I think it is because our religious denomination does not allow us to go to the hospital or take any medicine. We are supposed to just pray [...] But my mother needs medical assistance (She started to sob) (Young woman 4).

The continuum of care and support for home-based care patients and their families was also investigated. The results of this investigation are discussed in the following sections.

7.4.2 Palliative care

In order to provide care that would improve the quality of life of both the patients and their families faced with the life-threatening conditions of HIV and AIDS, the key informants reported that they are offered services to ensure that the patients experience relief from both pain and other distressing symptoms. This work is carried out by volunteers in collaboration with health care workers once a patient has been given a thorough and timely assessment of his or her condition. The difficulties faced by patients may range from physical difficulties to difficulties which are psychosocial and spiritual in nature.

The key informants working for the hospital reported that they trained volunteers in administering pain relief medication such as paracetamol. In addition, these volunteers assisted patients with psychosocial and spiritual issues to help them live healthy and productive lives. Some patients were on ART and, thus, the volunteers assisted in ensuring compliance and consistency as regards these patients taking their medication.

The women volunteers also reported that they assisted the patients to deal with personal issues related to their illnesses. When the time came for a discussion on issues relating to dying, they would counsel the patients on such issues. The volunteers reported that these death were usually discussed when family members were present.

Dying is a natural thing. We will all die someday. So issues regarding death are discussed first with the family if the patient is not getting better. We are trained well enough to counsel others on such issues. We later counsel the patient on what may come. It is a delicate matter. But we do manage to assist the patient to calm his/her fears (Woman in FGD 1).

Assistance is also offered even after the death of the patient, with the volunteers indicating that they would assist the family both during and after the funeral. In addition, counselling during bereavement is also offered to the family.

7.4.3 Education on nutrition and food supplements

The key informants also noted that, during training, they taught the care givers about the basic nutrition necessary for a person who is immuno-suppressed and

what such a person should eat. The recommended foods would assist the patient in combating some of the opportunistic infections by boosting their immunity.

Foods such as fruits and vegetables are known to assist in increasing body defences because they have the vitamins and minerals which assist people to stay healthy. These foods are also readily available in the villages. We teach care givers to have a garden near the home where they grow some of the vegetables (Key Informant 3).

The women volunteers corroborated this statement. Women in the second FGD reported that they even had a communal garden in which they grew green vegetables such as mustard, kale, rape, *Amaranthus sp.* (locally known as *bonongwe* (i.e. in the Chichewa language), as well as carrots, tomatoes and onions. One woman said,

We also use onions to treat simple injuries like open sores. It works (Woman volunteer in FGD 1).

However, the majority of both the elderly and the young women carers stated that they had not been trained on what to feed the patients when they were at home. An elderly woman said:

The patients ate what everyone else ate in the family. There is nothing made especially for the patient (Elderly woman 4).

The young women also reported that it was extremely difficult for them to ensure that their parents or guardians received the special foods which the health care worker suggested as they were in dire need of financial assistance. One young woman stated:

As it is we can barely survive as we do not have food in the home [...] so to prepare something special for my mother is impossible (Young woman 4).

Financial constraints were mentioned as a major obstacle to meeting the dietary needs of the patients.

7.4.4 Continuum of care and support

The interviews conducted with the key informants revealed that the home-based care programme encompassed a number of services which were linked to providing care and support to home-based care patients and their families. These services are discussed in the following sections.

Psychosocial and spiritual care

The key informants mentioned the psychosocial and spiritual care that the patients and their families received. This type of care was provided primarily by trained volunteers and community religious leaders and involved counselling sessions for the patients and the affected families. In addition, the religious leaders also offered prayers and spiritual guidance while members of a patient's church would sometimes visit the family and prayed with them. This was deemed to be an extremely powerful practice which was performed in order to quell the patient's fears and give them peace.

Basic equipment, drugs and supplies

Working in close collaboration with the hospital, the volunteers were provided with basic equipment, drugs and supplies. In an interview a key informant explained how this was done. She explained the process as follows:

When the volunteers have been nominated from their respective villages, they undergo a ten-day training workshop. After the training, they are given a first-aid kit in which all basic first-aid equipment and supplies are included. They also get gloves, soaps, basic painkillers, and antiseptic creams. When these supplies are finished, they go to their nearest health centre or hospital to replenish the box [...]. But, sometimes, they are told to use any available alternatives such plastic containers and bags (Key Informant 2).

Skills transfer to primary caregivers

All the key informants mentioned the training of volunteers as a way of transferring the requisite skills. In addition to the initial training, periodic refresher courses are also offered to the volunteers as soon as new knowledge about HIV and AIDS emerges and new ways of providing care and support to those suffering from HIV and AIDS are developed.

The key informants also mentioned that such training was also offered to those who were caring for the HIV-infected at home, especially when the patient was admitted to hospital and then discharged. When the patient was discharged the hospital nurse responsible for home-based care services would give the care giver some basic training on what ought to be done at home.

This finding was corroborated by one elderly woman whose daughter had been admitted to hospital. Then, on the day on which she had been discharged, the health care workers explained to her mother everything she needed to do at home when providing care for the patient. She recalled,

They said, 'remember to use gloves when you are washing and cleaning her. Ensure the patient sleeps on clean beddings and eats food that is soft.' My daughter was on TB drugs and ARVs. They reminded me to ensure that she should not skip her dosages and also to ensure she has enough fluids such as clean water to drink [...] they told me many things (Elderly woman 3).

Infection prevention and control in the home

The key informants reported that care givers, such as volunteers and the women in the home, are trained in giving bed baths and in infection prevention and control. They are trained to use products which are available locally, such as soaps, to wash the patients, their clothes and their bedding. If a patient developed bed sores, the care giver had to clean the sores and make sure that they did not become septic. The key informants also revealed that HIV-infected people are prone to developing oral thrush. Should such a problem arise, the caregivers were instructed how to control it by giving the patient either food containing garlic or raw garlic for the patients to chew. The women volunteers believed that this was an extremely effective remedy. One of the women volunteers stated:

We have some garlic in our communal garden which we give patients who have oral thrush. It works quite well (Woman in FGD 2).

Monitoring patients on drugs

The health care key informants also mentioned that, in order to ensure the effective treatment of opportunistic and chronic diseases, the women volunteers were trained in how to monitor patients who were taking medication for such diseases, in particular, tuberculosis and AIDS.

Total drug intake compliance is essential for the complete cure of TB. The volunteers assist in ensuring that the patients under home-based care do take their medications as prescribed by the doctors (Key Informant 2).

Another key informant reported that the volunteers were given sufficient training to enable them to understand HIV and AIDS as long-term medical problems and also that people on ART required the support of everyone, including family members and

health care workers. In order to achieve compliance with the required dosage, volunteers and care givers were taught how to assist the patients to remember to take their medication.

Discharge planning and referral along an HIV and AIDS continuum of care

The key informants working at the hospital noted that a patient who had been admitted to hospital and who had been told that he or she had contracted HIV, received counselling together with his or her care givers about the condition and also about the services that would be required to enable the patient to live a healthy and productive life. In addition, the health care workers also provided information on where the patient could go to access further treatment.

This is particularly important if the patient has conditions which need further care, such as TB treatment and ART. The patient is given a referral letter to present to the nearest health facility which can offer continuum of care (Key Informant 3).

However, many of the women carers indicated that it was often extremely difficult to follow the advice given, because taking the patient to a clinic or health centre regularly required money. Some families had to borrow the money needed to take the patient to the nearest health facility. The women volunteers reported that there were times when they tried to assist families by bringing the necessary services to the patients' homes.

Care for carers – at all levels of care

The key informants reported that they also gave some form of counselling to the carers of HIV-infected people, in particular about the disease itself and issues relating to stigma. However, all agreed that, in the main, the carers did not receive very much psychosocial support from those qualified to provide such support. The main reason for this was that there were very few people in the district who were qualified to offer such services to care givers.

The carers, especially those who were caring for the chronically ill at home, reported that they had not received psychosocial support from those qualified to assist them and, therefore, that they were left to deal with most of the psychosocial problems

they faced alone. A few of them indicated that they had received a degree of counselling from the women volunteers who came to assist them at home.

These volunteers have been my source of comfort. When my daughter became very ill, I was suffering from extreme exhaustion and had nightmares. The volunteers used to visit me on a regular basis and assisted me take care of her and counselled me well. I felt a huge relief (Elderly woman 2).

