Identifying the Potential Barriers and Facilitators that can contribute to the Level of Antiretroviral Treatment Adherence among People Living with HIV and AIDS in the Rural District of Chongwe, Zambia.

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ABSTRACT

According to the Demographic and Health Survey in Zambia the national HIV prevalence among population aged 15-49 years was 14%. In 2002 the Government of Zambia introduced Antiretroviral Therapy (ART) in two of the largest hospitals in Zambia: Lusaka and Ndola hospitals. As many people begin accessing ART in rural areas in Zambia, one of the major challenges is ensuring that those receiving ART adhere to treatment to avoid the emergence of drug resistance and treatment failure. The research therefore set to identify the potential barriers and facilitators to antiretroviral treatment adherence among people living with HIV and AIDS in the rural district of Chongwe, Zambia.

A descriptive qualitative study was conducted over a period of three weeks from 11th December to 29th December 2008. The perceptions, opinions and experiences of PLHIV on ART and those of the health workers and treatment supporters were explored through in-depth interviews and focus group discussions. In-depth interviews were conducted with nine persons living with HIV (PLHIV): 5 females and 4 males. Two focus group discussions were conducted with members of 2 different PLHIV support groups from Refunsa and Chimusanya villages served by the ART clinic of St Luke Mission Hospital and another with a group of ART treatment supporters. In addition, interviews were held with five key informants, who were health workers from the ART clinic in St Luke Mission Hospital in Mpanshaya.

Reported barriers to adherence among PLHIV in rural areas included experiencing side effects to ART drugs, stopping medication due to improvement in wellbeing, a lack of understanding of the importance of adherence, and forgetting to take their medication due to alcohol consumption. Other barriers included stigma and discrimination, inadequate food to support ART uptake and non disclosure of one's status for fear of being rejected especially for women who feared rejection in relationships. Another key barrier to adherence was the religious belief held by some PLHIV that one would get healed after being prayed for and therefore discontinued treatment.

Key facilitators to adherence identified in the study included getting into a regular routine of taking antiretroviral drugs (ARVs), knowledge of and belief in the efficacy of ART, disclosure of HIV status, access to social support and nutritional support. Other facilitators identified were use of treatment supporters who provided support to PLHIV by providing them with on-going adherence counseling, and making referrals to the ART facility for further support, mobile ART clinics that have brought ART services closer to the rural communities and the adaptation of strategies such as clocks and use of alarms by PLHIV to remind them to take their medication. Although better health resulting from taking ARVs was citied as a barrier to adherence it also acted as a facilitator to adherence as better health motivated PLHIV to continue taking their medication.

In conclusion, based on the findings from the study a series of recommendations were made to inform the current ART adherence information and counseling strategies used by the ART facility at St Luke Mission Hospital in Mpanshaya - and other ART programmes

being implemented in similar rural health facilities in Zambia. The recommendations included the need for the ART facility to address alcohol abuse among PLHIV taking ART, addressing perceptions on ARVs in the community, reviewing of the counseling programme, caring for treatment supporters, strengthening food security and livelihood opportunities for PLHIV and their families and increasing collaboration between the ART facility and the churches.

DECLARATION

I declare that *Identifying the potential barriers and facilitators that can contribute to the level of antiretroviral treatment adherence among people living with HIV and AIDS in the rural district of Chongwe, Zambia* is my own work. This research work has not been submitted for any degree or examination in any other university, and that all sources
I have used or quoted have been indicated and acknowledged by complete references.

Full Name: Charity Sisya   Date: 27th October, 2010

Signed:

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ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
ARV	Antiretroviral
CBOH	Central Board of Health
CHBC	Community and Home Based care
CSO	Central Statistics Office
FGD (s)	Focus Group Discussions
HAART	Highly Active Antiretroviral Therapy
HBC	Home based care
HEPS	High- energy protein supplements
HIV	Human Immunodeficiency Virus
IGAs	Income generating activities
MOH	Ministry of Health
NAC	National AIDS Council
PLHIV	Person living with HIV
PMTCT	Prevention of Mother to child transmission
SMS	Short messenger service messages
TB	Tuberculosis
UNAIDS	United Nations Joint Programme for HIV and AIDS
USA	United States of America
UTH	University Teaching Hospital
WHO	World Health Organization

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CHAPTER ONE

A DESCRIPTION OF THE STUDY

1. Introduction

HIV and AIDS continues to be a serious pandemic worldwide. As of 2007, the estimated number of persons living with HIV (PLHIV) in the world was 33.2 million and Southern Africa remains the most affected region with just under a third (22.5 million) of PLHIV (UNAIDS, 2006). With a population of over 10 million, the Zambian National AIDS Council (NAC) states that Zambia is one of the countries worst affected by HIV and AIDS in Sub Saharan Africa (NAC, 2006). A Demographic and Health Survey conducted in the country in 2007 (Central Statistics Office, 2007) put the national HIV prevalence rate among 15-49 year olds at 14%.

The HIV prevalence in Lusaka is currently 18% and is, one of the highest in Zambia (CSO, 2007). This is above the national HIV prevalence rate for ages 14 to 49 year (CSO, 2007). The Zambia Demographic Health Survey (CSO, 2007) also shows that HIV infection rates are higher among women than men between the ages of 35-39 years, at 16% and 14% respectively. HIV and AIDS had adverse effect on the social and economic development of Zambia (NAC, 2006). The Joint United Nations Programme on HIV and AIDS (UNAIDS, 2007) states that about 1.1 million Zambians are living with HIV and AIDS, 57% of which are women. Of the people infected with HIV, only 27% were on antiretroviral therapy (ART) and many of these are food insecure without any nutritional support (NAC, 2004).

It has long been recognized that there is a complex web of issues that are contributing to increased prevalence of HIV and AIDS – many of which are found in Zambia. These include poverty, socio-economic disparities, multiple concurrent partnerships, intergenerational sex, transactional sex, combined with low and inconsistent use of condoms, and gender based violence (UNAIDS, 2008). The level of poverty in many rural areas in Zambia has deepened given that the HIV epidemic has affected the most economically productive age group (NAC, 2004). In general, the high poverty level is one of the major factors influencing HIV transmission in Zambia as it directly or indirectly creates vulnerability to HIV and AIDS in Zambia (NAC, 2005).

In some of the communities, socio-cultural practices like widow inheritance, sexual cleansing (a practice where a surviving spouse is required to have sex with a relation of the deceased), dry sex, which results in bruising and lacerations in the vagina among others; have increased the vulnerability of women to HIV transmission. In addition, gender inequality and the resultant imbalance of power in sexual relationships has increased the vulnerability of women to HIV because they are unable to negotiate condom use or lack the necessary skills to be self-assertive in sexual relations (NAC, 2004).

1.1. Universal Access to Antiretroviral treatment

In 2002, given the high rates of HIV infection, and following the World Health Organisation (WHO) and UNAIDS' initiative to provide antiretroviral treatment (ART) to three million people with HIV and AIDS in developing countries by 2005 (commonly referred to as the “3 by 5” initiative), the Zambian government decided to make antiretroviral therapy widely available to everyone in need of treatment. Consequently, three million United States dollars was allocated in 2004 for the purchase of antiretroviral drugs for 10 000 people, to be provided through public health services in Zambia (NAC, 2004). Treatment in the public sector was initially delivered at a subsidized rate. In the same year, 2004, the government introduced Antiretroviral Therapy (ART) in two of the largest hospitals in Zambia: the University Teaching Hospital (UTH) in Lusaka and the Ndola Central Hospital in Ndola city. In 2004, the government announced that antiretroviral therapy would be provided free of charge in public hospitals at both districts and provincial levels. A comprehensive implementation plan to roll out access to treatment across the country has since been developed (NAC, 2004).

By August 2005, treatment and laboratory costs at public institutions also became free. This facilitated increased treatment access for more people living with HIV. As a result by end of 2005 more than 50,000 out of the estimated 200,000 PLHIV in Zambia were on ART (NAC, 2006).

ART can now be accessed in many primary care clinics and hospitals throughout the country including those in Chongwe district where this study took place. Since 2005, substantial progress has been made in Zambia towards ensuring that those needing treatment, access it. As of 2007, UNAIDS & WHO (2008) estimated that in Zambia 54% PLHIV received treatment out of the 330,000 needing it.

An increase in ART availability and access to them notwithstanding, it is suggested that one of the factors contributing to the success of the ART programme in Zambia is for PLHIV to maintain consistent adherence to their ART regimes. High levels (at least 95%) of adherence to ART are needed to ensure optimal benefits (WHO, 2006). Poor drug adherence leads to treatment failure and accelerated sickness, which in turn creates the potential for drug resistance (WHO, 2003).

In order to provide those on ART with the necessary support to achieve and sustain this level of adherence the government of Zambia, through the National AIDS Council, put in place a National Strategic Framework (NAC, 2004) outlining national priorities and programmes in prevention, treatment, care and support. Additionally, NAC put in place national guidelines on the management and care of HIV, including guidelines on provision of ART, home based care (HBC), counseling and peer and social support to improve the quality of life for PLHIV (NAC, 2004).

1.2. Problem statement

In Zambia some research has been conducted on individual and community perceptions, knowledge, attitudes and experiences of HIV and AIDS and related treatment, treatment adherence, and HIV related stigma and discrimination (International HIV/AIDS Alliance, 2003). However, little of this research has focused on the facilitators and barriers that are experienced by PLHIV taking ART and living in *rural* settings in Zambia. Establishing whether there are unique facilitating factors and barriers to ART adherence in rural areas in Zambia – which are different from those experienced by PLHIV on ART in urban areas, could enable ART programme managers and health workers to put in place, if required, specific strategies to encourage and support drug adherence in more rural settings in the country. This in turn, would serve to support the scaling up of antiretroviral treatment programs in rural areas in Zambia.

1.3. The Study context

The research study was conducted at St Luke's Mission Hospital in the rural town of Mpanshya, which is located within Chongwe District in Lusaka province. Besides Mpanshaya village, two other villages, Rufunsa and Chimusanya – both approximately X kms from Mpanshaya village, were sampled for the study. Mpanshya is approximately 200 km from Lusaka, the capital city of Zambia. St Luke's Mission is the only hospital in Chongwe district and provides a service to a rural population of almost 190, 000 people. In addition, seven rural health centers from the surrounding villages refer cases to St Luke's Mission Hospital. It is officially a District Hospital and the Chongwe District Health Management Team provides partial funding for the hospital and its staff.[1] A Hospice, attached to the hospital, is responsible for the ART programme. The ART programme has been in place since 2005. At the time of the study, in September 2008, 731 PLHIV were on ART (ART facility hospital records).

While staff that deliver treatment at the ART facility at St Luke Mission hospital suggest that the quality of life of people on ART has improved overall, they acknowledge that

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[1] The hospital is run and managed by the Borromeo Sisters and has a Hospital Manager, one doctor, a Voluntary Services Overseas (VSO) volunteer, a Clinic officer, one sister in charge and six nurses. The hospice is staffed by a VSO volunteer nurse, 5 counselors and in addition the hospice is supported by 80 community caregivers who also have been trained as ART treatment supporters.

PLHIV are facing challenges around ART adherence. To date, however, these challenges have not been documented in any rigorous form and have consequently not influenced the content and process of the consultation sessions the ART staff have with their HIV positive patients. Understanding the barriers and facilitators to adherence in this rural context would therefore contribute to improving the practice within the ART programme, and in providing a continuum of care for PLHIV and AIDS (Personal communication between VSO staff and St Lukes Mission Hospital ART staff, 31st May 2007).

1.4. Structure of the mini-thesis

The rest of the report has been divided into the following:

- Chapter two mainly focuses on the literature review highlighting barriers and facilitators to adherence in developed and developing countries;
- Chapter three focuses on the methodology used in the study;
- Chapter four focuses on the presentation of the results;
- Chapter five presents an analysis and discussion of the findings and
- Chapter six is the conclusion, limitations of the study and highlights recommendations arising out of the study.

CHAPTER TWO

LITERATURE REVIEW

2. Introduction

The literature review provides an overview of facilitators and barriers to ART adherence issues amongst people living with HIV. It further provides examples of research conducted in both developed and less developed countries to review the) that influence adherence amongst PLHIV living in rural settings similar to Zambia.

As a result of provision of ART in many countries, including Africa, there has been a dramatic reduction in HIV-related morbidity and mortality (Attawell & Mundy, 2003). However, it is commonly recognized that many patients experience difficulty in following treatment recommendations generally (not only related to HIV) worldwide. For example, WHO has noted that adherence to long-term therapy for chronic illness including HIV and AIDS, in developed countries averages 50% and the rates in developing countries are much lower (WHO, 2003).

Research shows that poor adherence to antiretroviral drugs will have an effect on the effectiveness of treatment and this increases the likelihood of drug resistance (WHO, 2003). Non-adherence could also lead to treatment failure, disease progression and death (WHO, 2003; Stringer *et al.* 2006). Several authors state that very high level of adherence (greater than 95%) are required for antiretroviral therapy (ART) to be effective and to prevent the emergence of resistant viral strains (Paterson *et al*. 2000; Lckovics *et al.* 2002). Given that developing countries have limited access to ART, ensuring early adherence is important as treatment options for HIV become limited once resistance develops (Chesney, 2003).

