



**The Experiences of Caregivers Looking after a Child living with HIV and AIDS
in rural Malawi**

A

Thesis

for

Doctor of Philosophy in Nursing (PhD)

by

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Summary

The aim of this study was to examine how caregivers manage their day-to-day living and health care needs, care for themselves and their sick children living with HIV and AIDS in rural Malawi. The study used a longitudinal descriptive qualitative research design, through the “lens” of a narrative approach as a theoretical framework to explore the experiences of caregivers looking after a child living with HIV and AIDS in rural Malawi. In-depth Interviews (IDIs) with women caregivers (n=20) recruited from Mponela Rural Hospital catchment area were conducted and all twenty women caregivers participated in in-depth interviews. Direct Observations (DOs) of the environment where interviews were conducted and at the local Mponela Rural Hospital were used to explore the primary care and support available for these women caregivers and their children. Data were analysed manually using thematic analysis of the narrative accounts. An in-depth case study of one caregiver’s experience, using narrative analysis, is presented to exemplify some key elements of all the women caregivers’ experiences. This approach enables the reader to better understand how women constructed their stories in their own particular cultural context. Results identified a number of key issues facing women caregivers of children living with HIV and AIDS in rural Malawi. Key issues include: ***Caring responsibilities***- the caring responsibilities were extensive and intensive. ***Disclosure and stigma***- women caregivers were selective in their disclosure of HIV and AIDS status. ***Clinical care and support*** – women caregivers accessed only government health institutions. ***Invisibility of women caregivers***- individual women caregivers were invisible to many including policy makers. ***Women’s caregiving services not recognized***- women’s caregiving services were not recognised by policy makers. ***Challenges faced by women caregivers***-women caregivers had many challenges related to caregiving services. ***Gender issues***- An important finding was the impact of gender on these women’s experiences. ***Highly resilient and motivated***-despite the challenges, women caregivers were resilient and highly motivated.

Declaration

I, Mandayachepa Chriford Nyando of Cardiff University School of Health Care Sciences hereby declare that this thesis for Doctor of Philosophy in Nursing (PhD Nursing); except where indicated by reference and direct quotation, is my own investigation work and the views expressed in this work are my own views.

Mandayachepa Chriford Nyando (Researcher)

Signature..... Date.....

Ownership and submission

I, Mandayachepa Chriford Nyando of Cardiff University School Health Care Sciences hereby also declare that no portion of this thesis has been submitted in substance for any other degree or award at any school of Cardiff University or any other university or place of learning, nor is being submitted concurrently in candidature for any degree or other award other than being submitted to Cardiff University, School of Health Care Sciences housed at Eastgate House on Newport road in fulfilment for the award of Doctor of Philosophy in Nursing (PhD in Nursing).

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Signature..... Date.....

Dr. Katie Featherstone (First supervisor)

Signature..... Date.....

Professor Billie Hunter (Second supervisor)

Signature.....Date.....

Dedication

This thesis is dedicated to my late father Mr. Matthews Nyando who died when I was 6 years old and I do not remember his face. I wish he was alive to be present during this time around and may his soul rest in peace. And to my two children Jack and Mwayi for their understanding during the four year period I was far away when they needed me most.

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Abstract

The aim of this study was to examine how caregivers manage their day-to-day living and health care needs, care for themselves and their sick children with HIV and AIDS in rural Malawi. The study used a longitudinal descriptive qualitative research design, using the “lens” of a narrative analysis theoretical framework to explore the experiences of caregivers looking after a child living with HIV and AIDS in rural Malawi. In-depth Interviews (IDIs) with women caregivers (n=20) recruited from Mponela Rural Hospital catchment area were conducted and all twenty women caregivers participated in in-depth interviews. Direct Observations (DOs) of the environment where interviews were conducted and at a local rural hospital were used to explore the primary care and support available for these women caregivers and their children. Data were analysed manually using the thematic analysis of the narrative accounts, combined with a detailed narrative analysis of one carers experiences to better understand how women constructed their stories in their own particular cultural context. A summary of the narrative analysis accounts of the rest of the 19 participants has been done to exemplify the main key issues each one of them had told in her story of caring for a child living with HIV and AIDS. Results identified a number of key issues facing women caregivers of children living with HIV and AIDS in rural Malawi:

- *Caring responsibilities*- Women caregivers’ caring responsibilities for children living with HIV and AIDS were extensive and included physical and psychological care and support.
- *Disclosure and stigma*- The majority of women caregivers were selective in their disclosure of HIV and AIDS status of children. They disclosed only to very close relatives and significant others such as village headmen but also to anyone who asked them about the HIV and AIDS status. These women caregivers experienced stigma as they looked after children living with HIV and AIDS. For example women caregivers were told that they and their children were “already dead people” and believed that they were shunned by their community.

- *Clinical care and support* –Women caregivers accessed these only in government health institutions despite a number of private health and non-governmental institutions available in this area.
- *Invisibility of women caregivers*- Individual women caregivers were invisible to many policy makers and their family and community members and yet they provided the much needed care and support to a vulnerable group of people living with HIV and AIDS- the children.
- *Women’s caregiving services not recognized*- The women’s caregiving services (care and support) were not recognised by policy makers. Although these women provided the bulk of primary care giving services to the children living with HIV and AIDS, this was not acknowledged and thus, they were not supported adequately.
- *Challenges faced by women caregivers*-Women caregivers had many challenges related to caring for a child living with HIV and AIDS in very limited resource setting of rural areas of Malawi. The major challenge was lack of material, monetary and food support for them to take care of children living with HIV and AIDS.
- *Gender issues*- An important finding was the impact of gender on these women’s experiences. Women caregivers were controlled by their husbands and they were not able to make decisions about their own health. Their respective husbands were making such decisions. This was a culturally sensitive finding and women caregivers were powerless and this placed them at increased risk of contracting HIV and AIDS.
- *Highly resilient and motivated*-Despite the challenges, women caregivers were resilient and highly motivated in caregiving to children living with HIV and AIDS.
- *What next?*-The findings have implications for policy and practice, as well as further research which needs to be undertaken.

Chapter 1a

Introduction of the thesis

Title

The experiences of women caregivers looking after a child living with HIV and AIDS in rural Malawi

Motivation for the study

Twelve percent of Malawi's population is living with Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS) (MDHS, 2010). The HIV and AIDS pandemic in Malawi challenges individuals, families, traditional institutions, government and non-governmental organizations to provide support and long term care to patients living with HIV and AIDS, patients dying of AIDS and to their caregivers since it was first identified in Malawi in 1985 (NAC, 2003 and NSO, 2004a). In addition to this challenge, there is very little information about how caregivers of children living with HIV and AIDS manage the burden of caring for such children especially in the rural areas of Malawi. Support and care are crucial resources for the sick and their caregivers and yet without documenting personal, specific, culturally sensitive needs of caregivers and the person living with HIV and AIDS and the way they deal with their conditions, resources may be spent inappropriately without benefiting the individual and their caregivers (Popper, et al. 1999a). In Malawi to date, very little is known about the caregivers experiences as they support and care for those children living with HIV and AIDS. Understanding the needs, issues and problems caregivers and patients face and the type of care and support caregivers of children living with HIV and AIDS get for their sick children will assist institutions to identify gaps in care and support as well as determining the culturally specific context of the care and support needed.

Aims and objectives

The main research questions were: 1) what are the roles of traditional, social and clinical institutions in care provision and support to children living with HIV and AIDS and their caregivers? 2) What are the experiences of caregivers of children living with HIV and AIDS as they provide the care to such children? The main aim of the study was to examine how women caregivers manage their living and health care needs, cope with the disease, and care for themselves and their sick children with the overall purpose of enhancing the quality of care and support those women caregivers provide in rural areas of Malawi. The aims and objectives were achieved by using in-depth qualitative research methods to understand the experiences of this hidden population of carers of children living with HIV and AIDS. This then formed the basis for evaluating the adequacy of individual, family, traditional and institutional support for this population within rural Malawi.

The philosophical frame work

The philosophical theoretical framework that was utilized to inform this study and that was used as a “lens” to look at the world of caregiving of children living with HIV and AIDS was the narrative framework. The narrative approach was found to be relevant to this study because its principles are consistent with storytelling, and the women caregivers expressed their caregiving experiences of looking after a child living with HIV and AIDS in rural Malawi through storytelling.

Research design, data collection methods, analysis and presentation

The study used a longitudinal descriptive qualitative research design. Data collection involved in-depth interviews with women caregivers (n=20) and direct observations of the environment where care was taking place and of a local Rural Hospital to explore primary care and support for this particular type of clientele (patient) population. Data collection took place within the Mponela Rural Hospital catchment area (2011-2012). Thematic data analysis was carried out to represent the experiences of carers and detailed narrative analysis of one caregiver has also been

carried out to better understand how women constructed their stories in their own particular cultural context.

Thesis overview

This section introduces all chapters for this study that have formed the structure for the thesis.

It should be noted that HIV is commonly called “*Kachilombo*” in local dialect of Chichewa which means “*a small animal*” in English. The name “*small animal*” is a polite and a respectful name to describe HIV to avoid embarrassing the person infected. This term is used in data extracts throughout the thesis.

Chapter 2: The global emergence and identification of HIV and AIDS

This chapter covers the history of Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS), its prevalence, epidemiology, diagnosis and classification, disease progression and HIV testing and treatment. HIV and AIDS are global health emergencies (WHO, 2009). They have affected almost each country worldwide (UNAIDS, 2009; WHO, 2009). In those countries that are most affected, individuals are either infected or are affected with HIV and AIDS. Those who provide care for individuals who are infected with HIV are affected in terms of physical caring, and emotionally, psychologically and economically (UNAIDS, 2009; WHO, 2009).

Chapter 3: Literature review of caregiving in the context of HIV and AIDS

Within this literature review chapter, the discussion focused on the literature related to living with long-term chronic conditions such as HIV and AIDS and the experiences of care giving for such conditions more broadly. The literature review takes the form of a narrative review, underpinned by a systematic literature search. This chapter also shows data bases that were used. This chapter is informed by a sociological perspective on caring, mainly focusing on the gendered nature of care in general and childcare in particular, how women combine work and child care, and

the importance of local context and culture in the decisions people make about caring, work and parenting. The wider issues of caring for healthy children are discussed first, before reviewing the literature focused on caring for children with chronic conditions and the particular challenges of caring for children affected by HIV and AIDS.

Chapter 4a: Methodology

This chapter has discussed the methodology for this study which embraced principles from one of the theories of social science namely the narrative approach. The study objectives and aims, the setting, sample, sample size and sampling methods are discussed to form a thread that is consistent with the methodological outline for this study. The reasons why the narrative approach was selected for this study are discussed in this chapter too.

Chapter 4b: Research Methods

This chapter discusses the methods that this study used: In-depth interviews (IDIs) and Direct Observations (DO). This chapter also covers the study aims and objectives, the study design, setting, population, sample size, sampling method, inclusion and exclusion criteria. How the study was conducted is explained, including enrolment, recruitment process, data collection procedures, approach to data analysis, and field experiences finally trustworthiness and methodological issues are considered.

Chapter 5a: Case study: The story of Mayi Salima (Pseudonym)

This chapter discusses one woman caregiver's story and provides an in-depth narrative account about how she cared for her child living with HIV and AIDS in her village. This specific woman's story was chosen because her story had exemplified some of the key features in the wider perspective in terms of marital problems and how she had struggled on her own to get food and other resources for her family. She also demonstrated special skills and knowledge of caring for her child who was living with HIV and AIDS in the rural setting of Malawi and was able to describe her

experiences in great detail and showed commitment to be interviewed as she walked a long distance to find the research team at the hospital. In short, she was a good story teller regarding her experiences of looking after a child living with HIV and AIDS in rural setting of Malawi.

Chapter 5b: Narrative summaries of each woman caregiver

Chapter 5b provides narrative summaries for each woman caregiver interviewed in this study and grouped them within the overarching key themes. The narrative summaries are grouped into major themes, for example, caring responsibilities where the narrative summaries of Mayi Dowa, Mayi Kasangadzi and Mayi Machentche are grouped to show the ways in which the women's narratives reflected this theme. The other grouping of narratives includes the invisible nature of caring (n=5), husbands making the decisions (n=5), disclosure and stigma (n=3), resilience and challenges (n=3). Please note that Mayi Salima's narrative summary is not included.

Chapter 6: How women caregivers discover their HIV status and their experience of the diagnosis

This chapter is about the study findings on how women caregivers discovered their HIV status and their experience of this diagnosis. This chapter also shows that women caregivers were interviewed for the first time about their family lives in general and specifically about their caring experiences of children living with HIV and AIDS among other findings. In this study, all women were primary caregivers to their children living with HIV and AIDS in rural Malawi. They had similar limited resources and lived in a similar rural environment and the general care they provided included feeding the child, washing clothes, bathing, giving medicines, providing a good sleeping place, cleaning the house and taking the child to the hospital when necessary.

Chapter 7: HIV and AIDS disclosure and stigma

This chapter discusses the findings related to HIV and AIDS disclosure and stigma. HIV and AIDS disclosure and stigma issues are a very important consideration in HIV prevention and control because if individuals disclose their HIV status, they may have accepted to live positively with it and therefore can help prevent its spread (UNAIDS, 2010; UNDP, 2009). These women caregivers interviewed in this study described in the narrative form how they lived with the disease and their disclosure practices.

Chapter 8: HIV and AIDS caring responsibilities

This chapter covers the findings on the caregivers' responsibilities as they looked after their children living with HIV and AIDS in rural Malawi. All twenty women caregivers described their child's illness as a heavy burden in the face of poverty in the rural areas of Malawi in general and in their families in particular. Caring a child who has a life long illness such as HIV and AIDS was a difficult task as they reported in their storytelling of the caregiving experiences. In addition to looking after the child living with HIV and AIDS, they also talked of taking care of their other children who were HIV negative. However, these women demonstrated that they were highly motivated and resilient in looking after their children.

Chapter 9: The Clinical care and support available for children and their caregivers living with HIV and AIDS in rural Malawi

This chapter of the findings focused on the caregivers of children living with HIV and AIDS that live in rural areas of Malawi on the care and support that is available to them and their children. Individual care and the support available to care for children living with HIV and AIDS were examined too. The evidence discussed is based on the data generated by this research from the field notes and observations made at Mponela Rural Hospital and extracts from the data are included to illustrate the discussion.

Chapter 10: Discussion and Recommendations

Chapter ten is the final discussion and recommendations chapter for this thesis where key issues as discovered by this study are discussed. The key findings relate to the extensive caring responsibilities of the women, which are invisible and not recognised; the challenges they experienced; how they managed disclosure and possible stigma; and the unexpected finding that these women were resilient and highly motivated caregivers. The strengths and limitations of the study are discussed and recommendations for policy, practice and further research are made. In the chapter 1b that follows the researcher has focused on the background information about HIV and AIDS specifically looking at the global emergence and identification of HIV and AIDS.

Chapter 1b

Background: The global emergence and identification of HIV and AIDS

Introduction

This chapter sets the scene and provides a background to the study and describes the history of the emergence of Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS) as one of the most politicized, feared and controversial diseases in the history of modern medicine - a reputation that stands today (CDC, 1982a). It goes on to examine the classification and diagnosis of the condition, prevalence rates, the modes of transmission disease progression, counselling and testing and treatment and the impact of transmission from mother to child.

History of HIV and AIDS

Although Africa is generally considered as the origin of HIV and AIDS, first reports appeared in various publications in the United States of America (Nicholas and Frederic, 2010; Centres for Disease Control and Prevention (CDC), 1982a). At the beginning of the 1980s various reports began to emerge in California and New York of a small number of men who had been diagnosed with rare forms of cancer and/or pneumonia (Centre for Disease Control and Prevention (CDC), 1981). The cancer, Kaposi's sarcoma, had previously only affected elderly men of Mediterranean or Jewish heritage and young adult African men (Black, 1986; CDC, 1982b), while pneumonia, *Pneumocystis Carinii* Pneumonia (PCP), was generally only found in individuals with seriously compromised immune systems (Shepard, 1997). However, these men were young and had previously been in relatively good health (Shepard, 1997; Black, 1986) and the only other characteristic that connected them was that they were all gay (Black, 1986).

The first official documentation of the condition was published by the US Centre for Disease Control and Prevention (CDC) on 5th June 1981 (CDC, 1982a). Entitled "*Pneumocystis Pneumonia – Los Angeles*", the report detailed the cases of five young gay men hospitalized with serious PCP, cytomegalovirus, and disseminated

candida infections (CDC, 1982c). By 1982 the condition had acquired a number of names - GRID (gay-related immune deficiency), 'gay cancer', 'community-acquired immune dysfunction' and 'gay compromise syndrome' (Oswald, et al., 1982). It was not until July in 1982 at a meeting in Washington, D.C., that the acronym AIDS (Acquired Immune Deficiency Syndrome) was suggested (Grmek, (1990). The CDC used the term for the first time in September 1982, when it reported that on average of one to two cases of AIDS were being diagnosed in America every day (Grmek, 1990). At that time within the popular press, AIDS had become a disease of the "four H club" – homosexuals, heroin addicts, haemophiliacs and Haitians – even though there had been cases among non-drug users, non-Haitian women and children (Grmek, 1990). The absence of HIV discovery had led to rapid and silent spread of this epidemic (UNDP, 2009), which, coupled with the lack of HIV testing brought untold suffering to the patient populations (WHO, 2006).

Initially the mode of transmission appeared to be restricted to injections and men who had sex with men (CDC, 1982a). However, by 1985, HIV and AIDS cases started to be reported in different countries affecting not only men having sex with men but heterosexual groups (WHO, 2006). During that time, various potential causes were considered, including: lifestyle factors, chronic drug abuse and many other infectious agents (Nicholas and Frederic, 2010). HIV was not identified until two years later in 1983 (Nicholas and Frederic, 2010).

Countries in Africa started reporting more and more cases of HIV and AIDS more than any other continent in the world (UNDP, 2009; WHO, 2006). Sub-Saharan Africa, reported more than the rest of Africa by the end of 1990s (WHO, 2006). Currently, countries in Sub-Saharan Africa still report more cases of HIV and AIDS than any other continent in the world (WHO, 2009; WHO, 2006). Among HIV and AIDS issues that are reported in countries (particularly in Sub-Saharan African countries) include but not limited to stigma, discrimination, increased rates of HIV infection (prevalence rates) and political inaction to combat the HIV and AIDS (UNAIDS, 2009; WHO, 2006). The first published reports on HIV and AIDS have shown the Americans were the first to do so in its early stage but there was political inactivity and lack of commitment by politicians at all levels. The paragraphs that

follow discuss stigma, discrimination and political inaction in countries around the world in general.

Stigma, discrimination and increasing prevalence of HIV and AIDS

From the outset, a diagnosis of HIV and AIDS was associated with a high level of discrimination and stigma (Altman, 1983). This prejudice arose in part because HIV and AIDS was linked to groups, such as gay men and intravenous drug users, that were already highly stigmatized, but also because evidence-based information about what was causing AIDS, and how it might be passed on, was inadequate (Simons, 1983; Altman, 1983). While most of the scientists investigating AIDS already strongly suspected that it was related to sexual contact and the transfer of contaminated blood, there was no definitive evidence at the time to prove these were the only routes of transmission (Black, 1986). Jacobs (2004) further contends that for a while the American government completely ignored the emerging AIDS epidemic. In a press briefing at the White House in 1982, a journalist asked a spokesperson for President Reagan

“...does the President have any reaction to the announcement – the Centre for Disease Control in Atlanta, that AIDS is now an epidemic and have over 600 cases?”

The spokesperson responded - *“What’s AIDS?”* To a question about whether the President, or anybody in the White House knew about the epidemic, the spokesperson replied, *“I don’t think so”* (Jacobs, 2004).

Centres for Disease Control and Prevention (CDC) (1988) further acknowledge that while the United States of American federal government failed to respond to the epidemic, a number of non-governmental organizations (within USA) were founded in most affected areas of America, such non-governmental organizations as The Kaposi’s Sarcoma Research and Education Foundation in San Francisco (later renamed the San Francisco AIDS Foundation) and, in New York, Gay Men’s Health Crisis (GMHC). In 1982 GMHC distributed 50,000 free copies of its first newsletter about the syndrome to hospitals, doctors, clinics and the Library of Congress (CDC, 1988). By 1985 the US government had given five pharmaceutical companies

licenses to develop a test, and in March in 1986, the first blood test for identifying antibodies to HIV was made commercially available (Abbott, 2008). The test was produced by Abbott Laboratories, and soon began to be used in a number of blood transfusion centres (Grmek, 1990; Abbott, 2008). At that time 73 cases of haemophilia-associated AIDS had been reported (Grmek, 1990; Abbott, 2008). It is estimated that by 1986 (when a heat treatment was introduced to kill HIV in blood products), more than half of all haemophiliacs in America had become infected with the virus (Grmek, 1990).

The Centre for Disease Control and Prevention (CDC) (2008) estimated that at the end of 2006, 1.1 million adults and adolescents (prevalence rate: 447.8 per 100,000 population) were living with diagnosed or undiagnosed HIV infection in the United States. The majority of those living with HIV were non-white (65.4%), and almost half (48.1%) were men who have sex with men (MSM) (CDC, 2008). The HIV prevalence rates for blacks (1,715.1 per 100,000) and Hispanics (585.3 per 100,000) respectively, was 7.6 and 2.6 times the rate for whites (224.3 per 100,000) (CDC, 2008). CDC (2008) further explain that among the estimated number of persons living with HIV at the end of 2006, 46.1% (1,715.1 per 100,000 population) were black, 34.6% (224.3 per 100,000) were white, 17.5% (585.3 per 100,000) were Hispanic, 1.4% (129.6 per 100,000) were Asian/Pacific Islander, and 0.4% (231.4 per 100,000) were American Indian/Alaska Native (CDC, 2008). Males accounted for 74.8% of prevalent HIV cases (685.7 per 100,000). It is worth noting that it was the grassroots communities most affected, who led the way in research related issues concerning HIV and AIDS (CDC, 2008).

CDC (2008) highlighted that the greatest percentage of cases was attributed to male-to-male sexual contact. This accounted for 48.1% overall cases and 64.3% for men only (CDC, 2008). High-risk heterosexual contact, defined as heterosexual contact with a person known to have, or to be at high risk for HIV infection (e.g., an injection drug user) accounted for 27.6% of prevalent cases overall (12.6% of cases among men and 72.4% of cases among women) (CDC, 2008). Injection drug use (IDU) accounted for 18.5% of total cases (15.9% of cases among men and 26.3% of cases among women) (CDC, 2008). The remaining cases were attributed to men who reported both male-to-male sexual contact and IDU (5.0%) or whose

transmission category was classified as others (0.8%; including haemophilia, blood transfusion, perinatal exposure, and risk factors not reported or not identified) (CDC, 2008). Overall, an estimated 232,700 (21.0%) persons living with HIV infection had not been diagnosed as at the end of 2006 in the United States of America (CDC, 2008). The discussion that follows focuses on the origins, classification and transmission of HIV.

The origins, transmission, and classification of HIV

Origins

In their study of genetic diversity and geographic distribution of HIV, Peeters et al., (2008) traced the emergency of human immunodeficiency virus HIV 1 and HIV 2. They suggest it resulted from interspecies transmission from simian viruses (SIV) (Peeters et al., 2008). SIVcpzPtt infecting chimpanzees, and from which the HIV 1 (subgroups M and N) is derived (Peeters et al., 2008). This is still found within the Pan Troglodyte's population of southern Cameroon chimpanzees where the study was conducted (Peeters et al., 2008). Scientists agree that interspecies transmission between humans and sooty Mangabey monkeys (implicating SIVsmm from sooty Mangabey monkeys) have occurred because the practices of hunting and meat preparation in the bush still expose humans in Africa to SIV infection to this very day, and new interspecies transmission of these viruses may remain a possibility (Peeters et al., 2008; Hirsch et al., 1989; Popper et al., 1999).

There are two distinct types of HIV, HIV- 1 and HIV- 2 and each are composed of multiple subtypes called clades (Gao et al., 1999). All clades of HIV tend to cause similar diseases, however, the global distribution of the clades differs (Hirsch et al., 1989). Genetically, HIV1 and HIV 2 are superficially similar but each contains unique genes and its own replication process (Hirsch et al., 1989). HIV 2 has a slightly lower risk of transmission and HIV 2 infection tends to progress more slowly to acquired immunodeficiency syndrome (AIDS) (Popper et al., 1999; Hirsch et al., 1989). This may be due to a less-aggressive infection rather than a specific property to virus itself (Popper et al., 1999). Mellors et al., (1997) and Popper et al., (1999) further discovered that persons infected with HIV -2 tend to have a lower

viral load than people with HIV- 1 infections. HIV- 2 is rare in the developed world, and has been researched less than HIV -1 (Rodrick et al., 2006). This feature has implications for vaccination development endeavours (Hirsch et al., 1989) and has led to the situation where, most research for vaccine and drug development focuses mainly on HIV 1 (Rodrick et al., 2006). This may also be the reason that societies have responded differently to HIV - 1 and HIV -2 epidemics, because more emphasis is placed on HIV- 1 (Rodrick et al., 2006). The modes of transmission of HIV have been extensively studied and are discussed in the next section.

Modes of transmission of HIV

HIV is generally a sexually transmitted infection with the other major modes of transmission the direct exchange of blood and blood products and from mother to child (WHO, 2009; UNAIDS, 2010). However, it is important to note that the most common route varies from country to country and even city to city, reflecting the population in whom HIV was first introduced and the local practices (WHO, 2008; WHO, 2006).

Mother to child transmission of HIV

One of the key health problems in relation to HIV infection is the transmission of HIV from the mother to the child (UNAIDS, 2009). In 2002, an estimated 800,000 children were infected with HIV-1 through mother to child transmission and more than 90% were in resource poor countries such as Malawi, Uganda and Zimbabwe (Jackson et al., 2003). In 2005, it was estimated that 280, 000 to 360, 000 infants were newly infected through breastfeeding alone worldwide and majority of these were in resource poor countries (Coovadia et al. (2007). In contrast, in more developed countries, the transmission from mother to child of HIV -1 has been drastically lowered because of the use of Paediatric AIDS Clinical trials Group (PACTG) 076 zidovudine regime that is given to mothers during pregnancy (Jackson et al., 2003).

Mother-to child transmission of HIV-1 infection can take place during pregnancy, the intrapartum period, or postnatally (Leroy et al., 1998). Unborn children to HIV-1

infected mother have a high risk of acquiring HIV – 1 while in the uterus or during breastfeeding (Newell and Bryson, 1997). HIV-1 transmission from an infected mother to her child is estimated to be responsible for more than half of all the transmissions occurring in late pregnancy (Guay, et al., 1999). This is because as the placenta becomes mature its polarity makes it easier for the HIV – 1 to cross over to the child from the mother (Leroy et al., 1998). To minimise or prevent these infection scenarios, research has shown that administering antiretroviral medicines such as zidovudine or nevirapine to the pregnant mother has proved to be a success (Guay et al., 1999) and reduces mother to child transmission by at least 37 to 38 percent (Jackson et al., 2003). Coutoudis et al. (1999) states that the provision of antiretroviral treatment such as zidovudine or nevirapine to women during pregnancy, neonatal, and breastfeeding periods, is an important strategy and offers a less complex and more affordable approach in less developed countries. Once clinical features of HIV and AIDS are manifested and the woman is diagnosed HIV positive, then antiretroviral medicines must be commenced so that the risk of mother to child transmission is minimised (Jackson et al., 2003). The following paragraphs focus on classification, diagnosis, testing and treatment of HIV and AIDS.

HIV disease staging and classification

There are two HIV disease staging and classification systems currently in use (WHO, 2007), the U.S Centres for Disease Control and Prevention (CDC) and the World Health Organization (WHO) system (WHO, 2007). In both systems of HIV disease staging and classification, a simple laboratory assessment of HIV seropositive has to be performed and then the patient is confirmed HIV positive before proceeding with the staging and classification process (WHO, 2007). The discussion will first focus on the CDC HIV disease staging and classification system.

The CDC HIV disease staging classification and system: The CDC HIV disease staging and classification system assesses the severity of the HIV infection by CD4 cells count and by the presence of specific HIV-related conditions (WHO, 2007 and AIDS Education and Training Centres (AETC), 2009). The bench mark for AIDS definition is the CD4 cell count of <200 Cells/microL or CD4 percentage of <14 (CDC, 1999). The patient should also have HIV related conditions and symptoms

(WHO, 2009; CDC, 1999). The CDC staging and classification system is mainly used in clinical and epidemiologic settings with good and up to date laboratory equipment and well trained laboratory technicians (WHO, 2007). The CDC system was last reviewed in 1993 but is still a reliable system to use (CDC, 1999). See appendix 1 for the table of CDC HIV disease staging and classification system.

The WHO HIV clinical staging and disease classification system: The WHO clinical staging and classification system, unlike the CDC system, can be used in resource poor settings, without access to CD4 cells count measurement or other diagnostic and laboratory testing methods that may be expensive (WHO, 2007) such as the site of this study. The WHO system uses mainly the clinical manifestations of HIV (WHO, 2007). The clinical manifestations of HIV infection may be easily recognised and treated by clinicians in diverse settings, resource poor settings and by different clinicians with different levels of training, knowledge and expertise (WHO, 2009). The WHO developed this system of HIV disease classification in 1990 and revised it in 2007 (WHO, 2007). (See appendix 2 for the tables of WHO HIV clinical disease staging and classification). The section that follows focuses on treatment for HIV and AIDS.

Treatment for HIV and AIDS

In the early years of this epidemic in America, treatment for people diagnosed with AIDS consisted mainly of suppressing opportunistic infections (CDC, 2008). For more than a decade, the only real treatment options for people living with HIV and AIDS were suboptimal single or dual antiretroviral therapies, nutrition, care, and support (Teixeira et al., 2001; CDC, 2008); CDC, 2008). The first HIV and AIDS medicines were introduced in USA in 1987 (CDC, 2008). Zidovudine, also called Retrovir (AZT) was a drug that had previously been used (though not successfully) to treat cancer (CDC, 2008). The drug had toxic side effects and was initially very expensive; however, for most people living with HIV and AIDS it offered the only chance of survival (CDC, 2008). Other drugs were introduced in late 1980s and early 1990s, but the breakthrough occurred in 1996 when protease inhibitors were introduced that were truly effective and the “triple combination” therapy meant that people were able to suppress HIV on a long-term basis (CDC, 2008; WHO, 2009,

UNAIDS, 2009). From that time on, millions of HIV positive Americans have taken antiretroviral (ARVs) medicines to keep their HIV infections under control (WHO, 2009; CDC, 2008). Although life for many HIV positive people in America may not be as difficult as for those living in resource limited parts of the world, there are still many challenges (WHO, 2009; UNAIDS, 2009). Apart from facing discrimination, both socially and in the employment, many people living with HIV and AIDS also struggle to afford and access antiretroviral treatment and general HIV care (WHO, 2009; UNAIDS, 2009 and CDC, 2008). With proper HIV counselling and testing, some strides in HIV and AIDS treatment, care and support can improve the lives of those infected because HIV counselling and testing (HTC) is the main step in the control of the epidemic (WHO, 2009; UNAIDS, 2009). HIV counselling and testing is the next section that will be discussed.

Strategies for the identification and management of people with HIV: counselling and testing

HIV counselling and testing (HTC) is a critical individual decision stage in the diagnosis and management of HIV and AIDS (WHO, 2009; UNAIDS, 2009). Counselling is conducted prior to an HIV test because it has the potential of producing stress and emotional feelings in a client, whatever the results may be (UNAIDS, 2010). When the results are negative, this may mark a turning point for a change in risk behaviours (WHO, 2007). When the results are positive, it is another turning point but with much psychological trauma that may lead to catastrophic consequences on the life of the patient (WHO, 2009; UNAIDS, 2009). Individuals may consider it as a death sentence (UNAIDS, 2009). Therefore, HIV testing and counselling calls for a greater responsibility for both the counsellor and the patient (WHO, 2009; UNAIDS, 2009). In order to achieve a less traumatic post-test experience, there are strategies for counselling that may be followed (UNAIDS, 2009). HIV and AIDS Counselling is a process that takes time and resources to accomplish desired results (UNAIDS, 2009). Effective HIV and AIDS counselling has to be done in private, in secluded rooms away from any disturbances and three sessions must be conducted before the HIV test is done to ensure that the client has understood the implications of the results either way such as positive results or negative results (UNAIDS, 2009 WHO, 2007).

HIV counselling and testing (HTC) requires a great sense of professionalism on the part of the counsellor and a sense of responsibility and accountability on the part of the patient (WHO, 2007). HTC requires a minimum of three sessions of counselling before the individual is tested even if the individual volunteers to be tested (WHO, 2009; UNAIDS, 2009). This is to ensure that the patient has an informed HIV testing and may accept the results with minimal psychological trauma (UNAIDS, 2009). In order to avert a crisis (whatever results may be) there are proven strategies for HIV counselling and testing (UNAIDS, 2009). In the United States of America for example, there are established guidelines approved in 1993 by Centres of Disease Control and Prevention (CDC) where individuals have a choice of either being tested by using an anonymous or confidential strategy (CDC, 1999).

The strategy of anonymous HIV counselling and testing has changed the HIV surveillance in the USA and has increased HTC uptake in many USA clinics (WHO, 2009; CDC, 1999). However, although the HIV testing and counselling uptake was increased, patient surveillance was low as it was difficult to follow up patients (CDC, 1999). In contrast, the confidentiality strategy requires that the patient's name and results are known by the clinic and by a few staff (AIDS Education and Training Centre (AETC), 2009). The patient's name is clearly marked on the blood sample taken under strict confidentiality rules (AETC, 2009; CDC, 1999). This approach has a lower uptake than an anonymous clinic because patients do not trust that confidentiality will be adhered to (CDC, 1999; AETC, 2009). In Maryland State in USA for example, the uptake of HIV surveillance using non-name-based unique identifiers document (anonymous) had recorded 50% incomplete reporting because of the uniformity in the codes that made it difficult to delineate individuals for reporting (CDC, 1999; AETC, 2009). Maryland State therefore reverted to a strategy where a unique code (confidential) was linked to a patient name in the records for easy surveillance of HIV patients (AETC, 2009; CDC, 1999). This method improved the statistical records to 88% because patients were followed properly (AETC, 2009; CDC, 1999). However, the uptake did not improve because of the confidentiality strategy as discussed earlier (AETC, 2009). The following section focuses about the future of HIV treatment.

The future of HIV treatment

Preventative vaccine trails have been conducted in East African countries (Kibuuka et al., 2010) and the results revealed that the HIV vaccine was safe and tolerated by research subjects and that HIV-specific T cell responses were detected in 63% of the research participants (Kibuuka et al., 2010). This vaccine trail again offers a window of hope for a more elaborate vaccine trail regimen for HIV because it appears that the vaccine is well tolerated by the T cells thereby improving the immune system (Kibuuka et al., 2010). However, there is no conclusive support that points to the development of drugs or vaccines that will cure or prevent HIV infection.

According to NIAID (2010), the key focus of research has been the development and testing of HIV vaccines, prevention strategies and new treatments for HIV. However, the future focus of research according to (NIAID, 2010) includes:

- Control of sexually transmitted infections
- Modification of personal behaviours
- Pre-exposure prophylaxis (PrEP)
- Ways to prevent transmission from mother to child.

Conclusion

This chapter has discussed the emergence of HIV and AIDs and shown that it is still a global health problem (WHO, 2009; UNAIDS, 2009). It has also described HIV and AIDS disease staging and classification, diagnosis and treatment of people living with HIV and AIDS (WHO, 2009; CDC, 1999). It has also discussed the two types of HIV, thus HIV 1 and HIV2 their related distribution. It has explored the different ways in which diagnosis and treatment options are directed to key populations in both resource rich and resource limited settings. In the next chapter, the discussion will focus on the impact of HIV and AIDS in Africa including Sub-Saharan Africa where Malawi as a country is geographically situated.

Chapter 2

The Impact of HIV and AIDS in Sub-Saharan Africa and Malawi

Introduction

In the previous chapter, the discussion centred on the history of the emergence of HIV and AIDS, and understandings of the classification and diagnosis of the conditions. This examined the modes of transmission and the transmission from mother to child, disease progression and HIV counselling and testing and treatment. In this chapter, the discussion focuses on the impact of HIV and AIDS in a resource-poor setting: Sub Saharan Africa. It will examine how the countries' most heavily affected in the region, Malawi, Zambia, Mozambique and South Africa.

HIV and AIDS have caused great economic and social burden in these countries (UNAIDS, 2009; UNDP, 2008) and has reduced life expectancy by more than 20 years, slowed economic growth, and worsened household poverty (UNDP, 2008). The natural age distribution in many national populations in sub-Saharan Africa has been dramatically reduced by HIV, with potentially dangerous consequences for the transfer of knowledge and values from one generation to the next (UNDP, 2005). In addition, the 'cultural safety nets' such as community help for a family faced with a chronic illness have vanished (UNDP, 2005) because all families within the communities are either infected or affected (UNAIDS, 2010). In sub-Saharan Africa alone, the epidemic has left almost 12 million children aged less than 18 years as orphans (UNDP, 2008, UNDP, 2005). This chapter in short, will explore global policies on HIV and AIDS, the impact on HIV and AIDS in Southern African countries, underlying causes of high prevalence rates. It will finish with a discussion of the situation in Malawi to set the scene for the study.

Global policies

HIV and AIDS have prompted mobilization of political, financial and human resources as never before in many countries in the world including the Sub Saharan countries (UNDP, 2005). In addition HIV and AIDS have ignited many challenges

that have led to a strong level of leadership and ownership by the communities and countries most heavily affected (UNDP, 2005). In 2000, global leaders embraced a series of Millennium Development Goals that reflected newfound energy to make the world safer, healthier, and more equitable (UNDP, 2005; WHO, 2008).

Millennium Development Goal 6 states that, by 2015, the world will have slowed and begun to reverse the global HIV epidemic (WHO, 2008). By making the HIV response one of the overriding international priorities for the 21st century, world leaders acknowledged the central role of the HIV response to the future health and well-being of our increasingly interconnected planet (UNDP, 2005; WHO, 2008).

Although world leaders have championed this endeavour, much needs to be done at the implementation level because many developing countries require an enormous amount of resources to achieve this goal (UNDP, 2009a; UNAIDS, 2009). It is therefore not only planning but also implementation that is needed (UNDP, 2009b). For instance, towards the end of the last Century, world leaders developed an agenda to drive forward health issues worldwide and called “Health for all by the year 2000” (UNDP, 2009a). The question is and still remains the same- Did the world achieve this goal? And now with the ambitious “the Millennium goal number 6” are world leaders ready to mobilize resources to achieve this goal among others? Of course there is the global fund set aside to combat HIV and AIDS, malaria and tuberculosis (UNDP, 2009; UNAIDS, 2009). These conditions are all major diseases that require tackling individually and not as a group (UNDP, 2005; WHO, 2008). The danger that may be anticipated is that the resources may be used more on one condition leaving the others aside depending on the magnitude of that condition in a particular region or country (UNDP, 2010). In Sub Saharan African countries for example, the emphasis may be put on HIV and AIDS because it is a major health problem overriding tuberculosis and malaria which have been equally national health problems for many years before the advent of HIV and AIDS (UNDP, 2009a). Malawi is one of the Sub-Saharan African countries and as a signatory to many United Nations statutes including the Millennium Development Goals, has embarked on the implementation of the Goals including goal number 6 (MDHS, 2010). The following discussion focuses on the HIV and AIDS in Sub-Saharan Africa.

HIV and AIDS in Sub-Saharan Africa

Sub Saharan Africa includes over 20 countries, however, the focus here is on Mozambique, Zambia, South Africa, Tanzania because they share borders with Malawi and the cultures are similar, while South Africa has direct trade links with Malawians and hence has an influence on HIV and AIDS policies and practices.

It is estimated that 12 million people have died from HIV-related illnesses since the start of the epidemic worldwide, of which approximately 9 million were Africans (UNDP, 2009b). It follows that the cumulative affected population in Africa taking into account spouses, children and elderly dependents must be of the order of 150 million (WHO, 2008). This is a staggering proportion of the total population in Sub-Saharan Africa - more than one quarter of Africans are directly affected by the HIV epidemic (UNAIDS, 2009) and overall few people can remain unaffected through the illness and death of relatives, friends and colleagues in this region (WHO 2008; UNAIDS, 2009). Sub-Saharan Africa is thus more heavily affected by HIV and AIDS than possibly any other region in the world (Mandell, et al., 2010).

UNDP (2009a) highlight that of the global total of 30 million persons living with HIV and AIDS in 1997, some two-thirds (21 million) were in Sub-Saharan Africa. Ten years later (2007), 22.5 million people living in this region were estimated to be living with HIV infection (Mandell, et al., 2010). In addition, Mandell, et al., (2010) further explains that 61% of this group were women, making the Sub Saharan region the only region in the world where figures of HIV infection in women exceed that of men with infection occurring at younger ages for girls (with girls and young women in some countries outnumbering boys and young men by factors of 5 or 6 in the age range 15-20) (UNDP, 2009a; UNDP, 2008). One consequence of the high HIV infection rates among women is the increasing number of children with HIV (through mother to child transmission of HIV (UNDP, 2009a). HIV infection is also concentrated in the socially and economically productive groups aged 15-45 (UNDP, 2008). The following section discusses the impact of HIV and AIDS in Southern African countries.

There are now many countries in Southern Africa with high HIV infection rates in adults in the range of 20-25% (UNDP, 2009b). The gap between rural and urban

HIV rates that was previously substantial is now narrowing rapidly in many countries because of urbanization that has led to increased migration of rural population to urban areas in search of economic opportunities (UNDP, 2009b) and for some urban populations HIV is now as high as 40-50% (UNDP, 2009b). It is estimated that there are presently some 8 million children in Africa who have lost one or both parents to HIV-related illnesses, and that by 2010 these numbers will have increased to some 40 million (WHO, 2008 and UNDP 2008). In many countries in Africa the proportion of children who have lost one or both parents will be as high as 20-25% by the end of the first decade of the new millennium and many of these will be in Sub-Saharan African countries (UNDP, 2009a). These trends have direct implications for intergenerational poverty and impose immense challenges for policy makers as well as being devastating for families and communities (WHO, 2008).

HIV infection is not confined to the poorest even though the poor account for most of those infected in Africa (WHO, 2006 and WHO, 2008). There is limited evidence for a socio-economic gradient to HIV infection, with rates higher as one move through the educational and socio-economic structure (UNDP, 2009a). It follows that the relationships between poverty and HIV are far from simple and direct and more complex forces are at work than just the effects of poverty alone (UNDP, 2009a). Indeed many of the non-poor in Africa have adopted and pursued life styles which expose them to HIV infection, with all the social and economic consequences that this entails (UNDP, 2008 and WHO, 2008). It follows that the capacity of individuals and households to cope with HIV and AIDS will depend on their initial endowment of assets - both human and financial (UNDP, 2009a). The poorest by definition are least able to cope with the effects of HIV and AIDS so that there is increasing misery for affected populations (WHO, 2008, WHO, 2006 and UNDP, 2009a). However, even the more affluent find their resources diminished by their experience of infection (morbidity and death), and there is increasing evidence in urban communities of an emerging class of those recently impoverished by the epidemic (UNDP, 2009b; UNAIDS, 2009b).

The effects of HIV and AIDS are reflected in the changes to life expectancy which is the best summary indicator of the effects of HIV and AIDS on countries with high levels of HIV prevalence (UNAIDS, 2009a). This data illustrates the demographic

impact of the epidemic on African populations (UNDP, 2008). In many countries in Sub Saharan Africa, adult mortality has doubled and trebled over the past decade and this is directly attributable to HIV and AIDS (UNDP, 2009a and UNDP, 2008).

What is now being experienced by these populations are levels of life expectancy, which were typical of Sub-Saharan Africa in the 1950s. This is not confined to those living in poverty but nevertheless, is concentrated on those living in poverty who account absolutely for most of those who die from HIV-related illnesses (UNAIDS, 2009b). Thus there is a correlation between socio-economic status and infection rates, and between socio-economic status and mortality rates.

This situation reflects HIV infections which occurred in the late 1980s and since then, HIV prevalence in many Sub Saharan countries has intensified rather than diminished (WHO, 2006). For example, in Swaziland, average life expectancy fell by half between 1990 and 2007, to 37 years. In 2008, more than 14.1 million children in sub-Saharan Africa were estimated to have lost one or both parents to AIDS (UNAIDS, 2009; WHO, 2009).

A key question is why Southern Africa as a whole has the highest HIV infection within the Sub Saharan Africa? Mandell, et al., (2010) contend that a multiplicity of risk factors such as the lack of male circumcision, male sexual violence, multiple partnership and migratory patterns seem to create favourable grounds for the spread of HIV in this region. However, no single factor is responsible for this scenario because the influence of these factors differ in countries within the region (Mandell, et al., 2010). The following section centres on countries with close geo-political links with Malawi.

Countries with close geo-political links to Malawi

This section will explore the countries with close links to Malawi thus South Africa, Zimbabwe, Zambia, Mozambique and Tanzania. Malawi shares borders with Tanzania to the north, Mozambique to the southeast and Zambia to the west (World Atlas, 2012). Mozambique and Zambia are in the Southern Africa region while Tanzania is in the East Africa region (World Atlas, 2012). Malawi, Zimbabwe and Zambia were once one country called Rhodesia and Nyasaland during the colonial rule and the tribal groupings are similar too (Phiri, 2009). This means that the culture

in these three countries is similar and they share many day to day cultural features such as diet (UNDP, 2009a). The borders of these three countries are porous and people cross borders at will and at any point (UNDP, 2009b). Some families live across these countries and hence the culture is similar (UNDP, 2009a). South Africa does not share borders with Malawi directly, however, it has a great influence on Malawian because of its close direct trade links with Malawi (UNDP, 2009b). In addition, there has been inter-marriages among residents of these two countries for many years (WHO, 2009; UNAIDS, 2009; UNDP, 2009b).

HIV and AIDS in South Africa

HIV and AIDS are on the increase in South Africa (Mandell, 2010). The lack of political will to control the spread of HIV has also been noticed and now the government of South Africa has acknowledged that HIV and AIDS exist (Mandell, 2010). However, the political will came late as during that period when the politicians were denying the existence of HIV and AIDS, the HIV infection was spreading fast because there was no commitment from the government of South Africa in terms of economic resources to control the spread of HIV (Mandell, 2010).

In South Africa, young women are still disproportionately being infected by HIV as compared to young men (Mandell, 2010). A national household survey carried out in 2005 in South Africa, showed that 15.5% of women aged 15 to 24 years were infected with HIV in comparison with 4.8% of young men (Mandell, et al., 2010). Mandell et al (2010) insists that the increased partner numbers and inconsistent use of condoms were hugely associated with HIV infection. The survey further revealed that young men who attended at least one educational programme on behavioural change were less likely to be infected with HIV (Mandell, et al., 2010). Therefore, an understanding of sexual networks is crucial to comprehend the rapid heterosexual spread of HIV and its disproportionate effect on women more especially in the whole Southern African countries including Mozambique (Mandell, et al., 2010).

Mozambique

The borders between Malawi and Mozambique are political in nature (UNCEF, 2008) and people have relatives that live in either of the two countries and have

gardens either in Mozambique or Malawi (UNCEF, 2008). Most Mozambiquans do their shopping in Malawi cities and use Malawi currency (the Kwacha) because it is too far for them to go to Maputo which is about a thousand kilometres while Lilongwe, the capital of Malawi is just 200 kilometres or less (UNCEF, 2008). Levels of AIDS infection has just started to level off in Mozambique (UNICEF, 2008) with the latest data indicate a prevalence rate of 16 per cent among the 15 to 49 year old population against a population of 19.1 million people. An estimated 1.6 million people were living with HIV or AIDS in Mozambique in 2008 (UNCEF, 2008; Mandell, et al., 2010), with an estimated 450 people becoming infected every day (UNICEF, 2008).

Zambia

It is estimated that 920,000 people in Zambia are infected with HIV out of a total population of approximately 12.3 million (UNAIDS, 2009). Sixteen percent of Zambian adults are HIV+ (women - 18%, men - 13%) (UNAIDS, 2009) and in urban areas, two in five women aged 25-39 are infected (UNAIDS, 2009). In addition to those infected, many others feel the impact and usually, family members are either infected or affected by HIV and AIDS (UNAIDS, 2009). The number of people dying as a result of AIDS in Zambia is estimated at 89,000 per year, leaving behind a growing number of AIDS orphans, currently estimated at 801,000 (UNAIDS, 2009). Nevertheless, new cases appear to be declining as high-risk sexual behaviours become less common (UNAIDS, 2009). Despite declining incidence, mortality is likely to continue climbing for at least a few more years (WHO, 2009; WHO, 2003).

Knowledge of HIV/AIDS is fairly high in Zambia (WHO 2003, UNCEF, 2008). The Demographic Health Surveys (DHS) conducted in Zambia in 1996 and 2002 reported that the proportion of men and women having ever heard of AIDS remained at 99% (WHO 2003, UNCEF, 2008). By 2002, the survey showed that 77.9% of women and 85.5% of men knew of two or more ways of avoiding HIV/AIDS (WHO 2003, UNCEF, 2008). However, from 1996 to 2002, the percentage of Zambians that believed that there was no way to prevent HIV/AIDS increased for men from 2.3% to 4.2% and decreased for women from 8.6% to 6.1 (UNDP, 2009b; WHO, 2003).

All these countries with close geo-political links to Malawi share similar HIV AIDS prevalence rates, and as we will see in the next section/ later in the chapter, these are comparable to those in Malawi. The following sections discuss the causes of their high HIV and AIDS prevalence rates.

Causes of the high prevalence rates

There are a number of causes of the high rates of HIV and AIDs within these countries (Malawi, Mozambique, and Zambia) and they are all linked to long-standing cultural factors and practices (UNCEF, 2008). The practices of male circumcision, and sexual behaviours that make women particularly susceptible to infection and the underlying context of poverty (UNAIDS, 2010).

Poverty and HIV Infection

UNDP (2009a) and UNAIDS (2009a) argue that it is easier to understand some of these complex issues if the bi-causal relationships are examined, specifically by looking at the stages of the epidemic in order to isolate some of the causal and consequential factors at work. But what needs also to be kept in mind are the aggregative effects of the HIV epidemic, for it will not only impoverish individuals and communities but will also erode the capacity of the socio-economic system through the loss of human resources (UNDP, 2008 and UNDP, 2009b). The characteristics of poverty and some of the causal factors at work which contribute to a "culture of poverty" - the fact that the children of the poor often become the poor of succeeding generations (UNAIDS, 2009b). These are also associated with low levels of human and financial resources, such as low levels of education, associated low levels of literacy and marketable skills, leading to poor health status and low labour productivity as a result (UNDP, 2008).

Households living in poverty typically have few if any financial or other assets and are often politically and socially marginalised (WHO, 2008). These conditions of social exclusion increase the problems of reaching these populations through programmes aimed at changing sexual and other behaviours including care and support for the sick and those that take care of them (WHO, 2006; WHO, 2008). A key aspect of poverty is its impact on health status and high levels of undiagnosed

and untreated sexually transmitted infections (STIs), which is now recognised as a significant co-factor in the transmission of HIV (WHO, 2006). It is not at all surprising in these circumstances that this group adopt behaviours which expose them to HIV infection such as unprotected sexual intercourse and working in the sex industry (UNDP, 2008). It is not simply that information, education and communication (IEC) activities are unlikely to reach people living in poverty (which is too often the case), but that such messages are often irrelevant and inoperable given the reality of their lives (UNDP, 2009a) and they are unlikely to have either the incentive or the resources to adopt the recommended behaviours (WHO, 2006). Indeed to take the long-view in sexual or other behaviours is antithetical to the condition of living in poverty (WHO, 2009a; UNAIDS, 2009a) it is the here and now that matters, and it is argued that policies and programmes that recommend deferral of gratification will, and do, fall on deaf ears (UNDP, 2008; UNAIDS, 2009a).

Even more fundamental to the conditions of poverty is social and political exclusion (UNDP, 2009; UNAIDS, 2009b). It has been suggested that HIV-specific programmes are often neglectful of the interests of poorest groups and are rarely related to their needs, with much of the money intended for such programmes allocated to administration (UNDP, 2008). More generally the absence of effective programmes aimed at sustainable livelihoods, which also limits the possibilities of changing the socio-economic conditions of those living in poverty (WHO, 2006). Thus, unless the realities of their lives are changed, they will continue to practice behaviours which expose them to HIV infection (and all the consequences of this for themselves and their families) (WHO, 2006; WHO, 2008; UNDP, 2008; UNDP, 2009). The paragraphs that follow consider other cultural factors that may influence HIV /AIDS transmission and infection, and which have important implications for prevention strategies

Male circumcision

In Sub-Saharan Africa, the rates of circumcision vary and this has important implications in HIV prevention strategies (Craiel, et al., 2001). In Southern Africa, where one in three adults is infected, in some countries, only 20% of men are circumcised (Bailey, et al., 2007). A study conducted in four cities with different levels of HIV prevalence in Sub Saharan Africa concluded that there was no

association at population level between patterns of risky sexual behaviour and the level of HIV prevalence (Carael, et al., 2001). However, two variables were identified as independent risk factors: the lack of male circumcision and HIV-2 infection (Carael, et al., 2001). In addition, efficacy studies in Kenya, South Africa, and Uganda indicated that male circumcision reduced the risk of female to male sexual HIV transmission by 60%. As a result of this study, WHO and UNAIDS recommended that male circumcision be part of a comprehensive HIV prevention strategy in 2007 (Gray, et al., 2007). However, it is argued that more research is required to determine whether male circumcision provides a degree of protection to the partners of infected men (Bailey, et al., 2007). It is not known if the trial findings were the effect of lower levels of risk behaviour in circumcised men because they were uncertain if they were properly healed from the circumcision (Bailey, et al., 2007). Thus little is known about the long-term behavioural impact, if any of introducing male circumcision (Gray, et al., 2007 Mandell, et al., 2010). Other factors are also important, for example, poverty aggravates the rate of HIV infection because girls and boys need money to buy their life necessities such as food and clothes and are also more likely to take part in high risk behaviours such as unprotected sexual intercourse and sex work (NSO, 2010).

The following section discusses HIV and AIDS among young women and children in Malawi and Zambia.

HIV and AIDS-young women and children in Malawi and Zambia

Girls and young women are more vulnerable to infection because they often lack the power to refuse unsafe sex, to choose their partners, to generally influence sexual behaviour and in addition, are biologically more vulnerable to infection (UNAIDS, 2000). On the other hand, boys may be unable to ignore peer pressure to start having sex at an early age and to have multiple partners and frequent sexual encounters (WHO, 2008; UNAIDS, 2000). In Zambia and Malawi, high prevalence rates are fuelled by cultural factors of early initiation of sex, unprotected sex with non-regular partners, concurrent sexual partnerships, low incidence of condom use among high risk groups and individuals, sexual violence against women, and poverty, that forces

women and girls to sell sex for food, good grades, small gifts, or money (WHO, 2003; UNCEF, 2008).

The most at risk individual in Zambia, however, is the seronegative partner in a discordant couple (a couple where one is HIV positive and the other one is HIV negative and do have unprotected sexual intercourse) . Annually there is an 11.8% seroconversion of negative partners. It is estimated that 21% of couples are discordant in Lusaka (UNCEF 2008).

In addition, other groups at comparatively high risk include highly mobile populations such as migrant workers, sex workers, long distance truck drivers, minibus drivers, refugees, prisoners, uniformed personnel (such as the military and police), and fishmongers because they are away from home for long periods of time and are a transient population (WHO, 2003).

Summary

This review shows the ways in which HIV infection is and remains a challenging infectious disease within sub-Saharan Africa. There is a large body of evidence that suggests that in the Sub-Saharan region, a range of social-cultural practices seem to fuel the rates of HIV. Although these countries share more or less similar cultural practices at a larger perspective, there are distinct differences among the tribal groups within the countries that fuel the transmission of HIV (UNDP, 2009). This is accentuated by poverty, low literacy levels and resistance to change behaviours that all put individuals at risk of contracting HIV (Avert, et al., 2005). This review will now focus on HIV and AIDS in the context of Malawi.

Malawi

Malawi is a small state in the Sub-Saharan Africa and in Southern Africa region and gained its independence from the United Kingdom in 1964 and it is among the poorest countries in Sub-Saharan Africa and Southern Africa region (BBC, 2009). Its population is 13.3 million people (NSO, 2010) and it is surrounded by Mozambique to South and East and Zambia to the West and Tanzania to the North) World Atlas, 2012).



Source: *The Journal of African History* page: 258

Malawi is referred to as the “Warm Heart of Africa” because of the warmth and friendliness of its people (Phiri, 2009). Malawi people are Bantu origin and they comprise many different ethnic groups (Phiri, 2009). These are Chewa, Nyanja, Yao, Tumbuka, Lomwe, Sena, Tonga, Ngoni, Asian, and Europeans (Phiri, 2009; Englund, 2002). The Chewa people form the largest part of the population group and are largely in the central and southern parts of Malawi (Phiri, 2009; MDHS, 2010). The Chewas are presently over 12 million and they occupy a region spanning from

East Zambia through Central Malawi to Northern Mozambique (Englund, 2002; Chimbiri, 2007). Malawians live with their extended families in villages headed by a village headman or village head woman (Phiri, 2009; Englund, 2002) and traditionally there is a spirit of cooperation as family members share both work and resources (Phiri, 2009). The following section discusses poverty, social profile and vulnerability in Malawi.

Poverty, Social Profiles and Vulnerability in Malawi

In Malawi, levels of poverty has not changed significantly for the past seven years (UNDP, 2009b; OPC, 2006) and according to Integrated Household Survey 2004/05, the current status of poverty in Malawi shows that 52.4 percent of the population live below the poverty line (OPC, 2006). This translates into about 6.3 million Malawians who are poor, with the poorest people in the Southern Region and rural areas poorer than urban populations where poverty rates are at 25.0 percent (OPC, 2006).

Female headed households are worse-off and income inequality persists in Malawi with the richest 10 percent of the population having a median per capita income that is eight times higher (MK50,373 per person per annum) than the median per capita income of the poorest 10 percent (K6,370 per person per annum). However, the overall poverty figure masks fluctuations in poverty (MDHS, 2004). That is approximately 30 percent of the poor moved out of poverty during the period, while 30 percent of the non-poor moved into poverty (MDHS, 2010). Malawi also has a very young and rapidly growing population, and this is a key factor explaining Malawi's high and persistent poverty rates (MDHS, 2004). More than half of the poor in Malawi are children (NSO, 2008). This suggests that there is continued economic vulnerability in Malawi. In general, Malawi communities have experienced a decline in social and economic growth in the last 10 years (MDHS, 2010; MDHS, 2004).

Food security is a continuing threat, (OPC, 2006), with the majority of the Malawians living in rural areas where they experience acute shortage of food during certain months of the year (rain season) from December to March (MDHS, 2010;

OPC, 2006). As can be seen from the table that follows, approaches to improve health indicators have been unsatisfactory (OPC, 2006).

Trends of selected health indicators for Malawi

Indicator	Baseline-2004	Malawi Public Regulation Service (MPRS) target	Current situation (2004)
Maternal mortality rate	1,120/100,000 deliveries	400/100,000	1120/100,000
Deliveries conducted by trained health personnel	56%	-	58%
Contraceptive prevalence rate	25%		33%
Infant mortality rate	104/1,000	90	76
Under five mortality rate	189	150	133
Fertility Rate	6.3	5.5	6.0
Children underweight (%)	30	20%	22%
Under 1 immunization rate	54%	-	55%
Impregnated Mosquito Nets (treated mosquito nets) (ITN) Coverage	13%	-	42%
HIV prevalence rate	-	-	12.4%

Source: MDHS 2004

The following section centres on the Malawi and HIV and AIDS.

Malawi and HIV and AIDS

The 2004 Malawi Demographic and Health Survey (MDHS) indicate that HIV and AIDS as well as other Sexually Transmitted Infections (STIs) pose a great risk to the Malawi nation (NSO, 2004). The total number of people infected with HIV was

estimated to be between 700,000 and one million people in 2003 (NSO, 2008) and this includes 60,000–80,000 HIV-positive children under age 15. One-third of those infected live in urban areas and two-thirds in rural areas (NAC, 2004). AIDS related deaths constitute personal, economic, and social tragedies in the lives of surviving family, friends, and employers (NSO, 2004).

In Malawi, the principle mode of HIV transmission is heterosexual contact and perinatal transmission (UNAIDS, 2009). Heterosexual transmission accounts for 90 percent of HIV infections in the country (NAC, 2004b), with perinatal transmission, when the mother passes HIV to the child during pregnancy, delivery or breastfeeding (representing 9 percent of all HIV infections) (NAC, 2004b). It was estimated that approximately 20 percent of babies born to HIV positive mothers will be infected around the time of birth. About one-half of children infected during the perinatal period will die before their fifth birthday (NAC, 2004b). In addition; the children of HIV-infected parents who are not themselves infected are still at a great disadvantage, due to the health and social consequences of possibly losing one or both parents to AIDS. It is estimated that between 1990 and 2003, the number of children under 18 who were living without one or both parents in Malawi grew from about 800,000 to 1.2 million with this increase associated with the result of a sharp rise in the rates of adult mortality (NAC, 2004a). The following section focuses on the policy response of Malawi government to HIV and AIDS.

Policy Response to HIV and AIDS

The future course of Malawi's AIDS epidemic depends on a number of important variables, including the level of public awareness about HIV and AIDS, the level and pattern of risk-related behaviours, access to high quality services for Sexually Transmitted Infections (STIs), and provision of HIV testing and counselling (NAC, 2004b). However, the impact of AIDS is now affecting all sectors of Malawian society, and the nation's response needs to be matched with multiple strategies and interventions (NAC, 2004a). The National AIDS Commission (NAC) is leading efforts to reduce the barriers to effective HIV and AIDS programmes and has identified key challenges and opportunities to properly lead an effective national effort (NAC, 2004b; NAC, 2000). At policy levels, the Malawi government also included HIV and AIDS in its development strategy plan called "The Malawi

Growth and Development Strategy” that had run 2006/7 to 2010/11 period (MDHS,2010). A new policy document to replace that document is under formulation (MDHS, 2010).

WHO/UNAIDS/UNICEF (2009) suggest that the AIDS crisis is one of a multitude of problems currently faced by Malawi, alongside poverty, food insecurity and other diseases such as malaria. These problems are interlinked and the Government has acknowledged that a multifaceted approach is needed to tackle them (OPC, 2006). For instance, programmes to increase access to HIV treatment must run parallel with campaigns that address malnutrition, as ARVs should be accompanied by a good diet to be effective (NAC, 2004a). NAC, (2004a) adds that equally, efforts to strengthen the country’s economy need to be co-coordinated with the fight against AIDS, because one of the most significant economic problems is the lack of human resources caused by AIDS. The following sections discuss the Malawi growth and development strategy amidst the HIV and AIDS epidemic.

The Malawi Growth and Development Strategy

The Malawi Growth and Development Strategy (MGDS) was the overarching strategy from 2006/07 to 2010/2011 fiscal years (OPC, 2006). The purpose of the MGDS was to serve as a single reference document for policy makers in Government; the Private Sector; Civil Society Organizations; Donors and Cooperating Partners and the general public on socio-economic growth and development priorities for Malawi (OPC, 2006). However, the overriding principle of the MGDS is to reduce poverty through sustainable economic growth and infrastructure development (OPC, 2006). The MGDS identified six key priority areas which define the direction the country intends to take in the next five years to achieve economic growth and wealth creation which are critical for immediate improvement in the economic well-being of Malawians (OPC, 2006). These are the key policy priority areas 1) agriculture and food security; 2) irrigation and water development; 3) transport infrastructure development; 4) energy generation and supply; 5) integrated rural development; 6) prevention and management of nutrition disorders, and HIV and AIDS.

The National HIV and AIDS Policy has been formulated in major part to consolidate these efforts, to expand interventions that have great promise and to direct the response to areas that call for attention (OPC, 2003 and NAC, 2003). It is a unique policy in that it is 'home-grown', designed to respond to the particular experiences of Malawi, addressing the specific issues by developing appropriate local strategies. Broad consultation and participation during the development of the policy make it a truly shared vision of how Malawi, as a country in the grip of HIV and AIDS epidemic, should respond (OPC, 2003 and NAC, 2003).

The policy provides technical and administrative guidelines for the design, implementation and management of HIV and AIDS interventions, programmes and activities at all levels of the Malawi society (OPC, 2003). It offers guidance on critical intervention areas, among them, social and economic support for people living with HIV and AIDS (PLWAs). It suggests a response that goes beyond the typical token representation; provision of care and support for treatment to achieve a better quality of life for all Malawians living with HIV and AIDS; and protection of their human rights and freedom (OPC, 2003 and NAC, 2003). People living with HIV and AIDS were represented by those that were HIV positive in consultative meetings that led to the formulation of the policy as well as community key leaders such as chiefs (OPC, 2003). Major issues such as human resources, gender and stigma have been carefully incorporated into the policy (OPC, 2003 and NAC, 2003). It is argued that The national HIV and AIDS policy has helped bring down the HIV prevalence rate from 15% in 1980s and 1990s to 12% in 2000s (MDHS, 2010). This is attributed to effective Information, Education and Communication (IEC) strategies on HIV and AIDS that had helped change in sexual behaviour of the people of Malawi (MDHS, 2010). It is thought that many people (20.3% of Malawi's population) use safe sex practices such as use of condoms (MDHS, 2010). Sixty-one percent (61%) of those people living with HIV and AIDS in Malawi AIDS have access to antiretroviral (ARVs) medicines (MDHS, 2010).

However, recent trends indicate that there has been little progress in reducing poverty. The Human Development Index has stagnated since the mid-1990s (OPC, 2006). While there have been improvements in the education and literacy, the most

recently available statistics show that several health indicators have worsened over the past decade. Among others, the number of physicians per population has fallen by half, and life expectancy has fallen from 46 years in 1987 to 37 years in 2005, largely due to the HIV and AIDS epidemic. Childhood immunization has also decreased from 82 percent in 1992 to 64 percent in 2004 (OPC, 2006). Maternal mortality rates have increased from 620 in 1992 to 960 in 2004, although they are now on a decreasing trend (MDHS, 2010). Child malnutrition has remained virtually unchanged since 1992, and almost half of children under five years of age in Malawi have stunted growth, and 22 percent are severely stunted (DHS, 2004). With these statistics in mind, there are key issues that are directly affected by HIV and AIDS in Malawi. The following sections focus on the key issues surrounding the HIV and AIDS epidemic in Malawi.

Key issues surrounding the AIDS epidemic in Malawi

Human resources

WHO (2009) and NAC (2004 b) contend that one of the biggest challenges currently facing Malawi is the lack of human resources available within the country. In terms of the AIDS epidemic in Malawi, this problem has been most significant in the healthcare sector, where attempts to increase access to HIV testing and treatment have been hindered by a severe shortage of staff (MDHS, 2004). Malawi has just one doctor per 50,000 people one of the lowest levels in the world (UNAIDS, 2009) and has 37 nurses per 100,000 people (Shell, et al. 2011). Around 60 registered nurses are trained every year, but at least 100 others leave the country annually to seek employment abroad (MDHS, 2010). Although funding for healthcare has increased, there are simply not enough trained staff available (WHO/UNAIDS/UNICEF, 2009).

While the shortage of medical staff in Malawi has partly been caused by factors such as immigration and inadequate access to education, it has also been directly aggravated by AIDS (WHO, 2009; UNAIDS, 2009). The National Association of Nurses in Malawi (NONM) revealed in 2008 four nurses are lost to HIV and AIDS related illness every month (MDHS, 2010). HIV prevention and treatment for health care workers is particularly necessary in Malawi if targets to scale up treatment to 245,000 people on ARVs by 2010 are to be met (WHO/UNAIDS/UNICEF, 2009).

HIV and AIDS impact all sectors of Malawi's workforce (UNAIDS, 2010). Many people are either providing home based care for someone with HIV or are suffering from HIV or AIDS themselves, leaving them unable to attend work (UNAIDS, 2010; NAC, 2008; UNDP, 2009). This has particularly affected farming communities, which are based in rural areas where access to HIV treatment is likely to be limited (MDHS, 2010; UNAIDS, 2010). Drought, compounded with farmers and their families dying from AIDS, causes national food shortages (UNAIDS, 2010). As Toby Solomon, commissioner for the Nsanje district describes:

"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." (WHO/UNAIDS/UNICEF, 2009 p. 10)

United Nations Fund for Population Activities (UNFPA) (2001) revealed that it was not only the poorer sections of Malawian society that had been affected by the human resources crisis. In 2000 parliamentary records revealed that 28 Members of Parliament in Malawi had died from AIDS in just four years (UNFPA 2001). Two years later, cabinet minister records stated that around 100 key officers in government ministries had died from AIDS in the previous six years, and that many of those still in employment were unable to attend work regularly because of their diagnosis (UNFPA, 2001, NAC, 2004). HIV and AIDS are conditions that are destabilising across the society and the section that follows looks at the gender inequalities in relation to HIV and AIDS.

Gender inequalities

As is the case in many nations, women in Malawi are socially and economically seen as subordinate to men (UNFPA, 2001). This inequality fuels HIV infection, as traditional gender roles allow men to have sex with a number of partners and put women in a position where they are powerless to encourage condom use (NAC, 2004b). Many women are taught never to refuse sex with their husbands, and sexual abuse and coerced sex are common (UNAIDS, 2010; NAC, 2004a). Women in Malawi are not empowered to negotiate sex with male partners because of cultural issues (NAC, 2004a; NAC, 2004b). In some communities, traditional practices such as 'wife inheritance' – where a widow is married to (or required to have sex with) a relative of her husband upon his death – may also increase the risk of HIV

transmission, particularly in cases where AIDS was the cause of death of the woman's previous husband (UNFPA, 2001). Such rituals have been condemned by the Malawian Government and AIDS organizations working in the country, however changing a tradition that has persisted for generations is a slow process (WHO/UNAIDS/UNICEF, 2009).

WHO (2009) further argue that HIV infection in Malawi has disproportionately affected female, and younger women. For instance, AIDS affects more than four times as many women as men amongst the 15-19 age group in Malawi, and about a third more women than men amongst the 20-25 age group. However, amongst those who are over 30 the trend reverses, as more men than women are affected. This pattern reflects the fact that younger women are often married to older men, or coerced into having sex with them. Age at first sexual intercourse is considered to be one of the high risk factors in contracting HIV and AIDS (MDHS, 2010). Fourteen percent (14) of women aged between 15 and 24 years and 22% of men aged between 15 and 24 initiated sexual intercourse before or at the age of 15 years (MDHS, 2010). Nearly one in five adolescent females (15-19yrs) reported force or coercion used in their first sexual experience (UNAIDS 2009, NAC, 2004a). According to MDHS (2010) the percentage for forced or coerced first sexual contact was 17.7% by 2010 in Malawi.

Conclusion

This chapter has explored the impact of HIV and AIDS in Africa and Sub-Saharan Africa particularly countries that have a close link with Malawi. It has also explored how poverty and cultural factors impacts on the management of HIV and AIDS in Malawi. It has highlighted the particular risks faced by women, girls and children in terms of HIV and AIDS epidemic in Sub-Saharan Africa and Malawi. The following chapter 3 will examine the literature reviewed in the wider context of caring in the context of HIV and AIDS.