All the young women indicated that they had not received care and support from the officials who were meant to assist them and, thus, that they had been left to deal with an enormous number of personal problems on their own. Most of them suffered from insomnia and a sense of stigma.

I have never been visited by anyone from the hospital to come and assist me to deal with my mother's illness. I feel that I am on my own. There are a lot of things I would like someone to assist me to deal with but that is not possible because I do not know how to go about accessing help. I feel helpless. I do not sleep well. I feel depressed. I am always worried (Young woman 4).

Staffing

As reported in the previous sections, the Ministry of Health is responsible for the home-based care programme in Malawi. The staff members who provide direct care and support to those who are infected with HIV work under directly the auspices of this ministry. This was reported by the key informant health care workers who were interviewed.

However, according to the key informant from the Ministry of Local Government, the problem of HIV and AIDS requires a multi-sectoral approach and that this, in turn requires collaboration between the Ministries of Health, Agriculture and Local Government, the National AIDS commission and other stakeholders. This is particularly important in view of the impact of AIDS on all sectors of life. If the effects of the pandemic are to be mitigated efforts on the part of all sectors of government and civil society are required and it is for this reason that all the ministries and organisations mentioned above have personnel who are engaged either directly or indirectly in HIV and AIDS work.

Financing and sustainability

As regards the financing and sustainability of home-based care, the key informants reported that the programme is funded primarily by the government through the National AIDS commission and, in turn, through numerous donors, including the Global Fund.

One key informant mentioned that their districts produced plans and submitted such plans to the NAC. The NAC then publicised the plans and provided funds according to the needs and budgets of the district concerned. This is done on an annual basis.

Monitoring and evaluation

Monitoring and evaluation are extremely important to the programme as the funding agencies and government wish to see the results of the money which has been spent. In addition, such monitoring and evaluation assists those on the ground to improve their services.

The key informants reported that each level of the programme was tasked with collecting data for the purposes of monitoring and evaluation. This information was then collated and sent to both the Ministry of Health and to the NAC for their records.

Characteristics of the volunteers

The study found that the volunteer care providers included both males and females but that there were more females than males providing home-based care in the communities. These volunteers had been identified in their communities by the village headmen in conjunction with the health surveillance assistants i.e. Ministry of Health officials. Many of these volunteers who lived in the same communities as those for whom they cared were able to read and write, especially English, while those who were illiterate were supported by other care providers who were literate.

The major traits are that the volunteers are trustworthy, committed and willing to work. Honesty is of paramount importance because the chronically ill people need to feel that they are being cared for by friendly people who are empathetic to their situation. These volunteers are also able to maintain confidentiality (Key Informant 2).

Roles of the volunteers

The study found that the volunteers performed a variety of duties, including identifying and recruiting those patients who required home-based care as per the recommended criteria. The interview conducted with a nursing officer in charge of home-based care in the district revealed that the volunteers provided a number of services, including basic nursing and patient care such as bathing, feeding, mouth washing, turning the patient and pressure area care.

The volunteers assisted in the transfer of nursing skills to the primary care giver; thus ensuring a healthy home environment for the patient. They also assisted in seeking assistance from community members who were able to help in managing simple ailments, such as coughs, fever, diarrhoea, vomiting, skin problems etc.

As discussed in the section on the provision of care, these volunteers were trained to provide psychosocial support and nutrition counselling to patients and their families. A key informant also reported that the women volunteers played an extremely role in the provision of home-based care as they assisted in referring patients to health and other support services and groups (for example religious groups).

In order to ensure that some level of documentation was kept, the volunteers kept records on the care given to patients and provided monthly reports to an immediate supervisor. In addition, they monitored the drug intake, any side effects of the drugs taken and adherence to medication regimens of patients on long-term drugs, including ARVs.

The health care worker key informants also reported that the volunteers assisted in providing services when the patients were being discharged from hospital or from the programme if they did not require care at home. They also conducted follow up visits either to provide support or to conduct an assessment on whether support was needed. The volunteers also would conduct home visits of the discharged patient where they would advise the patient to try to become active again, particularly the patient has been ill for a very long time. One key informant summed up as follows:

These volunteers play a crucial role in the whole home-based care programme because of the amount of work they do. There are many patients who need care and support in this district and here at the hospital. There are very few of us who can provide such services. We get really overwhelmed

most of the time. They do this work without pay and sometimes at great personal strain (Key Informant 3).

7.5 Summary

The findings discussed in this chapter revealed a number of issues. Firstly, the data showed that the home based-care programme in Mzimba involves a number of stakeholders who work in close collaboration to ensure that the programme goals are achieved, in particular, mitigating the effects of HIV and AIDS in the Mzimba district. These stakeholders include the Ministry of Health, which coordinates the home-based care programme through the Directorate of Nursing, and Ministry of Local Government which works through the District AIDS Committee. There are also a number of other stakeholders which work with these major role players. These include faith-based organisations, community-based organisations, non-governmental organisations and individual members of society. The home-based care programme in Mzimba is currently being run in accordance with the guidelines proposed by WHO and which ensure that best practices are observed. However, the views of women caregivers were often contradictory to those of the key informants. In particular, it appeared that there was a gap between the key informants' reports of what happens and the women caregivers' reports as to reality as they experience it. It became apparent that the home-based care programme was experiencing major problems as far as a shortage of resources, such as money, was concerned. This, in turn, has impacted on the way in which the various stakeholders, particularly the health care workers, have responded to the many challenges that the women caregivers and their patients encounter.

CHAPTER EIGHT

CONCLUSIONS AND RECOMMENDATIONS

8.1 Introduction

The main aim of the study was to discover the kind of challenges which were faced by women providing home-based care in Mzimba, Malawi by determining firstly, the gender-related difficulties which made women who provided home-based care vulnerable to HIV infection; secondly, understanding the socio-cultural challenges women who provided home-based care experienced; thirdly, investigating the socio-economic challenges encountered by women providing home-based care; and lastly, investigating the best practices in home-based care as implemented in Mzimba.

The study thus strived to develop a deeper understanding of the role of women in the provision of care for the HIV-and AIDS-infected and -affected; widen understanding of the home-based care programme in Malawi; and to add to sociological understanding of home-based care as an intervention.

8.2 Challenges faced by women caring for HIV-infected patients

The findings of the study have revealed that women providing home-based care in Mzimba face a myriad of challenges. These challenges include gender-related vulnerabilities to HIV-infection; the burden of care; and psychological, socio-cultural, and socio-economic challenges.

8.2.1 Gender-related vulnerabilities

The study revealed that young women were particularly in danger of becoming infected with HIV as they tried to make life-long partnerships with men. The young women who were interviewed had experienced the dilemma of protecting themselves from HIV-infection while at the same time engaging in sexual encounters with men who would be potential suitors. A close link can be drawn between orphanhood and HIV-infection for young women. Almost all of the young women participants reported that their lives became desperate when their parents or guardians died. It was this desperation which led to them to engage in risky sexual relationships as they found themselves in dire need of money to sustain their

existence. It was apparent that the young women were vulnerable to becoming next generation of HIV and AIDS victims as a result of the extreme hardships they experienced during their parents' or guardians' illnesses and after they had died. They pursued older men in the hope that they would provide for them, or married polygamous men in order to escape poverty and a life of deprivation. Some young women became widows at young age having married older men who were already HIV-infected. The predicament of making such partnerships is heightened for women as their ability to protect themselves is often socially, culturally and economically limited. The inability of women to negotiate condom use with sexual partners is well documented. The dilemma also emerges as they try to find a life partner (or husband) (Ashford 2002; Enarson, 2007; Sternberg & Hubley, 2004; Nzewi, 2009).

Gender vulnerability to HIV-infection was not limited to the young women. The study has also revealed that older women were also at risk of HIV when their sexual partners did not use condoms with them. This was even more precarious when the men had other sexual relationships outside their marriage or stable relationship and did not use condoms to protect themselves from HIV and other sexually transmitted infections. It did emerge, however, that the older women were more knowledgeable about the disease and were more empowered to demand condom use from their husbands or boyfriends. This finding is supported by other studies which have also shown that most women are infected due a paucity of negotiation skills when it comes condom use and that having regular sexual partners is a major route for HIV-infection in many women (Nzewi, 2009; Gupta, Whelan & Allendorf, 2003). Lack of condom use or inconsistent condom use was also found to be a major cause of unwanted or unplanned pregnancies, especially in the case of the young women.