2.1. Barriers and facilitators identified as affecting adherence in developed countries

In developed countries several studies have been conducted to ascertain what kinds of factors contribute to adherence or non-adherence among people living with HIV and AIDS. The following are the barriers to adherence in developing countries:

2.1.1. Inadequate knowledge and patient belief systems

Several studies (Robert, 2000; Chesney, 2003; Murphy *et al*.2000 and Sidat; Fairley & Gierson.2007) have noted that patients who have inadequate knowledge and understanding of the relationship between adherence, viral load and disease progression were more likely not to adhere to medication. For example, in a qualitative study on experiences and perceptions of patients with 100% adherence to Highly Active Antiretroviral Therapy, conducted in Australia, Sidat *et al.* (2007), argue that decreased adherence to ART has been found to be a result of patients' disbelief, non acceptance of the disease and perceived lack of benefit of the treatment.

2.1.2. Regime complexity as a barrier to adherence

Studies conducted in the USA (Murphy *et al*. 2000; Roberts, 2002; Chesney, 2000 and Chesney, 2003) cite that regimen complexity which included taking multiple daily doses, sometimes with food restrictions greatly impacted on the PLHIV's willingness to adhere to medication. In addition, PLHIV that faced challenges such as following special drug regime instructions, sleeping through the dose time and changes in the daily routines were more likely not to adhere to their medication.

2.1.3. Side effects as a barrier to adherence

The issue of side effects has been noted to have an effect on patient's ability to continue taking prescribed medication (Roberts, 2002; Murphy *et al*.2000; Ammassari *et al*. 2001; Chesney, 2000; Ichovics and Meade 2002). For example, Ammassari *et al*. (2001), in their cross sectional multicenter study conducted in Italy found that patient-reported symptoms and medication side effects such as anxiety, fatigue, abnormal fat accumulation, diarrhea, nausea, anorexia and insomnia were reported among people who were not adherent to ART medication.

Although several authors (Chesney, 2000; Ichovics and Meade 2002) have also cited side affects and symptoms, and suggest that patient's views about medications may be complex and vary according to the type of regimen. The authors state that increased understanding of side effects and how to manage these assisted people on ART to continue taking their treatment and not get discouraged when they were experiencing intense side effects (Chesney, 2000; Chesney, 2003; Ichovics and Meade 2002).

2.1.4. Drug abuse, alcohol abuse and psychological factors

In addition, certain patient-related factors such as active drug and alcohol abuse and psychological factors such as anxiety and depression have been identified as critical factors that can contribute to non-adherence to ART as this influences PLHIV's ability to take their medication (Chesney, 2000; Power *et al*. 2003; Methta *et al*. 1997).

2.1.5. A non supportive patient - provider relationship

A non-supportive patient – provider relationship has been known to be a barrier for PLHIV to adhere (Murphy *et al*. 2000; Chesney, 2002; Chesney, 2003). Where PLHIV were unhappy with the quality of the health care provider relationship that included patient's lack of satisfaction with their provider and quality of communication with the provider, this has contributed to lack of adherence. Chesney (2003) noted that treatment becomes complex, side effects go unmanaged and patients are less likely to adhere as they cope alone with such difficulties when the patients become frustrated as a result of miscommunication.

Laws *et al.* (2000) in their study conducted in Massachusetts, USA on how people with HIV understand and experience the problem of adhering to antiretroviral medication regimes found that most patients were unable to recognize non-adherent behaviour and did not understand the consequences of missing doses. However, it was also noted that patients in the study did not discuss the issue of non-adherence with their physicians. Of the 25 respondents interviewed, 84% of the patients reported non-adherent behaviour, which included ceasing treatment, having medication 'holidays', sleeping through doses and skipping doses due to side effects (Laws *et al*. 2000).

2.1.6. Lack of social support

While social support may be different, the quality of the social support from a partner, friend and family members can influence adherence to treatment. Lack of satisfaction with social support has been known to result in non-adherence to medication among people taking ARVs. Perceived support from family members or a partner has been associated with adherence to HIV treatment as people were more comfortable and did not feel threatened to take the prescribed medication at the required time (Power *et al.* 2003; Turner, 2002).

2.2. Facilitators to adherence among PLHIV in developed countries

The following are the facilitators to adherence among PLHIV in developed countries.

2.2.1. Belief in the efficacy and knowledge of medication

Sidat *et al.* (2007) cite a combination of factors as contributing to achieving 100% ART adherence. These include PLHIV knowledge of ART and readiness or willingness to take it. For patients in the Australian study who consider taking medication as a life style and see ART as a lifeline responsible for improvements in their life, this reinforced their commitment to continue adhering to their treatment as it prolonged life and improved their quality of life. Therefore, patients who believed that taking treatment would prolong their lives were more likely to adhere to ART. Decreased adherence to ART has been found to be a result of patients' disbelief, non-acceptance of the disease and perceived lack of benefit of the treatment (Sidat *et al*. 2007).

2.2.2. Supportive clinic-patient relationship as a facilitator to adherence

The nature of the clinic-patient relationship can also contribute to adherence. Research findings in several literature sources (Chesney, 2000; Chesney, 2003 and Sidat *et al*. 2007) highlight the importance of clinic-patient relationship that included patients feeling supported by their health care provider to take ART. Chesney (2003) and Sidat *et al.* (2007) suggest that patients that feel supported by their health provider are better able to continue taking their treatment.

2.3. Barriers and facilitators identified as affecting adherence in developing countries

There are obvious similarities in terms of the barriers and facilitators to ART adherence that operate in *both* the developed and developing world. These include side effects (Ammassari *et al*. 2001; Chesney 2000; Ichovics and Meade 2002; Dahab *et al*. 2008) which develop as a result of taking medication, patient and client relations (Chesney 2000; Sidat *et al*. 2007), and alcohol abuse (Chesney, 2000; Power *et al*. 2003; Methta *et al*. 1997; Dahab *et al*. 2008; Weiser *et al.* 2003) which results in PLHIV not taking their medication consistently and therefore not adhering to medication.

2.3.1. Socio-economic circumstances and cost of ART

However, studies related to ART adherence conducted in developing countries indicate that there are slightly different and/or additional reasons that account for non-adherence or adherence in these settings. Most of these can be attributed to differences in socio-economic conditions and the accessibility of treatment.

In some developing countries such as Botswana, Malawi and India, the cost of ART was perceived as a significant barrier to adherence to ART (Weiser *et al*, 2003, Kumarasamy *et al.* 2005; Oosterhout *et al*. 2005. For example, a formative qualitative study conducted in Chennai, India (Kumarasamy *et al.* 2005) which examined the barriers and facilitators of ART adherence identified cost of ART as the main barrier, which often resulted in patients having to sell their jewels and property or borrowing money to fund their treatment, and having to take self imposed "drug holidays" - in other words taking their medications only when they can afford to do so and stopping their medication when they can no longer afford it. Similarly, a study conducted in Botswana (Weiser *et al*. 2003) found the cost of ART to be perceived by both patients and health care providers to be the most significant barrier to ART adherence. Another cross sectional study conducted in Malawi to evaluate antiretroviral therapy results in a resource-poor setting by Van Oosterhout *et al*. (2005) concluded that one of the most important reasons for non-adherence was personal financial reasons. The patient's economic condition interfered with their inability to take treatment.

A cross sectional study conducted among HIV positive individuals in Costa Rica to determine prevalence, predicators and reason for non-adherence to antiretroviral (Stout *et al*. 2004) cited difficulty in finding transportation to the clinic, in particular those that were reliant on public transportation as this involves a significant amount of time, money to get to the clinic for consultations tests and prescribed antiretroviral drugs.

Another study conducted by Uzochukwu *et al.* (2009) on determinants of non-adherence to subsidized anti-retroviral treatment was conducted in southeast Nigeria. Results from this study demonstrated that even though treatment was subsided ensuring that issue of cost of drugs was addressed other factors such as, treatment being a reminder of one's HIV status and selling of ones' own drugs to those unable to enroll in the project were key reasons for individuals not adhering to the treatment

2.3.2. Stigma and discrimination

In addition, various authors (Kumarasamy *et al*. 2005; Dahab *et al*. 2008; Weiser *et al.* 2003) have citied stigma and discrimination as a significant barrier to ART adherence. Issues raised in relation to stigma were fear of disclosure of HIV positive status to others as this would result in rejection, negative reactions from others and stigmatizing the HIV positive person or their family members. This was seen as contributing to increased difficulty of taking medications in public, or of attaining ART adherence support from family members or HIV and AIDS - related care (Kumarasamy *et al*. 2005). In addition, Weiser *et al.* (2003) identified a non-supportive home and work environments as critical barriers to adherence.

2.3.3. Denial of one’s HIV status and feeling better as a result of taking ART

A lack of acceptance of one’s HIV status was seen as barrier to adherence among PLHIV in developing countries. A qualitative study conducted in a South African workplace programme by Dahab *et al.* (2008) looking at patients & providers’ perspectives on barriers to and enablers of HIV treatment adherence reported that the main barriers were denial of existence of HIV or one’s positive status. As a result people on ART discontinued treatment, as they did not feel that it was necessary to continue with it. The same study also found that PLHIV stopped taking their medication as result of feeling better.

2.3.4. The influence of religious beliefs

Although stigma is highlighted as a barrier in India and Africa, religion also seems to have a role in the stigmatization and discrimination of PLHIV. Religion plays a central role in many communities in Africa, shaping their beliefs, perceptions and attitudes. Zou *et al.* (2009) in their exploratory study conducted in Tanzania with parishioners (whose HIV status was unknown) attending Catholic, Lutheran, and Pentecostal churches in both urban and rural areas, which probed associations between religious beliefs and HIV stigma, disclosure, and attitudes toward ARVs treatment found that HIV related stigma was associated with the belief that HIV was a punishment from God and that people living with HIV were not living according to God’s word.

However, findings from the same study indicated that although the majority of respondents believed that prayer could cure HIV, almost all the respondents indicated that they would begin treatment if they were HIV positive. Findings from this study indicated that refusal to take treatment was associated with a lack of education and a lack of knowledge of ARVs (Zou *et al.* 2009). However a prospective observational study conducted by Wanyama *et al.* (2005) in Uganda, with PLHIV on ART, highlighted something different in particular: that 1.2% patients discontinued their ART as they believed that they no longer needed the treatment because of their belief that they had been spiritual healed.

2.3.5. Forgetfulness, being busy and being away from home

Sarna *et al.* (2006) and Stoul *et al.* (2004) both cited various reasons for ART clients missing doses. In an exploratory study conducted in India by Sarna *et al.* (2006) on adherence to ART and sexual risk behaviour among ART clients, the reasons for missing doses included being busy with other things, forgetting and being away from home. Stout *et al.* (2004) have similar findings in their research citing forgetfulness, falling asleep through dose time, being busy with other things and being far from home as reasons for non-adherence.

2.3.6. Substance abuse, side effects and severe depression

Substance abuse such as alcohol was also a key barrier in adhering to ART among PLHIV on ART in the developing countries (Dahab *et al*. 2008; Weiser *et al*. 2003). In addition, side effects were also identified as a significant barrier to ART adherence (Dahab *et al*. 2008). Not only did alcohol and side effects impact on PLHIV’s ability to adhere to medication, lower adherence was associated with severe depression (Sarna *et al*. 2006).

2.3.7. Lack of food and resources to support ART adherence

Studies have been conducted in various countries in Africa that cite lack of food and resources as a barrier to adherence among PLHIV (WHO, 2006; Weiser *et al*. 2003). For example, a multi-country study conducted in Tanzania, Botswana and Uganda showed that hunger and the need for more food in the initial stages of ART resulted in ART users missing the required doses (WHO, 2006). The study found that in many instances taking ARV made people hungrier and, due to lack of resources, to buy additional food some ART users resorted to taking their ART at times when food would be available (WHO, 2006).

2.3.8. Use of traditional medicine as barrier to adherence

Dahab *et al.* (2008) in a study conducted in South Africa cited the use of traditional medicines as a barrier to ART adherence as it caused people on ART to stop treatment for the duration of the traditional treatment.

2.3.9. Inadequate drug supply and long waiting times at the clinics

Sarna *et al.* (2006) also found out that PLHIV missed doses as a result of pills being unavailable which was attributed to the public sector dispensaries running out of stocks. Similar findings of shortages of drugs were citied by Oosterhout *et al.* (2005), in a cross sectional study conducted in Malawi to evaluate antiretroviral therapy results in a resource-poor setting. Another study conducted by Uzochukwu *et al.* (2009) on determinants of non-adherence to subsidized anti-retroviral treatment was conducted in southeast Nigeria. Results from this study demonstrated that even though treatment was subsidized ensuring that issue of cost of drugs was addressed other factors such as non availability of drugs at the treatment center resulted in PLHIV not adhering to their medication.

Besides drugs being of out stock in the ART facilitates, a key issue around patient provider relations identified in developing countries was the issue of long waiting times at the clinic. This resulted in people on ART being dissatisfied with the services being provided and were likely to stop going to the clinic to pick up their medication (Dahab *et al*. 2008).

While it is has been acknowledged that the provision of drugs in many African countries has improved the lives of people, there are concerns about low adherence and the feasibility of scaling up ART programmes in resource-poor and constrained settings. Harries *et al.* (2001) argue that it is not just providing drugs that is important but unregulated access to drugs. Many countries in the Sub- Saharan Africa for example have challenges in the ability of the health systems to cope with the roll out of ART. If this is not addressed, it could lead to widespread rapid emergence of drug resistant strains, increased treatment failure that reduces treatment options of individuals and leading to transmission of drug resistant strain of HIV.

The authors Harries *et al.* (2001) argue that current provision of ART in Sub- Saharan Africa is characterized by having few health care workers skilled in the provision of and management of ART, inadequate monitoring of viral load, immune status or side effects due to poor infrastructure, weak distribution and procurements systems and lack of monitoring systems to check drug adherence or drug effectives. Other concerns pointed out by the authors are about theft of medicines from public health facilities for sale in the market, shops, and private clinics and across the national boarders.