Chapter 3

Literature review of caregiving in the context of HIV and AIDS

Introduction

In the last chapter the researcher discussed the high impact of HIV and AIDs on women and children, and the heavy burden placed on carers in resource poor countries. Within this literature review chapter, the discussion will focus on the literature related to living with long-term chronic conditions such as HIV and AIDS and the experiences of care giving for such conditions more broadly. Bury (1991) defines chronic illness as a long-term and perhaps a permanent event in a person's life and that the person will need health and social care for the rest of his or her life. Such illnesses include diabetes, epilepsy and HIV and AIDS (Bury, 1991 Kelly; Field, 1996). People living with HIV and AIDS (PLWHA) face a multitude of problems ranging from stigma, lack or shortage of medicines, poor quality care and psychosocial and economic issues (UNAIDS, 2010). Bury (1991) further explains that these chronic diseases are characterized by dependency on others for care. Encounters with professionals and non-professionals in caring may offer hope of recovery (Bury, 1991). However, HIV and AIDS is a life-long disease that will demand ongoing care and support from caregivers due to its nature (Kelly and Field, 1996; UNAIDS, 2010). This chapter therefore focuses on the literature related to one of the most important groups in the management of people living with HIV and AIDS: caregivers, who are the main focus of this study. The literature review takes the form of a narrative review, underpinned by a systematic literature search. This chapter is informed by a sociological perspective on caring, mainly focusing on the gendered nature of care in general and childcare in particular, how women combine work and child care, and the importance of local context and culture in the decisions people make about caring, work and parenting.

The wider issues of caring for healthy children are discussed first, before reviewing the literature focused on caring for children with chronic conditions and the particular challenges of caring for children affected by HIV and AIDS. The differences between primary and secondary caregivers are also considered, as well as the particular challenges experienced by caregivers living in hard to reach areas, as

these issues are central to the focus of this thesis. Finally the policy responses to these challenges are discussed. The chapter begins by describing the methods used to search and review the literature. It will then consider the key themes that emerged from the review which are of relevance to this study.

Literature search methods

The literature search was designed to detect published and unpublished English language studies that discussed HIV and AIDS in general and caring and support in particular. The search of the studies was conducted both electronically and by hand searching between a period of early January 2010 and June 2014. It was a continuous and systematic process of literature review covering a variety of topics as they emerged from the data analysis. The literature search started prior to data collection to inform the construction of the research questions and then the researcher returned to the search throughout the study and especially following data analysis to inform the interpretation of the analysed data. The studies searched were in English language and published between 1980 and 2014. However because of the nature and the need for classic information for this topic, some relevant studies outside this period were used.

Electronic search

The OVID SP and Google search engines via Cardiff University information services website were used to access the following electronic databases:

- Medline
- Google scholar
- EMBASE
- Cochrane Controlled Trials Registers for randomized controlled trials
- Scopus
- PubMed
- EBSCOhost
- Cumulative Index for Nursing and Allied Health Literature (CINAHL)

It was decided to search many relevant data bases to detect more published potential studies rather than to limit to only a few, as a single electronic database cannot have all published medical and nursing studies (Tranfield, et al. 2003). By searching this way, wide coverage was achieved that reduced the possibility of selection bias. Other databases such as SIGLE and Dissertation Abstracts International were also checked for unpublished articles.

Reference checking from journals and textbooks

References of all retrieved reports and articles were further searched and reviewed, in order to identify additional relevant papers.

Searching for additional sources

There were some limits to the searching that was undertaken because of limited time. For example, literature that was not easily accessible via the databases (for example, non-indexed studies or conference abstracts) was not tracked down. Cardiff University librarians provided support in order to identify any recent studies relevant to the topic that had not yet been indexed by databases that were searched. Furthermore, the two supervisors gave their expert advice concerning relevant articles. Hand searching for relevant articles within Cardiff University libraries was also undertaken, accessing the libraries of other disciplines as well as Health Care such as Social Science libraries. However, Hand searching did not find any relevant articles for this topic.

Searchable terms (keywords)

The Literature search was widened by including three components of PICOS terms i.e. population (sample) (P), Intervention (exposure) (I) and outcome (O). Within each component 'OR' was used to combine the terms and between each component 'AND' "IN" were used to combine searchable terms (keywords). The statement of the main topic of the review "The experiences of women caregivers looking after a child living with HIV and AIDS in rural Malawi" was broken down into searchable phrases. For example, in this statement, phrases like "experiences of women

caregivers”, “HIV and AIDS in Malawi” “Caring for children living with HIV and AIDS” “Rural Malawi and HIV and AIDS” were used. The keywords were selected for searching the potential studies. These key words were divided into two lists. The first list was for those key words used in the initial search and a second list of key words used after data analysis. The following keywords and phrases were used during the search of the studies:

Initial list of key words prior to data analysis

- HIV and AIDS history
- HIV and AIDS and stigma
- HIV and AIDS and disclosure
- HIV and AIDS care and support
- Malawi and HIV and AIDS
- Rural Malawi and HIV and AIDS
- Men care and support

A list of key words after data analysis

- Invisibility in care and support
- Resilience in care and support rural areas
- Gender and caring and support
- Women care and support in Malawi
- Hard to reach areas
- HIV and AIDS caring or support
- Stigma and disclosure
- HIV and AIDS caring responsibilities

The studies that were searched helped to inform the discussions prior, during and after data analysis. The discussion that follows includes caring for well children, paid and unpaid child care, child care: balancing acts work and care for working mothers, who should do this work? The discussion also includes caregiving impact on families with children with disabilities or chronic diseases, caregiving and HIV and AIDS, secondary caregivers’ support to primary caregivers and primary caregiving. The discussion has further covered women caregivers, males as

caregivers in their families or communities, the changing caregiving profile in the face of HIV and AIDS, a change in the task by primary caregivers, hard to reach areas. Scale-up caregiving services to HIV and AIDS individuals, social incentives and protection for primary caregivers have also been discussed. The last part of the discussion is the conclusion of the chapter.

Caring for well children: is it women's work only?

The issue of who cares for children has become controversial in many countries (Williams, 2009). Traditionally, and in many parts of the developing world, it is seen as women's work, whether this is caring for children in the home as a parent, or as paid employment (Williams, 2009). It is frequently seen as low status work which receives little recognition (Williams, 2009; Williams, 2004a). This may create challenges for women as they try to balance their working acts – the need to balance work and childcare for working mothers (Williams, 2009). Being seen as a 'good mother' is important to women (Holland, et al. 2008; Duncan, 2003; Williams, 2004c); but what is being a 'good mother' varies from culture to culture and between different social groups (Duncan, 2003).

Paid and unpaid childcare

In all sectors of caring for children, women are the main caregivers in many countries and societies (Williams, 2009; Williams, 2004a). For example a quantitative study by Finch (2003) found that in the UK 97.5% of child care workers were women, and 98.9% were nursery workers, 97.7% were child-minders and 94.0% were playgroup workers. Finch (2003) study also illustrated the number of women in care related jobs such as nursing, with 89.8% of nurses were female (Finch, 2003). This work is 'shadow work', low status work that is largely unacknowledged and invisible, not seen as valuable in a world that values profit and measurable outcomes (Finch, 2003). Traditionally, women have been seen as having innate caring skills that are just part of being female and hence the traditional role as front-line unpaid caregivers (Finch and Groves, 1983). Ungerson (1983) further explained that women are traditional caregivers because they spend more time with

children that inevitably need caring than men. This scenario gives women to be seen as traditional caregivers than men (Finch and Groves, 1983).

These findings show that women still dominate in care related jobs as compared to men but the trend is slowly changing (Finch, 2003; Oki, 2012; Belluck, 2011). Oki (2012) explains that increasingly, many women in developing countries migrate to developed countries to make money or to study leaving their young children with their male spouses to care for them. However, Oki (2012) explains that times have changed because now it is impossible for a family to live only with the man's earnings because life styles have changed and the cost of living have gone exceptionally high. Thus both parents should take equal share of caring for children as both are expected to be in gainful work to survive in these days of economic hardships (Oki, 2012; Belluck, 2011). Men are therefore expected to take an equal share of caring for children in families (Oki, 2012). The section that follows looks at child care and how parents balance work demands with child care.

Child care: balancing acts work and care for working mothers

In a qualitative study conducted in the United Kingdom by Duncan (2003) examined how mothers viewed "good mothering" and how they saw taking employment versus child care. Duncan's (2003) research concentrated on the process and meanings that women attach to and shape the decisions women make whether to be at home looking after a child or to be at work. Although there are obvious differences in whether women work part time, full time, or not, and in what type of child care support that they prefer, there are things that are common (Duncan, 2003; Williams, 2004b; Williams, 2004a). Critical to this is the woman/worker identity (Holland, et. al. 2008; Duncan, 2003). In this context therefore, if one understands that being a good mother means being a provider for the children, then most likely, that mother will find full time work as the best option for her (Duncan, 2003; Williams, 2004a; Williams 2004c). What it means to be a good mother is influenced by the ethnicity, social networks, as well as the local conditions and customs of female and male caring and employment and culture (Doyal, 1995; Williams, 2004a; Duncan, 2003; Williams 2004c).

Often mothers have difficulty identifying themselves as a good child care mother or a full time worker as illustrated by Williams (2004a) in her qualitative study in the United Kingdom. One of Williams's participants in her study confirmed this notion:

"I'd love to go out to work, I'd love to go back full time...I think I'd be better off financially if I was working than I am now because I only get £68 per week on benefits....My mum is one parent and she thinks like most old people that if you have children you should be with them. You don't have children to bugger off and leave them with someone else... I sometimes agree with her. That's the idea of parenting, being with them, isn't it?"

Williams, (2004a) 58

This mother although she had an incentive to work, it was difficult for her to decide whether to go back to full time work or not because of her strong moral values of her own and the views of her mother about what was right for her children (Williams, 2004a).

Who should do this work?

The qualitative study by Williams (2004a) showed that women had mixed feeling and views when it came to what type of child care that they preferred. Mothers, whose identities were deep rooted in motherhood than paid work, felt that they as mothers were best suited to provide child care services by them alone (Williams, 2004a). But research suggests that that was not surprising at all because of their strong maternal convictions of being a mother (Holland, et al. 2008 and Williams, 2004a). The lower costs and greater convenience often strengthened preferences for informal care but did not outweigh these moral and social factors for working class mothers (Williams, 2004a). Most professional working mothers preferred nursery type of child care because they thought it was better for their children to socialize with others and become good individuals (Holland, et. al. 2008; Williams, 2004a). In summary, the issue of who cares for the children has become controversial in many countries (Holland, et. al. 2008; Williams, 2004a). Traditionally, and in many parts of the developing world, it is seen as women's work, whether this is caring for children in the home as a parent, or as paid employment (Williams, 2004a). It is frequently seen as low status work which receives little recognition and the caregivers are invisible (Williams, 2009; Williams, 2004a). Child care services are either provided privately in families or publicly in nursery child care services

(Williams, 2008; Holland, et.al. 2008). The section that follows discusses caregiving for children with disabilities or chronic diseases and how this impacts on families.

Caregiving impact on families with children with disabilities or chronic diseases

In any family around the world, caring for a child who is not sick is a daunting task and challenging (Corman, et al. 2005). It is particularly very challenging for families looking after a child with disabilities or chronic diseases and it is one of the circumstances where a few men take up the caregiving responsibilities (Goudie, et al. 2010); Koshti-Richman, 2009). In a quantitative study conducted in Ohio State in the United States of America Goudie, et al. (2013) explored caring for children with disabilities or chronic diseases and its impact on families and found that 14.8% of their sample of parents were divorced due to lack of parents' social interaction and 57% although still married but were considering a divorce because of lack of parents' social interaction. Goudie, et al. (2013) further explain that 26% of the parents had changed their work schedule cutting back working hours and hence reducing family income in order to provide care (Goudie, et al. 2013). Goudie et al. (2013) also state that for 32% of the parents one of them had to stop work altogether in order to allocate more time to caring for the child with disability. Goudie, et al. (2013) and Goudie, et al. (2010) cite special challenges including increased financial expenditure related to health care needs, a high demand on time, employment constraints, constrained earning potential, and emotional stress. A demand on time is particularly one of the major challenges because caregiving limits parents' social interaction and their potential to advance in education or their careers and may lead to relationship breakdown that includes marriage breakdown (Goudie, et al. 2010; Goudie, et al. 2013).

Corman et al. (2005) adds that children with disabilities or chronic diseases access health care services more than children without disability or chronic diseases. This put strains on the family because the family has to coordinate health care requirements and usually needs additional investments of patience, time, and resources (Corman et al. 2005). The study by Goudie, et al. (2013) supported this, revealing that emotional hardship and utilization of health care services exerted a lot of emotional pressure on these families. The study results also showed that a family

member who was working had to change or give up work in order to concentrate on caring for a child with disabilities or chronic diseases (Goudie, et al. 2013). For the family that was not working, the study revealed that increased health insurance payment was a burden to such a family because they dependent on state insurance (Goudie, et al. 2013). The study further showed that 28% of the families caring for child with disabilities or chronic diseases spent 11 or more hours a week providing or coordinating health care needs and 30% of families, both parents gave up work altogether in order to allocate adequate time for caregiving (Goudie, et al. 2013). Goudie, et al. (2013) further explain that the more severe the disability or chronic disease, the more the time was required for both parents to take care of such a child and hence had influenced both parents to make the very difficult decision of giving up work. The paragraphs that follow look at caregiving in relation to people living with HIV and AIDS, both adults and children.

Caregiving and HIV and AIDS

Kiragu, et al. (2008) argues that caregivers of people living with HIV and AIDS are usually referred to as lay or community care providers. This is a general definition. However, United Kingdom Consortium on AIDS and International Development (UKCAID) (2012) contends that it is important to define this group further into primary and secondary caregivers. UKCAID, (2012) explains that primary caregivers are both adults and children looking after other family members who are sick and are usually women and often are older women who are looking after sick adults and children. However, Bunnell, et al. (2006) argues that there are children who are also taking care of adult or fellow children who are living with HIV and AIDS in their families. This is especially so in developing countries and the situation is more evident in sub-Saharan African countries where children look after sick children or parents whose spouses or parents have died of HIV and AIDS respectively (Bunnell, et al. 2006). These child caregivers are often young girls looking after sick close relatives who may be parents and grandparents (UKCAID, 2012). Most often primary caregiving type of care takes place within families and outside the formal situations and they are therefore, invisible (UKCAID, 2012; Bunnell, et al. 2006). Secondary caregivers according to UKCAID, (2012) and Bunnell, et al. (2006) are those in paid caregiving situations such as those working in

hospitals or in communities and are professionally trained to give the care and because secondary caregivers are in formal or informal economies, they are therefore visible to the public and policy makers. Secondary caregivers are paid a salary or stipend and may be fulltime workers or volunteers (Bunnell, et al. 2006). In normal circumstances, secondary caregivers offer support to primary caregivers (UKCAID, 2012; UNAIDS, 2010).

The relationship between primary and secondary caregivers is important. Primary caregivers look up to secondary caregivers as a critical resource for support in terms of providing advice, counselling and supply of medical equipment and supplies such as provision of treatment (ARVs), nutritional supplements for them (primary caregivers) to provide the care to their family members more effectively (UKCAID, 2012; Bunnell, et al. 2006). Secondary caregivers offer support to primary caregivers in the form of social protection as well that may include but not limited to social grants or cash transfers, processing and accessing health care services in their local areas, legal support and many more social support services (Siziya and Hakim, 1996; WHO, 1997; UKCAID, 2012). In many countries most of the secondary caregivers are primary caregivers in their own families too (UKCAID, 2012). The majority of both primary and secondary caregivers are women although there may be some male caregivers (UNAIDS, 2010; Gibson, 2013; UKCAID, 2012). Given the importance of this relationship the researcher will discuss each of them separately and the first to be discussed is the secondary caregivers' support to primary caregivers.

Secondary caregivers' support to primary caregivers

Secondary caregivers include paid caregivers such as volunteers and local community health workers as opposed to nurses and doctors; they are non-professional or para-professional health care providers with basic training in counselling people living with HIV and AIDS, primary health care, sanitation, other chronic diseases, and provision of services in a sick person's home (WHO, 1997; UNAIDS, 2010; UKICAD, 2012). However, Hayes (2010), Kiragu et al. (2008) and Waring (2011) explain that in real life situations, this category of secondary caregivers do more than what has been described by WHO (1997), UNAIDS (2010) and UKICAD (2012) because they link the people living with HIV and AIDS to

primary (Health centres) and secondary (district or central hospitals) healthcare services. They also offer development support, act as interrogators between the community and the formal caregiving services (hospitals), and they offer social, legal, psychological counselling (Hayes, 2010; UKICAD, 2012). Secondary caregivers thus provide a range of support to primary caregivers looking after people living with HIV and AIDS in general and to children in particular (Hayes, 2010; UKICAD, 2012; UNAIDS, 2010). Their role is especially important in hard to reach areas such as rural Malawi (Hayes, 2010). The discussion will now focus on some of these support services offered by secondary caregiving services one by one.

Secondary caregivers offer support to primary caregivers in the form of nutritional services that include nutritional screening and distribution of food supplements (rations) to people living with HIV and AIDS that includes female primary caregivers of children living with HIV and AIDS (WHO, 1997; UNAIDS, 2011; Waring, 2011). Secondary caregivers also offer support to primary caregivers in the form of counselling to all clients that are on ARVs about nutritional importance in relation to ARVs (UNAIDS, 2011). They also support primary caregivers how to increase their food security through feeding, gardening and farming programmes (UKCAID, 2012; Gibson, 2013).

Secondary caregivers also give an on-going counselling and psychosocial support to primary caregivers (UKCAID, 2012; Gibson, 2013). The support may take place during bereavement, formation of local support groups, teaching of basic life supporting skills such as income generating activities (IGA) so that primary caregivers can be self-reliant on money and other items (WHO, 1997; UNAIDS, 2011; Waring, 2011). Waring (2011) further explains that secondary caregivers support the primary caregiver in the form of volunteering activities. The activities include teaching orphans and children living with HIV and AIDS on how to live positively with the disease (Waring, 2011). This is some form of formal education; and giving some educational materials at local levels (Waring, 2011). Siziya and Hakim (1996) add that secondary caregivers also support primary caregivers by growth monitoring and screening of children living with HIV and AIDS at local or village levels as well as helping interpret the screening findings and offering some on the spot counselling services based on the findings of the screening.

Secondary caregivers also have a broader role in strengthening community and health systems. Siziya and Hakim (1996) explain that secondary caregivers provide a link between primary caregivers and other partners in care of children living with HIV and AIDS and any other people living with HIV and AIDS. WHO (1997), DFID (2011) and UKCAID (2012) explain that the linkages formed help build partnerships and increase coordination among other support groups. These may include social workers, church groups, hospitals, government, traditional healers, farming groups, other health professionals, clinics, traditional leaders, NGOs, caretakers (people who sit in when the main caregiver is away), religious leaders and traditional birth attendants just to mention but a few (WHO, 1997; DFID, 2011; UKCAID, 2012). UNAIDS (2011) also states that some secondary caregivers are asked to collect statistics on HIV and AIDS and the numbers of orphans in the community they are working in and send to their relevant authorities so that the support to primary caregivers is supported by official statistics. Statistics for HIV and AIDS is an important aspect in HIV and AIDS care and support because statistics provide evidence of the magnitude of the HIV and AIDS in a particular community and hence support is properly planned (UNAIDS, 2011).

Secondary caregivers also play a key role in supporting clinical care. Kiragu et al., (2008) states that one of the most important support that secondary caregivers give to primary caregivers is teachings on adherence to ARVs, Tuberculosis (TB), Prevention of Mother to Child Transmission (PMCT), and any other medicines that prevent opportunistic infections. Hayes (2010) and Bunnell et al. (2006) add that secondary caregivers offer support to primary caregivers on how to handle side effects of some ARVs and also help track people living with HIV and AIDS who are lost. They also provide support on bedside care such as personal hygiene and wound care to bedridden people living with HIV and AIDS, including children (UNAIDS, 2011). In some circumstances, they help make referrals to hospitals and may also conduct clinics within the communities where they screen and ensure appropriate decisions are made in the best interests of the patients and the primary caregivers (WHO, 1997; UNAIDS, 2011). Secondary caregivers also provide support to primary caregivers in terms of legal, human rights and advocacy activities.

UNAIDS (2011) and UKCAID (2012) explain that secondary caregivers act as information sources to primary caregivers in the form of conducting campaigns against stigma and discrimination and they advocate for a better and more inclusive services and funding for primary caregivers of people (children) living with HIV and AIDS. Kiragu et al. (2008) also argue that secondary caregivers also may provide solutions to some of the cultural practices such as land grabbing and wife inheritance which both may trigger conflicts and may leave people living with HIV and AIDS vulnerable to abuse and of course may expose them to further re-infections, including children. Grabbing a wife is a cultural practice where men marry other men's wives while wife inheritance is a cultural practice where a man is asked to marry a widow upon approval by the widow herself so that children of the deceased are taken care of and they should not feel the gap left by their biological father (MDHS, 2010; Kiragu et al., 2008). In some circumstances, secondary caregivers refer and escort primary caregivers to human rights groups or organizations or to legal experts when need arises (DFID, 2011; HelpAge International, 2008). Secondary caregivers also support primary caregivers in terms of behavioural change communication and education.

Hayes (2010), Bunnell et al. (2006) and UNAIDS (2011) explain that secondary caregivers help primary caregivers get engaged in community education on HIV counselling and testing, treatment and prevention, family planning and sexual health. This includes the distribution of HIV and AIDS prevention and family planning materials such as condoms with an aim of promoting a change in behaviour by the community (UNAIDS, 2010). Behavioural change is one of the main aspects of HIV and AIDS prevention efforts because unless people change behaviour regarding their sexual life and follow preventive methods to reduce the spread of HIV, the HIV and AIDS prevention programmes are useless as re-infection will affect the already achieved positive results (UNAIDS, 2010; UNAIDS, 2011; DFID, 2011).

Kiragu et al. (2008), UNAIDS (2011) and UKCAID (2012) contend that secondary caregivers also support primary caregivers by helping them engage in livelihood, income generating vocational skills and training activities to raise resources for their own caregiving activities so that they can help their clients properly. Kiragu et al. (2008) and UKCAID (2012) further add that secondary caregivers help in

distributing some resources such as clothes, school fees, nutritional supplements and they make sure that primary caregivers have necessary documentation that may be required for government support mechanisms. These may include but not limited to wills, birth certificates, and medical records (Kiragu, et al., 2008; UKCAID, 2012). The support services that secondary caregivers offer to primary caregivers offer the primary caregivers some relief because they are in unpaid caregiving and are virtually invisible (UKCIAD, 2012). In summary, secondary caregivers give support to primary caregivers in a number of important areas as discussed above. These include but not limited to income generating activities, providing important information in relation to caring and strengthening the link between the community and the conversional health systems. The following paragraphs focus on the actual caregiving activities by primary caregivers.

Primary caregiving

Globally, most care is borne by primary caregivers who mostly live in hard to reach areas such as rural settings of most developing countries (UNAIDS, 2011; UNAIDS, 2010). Primary caregivers who take care of children in a resource limited country face a particularly daunting task because children need special care and support as they rely on an adult for all their needs (UNAIDS, 2011; Hayes, 2010).

Care in hard to reach areas is provided by female primary caregivers (UNAIDS, 2011). Majority of children living with HIV and AIDS and those who have been orphaned with HIV and AIDS and any other epidemic are also cared for by these female primary caregivers in these hard to reach areas (UNAIDS, 2011; UKCAID, 2012; Bunnell, et al., 2006). UNAIDS (2011) and Kiragu et al. (2008) describe the range of care provided by the female primary caregivers as including: seeking health care services, giving of prescribed medicines, providing adequate food, sanitation of the houses and the surrounding areas, washing clothes, providing shelter, clothing and bathing. These physical care activities form the bulk of caregiving services by these female primary caregivers (Hayes, 2010; Kiragu et al., 2008). It is this hard to reach rural areas that may make the hard working female primary caregivers invisible and yet they do the important job of caring (UKCAID, 2012). What female primary caregivers give to their children living with HIV and

AIDS are the essential needs of daily living and they are provided for free because mostly they are provided by family members and hence taken for granted that it is their responsibility to provide the care (UNAIDS, 2011; Kiragu, et al., 2008). However, Gibson (2013), Kiragu et al. (2008) and Siziya and Hakim (1996) argue that these women still need support from government, non-governmental organizations (NGOs), other family members and secondary caregivers (Gibson, 2013; Kiragu, et al., 2008; Siziya and Hakim, 1996). As discussed earlier, there is an expectation that this care will be provided by women.

Women caregivers

In most countries in Africa including Malawi caregiving is considered a woman's responsibility and often stigmatised, underrated and with low or no pay at all (UKCAID, 2012; UNAIDS, 2010; WHO, 1997; Kiragu, et al. 2008)). However, Bunnell et al. (2006), WHO (1997), Kiragu et al. (2008), Gibson (2013) and UNAIDS (2010) explain that women play an important role of typically being the custodians of their family, community and individual's wellbeing and they play a heroic role in tasks that they undertake in the context of HIV and AIDS care and support and hence should be properly recognized. This view is also supported by United Kingdom Department for International Development (DFID) (2011) writing in its new strategic vision for women and girls (DFID, 2011). DFID (2011) states that deliberate global policies that seek to enhance the remuneration package and extend the social protection for women caregivers and strengthen their positive attitude from other sectors of life must be put in place in all developing and developed countries as a matter of urgency. By properly rewarding women caregivers for people living with HIV and AIDS, the world would promote positive attitudes towards them and hence attracting more women to go into care work especially looking after people living with HIV and AIDS (DFID, 2011). However, it must be remembered that in many cultures in the world, women do not have much choice about caring roles because; social and cultural gender norms demand that women do take up the caring role (Gibson, 2013; UNAIDS, 2010; Bunnell, et al. 2006; DFID, 2011). This is because traditionally, women take care of children and sick relatives in the families and the community as a whole and for those that may want to refuse are either ostracised or pressured to conform by peers and that men

who take on caring work are ridiculed and their masculinity is seriously questioned by their communities including women too in that community (UKCAID, 2012; DIFD, 2011; Bunnell, 2006). The following paragraph looks at men as caregivers in their families or communities.

Males as caregivers in their families or communities

As earlier on argued, caregivers are predominantly women but of late there are innovative programmes that work with men to change this scenario (UKCAID, 2012). For example DFID had embarked on a programme in Eastern Cape of South Africa called the Sonke Gender Justice where gender sensitization workshops were run so that men take a leading role in organizing caregiving and encourages men to take a leading role as well in caregiving (DFID, 2011). The programme showed that men were positive towards caregiving and that what they needed was just support (DFID, 2011; UKCAID, 2012). In that programme, some men were selected as role models in caregiving to people living with HIV and AIDS so that other men could be attracted to caregiving (DFID, 2011). There are also some other factors such as the increased number of people living with HIV and AIDS that need the care that have influenced men to take an active role in caregiving of people living with HIV and AIDS (Waring, 2011). Factors such as the introduction of ARVs lately have also helped to change the way caregiving is viewed and how they promoted home based caregiving in many communities in the context of HIV and AIDS (Waring, 2011; UNAIDS, 2010; UKCAID, 2012). It is worth remembering that there are other older men who are caregivers to their grandchildren whose parents died due to HIV and AIDS and the grandchildren became HIV and AIDS orphaned (UKCIAD, 2012). The section that follows discusses the primary caregivers and the economic and social costs of unpaid caregiving.

Unpaid caregiving and the economic and social costs

Kiragu et al. (2008), UNAIDS (2011) and UKCAID (2012) state that primary caregivers face a daunting task of giving the care to people living with HIV and AIDS especially those caring for children because the cost of caring is devastating. Studies have shown and estimated that the cost of care for people living with HIV

and AIDS may be twice as high as those with other diseases because of the cost of ARVs and nutritional supplements (DFID, 2011; UNAIDS, 2010). UKCAID (2012) states that in Mozambique for example, the average cost of caring for people living with HIV and AIDS and orphaned children due to HIV and AIDS who were themselves living with HIV and AIDS was estimated at \$30 per month and for any adult person living with HIV and AIDS was estimated at \$21 and yet the monthly average income for an adult in Mozambique was \$12 in 2010. UNAIDS, (2011) explains that secondary caregivers who are in paid caregiving, such as those receiving stipend or salaries used their own limited resources to cover the cost of transport for follow up visits of clients in their homes. Secondary caregivers sometimes use their limited resources to buy supplies for the primary caregivers to use as they care for their loved ones (DFID, 2011; WHO, 1997; UNAIDS, 2011). For instance, in a study conducted in Mozambique by DFID, in 2011 showed that 87% of 1, 366 secondary caregivers reported that they used their own money to cover the considerable transport costs of visiting and providing supplies (including accompanying them to the hospital) to primary caregivers so that they (primary caregivers) were able to care . This was especially the case for those looking after children living with HIV and AIDS who found it hard to get resources.

UKCAID (2012) add primary caregivers who are normally family or community members and live in hard to reach areas face discrimination and negative treatment by employees in the hospitals and clinics. This is confirmed by a Zambian study in which Kiragu et al. (2008) found that all 1, 424 hospital workers who participated were discriminated by fellow workers when they offered care and support to hospitalised patients living with HIV and AIDS. Despite this, most hospital workers who provided the care and participated in the study expressed pride for the care that they were giving and were not deterred by stigma and discrimination (Kiragu et al., 2008). Hayes (2010) and HelpAge International (2004) attributes this situation partly to low status attached to home or community caregiving by those in formal and paid caregiving services and the fact that primary caregivers are poorest of the poor and that they live in hard to reach areas and themselves live with HIV and AIDS as well. Primary caregivers that live in hard to reach areas although they are marginalized; they represent key affected populations of any state of country (Hayes, 2010; UKCAID, 2012; DFID, 2011). In addition, low evaluation of their caregiving

activities by formal caregivers like the health care workers such as nurses, medical doctors makes it hard to reward their work appropriately (UKCIAD, 2012). Constant primary caregivers' exposure to illness, fatigue, dying, death, general decline in their health and welling being, burnout and HIV and AIDS stigma that lead to high levels of isolation and invisibility. (Hayes, 2010; Kiragu et al., 2008; HelpAge International, 2004). The following section discusses the caregiving role and the personal, social and political value.

The caregiving role and the personal, social and political value

Both primary and some secondary caregivers work in extremely difficult situations because they are in either hard to reach areas or use their meagre salaries to support the care respectively (Gibson, 2013). However, Literature reviews have shown that caregiving services are a source of pride and satisfaction to both groups (UKCAID, 2012). For example, both the primary and secondary caregivers recognize the caregiving as expression of their religious faith, the love of family members and their community members who are living with HIV and AIDS, a commitment to their families and a sign of developing their community (Gibson, 2013). Gibson (2013) highly commends one Malawian woman who established an orphanage for children whose parents died of HIV and AIDS and who are living with HIV and AIDS (Gibson, 2013). The orphanage is called Kondanani (love each other) Gibson, 2013). Kondanani has given hope to otherwise vulnerable and neglected children living with HIV and AIDS as they find tender loving care (TLC) from the caregivers in that orphanage.

“Kondanani is truly an oasis of tranquillity, education, and equipping; the babies are such a bundle of joy and I’m sure that among these wonderful men and women we will find future presidents, doctors, nurses, pastors, and business people and so on.” Gibson, 2013 page 12

DFID (2011) in its Mozambique study states that primary caregivers looking after children living with HIV and AIDS can help shape their character and help construct a positive identity around their care work and may also experience the care of such children as source of happiness and strength. This is in agreement with Gibson (2013) as explained in the above quotation that if children living with HIV and AIDS can be well looked after by these primary caregivers and that adequate support is given to them; such children would have a brighter “future” such as they can be

“future presidents, doctors, nurses, pastors and business people”. The children will develop a sense of communal solidarity and self-worth as they see their primary caregivers work so hard in a resource limited environment and facing the most hard and difficult situations since the epidemic started (Gibson, 2013; UKCAID, 2012). Networking, organizing and peer learning among caregivers thus have the potential to increase political and decision-making power in their communities. However, much as these initiatives can help secondary caregivers, it is evident that, remunerations and formal non-volunteer work are an important recognition of social, political and personal value which are not available to primary caregivers (DIFD, 2011; UKCAID, 2012). The paragraph that follows discusses the changing caregiving profile in the face of HIV and AIDS.

The changing caregiving profile in the face of HIV and AIDS

The advent of HIV and AIDS has changed the primary caregivers’ profile when caregiving among the rural communities in Malawi (Gibson, 2013). The change in primary caregiving profile had been necessitated by the fact that HIV and AIDS were viewed as life threatening and hence a death sentence (Gibson, 2013). Gibson (2013) explains that primary caregivers in the rural settings of Malawi were so overwhelmed with the increased demand of caring for people living with HIV and AIDS especially children living with HIV and AIDS because there was no cure and still there is no cure for HIV. When they dedicated their time and efforts caring for such children, they knew that the child would die anyway and it was a major source of frustration to them (Gibson, 2013). But the introduction of and scale-up of ARVs or ART has seen a dramatic increase in funding of ART and a resultant effect of an increase survival rate of people living with HIV and AIDS for both adults and children with subsequent effect on caregivers (Gibson, 2013; WHO, 1997). UKCAID (2012) however contends that the major part of funds are channelled towards the expansion of AIDS treatment and at times a limited amount of funding has been used to provide support for caregiving activities and only for secondary caregivers in the form of incentives and rarely for their salaries. UKCAID (2012) further explains that in recent years, there are two trends that have evolved: the growing recognition of the importance of professional community health care providers in lessening the burden of caregiving by secondary caregivers and the

importance of professional community health care providers in scaling up and extending the services to areas that are hard to reach such as rural areas. The populations that live in hard to reach areas are usually not reached by the formal health systems and hence are denied the quality health care services (Gibson 2013; WHO, 1997; DFID, 2012; UKCAID, 2011). Therefore, the link that is provided by secondary caregivers to primary caregivers has also helped change the caring profile of primary caregivers because they receive some proper advice on how to care and support their wards (Kiragu, 2008; UKCAID, 2011; DFID, 2012). The section that follows looks at the change in the task by primary caregivers.

A change in the task by primary caregivers

In 2006 WHO provided guidelines that helped formal health care systems recognize the work done by primary caregivers (UKCAID, 2011). The guidance helped reduce the overburden and pressure and insufficient medical professionals and called for a major shift in approach (DFID, 2012; UKCAID, 2011).

“This approach involved the devolution of many of the tasks by medical staff to individuals generically described as “community health workers”. Unfortunately these initial guidelines only really referred to government employed health workers and gave no attention to non-governmental community health workers such as professional health caregivers. The guidelines also barely touched on how these workers taking on new roles would be supported apart from stating-countries should recognize that essential health services cannot be provided by people working on voluntary basis if they are to be sustainable.”

UKCAID, 2011 page 7

As can be seen in the quotation above, primary caregivers are not mentioned in the WHO guideline but only professional community health caregivers. This marginalization at international level of primary caregivers leaves them with nothing but being at the blunt end of caregiving services and yet they play a crucial role of caring people living with HIV and AIDS in their families and communities (Kiragu et al. 2008; Gibson, 2013; WHO, 1997).

Hard to reach and scale-up caregiving services to HIV and AIDS individuals

UKCAID (2011), DFID (2012) and Gibson (2013) explain that realising and recognizing the importance of primary and secondary caregivers' work in looking after people living with HIV and AIDS is the step in the right direction in an effort to improve the caregivers' care and support as they look after their wards. However, the concept of up-scaling HIV and AIDS care and support and reaching the hardest to reach and most invisible caregivers is relatively new and has not been widely accepted in many countries in the developing world (UKCAID, 2011; DFID, 2011; Gibson, 2013; Kiragu et al. 2008). This is evident by the fact that UNAIDS launched treatment plan (platform) in 2010 called treatment 2.0. This is one of the first global HIV and AIDS health initiative to identify and recognize the importance and the positive impact primary and secondary caregivers and community mobilization have on scaling up HIV and AIDS activities (UNAIDS, 2010). This also helped to extending the reach of HIV counselling and testing to rural communities, HIV prevention practices geared to reduce the spread of HIV, HIV treatment (ARVs) adherence and also helped reducing stigma towards people living with HIV and AIDS (UNAIDS, 2010). The extension is meant for reaching those communities that are in hard to reach areas such rural areas of developing countries such as Malawi (Gibson, 2013 and UNAIDS, 2010). This deliberate move to reach the population that live in hardest to reach areas is a noble one so as to help provide social protection and give the most needed incentives to primary caregivers (UNAIDS, 2010). The section that follows discusses the social incentives and protection for primary caregivers.

Social incentives and protection for primary caregivers

What primary caregivers require are basic things of life support such as food, clothes and shelter (Kiragu et al., 2008, UNAIDS, 2010 and Gibson, 2013). UNAIDS (2010) and UKCAID (2011) argue that primary caregivers really require two types of support: economic and psychosocial. Economic support could be provided through social protection mechanism that may include but not limited to income generating activities, care grants and allowances, microcredit, cash or food sustainability activities and old age pension (UNAIDS, 2010; UKCAID, 2011). UNAIDS, (2009)

considers social protection for people living with HIV and AIDS as one of the top 10 priorities in its 2009-2011 outcome framework, with much emphasis on ensuring that there is adequate access to social and cash transfers to primary caregivers. UNAIDS (2009) further explain that social protection must be HIV and AIDS-sensitive and not HIV and AIDS exclusive in order to ensure maximum caregiving results. Strengthening health promotion and anti-poverty activities and development efforts can help achieve the overall desired results of caregiving for primary caregiver (UNAIDS, 2009; UKCAID, 2011). UKCAID (2011) adds that this approach is backed up by evidence that indicates that in poor countries that have high HIV and AIDS prevalence rates, targeted cash transfers programmes to the poorest of the poor tend to have substantial HIV and AIDS mitigation impact.

However, while targeted cash transfers programmes to the poorest of the poor are important, policy recommendations advocate HIV and AIDS care and support in a broader sense (UNAIDS, 2009). These should include some reliable social welfare policies in developing countries that also include incentives to promote access to services such as school fees waivers, child protection systems strengthening, strengthened family and community support services for excluded and vulnerable groups (UNAIDS, 2009; UKCAID, 2011). Deliberate legislative and policy reform designed to targeting these groups are also paramount in this regard (UNAIDS, 2011). UNAIDS (2010) and UKCAID (2011) highlight the second type of support needed for primary caregivers: psychosocial and practical support that includes access to HIV counselling and testing, basic training in physical and psychosocial care. (Gibson, 2013; UNAIDS, 2010; UKCAID, 2011). UKCAID, (2011) singles out those primary caregivers that look after children living with HIV and AIDS to be given extra support and attention because children by birth are already vulnerable. Grandparents looking after their grandchildren living with HIV and AIDS also require special care and support because they are old and weak (UKCAID, 2011; UNAIDS, 2010). The special care and support primary caregivers and grandparents looking after children/grandchildren living with HIV and AIDS may include but not limited to training and guidance in parenting role in later life for the children and the integration challenges that may arise (UKCAID, 2011). It is worth remembering that a secondary caregiver is a critical resource to provide support to primary caregivers in this regard (UNAIDS, 2010).

Conclusion of the chapter

This literature review has shown that caring for people living with a chronic illness such as AIDS and children still remains the responsibility of women in many societies in the world although some studies have begun to show that men are getting involved but at a very limited scale. The literature review has also provided particular insights into the fact that primary caregivers play an important role by giving the care and support to the most vulnerable group of people, the people that live with HIV and AIDS. Secondary caregivers also play a major role by supporting the primary caregivers as discussed in this chapter. However, the literature evidence suggests that primary caregivers remain invisible and that this is gendered work, and as result a lot of effort is still needed to recognize and properly support primary caregivers especially those who live in hard to reach areas. This study aims to contribute to that evidence base by providing research based information about the experiences of women caregivers of children living with HIV and AIDS in rural areas of Malawi. Rural areas of Malawi are hard to reach areas too. However, it is important to note that primary caregivers are beginning to be recognized at international level as seen by deliberate policies and guidelines formulated by UNAIDS in 2010. This is a key development although it is still not embraced by many governments in developing countries where the majority of the populations live in rural and hardest to reach areas (UKCAID, 2011; Gibson, 2013; UNAIDS, 2011; UNAIDS, 2010).

Conducting this literature review has revealed a range of papers of relevance to the research questions which this study seeks to answer. This literature review provides broad evidence that is of relevance to the study, but that there are gaps related to the specific experiences of unpaid women caregivers for children living with HIV and AIDS in remote rural areas of resource poor countries such as Malawi. Given that the literature review indicates that a considerable amount of care is provided by these primary caregivers, it is very important to better understand their experiences in order to provide better support and inform policy. Supporting and informing policy in relation to primary caregivers in hard to reach and very rural and resource limited areas is the underpinning aim of this study.

In particular, it was noted during this literature review that no studies had been conducted in Malawi in relation to the study topic. The closest study was conducted by Chimwaza et al. in 2004 in a southern Malawi district of Balaka. However, this research focused on caregivers (women and men) looking after a chronically ill adult person. There was no specific focus on HIV and AIDS or on children and their caregivers and therefore any particular issues related to this group were not identified. The literature review therefore indicates that there is a gap in the current knowledgebase, which this research study seeks to address. The lack of knowledge in relation to caregivers' experiences suggests that a qualitative study design is most appropriate, and this will be described in detail in the following methodology chapter.

Chapter 4a

Methodology

Introduction

The methodology for this study embraced principles from one of the theories of social science namely the narrative inquiry. The study objectives and aims, the setting, sample and sampling methods are discussed to form a thread that is consistent with the methodological outline for this study. The reasons the narrative inquiry approach was selected for this study will be discussed in this chapter.

The philosophical theoretical framework

The philosophical theoretical framework that was utilized to inform this study and that was used as a “lens” to look at the world of caregiving of children living with HIV and AIDS in a rural setting of Malawi was the narrative analysis theoretical framework. In order to find a relevant theoretical framework for this study, an extensive literature review was conducted. The social science theories explored include narrative inquiry, symbolic interactionism and ethnographic approaches. After a careful scrutiny, narrative inquiry was found more relevant to this study because its principles are consistent with storytelling and women caregivers expressed their caregiving experiences of looking after a child living with HIV and AIDS in rural Malawi through storytelling. In addition, narrative inquiry is descriptive in nature and it helped guide the researcher during analysis of data. These two issues will be discussed in details later in this chapter.

Why Narrative Inquiry

In this section narrative inquiry is explained and the various perspectives of those using this methodology are described. There are a range of approaches to narrative research depending on the purpose of the study such as description, explanatory and theory building. At the end of the chapter the researcher will explain how a theoretical framework of narrative inquiry has been used to meet this study’s aim of describing the experiences of the women caregivers.

What is the narrative inquiry approach?

Riessman (2008) explains that narrative inquiry refers to a family of methods for interpreting texts that have in common and storied form. Riessman (2008) further hints that there are conflicts and disagreements amongst those holding varying perspectives but analysis of qualitative data is the only component of the broader field of narrative inquiry, which is a way of conducting case-centred research. The analytical methods in narrative inquiry are appropriate for interpreting many kinds of texts such as oral, written and visual (Riessman, 2008). The cases that form the basis for analysis may be individual cases, identity group's cases, communities' cases, organizations cases or even the nation's cases in terms of political narrative (Riessman, 2008). Paying attention to sequences of actions and events distinguishes narrative analysis from any other analysis of qualitative data (Riessman, 2008). Thus in narrative analysis, the investigator focuses on particular actors, in particular social places, at particular social times (Riessman, 2008). For instance, in this study, the particular actors were women caregivers, the particular social places were their homes in remote rural villages where caregiving was taking place.

Therefore, as a general field, narrative inquiry is grounded in the study of the particular groups of people or individuals who share the same characteristics and the analyst is interested in how a writer or speaker assembles and sequences events and uses language to and/or visual images to communicate meaning, that is make particular points to an audience (Riessman, 2008; Riessman, 1993). Riessman (2008) adds that the narrative analyst interrogates intention and language that is, how and why incidents are storied and not merely the content to which language refers. For instance, for whom was this constructed and for what purpose? In this study, the stories were constructed by the women caregivers for themselves and their children that they were caring for and it seems from the data that were collected, they often were using stories to understand the meaning of HIV and AIDS in their lives and how to take care of their children living with HIV and AIDS. Why is the succession of events configured that way? What cultural resources does it ask for or call up? What does the story accomplish? Are there gaps and inconsistencies that might suggest preferred, alternative or counter-narratives? Was there another audience for

their stories? Or were there other people in their communities? (Riessman, 2008; Riessman, 1993; Riessman; Quinney, 2005). Again in this study, questions were targeted to finding out what practical and psychosocial resources that women caregivers were using when caring for the children living with HIV and AIDS and individual life experiences of caregiving through storytelling to that effect. Children living with HIV and AIDS were the main “*actors*” whose story was told by women caregivers and “*actors*” is one of the features of narrative analysis theory (Bal, 1985).

There are a number of key features of a narrative approach:

Focal actor or actors: The story is always about someone or something, hence narrative is always for someone and something (Bal, 1985). Here, the focus of the story is about something or someone who may be called the *actor* or *actors* of the story (Bal, 1985). The objects and characters in the story are regarded as part of the story (fabula as the French call it) (Bal, 1985). In this study, the actors were children living with HIV and AIDS looked after by their caregivers who were women caregivers.

Sequence in time: Narrative should include clear beginning, middle and end although frequently stories may still represent time and sequence (Bruner, 1990). Even sequence is part of a story what the French call the fabula and that is a deep structure of a story (Pentland, 1999). The characters in a story may not be identified or even named and they may not be developed but with sequence, they give a thread that ties the events in a narrative together (Bruner, 1990). For example in this study women caregivers explained what time they gave a particular type of care and where and how they started and how they finished it. It is the responsibility of the researcher to ensure that the story forms a thread that is coherent (Pentland, 1999; Bruner, 1990).

Identifiable narrative voice: Bal (1985) confirms that a narrative is something that someone has narrated about something or an activity that has been experienced and narrated hence; there must be an identifiable narrative voice that does the narrating. The voice does reflect a specific point of view as many points of view are always possible (Bal, 1985). Narrative voice generally is not regarded as part of the deep structure (Bal, 1985; Pentland, 1999; Remmon-Kenan, 1983). In this study, “*the*

identifiable narrative voice” are the women caregivers who narrated the stories of caring a child living with HIV and AIDS in rural Malawi.

Canonical or evaluative frame of reference: Narrative encodes, implicitly or explicitly contain standards against which actions of the characters may be judged as they carry the meaning and the cultural values of the narrated incident (Bruner, 1990). However, canonical is not part of the deep structure of the story just like the narrative voice is (Bruner, 1990). Canonical here means all the writings or works known to be existing by a particular person and one tends to refer or evaluates them (Bruner, 1990). In this study, there were no writings that existed for the women caregivers as it was for the first time that they were interviewed in their life time hence there were no records to evaluate their previous work of caring.

Other indicators of content and context: Narrative texts contain more than just the bare events in particular, but rather, they contain a variety of textual devices that are used to indicate attributes of the characters, time, place, attributes of the context and many more (Bal, 1985). The above elements of narrative texts do not advance the plot, but rather, they give information that may be essential to the interpretation of the events (Barthes, 1977 and Pentland 1999) further argues that many kinds of data have narrative qualities, regardless of whether they meet a definition of narrative in any way. The plot is a literary term referring or defined as events that make up the story, particularly as they relate to one another in a pattern, in a sequence, through cause and effect and how the reader views the story (Pentland 1999; Bal, 1985). For instance, one can collect narrative data from electronic database (Pentland, 1999), or from published sources (Martin, et al. 1983) from historical records, students projects (Pentland, 1999), or as told by an organizational member (Boje, 1991) or from interviews as the researcher may find it fit based on the research design (Orbuch, 1997). Therefore narrative is just more than data (Orbuch, 1997). In this study, the narrative data was collected through the interviews and direct observations using a longitudinal descriptive qualitative study design. The data contained contextual and cultural information that helped the researcher to understand the women’s stories.

Developing descriptive analysis using narrative inquiry

Corsaro and Heise (1990) argue that the narrative inquiry is relevant and an important aspect to a broad range of the theoretical concerns because in narrative, there is an explanation that plays a major role. Pentland (1999) poses a question; what is the role of explanations in narrative? Since narratives are in a sequence of events, and time, and just descriptive in nature and hence it is best suited to the development of any description of events or activity in a simple way (Pentland, 1995). Thus, every narrative contains a description of a process of events that took place or are taking place and is followed by an explanation because reasons have to be given why an activity is done that way (Bal, 1990). In this case, Abbott (1990) states that narrative in the generic sense of process or storytelling can be arguably used to create an empirical sociological research in which processes, events, actions and agents are at the core of the descriptive analysis. Abbott (1990) therefore, identified three categories of questions that may be addressed: 1) the existence and classification of sequential patterns 2) the antecedents (something existing or happening before, especially as the cause or origin of something existing or happening later) of these patterns, and 3) consequences of these patterns. Pentland (1999) agrees that these questions clearly can be approached in purely descriptive terms such as what are the patterns? What are the antecedents and the consequences? The description is an essential first step in developing a theory using narrative data if one wishes to develop a theory but it is adequate just to describe events as they occurred (Abbott 1990).

Antecedents and consequences

Abbott (1990) noted that a great deal of sociological researchers or scholars will measure correlations between antecedents and consequences and make inferences about the intervening causal sequences of events without actually observing them. In this situation, a theory about demographics, communications, resource use and arrangements of activities in terms of time of the day may be described and explained (Abbott 1990). This process may take place in social studies conducted by renowned scholars and yet as Abbot (1990) puts it, a typical data contains no

information on the causal chain of events that explains why variables are reflected despite that antecedents and consequences are measured, correlations are computed and results are reported hence an aspect of narrative is necessary to enrich that description of data. Shaw and Jarvenpao (1997) and Pentland (1999) argue that it is the responsibility of the researcher to fill in the missing events because without explanations in the stories or narratives there the events are not clear and incomplete. This argument is supported by Lawrence (1997) who endorsed that although examining the intervening process may be time consuming and expensive, it is a necessary event to undertake if one wants to build an explanatory from narratives. Lawrence (1997) further explains that a purely instrumental theory which posits (to suggest something as a basic fact or principle from which a further idea is formed or developed) a connection between variables but lacks explanation, is not viewed as a theory at all generally.

Sequential Patterns

In developing a description of stories in narrative, the pattern of words and how they are sequenced by the narrator plays an important role (Lawrence, 1997). Pentland (1999) adds that for the reasons brought about by Lawrence (1997), sequential patterns are critical to description and explanations in narrative analysis. There is a need of a chain of events that connect antecedents and consequences (Pentland, 1999). However, Pentland (1999) further observes that there must be a description of events before an explanation. Thus the description of sequential patterns before the explanation of the sequential patterns is done first before anything else (Pentland, 1999). In any case, unless a sequence of events is identified, any explanation will purely be non-factual (Pentland, 1999).

Simplicity, accuracy and generability of sequential patterns

Weick (1990) observes that the conceptualization and description of sequential patterns make a classic trade-off among simplicity, accuracy and generability. Pentland (1995) states that for the sake of simplicity, the description process acts as fixed sequence such as A=B=C. However, he further argues that this simplicity typically entails a sacrifice in accuracy because most real processes cannot be

described as single sequence narrative, but rather even a single process can generate an enormous variety of different sequences of events (Pentland, 1995). In fact, as Abbott (1990) explains, if one had the narrative data in hand, the next step would be to test for the existence of the sequential patterns. Therefore, regardless of how one chooses to make the trade-off among simplicity, accuracy and generability, the basic logic of explanation is the same (Abbott, 1990; Abbott, 1992). The explanation is on the connection between antecedents and consequences by describing the events that connect them (Einhorn and Hagarth, 1986). It is however, worthy noting that merely describing the patterns of events does not, by itself, explain the underlying process that generated the patterns but mix with explanations would (Pentland, 1995). To this effect, explanations require an insight into what happened in order to drive the process of description of events (Abbott, 1992). This requires understanding the levels of narrative structure (Abbott, 1992).

Levels of narrative structure

Pentland (1999) stated that when the construct in question is a story then the tools of narrative approach may provide some important guidance such as the levels of narrative structure. However, there may be a basic problem to move from surface levels to deeper levels (Pentland, 1999). Fortunately, Pentland (1999) has provided solutions on how one can move from surface levels to deeper level. These have been done by tabulating the three levels of narrative structure and give the definition for each level with relevant examples as detailed in figure 1 below that shows the original levels of narrative structure by Pentland 1999.

Figure 1: Levels of structure in narrative (original Pentland, 1999)

Level	Definition	Examples
Text	Particular telling of a story by a specific narrator	Actual text of his or her story: “When I showed up at the interviews...”
Story	Version of a story (fabular) from a specific point of view	A new employee’s own version of how he or she was hired
Fabular (French for story)	Generating description of a particular set of events and their relationships	How a particular person was hired: What happened, who did what
Generating mechanisms	Underlying structures that enable or constrain the story (fabular)	Overall recruiting process: how people in general are hired (hindrances or cause of delays or failures and successes and their causes)

Pentland 1999: Building Process Theory with Narrative: from description to Explanation Page 719

The levels of narrative structure

There are basically three levels of narrative structure as stipulated by Pentland (1999). However, on the levels structure there appear to be four because the story (English) and the fabular (French) mean the same thing –the story (Pentland, 1999). The first is the text level where a particular telling of a story by a specific narrator is done and this is a transcription of a verbatim of a story if interviews were conducted or already existing text (Pentland, 1999). For example, the actual words said by the

narrator who is the storyteller and then put into text for easy reading by the researcher (transcription) could be “When I showed up at the interview....” Then there is the second level; the story which is also called the fabula by the French is from specific points of view, for example, a new employee’s own version of how he or she was hired and what actually happened; failures and successes and what caused them (Pentland, 1999). This is the story without the input of the researcher as told by the storyteller but the researcher can read to appreciate how the relationships of events are connected to pave way for generating mechanisms level which in fact is outside the standard of narrative analysis (Pentland, 1999). The third level is the generic description of a particular set of events and their relationships (Pentland, 1999). An example of this level is how a particular person was hired: what happened, and who did what in the process of recruitment (Pentland, 1999). This culminates into the generating mechanism which is the underlying structures that enables or constrains the story (Pentland, 1999). For example how the overall recruitment process was conducted: how people are hired in general (Pentland, 1999). This might be a routine work process like recruiting or budgeting, that repeats periodically and this level can be described using generative grammar because one nominal process (such as recruiting) can generate a nearly infinite number of specific variations (Pentland, 1999; Bal, 1985). Here one can go deeper into the story thereby engaging into explanatory process of the told story (Pentland, 1999). In here, the why, the how and the what are in full swing (Pentland, 1999).

It is interesting to note that this generating mechanism level is actually outside the narrative theory which is more concerned with the way specific events are narrated rather than with explaining why those events occur in the first place but there is no restrictive measures to explain why an event occurred that way by the researcher so that it becomes clear (Pentland, 1999). Therefore, narrative analysis begins at the text level up to the story level (fabular) only because they refer to specific set of events, actors, and their relationship such as who does what in what manner or sequence and so on and the researcher can choose to stop at these two levels without extending to the generating mechanism level (Bal, 1985; Pentland, 1999).

In summary, the levels are in two aspects (Pentland, 1999). The first aspect includes the first two levels - the text and the story and it is where the story was told and how

it was told by the narrator (the participant) and in what manner or sequence and put into a text for easy reading by a researcher or it is already in a text (Pentland, 1999). The second aspect is the generating mechanisms aspect and it is when the researcher re-tells that story in his or her own style so that it makes more meaning and it becomes coherent and flows properly without necessarily changing the meaning and can extend by explaining why certain events took place that way or can just re-tell the story to make it clearer (Pentland, 1999; Bal, 1985).

The application of levels of narrative structure to this study

Pentland (1995) indicates that at the deepest level the generating mechanisms drive the process of description of events. As conceptualized by Pentland (1999), this level of narrative structure may involve a routine work process such as feeding a sick because this may be a routine caregiving process to a child living with HIV and AIDS. Through the generating mechanisms the researcher can describe and explain why the feeding of a child is done that way and in this study, the researcher described and explained why some procedures were done in particular ways. Pentland (1995) further explains that this level can be described properly by generative grammar. For example feeding the child living with HIV and AIDS can generate nearly an infinite number of specific variations as one can go deeper, thereby engaging the explanatory aspect of events (here the *whys* will be answered). For example one of the participants in this study narrated “the child was breathing weakly...” and she decided to take the child to the hospital for treatment that did not work at first. The researcher then can explain how the participant noted that the child was “breathing weakly” and why the decision was made to take them to the hospital and so forth.

Pentland (1995) therefore notes that this level is outside the scope of standard narrative analysis framework, which is more concerned with the way specific events occur in the first place. This implies that the narrative theory starts at the text level up-the story (fabula) level which refers to a specific set of events, actors and their relationships for example, who does what, in what sequence and so forth (Pentland, 1995; Bal, 1985). In this context and in this study, as caregivers provided the care in the rural areas, there was a need to establish who did what and in what sequence of

events. In the example “the child was breathing weakly.” and the decision to take the child to the hospital and that “the treatment did not work at first,” the researcher explained why the treatment failed at first and who did what for that treatment to fail.

In narrative analysis, the story (fabula) level is often hypothesized to encode those aspects of a story that are preserved under translation between languages, between media or simply from one telling of the story to the next or simply from one caregiver’s story to the next (Pentland, 1995). In this study, this level was critical when the researcher translated the verbatim of interviews from Chichewa language to English language and from one caregiver’s story to the next for all the 20 caregivers. Although intuitively the stories may be recognized on the same basis, but the surface details are greatly different and it was exactly that way in this study (Pentland, 1999; Schafer, 1992). Thus in this study, the story (fabula) level helped encode an objective version of the basic events and characters required to uniquely identify a particular story from one caregiver to the next (Pentland, 1999). For example, in this study, one caregiver described the process by which a specific child was fed differently from the other but it remained the story of feeding a child. It is important to note that the story can also be generated in the sense that one underlying event structure can be reproduced in many different texts and translations (Schank and Abelson, 1977; Pentland, 1999). In a similar manner, one caregiver’s story of caring for a child living with HIV and AIDS was similar to another, but the underlying events were different based on the conditions and place the story took place and at under what circumstances. For example, a caregiver telling a story of caring her child as single parent and another told a similar story but was living with her husband. The stories were different although they were similar because they shared the same characteristics of being in extreme poverty and living in rural areas.

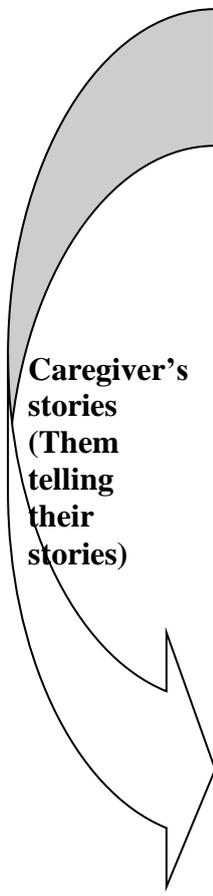
The next level concerns the point of view or focalization with which the events in the story are perceived and narrated (Pentland, 1995; Bal, 1985). This is the level where narrative voice and evaluative context enter into narrative structure (written down) (Pentland, 1999). Focalization here introduces subjectivity inherently to the extent of striking objectivity (Bal, 1985; Pentland, 1995). Focalization is therefore a threat to validity here because it is selective and value laden rendering of events (Pentland, 1999). Brown (1998) and Simon (1992) noted that one would expect stories such as

of caring for a child living with HIV and AIDS to be very different even though they may recount the same underlying events such as feeding or bathing, medications and visits to the hospital. They further state that researchers can also focalize on subjects when they choose what to measure and what to report (Brown, 1998; Simon, 1992). For example, within the caring process of a child living with HIV and AIDS, the procedure of giving of medicines to the child was very different from the assessment procedure by the individual caregiver of the same child or from child to child although they have similar characteristics of living with HIV and AIDS. Or it was the way the individual caregiver told the story about this everyday caring work that made the difference and the researcher focalized on individual caregivers when re-telling the stories of caregiving.

The final level is the text of narrative that seems to be at the surface but specifically narrated (Pentland, 1999). This is the level at which individuals account for and make sense of their actions and those of others (Pentland, 1999). This is the level at which data collection is done (Pentland, 1999). It is the level where the verbatim transcription is done and that is the main narrative aspect (Pentland, 1999). But Boje (1991) warns about the fragmented, elliptical (put in a manner that is difficult to understand) situated and strategic nature of this discourse and it is the responsibility of a researcher to put such fragmented stories into coherent and more fluent story without changing the meaning. Even with a specific point of view, there are still ways to actually tell a story (Boje, 1991). Pentland (1999) explains that there are enormous variations at each level of narrative structure. For example, a single process can generate many different performances each which can be seen nearly infinite variety (Pentland, 1999). In this study, individual caregivers told stories on a single care process that generated many different performances. For example assessing the child's illness was a process each caregiver performed but they differed considerably. Please see figure 2 below that illustrates the modified narrative structure.

Figure 2: The modified narrative structure from Pentland (1999): applied to this study

Level	Definition	Example
Text	Particular telling of a story by a specific caregiver.	Actual text of caregiver’s story: This is from the verbatim to transcription of the story to form a text that can be read. For example: “I could see that the medicines have finished but the child was still sick..”
Story	Version of a Story (fabula) from a specific point of view is told thus generic description of a particular set of events and their relationships of caring a child with HIV and AIDS.	A caregiver’s own version of how they give the care to a child with HIV and AIDS. How a particular child with HIV and AIDS is cared for: what happened? Who does what? For Example: “I took the child to the hospital for treatment that did not work at first..”
Generating mechanism	Underlying structures that enable or constrain the story of caring a child with HIV and AIDS.	How children with HIV and AIDS in general are cared for. ‘I do the everyday caring, but although their father is absent, he makes all the decisions about when the child goes to hospital...’



Modified from Pentland (1999): Building process theory with narrative from description to explanation Page, 719

In this study, an individual caregiver told real life stories and this modified structure was used as a guide during the narrative process.

Pentland, (1999) states that the narrative approach starts from the text level where the verbatim is transcribed (where interviews were conducted) into a text (or existing text) up to the story where a version of a story from a specific point of view is told thus generic description of a particular set of events and their relationships are expounded and in the case of this study, a generic description of caring a child living with HIV and AIDS was expounded. This is the main narrative aspect of this approach, however, the researcher has the opportunity of going deeper into the story by re-telling the story to generate mechanisms of that story such as explaining the underlying structures that enabled the story to succeed or fail (Pentland, 1999; Bal, 1985). In the example that was given earlier on for this study, the researcher was at liberty to explain why treatment failed in the first place and so forth. Or in this example “I do the everyday caring, but although their father is absent, he makes all the decisions about when the child goes to hospital...” The researcher was at liberty to explain why the father made all the decisions while the father was absent and did not take part in the caring of the child. As explained by Pentland (1999), the explanations were given to ensure that the stories became clear and coherent, otherwise, the researcher could have just transcribed the verbatim into a text and just showed the relationships between the stories of caring a child living with HIV and AIDS in a rural areas of Malawi by merely describing them. That was adequate based on the principles of narrative analysis but would not have increased understanding. Below is additional explanation of individual life experiences through storytelling to help explain why the narrative approach was relevant and suited for this study.

Individual life experiences through storytelling

Experiences in one’s life can be interpreted to reveal intersections of cultural, social and political perspectives (Riessman, 1993). Often individuals recapitulate and interpret their life experiences through story telling (Riessman, 1993). Narrative is viewed by many leading scholars from different disciplines as the organizing principle of human actions through story telling (Bruner, 1986; Riessman, 1993). Storytelling is what is done with research material (data) and what the story tellers

(participants) do with researchers (Riessman, 1993). The mechanical tactics adopted from the natural science help to provide an objective description of stories following the object investigations (Riessman, 1993). Then this is what narrative analysis is all about (Riessman, 1993). In this study, narrative was a suitable approach as it became apparent that the women caregivers used a storytelling approach to describe and make sense of their experiences of caregiving. This was the only way women caregivers were able to express their experiences of caring a child living with HIV and AIDS.

Interpretations of personal stories

From the humanistic point of view, only people tell stories (Riessman, 1993). Interpretation in this respect is therefore inevitable because narratives are representations of what people experience (Riessman, 1993). Individuals construct past events (antecedents) and actions in personal narratives to claim identities and construct their lives (Riessman, 1993). As Rosenwald and Ochberg (1992) cited in Riessman (1993) observe that

“Personal stories are not merely a way of telling someone (or oneself) about one’s life, they are the means by which identities may be fashioned” (Rosenwald and Ochberg, 1992 cited in Riessman, 1993:2

Individuals are usually the autobiographical narrators by which they tell about their life experiences that are private (Attanucci, 1991). These individual private constructed stories mesh with a community of life stories “deep structures” about the nature of life itself in such a community and when individual private stories and that of the community as a whole, they shape the culture of such a community through a language that is understood by all community members and cultural identity and the way of dealing with certain situations in such a community is born (Riessman, 1993).

Riessman (1994) agrees that storytelling and its favourable interpretation is essential in shaping the particular community’s way of dealing with different situations affecting such a community. Therefore, obtaining credible personal data in

qualitative research is an important step in developing the “theory” that adds knowledge and a new way of dealing with situations in a community (Golden-Biddle and Locke 1993).

Traditional approaches to qualitative analysis often segment the texts in the service of interpretation and generalization by taking bits and pieces snippets of responses edited out of context (Lieblich, 1998). They eliminate the sequential and structural features that characterize narrative accounts (Riessman, 1993). Bruner (1990) therefore, agrees that a primary way individuals make sense of experiences is by casting them into narrative form. This is true especially in difficult life transitions and trauma (Riessman and Quinney, 2005). Narratives therefore, are essential meaning making structures, they must be preserved and not fractured or segmented by investigators who must respect the subject’s ways of constructing meaning and analyse how they are accomplished, and hence they must remain a unit when interpreting them (Riessman, 1993). So in the data chapters of this study, the researcher has maintained this principle of respecting the subject’s ways of constructing meaning by presenting the subject’s narratives in their own way.

Personal Narratives as Data

Golden-Biddle and Locke (1993) explain that in everyday life, it is not difficult to locate narrative stories of personal experiences because individuals act and tell their experiences to another individual. This is because everyone is able to recall a conversation one has had with someone in exquisite detail (Golden-Biddle and Locke, 1993). One is able to re-tell what was said and what happened next (Golden-Biddle and Locke, 1993). This is a recapitulation of every moment that had special meaning at that moment (Riessman, 1993). Nelson (1989) states that telling stories about past events is a universal human activity, one of the forms of discourse we learn as children, and used throughout the life course by people of all social background in many different settings. That the narrative impulse in human beings is so natural that the form is almost inevitable for any report of how things happened, a solution to the problem of how to translate knowing into telling (Riessman and Quinney, 2005).

In this regard, research interviews are no exception (Attanucci, 1991, Riessman, 1993). Subjects if not interrupted with standardized questions will tell their stories for lengthy turns and may sometimes organize replies into long stories (Attanucci, 1991, Riessman, 1993 and Riessman and Quinney, 2005). Therefore, in this study the style of asking women caregivers was free flowing in an informal discussion so that women were encouraged to tell their stories describing the caring of a child living with HIV and AIDS. This style enabled women caregivers to open up and express themselves freely. Probing questions were used where necessary. There were a few of women caregivers who were shy to be interviewed mainly because it was their first time to be interviewed and it was a cultural issue where women in Malawi are generally shy to new issues.

Stories are told through a language that is viewed as a transparent medium, unambiguously reflecting stable and singular meaning (Riessman, 1993). Therefore, language is understood to be deeply constructed of reality and not just a technical device for establishing meaning (Riessman, 1993). “Subject’s stories do not mirror a world out there, but rather; they are constructed, creatively authored, rhetorically replete with assumptions and interpretive tendencies” (Riessman, 1993). Because narrative approach gives prominence to human experiences and their imaginations, it is well suited to studies of subjectivity and identity (Riessman, 1994). Therefore, studying narratives and make meaning out of them is useful as they reveal social life through those individual stories (Riessman, 1993).

The methodological approach in narrative analysis helps examine the subject’s story and analyse how it is put together; the cultural and linguistic resources it draws on, and how it persuades a listener of authenticity (Riessman, 1994). Therefore, analysis in narrative studies opens up to another form of telling about experiences, not simply the content to which language refers (Riessman, 1993). The question asked in narrative analysis is **why** the story was told in that way and **how** do we interpret such personal stories (Riessman, 1993; Riessman, 2008). For example, in this study the way that women told their stories indicated their low status in society without them making this explicit in the content of the narrative.

In this study, women caregivers told the researcher their stories of caregiving, this approach was more appropriate and suitable to analyse data. The narrative approach was used as a “lens” to view the wider world of caregiving and social support of children living with HIV and IDS in rural areas of Malawi.

Individual stories of ill health- the narrative and illness related studies

Riessman (1994) and Riessman and Quinney (2005) have emphasized and repeated that the primary way human beings make sense of their experiences is by casting them in narrative form and this is especially the case in trauma experience irrespective of the cause be it illness, physical or psychological. Individuals, be it patients or any one, become autobiographical narrators by which they tell about their lives' experiences (Riessman and Quinney, 2005). The telling of personal stories in narratives is common in health research interviews (Riessman, 1993). Narratives are important form of discourse in health related research because they allow for the construction and expression of meaning which is an essential activity of human nature and help improve the lives of clients or patients (Riessman, 1994).

Use of narrative in health and illness

Hyden (1997) stated that any illness brings about a disruption and a discontinuance of an on –going quality of life. The usual current of daily life activities are obstructed and perhaps blocked by illness altogether (Hyden, 1997). Illness may revise people's conceptions of what is changeable, and people may be forced to change premises upon which they plan to and evaluate their lives (Charmaz, 1992). Hyden (1997) further argues that acute illness, in the best of cases, has mainly only a temporary significance in people's lives; it may constitute a transitory and limited disruption and may cause people to re-examine their lives in the light of their frailty. On the other hand, chronic illness usually changes the very foundation of peoples' lives because the illness creates new and different life style conditions (Hyden, 1997). People or individuals often tell stories of their illness to the concerned person or the person they view can help them such as the physician or the nurses (Hyden, 1997).

Hyden (1997) also contended that illness can be experienced as a more or less external event that has intruded upon an ongoing life process. Bury (1982) added that at first the illness may look to lack all connections with earlier events, and thus it

ruptures people's sense of temporal continuity and if the rupture is not amended, the very fabric of peoples' lives may be ripped off to shreds. It is in this context that narratives become particularly captivating in researchers' minds (Hyden, 1997). Hyden (1997) ascertains that narratives offer an opportunity to knit together the split ends of time, to construct a new context and to fit the illness disruption into a temporal framework. Labov (2006) and Hyden (1997) add that narrative can provide a context that encompasses both the illness event and surrounding life events and re-creates a state of interrelatedness. This can only be achieved when individuals narrate their experiences of the illness through storytelling technique (Hyden, 1997).