A link can be made by looking at the gender, power and feminist theories and the vulnerability of women to HIV. Lack of empowerment renders these women unable to make informed decisions about their sexual health and demand protection from HIV infection. The theory of cathexis also applies in this finding as it implies appropriate sexual behaviour for women is dictated by society including emotional and sexual attachments of women to men (Wingood et al, 2000: 544).

This study also revealed that women carers are insufficiently trained and therefore lack in-depth knowledge relating to HIV infection. Moreover, because of poverty, women who provided care to the HIV infected stood a great risk of being infected because they could not afford protective gear when providing care. Akintola and Hangulu (2014) also found that volunteers who provided home-based care had insufficient training on infection control. They also found that materials required for the maintenance of hygiene and protective equipment were in short supply and the protective equipment supplied was of poor quality (ibid).

8.2.2 Burden of care

Responses from all three women participant groups reveal that the women in the community take on the bulk of the responsibility of caring for those who are HIV-infected and -affected. Even where men were present and could assist, they still left most of the caring work to women. The caring work included such activities as: cleaning the house of the patients, washing the bedding, drawing water for the house, cooking meals, feeding the patients, giving bed baths to the patients, treating the pressure sores with medication supplied by the hospital, collecting firewood, and counselling the patients and their families.

These types of caring activities are generally considered women's work in Malawian society. This is also the case in many other African societies. Male participation in home-based care activities was found to be very minimal. In this study, however, women reported that when there was a male patient, a man would be involved in providing care to that patient, but if there were no males in the family or community willing to care for that patient, women would provide the required care. Almost all the patients in this study were female except one who was later cared for by his brother when his condition deteriorated.

The women in the study suffered a "triple burden of care" as evidenced by the amount of work that they had to do. They cared for the family and its needs, the chronically ill and their needs, and they had to tend to the gardens to produce food. This is the pattern in most developing countries, particularly where HIV and AIDS are epidemic. Over and above this "triple burden of care" the women also had to care for orphaned and vulnerable children whose parents or guardians were victims of HIV

and AIDS. The burden of care for the young women was enormous as they themselves were trying to cope with the demands of the situation in which they found themselves.

Related to the burden of caring for the HIV-infected and -affected was a lack of medical knowledge among the women carers concerning the disease's progression and concerning the medication regimen to which patients must adhere. The study has revealed that the women caregivers were not adequately trained to understand the treatment that the patients were on what needed to be done. Treatment outcomes are directly linked to proper knowledge of the treatment regimens that the patients are put on. Most of the women were barely literate and could not always understand the technical medical language associated with HIV and AIDS treatment and care. As the responsibility for ensuring adherence to that whatever medication the patients were put on lay with the carers, their lack of medical knowledge was found to be a great frustration for them. This was more prominent among the young women and the elderly women, and to a lesser extent among women volunteers.

The burden of care was also found, to be influenced by their marital status. Those who were single or widowed, as was the case for most of the young women and elderly women interviewed, found that their gender roles were much more challenging because they lacked the support that can come from being married. These women were left to shoulder the burden of care predominantly on their own.

Chronic exhaustion was mentioned in most of the women's descriptions of their experience but particularly in the accounts of the elderly women.. The elderly women in this study recounted feeling extremely exhausted after a day's work caring for those who were chronically ill. This was primarily as a result of the fact that their workload had increased.

The provision of palliative care to those living with HIV requires particular and specialised skills. In the main, the women who provide care to the chronically ill in Mzimba are not health care professionals but ordinary people who have been forced by circumstance into caring for the sick or they have volunteered to assist others. The study found that the women who were interviewed lacked advanced medical knowledge concerning the disease and, thus, that they struggled to understand and

assist those who needed their care. In particular, they struggled to understand some of the symptoms and signs of the disease and to know which drugs were required in order to alleviate the suffering. In addition, they reported that sometimes they did not understand nor could they remember the medicine dosages prescribed for the patients. These issues were also exacerbated by their lack of education.

Feminist theories of difference and inequality can be used to discuss the burden of care which the women caregivers are experiencing. In this society, care can be provided for by both men and women but as this study has shown, it is the women who are left to carry out most of the care-giving activities. Women are treated differently and experience inequality as far as sharing the burden is concerned.

8.2.3 Psychosocial challenges

Closely related to the burden of care are the psychosocial challenges reported by the women. It was found all three groups of women suffered from a range of psychological problems which included: extreme worry, anxiety, mental exhaustion, nightmares, a sense of being overwhelmed, feeling depressed and a sense of loss, a lack of appetite, and a lack of interest in their own personal care when caring for those who were chronically ill.

The findings of this study are similar to other studies that have been carried out looking at the psychosocial effects of caring for HIV-infected and -affected people (Akintola, 2004; Primo, 2007). In this study, the young and elderly women were found to have suffered more psychological effects than the women volunteers. The reason for this is possibly that women volunteers had undergone training in how to care for the HIV-infected and -affected. The women volunteers, however, reported a feeling of being overwhelmed by the large number of people in the community for whom they provided care. Consequently care work left them feeling mentally and physically exhausted. Psychological challenges have also be reported by Akintola (2006) found that women volunteers in South Africa experienced stigma and discrimination, mental ill health, a sense of incompetence or helplessness, feeling emotionally burdened and distressed, unhappiness, a fear of death, psychological trauma, and a feeling of guilt. In this study, however, it was found that the women did not suffer stigma and discrimination. In fact, the women volunteers felt that their social status

had been somewhat elevated as they were considered more knowledgeable about the disease than the general public. They were even asked to assist at the hospital providing counselling services for those who needed to be tested for HIV. The women volunteers in this study also reported that they still felt motivated enough to continue to providing care knowing as they did that people depended on them. This is the encouraging aspect of this study. These women also felt stronger in handling their own struggles due to the experience of assisting those who needed them and because of the resilience forged in those who had been helping others.

8.2.4 Socio-cultural challenges

Socio-cultural challenges appeared to be a major issue. This was evident in the way the gender roles were culturally determined as far as caring for the sick was concerned. It was also evident in the shouldering of the burden of care for those who were chronically ill with HIV.

In terms of gender roles, women face significant challenges as a result of the plurality of roles they perform. In addition to caring for the chronically ill, the women carry out the household chores, farming activities, child-rearing, and community-related activities. This finding is similar to other studies which have shown that, in contrast to men, women tend to play multiple roles in the families and communities (Ngwira, 2001; Urdang, 2006). Ogden (2004) observes, however, that the role of caregiver is principally a woman's but that in the context of HIV and AIDS men do at times take on more of the work as the epidemic progresses. Akintola (2004) also corroborates this, finding that women were the primary caregivers for those in need of home-based care in South Africa. The playing of multiple roles becomes overwhelming and the women themselves need support. "Who cares for the carers.....?" was Ogden's apposite question (2004:1). Some women carers had formed their own support groups to address this lack of support for themselves.

Some of the women who were widowed reported, however, that even when their husbands were alive, their support from was minimal. This can be explained by facets of Ngoni culture prevalent within their community where women were supposed to carry out most of the household chores, were responsible for food production, and were responsible for caring for those in greatest need.

8.2.5 Socio-economic challenges

Socio-economic hardship experienced in households was a recurring theme. Daily survival was extremely difficult, especially for the young women. Lack of money to buy even basic necessities was mentioned by all research participants as a major challenge. The problem of poverty was exacerbated by their low literacy levels which made it very difficult for them to find gainful employment or get a loan from the banks.

Studies have shown that women in most developing countries are at the bottom of the socio-economic ladder (Ngwira, 2001; Ogden, Simel & Caren, 2004; Tumwine, 2007). This was also found to be the case in this study. Due to a lack of proper and adequate education, the women experienced extreme poverty and were not able to care for their families. It was apparent that each socio-economic challenge experienced by these women stemmed from their inability to earn a living. This inability in consequence left them with even fewer chances to make improvements in their lives. Most reported that they were involved in small-scale businesses, such as selling firewood, charcoal, maize for popcorn, timber, food stuff, second-hand clothes, and groceries, such as soaps, salt, matches, etc. in order to survive. A few of them had tried to go into business but had run out of money and could not continue. Women also had to negotiate between continuing with the business or spending time assisting those who needed care. This was a difficult balancing act and one that ultimately affected their financial security detrimentally.