2.4. Facilitators to ART adherence in developing countries

Perceived benefits by PLHIV of taking ART were identified as facilitators to adherence (Kumarasamy *et al*. 2005; Sarna *et al*. 2006; Dahab *et.al*.2008). Kumarasamy *et al.* (2005) identified facilitators of adherence to include perceived benefits of ART and proper adherence such as better health, living longer and gaining weight, perceptions about consequences of non-adherence and availability of social support (Kumarasamy *et al.* 2005). Another study conducted by Sarna *et al.* (2006) in India cited similar reasons for regularly taking medications. Patients in the study who reported never missing medications cited the desire to be healthy and avoid illness, the desire to live for their families and family support as important factors contributing in their taking medications regularly. In addition, doctor's advice and emphasis on taking medications regularly were important factors to adherence.

2.4.1. Use of strategies by PLHIV to support ART adherence

The same study conducted by (Sidat *et al.* 2007) also identified commonly used strategies that PLHIV on medication used to remind themselves to remember to take their medication, including PLHIV receiving short messenger service messages (sms) in their mobile phones organized by their care provider, setting up a mobile telephone alarm or table clock alarm and using pill boxes.

2.4.2. Social support from friends, family and treatment supporters

Dahab *et al.* (2008) also identified self-efficiency, social support, an effective adherence programme, the ability to fit ART into daily life schedule, and a desire to stay alive for the sake of others as facilitators to adherence (Weiser *et al*. 2003; Dahab *et al.* 2008). In addition, Cortez *et al.* (2004) in the their research in providing ART in poor resource settings in South Africa cited and recommended that to attain high levels of adherence, community based ART initiatives need to have a strong-patient centered approach, comprehensive counseling which includes well trained lay counselors that provide one-on-one counseling for people taking ART and peer support through support groups. Similarly Nachega *et al.* (2006) in their study conducted in South Africa identified the use of treatment supporters such as family members or friends being in contact with the patient and directly observing them as they take their medicine as a key strategy piloted in South Africa and recommended to minimize non-adherence were ART is being provided in resource –limited settings (Nachega *et al*. 2006).

2.5. Barriers and facilitators identified as affecting ART adherence in Zambia

Zambia provides a case of a setting with limited resources in Africa. The major concern in many resource-limited settings is the potential of emergence of drug resistant viral strains. Therefore to prevent this optimal adherence is required. Only a few studies have been conducted in relation to ART and adherence in Zambia to date, however. The first study explored experiences of HIV and AIDS related treatment in urban and rural setting in 2002 and 2003 (International HIV and AIDS Alliance 2003), and the second study focused on the experiences of treatment users and heath care workers (International HIV/AIDS Alliance (2004) in Zambia. Both studies focused on urban settings, although the community consultations had a component on a rural setting, and thus do not necessarily address the potential barriers and facilitators faced by PLHIV in rural areas. To the best of my knowledge there is very little information is available on the factors that contribute to the levels of adherence in Zambian rural communities.

The study on experiences of treatment users and heath care workers (International HIV and AIDS Alliance, 2004*)* was a preliminary baseline research study conducted in Lusaka and Ndola districts in August 2004. The International HIV/AIDS Alliance study found that treatment users faced various barriers to treatment including costs of treatment and travel, lack of information on services being provided and information on antiretroviral drugs and how they work. The same study identified stigma and discrimination as another main barrier as this contributed to people not to being able to access treatment or care for fear of being perceived to be HIV positive (International HIV/AIDS Alliance, 2004). These findings are similar to findings in other parts of developing countries. This study also suggested that whilst there was a high level of adherence in the early stages of treatment, interviewees showed little indication of how best they could maintain adherence later on (International HIV/AIDS Alliance, 2004).

As noted in other developing countries, PLHIV taking medication in Zambia have used various reminder strategies to support the uptake of ART. The International HIV/AIDS Alliance *et al.* (2007) identified strategies used to promote adherence included patients using an alarm, clock and radio to remind one on when to take the drugs, children, family members including spouses and home based care workers reminding patients to take their drugs (International HIV/AIDS Alliance *et al*. 2007).

2.6. Conclusion

This literature review sought to provide an understanding of barriers and facilitators to adherence among people living with HIV in developed and developing countries. The literature suggests that whilst some factors - such as side effects, patients' attitudes, beliefs, and fear of disclosure - contribute to non-adherence in both developed and less developed countries, there are some unique factors that contribute to non-adherence among people living with HIV in the developing world. For many developing countries, particularly in the Southern Africa these factors include costs associated with treatment, stigma and discrimination, being away from home, running out of pills and long waiting times at the ART facility.

Facilitators to adherence in both developing and developing countries included knowledge of medication, belief in the treatment and social support from friends, family members. More specific to developing countries such as countries in Africa, nutritional support and use of treatment supporters contributed to individuals adhering to treatment regimes.

However, it is also clear from the literature review that the issues of adherence to ART, particularly in rural Southern Africa, are still not adequately explored. Gil *et al.* (2005) in their work on ART adherence in sub-Sahara Africa argue that most African adherence studies to date have limited their scope to reporting on adherence rates and population risk factors. Not much is focused on qualitative research to determine why a patient is not being adherent and examining the factors that foster sustained adherence. As Zambia is working towards meeting the universal access to treatment by 2010, there is a need to identify and understand the factors that can contribute to adherence among people living with HIV – specifically in rural settings. In light of the discussion in this chapter, the researcher has tried to explore this further through this study.

CHAPTER THREE

METHODOLOGY

3. Introduction

The aim of this study was to identify the potential barriers and facilitators of adherence to antiretroviral treatment among adult PLHIV in rural Chongwe district of Zambia and provide recommendations on how best to support ART adherence in a rural context. The following were the objectives of the study:

1. To explore with PLHIV on ART in the rural district of Chongwe, their knowledge, perceptions and beliefs about the importance of ART
2. To explore with PLHIV on ART the barriers and facilitators to ART adherence and how best to offer PLHIV ART adherence support.
3. To explore with health workers and ART treatment supporters associated with St. Luke's Mission Hospital in Chongwe the perceived barriers and facilitators to ART adherence among PLHIV and how they can best offer PLHIV ART adherence support.
4. To synthesize study findings and recommendations on how best to support ART adherence and implementation of ART adherence strategies; specifically in the context of a rural district.

3.1. Study Design

The researcher conducted a explorative qualitative study. A qualitative study was used in order to gain in-depth insights into barriers and facilitators to ART adherence among

PLHIV in rural areas. The perceptions, opinions and experiences of PLHIV on ART regarding the barriers and facilitators influencing ART adherence were explored using the qualitative methods of in-depth interviews and focus group discussions (FGDs). Similarly, interviews and FGDs were conducted with health workers at the Health facility and ART treatment supporters respectively to explore how they can offer appropriate ART adherence support to PLHIV in a rural health facility.

3.2. Study Population

The study was conducted at St. Luke Mission Hospital in Mpanshya village and two other villages, namely Rufusa and Chimusanya. These two villages were part of the ART outreach centres for the health facility. These two villages were selected out of a group of seven outreach centers (villages) associated with the health facility on the basis that these villages had functional support groups. These support groups met regularly and it was therefore anticipated that the groups would provide rich perspectives on barriers and facilitators to adherence. The study population consisted of the following:

PLHIV interviewees: Eight PLHIV (four women and four men) on ART, one female PLHIV on 'pre ART'[2] were interviewed through in-depth interviews. Demographic characteristics of PLHIV are summarized in chapter four (the results section).

Characteristics of PLHIV support group members[3]

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[2] PLHIV on pre ART have been enrolled to start accessing ART but have not yet started. These are usually provided with counseling, information on ART and monitored by the health facility.

[3] A support group in Zambia is usually made of up people living with HIV and AIDS and is normally registered with the Network of people living with HIV and AIDS in Zambia.

Two FGDs were conducted, with a total of 23 PLHIV from two support groups in Rufunsa (13 PLHIV) and Chimusanya (10 PLHIV) villages. The support groups mainly constituted PLHIV that had tested positive for HIV and knew their status. The FGDs therefore, included people on ART treatment and those not yet on treatment. The researcher did not get detailed demographic characteristics from these FGD members.

Treatment supporters: In addition, nine (five men and four women), caregivers4 who are treatment supporters from Chimusanya village, participated in a FGD. The group included a pastor, two teachers, a PLHIV and five community members, who were subsistence farmers. The treatment supporters were all trained and were linked to the ART facility at St Luke Mission hospital. The treatment supporters' key role was to conduct home visits in the community to support PLHIV placed on treatment and the PLHIV's families through counseling, providing information and referrals to health facility when needed.

Key informants: The health facility has a total of 13 health care workers. Five of these (two females and three males) were interviewed and formed part of the ART facility that provided ART services in the community. The interviews with key informants were conducted to compliment the information from the in-depth interviews with PLHIV. The following were the Informants:

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[4] A caregiver in this study is a trained care provider who provides health services such as counseling, support of adherence, and making referrals at the community and home level. This caregiver or provider is usually linked to community and home based care programmes supported by NGOs, FBOs and other organizations in this case the caregivers are linked to the health facility.

- The ART nurse responsible for the hospice, coordinating the ART facility and outreach activities.
- The counselor, providing counseling for testing care and support.
- The hospital nurse supporting the ART facility.
- The Environmental Health Technologist responsible for supporting adherence, care and support at the health facility.
- A Doctor on short-term placement responsible for screening patients at the health facility.

3.2.1. The selection process for in-depth interviews with people living with HIV

A meeting was held with key hospital staff in December 2008 to explain the purpose of the research and discuss how best PLHIV interviewees ought to be sampled. Based on the random sampling criteria identified by the researcher, hospital records (specifically those with registrations of 'pre ART' services and ART services) from all the 7 villages or outreach centres were provided by the health facility to the researcher in December 2008. There were a total of 731 people living with HIV and on ART that were clients of the facility, attending the hospital and being followed up in the villages. These were seen by staff and followed up in the villages using the outreach activities. Interviewees were randomly sampled from this original register list, where an initial 25 potential interviewees were randomly selected. This provided the researcher with a range of people who had various experiences of ART adherence. The researcher then worked with the health worker to trace and identify the homes of the randomly selected PLHIV over a period of one day in December 2008.

From the initial list of 25 PLHIV randomly selected, the researcher ended up with a list of 11 key potential interviewees[5]. The original list of 25 was reduced to 11 as some of the potential interviewees could not be interviewed due to various reasons such as their death or unavailability at their homes at the time for the interview. Others could not be accessed due to the fact the villages were very far from the health facility (for example, 120km) and the poor road networks and heavy rains made the way to their villages impassable.

From this second list of 10 PLHIV on ART and one on pre-ART, the researcher was only able to interview three PLHIV (one female and two males) from Mpashaya village. The remaining PLHIV on the list could not be interviewed because some were not available for the interview because they had traveled to the city (Lusaka) and another PLHIV, who was identified as an alcoholic, could not be located. Furthermore the ART center confirmed that the latter person was not adhering as a result of alcohol abuse. As data collection was conducted during December, one of the rainy season months, the remainder of selected PLHIV could not be assessed due to heavy rains, which made the road to their villages impassable.

To ensure that saturation could be reached, an additional five PLHIV were purposively selected from the two FGDs conducted in Rufusa and Chimusanya villages with support groups of PLHIV– which are described in the next section. Of the five PLHIV, two PLHIV interviewees (one female and one male) were selected from the first FGD with a support group held in Refusa village. The remaining three PLHIV (two females and one

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[5] 10 PLHIV were on ART and one PLHIV was on Pre-ART

male) were selected from the second FGD with a support group held in Chimusanya village. The selection of the five additional PLHIV interviewees from these FGDs was done on the basis of information gathered during the FGDs. The PLHIV were chosen because they did not contribute much during the FGDs and were willing to participate in the in-depth interviews. The FGDs with support groups of PLHIV were conducted on 29th December 2009.

An additional PLHIV was identified for an in-depth interview during the FGD with the treatment supporters in Chimusanya village. During the conversation with treatment supporters, it was highlighted in the FGD, that a female PLHIV had stopped taking drugs due to religious reasons. As this was a unique case that would provide interesting insights on adherence, with support of the treatment supporter linked to this PLHIV and the Environmental Health Technician, an appointment was set up with the PLHIV to conduct the interview at their home on the same day of 29th December 2009. This interviewee did not participate in any of the FGDs with support groups.

3.2.2. The selection process for key informants – Health care workers

From a total of 13 health care workers working within the hospital, six key informants that worked in the ART facility were identified of which five were interviewed. These worked both in the hospital and were part of the ART outreach programme (ART mobile clinic). One staff member declined to participate in the interviews because he did not feel comfortable to participate in the process. The interviews were conducted on 28th December 2008 with the following informants:

- The ART nurse responsible for the hospice, coordinating the ART facility and outreach activities
- The counselor, providing counseling for testing care and support.
- The hospital nurse supporting the ART facility.
- The Environmental Health Technologist responsible for supporting adherence, care and support at the health facility
- A Doctor on short term placement responsible for screening patients at the health facility

3.2.3. The Selection process for focus group discussions with support groups of PLHIV and treatment supporters

A total of three FGDs were held with 2 support groups of PLHIV (23 PLHIV in total) and one with nine treatment supporters in Rufunsa and Chimusanya villages. The FGD with treatment supporters was held in Chimunsanya village.