Individuals narrate significant events in their lives such as that of being ill at one point especially when the illness is chronic or lifelong (Riessman, 1994). Clients (patients) naturally present their experiences in this way to clinicians, nurses and doctors who help them re-tell and re-construct new, more fulfilling narratives (Misher, 1990). Social scientists have recently discovered the use of narrative to study social life in ill health although narrative is an old phenomenon (Riessman and Quinney, 2005; Bruner, 1986; Riessman, 1994). This is because realist assumptions from natural science have proved to be limiting for understanding social life especially in ill health (Riessman and Quinney, 2005). Leading American scholars from anthropology, history and psychology have now turned to narrative as the organizing principle for human researches in illness or wellness (Bruner, 1986).

Language use in narrative of ill health

Riessman (1994) contends that the culture of any discipline speaks itself through individual's stories and this applies to the culture in the health sector. Individual narrators speak in natural and cultural terms; in their own language they are familiar with for easy communication and understanding amongst themselves (Rosenwald and Ochberg, 1992). Researchers therefore must use the same language that individuals (subjects) speak during data collection and when verifying the facts but during analysis, researchers can re-cast (re-tell) the stories in their own style of writing and in their own language (English in the case of this study) that other researchers can easily understand (Rosenwald and Ochberg, 1992).

Examples of studies that used narrative in health related issues

Riessman (1993) has highlighted three studies in health sector that used narrative effectively. The three studies exemplify the necessity of and applicability in the use of narrative in trauma. Riessman (1993) cited Robin's study that examined the life experiences told in interviews by 30 delinquent girls in Massachusetts in the United States of America. In this study, the thirty girls told stories about their private lives as prostitutes. In the findings, the girls made connections between their public actions, delinquent behaviour and their private life.

While Hyden (1992) used narrative approach to examine the physical violence in marriages among 20 Swedish couples where the wives were assaulted by their husbands, it became apparent that narrative approach was more appropriate than any other method because stories were told by wives about the behaviour of their husbands. She had a set of repeated interviews that lasted for two years. She studied how each spouse made sense of the violent episodes through narrativizations, how language differed from husband to wives and what happened to the accounts (and these marriages) over times. Using the narrative approach, Hyden (1992) observed a typical three-part sequence-verbal fight, violent incident and aftermath- which husbands constructed differently because of the contradicting standpoints.

Riessman (1990) examined 104 wives who were separated due to physical abuse in marriage that ranged from rape by their husbands to verbal violence. This was a sample of working class women who were raped by their husbands and Riessman used the narrative approach. Riessman (1990) while applying the narrative approach, observed that women were free to explain what constituted rape in marriages and the resultant divorces via storytelling.

Lessons learnt from the three studies

The three studies highlighted above are social in nature but with serious health implications. The three stories have also revealed how social work investigators in all different diversity have begun to recognize and analyse narratives in research interviews with health related implications or issues (Riessman, 1994). Thus narrative analysis allows some unpacking of text that is paying more attention to language and representation of experience in the talk of subjects in order to interpret

the told stories (Riessman, 1993). The degree of the narrative analysis depends on the research questions and the theoretical orientation of the researcher (Riessman, 1994). In the case of this study, a longitudinal qualitative study design was consistent with the principles of a narrative approach as meeting with the caregivers on more than one occasion facilitated rapport and encouraged storytelling. A narrative analysis approach was also appropriate for the research questions which required a description of events and experiences in the caregiving process. A longitudinal qualitative study design was suitable for this study because these women caregivers had not been interviewed in their lives, it was necessary to go back to them after 12 months after the first interviews to develop a trusting relationship between the researcher and women caregivers as seen during the second phase of interviews that women were more relaxed.

The approach for this study and conclusion

The aim of this study was to examine the experiences of caregivers of children living with HIV and AIDS in rural Malawi. The narrative principles of description and explanation as identified in literature review therefore were well suited for this study. In-depth interviews helped generate detailed qualitative data in narrative form as stories, with direct observations used to provide the wider cultural context. Caregivers were asked to tell their stories of caring and the levels of the narrative structure were instrumental during the analysis of the narrated stories so as to develop understandings of their caring experiences. Features of narrative as outlined by Bruner (1990) and Bal (1985) also helped in the organization of the narrative data within this study. In the second part of this chapter the researcher will discuss the research methods used in this study.

Chapter 4b

Methods

The study

The main aim of this study was to examine how caregivers manage their living and health care needs, cope with the disease, and care for themselves, and their children living with HIV and AIDS. This was achieved by obtaining the carers perspective to examine the practices, problems, and anxieties, support systems and perceptions that caregivers for children living with HIV and AIDS experience as they give the care and the challenges family members caring for these children face as a basis for identifying the adequacy of individual, family, traditional and institutional support.

The main questions for the study were:

- What are the roles of traditional, social and clinical institutions in care provision and support to caregivers of children living with HIV and AIDS and their sick children?
- What are the experiences of women caregivers of children living with HIV and AIDS as they provide the care to such children?

The study design and data collection methods

The design for this study was a longitudinal descriptive qualitative design. This study used qualitative research methods of in-depth interviews and observation because they were most relevant and consistent with the study design and questions that required a detailed examination of experiences of caregivers looking after a child living with HIV and AIDS in rural Malawi. Women caregivers were asked to describe their experiences as they cared for their children living with HIV and AIDS in rural Malawi and their stories have been analyzed by using a thematic analysis approach which is descriptive in nature, combined with narrative analysis to better

understand how women constructed their stories in their own particular cultural context.

In order to access the experiences of caregivers, in-depth narrative interviews were the appropriate qualitative research methods. For example, in-depth interviews allowed the researcher to tap into the women caregivers' "natural" storytelling and in turn, also allowing women caregivers to provide detailed information on how they manage their living and health care needs, cope with the disease, and care for themselves, and their sick children. Direct observations methods were used concurrently with in-depth interviews to enrich data. The observations were of the environment where clinical care was provided to this group.

The setting

The Study was conducted around Mponela Rural Hospital catchment area. Mponela Rural Hospital is the primary health care hospital situated in the central region of Malawi at a rural trading center called Mponela. Mponela Rural Hospital was chosen because it is one of the most rural hospitals serving the poorest people living in the rural areas of Malawi. The poorest people that live in the rural areas of Malawi are the most vulnerable and marginalized because they do not access such amenities as electricity, good tarmac roads and good nutrition (and yet 85% of Malawi's population live in rural areas and it is where HIV and AIDS rates are high) (MDHS, 2010). These amenities are available to people that live in cities and towns of Malawi (15% of Malawi's population) (MDHS, 2010). Mponela Rural Hospital was used as an entry point where research subjects were recruited and then subjects were followed-up to their homes to examine how they cared for and stayed with their children that were or are living with HIV and AIDS in a rural setting of Malawi. A sample was selected from a population of women caregivers that attended ARV clinic at Mponela Rural Hospital.

Study sample and sampling method

The study targeted female caregivers who looked after children from the rural villages in the catchment area of Mponela Rural Hospital. The majority were aged

between 18 and 45 years, although there were two female caregivers whose ages were above 70 years. Female caregivers were the focus of this study because in Malawi, culturally, most of the care given to sick or healthy children is borne by women. Whilst there are a small number of male caregivers, because caring is regarded as a woman's responsibility by most men in Malawi, it was difficult to trace them hence it was only possible to recruit women caregivers to the study.

To obtain a detailed exploration of the experiences of this group, a sample of 20 women caregivers was chosen to represent a wide rural population of Mponela Rural Hospital catchment area in Malawi. Five participants were deliberately chosen from each of eastern, western, southern and northern areas of Mponela Rural Hospital so that all areas were represented. The sampling method for this study was purposive sampling to ensure that the sample of women represented some of the key features found in the wider population in the rural areas of Malawi (Platt, 1992). Purposive sampling method is a research practice where research participants are chosen intentionally by the researcher to represent some predefined and explicit conditions or traits (Platt, 1992; Luborsky and Rubinstein, 1995). In this study, women caregivers that lived in rural areas surrounding Mponela Rural Hospital were intentionally selected by the researcher because they met the predefined and explicit traits that were required. These explicit and predefined traits included: caring for a child living with HIV and AIDS in a rural setting for not less than two years, have lived around Mponela Rural Hospital for a period of not less than five years so that they were conversant with the cultural values of caring among the Achewa tribe that have lived in this area from time immemorial, they were over 18 years of age and particularly were women caregivers whose age was between 25 and 45 years old and they had no mental health problems. Being in a rural setting, it was difficult to reach these subjects.

Interviewing a hard to reach population

This is a hard to reach and hidden population of Malawi because of poor communication infrastructures such as bad quality roads (MDHS, 2010). Judging from the data collection experiences with this group, no one has explored their perspectives and experiences of caring a child living with HIV and AIDS before.

They were interviewed for the first time in their lives. Malawi culturally is a male dominated society and such cultural factors meant it was hard to reach this group because they needed to get permission from their spouses for them to be interviewed or any male relative if the husband had died (MDHS, 2010). Thus, no-one has ever asked their opinion because their views are seemingly not valued. Because of this patriarchal and male dominated culture, traditionally women do not have a voice (MDHS, 2010). In addition, rural women live in poverty and are uneducated and their main focus is on survival of them and their children (MDHS, 2010). Therefore, accessing them was a challenge as they lived in remotest areas and were busy finding means of surviving and also had to defer to men before they could be interviewed. During the interviews it became apparent that being asked their opinion and their inner life work was difficult. There is also a culture of secrecy among women in general in Malawi (MDHS, 2010). Women caregivers still lived with that culture of secrecy and in addition, they felt caring a child living with HIV and AIDS was a shameful thing and hence it was hard to access them. Some of the women caregivers did not want people to know that they were HIV positive and that their child was living with HIV and AIDS and hence not used to discussing their experiences with anyone else in this regard. Women caregivers told their stories on how they cared for the child living with HIV and AIDS and because they were telling stories, a narrative approach was selected as it has principles that are consistent with storytelling.

Methods

A total of 20 in-depth interviews with 20 different women caregivers were conducted using the qualitative In-depth Interviews and Direct Observations. Direct observations were carried out in the wards/outpatients at Mponela Rural Hospital.

Interviewing: gender issues

Initially, the researcher felt that the participants should be interviewed by a woman. However, the participants stated that they did not want to be interviewed by a female interviewer; they preferred to be interviewed by the male interviewer because they stated that felt comfortable and free to talk to a male person on such sensitive issues of HIV and AIDS. Therefore; a decision was made after consulting the research

supervisor in the United Kingdom for the male researcher (the Principal Researcher-Mandayachepa Nyando) to carry out the interviews.

Interviewing: translation issues

Face- to –face in-depth interviews with the female caregivers were conducted in Chichewa, but were translated into English. The researcher speaks Chichewa language and it is his first language. Both the Chichewa and English versions were proof read by a linguistic expert at University of Malawi to ensure validity and reliability of the translation of the data collected. The research supervisor who is an English language speaker also proof read the translated versions of all the interviews to ensure that the original story content was maintained.

The original data collection plan

The sample size for this study was originally to be twenty (20) female caregivers and the ethics committees for Cardiff University and Kamuzu College of Nursing approved it. However, the Malawi College of Medicines ethics committee recommended a sample size of 40 women caregivers. Thus 20 in-depth interviews (IDIs) and two focus group discussions (FGDs) comprising 10 women caregivers each were planned. But during the first phase of data collection, where 20 in-depth interviews were conducted, all female participants indicated unwillingness to talk in a group about their caregiving experiences despite that they accepted to participate during the recruitment process. Therefore, in consultation with the supervisor, a decision was made to end those focus group discussions. In addition, adequate data were generated during in-depth interviews. Therefore, the sample size of forty had been reduced to 20 as it was originally designed. This study was a longitudinal descriptive study and required a detailed exploration of their experiences of caring and 20 women caregivers provided detailed information about caring a child living with HIV and AIDS and the caregiving experiences. Therefore, this sample size of 20 women caregivers was adequate to obtain the information that was required. Detailed information was generated during the in-depth interviews that comprised twenty (20) female caregivers who were sampled purposively as described below.

Sample and sampling method

A sample of 20 women caregivers was selected. The sampling method for this study was purposive because the female caregivers had characteristics that met the inclusion and exclusion criteria for this study. Participants also showed willingness to take part in the study.

Ethics and recruitment

Ethics

Ethics is an important aspect of a research process because it helps protect research participants (Redman and Fry, 2000; Penticutt, 1991). There are ethics principles such as the principle of non-maleficence which means do no harm (Redman and Fry, 1997). Autonomy is the personal rule of the self that is free from both controlling interferences by others and from personal limitations that prevent meaningful choice (Redman, et al., 1997; Redman and Fry, 1996). Autonomous individuals intentionally act with understanding, and without controlling influence (Redman and Fry, 1996). Respecting autonomy of individuals is one of the fundamental guidelines of any research (Penticutt, 1991). Autonomy in research is not simply allowing participants to make their own decisions to participate but researchers must have an obligation to create the conditions necessary for autonomous choice in their participants. For the researcher, respect for autonomy includes respecting an individual's right to self-determination as well creating the conditions necessary for autonomous choice (Penticutt, 1991; Redman, et al., 1997; Redman and Fry, 1996).

Researchers should promote autonomy and reduce risks of harm to research participants and researchers must not do anything that would purposely harm research participants and while at the same time take into consideration the benefits (Redman, et al., 1997). This is what ethics committees look for in any research protocol. Another ethics principle is the principle of beneficence and beneficence is the action that is done for the benefit of others (Redman and Fry, 1996). Beneficence actions can help to prevent or remove harm or to improve the situation that may seemingly harm others (Redman and Fry, 1996). Researchers are expected to refrain

from causing harm but at the same time are expected to conduct research for the benefit of the population concerned (Redman and Fry, 1996).

Researchers must weigh the benefits and risks and explain how they will achieve their study without causing harm on their study participants Penticutt, 1991 (Penticutt, 1991). This is what research ethics committees look for in any study protocol. However, one of the common dilemmas that arise is trying to balance the principles of non-maleficence and beneficence (Penticutt, 1991; Redman and Fry, 1996). This balance is the one between the benefits and risks of the research and plays a major role in every study decision (Redman, et al., 1997). By providing an informed consent, researchers give the participants the necessary information to understand the scope of potential risks and benefits in order for them to make a decision of whether to participate or not and this in itself help promote autonomy (Redman, et al., 1997). Nonetheless, the potential benefits of the study must outweigh the risks in order for the research project to be ethical (Redman, et al., 1997). Ethics is one important part of research that deals with issues of protecting research participants (Redman, et al., 1997). There are institutional review boards that are charged with the responsibility of ensuring that research participants are protected by researchers (Penticutt, 1991). This study modeled the ethics process of Oxford University Centre for AIDS Interdisciplinary Research in the department of Social policy and social Work. Please refer to appendix 5.

Modelling the ethics process approach

The ethics approach was closely modelled on the recruitment and consent procedures used by the Centre for AIDS Interdisciplinary Research at Oxford (CAIRO), within the Department of Social Policy and Social Work, Oxford University. Dr Lucie Cluver had acted as a scientific advisor to UNICEF, the WHO, and the South African National Action Committee for Children Affected by AIDS (NAC, CA) and had conducted a large number of studies examining the impact of HIV and AIDS in the rural areas in the Republic of South Africa. Dr. Cluver granted this study permission to use the Centre's approach during a consultative meeting on 29th July, 2010 at Oxford University, Department of Social Policy and Social Work for this study and via email. This study also reflected the UK National Health Service (NHS)

guidelines on research ethics (See appendix 5). Following this modelling, the ethical approval was obtained from all the three relevant institutional review boards as explained below.

Ethical approval

The study was conducted after approval from the School of Nursing and Midwifery Studies Research Ethics Committee, Cardiff University and Kamuzu College of Nursing and Malawi College of Medicine Research Ethics Committees, was granted. For the ethics approval to be obtained, the three institutional review boards required that subjects were properly protected and detailed information about areas that were covered to obtain the approval are discussed below under different subheadings.

Confidentiality in the community

In all the research protocols such as protocols for initial contacts, interview guides and letters to the community leaders, there were no mention of HIV and AIDS. All correspondence was referred to health and wellbeing issues to avoid issues associated with stigma and discrimination. Talking about HIV and AIDS issues was avoided when dealing with the community but we talked of a study examining health and wellbeing issues of the children.

Approaching key officers and the clinician

Upon receiving approval from all necessary ethics committees (the Cardiff University School of Nursing and Midwifery Studies Research Ethics Committee and Kamuzu College of Nursing Research Ethics and Publication Committee and College of Medicine Research Ethics Committee) the researcher sought permission from the District Commissioner, the District Health Officer (DHO) for Dowa district and the Officer In-charge for Mponela Rural Hospital and other relevant authorities as outlined later in this document, to conduct this study at Mponela Rural Hospital. The researcher approached a clinical officer who reviewed patients at Mponela Rural Hospital with a request to interview some of the participants. In addition, the researcher also approached the community nurse responsible for home based care at

the hospital, with a request to interview participants on home based care in their respective homes.

Confidentiality and recording

The participants were fully informed about the study that the discussions would be recorded and that hand written notes were taken as a backup to the tape recorder. The duration of the interview on average lasted approximately 1 hour and forty-five minutes each. How data would be managed and kept secure throughout the period of data collection, during and after data analysis was also explained to the participants.

Hand recorded notes

Participants were also explained that the interviews would also be recorded by hand to supplement the data recording machine so that they were made aware and not get surprised when they saw the researcher writing notes. Although in actual practice, this was stopped as subjects were uncomfortable with note taking. Notes were only taken during direct observation at the hospital.

Withdraw from the study

Participants were informed that they were at liberty to withdraw from the study at any time they felt that they did not want to continue and that they could withhold information if they did not feel sharing it. No repercussion was exercised on them for their decision to withdraw such as their legal rights to treatment and any medical care were not affected in any way. They were informed that they could still participate in the study at a later time if they changed their mind.

Benefits for participation

Female caregivers participating in the study were fully informed of the reasons for their participation and the costs, risks and benefits of their participation in the study were also explained to them. Participants were also informed that there were no

direct or indirect benefits for them for participating in the study. However, their immediate benefit was the feeling that they had contributed to the improvement of care giving to children living with HIV and AIDS in the rural areas of Malawi.

Risks as a result of participation in the study

Participants were referred to the trained counselor at Mponela Rural Hospital if they showed any discomfort as a result of their participation in the study after data collection process was completed. If they started crying, the interviews were suspended or terminated immediately and counseling sessions were arranged for them after obtaining consent. Then they were referred to the qualified counselor at the hospital to continue the counseling process. After satisfying all the requirements the approval and permission were granted from the three institutional review boards and officers and community leaders in the district as detailed above, the recruitment process begun as explained below.

Recruitment process

Upon receiving approval, the researcher sought permission from Dowa District Health Officer to conduct this study at Mponela Rural Hospital. Please refer to appendix 8 for all letters. The researcher approached the nurse responsible for HIV and AIDS care at the hospital who reviewed patients at the HIV and AIDS Clinic with a request to interview some of the participants. The same nurse was also responsible for home based care activities for patients living with HIV and AIDS around Mponela Rural Hospital.

Inclusion and exclusion criteria

The twenty (20) female caregivers of children living with HIV and AIDS that were recruited for the study fulfilled the following criteria:

- Willing to participate and the interview did not interfere with the immediate care needs of their child living with HIV and AIDS

- Caring for children with HIV and AIDS and were above eighteen (18) years of age and the children living with HIV and AIDS were between one and thirteen years of age. A minimum of 18 years was ideal to ensure that the female caregivers are mature and had adequate experiences.
- Living or have lived within Mponela Rural Hospital catchment area for not less than five years and had cared for a child not less than two years at the time of data collection. This was to ensure that the caregivers understood the culture of the area when it came to caring for a sick child and had adequate experience of caring for such a child.
- Caregivers whose children were not critically sick.

After meeting the above criteria, subjects were enrolled into the study as discussed below. For details of the characteristic of the research participants please refer to appendix 4.

Enrollment

The nurse responsible for HIV and AIDS at Mponela rural hospital approached the prospective participant at the clinic with the intent to ask her to participate in the study. At the initial contact with the prospective participant, only major components of the study were given. When the participant indicated willingness, the investigator asked the participant for the best place for the interview to be conducted. They all preferred to be interviewed at their respective homes where they felt relaxed and comfortable. Necessary arrangements including accompanying the patient home to know the place were made. The investigator arranged for a date and time that was suitable to the caregiver and the child for the interviews. The full details of data collection have been discussed already but what follows is a discussion on why this study chose interview methods and it was supported by the theoretical literature.

Data Collection

Generating relevant information for my study

After obtaining permission to conduct this study (please see appendix 3 and 7), data collection began in May in 2011 and finished in July, 2012. In order to generate information relevant to this study, in-depth interviews and direct observations were used. Key issues (themes) were identified based on the Escalada, et al. (1997) steps of key issues or themes identification. That is breaking down the major topics into discussion points or themes/key issues first before proceeding with in-depth interviews in order to map out a clear outline for possible questions. For this study, the following are the key issues/themes: 1) the needs, physical and emotional problems of care givers of children with HIV and AIDS. 2) The type, resource and perceived adequacy of support received by caregivers and their children living with HIV and AIDS.3) the constraints to receiving care and support for children with HIV and AIDS. 4) The role of traditional and social institutions (i.e. families, governmental and non-governmental) in care provision and support to children with HIV and AIDS and their caregivers.5) the perceptions, beliefs, feelings and opinions about the care and social support caregivers and children living with HIV and AIDS receive. The above key issues/themes provided a basis an outline of possible questions for my study. Data were collected using In-depth Interviews (IDIs) and Direct Observations (DOs).

Narrative Interviews

The researcher interviewed 20 women caregivers of children living with HIV and AIDS that lived in rural settings of Malawi. Narrative interviews were conducted in their homes. During the narrative interviews, participants were asked about their practice of care, needs, problems, support, and resources related to caring a child living with HIV and AIDS in their own homes in the rural areas surrounding Mponela Rural Hospital. Mponela Rural Hospital catchment area was the setting for this study.

Types of narrative interviews

Narrative interviewing is defined as a conversation with a purpose, a guided conversation that aims to understand the perspectives, interpretations, and meanings given by interviewees to specific issues (Kvale, 1996). Enosh and Buchbinder (2005) argue that even though such a definition is inclusive and extensive, it implies that the role of the interviewer in the process of narrative production is relatively passive. The interviewer is mainly considered the facilitator of data production by the interviewee rather than an equal partner in data production (Enosh and Buchbinder, 2005). However, a narrative interview is a two way process where exchange of facts may occur during the conversation, therefore, both the interviewer and the interviewee should be seen at an equal footing (Enosh and Buchbinder, 2005).

Narrative interviews are the most popular methods for data collection in many social scientific studies irrespective of the design; be it quantitative or qualitative (Denzin and Lincoln, 1994). The use of narrative interviews is even more critical in qualitative research methods because the qualitative research interviews seek to describe the meanings of the central themes in the real life experiences of the research participants. The major task in qualitative interviewing is to understand the meanings of what the interviewee says (Kvale, 1996; Kvale, 2009; McNamara, 1999). Kvale (2009) further believes that qualitative interviews seek to cover both facts meaning, though it is usually more difficult to interview at meaning level. Interviews are particularly useful in unearthing the stories behind the subject's experiences. In this case, the interviewer can pursue in-depth information around the topic (McNamara, 1999). Krueger (1988) and Kumar (1988) add that narrative interviews may be useful as follow-up to certain subjects questionnaires for the furtherance of investigation on their responses. Interviews and direct observations are becoming more and more popular methods for data collection in many qualitative research methods (Foddy, 1993). This is because the qualitative research interviews seek to describe the meanings of the central themes in the real life experiences of the research participants in detail and hence provide the rich data that is needed in the study (Denzin and Lincoln, 1994; Kitzinger, 1995; Foddy, 1993). There are different types of narrative interviews as discussed below.

An interviewer may use a variety of narrative interviews depending on own preferences and the qualitative research design (Hollowitz and Wilson, 1993). There is the informal, conversational narrative interview where no predetermined questions are asked in order to remain as open and adaptable as possible to the subject's nature and priorities; during the interviews, the interviewer follows the flow of the interview (Pawlas, 1995; Trochim, 2002). The semi-structured interview is another type. The intention in this type is to ensure that the same general information areas are collected from each participant; and it provides more focus than the conversational approach, but still there is a degree of flexibility and adaptability when getting the information from the participants (Hollowitz and Wilson, 1993). This type facilitates faster interviews that can be more easily analysed and compared (Campion, et al., 1994). There are different types of narrative interviews and the most popular one among social scientists are the in-depth interviews. Focus group discussions (FGDs) and are a rapid assessment, semi-structured data gathering method in which purposively selected sets of participants gather together to discuss issues and concerns based on the list of key themes drawn up by the researcher or facilitator (Kumar, 1987). The discussion will focus on the approach used in this study; the in-depth interviews. In-depth interviews that used semi-structured interview approach merely to guide the discussions and direct observations only.

In-depth Interviews (IDIs)

The in-depth interview is the approach where the focus is on the same one or two topics which are explored in great detail (depth and not breadth) (Britten, 1995). The follow-up questions are on what the interviewee says, on one to one basis (Britten, 1995; Sommer and Sommer, 1997). This approach or format is useful for those not practised in interviewing and therefore are learning how to use them (Britten, 1995). Kvale (2009) highlights the strengths of in-depth interviews. In-depth interviews are of more quality and uncover the best thinking of each and every participant without the drawbacks of group dynamics (Kvale, 2009; May, 2002). There is also more quantity of information researchers can collect, at least twice as much the amount of information per participant in each in-depth interview per 20 minutes time than in a typical focus group discussion (Mason, 2002). The information is in more depth and captures all the relevance and salience of qualitative information of a focus group

(Mason, 2002). Each participant's interview can be taped, transcribed and used the data in multiple ways (May, 2002). Well trained coders can get beyond surface answers and produce a rich data base of interviews that generate analyst's reports, identify broad themes and produce a body of knowledge of range and depth (Kvale, 2009).

However, Kvale (2009) and Kvale (1996) mention some of the drawbacks of in-depth interviews. In-depth interviews require a skilled interviewer for quality data to be collected and to remain focussed on the topic, otherwise, more time will be spent on irrelevant information that may be difficult to analyse. Lack of structure may lead to results being susceptible to interviewer interpretation and increase the bias (Kvale 2009). Data is soft and difficult to analyse and interpret (Kitzinger, 1995). More time is also required to process the data (Mason, 2002). The in-depth interviews may be expensive to conduct as it requires more training among other logistics (Mason, 2002). However, benefits outweigh disadvantages and again, the disadvantages can be overcome if well prepared (Kitzinger, 1995).

Questions: In-depth interviews

In order to get qualitative data on experiences of care givers, in-depth interviews were ideal qualitative research methods because they helped to get detailed information. The types of topics in the questions adapted the sequence suggested by Dick (2002) as indicated below.

- *“Behaviour-What a person has done or is doing.*
- *Opinion/values-What a person thinks about the topic.*
- *Feelings-What a person feels rather than what a person thinks.*
- *Knowledge-to get facts about the topic.*
- *Sensory-What people have seen, touched, heard, tasted or smelled.*
- *Background/demographics-standard background questions, such as age, education etc”.*

Types of topics in questions and their sequence

The main questions for my study are:

- What are the roles of traditional, social and clinical institutions in care provision and support to children with HIV and AIDS and their caregivers?
- What are the in-depth understandings of the experiences of caregivers of children living with HIV and AIDS as they provide the care to such children?
- What are everyday life experiences of children living with HIV and AIDS from the women caregiver's perspective?

In order to generate information relevant to this study, the above study questions were answered via in-depth interviews and used the sequence based on the Dick's (2002) framework as discussed below.

Behaviour- *This is what an individual has done or is doing or has experienced.* In my study, the question that seeks to investigate what a person has done, or is doing or has experienced is as follows:

Question:

1. According to your experiences, what are the needs, physical and emotional problems of caregivers of children with HIV and AIDS?

Opinion/values- *This is what a person thinks about the topic.* The following question enabled participants to explain their opinion/values about the type, resource and perceived adequacy of support for caregivers and their children.

Question:

2. In your opinion, what are the type, resource and perceived adequacy of support for care givers and their children receive?

3. In your opinion what are the roles of traditional and social institutions (i.e. families, governmental and non-governmental) in care provision and support to children with HIV and AIDS and their caregivers?

Feelings- This is what a person/individual feels rather than what a person thinks.

The following question in my study will unearth the feelings of participants about the care and social support care givers and their children receive.

Question:

4. What are your perceptions, feelings, values and beliefs about the care and social support care givers and their children receive?

Therefore, the full sequence and structure of the questions were as follows:

1. According to your experiences, what are the needs, physical and emotional problems of care givers of children with HIV and AIDS?
2. What are your perceptions, feelings, values and beliefs about the care and social support care givers and their children receive?
3. In your opinion, what are the type, resource and perceived adequacy of support for care givers and their children receive?
4. In your opinion what are the roles of traditional and social institutions (i.e. families, governmental and non-governmental) in care provision and support to children with HIV and AIDS and their caregivers?

Where necessary, probes would follow each question depending on the responses of the subjects on the topic in each question. The interviews were tape recorded and transcribed in English language ready for data analysis.

Questions during in-depth interviews

For in-depth interviews, there are other very important issues about the questions during the actual in-depth interviews' period that the researcher must keep in mind. Below are some of them (Dick, 2002).

A question for information contextual tapping- This is the key question or questions that solicit information that one requires and must be direct to the point. This question sets the pace and must be broader enough and not direct to avoid scaring the participants. The question must aim at trapping the information that provides a context later on i. e. in late phases of the interviews. For example a question may read: In your work as a caregiver for these children, may you explain the experiences your face.

Probe questions- This should be done carefully and before moving on to the next set of questions. Use these probe questions for sensitive information. Probe questions may not or may be included in the in-depth interview guide. It depends on the researcher's preference (Escalada, et al., 1997). Escalada, et al., (1997) further adds that researchers need to organize a preparatory meeting with subjects so that a briefing is done before the actual interviews are conducted. They further argue that the meeting is used as familiarization meeting between the researcher and the research participants.

Preparation

It is good to meet the participants face to face prior to the session so that they know the researcher and get used to him/her although it is not always possible (Escalada, et al., 1997; Sommer and Sommer, 1997). This time the researcher may explain the purpose so that research participants are aware beforehand (Sommer and Sommer, 1997). This reduces anxiety and stress in them, so make it a point that pre-interview meetings are made with research participants (though briefly) especially in any interviews (Escalada, et al., 1997; Sommer and Sommer, 1997). In this study, pre-interview meetings were conducted between the researcher and each woman caregiver during the recruitment process where arrangements were made for the date and time for the interviews. Escalada, et al., (1997) and Sommer and Sommer,

(1997) describe that at such preparatory meetings, the following issues are discussed with participants:

An introduction- This is where the interviewer starts the discussion by introducing oneself. There is a need to clarify who you are and what your roles will be during the whole discussion process. The interviewer needs to explain whether the data collection is being done on behalf of another one or it is one own data. During the introduction, the interviewer provides the overview of the session. This may include, among other issues the following:

Purpose- Explain the reasons for the interviews and its intentions. And also who will get access to the information need to be made clear to the subjects at the introduction stage.

Process- Explain the overview of the process in brief and give time for questions. There is also a need to explain what will be done with the data such as analysis and who will use the information after it has been processed. Reassure the participants that the information will not be passed on to someone in raw and that no names are going to be recorded. If using electronic gadgets, tell them reasons for such gargets and let them take time to see it so that they comfortable with it and again, they will concentrate during the discussion or they will be interested in the garget itself.

In-depth Interviews Instruments (Guides)

Data were collected using an in-depth interview guide developed by the researcher by using the research questions and pre-testing the guide was done. Pre-testing interviews were conducted with students of Kamuzu College of Nursing after obtaining permission from the College management and consent from the students themselves. This pre-testing helped test the consent tools, find out if participants would understand the questions and corrections were made whenever possible. The pre-testing also helped check the data collection process, analysis and interpretation for accuracy. The pre-testing also helped determine the possible duration per topic, and indeed per question before moving on to the next question or topic. Where

possible, corrections were done before the actual data collection process was conducted following the data collection procedures below.

Data collection procedures

Participants were offered a mat (brought by the researcher) where the researcher and participants sat and conducted the in-depth interviews inside their houses. The interviewer checked if the participant was comfortable. The interviewer showed the participant the tape recorder which was used to record the discussion and informed the participant how the tape recorder worked. The interviewer checked again with the participant that it was okay to record the interviews from the time it started. All the interviews took place inside the house of the participants and there was no noise or any other persons listening to the discussions. The participants were informed to ask questions when they felt were not clear. All participants were read out the consent form and allowed them to ask questions for clarification on anything that was unclear. Participants were asked to provide a verbal consent and were recorded without them mentioning their names. Participants were told the reason for not using their real names thus to maintain anonymity and confidentiality. The in-depth interviews were tape-recorded. The recruitment, consent process, and interviews were conducted and written in Chichewa, and translated into English for data analysis.

Direct Observations

To enrich the data collected by the use of In-depth interviews, direct observations methods were used concurrently. Observations are one of the methods in qualitative data collection. Enosh and Buchbinder (2005) ascertain that observations involve the researcher watching what is going on about a phenomenon and takes notes. Enosh and Buchbinder, (2005) also note that there are two types of observations. The participant observation is when the observer or the researcher becomes part of the culture or the context being observed but it requires more time and it is very demanding. Enosh and Buchbinder, (2005) explain that the observation usually requires months or years of hard work because the researcher needs to be accepted as their own in the setting and be assimilated into the culture or context under study.

This is done to make sure that the observations made are natural and equal to the real natural environment (Enosh and Buchbinder, 2005).

Kvale (2009) adds that other type is the direct observation which is different from the participant observations in many ways. The direct observer does not become part of the culture but strives to capture what is happening without obstructing the actions or the activities. The observer watches the activities to ensure that there are no biased recordings. The observer may use video recorders and later watch what was happening or directly being there and be recording the activities (Wengraf, 2006). The direct observations are more focused than participant one. Here, the observer is watching certain simple situations or people and does not get immersed in the whole context or the phenomenon under study (Kvale, 2009). The direct observation does not take a long period to be accomplished and therefore, it is well positioned for research designs that are short (Wengraf, 2006). Good for academic research like this one because they are usually shorter as they are time fixed (Wengraf, 2006). The direct observation may be done under certain conditions as the research design may require such as child and mother interactions, caregiver and child interactions and so forth (Wengraf, 2006).

In this study, the direct observations were conducted because the study was an academic and had a short period i.e. between four to eight months of data collection. The researcher also needed to observe the emotions of the caregivers, the environment where the care was provided and the support provided by the hospital staff to women caregivers. This method complemented the in-depth interviews described above. Nurses working at the children's ward and at the ART clinic at Mponela Rural Hospital were observed on how they gave the care to children living with HIV and AIDS. The observations included, among others, the body language, behaviour, and attitudes as the care are delivered. Field notes were maintained during the direct observations. Data then was analysed using the iterative narrative approach. These data will be presented in the next chapter.

Approach to data analysis

After data collection that used in-depth interviews and direct observations methods, data were analysed manually using the thematic analysis of narratives, to better understand how women caregivers constructed their stories in their own particular cultural context. Data collected using the in-depth interviews method was largely analysed and then enriched with data from direct observations. Thematic analysis is historically a conversational practice in qualitative research which involves searching through data to identify any recurrent patterns (Charmaz, 2002). Patterns of words form a theme and a theme is a cluster of linked categories conveying similar meanings and usually emerges through the inductive analysis process which characterise qualitative paradigm in qualitative research (Charmaz, 2002). The exploratory power of this popular technique can be enhanced by the analyst lacking previous knowledge of research topic as they are not guided by any preconceptions (Charmaz, 2002). Thus the analyst does not have to be an expert in the research topic (Charmaz, 2002). However, in order to begin analysis, a researcher must have at least some conceptual understanding to guide the insight processes (Charmaz, 2002; Braun and Clarke, 2006).

There is no simple distinction between qualitative (naturalistic, contextual, idealist) and quantitative (experimental, positivist, realist) methodologies (Charmaz, 2002; Braun and Clarke, 2006). Since analysts move back and forth between new concepts and the data, all research involves processes of induction and deduction, especially data collected in narrative accounts whereby induction creates themes and deductions verifies them (Braun and Wilkinson, 2003).

Thematic analysis, narrative analysis, and grounded theory are methodologically similar analytic frameworks but the manner in which themes, concepts and categories are managed differs considerably between the three approaches (Charmaz, 2002; Braun and Clarke, 2006). They both attempt to represent a view or reality via systematically working through text to identify topics that are progressively integrated into higher order themes that form the main themes of the study, via process of de-contextualization (Charmaz, 2002; Braun and Clarke, 2006). Their procedures are more conceptually demanding than content analysis which uses a

much simpler ordering of data either through a table or just an outline indicating main themes where more information is added to (Charmaz, 2002; Braun and Clarke, 2006). However, thematic analysis and content are often confused (Charmaz, 2002). The former, through focussing purely upon meaning, promotes a more discursive interpretation since individual codes can cross-reference multiple themes and is more appropriately used to statistically test any hypotheses (Charmaz, 2002). Narrative analysis involves re-telling the story and interpretations of the story told is key (Riessman, 2008; Pentland, 1999). In narrative analysis, the researcher may combine the thematic analysis approach with it or vice versa for helping organizing the data especially when data is collected in narrative form (Riessman, 2008; Pentland, 1999). There is a thin line between the two approaches (narrative analysis and thematic analysis) when it comes to data organization (Pentland, 1999). In this study, the researcher combined the two approaches of data analysis. Thematic analysis was used to help identify and organize themes while the narrative approach was used for re-telling the story of caregivers as data was collected in narrative accounts or forms. In addition, the narrative analysis approach is well suited when stories are told and in this study, women caregivers told stories of caregiving to children living with HIV and AIDS in rural areas of Malawi.

In thematic analysis, a table has to be drawn indicating themes and sub-themes (Charmaz, 2002) and in this study a table of 12 main themes that emerged from the narrative accounts for each caregiver was drawn. Each transcript was read several times to identify any content that corresponded to any one main theme and that content was put to that corresponding theme. In the process of doing this, some new themes emerged that formed the sub themes for each of the main themes. Using the narrative analysis approach, the narrative accounts were re-told in the researcher's own words as it is with the principles of narrative analysis. One case study (Mayi Salima) was analysed separately using the same combined thematic and narrative analysis approaches. Below is the approach of data analysis that was used.

Data from in-depth Interviews

After data had been collected following the sequence/ structure of questions described at each interview method earlier on in this chapter, data were analysed manually using narrative analysis and thematic analysis of the narratives. This

approach was chosen because thematic analysis helped to identify and organize themes and that themes were built from multiple sources of data which this study had used such as in-depth interview tapes, daily field notes, direct observations (Smircich, 1983). The narrative analysis approach also helped to re-tell the stories as data were in narrative form (stories).

Analysing and managing data

(i) Analytic process

This study used the thematic analysis approach of qualitative data analysis and utilized four steps of thematic analysis of qualitative data based on Hawe, et al., (1990) outline to help organise the data. The four steps used were:

1. *Organise the data* – Prepare the data for analysis by way of transcribing the interviews into text and format the document so that the margins could be used for identifying individual bits of data for grouping or categorising. This can be done by assigning line numbers as identifiers for cross referencing (Hawe, et al., 1990). In this study, firstly, data were transcribed from the tape recording into a text for easy reading through and I looked for major themes or categories so as to be able to have the overall picture of the complete set of data.
2. *Shape the data into information*
Read the text and noting items of interest and conduct:
 - a. *Initial reading of the text*-an inductive approach to thematic analysis that allows themes to emerge from data, rather than searching for pre-defined themes (Hawe, et al., 1990). During the first reading make note of major issues as they come to mind in order to acquire a sense of the various topics embedded in the data (Hawe, et al., 1990). In this study, Words and sentences that contained information relevant to each theme were grouped together in a table form. Then preliminary categories were created by the researcher.
 - b. *Re-read the text and annotate any thoughts in the margin*- Examine the text closely. Line by line, to facilitate a micro analysis of data (Hawe, et al., 1990). This also promotes open coding which identifies any new information by de-contextualizing bits of data embedded within the primary material (Hawe, et al., 1990). In this study,

the content and boundaries of each category were noted and defined by the researcher. Changes and redefinitions of the categories were made in an on-going creative process.

- c. *Sort items of interest into proto-themes (the first elements of data)*- Hawe, et al. (1990) states that this is where themes begin to emerge by organizing items relating to similar topics into categories. Computers are great for pasting the lines references together (Hawe, et al., 1990). This should be a fluid process so categories can be modified, developed and new ones allowed to emerge freely (Hawe, et al., 1990). At this stage keeping the themes as simple as possible assists flexibility in the categorization process whereby any re-ordering of the clusters of categories can help create and re-define the initial themes (Hawe, et al., 1990). For this study, all recorded units with information relevant to the interview questions were referred manually to categories which in turn were referred to themes by the researcher.
 - d. *Examine the proto-themes and attempt initial definitions*- This phase of trawling back through the data examines how information was assigned to each proto-theme in order to evaluate its current meaning. A provisional name and flexible definition should now be created for each emerging theme (Hawe, et al., 1990). In this study, names were given to main themes that were developed. Information that was contrary to what the majority are bringing up were coded as well and treated as a new emerging theme or a sub-theme and names were assigned to them. –
 - e. *Re-examine the text carefully for relevant incidents of data for each proto-theme*- This second process of trawling through the data is also called axial coding (Hawe, et al., 1990). It involves re-contextualization whereby any data is now considered in terms of the categories developed through this analysis (Hawe, et al., 1990). Taking each theme separately and re-examining the original data for information relating to that is a vital stage in the analytic process because human perception is selective and the relevance of data can be easily overlooked (Hawe, et al., 1990). Furthermore, pieces of data previously assigned to a theme may in fact be contradictory (Hawe, et al., 1990).
3. *Interpret and summarise the information* - Construct the final form of each theme- the name, definition and supporting data are re-examined for the final construction of each theme, using all the material relating to it (Hawe, et al., 1990). This stage of re-

contextualization focuses more closely upon the underlying meaning of each theme (Hawe, et al., 1990). In this study I looked for a range of views expressed, to make sure that all opinions or views were represented in the summary. Operational definitions of codes (pseudonyms) words were written on each analysed document and were maintained as such throughout the project.

4. *Explain the information* – Reporting each theme- and finalizing the name of each theme, write its description and illustrate it with a few quotations from original text to help communicate its meaning to the reader. Then describe what the information mean, without making any assumptions. In this study, using the codes, a smaller number of themes or categories were generated. This was done by grouping the codes into themes and sub themes that were relevant to each other. Quotations from the interviews have been included in the description of the meaning of the information to help explain the theme under discussion. The main themes and sub themes were then presented as results in narrative format

Data collected from direct observations

This set of data was used to enrich data obtained from the in-depth interviews and therefore analysed concurrently with it. A similar approach was used as explained under in-depth interviews in the previous sections. A summary of how data was analysed and managed is explained below.

(ii). Managing data

Every in-depth interview was tape recorded. Data analysis occurred concurrently beginning with transcribing verbatim by the researcher every day and identifying main themes for practices, needs, problems, care, social support and constraints to receive care and support for both children and caregivers. Field notes were taken during direct observations that included emotional expression such as tone of voice, facial expression, mood variability, and where the participant did not want to be tape recorded. Notes of non-verbal communication during the interviews helped during the analysis and interpretation phase as the researcher was able to know how the participants reacted to some questions. The transcripts and quotations were translated from Chichewa into English and thereafter checked by an independent person (a

linguistic expert) to ensure that the original meaning and interpretations are not lost or distorted. The researcher used pseudonyms to each interview as identification codes. The pseudonyms were also used on audiotapes, transcripts and any other data. All documents were stored in a secure location only accessed by the researcher and the supervisor. A lever arch file was used to store field notes, informed consent forms, interview guide, interview transcripts and any other study materials.

Presentation of the results

Results are presented in a thematic format highlighting major and minor themes derived from the narrative data. Direct quotations were included to support the point in question. A detailed narrative analysis of one caregiver has also been carried out to better understand how women constructed their stories in their own particular cultural context. The section that follows discusses the trustworthiness and limitations of the study.

Ensuring trustworthiness of qualitative research and examining the limitations of the study

In this study, rigour achieved through the use of Guba's model (Krefting, L. 1991) to assess the trustworthiness of qualitative data. I will go through each in turn:

Triangulation

Triangulation can include using a range of research methods (observation and interviews) and a range of study sites (different areas or locations) to ensure trustworthiness (Shenton, 2004). In this study I ensured that the study drew on a range of data to compensate for the potential limitations of the use of one data set and to develop a wider scope of the field to help capture the wider experiences and context of being a carer looking after a child with HIV in rural Malawi. To do this I used narrative approach to the interviews and carried out multiple interviews with participants. Once the experiences of hospital care in terms of diagnosis and treatment became an important theme in these accounts, I then also carried out ethnographic observation in the local hospital setting to explore the care provided and how diagnosis and treatment was organised for this group. In addition, this was

also used to verify and explore in more detail participants experiences and accounts and to understand the ways in which these women were visible or invisible in this setting and whether HIV diagnosis was focussed on their child or whether the clinical teams recognised the risks of the mother (Shenton, 2004; Krefting, 1991).

Verification

This approach (triangulation) also helped to provide a depth to the analysis and was particularly helpful in developing the typologies (Shenton, 2004; Krefting, 1991). For example, the participants were talking about the role of the hospital setting in their diagnosis and care and it became apparent that this setting needed to be examined to explore their role in the care of this group.

After the initial analysis of the first interviews, it was important to go back to the participants for a further interview with questions developed and refined by an initial analysis to test initial findings, look for negative cases, and to develop the analysis further. My approach to data collection and analysis was iterative- I went back and forth, collecting data, carrying out initial analysis and then going back to Malawi to carry out further data collection. This allowed me to start developing my analytic themes and typologies and then re-visit the field, carrying out further interviews with my participants and carrying out observation of the hospital setting when that became an important theme in the analysis (Shenton, 2004). This allowed me to search for negative cases and to test and refine my analysis (Shenton, 2004; Krefting, 1991).

Developing trust with participants

My approach to recruitment of participants was that this would take time. These women were hard to reach – they lived in rural Malawi and were also a highly stigmatised group, so this took time to recruit participants and often I had to visit these women in their homes on a number of occasions to introduce myself, talk to them, and gain trust. Often this involved driving them to or from their hospital appointments or spending the day attending funerals or a wedding or other celebrations and events in the village.

These women were unused to having a voice and no-one had ever asked their opinion or about their experiences, so they were often unsure why they were being asked or why anyone would think their experiences were important. This meant that the recruitment and discussion with participants and what the interviews would involve took time and sensitivity. In addition, because this group had low levels of literacy, I was very careful to describe the study, what it involved, how it would be used, issues of confidentiality (particularly important given the highly sensitive and stigmatised topic) and that they could withdraw at any point.

My supervisors and I did initially have concerns that the women would prefer to be interviewed by another woman and we organised that this was available and the preferred option. However, once I spent time with the women and they agreed to participate, they were all clear that they were happy for me to carry out the interviews. Importantly, all of the women I approached agreed to be interviewed; however, some of their husbands decided that they did not want their wives to participate.

Iterative questioning

In addition, I examined the research topic and gained a picture of their experiences using a number of approaches, this was particularly important with this group – they were unused to being asked to describe their experiences or feelings and had never been interviewed before. During the initial interviews with women it became apparent that this was a difficult topic for them to talk about and were unused to talking about their experiences and feelings and this strengthened my decision (with my supervisors) to carry out a series of interviews with these women. When I went back to talk to them for the second interview, this was much easier, the women were all really pleased to see me, made a great effort to be available for interview (some walking a great distance to see me at the rural hospital) and were much more able to describe their experiences and what had happened to them since I had last seen them. This allowed me to re-visit previous topics and discuss their experiences once more; this helped to verify and to extend the quality of the data I obtained and my analysis.

Debriefing sessions

Throughout the process of data collection and analysis, there was close discussion with my supervisors Dr Katie Featherstone and Professor Billie Hunter. They checked the analysis and development of themes and typologies at each stage and also carried out a separate coding and thematic analysis of transcripts so that we were able to discuss the approaches to analysis and the different interpretations we had made. This allowed me to develop my analytic approach. Throughout this process I presented emerging findings at a number of postgraduate symposiums and conferences and this helped me to test and refine my approach, with the audience providing helpful and constructive peer review. In addition, after each interview, verbatim of transcripts were cross checked after translation from Chichewa to English language by a language expert at University of Kamuzu College of Nursing. All letters are at the appendix section of this study. Data that was collected during the first phase (between May and July 2011) was verified with participants during the second phase of data collection in 2012 between April and July, 2012.

Reflective commentary

Throughout the fieldwork and analysis I took detailed notes of the process and my experiences. In addition, because I was in Malawi for extended periods of time during fieldwork I sent regular long descriptive accounts to my supervisors to give them an insight into this work- this also helped me to see the field from their perspectives as an outsider and to consider some of my taken-for-granted knowledge about Malawi and life for my participants- being a woman, living in rural Malawi and caring for a child with HIV.

Limitations

This study had a number of limitations, particularly issues of power, gender and language. I will discuss each of these in turn.

Power and the interviewer

The power and status of the interviewer plays a major role in the quality of data collection (Randall et al., 2013). The collection of quality data in developing and, even more increasingly in developed countries worldwide, data collection methods must take into account and aim to minimise the effects of the potential power and status of the interviewer on participants (Weinreb, 2006; Weinreb et al., 2009; Blom et al., 2011; Becker et al., 1995). The power of the interviewer is characterized by the choice of research participants, their level of literacy, gender issues, language used, tribe and culture of both the interviewer and the participants, position in the society of the interviewer, dressing of the interviewer, urban living and rural living and poverty levels of the participants (Randal et al., 2011b). A number of these key factors will be discussed: language, explanation to participants, gender and then gender and language. These have been selected because they are directly relevant to this study and informed my approach to the design, fieldwork and analysis.

Language

Most African countries are multi-lingual and many of the concepts and definitions of the research topic under examination apply (Randall et al. 2013). In most studies, multi-lingual local languages are used in data collection and may be difficult to translate into local languages for the specific area or region where the study is conducted unless the interviewer speaks the language to be used (Randall et al. 2013; Blanc and Croft, 1992; Blom et al., 2011). It is particularly important that the interviewer collects data in the everyday language the participants speak because it reduces the impact of the relationship between the interviewer and participants (Power et al., 2010). When a local language is used, participants are more likely to regard the interviewer as their own and feel relaxed during the interviews (Randall et al. 2013; Blanc and Croft, 1992; Blom et al., 2011). In this study, the researcher (interviewer) comes from the same area and is of the same tribe and speaks the same language as that of the participants – Chichewa and this language was used throughout the interviews. Randall et al. (2013) noted that in Tanzania, Uganda and Burkina Faso, the potential effects of the sex of the interviewer on the quality of data

can be reduced by employing the data collector who speaks the same language and comes from the same area as participants feel that they are being interviewed by one of their own. Randall et al. (2011) add that the effects of one's position in the society are reduced with the employing of interviewers who speak the same language as the participants and that the individual must come from the same tribe and area too.

Explanation to participants

Weinreb (2006) and Weinreb et al., (2009) ascertain that a detailed explanation of the whole data collection process and a careful recruitment procedure helps to reduce the interviewer-participant power relations. In this study, a detailed explanation and a careful recruitment of participants were carried out (for further details refer to chapter 4b).

Gender

Gender is a major issue in African countries and men tend to hold more power than women and this is a deep rooted cultural issue (Becker et al., (1995). The same approach, using a detailed explanation helps to reduce the interviewer-interviewee power relations in order to reduce the impact of gender during the interviews (Power et al., 2010). In a study conducted in African countries of Tanzania, Senegal, Burkina Faso and Uganda by Randall et al. (2013) regarding power of the interviewer revealed that men still hold more power than women in families and men are still the decision makers. The study by Randall et al. (2013) added that face-to-face interviews conducted by the opposite sex were better conducted if a thorough explanation was made to the participants about why an opposite sex would conduct the interviews (Randall et al., 2013). It is particularly important to thoroughly explain to the participants where a male interviews a female (Randall et al., 2013; Weinreb and Mariano, 2009). In any African culture, frequent visits are important before the interviews are conducted so that the female participants get acquainted with the male interviewer and also that the female interviewees are given a choice of the sex of the person to interview them (Weinreb and Mariano, 2009; Randall et al., 2013). In this study, the researcher made more than one interactions or visits before

the interviews were conducted and above all, all female participants were given a choice either to be interviewed by a female interviewer or a male interviewer and they all preferred to be interviewed by a male interviewer; in this case, the researcher. No reasons were given for their choice.

Gender and language

The issues of the interviewer's position in society matters most when the interviewer, whether it is a male or a female, when he or she is a total stranger and does not speak the local language of the participants (Becker et al. 1995; Randall et al., 2013; Power et al., 2010; Blom et al., 2011). In such cases, the interviewer must have an interpreter that comes from the same area and let the interpreter do the more talking (Power et al., 2010; Blom et al., 2011). However, participants must also be given a choice regarding the sex of the interpreter (Power, et al., 2010). Researcher must avoid imposing an interpreter on to the participants, because doing so would risk poor quality data being collected (Blom et al., 2011). If the situation demands that it is the only interpreter available, then the participants must be informed well in advance and that participants must be given a choice to participate or not and make sure that a thorough explanation is given that their rights are not infringed in any case (Becker et al. 1995; Randall et al., 2013; Power et al., 2010; Blom et al., 2011). Studies have shown that the effects of sex and the power of interviewer can be reduced by a through explanation of the whole data collection process (Randall et al., 2013; Power et al., 2010). In studies conducted in Sub-Saharan African countries have ascertained that men still hold more power and it is a sensitive cultural issue that is deep rooted (Berker et al., 1995). For example, in the African context, Becker et al., 1995; in a Nigerian study found that the effects of sex during interviews can be reduced by offering participants a choice who they want to interview them.

Within this study it appeared to be important that the researcher was from Malawi and spoke the same dialect as our participants. Whilst none of the participants wanted a female interviewer, despite this being available for them, we cannot know how power and gender relations have informed and influenced the participants' descriptions of their lives. However, the strategy of spending time with the participants to discuss the study and making multiple visits to see them seemed to

develop trust as demonstrated in their willingness to describe their lives and to disclose sensitive issues to the researcher including difficulties in their marriage, how they and their child became infected with HIV and the everyday difficulties of survival, trust and disclosure of their HIV status to others.

Methodological issues: Field experiences in Malawi

Introduction

During the field experience, the researcher learnt many things. The researcher's time spent in the field was interesting and at times challenging. It presented many opportunities but also the need to reflect on the difficulties of being a researcher in a hard to reach areas and with an 'invisible' sample of women. These experiences are discussed more in the section that follows. Field experiences that I encountered really required quick decision making with the supervisor who was thousands and thousands of kilometres away from Malawi in the United Kingdom. I also needed to work within the means of research participants. There had been incidences where the participant would give a date and time to conduct the interviews but the unexpected things occurred. The field experience also indicated that key people in the community needed to be handled with care as they were so unpredictable with the time and schedule. It meant literally checking with them on daily basis on when and what time I would meet them. Please do read on.

Access and briefing meetings with governmental and non-governmental organizations

The researcher conducted eleven (11) different meetings with different governmental and non-government organizations for access and briefing purposes and to inform them of what my study was all about.

Meetings with key people in Dowa district

Dowa district is one of the nine districts in the central region of Malawi. I had conducted several meetings with key people and officials to seek permission for this study.

Meetings with the District Commissioner (DC)

The preparatory meetings were conducted mainly to brief them and obtain permission to conduct the study at Mponela Rural Hospital catchment area. The researcher conducted meetings with the District Commissioner (DC), the Director of Nursing services in the Ministry of Health, the District Health Officer (DHO), Officer in charge of Mponela Rural Hospital and the Traditional Authorities (TAs) Mponela, Dzoole, Kayembe and Chakhaza. He also conducted meetings with the following non-governmental organization: World Health Organization (WHO), United Nations International Children's Education Fund (UNICEF) and The Basics of the United States International Development Agency (USAID).

Meeting the DC for Dowa

The meeting with the DC was re-scheduled earlier than the booked date because he was going away for a month therefore, on one day, he conducted two meetings; one at the Malawi Ministry of Health Headquarters with the Director of Nursing and Midwifery Services. The researcher sought permission from the Director of Nursing Services to meet her in the morning as in the afternoon of that day, the 12th April 2011, the meeting with Dowa DC was brought forward that was on the same day. Fortunately, although she was a busy lady, she accepted to meet me at 10 am of that day. In the afternoon, the trip to Dowa which is about some 34 kilometres from Lilongwe and the road is a dusty road with many pot holes and stones was made. In short it is a rough road and a car with high suspension had to be used. The car used consumed more fuel than the small car that was mostly desired. The meeting with the DC was very successful and he was very supportive about the study project. He gave permission to conduct the study at Mponela Rural Hospital catchment area.

The meeting with the Director of Nursing Services (DNS)

The researcher conducted this meeting with the DNS on 12th of May, 2011. This meeting was very successful as the director of nursing services was very supportive of the study project and she stated that there was no study in this particular area in Malawi as far as she could remember. Therefore, she asked me to continue involving the Malawi Ministry of Health in this research project. She requested if it could be possible to include intervention components in the study project so that it could be used as a pilot for the whole country. This request was discussed with the supervisor by email and text messages on the same day, the 12th of May, 2011 and there were high indications that an intervention component would be mapped out.

Meeting the Traditional Authorities (TAs) (Local leaders)

The researcher had conducted various meetings with the T/As on separate dates because they are very far apart. The meeting with TA Kayembe was done on 17th May and it is 48 Kilometres from Mponela and 133 kilometres from Lilongwe. At Kayembe, the meeting was conducted with an official (court clerk) because TA herself was sick and she could not talk. Instead her clerk represented her and he was very supportive too and gave the verbal permission to go ahead with the study. By that time, the DC had already written all the concerned TAs and the T/As were simply waiting to welcome and hear from the researcher. Therefore it was easy to talk to them as the DC had already informed them and they had a written permission from the DC. The meeting with TA Mponela was done on 22nd May, 2011 (Sunday) because that was a convenient date for him and he was very supportive too and he granted me permission verbally to conduct the study in his area that forms part of Mponela Rural hospital.

At TA Dzoole, this is the researcher's TA and the TA was represented by his official (court clerk). The TA had gone to church but he told his clerk about the visit to his headquarters. The official was waiting for researcher. Surprisingly, the official knew the researcher by name. The T/A official immediately ushered the researcher in the office with gratitude. *"We just talked shop and he said the DC had already told us we are very happy that our own son is doing this we wish you well."* At the end, he gave permission very happily and the researcher left for Lilongwe which is some 60 kilometres away. T/A Chakhaza' meeting was cancelled the first scheduled meeting because he was busy. However, the meeting was held on 24th May, 2011. Here again

just like meetings with all other TAs except TA Mponela, the clerk represented the T/A as the actual T/A was busy installing a village headman. The permission was given with happiness. Other very important meetings were conducted with non-governmental organizations that deal with issues of HIV and AIDS and issues that affect children.

Meetings with Non-governmental organizations

World Health Organization (WHO)

This meeting was held on 9th July 2011 after several failed attempts to meet in June. The desk officer responsible for children issues expressed support and joy when briefed about the project of caregivers looking after a child with HIV and AIDS in rural Malawi. She was very overjoyed as this area had not been studied especially targeting caregivers of children with HIV and AIDS and being in the rural areas of Malawi. She therefore, requested that her office be furnished with a complete report of the study.

United Nations International children's Education Fund (UNICEF)

This meeting was held on 13th July 2011 at UNICEF House at 10am. The desk officer responsible for children welfare and health was very excited with the briefing and asked for a full report of the research. He however mentioned that he would brief the HIV and AIDS coordinator who was not in the office at the time of the discussions. The officer responsible for all children's programmes at UNICEF and also responsible for community mobilization was very supportive of the study because it targeted rural communities of Malawi.

The Basics meeting

The Basics is a non-governmental organization that focuses on child survival programmes in Malawi and its projects are in rural areas. Basics have projects such as food supplements for children and malaria control project. This meeting failed to take place on 14th July, 2011 because they cancelled at last minute as they were busy with the emergency meeting focussing on funding issues with their head of mission

to Malawi. Efforts to re-schedule the meeting proved futile as the desk officer responsible for children's programmes at The Basics was busy drafting the new proposal for funding but we spoke on the telephone and expressed support for the project and would want to be part of the intervention team later on.

Ethics approval

The ethics approval from Malawi College of Medicine Ethics Committee (COMREC) was given on 21st May, 2011. This was another daunting experience as time was a stumbling block. In other words, there was limited time for the field work as this was a PhD study. The COMREC delayed to meet and the researcher spent the whole month of April waiting for them. He had to talk to my sponsors, the Malawi Government to intervene and finally, COMREC met and permission was granted on 23rd May, 2011. What frustrated the researcher most was the fact that he sent the document to them in February, 2011 including all the necessary charges only to find that they had not met till May but with a lot of pressure from the researcher. Kamuzu College of Nursing Ethics Committee gave the approval in March, 2011 and sent the document to COMREC in the same month.

Funding

The Malawi government funded the first field activities to the tune of £2, 661.75, plus a return air ticket. There were no problems with funding. The cheque was released two days before the date of approval by COMREC and data collection started the next day. Second field trip was funded by Cardiff University and the Malawi government. Cardiff University provided £1, 250.00 and was used for day to day operations of the study and the Malawi government provided an air return ticket.

Field notes

Field notes (hand written notes) during the in-depth interviews were stopped being taken as participants felt disturbed with the writing but were comfortable with the chatting only but were recorded soon after the interviews (in the absence of the participant) and therefore, the tape recording was paramount during data collection.

However, during transcription, an effort was made to indicate the emotions of the participant for every interview. Field notes were more relevant during direct observations at the hospital thus at the children's ward and at the ART clinic.

Cost

The data collection process was costly because the interviewer was staying in Lilongwe some 68 KM from Mponela Rural Hospital and that Mponela Rural hospital was just a base but the interviews were conducted in the villages whose average km was 10 from Mponela to such villages. There was a special trip to each of the participant's home with the hospital matron who helped to recruit the participants to obtain consent and book an appointment. A special trip was necessary because women were busy in their gardens harvesting their crop produce and therefore, we had to follow them in their fields which were some 4 to 5 km from their homes. Fortunately enough, all the interviewees were well prepared by the matron and were expecting the research team at any time.

Participant busy working in the gardens

On 27th May, the interviews were conducted in the house some 11 km away from Mponela. The interviews went on very well. Despite booking the participant on this date and the time that she would be available, she went to her ground nuts field where we had found her on the date and day that the interview had to be conducted. We picked her from the ground nuts garden and the interviews were done successfully at her house but we had to drop back her ground nuts garden. On one occasion, the interviewee was not available as she went to a funeral and we postponed the interviews to a later date. We went there for three times without meeting her but at last we met her and booked the appointment with her. She was very eager to be interviewed and the date was set. On the set date, she had gone to the funeral of the relative and therefore, the interviews were postponed again. The distance is 10 km from Mponela Rural hospital and 70km from Lilongwe. On 11th June, the interviews were conducted and she was very apologetic for the failed meetings and interviews.

Fuel shortage

Malawi was hit by fuel shortage and it had a bearing on the project as the researcher was worried he would need to cancel the appointments due to lack of fuel. However, he cancelled only once and the interviews were conducted a week later when he had found fuel.

Communication with the supervisor Dr Kate Featherstone in the United Kingdom

The supervisor was constantly briefed on the progress of the data collection on weekly bases via text messaging and emails. However, email communication was a bit of a problem due to failure of the email system in Malawi and at times due to power outage and off-course, the researcher was working in the rural areas where he could not have time and facilities to communicate by email. The most helpful mode of communication was text messaging via the mobile telephone even if he was in the rural areas. The mobile network is available to every area of Malawi and it was very handy and helpful.

Some incidences to remember

The sick child by the wayside

On the way back home, the researcher found some women stranded with a child who went into fits. A closer look at the child indicated that the child was very sick and then the researcher took them to Mponela Rural Hospital. Again all the roads to the TAs are dusty and bumpy and narrow. These two women were coming from a traditional medicine man that had the child tattooed all over the body and yet the child had cerebral malaria. Fortunately, the child survived at the hospital.

The male dominance in a family

One of the participant's husbands was very angry because the wife accepted to participate in the study. The husband got to know when the wife had showed him the consent form. The researcher had to get the hospital in charge for ARV clinic to intervene as the husband threatened that the child should stop going to receive the ARV. Later the husband apologised for his behaviour and he said that he would not have reacted like that if his wife had explained to him as clearly as we did. The woman was persuaded by her husband to continue participating in the study but we decided to exclude her from the study until further notice because we were not sure of the husband's behaviour at home as the woman continued to insist that she didn't want to continue participating in the study although she would have loved to continue as she earlier indicated.

Demonstrations and disturbances

At the time of the data collection, there had been demonstrations and severe disturbances in Malawi by the public. The Malawi citizens were not happy with persistent fuel shortage, shortage of foreign exchange money (Forex) and some governance issues. These had a heavy impact on the plan of the project and dates were changed frequently for the interviews. This was in addition to factors affecting directly to an individual participant such as funerals in the villages or nearby villages and the death of a son who was working in town and brought home for burial.

Conclusion

This chapter has discussed the methods that this study used during data collection. The methods were in-depth interviews and direct observations. It has also discussed the trustworthiness, limitations and reflexivity. Issues of power and the interviewer have also been discussed in this chapter. The last section of the chapter has shown some of the notable field experiences. The chapters that follow- mark the beginning of analysis chapters. Chapter 5a is a detailed narrative analysis of one woman caregiver called Mayi Salima (pseudonym).

Chapter 5a

Case study - the story of Mayi Salima (Pseudonym)

Introduction

In the previous chapter, the discussion has been on research methods used in this study. This chapter provides a case study of Mayi Salima on her experiences of looking after a child living with HIV and AIDS in a rural setting of Malawi. Her story provides in depth insights into experiences that many other caregivers shared.

Mayi Salima

Mayi Salima (pseudonym) is a thirty four year old woman caregiver of Bimphi village in Traditional Authority (T/A) Msakambewa in Dowa district. In this chapter the researcher provides an in-depth case study of Mayi Salima's experiences, based on two interviews in 2011 and in 2012. This specific story (Mayi Salima's) was chosen because of her circumstances and experiences represent those of the other women in this study. She was also a very good storyteller of her caring experiences. She was also keen to share her experiences and gave rich accounts of her life that provided in-depth insights. She was a single parent following her husband's death from HIV and AIDS. Her marriage was polygamous and her husband had complex and secretive life style. However, she reported that neither her husband nor the hospital staff disclosed to her that her husband was HIV positive. She and her child were HIV positive and she experienced stigma from some members of her community especially those from her own village. However, she experienced no stigma from the majority of her community including her immediate family members. However, as a single parent she was struggling to find resources for her family of three children.

Mayi Salima was born in 1977 and she was "34 years" old at the time of the interview. She was a widow with three children and one of them was HIV positive and developed AIDS. Mayi Salima as a woman caregiver had two children who were HIV negative to look after. They were a girl who was "13 years old" and a boy

who was “11 years old” at the time of the interview. Her husband died of HIV and AIDS and she was also HIV positive and suffering from AIDS.

Mayi Salima lived in a very remote rural village where tarmac roads did not exist and telephones were very poor. The accessibility of the village was also difficult because of the type of terrain, which was characterized by hills, ditches and rivers. Mayi Salima described the terrain when she stated that “*but we pass through many villages up land.*” When she used the word “*up land*” she described how hilly the terrain was. The only telephone communication was by mobile telephone and this communication facility was expensive and Mayi Salima could afford it.

“I have walked to come here. The distance is still far so that one passes through several villages to arrive here. Aaa, I cannot tell how many kilometres but we pass through many villages up land.”

Mayi Salima showed her commitment to participate in this research because she had to “*walk*” a distance of approximately eight kilometres up and down the hills and crossing ditches. By that time, the research team had gone to her village and missed her on two occasions. When she was told by her relatives that a team from the hospital had come to the village on two occasions looking for her, she decided to follow the team to the hospital the following day. She described the distance she had walked when she stated that “*I have walked to come here. The distance is still far...*” When she stated that “*the distances is still far*” she was emphasizing how far she had walked to reach the hospital for the interview with the research team. The interview lasted approximately one hour fifteen minutes and was conducted at the hospital in a quiet room away from the busiest hospital environment to ensure confidentiality and privacy. Mayi Salima was happy and relaxed and seemed to be enjoying as she was smiling and laughing during the interview. Then after the interview, Mayi Salima was escorted to her home village by car.

Life as a single parent

Mayi Salima was a single parent and she “*lived alone.*” “*Me, I can say I don’t have a husband. My husband died in 2010 in April.*” The child living with HIV and AIDS was four years old at the time of the interview. “*In 2007, it is when this child was born.*” Mayi Salima was the primary caregiver for the child. The child may have

acquired HIV during birth process. She explained that *“this child was born with the disease”*, confirming that the child acquired HIV at birth or while in the uterus because Mayi Salima was also HIV positive. When she stated *“this disease”* she was referring to HIV and AIDS. She described her marriage as not a happy one because her late husband had married many other women before he died in 2010. She described the marriage situation when she stated that *“my husband married six women before he died in 2010.”*

“Majority of us women who care for children living with HIV and AIDS live alone. Our husbands died mostly from the HIV and AIDS related diseases... Me, I can say I don't have a husband. My husband died in 2010. He died of sores in the stomach but it was ignorance. He died of the current disease. What he was suffering from was coughing and opening bowels and we went to the hospitals and they told us that he had wounds in his abdomen.”

Mayi Salima stated that her husband died of *“sores in the stomach.”* This was the diagnosis her late husband was telling significant others to conceal the real diagnosis of HIV and AIDS probably for fear of stigma. The real diagnosis according to Mayi Salima was HIV and AIDS. AIDS as the name implies is a collection of different signs and symptoms of diseases and some of the signs and symptoms are *“sores in the stomach and wounds in the abdomen”* and these signs and symptoms were present in Mayi Salima's husband. She further stated that *“it was ignorance; he died of the current disease.”* The word *“ignorance”* indicated that Mayi Salima had some knowledge that *“sores in the stomach, wounds in the abdomen, coughing and frequent opening of loose bowels”* are common signs and symptoms among AIDS patients. She stated that *“he died of the current disease.”* The phrase *“the current disease”* refers to AIDS in this context. Mayi Salima stated that her late husband was suffering from AIDS related conditions. *“He was found with the small animal of HIV (Kachilombo) and then we buried him in April, 2010 and in October, 2010, I went to my home village and when I arrived at my home village called Bimphi, I became sick.”*

HIV is commonly called *“Kachilombo”* in local dialect of Chichewa which means *“a small animal”* in English. The name *“small animal”* is a polite and a respectful name to describe HIV to avoid embarrassing the person infected. She was certain that her husband had died of AIDS because soon after arriving at her home village

from the matrimonial village, she also “*became sick in October of 2010.*” Her husband was “*buried in April in 2010*” of the same year.