Socio-economic hardship also affects food security. The women reported that they had insufficient money to afford farm inputs. Most of the women reported that food insecurity and trying to ensure there was enough food for everyone were major challenges which affected all in their households. Food insecurity was also affected by a lack of labour to work in gardens and exacerbated by the high number of dependants the women were left to care for.

The findings of the study revealed high dependency ratios existed. The women were caring for their own children and grandchildren, and also for the children of either sick or deceased relatives. These high dependency ratios within the context of home-based care mean that the women find themselves overwhelmed by their caring roles.

In addition to the challenges of providing care to those infected and affected with HIV and AIDS, providing home-based care has a number of effects on the women as individuals and on the whole household collectively. These effects are borne out in household income, accessing basic necessities, food production, and health care expenses.

In terms of household income, most of the women reported that providing home-based care affected the household income adversely, meaning there was insufficient money for the entire household and its needs. Household income was also more acutely affected when patients required extra medical attention or more nutritious foods. It was found, too, that home-based care has an effect on household finances as a result of health care expenses. Most of the women reported that patients required more than the usual health care required by other household members. For example, patients needed more visits to the hospital for check-ups and other consultations. This required money to transport the patient. At other times patients had to have medication which meant families or volunteers had to find or collect money in order to purchase the medication. At times, if the family could afford it, they would consult a private doctor which would be much more costly than a public doctor.

This study found that women carers felt their income shrinking because either the number of people bringing in an income had been reduced or the main earner was the one who had become ill. Money available for basic necessities in the home was found to be insufficient. The young and elderly women in this study were more severely affected by the difficulty of acquiring basic necessities.

Food production was also affected by the care work undertaken by the women in this study. Most of the women reported home-based care had a negative effect on their household food production as there was either not enough time to spend working in the gardens or there was not enough money to buy the necessary farm inputs. Without enough money for farm inputs, such as seeds and fertilizer, and without enough labour for farming, food insecurity in these homes was felt intensely.

Having insufficient funds at their disposal to carry out other important activities was something mentioned by all the women in this study. They emphasised that as much as home-based care activities were important, they also needed to carry on/conduct other activities, such as running a business, working in the garden, or getting involved in community or church activities.

8.3 Coping mechanisms

Various strategies were used by the women to cope with the challenges and negatives effects of caring for those who are chronically ill with HIV. These included mobilising included seeking assistance from their friends and family; dividing up the work; creating therapy sessions; conducting informal business; selling off some of the family property; and sending children away to relatives.

Some of the women reported that they usually asked for help from friends and family members when they found they were financially struggling to cope. Young and elderly women reported that they asked for assistance from friends, family members, and any other well-wishers: depending on the safety net that family, friends and well-wishers provide had become a lifeline for these women. It was found that this safety net did not only provide material goods but also emotional and physical support. Elderly women depended on extended family and friends more for emotional support when dealing with the illness of their family members. Even after the person had died, the circle of friends and family remained in the home for a time to offer emotional support. Young women, on the other hand, depended financially on friends of their parents or guardians. From these findings, it seems apparent that young women struggled a great deal in procuring financial and material assistance from those who were willing and able help. As a consequence, they tended to look for alternative ways of coping with their socio-economic difficulties. Most of these young women looked for men to assist them. Some were coerced into a marriage or a relationship with a man. These relationships and marriages had long-lasting negative effects on their lives, for instance, forcing them to leave school early.

Another strategy for coping with the difficulties in which these women found themselves was to sell whatever the family owned to raise money. This was found to

be common among elderly women who had no other way of raising money for the family's needs. They sold off some of the family land and other sellable household items, such as furniture, in order to cater for pressing financial needs. The selling of household goods and family property led to further economic hardship as vital assets were lost with no means of replacing them.

Conducting therapy sessions among themselves was a valuable coping mechanism. These women sat and talked about their problems within a group. They shared their stories and the group offered them a chance to be heard and express their troubles. Most of the women had had similar life shattering experiences and thus had empathy for one another. The volunteer group also shared the work amongst themselves which allowed women time off to tend to other chores.

Another way of coping with the challenges of home-based caring was to send the children affected in the household away to live with relatives for a while. This was common among the elderly women. When they could no longer cope, particularly with caring for the children in the affected household, they asked for help from their own closest relatives.

8.4 The home-based care programme and its components

The home-based care programme is run by the health sector and provision of care is coordinated by the medical staff at the Ministry of Health. The programme in Malawi is structured in such a way that it allows for a multi-sectoral approach to the epidemic of HIV and AIDS. Various sectors of public, non-governmental, religious, and civic organizations are involved in different ways to combat or mitigate the epidemic and its effects. The structure of home-based care was found to be an advantage because the provision of care is mainly medical in nature. At medical facilities, care provided includes the following services: bed bathing, administration of drugs, and the feeding of the patients. Problems arise when patients are discharged from hospital. It was found that there was little or no follow up with medical care from the medical workers when patients went home. Patients who had been discharged from hospital had to be cared for by family or friends.

The Ministry of Health conducts training sessions for master trainers, trainers, and caregivers on issues relating to home-based care. It also conducts refresher courses for volunteers in the home-based care programme to impart new knowledge or services introduced into the programme or to refresh the knowledge of those who have been part of the programme for a long time. In order to do this, the Ministry of Health organises training workshops on a regular basis to ensure that new knowledge about HIV and AIDS is shared to those who require it and that it is implemented rapidly. While the Ministry of Health endeavours to ensure that training is conducted on a regular basis, training is dependent on the availability of funds.

The Ministry of Health's programme implementing system is well-organised which ensures both that there is a policy on home-based care and that it is implemented effectively and efficiently. It is here that best practices are important: provision of care at the hospital and continued care at home as an outpatient, if the patients are on ART or any other long term medication, is essential. The patients are visited by well-trained volunteers who assist them in every aspect of their health and wellbeing. The programme is also implemented in such a way that accountability regarding finances is required and that ensures members of staff involved are not only well-trained but have clear reporting procedures for the purposes of proper monitoring and evaluation. It is important to explain here that the home-based programme is the putative government implemented policy not necessarily the reality. In reality, issues relating to home-based care programme are slightly different as it will be shown in the following sections.

The home-based care programme in Malawi provides the services it is meant to as per the WHO guidelines. According to the WHO guidelines, provision of care must be guided by health professionals who should ensure that care is complete by making sure that basic physical care, palliative care, psychosocial support and counselling, and care of affected and infected children are all provided in the home (WHO, 2002:35). However, in this study, when looking at the findings from the women carers interviewed, the picture is somewhat different. Women, for example, are left to offer care for the chronically ill with little or no support from the health professionals unless the patient is admitted to hospital when the illness has worsened. Palliative care for illnesses such as AIDS-related diseases has been found

to overwhelm the women carers. It has been found that the women carers do not have enough/sufficient knowledge of how to deal with; for example, the psychosocial issues that the patients' experience. The health professionals who assist these women were also found to be overwhelmed by the work that they do. Other studies in Malawi have shown, too, that the ratio of health care workers to patients is extremely high, and higher still with the advent of HIV and AIDS which has increased the number of people in need of health care. This dearth of health care workers is also the consequence of the brain drain from Malawi, with more highly skilled workers moving to other parts of the world in search of better opportunities (Harries, Hargreaves, Gausi, Kwanjana, Salaniponi. 2002; Muula, 2006; Panulo Jr, Muula, Maseko, 2006; Cometto Tulenko, Muula, Krech, 2013).

The assistance that these women carers expect to get from other non-governmental, civic, religious and community-based organisations is very limited. Compared to the information obtained from the Key Informants the women provided a different perspective on giving care to ill family members to the extent that the ideal proved far removed from the reality these women experienced. It is apparent that there is a gap between what is supposed to happen and what is actually happening in communities. The women in this study who provided care to those infected and affected with HIV and AIDS also reported that the technical support they received was in fact far from adequate.

8.5 Home-based care best practices

According to the WHO (2002), a well-functioning home-based care programme follows these precepts: the provision of care which includes physical and palliative care; the continuum of care which includes hospital care and care after discharge from hospital; having staff to carry out home-based care activities; having sufficient funds to ensure sufficient supply of medical necessities; the continuation of all relevant activities; and the regular monitoring and evaluation of the programme.