Each of the seven villages had a support group of PLHIV and that was supposed to meet once a week. Given that the initial decision was to work with two support groups of PLHIV, support groups of PLHIV were purposively selected with assistance from the ART nurse and the Environmental Health Technician. The two villages were selected because they had functioning support groups.

The ART nurse and the Environmental Health Technician were also responsible for selecting treatment supporters. As Chimunsya village was already selected for conducting a FGD with a support group, treatment supporters were therefore selected from the same village.

3.3. Data Collection

Data was collected in the month of December over a period of three weeks, from the 11th of December to 29th December 2008. Data was collected through in-depth interviews from nine PLHIV, five key informants and from three focus group discussions (two with PLHIV support group members and one with treatment supporters on 29th December 2008). The researcher mainly conducted the interviews with PLHIV, key informants and FGDs. The researcher also had support from another colleague from Zambia OPEN University. This colleague observed the interviews and FGDs and also supported with data collection; for example, he specifically facilitated discussions with one support group of PLHIV in Chimusanya village.

The ART nurse and the Environmental Health Technician were responsible for coordinating and ensuring that time was booked to meet with the treatment supporters and the support groups. The ART nurse was also responsible for working with support groups in the villages and assisted the researcher to identify functioning support groups. The Environmental Health Technician who was a staff at the ART facility was assigned to assist the researcher to identify homes of interviewees, setting up meetings and introduce the researcher.

3.3.1. The procedure for conducting in-depth interviews with PLHIV and interviews with key informants

In relation to the PLHIV interviewees the researcher, with assistance from the Environmental Health Technician, visited some interviewees in their homes and arrangements were made to have the interviews done in a private place at their home. Three in-depth interviews were conducted on the 26th of December 2008 and six in-depth interviews were conducted on the 29th of December 2008. The researcher conducted four interviews at the houses of the interviewees as this was much easier to arrange and the setting was comfortable for the interviewees. However this posed a challenge for the researcher who was sometimes required to provide details about the meeting to other members of the family who were present during the visit. Although family members knew the status of their HIV positive family members, to ensure confidentiality for interviewees, the researcher emphasized that she was a student who came to learn from the experiences of their family members. The other five in-depth interviews were conducted at the health facility in Rufusa and at a school in Chimusanya respectively as these PLHIV were selected from the support groups of PLHIV that had come for FGDs.

In addition, the researcher had to make a courtesy call to the local headman in Mpashaya village so that the purpose of the visit could be explained to the traditional leadership in the community[6]. The researcher explained to headman that it was a learning visit that will contribute to the studies that researcher was involved in and this was part of the requirement of the studies the researcher was doing.

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[6] Paying a courtesy call visit on the local leadership is a sign of respect and it is encouraged within the communities.

For in-depth interviews, the local language Njanja was mostly used as this was preferred by the interviewees. The interviewees were informed about the study in the local language and assured that their participation or non-participation would not impact on the quality of care they received at the hospital. The participant information sheet (Appendix 8) consent information (Appendix 10) was given to everyone taking part in the research, read with the interviewees and consent regarding understanding and willingness to participate in the research was sought before the interview.

Once consent was given, each PLHIV interviewee was given a code number which as used in the consent form. Individual, face-to-face interviews were conducted using a semi structured interview guide. The interviews took approximately one and half to two hours depending on the ability of the interviewee to articulate themselves and their openness to provide detailed information during the interviews. In total, in-depth interviews were conducted with nine PLHIV as the researcher believed at this point saturation had been reached and no new information was emerging from the interviews.

The interview guide for PLHIV was pre-tested with three PLHIV on ART at a peri-urban community based organization in Lusaka prior to conducting the research. The interview guide was refined based on feedback received to ensure that questions were culturally appropriate.

The interview questions with interviewees were mostly open ended and included a focus on demographic factors, understanding of adherence and antiretroviral drugs, perceived benefits of ART, possible reasons for non and good adherence, types of support mechanisms available, and participants thoughts on how adherence could be facilitated, supported and sustained. (An interview guide for in-depth interviews is contained in Appendix 4). All interviewees were thanked at the end of the interviews and an amount of K10, 000 ($2) was given, to thank the nine PLHIV.

Similarly, with the five interviews with key informants, appointments with each one of them were made and interviews were held in their homes on the 28th of December 2008. A participant information sheet was provided to staff and consent was sought before interviewing them. The interview questions with key informants were mostly open ended and these included demographic factors, type of training they had received, possible reasons for non-and good adherence among PLHIV, types of support mechanisms available for PLHIV on ART, and informants thoughts on how adherence could be facilitated, supported and sustained (See Annex 5 for interview guide).

3.3.2. The Procedure for conducting Focus Group Discussions

In relation to FGDs, a total of three FGDs were held. Two FGDs were held with 2 support groups of PLHIV and one with treatment supporters. The health worker, a counselor from the ART facility, who as part of their job has the responsibility to coordinate support groups and work with treatment supporters, supported the researcher in identifying the support groups and the group of treatment supporters. PLHIV and treatment supporters were informed of the FGD meeting a week prior to the FGDs meeting dates. The counselor liaised with the chairperson of the support groups and asked if the researcher could meet the 2 support groups of PLHIV on 29th December 2008 and treatment supporters on 29th December 2008. As these were not the normal meetings days for the support groups, these meetings were specifically set up to enable the researcher conduct the FGDs. These meetings were arranged at a central place within the selected villages.

The first FGD was conducted with a support group of 13 PLHIV at the local health centre in Rufusa village, and the second and third FGDs (with a support of 10 PLHIV and nine treatment supporters respectively) were conducted at a local school in Chimusanya village. An interview guide was used for all the FGDs. All the FGDs explored issues on ART and adherence and tried, through the group discussion process, to ascertain what the possible barriers and facilitators to adherence among PLHIV were. The FGDs were also designed to provide insight into what they (PLHIV and the treatment supporters) perceived would be necessary support-to-support adherence among PLHIV in rural settings (See Appendix 6 for FGD guide with support groups and appendix 7 for FGDs with treatment supporters).

Before the FGDs were conducted a participant information sheet (Appendix 9) was given to all participants of the FGDs and an explanation was provided about the research in both English and Njanja the local language. Participants were asked if they understood what was being asked of them and were given an opportunity to ask questions and given an option not to participate. Consent was given verbally and the chairperson of the support group signed on behalf of the group. The need for confidentiality was explained emphasizing that issues discussed in the FGDs were not to be taken beyond the discussions.

English and the local language Njanja was used through out the discussions. The discussions took approximately one hour to one and half hours. An amount of K10, 000 ($2) was given, as transport reimbursement to all the participants in the FGDs. Snacks were also provided for participants in the FGDs.

3.4. Validity

To ensure rigour, data sources were triangulated through different qualitative data collection methods: individual in-depth interviews with PLHIV, the FGDs with PLHIV support group members, ART treatment supporters and interviews with key health staff at the ART facility.

During the process of each interview, the researcher presented a key summary of discussions points at regular intervals to allow validation from key interviewees. The researcher also took field notes during the in-depth interviews and FGDs and these sessions were transcribed. Each day, the researcher documented reflections and observations made through out the process of data collection and the analysis exercise. The researcher also used peer review and member checks. At the end of each day, the researcher had a briefing session with the colleague from Zambia OPEN University. Through this process, questioning of research findings was done and this enabled the researcher to gain additional insights on facilitators and barriers to ART adherence in rural communities.

3.5. Data Analysis

Interview questionnaires and field notes were reviewed several times. Data analysis started during the data collection exercise. A thematic analysis approach was used. Based on the research objectives some broad themes or categories related to barriers and facilitators to ART adherence were identified by the researcher and the assisting researcher during the data collection exercise – along with the proposals interviewees and key informants made about their desired adherence support. These formed the core themes around which all the data was clustered. Relationships between these categories were then compared, and inconsistencies, variations and new insights identified. Direct quotations have also been used during the write up of the report.

3.6. Ethical Considerations

After the University of the Western Cape approved the protocol, permission to conduct the research at St. Luke Mission Hospital in Chongwe district was requested through the hospital management team. In addition, the researcher was asked to send the protocol to the ethics committee at University of Zambia for further approval (see Appendix K for the approval letter from the Ethics Committee).

As per custom in many villages, the researcher also made a courtesy call on the local headman in Mpahasya village. This did not in any way impact on the confidentiality. The purpose was to greet and let the village headman know that the researcher was visiting his community to learn more on issues pertaining to ART and adherence in the community.

Participation in this research was voluntary and participants were provided with information about the research. Participants in the FGDs were informed by the health worker a week prior to the meeting with FGDs. Participants were asked for their informed consent prior to the interviews commencing. The identities of the PLHIV in-depth interviews were protected both during the interview phase and in the write up of the results by assigning codes to participants, which ensured their anonymity. In the event that the participants needed assistance (such as counseling support or a referral) arrangements were made with the relevant staff at the hospital to provide the required support and follow up. It was important that the researcher minimized any harm caused during the interview process. In addition, information on PLHIV support services for participants who might need additional counseling or support following the interview was provided by the researcher and identified concerns raised during interviews and FGDs were fed back to the ART facility.

CHAPTER FOUR

RESULTS

4. Introduction

This chapter reports on findings from in-depth interviews with PLHIV on ART, key informant interviews with health care workers, focus group discussions with caregivers (treatment supporters) and two support groups of PLHIV. The results focus on the following themes and issues:

- Demographic information about PLHIV on ART that participated in the in-depth interviews.
- The knowledge, perception and opinions about the importance of ART treatment from the perspectives of PLHIV.
- The barriers that PLHIV have either experienced or anticipate will affect their level of ART adherence.
- The facilitators that PLHIV have either experienced or anticipate will affect their level of ART
- Suggestions from interviewees, support group members, treatment supporters and health care workers of what can be done to improve the adherence support currently offered to PLHIV on ART adherence at ST Luke Mission Hospital, in Chongwe district. .

4.1. Description of PLHIV that participated in individual interviews

Basic demographic information about the nine PLHIV consisting of five females and four males– that participated in the in-depth interviews was collected in order to provide some background information on the interviewees. In-depth interviews were held with PLHIV from three villages, the ART facility is located at St Luke Mission in Mphashya village. Table 1 below summarizes these demographic characteristics:

Table 1: Demographic characteristics of PLHIV interviews

Number	Belonging to a support group	Sex	Age	Marital Status	Education attained	Occupation	Length of time on ARVs	Mode of transport to ART clinic	Duration of travel to ART clinic
Mphashya Village									
1	Yes	F	22	M	Secondary	Selling alcohol Nthemba[7]	Not yet[8]	On foot	20 minutes
2	Yes	M	32	M	Secondary	Farming	1 year & 1month	On foot	30 minutes
3	No	M	40	M	Primary	Watchman and farming	3 months	On foot	15 minutes
Rufunsa Village									
4	Yes	F	27	M	Primary	Farming	3 years	Borrows a bicycle	2 hours
5	Yes	M	38	M	Primary	Farming, piece work	1 year & 6 months	On foot	2 hours
Chimunsanya village									
6	No	F	26	S	Primary	Selling cassava, poultry farming	4 years	Bicycles	3 hours
7	Yes	F	30	S	None	Farming, piece work[9]	2 months	On foot	3 hours
8	No	F	42	M	Primary	Farming and selling flitters	4 years	On foot (Mobile clinic)	10 minutes
9	Yes	M	44	S	Secondary	Farming	1 year	On foot (Mobile clinic)	30 minutes

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[7] Nthemba in the local language is a local shop or kiosk

[8] PLHIV had been on Pre-ART since 2006. This interviewee was receiving introductory information, counseling and monitoring before initiating ART.

[9] Working on other people's farms which included jobs as labourers such as weeding, planting and digging

As can be observed from the table above, the nine interviewees were aged between 22 and 44. Five of the interviewees had attained primary education and three, secondary education.