Marriage and her husband’s polygamy

Overall, 84% of all married women in Malawi are in monogamous unions and 12% are in polygamous unions with one co-wife and 3% are in polygamous union with two or more co-wives (MDHS, 2004; MDHS, 2010). The legal age for a woman to get married in Malawi is 16 years but with consent from her parents (MDHS, 2004 and MDHS, 2010). The traditionally and customary accepted age for a woman to make an independent decision to get married is 18 years of age (MDHS, 2004; MDHS, 2010). Traditionally, children are expected to be born within marriages and they are said to be legitimate children (MDHS, 2010).

Mayi Salima married her husband in 1996. The wedding officiation took place at the “*Last Christian Church*” of her village. The reception took place in her home village too. She looked back on that time and described their marriage “*we had our wedding when we were all the youth.*” She was looking back into the past when she was innocent and with a hope of a good married life. However, Mayi Salima explained that her wedding was postponed for a year because her husband had “*impregnated another woman.*” They had to sort out that issue first. She further stated that she “*loved*” her husband and she still married him despite that he had “*impregnated another woman.*” She narrated that it was “*love*” that made her still marry her husband “*although he had a bad behaviour.*”

A Polygamous marriage

However, sometime after that wedding, her husband started to marry other women in addition to Mayi Salima. This was how she narrated the situation:

“I was the first wife. We married each other when we were all the youth and we had our wedding here at the Last Church. He married the other women when he married me already.”

One year had elapsed without a child in Mayi Salima’s marriage; till “1998” when their first born daughter was born to them. Malawi tradition expects that a newly

married couple should have a child within one year of their marriage. If the couple fails to achieve this within one year, it is a socially traumatic experience in that marriage and the social trauma is felt more by the woman than a man because typically men within this culture defend themselves by saying they are capable of impregnating any woman and if the wife is failing to conceive, then it's the wife's fault. It was most likely that Mayi Salima experienced this social stigma because she failed to conceive for a period of one year. The social trauma was more on Mayi Salima considering that her husband has a child with another woman. When one year has elapsed for the couple without a child, tradition intervenes. It is usual for the elderly women in that village to summon the wife and ask if there is any problem with her and if they could do anything to help. Mayi Salima might have experienced this situation and she described "*what happened:*"

"What happened is that he started marrying other women when we had one child in 1998 because we had our wedding in 1996 and 1997 finished without a child and in 1998 we had our first born child... He married six wives."

Her marriage experiences began to change for the worse when Mayi Salima had delivered her first child "*in 1998.*" "*We had our first born child in 1998.*" The following year in 1999, her husband "*married*" another wife whom he divorced within a short period as she put it "*they did not stay longer together.*" By that time Mayi Salima was "*still with him at his home village*" of Kachulu.

"I was still with him at his home village. And then in 2001, he married another woman and he chased that one and in 2004 he married another one and I said enough is enough I went to my home leaving him with his new wife."

Mayi Salima described her husband's other marriages "*as not stay longer*" with the other wives and that he kept on "*chasing*" them. "*He married another woman and he chased that one.*" Mayi Salima was the "*first wife*" among the "*six wives.*" Being the "*first wife,*" Mayi Salima was a senior wife and by Malawi tradition, she was supposed to be respected by other junior wives. In addition, she should have been accorded first priority in everything related to marriage matters by her husband and the junior wives. She described her seniority when she stated that "*I was the first wife.*"

In 2001 her husband "*married*" his third wife. When Mayi Salima's husband "*married*" a fourth wife, Mayi Salima was fed-up with her husband's behaviour.

She had had “*enough*” of “*what was happening*” and she showed her displeasure when she stated that “*I said enough is enough*”. Traditionally, Chewa women in Malawi persevere a lot and when she stated “*enough is enough*” which means “*basi*” in local dialect of Chichewa, it meant she had seen worst things and she left the husband for her home. Mayi Salima had demonstrated the same spirit of perseverance because she had left her husband when “*he had married a fourth wife.*” She went to stay at her home village.

“Yes, we could leave each other. What happened is that he started marrying other women when we had one child in 1998 because we had our wedding in 1996 and 1997 finished without a child and 1998 we had our first born child. Then when we reached 1999 to 2000, he married another wife. Then when he married that woman, they did not stay long together, the marriage ended. I was still with him at his home village.”

They separated from 2001 to 2004 and she confirmed her separation when she stated that “*yes, we could leave each other.*” During that period, her husband was living together with his new wife at his home village. Somewhere within the year 2004, her husband went to her village with his men who were marriage advocators or marriage counsellors to “*apologise*” to Mayi Salima. She described it when she stated that “*and in 2004 he came to apologise.*” Marriage advocators or counsellors are usually elderly men or women who are chosen by parents of the woman or a man to be marriage advocators or counsellors of a said marriage. It is customary that both sides should have two marriage counsellors each making a total of four per marriage. After lengthy discussions, she “*accepted*” to go back to her husband’s home and continued to stay with him as a husband and a wife. She confirmed this when she stated that “*and we discussed at length and I accepted to go back to him.*”

Discovery of HIV and AIDS

Discovering that she was HIV positive was a traumatic experience to Mayi Salima because she discovered it when her child was sick late after the death of her husband.

Her husband becomes ill

In 2004, Mayi Salima “*accepted to go back*” to her husband’s village after reconciliation discussions. During that time, (2004 to 2007) she had also unprotected

sex with her HIV infected husband. The unprotected sex resulted her into being pregnant and acquiring the “*small animal*” in the process. In 2007 the child living with HIV and AIDS was born. By then the husband had already begun getting sick that resulted in frequent “*hospital admissions*” to different hospitals including Mponela Rural Hospital. She knew then that her husband had done the HIV test. The HIV test results were positive and that he was suffering from AIDS as Mayi Salima puts it “*I can say that he tested for HIV testing...*”

However, she reported that neither her husband nor the hospital staff disclosed to her that he was HIV positive. “*But he did not tell me that he was HIV positive.*” During her husband’s frequent “*hospital admissions,*” she acted as his guardian leaving family activities and children at home unattended. She spent much time in the hospital caring for her husband. She lost the much needed time to work in her gardens because she spent the time looking after her husband at the hospital until he died in 2010. “*And we went to different the hospitals and they told us that he had wounds in his stomach.*” However, this symptom was not clear to her then that it was a symptom of HIV.

Mayi Salima stated that she used to take her husband to “*the hospital alone*” without the support of the husband’s relatives; that was unusual in the context of Malawian culture. Her father in law, who lived within a village that was across the river and it was about two to three kilometres away, did not help his son when he was sick. “*I had gone to the hospital with my late husband alone.*” That was contrary to Malawian culture. In Malawi, when a man like Mayi Salima’s husband becomes sick, close relatives, especially men together with the wife of the sick man, would escort that man to the hospital and be at the bedside of that sick man till his discharge or his death.

Discovery: when her child becomes seriously ill

Mayi Salima’s child became sick two months after her husband had died. Her husband died in April in 2010 and the child became sick in July of the same year. Mayi Salima clearly narrated signs and symptoms of the child’s illness. These signs and symptoms were “*the body being hot, pins and needles in the chest and breathing*

weakly.” These are clear signs and symptoms of pneumonia in a child of that age group. Pneumonia is a common chest infection among child under the age of five years and Mayi Salima’s child was within this age bracket (4 years) at the time of data collection. It was possible that the child was “*suffering*” from pneumonia.

“This one she was really suffering from when the body was hot, she could develop pins and needles in the chest. She was breathing very weakly and when I do come here at the hospital, I was admitted with the child.”

Mayi Salima stated that when she noted these signs and symptoms, her first action was to go to the hospital where she was always “*admitted*” with the child’s illness as she described that “*and when I do come here at the hospital, I was admitted with the child.*” Mayi Salima realised that going to the hospital with a child who was “*breathing weakly*” was the best option because “*breathing weakly*” in a “*sick*” child is one of the danger signs of a serious chest infections such as pneumonia. This was why she was always admitted to the hospital each time the child had such signs and symptoms of “*breathing weakly.*” Mayi Salima suspected that the child might have been suffering from HIV and AIDS.

Develops the symptoms of full blown AIDS

Mayi Salima had some knowledge of signs and symptoms that indicated that her child was sick and needed to get urgent treatment. The commonest signs and symptoms reported by her were “*coughing, the body being hot to touch, chest pains, unable to breathe properly, vomiting, and opening bowels frequently general body weakness, sores and rashes all over the body.*” She was worried with her child when she had developed these signs and symptoms.

“This one, she was really suffering from when the body was hot, she cloud develop pins and needles in the chest and feeling pains everywhere. She was opening bowels frequently, coughing and she was very thin. She was breathing very weakly and she developed small eruptions all over her body and she was not growing at all.”

When Mayi Salima stated that “*this one was really suffering,*” she was referring to the child living with HIV and AIDS and that the child was very sick. She described the signs and symptoms of the “*suffering*” as “*developing pins and needles in the chest, body hot to touch, feeling pains everywhere, opening bowels frequently, vomiting, coughing, she was really thin, breathing very weakly, developed small eruption all over the body and she was not growing at all.*” This was a very

remarkable description of “*suffering*” by a village woman who was not educated because she described accurately signs and symptoms of a major chronic or lifelong disease.

By stating these signs and symptoms, Mayi Salima described signs and symptoms of the respiratory system infections when she stated that “*the child developed pins and needles in the chest, breathing very weakly, coughing and feeling pains everywhere.*” Secondly, when she stated that “*the child was opening bowels frequently and vomiting*” she was describing signs and symptoms of gastrointestinal system infections. Thirdly, when she stated that “*the child developed small eruptions and sores all over the body*” denoted signs and symptoms of skin infections. Fourthly, when she stated that “*the child was really thin and was not growing,*” she was summarising that the child had developed AIDS because of the eminent signs and symptoms of AIDS were unintentional marked weight loss and she described it as “*the child was very thin.*” Fever over a month that is another sign and symptom of AIDS and she described it as “*the body was hot to touch.*” Failure to thrive that was ably described by Mayi Salima as “*really thin and not growing*” is one of the common signs and symptoms of AIDS in children under the age of five years. Mayi Salima’s child was 4 years at the time of the interviews.

HIV diagnosis of her child

At the hospital, Mayi Salima was told to have the child tested “*for HIV*” and she accepted. “*They found that she has the small animal of HIV.*” The nurse then immediately advised Mayi Salima to “*stop breastfeeding the child*” to prevent further re-infection.

“And for me to be found with the problem it’s when this child was getting sick. She was getting sick frequently and then I came at the hospital and they told me to have her tested for HIV. And when they tested it, they found that she has the small animal of HIV and because of this, you must stop breastfeeding her and you have to come here Tuesday so that you meet the doctor.”

When Mayi Salima stated that “*and for me to be found with the problem*” she referred to the “*problem*” of caring the child who was living with the “*small animal of HIV*” and AIDS and not her being HIV positive because “*by then she was not sick*” herself and she had not taken the “*small animal of HIV*” test. She referred to

looking after a child living with HIV and AIDS as a “*problem*” because Mayi Salima was an experienced mother of three children and she knew how difficult it was to look after a child who was HIV negative. Therefore, looking after a child who was living with the “*small animal of HIV*” and AIDS was a daunting task as the child required close observations and supervision because the child got sick frequently.

Mayi Salima’s discovery of her own HIV status

It was later that Mayi Salima discovered that she was also HIV positive when she too “*became sick.*” Mayi did not attend the antenatal clinic hence did not test for HIV. She stated that “*she only found that she was HIV positive herself when she became sick*” and went to the hospital for treatment. She had an HIV test at the hospital whose results were positive. Mayi Salima stated that “*she was very weak*” at the time of the HIV test.

“.....after finishing the lessons, I started receiving the medicines for the child. The medicine of ARVs and it’s when I saw that I became sick and I came here for the test and they said you have the HIV as well. Then I came again for the lessons and I was very weak and they had put me on Chiponde and the ARVs and from last year till now I am receiving the said medicines together with the child. And then it was when I saw that I became sick and I came to the hospital for the HIV test and they said that you have the small animal in your blood as well.”

Immediately, Mayi Salima was placed on “*Chiponde and ARVs*” because “*she became sick and very weak.*” Mayi Salima must have been “*very sick and weak*” for her to be put on food supplements because “*Chiponde*” is reserved for people living with HIV and AIDS who are “*very sick and weak*” and are also malnourished. “*ARVs*” are normally commenced after other opportunistic infections such as pneumonia and tuberculosis are first cleared.

HIV and AIDS disclosure and stigma

When an individual discloses to any significant others it indicates that they have accepted and live positively with HIV. Mayi Salima’s husband did not disclose to her his actual diagnosis of HIV and AIDS. However, Mayi Salima described that “*she tells anyone who asks her*” about her HIV seropositive status.

Informing her biological parents

Mayi Salima explained that she disclosed to “*her parents*” that she and the child have a “*small animal in their blood called HIV that causes AIDS and that any time they could develop AIDS.*” She told her “*parents*” so that they knew what she was “*suffering*” from. Mayi Salima further states that the duration of her illness also contributed to disclosure to her parents when she says that “*I was sick for a long time.*” Her parents were not “*surprised*” because they knew that her husband “*died of the same diseases.*” However, she also states that she did not tell them immediately, but only disclosed to “*her parents*” when she was “*very sick.*”

“I told my parents depending on how sick I was because I was sick for a long time and I told them that I went to the hospital with my elder sister and they tested me for HIV and they have found with me in my blood the small animal of HIV that causes AIDS and that any time we can develop AIDS. They were not surprised because they knew that my husband died of the same disease.”

Informing the parents of her late husband

Mayi Salima also told parents of her late husband that she and her child were HIV positive. However, Mayi Salima had problems with her father in law because he did not accept that his son died of HIV and AIDS. These parents were in denial probably this was why they did not go to the hospital with him.

“The father of my children is from Kachulu village T/A Mponela and they know about it. I told them after I had gone to the hospital with my late husband that they tested him for HIV.”

When Mayi Salima stated that she informed them that “*they tested him for HIV*” she was informing her father in law in a diplomatic manner. In Malawian culture, when the daughter in law talks to the father in-law she cannot be direct with issues, she has to express issues in a disguised manner to show respect to the father in-law. It was only after Mayi Salima and her child were tested HIV positive that the father in law then acknowledged that his son died of HIV and AIDS and all her husband’s relatives “*agreed*” with her that she was telling the truth that her husband had been “*suffering from AIDS*” and died of AIDS in 2010.

“And told them that I had gone to the hospital with her and that they have found her with the small animal called HIV that starts the disease of AIDS... As you remember

I told you a few days ago when her father was sick that the disease he was suffering from was not what he was telling you of sores in the stomach but AIDS but you did not believe me. They agreed with me this time because at first they denied that their son did not die of AIDS. And that I was right and that the child is now on medicines of ARVs.”

Informing the village headman

Every village in Malawi is presided over by the village headman or village headwoman. Mayi Salima disclosed to her village headman that she was HIV positive and that she was also on ARVs when she stated that *“and I even I told him that I too do receive the medicines.”* As the head of the village responsible for everyone in that village, *“he needed to know”* that she was HIV positive and that she was on ARVs as well.

“Yes, I told the village headman because as the chief of the village he needed to know as the child was getting sick frequently so I did not hide that she is receiving the medicines and I even I told him that I too do receive the medicines.”

In Malawian culture, the village headman is the owner of the village and everyone in that village belong to him or her. This was why Mayi Salima emphasized this point when she states that *“as the chief of the village, he needed to know.”* He or she is the custodian of the traditions and customs of that village. The village headmen or women command a lot of respect among their subjects and they are informed of anything that takes place in the village including chronic illnesses and deaths.

“...so he knows it and it is not a new thing to him. I told him because I wanted him to know so that he should not be surprised of the disease that I am suffering from but he should know what I am suffering from.”

Mayi Salima used the phrase *“he should not be surprised of the disease”* and it ascertained the point that the village headman was responsible for everything in the village including diseases among his subjects. She also stated that *“she wanted the village headman to know what she was suffering from”* and she repeated it *“but he should know what I am suffering from.”* This emphasis indicated how important it was to inform the village headman about her HIV and AIDS status. Normally, village headman’s subjects report to him about the illness if that illness is chronic such as HIV and AIDS or it is an acute one and is expected to keep the information confidential.

The village headman takes care of all the deaths in the village. In Malawian culture, when one die in the village, that person stops being a family member and belongs to the whole village under the leadership of the village headman. In other words, the dead person is a property of the community of that village. Family members are only consulted on some important issues like the date of the burial and food. All the administrative issues of the funeral are done by the village headmen or women. Therefore, Mayi Salima informed her village headman in anticipation that if the child dies or indeed she dies; her village headman would be in a better position to inform the people of what was happening to her and the child.

Informing members of her community

Mayi Salima stated that “*she tells anyone who asks her*” about HIV and AIDS status of her child and for herself. She described that there was no reason to “*hide it*” as people do “*see*” her going to the hospital every month to receive ARVs and she strongly felt that people would know it in one way or another so “*why hide it?*” “*These are not the days to hide it.*” This statement showed that Mayi Salima had accepted the HIV and AIDS status with an open mind and that she was living positively with it hence talking about it openly to anyone who “*asks her.*” “*Who does not know about AIDS these days?*” By asking this question, she was communicating that HIV and AIDS cases were common and very well known to everyone in her area and therefore no need to “*hide it to them.*”

“People here know it anyway.” “I do not hide to anyone. People here know it anyway. There is no reason really to hide it. People do know because they see me coming here at the hospital and see me on the line for the ARVs and they know it. In short, they know it. These are not the days to hide it. Why hiding it? Who does not know about AIDS these days?”

Issues of stigma

Mayi Salima indicated that she had never experienced any stigma because her child was HIV positive or because she was HIV positive. She stated that she just “*heard*” about it some time back when HIV had just started. “*Mmmm but as for me that behaviour of segregation I just hear it from other people. I just hear it really.*” Mayi Salima stresses that “*I just hear it really.*”

She further stated that *“it has never happened to me”* and it was because *“she was too open”* and *“she told everyone who asked”* her about HIV status and she told them that she was *“HIV positive.”* Therefore, she thought that people in her village and the surrounding villages had accepted her and her child that they were *“HIV positive.”* She was living positively with it and people in her village and other surrounding villages *“do live”* with her in a *“lovely manner”* and they were all free to *“talk”* to her. *“I do live with people at home and those surrounding my house in a lovely manner and they are free to talk to me.”*

The sentence *“I do live with the people in a lovely manner”* pointed out that previously people used to isolate individuals living with HIV and AIDS. When Mayi Salima stated that *“and we eat from the same plate”* was another pointer to how people used to isolate individuals living with HIV and AIDS. People used to refuse to eat from the same plate with individuals living with HIV and AIDS. It is customary in Malawi that people *“eat from the same plate”* and it is a sign of unity, togetherness and love among families and demonstrates a spirit of sharing among the communities.

“Mmmm but as for me that behaviour of segregation I just hear it from other people. I just hear it really. It has never happened to me or to my child. It is because I am too open and I do tell everyone that I am HIV positive and they feel sorry for me and they have never shown to me any negative behaviour to me. I do live with the people at home and those surrounding my house in a lovely manner and they are all free to talk to me and we eat from the same plate. In short, there is nothing about segregation for me that I have experienced since I was found with the HIV.”
Stigmatisation in the past

Mayi Salima stressed that she had *“never experienced”* stigma since she was diagnosed with HIV. However, Mayi Salima stated that she felt stigmatised in the past when her husband was sick and following his death. Some *“people were whispering”* to each other that Mayi Salima’s husband died of HIV and AIDS. She stated that she was not *“worried”* about it even if she *“heard it herself.”* *“At that time people were whispering to each other that he has died of the AIDS disease because he was marrying too many women and then I was just hearing it I did not worry about it.”*

When she stated that people were *“whispering to each other”* that her husband died of *“AIDS”* because he was *“marrying too many women,”* she was referring to the

fact that “AIDS” in Malawi is associated with promiscuity because HIV, is one of the Sexually Transmitted Infections (STIs). Therefore, people in Mayi Salima’s village or area attached the death of Mayi Salima’s husband to “AIDS” because he was “*marrying too many women*” which is a sign of promiscuity and the likelihood for him to have contracted HIV was high. Mayi Salima’s husband was in marriage with other three women because Mayi Salima confirmed that they were in “*separation*” for a few years until the husband sent “*his relatives to apologise to her to accept him back.*” Promiscuity among married individuals is not acceptable in Malawian culture and if one is known to be practising it, he or she becomes ridiculed by their peers. That was why “*people were whispering to each other*” in the presence of Mayi Salima.

The above section of this chapter has looked at the marital experiences of Mayi Salima, how she and her child discovered that they were HIV positive and she informed significant others such as her immediate family members and the village headman and issues related to stigma. The section that follows looks at the impact of HIV and AIDS on Mayi Salima’s life.

The impact of HIV and AIDS

In this section, the discussion will focus on the struggle of caring for a child living with HIV and AIDS, poverty and the daily struggle to provide for her family, caring for a child living with HIV and AIDS, monitoring their health, the threat of malnourishment, decision-making to take the child to the hospital, feeding the sick child and future plans for her sick child. The first to be discussed is her struggle when caring for her child living with HIV and AIDS and the rest will follow.

The struggle of caring for a child living with HIV and AIDS

Mayi Salima was a single parent who was HIV positive and was looking after a child living with HIV and AIDS in the rural areas of Malawi. She showed determination to do what she could to look after her children despite that she was also sick frequently herself. Mayi Salima was not satisfied by the care she provided to her child as she lamented “*to say that I can care for the child the way it should be, it is not*

possible.” She stated it was because she was a “*single parent*” who was struggling to find necessary resources for the three children. However, she was trying hard as she “*finds some things that are needed but in a difficult way.*”

“How I do now is to cook porridge in the morning when we drink the medicines... as I am a single parent, to say that I can care for the child the way it should be, it is not possible. I do find some things that are needed but in a difficult way.”

Poverty and the daily struggle to provide for her family

People living with HIV and AIDS need a lot of resources in terms of food, money and clothes because HIV and AIDS are lifelong conditions. The available resources in the family are depleted because of the nature of HIV and AIDS conditions.

Families are left poorer than before when a person living with HIV and AIDS dies and Mayi Salima is no exception. She was left poorer than before when her husband died because she spent much time caring for him at the hospital than working in her gardens. She had less maize, no money and had no house of her own until a year later after her husband had died. She was still struggling with poverty in the face of HIV and AIDS in her family.

“To talk about my needs, I lack so many things and I do have problems to find the necessities as I have three children. The one with the problem is this one. The other ones are fine. I took them for blood test and they are all found to be well. So it’s me and her who are touched with the small animal. The problem is for me to find help I do ganyu (piece work) more especially this year things are not looking good in terms of finding money. I do a lot of ganyu of harvesting crops like maize and ground nuts. That is that.”

Mayi Salima stated that she “*lacked many things*” to support her family properly. She further explained that she found “*problems*” for her to get “*necessities*” for her family because she had “*three children*” to look after. When she used the phrase “*lack many things*” she was indicating that she could not afford to find basic lifesaving commodities such as food. Worst still, Mayi Salima added that her being HIV positive was another barrier because she “*got sick*” often. “*Piece work*” (called “*ganyu*” in local dialect of Chichewa), and according to Mayi Salima, was one of her main sources of income generating activities in her family. “*I do a lot of ganyu of harvesting crops like maize and ground nuts. That is that.*” The sentence “*that is that*” indicated that “*piece work*” was one of her main sources of money (income) in

her family. Therefore, if she fell sick, she would not be able to work and consequently lost the much needed food, money and any material resources.

She further stated that the economic outlook of that year (2011) when the interviews were conducted was generally bad for her. *“More especially this year things are not looking good in terms of money finding.”* This statement indicated that the economy in her village was bad because it was where she got many *“piece work”* for her to find money for the family or it may mean that the economy of Malawi in general was bad that year. *“Piece work”* is a common practice in Malawi and some people survive on it only just like Mayi Salima. Therefore, when she said *“things were not looking good”* in that year, she was emphasizing the fact that it was not only her affected, but many more people were affected. This may not apply to her village only but to most parts of rural Malawi in general.

Mayi Salima further emphasised how difficult things were in her village. *“Life in the village is hard and difficult.”* she ate what was available which depended whether she would find *“ganyu”* so that she could earn money to buy *“relish”* of the day. The relish of the day could have been green vegetables, sun dried fish and beef. She sometimes begs from neighbours or relatives in her village or she just went into the field and fetch for the locally available vegetables called *“kazota”* that were free for everyone. These are types of vegetables that grow naturally in the gardens and one is free to pluck them from anyone’s garden for free. That was a hand to mouth situation and there was no budgeting for food because it was not known what type of *“relish”* would be available on a particular time or day.

When she stated while laughing, that *“(laughing) the life in the village is difficult one. We eat the relish that is found at that time.”* The *“laughing”* here did not mean that she was happy but feeling sorry for herself for being in such a situation at the age of *“34 years.”* At this age it was when she should have been enjoying the fullness of life. Instead, she was miserable and struggling with life. However, her mood became more positive when she stated that *“she was a hard working woman”* and she got what she wanted *“through hard work.”* She *“laughed”* again. The *“laughing”* here was an indication of self-acknowledgement of being a hard worker and she stated this very proudly.

Supporting her family

Mayi Salima further stated that when she had money “*through hard work*” of “*piece work*,” she could afford to “*buy eggs and meat*” from the nearby “*village grocery shops*.” She proudly stated that her child who was HIV positive “*did not choose what type of meat to eat*.” that was good because the child got animal protein that was necessary for the child to grow.

“(Laughing) when we have chance after ganyu we can buy eggs and use them for relish on that day. Or if we can find a bit of meat at the village grocery shops we can buy and eat it. We buy any meat... she does not choose which meat to eat even pig meat, she eats it”

However, Mayi Salima spent much of her time doing “*ganyu*” in other “*rich peoples’* gardens and not in her gardens. The end result was that she had less farm produce and hence sold less thereby perpetuating the poverty in the family. It was a vicious cycle of poverty in her family as she lived in the village that is in the rural areas of Malawi where poverty is endemic and rampant. Mayi Salima further admitted that “*she did not get any help from anyone*” but she relied on “*piece work*” or going into other peoples’ gardens after owners have harvested their crops to “*search for maize that has been left over*.” She sold whatever she had found during the greening (picking maize left in other people’s gardens).

“Aaaa I don’t find help from anyone else but if I do piece work (ganyu) or as of now I do go to the gardens to search for maize left that has been over in the gardens then I sell it. But to say someone does help me, that is a big lie.”

When Mayi Salima states that “*I search maize that has been left over in other peoples’ gardens*” is an indication that she was in a dire poverty because only very poor people search maize in other people’s fields after owners have harvested. In Malawi, this is considered a demeaning exercise to any individual adult by all standards and is a sign of desperation and grave poverty. This is what HIV and AIDS can bring to family; family resources are depleted and the family is left poorer than before.

Caring for a child living with HIV and AIDS

Mayi Salima was an industrious caregiver who did not stay idle at home. She went out in search for “*piece work*” (ganyu) in the village so that she could find money for her family. For example, “*she could earn K30 (20 pence) for a pail of maize she has sheared.*” She took “*K25 out that money and buys soap for the washing of the clothes of the child and herself.*” She admitted that it was a hard job just to get money to buy a tablet of soap that was at a cost of K25 which was equivalent to 9 pence.

“And I do wash her in the morning too. As for soap, when I have done ganyu for shearing maize I do buy. One pail of maize is K30 and then I take that money to buy soap about K25 and see that we bath with it for some days and we wash with it though it’s a difficult way of doing things.”

Mayi Salima conceded that she used “*the same soap for both washing clothes and bathing*” but she quickly pointed out that it was “*a difficult way of doing things.*” The tablet of “*soap*” that she used “*for both washing clothes and bathing*” is called Maluwa and is mainly used for washing clothes. But because she could not afford the luxury of bath soap such as lifebuoy soap, she used the same soap “*for both washing and bathing.*” In addition, lifebuoy soap is an antiseptic soap used for good hygiene and helps keep the skin healthy and it could have been ideal for her and her child but because it was expensive, she could not afford it. While Maluwa soap was cheap and used only for washing and not for bathing because it was only a detergent soap hence cheap. It is “*a difficult way of doing things*” underscored the hardship she was going through to find even money for Maluwa because to shearer “*one pail full of maze*” she got K30 Malawi Kwacha which was equivalent to 10 pence was a hard job. And then one tablet of Maluwa soap was costing K25 and she remained with K5 only. This was indeed tough for her considering that her health was also compromised with her HIV status.

Monitoring health status: Monitoring and prevention

Mayi Salima indicated that the child needed maximum care when the child was “*not sick*” so that the child was prevented from “*getting sick.*” when the child was well would be eating any amount of food and able to take medicines without problems, unlike when “*the child was sick,*” it became difficult to feed and give her medicines. “*It is when she is fine but not when she is sick. Child is fine, happy and growing well because she is on ARVs. But before the ARVs, the child was not growing well and was sick and thin most of the time. But I should say it’s when she is fine that the child needs good care but not when she is sick because she needs that care so that she does not get sick. When I look in her eyes, I see that she is much better now and growing well too.*”

Mayi Salima knew which areas of her child’s body to check to determine if the child was well or not. She “*looked in the eyes of her child.*” This level of care showed that Mayi Salima was a determined caregiver to her sick child and did not leave anything to chance. She took particular interest in her child living with HIV so that the child “*did not get sick.*” “*When I see in her eyes, she is much better than before.*” With this statement, she confirmed that the child’s eyes were looking good and according to her, it meant that the child’s health had improved.

Mayi Salima ensured that her child got “*good food.*” “*I do buy her some good things like good food though not adequate.*” She realised that “*good food*” was part of treatment of HIV and AIDS. Good nutrition is part of ART regimen. Antiretroviral Therapy (ART) training is in three sections. Section one comprises counselling for HIV and AIDS sessions, section two comprises antiretroviral drugs (ARVs) and section three is nutritional therapy. The knowledge portrayed by Mayi Salima is awesome because not many people in the village can demonstrate this level of understand in regards to management of HIV and AIDS. The phrase “*some good things*” showed that not only did Mayi Salima give her child “*good food*” but other “*good things*” too, which she did not elaborate.

“*She has improved like this because she is now receiving the medicines of ARVs but also when I have found some money I do buy her some good things like good food though the food was not adequate. And now I see that there is a change unlike the way she was before.*”

Mayi Salima conceded that she did not find enough “*good food*” for the child. “*I though the food was not adequate.*” She lamented that if she had all the necessary resources such as enough money she could have been providing her child with adequate “*good food and other good things.*”

Decision-making to take the child to the hospital

Mayi Salima was admitted to the hospital with the child as a general admission. It was a general admission because the child was not diagnosed HIV positive by then. The decision to take the child to the hospital was made by Mayi Salima because she was the one who was caring for the child and could notice that the child was “*very sick*” and that the child needed “*to be taken to the hospital.*” She stated that even if the husband was alive, “*she was deciding to take the child to the hospital*” whenever “*the child was sick*” because she was the one who was looking after the child and not her husband.

“It was me who decided to take the child to the hospital because I saw that the child was sick, was very restless at home and a certain doctor called a Mr Who writes at the children side told me that you come here with the child very sick...”

When Mayi Salima stated that “*it’s me who decided to take the child to the hospital*” emphasized the point that indeed she was responsible for decision making for her child’s care. “*Because I saw that the child was sick, was very restless at home*” marked a point when the actual decision was made to take the child to the hospital. She made the decision when the child was “*very restless at home.*” Mayi Salima here demonstrated the knowledge that she knew when the signs and symptoms got worst and that was the point to take the child to the hospital. This was yet another remarkable judgement by her as a rural woman who was not educated to note that here, signs and symptoms were getting worse and I now have to go to the hospital.

Child’s hospital admissions

Mayi Salima had on several occasions been admitted to different hospitals so that the child could receive proper treatment. Mayi Salima was admitted to the hospitals with the child many times in a year lasting at least “*three to four*” days per hospital admission.

“And when I do come here at the hospital, I was admitted with the child I could stay in the hospital for three to four days and I do go home.”

However, before the child started the ARVs, she could not get better even if the child had received medicines from the hospital. Frequent hospital admissions were therefore, not effective before the child was diagnosed HIV and commenced on ARVs. *“The child could get better only for two to three days and then gets sick again.”* She described her disappointment at the lack of improvement with the hospital treatment. *“I could see that the medicines have finished and yet the body was still hot and not cooled.”* The child lost weight to the extent that Mayi Salima was in despair and thought the child was going to die at any time. *“Then she reached a point of being failure to thrive (ananyentchera zedi amaneyu) and she was very thin...”*

“She was breathing weakly and when I do come here at the hospital, I was admitted with the child. I could stay in the hospital for 3 to 4 days and I do go home and at home I could stay for 2 to 3 days and I could see that the medicines have finished and yet the body was still hot and not cooled. Then she reached a point of being failure to thrive and she was very thin and she was finished and I do make her drink the medicines the way I was told the measurements and it’s now that she is feeling better and growing well.”

When Mayi Salima stated that *“she was finished”* she was referring to the child that the child was almost dead and she lost hope. *“This child, we will see how it is going to be.”* This statement indicated that she was not sure if the child would survive.

However, her despair turned into hope and optimism when the child was commenced on ARVs as she stated that *“...and I do make her drink the medicines the way I was told the measurements and it is now that she is feeling better.”* When she said *“and I do make her drink the medicines”* she was referring to ARVs because the child started *“getting better”* with the introduction of ARVs. She further explained that she gave ARVs to the child according to the *“measurements she was taught at the hospital.”* The results are that *“the child was then feeling better and growing well.”*

The threat of malnourishment: Food supplements

When the child is malnourished, that child must be put on food supplements irrespective of the ailment. This is one of the Malawi government policies in order to eradicate malnutrition in children. Mayi Salima’s child was malnourished and hence

was put on the food supplements programme. In addition, the child continued to receive other food supplements from the hospital called "*Likuni phala flour*" so that she could gain weight quickly. As Mayi Salima narrates it:

"It was Likuni phala flour that I used to receive for her and I walked with her till when we reached the point where they said now she is getting better and continued giving her the medicines and continued caring for her as you are doing now."

When Mayi Salima stated that "*I walked with her till when we reached the point where they said now she is getting better*" she was talking about the frequency and period she had been visiting the hospital nutritional clinic. When she stated "*we*" she was referring to the child. The phrase "*walked with her*" indicated the period she had been going with the child to the hospital. And the phrase "*we reached the point*" meant that her child had reached a bench mark weight where she no longer required food supplements and therefore be weaned from food supplements. It is usually the weight for age limit. Here it meant that her child must have attained an age for weight limit and hence stopped from receiving food supplements. "*They said now she is better*" and she was advised to continue with the good care that she gives to the child by "*continuing giving her the medicines.*"

Here the word "*medicines*" indicated all other related prescribed medicines including ARVs because by then, the child was commenced on ARVs. And Mayi Salima stressed that she was advised to give her child other necessary care when she stated that "*and continue caring for her as you are doing now.*" This statement also showed that the hospital personnel were satisfied with the care Mayi Salima was giving to her child as otherwise they would have prolonged the hospital admission period until Mayi Salima demonstrated ability to care for the child. She would have been placed on lessons for children living with HIV and AIDS once more.

Mayi Salima was knowledgeable about the phases of food supplements she was receiving from the hospital. The hospital gives food supplements depending on the condition and level of malnutrition of the child. The hospital first starts with the high protein and high energy food supplement such as "*Chiponde.*" "*Chiponde*" is a plump made from ground nuts and it is high in protein and fats. The proteins help build the tissues while the fats provide the warmth and generate energy in the body

of the child. In this way the child gains weight quickly. Mayi Salima has this information though narrated differently. When the child reaches weight for age level, that child is switched to another less protein and energy food called Likuni phala. Mayi Salima confirms this point when she states that *“they told me that since she has been feeling well, there was no need to continue receiving Chiponde for the child.”* *“Likuni Phala”* is a maintenance food supplement. *“Likuni phala”* is flour made from the mixture of soya beans, maize and ground nuts. This how she narrates it:

“They told me that since she has been feeling well, there was no need to continue receiving Chiponde for the child. And they put her on Likuni phala after chiponde so that I should be cooking porridge for her. I did receive Likuni phala for several months and I still do have the cards I used to receive Likuni phala.”

When Mayi Salima stated that *“I did receive Likuni Phala for several months”* showed that the child had been on Likuni Phala for a longer period and this indicated severe malnutrition of the child. Mayi Salima described severe malnutrition of her child as being *“very thin.”* She also indicated that she had hospital “cards” as evidence to demonstrate that the child had been receiving food supplements from the hospital. *“And I still do have the cards I used to receive Likuni Phala.”* Here Mayi Salima was demonstrating the importance of keeping hospital records safe because they may be required for future reference when the child gets sick again. She would be able to produce them when required.

Hospitals in Malawi provide *“Likuni phala”* for free to malnourished children on a regular basis. In fact all the services in Malawi hospitals are free that includes food supplements such as *“Likuni phala and Chiponde.”* But sometimes *“the hospitals do run out of Chiponde and Likuni phala.”* However, *“Likuni phala”* is scientifically blended food supplement and villagers like Mayi Salima do not know how to make it. Nurses teach caregivers of children living with HIV and AIDS how to make *“Likuni phala”* at home. Mayi Salima had to be taught how to make Likuni phala at home as she demonstrates in her narrative below:

“But there was a time when the hospital had run out of Likuni phala. They told me to take soya, maize and ground nuts, mix them and mill them together. But soya has to be roasted a bit. And when you have milled the mixture, be cooking the way you have been cooking Likuni phala you received from the hospital. If you can find money,

though it is difficult, you should add sugar to the porridge and continue feeding the child.”

Mayi Salima stated that she was taught *“to mix soya, maize and ground nuts and mill the mixture in order to make soya flour.”* However, Mayi Salima stressed the point that the hospital personnel told her to *“add sugar when she had money to buy it.”* This showed that the hospital personnel realised how poor she was and it was only a recommendation.

Feeding the sick child

In the morning, Mayi Salima *“prepared Likuni Phala.”* Then after eating the *“porridge,”* Mayi Salima and her child also took *“the medicines around 6 o’clock in the morning.”* The word *“porridge”* here referred to *“Likuni Phala.”* In the afternoon, Mayi Salima cooked nsima.

“What I do now is to cook the porridge in the morning then drink the medicines and then in the afternoon we eat nsima. As a single parent, to say that I can care for the child the way it should be, it’s not possible. I do find some things that are needed but in a difficult way.”

Specifically for the sick child, Mayi Salima *“cooks the porridge in the morning.”* This time the word *“porridge”* referred to *“porridge”* made from maize flour only when she had run out of homemade *“Likuni Phala.”* This was because Mayi Salima ensured that her child should eat something in the morning before *“the child drunk the medicines.”* The word *“medicines”* here referred to ARVs and not any other medicines.

Careful food preparation

When Mayi Salima stated that *“the way the life of me and my child”* she demonstrated the realization that her life and that of her child were compromised by HIV infection and hence she needed to take extra care in terms of how she prepared food for her and the child. She knew that she must preserve the necessary proteins and vitamins in the food that she prepared by following the instructions she had

learnt at the hospital. Mayi Salima demonstrated that she understood well lessons that she took at the hospital on caring a person living with HIV and AIDS. *“There are no vitamins in relish cooked using chigendere and that is what we learnt at the hospital.”*

“In the morning, we use m’nkhwani, mpiru (local green vegetables) and we find them as we did with the lessons that usually be eating green vegetables most of the time because in them there is a good help for you in your bodies but don’t use relish that is cooked using chigendere (locally made soda) because chigendere kills vitamins in the relish. For me and the way the life of me and my child, I don’t like relish cooked using chigendere. There are no vitamins in relish cooked using chigendere and that is what we learnt at the hospital. The life in the village is difficult one. We eat the relish that is found at that time. When we have a chance after ganyu, we can buy eggs and use them. Or if we can find a bit of meat at the grocery shops, we buy and eat it. We buy any meat. She does not choose which meat to eat even pig meat she eats.”

Support from her parents

“Mmmm! my parents? My parents are old and they cannot help me. My parents are old and I cannot say that they can take care of my children, no, it is not possible and it cannot work out well. Especially my father is very old and he is sick too. But when I am away, they can cook their food and call my children to eat with them. They all eat together. That is what I can say. But to say that they can help me no, it’s going to be a big lie. My father is sick and my mother is old too. It should be me helping them and not them helping me because they are old now. When parents are old, they need the support from their children but I cannot help them as I am sick too. My parents do help me at home but the help is not that they buy me goods, no, but food when I cook and they cook at their house, and we eat together but I do help myself.”

Mayi Salima’s both parents (father and mother) were still alive at the time of data collection and were living nearby *“but they are old and they cannot support her.”* Her parent’s house was about 10 metres from that of Mayi Salima’s house. In fact the tradition in Malawi is that when parents grow old, it is the responsibility of the children to take care of the parents. Therefore, it is her responsibility to take care of her parents since *“they are old.”* This is why she strongly stated that she could *“not get support from her parents.”* She emphasizes this point when she explains that *“it should be me helping them and not them helping me because they are old.”*

She further stressed that *“it is not possible”* that her parents can *“help her”* because she knew it very well that traditionally she was responsible for caring for them and not them caring for her. She further stated that she could not expect her father to be

helping her because *“he was very old and sick.”* However, because of the condition Mayi Salima was in, her parents were helping her though they were old. *“....But I cannot help them as I am sick too.”* The help that she got from her parents was in the form of food. When her parents had cooked food *“they all ate together.”* *“But when I am away, they can cook their food and call my children to eat with them.”* Mayi Salima clearly described the type of support that she got from her parents. *“My parents do help me at home but the help is not that they buy me goods, no, but food when I cook and they cook at their house, and we eat together but I do help myself.”* Mayi Salima further emphasized that she *“did help herself”* and the only help that she got from her parents was food when *“they eat together”* as it is with the Malawi tradition.

However, her father died in July, 2011 soon after the first phase of the interviews. This was discovered during the second phase of data collection in July 2012 (RIP). This is how she explained it: *“the old man, I mean my father who was sick by the time you came here last year, left us a week after we discussed with each other. We buried him the following week. That was in July last year.”* At this point, she became emotional and started shedding tears. The discussions were suspended for about 20 minutes and then terminated thereafter because Mayi Salima became so emotional that we could not continue with the discussions. The qualified HIV and AIDS counsellor who accompanied me started counselling her. We left after she had been properly counselled.

Support from other relatives

Mayi Salima had received support from other relations. Her elder brother in law bought clothes for the children including the one with HIV and AIDS. When she states that *“their elder father”* she was talking about her brother in law was older than her late husband and was still alive. And the word *“their”* was referring to her children. The *“elder brother in law”* specifically bought the child with HIV and AIDS a *“skirt and a blouse.”* For the boy, he bought a *“short and a shirt and for the girl he bought a dress.”* That was in 2010 and *“their elder father”* had not bought any clothes for her children in 2011, at least by the time of data collection he had not done so.

“Mmmm last year (2010), only their elder father that is an elder brother to their father bought them clothes each for one of them. Like for her he bought a skirt and a blouse. Then he bought the boy a short and shirt and for the girl he bought her a dress. That is all.”

Her elder brother in law did not help her children in 2011 because *“their grandfather from the father’s side had just recently died in May, 2011”* and he could not help them as he was busy with the funeral issues that required more money and other resources. She also realises that help from the matrimonial village could be a problem in 2011 because her mother in law who is alive *“is older than her father in law who died”* and therefore they could not manage to help her children. Mayi Salima knows that when a family member dies, many items are used to support the funeral service.

This was why she sympathized with her brother in law that *“he had not helped them this year (2011) because their grandfather from their father’s side just died recently in May 2011 and the help can be a problem as a result of that.”* She further stated that the grandmother from the children’s father’s side was *“very old”* and therefore, could not help her children. *“The grandmother from that side is very old than the one who died.”* The phrase *“that side”* referred to the side of her late husband. She thought that she could not expect any help in 2011 from her husband’s relatives because of the death of her father in law. *“And the help can be a problem as a result of that.”* The phrase *“as a result of that”* referred to the death of her father in law.

Support from the church groups

Mayi Salima belonged to *“the Last Church”* (Christianity) that was situated within her village. She indicated that she did not get any support for the child from any church groups including her own *“Last Church.”* *“No, church members do not help me.”* However, some members of the *“Last Church”* community were aware that the child was HIV positive and was on ARVs what she called *“the medicines.”* Not everybody though was told that the child was HIV positive.

“But some other people know that she is like this but not the church as the church, no.” *“On the side of the church, they don’t know that the child is like this but some other people know that she is like this but not the church as the church no. But some members of the church do know that she receives the medicines.”*

Despite that some members were aware that the child was HIV positive, *“they don’t still help her.”* This is contrary to what used to happen in the past. In the past when someone was sick in the village, the village members used to give that family maize flour, live chickens, money, relish of different types and working in the garden so that when he or she gets better or when the child gets better, will at least harvest something. The village headman was responsible to organize such activities. But now all that is gone. The church community was in the forefront to help with material resources besides offering prayers. Now all that is gone too. Many people were becoming sick due to HIV and AIDS and people became tired and resources were depleted hence the change in the support offered by the community.

Support from friends during hospital admission

Mayi Salima was getting support from well-wishers and friends when she was admitted with the child at Mponela Rural Hospital. At first she felt people from the village who came to visit her child were not helping at all until they started bringing something for the child. She stresses it when she narrates that *“no, there was no one who helped me when I was in the hospital.”* She did not value visiting her without carrying anything was important at first as she puts it *“yes, those who came from the village just to see her and say: how have you awoken up with her?”* Traditionally, Malawians carry something to give to the sick person in the hospital and at that time, Mayi Salima was visited by people who did not carry anything to give her. However, she realised that by visiting her child at the hospital even if one did not bring anything during the visit was important. She stated that *“aaa! yes, when one is with the disease and your friends come to visit you, it is like that friend has taken a bit of the burden of the disease. It is like you have been relieved of worries one had for the illness.”* She noted when relatives or friends visit her at the hospital was very important because they were relieving her of the stress. She appreciates the hospital visits by *“friends”* when she stated that the villagers were *“carrying with them maize flour, firewood and some other things during the hospital visits.”* She did not elaborate on *“some other things.”*

Other sources of support

Mayi Salima indicated that *“she did not get any support from anyone else.”* She supported herself by doing ganyu.

“Aaaa, I don’t find help from anyone else but if I do the ganyu or as of now when I do the gardens for search for maize leftovers (greening) in the gardens, then I sell but to say someone does help me, that is a big lie.”

Mayi Salima emphasized that no one helped her when *“But to say that someone does help me that is a big lie”* and she was closing it completely that no one indeed *“helped her.”*

Support to relieve stress

Mayi Salima indicated that she was not very stressed with the child hospital admissions because she was *“relying on the nurses and the clinicians for help.”* The only strategy she had to relieve her stress was reliance on health workers for her and she admitted that they were helping her child a lot. *“I don’t get stressed up with the illness of the child when am in the hospital because I rely on the doctors to help me and they do help a lot.”* When she stated that that *“I rely on the doctors”* she was talking about any health worker in the hospital and not necessarily the physicians because Mponela Rural Hospital was managed by Clinical Officers (Para-medics) and Nurses. There was no doctor. The doctor was only stationed at the district hospital that acts as the referral centre for the district. She said she *“relied”* on health workers because *“they helped her a lot”* and she narrated it; *“I rely on doctors to help me and they do help me a lot.”* The type of help to relieve stress was not elaborated by Mayi Salima.

Support from non-governmental organizations

Mayi Salima stated that she *“has never heard of any organization that supports people living with HIV and AIDS in her area.”* She only knew *“that government hospitals”* do help her and it was where she got the ARVs and *“chiponde or soya”* and many more items. Mayi Salima argued that *“no, I have never heard of any non-*

governmental organization that helps people that are touched in my area. It's only the government hospitals that give us ARVs and some other help like Chiponde, soya and others.” When she said “*touched*” she was describing people living with HIV and AIDS and this was what people in the villages call them to avoid stigmatization. This was a polite and friendly way of describing them. It was not an offensive statement or word. Therefore, Mayi Salima stressed that “*she had never heard of any non- governmental organization*” that could or helped people living with HIV and AIDS “*in her area.*” It was only “*the hospitals*” that belong to “*the government*” that help people living with HIV and AIDS including her and her child. This was against a background that at Mponela Trading Centre, there were two well known “*non-governmental organizations (NGO)*” that were solely for people living with HIV and AIDS. These were Mponela AIDS Information and Counselling Centre (MAICC) and National Association of People Living with HIV and AIDS of Malawi (NAPHAM). These organizations were just very close to Mponela Rural Hospital. MAICC offices were about 500 metres from the hospital while NAPHAM offices were just about 50 metres opposite the out-patient department main entrance of the hospital.

The paragraph above has focused on the support Mayi Salima had experienced from non-governmental organizations in her area. The paragraphs that follow will focus on her plans for the future of her child living with HIV and AIDS.

The future

Mayi Salima has future plans for her child that covers if she dies who will take care of her child living with HIV and AIDS. This will also focus on her preferred business, most important things needed to care for the child well, a good house (a house that does not leak when it's raining), and the establishment of HIV and AIDS women committees in her area who were looking after children living with HIV and AIDS.

Mayi Salima's preferred business

Mayi Salima preferred to be conducting small scale business to supplement her earnings. Mayi Salima was quick to mention that if she had the capital, she would prefer to be “*selling small fish*” called matemba. She would be going round in the villages, “*exchanging the fish with maize*” and then sell the maize.

“I would like to be doing the business of selling fish or exchange fish with maize and then sell the maize and like that until I get more money. It is a good business but the Kabwandire (selling second hand clothes) is more lucrative than selling fish.”

Mayi Salima indicated that the capital for selling fish would be in the range of between “*K2, 000.00 to K3, 000.00 (£20 to £40).*” The capital then was small and she could afford it. However, she did not mention the exact amount of her capital for her previous business of selling fish. She only proposed for the new capital she would have wanted if she had the money. This amount included the transport to the market where she could be ordering the fish.

“The fish I ordered from Chimwaza and that was some time back before I was found with this problem. I did this business of selling fish before. The fish are now expensive and when they are dear, one pail can be like K3, 000.00 and that can be a good capital. Or K2, 000.00 can be a good capital one can start the business. One also considers the transport to and fro Chimwaza market.”

Most important things needed to care for the child well

Mayi Salima was a hard working woman. She had good ambitions for her sick child. She cited things that she feels if she had them, she would be caring for the child the way she wants. She would like to have a “*good capital to start “business.”*”

“Me, what I think in my life for me is to care for this child very well and is for me to find capital for the business and in addition to be growing more maize or I should grow more ground nuts and if I can be selling these crops I can say I will be able to care for her well.”

She would like to be “*growing crops such as maize and “ground nuts*” as a business venture so that she could be “*selling*” them and earn more money. She stated if she grew more maize, she would have adequate food that would last throughout the year and sell the surplus to earn money. She thought of keeping “*domestic animals*” as one way of improving monetary resources so that she could care for her child well. She gave an example of “*keeping goats, pigs and chickens at her house for cash and*

for food as well.” If she has enough money, she can even tame “*the cows.*” She felt that a capital of “*K3000.00 to K5000.00*” would be enough to buy one or two “*goats*” to begin with. Mayi Salima knew what animals she could “*manage to keep*” and what animals she could not “*manage to keep.*” She felt that a “*cow* was too demanding and required more food to feed it and therefore she could not manage it. In additions, she could not afford to buy it as one cow’s price was between K60, 000.00 to K120, 000.00 (£300 to £600) each.

“Or if I can find money and have a domesticated animal that can help too. Domesticated animals like pigs or goats or chickens and we cannot mention of a cow because it’s too high for me. I cannot manage to buy it and let alone looking after it. A goat at K3, 000.00 can be found in the villages. Or if I can have K5, 000.00 I can have the domesticated animals and the life can be good on the side of the child and myself as well.”

A good house (a house that does not leak when it’s raining)

Mayi Salima mentioned a “*house*” as one of the most important things that she required for her to look after the child very well. She had a “*two bed roomed house.*” The house was made from mud and “*grass thatched.*” She lamented that as the children were “*growing,*” she would require a much “*bigger house*” than what she had. She built the house “*herself.*” She had to work hard at her brother’s farm to earn “*K5, 000.00*” that she paid the people she hired to build her house. She confirms this when she states that “*So I told people to build it for me.*” She sacrificed “*not to buy clothes*” that year so that she could have a house of her own and she managed it. She is a strong willed woman and she could get what she wanted and she worked for it.

“Eeeee, the house is very important. Me I have the house but its small with two bedrooms. Now the children are growing especially the girl and the boy, therefore I will need a bigger house than what have now. I have a house that is grass thatched one and I built it myself. I built that house alone. I went to my brother last year and I did ganyu of tying tobacco bundles and he gave me K5, 000.00 (£50) and I decided to build my house. So I told people to build it for me. I did not buy clothes but build the house and I paid for everything myself.”
HIV and AIDS women committees

Mayi Salima wished if there could be a “*committee or an organization*” in her area of women who were caring the child with HIV and AIDS or the women who were

HIV positive so that she could get some “*ideas*” from such a committee or group. She strongly believed that from such a group she could gain knowledge on how to care for her child well as she could get some experiences from other people who were HIV positive and were also caring a child with HIV and AIDS. She explained this when she states that “*yes, such a committee or organization is important because I can get some ideas on how to care for the child which on my own I cannot.*”

Conclusion of the chapter

The above section of this chapter has discussed Mayi Salima’s future plans for her child where she narrated that her sisters would be looking after her child if she was dead. She also wished to have a big and spacious house for her and her children. She also wished there was a committee in her area where women caregivers could be sharing their day to day experiences of looking after children living with HIV and AIDS. She also preferred to be involved in income generating activities for her family such as conducting small scale business of selling second hand clothes and keeping domesticated animals such as chickens, pigs and goats.

In this chapter the discussion has been on the case study of one particular woman caregiver- Mayi Salima. Mayi Salima’s story had been chosen because of her circumstances and experiences represented those women caregivers in this study in general. Mayi Salima’s case study has given important insights into caregiver experiences, and what these were based on her detailed counts of her experiences. She has provided how a single female parent struggled with life in the face of HIV and AIDS and at the same time looking after a child living with HIV and AIDS in addition to looking after children who were HIV negative. Her experiences such as pursuing an open policy about HIV and AIDS disclosure as a strategy to deal with stigma from the community surrounding and disclosing to very close relatives and key figures in her community such as the village headman were captivating and inspiring. She also demonstrated a spirit of resilience in the face of high levels of poverty and HIV and AIDS in her family by conducting piece work in the gardens of other people as a way of beating hunger and poverty in her family.

Although she was sick herself, (suffering from AIDS) she worked hard to fend for her three children as a single mother. Mayi Salima was also invisible to other local non-governmental organizations such MAICC who did not offer support to her. The only little support that Mayi Salima had was from her old and aging parents who provided food to her children but not always. In short, Mayi Salima had no support from any one that she could quantify apart from the hospital that offered support not to her but to her child who was living with HIV and AIDS despite the fact that she was living with HIV and she had developed AIDS. Mayi Salima also showed perseverance in her troubled marriage. She lived with her husband despite that he continued marrying other women and she said enough was enough when her husband had marriage a fourth wife and she left him although she accepted him back a few years later. She looked after her HIV infected husband who did not disclose to her that he was HIV positive very well till his death although her father in law did not agree when Mayi Salima told him that his son had HIV and AIDS. But later the father in law agreed with Mayi Salima that his son had died of HIV and AIDS when Mayi Salima and her child were diagnosed with HIV.

This chapter 5a has provided a case study of Mayi Salima on her experiences of looking after a child living with HIV and AIDS in a rural setting of Malawi. Her story provides in depth insights into experiences that many other caregivers shared. The chapter that follows is chapter 5b provides narrative summaries of the 19 women caregivers interviewed in this study.

Chapter 5b

Narrative summaries of each woman caregiver

Introduction

In chapter 5a, the researcher has provided a detailed account of thematic analysis of narratives of one caregiver whose pseudonym is Mayi Salima. In this chapter, the researcher has presented narrative summaries for each woman caregiver interviewed in this study and grouped them within the overarching key themes. The narrative summaries are grouped into major themes, for example, caring responsibilities where the narrative summaries of Mayi Dowa, Mayi Kasangadzi and Mayi Machentche are grouped to show the ways in which the women's narratives reflected this theme. The other grouping of narratives includes the invisible nature of caring (n=5), husbands making the decisions (n=5), disclosure and stigma (n=3), resilience and challenges (n=3). Please see the table below that shows the main themes and the related narrative summaries. Please note that Mayi Salima's narrative summary is not included.

A table showing main themes a number of related narrative summaries

<i>Main theme</i>	<i>Number of participants' narrative summaries</i>
Caring responsibilities	3
Invisible nature of caring	5
Husbands making decisions	5
Disclosure and stigma	3
Resilience and challenges	3

As indicated in the above table, narrative summaries have been grouped in their relevant themes. However, some narrative themes also seemed to be cutting across and an effort was made to group them where they fitted most.

Caring responsibilities

The extensive caring responsibilities recounted by the women caregivers reflect the findings from other studies conducted in different countries. It highlights that care and support for sick individuals in families is borne by family members and mostly by women family members (Fishman, 1978; Glaser, 1987). This study revealed similar findings and below is the narrative summaries of women caregivers regarding the findings of caring responsibilities.

Mayi Dowa

Mayi Dowa was a 36 year old, with a 5 year old girl, both living with HIV and AIDS and taking ARVs. Mayi Dowa described how she was feeding her child with food supplements she had been receiving from the hospital. She however, described that the hospital personnel decided to stop food supplements for her child because the child had reached what she called “*a weaning body weight.*” “*The hospital has told me that they will stop giving my child Likuni phala because they say she had reached the scale for her to stop it but look at her, she is still sick and weak (here she was sad and tears were seen down her cheeks-the interview was suspended for a while and she said that the interview could go ahead and apologised for her tears. She was properly counselled).*” She further described that she was powerless “*in the eyes*” of the hospital staff as she explained that “*everything was in the hands of the of hospital staff*” and that “*there was nothing*” that she could do even though her child was “*still weak and looking sick.*” Here, the researcher in consultation with the study supervisor in the United Kingdom intervened and the hospital continued to provide all the food supplements to her child because it was a matter of life and death. She stated that her “*child had gained weight from 4.1 kilograms to 8.1 kilograms*” at the time of interviews. The child was looking health when the researcher visited Mayi Dowa in June, 2012 during the data verification period. May Dowa was happy and the child looked happy and healthy too. She explained that her “*child continued to receive food supplements and that she was very grateful to the research team.*” Mayi Dowa was a good example of caregivers’ caring responsibilities of a child living with HIV and AIDS.

Mayi Kasangadzi

Mayi Kasangadzi, 29 years old, HIV + not on ARVs, widow, husband died of HIV and AIDS. She was looking after a 6 year old female child living with HIV and AIDS and on ARVs. She narrated that the health of her child started to improve when the child was diagnosed "*HIV positive*" and started the ARVs. She described that "*she really appreciated the introduction of ARVs to the child and now the child is growing well.*" She confirmed this statement when she said that "*and I can say that since my child started receiving ARVs and Likuni phala, chiponde and milk, she has improved much better and she is growing well now and I am happy for this.*" She stated that the introduction of ARVs marked the beginning of some happiness in her life as the child stopped being "*sick frequently and was growing well*" and looked healthy at the time of the interviews. She also expressed gratitude to the hospital for helping her child when she stated that "*I just thank the hospital.*" She demonstrated her dedication to caring her child in the sense that she followed the advice given at the hospital on how to give medicines (ARVs) to her child. She never missed it and she gave exactly the way she was taught. She demonstrated her responsibilities of care and support and stated that the introduction of ARVs improved the life of her child. She also thanked the hospital for supplying food supplements to her child. "*I just thank the hospital for giving my child Likuni phala, chiponde and milk.*"

Mayi Machentche

Mayi Machentche was 39 years on HIV + but not on ARVs, in monogamous stable marriage, husband HIV + and on ARVs and supportive. The child was 11 years old male, on ARVs as well. Mayi Machentche described how she was checking stocks of ARVs for her child and that of her husband. She described that ARVs were given under "*strict rules*" to avoid recipients develop resistance what she called in a local language of Chichewa "*kuwopa kuti ma ARVs asasiye kugwira ntchito yake bwino*". She stated that each recipient is taught to check stocks and report at each hospital visit. She described that she checked ARVs stocks for both her child and that of her husband and reported to the health worker at each visit. She narrated that she followed these rules very well including how to give HIV and AIDS medicines maintenance doses to her child. Mayi Machentche was dedicated to ensure that her child had taken the ARVs and she had double responsibilities too as she was

required to look after her husband who was on ARVs. She had to ensure that she had audited his ARVs as well. This was a good example of caring double responsibility of a woman caregiver.

Invisible nature of caring

The unpaid work conducted in families by family members in most cases is not recognized by anybody within the family or the community at large (Glaser, 1987; Boulding, 1985; Daniels, 1984). The unpaid work conducted by family members includes caring for the child (whilst they are sick or well), housekeeping activities and sourcing food and other resources the family needs to survive. The narratives show how women caregivers providing this type of care within their families were also invisible and below are the narrative summaries.

Mayi C

Mayi C, a 34 year old woman and she and her 7 year old child are both living with HIV and AIDS and receiving ARV treatment. However, although she was in a monogamous marriage, her husband refused to have an HIV test. She stated that he blamed her for bringing HIV into the family. Mayi C stated that her husband had not gone for HIV test and she “*could not force*” him to do so because he was her “*husband and needed to be respected.*” She did not know why “*he refused*” to go for the HIV test and she remained quite as a sign of respect of her husband. This husband dictated issues in the family. She was unaware of her risk of contracting HIV and was not tested during her pregnancy and it was only when her child tested HIV positive that she was also a diagnosed HIV positive “*Those thought were too far from me and I don’t know whether it was being young or childishness, I don’t know. If I thought of that I could have tested for HIV when I was pregnant. These thoughts were far from me.*” When she stated that “*my husband did not think of it either*”, she referred to taking the child to the hospital for HIV test.

Mayi Mpanda 2

Mayi Mpanda 2 was a 39 year old lady, widow, living with HIV and AIDS on ARVs as well. She was looking after a 5 year old female child living with HIV and AIDS on ARVs too. Mayi Mpanda 2 was one of the women caregivers who talked

less and it was difficult to get information from her. She stated that she was “lazy” going to the hospital for antenatal services that include HIV test but she knew that she was HIV positive. She stated that she did not follow the protocol for an HIV infected woman who was also pregnant as she stated that “*taking medicines that protect the unborn child. They call it nevirapine. No, I did not think of it at all. I went to the hospital too late and the doctor told me that I was late to start nevirapine. I feel the hospital failed me as my child was not protected (Laughter) its true I did not go to the hospital because I was only lazy that is all. Nothing really I can say stopped me from going to the hospital with the pregnancy of this child.*” It is not known why she was told that it was “too late” for her “to start nevirapine” while she was pregnant as all pregnant women start nevirapine at any stage of pregnancy. She stated that she felt “*she was failed by the hospital*” and her child was not protected. Mayi Mpanda 2 regretted her behaviour of not going to the hospital in time for “*the medicines that protect the unborn child*” when she knew that she was HIV positive and pregnant as well.

Mayi Mpanda 3

Mayi Mpanda 3, 26 years old, in a stable monogamous marriage HIV + on ARVs, husband HIV+ but not on ARVs. The husband was supportive. Child was a male aged 3 years old, on ARVs. Mayi Mpanda 3 described how she discovered her HIV and AIDS status. She discovered that she had HIV when the child was getting “*sick frequently*” and she decided to “*get help from the traditional healer first.*” She later realized that “*the traditional healer*” did not “*examine*” the child very well as she put it; “*I tried very much there at the traditional healer but he could not tell me the truth about the illness of my child. I guess this is because at the traditional healer, they don’t examine the patient as it is at the hospital.*” Therefore, she “*saw*” the need to go to the hospital for proper “*examination*” of her child and for herself too. Mayi Mpanda 3 however, reported that at the hospital, the HIV test reagents were out of stock therefore, she decided not go back home without an HIV test for her and her child and she went to “*Mponela AIDS Information and Counselling Centre (MAICC)*” where she was also told that they had run out of the HIV test kits too. Mayi Mpanda 3 described that she did not give up and went to a private clinic called Banja La Mtsogolo (BLM) where she had the HIV test done and that the HIV test results were positive for both the child and herself.

Mayi Mpanda

Mayi Mpanda was a 22 year old widow, HIV + and on ARVs. Her child was HIV +, male, aged 6 years and on ARVs too. Mayi Mpanda was another woman caregiver who did not talk much about issues concerning a child living with HIV and AIDS. She was not willing even to talk about her issues surrounding the care that she gave to her child. However, she was able to describe how the child was discovered with HIV. *“How it started I just wandered that the child was just sick sick sick then I wandered and decided to go to the hospital and I went with him to MAICC and there they tested him and he was found with the small anima’*. She discovered her HIV positive status after her child was diagnosed first. She lived with it without knowing that she was HIV positive until the child was sick and diagnosed first. She was invisible to health care workers despite that she had been going to the hospital herself and she was not tested HIV first.

Mayi Zomba

Mayi Zomba was a widow, 35 years old looking after a female child aged 5 years, HIV + and on ARVs too. Mayi Zomba described that a few of women caregivers discovered that they had HIV when they became sick and had sought hospital treatment where they were investigated for a range of other diseases first before they were tested for HIV. The other tests included TB tests. She stated that the hospital told her that these other tests were conducted to rule out other opportunistic infections such as Tuberculosis (TB) she was talking about. Mayi Zomba also expressed that her child was suffering from similar *“disease of vomiting blood”* just like her therefore; she decided to go to the hospital with the child. While at the hospital, she was *“given”* sputum containers for her to cough in sputum for tuberculosis screening at Dowa district hospital. *“...and when I reached there, I was given bottles for me to put in sputum for the big cough. And I gave the sputum for the big cough.”* She further stated that when the results had come, she had no tuberculosis and the hospital personnel asked her to have HIV test and she accepted. When she stated that *“the results told me”* she meant that the hospital personnel told her that she had no tuberculosis, but she had *‘the small animal of HIV:’* She was another good example of being invisible to health workers and her HIV and AIDS

treatment. The delayed had an implication regarding the care and support of her child living with HIV and AIDS.

Husbands made decisions

An important finding is the impact of gender on these women's experiences. Culturally, women in all the countries in Sub-Saharan Africa must seek permission from their husbands regarding their health; be it reproductive or general health including seeking a test for HIV (Rutenberg, et al., 2000; WHO, 2005). Married women cannot seek health care services without consulting their husbands because doing so will be regarded as disrespectful to the husband and such a woman would be reprimanded by a group of elderly women in that community (Rutenberg, et al., 2000; WHO, 2005). The narrative accounts within this study confirmed these observations and below are the narrative summaries.

Mayi B

Mayi B, 31 years old, HIV positive and on ARVs, looking after a 9 year old child who was also HIV positive and receiving ARV treatment. However, her husband refused to have an HIV test and blamed her for bringing HIV in the family. Mayi B was one of the women caregivers who spoke very little about their husbands; however she described her husband *“as a drunkard...My husband is like he is using the money for two families one it is me and the other is the beer that he drinks and he uses a good part of the money (salary) on beer. He drinks a lot of beer and that for him to care for the family is a big problem.”* Her husband did not want her to be involved in this research and hence Mayi B withdrew voluntarily from the study.

Mayi F

Mayi F was 28 years old and her 3 year old daughter both living with HIV and AIDS and on ARVs. She was in a monogamous marriage with her second husband and he refused an HIV test. Her husband refused to go for the HIV test because he *“blamed the wife to have brought HIV in the family.”* This *“worried”* his wife so much. *“I was very worried and I can tell you right from the beginning when they found me with HIV when I was pregnant I was very worried”*. She described her husband response as suggesting the child was not his child because he often stated that *“you*

are the one who is HIV positive and not me.” She further explained that her husband often stated that *“it is me who brought HIV in the family and not him.”* Mayi F further described that he distanced himself from the child because the child was HIV positive. She stated that her husband denied responsibility and instead, blamed her *“I said okay let it be and only God knows who brought this problem in the family. I was in a difficult period and I was really hurt and I hate that period. Until when the child was born, there was no peace in my family.”* Mayi F lamented that there was *“no peace in her family”* because the child was HIV positive and that she was HIV positive too. She stated that *“she hates that time (during pregnancy)”* she discovered that she was HIV positive because her husband traumatized her psychologically, up until the child was born. The husband did not want to be tested for HIV. Mayi F was an example of women who were controlled by their husbands and lived in a complex marital status. Her husband refused responsibility of taking an HIV test and blamed his wife for the HIV in the family. Despite all these challenges, she still continued to strive to care for her child single handed. This was also another example of being resilient in care and support of her child living with HIV and AIDS.

Mayi Kasangadzi 4

Mayi Kasangadzi 4 was a 26 year old woman living with HIV and AIDS, on ARVs, in a complex polygamous marriage. She was caring for her female child who was also living with HIV and AIDS aged 7 years. Her husband was HIV positive and on ARVs too but she believed he was not concerned about his HIV status or the possibility that he might have infected others because he continued to marry other women. She described being *“the first wife”* but her husband had two other wives that she described that *“they were below her.”* She thought that a man with *“three wives”* may not be able to take care of all the needs of each wife adequately and therefore, there were many problems associated with polygamy. She went on to plead that *“let him leave the other two wives and he should remain with me alone because of the problems that are in this house, I think that can help a lot in caring for the child.* She described feeling helpless and powerless and she expressed it all in the narration that follows. She tried to reach her husband during the period when they were on *“separation”* so that he could assist her with money to take care of their HIV positive child. However, she could not reach her husband as she found out that her husband *“had changed his telephone numbers.”* In response, she sought

help from her father in law when her child was very weak and needed to go to the hospital with the child and ‘*the grandfather of the child,*’ gave her K200.00 (50 pence) for “*transport*” to take the child to the hospital and obtained ARV medicines. However, “*by chance*” Mayi Kasangadzi 4 was able to track down her husband and seized the opportunity to talk to him about the problems she was facing caring for the child who had HIV and AIDS. She described her husband as not showing any “*remorse*” about passing HIV onto their child. However, when she discussed the child’s condition and the problems that she was facing when caring for the child her husband was ‘*concerned.*’ And her husband arranged that the child be admitted at Mponela Rural Hospital that was near his base at Mponela trading centre. Mayi Kasangadzi 4 is a good example of living with a husband with complex life style and controlling. She was powerless to stop risky behaviours and she could not do anything about at all.

Mayi Lilongwe

Mayi Lilongwe was a 40 year old lady living with HIV but not on ARVs, not yet developed AIDS. Her husband died of HIV and AIDS. Her 8 years old boy was born HIV negative and acquired the virus when he was 6 years old. Mayi Lilongwe stated that she was powerless to prevent risky behaviour conducted by her husband before he died. Mayi Lilongwe stated that the child with HIV and AIDS was born without it because “*she was HIV negative when this child was born.*” She “*believed*” that the child got “*the small animal*” from his father as they used to “*share razor blades*” and this was what she said “*his father used to shave him using his razors which he has been using to shave for himself.*” She further stated that even when her husband had just finished shaved his beards, she could see him use the “*same razor blades*” cutting “*the child’s finger nails*” but she was powerless to stop him. She further stated that it was rare that married women could confront their husband in this culture because doing so would seem to be challenging the husband and it was unacceptable to do that. “*Us women are supposed to be submissive to our husbands because our husbands are heads of our families.*” This is an example of women being powerless to stop risky behaviours by their husbands in the face of HIV and AIDS. Stopping him would have been interpreted as being not being sub-missive to her husband and a sign of disrespect to the husband too.