The findings show that these basic tenets are in existence within the home-based care programme of Malawi. However, the lack of availability of staff hampers the proper implementation of the provision of care. There are insufficient health care workers to ensure that care provision is carried out effectively and efficiently. This

shortfall is being filled in by women volunteers. However, they too are becoming overwhelmed resulting in patients being left to the care of elderly and young women.

This study has also revealed that there is willingness among women volunteers to improvise and supplement where there is a need. This, they do out of their own initiative and goodwill. For example, some have grown vegetables for patients and their families; others have put money together to buy painkillers for patients. These actions demonstrate the essential elements of empathy for the other. This work was not, however, acknowledged by those formal institutions working with these women. There is an underlying assumption that these women volunteers will continue to 'fill in the gaps' because the volunteers know the patients and their families; that is, because they are operating within their own communities. But as Ogden, Esim, Grown (2006:333) observe, women continue to be taken for granted, it is assumed that they will provide care and support and continue to do so for family members and loved ones *ad infinitum*, without a sense of the cost and value of their work to society and economy in general.

Women continue to bear the brunt of the caring activities, as this study has shown. They continue to so because conventionally when there is a crisis in the family or community women have been the primary care givers. Literally they have had to care, whether out of love, duty or simply a lack of options (Ogden et al (2006:333). This study has also shown that women continue trying to ensure that the social safety nets of caring for those in need are maintained. The findings show too, however, that women care givers are struggling to ensure the chronically ill and those affected by HIV and AIDS are cared for. As Ogden et al. (2006:334) argue in their paper, many such social safety nets, which in a time of crisis in before the AIDS era ensured that others were cared for, have been now seriously eroded in most communities where HIV and AIDS are epidemic.

Spiritual care features highly as part of the continuum of care. Malawi is a very religious country; most people start and finish their days with prayer. This study ascertained that the volunteers assisted in providing spiritual care for the patients and their families. Religion permeates life in most parts of Africa. Sachs (2007:6)

argued that religion in Africa creates a “framework of community, crossing lines that ordinarily divide and linking individuals and families in powerful social bonds.... and it is more than a set of beliefs or rituals”. The finding of this study seems to corroborate Sach’s assessment. Women who were caring for those infected and affected by HIV and AIDS relied on their faith to carry out the tasks they needed to because to them their religious beliefs enjoined them to be compassionate to those in need. As Sachs (2007:10-11) said, “faith motivates compassion.... and that caring for those in need is done because of their faith”.

This study determined that women volunteers were given some training at the beginning of their caring role and were given refresher courses in order to provide effective palliative care. According to the WHO, it is vital that those assisting the HIV-infected are given some training concerning how to provide the correct care. The WHO (2002:36) defines palliative care as the “combination of active and compassionate long-term therapies intended to comfort and support individuals and families living with a life-threatening illness”. Training includes all aspects of palliative care, infection control, and the administration and monitoring of medication the patients may be taking to ensure compliance.

The home-based care programme is mostly funded by the Global Fund to Fight AIDS, Tuberculosis and Malaria. It was founded in response to funding inadequacies in most countries in order to fight these three major diseases. According to the Global Fund reports (2012 and 2011), the organisation has so far provided 3.6 million people with HIV treatment, and this accounts for about 21 percent of international public funding for HIV and AIDS worldwide (Global Fund 2011 and 2012).

Countries in sub-Saharan Africa which have a high disease burden have benefited immensely from this fund. According the Global Fund report of 2012, 2.3 million people have received ART through Global Fund-supported programmes. Such countries include Ethiopia, Ghana, Guinea, Malawi, Namibia and Tanzania, had their ART programmes were funded exclusively by the Global Fund.

Also of interest to this study was the character of the women volunteers. In order to understand the challenges faced by women volunteers, it was important to find out what kind of people the volunteers were. In order to provide proper care to the

people who are infected with HIV, the volunteers needed to have a character attuned to the work. The findings show that these women do not receive remuneration for the work they do, yet despite many challenges they continue to find ways and means of assisting those who require help.

Women perform tasks which are carried out in tandem with their other daily responsibilities and roles in the households. These tasks include all the work associated with providing for the household and family including food preparation and production; household chores, such as drawing water, washing clothes and bedding; caring for children (i.e. giving them psychosocial care and support); and caring for the sick (i.e. washing the patient, his/her clothes, cooking for him/her, sometimes even feeding him/her, and giving medicines). Urdang (2006:166) also found that women carers carry out many tasks within the household, "maintaining a household and family, [...] food preparation, water collection, cleaning, washing clothes, child rearing, caring for the sick, providing emotional support, passing on social values, as well as informal education".

It is important to state that the women carers performed these tasks without expecting remuneration for their work. They did it either because they were related to the person who was ill or they volunteered to do so out of compassion and love. Akintola (2004) suggested that the major element of care is the showing of compassion and love to the patients, and this was often achieved through providing spiritual support to those who were infected and affected by HIV and AIDS by praying with them and encouraging them to remain hopeful. Studies have also shown that this kind of care is of great importance and central to a patient's recovery. Moreover, through this care people living with HIV and AIDS begin to feel that they are loved (Sachs, 2007; Akintola, 2004).

Women form the majority of care givers as has been found in this study. Culturally, men tend not to be socialised to provide care in times of crisis. Akintola (2006:6) found in a study in South Africa that women reported that very few men were interested in giving care to sick people; some of the justifications given included the fact that women are the ones who give birth and this was presumed to make them more compassionate than men. Other studies also show that men, in general, in

Africa do not participate in caring activities and this can be seen in the prevailing norms of sexuality and masculinity in traditional African societies (WHO, 2000; Akintola, 2004b; Leclerc-Madlala, 2003).

8.6 Shortcomings of the home-based care programme in Mzimba

The study has revealed a number of shortcomings within the home-based care programme in Mzimba. These were: lack of formal training for the women caregivers at home; lack of care and support from the formal health service providers; lack of basic equipment, drugs, and supplies; lack of funds for care and support; lack of trained professionals to offer holistic services to those caring for the infected and affected with HIV and AIDS; and lack of funds.

Lack of formal training was found to be a major shortcoming especially for the elderly and young women carers. They did not have the required knowledge to provide proper care and support to the patients on home-based. They lacked knowledge on proper nutrition and food supplements, drug administration and adherence, and infection control.

There was lack of care and support from the formal health providers which was felt especially by the elderly and young women carers. Due to multiple health related complications which the patients experienced, these women needed care and support at the household level so that they could manage the complications properly. Although, the home-based programme insists that when such a situation arises, the patients should be transferred to a hospital, lack of money affected the referral of such patients as the women carers did not have required funds to hire a vehicle to take the patient to the hospital.

Lack of trained professionals to offer specialised services to those who were infected and affected with HIV and AIDS was evident in this programme. Most of the women caregivers suffered from a number of psychosocial problems which came as a result of providing home-based care. They did not receive any psychosocial counselling and care because there was no one to provide such service in Mzimba.

The role of volunteers is crucial in the provision of care and support to those who are on home-based care. However the volunteers are also experiencing their own

personal difficulties due to the pervading poverty that exists in this society. Lack of funds within the programme means that these very important players do not get any monetary remuneration and this has been found to be a weakness in this programme. Lack of funds also affects the effectiveness of the programme as the activities such as trainings are not conducted regularly, monitoring and evaluation activities are affected, and even to employ more professionals to assist in the activities of the programme is not possible.

8.7 Relevance and contribution of the study

It is believed that this research study has contributed to a deeper understanding of the issues involved in caring for people who are infected and affected with HIV and AIDS in Malawi. In particular, the study has added to the existing body of knowledge on the challenges facing primary caregivers. A central theme that emerged from the study is the role played by poverty in the lives of these women caregivers and the extent to which care work significantly increases their poverty, forcing the poor, in particular, into greater poverty and deprivation than was previously the case. All the women in this study have experienced, and continue to experience, the extreme effects of poverty as, most were born in poverty, they grew up in poverty, and they continue to experience poverty throughout their lives. Thus, poverty pervades each of these woman's entire life and HIV and AIDS have made an already precarious existence worse. In other words, home-based care and its related challenges have added to the poverty load that the women experience. It is also due to poverty that these women become vulnerable to HIV infection as they provide care to the infected because they cannot afford to buy materials that can protect them from infection. At a socio-cultural level the women face challenges which would enable and empower them to demand protection from their sexual male partners. At a socio-economic level, the women in this study experience socio-economic hardships which make them engage in dangerous sexual relationships in order to survive.