4.2. Knowledge, perceptions and opinions on the importance of ART treatment

4.2.1. The perceived benefits of taking ARVs

When asked what they knew about ARVs and the purpose of taking ARVs, many of the PLHIV participating in the in-depth interviews suggested that ARVs made them ‘stronger’ by ‘boosting’ the body, providing their bodies with renewed energy to ‘fight the virus’ and thus, prolonging ‘life’. Two of the nine PLHIV interviewed described the benefits of ART as such:

> *… [ARVs] make the virus weaker and help me get stronger, gives me energy.*

Female PLHIV, interviewee # 4

> *…because it [ART] boosts the body, the body has energy, [and] strength and [it] can fight the virus.*

Male PLHIV, interviewee # 9

One PLHIV that participated in the in-depth interviews particularly acknowledged that the ARVs did not only give him “long life” but it improved his life and at least ensured that he would be present to watch his children grow- as stated in the following words

> *…they [ART] give long life, this ensures that the children can grow and I do not leave them young.*

Male PLHIV, interviewee # 2

The perception that ARVs prolong life was also highlighted during the FGDs with the two support groups of PLHIV. Participants in these FGDs argued that ARVs improved their health and strengthened their immune system by keeping their CD4 counts high. The group indicated that this reduced the “HIV viruses” in their bodies, making them feel better and stronger. As a FGD participant summarized below:

> *The [ARVs] boosts the CD4 count to go high, this helps to*
> *Reduce the HIV virus and improves our lives so that we*
> *can go pa songolo [local term to mean moving forward].*
>
> FGD participant in Rufunsa

4.2.2. Knowledge about names and how ARVs are supposed to be taken

Of the eight PLHIV on ART and who were interviewed individually only four were able to name the drugs they were taking. Of these four, three said they were on Nevirapine/Zidovudine/Lamivudine while one was on Truime 30. At the time of the study, based on the Zambia National guidelines on ART, all these drugs were part of the first line regime. The other four interviewees were not able to name the ART drugs they were taking – although one mentioned that ‘he was not sure but thought he was taking Truime 30’ and two other interviewees could describe the color of the drugs they were taking:

> *I cannot remember the names but the drugs were yellow and white.*
>
> Female PLHIV, interviewee # 4

> *I do not know the names but they [drugs] are white and I have two bottles.*
>
> Female PLHIV, interviewee # 7

All of the PLHIV, apart from one understood the importance of taking their medication at the prescribed time(s). However, one interviewee, who mentioned taking medicine in the morning and evening, did not seem to know what he was taking specifically and for how long he was supposed to take the medicine:

> *…I have no idea what I am taking. I was not told about the drugs, information was not adequately given to me. I take my medicine at 6:00 hours in the morning and 18:00 hours in the evening. I do not know how long I have to take them. I was told when I started taking the medicine that I will take for 4 months.*

Male PLHIV, interviewee # 3

Pre-ART therapy is supposed to prepare PLHIV to initiate treatment. The study revealed that in the nine interviewees the PLHIV who had attended pre-ART for two years had areas where they lacked understanding. Although she understood that ARVs were to be taken for life, she did not know *how* they were to be taken. As stated in the following words:

> *I do not know if you need to take 1 or 2 tablets a day, I am not sure,*
> *[but] you are not suppose to stop [taking the medication].*

Female PLHIV, interviewee# 1

When asked if they were on any other medication besides ARVs, seven of the nine PLHIV interviewees said that they took Septrin. Four of those on Septrin said it was meant to protect them from coughs and Tuberculosis. One interviewee on Septrin had this to say about the drug:

> *…I take Septrin once a day so that I should not cough, this reduces the cough and I started taking this since I was [diagnosed HIV] positive.*

Male PLHIV, interviewee # 5

An interesting finding from the participants in FGDs with supports group of PLHIV in Rufunsa was that were of the impression that those not belonging to any support group of PLHIV had a tendency to mix medication. and did not understand the role of ARVs.. These "Outsiders" or non-support group members were perceived to consult traditional healers and, were therefore, taking traditional medicines together with conventional (ART) medicine, which the ART facility did not encourage. As a FGD participant in Rufunsa Support Group said:

> *…Those that do not belong to a support group, go to the traditional doctors, these do not understand and do not know*.

PLHIV FGD participant, Rufunsa support group

4.3. Reported non-adherence and knowledge of the consequences of skipping medication

When asked whether they had missed a dose of their medication in the past month, most of the interviewees indicated that they had not missed any dose and only two shared how their treatment regime had been interrupted. In the first instance, a male interviewee shared how he had missed taking his medication on one occasion because he had felt ill and had sought help at the local clinic. However, because of this he was not able to return home to access his medication for that day:

> *…I am a watchman, was working over-night, and went to the clinic last night [the night before]. I was not feeling well and missed a dose in the morning as the medicine was at home.*
>
> Male PLHIV, interviewee # 3

In the second instance, a female interviewee said she had completely stopped taking drugs on the doctor's recommendation because she experienced frequent side effects. She explained this as follows:

> *Due to side effects, I stopped taking the drugs, as the clinical staff stopped me from taking the drug. I need to get back [to the Hospital] and get a blood test.*
>
> Female PLHIV, interviewee # 6

This PLHIV indicated that she had been off medication for a month before the interview. However, before the interview, a treatment supporter identified this PLHIV during the FGD with treatment supporters as having stopped medication due to supposedly a Pentecostal pastor encouraging her to stop her medication. What was surprising for the researcher was that the PLHIV in question had indicated that staff at the hospital stopped her from continuing her medication.

Some interviewees seemed not to understand the consequences of skipping medication. As seen below, three out of the eight PLHIV individual interviewees on treatment admitted they did not know what would happen if they failed to take treatment:

> *I do not know what happens when one does not take the medicine.*
>
> Female PLHIV, interviewee # 7

> *I hear from people that you can die quickly*.
>
> Female PLHIV, interviewee # 8

> *Hmm… I do not know (holding his head).*
>
> Male PLHIV, interviewee # 3

4.4. Accessing information about ARVs

It was clear from PLHIV participating in the in-depth interviews that the health facility was their primary source of information about ARVs. Seven of the nine interviewees said they accessed this information specifically from a counselor or doctor at the health facility who provided them with both counseling and information regarding the drugs. As a female PLHIV interviewee stated:

> *…Before I started taking the ARVs, I did not know anything about this. When I started taking the drugs that is when I knew about the drugs.*
>
> Female PLHIV, interviewee # 4

Another interviewee said that he was encouraged to go for an HIV test after his wife fell ill and was admitted to hospital. Whilst at the hospital he learnt about ARVs:

> *I was in hospital and my wife was sick. When my wife was tested, I also tested and I was told that I am positive. The counselor at the ART clinic [then explained to] me about ARVs.*

Male PLHIV, interviewee # 5

Of the two other PLHIV, one indicated that they got the information from the community counselor and the other got information from their support group. Although during the in-depth interviews the health facility was highlighted as a major source of information about ARVs and HIV and AIDS, the FGDs with support group of PLHIV tended also to emphasize the importance of support groups in providing information, support and encouragement to PLHIV – including information about ARVs. A FGD participant summarized the role of support groups as follows:

> *Being in support group helps me, as we share the challenges in the groups, this removes fear… If I have a problem I go to my [support group] friends for support.*

FGD participant, Rufunsa Support group

4.5. Barriers that PLHIV have either experienced or anticipate will affect their level of adherence to ART.

Several themes emerged from the in-depth interviews with PLHIV on ART, the FGDs with PLHIV support group members, 13 from Refunsa village and 10 from Chimusanya village. The barriers ranged from side effects to religious beliefs and are described below:

4.5.1. ARV Side effects

PLHIV cited side effects as one of the negative experiences associated with taking ARVs. All the eight interviewees on ART said they had experienced several side effects, such as pain in their feet, swelling of feet, loss of appetite, dizziness and skin rashes. However seven of them indicated that this did not cause them to stop taking the ARVs. Support group members, treatment supporters as well as heath workers also highlighted side effects as a key barrier to adherence to medication. A FGD participant had the following to say:

> *Side effects make some to stop taking ARVS, although one should continue taking the drugs and not stop. If they feel sick they should go to the clinic*
>
> FGD Participant, Rufunsa Support group

Despite indications from interviewees and PLHIV in support groups that one should not stop taking medication, there were obviously instances where patients defaulted. For example, one female PLHIV interviewee said she had stopped taking the ARVs because of the side effects.

4.5.2. Improved health and lack of understanding of the importance of adherence

During the in-depth interviews PLHIV said that some PLHIVs in the community stopped taking drugs because they felt better and healthier and that their quality of life had improved. A health worker supported this phenomenon, emphasizing what a challenge it was to ensure that PLHIV continued to take their treatment was when they felt healthier:

> *…when PLHIV are sick they will adhere, but when they feel better they "forget"…They are hard nuts to crack*

ART clinic staff, St Luke Mission Hospital

4.5.3. Shame and fear of embarrassment

Shame and embarrassment associated with taking ARVs was also highlighted as contributing to PLHIVs not adhering to treatment. PLHIV's fear or shame and embarrassment acting as a barrier to ARV treatment adherence, seems to stem from their concern that community members may be able to identify them as a person having HIV through noticing that they are taking medication (ARVs) associated with HIV infection. PLHIVs said they feared they would be laughed at if seen taking ARVs and, therefore, did not to take their medicine at the appropriate time or, in some cases, at all.

A male PLHIV shared how he anticipated the community would treat him if they knew he was taking ARVs and how this influenced his behaviour vis-à-vis medication:

> *I used to experience side effects such as legs swelling. Since it was the first time taking the medicine I used to feel shy to take the medicine so I took the drugs in hiding [because] I feared being laughed [at] by others - especially people in the community*.

Male PLHIV, interviewee # 9

Similarly, FGDs with support group members also cited embarrassment as sometimes hindering PLHIV in the community to adhere to drugs. The fear of being labeled by the community was raised as a barrier to taking medication. Terminologies used by people in communities such as "*kanayaka*" (Nyanja for the HIV virus has hit her or him) were often heard by themselves when reference was made to PLHIV. Consequently some PLHIV generally hid from neighbours, community members and family members that they were on medication. They were also afraid of taking their ARVs in public.

PLHIV in FGDs in Rufunsa and Chimusanya villages also identified stigma in the community as a factor contributing to non-adherence to treatment among other PLHIV in the community. Consequently PLHIV sometimes ended up going to ART centers outside their communities for fear of being seen by people. A male PLHIV support group member summarized it, this way:

> *Stigma and discrimination is still a problem. Some PLHIV usually have neighbors laughing at them saying that "kanayaka" [so] they cannot manage to take them [ARVs] for life [because of] being laughed at. And also if they – PLHIV- feel sick they should go to the clinic. For example, people feel shy [to do this] as people will laugh at them and because people do like gossiping.*
>
> FGD participant, Rufunsa Support group

4.5.4. Alcohol abuse as a barrier to ART adherence

Although the PLHIV interviewees did not cite alcohol abuse as hindering adherence among them, alcohol abuse was citied by the two FGDs with the support groups and key informants as an emerging problem within the community. For example, a male PLHIV sampled for the interview could not be located at the time of the interview and the ART clinic staff suggested he might be too drunk to interview. It was later also discovered that he was a defaulter, and the reason he had defaulted on medication was due to his high alcohol intake.

PLHIV from the Rufunsa FGD argued that PLHIV within the community who abused alcohol found it difficult to adhere to treatment. They had difficulties remembering to take drugs and were, therefore, unable to adhere to treatment. Two health workers at the health facility also agreed with this conclusion. This problem seemed largely prevalent among males. As a health worker noted,

> *Use of alcohol is a problem…due to beer drinking on the part of men-when sick they will adhere, when they feel better they "forget".*
>
> ART clinic staff, St Luke Mission Hospital

It is likely that alcohol abuse is contributing more to a lack of ART adherence amongst male clients than female clients given the cultural context where alcohol consumption is more acceptable among males than females. Males intake is also excused because it is perceived as a pass time activity. The researcher did not, however, have sufficient time and resources to explore this further to determine its validity and reasons behind the trend.

4.5.5. Non - disclosure of HIV status to partners or spouses

Disclosure of HIV status to one's partner and issues of adherence were also brought up in the FGDs with PLHIV and treatment supporters. Although this was not highlighted as something that any PLHIV in the Rufunsa or Chimusanya support groups had personally experienced, it was something they heard was happening with PLHIV in the community.

Treatment supporters also cited betrothal as a contributor to lack of adherence. Specifically, it was suggested that people about to marry stopped taking their medicine because they did not want their partners to know they were HIV positive and disclosure of their HIV status might result in rejection. As a treatment supporter in Chimusanya village stated:

> *…When people want to get married, some people stop [taking their medicine] because they have met someone to marry and they do not want them to know their status.*
>
> Treatment supporter, FGD in Chimusanya

4.5.6. Perceptions on the impact of ART on sexual desire and women's ability to conceive

The FGDs with support group members in Rufunsa village noted several commonly held beliefs about ARVs amongst community members and PLHIVs that reduced adherence. For example, a male PLHIV in the FGDs said he believed ARVs "made one *loose*," because they increased one's desire for sex. When probed further, PLHIV in the support group seemed to agree and giggled when the comment was made. This appeared to be an issue that was accepted and believed to be true among the PLHIV generally - amongst the FGD participants

Another interesting point expressed during the interviews with health workers was that husbands discouraged wives from taking medicine, in particular ARVs because it was believed that women on ARVs would not be able to conceive. It would have been interesting to explore this further with the females in the support groups.

4.5.7. Religious beliefs as a barrier to taking ARVs consistently

Religious beliefs are central in shaping lives and behavior in many communities in Zambia. The beliefs affect ART treatment as well. Although issues of faith or one's religious beliefs were not particularly highlighted during the in-depth interviews, the perceived association between ARV treatment and Satanism was strongly brought out in both FGDs. A treatment supporter from Chimusanya village reported that it was common knowledge that there was a tendency among pastors in Pentecostal communities to stop PLHIV from taking HIV medication:

> *One of my clients, a female PHIV stopped taking drugs due to religious beliefs and she said that their church pastor has urged the PLHIV to stop taking the drugs. Although we all know that she stopped due to church reasons, she won't accept [that this is true], but she has now defaulted and is not taking any medications.*
>
> Female Treatment supporter, FGD in Chimunsanya

The PLHIV from one of the support groups in particular stated in the discussion that some churches were using the Bible to discourage people from taking drugs. A FGD participant in Rufunsa had this to say:

> *…I am taking ARVs and the [people from the church] believe that they [ARVs] are Satanic. I do not know whether [it is] because they talk to God [but] people stop taking drugs. [As a result] some have died and others are now sick.*
>
> FGD participant Refusna support group

This statement by treatment supporters and PLHIV was collaborated by a health during the interviews with informants who had the following to say:

> *…Church pastors are preaching about God healing. PLHIV are therefore neglecting their medication...*
>
> ART clinic staff, St Luke Mission Hospital

4.5.8. Inadequate food and nutritional support to help adherence to ART

Lack of adequate food was cited as a key factor in contributing to non-adherence among PLHIV on treatment.. PLHIVs, the FGDs in Rufunsa and Chimunsya and three health workers all indicated that people in the community stopped taking drugs because the drugs made them very hungry.