Mayi Ntchisi

Mayi Ntchisi was a 35 year old lady in monogamy stable marriage; HIV +, on ARVs, husband alive and had HIV and AIDS on ARVs too. She was looking after a male child living with HIV and AIDS and was on ARVs. The child was 6 years old. Mayi Ntchisi was one of women caregivers who were difficult to get information from however, she explained that she discovered that she had HIV when her child was getting “*sick*”. Mayi Ntchisi further stated that together with her husband decided to take the child to the hospital and all of them were tested for HIV at that hospital visit and the HIV test results were positive for all three of them. “*And when he was seen, by then, we had our blood tests too for HIV the three of us. They found the small animal of HIV in our bloods as well as the blood for him.*” After the HIV seropositivity results, they were all commenced on ARVs and she ascertained it when she stated that “*when he was found with it, they told us to start receiving the medicines.*” The word “*medicines*” here referred to ARVs. Mayi Nsanje here demonstrated that as a family, they took a collective decision to go for the HIV test and her husband was supportive too.

Disclosure and stigma

While the importance of stigmatizing aspects of HIV have been widely acknowledged, very little consideration has been given to how social stigma interacts with HIV disease components in the illness experiences of HIV infected individuals and their outcomes (Muller and Poggenpoel, 1996; Alonzo and Reynolds, 1995). Stigma and disclosure of an illness are inter-related and they influence the management of that illness (Greeff, et al., 2008). Disclosure refers to voluntary telling someone of one’s concealed phenomenon (Sandelowski, et al. 2004). Disclosure is the main component in the management of HIV and AIDS because individuals are better managed if they reveal that they are HIV positive (Greeff, et al., 2008). The narrative accounts within this study has indicated that problems in managing disclosure and the impact of stigma are key aspects these women face in their care of a child living with HIV and AIDS. Below are the narrative summaries regarding disclosure and stigma.

Mayi Kasungu

Mayi Kasungu was a grandparent who was HIV negative, aged 70 years plus and a widow, looking after an 11 year old niece living with HIV and AIDS and on ARVs. The niece's father was alive but was not helping Mayi Kasungu with resources to take care of the child. Mayi Kasungu described that there was a culture of secrecy regarding the presence of HIV and AIDS in the family. She ably explained that the child's father "*made a big mistake*" to them as an extended family because he knew he was HIV positive but he could not tell his wife. She stated that he was even on ARVs but he was "*hiding*" them from his wife and the results were that his wife died of HIV and AIDS without knowing that her husband was HIV and AIDS and that he was on ARVs. When she stated that "*her mother died of the same disease called HIV and AIDS*" she stated that her niece's mother died of HIV and AIDS. She further stated that her sister in law got sick soon after delivery of the child and the child was just "*three months*" old when she died. She said that her brother "*gave the child*" to her soon after the death of his wife. "*I have given you the responsibility to be taking her to the hospital.*" She further explained that although he gave the "*responsibility of taking the child to the hospital,*" he did not support his sister in looking after the child. This was a good example of being resilient in care and support despite being old; she managed to find resources to take care of her niece. She was caring her niece without the support of her father who was still alive at the time of the interviews.

Mayi Lusa

Mayi Lusa was one of the women caregivers who spoke very little. Mayi Lusa was a 46 year old woman and in a happy monogamy marriage and her husband was alive and HIV+ but not on ARVs yet. She stated that her husband was supportive and she said that she was HIV positive and on ARVs and that she got sick frequently. The child was a male child aged 11 years living with HIV and AIDS and on ARVs too. Mayi Lusa stated that she told the village headman that the child was "*HIV positive*" because the village headman was "*a big person.*" a well-respected figure in the village and it was a way of respect. She further stated that she did not tell anybody in her village including "*her own friends.*" except the village headman. She added that "*the boy's friends just played with him without knowing that he was HIV positive.*" She also described that "*life in the village was a difficult one.*" She extended her

story by stating that if her son went “*playing with friends*” and they knew that he was HIV positive, “*they would be mocking him.*” “*Let us say if he wants to play with friends, they would be mocking him that this one has a small animal don’t play with him and that is not good because we are killing his freedom.*” Mayi Lusa was protective of her son. She did not want her child to experience stigma.

Mayi Muyeza

Mayi Muyeza River was a widow and HIV + on ARVs. She was looking after a 4 year old female child, living with HIV and AIDS and was on ARVs too. She was one of the women caregivers who spoke very little despite probing. Mayi Muyeza stated that she had experienced stigma behaviours during her caregiving experience of her child. “*Ooo! one may want, let us say to go another home like that one and ask to be lent a scissors for me to shave my child, they will deny you and tell you that it got lost and if you go to another home it will be the same and behind you they will be saying we cannot give her because she can give us the small animal of AIDS. And now we have just decided not to borrow anything from anyone in this village. We are now used to it and we don’t even think about it. And we don’t even hate them for their attitudes now we live our life the way we do on daily basis. We don’t even worry about them we let them talk and we move on and only God knows everything.*” Mayi Muyeza had a strategy of dealing with stigma associated with HIV and AIDS. She decided to ignore the people and moved on with her life.

Resilience and challenges

A key unexpected finding for this study was the resilient response of these women caregivers to their situations. Resilience has been identified in other studies of caregivers worldwide. All families face challenges and crisis of varying degrees (Walsh, 2007). The crisis may range from sudden death of a family member to a family member living with a life-long disease such as cancer, HIV and AIDS and diabetes (Walsh, 2003). Below are the narrative summaries where women’s accounts illuminate their resilience as caregivers.

Mayi Bua

Mayi Bua was a 34 year old woman living with HIV and AIDS on ARVs who was in a stable monogamous marriage and her husband was still alive at the time of the interviews. Her male child was living with HIV and AIDS and was 2 years old. Mayi Bua stated that she had double responsibilities of being primary caregiver for both her child and her husband who *“was also touched with the small animal (HIV positive) and was on ARVs.”* She complained that *“she did not have enough resources to take care of the two individuals living with HIV in her family because her husband was “often sick” and was frequently admitted to hospital.”* She stated that her husband was a subsistence farmer *“whose income was limited to certain months in a year.”* She also stated that her husband was unable to support his family adequately because *“he was frequently sick and weak and therefore,”* he could not *“work properly in the garden that was his main source of income.”* This also made him unable to help out with caring for his sick child. Mayi Bua further stated that this meant that Mayi Bua’s husband did not dominate in the family affairs and Mayi Bua described that she had taken over the running of her family and took care of both the child and her husband who were living with HIV and AIDS and on ARV treatment. *“I can say here that my husband is no longer in-charge of family affairs but me because he is perpetually sick and weak and therefore I have taken over as the head of the family and I make decisions.”* Despite all the challenges that she was facing, Mayi Bua continued to take care of her child and her husband within her means.

Mayi Dedza

Mayi Dedza, 32 years old, was a widow, and both she and her 8 year old daughter were HIV positive and on ARVs treatment. Her husband died of HIV and AIDS. She described that despite acute shortage of material and monetary resources she was very resourceful to ensure that her child was cared for to the best of her capabilities in the face of acute shortage of resources for caring. She described that she *“gave her children ARVs after the child had taken the morning porridge.”* Mayi Dedza lamented that as a single parent she could not take care of the child because life in the villages was hard. *“I do find some things that are needed but in a difficult way. It is especially difficult this year to find all that I need because of being a single parent.”* Her time was spent looking after her children and trying to support the

family through working in other peoples' gardens to tender their crops 'Sometimes I do go in the village asking for ganyu (piece work) from other well to do people but this is hard as times have changed here in the village. No ganyu is available as everybody is complaining of hard times, I mean in general people have no money as they used to have in this village. Even those people we think are well to do in this village are complaining of the same.'

Mayi Nsanje

Mayi Nsanje was a 70 plus year old grandparent and was living with her husband. They were both HIV negative. Mayi Nsanje was looking after her granddaughter aged 6 years and living with HIV and AIDS on ARVs. Mayi Nsanje was concerned about the future of the child "A aa in future, I don't know it as I don't know about the limit of my life as you can see I am an old lady. As I have told you already that I don't have energy but I cry for a Good Samaritan who can be helping me on the side of this child. I can only thank that person that now someone can help the child and I can concentrate on the boy who is not sick. Here, she wanted a good person to help caring the child living with HIV and AIDS so that she could concentrate taking care of the other child who was HIV negative. Mayi Nsanje, though old, had clear future plans for caring for the child living with HIV and AIDS.

Conclusion

Chapter 5b has provided narrative summaries and their relevance to the main analytic themes. The chapters that follow will explore these themes as they occur across the data set, in more detail. The chapter that follows (chapter 6) discusses the finding on how women caregivers discovered their HIV status and their experience of the diagnosis.

Chapter 6

How women caregivers discover their HIV status and their experience of the diagnosis

Introduction

In the previous chapter the discussion focussed on the clinical care and support that is available for children and their women caregivers living with HIV and AIDS in rural Malawi. In this chapter, the discussion will focus on how women caregivers discover their HIV status and their experience of this diagnosis. The discussion will start with the women caregivers themselves.

The women caregivers

Whilst, traditionally in Malawi men are considered to be the head of families, it is women who are the main carers in general and often the main providers for their families (MDHS, 2010). The majority of these women live in rural areas of Malawi (NSO, 2008). These women are not educated and therefore illiterate (MDHS, 2010). They are also in the lowest income quintile (NSO, 2008) and so struggle to get material and food resources to fend for their family members (MDHS, 2010 and MDHS, 2004). They were interviewed for the first time about their family lives in general and specifically about their caring experiences of children living with HIV and AIDS. In this study, all women were primary caregivers to their children living with HIV and AIDS in rural Malawi. They had similar limited resources and lived in a similar rural environment and the general care they provided included feeding the child, washing clothes, bathing, giving medicines, providing a good sleeping place, cleaning the house and taking the child to the hospital when necessary.

All of the children had been living with HIV and AIDS since they were born except one child who was born HIV negative to an HIV negative mother but later the child was diagnosed HIV positive. Children's ages ranged from two to thirteen years. All of the children that the women caregivers were looking after were sick at the time of interviews but they did not require hospital admission. The section that follows looks at how women caregivers discovered the HIV and AIDS status of themselves and

their children. The participants are referred to by pseudonym, and that further information about each woman is in the list of participants in the appendix section of this thesis. Please see appendix 3.

Caregiver's discovery of HIV and AIDS

All these women caregivers were responsible for making decisions to go for HIV Counselling and Testing (HCT). Their decisions were usually influenced by the health status of others, such as their child getting sick frequently. A smaller number were diagnosed because they became sick themselves or because they were re-marrying.

Caregiver tested only after their child became sick or through routine screening

The HIV status of most of these women did not appear to be treated as a priority by the clinic. They were only diagnosed either because they were tested once their children became sick or during routine screening of their pregnancy; as a result the majority discovered that they were HIV positive after their child became sick and they sought hospital treatment for them.

HIV diagnosis following child's diagnosis

Nine of our women caregivers interviewed were diagnosed HIV positive by the hospital service after their child became ill and was diagnosed HIV positive. It is mandatory in Malawi that every sick child who is admitted to a hospital is tested for HIV. A smaller number of women caregivers were diagnosed HIV positive when the child they were looking after had become sick and had gone to the hospital for treatment but they were tested for HIV first before the sick child. For example Mayi F stated that she discovered that she was HIV positive when her child was "*sick*" and she had "*gone to the hospital for HIV test*" and she reported that she was found with "*the small animal.*" Mayi F stated that when she had gone to the hospital, "*doctors*" decided to test "*her first*" for HIV and then thereafter, they "*tested the child*" too. She described that the HIV test results showed that she had the "*small animal in her blood*" and so too had her child.

“The child was opening bowels and vomiting and it so happened that she started showing rashes on her body then I decided to go to the hospital. I asked for the HIV test for the child and at the hospital they told me that we will not test the child but you first. Then I was tested for the HIV and I was found with the small animal. I was HIV positive. I have the small animal that starts the disease of AIDS. Then I thought that may be the child got it from me then I took her to the hospital then I told the doctors then they helped the child and they started her on medicines.”

Similarly, Mayi Dedza discovered that she had HIV when her child “became sick” and she had taken her child to the hospital for the HIV test because she noted that “the child could be very sick”. After the child was tested for HIV, she had her HIV test done at the same time and the results were HIV positive as she stated that “we had it together.”

“It’s because he could be very sick and then we took him to the hospital and he could be wondering what has he eaten but he should know that it’s the same disease. It’s at the same time I went to have him tested for the blood test for the small animal. That was last year (2010). We had it together.”

Diagnosis during screening because of pregnancy

Mother-to child transmission of HIV infection can take place during pregnancy in the intrapartum duration or postnatally therefore; every pregnant woman must be screened for HIV during the entire period of pregnancy (Leroy, et al., 1998). Unborn children to HIV infected mother have a high risk of acquiring HIV while in uterus or during breast feeding (Newell and Bryson, 1997). HIV transmission from an infected mother to her child is estimated to be more than half of all the transmissions occurring in late pregnancy (Guay, et al., 1999).

Four of women caregivers in the study were diagnosed HIV positive during the routine pregnancy screening procedures in order to protect the unborn child from acquiring the HIV. Mayi Dowa was one of the four women caregivers who were diagnosed HIV positive in pregnancy during the routine screening. “She had the HIV test when she was pregnant and the results were HIV positive.” Mayi Dowa explained that she could not attribute her child’s illness to her HIV positive status because she felt that since “she had followed all that was required during pregnancy and delivery for the child to be HIV negative.” “They asked me if I had taken the medicines before the labour started, and I said yes, I did drink the nevirapine.”

“Nevirapine” is the antiretroviral (ARV) drug of choice in Malawi that is still being used to prevent the transmission of HIV from mother to child while still in the womb. That was an emotional time for her as she explained that *“I was very sad and I started crying because I followed what was required for my child to remain without HIV.”* She received *“nevirapine”* during pregnancy and at delivery time and therefore expected that her child would be HIV negative and not HIV positive as the situation had been. She again stressed that even *“the child was given nevirapine at birth time”* to ensure that the child remained HIV negative. It is part of the prevention of HIV from mother to child programme for the child to be given nevirapine at birth born to HIV positive woman, it was reasonable for her to expect this.

“They asked me that when I was pregnant for the child did I test for HIV and I said yes. And I told them that I am HIV positive and am still HIV positive till today and they said ohh that is why the child is looking like this. They asked me if I had taken the medicines before the labour started, and I said yes, I did drink the nevirapine and the child was given nevirapine too at birth time. I was very sad and I started crying because I followed what was required for my child to remain without HIV. They were all surprised and asked each other what was happening looking how things were done. The lady followed the protocol for nevirapine and the child looks to be HIV positive.”

A smaller number unwilling to disclose how they were diagnosed HIV positive

Mayi Mpanda was one of the women caregivers who did not talk much about issues concerning a child living with HIV and AIDS. Malawi’s culture does not expect any person to talk openly about marital issues to a stranger or someone one has just met for a few days like the researcher in this case or the care she had been giving to her child. However, she was able to describe how the child was discovered with HIV. She stated that *“I went to government”*, where the child was commenced on ART after being tested HIV positive at Mtengowanthenge mission hospital. When she used the word *“government”* she was referring to Mponela Rural Hospital which is a government health facility. At Mponela Trading centre, there were other private health institutions and Mponela Rural Hospital was commonly referred to as *“government”* by the local people to distinguish it from the private health institutions at Mponela trading centre.

“How it started I just wondered that the child was just sick sick sick then I wandered and decided to go to the hospital and I went with him to MAICC and there they tested him and he was found with the small animal and from MAICC I went to government and at government they started me on education and I did the education and then they put him on medicine and that child is on medicine now. He was opening bowels (diarrhoeas) when he opened the bowels; he said the abdomen was painful I mean in his stomach. Then things just appeared on his face and then the whole body was filled with small wounds.”

Lack of knowledge about diagnosis

There were some caregivers who reported that they did not know how they were diagnosed HIV positive. However, they talked about being HIV positive and they described it briefly. Mayi Lusa for example, narrated being HIV positive without elaborating how she was diagnosed HIV positive. She was very brief in her response despite probing. She only stated that she had the HIV and could not explain more on what happened for her to be discovered with HIV. She did not respond to the questions easily, instead she was talking around the topic in a very different and difficult manner that was difficult to understand.

“Let us be like the way we are maybe it’s our bad luck as am also touched and his father is also touched with the HIV (inenso ndine wokhudzidwa bamboo akenso ndi wokhudzidwa). We see that in our house there is nothing that disappoints us. We just stay the way any other person can stay. (At this point, she started crying and she had tears all over her face. The discussions were immediately terminated and a qualified HIV and AIDS counsellor was called in and she took over and started the counselling process.)”

The above section has looked at how women caregivers discovered their HIV and AIDS status. Majority of them discovered their HIV and AIDS status through the diagnosis of their sick children. Some of them had known it through routine pregnancy screening procedures at the antenatal clinic. However, there were others who were not willing to disclose how they discovered their HIV and AIDS status. The following section looks at the husbands and families and their decision making about HIV testing.

Husbands and families: decision making about HIV testing

In the majority of the families, their husbands decided to take an HIV test following the illness of the child. Whilst the majority of the husbands accepted the HIV test results, a minority did not accept the results instead, blamed their wives for bringing HIV in the family. However, there were other husbands who refused to take the HIV test all together and blamed their wives for the HIV status of the child.

Following a child's illness, the women decide to be tested

Overall, these women caregivers believed the whole family should have the HIV test after noting that the children were getting sick frequently, for example, the family of Mayi Ntchisi. Mayi Ntchisi was one of women caregivers who were difficult to get information from; however, she explained that she discovered that she had to have HIV test when her child was getting “sick”. Mayi Ntchisi further stated that together with her husband decided to take the child to the hospital and all of them were tested for HIV at that hospital visit and the HIV test results were positive for all the three of them. “*And when he was seen, by then we had our blood tests too for HIV. They found the small animal of HIV in our bloods as well as the blood for him.*” The phrase “*as well as the blood for him*” referred to her husband blood for HIV test. After the HIV sero-positivity results, they were all commenced on ARVs and she ascertained it when she stated that “*when he was found with it, they told us to start receiving the medicines.*” The word “*medicines*” here referred to ARVs.

“At first, his body was always hot and coughing the cough and then in the house when we saw that, me and my husband together decided to take him to the hospital so that he could be seen well. And when he was seen by then we had our blood tests too for HIV. They tested for us about the disease that can be found in our bloods. They found the small animal of HIV in our bloods as well as the blood for him. The child's blood was bad with the HIV as well. When he was found with it, they told us to start receiving the medicines.”

Husbands' acceptance of HIV test

In this study, the majority of the husbands accepted to be tested HIV. For example, the husband of Mayi Muyeza accepted to be tested HIV during the time he was marrying his wife and when their child was getting sick frequently. However, Mayi Muyeza's husband knew that his wife was HIV positive during the pre-marriage HIV

testing period as Mayi Muyeza explained that she discovered that she was HIV positive when she just married her third husband. She stated that the second husband died of wounds that she called “*shingles*.” When she had just married her third husband they decided to take the HIV test. At the HIV test, she was found with “*the small animal*” and that her current husband was HIV negative. Mayi Muyeza also stated that “*but later when the child started being sick frequently, they decided to go to the hospital for HIV test for the child and for her father.*” The child was found with “*the small animal*” so too was her husband.

“The beginning of being sick me am the third person to be married to this man. For me to come here to marry this man I got married to another man and the marriage finished with that other man. And my first and second husbands died. The second one died and when he died, I did not go for testing HIV and he was just getting sick often and he had shingles. And we were just saying its wounds until he died. When I came here, we went for HIV testing and I was found with the small animal and he was found negative. Then he still said I will marry you although you have that problem. We took each other and we started having unprotected sex and we bore a first child who is four years old now. Then we went for HIV testing with her and she was found with the small animal and her father went for HIV testing and this time he was found with it. It means we gave each other the small animal. We have two children at the moment and she second one has six months. Then when we were at that point, we were put on education on how to care for the child with HIV and ourselves.”

Mayi Muyeza conceded that she gave the child and her husband “*the small animal*” although she did not put it straight forwardly but she stated that “*we gave each other the small animal*”. She very well knew that her husband was HIV negative at the beginning of their marriage and that it was obvious that she passed on HIV to her husband and the child. “*When we took each other he had the small animal test and it was not found in his blood then but in my blood it was found.*” Her husband knew that the lady he was marrying was HIV positive and that he was HIV negative and he still insisted to marry her despite the lady’s HIV sero-positivity status. They had the HIV test before he married the woman. “*When I came here, we went for HIV testing and I was found with the small animal and he was found negative. Then he still said I will marry you although you have that problem.*” The word “*problem*” here referred to HIV sero-positivity of his wife. Was that the typical example or situation where some people have commented that love is blind? The man also knew that he married a woman who had been married to many men before he married her and that all men had died. Mayi Muyeza explained it well “*for me to come here to marry this*

man I got married to another man and the marriage finished with that other man and my first and second husbands all died. The second one died and when he died, I did not go for testing HIV and he was just getting sick often and he had shingles.”

Husbands refusing to be tested HIV

However, some husbands refused to be tested for HIV and instead blamed their wives for bringing HIV in the house. For example, Mayi Zomba discovered that she has HIV during antenatal routine screening and told her husband about the HIV positive results but her husband was not happy and blamed her for bringing HIV in the family. He also refused to be tested for HIV instead; he accused his wife that *“she had brought the HIV in the family and not him.”*

“And we know that as adults, we got the HIV because of having sex without knowing each other’s HIV status and we gave HIV to the child who is innocent and this is a big sin to us parents. We just married each other without an HIV test. I was tested for HIV when I was pregnant and my husband refused to go for the test. He said he could not go for the test as he feels he is fine in his body and it means the disease has come in this house by you and you have given me the HIV. I did not refuse it because I have it and may God forgive me but if it is true that it is me who brought the disease in the house, then God must forgive you and me as well. Let us be staying though it is not smooth. He has now agreed that it might not be me who brought the HIV in the house but him as well.”

Mayi Zomba was conversant with HIV and AIDS issues because she narrated that it was a *“big sin”* to them as parents because they had unprotected sex without taking HIV test first. That act as she said made the child acquire HIV from them as parents and she further stated that the child was *“innocent.”* She also stated that her husband at first *“accused her”* of bringing the HIV in the family and *“he refused”* to take the HIV test. Mayi Zomba further explained that *“he still does not want to take the HIV test”* but had conceded that it may not be the wife who had brought *“the HIV in the family but him as well.”*

The above section has looked at the husband and their families’ decision making regarding HIV testing. Majority of the husbands decided to take the HIV test but minority decided to decline to take the HIV test. The section that follows looks at the delay in seeking diagnosis and treatment after the HIV testing.

Delay in seeking diagnosis and treatment

The majority of women caregivers had sought diagnosis and treatment late. They tested for other diseases first before the HIV testing that delayed the HIV and AIDS diagnosis.

Caregivers tested for other diseases first

A few of women caregivers discovered that they had HIV when they became ill and had sought hospital treatment where they were investigated for other diseases first. For instance, Mayi Bua explained that she was diagnosed HIV positive after she “*felt being sick*”. “*I saw that me I started being sick*. However, she further stated that she had other tests for other diseases such as TB tests first before she was tested for HIV to rule out other opportunistic infections such as Tuberculosis (TB) . Importantly, this testing was done during breastfeeding, when she could have been taking preventative measures to ensure she did not transfer HIV to her child.

“Me when I had taken the pregnancy for this child in 2004 at the beginning and at the end of 2004 this child was born on 18th August 2004 at Madisi Hospital. When he was born, I didn’t know anything and I continued breastfeeding him. Then I wondered in the middle of breastfeeding the child, I saw that me I started being sick. I was having malaria frequently, vomiting, and it was found out that the disease I was suffering from was like vomiting blood, and I saw that even the young child was suffering the same disease of vomiting blood. The child was vomiting blood the same diseases I was suffering from same diseases and on the same day. Then on my own thinking I decided to run to the hospital and when I reached there, I was given bottles for me to put in sputum for the big cough. And I gave the sputum for the big cough.”

Mayi Bua also expressed that her child was suffering from similar “*disease of vomiting blood*” just like her therefore; she decided to go to the hospital with the child. While at the hospital, she was “*given*” sputum containers for her to cough in sputum for tuberculosis screening at Dowa district hospital. “*...and when I reached there, I was given bottles for me to put in sputum for the big cough. And I gave the sputum for the big cough.*” The phrase “*big cough*” is the Malawian name for tuberculosis and it is referred to as “*Chifuwa cha chikulu*” in a local language of Chichewa. The name comes from the persistent coughing when one suffers from tuberculosis. Mayi Bua described that the “*big cough*” (TB) screening was done at Dowa district hospital although the sputum for TB screening were collected at

Mponela Rural Hospital because Mponela Rural Hospital being a small rural hospital did not have laboratory facilities for TB screening. She further stated that when the results had come, she had no tuberculosis and the hospital personnel asked her to have HIV test and she accepted. When she stated that *“the results told me”* she meant that the hospital personnel told her that she had no tuberculosis, but she had *‘the small animal of HIV:’*

“They sent the sputum to Dowa district hospital and the results told me that I had no big cough. Then I continued being sick from the same disease. Coughing up blood and the child was also coughing up blood. This time I was still breastfeeding him and I didn’t know what was happening. Then they told me that what is going to be done is for you to have your blood tested for HIV and when they tested my blood they found me with the small animal and the child was tested as well and the child was found with the small animal as well. They said because you are very weak, what we are going to do is that on Tuesday, come here early in the morning so that the ambulance takes you to Dowa District Hospital. After arriving at Dowa Hospital, they told me that we are not going to delay you. You must start lessons for HIV and AIDS. I did my first lessons.”

Mponela Rural Hospital is a small hospital and cannot handle seriously ill adult patients and therefore, Mayi Bua together with her child were referred to Dowa District Hospital for further management. At Mponela Rural Hospital they *“did not delay her”* because she *“was very weak”* and an ambulance was arranged to take her to Dowa district hospital where she was admitted together with her child. At Dowa district hospital, she was immediately started on a process of HIV and AIDS counselling as she put it: *“After arriving at Dowa Hospital, they told me that we are not going to delay you. You must start lessons for HIV and AIDS. I did my first lessons.”* Therefore, Mayi Bua started HIV and AIDS *“lessons”* as part of the process for the treatment for herself and that of her child.

There were a smaller number of women caregivers in this study who were tested during pregnancy but could not stop breastfeeding their children because they had no money to buy optional children foods such tinned children milk. This facilitated the transmission of HIV from the mother to the child through breast milk. Mayi F for instance stated

“she could not stop breastfeeding her child because she could not afford breast milk substitutes.”

“Yes, they told me to stop breast feeding my child because they said I could pass the small animal to the child but I could not manage it as I have no money to buy milk for the child from the grocery shops. It is very hard for us people that live in the villages to stop breast feeding the child even if we know that we should not do so.”

This section has have looked at women caregivers’ delayed HIV and AIDS diagnosis and treatment noting how they were diagnosed following the test of other diseases which delayed the treatment at the hospital. However, there were other reasons for delay, such as seeking the traditional healers’ services before seeking hospital treatment.

Seeking traditional healer’s services first before the hospital’s

Some caregivers sought help first from the traditional healers before seeking hospital care. Mayi Mpanda 3 for instance, stated that she discovered that she had HIV when the child was getting “*sick frequently*” and she decided to “*get help from the traditional healer first*” but she did not get the help that she desired.

“The child was getting sick frequently. He was getting his body very hot. If he wanted to eat food, he was vomiting. When he goes to school, I see that immediately, they bring him back and they tell me that the child’s body is hot and some people advised me to go the black medicine men I mean the traditional healers. People told me that I should go with the child to the traditional healer for help but to no avail.”

She described that later she realized that “*the traditional healer*” does not “*examine*” the patient very well as she put it; “*I tried very much there at the traditional healer but he could not tell me the truth about the illness of my child. I guess this is because at the traditional healer, they don’t examine the patient as it is at the hospital.*” Therefore, she “*saw*” the need to go to the hospital for proper “*examination*” of her child and for her examination too. She also wanted to hear the truth from the hospital.

“Then I saw that I needed to go to the hospital. I thought as a human being that mmmm I should go to the hospital. I am just delaying myself with the traditional healer’s medicines. Then I just put my child on my back and started off to Mponela Rural Hospital. When I arrived at the hospital, they told me that the book is full (the health passport book) with the same type of the disease. What is wrong with the child? And I said I don’t know that is why I have come here.”

When Mayi Mpanda 3 says “*the book*”, she is referring to the Malawi health passport. In Malawi, the government introduced the health passport where one’s conditions are described and one is expected to take and present his or her health

passport to the doctor or the nurse each time see them for continuity of care. Mayi Mpanda 3 however, described that at the hospital, the HIV test reagents were out of stock therefore, she decided not go back home without the HIV test for her and her child and she therefore went to “MAICC” where she described that she was also told that they had run out of the HIV test kits too. Mayi Mpanda 3 did “*not give up*” and decided to seek the HIV test from a private clinic called “*Banja La Mtsogolo (BLM)*” where she had the HIV test done and that the HIV test results were positive for both the child and herself.

“And they told me to go to MAICC. And then I went with him to MAICC and at MAICC they told me that equipment for blood testing is out of order. Then I thought mm I should not give up, I went to Banja La Mtsogolo (BLM) clinic at Mponela trading centre. When I went there, I was lucky as they tested him and me blood for HIV and he was found with the small animal. And they told me that we have found it with the child and we have found it with you as well.”

The HIV sero-positivity status of most of women caregivers in this study was not treated as a priority because they were only diagnosed HIV positive either because their children were sick or during routine screening at the antenatal clinic services. However, some women in this study did not seek hospital services first but traditional healer’s services that may have delayed the early diagnosis of HIV for their children. This is because most traditional healers live within the community and can easily be accessed and they are free of charge or one can be allowed to pay them at a later date which may not be paid at all as long as the service user tells the traditional healer that he/ she has no money. In some circumstances, the women caregivers were tested for other opportunistic infections first before the HIV test that took time and delayed the HIV and AIDS treatment in the process. Grandmothers who were looking after their HIV positive grandchildren had their ward diagnosed HIV late largely because they did not properly interpret the early signs and symptoms of HIV infection or they sought opinions from their peers too late as seen in the narratives discussed above.

The above section has looked at how and why women caregivers delayed the HIV and AIDS diagnosis and treatment through testing of other diseases first before testing for HIV and through seeking traditional healer’s medicine first before seeking hospital treatment. The following section looks at the husbands’ control of the family’s situations.

Husband's in control

Some of the women caregivers described that men were always in control of the women's situations. For example, Mayi Ntchisi was one of the caregivers who did not want to talk more about her experiences of caring for the child living with HIV and AIDS. Nevertheless, she stated that despite the fact that she cared for the child, the father of the child could have provided more information about the child and not her.

"His father can explain well because we were together and he knows much of the information than what I do know. He was the guardian too for the child but I was there as well. But the main guardian was his father. But I am the one who takes care of him. And I do go to the hospital to be receiving his medicines and not his father."

Here Mayi Ntchisi stated that her husband would be in a better position to provide information for the child and at the same time she conceded that she was the one who cared for the child including taking the child to the hospital was her responsibility too. However, she left it to her husband to take control of the situation when she stated that *"his father can explain well because we were together at the hospital and he knows much of the information than what I do know."* She again stated that *"he was the guardian too for the child but I was there as well."* This description showed that she was powerless to provide information despite being the one responsible for the caregiving to the child. This indicated that she wanted the husband to take a leading role because he was the head of her family. Here, it meant that her husband's voicing of the information would be seen as carrying more weight and authoritative than her. She also described that the *"main guardian"* at the hospital was the father of the child and yet she was the one who looking after the child. She agreed she was the one that provided the care *"but I am the one who takes care of him."* The care package included taking the child to the hospital and she stated *"and I do go to the hospital to be receiving his medicines and not his father."* When she stated that *"the medicines"* she referred to ARVs.

Three of our women caregivers described that they were under control of their husband and therefore could not speak more despite the fact that their husbands were not present during the interviews. Mayi F is one of the women who could not talk much and did not want to talk in details about issues involving her husband and herself. She however stated that her husband has not gone for HIV test and she

“cannot force” him to do so because he was her *“husband and needed to be respected.”* She did not know why *“he refuses”* to go for the HIV test and she remained quiet as a sign of respect of her husband. She confirmed he is *“my husband, I need to respect him.”* This statement also showed that the husband dictated issues in the family because the fact that she did not want to talk about issues that involve her husband, showed that she was submissive to her husband as the head of her family who needed respect. *“I cannot force him, he is my husband. I need to respect him.”*

“I did not think of taking the child to the hospital. My husband, no he did not think of it either. I don’t know really and up to now my husband has not gone for his HIV testing. He refuses to go. I cannot force him, he is my husband. I need to respect him. Those thoughts were too far from me and I don’t know whether it was being young or childishness, I don’t know. If I thought of that I could have tested for HIV when I was pregnant. These thoughts were far from me.”

When she stated that *“my husband did not think of it either”*, she referred to taking the child to the hospital for HIV test. She also knew that she could have been tested for HIV when she was pregnant. She attributed not doing so to her *“being young or being childish”* implying self-criticism. She again alluded that *“if she had thought about the HIV test,”* she could have done it when she was pregnant.

Another example was Mayi B who spoke very little about her husband. She described her husband as *“a drunkard”* and that *“he does not care about his family because the care that he gives is seen to be inadequate.”* She therefore stated that because of her husband being *“a drunkard, the life is a problem”* in her family.

“The life is a problem because my husband is a drunkard and the care that he gives is seen to be inadequate. My husband is like he is using the money for two families one it is me and the other is the beer that he drinks and he uses a good part of the money (salary) on beer. He drinks a lot of beer and that for him to care for the family is a big problem.” She states that she feels as if they were two wives to him because her husband *“likes using the money for two families, one it is me and the other is beer that he drinks and he uses a good part of his money (salary) on beer.”*

The words *“two families”* here referred to two wives. She concluded by stating that her husband *“likes beer”* more than her family when she said that *“he drinks a lot of beer and for him to care for the family is a big problem.”* That was the husband who did not want his wife to be involved in this research and the husband had to under a

counselling session with a qualified counsellor at the hospital. Later the wife withdrew from the study.

The above paragraphs have looked at the how husbands took control of the family's HIV and AIDS situations. The paragraphs that follow looks at the men denying responsibility in the HIV and AIDS situation

Men denying responsibility

A smaller number of our women caregiver in the study expressed the beliefs that their husbands refused to take responsibility for their family affairs. Mayi Dowa was one of them and she was still living with her husband at the time of the interviews, however, the marriage was not stable because of the HIV and AIDS in the family. Mayi Dowa and her child were HIV positive but her husband refused to go for the HIV test because he blamed the wife, who he believed had *"brought HIV in the family."* Mayi Dowa describes herself as *"worried"* about this situation.

"I was very worried and I can tell you right from the beginning when they found me with HIV when I was pregnant I was very worried. When I told my friend I mean my husband he said that is your problem it should not affect me. It is you who has brought this problem in this house. And he said you are the one who is HIV positive and not me. And even your child gets sick too often and the child must have the HIV too."

She described her husband response as suggesting that the child was not his child because he often stated that *"you are the one who is HIV positive and not me."* She stated that husband often blamed her for having *"brought" HIV in the family.* *"It is you who has brought this problem in this house and even your child gets sick too often and the child must have HIV too."* The phrase *"your child"* denoted that he sees the child as not his, but his wife's only. He distanced himself from the child because the child was HIV positive. This was one of many examples where men denied responsibility for infecting the family with HIV. Instead, they blamed their wives who were powerless about the whole situation.

"I said okay let it be and only God knows who brought this problem in the family. I was in a difficult period and I was really hurt and I hate that period. Until when the child was born, there was no peace in my family."

Mayi Dowa lamented that there was *"no peace in her family"* because the child and herself were HIV positive. She stated that *"she hated that time (during pregnancy)"*

she discovered that she was HIV positive because her husband traumatized her psychologically, up until the child was born. Her husband did not want to be tested for HIV. The above paragraphs have showed that men were denying responsibility about HIV and AIDS situation in the family. The paragraph that follows shows how women caregivers were powerless to prevent risky behaviour in relation to HIV and AIDS because of the husband's denying responsibility.

Women powerless to prevent risky behaviour

A number of our women caregivers described the risky health behaviour that their men were indulged in and they were powerless to prevent them. Mayi Lilongwe for instance stated that the child living with HIV and AIDS was HIV negative when she was born, because she was negative during her pregnancy: *"this child was born when I was HIV negative. I did not have the small animal and yet he has the small animal of HIV."* She believes that the child got HIV from his father because the child was a *"loved boy"* of her husband and whatever her husband was doing he involved the child including *"sharing razor blades."*

"Look now; this child was a love boy of his father so much that they used to go anywhere together sharing everything together including razor blades." She *"believed"* that the child got *"the small animal"* from his father as they used to *"share razor blades"* and that was what she said *"his father used to shave him using his razors which he has been using to shave for himself."*

Mayi Lilongwe explained in details of what was happening between her husband and the child. She stated that when her husband had just finished shaving his beard, she could see him use the *"same razor blades"* cutting *"the child's finger nails"* but she was powerless to stop him. *"I did not do anything to stop him doing what he was doing and in the end the child has HIV and AIDS now."* She meant that she could not do anything at all as she felt powerless before her husband. In Malawi culture it is rare that married women could confront their husband because it is unacceptable to challenge her husband; women are supposed to be submissive to their husbands as the head of their respective families.

"Look now; this child was a love boy of his father so much that they used to go anywhere together sharing everything together including razor blades. His father used to shave him using his razors which he has been using to shave for himself. Whatever his father was using like food they would eat together or razor he used to cut his finger nails, he would use the same for the child. I believe this is how he got the small animal of HIV from his father. He was born without the small animal and I

tested him when he was 6 years old and when he was 8 years old again and he did not have the small animal. But in 2010 it's when I noted that he was getting sick often and I went with him for HIV testing as I told you and he was found to be HIV positive, he has the small animal. What was happening is that the razor he had used to shave his beards, he was using the same razor to cut short the child's finger nails and even shaving his hair. I did not do anything to stop him doing what he was doing and in the end the child has HIV and AIDS now."

How the child contracted the HIV was not known and this was her explanation of events. The above paragraphs have showed how husbands denied responsibility about HIV and AIDS in their families. The paragraph that follows shows how only one husband was supporting this wife in the event of HIV and AIDS in the family.

Supportive husband

In this study, only one woman caregiver described having a supportive husband and she was Mayi Mpanda 3. Mayi Mpanda 3, the child and her husband were all living with HIV and AIDS and they were all on ARVs regimen. She confirmed it when she stated that *"the whole family is on medicines of ARVs."* Her husband was supportive and that was shown in her statement;

"when I told my husband, he told me that do not worry; the most important thing is that we should be on medicines." She did not talk any more about her husband.

"When I told my husband, he told me that don't worry the most important thing is that we should be on medicines. The medicines for me and the child were started the same last year 2010. We all started together at the same time. For me it took 8 months when I was receiving them and the 9th month it is when I started receiving for him as well after I had gone through his training on the ARVs and the care at Mponela hospital. The whole family is on medicines of ARVs."

When the husband talks of the *"medicines"* he refers to ARVs and she states that *"we all stated together at the same time."* And she further states that the *"whole family is on the medicines of ARVs."* Male dominance and complex life styles were well described by the women caregivers. Males were involved in high risk behaviours such as marrying an HIV infected lady while they are HIV negative, getting involved in polygamous relationships and yet they are already HIV positive and on ARVs. These behaviours complicated the care and support our women caregivers were getting from their husbands. Majority of husbands did not give adequate support to their wives during the caring process except one husband who was supportive. The section that follows looks at the male dominance and their complex life styles in families.

Male dominance and their complex life styles in families

As seen in the previous sections of this study, women caregivers often appeared to be under the control of their husbands. Within Malawi, married women still experience male dominance because of cultural prescriptions that demand that a man is the head of the family and therefore, dictates all family affairs. Married women therefore, may have little or no say on matters affecting their lives and before a woman makes a decision that affects her life, she must seek approval of her husband. For example if the woman wants to take an HIV test, she may require asking her husband for permission. These behaviours may be covert or public. This can be seen in the stories these women told about the care that they give to children living with HIV and AIDS in rural Malawi. Most of the women interviewed were reluctant to talk more about issues involving them and their husbands as a result, they talked less. The paragraph that follows looks at the complex life style in a polygamous marriage, presented as a case study of one family.

Complex life style in a polygamous marriage: a case study

In this study, a small number of women were in polygamous marriages and they explained that their husbands lead complex life styles because of the polygamous marriages. For example, Mayi Kasangadzi 4 narrated that she had marital problems with her husband, which she attributed to her husband having three wives and did not care much about her. Mayi Kasangadzi 4 tried “*separation*” on several occasions to help sort out their marital problems but to no avail as she stated that “*by then we were on separation.*” Her husband was HIV positive and on ARVs too but she believed he was not concerned about his HIV status or the possibility that he might have been infecting other women in the polygamous marriage because he continued to marry other women.

Although she was his wife, she believed that she had no say about the situation, instead she remained quiet and struggled alone looking after two children who are HIV negative and their child living with HIV and AIDS. Mayi Kasangadzi tried to reach her husband during the period they were on “*separation*” so that he could assist her with money to take care of their child living with HIV and AIDS. She contended that the care that she needed help with was “*transport*” money to go to the hospital with the child as she put it “*at home I had problems with transport.*” She

failed to contact her husband because she “lost his telephone number” and also found out that her husband “had changed his telephone numbers.” She described feeling helpless and powerless.

“By then we were on separation. At home I had problems with transport as I told them. I had nothing to do on the transport part I could not reach her father I lost his telephone number and he changed the number as well I had no one to help me.”

Mayi Kasangadzi 4 noted that her child living with HIV and AIDS was getting sicker by each passing day; she decided to seek help from her father in law because she needed to take the child to the hospital. She explained that her father in law, who she described as ‘the grandfather of the child,’ gave her K200.00 (50 pence) for “transport” to take the child to the hospital.

“I thought of the grandfather of the child who was staying in the same village. I went to the grandfather with the documents from the hospital where they had written about the history of my child’s illness. I showed the grandfather of the child all that and when he had seen them I thought maybe he could have helped me. This grandfather was from the father’s side of the child. When the grandfather had seen the child he helped me with transport money worth K200 so that I could go to the hospital. Then the following day I went to the hospital and they gave me medicines for the other diseases because they could not start the ARVs medicines because she was very weak.”

However, “by chance” Mayi Kasangadzi 4 was able to track down her husband because she her husband was attending “the marriage engagement ceremony” of her brother in law at a nearby hall and she knew that her husband would be attending the that family function and she seized the opportunity to talk to her husband about the problems she was facing when caring the child who has HIV and AIDS. Mayi Kasangadzi 4 decided to present in a different way to her husband by grooming herself well. “I got ready, I bathed well.”

“When I went back home, by chance there was marriage engagement of the son to my grandfather who is the brother of my husband. And when her father (her husband) heard that there was marriage engagement, he left his home at Mponela where he was staying, and he came to Lilongwe. When I realised that the father of the child would not miss to go there at the engagement, I got ready, I bathed well and I went to the hall where the function of engagement was taking place and my objective was to meet the father of the child. By then I left the child at home because the child was not well and I wanted to tell him about how the child was and what the hospital nurse had told me about the life of my child. Luckily enough when I reached at the hall, I met the father of my child and I told him that I wanted to talk to you.”

Finally she managed to meet her husband at the marriage engagement ceremony. At first during the discussions, her husband did not show any “remorse” about passing HIV onto their child. As Mayi Kasangadzi 4 continued discussing the child’s condition and the problems that she was facing with her husband; her husband then became ‘concerned.’

“He didn’t show any remorse when I started discussing with him the child’s condition when we were inside the hall. Then we went outside and discussed that I wanted you the child is not well. I have been going to the hospital with the child on several occasions. But the child has been found with the small animal of HIV that starts AIDS. But now, the child is very weak and when he heard it he was concerned and we left by the car of his relative from the hall to go to the house to see the child.”

After discussing it, they left for the house where the child was. Upon arriving, the husband “carried the child in his hands and started crying.” Then he asked for all the hospital documents and he looked at them. Then they went to the market where he had “bought food items that the child liked most such as rice, spaghetti, meat and vegetables.”

“At home, when the father had seen the child, he started shedding tears. He started crying and he picked up the child in his hands and continued crying. And then within a short time he said give me all the books from the hospital so that I should see them. I gave him together with the x-ray film and he saw them all as I told you that he had gone to school as he is a civil servant, and he saw that the child was HIV positive and is not well and the way the child was appearing was very sick. Then he asked me what he child was eating? This child is eating food that is rice only and the rice should be with meat, “supergate” (spaghetti) or with beans with that it’s when she eats. But if I have no money and I have just cooked vegetables only, or with beans and nsima, this child can stay for two days without eating. Or if I cook Irish potatoes just boiling them or make chips then she will eat them.”

Then her husband arranged that the child be admitted at Mponela Rural Hospital, close to him so that he could help well. He asked his wife to pack her items and followed him to Mponela Rural Hospital the following day. That was how she found herself back to her husband but still the husband has other two wives to take care of.

“Then the father of the child was very kind when he saw that the child was very sick and he knew that if I had gone to the hospital she was going to be admitted. As I am telling you that his job he is supposed to be staying at Mponela, then he told me that as the situation is right now, this child will be admitted so you need to come to Mponela Rural Hospital because as you know my job if she gets admitted at Kamuzu Central Hospital, I will have problems coming to see her. Here is the money for you to catch the bus tomorrow morning with the child come to Mponela. Get prepared,

pack all your items and come to Mponela Rural Hospital and I will take all the books for the child and I will give them to the big doctor at Mponela Rural Hospital. What I want is when you arrive at Mponela Rural Hospital; he should know where to start from so that the child is assisted quickly and properly.”

Mayi Kasangadzi 4 described that she was “*the first wife*” but her husband had other two wives that she described as being “*below her.*” She believed that a man with “*three wives*” may not adequately be able to take care of all the needs of each wife and therefore, there were many problems associated with polygamy. She also believed that “*there are few men who could properly take care of many wives in a polygamous situation like hers.*” She contended that “*such type of men cannot exceed the number ten.*” They are rare.

“I can say that am the first wife but there are other two below me and that means we are three wives and I can say that as you know in the family when a man has many wives, things are a problem. There are very few men who can manage to care for all the women in the same way, may be such type of men cannot exceed the number of ten. And for me I can say that I meet a lot of problems for the child because sometimes I can be upset by my husband. And if it like that I think too much of such things and it leads to me to forget to give medicines to my child because her father has disappointed me or because her father has slept outside and not at my house. So things like these make me fell upset sometimes.”

She pleaded that “*if possible her husband should understand the situation she was in*” and divorced other two wives because he had no children with them. She wished her husband could have concentrated on caring for his children and her alone. She found it hard to take the child to the hospital at night alone. That was why she wished her husband was always at home so that he could help out quickly when the child got very sick at night. She had the belief in her husband that he was capable of helping out when the child was sick at any time of the day. She was also disturbed with her husband’s behaviour to extent that she “*forgot*” to give medicines to the child.

“And for me I can say that I meet a lot of problems for the child because sometimes I can be upset by my husband.” She concluded by stating that “*let him leave the other two wives and he should remain with me alone because of the problems that are in this house, I think that can help a lot in caring for the child.*”

“Me if it’s possible my husband should understand the situation at hand because to the other two wives there are no children. If God can enter in his heart and he should leave the other two wives and remain with me only so that together we can care for the children very well I think that can be good for the children. But so that we can be staying together on daily basis in our house so that we see the child while we are all

together and that when she is sick we can help her well and that if she wants anything in her life, her father should be there with me as am the mother of his children. Let us say the child is sick in the middle of the night and her father is at the other wife's house, it is difficult for me alone to handle such situations but with him around it could be easier. Let him leave the other two wives and he should remain with me alone because of the problems that are in this house, I think that can help a lot in caring for the child.

Conclusion of the chapter

This chapter has discussed women caregivers who were living in very poor rural areas of Malawi where accessibility was difficult. These women caregivers were controlled by husbands who were regarded as heads of their families. This is what tradition demands in Malawi and women caregivers stated that disobeying the husband decisions would seem undermining his authority and it was not acceptable in their tradition. This chapter has also discussed how women caregivers discovered their HIV and AIDS status and that their health related decisions were usually influenced by the health status of others, such as their child getting sick frequently and it is when they decided to seek nursing and medical services in their areas. The discussion has also focuses on a women caregiver who sought traditional medicine first before hospital treatment and this delayed the child's HIV and AIDS diagnosis and consequently, delayed the treatment too. Issues of gender affected their experiences have been discussed and that women had to seek their husbands permission to take an HIV test. Husbands frequently took control of the family's HIV and AIDS situations, but also dominated family affairs by complex life styles and denying responsibility and also men denied responsibility of bringing HIV and AIDS in the family and they pushed the blame to their wives. The Chapter that follows looks at the women caregivers' experiences of HIV and AIDS disclosure and whether they experienced stigma or discrimination.

Chapter 7

HIV and AIDS disclosure and stigma

Introduction

In the previous chapter, the discussion was on how women caregivers discover their HIV status and their experience of diagnosis and in this chapter, the discussion will dwell on HIV and AIDS disclosure and stigma. HIV and AIDS disclosure is a very important step towards HIV prevention and control because if individuals disclose their HIV status, they may have accepted to live positively with it and therefore can help prevent its spread. However, not every individual may be willing to go for HIV test and even if he or she does, that person may not disclose especially when the results are HIV positive. This is because in Malawi HIV is associated with a negative connotation of promiscuity. The women caregivers interviewed in this study described in the following narratives the difficulty of disclosure and the decisions they made about who to trust. The discussion will on disclosure decisions: keeping secrets and who to trust; secrecy, fear and shame; managing disclosure, making judgements and fearing repercussions; who they disclosed to; impact of disclosure and culture of silence and mistrust in marriages.

Disclosure decisions: Keeping secrets and who to trust?

In this study, two of women caregivers explained that it was hard to “*trust anyone with HIV information*” because HIV and AIDS were a shameful disease. Mayi Mpanda 2 for instance stated that she had not told anyone that her child was HIV positive apart from her sister. She told her elder sister because she “*keeps secrets.*” She added that she could not tell other people because she could “*not trust*” them with such information. She confirms this when she states that “*and one cannot trust another person on such illness.*” The phrase “*such illness*” refers to HIV and AIDS. “*Aaaa, there is nothing that they say. Because they don’t know that the child has HIV and me too they don’t know it either. Yes, they will be surprised. (Laughter showing that she was happy) there I will tell them that that one is the doctor for the child who sees him at the hospital. Yes, my elder sister knows about it that he has HIV. I told her because she can keep his secret for me and my child because other people would not keep it. And one cannot trust another person on such illness. The other person would be telling other people all over the village and it’s not good at*

all. When everyone, it is a shameful thing that everyone should know that I am HIV positive and also that my son is HIV positive. It's not good and very shameful. And also there may be other people who are HIV positive but are not known by the public why should I go public. In short it's a shameful thing to tell people that you are HIV positive."

She also stated that there were "other people" who are HIV positive but they have not told anybody. She explained that "it is a shameful thing" to tell other people about HIV serostatus because as earlier on discussed, HIV and AIDS in Malawi is associated with promiscuity and she did not want to be "labelled" as a prostitute. The paragraphs that follow look at the secrecy, fear and shame in relation to the child's HIV and AIDS status.

Secrecy, fear and shame

A smaller number of women caregivers explained that HIV was a secretive issue and a shameful one too. Mayi Mpanda 2 for example stated that stigma had never happened to her but she pointed out it was because she had not told anyone of her HIV status. She said that it was "a shameful thing" to tell someone that she was HIV positive. She stated that it was a "shameful thing" because of "the way one gets it through sexual intercourse." Therefore, it is not just that it implies promiscuity, but also the mode of transmission that is stigmatising about HIV and AIDS.

"One gets ashamed with it. (Silence for 2 minutes here) It's different from malaria. This HIV disease is really different because of the way one gets it through sexual intercourse and it's a shameful thing that people should know it and they will be saying eee that one likes sexual intercourse and look she got the HIV and again, many people will be running away from you. I mean segregating you they don't want to eat nsima with you from same plate, not sitting on the same mat and so forth."

She further stated that because HIV was a sexually transmitted infection, and if people knew that she had it, "they would be running away from her" and they "would be saying eee that one likes sexual intercourse and look she has got the HIV." She further described that people would not be "eating nsima with her from the same plate and they would not sit with her on the same mat and so forth." This was one example of incorrect information about HIV mode of transmission that still potentially existed in the community. Mayi Mpanda 2 was quick to mention that stigma had never happened to her but "she just thinks may be it could occur." "No,

it has never occurred to me I just think that may be it can occur to me in future when people get to know they may start segregating me. I think I will not do anything. I will just look at them.”

In this study, one of the two women, Mayi Kasangadzi 4, who did not trust anyone and she felt that HIV and AIDS were a shameful disease and she stated that she was “*ashamed*” of her HIV positive child because the child’s hair was like she “*poured medicines*” on it. The child’s “*abdomen was thin and she could count the ribs*” of her child. She summarises that she was “*ashamed of how the child was looking.*” She describes that her child was “*very thin.*”

“It took me time for me to settle because I was ashamed that my child was HIV positive. The hair of my child was like I had poured medicines (the hair was pale) and the abdomen of my child was very thin and one would count the ribs and I was very ashamed because of how the child was looking. She was very thin.”

Mayi Kasangadzi 4 felt ashamed because she felt responsible for her child being HIV positive and she was careless when she was pregnant for this child and hence she felt she was not a good mother. “*I was ashamed that my child was HIV positive.*”

May Kasangadzi 4 further described that “*she could not bath her child in public such as outside the house because she was ashamed of the way the child was looking like.*” She added that “*some of her friends could come to her house*” with the intention to support her but she knew that they were visiting her in “*bad faith.*” She stated that they “*were scorning*” her child. She described her child as “*looked like a ghost.*” She further stated that other people could go to her house “*deliberately*” and “*ask to see the child*” with the intention of just “*looking*” at the child. She knew that such people were coming to her house “*not in good faith but to laugh*” at her child. She ascertained that she did not like such behaviours and she was “*worried and not happy*” about them.

“I could not bath my child in public like outside I was very ashamed. In addition I was with my friends who were scorning at my child that she looked like a ghost. And these people would come home deliberately with the intention to see the child but in bad faith. And they would ask where is the child with the aim to see how my child was looking like. And I knew that these people were not coming in good faith but to come and laugh at my child. I didn’t like these issues and I was worried and not happy.”

She also stated that her child “*was refusing to eat*” and that contributed to the child being “*thin*” and made her be “*ashamed too.*” She ascertained this when she stated that “*but the other major thing was that my child was refusing to eat and she could stay for three days without eating as a result, she became thin.*” Nevertheless, there was one family that used to “*help her.*” She stated that “*God should bless that family.*” The only source of “*worry*” was those people who ridiculed her child. She confirmed this when she stated that “*It was like my child was for a show to other people and I didn’t like it. It was like they were coming to laugh at my child and I didn’t like it at all. One would count the child’s ribs.*” Therefore she felt bad about it and she thought that she had failed to take care of her child properly and hence her peers would be laughing at her. She also continued to narrate that her child was “*refusing to eat.*”

“But the other major thing was that my child was refusing to eat and she could stay for three days without eating as a result, she became thin. However there was one family that was helping me when I ask things from them till today I put that family in the hands of God so that God should bless that family. That family was helping with ndiwo, transport money to go to the hospital or salt. About the worry of my child, it was people who were coming to see my child and not necessarily my child. It was like my child was for a show to other people and I didn’t like it. It was like they were coming to laugh at my child and I didn’t like it at all.”

Having looked at the secrecy, fear and shame in relation to the child’s HIV and AIDS status, the paragraphs that follow look at managing disclosure, making judgements and fearing repercussions.

Managing disclosure, making judgements and fearing repercussions

In this study, one of the women caregivers made judgement before disclosing her HIV status and that of her child to others. Mayi Kasangadzi feared the repercussions from disclosure and she stated that “*there are some people*” that she did not want to know that her child has “*the small animal.*” She expressed that she did not trust other people on the issue of HIV positive status disclosure because “*they don’t keep stories to themselves.*” She further emphasized that “*the whole area would know that her child has the small animal and it is not good for the child.*” Here caregivers were managing disclosure on the basis of who is trustworthy.

“Me I can say that not that people should not know but sometimes there are different people. There is a person who you can tell the story and will keep to himself or herself

and there is another person who will tell everyone in the area and you don't want that sort of a person to know. As my child is young but will be growing and I do have the hope that one day I want my child to work anywhere (laughter here she was happy) I have the hope that my child will finish her school and will work and if I tell anyone else and when the child grows people will be telling her that you have HIV that starts AIDS I think that is not good for the child. The child will not have peace in her mind and will not be free to associate with her friends.

She further added that it was not good for the child if everyone knew that she had HIV because the child was “*still growing*” and she would want her child to “*work anywhere*” when she grew up. Here Mayi Kasangadzi was happy as she narrated this story while “*laughing*.” She further explained that the child “*will not have peace*” in mind when she has grown if everyone knows that the child has “*HIV that starts AIDS*.” This may result into “*the child not freely associating with her friends*.” Here she implied that being HIV positive could restrict her child's life in the future and that could have an implication in the child's social life such as securing a gainful employment.

Happy to disclose, stigma an issue of the past

However a smaller number of women caregivers such as Mayi Mpanda 3 stated that stigma was the thing of the past. It does “*not occur*” anymore. She stated that there was no segregation.

“Aaa to say he should not play with his friends because he is HIV positive? It does not occur here.” “There is no segregation here. Aaaa to say he should not play with friends because he is HIV positive? No it does not occur. Maybe long long time ago when HIV and AIDS had just started one would say it occurred but now it is just like any other illness. Here in this area, I have never seen segregation behaviours because one has HIV and AIDS maybe we could be seeing it later on in future. But as of now people don't do that we chat we eat together we work just like any other person, so why segregation?”

She added that in her area “*she had never seen segregation behaviours against HIV and AIDS people*.” She also casted doubts whether stigma would occur in future when she stated that “*maybe we could be seeing it later on in future*.” She emphasized that “*but as of now, no, people don't do that we chat, we eat together, we work just like any other person, so why segregation?*” when she states that “*we work just like any other person*” she was referring to the fact that she was well both physically and psychologically and that she worked just like any other person who

was HIV negative and that there was no difference between her and a person who was HIV negative. Women caregivers had different attitudes about HIV. Some took it as just like any other disease and were open to tell anyone who asked them about it while others felt it was a shameful disease and they chose who to tell.

Who they disclosed to

So who did women caregivers disclose their HIV and AIDS and that of their sick children to? Some described having an 'open policy' on HIV and AIDS.

Open policy

Two of the women caregivers described that they had an open policy of telling anybody who asked them about their HIV and AIDS. Mayi Bua explained that she *“did not hide it”* and she *“tells everybody”* who asked her about HIV and AIDS. And *“I tell everybody that I have HIV.”* She was also aware that at one time she may *“suffer from AIDS”* as she described that *“and I may suffer from AIDS any time.”* She stated that she told anyone who asked her that *“she went for an HIV test and they had found her with the small animal.”* When she states *“the small animal”* she referred to HIV. However, she stated that *“since she started ARVs till then, the disease that I suffered now was malaria only and I don't suffer from any other disease.”* She was proud of herself when she compared with those who were HIV negative. She also explained in addition to self-disclosure, she would also tell anyone who asked her about her child's HIV positive status. *“And my child is on the ARVs too. I tell them this.”*

“I don't hide it. I tell everybody that I have HIV and I may suffer from AIDS any time. I told them that I went for the HIV testing and they found me with the small animal. When you see me and my child being sick it is because we were found with the small animal. But since I started the ARVs and till now the disease that I suffer now is malaria only and I don't suffer from any other disease. And my child is on the ARVs too. I tell them this. Just like any other person who gets sick from malaria. I may be different to those who are HIV negative because I don't get sick too often.”

She attributed the change in behaviour of being stigmatized against having HIV and AIDS by other people to her being open to them about HIV and AIDS. She told them that she and her child are HIV positive. She told other people that *“when you see me*

being sick it because I was found with the small animal.” She further stated that the very same people have turned around and praise her. *“It’s when they say look now the person we use to scorn at is fine and working just like us. Now she is strong and works hard more than us really. And look now she has her food in her house more than us.”* However, the disclosure was limited to certain members of the family or society. The paragraph that follows looks at the limited disclosure to immediate family members only.

Limited disclosure to immediate family members

The Majority of women caregivers disclosed their HIV positive status only to very close relatives and hospital personnel. Six of our women caregivers disclosed their HIV status and that of their child to their close relatives such as family members. Mayi Dedza is one of the women caregivers who disclosed to her mother and her uncle that the child had *“the small animal”* because she wanted to be helped when the child got *“sick.”* *“It is because he could be very sick and then we take him to the hospital and he could be wondering what has he eaten but he should know that it’s the same disease.”* When she says that *“it’s the same disease,”* she was referring to HIV and AIDS. She further states that *“she did not tell anybody”* in her area including her village headman because as she put it *“they don’t keep secrets.”* *“It is because today’s chiefs will be telling everybody that that child has the small animal and I did not want that to happen to my child.”* She wanted only her close relatives to know about because she did not want her son to be stigmatized when she plays with other children and this was how she narrated it:

“I don’t want his fellow children to segregate him.” “My mother and the owner of that house do help me at times. (She pointed the house where I had parked the car.) He is my uncle. It is because he could be very sick and then we take him to the hospital and he could be wondering what has he eaten but he should know that it’s the same disease. I did not tell anybody in this area. It is only him my uncle. It is because today’s chiefs will be telling everybody that that child has the small animal and I did not want that to happen to my child. I don’t want his fellow children to segregate him. Yes, it can occur based on the life of today. They could be segregating him that he has the small animal he has the small animal don’t play him. No, he does not know as he is still young. No, his brother does not know about it as he is still young too.”

She further explained that the stigma “*could occur based on the life of today.*” When she states that “*the life of today*” she meant that life was different from the time she was young. How different, she did not expound her thinking.

Mayi Kasangadzi 4 was another woman caregiver who disclosed to her close relatives about the child’s HIV and AIDS status. She stated that she told her relatives who were “*living in Lilongwe*” because when she was admitted with the child, they were visiting her and therefore she told them about the child’s HIV status. She further explained that she disclosed it to her relatives for her to “*reduce stress in her mind*” and also they encouraged her and the child to start the ARVs regimen. She again emphasized that she wanted her relatives to know about it so that they knew what the child was suffering from.

“My relatives are in Lilongwe they know it because when I was admitted at the hospital they came and I told them. I told them to reduce my stress in my mind and they encouraged me not to worry as she has started the ARVs. They should also know that our relative has a child and the child is so and so. That the child is touched by HIV and AIDS.”

After disclosing to immediate family members only, women caregivers also disclosed to key people in the societies.

Focussed disclosure to key people

A smaller number of our women caregivers disclosed their child’s HIV status and theirs to the village headmen of their respective villages for various reasons. For example, Mayi Lusa stated that she told the village headman that the child was “*HIV positive*” because the village headman was “*a big person.*” The word “*a big person*” implies that the village headman was a well-respected figure in the village and it was a way of respect. “*In this village only the village headman knows that he is HIV positive so that he knows as he is a big person.*” She told “*a big person*” because if the child had fallen sick she would inform him for help. She further indicated that if the child “*failed*” she would have nowhere to go and report. Here the word “*fail*” referred to when the child dies. Tradition in Malawi has it that when a person dies in a village, that dead person ceases to be a property of the family but the entire village under the leadership of the village headman.

“In this village only the village headman knows that he is HIV positive so that he knows as he is a big person. May be sometimes he can be very sick at night and or he may only “fail” where to go if such things appear to you if you did not tell the chief. Even my own friends do not know about it. Nobody knows about even his friends they just play with him without knowing that he is HIV positive. As you know the life in the village that it’s a difficult one some can put so many things. Let us say if he wants to play with friends, they would be mocking him that this one has a small animal don’t play with him and that is not good because we are killing his freedom.”

She further stated that she did not tell anybody in her village including “her own friends.” except the village headman. She added that “the boy’s friends just play with him without knowing that he is HIV positive.” She also described that “life in the village is a difficult one.” She extended her story by stating that if her son goes “playing with friends” and if the son’s friends knew that he was HIV positive, “they would be mocking him.” “Let us say if he wants to play with friends, they would be mocking him that this one has a small animal don’t play with him and that is not good because we are killing his freedom.”

Here, the Mayi Kasangadzi 4 had a strong sense of protecting her child. Women caregivers explained that they disclosed to hospital personnel especially nurses. Mayi Kasangadzi 4 for example stated that she “told” nurses at Mponela Rural Hospital first because

“they were the ones helping her child.” “me I can say that the nurses here at Mponela Rural Hospital were aware, and they are the ones who helped me that the child should start the medicines. So I can tell you that nurses here at Mponela Rural Hospital are aware of my child’s situation.”

She stated that “some of Seventh Day Adventist church members know that the child has “the small animal.” She added that only women church members knew that her child had “the small animal” because “they could be encouraging each other in prayers.”

“That is why I don’t just tell anybody but to those people I pray with at Seventh Day Adventist church some of them know here at Mponela. I tell them as my fellow women so that we could be encouraging each other in prayers.”

The above section has looked at who they disclosed to, the section that follows looks at the impact of the women caregivers of their disclosure of HIV and AIDS status.

Impact of disclosure

The section that follows looks at the impact of HIV and AIDS disclosure. The discussion will be on acceptance: times have changed, experiencing stigma and discrimination, the already dead people, close relative refusing to take care of a child living with HIV and AIDS and subtle stigma.

Acceptance: Times have changed

Only one of our women caregivers felt that times had changed and therefore there was no stigma associated with their diagnosis. Mayi Ntchisi stated that she had never experienced any stigma and there was “*no such a thing in her area.*” She attributed lack of stigma behaviour in her area to the fact that people now knew that HIV could affect anybody and therefore, “*there is no need to laugh at each other.*”

“No there is no such a thing in this area. This is because people now know that HIV can affect anybody and therefore, there is no need to laugh at each other. But when HIV just started, some people were talking bad for the one with HIV and they would say, look at him or her he is a walking dead person and any time he is going to die. Don't be with that person as he or she will give you AIDS. But now people know the truth about HIV that it does not spread through casual contact but through sexual intercourse. There is love everywhere now as they know that HIV can touch anyone.”

Experiencing stigma and discrimination

However, majority of women caregivers felt that they were shunned because their child they were looking after was HIV positive. Mayi Lusa was one of them and she admitted that her child had never experienced any stigma but she pointed out that there were possibilities that the child might be “*mocked by friends*” when “*playing*” with them. She emphasised that it had been happening before. She coined that “*let us say if he wants to play with friends, they would be mocking him that this one has a small animal don't play with him and that is not good because we are killing his freedom.*” She further confirmed that stigma existed before, “*ooh yes, this behaviour still exists.*” However, Mayi Lusa was not very sure if stigma did really exist although she confirmed it did occur. This was because she later stated that “*there are signs that this type of speaking*” occurred and she had never experienced

it herself. She thought some mocked people living with HIV and AIDS saying that *“even if you work hard, it will not help you.”*

“There are signs that this type of speaking and others even say aaa you people with the small animal even though you work hard, it will not help you at all. We just say okay, each one should concentrate on his side of the story. If you don’t have that is your chance. Let us be like the way we are maybe it’s our bad luck as I am also touched and his father is also touched with the small animal. We see that in our house there is nothing that disappoints us. We just stay the way any other person can stay.”

Nevertheless, Mayi Lusa described that she was not concerned with such type of people and she *“just said okay”* let us be like the way we are, maybe it’s our bad luck as I am also touched and his father is also touched with *“the small animal.”* It was difficult to tell if Mayi Lusa had experienced stigma as she did not clearly state it. Having looked at the experiencing of stigma and discrimination, the paragraph that follows looks at another form of stigma-the already dead people.

The already dead people

In our study, one woman caregiver described that some people who were HIV negative labelled her and her child as already dead people. Mayi Bua stated that she experienced stigma when she had just been diagnosed with HIV. She said that people used to tell her and her child that *“they were already dead people”* and she further explained that those without HIV *“were dying leaving her and her child behind.”* She felt *“puzzled”* as to why people who were HIV negative were *“dying leaving her and her child”* who was told that *“they were already dead people.”*

“I don’t know why but it’s because of bad life because they say me and my child were already dead people we are just waiting for the time. And what is puzzling us is that those who have no HIV are dying leaving us behind, me and my child.”

She also explained that she did not mind them and she did not *“take the issue far”* but she left everything in *“the hands of God.”* She explained that she wished to have reported them to *“police or to hospital”* authorities about it.

“Aaa me I just leave it in the hands of God and I have never gone far with it but I wish to do with it somewhere far. I wish to go to the government to report it. Like at the police, or at the hospital to tell them that some people are scorning us, are

despising us. But I have noted that the people who were saying those things have now changed. But they don't give us any help."

She added that she had *"noted that people who were saying those things have now changed."* She further stated that people used to say many things to them

"Because me and my child have AIDS and there are many things that they were saying to me and my child. Like don't be with them don't stay together with them they will give you HIV and AIDS. Don't eat with them together. These people are AIDS people they will give you AIDS. Now they have changed because they are now coming to my house and be chatting with me and my child. And I just stay together me and my child."

Close relative refusing to take care of a child living with HIV and AIDS

A smaller number of our women caregivers explained that they were left with a responsibility of looking after child living with HIV and AIDS because the close relatives disowned them. For example, Mayi Kasungu was an old lady looking after her niece. She was over 70s at the time of the interviews. She explained that she was taking care of the child because her relatives from maternal side refused to take her as the child was considered by them as a *"dead girl"* because she had HIV and therefore disowned. However, She continued to state that they took the rest of the children because they were HIV negative

"but the 3rd one has the small animal and they don't know it." "She was my sister in law. My brother married her. When her husband who was working at the hospital died, she married my brother. When she married my brother, I wondered saying my brother, your first child with this woman has no HIV and your second child has the HIV, what is happening? The 3rd one has the HIV and the 4th one had the HIV but died. The other children are not with me, no, their mother's side refused us to take them here. They live at Dowa Boma area where she was coming from. So they only asked us to take child because they know that she is HIV positive and they say she is a dead girl."

Subtle stigma-don't lend, shun them

A smaller number of our women caregivers described that they were denied anything in their community including borrowing items from their neighbours. Mayi Muyeza was one of them and stated that she had experienced stigma behaviours during her caregiving experience of her child. *"Ooh yes, it was there and it appeared more frequently."*

“Ooo! one may want, let us say to go another home like that one and ask to be lent a scissors for me to shave my child, they will deny you and tell you that it got lost and if go to another home it will be the same and behind you they will saying we cannot give her because she can give us the small animal AIDS. And now we have just decided not to borrow anything from anyone in this village. We are now used to it and we don’t even think about it. And we don’t even hate them for their attitudes now we live our life the way we do on daily basis. We don’t even worry about them we let them talk and we move on and only God knows everything.”