In terms of relevance and contribution of the study, all the challenges which have been documented have been studied by using feminist theories. The study has added to the body of knowledge by focusing on the plight of the women carers using a gender lens. It is apparent that these women have experienced these

challenges because their society treats them differently and unequally from and their male counterparts. Feminist theories have also shown how gender and power are used to deny the women an education, land, and even property - all of which would accord these women skills and capabilities to advance theirs and their dependants' lives.

8.7.1 Relevance for society

As a low-income country, Malawi has experienced an exceedingly heavy economic and social burden as a result of the impact of HIV and AIDS. This study has shown that the burden of care is borne by those communities and households that are trying to deal with the immediate and direct effects of the HIV and AIDS pandemic. Although the levels of HIV prevalence in Malawi are beginning to decline, this study has shown that the negative effects of the pandemic continue to permeate communities and households. In addition, the study has shown also that those who provide care experience severe difficulties arising from the immiserating conditions in which they live.

As a country, Malawi signed up to the eight Millennium Development Goals (MDGs) of 2005 which envisaged that, by 2015, the developing countries would have eradicated extreme poverty and hunger; achieved universal primary education; promoted gender equality and empowered women; reduced child mortality; improved maternal health; combated HIV and AIDS, malaria, and other diseases; ensured environmental sustainability; and developed a global partnership for development (UNDP, 2014). This study has contributed to the understanding of the status of the country as measured in terms of these UN MDGs. It is clear from the findings of the study that the country still has much to do as far as the status of women is concerned, especially where education, poverty, equality, empowerment, and health issues are concerned. The study has shown that, in terms of all these issues, women in Malawi are still lagging behind men.

8.7.2 Relevance for understanding of the home-based care programme in Malawi

The study contributes to an understanding of home-based care in Malawi. Home-based care in Malawi began as a reaction to a desperate situation when large

numbers of very ill people were hospitalised in the country's already overcrowded hospitals. Although the numbers of patients in hospitals may since have declined, largely because patients are discharged as soon as they begin to feel sufficiently strong to continue with only ambulatory care, it is clear that home-based care is not a simple and easy care pathway. It is fraught with many difficulties that are intractably entwined in the socio-economic and cultural fabric of the society in which the patients live.

This study has also found, however, that the home-based care programme policy in Malawi does have the elements relevant to make it a properly functioning programme but due to a lack of human resources the programme is unable to effectively fulfil its mandate.

8.7.3 Contribution of the study

Home-based care has been studied by numerous scholars using different methodologies. In this study, home-based care was studied employing qualitative sociological methods. It is also one of the few studies in Malawi to have looked at home-based care and its challenges using sociological methods and paradigms.

This study employed concepts of gender and power, and feminist theories, to understand the challenges that women who provide care to the chronically ill experience. Due to the low socio-economic status of women, they experience many socio-economic and cultural challenges. The feminist theories referred to in this study noted that women played a major role in caring for the chronically ill. Women, however, experience a separate set of challenges to those experienced by men because they inhabit a less privileged status and their life chances are culturally, socially and economically delimited. Gender inequality in Malawian society, and more especially in Mzimba, is the result of socially constructed impediments. These women live in an unequal and oppressive society and this study has shown the manner in which women are subject to a number of interrelated gender-related impediments.

8.8 Conclusions

The conclusions drawn by the study in relation to the home-based care programme and associated best practices are based on the WHO guidelines, which are intended to inform the functioning of the home-based care services. This chapter discussed the study's findings in light of the home-based programme itself and also the best practices present and implemented in Malawi.

The findings indicate that there is a well-functioning home-based programme framework in Malawi. However, it would appear that there is a significant discrepancy between policy and practice. The formal policy is in line with existing WHO guidelines and, yet, practices on the ground indicate that a significant gap exists between the two and that it is essential that this gap be addressed. The challenges experienced by these women are a clear indication that the practice of home-based care is in need of critical re-evaluation. This burden of care has made the already precarious lives of women in this society more difficult.

Home-based care may also have adverse effects, especially on very young and elderly women. As emerged from this study, these two groups of women have been left with very few life chances as a result of caring for those infected and affected by HIV. It is only in relation to the women volunteers that it was possible to discover a positive effect of their caring for those infected and affected by HIV, as these women have been recognised for the invaluable work that they do in the community and, through this, they have gained respect and self-esteem.

The burden of caring for those who are HIV-infected and affected consisted not only of caring for those who were chronically ill, but that it extended to the care they gave to the whole family, including orphaned and vulnerable children. The women in this culture produce the food, they care for the ill, and they carry out the household work in their own homes. This triple burden is, in turn, exacerbated by the magnitude of HIV and AIDS-related illnesses. It is, thus, clear that these women are overburdened and that this affects their ability to care for themselves effectively. All the demands placed upon them and their time affect their mental health and wellbeing. These are women who are overwhelmed.

Gender disparities and lack of women empowerment have led to women being unable to negotiate for safe sex. The socio-cultural status of women in Malawian society and, in particular, in Mzimba, is also extremely low which leads to their HIV-vulnerability. Women are not expected to be sufficiently empowered to demand protection against STIs in their sexual relationships. It was evident from those women who had been infected by their sexual partners, such as husbands and boyfriends that their lack of empowerment led to their HIV infection. The inability to negotiate safe sex also stemmed from their deprivation, as the majority of the women were desperate to find a man who would ensure their personal needs were met. Essentially, it seems almost impossible for the women in this community to remain HIV-negative. At some point in their lives they are highly likely to become vulnerable to HIV and AIDS to the extent that engaging in risky sexual practices to find and keep a man becomes the only viable way of securing care for themselves and their dependants. The culture from which these women came was clearly detrimental in this respect. They had been socialised to be dependent on men and to expect men take care of them.

As a direct consequence, women in this community experience extreme hardship and that is also why they, especially the young women, become infected with HIV as their socioeconomic vulnerability leads to their vulnerability to HIV. The lack of economic resources is also exacerbated because there are often several dependants in most of the households who require care and resources in addition to the HIV-infected patients. Thus, the high dependency ratio in the women's homes often leads to a low quality of life, particularly for the children, who are often forced to leave school.

In addition, their low levels of education exacerbate the situation, rendering them dependent on men for their economic survival, in particular because their low educational levels result in a dearth of employment opportunities for them. As the study has shown, some women find themselves taking in a lover or marrying a polygamous man and becoming infected with HIV as a result of such relationships. The study clearly showed that the women who participated in the study are unable to move out of the socio-cultural hierarchy which places them at the bottom of this hierarchy.

8.9 Recommendations for policy and practice, and further research

It is apparent that women carers in Malawi especially in Mzimba face difficulties too enormous for them to overcome on their own. From the above conclusions the study makes the following recommendations:

- There is a need to revisit the way the home-based care programme is structured in Malawi. There are a number of crucial services which are not provided for in the continuum of care. Services such as psychosocial support for both infected and affected people is lacking at community level, for instance.
- There is a need for close collaboration between the medical staff and the community to ensure that the home-based care patients are continually monitored and offered services in their communities. It was a repeated theme that the medical personnel at the hospital did not come into the homes of those who were chronically ill and bedridden at home.
- Men of this society need to be sensitised to understand and appreciate the huge burden that women have had to carry for a very long time. This knowledge and appreciation would encourage men to participate actively in community tasks, particularly home-based care activities.
- The issue of extreme poverty was a major theme across the data gathered. The challenges that women face are closely linked to their grave economic difficulties, and these often lead to the making of poor livelihood choices. Unless the issue of poverty is addressed, the challenges documented in this study will continue to burden the people of this area and the country as a whole.
- There is still a need for further more detailed social science studies to be conducted in this area as a number of aspects were beyond the scope of this study. For example, it was observed that there were many of orphaned and vulnerable children who were left to fend for themselves. These children were raising one another and the difficulties they face are not well documented, especially in Malawi. Moreover, this research study was carried out in one area of Mzimba. Therefore, more social science studies need to be conducted in other districts in Malawi in order to make comparisons with the findings of

this study. Such districts would include those which have matriarchal social systems, especially those in the south and central regions of Malawi. such studies would not only increase the understanding of the challenges that women experience when providing home-based care to infected and affected with HIV and AIDS, but also produce data which could enable social scientists comparative analysis based. Additionally, further research using both quantitative and qualitative methodologies to study the impact of home-based care on women caregivers would provide data which would bring a different view of the challenges. Lastly, there is a need for studies to be conducted focusing on how older women who provide care cope with loneliness and isolation, and looking at socio-economic factors within their households.