4.5.9. Forgetfulness and being busy as barriers to adherence

Whilst in discussion with key informants, it was suggested by one health worker that forgetfulness and busyness hindered adherence to medication**,** however, these issues were not raised in either the in-depth interviews with PLHIV or the FGDs with the support groups of PLHIV or by the treatment supporters.

4.6. Facilitating factors that they have either experienced or anticipate will affect the level of ART adherence

From the in-depth interviews with PLHIV on ART, the FGDs with members of the two support groups of PLHIV (most of who were on ART) and the interviews with treatment supporters, several themes emerged as adherence facilitators among PLHIV in this rural setting. The facilitating factors identified included the following:

4.6.1. Better health resulting from taking ARVs

Interviewees acknowledged they had been very ill prior to ART. They said they felt much stronger and were more productive after starting ART treatment. They were also able to engage in more physically demanding tasks such as gardening. Interviewees specifically said that ARVs gave them "*energy*" and improved their physical health and general well being. The health improvements experienced were reported as a factor that encouraged PLHIVs to continue with treatment. Additionally, interviewees indicated that ARVs prolonged their lives. This motivated the interviewees to continue with ART treatment as it accorded them the opportunity to live and care for their children. A male PLHIV interviewee said the following regarding this during an in-depth interview:

> *…I was weak, now I am strong like other people that are not getting sick. I am now able to do especially the jobs that I would not manage, for example carrying heavy loads. I was unable to walk long distances, as I got very tired quickly. Now I am able to walk.*

Male PLHIV, interviewee # 2

Another male PLHIV said

> ...*I now have energy or strength to perform a lot of tasks such as gardening and working in small fields that do not require a lot of strength. I can now also do some piecework that assists me with raising resources to meet the needs of my family*.

Male PLHIV, interview # 5

4.6.2. Knowledge of ARVs and belief in the potency of ARVs

A PLHIV's knowledge of what ARVs can do and belief in their potency was noted as a factor that facilitates adherence to treatment. The support group of PLHIV and the four health workers interviewed identified knowledge of ARVs and what the ARVs were able to do as factors encouraging patients to continue with ARVs.

FGD participants in Rufunsa emphasized the role confidence in the effects of ARVs had in supporting adherence, as recorded from a FGD participant below:

> *…. If you believe that these work for [your] life, you go continue taking the drugs. ARV is like a "pillow", it's a place of rest. We also call the ARVs the headman, if you throw away the ARVs or the headman then the whole village is lost.*

FGD participant, Rufunsa support group

> *… I know my status so I take my medicine so that the virus should not be strong. I know that the only drugs that can help me is the ARVs. I know that I am sick and I need to ensure that I am healthy. So I take my drugs so that I do not go back to bed…*
>
> FGD participant, Rufunsa support group

4.6.3. Getting into a regular routine of taking ARVs

Becoming used to the routine of taking ARVs and other drugs at stipulated times in a day were also identified as facilitating adherence. A PLHIV pointed out, during in-depth interviews, that the habit of taking the drugs at a specific time had assisted him adhere to ARVs.

> *…After it was explained to me how to take the drugs, I committed to taking the drugs at the right time. I am now used to it. It is a daily routine. I understand the value of treatment and I have seen what has changed in my body. I am scared if you do not take the drugs, I might go back to the old point where I was so sick. I am used to waking up at 05:00hrs. I take [the medicine] at 6:00 AM the routine is in my head; I just know that it's time to take my medicines.*
>
> Male PLHIV, interviewee # 2

This was supported in a FGD with a support group, where a female PLHIV participant stated:

> *.... It is now routine. You know that you need to take the drugs in the evening when you are cooking nshima [pap or porridge]. You know that it is time.*
>
> Female PLHIV, support group member, FGD

4.6.4. Disclosure of HIV status and access to social support

Interviewees were asked if they had disclosed their HIV status to family or any close friends, and whether this helped or deterred intake of ARVs. All the interviewees indicated that they had disclosed to someone such as a spouse, other family members and friends. The social support structure PLHIV identified included family members, friends and PLHIV support groups. Family members such as spouses, parents and children were identified as helping PLHIV remember to take their medicine. Disclosure to family, therefore, assisted in creating an environment conducive to taking the ARVs. One male PLHIV pointed out when asked if he had disclosed his status:

> *…Yes, wife knows, my sister. My wife knows that I am taking drugs, my sister knows. My wife assists…if I am going far away she reminds me to carry my medicines so that I can take them any time. Disclosing has made it easier to take my drugs.*
>
> Male PLHIV, interviewee # 2.

Another participant during the FGDs had the following to say

> *Being open, our families remind us to take the medicine especially grandchildren. They tell you "grand mother it's now 8:00 hours take your medicines". Being in a support groups also helps. We share the*

> *challenges in the groups. This removes fear. If I have a problem I go to my friends to get support.*
>
> FGD participant, Rufunsa support group

4.6.5. Adoption and implementation of strategies to support ARV adherence

There was general agreement among interviewees and support group members that they used many strategies to help them take their medicine regularly and on time, including the use of clocks, wrist watches, alarms, cell phones and radios. An interesting strategy a FGD participant disclosed was linked to farming seasons, where medicine intake was linked to the *time* they were preparing to go out to the fields. Another female said she based the time she took medicine on the cockerel's behavior. She had the following to say:

> *…We use cell phones to remind ourselves. We also use the chicken crowing. For example, chickens get in their "house"[chicken pen] at a particular time in the evening and get out at a particular time in the morning. So based on the chicken's behaviour I know that it's about time for my medicine.*
>
> Female PLHIV, FDG, Rufunsa support group

During the FGD, another PLHIV had the following to say about strategies to help him adhere to medication:

> *… We also use clocks and "disco" [digital] wristwatch to help us remember the time to take our medication.*

FGD participant, Rufunsa support group

4.6.6. Availability of and access to treatment supporters and ART Mobile

The in-depth interviews and FGD with support groups of PLHIV emphasized the role of treatment supporters in helping ART patients adhere to treatment. Treatment supporters encouraged and advised PLHIV to take their medicine during home visitations with PLHIV. Treatment supporters also helped patients correctly count drugs they were taking, followed up on appointments and referred PLHIV for medical attention. This reinforced adherence support for PLHIV in the community during treatment. A health worker also emphasized the important role trained treatment supporters who paid weekly visits to patients had in sustaining adherence.

PLHIV in the community not only had access to the treatment supporters, but it was highlighted by key informants that the ART facility has initiated an outreach programme (ART mobile clinic) that visited the seven villages once a month. This had contributed to ART patients adhering to treatment as services were brought much nearer to PLHIV in communities.

4.6.7. Availability of and access to food and nutritional support

As seen earlier, inadequacy of food and additional nutritional support presented itself as a barrier to adherence to ART. The opposite on the other hand served as an ART adherence facilitator. Interviewees and members of the support group in the FGD cited availability of food and access to nutritional support as a key factor in supporting treatment. PLHIV pointed out, as seen above, that medication increased their appetite. Most PLHIV, therefore, needed food and food supplements to make the intake of ARVs effective. PLHIV acknowledged the role of food support from the ART facility in enabling and motivating adherence to treatment.

The support with food that PLHIV received was in the form of food parcels, which included mealie meal, sugar and cooking oil. The ART health facility provided food parcels as part of the ART programme, in addition to its key responsibilities including community and home based care. However, PLHIV that participated in the in–depth interviews and during the FGDs indicated that the food distributed was insufficient and suggested the programme increase the quantities of food given to people on ART.

4.7. Health systems challenges and suggestions from health workers to supporting adherence to ART among PLHIVs

The health care workers outlined several health systems challenges they felt contributed to PLHIVs reducing adherence to medication in rural areas and offered some suggestions on how these could be addressed. These challenges and suggestions were:

- (Long) distances between patients' homes—the communities—and the health center,
- Shortage of human resources at the health center leading to work overload. This negatively affects staff's ability to spend sufficient time and give quality care to clients during counseling. It was suggested by two health workers that the St Luke Mission hospital should increase the number of staff and also employ a doctor specialized in ART.

- Although the health workers in the ART facility have some ART training, they felt that there was inadequate follow-up training, resulting in their inability to be conversant and up to date with developments and issues relating to ART. The health workers suggested they have more access to refresher courses and workshops.
- Although the ART facility had a mobile clinic which visited the villages once a month, the health workers indicated that there was insufficient transport to enable staff and treatment supporters access to hard-to-reach patients in communities. Increasing transport and the number of bicycles for treatment support would assist in this.

A health worker cited the shortage of human resources and consequent work overload on staff at the health center as a challenge.Shortages of specialized staff implied that the level of work and the number of tasks allocated to each serving member of the health staff increased and kept on changing. . This in turn had a negative bearing on staff's ability to attend to their prescribed duty of counseling and caring for ART patients.

Although PLHIV during in-depth interviews did not cite any specific health systems factors as affecting their ability to adhere to treatment, participants in FGDs with support groups members in Rufunsa pointed out that they spent long hours at the community health centers (in the villages) and the main hospital. The reason for this was there were not enough key health staff such as doctors and nurses to provide support at the health center although these were not given as health systems factors.

4.8. Suggestions from PLHIV on ART, and treatment supporters for supporting PLHIV adherence to medication

St Luke mission hospital has been implementing the ART programme since 2004. The in-depth interviews and FGDs support group members and treatment supporters brought out several suggestions on how the ART facility could help improve adherence to treatment. The following were recommendations for supporting ART adherence in rural areas:

4.8.1. Access to Income generative Activities (IGAs) and seed packs to support farming

When asked during in-depth interviews PLHIV highlighted the need to have access to income generating activities such as poultry to enable theme have income. As most of them were involved in farming, they also indicated that provision of seeds to support their vegetable gardens and farming would be helpful in making PLHIV stick to their treatment. Two PLHIV had the following to say:

> *…like we do gardening, may be we can be supported with seed for farming*
>
> Male PLHIV interviewee, # 2
>
> *Money is needed for example, support groups need money for IGAs such as poultry, if one gets sick, you can use the money for things that are needed.*
>
> Male PLHIV interviewee # 7

Participants during the FGDs with support group of PLHIV were also of the same of view and summarized it as follows:

> *We need to increase our incomes, fertilizer is very difficult [to access] we need support to increase food production to have more food and IGA such as poultry and piggery to use for our children and ourselves*
>
> *FGD, participants, Rufunsa Village*

4.8.2. Sustained nutritional support for PLHIV on ART

Three PLHIV during in-depth interviews highlighted the need to have access to more food. One PLHIV in particular indicated that food should be increased during the periods in the year when there was less food. She had the following to say:

> *Food is not usually enough, so we need more food especially during the [dry seasons of farming]*
>
> Female PLHIV interviewee, # 8

Participants in the FGDs with support groups of PLHIV also had a similar view. Hunger and the need for adequate food had an impact on adherence to ARVs. The ART facility gave PLHIV food rations including a packet of 1 kg sugar, a bottle of cooking oil (750ml), high-energy protein supplements (HEPS) and a bag of mealie–meal (10kg). This package was, however, rationed out for a month only. Participants in the FGD with support of group of PLHIV in Refunsa suggested that the duration for which the food ration was provided be increased from one month to three. Most PLHIV tend to be too sick to work and be self-sustainable when initiating treatment. Increasing the number of months from one to three would help PLHIV adhere to treatment.

4.8.3. Support and increased emphasis on education and counseling on the importance of HIV status disclosure to partners

Treatment supporters suggested that the ART facility should encourage partners to disclose their HIV status to one another. Women should especially be encouraged to disclose their HIV status to their male partners since they were more likely to discover their status because they are usually tested for HIV during pregnancy. Treatment supporters suggested that the ART facility should not only emphasize but also provide and encourage clients to attend couple counseling to enable people to disclose their status to their partners.

4.8.4. Necessary equipment and training for treatment supporters

In the FGDs with treatment supporters, they indicated that they worked for no pay in most communities. The treatment supporters indicated that they sometimes received some incentives provided by the ART facility, which included an allowance of K100, 000[10] and food parcels, which were not sustainable. In addition, most of these treatment supporters indicated that they faced many challenges such as walking long distances to attend to patients. The treatment supporters also lack home-based care kits, which are essential to providing quality care and support for the communities. To be effective in supporting ART adherence, Treatment supporters said they needed bicycles for transport and to access distant and remote places, umbrellas and gumboots to use during the rainy season.

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[10] K100, 000 is equivalent to $ 21.00. Source: *The Zambia Daily Mail*, Tuesday, October 26, 2010.

4.8.5. Increase in the number of treatment supporters and Training for treatment supporters

To support adherence to ART, PLHIV during the in-depth interviewees were of the view that the ART facility should increase the number of treatment supporters so they can visit and support more PLHIV in the villages. Participants in the FGDs with support groups of PLHIV indicated that more people who are on ART should be used as treatments supporters as they would be able to teach and encourage others from their experience of being on ART. Ongoing training for treatment supporters was cited as important. Training would ensure that treatment supporters had the most up to date information to provide the necessary support to PLHIV and affected families in the communities and at household level.

4.8.6. Increasing awareness of the importance of adherence to ARVs among community leaders

Participants in the FGDs with support groups of PLHIV and treatment supporters identified the involvement by key community leaders as essential to addressing adherence in the communities. Community leaders are custodians of local culture and help influence behaviour in communities. The participants in the both FGDs suggested that it would be important to work with village 'headmen' and 'church leaders' to address such issues of ART and adherence.

> *The Health facility should work with the church leaders and headmen to address the issues of the churches stopping people from taking medicine*
>
> Treatment supporters, FGD inChimunsanya village

Community leaders' involvement would entail training the local leadership in order to increase their knowledge and awareness of HIV, ARVs and ART adherence issues.