When Mayi Muyeza had strategies of how to deal with stigma and stated that *“we are now used to it and we do not even think about it. We don’t even hate them for their attitudes now we live our life the way we do on daily basis. We don’t even worry about them we let them talk and we move on and only God knows everything.”*

She is indicating how she was coping with it and showing resilience strategies.

Mayi Muyeza gave an example of what used to happen to her such as people used to refuse to borrow her items if she had asked them. For instance she stated that if she wanted to borrow a pair of scissors to *“shave her child,”* people would tell her that *“it got lost”* but in actual sense, they did not just wanted her to use their pair of scissors. She explained that *“... to be lent a scissors for me to shave my child, they will deny you and tell you that it got lost and if go to another home it will be the same and behind you they will saying we cannot give her because she can give us the small animal AIDS.”* To overcome this stigmatizing behaviour, Mayi Muyeza stopped borrowing anything from other people. *“And now we have just decided not to borrow anything from anyone in this village. We are now used to it and we don’t even think about it.”* She further stated that they had stopped worrying about it and they *“moved on”* with their life and that *“only God knew about everything.”*

The above section of this chapter has discussed disclosure decisions: managing disclosure, who they disclosed to and the impact of disclosure. The section that follows looks at the attitudes of others towards the caregiving.

Attitudes of others

A small number of the women caregivers explained that in the course of taking care of their children, other women caregivers were jealous because their children were growing well and not getting sick frequently. Mayi Kasungu was one of the women caregivers whose care was perceived as good and she believed that other women

caregivers were jealous of her care that she gave to her ward. Mayi Kasungu was an old lady in her 70s and she was looking after her niece. The niece was eleven years old and HIV positive at the time of the interviews. Mayi Kasungu experienced what she called “jealous” behaviours from other people whose children died of HIV and AIDS as she cared for her niece. She recalled that in her village, there “were many children” that had “the small animal.” She stated that “they are all died.” “The other two are in the grave.” She further stated that her ward was the “third” child known to be HIV positive in her village.

“One thing I remember is that there were many other children with the small animal. They are all died. She was the third one here but the other two are in the grave because there was no care for them. Others are jealous of her now as she is growing well now. The other people whose children died of HIV and AIDS and were receiving treatment together with her are jealous. They ask me what type of medicines your child gets. And I answer them that it’s the very treatment that your children were taking. But they say no you are lying the doctors do give you and your child a different type of medicines.”

She stated that because the child she looked after was still alive some “people are jealous of her.” “The other people whose children died of HIV and AIDS and were receiving treatment together with her are jealous.” She stated that those jealous people were also “receiving treatment together with her.” The problem with jealous people reached high “levels” so much so that they had to consult the “village headman” of her village for mediation. “We reached to the level that the village headman had to judge us.” The village headman had to intervene because she “heard one of them despising my child.” There was one particular woman who was very jealous of her and she had heard her talking ill of her child.

“We reached to the level that the village headman had to judge us because one of them I heard her despising my child and I answered her that is that my child that you are talking about? But she refused at first. Later, when we asked the village headman to intervene, she accepted that indeed she had said all that because it pains her that her child died and this one is still alive. How come that mine died and hers is still alive. The village headman just said it’s the good care that she gives to her. Everybody in this village knows that you were not caring your children like she is doing so do not bother her anymore.”

The village headman continued to reprimand the jealous woman that she “needed to follow the instructions given to her at the hospital.” “You needed to follow all the instructions that the hospital gives you and I hope that is what she is following.” The

jealous woman conceded that she did not “*follow hospital instruction on caring for her child*”. Mayi Kasungu further adds that the jealous woman was “*ashamed*” “*and only said I think it is like that. May be I did not follow the hospital instructions.*”

The above section of this chapter has discussed attitudes of others towards caregiving. The section that follows looks at the culture of silence and mistrust in marriages.

Culture of silence and mistrust in marriages

After discussing the disclosure decisions and who they disclose to, the following section will look at the culture of silence and mistrust in marriages. Malawi in general has a culture of silence when it comes to sexual issues. It is even very difficult to talk about it in private and is considered as a taboo. In this study I found that the women described that they could not talk openly about sexual issues or HIV with their husbands. There appeared to be a culture of silence in their marriages and this lead to mistrust among couples. These women explained the way in which their husbands dominate in their families. They further explained that the culture of silence on the part of women has led to men dominating and blaming their wives for family misfortunes. They believed that their husbands did not reveal their undercover dealings to their wives and this included when the man was discovered with HIV and AIDS. This was evident during the interviews as most of women interviewed indicated that their husbands were pushing the blame to them for family misfortunes such as HIV and AIDS in the family whilst denying their own HIV positive status. The following are narrations from women caregivers on the culture of silence and mistrust in marriages. The first to look at is the consequences of failure to disclose and decision making.

Consequences of failure to disclose and decision making

Four of our women caregivers in the study narrated that the culture of silence meant that they did not have the information they needed about their partners’ health and lifestyle and this meant they were unable to make decisions that affected them directly in their families and as a result, they suffered the consequences. For example, Mayi Kasangadzi stated that her husband was HIV positive and did not tell

her. Her husband did not disclose his HIV status and took his medications (ARVs) in secret. He only disclosed once their child became seriously ill and was diagnosed with HIV. He has left them and does not support them financially. She narrated that *“the father of the child has tested and he is HIV positive and he drinks ARVs.”* She further described that but *“he did not tell me at first until this child was born.”* By then she described that they were on separation for the second time.

“Although am married and in addition we are on separation with my husband and am an orphan.” “This child the 3rd born who has HIV that starts HIV and AIDS I can say that at the time I was in Lilongwe with her when I went to test HIV blood testing at Baylor, it was the time when she was sick. This child was very sick and I told the Baylor people that I was an orphan, although I am married and in addition we are on separation with my husband and am an orphan.”

Mayi Kasangadzi lamented that her child had HIV and she wondered how the child got *“the small animal.”* She further stated that she was *“searching herself how the child got the small animal?”* She complained that had she known that she would be struggling herself with the sick child like that, she would not have gotten pregnant in the first place. *“If I was sleeping on my own, could I have been pregnant of this child?”* She asked herself. This showed that she was bitter with her husband who was not helping with the care of the child. *“Yes, the child is like this and where is the father of the child?”*

“I was searching myself how did my child get the small animal? If I was sleeping on my own, could I have been pregnant of this child? Yes, the child is like this and where is the father of the child? And the father, is it true that he should leave me like this and yet I told him that at the scale I was found with the HIV that starts the disease of AIDS. Is this true that her father at Mponela is eating nsima and it settles in the abdomen. And he stays with other women and he is happy daily and yet the child is like this very sick. So I was praying every day. I was telling God in heaven that where there is the father of this child, God should reach him and whisper in his ears to come and help me to care for this child. So that he can remember his child. It was painful that I was struggling to care for the child and yet the father of the child is alive. I don't do any business and I could not find any money to help my child. I was very upset when I was thinking that the father of the child is working and receives money at the end of every month and yet am struggling here like this. These things were painful and I was crying every day. But my friends whom I chat with were very good. They were encouraging me not to worry as this disease has affected almost everyone in the world.”

She complained that her husband had deserted her and was living at Mponela trading centre some 60 kilometres from Lilongwe where she was living with her sister as they were on *“separation.”* She complained that she was *“struggling”* with the

child alone while her husband was “*eating nsima*” and that “*nsima could settle in his abdomen.*” Here she meant that her husband was eating contently and with joy while she was struggling with the child at home alone. She was wondering that “*was it true*” that her husband had left her with such a big responsibility of looking after a child with HIV and AIDS while he was enjoying his life with “*other women away from her.*” Here the husband showed no concern about the child’s condition and did not bother to help her. She was all alone “*struggling*” with the care of the child and with no support from the father of the child. She turned to “*God to in heaven*” and asked God to “*tell the father of the child*” wherever he was that the child was sick and that the child needed his support. She further stated that “*God*” should “*whisper in the ears of her husband so that he can remember his child.*” This showed that the husband cared less and the fact that he did not tell her that he was HIV positive until the child was discovered GHIV positive. He was on ARVs secretly and they did not talk about it in their family.

Mayi Dedza was one of the four women caregivers who had family problem because her husband did not tell her that he was HIV positive. Her husband is dead (2003) and although she did not state directly, she indicated that she believed he was sleeping with other women and passed on HIV to her- and did not disclose his status to her. “*I do not know what killed him.*” However, she further explained that “*you men are difficult.*” She did not explain further about the words “*you men are difficult*” but she added that “*you take diseases out there and give it to someone who is innocent at home.*” This showed that she believed that her husband passed “*the small animal*” to her. She again stated that “*men do cheat women in families and they don’t tell you (us).*”

“My husband died long time ago in 2003. ... but am not okay because I have it as well. I don’t know, you see you men you are difficult. You take diseases out there and give it to someone who is innocent at home. Men cheat women in families and they don’t tell you.”

Mayi Kasungu was one of the four women caregivers in her late 70s of age. She was looking after her eleven year old niece. The niece was HIV positive and she was on ARVs. She described that her brother married a lady despite knowing that the lady he was marrying then had already been diagnosed with HIV. Her brother was still alive at the time of the interviews but the lady that he married died and she was then

caring for her brother's HIV positive child. Mayi Kasungu's brother hid his HIV status from his wife and said the drugs were for someone else when asked by her and she died without knowing her husband's HIV status. Her brother who is the father of the child decided to hand over his daughter to his sister to look after her. He had since remarried. She explained that her brother married a lady who was HIV positive and she *"wondered saying my brother, your first child with this woman has no HIV and your second child has the small animal, what is happening?"* The phrase *"this woman"* refers to another wife of his brother before he had married the mother of the child who is HIV positive.

"They took the first one because they know that child is HIV negative and they think the 3rd one is HIV negative so they took that one too. But the 3rd one has the small animal and they don't know it. But the elder one knows it and they take each other to be receiving ARVs at Dowa district hospital. I think by now they should know that the 3rd one has HIV but they cannot say go to your father as the decision to give us this one was made in presence of chiefs and some elder people of that area. But they have lost this child to us as now she is productive. She cooks nsima for me and we live happily together. My husband died some time ago and now I have someone who I talk to in this house".

May Kasungu explain that the father of the child made *"a big mistake to us"* because *"he knew that her mother died of the same disease called HIV and AIDS."* When she says *"he made a big mistake to us"* she meant that he should not have married his wife because she was already known to be HIV positive but he went ahead and married her.

"And her father he made a big mistake to us because he knew that her mother died of the same disease called HIV and AIDS. The man was receiving the ARVs and not the wife and this is how it happened. He was hiding it. Then his wife was in the middle of being sick after the birth of their 4th child. We saw that I took her to the hospital and we were admitted there and the newly born child had just finished 3 months. Then doctors were just saying it's just like any other disease. The lady was confused. She could behave like a mad person and at a certain period behaving very well while at the hospital. Then we noted that the person had become very thin. The husband should have told his wife that the medicines which were found in the house belonged to him. He used to go to the hospital to get the medicines and be giving her and she could get better and when he stops giving her she could be sick again."

This section above has looked at the culture of silence and mistrust in marriages and how this leads to failure to disclose and the consequences for decision making.

Conclusion of the chapter

In this chapter, the discussion has been on disclosure decisions: keeping secrets and who to trust, secrecy, fear and shame. Women caregivers had selective disclosure. They disclosed only to close relatives and significant others such as the village headmen and they also had to disclose based on the trust and secrecy of the individuals that they selectively disclosed to. Women caregivers had to manage disclosure issues surrounding them such as making good judgements before they disclosed for fear of repercussions. Women caregiver carefully decided who they disclosed in order to mitigate the impact of disclosure. The culture of silence and mistrust in marriages has been discussed too. This culture led to the development of mistrust and husbands resorted to hiding their HIV and AIDS status to their wives and consequently infecting them with HIV and this was as a result of failure to disclose and failure to decision making. The next chapter will discuss HIV and AIDS caring responsibilities.

Chapter 8

HIV and AIDS caring responsibilities

Introduction

In this chapter the analysis moves from a discussion about the participants' experiences of disclosure decisions to considering in detail the different elements of their caring responsibilities. These includes: practical care, resources and poverty, who gives the care, monitoring and surveillance, prevention, treatment at home and effects on caregivers – practical strategies, resilience and optimism and attitudes of others on caring. The chapter begins by describing the different family members who provided care.

Who gives the care?

In this sample, caring was provided by both biological parents and non-biological parents. Only two children living with HIV and AIDS were looked after by grandparents. They were a grandmother looking after a niece and a grandmother looking after her granddaughter. The rest of the children were looked after by their biological mothers. The discussion starts with the grandparent looking after a niece.

Grandmother carers

Grandmothers were often carers because the biological parents of the children living with HIV and AIDS that they were looking after had died due to AIDS. One such grandparent was Mayi Kasungu. Mayi Kasungu was an old lady about 70 plus years who was looking after her niece at the time of the interviews. Her husband died many years ago and she was only living with her niece.

“Eee! I cannot remember nor know the years when she was born as am an old woman (she was in her late 70s or she may be 79 years old) I did not even go to school so I cannot know the years really. But his wife is in the grave for 5 years now since she died.”

Mayi Kasungu here was trying to recall when her niece was “born” but she failed. Mayi Kasungu was a good example of rural women who could not read and write as

she confirmed that she “*did not even go to school so she could not know the years really.*” She could not remember some events leading to HIV and AIDS seropositivity of her niece. The word “*years*” referred to her actual age. However, she remembered when the child was discovered with HIV. Mayi Kasungu stated that she took the child to Mponela AIDS Information and Testing Centre (MAICC) for HIV test as she narrated:

“...And silently I whispered to her that I have come with my friend here, this child is my brother’s daughter but she stays with me. And she wondered saying aa eeh, and I said yes, and she said eee not you? And I said no, not me off-course I have come with her to be tested and not me and she said okay. ...My friend here I have tested her for HIV and she has the HIV in her blood. Here I was worried and I said to myself, eee and where did she get this HIV this child. But we were given the paper and the lady told us to go to the hospital for the medicines that stop the small animal.”

This narrative gives an insight into extended family bonds and responsibilities. As Mayi Kasungu puts “*here I was worried and I said to myself, eee and where did she get this HIV this child.*” Then there was a grandmother who was looking after a granddaughter whose both parents died due to HIV and AIDS and the researcher attended the burial of one parent-the father of the child. The researcher had booked an appointment to interview this grandmother and on arrival, the researcher found that there was funeral service in the village and that it was the father of the child who was living in town (Lilongwe) and died the previous day. The interviews were postponed and the researcher had to go back after three weeks of mourning were over to rebook the appointment for the interviews and were done a week later of the appointment day.

Another grandparent looking after a child living with HIV and AIDS was Mayi Nsanje and she was in her early 80s. When she stated that “*this was not showing very well*” she was talking of the signs and symptoms of the child’s illness and that they were not exhibiting very clearly to her. Therefore she “*sought hospital help*” so that she could know what the problem with the child was. At the hospital, she was told that “*the child had the small animal in her blood.*” At that point, “*she remembered that the child’s parents died of the same disease.*” Here the phrase “*the same disease*” referred to HIV and AIDS because the child’s parents died of HIV and AIDS. “*They all died of the small animal disease.*” She described that since both parents of the child died then “*the child had to be staying with her*” as a grandparent. When she used the word “*we*” she was referring to herself because that

was how elderly people talk of themselves in Malawi. It was a way of self-respect and it was in order in Malawian culture.

“It was the time when her mother was dying, this was not showing very well but I should say that we just noted that she had frequent attacks of malaria. Then it was the mother getting sick and she died. Then her father died too. They all died of the small animal. And it was found that the child had to stay with us grandparents. As we were staying with the child, we were wondering that she was not happy and the hair was straight (pale hair).” Then we decided to come to the hospital for help and they told us that the child had the small animal in her blood.” It’s when we remembered that her parents had died of the same small animal disease.”

The above section has discussed two grandmothers’ experiences as they gave care to their grandchildren. One grandparent was looking after the niece while the other one was looking after the granddaughter. The care that the two grandparents gave was similar in the sense that they lived in the same area with similar resources and also they both had their grandchildren tested for HIV at their initiative. They took their children to HIV testing centres. The only difference is that Mayi Kasungu who looked after her niece had the HIV test at a non-governmental organization- MAICC while Mayi Nsanje had her granddaughter tested at the governmental institution- Mponela Rural Hospital. The section that follows will look at the actual practical care of a child living with HIV and AIDS in a very poor rural setting of Malawi.

Practical care of a child living with HIV and AIDS

All twenty women caregivers in this study described their child’s illness as a heavy burden because they had limited resources for caring the sick child. Caring a child who has a life long illness such as HIV and AIDS is a difficult task. In addition to looking after the child living with HIV and AIDS, they also talked of taking care of their other children who were HIV negative. However, these women demonstrated that they were highly motivated and resilient and looked after their children well and showed interest as they cared for them. This was manifested by their positive attitude when caring their children that are living with HIV and AIDS. They constantly observed their children. When they noticed signs and symptoms of any illness they immediately took actions such as taking the child to the hospital for treatment. This is seen when one of the caregivers Mayi Zomba described that her child was “*really suffering*” because she had noticed signs and symptoms of “*a certain illness*” in her

child. The caring activities were taking place in the face of poverty in all families of our caregivers in this study.

All caregivers that participated in this study were happy during the interviews as they were laughing at times as they expressed their experiences. The mood was generally good and a happy one except where sad stories were rekindled. All women caregivers interviewed described similar routine care activities. The majority of women caregivers were mothers caring for their children, except for a grandparent caring a granddaughter and an elderly aunt caring for her niece. All were the main caregivers to their children living with HIV and AIDS children were sick at the time of data collection. All children had been living with HIV and AIDs since the age of two years. These women have similar limited resources and live in a similar rural environment and the general care they described includes feeding the child, washes clothes, bathing, giving medicines, providing a good sleeping place in the house, cleaning the house and taking the child to the hospital when necessary. They also described children illnesses in terms of how they discovered the HIV status, signs and symptoms and how they give treatment. Giving food supplements to a child living with HIV and AIDS was one of the practical care responsibilities that women caregivers had.

Food supplements

When the child is malnourished, that child must be put on food supplements. This is one of the Malawi government policies in order to eradicate malnutrition in children. Most of children living with HIV and AIDS are malnourished and hence were put on food supplements programme. Mayi Zomba whose child was on food supplements programmes stated that the child continued to receive other food supplements from the hospital called "*Likuni phala*" so that she could gain weight quickly. This is how Mayi Zomba narrated it:

"Yes, I cook special porridge for the child but I do give some to the other child who is 9 years old. Now I am receiving soya flour and Likuni phala from the hospital and we cook that for both children. It is Likuni phala flour that I do receive for her."

Mayi Zomba not only gave food supplements to the child living with HIV and AIDS to her other children who were HIV negative to ensure that they were not

malnourished too because she struggled to get food for the whole family. She had acute shortage of food in her family.

“We don’t have food in this house and I struggle to find food. I tell you it’s hard to live here in villages where one has nothing to rely on.”

Mayi Zomba was sad when she had said this statement and had tears running down her cheeks. The interview had to be stopped for about 20 minutes and the interviews started again at her request because the researcher wanted to terminate it after the counselling was done by the qualified hospital counsellor who was with the researcher during all the field trips.

Mayi Dowa, whose child, just like any other caregiver’s child in this study, explained that her child was “receiving” food supplements from Mponela Rural Hospital and from Dowa District Hospital. She stated that she used to receive “milk, Likuni phala and Chiponde for a period of eight weeks.” She further explained that the “child was changed to porridge.” This was how she put it:

“Aaaa! I can say that it is only the hospital people and they used to give me milk, Likuni phala Chiponde and I continued to receive it from here at Mponela Rural Hospital and I started receiving milk and chiponde at Dowa district hospital. When I arrived here at Mponela hospital, I received for 8 weeks and then they changed to porridge.”

When Mayi Dowa used the word here “porridge,” she was referring to “soya porridge.” She contended that she used to receive soya porridge “three times” but she did not indicate whether it was per week or per day or per month. However, Mayi Dowa further lamented that the hospital staff told her that her “child would stop receiving soya porridge” as food supplement because her child had “reached” the weaning weight. She confirmed this when she stated that “soya porridge and I have received for three times and am told that they will stop even giving the child the soya porridge.”

She further described that she was powerless in “the eyes” of the hospital staff as she explained that “everything lied in the hands of the of hospital staff” and that “there was nothing” that she could have done. She continued to explain that she was “just being helped” and therefore, “it was up to the hospital people to decide.” She further stated that her child was “still weak and looking sick.” Here, the researcher in

consultation with the study supervisor in the United Kingdom intervened and the hospital continued to provide all the food supplements to her child because it was a matter of life and death. She stated that her child had gained weight from 4.1 kilograms to 8.1 kilograms at the time of data collection. Mayi Dowa explained all this in the narrative that follows.

“Soya porridge and I have received for three times and am told that they will stop even giving the child the soya porridge. I said no problems as everything lies in your hands there is nothing that I can say about it because I am just being helped so it’s up to you the hospital people to decide. The child has reached the stage that the child should stop receiving food supplements from the hospital. But my child is still weak and looking sick. The child is now weighing 8.1kg when the child started the weight was 4.1kg.”

Feeding the sick child

All women caregivers described similar routines when caring for their children in respect to feeding as they live in a similar environment with similar resources. They prepared *“Likuni phala in the morning.”* As one of them Mayi Lilongwe accounts how a day’s activities are when she stated that *“then after eating the porridge they all take their medicines around 6 o’clock in the morning.”* The words *“porridge and medicines”* here refers to Likuni Phala and ARVs respectively. In the afternoon, they cook *“nsima.”* They reported that they do experience problems of finding food as one of them Mayi Lilongwe narrated that she *“does fall short”* of caring her child the way she wanted it to be cared for largely because she is a *“single parent”* and she was *“struggling”* to find resources as she recounts in the quotation that follows.

“What I do now is to cook the porridge in the morning then drink the medicines and then in the afternoon we eat nsima. As a single parent, to say that I can care for the child the way it should be, it’s not possible. I do find some things that are needed but in a difficult way.”

Homemade food ingredient (nsinjiro made from ground nuts)

However, to enrich the maize flour porridge with some proteins, all caregivers reported that they do add to maize flour porridge ground nuts flour called *“nsinjiro”* in local language of Chichewa. Nsinjiro is a popular ingredient in Malawi dishes and is locally made from ground nuts. Every Malawian woman whether she lives it in

cities or in villages knows how to make nsinjiro. This is how one of them Mayi A recounts it:

“This is what I do every day. In the evening when am not very busy, I do cook for her m’gaiwa porridge I add nsinjiro and a bit of sugar if I have found it and then give her. It is not easy these days to find nsinjiro especially here in the villages.”

Nsinjiro is added to vegetables, porridges and rice if one wants it that way. It is cheaper because it is made from ground nuts that are one of the main food and cash crops in Malawi and therefore, readily available in many parts of Malawi. Nsinjiro already made are available in most shops and one can easily buy from the shops and are cheap too. Villagers like women caregivers do make their own nsinjiro as nsinjiro is largely originated from the rural areas of Malawi. When people move from the village to town, they take with them their traditional life styles and continue it in town, hence nsinjiro found its way in Malawi towns and cities and it is now a commercialised commodity. However, Mayi A narrated that *“it was not easy to find nsinjiro especially in the villages.”* This was a puzzle to the researcher as nsinjiro was readily available in rural villages of Malawi throughout the year as ground nuts were locally grown and hence available to each family household.

One of the participants Mayi Mpanda 3 conditionally was giving her child *“m’gaiwa”* porridge. She stated that *“in the evening when am not very busy, I do cook for her m’gaiwa porridge.”* M’gaiwa is flour made from whole grain of maize and it is rich in fibre and some vitamins. It is ideal for children who are living with HIV and AIDS. This is the trend in the villages and it was echoed by all the women caregivers interviewed. However, they enrich m’gaiwa porridge with proteins by augmenting it with *“nsinjiro.”* *“Nsinjiro”* adds good palatability to m’gaiwa porridge as well and the child may like it too. However, Mayi Mpanda 3 was giving her child other food alternatives as snacks in between main meals. She did not elaborate what alternative food stuffs she gave to her child.

Food alternatives

Food alternatives are limited in a resource poor region such as rural Malawi. Women caregivers explained that they do give their children narrow variety food alternatives. One of the caregivers Mayi Muyeza does give her child *“bananas in the morning.”*

She states that she and her husband do “grow bananas” and that they “don’t sell” bananas because they give them to the child who is sick. This is how she puts it:

“Many people including us grow ground nuts and we take from our gardens or if we don’t have, we buy from other people. We have bananas at our garden and we prepare them and give her. We don’t sell our bananas we use them for ourselves. We eat them all. When eat them the whole week as well. When we don’t have bananas we buy from other people. After nsima, we give her the banana in the morning. I do give her porridge mad from m’gaiwa in the morning and I mix it with ground nut flour and I do give her to eat.”

She was giving her child bananas as a snack as she stated that “in the morning, I cook maize flour porridge m’gaiwa and I add nsinjiro. When we do not have, we buy from other people.” All the caregivers explained that after feeding the child they “washed” (bathed) the child and the child’s clothes.

Nsima with M’nkhwani (or vegetable of the day) only

One of the caregivers Mayi Mpanda 3 expressed that the first thing she did in the morning was to “wash her face” as she described “when I wake up in the morning I wash my face.” She stated that her activities in the morning were sequential every day. She explained that she was washing her face, cooked porridge, gave the child the “porridge” to eat and took her ARVs and gave the child ARVs and finally sent the child away to play with friends as seen in the quotation that follows. “And I take the medicines and have her drink it and then I cook porridge and she drinks the porridge and then she goes to play with friends.” She stated that she realized the importance of the child to “play with friends.” After the child had been given what was due in the morning, she ensured that the child went to play with friends. This was what she said: “and then she goes to play with friends.”

Mayi Nsanje explained well how she cooked “relish” in the morning so that she could eat it together with nsima during lunch time. She explained that she cooked her vegetables like “m’nkhwani” by not adding locally made soda called “chigendere” because she knew that “chigendere” killed vitamins in the relish. She preferred to cook her relish by using salt only so that she could preserve “the vitamins” in green vegetables such as m’nkhwani or cauliflower called “mpiru” in local language of Chichewa. Mayi Nsanje confirmed this point when she stated that “but don’t use

relish that is cooked using chigendere (locally made soda) because chigendere kills vitamins in the relish.” The word “use” as utilised by her here means eating. Therefore by saying “do not use” means “do not eat.” This was another extraordinary knowledge on preparation of green vegetables by village standards. She stated that she got this knowledge from the training of caring for a child living with HIV and AIDS at the hospital. To ensure that she did not cook her green vegetables with chigendere, she emphasized that *“for me and the way the life of me and my child, I don’t like relish cooked using chigendere.”*

When she stated that *“the way the life of me and my child”* she demonstrated the realization that her life and that of her child are compromised by HIV infection and hence she needed to take extra care in terms of how she prepares her food and food for the child. She knows that she must preserve the necessary elements such as proteins and vitamins in the food that she prepares by following the instructions she had learnt at the hospital. She demonstrated that she understood very *“well the lessons”* at the hospital on how to care a person living with HIV and AIDS when she stated that *“there are no vitamins in relish cooked using chigendere and that is what we learnt at the hospital.”* This was how Mayi Mpanda 2 narrated the process of cooking her green vegetables without the use of *“chigendere:”*

“In the morning, we use m’nkhwani, mpiru and we find them as we did with the lessons that usually be eating green vegetables most of the time because in them there is a good help for you in your bodies but don’t use relish that is cooked using chigendere (locally made soda) because chigendere kills vitamins in the relish. For me and the way the life of me and my child, I don’t like relish cooked using chigendere. There are no vitamins in relish cooked using chigendere and that is what we learnt at the hospital.”

Relish is the main part of a Malawian dish. It determines how well off one is by eating good relish at every meal. Good relish may constitute meat, green vegetables, and nsima or rice. The family that can afford these three at every meal is a well off family. However, most families that live in rural areas of Malawi can afford only two pieces at every meal, that is green vegetables and nsima and they eat this twice a day, during lunch time and at dinner time in the evening. In short, a diet that constitutes protein products, carbohydrates and vitamins is ideal for everyone to lead a healthy life. Mayi Mtiti states that she cannot afford this type of diet and she only affords a

diet that consists of carbohydrates and vitamins that is nsima and green vegetables. She however explains that she does afford meat products once in a while.

Nsima with eggs, meat and vegetables

Most families in Malawi cannot afford meals three times in a day and it is particularly true for the people that live in the rural areas. The common sources of proteins therefore are eggs as one of the caregivers Mayi Muyeza narrated that she “buys eggs” within the village if she had money. But she was quick to mention that she prepared vegetables that were in season and that she could afford at a particular time. “*We eat the relish that is found at that time.*” The phrase “*at that time*” may indicate vegetables in the season or what she could afford at a particular “time.” She explained that she provided her child almost a balanced diet as she stated that she sometimes managed to buy “*meat and eggs*” for the child to eat. “*We buy eggs and use them to feed the child who is sick.*”

Washing child's clothes

All women caregivers described that keeping the child clean and smart all the time is part of the lessons that women caregivers are taught at the hospital when the child has just been diagnosed HIV positive. As one of the caregivers Mayi Dowa, narrated that she cared for the sick child by washing the child's clothes. She also “*washes her child in the morning.*” She used soap to wash the child and child's clothes in the morning. When she states “*washes the child*” she meant bathing the child. She emphasized this point when she states that “*and I do wash her in the morning too.*” She stated that she normally washed child's “*clothes in the morning*” so that they were sun dried during the day. She explained that she was an industrious caregiver who did not stay idle at home. She stated that she went out in the morning after the household chores like feeding the child, washing clothes, making the house clean and drawing water for the home to search for piece work. All women caregivers stated that they did the same type of care even when the child was sick. The paragraph that follows looks at the effects of caregiving on the caregivers and what practical strategies they had put in place to cope with the effects.

Effects on caregivers – practical strategies, resilience, optimism

All caregivers in this study indicated that they had put practical strategies in place to sustain their caregiving. The section below looks at this aspect and beginning with adequate food reserves at their houses through a business venture.

Adequate food reserves at home (house) through a business venture

All twenty women caregivers expressed that food was a very important aspect in the caring of a child with HIV and AIDS. This was because ARVs alone without adequate and good quality food do not work well. All twenty women caregivers showed that they were hard working women. They had good ambitions for their sick children. They cited things that they felt if they had them, they would be caring for their children the way they wanted. They all mentioned that they would like to have a “good capital” to start “business.” For example, Mayi Kasangadzi 4 explained that she would be happy if she had been conducting some small business.

“Me, what I think in my life for me is to care for this child very well and is for me to find capital for the business and in addition to be growing more maize or I should grow more ground nuts and if I can be selling these crops I can say I will be able to care for her well.”

She would like to be “growing crops” such as “maize and ground nuts” as a business venture so that she could be “selling” them and earn more money. She stated if she grows more maize, she would have adequate food that would last throughout the year and sell the surplus to earn money.

However, other women caregivers mentioned keeping domestic animals such as goats, chickens as a way of boosting their sources of income and food. For example Mayi Machentche believed of keeping “domestic animals” as one way of improving monetary resources so that she can care for her child well. She gave an example of keeping goats, pigs and chickens at her house for cash and for food as well.

“Or if I can find money and have a domesticated animal that can help too. Domesticated animals like pigs or goats or chickens and we cannot mention of a cow because it’s too high for me. I cannot manage to buy it and let alone looking after it. A goat at K3, 000.00 can be found in the villages. Or if I can have K5, 000.00 I can have the domesticated animals and the life can be good on the side of the child and myself as well.”

After having looked at the Adequate food reserves at home (house) through a business venture, the paragraphs that follow look at resources and poverty for the women caregivers looking after child living with HIV and AIDS.

Resources and poverty

People living with HIV and AIDS need additional resources in terms of food, money and clothes because HIV and AIDS are lifelong conditions. This supports the evidence discussed in chapter 3. The available resources in the family are depleted because of the nature of HIV and AIDS conditions; in particular adequate good quality food for ARVs to be effective. The persons also require good clothes that are washed frequently to avoid catching other infections because they already have compromised immune system. All these require that the family resources are directed mainly towards an individual living with HIV and AIDS and by the time that individual dies, the family is left with less resources than before. In other words, families are left poorer. To compound this problem, it is well documented elsewhere that most rural families in Malawi are poor and that they live on less than one US dollar per day (MDHS, 2010). Therefore, poverty is one of the major hindrances to good care of people living with HIV and AIDS in rural settings of a limited resource country like Malawi. This was no exception to all our 20 women caregivers interviewed in this study.

Mayi Dowa explained that there was worsening of poverty in her family due to HIV and AIDS. She was facing problems in finding resources for their families and for the children that lived with HIV and AIDS. She alluded that *“her family was very poor”* and that *“life was very difficult especially with HIV and AIDS in the family.”* *“My family is a very poor family and we lead a very difficult life. Yes, my husband is a business man but at present, money is a problem because he has no capital to continue with his business of selling dried fish at the market. He is no longer doing his business. He likes selling fish as his business. Since this child became sick and I was at Dowa District Hospital for a month, he has not been selling fish. Because of the support he was giving me at the hospital, the money he used to buy fish as capital has gone down and he can’t order any fish now.*

Mayi Dowa further described that she used to *“get support from her husband”* who had a business of *“selling dried fish”* but he had stopped because *“the capital”* for

the business was used up when the child living with HIV and AIDS was admitted at the hospital. Her husband used the capital to support her with food and soap and other items that she needed to care for the child at the hospital. So they were so tightened up in terms of money to support the child

“This is because the capital was very small already it means that it got finished from that day up to reach today, we just say thank you God for keeping us a live till now and it is down and you have given us today’s food. Even when we don’t have adequate food and that there is no food we still thank God to say this is what you God has arranged that today we go without food and when you arrange again, we will have food. God does not leave us alone, He loves us every day.”

This statement indicated that the family found solace in God when they did not have food and even if they have food as well. Religion plays a major role in providing comfort in families in dire needs in Malawi and Malawi is a religious country where 85% are Christians and 15% Muslims (MDHS, 2010). Religion is used as a major psychosocial therapy for many families in Malawi especially in difficult times (MDHS, 2010). There is a strong sense in these narratives of coping by taking it day by day, being thankful for the small things, drawing on religion for solace. These are all known to be elements of resilient behaviour, something that you could pull out more perhaps.

Monitoring and surveillance

All women caregivers in this study were surveying their child for signs for the development of AIDS in their children living with HIV. All women caregivers explained clearly the signs and symptoms of the child’s illness. They usually described similar main signs and symptoms but also noted different signs and symptoms in a particular child. The commonest signs and symptoms they reported were *“coughing, the body being hot to touch, chest pains, unable to breathe properly, vomiting, opening bowels frequently, general body weakness, sores and rashes all over the body.”* Mayi Mpanda for example described signs and symptoms of her child’s illness.

“During the days I didn’t know she was getting sick frequently. She used to feel cold, opening bowels and feeling hot on the body, coughing and ee different diseases were in her so I decided that I needed to know where the lives of children were (health status of children). This one, she was really suffering from when the body was hot, she cloud develop pins and needles in the chest and feeling pains everywhere. She was opening bowels frequently, coughing and she was very thin. She was breathing

very weakly and she developed small eruptions all over her body and she was not growing at all.”

When Mayi Mpanda stated that *“this one was really suffering,”* referring to the child living with HIV and AIDS and the child was very sick. The phrase *“really suffering”* denotes how seriously sick her child was and she goes on to describe the signs and symptoms of the *“suffering.”* By stating the range of these signs and symptoms, she is actually describing clearly the *“suffering”* as being a full blown AIDS, which is a collection of different signs and symptoms of different diseases that affect different body systems.

All 20 women caregivers demonstrated knowledge on which areas of their children’s body to check to determine if the child was well or not. For instance one of them Mayi Mpanda 2 stated that she *“looks in the eyes of her child”* to see if the child was sick or not sick. Medically speaking, eyes are used to determine the level of haemoglobin of a person. Medical personnel use the mucous membranes of the eyes to estimate the level of haemoglobin. This woman caregiver demonstrated exceptional level of surveying the child’s signs and symptoms *“by looking into the child’s eyes.”* Whether this caregiver checked *“the eyes”* to determine the level of haemoglobin for her child, was something that was beyond comprehension because she had no medical knowledge of that level. This level of care showed that women were determined caregivers to their sick children and did not leave anything to chance. They were resilient and demonstrated high level of motivation to care despite limited resources. They had taken particular interest in HIV infected children so that they did not get sick. One of them Mayi Mpanda 3 also stated that *“When I see in her eyes, she is much better than before.”* Checking the child’s eyes was a common practice by all our women caregivers in the study. There are other things that one can see from looking at the eyes other than just haemoglobin level by medical personnel. Non-medical people may look into someone’s eyes to check whether someone is bright or dull eyed. These are ways that lay people can make assessments of health and illness states too. The paragraph that follows looks at the how women caregivers’ practised preventive measures for their children.

Prevention

Women caregivers indicated that their children need maximum care when they are not sick so that the said child was prevented from getting sick. They explained that at the time when the child was not sick, the child will be eating the required amount of food and would be able to take “*medicines without problems,*” unlike when the child was sick, “*it became difficult to feed and give her medicines.*” One of the women caregivers Mayi Mpanda 2 emphasized this point “*it is when the child is fine but not when the child is sick.*” She explained just like others, that her child “*was fine, happy and growing well*” because she was on ARVs. But before the ARVs, the child was not growing and was “*sick*” most of the time. The child was able to play with her fellow children too.

“The most care is needed when the child is well and even when he is sick the care should not change at all. It has to be the same. The care has to be the same so that he does not get sick often to prevent him from getting sick. When he is well or sick care for him well the same.”

As part of the comprehensive care, the caregivers ensured that their children got “*good food.*” However, they could only “*buy*” it when they “*had some money.*” Another caregiver Mayi Kasangadzi 4 described this point “*I do buy her some good things like good food though not adequate.*” She realised that good food was part of treatment of HIV and AIDS. “*One could not rely on ARVs only without good nutrition.*” In fact Antiretroviral Therapy (ART) is in three sections. Section one comprises counselling for HIV and AIDS sessions, section two comprises antiretroviral drugs (ARVs) and section three is nutritional therapy. The phrase “*some good things*” showed that Mayi Mpanda 2 did not only give her child good food but other “*good things*” too which she did not elaborate. This is a spirit demonstrated by all caregivers and one of them Mayi Zomba ascertained this when she states that

“i can differentiate the help from the time the child was sick till now because of the help from the hospital. The hospital has helped me greatly. And at the hospital they gave me the medicines for TB and the child is still drinking the TB medicines and the child is also receiving the medicines for the ARVs. The results are at the hospital and I have not yet gone to get them. I am also on the ARVs myself too. My husband has not started because he says that he is fine. I just said okay it is up to you and am not forcing him to have the HIV test. She has improved like this because she is now receiving the medicines of ARVs but also when I have found some money I do buy

her some good things like good food though not adequate. And now I see that there is a change unlike the way she was before.”

It was very difficult to “find” food in the villages during certain months in Malawi (December to February) because by this time, maize which is a staple food is in low supply and the one in the garden is not yet ready for use. But the problem of food scarcity was even worse in most families that were looking after a child living with HIV and AIDS because the caregivers were often sick and were widows too. Mayi Mpanda 3 conceded that she “found it difficult” to get good food for her child when she stated that “though not adequate.” She lamented that if she had all the necessary resources such as enough money she could have been providing her child with adequate “good food and other good things.” This was a genuine wish and was expressed by all our 20 women caregivers in this study. The above section of this chapter has discussed the practical aspect of caring a child living with HIV and AIDS. The section that follows looks at giving treatment at home.

Treatment at home

Women caregivers in this study were taught how to give treatment at home during the training sessions for HIV and AIDS when the child or themselves had been diagnosed with HIV and AIDS.

The turning point of child’s health status

All 20 women caregivers in our study attributed improved health status of their children living with HIV and AIDS to introduction of ARVs. One of the caregivers Mayi Dowra described that the health of her child started to improve when the child was diagnosed “HIV positive” and started the ARVs. “In the evening I also give quarter tablet of ARVs and CPT.” She further stated that she “gives her child medicines in the morning” as she was advised at the hospital. She explained that she really appreciates the introduction of ARVs to child and “the child was growing well.” “And I can say that since my child started receiving ARVs and Likuni phala, chiponde and milk, she has improved much better and she is growing well now and I am happy for this...” The introduction of ARVs marked the beginning of some happiness in her life as the child stopped being “sick frequently and was growing”

and looking health at the time of the interviews. She also expresses gratitude to the hospital for helping her child. Mayi Dowa realized the importance of nutrition in the management of HIV and AIDS because she made sure that she gave food to her child living with HIV and AIDS soon after the ARVs. *“And CPT but on the side of food porridge, I give the porridge around 8am. I gave the child soya that I receive from the hospital.”*

“I just thank the hospital.” “In the morning around 6am I gave the child half tablet of ARV and quarter tablet of Bactrim and they call it CPT (co-trimoxazole Preventive Therapy). I give quarter of a tablet of ARVs and CPT but on the side of food porridge, I give the porridge around 8am. I gave the child soya that I receive from the hospital. And I can say that since my child started receiving ARVs and Likuni phala, chiponde and milk, she has improved much better and she is growing well now and I am happy for this. I just thank the hospital. But before she started ARVs, I thought she was going to die and I lost hope.”

One of the routine caring activities that all our 20 women caregivers mentioned was giving medications to children in a manner that they were taught at the hospital. They stated that they gave ARVs almost at the similar time because the time suited their routine work in the villages. For example, four (4) of the caregivers Mayi Dedza, Mayi F, Mayi Ntchisi and Mayi Kasangadzi 4 narrated how they gave their children ARVs and other related medications and it was similar to all twenty caregivers interviewed. Mayi Dedza and Mayi Kasangadzi 4 stated that *“they give their children in the morning ARV dose at 6 am and then they do take theirs too at the same time.”* They explained that they gave their children ARVs after the children had taken the morning *“porridge.”* Mayi Dedza for example described how she gave ARVs to her child.

“This is how I do now is to cook porridge in the morning when we drink the medicines... because I am a single parent, to say that I can care for the child the way it should be, it is not possible as life in the villages is hard. I do find some things that are needed but in a difficult way. It is especially difficult this year to find all that I need.”

Women caregivers were advised to take stock of the ARVs for their children. The paragraph that follows looks at the stock checking of ARVs drugs by women caregivers.

Stock checking of ARVs drugs

ARVs are given to recipients under strict rules to avoid development of resistance. Each recipient is taught to check stocks and report at each hospital visit. All 20 women caregivers in our study explained that they do check stocks and reported to the health worker at each visit. One of the caregivers Mayi Machentche narrated that she followed these rules very well including how to give HIV and AIDS medicines maintenance doses to her child. She had been asked how many tablets were left on each visit to the hospital. *“They asked us how many tablets are you left with at home, and we said they are there eight oohh wait a minutes, it was nine and not eight tablets left.”* The word *“medicines”* here refers to ARVs and not any other related medicines because it is only ARVs that are well audited. All women caregivers understood the importance of stock checking of ARVs as they complied to bringing the remaining tablets to the hospital at each visit.

ARVs maintenance doses

All 20 women caregivers interviewed in this study also reported that maintenance drug administration was their responsibility and they all follow the same drug dosages as one of them Mayi Zomba narrated that she *“was giving her child the maintenance dosages of ARVs as recommended at the hospital.”* Our women caregivers also stated that at first, their children were given paediatric tablets of ARVs and later switched from the paediatric tablets to adult tablets because they said that children had had gained weight that required the child to take an adult tablet. Mayi Machentche confirmed this when she explained that *“and when I came to bring the medicines, they told me that today we will change for the child and you should be giving the child a quarter tablet in the morning and in the evening half tablet.”*

The above paragraph has looked at ARVs maintenance doses and the paragraphs that follow will describe food supplements for children on ARVs which is part of the treatment at home.

Duration of caring the child living with HIV and AIDS

All twenty women caregivers interviewed in this study described that they were looking after a child living with HIV and AIDS for more than two years and had lived at the same location for more than five years. They described that caring responsibilities of a child living with HIV and AIDS took a form of physical, spiritual, emotional or psychosocial caring. All caregivers described mainly taking the child to the hospital for physical caring and medical and nursing care. All caregivers interviewed explained that the decisions about the child caring process were made by women caregivers themselves because they were the ones who are with the child all the time and because caring in Malawi is traditionally borne by females.

In the second half of the chapter we will move from discussing the specific care that was provided by caregivers to considering their strategies for being self-sufficient and remaining resilient.

Hope for the future

All 20 women caregivers in our study explained that they were looking to the future with optimism and good hope for their children and for themselves. For instance, Mayi Kasangadzi 4 stated that she would like to start “*business*” but she was held back because organizations ask for “*a deposit*” for a loan.

“Me I can say it is difficult because other organizations they want you to have some money for you to join or deposit at the bank if you have that money at the bank they can give you the loan for business. It depends with the loan that one wants. For example if you want K40, 000, 00. The deposit would be K10, 000, 00. I can’t afford that as you can see me here, I have nothing. I wish I could be doing business. What I want is to be selling second hand clothes because I have done that business before.”

She further stated that the organizations demanded a deposit of K10, 000, 00 (£40) if she wanted to take a loan of K40, 000, 00 (£150). Therefore she could not afford it. She would like to be “*selling second hand clothes*” as her choice of her business.

“What I want is to be selling second hand clothes because I have done that business before.”

Having discussed the hope for the future above, the paragraphs that follow will discuss giving ARVs to children at home. The above paragraphs have looked at the women's experiences when they looked after their sick child well. They experienced jealous and envy by other women whose children died of HIV and AIDS in the same area.

Conclusion of the chapter

In this chapter the discussion has been on HIV and AIDS caring responsibilities. The main issues that have been discussed are the practical care of a child living with HIV and AIDS. The care was provided by women in the age range of between 18 and 45 years except two grandparents (over 70 years of age) who looked after their grandchildren. Culturally, caring children in Malawi is a woman's job unless under some circumstances where the man can help such the mother has died and that the man has no female relative to take care of the child which is very rare as there is an extended family system in Malawi. The physical care that women caregivers provided were similar as they all lived in a similar environment where resources were the same too-very limited resources. The physical care included preparing food and feeding the child with food locally sourced that was rich in proteins. The food was augmented with locally made groundnut flour called nsinjiro. Women caregivers were providing the care amidst acute shortage of resources compounded by high levels of poverty. Women caregivers lived in rural and remotest areas of Malawi where poverty levels are very high. For them to source food resources, they had to do piece work in other people's gardens which is not part of Malawian culture and women caregivers had to do it as a copying strategy. Part of the care apart from feeding, bathing the children and washing their clothes also involved close monitoring and surveillance of the child's condition such as checking for signs and symptoms of any diseases. In this way women caregivers ensured that their children were prevented from getting worse or catching other diseases. The care also involved giving treatment at home; women caregivers were giving ARVs and other prescribed medicines at home. They were taught at the hospital during the training sessions of HIV and AIDS on how to give treatment at home. However, there were some issues regarding caring the child living with HIV and AIDS. Those women caregivers who cared their children properly survived and they attracted jealous from

those that they did not care their children properly and that the children had died. The next chapter that follows focuses on the clinical care and support available for children and their caregivers living with HIV and AIDS in rural Malawi.

Chapter 9

The Clinical care and support available for children and their caregivers living with HIV and AIDS in rural Malawi

Introduction

In the previous finding chapters, the discussion focussed on interviews conducted. This chapter takes the form of an ethnography based on the observations and field notes made at Mponela Rural Hospital. Chapter 9 will discuss the clinical care and support that is available for children and their women caregivers living with HIV and AIDS in rural Malawi to provide a context for the interviews with the caregivers and enable a comparison to be made between the services that are available and what the caregivers accessed. Individual care and the support available to care for children living with HIV and AIDS will be examined. The evidence discussed is based on the data generated by this researcher through observations and field notes and extracts from the data are included to illustrate the discussion. The rural settings where this study was conducted are characterised by high levels of poverty (MDHS, 2010). Rural communities depend on subsistence farming that brings in food and money for families once in a year (NSO, 2008). In addition, roads are poor, and telephone communications are limited too (NSO, 2008). All these factors may impact negatively when providing the care to such children (MDHS, 2010). The actual sites of care and support for children living with HIV and AIDS in rural Malawi are the small rural hospitals and within the family homes. This chapter will therefore provide a backdrop to the study by examining the care available and the support provided by government funded healthcare institutions (hospitals) with infrastructures that are often sparse and resource poor, and non-governmental organizations within the community.

Government funded healthcare institutions

The Malawi government provides 67% of health care needs to the Malawi's population of 13.3 million people (MDHS, 2010). Most government health care institutions are situated in rural areas of Malawi where the majority of the Malawi's

population live (MDHS, 2010). One of these rural government health institutions is Mponela Rural Hospital that was the entry point and a recruitment centre for my study. The section that follows looks at emergency assessment and admission at Mponela Rural Hospital.

The hospital setting: Emergency assessment and admission of children

Mponela Rural Hospital provides medical and nursing care support for children living with HIV and AIDS in this area. Mponela Rural Hospital is a government health institution, 60 kilometres north of the capital city of Malawi, Lilongwe. The hospital is along the main M1 road that goes to the northern region of Malawi. The total official bed capacity of Mponela Rural Hospital is 82 beds. This section will describe the two main routes as inpatient and outpatient of admission and care. The out-patient route is first discussed in the paragraphs that follow.

Out-patient route

Here mothers self-refer and arrive with their sick children to be assessed by the medical assistant and those that need admission are referred (thus children with severe symptoms) to the children's ward for in-patient care and those that do not require admission are sent home to continue the treatment as out-patients. However, it was observed that it was often difficult to make a diagnosis of some ill children and to decide on whether a child needed to be admitted, because some children did not present with a history of fever, whilst others were presented to the clinician in a deep sleep. Therefore, the clinician would send such children to the ward for admission and longer observation than was possible in the outpatient department. There were many children too at the outpatient department and the clinician was unable to spend time to thoroughly assess the child. In this example of a mother attending with her sick child, the clinician made a decision based on guiding criterion: a visibly weak child, unconscious child, diarrhoea, fever beyond 38 degrees Celsius or a history of it, convulsions, or a history of it, severe malnutrition and acute otitis media:

There was a lady Mayi Shawa (pseudonym) with her boy child Thambo aged two years (pseudonym). Mayi Shawa's Thambo was not thoroughly assessed and was sent to the children admission ward because Thambo had a deep sleep and the clinician interpreted it as unconsciousness and therefore required admission. While on the ward, Thambo was awake and had only a fever of 38 degrees Celsius and was diagnosed having simple malaria. Thambo was treated with oral anti-malarial medicines and was sent home after two hours of observations on the ward. *"Tambo was just in deep sleep and does not require admission to the hospital and will send him home to continue the treatment but come with him if he does not improve."* The nurse informed Mayi Shawa.

The nurse's information about admitting a child to the hospital leads to the next route of admission to the hospital-the in-patient route.

In-patient route

This route is where sick children are admitted and continue the care as in-patients. Here, the care included on-going treatment and monitoring and it focused only on sick children while the women caregivers were not considered in terms of care and support. The caregivers were admitted together with their sick children so that they could continue caring for them but they were not themselves admitted as patients or included in the assessment or diagnosis of HIV. Hence, the women caregivers were missed from the care provided by the hospital despite the fact that they were a very critical resource when it came to caring of children living with HIV and AIDS and if their child is diagnosed with HIV, then the mother will also be at risk. Sick children that did not require admission were treated as outpatient and were sent home on medications. Therefore, clients were sent home on medications, admitted or referred to the Antiretroviral Therapy (ART) clinic. However, children also came to ART clinic directly from home (self-referred) and if the assessment indicated that the child could have an infection, the nurse decided to admit that child to the children's ward for proper screening. This was done when the guardian had given consent to do so. Children who came directly to the ART clinic were weighed in the screening room just like any client who attended the clinic. The above sections have discussed two

main routes to the hospital, thus out-patient and in-patient. The sections that follow will look at services offered at these two routes. The first to be discussed is the out-patient services.

Outpatient services

Out-patient services are the main entry points to in-patient services in many hospitals in Malawi. The section that follows looks at these services including the referrals to antiretroviral therapy (ART) outpatients' clinic, enrolment, counselling and testing and an emotional and highly charged time when one gets the results for an HIV test.

Referrals to antiretroviral therapy (ART) outpatients' clinic

Referrals to the ART clinic were from three sources. Direct from home to the ART clinic, from the children's ward and from the general outpatient department of the hospital. When a mother had been admitted to the children's ward with a sick child and accepted to have the child and herself be tested for HIV, then she was referred to the ART clinic where a thorough and a more detailed process for HIV testing and counselling (HCT) was conducted.

Enrolment, counselling and testing

At the ART clinic, the child was thoroughly assessed and counselling was conducted for HIV testing. The counselling was done with the guardian who was usually a close relative such as a mother. Once this process was completed, the child then went for a rapid test for HIV. If the child was HIV positive and that child was under 12 months old, and exhibited no signs for severe presumptive HIV infection, that child was enrolled at the HIV care clinic (ART) where she or he was put on Co-trimoxazole Preventive Therapy (CPT) and growth monitoring. Growth monitoring was done to rule out malnutrition and the child was also put on Likuni Phala (Vitameal) (a mixture of maize, soya beans and ground nut flour) But if the child was less than 12 months of age and had a rapid HIV testing done and was negative, that child was tested for HIV once more at 12 months and at 24 months. If still

negative, the child would be discharged and I witnessed such cases at the ART clinic during my observations period. For example:

One an 11 months old boy called Masautso (pseudonym), arrived under the care of his mother Nabanda (pseudonym), and was referred to the ART clinic from the children's ward. Masautso had already been sick for three months and had to be tested for HIV because Nabanda, the mother was HIV positive. On arrival at the ART clinic Nabanda looked sad and stressed. Masautso was admitted to the ward because he was suffering from Malaria. The rapid HIV test results were negative. Nabanda was very happy and had tears of joy running down her cheeks and she hugged the nurse. She sighed heavily and said "*glory be to God. My child is HIV negative! My child does not have the small animal in his blood.*" Then the nurse explained to Nabanda that she should continue not to breastfeed the child and should report back to the under-five clinic every month for growth monitoring and vaccination purposes. Nabanda was also told to report to the hospital if the child became sick. The nurse advised Nabanda that Masautso would be re-tested for HIV at the age of 24 months. If still negative, the child would be discharged from the ART clinic. The discussions were very friendly and polite. Then, Nabanda was happy and continuously nodded her head in approval of what was being discussed. Nabanda dressed in white dress that was old and clean and she was relaxed and happy throughout the discussion with the nurse.

An emotional and highly charged time

At 12 and 24 months, children are re-tested to determine their HIV status and thus, this is a highly charged and emotional time for parents and guardians. For instance, guardians waited for the results with a great deal of anxiety and stress because if the child was found to be HIV positive, it meant a life-long caring of a child living with HIV and AIDS. If the results are negative, it was a great relief to the guardian. If the child was HIV positive and if that was the child's first visit to the clinic, then the child was sent to the registration room for registration, the same process applied to children who were born to HIV positive mothers only because they were exposed to HIV and usually, they were with their mothers who attend the ART clinic. I had a chance to observe one female child called Chisomo (pseudonym) who was escorted

by her 19 year old aunt called Najere (pseudonym). Chisomo and Najere came to the clinic from home for re-supply of ARVs.

Chisomo was 24 months old and was re-checked HIV using the rapid test.

This child was born to a mother who was HIV positive and the mother died three months after the birth of the child. Chisomo was being cared by sister of her late mother Najere who was 19 years old and still in school.

Fortunately, Chisomo was HIV negative and Najere who was looking after the child was visibly very excited upon receiving the good news. Najere said that *“God is great and she would continue looking after the child with a relief because she was worried that the child could be HIV positive.”* She danced in the ARV room to demonstrate how happy she was. She however, requested that *“the nurse should not discharge Chisomo because she would not manage to find food to feed Chisomo.”* This was because the hospital supplied supplementary food to all children who are registered at the ART clinic including Chisomo. The nurse agreed to this as a way of supporting her for the good work that she was doing of caring a child living with “HIV and AIDS” when she was still so young and no experience of looking after a child of her own. Najere jokingly said that *“this is my first born girl and any man who would want to marry me should accept me and Chisomo. If that man does not accept me and my daughter here then, that will be the end of it no marriage with me.”*

However, if the child was HIV positive, that child was registered at the ART clinic and started on Antiretroviral Therapy for life. And I witnessed this type of children during my observation period at the ART clinic.

There was a boy child called Madalitso (pseudonym) who was 24 months old under the care of her mother Naphiri (pseudonym) who was HIV positive. Madalitso was tested HIV positive after the rapid test. Naphiri was visibly shaken and sad and started crying because she hoped that her son would be HIV negative as she had followed all that was necessary to protect the child. The nurse called in the qualified HIV and AIDS counsellor to continue the counselling in another room so that she could continue reviewing other clients. I followed this woman into another room where counselling continued. It took approximately 30 minutes for the woman to stop crying. Then the counsellor asked if it was possible that they could talk about the

situation. Naphiri stated that “*no, they should fix another date for the discussions.*” They did set a new date for the counselling but the counsellor asked Naphiri “*if there was anything that she wanted before she left for home.*” Naphiri asked for transport to take her to her home village that was about three kilometres away from the hospital. There was no hospital ambulance to take her home. However, I offered my car and together with the counsellor, we escorted her to her village. On the way Naphiri brightened up and the counselling continued. We deliberately took a longer route to buy time for the counselling to be effective. Naphiri was happy and would certainly report back to the ART clinic for her appointment in three days’ time. Upon arriving at her home, Naphiri gave us ground nuts about one kilogram each. That was Malawian tradition to give to a visitor something when she/he visits your home.

If the child was 24 months old and above, and that rapid HIV antibody test was positive, then that child was HIV infected. If already on ART, the child would continue with ART but if not, then the child would continue with pre-ART follow-up but in the HIV Care Clinic at the hospital. All children with confirmed HIV infection were enrolled for ART or for HIV Care to ensure that they could be started on ART as soon as they became eligible for ART.

Services at Antiretroviral Therapy Clinic (ART clinic) building

The above section of this chapter looked at the referrals to antiretroviral therapy (ART) outpatients’ clinic, enrolment, counselling and testing and an emotional and highly charged time when one gets the results for an HIV test. The section that follows describes the services that are offered at the ART clinic building. This will include waiting for counselling – opportunities for health promotion, registration of clients, counselling, eligibility and starting antiretroviral therapy, general screening, monitoring of nutritional status, clinical monitoring, CD4 monitoring and monitoring treatment failure/HIV drug resistance.

The ART building

The ART clinic at Mponela rural Hospital was housed in a standalone building with 5 activity rooms. These were: reception area, registry room, general screening room, consultation room and the ARVs room. Clinic starts at 13:30 on Tuesdays and Fridays and ends at any time depending on the number of clients on that day. The clinic does not close until everyone who had come for the service has been attended to. On the days that I observed the services, the clinic was closing at 19:00 and at times 20:00. The main work of the ART clinic was the review of clients who were already on ARVs or for those who are starting the ARVs it acted as the main service of all the services provided at the ART clinic. It was because major decisions are made regarding ART after the review. The nurse who is trained in ART services is responsible for this and she was also in-charge of the ART clinic at Mponela Rural Hospital. She prescribed and changed the ARVs for clients depending on the problems the client is facing with the current regimen and based on the laboratory results. She also conducted counselling of new and old clients depending on the need of each individual client. The sitting arrangement in this room was at the same level, with the nurse sitting side by side with the client and the approach was very friendly. After the client had received ARVs, he/she was asked to go back to the registry room where she would deposit his/her data card for safe keeping. Clients did not take data cards home.

Waiting for counselling – opportunities for health promotion

The reception of clients was in an open area where clients sat in first come and first serve basis. Receiving of clients was conducted by one of the HIV and AIDS counsellors. The counsellor welcomed them and a short prayer was said by one of the clients. Then the counsellor reminded all of them to maintain peace and calm and she also reminded them to remember their unique numbers for them to get data cards from the registry room. After getting the data card from the registry room, they had to go back to their seats waiting to be weighed. They were weighed to determine if they had started gaining weight because weight gain was one of the indicators that the ARVs were working well in their bodies. After being weighed, they waited for their turn to go into the ARV room. While waiting for their turn, they chatted with

each other and in the process laughing. The place was peaceful and orderly. Sometimes they sang songs of encouragement to people living with HIV and AIDS. The song was spontaneously started by one of the women while waiting for the services:

Stanza one

Leader: Kanthu aka aka kadanditengera matenda aka (x2). (This thing has given me the disease x2)

Everybody: Kanthu aka aka kadanditengera matenda aka (x2). (This thing has given me the disease x2)

Leader: Ine n'dula (x2) (I will cut it off x2)

Everybody: Dulaaaa (Cut it off)

Stanza two

Leader: Kanthu aka aka kadanditengera matenda aka (x2). (This thing has given me the disease x2)

Everybody: Kanthu aka aka kadanditengera matenda aka (x2). (This thing has given me the disease x2)

Leader: Ine m'mata (x2) (I will seal it off x2)

Everybody: Mataaaaa (Seal it off x2)

At the time of data collection, there were a few men among the clients waiting to be served and they participated in the song. This song appeared to produce solidarity amongst the group, but importantly was also an opportunity for health promotion. The word “thing” in stanza one means the penis and they will “cut the penis off” to stop it from spreading HIV and AIDS. The leader mimics “the cutting off” of the penis and dances to the tune of the song. In stanza two, the word “thing” means the vagina and they will “seal it off” to stop the vagina from spreading HIV and AIDS. The leader mimics “the sealing off” of the vagina while dancing to the tune of the song as well. The leader would stand in front of the group and started the song, which was popular and created a lot of laughter. They all clapped hands while singing this song. The song kept everybody happy and laughing.

At this point, while they were waiting to go to the ARVs room for assessment and re-supply of ARVs, the qualified counsellor then continued telling all clients about positive living with HIV and AIDS. Then she asked if there was anyone with a special problem so that he/she could be given a priority to be seen by the nurse in the ARV room. On this day, there was no one with a special problem such as acute

malaria or acute pneumonia. If there was one, then the nurse in the ARV room would have seen that person first before referring that individual to the clinician (the medical assistant) who sits in the consultation room if need be. Otherwise, the nurse handled most of the problems by herself. The female counsellor emphasised the importance of being seen by the nurse first in the ARVs room. It is the nurse who will decide whether to refer patients on to the clinician or not.

Registration of clients

An important function of these counselling meetings was also to emphasise to each patient the importance of memorising the unique number that is assigned to each individual attending the clinic. When clients arrived at the ART clinic, she or he would go to the registry room and told the clerk his/her unique number and then the clerk would give him\her his or her card. Then the person went back and sat on the bench to wait for his or her turn to be weighed. After weighing and other measurements were done in the screening room, the person went back to his/her bench. For example, Mr Thalo (pseudonym) was HIV positive and had come to the ART clinic for the first time. He was discharged from the general male ward within the hospital where he was treated for severe pneumonia and malnutrition caused by the HIV infection and referred to the ART clinic to be registered so that he could continue getting the maintenance services for people living with HIV and AIDS. Mr Thalo was still weak and could not walk properly and was supported by his 19 years old son Chalo (pseudonym):

Mr Thalo and together with his son Chalo had undergone the HIV and AIDS counselling process. The counselling process was mainly on the care of the patient data card and the unique number that he was given. Mr Thalo was told that the patient data card would be retained in the clinic each time he visits the clinic for safe keeping. He was told that he needed to remember the unique number that he was given. Because he was still weak, he kept on telling his son Chalo to listen attentively as he relied on him. The unique number was actually his birthday plus the hospital number, making it easy to remember. Once he mentions his birthday, the clerk would easily retrieve his card and give him for the ART procedures. After receiving the care, he would leave the card in the registry room. Mr Thalo was happy and accepted the

procedures. They offered him a cup of tea and he gladly accepted it and Mr Thalo and his son Chalo had each a cup of tea in the counselling room.

Counselling

Every client who was eligible for ART had to undergo counselling irrespective of age, with all HIV positive children accompanied by a guardian who was usually a mother or a grandmother if the mother had died. Counselling was in three steps code named C1, C2 and C3. The registry conducts C3 only and they just verified if the client had understood the information during C1 and C2 counselling sessions, which focused on what HIV was all about, how HIV was spread, how to live positively if found HIV positive and nutrition just to mention but a few examples. In addition, specialist counselling services were offered for women who were pregnant and HIV positive or had yet to be tested. Mother to Mother counselling and Prevention of Mother to Child Transmission of HIV and AIDS (PMTCT) counselling was offered. Nutritional counselling was also done in the same room. It was in the same room that supplementary food was given out to clients of all ages through a programme called Supplementary Food Programme where they gave out Likuni Phala. And there was another food programme called Ready to Use Therapeutic Food Programme (RUTFP) where they gave out Chiponde. Chiponde is a Chichewa name for peanut butter.

Counselling services also centred on strengthening of positive living with HIV and AIDS. The information in positive living counselling service included: Good nutrition, good hygiene, prompt seeking of medical care, avoid drinking and smoking, avoid getting pregnant, avoid worries. Women are encouraged to join support groups that are set in their communities by local non-governmental organization such as Mponela AIDS Information and Counselling Centre (MAICC) or EveryChild or National Association of People living with HIV and AIDS of Malawi (NAPHAM). They also emphasise the importance of safe sex practices such as abstinence and if they cannot abstain, they tell clients the correct use of condoms to avoid re-infection.

Eligibility and starting antiretroviral therapy

- All children provide blood samples for testing as soon as possible from 6 weeks of age so that perinatal HIV infection can be detected so as to allow commencement of ARVs as early as possible.
- Once the child has commenced on ARVs, scheduled visits are arranged. The guardian, who was usually a mother, was counselled on adherence to appointments or the scheduled visits for the ART services to be effective for the child.
- Children under 12 months of age are universally eligible for ARVs as long as they are confirmed to have HIV infection by DNA-PCR regardless of WHO stage and CD4 count or CD4%. Children aged between 12 months and 24 months old are universally eligible for ARVs if confirmed HIV infected by HIV antibody rapid test or by DNA-CPR regardless of WHO stage and CD4 count.
- Children aged above 24 months old and are under 5 years of age are eligible for ARVs if they are confirmed HIV infected by HIV rapid antibody test and WHO stage 1 or 2 and CD4 \leq 750 cell per square millimetres or \leq 25% or WHO clinical stage 3 or 4 regardless of CD4 count. Children aged 5 years and over are eligible for ARVs if confirmed HIV infected by HIV rapid antibody test and WHO stage 1 or 2 and CD4 count \leq 350 cell per square millimetres or WHO clinical stage 3 or 4 regardless of CD4 count.

As a routine procedure, before the child starts ARVs, the guardian and the child receive yet again another counselling process to ensure that they will adhere to ARV regimen. The counselling process is done in groups first and then to individuals later.

This is because ARVs are life -long and require:

- 1) Commitment to lifelong adherence
- 2) Dosage and interval of taking ARVs
- 3) Potential side effects
- 4) Date of next appointment
- 5) Positive living with HIV

I was not able to observe individual counselling sessions because they are strictly confidential.

Scheduled visits are arranged as follows:

- 1) Monthly visits until age 6 months then, three monthly visits from 6 months to 24 months.
- 2) Discharge only after obtaining a negative HIV rapid test at 24 months and if at least 6 weeks after stopping breastfeeding.
- 3) All children who were found HIV positive but not yet eligible for ART are enrolled in the pre-ART follow-up schedule. Visits are monthly then 3 monthly but schedules are arranged that is more frequent visits, if the child is observed being sick and does not gain weight as expected.
- 4) Keep in pre-ART follow-up until the child starts ART.

General screening

All clients who have signs and symptoms of any physical illness are seen by the clinician who sits in one of the rooms at the ART clinic. Clients with opportunistic infections or who have complained of any other diseases are referred to the clinician by the nurse for further management. The clinician prescribes other supportive treatments such as antibiotics. Clients are referred to the clinician by the nurse in the ARVs room. There was no qualified doctor at the hospital only two medical assistants and one clinical officer and they were called clinicians. It is very rare that the clinician will be available to review clients because of shortage of clinicians at the hospital and hence the nurse who reviews clients in respect to ARVs is responsible for such type of services. Although ARVs are the focus, this clinic also carries out a series of checks: nutritional checks, clinical checks, CD4 checks and monitoring treatment failure/drug resistance.

Monitoring of nutritional status

The child is also monitored for nutritional status at each visit and this is part of the ART package. If the child nutritional status is compromised, then the child is

enrolled in food supplement programme. They monitor nutritional status by measuring and examining the child's body:

One boy Tsamba (pseudonym) child who was 4 years old and escorted by his mother Naphale (pseudonym) was weighed and the weight was 26 kilogram. He was looking healthy and happy. His clothes were clean. His height was 93 centimetres. Height and weight measurements are done in nutritional assessment room by the Health surveillance Assistant (HAS) who was not a trained nurse but a qualified HIV and AIDS counsellor. Then the head to toe assessment was done when the child was on his back on a couch. This assessment was done by the nurse in the ARV room because this aspect of measurement could only be done by a qualified nurse because she could properly interpret its findings and gave proper advice to the client. The child was sent home with some ARVs to continue taking them after the assessment. In normal circumstances, there is a nurse in the monitoring room but because of acute shortage of nurses at Mponela Rural Hospital, this is done in the ARV room. At the time of the data collection, there were only six nurses at Mponela rural hospital and this figure included the hospital matron but the hospital official establishment showed that there should have been 15 nurses.

Clinical monitoring

A check list is used to monitor and actively screen every HIV positive child for clinical symptoms at every visit. This is based on the World health Organization (WHO, 2004) check lists of staging for HIV and AIDS.

CD4 monitoring

CD4 count monitoring is done routinely at each visit for children confirmed HIV infected at every 3 months visit who are not otherwise eligible for ART. CD4 count monitoring is stopped once the child has CD4 results or a clinical condition which makes that child eligible for ART. These are spelt out on the check lists for ARVs eligibility stipulated by (WHO, 2004). For more details on this aspect please refer to chapter 1.

Monitoring treatment failure/HIV drug resistance

This is a continuous process until the child dies. This process is life-long as long as the child is on ART. Blood samples are collected every 6 months and sent to the central laboratory in Lilongwe and usually results take about a week to come back and they show which drugs the child is still sensitive to and which ones the child has developed resistance. The laboratory report also includes what type of ARVs should be used to replace the one the child has developed resistance. The above section has discussed the services offered at the out-patient route. The section that follows looks at the services offered at the in-patient route.

In-patient services

The section above the discussion focussed on the in-patient services that are offered at the ART clinic building. A range of services were offered. It was noted that care was sometimes affected by the lack of medical and nursing staff; however observation also indicated that both patients and staff generally worked at achieving a positive atmosphere. The section that follows will discuss the in-patient services and will cover: the in-patient care, nutritional care, the children's ward and HIV and AIDS testing and counselling for inpatients.