8.10 Concluding remarks

This study has revealed a number of issues that were otherwise not documented and therefore not known outside of this community. It is apparent that the plight of women in Mzimba has been exacerbated due to an increased burden of care for the infected and affected with HIV and AIDS. As long as the hospitals are unable to cope with caring for the chronically ill people, women will continue to provide home based care. The most effective way to alleviate the burden of care would be to institute measures and interventions which would provide assistance that would alleviate their plight and allow them to function more effectively.

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APPENDICES

Appendix 1: Department of Sociology Ethical Clearance Letter

Proposed title: Challenges faced by women providing home-based care in Malawi: a qualitative study in Mzimba

Principal investigator: NELLIE DOMINICA MYBURGH (Student number 3660-001-6)

Reviewed and processed as: Class approval (see paragraph 10.7 of the UNISA Guidelines for Ethics Review)

Approval status recommended by reviewers: Approved

The Higher Degrees Committee of the Department of Sociology in the College of Human Sciences at the University of South Africa has reviewed the proposal and considers the methodological, technical and ethical aspects of the proposal to be appropriate to the tasks proposed. Approval is hereby granted for the candidate to proceed with the study in strict accordance with the approved proposal and the ethics policy of the University of South Africa, but only after proof of registration has been sent to the Chair of the Department of Sociology.

In addition, the candidate should heed the following guidelines:

- To please make sure that you are registered and that all outstanding fees have been paid.
- To only start this research study after obtaining informed consent
- To carry out the research according to good research practice and in an ethical manner
- To maintain the confidentiality of all data collected from or about research participants, and maintain security procedures for the protection of privacy
- To work in close collaboration with your supervisor and to record the way in which the ethical guidelines as suggested in your proposal has been implemented in his research
- To notify the committee in writing immediately if any change to the study is proposed and await approval before proceeding with the proposed change
- To notify the committee in writing immediately if any adverse event occurs.

Approvals are valid for ONE academic year after which a continuation must be submitted.

Kind regards



Dr Chris Thomas
Chair: Department of Sociology
Tel + 2712 429 6301

ONLY
VALID IF
STUDENT IS
CURRENTLY REGISTERED.
PROOF OF CURRENT REGISTRATION
REQUIRED.



**Appendix 2: Letter of Introduction from the Head of Department of Sociology,
University of South Africa**

17 April 2014

TO WHOM IT MAY CONCERN

This is to certify that Mrs NELLIE DOMINICA MYBURGH is a doctoral student duly registered in the Department of Sociology at the University of South Africa (UNISA). She is undertaking research leading to the production of a thesis on the subject of "CARE FOR THE INFECTED AND THE AFFECTED: A CASE OF HOME BASED CARE IN MALAWI." During the upcoming Easter holidays Mrs N D MYBURGH will be travelling to the Republic of Malawi to conduct primary data collection for her doctoral thesis.

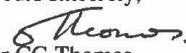
I would like to invite you to kindly assist Mrs N D MYBURGH in this project, by facilitating access to potential interviewees and/or granting her an interview covering relevant aspects of this topic.

The project is in compliance with the UNISA policy on research ethics, and was granted the requisite ethical clearance. Be, thus, assured that any information provided will be treated in the strictest confidence and none of the participants will be individually identifiable in the resulting thesis, report or other publications. You are, of course, entirely free to discontinue your participation at any time or to decline to answer particular questions.

Any enquiries you may have concerning this project should be directed to me at the address given below. Alternatively, feel free to contact Mrs N D MYBURGH's doctoral promoter, Professor Carol Allais by telephone on +27123460510 or by email (carol.allais@gmail.com).

Thank you for your attention and assistance.

Yours sincerely,


Dr CG Thomas

Chair of Department
Department of Sociology
Theo van Wijk Building Level 9-02
Tel: +27 (0)12 429 6560
E-mail: Thomacg@unisa.ac.za.



Appendix 3: Demographic sheet

Date:

Facilitator:

Recorder/Observer:

Location:

Respondent /participant Group:

Age/ Age Range:

Sex:

Reasons for Selection of participant /participant Group:

Education Status:

Marital Status:

Ethnic Group:

Verbal Consent ()

Written Consent: ()

Signed:.....

Appendix 4: Consent form

Introduction: "My name is.....I'm conducting research for my Doctorate studies with University of South Africa. I am interviewing women here inin Mzimba [name of village or site] in order to find out about woman's views on the challenges regarding provision of HIV AND AIDS and home-based-care. Moreover the information collected will be used to open and develop a dialogue on HIV AND AIDS and home-based-care issues amongst people.

Confidentiality and consent: I am going to ask you some very personal questions that you may find difficult to answer. Your answers are completely confidential. Your name will not be written down, and will never be used in connection with any of the information you tell me. You do not have to answer any questions that you do not want to, and you may end this interview at any time you want to. However, your honest answers to these questions will help me better understand what women think and say about HIV AND AIDS and home-based care. I would greatly appreciate your help in responding to this study.

With your permission I would like to tape this interview. Would allow me to do so?

Yes	No
-----	----

The questions will take about 1 hour to be answered. Would you be willing to participate?

(Signature of interviewer certifying that informed consent has been given verbally by participant)

Appendix 5: participants: social groups and characteristics

Summary of Selection Criteria

Objective	Method	Respondent group	Rationale	Sampling Procedure	Number of participants
To understand the challenges relating to the gender burden of care and coping mechanisms of women who provide home based care	Individual In-Depth Interviews; Time-Activity Profiles	Elderly women (50+ years old) ²⁵ caring for the infected and or affected for example their children, grandchildren who may be orphans, or other vulnerable children	To obtain wide-ranging data from participants who have in-depth knowledge in the research problem	Purposive sampling	5 participants
To understand the socio-cultural and economic challenges which make young women susceptible	Critical Incident Narratives	Young women (18-24 years) ²⁶ who have dropped out of school to care for their parents or guardians;	To obtain data on sensitive subject matters	Snowballing sampling or Purposive sampling	5 participants

²⁵ Although there are commonly used definitions of old age, there is no general agreement on the age at which a person becomes old. In Africa, the definition has a different meaning as compared to other parts of the world. For the purpose of this study, the researcher used age of 50 years which is a working definition to mean "older" or "old" as was agreed at the 2001 Dar es Salaam Minimum Data Set (MDS) Meeting (WHO <http://www.who.int/healthinfo/survey/ageingdefnolder/en/>).

²⁶ As is the case with the elderly, there is no agreed definition for young women. In most literature, 15 to 24 years is considered the age range of young people. However, for this study, the researcher used the range of 18 to 24 years to be used for recruiting participants for ethical reasons.

and vulnerable to HIV infection as they provided home-based care;					
To investigate the socio-cultural and economic effects of home-based care on women who work as volunteers	Focus Group discussion; Social ranking activities	Women providing home-based care as volunteers;	To collect information from the group which would otherwise be difficult to access	Purposive and snowballing sampling	6 participants
To investigate which are the best practices in home-based care	Key Informant Interviews; Checklist	National AIDS Commission Home-Based Care programme officials Medical doctors or healthcare workers working in the district	To gather data from this group of participants who have specialised knowledge of home-based care	Purposive sampling	2 participants

Appendix 6: Data collection tools

Appendix 6a: Pair-wise ranking activities

1. The group chose a set of activities which they do in a day which were to be discussed and prioritised.
2. Six activities were chosen to be discussed. These included: caring for the sick, cooking, drawing water, collecting firewood, tending to the garden, community development activities.
3. Each of these activities was written down on a separate card.
4. The researcher then asked the group to look at the activities again. The researcher then put two cards in front of the group and asked them to choose the activity which demanded a lot from them in terms of time and energy. The activity which was more demanding was put as first.
5. The researcher then presented a different pair and repeated the comparison until all possible combinations had been considered (all boxes of the matrix had to be filled). To keep the participants interested, the researcher picked different pairs each time. Rather than comparing item A against B, item A against C, item A against D, researcher then compared A and B, then C and D, then E and F, then C and A, etc.
6. An answer matrix was created and the researcher conducted the same activity with the rest of the cards.
7. After all the activities were ranked, the researcher then took the ones that were ranked first and asked the group to rank them again in order to come up with a first, second, third, fourth, fifth and then sixth.
8. While conducting these activities, the researcher asked the participants to give reasons for their choice. These responses were written down.
9. A list of the activities was created according to the participants' preferences.