4.9. Summary: Facilitators and the Challenges of adhering to ART in Chongwe District

Several themes on barriers and facilitators to adherence emerged from the interviews and focus group discussions held in three villages in Chongwe district. Barriers to adherence included factors related to (a) the client and their religious beliefs, their perceptions and knowledge of ARVs, and their abuse of alcohol; (b) therapeutic factors such as the side effects of the medication; and (c) socio –economic factors such as stigma and discrimination, and fear of rejection from partners resulting in non disclosure of HIV positive status.

The facilitators to adherence included access to food to support ART intake, the availability of social support from family members and friends, feeling well, being able to lead a productive life, getting into a routine of taking medication, knowledge and belief in the efficacy of ARVs, use of treatment supporters and provision of mobile ART services.

Several suggestions were made that could improve adherence support including access to IGAs and seed packs to PLHIV on treatment, sustaining nutritional support for PLHIV, increasing the number of treatment supporters and training them, providing bicycles to treatment supporters, working with community leaders such headmen and pastors and health care workers, accessing refreshers courses and workshops in ART management and delivery.

The next chapter focuses on discussing and interpreting the research findings.

CHAPTER FIVE

DISCUSSION

5. Introduction

The study set to find out the barriers and facilitators to ARV medication among PLHIV in rural areas and specifically, in Chongwe district in Zambia. A range of factors related to the barriers and facilitators to adherence were identified through in-depth interviews with nine (five women and four men) PLHIV and three FGDs, two with members of support groups of PLHIV (23 PLHIV in total) and one with nine treatment supporters. In addition, interviews were also held with five key informants who worked at the ART facility at St Luke Mission Hospital.

FGDs were held with two functioning PLHIV support groups from two different villages served by the ART facility. FGDs were held to validate the findings from the nine in-depth interviews. Interestingly, the researcher observed that it was seemingly much easier for the PLHIV participants in the FDGs, as they reflected on their own experiences, to identify facilitating factors rather than barriers that contributed to adherence. Interestingly, as members of a PLHIV support group the PLHIV tended to associate PLHIV that were not part of any support group as being the ones who were more likely to experience barriers. On the other hand, PLHIV during the in-depth interviews tended to refer to *themselves* and their own experience in relation to facilitators and barriers.

Not surprisingly, the study has shown that there are many factors that are similar to urban settings that impact on ART adherence among PLHIV living in rural settings. The factors identified can either be categorized into barriers or facilitators to adherence. The following were the specific issues that either were barriers or facilitators to adherence:

5.1.1. Acceptance of one's HIV status and belief in the efficacy of the ARVs

It was clear from the interviews that the acceptance of one's status and belief in the efficacy of ARVs contributed to PLHIV's ability or inability to adhere to treatment. ART users who had accepted that they were HIV positive and understood that treatment could assist in prolonging their lives were more likely to adhere than those that lived in denial. This was evidenced in a FGD with a support group of PLHIV in Rufunsa village, where participants agreed that PLHIV who denied having HIV usually refused to take their drugs. The participants in the discussion indicated that, because they knew ARVs were the only medication that could keep them strong and healthy, this motivated them to continue to take their medication. This finding has been supported by several research studies indicating a strong association between the acceptance of one's status and belief in the efficacy of the treatment (Sidat *et al.* 2007; Dahal *et al.* 2008).

Interestingly, despite indicating an understanding of the potential of ARVs to prolong life, some interviewees in the in-depth interviews did not yet grasp the implication of interrupting doses. This finding is similar with a qualitative study conducted in Massachusetts by Law *et al.* (2005), which indicated that although most interviewed patients (84%) on ARV medication reported non-adherent behavior such as interrupting doses, "holidays" and as forgetting doses, most did not consider their behaviour as being non adherent. Only a few in this study were reported to have understood the possible consequences of interrupting doses (Law *et al.* 2005). Chesney (2004) notes that it is not only important for individuals to understand the consequences of non-adherence, treatment failure, disease progression and death; but also the challenges that exist when treatment failure occurs. In addition, PLHIV on treatment need to be aware of the lack of treatment options available when drug resistance develops. Community consultations on experiences in HIV and AIDS related treatment in urban and rural settings in Zambia (International HIV and AIDS Alliance, 2004) found that people in rural settings often lacked basic information about HIV and AIDS. A clear understanding of what happens when one misses doses both before initiating ART (pre ART) and during ART is thus crucial in motivating PLHIV to continue their treatment.

The new ART protocols on Antiretroviral Therapy for Chronic HIV infection in Adults and Adolescents in Zambia has indicated that "not skipping doses or stating and stopping therapy" are a good measure of adherence (MOH, 2007:15). Whilst the ART facility at St Luke Mission hospital does provide adherence counseling during pre ART stage and provides follow up adherence counseling when PLHIV are on ART, the lack of understanding about the importance of not skipping doses on the part of some interviewees on ART suggests the current counseling might need to be reviewed in order to address this.

5.1.2. The importance of addressing perceptions of impact of ART on sex and women conceiving at both individual and community level

The finding from this study also suggests that there were several commonly held beliefs and perceptions about ARVs that are contributing to non-adherence among PLHIV. These perceptions included the belief amongst PHLIVs that ARVs made PLHIV "loose" and want more sex. Another perception was that women on ARVs would be unable to conceive. FGD participants and one of the health workers suggested that husbands stopped their wives from taking ARVs as a consequence of this perception. These findings suggest that there is still a need for more education about ARVs (and specifically what they do and do not do) amongst PLHIVs and the broader community who provide support to PLHIV. In addition, within the existing couple counseling being provided at the ART facility, it would be useful for the ART facility to look at how to support the female PLHIV to be adhere and take their right to treatment.

5.1.3. The role of food and nutritional support in facilitating adherence

The findings from this study indicated that food is crucial to support the intake of ART and therefore, in supporting adherence in rural communities. This has been acknowledged to be of importance particularly in rural settings by International HIV/AIDS Alliance (2004: 15) when they noted that, "… in rural areas things taken for granted in towns, such as access to food and medical care, are in chronically short supply; poverty is particularly deep".

Some interviewees acknowledged, during the in-depth interviews and in all three FGDs, that food was important in ensuring that PLHIV on treatment adhered to it. It was also noted specifically by members of the PLHIV support groups and the treatment supporters in the respective FGDs that sometimes PLHIV were not adhering to treatment as a result of lack of food. Studies in Botswana, Tanzania and Uganda (WHO, 2006; Weiser *et al*. 2003) also highlighted the need for food support to be available to PLHIV especially when they are starting to take the drugs.

During in-depth interviews most of the PLHIV and in the FGD with treatment supporters it was suggested that the food packages the PLHIV currently receive for one month should be increased to three months. The current provision in relation to food support for PLHIV on ART as indicated in the Zambia National HIV and AIDS strategic framework (2006-2010) states that the “strengthening of nutrition education among PLHIV and supporting access to micronutrient supplements and access to nutritious food for PLHIV” are some of the core strategies to be used in promoting appropriate nutrition and positive living among PLHIV (NAC, 2006: 29).

Weiser *et al*. (2010), found through open-ended interviews with 47 PLHIV in Uganda that food insecurity influenced access to medical care and adherence to ARVs. Findings from in depth interviews during this research indicated that PLHIV were so sick before starting ARVs that they were unable to grow food or earn income to buy food. – The provision of food to support the nutritional needs of PLHIV in the short term is therefore necessary to encourage ART adherence..

During discussions with the support group of PLHIV in Rufunsa, participants acknowledged the need to increase individual food production through support with fertilizer and income generating activities to enable PLHIV to have adequate food. The current national response and guidelines in the Zambia National Strategic HIV and AIDS framework to mitigate the socio-economic impacts of HIV, emphasizes the "promotion of food security, livelihoods and income generation for PLHIV and their caregivers and families" as a key response to address food insecurity (NAC, 2006: 31). In the light of this policy, there seems to be a gap between what is happening at the ART facility in terms of IGA support for PLHIV and the policy. An emphasis therefore in an ART facility based in a rural area should therefore be to link PLHIV and their families to sustainable livelihood and economic support programmes.

5.1.4. Alcohol abuse as a key barrier to adherence

Support group members, treatment supporters and health workers cited alcohol as a key barrier to adherence. For example, it was noted by support group members that in their experience, PLHIV on ART who abused alcohol were usually unable to stay on treatment as they did not remember to take their medicines when drunk. This finding is consistent with other studies, which have indicated that the abuse of substances such as alcohol and the use of active drugs resulted in PLHIV not adhering to medication (Chesney, 2000; Power *et al*. 2003; Methta *et al*.1997; Dahab *et al.* 2008).

The key informants, specifically the health workers in the study suggested that there seemed to be more men than women abusing alcohol and therefore defaulting in terms of their treatment. Although the new ART protocols on Antiretroviral Therapy for Chronic HIV infection in Adults and Adolescents in Zambia (MOH, 2007:15) is clear on the need to “counsel patients to avoid drug abuse and to refrain from excessive alcohol use” there was no indication of a specific programme within the community or at the facility that addressed the issues of alcohol abuse in relation to ARVs. Given the experience of health workers at the ART facility, particular focus ought to be given to men’s vulnerability to alcohol abuse. In addition further research would be useful to provide an understanding of the specific issues related to alcohol and ART in rural communities.

5.2. Commonly used strategies to support ARV adherence by PLHIV on ART

The study found that PLHIV in a rural study setting adapted similar strategies to support them to adhere to ART as to those in urban settings. PLHIV taking part in in-depth interviews and in the FGDs highlighted the types of strategies they used to help them take their medicine regularly and on time. These included the use of clocks, wristwatches, alarms, cell phones and radios. Similarly, an Australian study Sidat *et al.* (2007) found that PLHIV commonly used various strategies such as PLHIV receiving sms messages on their mobile phone organized by their care provider, setting up mobile phone alarms or table clock alarm and using of pill boxes.

An interesting strategy a PLHIV interviewee disclosed was linked to farming seasons, where the PLHIV said their medicine consumption was linked to the *time* they were preparing to go out to the fields which in the rural context is done very early in the morning. Another female interviewee said she based the time she took medicine on a cockerel’s behavior. The latter two examples suggest that some PLHIV seemed to develop coping mechanisms that were unique to the rural environment. PLHIV seem to be using a combination of strategies to enable them remember what time to take their medication although it was not possible to determine how reliable some strategies are in supporting adherence.

5.3. Disclosure and social support in families, among couples, friends and partners

The findings from this study related to disclosure and social support from families and friends is consistent with other research findings on the role of social support in barring or facilitating adherence to medication (Weiser *et al.* 2003; Dahab *et al.* 2008; Turner, 2002). PLHIV during in-depth interviews and PLHIV in support groups suggested that where they had disclosed to family members and found themselves in a supportive home environment it was easier to take the medicines. For example, most interviewees during in-depth interviews indicated that their children, mothers and other family members or friends reminded them to take their medicines at the right time. Turner (2002) argues in her review of literature in the USA on adherence to antiretroviral therapy that PLHIV who have a good support system that includes family, friends, other role models and members of the health care team may be more likely motivated to adhere to treatment.

The new ART protocols on Antiretroviral Therapy for Chronic HIV infection in Adults and Adolescents developed by MOH in Zambia also indicates that patients should be “encouraged to identify treatment supporters such as family members and buddies and to include them in counseling, and supporting patients to overcome obstacles such as disclosure (MOH, 2007:15). In addition, the support group for PLHIV was also highlighted as being an important mechanism for receiving support: in providing information on ART, giving support to one another, and providing a forum to share experiences and enabling one to feel accepted. The ART protocol guideline also identifies linking patients to support groups as one of the key ways to support adherence (MOH, 2007). Cortez *et al.* (2004) in their research to provide ART in poor resource settings in South Africa cited and recommended that to attain high levels of adherence, community based ART initiatives need to have among other things peer support for PLHIV through support groups.

However, accessing support from one's partner and/or family does of course require disclosure of one's HIV positive status. The FGDs with both PLHIV in support groups and treatment supporters revealed that women in particular were perceived to be afraid of disclosing their status and use of ARVs to their partners. Treatment supporters in particular suggested that the reason for this was that they feared that the disclosure of their status would lead to them losing their spouse or partner. For single PLHIV there was a fear that disclosing their HIV positive status would mean they would not get married. Interviewees thus suggested the fear of rejection within relationships, as a key barrier to treatment adherence. Women seem to face negative consequences as a result of their disclosure of their HIV status. Kumarasamy *et al.* (2005) have also indicted the complexities of disclosure and its consequences especially for women.

In addition, it was suggested by treatment supporters' that husbands were known to discourage their wives from taking ARV because it was believed, among men, that women on ARVs could not get pregnant. As mentioned previously there is need to correct incorrect beliefs amongst both PLHIV and their support network including spouses, family members and the wider community to maximize adherence support.

In looking at gender dimensions to accessing treatment in rural areas, community consultations conducted in Zambia by International HIV and AIDS Alliance (2004) on experiences of HIV and AIDS related treatment in urban and rural settings found that women in general needed much more information and education on HIV and AIDS and treatment as they were particularly vulnerable.