The in-patient care

In patient care is the medical service rendered to any patient who has been admitted to various wards of any hospital. In-patient services at Mponela Rural Hospital include: medical, surgical (minor surgeries only), maternity and children in-patient care services. The bed number for male ward was 10, female ward was 11 and maternity ward had 6 beds while children's ward had 55 beds. Therefore, the total hospital official bedstead is 82 beds. The person in charge of in-patient care services was the matron of the hospital who was assisted by one clinician-the medical assistant.

Nutritional care

Mponela Rural Hospital just like any other government hospital in Malawi provided food to all in-patients for free. This is because good nutrition is a major integral aspect of managing patients; without adequate and good quality food, medications do not work well. There are some medicines that need to be taken with food or immediately after a meal. Realizing that the majority of Malawians are poor and cannot afford a good nutrition for their sick relatives that are admitted to the government hospitals, the Malawi government offers food to its patients for free.

The children's ward

The children' ward was in a new building opened in March, 2012 and therefore, everything was new except beds that were old. The official bed capacity for the ward was 55 beds but because of high demand, the hospital management squeezed in the spaces extra beds to add up to 74 beds. However, of the 74 beds, only 30 have mattresses. All beds on this ward are normal single hospital beds, there are no paediatric beds, even though it is a children's ward. The children's ward is a single big hall divided into three bays. Sick children are triaged into the three bays according to the seriousness of the illness. Bay one is close to the nurses' station and it is where very sick children are allocated for close observations. There are 20 beds on this bay and it is always full with very sick children. Bay two is in the middle of the ward with 30 beds. This bay holds children who have improved from bay one and are continuing with treatment. Bay three has 24 beds. This is the bay where one would find chronic and lifelong conditions such as TB, anaemia, and HIV and AIDS.

Allocating and monitoring children within the ward

At the children's ward, at the start of the day the only nurse on the ward prepared her medication trolley and started giving out tablets first bed by bed. There were 56

children on this particular day and 9 children were HIV positive and had developed AIDS:

After the nurse had finished giving out tablets, she started giving injections to all sick children that were on injectable medicines. This took her two hours to finish in the overcrowded ward and it seemed too much work for one nurse. Then she started the process of discharging 15 children home, which took her about 1 hour to finish. But in between, she was also busy admitting new sick children on the ward. There was no clinician to help her out. In normal circumstances, the clinician would be responsible for discharging children home. On this particular day the nurse was doing all these activities all alone.

The nurse also re-assessed all children. The re-assessment and observation of each child in the ward lasted for approximately two hours in total and once a child is confirmed that he or she requires admission, the nurse starts the process of admission, assessment and monitoring the child. For example, the nurse admitted the female child called Chimwemwe (pseudonym) aged three years under the escort of her mother called Nachisale (pseudonym) based on the visible clinical signs and symptoms of cerebral malaria:

Nachisale brought Chimwemwe to the ward from the OPD accompanied by three other women. The nurse quickly and politely took Chimwemwe from her mother Nachisale and laid her on the examination couch in the examination room. Then the nurse started examining Chimwemwe from the head to toes. The nurse looked in Chimwemwe's eyes, lifted one hand at a time and then the legs in a similar fashion. Each time the nurse lifted the Chimwemwe's legs, Chimwemwe screamed. This is a sign of cerebral Malaria or meningitis. The nurse placed a mercury thermometer in Chimwemwe's armpit. After three minutes, the thermometer clicked and the nurse removed it from Chimwemwe's armpit and the body temperature reading was 38 degrees Celsius. Therefore, Chimwemwe had fever of 38 degrees Celsius. Chimwemwe was also vomiting; had fast respirations of 26 breaths per minute. Chimwemwe was admitted on bay one for quick action and close observations. Then the nurse withdrew blood from Chimwemwe's

left arm and sent the blood sample to the laboratory for rapid malarial parasites testing that takes about fifteen minutes. After withdrawing blood from Chimwemwe's arm, the nurse immediately connected an intravenous drip of quinine to the needle that was still in situ into the vein of Chimwemwe. Within fifteen to twenty minutes, the laboratory results were out and they showed that Chimwemwe had malarial parasites 4+. The nurse then politely started asking some questions in relation to Chimwemwe's illness. One of the questions that the nurse asked Nachisale (the mother) was that *"for how long Chimwemwe had been sick?"* and Nachisale answered that *"it was about late in the afternoon that the previous day that the child only said he had experienced headaches but was playing well with friends. Then it was this morning that she just started shaking the whole body continuously. Then I told my neighbours and we brought her here."*

By that time, Nachisale was very apprehensive and her voice indicated that she was anxious and not herself as she was stammering in her response to the questions. Nachisale had put on an old and torn dress that appeared to have been washed some few days ago and came from the villages surrounding Mponela Rural Hospital: Then the nurse reassured Nachisale that everything would be fine with Chimwemwe because Chimwemwe had cerebral malaria that would be treated quickly with quinine. Nachisale was sweating profusely, and looked very anxious. The nurse also asked Nachisale what Chimwemwe had eaten before the onset of the shaking of the whole body. Nachisale answered that *"the child had eaten m'gaiwa porridge."* Nachisale had her Chitenje (a traditional piece of cloth used by women to wrap around their waist) tied her waist not the usual manner, a sign that she left her house in a hurry. She looked really worried. Then Chimwemwe was continued with the intravenous quinine after the laboratory results confirmation that she had cerebral malaria. By the third day, Chimwemwe had improved and body temperature dropped to 37 degrees, was playing with other children. Chimwemwe was discharged home on the fifth day of her admission.

Therefore, the nurse made these important decisions based on her detailed re-assessment of each and every child. The admission procedure included re-assessing sick children to determine if indeed they needed to be admitted. Nurse 1 was re-

assessing them because some children were rushed through to the ward from the out-patient department without proper assessment. I observed that some children required taking home treatment while others indeed needed to be admitted.

The nurse allocated sick children to the bays according to the seriousness of the illness of the child. Those that were very sick were placed on bay one that was closer to the nurse's station and those that were not so seriously sick were put on bay two and those recovering were moved to bay three. The triaging was made based on her assessment of the children. Children that had signs and symptoms of a serious condition such as cerebral malaria were placed on bay one. Most children who were placed on bay one had high fever of about 38 degrees Celsius, neck stiffness, vomiting and at times diarrhoea. Later in the afternoon she prepared discharge slips for the children that she had discharged. On this particular day, the nurse re-allocated 11 children from bay one to bay two because all these children had improved and therefore needed to continue treatment on bay two. In so doing, she created space for new critically sick children that required to be observed closely, hence allocating them to bay one. On this day, she allocated four children to bay one. There were some cases that she needed to refer to the clinician.

For example, there was a ten year old male child called Lirani (pseudonym) under the care of his mother called Naliwodi (pseudonym). Lirani had projectile vomiting and the nurse immediately called for the clinician to re-assess Lirani. The clinician re-assessed Lirani and the nurse and the clinician together, decided to refer Lirani to Dowa district hospital for further management. At that time, the working and tentative clinical diagnosis was "*query intestinal obstruction.*" At the same time, the nurse was also started counselling Naliwodi because Naliwodi did not want Lirani to be referred to Dowa district hospital as it was far from her home village and that it was going to be difficult for her relatives to visit her with food items such as nsima. Later after lengthy discussions Naliwodi accepted that Lirani be referred to Dowa district hospital for further management.

HIV and AIDS testing and counselling for inpatients

HIV and AIDS counselling started for the newly diagnosed after the child's condition had stabilised and then the nurse on the ward referred them to the HIV and AIDS counsellor who worked at the ART clinic. Every mother who had been admitted with the child had to go through HIV and AIDS counselling. It is the policy of the Malawi Ministry of Health. However, consent was still obtained from the mother prior to HIV counselling and testing process. The mother would give a verbal consent first and then a written one was done at the counselling room with HIV Testing and Counselling (HTC) counsellor. Routine confirmation of HIV infection for the child was done by 1) asking the mother about most recent HIV test and review their health passport for previous HIV test results. 2) Offering HIV testing if never tested, tested negative more than three months, and 3) the mother claims to have undergone HIV testing at any time in the past but without documentation. Every child to be tested for HIV is referred to ART clinic for a detailed process of HIV Testing and Counselling. For example:

One lady Mayi Phale (pseudonym) had come with a two year old male child called Dala to the children's ART clinic. Mayi Phale was referred to the ART clinic from the children's ward. Dala looked weak and emaciated and had marked weight loss. Mayi Phale had dressed in a clean but old dress and she looked miserable and sad. She looked worried and very concerned with Dala's illness. Mayi Phale explained to the nurse that Dala was having a hot body all the time for the period of three weeks. When the nurse had checked the body temperature, it was 38.6 degrees Celsius. The nurse then asked Mayi Phale "*if Dala had been tested HIV before.*" Mayi Phale stated that "*no, the child had never been tested for HIV.*" Then the nurse started the counselling process that lasted approximately 1 hour and 45 minutes. The HIV test was done and the Dala was HIV positive. Mayi Phale requested that she should be tested as well. She was tested according to her wish and she was HIV positive too. Mayi Phale was a widow and her husband died some three years ago while she was still pregnant for the two year old Dala. Mayi Phale looked depressed with her being HIV positive and the post HIV testing counselling continued by another counsellor in another room. In that room,

Mayi Phale was told that it was good that she had gathered courage to be tested HIV because if she would see such signs and symptoms as continuous fever over a month, frequent bouts of diarrhoea, coughing, and unexplained weight loss, then she would report to the hospital immediately for treatment. She would be commenced on ARVs. Mayi Phale was told that her child would be commenced on ARVs on that day. Mayi Phale's mood brightened and she was referred back to the nurse in the ARVs room to continue the management of the child and that of herself.

Importantly, it demonstrated how women were often only diagnosed HIV positive because their children became sick, admitted to the hospital and tested. The section that follows describes the discharge of a child from the hospital.

Discharging a child

Discharging a child from the hospital is discussed under following subheadings: who conducts the discharges, category one discharges, category two discharges, category two discharges and category three: death.

Who conducts the discharges?

The nurse usually conducted daily routine rounds to assess children so that she could discharge those that had improved to continue treatment at home to reduce overcrowding in the ward. This was a routine activity of every nurse to re-assess her or his patients on the ward and she or he included the assessment findings into his or her day duty report. The discharge process of children was in three categories:

Category one discharges

This was a child who was discharged after being treated for an illness and that child was HIV negative. This was a straight-forward discharge process. The nurse gathered the child's paper work that was processed during the admission period. She also gathered the hospital discharge slip book where she would write the discharge details. This book was in triplicates. The discharged patient took the original

discharge slip. The other two slips are left in the book for hospital records purposes and use.

Category two discharges

This was the discharge of a child living with HIV and AIDS and was on ARV treatment but had suffered from other opportunistic infections. The discharge process for such a child was in two phases. They are the phases of the opportunistic infection or general illnesses such as pneumonia and the phase of HIV and AIDS. During the discharge of the HIV and AIDS phase, the nurse started the process of checking with the mother how to give the ARVs at home and she corrected where the mother made a mistake or reminded the mother if she had forgotten some aspects of giving ARVs to the child while at home. Then after this discussion, the guardian was sent to the pharmacy to collect the ARVs and returned to the ward to deposit the child's case file. Then the guardian went again in the private counselling room for the discussions with the nurse about giving of the ARVs at home. For example, there was a 9 year old boy child called Thanzi (pseudonym) who was under the care of his mother called Mayi Thalo (pseudonym) who was discharged home after he was treated for bilateral pneumonia.

Mayi Thalo had gone through the general discharge process with the nurse first and then the HIV and AIDS (ARVs) discharge process:

Mayi Thalo was lead into the room that was used for HIV and AIDS counselling and I was not allowed to attend the meeting because it was confidential and private. The meeting took approximately 1 hour 45 minutes and Mayi Thalo was seen going to the pharmacy with the child's case file for the second time. When she had come back, she went straight into the same counselling room and the nurse immediately followed her into the room. That time, they took about 20 minutes and Mayi Thalo and the nurse were observed happy and laughing. Mayi Thalo looked relaxed and happy. Then Mayi Thalo started bidding farewell to other mothers who had sick children on the ward. They looked happy and enjoyed each other's company. Then Mayi Thalo came to us and bade farewell by shaking hands with the nurse and me. Mayi Thalo asked for transport because she came by an ambulance but at that time the ambulance had gone to the field to pick other patients to

bring them to the hospital. Therefore, she was given K2, 000.00 (£5) by the researcher for transport. She was very happy and appreciated it by asking the researcher to visit her and her child at her home. We exchanged jokes there and then Mayi Thalo and her child Thanzi left for their home. This child was not recruited for the study.

Category three: death

Category three was discharging a child who has died. This was one of the most difficult and laborious discharge processes. When the child had died in the hospital, the nurse called the clinician to certify the death. Or if there was a nurse trained to certify death, then that nurse would certify it. The death certificate was signed by two clinicians thus the one who certified the death and the witness. After this process, the child's body was prepared and the procedure is called the Last Office (LO). Relatives were allowed to observe the whole LO procedure to ensure that some cultural values are observed such putting the hands and legs straight and covering the mouth and nostrils. After the LO procedure was done, the nurse and the guardians, would take the dead child to the mortuary for safe keeping until the relatives agreed when to take the dead body home for burial.

The above section of this chapter has looked at two main routes of hospital services the out-patient route and the in-patient route and the services that are offered to patients on t both routes. The section that follows will look at the services that are provided by the non-governmental organization within Mponela rural Hospital catchment area.

Non-governmental organizations (NGOs) at Mponela

This patient group also have access to support and treatment from a range of NGOs. There are three main NGOs at Mponela Trading Centre (MTC) whose main objectives are to mitigate the impact of HIV and AIDS among people living with HIV and AIDS within Mponela Rural Hospital catchment area. Two of these are; Mponela AIDS Information and Counselling Centre (MAICC) and National Association of People Living with HIV and AIDS of Malawi (NAPHAM) who

target both adults and children, while EveryChild targets any vulnerable child including those living with HIV and AIDS. Interviews were conducted with all the three NGOs and field notes were taken too. Most of their activities are similar in both design and implementation. The paragraphs that follow look at one of the non-governmental organization- Mponela AIDS Information and Counselling Centre (MAICC).

Mponela AIDS Information and Counselling Centre (MAICC)

This local non-governmental organization (NGO) was established in 1992 by local people at Mponela Trading Centre “*with the support from Dowa District Health office (DHO).*” The main aim then was to reduce the incidence of “*Sexually Transmitted Infections (STIs)*” that were high at Mponela Trading Centre. The group that started it named it *Mponela Trading Centre Support Group (MTCSG)*. MAICC as a local NGO has its net cast wide in terms of its activities. MAICC focused on many activities but the most notable ones included: teaching, supply of various items, Children therapy clinics, anti HIV and AIDS clubs in schools, supply of farm inputs, the village bank, education fund and field trips. Members for MAICC are people living with HIV and AIDS *but they must pay a fee of 100 Malawi Kwacha* which is equivalent to 5 pence. The officer in charge of MAICC discussed their services:

Community out-reach activity

The researcher accompanied the community out-reach team to Mdolera Village AIDS group that was some 20 km away from the office. At the community, the activities are led by the village headman and he takes charge of all the activities. He was directing where and who to help. The team was divided into child growth monitoring, nutrition supplement, clothes or blankets distribution, agricultural and treatment teams.

Services and support for children living with HIV and AIDS

MAICC had established a clinic for children living with HIV and AIDS. These clinics are for its members only. They call them “*children therapy clinics*” where they teach parents good “*personal hygiene*” and they also “*encourage parents to send children to school*” despite that the child has “*the small animal.*” MAICC encourages parents to send their children to school because the sick children have “*the right to education too*” just like any other normal child. This is because being HIV positive “*is not the end of life.*” The officer in charge of MAICC confirms this in the narrative below.

“But we also have in every month; we have what we call children therapy clinics. This is a group of activities that are done for every child. We teach parents on hygiene, encouraging parents to send the child to school. As you know that people usually say that when a person has the small animal then that means that is the end of life. But we encourage sending the child to school so that the right to education is fulfilled. We also work together with health advisors that live in the villages so that they can reach out to such parents in the villages. In short the centres are used for growth monitoring, health education, hygiene measures and all the immunizations are done there.”

Nutritional services

Children living with HIV and AIDS were given 10kg of Likuni Phala each irrespective of the weight and age of the child and as long as that child was registered with MAICC as a member. Then they were referred to Clothes and blankets distribution team. In addition, children who are HIV positive are weighed and Mid Upper Arm Circumference (MUAC) is taken too. After this stage, children and their mothers are referred to nutritional supplement team. There is no talking or counselling but charting with clients asking them if there were any problems in a very informal way.

Clothes and blankets distribution team

All children living with HIV and AIDS were given a shirt and a short if it is a boy and a dress for the girl. They gave to any child as long as that child is their member. However, there was a problem with the distribution of items because some mothers claimed that the village headman had included his relatives' children on the list who were not HIV positive. Therefore, the distribution of clothes was temporarily suspended to sort out the problem. This problem was solved by following a list that the team had brought from Mponela and disregarded the village headman's list much to his annoyance and he left the place in protest.

The problems of access to support and corruption

The team leader had to call what was called a crisis intervention meeting with the group members. All group members were either HIV positive or have a child who is HIV positive and were registered members of MAICC. MAICC works through the groups and not through individuals. If someone does not join the group, that person does not benefit from MAICC activities. I attended this meeting and it was a very hot meeting and women were very angry with the village headman and demanded that he should be replaced with another village headman who was a woman and they believed that she was an honest woman. It was also alleged that he was selling items that MAICC could bring to the community for him to distribute to bonafide beneficiaries.

The Mponela team had no choice but to call the beleaguered village headman and asked him what had been happening. He accepted all that was said against him and he accepted to be replaced by another woman village headman. Everybody was happy with what had happened. Women danced after the village headman was replaced with a village headwoman. It looked it had been their wish to replace the village headman judging from the ululation and the dancing of the whole group of women. One of them was heard saying that *"I am extremely happy because he was pompous with poor people's items. He took them as his properties. We are equal now. We will be suffering at an equal footing."*

In total, we had seen 46 clients and out of these, 31 were women. 16 of the 31 women had their children who were HIV positive and the mothers were HIV positive too. The researcher joined in the meeting MAICC officials organized where it was decided that the officer in charge at MAICC should go and sort out the problem between the village headman and clients regarding distribution of items to eligible beneficiaries because the crisis intervention was temporary and outside the regulations of constituting a group's leader. It was done to calm down the situation. The MAICC team from Mponela promised to go back to the group to elect other committee members to serve for a period of two years. The team out reach left for Mponela late in the evening around 6pm and the researcher reached his Lilongwe base late in the night at 9pm.

This was one of the most interesting activities as the researcher saw for himself what most caregivers interviewed had been talking about - that is the behaviours of some village headmen regarding distribution of relief items to eligible beneficiaries. What the researcher had observed is that none of the participants who were recruited in the study were members of MAICC group, therefore could not benefit from MAICC activities. No wonder therefore, they did not talk or know about MAICC's activities.

Losing clients to death

MAICC further states that "it lost" many of its members during the period that ARVs were in acute short supply. It attributed "the loss" of its members to the fact that they could not manage to access ARVs because the ARVs were available in central hospitals only. Their members could not manage to go to such hospitals because it was far and outside MAICC' catchment area and therefore, they could not manage to give transport to its members and it affected almost everybody. The problem was too big for MAICC to handle as a local NGO.

"Not many people could manage to come and get ARVs from a distance of 60km on foot. In the process, we have lost many of our members through deaths. Now we have an ARVs clinic opened at Kayembe and there many people living with HIV and AIDS. But also we have transport and if the hospital does not have enough transport we provide our vehicles to help out so that our members still get the ARVs. The hospital can have all the necessary items but they don t have transport we give them.

We give them the vehicle so that we reach out to people in time. We also have motor cycles and sometimes we give them so that they can still help our members in the villages.”

However, MAICC explained that the situation had improved because the United Kingdom government that supports the purchase of ARVs in Malawi had pledged to support the health delivery system by way of buying ARVs for people living with HIV and AIDS. *“But it looks like things are going to improve as donors especially UK had pledged to resume support to health system in Malawi. They buy ARVs for our clients through ministry of health.”*

Conclusion of the chapter

In summary, the hospital and NGOs supported women caregivers of children living with HIV and AIDS in this area to their children only and not the caregivers themselves. The hospital supported the women caregivers by offering in-patient, outpatient and ART services to their children living with HIV and AIDS. The hospital provided HIV testing and counselling, provision of ARVs, nutritional supplements, growth monitoring, CD4 monitoring, clinical monitoring and monitoring of ARVs side effects. There was usually a great deal of anxiety when guardians awaited HIV tests results that could have been positive or negative. If the child was HIV negative, the child was weaned from ART services but if found HIV positive or born to HIV positive mother, the child was registered for ART services at the clinic. The care and support focussed on children living with HIV and AIDS and not their caregivers hence, they were missed too even in the hospital.

In addition, there were other support services available to women caregivers in this area from non-governmental organizations such as MAICC but they needed to conform to the policies of such organizations such as enrolling as members for a membership fee of 100 Malawi Kwacha (5 pence) which and was paid once many could not afford. But this group of women caregivers were missed by NGOs as they reported that they did not even know the existence of such NGOs despite that the NGOs have been operating in this area since 1992. ART clinic at Mponela Rural Hospital was well organized and helped the clients with passion but the staffing

levels were not adequate. Both the government hospital and non-governmental organizations offered free services to women caregivers of children living with HIV and AIDS at Mponela Rural Hospital catchment area apart from the membership fee that the non-governmental organizations were charging. This observational data had some benefits. The benefits for generating this observational data were for the study and for the researcher's understanding of the women caregiver's experiences. The chapter that follows is the discussion chapter and it concludes recommendations for the study.

Chapter 10

Discussion and recommendation

Introduction

In chapters 5a to 9, the findings of this study were discussed. In this final chapter the focus is on key points that the findings chapters have revealed. These key points include the extensive caring responsibilities in caring for a child with HIV, the invisibility of these women caregivers, and their lives which were characterized by a lack of support from family members, their community, governmental and non-governmental organizations.

This study provides a number of key theoretical contributions to the field: the significant role men played in decision-making and the invisibility of women in the context of HIV. It has also revealed the culturally sensitive issue of men making decisions about the health of women caregivers and their children, which meant that these women caregivers were rendered powerless to make decisions about their own or their children's health. An important impact of their invisibility was that these women caregivers predominantly discovered their own HIV and AIDS status late and after they had discovered their children's diagnosis. Late diagnosis meant that they neglected their own health status as they concentrated on the health of their children and this had an impact on the long-term caregiving.

An additional key finding was that these women caregivers were selective in their disclosure of their HIV and AIDS status for fear of being stigmatized and shunned by their family and community members. They all experienced some form of stigma as they took care of their children living with HIV and AIDS; however, they had strategies of strategic disclosure in response to stigma. Despite all of these issues, these women caregivers remained resilient and highly motivated. They lived in very resource limited settings of rural Malawi but they continued to provide care and all had strategies of how to find resources and support their children. Lastly, this study demonstrated that these women were able and interested? in being involved in qualitative research and take part effectively in interviews.

Caring responsibilities

The extensive caring responsibilities of the women caregivers reflect the findings from other studies conducted in different countries. Care and support to sick individuals in families is borne by family members and most are women family members (Fishman, 1978; Glaser, 1987). The care and support are considered private and usually not supported by governments or any agency or institution such as other families or indeed other family members within the family (Daniels, 1984; Boulding, 1985 and Glaser, 1987). As seen within this study, women caregivers were the private and primary caregivers to their children living with HIV and AIDS and were always the sole providers of care. Women caregivers' caring responsibilities were extensive and they were on their own in supporting their children and in judging when they needed treatment, carrying out the everyday care and providing the support to ensure they were cared for adequately.

In this study women caregivers worked as primary caregivers to the children living with HIV and AIDS, however, they were not recognized as caregivers by their family members, their community and policy makers and hence they were invisible and their caring was of an invisible nature too. This scenario made their caregiving activities a big challenge for them and they had to work hard by themselves to find basic resources for the caring activities despite the fact that they were often sick too. This finding is supported by Chimwaza, et al. in 2004 in their study in a southern district of Balaka in Malawi where they studied individuals who had symptoms of a chronic disease including HIV and AIDS but were not diagnosed HIV positive. They also found that care providers to such a group of patients were not supported either within the family or outside the family within the community.

Women caregivers in this study were providing care to children that were known to them. Daniels, (1984) and Boulding, (1985) state that this is a key factor in ensuring that the care is less traumatic psychologically to the child. However, these women caregivers were not adequately supported by anybody in their own families and communities. These factors were likely to have had an impact on the health

outcomes for the children being cared for, as well as on the health of the women. The challenges for these women were compounded by the fact that they were living with their children in severely deprived settings and in abject poverty. Whilst these women caregivers provided what they could, they all experienced a severe shortage of the materials needed to provide good care.

Invisible nature of caring

The unpaid work conducted in families by family members in most cases is not recognized by anybody within the family or the community at large (Glaser, 1987; Boulding, 1985; Daniels, 1984). The unpaid work conducted by family members includes caring for the child (whilst they are sick or well), housekeeping activities and sourcing food and other resources the family needs to survive. However, because this unpaid work is done in families by family members, it remains unnoticed and the caregivers remain invisible too (Glaser, 1987; Boulding, 1985). Such work is also carried out by women in most societies around the world, because men are traditionally in paid work to support the family and are mobile and therefore, women caregivers remain invisible (Glaser, 1987). In addition, Fishman (1978) and Glazer (1987) agree that child caring is particularly the work of women in many societies around the world because men do not show interest to take part even if they are not in a paid work, as it is seen as low status work.

Women caregivers in this study were invisible because they were in unpaid work carried out within the families by mothers, aunts and grandparents. The women caregivers also experienced isolation and the end result was that women caregivers felt that they did not have the resources to provide the standards of care that they wanted. They were unnoticed by their own family members and communities, government and non-governmental organizations. A consequence of these women caregivers' invisibility in their own families and communities was that it led to delayed HIV and AIDS discovery for themselves with the result that their own illness went unnoticed too.

HIV and AIDS discovery

In this study, women caregivers' HIV and AID diagnosis was delayed because it depended on the health status of others; the children they were looking after were diagnosed first. In some situations, women caregivers' diagnosis was delayed because other tests had to be done first such as the diagnosis of tuberculosis, even though their children already had a diagnosis of HIV. Therefore, women caregivers in this study discovered about their HIV diagnosis late and their HIV infections often meant that their condition has deteriorated by the time they were diagnosed, and they were so weak that they required to be admitted to the hospital. This delayed their treatment and potentially had a negative impact on their long term outcomes. The delayed diagnosis or neglected health of the women caregivers' meant that they got sick and became weak and could not look after themselves or their children effectively.

Husbands made decisions

An important finding is the impact of gender on these women's experiences. Culturally, women in all the countries in Sub-Saharan Africa must seek permission from their husbands regarding their health; be it reproductive or general health including seeking a test for HIV (Rutenberg, et al., 2000; WHO, 2005). Married women cannot seek health care services without consulting their husbands because doing so will be regarded as disrespectful to the husband and such a woman would be reprimanded by a group of elderly women in that community (Rutenberg, et al., 2000; WHO, 2005). Men are the gatekeepers of general health care in their families (Rutenberg, et al., 2000). In this study, women caregivers' decision to take or seek health care services depended on the husband's decision. This study's findings have shown that husbands were the gatekeepers of health of the family members including the care in the families despite the fact that they didn't take part in the caregiving activities or take part in family life or everyday family support. Consequently women caregivers' health and that of their children depended on the decisions made by their husbands who were largely absent from the home. This had a number of consequences.

Firstly, women caregivers were not aware about the HIV seropositivity of their husbands because they were not consulted or told about their husbands' HIV status. Husbands being decision makers in families, decided not to inform their wives if diagnosed HIV positive. This culture of secrecy meant that wives became infected with the virus. The other consequence is that women had to consult their husbands to seek health care services and this in itself delayed their HIV diagnosis as it appeared that men could not grant the permission to do so for fear of being indirectly discovered that they were HIV positive if the woman was tested HIV positive.

The other consequence is that caring activities for the child in general were affected as the woman would be sick and could not seek health services until the husband had decided. The far reaching results of this was that either the child would die or the woman herself would die leaving the child living with HIV and AIDS without a mother who was the primary caregiver. In this study, women had no say in decision-making and were unable to protect themselves or their children from risky behaviour from their husbands; and most of the husbands were reported to have had multiple sex partners. This meant that the husbands delayed the health seeking behaviour of the women and women's conditions worsened as it meant delayed discovery of HIV and AIDS and access to its supportive treatment. Despite all this culture of controlling behaviour and secrecy of men in the families, men also denied responsibility of HIV and AIDS situations and in itself, delayed the health seeking behaviour of the whole family.

Disclosure and stigma

While the importance of stigmatizing aspects of HIV has been widely acknowledged, very little consideration has been given to how social stigma interacts with HIV disease components in the illness experiences of HIV infected individuals and their outcomes (Muller and Poggenpoel, 1996; Alonzo and Reynolds, 1995). Stigma as a concept in social science studies has been defined by various authors. Stigma is a multidimensional concept that centres on the issue of deviance (Greeff, et al. 2008). Goffman (1963) defined stigma as an attribute that is deeply discrediting within a particular social interaction. This term stigma as defined by Goffman refers to both a trait and outcome of being known to possess that trait (Greeff, et al., 2008).

In this study, women caregivers used a selective approach to disclosure of HIV and AIDS and only disclosed to people that they trusted such as family members and key community leaders such as the village headmen. Stigma and disclosure of an illness are inter-related and they influence the management of that illness (Greeff, et al., 2008). Disclosure refers to voluntary telling someone of one's concealed phenomenon (Sandelowski, et al. 2004). HIV and AIDS disclosure therefore is voluntarily disclosing without consent to someone and people living with HIV and AIDS maintain control over decision to disclose, selecting disclosure styles that range from full to selective disclosure (Sandelowski, et al. 2004). Hence disclosure without consent means revealing the HIV positive serostatus and this has a major role in the management of HIV and AIDS (Greeff, et al., 2008).

Chandra, et al. (2003) explains that the process of disclosure itself might be inherently stressful, even in cases with positive outcomes. Therefore, to facilitate better outcomes for people living with HIV and AIDS, and their significant others, one needs to examine factors that contribute to the decision to disclose (Chandra, et al. 2003; Sandelowski, et al. 2004). Chandra et al. (2003) state that some of the factors that influence disclosure decisions include anticipated disruption of relationship, fear of discrimination, concerns about employment benefits, the desire to protect oneself and others emotionally, protecting oneself from possible physical and verbal abuse, stigma concerns, concerns about confidentiality, timing, access to care; treatment and support, access to group therapy, and involvement in protection initiatives. In this study, women caregivers were motivated to disclose to others based on trust, but also because of the precariousness of their employment and because there was no support or safety net available to them.

Who to disclose to

Studies have shown that people living with HIV and AIDS make decisions who to disclose their HIV status based on various reasons. People living with HIV and AIDS prefer to disclose to close relatives such as children, partners (wife or husband), parents, family members, employers, health care workers, key people in their communities and close friends, (Greeff, 2008). In this study, whilst some

women caregivers said they didn't experience stigma, they all reported some level of stigma that ranged from not sharing basic things such as salt, not eating with them to being treated as the already dead people. In response, they all had strategies of who they felt they could disclose to and who they could not to avoid being stigmatized. They disclosed only to people that were close to them and those that they trusted. The disclosure decision based on trust came from the belief that the individual to be disclosed to could keep the information to herself or himself.

Courage to disclose: factors that facilitated disclosure

Most husbands appeared not to accept that they could be responsible for having brought HIV and AIDS in the family. As seen in this study, husbands refused to be responsible for the HIV status in the family instead, they blamed their wives for bringing HIV and AIDS in the family. Husbands did not inform their wives that they had been diagnosed with HIV and this culture of secrecy hampered disclosure and brought mistrust and animosity in families. Similar findings were noted in Greeff, et al. in 2008 in the five Sub-Saharan African countries of Malawi, South Africa, Botswana, Lesotho and Swaziland where partners reacted negatively to HIV positive status of their partners and animosity was seen too. In this study, it was one of the reasons why women didn't disclose, if women disclosed they were often blamed by men and their families for bringing HIV and AIDS in the family.

Managing stigma and disclosure

There are few incentives to motivate people living with HIV and AIDS to disclose their HIV positive status (Greeff, et al., 2008). Although deciding who to disclose to is a major stressor and holding back one's feelings may result in even more stress which may negatively impacts physical health, it is still imperative that someone knows one's HIV and AIDS status (Sandelowski, et al. 2004). Therefore, HIV and AIDS disclosure requires courage (Greeff, et al., 2008; Sandelowski, et al. 2004). Literature has shown that people living with HIV and AIDS manage stigma and disclosure by weighing the benefits of disclosure versus non-disclosure. At first, the reaction for family members and the community following HIV and AIDS disclosure is negative (Greeff, 2008; Sandelowski, et al. 2004). And this prevents others from

disclosing and denying the care and support from family members but fortunately, the negativity by family members and the community is often short lived and in turn, the family and the community slowly start to empathize and support the individual living with HIV and AIDS (Chandra, et al., 2003).

Stigma still exists in rural areas of Malawi as this study can reveal. In order to manage the stigma of their diagnosis, women caregivers in this study had developed strategies to deal with them. Although a small number talked openly about it, the majority chose to disclose only to very close family members and to key people in the villages such as the village headmen or village head women and some church leaders. The close family members that they disclosed to were parents, brothers, sisters and uncles. These women had to manage stigma and blame from their husbands, family members and the wider community some overt some subtle. Stigma is a barrier to effective care and support for people living with HIV and AIDS (Greeff, 2008; Sandelowski, et al. 2004). This barrier meant it was also hard for them to seek help from anybody else. In this study, there were additional barriers too such as in some communities, community members became jealous of the good care women caregivers gave to their children living with HIV and AIDS. Most health related studies have indicated that people living with HIV and AIDS prefer to disclose to immediate family members first and key or significant others as also seen in this study where women caregivers preferred to disclose to family members first and key people in their communities (Chandra, et al., 2003). The results of this study on stigma and disclosure has led to a better understanding of the experiences of disclosure as a whole because it has unearthed the hidden cultural sensitive issues in marriages regarding HIV positive status just as other studies had found (Sandelowski, et al. 2004). Stigmatization may lead to silence, denial and secrecy, and may affect not only care and support (management) but also it has serious implications in prevention (Greeff, 2008; Sandelowski, et al. 2004).

The main challenge and survival strategies

In this study, the main challenge that women caregivers had was that they received no support from family and community members. However, women caregivers had their strategies to survive in such an environment. They worked hard to care and

support their sick children and their success was sometimes looked upon with jealous and suspicion by the wider community members. They also worked very hard to find resources by conducting piece work in other people's gardens and houses. These survival strategies had worked for them, although at times they had nowhere to find piece work because the poverty levels were high in their community and that affected almost everyone.

Resilience and challenges

A key unexpected finding was the resilient response of the women to their situations. Resilience has been identified in other studies of caregivers. All families face challenges and crisis of varying degrees (Walsh, 2007). The crisis may range from sudden death of a family member to a family member living with a life-long disease such as cancer, HIV and AIDS and diabetes (Walsh, 2003). Family members charged with responsibility of caring for a family member may develop resilience when they take care of such a family member (Lin, et al. 2013) or face challenges such as death of a family member. However, studies have so far not shown **how** families develop this resilience and become motivated by these challenges or crisis (Patterson, 2002; Bayat, 2007). The concept of family resilience extends to the understandings of family functioning to include situations of adversity (Walsh, 1996; Walsh, 2003). Although some families are shattered by the challenges of a crisis or chronic conditions that induce continuous stress, what is remarkable is that many other families or family members emerge more resourceful and strengthened (Walsh, 1996; Walsh, 2003; Bayat, 2007).

Bayat (2007) explains that despite a growing interest in studying resilience in families, the topic has not been extensively explored in families with children who have disabilities or a chronic disease such as cancer or HIV and AIDS. Lin, et al. (2013) further adds that a caregiver who is usually a family member is under severe stress. The stress is continuous especially in family members who look after a child with chronic condition such as HIV and AIDS or cancer, as was the case in my study (Walsh, 2003; Lin, et al. 2013). The stress levels are of varying degrees with types of stress that may include emotional, social, cognitive, and instrumental imbalances that may disturb family welfare and functioning (Walsh, 2003; Bayat, 2007).

Experiencing hardiness in life is attributed to developing resilience (Lin, et al. 2013). Hardiness here means persistent, firm, and unwavering determination and having an inflexible will that is unyielding, while resilience means the ability to accept stressors but not internalizing them (Lin, et al. 2013). Researchers have analysed the defining attributes of hardiness that include determined attitudes of confronting influences that result from stressful conditions, rising up in resistance, enduring the hardship process, actively participating in the caregiving and believing in power of one's own behaviour to influence a situation (Lin, et al. 2013). Researchers agree on the measurement and attributes of resilience but not the factors that help family members develop resilience (Sinclair and Wallston, 2004). The personal attributes that researchers agree on include high moral standards, tenacity, personal competence, trust in one's personal strength and judgment, tolerance of negative effects, instincts, strengthening effects of stress, secure relationships, positive acceptance of change in one's life, control and spiritual influences (Sinclair and Wallston, 2004). But how resilience is developed or not needs further research.

In this study, women caregivers had many challenges related to caring for a child living with a life-long condition (HIV and AIDS) in the very limited resource setting of rural areas of Malawi. The major challenges were lack of material, monetary and food support for them to take care of children living with HIV and AIDS. In addition, the other major challenges were that men controlled decision making and there was a culture of secrecy in families and a broader context of stigma about the condition. Despite these challenges, women caregivers demonstrated a spirit of resilience as they continued providing the care despite acute shortage of necessary resources required for effective and good caring. They had clear strategies of finding resources in a hard way. They worked hard in other people's gardens to find money to buy food and other necessary materials needed for caring a child living with HIV and AIDS. They were growing food cash crops for food and money but at very small scale that the proceeds from the farming lasted only for four months in a year.

The big question is **how** do these women caregivers manage to be resilient and highly motivated in such a hard to reach areas of Malawi where resources for caring a child living with HIV and AIDS are so scarce and poor and they received no

support from their family members and the community at large. The findings of this study suggest that the crisis that women caregivers experienced led to an enduring ability or capacity exhibited as resilience and strength of a caregiver when responding to a chronic stress and problem-solving. Women caregivers in this study have shown that resilience is a capacity to deal with a stressful situation in a positive and diligent sense.

Their narratives reflect some of the attributes described in other studies e.g. trust in one's personal strength and judgment, tenacity and spiritual influences. However attributes identified in other studies such as secure relationships and sense of control were less evident. This is an area that needs further research too.

Discussion of Methods: women caregivers' involvement in research

People in rural, poverty stricken areas are usually referred to as "others," being geographically and socially positioned outside mainstream communities and denied the same opportunities as people in mainstream communities (Jonson, et al. 2004; Atkinson and Flint, 2001). In this study, the women caregivers lived in rural and hard to reach areas of Malawi. Accessing them was difficult due to poor communication infrastructure such as poor roads. Studies have shown that people living in such hard to reach areas with poor roads and no telecommunications (Atkinson and Flint, 2001; Freimuth and Mettger, 1990) are often marginalized in all aspects of life. Because of these preconceptions, people living in these rural and remotest areas are rendered powerless; and are left isolated by policy makers at governmental and non-governmental organization levels (Freimuth and Mettger, 1990; Atkinson and Flint, 2001). People living in hard to reach areas are rarely accessed by study teams and hence may not have experience of taking part in research or of being interviewed. If interviewed, they may talk less and show a great deal of anxiety and it is hard to persuade them to talk (Freimuth and Mettger, 1990). Similar findings were noted by Carmack's study of 2010 in Appalachian communities that live in rural and hard to reach areas where issues of economic, cultural and social inequalities were also discovered.

Similarly, in this study, these study women caregivers were interviewed for the first time in their lives and at first they talked very little about their experiences of caring

for a child living with HIV and AIDS. They were particularly reticent in providing information regarding their families and their husbands and their families' members. Being interviewed was a difficult concept for them because it was a new and an unusual experience in their lives. At first the women found it difficult to make sense of their experiences and being asked their opinion. However, once the approach was changed and a free flowing interviewing technique was used rather than the prepared interview topic guide, this appeared to provide more support to the women caregivers and they began to speak more freely of their experiences. Women caregivers also opened up to the interviews after a trusting relationship was developed between them and the researcher. The narrative approach encouraged women caregivers to freely express themselves and this enabled the researcher to access their stories/voices of caregiving through storytelling.

This approach has provided in-depth rich data which describes these women's experiences. Although the sample size was relatively small and restricted to one geographical location, there are many aspects of the findings that may be transferable to the experiences of other caregivers in low resource settings. In addition, more than one interview with most of the women caregivers was necessary as they became more relaxed, expressed their caregiving experiences more freely and therefore trust built up and rich data collected; in depth interviews plus direct observations enabled the researcher to better understand the context and the stories of caregiving by women in the rural areas of Malawi. The next step is an intervention program to improve support for this highly resilient and motivated and yet invisible group of caregivers.

This is the first study to explore the experiences of women caregivers looking after a child living with HIV and AIDS in rural Malawi. The findings throw new light on the experiences of these marginalised women that have implications for the way health delivery services in the field of HIV and AIDS especially care and support for those looking after people living with HIV and AIDS are provided. The main research questions were: 1) what are the roles of traditional, social and clinical institutions in care provision and support to children living with HIV and AIDS and their caregivers? 2) What are the experiences of caregivers of children living with HIV and AIDS as they provide the care to such children? The main aim was to

examine how women caregivers manage their living and health care needs, cope with the disease, and care for themselves and their sick children with the overall purpose of enhancing the quality of care and support that woman caregivers provide in rural areas of Malawi. The aims and objectives for this study have been achieved by using in-depth qualitative research methods to understand the experiences of this hidden population of caregivers of children living with HIV and AIDS. This study findings have provided information about the experiences of women caregivers looking after a child living with HIV and AIDS in rural settings of Malawi. This information has filled the gap that existed regarding the care and support of women caregivers in rural Malawi. This could then form the basis for a major study to evaluating the adequacy of individual, family, traditional and institutional support for this population within rural Malawi.

Recommendations

In this final section, recommendations for policy and practice implications are made and ideas for further research are suggested.

Invisible nature of caring

The study findings have shown that women caregivers are not recognized by policy makers in both governmental and non-governmental organizations, community and in families hence they remain invisible in their work.

Recommendations:

- Health services must develop policies and practices that are centred on women caregivers with an aim of recognizing them so that they are not missed and in particular, they are diagnosed early for prompt treatment without delay.
- Women caregivers must be included in all information dissemination regarding care and support because they are the primary caregivers who are looking after and supporting the individuals, including children, with a chronic disease such as HIV and AIDS. By targeting this information at this group of women, they will be able to improve their care.
- Health care service providers in Malawi must include family and community members in health education regarding care and support of children living with HIV and AIDS so that they appreciate the care offered by family members and hence begin to offer support.

Actions:

- Share the study findings with Dowa and Mponela Rural Hospital management teams as the first step towards influencing policy change.
- Organize meetings with women caregivers and share these findings and map out a way forward such as supporting the formation of support groups that can improve their visibility.
- Share these findings with local NGOs at Mponela such as Mponela AIDS information and Counselling Centre, National Association of People living with HIV and AIDS of Malawi (NAPHAM), EveryChild and the National Initiative for Civic Education of Malawi (NICE).

HIV and AIDS discovery

This study revealed that women caregivers were diagnosed late and this delayed their treatment and the care of the children was affected because the health of these sick children depended on the good health of their women caregivers.

Recommendations

- The interventions and other related support services must also focus on the woman caregivers because the survival of the child depended on the health of the caregiver.
- Health care professionals to include the mother during routine screening of the children living with HIV and AIDS.
- Health care facilities in Malawi must conduct their investigation of all suspected conditions such as HIV and AIDS, tuberculosis at the same time so that there is no delay in treatment of either.

Actions:

- Conduct meetings with health care staff at Mponela Rural Hospital ART clinic to sensitize them to including caregivers of children living with HIV and AIDS during the assessment of children.
- Encourage health institutions to adopt the policies from Maternal and Child Health services in Malawi where a mother and a child are assessed together each time they visit the health facility during the first 6 weeks of delivery. In this way, women caregivers looking after a child living with HIV and AIDS will not be missed.

Husbands making decisions

The significance of gender is an important finding as this study has shown that husbands or men are still in control regarding making decisions about issues in the family including decisions about the health of the family members.

Recommendations

- Husbands (men) in rural areas of Malawi must be sensitized to accompany their wives to the hospital so that they could benefit from the health education talks that are conducted before services are commenced.

- Traditional leaders in rural areas of Malawi must be encouraged to work towards changing the culture where men are regarded as heads of the family so that women are given a chance to contribute to the family matters including decisions on their own health issues.
- Husbands (men) in rural areas of Malawi must be encouraged and supported to discuss openly with their wives regarding the issues of HIV and AIDS in their families so that they can participate actively in its management.
- Health related organisations in rural areas of Malawi must ensure that men are included from the start in HIV and AIDS counselling sessions so that they can accept their responsibility in the spread and care and support for people living with HIV and AIDS in their families and are encouraged to disclose their diagnosis.
- Husbands (men) should be encouraged to actively take part in health education talks regarding HIV and AIDS so that their mind set is changed and they begin to take part in reducing stigma in families. They must be encouraged to open up and discuss HIV and AIDS with their family members.

Actions:

- Discuss with health organisations the importance of including men in HIV and AIDS counselling sessions so that men can understand their responsibility in the spread and care and support for people living with HIV and AIDS in their families and are encouraged to disclose their diagnosis to their family.
- Buddying support groups of man to man discussing HIV and AIDS issues are one of the many forums where men can be encouraged to discuss such issues and they can learn from and encourage each other.
- A follow-up study to focus on the experience of men and to understand the issues of diagnosis, risk, stigma, and disclosure from their perspectives and to identify ways in which they can be supported in early disclosure to family members.

Disclosure and stigma

This study has revealed that women caregivers took a selective approach to disclosure of HIV and AIDS. They disclosed only to people that they trusted such as family members and key community leaders.

Recommendations

- Women caregivers in rural areas of Malawi looking after children living with HIV and AIDS who are HIV positive must be encouraged to make their decisions as to who to disclose their status (to people that they trust) as a way of encouraging openness and this can gradually mark the beginning of acceptance of one's status by family and community members.
- Civic education about the impact of stigma on women caregivers has to be re-enforced as stigma against people living with HIV and AIDS still exists in rural areas of Malawi as this study has revealed though at the reduced levels.

Action:

- Civic education engagement with the whole community to encourage people to talk openly about their HIV and AIDS positive status and thus help reduce stigma. This positive thinking must be promoted at all levels in the health sector.
- Discussion at health appointments regarding the importance of disclosure?
- Formation of HIV and AIDS care and support buddying groups where women can share the caring experiences hence learning from each other's experiences.

Caring responsibilities and availability of resources for caring

This study has found that women are still the main actors regarding caring responsibilities of people living with HIV and AIDS especially for children living with HIV and AIDS.

Recommendations:

- Men should be encouraged to take an active part to care and support their children living with HIV and AIDS. This can be done through the discussion groups as recommended above.

- Families and the community must be encouraged to mobilise resources to support women caregivers for them to ably take care of their sick children.
- The government of Malawi must put policies in place that would encourage men to actively take part in the care of people living with HIV and AIDS including children. Primary and secondary school curricula should include gender issues so that boys are informed of their roles and responsibilities in the society from the early stage.

Actions:

- Discussions with traditional leaders in rural areas to bring back the traditional “safety nets” where a family in crisis was assisted by mobilising the community to work in that family’s garden, share food items and many more good community actions that were occurring then. This would benefit the family concerned in reducing the economic and social suffering.

Shortage of resources for caring

One important finding for this study is acute shortage of resources for caring children living with HIV and AIDS in rural areas of Malawi.

Recommendations

- Women caregivers should be encouraged to form clubs where they can be sharing ideas as to how to generate funds.
- The government of Malawi must put in place robust monitoring mechanisms of the activities of all non-governmental organizations to ensure that they serve the people they are intended to serve. Economic empowerment of rural women in Malawi must be accorded highest priority by policy makers so that women are less dependent on men and are freed from the controlling powers of men.

Actions:

- Local and governmental support for the formation of women caregiver’s clubs with the support of community worker and NGOs that already work in this area.
- Closer government monitoring of the activities and achievements of relevant NGOs, to ensure the needs of this client group are met.

- Support the development of farmers clubs for women caregivers and negotiate for soft loans with local NGOs at Mponela as a way of helping these women caregivers to improve their lives economically. This could form the basis for a pilot intervention study.

Summary of the study

This is the first study to explore the experiences of women caregivers looking after a child living with HIV and AIDS in rural Malawi. The findings throw new light on the experiences of these marginalised women that have implications for the way health delivery services in the field of HIV and AIDS especially care and support for those looking after people living with HIV and AIDA are provided. The main research questions were: 1) what are the roles of traditional, social and clinical institutions in care provision and support to children living with HIV and AIDS and their caregivers? 2) What are the experiences of caregivers of children living with HIV and AIDS as they provide the care to such children? The main aim was to examine how women caregivers manage their living and health care needs, cope with the disease, and care for themselves and their sick children with the overall purpose of enhancing the quality of care and support that woman caregivers provide in rural areas of Malawi. The aims and objectives for this study have been achieved by using in-depth qualitative research methods to understand the experiences of this hidden population of caregivers of children living with HIV and AIDS. This could then form the basis for evaluating the adequacy of individual, family, traditional and institutional support for this population within rural Malawi.

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Appendices

Appendix 1: HIV and AIDS classification tables

Table 1. CDC Classification System for HIV-Infected Adults and Adolescents

CD4 Cell Categories	Clinical Categories		
	A Asymptomatic, Acute HIV, or PGL	B Symptomatic Conditions,#* not A or C	C AIDS-Indicator Conditions*
(1) ≥ 500 cells/ μ L	A1	B1	C1
(2) 200-499 cells/ μ L	A2	B2	C2
(3) < 200 cells/ μ L	A3	B3	C3

Source: AIDS Education and Training Centres (AETC) 2009 page 2

Table 1 above shows that CDC mainly relies on laboratory technology to classify the HIV and AIDS. The CD4 cells count is the determining factor. The CD4 cell count category one in the table shows that the patient has more than 500 cells per micro litre. Such a patient is in clinical category one with no signs and symptoms therefore, no AIDS defining condition. The CD4 cell count of between 200 and 499 per micro litre, the patient may start showing signs of AIDS defining condition and start seeking medical help. While category Three, the CD4 cell count is less than 200 per micro litre, and indicates that the patient has full AIDS defining signs and symptoms. See table two to Three below for the signs and symptoms for each clinical category.

Table 2. CDC Classification System: Category B Symptomatic Conditions

Category B symptomatic conditions are defined as symptomatic conditions occurring in an HIV-infected adolescent or adult that meet at least 1 of the following criteria:

- a) They are attributed to HIV infection or indicate a defect in cell-mediated immunity.
- b) They are considered to have a clinical course or management that is complicated by HIV infection.

Examples include, but are not limited to, the following:

Bacillary angiomatosis
Oropharyngeal Candidiasis (thrush)
Vulvovaginal Candidiasis, persistent or resistant
Pelvic inflammatory disease (PID)
Cervical dysplasia (moderate or severe)/cervical carcinoma in situ
Hairy leukoplakia, oral
Idiopathic thrombocytopenic purpura
Constitutional symptoms, such as fever (>38.5°C) or diarrhoea lasting >1 month
Peripheral neuropathy
Herpes zoster (shingles), involving ≥ 2 episodes or ≥ 1 dermatome

Source: AIDS Education and Training Centres (AETC) 2009 page 4

In Table 2 above, the CDC classification uses mainly the symptoms a patient has in addition to the two main attributes which are: a) the patient should have HIV or has a defect in cell-mediated immunity and b) the patient is considered to have a clinical course or management of a condition that is complicated by HIV infection (AETC, 2009). Examples of conditions have been listed but they are not limited to this list. Note that table one and two are only classification for HIV infection only.

Table 3. CDC Classification System: Category C AIDS-Indicator Conditions

<p>Bacterial pneumonia, recurrent (≥ 2 episodes in 12 months)</p> <p>Candidiasis of the bronchi, trachea, or lungs</p> <p>Candidiasis, oesophageal</p> <p>Cervical carcinoma, invasive, confirmed by biopsy</p> <p>Coccidiomycosis, disseminated or extra pulmonary</p> <p>Cryptococcosis, extra pulmonary</p> <p>Cryptosporidiosis, chronic intestinal (>1-month duration)</p> <p>Cytomegalovirus disease (other than liver, spleen, or nodes)</p> <p>Encephalopathy, HIV-related</p> <p>Herpes simplex: chronic ulcers (>1-month duration), or bronchitis, pneumonitis, or esophagitis</p> <p>Histoplasmosis, disseminated or extra pulmonary</p> <p>Isosporiasis, chronic intestinal (>1-month duration)</p> <p>Kaposi sarcoma</p> <p>Lymphoma, Burkett, immunoblastic, or primary central nervous system</p> <p><i>Mycobacterium avium</i> complex (MAC) or <i>M kansasii</i> , disseminated or extra pulmonary</p> <p><i>Mycobacterium tuberculosis</i> , pulmonary or extra pulmonary</p> <p><i>Mycobacterium</i> , other species or unidentified species, disseminated or extrapulmonary</p> <p><i>Pneumocystis jiroveci</i> (formerly <i>carinii</i>) pneumonia (PCP)</p> <p>Progressive multifocal leukoencephalopathy (PML)</p> <p><i>Salmonella</i> septicaemia, recurrent (nontyphoid)</p> <p>Toxoplasmosis of brain</p> <p>Wasting syndrome due to HIV (involuntary weight loss $>10\%$ of baseline body weight) associated with either chronic diarrhoea (≥ 2 loose stools per day ≥ 1 month) or chronic weakness and documented fever ≥ 1 month</p>

Source AETC 2009 page 4

Table 3 for CDC is an AIDS disease defining classification. Note that all the examples given are main clinical indicators for a patient who has full blown AIDS (AETC 2009). The second classification system to look at is the WHO HIV diseases staging and classification system.

Table 4: WHO Clinical Staging of HIV/AIDS for Adults and Adolescents

Primary HIV Infection
Asymptomatic Acute retroviral syndrome
Clinical Stage 1
Asymptomatic Persistent generalized lymphadenopathy
Clinical Stage 2
Moderate unexplained weight loss (<10% of presumed or measured body weight) Recurrent respiratory infections (sinusitis, tonsillitis, otitis media, and pharyngitis) Herpes zoster Angular cheilitis Recurrent oral ulceration Papular pruritic eruptions Seborrheic dermatitis Fungal nail infections
Clinical Stage 3
Unexplained severe weight loss (>10% of presumed or measured body weight) Unexplained chronic diarrhoea for >1 month Unexplained persistent fever for >1 month (>37.6°C, intermittent or constant) Persistent oral Candidiasis (thrush) Oral hairy leukoplakia Pulmonary tuberculosis (current) Severe presumed bacterial infections (e.g., pneumonia, empyema, pyomyositis, bone or joint infection, meningitis, bacteraemia) Acute necrotizing ulcerative stomatitis, gingivitis, or periodontitis Unexplained anaemia (haemoglobin <8 g/dL) Neutropenia (neutrophils <500 cells/ μ L) Chronic thrombocytopenia (platelets <50,000 cells/ μ L)
Clinical Stage 4
HIV wasting syndrome, as defined by the CDC (see Table 3, above) <i>Pneumocystis</i> pneumonia Recurrent severe bacterial pneumonia Chronic herpes simplex infection (orolabial, genital, or anorectal site for >1 month or visceral herpes at any site)

Oesophageal Candidiasis (or Candidiasis of trachea, bronchi, or lungs)
 Extrapulmonary tuberculosis
 Kaposi sarcoma
 Cytomegalovirus infection (retinitis or infection of other organs)
 Central nervous system toxoplasmosis
 HIV encephalopathy
 Cryptococcosis, extrapulmonary (including meningitis)
 Disseminated non tuberculosis *Mycobacterium* infection
 Progressive multifocal leukoencephalopathy
 Candida of the trachea, bronchi, or lungs
 Chronic cryptosporidiosis (with diarrhoea)
 Chronic Isosporiasis
 Disseminated mycosis (e.g., Histoplasmosis, Coccidioidomycosis, penicilliosis)
 Recurrent nontyphoidal *Salmonella* bacteraemia
 Lymphoma (cerebral or B-cell non-Hodgkin)
 Invasive cervical carcinoma
 Atypical disseminated leishmaniasis
 Symptomatic HIV-associated nephropathy
 Symptomatic HIV-associated cardiomyopathy
 Reactivation of American trypanosomiasis (meningoencephalitis or myocarditis)

Source: WHO, 2007 page 12

In addition to the above classification above, WHO in 2007 also developed the immunological classification for established HIV infection. The main parameter in this classification is the use of laboratory technology to assess CD4 cells count levels in individuals with HIV infection (WHO, 2007). According to WHO, 2007, the CD4 count classification is age related. However, this immunological classification of CD4 cell count is expensive and requires well trained laboratory personnel. It can be extensively be utilized in resource rich countries (AETC, 2009).

WHO (2007) developed a special clinical staging of HIV and AIDS for children with confirmed HIV infection. See the table below.

WHO clinical staging of HIV and AIDS for children with confirmed HIV infection

Clinical stage 1
Asymptomatic Persistent generalised lymphadenopathy
Clinical stage 2
Unexplained persistent hepatosplenomegaly Papular pruritis eruptions Fungal nail infection Angular cheilitis Lineal gingival erythema Extensive wart virus infection Extensive molluscum contagiosum Recurrent oral ulcerations Unexplained persistent parotid enlargement Herpes Zoster Recurrent or chronic upper respiratory tract infections (otitis media, otorrhoea, sinusitis or tonsillitis)
Clinical stage 3
Unexplained moderate malnutrition or wasting not adequately responding to standard therapy Unexplained persistent diarrhoea (14 days or more) Unexplained persistent fever (above 37.5 degrees Celsius intermittent or consistent, for longer than a month) Persistent oral Candidiasis (after first 6-8 weeks of life) Oral hairy leukoplakia Acute necrotizing ulcerative gingivitis or periodontitis Lymph node tuberculosis Pulmonary tuberculosis Severe recurrent bacterial pneumonia Symptomatic lymphoid interstitial pneumonitis Chronic HIV-associated lung disease including brochioectasis Unexplained anaemia (<8g/dl), Neutropenia (>0.5x10 to the power 9 per litre) and or chronic thrombocytopenia (<50x 10 to the power 9 per litre)
Clinical stage 4
Unexplained severe wasting, stunting or severe malnutrition not responding to standard therapy Pneumocystis pneumonia Recurrent severe bacterial infections (such as empyema, pyomyositis, bone or joint infection or meningitis but excluding pneumonia) Chronic herpes simplex infection (orolabial or cutaneous of more than one month duration or visceral at any site). Oesophageal Candidiasis (or Candidiasis of trachea, bronchi or lungs)

Extrapulmonary tuberculosis
 Kaposi's sarcoma
 Cytomegalovirus infection: retinitis or cytomegalovirus infection affecting another organ, with onset at age older than one month.
 Central nervous system toxoplasmosis (after one month of life)
 Extrapulmonary Cryptococcosis (including meningitis)
 HIV encephalopathy
 Disseminated endemic mycosis (Coccidiomycosis or Histoplasmosis)
 Disseminated non-tuberculous mycobacterium infection
 Chronic cryptosporidiosis (with diarrhoea)
 Cerebral or B-cell non-Hodgkin lymphoma
 Progressive multifocal leukoencephalopathy
 Symptomatic HIV-associated nephropathy or HIV-associated cardiomyopathy.

Source: WHO, 2007 page 17

Examples of opportunistic infections

The following are such opportunistic infections and conditions:

- Candidiasis of bronchi, trachea, or lungs
- Candidiasis, oesophageal
- Cervical cancer, invasive
- Coccidiomycosis, disseminated or extrapulmonary
- Cryptococcosis, extrapulmonary
- Cryptosporidiosis, chronic intestinal (duration >1 mo)
- Cytomegalovirus disease (other than liver, spleen, or nodes)
- Cytomegalovirus retinitis (with vision loss)
- Encephalopathy, HIV-related
- Herpes simplex - Chronic ulcer or ulcers (duration >1 mo) or bronchitis, pneumonitis, or esophagitis
- Histoplasmosis, disseminated or extrapulmonary
- Isosporiasis, chronic intestinal (duration >1 mo)
- Kaposi sarcoma
- Lymphoma, Burkett (or equivalent term)
- Lymphoma, immunoblastic (or equivalent term)
- Lymphoma, primary, of the brain
- *Mycobacterium avium* complex or *Mycobacterium kansasii* infection, disseminated or extrapulmonary
- *Mycobacterium tuberculosis* infection, any site (pulmonary or extrapulmonary)
- *Mycobacterium* infection with other species or unidentified species, disseminated or extrapulmonary
- *Pneumocystis pneumonia*
- Pneumonia, recurrent
- Progressive multifocal leukoencephalopathy
- *Salmonella* septicaemia, recurrent
- Toxoplasmosis of the brain
- Wasting syndrome due to HIV infection.

Appendix 2: A table showing some of the characteristics of participants

Pseudonym	Marriage experiences	Place of care	Caregiver's age in years	HIV status	Child's age in years	HIV status
Mayi Salima	Widow- Polygamy- husband died of HIV and AIDS	Home and hospital	34	HIV + on ARVs	3	HIV + on ARVs
Mayi Kasangadzi 4	Polygamy First wife – husband alive	Home and hospital	26	HIV + on ARVs	7	HIV + on ARVs
Mayi Bua	Monogamy -Stable- husband alive	Home and hospital	34	HIV + on ARVs	2	HIV + on ARVs
Mayi Dedza	Widow- Husband died of HIV and AIDS	Home and hospital	32	HIV + on ARVs	8	HIV + on ARVs
Mayi Dowa	Monogamy Second marriage- husband alive	Home and hospital	36	HIV + on ARVs	5	HIV + on ARVs
Mayi Lilongwe	Monogamy -husband live	Home and hospital	40	HIV +	8	HIV + on ARVs
Mayi Kasungu	A grandparent Widow- husband died-	Home and hospital	70	HIV -	11	Granddaughter - HIV + on ARVs
Mayi Muyeza River	Widow- Husband died, HIV + on ARVs.	Home and hospital	32	HIV + on ARVs	4	HIV + on ARVs
Mayi Mtiti		Home and hospital	46	HIV + on ARVs	11	HIV + on ARVs
Mayi I	Widow, husband died of HIV, she HIV+	Home and hospital	36	HIV + on ARVs	2	HIV + on ARVs

Mayi F	Monogamy , second husband, refuses HIV test	Home and hospital	28	HIV + on ARVs	3	HIV + on ARVs
Mayi B	Monogamy , husband refuses HIV test	Home and hospital	31	HIV + on ARVs	9	HIV + on ARVs
May C	Monogamy , husband refuses HIV test	Home and hospital	34	HIV + on ARVs	7	HIV + on ARVs
Mayi Kasangadzi	Widow, husband died of HIV and AIDS, she is HIV +	Home and hospital	29	HIV + on ARVs	6	HIV + on ARVs
Mayi Nsanje	Monogamy grandparent	Home and hospital	79	HIV -	6	HIV + on ARVs
Mayi Mzimba	In second monogamy husband refuses HIV Test	Home and hospital	33	HIV + on ARVs	6	HIV + on ARVs
Mayi Mpanda 3	monogamy - husband HIV+	Home and hospital	26	HIV + on ARVs	4	HIV + on ARVs
Mayi Mpanda 2	Widow, HIV +	Home and hospital	39	HIV + on ARVs	5	HIV + on ARVs
Mayi Mantcheche	Monogamy - husband HIV	Home and hospital	39	HIV + on ARVs	11	HIV + on ARVs
Mayi Lusa	Monogamy Husband alive and HIV+ but not on ARVs yet	Home and hospital	46	HIV + on ARVs	11	HIV + on ARVs
Mayi Ntchisi	Monogamy , husband alive and HIV + happy	Home and hospital	35	HIV + on ARVs	6 years	HIV + on ARVs

	marriage					
Mayi Zomba	Widow, husband died of HIV and AIDS, she is HIV +	Home and hospital	34	HIV + on ARVs	5 years	HIV + on ARVs
Mayi Mpanda	Widow, husband died of HIV and AIDS, she is HIV +	Home and hospital	22	HIV + on ARVs	6	HIV + on ARVs

Appendix 3: Permission to conduct the study in Malawi

After professional approval from the stated ethics committees, further permission was sought and granted from the following:

- Dowa District Health Officer (DHO) who is the overall in charge of all health care services in Dowa district including Mponela Rural Hospital.
- The Officer In Charge at Mponela Rural Hospital.
- The District Commissioner for Dowa (DC) who is the overall in charge of all government departments in Dowa district including Dowa District Health Office.
- Senior Traditional Authority Chief Dzoole (ST/A), T/A Kayembe and T/A Chakhaza of Dowa Rural West in whose jurisdiction is Mponela Rural Hospital and are responsible for all the people in his area. They are the overall traditional leaders for this area.

And lastly permission will further be sought from the Group Village Headmen (GVH) and the Village Headman (VH) where the participant may come from.

Appendix 4: University of Oxford ethics document

University of Oxford CENTRAL UNIVERSITY RESEARCH ETHICS COMMITTEE (CUREC)

Not all research project leaders need to fill in this form. **Before starting work on this form**, please fill in CUREC's checklist (CUREC/1) which will show if you need to complete this form. Please also ensure you have consulted the following CUREC guidance documents available on the CUREC website (<http://www.admin.ox.ac.uk/curec/resrchapp/index.shtml>):

- [Guidance on approval process](#)
- [Glossary](#)
- [FAQs](#)

Definitions of terms marked with an asterisk are to be found in CUREC's glossary and guidance.

Attachments:

Child questionnaire (with information and consent form on first pages) x

Guardian consent form for child participation x

Adult caregiver questionnaire x

Adult caregiver information and consent form x

Example referral forms for children x

Child certificate x

Letter of support from the South African Department of Social Development x

'Measures and Constructs': Summary and provenance of items in child questionnaire x

SECTION 1: PROJECT TITLE, RESEARCHERS, AND CONTACT DETAILS

1. Person to whom IDREC/CUREC should direct correspondence.

***Principal investigator/supervisor/student researcher**

Title and name: Dr Lucie Cluver

Appointment: University lecturer

Department: Department of Social Policy and Social Work

Institution: University of Oxford

Address:

Department of Social Policy and Social Work
Barnett House

32 Wellington Square
Oxford, OX1 2ER

Phone: +44 1865 270325

Fax: +44 1865 270324

e-mail: lucie.cluver@socres.ox.ac.uk

Will you need training to participate in this project?

Yes No

FOR STUDENT RESEARCH PROJECTS ONLY

Name of Supervisor:

2. Full project title and proposed starting date:

Title: Young Carers for AIDS-ill family members in South Africa: Predictors for providing care and psychological, health, and educational outcomes

Starting Date: 30 August 2009

Office use only:

IDREC Ref.

No. _____

Date of Approval: / /

Application date: / /

Approval Period: from / / to / /

Signature of IDREC approver: _____

Name (printed) and position of approver: _____

Date applicant informed of approval: / /

3. Are you submitting this project to another ethics committee or has it been previously submitted to an ethics committee?

Yes - provide details.

No

- 1) University of KwaZulu-Natal Research Ethics Committee
2) University of Cape Town Health Sciences Research Ethics Committee
3) University of Witwatersrand Public Health Research Ethics Committee
4) Mpumalanga Provincial Research Ethics Committee
5) Provincial Health Research Ethics Committees if established in Western Cape, Gauteng, Kwa-Zulu Natal (not yet in operation)

We have discussed this application with all the committees 1-4 mentioned above, and with the Director of Health RECs at the National Department of Health, and all have requested that we submit to them subsequent to obtaining approval from Oxford University.

If other relevant approvals for this research are required (e.g. from other universities' ethics committees) please attach them.

4. Have you made use of professional/CUREC guidelines in framing your research project and preparing documentation?

Note: the CUREC guidelines are available online (<http://www.admin.ox.ac.uk/curec/oxonly/protocols/guidelines.shtml>) or by emailing curec@admin.ox.ac.uk

Yes - provide details.

No – explain why not.

We have made sure to use the CUREC guidelines in framing our research project and preparing documentation with regards to recruitment, training and administration of interviews, responding to participants experiencing acute distress, and recording details and making referrals in case of serious incidents. The consent forms we provide clarify the purposes of this study, in addition to the nature of the research to be conducted and explicit statements regarding participants' rights to opt-out at any point. Given that this study is taking place in South Africa, we have additionally used a number of other sources for guidelines, such as South African legislation, and these are detailed below.

5. Researchers involved in this project

Please supply one completed copy of this box for each researcher.