10. The results were presented as a matrix and as part of the findings chapter for volunteer women.

Appendix 6b: Time-Activity Profiles

The following steps were followed when conducting Time-Activity Profiles:

1. The researcher gave the participant a number of pieces of paper
2. The participant was asked to list all activities she did from the time she woke up to the time she went back to bed
3. Then she was asked to apportion time to each activity she performed
4. The researcher then compiled all the information to come up with a profile of time-activity

Appendix 6c: Individual In-Depth Interviews: interview schedule

Objectives 1:

To understand the challenges relating to the gender burden of care and coping mechanisms of women who provide home-based care

Respondent Group: Elderly women offering Home-Based Care at Home

INTERVIEW TIME:

Started at:.....

Ended at:.....

Background Characteristics

Q1 When were you born?

Month.....

Year.....

Don't Know.....

Q2 How old were you at your last birthday?

Age (in Completed Years)

Don't Know

Q3 Have you ever attended school?

Yes.....

No

Q4 What is the highest level of school you attended: primary, secondary or higher?

Primary

Secondary

Higher

None.....

Q5 How many total years of school have you attended up to now?

Years Completed

Q6 What is your current marital status?

.....

SECTION 1: HIV and AIDS knowledge

- How is HIV and AIDS spread?
- How does HIV and AIDS affect your daily lives?
- Has HIV and AIDS affected you personally?
- If so, in what way?

SECTION 2: Activities done

- You have been chosen for this study because you provide home-based care for someone in your family or community; please mention all the activities that you do when you are providing care to the chronically ill.
- Are you doing it because you are a volunteer or a family member (i.e. how related are you to the person or people)?
- What are the problems you face when you give this care?

SECTION 4: Socio-cultural and economic challenges

- How does offering this service help affect or improve your households and communities?
- Economic issues:
 - How do you make money to support the family?
 - Do you find time to engage in a business activity or be employed?
 - Do you get economic support from government, NGOs, church groups, well-wishers etc?
 - Please elaborate
- Social issues
 - Do you find that other people stigmatise you because you are caring for the HIV infected? Please explain.
 - Do you experience social pressure of any kind due to your caring for the HIV infected? Please explain.
 - Do you get social support from your family, community or government? Please explain.
 - Do you experience gender based violence due to the work you do?
- Psychological issues
 - Do you experience any negative feelings due to the work you do?
 - Please explain (stress, anxiety, guilt, worry, etc)
 - Do you deal with these feelings?
- Food security:
 - Do you always have enough food in your home?
 - What do you do when you do not have enough to eat?
 - Do you have a garden where you grow your own food?
 - Who works in the garden?
 - Do you always have enough inputs for growing the crops?

- Have you had to change your farming activities do to the illness that is in your home?
- What do you do to ensure there is food in the home?
- Education of the children
 - Are there children in your home who are going to school?
 - How many are they?
 - Have they experience any stigma?
 - Have they had to drop out of school? Why/ why not?
 - Please explain

- Social security: survival issues, subsidies, etc

SECTION 6: How do women and girls cope with the effects of home-based care activities in their homes?

- What home-based care activities do you perform which make you replace other household activities? What do you do to compensate for time lost when performing home-based care activities?
- How are you coping with the additional load of work which has been brought about by home-based care activities?
- As women, how does home-based care affect you?

Appendix 6d: Critical Incident Narratives topic guide

Objective 2:

To understand the socio-cultural and economic challenges that make young women susceptible and vulnerable to HIV infection as they provided home-based care.

RESPONDENT GROUPS: young women who are caring for the infected in their homes

Questions

1. Tell me all about yourself
2. How did you end up caring for your relative/ parent or guardian?
3. Please explain to me to your best knowledge on how this person came to be ill
4. How did he/she get infected?
5. What do you think should have been done to stop this person from getting infected?
6. What are the other methods that people use to protect themselves from getting infected?
7. In your opinion, how can women protect themselves from getting infected?
8. Can I ask you a personal question? Yes/No
 - a. If Yes, continue thus:
 - i. Do you have a sexual partner for example husband, boyfriend/man friend?
 - ii. What methods do you use to prevent HIV infection?
 - iii. Do you ask for protection every time you and your partner are about to have sex?
 1. If yes, how do you introduce the issue? Please explain
 2. If No, why? Please explain
 - b. If No, then do not ask this question.
9. Do you have any source of income for example work or a business?
10. How much do you make every month?
11. Does looking after your sick relative/ parent/guardian drain your financial resources?
 - a. If Yes, how?
 - i. How do you ensure you have more income to care for the patient?
 1. Please explain to me in great detail
 - b. If No, why?

Appendix 6e: Focus Group Discussions topic guide

Objective 3:

To investigate the socio-cultural and economic effects of home-based care on women who work as volunteers

RESPONDENTS: Women who provide home-based care as volunteers

Questions

Socio-economic challenges

1. Do you get paid money for the work that you do?
 - a. If yes, how much and how often do you get paid?
 - b. If No, why? Please explain
2. At a personal level, how does this work affect you? Please explain in great detail
3. Do you have time to work in your garden? If not, who do you get to do that work?

Socio-cultural challenges

1. Does this work make you stand out in your society such that other people admire you? In other words, does it give you some sort of prestige?
2. By working as a volunteer with people who are infected with HIV, do you feel in any way stigmatised or segregated?
 - a. Yes, why?
 - b. No, why not?

FOCUS GROUP DISCUSSION SESSION 2 (PICTURE INCLUDED IN THE THESIS WITH PERMISSION FROM THE WOMEN VOLUNTEERS)



Appendix 6f: Key informant interview schedule

Objective 4:

To investigate which are the best practices in home-based care in Mzimba,

RESPONDENTS: National AIDS Commission employee, donor employee, or local NGO employee

AIM: To investigate which are the best practices in home-based care.

1. PROVISION OF CARE

- a. Are people trained on how to provide home-based care?
- b. How is this training done
- c. Do they get formal certification for it?
- d. How is the provision of care organised?
 - i. Leadership
 - ii. Quality control

2. CONTINUUM OF CARE

- a. Who are the other providers of care to the home-based care?
- b. Do the patients have to go to access other types of care that they require or that care is brought to their home?
- c. Please give me the list of the types of care that the chronically ill people require?

3. EDUCATION

- a. Do providers continue to require refresher courses?
- b. What topics are covered during these courses?
- c. Who gives the funding for the courses?
- d. Where do they take place?

4. SUPPLIES AND EQUIPMENT

- a. Who provides the supplies and equipment that volunteers use?
- b. Please give me the list of those supplies and equipment that volunteers use?
- c. When they run out, how are they replenished?
- d. How are the equipment serviced?

5. STAFFING

- a. How are the volunteers recruited?
- b. How are they motivated to continue working?
- c. Do they get any monetary reward?

6. FINANCING AND SUSTAINABILITY

- a. Who are you funders?
- b. How do you manage your funds?
- c. How do you ensure that you have continuous flow of funds?
- d. Do communities get involved in the fundraising activities?
- e. In terms of sustainability, how are you going to sustain these activities?

7. MONITORING AND EVALUATION

- a. How is the monitoring done?
- b. Who is responsible in monitoring the activities?
- c. What kind of data is collected?
- d. How is this data collected?

- e. For who is this data collected?
- f. What happens at the end of each financial year?
- g. How is data stored and shared?

Appendix 6g: Checklist for home-based care programme

ACTIVITIES	AVAILABLE	NOT AVAILABLE
Provision of care		
Continuum of care		
Education		
Supplies and Equipment		
Staffing		
Financing and		

sustainability		
Monitoring and evaluation		