*For each researcher who requires training to participate in this project, describe training on a **separate page** and include the name of the trainer(s).*

*Associate researcher/student researcher	
Title and name: Professor Frances Gardner	
Appointment: Professor	
Department: Social Policy and Social Work	
Institution: University of Oxford	
Address: Department of Social Policy and Social Work 32 Wellington Square Oxford OX1 2ER	
Phone: +44 (0) 1865 270334	Fax:
e-mail: frances.gardner@socres.ox.ac.uk	
Role in this project: co-PI Qualifications and relevant experience for this project: DPhil; MPhil Clinical Psychology; supervisor of earlier project	
Will this researcher need training to participate in this project? <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No	

*Associate researcher/student researcher	
Title and name: Professor Don Operario	
Appointment: Associate Professor of Community Health	
Department: Community Health	
Institution: Brown University	
Address: Providence Rhode Island USA Phone: +1 401 863 6557 Fax:	
e-mail: don_operario@brown.edu	
Role in this project: co-PI Qualifications and relevant experience for this project: PhD (Psychology) Primary investigator on previous AIDS-affected children studies	
Will this researcher need training to participate in this project? <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No	

*Associate researcher/student researcher	
Title and name: Dr Mosa Moshabela	
Appointment: Senior Lecturer, School of Public Health, University of Witwatersrand Director, University of Witwatersrand Rural AIDS and Development Action Research Programme	
Department: School of Public Health	
Institution: University of Witwatersrand	
Address: Tintswalo District Hospital Acornhoek, Mpumalanga South Africa Telephone: +27 13 795 5076 Fax: +27 13 795 5082	
e-mail: mosa@agincourt.co.za ?	
Role in this project: co-PI Qualifications and relevant experience for this project: MD, MMED, Clinical Director of provincial HIV programme, specialist in HIV-TB infection	
Will this researcher need training to participate in this project? <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No	

*Associate researcher/student researcher	
Title and name: Professor Andy Dawes	

Appointment: Professor
Department: Department of Psychology
Institution: University of Cape Town
Address: Department of Psychology, University of Cape Town Rondebosch, 7700 South Africa Tel +27-21-683 5199; Fax +27-21-683 5199
e-mail: adkinloch1@gmail.com
Role in this project: Co-I
Qualifications and relevant experience for this project: MSc, has run multiple major studies on children and child abuse in South Africa
Will this researcher need training to participate in this project? <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No

*Associate researcher/student researcher
Title and name: Dr Lauren Wild
Appointment: Senior Lecturer
Department: Department of Psychology
Institution: University of Cape Town
Department of Psychology, University of Cape Town Rondebosch, 7700 South Africa Tel +27-21-6504607; Fax: +27-21-6504104
e-mail: Lauren.Wild@uct.ac.za
Qualifications and relevant experience for this project: PhD, Clin Psych, PI on prior studies of AIDS-affected children in South Africa
Role in this project: co-I
Will this researcher need training to participate in this project? <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No

*Associate researcher/student researcher
Title and name: Marisa Casale
Appointment: Senior Researcher
Department: Health Economics and AIDS Research Division (HEARD)
Institution: University of KwaZulu-Natal
Address: HEARD

University of Kwa-Zulu Natal, Durban Westville Campus
e-mail: casale@ukzn.ac.za
Role in this project: Student researcher Qualifications and relevant experience for this project: Extensive experience of project managing research with children in Durban area Degree course (if relevant): PhD Will this researcher be approved by the principal researcher as competent to obtain *informed consent from participants? YES
Will this researcher need training to participate in this project? <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No

*Associate researcher/student researcher
Title and name: Caroline Kuo
Appointment: DPhil Candidate, Evidence-Based Social Intervention
Department: Social Policy and Social Work
Institution: University of Oxford
Address: Barnett House 32 Wellington Square Oxford, OX1 2ER
Phone: +44 (0) 1865 270325 Fax: +44 (0) 1865 270324
e-mail: caroline.kuo@nuffield.ox.ac.uk
Role in this project: Student researcher Qualifications and relevant experience for this project: Previous experience with researching AIDS-affected families in South Africa Degree course (if relevant): DPhil Will this researcher be approved by the principal researcher as competent to obtain *informed consent from participants? YES
Will this researcher need training to participate in this project? <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No

*Associate researcher/student researcher
Title and name: Tyler Lane
Appointment: DPhil Candidate, Evidence-Based Social Intervention
Department: Social Policy and Social Work

Institution: University of Oxford	
Address: Barnett House 32 Wellington Square Oxford, OX1 2ER	
Phone: +44 (0) 1865 270325	Fax: +44 (0) 1865 270324
e-mail: tyler.lane@socres.ox.ac.uk	
Role in this project: Student research Qualifications and relevant experience for this project: Research coordinator on qualitative Young Carer study in Western Cape Degree course (if relevant): DPhil	
Will this researcher be approved by the principal researcher as competent to obtain *informed consent from participants? YES	
Will this researcher need training to participate in this project? <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No	

*Associate researcher/student researcher	
Title and name: Kerry Mauchline	
Appointment: DPhil Candidate	
Department: Social Policy and Social Work	
Institution: University of Oxford	
Address: Barnett House 32 Wellington Square Oxford, OX2 6HG	
Phone: +44 (0) 1865 270325	Fax: +44 (0) 1865 270324
e-mail: kerry.mauchline@socres.ox.ac.uk	
Role in this project: Student researcher Qualifications and relevant experience for this project: Previous work on Young Carer study, coordinator of Teen Advisory Group weekend Degree course (if relevant): DPhil	
Will this researcher be approved by the principal researcher as competent to obtain *informed consent from participants? YES	
Will this researcher need training to participate in this project? <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No	

SECTION 2: PROJECT DESCRIPTION

6. Description of project

Please give a description (300-800 words) of your project to supplement the information already provided in Section A of the checklist (CUREC/1), detailing those aspects of the project which involve *human participants, particularly any aspect which is beyond already established and accepted techniques. Please attach all other documents (e.g. questionnaire, recruitment advertisements, participant information, and consent forms) that you plan to use in the study. **Please note that detailed scientific background is not required unless directly relevant to ethical issues.**

Please see project details on www.youngcarers.net.au

The Centre for Evidence-Based Intervention at Oxford University, in collaboration with the Government of South Africa (Directorate of HIV/AIDS at the Ministry of Social Development, the Sector of Maternal and Child Health at the Department of Health, and the Directorate of Health in Education at the Department of Education) have identified a need for high-quality qualitative and quantitative research on health outcomes for Young Carers of AIDS-unwell adults in southern Africa.

The study has been devised with the input of the South African government departments (above) and with the National Action Committee for Children Affected by AIDS (NACCA). We have also consulted extensively with local and international NGOs, service providers such as social workers, nurses and medics, and with HIV-affected groups of children and at the South African AIDS Conference 2009.

Children living with AIDS-unwell and other unwell family members in sub-Saharan Africa often undertake medical, intimate, and emotional care tasks, as well as domestic responsibilities (Bauman, et al., 2006; Evans & Becker, 2007; Robson, 2000). Despite this, there is only one study from sub-Saharan Africa that quantitatively compares carers to non-carers ($n = 60$) (Gwandure, 2007). The results suggested that children who provide care for their parents suffer from poorer psychological outcomes than non-caring peers, and display poorer learning ability. Firstly, there is a need to see how young carers differ from non-carers in the amount of tasks they are carrying out (both caring and domestic), and how children living with a sick person differ from each other based on demographic characteristics. This will then allow us to accurately assess predictors for providing care. Secondly, there is a need to identify whether Young Carers experience negative outcomes in terms of health, education and social development. Thirdly, it is important to identify the causal mechanisms of such negative outcomes, in order to inform the design of interventions (thus requiring a longitudinal design).

This research follows a qualitative study carried out in the Western Cape Province from September to December, 2008, which was approved by DREC, IDREC at Oxford, and the Health Sciences REC at the University of Cape Town. In the qualitative study, 548 children were interviewed in urban and rural areas. Children self-identified as living with someone who was unwell, then agreed to participate after receiving informed consent. Of the 548, five interviews were terminated before completion upon participant request.

The longitudinal quantitative study which is the subject of the current application will be interviewing children in four provinces (Gauteng, KwaZulu-Natal, Mpumalanga, and the Western Cape), and their caregivers in one (KwaZulu-Natal). We aim to conduct face-to-

face interviews with 6000 children aged 10-18, and around 1500 face-to-face interviews with caregivers. For all participants, interviewers will first read information sheets and obtain informed consent from both child and primary caregiver. Interview booklets are structured and presented in the style of a teen magazine quiz. This is the result of a suggestion of a group of teens in our Teen Advisory Group, who helped guide our qualitative study.

(NB The 'Teen Advisory Group' are a group of 12 AIDS-affected children who advise the project on questionnaire design and content. This was approved by Oxford DREC in 2008)

Interview booklets will include standardised questionnaires regarding physical health, mental health, educational and social outcomes, risk and protective factors for Young Carers, and caregiver illness and symptoms. We are aware of the stigma surrounding HIV/AIDS in sub-Saharan Africa, and are therefore using a validated Verbal Autopsy (VA) (Lopman, et al., 2006). Though many children in our previous study were willing to disclose a parent's AIDS-illness, we want to ensure that there is no unintentional disclosure. This will also allow us to identify AIDS-illness when parents have declined to disclose status to their children for fear of stigma or upsetting them. Under no circumstances will we disclose possible AIDS-morbidity or mortality to the child or anyone else.

We will recruit participants using stratified systematic random sampling of South African census Enumeration Areas (EAs). Within each EA, Geographic Information System (GIS) mapping will produce random routes that determine which households will be approached for participation in a methodology developed for South African Census collection in rural and urban areas (Stoker, 1987). This will ensure that sampling was randomised throughout rural and urban areas, as densely populated urban areas are unsuitable for traditional street-based sequential sampling.

7. Literature search

If the research involves significant risk to the human participants please describe what literature searches have been undertaken to obtain information to aid risk reduction/management.

There is an extensive body of work, both in the UK and South Africa, on ethical concerns in research with 'vulnerable' children and young people. The proposed ethical guidelines for this study are informed by a number of sources. These include the ongoing academic debate on issues such as informed consent and confidentiality (Alderson & Morrow, 2004), the ethical requirements of the universities and research institutions involved in designing the research, and ethical guidelines from psychological research bodies such as the British Psychological Society (BPS, 2006).

Furthermore, key research guidelines and legislation in South Africa have been considered, including the Department of Health, Research Ethics Guidelines 2004, the Department of Health, Guidelines for Good Clinical Practice in South Africa, 2nd Edition 2006, the National Health Act 61 of 2003, the Children's Act 38 of 2005, the Children's Amendment Act 41 of 2007 and the Sexual Offences Act 32 of 2007.

SECTION 3: RESEARCH INVOLVING CONTACT WITH *HUMAN PARTICIPANTS

If the project does NOT involve contact with*human participants, but only use of data about them, do NOT complete this section, but go to Section 4. If you are not completing Section 3 please delete it from your application to save paper.

8. Description of participants

How many participants will be involved in the project?

7500 participants (6000 aged 8-18, 1500 adult caregivers)
-750 children from rural and urban areas in each province
-4 provinces (Gauteng, KwaZulu-Natal, Mpumalanga, Western Cape)
-Caregivers of children in KwaZulu-Natal (~1500)

9. Details of participants

- (a) What types of people will be recruited e.g. students,* children, people with learning disabilities? [Please see the [Glossary](#) on the CUREC website for information on how the meaning of *capacity to consent has been altered by the Mental Capacity Act 2005]

We will be interviewing children aged 8-18 in four provinces, and in KwaZulu-Natal we will interview both children and their caregivers. We will interview any age-eligible residents of any household that is selected by our random route mapping.

- (b) What will be the age range of participants?

The children we will be interviewing will be between the ages of 8 and 18 years. We will also interview children's caregivers in KwaZulu-Natal, who will mostly be adults, though there is the possibility that a child's primary caregiver is a sibling under the age of 18.

- (c) How will the competence of participants to give *informed consent be determined?

We will obtain informed consent from each participant in this study.

1) Consent for children to participate

In order to ensure fully informed consent for child participants, all children will be provided with information sheets describing the study in their first chosen language, which interviewers will explain. All explanations will be easily understandable for children in this study, and the child's right to decline participation and to withdraw at any time will be thoroughly explained. Only after the purpose of the study and the format of the interview have been explained will children be asked for their consent to participate.

2) Caregiver consent for child participation

Each child's caregiver will also provide consent for participation in this study, and will be provided with information describing the study in their first chosen language. In some circumstances, the child may wish to participate but the primary caregiver is unavailable, or too unwell to be able to give consent, and here the child can nominate another adult whom they trust in his or her place (such as an aunt, or social worker). These circumstances include children in child-headed households, children whose primary caregiver is not co-resident (ie is a migrant worker), and children whose primary caregiver is experiencing AIDS-related dementia.

In our prior qualitative work with Young Carers, we identified a very small but worrying group of orphaned children who wanted to participate in the study but who explained to us that they lived with a foster carer who was forcing them to undertake large amounts of domestic work against their will, and that the carer would not want the research to take place in case this was revealed. When consent was requested from the caregiver, they did

refuse. Under the provisions of our previous REC approval, we did not interview these children. However, we are extremely concerned that this resulted in a sample which was biased against some of the most disadvantaged children who we are aiming to understand.

We engaged in extensive discussion regarding this issue with colleagues at the University of Cape Town Health Sciences REC, at the University of Witwatersrand, and with Social Workers at Cape Town Child Welfare. We also consulted South African legislation, particularly the Department of Health Research Ethics Guidelines, 2004. These allow for unassisted consent for adolescents (adolescence is not defined) in the following circumstances: i) that the research contains no more than minimal risk to the child, ii) that the nature of the research is acceptable to the research ethics committee and to the community at large, iii) that the inclusion of adolescents in the study is justified, and iv) that the unassisted consent is justified. This has been used previously for studies where parents or caregivers would be unlikely to consent to adolescent participation, or where children do not want their caregiver to know they are participating, such as studies examining contraception use amongst sexually active adolescents.

We thus propose the following, and welcome further discussion on the issue: For adolescent children only (using the WHO definition of adolescence: 10-19 yrs), where the child specifically, and unprompted, states that their caregiver will not consent due to exploitative treatment of the child, we will ask the child to identify another trusted adult who would be able to give consent for the child to participate. (We would, of course, subsequently make social services referrals for all children in abusive situations – see below). As a research team, it is clear that we would *not* take advantage of this concession in order to sidestep caregiver consent where this is inconvenient – and it would be used only for this specific and small subset of children.

Further guidelines consulted on this issue include South Africa's Children's Act 2005, which allows for minors under 18 to participate in research if there is a therapeutic effect for them (DOH, 2004). Many of the children in our qualitative study expressed gratitude and thanks for the opportunity to express themselves and talk about living with a sick person. The British Psychological Society (BPS, 2006) suggests that where children are under 16 years of age, consent should be obtained from someone *in loco parentis*, but where that is not possible, the study should be taken through ethics committee approval. This recognises various issues in gaining adult consent, such as competency of children to consent as varying with age (What in UK case law is called 'Gillick competency' and is reflected in the South African Children's Act), and the potential for situations in which parental consent may not be appropriate or possible.

Any child who declines to participate before or after the interviewer has explained the project will not be interviewed, even if the caregiver or nominated adult agrees to or encourages participation.

3) Informed consent for adult caregivers

In one province, KwaZulu-Natal, we will be interviewing children's caregivers. This study will obtain informed consent for each adult caregiver. All adults will fill in 'opt-in' consent forms if they agree to participate. All information sheets, consent forms, and interview materials will be translated into participants' first language.

4) In cases of child-headed households

Where the primary caregiver in a family is a child (a very small subgroup of homes), the head of the child-headed household will be asked if they wish to participate in the child questionnaire. Whilst this does not provide as much information regarding household dynamics etc as the adult caregiver questionnaire, we do not consider the adult survey to be

an appropriate or fun format for children.

Copies of all information sheets, consent forms and interview materials are attached.

(d) What are the *defining criteria for participation in the study?

This study aims to increase understanding of children who care for sick relatives, particularly in comparison with children who do not provide care. Therefore, all children and caregivers will be considered for inclusion in this study if they are black African and their homes appear on one of the GIS mapping routes. With studies in Soweto finding a sick adult in 44% of households (Gray, et al., 2006), we are likely to get sufficient numbers of participants for each sub-group.

10. Recruitment of participants

(a) Describe how, where, and by whom participants will be identified, approached, and recruited.

We will identify households using stratified systematic random sampling of South African Enumeration Areas (EAs). Geographic Information System (GIS) mapping will produce random routes, using the same methodology developed for South African Census collection in rural and urban areas (Stoker, 1987). Other methods of recruitment have proved insufficient, such as traditional street-based sequential sampling, which does not work in densely populated informal areas, and Modified Respondent Driven Sampling (RDS), which we tried in our previous study. RDS had been designed for hidden at-risk groups, such as injection drug users (IDUs) or sex workers (Heckathorn, 1997). What we found was that as a 'hidden group' (Robson, 2004), Young Carers are also hidden from each other; the more involved they are with caring, the less likely they are to know other carers.

After identifying households, our interviewers will approach household members and ask if there are any children between 8 and 18 years of age. If there are (and their caregivers in KwaZulu-Natal), interviewers will give a brief description of the research. After they have been read the information sheets and been given an opportunity to ask questions, participants can decide if they want to participate in the research.

All recruitment will take place in Gauteng, KwaZulu-Natal, Mpumalanga, and the Western Cape.

(b) If your research involves any use of *personal data obtained from a *third party, describe the steps you have taken to ensure that the *third party has arrangements in place to permit disclosure.

N/A

(c) Will any *unequal relationships exist between anyone involved in the recruitment and the potential participants?

Yes

No

If yes:

(i) Describe the nature of the unequal relationship.

We will be interviewing children as young as 8 years old, and as the interviewers are adults

there exists an unequal age relationship. In addition, some of the children in this study will be affected by or infected with HIV/AIDS. Our qualitative study indicated many young carer children are devoting much of their time to providing care due to household illness, and as a result may not be attending school. For these groups there may be delays or difficulties in education, with which comes the potential for decreased understanding of the methods and needs of research. Even without these difficulties, many children may be literate, semi-literate, or literate in a language other than their first language.

There is also the unequal relationship that may exist between researchers and HIV+ adults. The adults who are sick enough with AIDS to require care from their children present us a group who may be experiencing depression or whose mental capacity may be affected by advanced stages of illness.

It is crucial that while recognising these inequalities, we make all attempts to reduce their impacts on children and adult participants. However, it is also important to recognise that in a positive and child-centred research environment, children and adults can benefit from the opportunity to interact with adult facilitators.

(ii) Explain how ethical problems arising from the unequal relationship will be resolved.

All attempts will be made to ensure that the research is a positive and participatory experience for all participants, and that all consent is both voluntary and informed. All interviewers will have experience in working with vulnerable children and with AIDS-affected families.

To ensure that children do not feel obliged to participate in the research, emphasis will be placed on their ability to refuse to participate, or to cease participation at any point during the research (*See attached Draft consent and information sheets*).

Following British Psychological Society Guidelines (2006), any avoidance by children of the interview situation will be taken as evidence of failure to consent. Children who refuse to participate, or who stop the interview, will still receive snacks and certificates.

All research materials will be provided in English and a host of local languages (such as Xhosa and Zulu). Interviewers will explain all aspects of the project to children and answer any questions they may have in child's preferred language.

It is important to recognise that the inequalities between researcher and participant can also function as a positive attribute. For example, children reported in feedback for the Young Carers qualitative (and previous) studies, that they appreciated the opportunity to speak to a sympathetic, motherly adult about their lives. They often took the opportunity to ask our interviewers about issues raised by the questionnaire, such as how to get a school-fees exemption. With this example, all children who could not afford school fees were also sent information and support letters to take to their schools in applying for exemption.

(d) Describe any *financial or other rewards which will be offered to participants.

All children will be given small snacks such as fruit to eat while being interviewed. Following participation all participants will receive a Certificate of Participation (attached) regardless of completion.

As in previous research which we have conducted, we will not use financial rewards as they have a tendency to lead to problems involving jealousy within the community or household.

Carrying around money also places interviewers and children at risk in high-crime areas of South Africa.

We have consistently found an overwhelming level of agreement to participate in these studies, based on an understanding of the policy-focused nature of the project, and its close collaboration with government and NGOs.

11. *Participant information

It is essential that written information is easily understandable by participants. Failure to provide this information in appropriate lay language is the most frequent reason for delays in ethical approval.

- (a) Will participants receive **written** information about the project before giving their consent?

Yes - please attach.

No - give reasons.

Child questionnaire (with information and consent form on first pages)

Guardian consent form for child participation

Adult caregiver questionnaire

Adult caregiver information and consent form

- (b) Who will give the participants the information and how?

All information sheets and consent forms will be given to children and their caregivers or nominated adult by the interviewer. All information sheets and consent forms will be read to participants in their preferred language to prevent illiteracy from hindering a participant's understanding about the methods and purpose of the study. All participants will be told they have the right to decline to participate, drop out at any time, and that all the results will remain confidential.

Once consent has been obtained from both the child and caregiver or nominated adult, the questionnaire booklet will be read to the child, and positioned so that both interviewer and participant can see the pack. Interview materials have been designed in conjunction with a Teen Advisory Group specifically to cater to our target group's tastes.

A full and independent pilot of the child questionnaire will be undertaken by an Honours Psychology student at the University of Cape Town, supervised by Dr Lauren Wild (July-Aug 2009). This will further allow scrutiny and participant input into improving the design and content of the questionnaire.

Following the interview, participants will once again be encouraged to ask any questions they may have regarding the research, and will be given an opportunity to have their book destroyed rather than included in the study.

- (c) Does the research involve deliberate *deception of participants?

Yes- explain why the real purpose of the research needs to be concealed and how and when participants will be told of the deception.

No

- (d) Please describe the basis on which you have decided how long participants will have to think about the information provided before giving consent.

Participants may consent to participate only after having the information sheet been read to them and there has been an opportunity for questions. This way they are fully informed about the study and have had the chance to ask any questions that might have arisen.

Participants will have the opportunity to consider consent for up to a week, before interviewers return. However, when we have previously offered participants periods of 24 hours to 1 week to consider consent, the vast majority have requested to participate immediately. In light of this, we propose that participants are offered the choice of whether to consent or refuse immediately, or to have 1-7 days to consider whether they choose to consent.

12. *Informed consent

- (a) Will you obtain written consent?

Yes - please attach *consent form.

- No - explain how consent will be obtained and recorded and why this method is used.

- (b) If participants are unable to give valid consent, how and from whom will you obtain consent? [Please see the [Glossary](#) on the CUREC website for information on how the meaning of *capacity to consent has been altered by the Mental Capacity Act 2005]

All participants should be capable of giving their own consent, and we will not interview any children or adults deemed incompetent. Special care will be taken to ensure that all participants are fully aware of and understand the research, and in these particular cases, all consent procedures will be supervised by a social worker or facilitator experienced in working with vulnerable children.

- (c) List those researchers who will, with the authorisation of the principal researcher (or supervisor in the case of student researchers), secure the consent of participants.

Marisa Casale (PhD candidate)
Caroline Kuo (DPhil candidate)
Tyler Lane (DPhil candidate)
Kerry Mauchline (DPhil candidate)
Research assistants yet to be hired (although in three provinces these will be Research Assistants who have worked for us on previous studies). All RAs will be thoroughly trained on gaining informed consent, and a random sub-set of interviews will be digitally recorded and reviewed independently, including review of informed consent procedures.

13. Consequences of participation

(a) What are the potential risks or actual ill effects of participation (if any) e.g. invasive procedures, distress, deception etc, and what will be done to minimise these risks

(i) to the participants?

The focus of this study is the impact of being a Young Carer for an unwell family member in South Africa. We do not anticipate that the interviews will cause any distress either to children or their caregivers. However, in order to reduce any risk of caregivers or children becoming distressed:

Interview materials are designed to look like teen magazine quizzes, so that participants have more fun while completing them.

As in all research with children, there is a small possibility that participants will take the opportunity to disclose difficult living circumstances or abuse. This study recognises that researchers have a responsibility towards children who may disclose information showing them to be at risk of severe harm.

In order to protect confidentiality of the participants from the stigma associated with HIV/AIDS, each interview will be conducted with as much privacy as possible. Though this is difficult in crowded areas, during our qualitative study we were able to come up with creative ways to obtain privacy (such as conducting interviews outside, or in local libraries).

Recent research in South Africa has carefully considered these issues. Guidelines are set out by the ongoing HSRC/UNICEF study on children's psychological adjustment in South Africa (Dawes, Bray, Kvalsvig, & Richter, 2007) and in the South African Children's Institute/ACCESS Child Participatory Poverty Research (ACCESS, 2002). These promise confidentiality except when a child is shown through the research to be at risk, in which case (with the child's consent) they will be referred to organisations that can provide assistance (ACCESS study), or caregivers will be told (UNICEF study).

It is to be noted that the majority of research with vulnerable children in South Africa considers it an ethical principle to provide help for children whom the research identifies as in need. For example, research undertaken by the Medical Research Council Unit for Anxiety and Stress Disorders routinely refers children to child psychiatric services or to the University of the Western Cape Child Psychology clinic where there is need for these services (Seedat, Nyamai, Njenga, Vythilingum, & Stein, 2004; Seedat, van Nood, Vythilingum, Stein, & Kamminer, 2000). A University of Cape Town study on child mental health referred children in need to social services, as does ongoing research in the Africa Centre on HIV+ caregivers and infants (Stein, et al., 2005). Following these, and protocols devised from research studies with similarly vulnerable groups (Bostock, 2002) the following protocol is proposed. This protocol has been used in our previous three studies with AIDS-affected children in South Africa, and has been approved by Oxford, University of Witwatersrand, and University of Cape Town Research Ethics Committees.

Informing all participants at the consent stage that everything said will be confidential unless it becomes clear that they are at risk of significant harm.

If information is disclosed that suggests that any member of the household is at risk of significant harm, the researcher will discuss concerns with the child at the end of the interview.

If the members of the household consent, the caregiver will be informed (unless this is thought to put the child at risk) and the researcher will discuss the possibilities for referral to child welfare, health organisations, etc. If the child does not consent to sharing of

information, and the harm is not considered to be significant, the child will be given information about self-referral agencies such as ChildLine SA. However, if the harm is considered to be significant the researcher will consult with social services or other organisations. If the decision is made to take action, the participant(s) will be informed (*Please see attached draft referral form*).

(ii) to the researchers?

No risks to the research staff as a result of this project are foreseen. There are the general risks of working in urban poor areas, and we ensure that all RAs and fieldwork staff are trained in awareness and safety measures. We provide all staff with panic alarms. Staff do not undertake interviews in any situation in which they feel uncomfortable or unsafe, and are encouraged to travel in pairs in areas which are less safe.

All staff cars are equipped with tools, spare tyres, water and oil, and all staff who are driving staff cars are trained in basic car maintenance.

(iii) to others (e.g. the university, family)?

No risks to others are foreseen.

(b) Is there a need for support or counselling?

Yes - describe the form of support or counselling and how, when, and by whom it will be conducted.

No

This study has an obligation to plan for the possibility of participants, child or adult, becoming distressed. All interviews will be trained and experienced in working with affected children and families. The research team will include a qualified social worker who will be available to discuss any issues with the families and children following the interviews. As discussed above, if there is a need for a participant to access more extensive support (such as seeing a counsellor or attending a clinic) referrals will be made (*Please see attached draft referral form*).

(c) Is there a need for debriefing or follow-up discussion?

Yes - describe the form of debriefing or follow-up discussion and how, when, and by whom it will be conducted.

No

We are obligated to any participant who may feel distressed following the study. All interviewers are trained and experienced in working with affected children and their families. If a participant is to become distressed, interviewers will be available to discuss any issues he or she may have, and make referrals if required. Interviewers also contact the project manager by cellphone when they have a particular concern, or when a participant requires information or discussion.

(d) Are there any potential benefits to the participants?

Yes - describe them below

No

Previous participatory studies with children in South Africa have been reported by child participants to be beneficial and stimulating (ACCESS, 2002; Clacherty & Budlender, 2003). Children in the qualitative study reported enjoying participating in the study, enjoyed the snacks and certificates they received, and many said they appreciated being asked questions about their lives, and appreciated the warmth and interest of the interviewer.

Indirect benefits include the research goals of informing government policy for their benefit, programming, and legislation for Young Carers in South Africa.

14. *Adverse events

How will adverse events be monitored and reported?

Please see above for protocols connected to any disclosure by children during research process. Interviewers will address any minor accidents or injuries which may happen as the research is taking place. Any adverse events will result in immediate contact with supervisors and in depth conversations to discuss appropriate actions.

15. Monitoring

Explain how and by whom (e.g. supervisor in the case of student research projects) the ethical aspects of the project will be monitored to ensure that they conform to the procedures set out in this application.

The student researchers will have weekly teleconference meetings with the supervisor, and several in person meetings while the supervisor is in the field.

All student researchers and RAs will be trained in responding to child disclosure and in communicating with children, by an independent Social Work lecturer (Dr Charlotte Ritchie).

The PI (Dr Lucie Cluver) is a qualified social worker, and will monitor ethical processes on regular field visits.

SECTION 4: RESEARCH INVOLVING COLLECTION, USE, OR

***DISCLOSURE OF *PERSONAL DATA**

Your project must meet the standards laid down in the Data Protection Act (1998) with respect to the collection, use, and storage of *personal data about *human participants.

Please delete questions or parts of questions that you are not required to answer to save paper.

16. Need I complete this section?

Does the project involve the collection, use or disclosure of personal information including sensitive and/or genetic information?

No – you need not complete this section. **Go to Section 5.**

Yes – you must answer questions in this section. **Go to Question 17.**

17. Type of activity proposed

Does the research involve:

(a) disclosure of personal information? Yes No**(b)** collection of personal information? Yes – go to **Question 18** No – go to **Question 20****18. Collection of information directly from individuals****(a)** Does the project involve collection of information directly from individuals about themselves? No – go to **Question 19.** Yes – answer the following questions:**(b)** Do the *participant information and the *consent form include the following:

the name of the study?	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> No
the name and status (e.g. doctoral student) of the researcher collecting the information and how to contact him/her?	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> No
the purpose of the study?	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> No
declarations that the participant has read the participant information sheet?	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> No
has had the opportunity to ask questions about the study and has received satisfactory answers to questions, and any additional details requested?	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> No
understands that s/he may withdraw from the study without penalty at any time by advising the researchers of this decision?	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> No
understands that this project has been reviewed by, and received ethics clearance through, the University of Oxford Central University Research Ethics Committee?	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> No
understands who will have access to personal data provided, how the data will be stored; and what will happen to the data at the end of the project?	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> No
agrees to participate in this study?	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> No
understands how to raise a concern and make a complaint?	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> No

If you answered 'no' to any of these questions, explain why this information has not been included in the participant information and the consent form.

(c) Are the consent form and participant information on headed letter paper which bears the name of the University and the name and address of the department to which the principal researcher is attached?

Yes

No - explain why not.

(d) Are the participant and the researcher who secures the consent required to sign, print and date their names?

Yes

No -explain why not.

19. Collection of information from a third party

(a) Does the project involve collection of information about an individual from a source other than the individual?

No – **Go to Question 20.**

Yes – complete the following sections.

20. Form in which data are to be stored

Are the data to be kept

(a) with an open identifier i.e. in non-anonymised form Yes No

(b) as anonymised but potentially identifiable data Yes No

(c) as anonymised, non identifiable data Yes No

21. Use or disclosure of information about individuals

(a) Does the project involve the use or disclosure of information potentially or actually ascribed to an individual?

No – **go to Question 22.**

Yes – answer the following questions

(b) Does the project involve use or disclosure of information without the consent of the individual whom the information describes?

No – go to **Question 22**.

Yes – answer the following questions:

22. Data collection, storage, and disposal

- (a) How many records will be collected, used or disclosed? Specify the information that will be collected, used, or disclosed e.g. date of birth, medical history, number of convictions.

Number of records: The number of children (6000) and the number of caregivers (~1500)

Type of information: Quantitative. We will be collecting child and caregiver date of birth, education history, what kind of care/domestic work the children are engaged in, responses to standardised questionnaires regarding physical, psychological, social and educational outcomes, and sick person illness and symptoms. We will not place emphasis on HIV/AIDS illness but are prepared for private disclosure. We are mainly relying on symptoms and the Verbal Autopsy (VA) for confirmation of AIDS sickness.

- (b) How, where, and under what security arrangements will electronic and paper data be stored? Who will have and control access to the information?

Electronic data will be stored on a password-protected computer, and paper data will be stored in locked cabinets. Availability of this data will be limited to lead researchers on this team.

- (c) When, how and by whom will the information be disposed of?

Information will be disposed of by lead researchers following completion of this study.

- (d) How will the privacy of individuals be respected in any publication arising from this project?

In reporting the findings of this study, we will omit names and only report locations in which the study took place. Data will be kept for a period of up to five years after collection in an anonymised version.

- (e) Have you explained in the *participant information and *consent form that maintenance of confidentiality of information is subject to normal legal requirements?

Yes

No – explain why not.

23. Adverse and unforeseen events

How will adverse and unforeseen events relating to the collection, use, or disclosure of information be managed, monitored and reported?

Any adverse events will be reported to the principal investigator. All precautions will be taken to ensure confidentiality for all participants. We do not anticipate adverse events of this kind due to the confidentiality of the participants' information.

SECTION 5: MISCELLANEOUS ISSUES

24. *Conflict of interest

- (a) Do researchers on this project have a financial or other interest in its conduct or outcomes?

Yes – give details.

No

- (b) If there is a conflict of interest, have you declared it in your *participant information and *consent form?

Yes

No – explain why not.

N/A

- (c) Are there any other potential conflicts of interest e.g. research findings that could compromise the researcher's relationship with the university?

None

25. *Peer review

Has this project been peer reviewed?

- Yes – explain by whom (e.g. by a, tutor, supervisor, funding body etc) and with what outcome

No – explain why not.

This project has been reviewed by all of the primary investigators, the South African Department of Social Development, the South African Department of Health, the South African Department of Education, the National Action Committee of Children Affected by AIDS, Save the Children and UNICEF.

26. Funding

List all bodies and individuals from whom funding has been or will be sought.

Source	Amount in £	Status of Funds	
		Available	Applied for
HEARD	£400,000	Yes <input checked="" type="checkbox"/> No <input type="checkbox"/>	Yes <input type="checkbox"/> No <input type="checkbox"/>
John Fell Fund	£67, 000	Yes <input checked="" type="checkbox"/> No <input type="checkbox"/>	Yes <input type="checkbox"/> No <input type="checkbox"/>
Economic and Social Research Council	£500,000	Yes <input type="checkbox"/> No <input type="checkbox"/>	Yes <input checked="" type="checkbox"/> No <input type="checkbox"/>
Leverhulme Foundation	£450,000	Yes <input type="checkbox"/> No <input type="checkbox"/>	Yes <input checked="" type="checkbox"/> No <input type="checkbox"/>

27. Reporting of results

(a) Will the project outcomes be made public at the end of the project?

Yes – describe the intended report and how and to whom it will be made available.

No – explain why not

The research will be of interest to government officials from various departments, including the Department of Social Development, Health, Education, and Agriculture. The feedback of findings to government will take place at a national level (to NACCA steering committee meetings) in addition to provincial level and district level local government.

Additionally, the study findings will be reported at key conferences (such as the South African AIDS Conference), and will be provided as a set of lay-term, 1-page ‘policy briefs’ which will be sent to NGOs and will be downloadable freely on our website. Results will also be reported on the study website www.youngcarers.netau.net

We will make all efforts to provide participant children and adults with ‘brief reports,’ regarding the progress of the research. This will focus on positives, and make no mention of HIV/AIDS.

(b) Will a report(s) of the project outcomes (for example, individual or group data) be made available to participants at the end of the project?

Yes – describe report and how it will be made available.

No – explain why not.

N/A

Feedback to participants is a key part of a child-focus research design (Herth, 1998). At each stage of review and data collection, the study will create ‘brief reports’: easily understandable summaries of study findings in lay language. These will focus on findings relevant to NGOs and schools in their work with children. In ongoing pilot work, local NGO staff and teachers have requested training sessions rather than paper reports, and the research team will aim to deliver this where possible.

All participating children and families will also receive ‘brief reports’ as described in section 27a.

28. Declaration by researchers

Full project title:

I/We, the researcher(s) agree:

- To start this research project only after obtaining approval from IDREC/CUREC;
- To carry out this research project only if funding is adequate to enable it to be carried out according to good research practice and in an ethical manner;
- To provide additional information as requested by IDREC/CUREC before approval is secured and as research progresses;
- To maintain the confidentiality of all data collected from or about project participants;

- To notify IDREC in writing immediately of any proposed change which would increase the risks that any participant is exposed to and await approval before proceeding with the proposed change;
- To notify IDREC if the principal researcher on the project changes and supply the name of the successor;
- To notify IDREC in writing within seven days if any serious *adverse event occurs in the course of research;
- To use data collected only for the study for which approval has been given;
- To grant access to data only to authorised persons; and
- To maintain security procedures for the protection of personal data, including (but not restricted to): removal of identifying information from data collection forms and computer files, storage of linkage codes in a locked cabinet and password control for access to identified data on computer files.

Signed by principal researcher:.....
 Date:.....
 Print name (block capitals).....

Signed by associate/other researcher:

 Print name (block capitals).....
 Date

29. Certification by *principal researcher/supervisor/student researcher and head of department

Full project title:

Certification by *principal researcher

I accept responsibility for the conduct of this research project.

I certify that all researchers and other personnel involved in this project are appropriately qualified and experienced or will undergo appropriate training to fulfil their role in this project.

Signed by principal researcher/supervisor/student researcher:.....

 Date:.....
 Print name (block capitals).....

Acceptance by head of department/other senior member of the department if the principal researcher is the head of department

I have read the research project application named above.

On the basis of the information available to me, I judge the principal researcher/supervisor/student researcher to be award of her/his ethical



responsibilities in regard to this research. I am satisfied that the proposed project has been/will be subject to appropriate peer review and is likely to contribute to existing knowledge and/or to the education and training of the researcher(s) and that it is in the public interest.

Name of head of department/other senior member of the department (e.g Chair of DREC, Director of Graduate Studies for student projects):

.....

Signature

Date.....

FINAL CHECK

To prevent delay please check each of the following before submitting the application.

Have you answered all relevant questions in Sections 1-5?

Have you defined all technical terms and abbreviations used?

Have you included all questionnaires and participant information, consent forms, advertisements, and surveys to be used?

Have you included all relevant approvals and supporting letters?

Have you declared all potential conflicts of interest?

Are all pages (including appendices and attachments) numbered?

Have you completed the declaration by researcher(s)?

Have you completed the certification by principal researcher and head of department?

Revised July 2008

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Appendix 5: Consent Forms and letters (English and Chichewa)

The Experiences of Caregivers Looking after a sick child in Rural Malawi.

CONSENT FORM FOR THOSE WHO CAN READ AND WRITE

Instructions to the participant: Please read carefully each section below before you complete it if you decide to give consent and tick in the space provided if you wish to participate in this study.

I confirm that I have read and understood the information for the above study. I have had the opportunity to consider the information, ask questions and have had satisfactory answers.	<input type="checkbox"/>
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reasons and that no repercussions of any type will be exercised on me for my decision to do so. I am also aware that my decision to withdraw will not affect my medical or legal rights for my child.	<input type="checkbox"/>
I also understand that the information I will provide will be accessed by other research team members for audit in the University. I therefore give permission for such individuals to access the information.	<input type="checkbox"/>
I also understand that I will be interviewed on two separate occasions at the interval of one month for the in-depth interviews and on one occasion for the group discussions in September, 2012.	<input type="checkbox"/>
I also understand that if I will experience any trauma as a result of my participation in this study, I should consult the research team who will put me in touch with the counsellor at Mponela Rural Hospital who will help me accordingly.	<input type="checkbox"/>
I have therefore, agreed to voluntarily participate fully in this study from the beginning up to the end for the whole duration of three years.	<input type="checkbox"/>

Signature of participant.....
Date.....

Name of a member of a research team.....
Date.....

Note to participant:

Please sign two copies: One for you and one for the research file.

Contacting us

If you have any queries about anything concerning the study, please contact the following individuals below through the in charge at Mponela Rural Hospital.

Mandayachepa Nyando

PhD Student, Room 418. Cardiff University, Eastgate House Campus, 35-43 Newport Road, CF 24 0AB, Cardiff, United Kingdom.

Telephone numbers: Mobile: (44) 7890719396

Email address: nyandomc1@cardiff.ac.uk.

Dr Kate Featherstone

Supervisor, Room 417, Cardiff University, Eastgate House, Campus, 35-43 Newport Road, CF 24 0 AB, Cardiff, United Kingdom.

Telephone numbers: Mobile: (44) 777 9900 402

Email address: featherstonek@cardiff.ac.uk.

Consent form (Chichewa, those who can read and write)

Zochitika Kwa osamalira mwana wodwala ku midzi ya ku Malawi.

CHILOLEZO: OTHA KULEMBA NDI KUWERENGA

Malangizo kwa wotengako mbali: Chonde werengani mwachifatse ndime zili m'musizi musanalembe kusonyeza kuti mwavomereza kutenganawo mbali mukafukufukuyi. Chongani m'malo mwapatsidwawo.

Ndikuvomereza kuti ndawerenga ndipo ndavetsetsa nkhani yonse bwino bwinobwino yo khudza kafukufukuyi. Ndinali ndi mpata wokwanira kuganizira za nkhanayi ndipo mafunso onse ndinali nawo ndayankhidwa mwachimvekere ndithu.	<input type="checkbox"/>
Ndamvetsetsanso kuti ndikutenganawo mbali mu kafukufukuyi mwakufuna kwanga, mosakakamizidwa ndi wina aliyense, ndipo ndiri ndi ufulu kusiya kutenganawo mbali nthawi ina iliyonse koma osapereka zifukwa ndipo palibe chimene chingachitike kwa ine chifukwa ndasiya kutenganawo mbali. Ndiponso kuti kusiya kutenganawo mbali sikusintha kalikonse po landira chithandizo cha ku chipatala cha mwana wangayu.	<input type="checkbox"/>
Komanso ndamvetsetsa kuti pali anthu ena ku yunivesiteko amene angawone zonse zimene ndingapereke pakafukufukuyi malingana ndi ntchito yawo yo wunika bwino pa zithu ngati izi. Choncho, ndikupereka chilolendo kwa anthu amenewa kuwona nkhani yonse ndingapeleke.	<input type="checkbox"/>
Ndamvetsetsanso kuti ndidzafunsidwa mafunso pa ndekha kwa magawo awiri pa m'pata wa mwazi umodzi komanso kuti pa dzakhala zokambirana pa gulu kumapeto a Setembala mu chaka cha 2012.	<input type="checkbox"/>
Ndamvetsetsanso kuti ngati ndingakumane ndi zopinga zilizonse chifukwa ndatenganawo mbali mukafukufukuyi, ndiyenela kuwonana ndi akuluakulu a kafukufukuyi kuti andipelekeze kwa mkulu wa pa chipatala cha ku Mponela amene adzandithandize moyenerera.	<input type="checkbox"/>
Choncho, ine ndamvomereza mosakakamizidwa kutenga nawo mbali mwatchutchu pa kafukufukuyi kuyambira pachiyambi mpaka kumapeto kwa zaka zitatu.	<input type="checkbox"/>

Sayinani apa

Tsiku.....

Dzina la m'modzi wa galu la kafukufuku

Tsiku.....

Chidziwitso kwa wotenganawo mbali

1. Chonde sayinani makope awiri: Imodzi yanu ndipo inayo ikakhala pa failo ya kafukufuku.
2. Ngati muli ndi nkhwana ina iloyonse pa za kafukufukuyi, chonde, wonanani ndi akuluakulu a ku chipatala cha ku Mponela kuti akuthandizeni moyenera komanso ndi amene angalumikizane ndi akuluakulu a kafukufukuyi.

Akuluakulu amenewa ndi awa:

Nyando, M. C. (Mr) - Wophunzira, Chipinda 418. Cardiff University, Eastgate House Campus, 35-43 Newport Road, CF 24 0AB, Cardiff, Ku Ulaya.

Lamya: Yam'manja: (44) 7890719396 Yosayendanayo: (O) (44) 292 0917 819
(H) 44 292 0198 866.

Email address: nyandomc1@cardiff.ac.uk

Dr Kate Featherstone, Wothandiza wo phunzira, Chipinda 417, Cardiff University, Eastgate House, Campus, 35-43 Newport Road, CF 24 0 AB, Cardiff, Ku Ulaya.
Telephone numbers: Mobile: (44) 777 9900 402. Landline: (44) 292 0917 800.

Consent form (English, for those who *cannot* read or write)

The Experiences of Caregivers Looking after a sick child in Rural Malawi.

CONSENT FORM FOR THOSE WHO CAN NOT READ AND WRITE

Instructions to the research team member obtaining the consent: Please read slowly and carefully to the participant each section below before you complete it. Allow adequate time for the participant to decide to give consent and answer any questions. Tick in the space provided if the participant wishes to participate in this study.

I confirm that the information for the above study was read out to me and I have understood it. I have had the opportunity to consider the information, ask questions and have had satisfactory answers.	<input type="checkbox"/>
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reasons and that no repercussions of any type will be exercised on me for my decision to do so. I am also aware that my decision to withdraw will not affect my medical or legal rights for my child.	<input type="checkbox"/>
I also understand that the information I will provide will be accessed by other research team members for audit in the University. I therefore give permission for such individuals to access the information.	<input type="checkbox"/>
I also understand that I will be interviewed on two separate occasions at the interval of one month for the in-depth interviews and on one occasion for the group discussions in September, 2012.	<input type="checkbox"/>
I also understand that if I will experience any trauma as a result of my participation in this study, I should consult the research team who will put me in touch with the counselor at Mponela Rural Hospital who will help me accordingly.	<input type="checkbox"/>
I have therefore, voluntarily agreed to participate fully in this study from the beginning up to the end for the whole duration of three years.	<input type="checkbox"/>

Right thumb print of the participant.....

Date.....

Name of a member of a research team..... Date.....

Note to participant

1. Please sign two copies: One for you and one for the research file.
2. If you have any queries about anything concerning the study, please contact the following individuals below through the in charge at Mponela Rural Hospital.

Nyando, M. C. (Mr) - PhD Student, Room 418. Cardiff University, Eastgate House Campus, 35-43 Newport Road, CF 24 0AB, Cardiff, United Kingdom.

Telephone numbers: Mobile: (44) 7890719396 Landline (O) (44) 292 0917 819
(H) 44 292 0198 866.

Email address: nyandomc1@cardiff.ac.uk

Dr Kate Featherstone, Supervisor, Room 417, Cardiff University, Eastgate House, Campus, 35-43 Newport Road, CF 24 0 AB, Cardiff, United Kingdom.

Telephone numbers: Mobile: (44) 777 9900 402. Landline: (44) 292 0917 800.

Consent form (Chichewa, those who *cannot* read and write)

Zichitika kwa osamalira mwana wodwala ku midzi ya ku Malawi.

CHILOLEZO: WOSATHA KULEMBA NDI KUWERENGA

Malangizo kwa wochitita kafukufuku: Chonde werengani mwachifatse kwa wotenganawo mbali mukafukufukuyi ndipo pelekani nthawi yokwanira kuti wotenganawo mbali aganizire bwinobwino ndime zili m’musizi musanalembe kusonyeza kuti avomereza kutenganawo mbali mukafukufukuyi. Chongani m’ malo mwapatisdwawo.

Ndikuvomereza kuti andiwerengera ndipo ndavetsetsa nkhani yonse bwinobwino yo khudza kafukufukuyi. Ndinali ndi mpata wokwanira kuganizira za nkhanayi ndipo mafunso onse ndinali nawo ndayankhidwa mwachimvekere ndithu.	<input type="checkbox"/>
Ndamvetsetsanso kuti ndikutenganawo mbali mu kafukufukuyi mwakufuna kwanga, mosakakamizidwa ndi wina aliyense, ndipo ndiri ndi ufulu kusiya kutenganawo mbali nthawi ina iliyonse koma osapereka zifukwa ndipo palibe chimene chingachitike kwa ine chifukwa ndasiya kutenganawo mbali. Ndiponso kuti kusiya kutenganawo mbali sikusinthika kalikonse po landira chithandizo cha ku chipatala cha mwana wangayu.	<input type="checkbox"/>
Komanso ndamvetsetsa kuti pali anthu ena ku yunivesiteko amene angawone zonse zimene ndingapereke pakafukufukuyi malingana ndi ntchito yawo yo wunika bwino pa zithu ngati izi. Choncho, ndikupereka chilolendo kwa anthu amenewa kuwona nkhani yonse ndingapeleke.	<input type="checkbox"/>
Ndamvetsetsanso kuti ndidzafunsidwa mafunso pa ndekha kwa magawo awiri pa m’pata wa mwazi umodzi komanso kuti pa dzakhala zokambirana pa gulu kumapeto a Setembala mu chaka cha 2012.	<input type="checkbox"/>
Ndamvetsetsanso kuti ngati ndingakumane ndi zopinga zilizonse chifukwa ndatenganawo mbali mukafukufukuyi, ndiyenela kuwonana ndi akuluakulu a kafukufukuyi kuti andipelekeze kwa mkulu wa pa chipatala cha ku Mponela amene adzandithandize moyenerera.	<input type="checkbox"/>
Choncho, ine ndamvomereza mosakakamizidwa kutenga nawo mbali mwatchutchu pa kafukufukuyi kuaymbira pachiyambi mpaka kumapeto kwa zaka zitatu.	<input type="checkbox"/>

Dindani apa ndi chala chachikulu cha ku dzanjadzanja.....

Tsiku.....

Dzina la m'modzi wa galu la kafukufuku Tsiku.....

Chidziwitso kwa wotenganawo mbali:

1. Chonde dindani makope awiri: Imodzi yanu ndipo inayo ikakhala pa failo ya kafukufuku.
2. Ngati muli ndi nkhwana ina iloyonse pa za kafukufukuyi, chonde, wonanani ndi akulu akulu a ku chipatala cha ku Mponela kuti akuthandizeni moyenera komanso ndi amene angalumikizane ndi akulua akulu a kafukufukuyi.

Akuluakulu amenewa ndi awa:

Nyando, M. C. (Mr) - Wophunzira,, Chipinda 418. Cardiff University, Eastgate House Campus, 35-43 Newport Road, CF 24 0AB, Cardiff, Ku Ulaya.

Lamya: Yam'manja: (44) 7890719396 Yosayendanayo: (O) (44) 292 0917 819
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Dr Kate Featherstone, Wothandiza wo phunzira, Chipinda 417, Cardiff University, Eastgate House, Campus, 35-43 Newport Road, CF 24 0 AB, Cardiff, Ku Ulaya.
Telephone numbers: Mobile: (44) 777 9900 402. Landline: (44) 292 0917 800.

In-depth Interview Guide

The Experiences of Caregivers Looking after a Sick Child in Rural Malawi

Can you tell me about your family

Probe for all family members their role, where they are, their health status

Probe for time frames- when did this happen? Etc...

[Draw a family tree]

Who do you have responsibility for in the family?

Who do you care for?

Who needs lots of care?

How long have you been caring for x?

Can you tell me about their illness?

When did they first become sick?

What happened?

When x was first sick what did you do and who did you go to?

What happened?

[Probe for the story about the journey seeking help and services, community leaders, traditional leaders, spiritual advisors, church or mosque members or groups etc.].

What happened – what illness do they have?

Does it have a name?

What does it mean for the child?

Probe for details

[Discuss for each child in turn]

Can we talk about the practicalities of being a carer- what is your daily routine?

Probe for- food, shopping, household chores

[Probe for time of day, routines and details of what they do throughout the day
write a timetable with the person of their daily routine]

Do you have any support in caring for x?

Probe for- family, friends, community

Spiritual issues and emotional support.

How does the church or mosque group help you?

Probes-emotional support, spiritual support.

How does the Community help you emotionally?

Disclosure

Who do you tell?

Who do you not want to know?

Who makes the decisions?

About the care the child needs?

Practical support- probe for physical, emotional? money? Food?
Any particularly difficult times when they needed support- did they get it?
What happened?

How do they feel about the support you get?
Family members, community (church, mosque)
Institutions, hospital, NGOs, other services

Experience of hospital and home-medication

Future?

Can you tell me about you

Sources of income? Who else helps them?
[What else is important to know about that individual?]

In-depth Interview Guide Part 2: Demographic Data

The Experiences of Caregivers Looking after a Sick Child in Rural Malawi.

1. Caregiver.

Nick name (pseudonym)

.....

Age.....

Sex.....

Occupation.....

Religion.....

Village.....

Traditional Authority.....

2. Child

Age.....

Sex.....

(NOTE: After finishing the discussions, thank the participants and organize logistical issues such as transport and food (snacks and drinks) if any left. Give the participants any left snack and drinks).

In-depth Interview Guide (Chichewa)

The Experiences of Caregivers Looking after a Sick Child in Rural Malawi

Tandiunzani za banja lanu.....

(Futsitsani za zimene ena apabanja amachita m'banjamo ndipo alikuti, ndiponso umoyo wawo ulibwanji?).

Futsitsaniso za nthawi yawo amachita chiyani?.

Kodi matendawa adayamba liti? ndipo adayamba bwanji?

(Jambulani ngati mtengo m'ndanda wa anthu pa banjapo)

Mumayang'aniranso ndani wina?

Ndani wina amene mumasamaliraso?

Amafuna chithandizo (chisamaliro) chambiri ndi ndani pa amene mwantchulawa?
Kodi mwakhala mukusamarira ujeniyu kwa nthawi yayitali bwanji?

Mungandiuze za matenda awo onse?

Adayamba liti kudwala koyamba?

Chinachitika ndi chiyani?

Kodi pamene ujeniyu adayamba kudwala munachitapo chiyani?

Fotokozani m'mene zidakuthandizirani zinezi.

Futsitsani adapita kwandani?

Chinachitika kumeneko ndi chiani?

Ndiuzeni m'mene zidakhalira zithu kumeneko.

(Funsani za nkhani yonse m'mene idayandera polandila chithandizocho ku akuluakulu a m'mudzi, mafumu, asing'anga amizimu, ku tchalitchi ku m'zikiti and magulu ena aliwonse omwe adathandizapo).

Kodi makamaka chinachitika ndi chiyani? Nanga ndimatenda anji amene alinawo anthu a pabanja panu?

Kodi matendawo ali ndi dzina ndipo dzinalo ndi dzina lanji?

Zimatanthauza chiyani kwa mwanayu zimenezi?

(Funsani za mbiri pamenepa).

(Kamabni za mwana aliyense payekha).

Kusamalira wodwala.

Tatiyeni tikambe tsopano za kusamalira wodwala. Kodi tsiku ndi tsiku mumachita chiyani posamalira wodwalayu?

(Funsitsani za chakudya, kugula zithu zofunika, nteho za pakhomu. Komaso funsitsaniso za nthawi pa tsiku, zochitika patsikuli komanso zochitika zones za tsiku lonse m'paka kulowa dzuwa).

Lembani tebulo ya nthawi ya banja lonse pa zochitika pa tsikulonse.

Kodi muli ndichithandizo china chilichonse posamalira mwanayi? Tafotokozanitu zonse.

Funsaninso za chithandizo ku chokera kwa apa banja, able ena komanso sthu ena a 'mudzi and delalo.

Tiyeni tikambe nkhani za mizimu

Zazo khumudwa mu'mtima

Kodi magulu kutchalitchi kapena kumzikiti amakuthandizani mu kakhumudwa?

(Funsani za akakhumudwa amalandira chithandizo chotani? Cha uzimu kapena chokhumudwa chokha?)

Kodi anthu a m'mudzi amathandizapo chiani mukakhumudwa?

Kuwulula za HIV ndi Edzi

Mumauza ndani za kudwala kwa mwanayu? Tafotokozani bwinobwino chifukwa chiani munauza amenewa? (Fusitsani panepa).

Nanga ndi ndani amena simufuna kuti adziwe? Tafotokozani ndi chifukwa chiani simufunira kuti adziwe.
(Futsitsani pamenepa)

Ndi ndani amalamula kuti chinthu chichitike pa banja panupa andipo chifuwa chiani?
(Fusitsani pamenepa)

Za chisamaliro chimene mwanayu amafuna

Fusitsani za chithandizo zochitika chenicheni monga zowoneka ndimaso, zokhumudwa, za ndalama ndiza chakudya.

Kodi mungandiuze za nthawi imene mumafuna chithandizo kwambiri? Tafotokozani ngati mumachipeza chithandizocho. (Fusitsani pamenepa).
Tafotokozani m'mene mumamvera mu'mtima mwanu pa za chithandizo chimene mumalandira pa kusamalira mwanayu.

(Fusitsani za chithandizo cha ku chipatala, pa banja, anthu ena amudzi and dela lonse, mabugwe ena a boma komanso omwe siaboma monga a tchalitchi, ku m'zikiti ndi ena otelo.

Tafotokozani za zochitika ku chipatala ndi ku kunyumba posamalira mwanayi makamaka pa mankhwala akuchipatala.

Nanga m'tsogolo muno mukuganiza kuti muzitani?

Tandiuzani za inu tsopano monga zaka zanu, mumapeza bwanji ndalama ndani wina amakuthandizani?

Kambani china chilichonse chokhudzana ndichisamaliro cha mwanayu chimene mwayiwala.

In-depth Interview Guide Part 2 (Chichewa) Demographic Data

The Experiences of Caregivers Looking after a Sick Child in Rural Malawi.

1. Caregiver.

Nick name.....

Age.....

Sex.....

Occupation.....

Religion.....

Village.....

Traditional Authority.....

2. Child

Age.....

Sex.....

Langizo: Mutamaliza zo kambirana thokozani onse amene atenganowo mbali komanso longosolani za mayendedwe awo chakudya ndi za kumwa zotsala apatse anthuwo.

Appendix 6: Letters

Cardiff University
School of Nursing and Midwifery Studies (SONMS)
Eastgate House Campus, 35-43 Newport Road
CF24 0 AB

26th January,
2011

The Chairperson
KCN Research Ethics Committee/Malawi College of Medicine Ethics Committee
Private Bag 1
LILONGWE

Dear Sir/Madam,

REQUEST FOR APPROVAL TO CONDUCT A STUDY ON EXPERIENCES OF CAREGIVERS LOOKING AFTER A CHILD WITH HIV AND AIDS AT MPONELA RURAL HOSPITAL

I am Mandayachepa Nyando, a PhD student at Cardiff University School of Nursing and Midwifery Studies (SONMS). I write apply for approval to conduct a research for my PhD studies. The title of the research is “Experiences of caregivers looking after a child with HIV and AIDS in rural Malawi”. This study will provide the much-needed understanding about the nature and extent of care and support currently available to caregivers of children living with HIV and AIDS and provide preliminary information about the needs and support as they care for such children in rural Malawi perspective. The findings will be used to begin to understand the process of care and support and to inform the design for pathways for health facilities to reach families in need of such care and support as they look after their sick children.

Any risks associated with it, like psychological trauma, an arrangement has been made with the qualified HIV and AIDS counselor within Mponela Rural Hospital to handle such issues. All ethical considerations will be observed to ensure that there is no violation on the rights of subjects throughout the study.

Your consideration will be highly appreciated.

Yours faithfully,

Mandayachepa Nyando
PhD Student

Dr Kate Featherstone
Supervisor

FROM: Cardiff University
School of Nursing and Midwifery Studies (SONMS)
Eastgate House Campus, 35-43 Newport Road
CF24 0 AB

TO : Dowa District Commissioner, (DC),
P.O. Box 1,
DOWA

DATE : 26th January, 2011

Dear Sir/Madam,

**A REQUEST FOR PERMISSION TO CONDUCT A STUDY AROUND
MPONELA RURAL HOSPITAL CATCHMENT AREAS**

I am Mandayachepa Nyando, a PhD student at Cardiff University. As a requirement to obtain the PhD degree at Cardiff University, there is a need to conduct a research study. The title of my study is: "Experiences of caregivers looking after a child with HIV and AIDS in rural Malawi. The research will be conducted within the catchment area of Mponela Rural Hospital. This covers the Traditional Authorities (T/A) Dzoole, Kayembe, Chakhaza and Sub T/A Mponela.

The aim of the study is to examine how caregivers of children living with HIV and AIDS manage such children (sick) and their living and health care needs, cope with the disease, and care for themselves. I am therefore requesting for permission to conduct the study in this area which is under your jurisdiction. Your consideration will be highly appreciated.

Yours faithfully,

Mandayachepa Nyando
PhD Student

Dr Kate Featherstone
Supervisor

FROM: Cardiff University
School of Nursing and Midwifery Studies (SONMS)
Eastgate House Campus, 35-43 Newport Road
CF24 0 AB

TO : Dowa District Health Officer (DHO),
P.O. Box 25,
DOWA

DATE : 26th January, 2011

Dear Sir/Madam,

**A REQUEST FOR PERMISSION TO CONDUCT A STUDY AROUND
MPONELA RURAL HOSPITAL CATCHMENT AREAS**

I am Mandayachepa Nyando, a PhD student at Cardiff University. As a requirement to obtain the PhD degree at Cardiff University, there is a need to conduct a research study. The title of my study is: "Experiences of caregivers looking after a child with HIV and AIDS in rural Malawi. The research will be conducted within the catchment area of Mponela Rural Hospital. This covers the Traditional Authorities (T/A) Dzoole, Kayembe, Chakhaza and Sub T/A Mponela.

The aim of the study is to examine how caregivers of children living with HIV and AIDS manage such children (sick) and their living and health care needs, cope with the disease, and care for themselves. I am therefore requesting for permission to conduct the study in this area which is under your jurisdiction. Your consideration will be highly appreciated.

Yours faithfully,

Mandayachepa Nyando
PhD Student

Dr Kate Featherstone
Supervisor

FROM: Cardiff University
School of Nursing and Midwifery Studies (SONMS)
Eastgate House Campus,
35-43 Newport Road
CF24 0 AB

TO : The Officer In Charge,
Mponela Rural Hospital,
P. O .Box 56,
MPONELA

DATE : 26th January, 2011

Dear Sir/Madam,

**APPLICATION FOR PERMISSION TO CONDUCT A STUDY AROUND
MPONELA RURAL HOSPITAL CATCHMENT AREAS**

I am Mandayachepa Nyando, a PhD student at Cardiff University. As a requirement to obtain the PhD degree at Cardiff University, I need to conduct a research study. The title of my study is: "Experiences of caregivers looking after a child with HIV and AIDS in rural Malawi". The study will be conducted within the catchment area of Mponela Rural Hospital. This covers the Traditional Authorities (T/A) Dzoole, Kayambe, Chakhaza and Sub T/A Mponela.

The aim of the study is to examine how caregivers of children living with HIV and AIDS manage such children (sick or well) and their living and health care needs, cope with the disease, and care for themselves. I am therefore requesting for permission to conduct the study in this area which is under your jurisdiction. Your consideration will be highly appreciated.

Yours faithfully,

Mandayachepa Nyando
PhD Student

Dr Kate Featherstone
Supervisor

Kalata ya ku Mafumu T/As

Ku chokela kwa : Sukulu ya Ukachenjede ya Cardiff
Eastgate House,
35-43 Newport Road,
CF24 0AB.

Kupita kwa Mafumu awa : Senior Chief Dzoole
M'ndolera Headquarters,
T/A Chakhaza
T/A Kayembe
Sub T/A Mponela

DATE : 26th January, 2011

Zikomo mafumu nonse,

**NKHANI YAKE: KAFUKUFUKU WA KASAMALIDWE KAMWANA
AMENE AKUDWALA.**

Ine ndine mwana wanu ya m'mudzi wa ko Kalonga, T/A Dzoole. Palipano ndiri ku sukulu ya ukachenjede yaku Ulaya (United Kingdom) yotchedwa Cardiff University. Pofuna ku kwaniritsa za sukuluyo, ndiyenera kuchita kafufuku wa m'mene ana wodwala amasamaliridwa. Ndipo ineyo ndidasankha dela la chipatala cha Mponela. Dela limeneli lili mudela lanu. Pamanepa ndikupepha chilolezo choti ndi chite kafukufukuyi. Makamaka ndizicheza ndi amayi amene akusamalira mwana amene wakhala akudwala kwa kanthawi ndithu.

Cholinga cha kafukufuku amaneyu ndikuti tiwone m'mene wodwalayo akusamaliridwa m'midzi ngati muno, zosowa zawo, ndiponso zopingapinga pa kusamalira mwanayo. Pakutelo kuti tiwone ndichiyani chimene tingachite kuti kusamalira ana oterewa kupite patsogolo.

Zikomo

Mandayachepa Nyando
Wophunzira

Dr Kate Featherstone
Wothandiza wo phunzira

Kalata ya kwa a Nyakwawa ndi a Gulupu (Village Headman and Group village Headman)

Ku chokela kwa : Sukulu ya Ukachenjede ya Cardiff
Eastgate House,
35-43 Newport Road,
CF24 0AB.

Kupita kwa Magulupu onse : Senior Chief Dzoole
M'ndolera Headquarters,
T/A Chakhaza
T/A Kayembe
Sub T/A Mponela

DATE : 26th January, 2011

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Zikomo,

Mandayachepa Nyando
Wophunzira

Dr Kate Featherstone
Wothandiza wo phunzira

Approval letters



UNIVERSITY OF MALAWI

Principal
K.M Maleta, MBBS PhD

Our Ref.:
Your Ref.: P.04/11/1066

College of Medicine
Private Bag 360
Chichiri
Blantyre 3
Malawi
Telephone: 01 877 245
01 877 291
Fax: 01 874 700

Email: comrec@medcol.mw

12th May 2011

Mr. Mandayachepa Nyando
Kamuzu College of Nursing
P.O Box 415
Blantyre 3

Dear Mr. M. Nyando,

RE: P.04/11/1066- Experiences of Caregivers Looking After a Child with HIV and AIDS in Rural Malawi

I write to inform you that COMREC reviewed your proposal mentioned above which you resubmitted for expedited review. The following points have been dealt with:

1. The information given now on methodology is now distinct.
2. The design of the study is now states – a cross sectional descriptive design.
3. Sample size and size of focus group has been given.

I am pleased to inform you that your protocol **was approved** after considering that you addressed all the queries raised in the initial review.



As you proceed with the implementation of your study we would like you to adhere the amended protocol ICH GCP requirements and the College of Medicine Research requirements as indicated on the attached page.

Yours Sincerely,



Dr. W. Mandala
For: CHAIRMAN - COMREC

WM/ck

Telephone: (+265) 282 244/211
Facsimile: (+265) 282 264

All Communications should be addressed to:
The District Commissioner



In reply please quote No. 4/17/150

DOWA DISTRICT ASSEMBLY

Private Bag 2,

DOWA.

19th May 2011

To: T/A Kayembe
STA Chakhaza
STA Mponela
TA Dzoole

Copy: District Health Officer

KAFUKUFUKU WOKHUZA NKHANI ZA OSAMALA ODWALA

Malingana ndi mutu ndalemba pamwambawu, landilirani bungwe la COMREC (College of Medicine Research Ethics Committee), omwe mayina awo nawa:

1. Mandayachepa Nyando
2. Lexa Chisale

Iwowa ali oloredwa kuchita kafukufuku wokudza za osamala odwala. Aloleni kuti apange kafukufuku mmadela anu.

Alandileni ndikupeleka thandizo monga mumachitila nthawi zonse.

A handwritten signature in black ink, appearing to read 'Mzilahowa', with a horizontal line extending to the right.

Christopher H. Mzilahowa
For: The District Commissioner

Telephone: + 265 1 282 222 / 208 1900
Facsimile: + 265 1 282 200
Email :dowa-hmis@malawi.net

All Communications should be addressed to:
District Health Officer



In reply quote ...DA/H/RES 01/11

DOWA DISTRICT HEALTH OFFICE

P. O. Box 25,

DOWA, MALAWI

1st February, 2011

To: Mandayachepa Nyando
Cardiff University
Eastgate House Campus, 35-43 Newport Road
Cardiff
CF24 0 AB

SUBJECT: Permission to conduct a study within Dowa

The District Health Management Team (DHMT) has reviewed the aim of your PhD study titled 'Experiences of caregivers looking after a child with HIV and AIDS in rural Malawi'.

I am glad to inform you that the site permission has been granted to conduct a study within Mponela Rural Hospital catchment area.

The District Health Office wishes you all the best and will give you the support needed.

Yours Faithfully,

A handwritten signature in black ink, appearing to read 'Owen U.U. Malema'.

Dr Owen U.U. Malema
District Health Officer – DOWA

Participant Information Sheet

The Experiences of Caregivers looking after a Child with lifelong illness in Rural Malawi

The aim of study

The aim of the study is to examine how caregivers of children with lifelong illness manage such children (sick or well) and their living and health care needs, cope with the disease, and care for themselves in the rural settings of Malawi.

Ethical approval

This study is being conducted after approval from the School of Nursing and Midwifery Studies Research Ethics Committee, Cardiff University and Kamuzu College of Nursing and Malawi College of Medicine Research Ethics Committees, was granted.

Voluntary participation

Your Participation in this study is entirely voluntary and your withdraw from the study at any time you feel like will not affect legal rights to access medical services for you and your child.

Confidentiality and anonymity

The data collection will be conducted under strict confidentiality and anonymity procedures and processes. Data collection will be conducted in a well-arranged private room with very minimal disturbances either at your home or at the hospital depending on what you prefer. Fake or nick names or letters will be used during the interviews so that you are not identified in order to maintain confidentiality and anonymity.

The components of the study

This study has two phases of in-depth interviews and one session of focus group discussions. You will be expected to participate in all the two in-depth interviews and in a focus group discussion.

Interview location

Depending on your preference for the place and time for interviews, I will arrange for a date and time that is suitable to you and your child for the interviews. The arrangement will be done without the intrusion of your privacy.

Confidentiality and recording

All the interviews will be tape recorded and that hand written notes will be taken as a back up to the tape recorder. The duration of the interview is planned for approximately two hours. All data collected will be kept in locked lockers in Lilongwe and at Cardiff University offices. A password will be used to lock all computer based data. Only the research team members will access the data. However, lecturers at Cardiff University will access the data for audit purposes.

Hand recorded notes

This is to emphasize to you that data will be recorded by hand to supplement the data recording machine so that you are aware and not get surprised when you see the research team member is taking some notes.

Withdraw from the study

You are at liberty to withdraw from the study at any time you feel like you do not want to continue. You are also free to withhold information that you feel like not sharing it. No repercussion will be exercised on you for your decision to withdraw such as your legal rights to treatment and any medical care will not be affected in any way. You are free to rejoin the study at a later time if you change your mind.

Benefits for participation

There are no direct or indirect benefits for your participating in this study. However, the immediate benefit is the feeling that you have contributed to the information that may lead to the improvement of care giving to children with lifelong illness in the rural areas of Malawi and during focus group discussions; you will have a chance to learn something from other female caregivers about caring a child with a lifelong disease.

Risks as a result of participation in the study

The topics covered in the interviews are likely to be highly emotional for you. The female interviewer and the leader of this study are experienced nurses with vast clinical experience and are also trained in counselling of people with lifelong diseases. Potential topics that may trigger emotional reactions may include loss and bereavement, depression and hopelessness. After each interview, the research team leader and interviewer will set time to discuss the issues that may have triggered emotional response to you and offer referral to the specialist services as the case may be.

Referral

You will be referred to the trained counsellor at Mponela Rural Hospital if you perceive any discomfort as a result of your participation in the study during and after data collection process. Again if you break down emotionally as a result of the interview questions or discussions, the interviews will be stopped and immediate counselling sessions will be arranged for you after you have given consent to do so. Then you will be referred to the qualified counsellor at the hospital. Necessary arrangements will be made with the qualified counsellor at the hospital to help you out of any emotional breakdown during the data collection period and thereafter.

Procedure for focus group discussions

There will be two focus group discussions comprising eight participants each group. A quiet room will be identified at the hospital where there will be minimum disturbances. Participants will sit in a circle so that they are able to see each other as they talk. The focus group facilitator will sit within the circle and tape recorders will be at the middle of the circle. Each group member will be assigned a fake name or letters to ensure confidentiality. You will be informed that you should not interrupt when one is speaking. The group will be dismissed at once after the discussions. The termination process will start during the introductions so that you get prepared. At the end of the discussions, transport logistics will be announced such as transport to

go home. Any leftovers of refreshments will be distributed to you at the end of the discussions.

Anonymity and Identifiable data

All personal identifiable data such as age, sex, occupation etc. will be put in separate sealed envelopes and treated with much care just like any other data that will be collected to maintain highest level of confidentiality.

Concerns

If you have any queries about anything concerning the study, please contact the following individuals below through the in charge at Mponela Rural Hospital.

Nyando, M. C. (Mr) - PhD Student, Room 418. Cardiff University, Eastgate House Campus, 35-43 Newport Road, CF 24 0AB, Cardiff, United Kingdom
Telephone numbers: Mobile: (44) 7890719396 Landline (O) (44) 292 0917 819
(H) 44 292 0198 866. Email address: nyandomc1@cardiff.ac.uk

Dr Kate Featherstone, Supervisor, Room 417, Cardiff University, Eastgate House, Campus, 35-43 Newport Road, CF 24 0 AB, Cardiff, United Kingdom.
Telephone numbers: Mobile: (44) 777 9900 402. Landline: (44) 292 0917 800.