5.4. Embarrassment, stigma and discrimination as a barrier to adherence

This study found that embarrassment, stigma and discrimination acted as barriers to adherence among PHLIV. It was noted during the FGDs discussions with support groups of PLHIV that HIV-related stigma and discrimination was a barrier to adherence among PLHIV. The participants in these FGDs highlighted that they were aware of ART users that felt embarrassed and shy about taking medicine in public or to be seen with side effects. This contributed to their inability to take their drugs in the presence of other people and contributed to their inability to adhere to their treatment

This finding is similar to findings a Zambian urban and rural research study conducted in Lusaka, Ndola and four villages in Southern province by the International HIV/AIDS

Alliance (2004). The study identified stigma and discrimination as one of the main barriers for PLHIV to access treatment or care for fear that their HIV, status is known. International HIV/AIDS Alliance (2004) in their study citied "fear and stigma" to be "particularly powerful" in the rural areas of southern province in Zambia as these were for example, seen to "discourage people from using voluntary counseling and testing (VCT) services and made it difficult for people with HIV to be open about their status" (International HIV and AIDS Alliance, 2004: 15). Other studies in developed countries have confirmed the finding that stigma and discrimination contributes to non-adherence to treatment (Dahab *et al.* 2008; Kumarasamy *et al.* 2005; Weiser *et al.* 2003).

5.5. Religious beliefs and their role in adherence to ART

An interesting finding in the research was the possible link between faith, healing and non-adherence. Treatment supporters, support groups members and health workers all noted that some religious groups (such as the Pentecostal churches) served as a major barrier to adherence. For example, some pastors were citied as urging PLHIV to stop treatment because they had been "healed" by faith and prayers. PLHIV from a support group in Rufunsa village cited cases of PLHIV who had died as a result of stopping their medication. In addition, one interviewee (# 6 in Table 1) was cited by treatment supporters as one of the PLHIV on ARVs that had stopped taking their medication as result of a pastor telling her to stop her medication. This finding is consistent with the findings in a prospective observational study, conducted in Uganda which found that 1.2% of patients discontinued ART because of a belief in spiritual healing (Wanyama *et al*. 2005).

It is also worth noting that there is a belief on healing of HIV as a result of prayer even among people who do not know their status. In an exploratory study conducted in Tanzania by Zou *et al.* (2009) on associations between religious beliefs and HIV stigma, disclosure and attitudes towards ARV, the majority of respondents from Catholic, Lutheran and Pentecostal churches believed that prayer would cure HIV. However, almost all of them indicated that they would begin ARV treatment if they became infected (Zou *et al.* 2009).

As one of the health workers pointed out faith can nonetheless also contribute to helping one continue with medication. Churches have traditionally played a key role in prevention, treatment care and support programmes in this community in Zambia. For example the current ART facility at St Luke Mission hospital is being implemented by Catholics nuns. In addressing adherence, there are opportunities for greater collaboration between the ART facility at St Luke Mission Hospitals and religious leaders. In addition, through using treatment supporters who are living with HIV, the ART facility can advocate for more positive involvement and education amongst religious leaders. Wanyama *et al*. (2005) argue and suggest that spiritual beliefs should be an important part of ART adherence counseling in resource-limited settings, requiring close collaboration between HIV care programmes and religious leaders to identify common goals and ensure successful treatment.

5.6. The role of treatment supporters as facilitators to adherence

The value of using ART treatment supporters has been citied by Nachega *et al.* (2006) as one of key strategies to support adherence of ARVs in communities. Treatment supporters and their support to PLHIV on ART is a key facilitator to adherence (Nachega *et al.* (2006). Findings of this study revealed that treatment supporters were responsible for providing adherence counseling, following up clients in their homes, checking clients' pills, making referrals and accompanying clients on their first day of receiving treatment. Treatment supporters were also the link between the ART facility and the communities.

However, during the research several challenges were suggested by treatment supporters in relation to their service provision and incentives: the need to have access to livelihood opportunities as the K100,000 allowance and food parcels treatment supporters receive was not adequate and sustainable. There was also the need for supporters to to have bicycles to access clients in remote areas and appropriate protective clothing such as raincoats and gum boots for the rainy season. It is very likely that responding to these basic needs will contribute to making the work of treatment supporters easier and ensure that they are adequately motivated.

5.7. The role of ART mobile clinics in facilitating adherence

Distances to a health facility and costs associated with accessing health facilities have been known to impact on adherence to ARVs (Weiser *et al.* 2003; Kumarasamy *et al.* 2005). In this study the issue of costs associated with accessing health facilities was not highlighted as a barrier to being adherent. This could be attributed to the fact that the ART facility had developed an ART outreach programme to reach communities by using mobile ART clinics. In addition, most of the services provided at the ART facility were free. Each village was visited once a month by a team from the St Luke's Mission Hospital's ART facility. However, it is possible that there are still areas that the outreach programme is unable to access as suggested by some key informants, who indicated the challenges they faced with transportation and accessing hard to reach areas.

5.8. Addressing health systems challenges to facilitate adherence in rural communities

Strengthened health care systems are important in supporting adherence to medication among PLHIV in urban and rural settings in Zambia. However, special focus needs to be placed on rural settings as "overall, lack of human resources and infrastructure for HIV testing, counseling and treatment are widespread in rural areas" (International HIV and AIDS Alliance, 2004:15). The findings from this study indicated that staff at the health facility has several challenges that they believe influence their ability to deliver better services to clients. The challenges they specifically cited included inadequate training in adherence counseling and support, inadequate transport to access the more distant villages, and too few staff available to counsel or attend to patients.

The Health workers in the study acknowledged the need for further training in ART and adherence although they felt there were not enough opportunities for access to training. The ART Protocols (MOH, 2007) state that one of the requirements for health providers is that they participate in continuous medical education in the use and monitoring of ART. In addition, the national guidelines on management and care of HIV and AIDS (2004:4) emphasize that "to achieve the goals of the health reform programme, health care workers both at institutional and the community level in both public and private health sector must be trained in HIV and AIDS management and care".

Harries *et al.* (2001) in their paper on provision of ART in Sub Sahara Africa and suggestion on a framework for delivering ART in Sub Sahara Africa cite government commitment as one of the key elements in provision of nationwide coverage of ART in a country. Although policy is in place to support the provision of ART the reality is that adequate resources have not been allocated in all countries to support ART roll out. Overall the health care system has been over stretched and strained, resulting in poor service delivery. It is acknowledged in Zambia that the high prevalence of HIV and AIDS related illness has seriously overburdened the health systems in Zambia (NAC, 2004).

5.9. Implications for policy research and practice in rural areas

This qualitative study was conducted among PLHIV taking ART and living in the rural areas of Chongwe district in Zambia. The findings indicated that there were several key factors that contribute to the level of adherence among PLHIV in rural areas. Findings from this study, highlight the challenges that exist when health facilities are located far from the communities they service and the ART facility do not have adequate transport to reach hard remote areas. Although St Luke Mission Hospital had outreach centres linked to the ART facility, bringing health services closer to communities remains a challenge. Distances to health services can therefore be a barrier to adherence. This implies that people will often prefer seeking alternative medicines such as traditional healers first, because they are closer; and resort to health services last. Although, further research is needed to ascertain if this is the case in Zambia, it was noted that traditional healers are more commonly used in rural areas than in urban settings (International HIV and AIDS Alliance, 2004).

Evidence from the study suggests that treatment supporters are key facilitators to treatment adherence among PLHIV in rural areas. Treatment supporters are the backbone for care and support services in communities and in supporting adherence (NAC, 2004). Treatment supporters need be valued and recognized and their work adequately resourced by government to support the provision of incentives and equipment. Cortez *et al.* (2004) in the their research in providing ART in poor resource settings in South Africa cited and recommend that to attain high levels of adherence, community based ART initiatives need to have a strong-patient centered approach, comprehensive counseling which includes well trained lay counselors that provide one-on-one counseling for people taking ART.

Faith plays a key role in shaping of values, beliefs, behaviors and attitudes of people in Zambia and the faith community has also played a significant role in the provision of care and support for PLHIV in Zambia. As the findings seem to suggest some PLHIV in the rural community are stopping treatment as a result of belief in being healed by faith. It will be important to explore this further to understand this and determine how best to work with churches to effectively support and sustain adherence of ART among PLHIV in rural communities.

As has been suggested elsewhere (Chesney, 2000; Power *et al*. 2003; Methta *et al*. 1997; Dahab *et al.* 2008) and in this study, the abuse of alcohol was highlighted as a key barrier to adherence especially among men in the community. The link between alcohol and ARVs needs to be understood in order to design sustainable approaches to provide support to PLHIV and families dealing with alcohol abuse.

Finally, the evidence from the study highlights the need to further address perceptions about ARVs at both individual and community level. The findings underscore the need to ensure that programmes at community level are relevant to emerging issues in the community and the need to have updated training for treatment supporters, as these are key in providing information to individuals and communities.

5.10. Conclusion

Adherence to ART is complex. The study showed that adherence depended on many factors. For example, at an individual level a belief in the efficacy of treatment and the acceptance of one’s HIV positive status acted as facilitators to adherence. At the same time believing that one could be healed (from HIV) after receiving prayers acted as a barrier to treatment. In addition, the abuse of alcohol, stigma and discrimination, the fear of rejection and the perceptions about how ARVs impacting on ones’ ability to give birth also acted as key barriers to adherence.

The study illustrated that social support through support groups and family members, the provision of food and nutritional support, the use of treatment supporters and mobile

ART services acted as facilitators to adherence. As PLHIV live in communities, perceptions of community members can act as barrier or facilitator to adherence. As seen from the study, there are some factors that are similar in both urban and rural settings. The International HIV/AIDS Alliance cite these as being food insecurity, use of traditional healers and stigma Community consultations conducted in both urban and rural settings in Zambia by International HIV and AIDS alliance (2004), revealed that some factors were particularly significant for rural communities. These included factors such as "access to food and medical care, which are in chronically short supply; poverty; language problems being complex; traditional healers were commonly used; people often lacked even basic information about HIV and AIDS and the fear and stigma are particularly powerful in rural communities, Overall, lack of human resources and infrastructure for HIV testing, counseling and treatment are widespread in rural areas" (International HIV and AIDS Alliance, 2004: 15).

CHAPTER SIX

CONCLUSION

6. Introduction

This study aimed to determine the knowledge, perception and opinions about the importance of ART treatment from the perspectives of PLHIV. The study also aimed to explore the barriers and facilitators that PLHIV have either experienced or anticipate will affect their level of ART adherence.

Through a series of in-depth interviews and focus group discussions with PLHIV and a FGD with treatment supporters the study identified several barriers and facilitators to ART adherence in PLHIV in rural areas. Reported barriers to adherence among PLHIV in rural areas included such things as experiencing side effects as a result of taking ART, feeling an improvement in health and thus stopping to take their medication, a lack of understanding of the importance of adherence, and the abuse of alcohol which resulted in PLHIV forgetting to take their medication. Other barriers included stigma and discrimination that impacted on the ability of PLHIV to adhere to treatment, inadequate food to support ART uptake, non disclosure of one's status for fear of being rejected especially for women who feared rejection in relationships and negative perceptions about the ARVS. Another key barrier to adherence was the religious belief reportedly held by some PLHIV that one would get healed after being prayed for and therefore treatment was discontinued.

Key facilitators to adherence identified in the study included getting into a regular routine of taking ARVs, knowledge and belief in the efficacy of ART, disclosure of HIV status and access to social support which enabled PLHIV to get support and adhere to medication and nutritional support that enabled PLHIV to have access to adequate food to support uptake of ART. Other facilitators identified were use of treatment supporters who provided support to PLHIV by providing them with on-going adherence counseling, and making referrals to the ART facility for further support, mobile ART clinics that have brought ART services closer to the rural communities and the adaptation of strategies such as clocks and use of alarms by PLHIV to remind them to take their medication. Although better health resulting from taking ARVs was citied as a barrier to adherence, it also acted as facilitator to adherence as better health motivated PLHIV to continue taking their medication.

6.1. Limitations of the study

The study had several limitations. Firstly, the selected sample of PLHIV interviewees from St Luke’s Mission hospital did not include all types of PLHIV groups that might have provided a different perspective on barriers and facilitators to adherence. For example:

a) The researcher recruited interviewees from the ‘active’ patient list of the hospital. The researcher therefore did not try and recruit those that had completely defaulted or stopped taking their medication.

b) From the ‘active’ patient list, the researcher was limited in terms of the ability to reach everyone on the list because of the season in the year, when the study was conducted. As a result, the researcher only interviewed those that were living within a distance of 45 minutes to one hour of driving from the ART facility at St. Luke Mission hospital. It is worth noting that the mode of transportation in many of the villages surrounding the heath facility is either use of bicycles or walking as there is no public transportation available. As it was the rainy season, some PLHIV could not be accessed as a result of long distances from their homes to the health facility and inaccessible roads (e.g. most “hard to reach places” were inaccessible due to impassable roads, and therefore no vehicle was able to get to the villages). Other villages were not accessible due to the limited time that the researcher had, as it would take more that an hour and a half minutes’ drive as opposed to the 45 minutes and an hour, respectively the researcher took to drive on visits to the two sampled villages. It was not therefore possible to get PLHIV that were living further than 45/1hr away from the hospital.

Secondly PLHIV during the in-depth interviews and FGDs may have provided responses that were aimed at pleasing or impressing the researcher and of wanting to be perceived as a ‘good patient’ and thus only reporting behavior that was perceived to have positive consequences. This is considered a possibility given that the researcher was introduced to the PLHIVs by one of the health workers from the ART facility at the St Luke Mission hospital. In addition, support group members in one of the FGDs tended to refer to ‘other’ PLHIV (i.e. those who were not part of the support group) and were – it was suggested - more likely to experience barriers to adherence than themselves. By referring to *others*, PLHIV did not then necessarily reflect on and talk about their own direct experiences – and the researcher was thus provided at times with information, which appeared to be largely hearsay.

6.2. Recommendations

St Luke Mission Hospital has been providing care and support to PLHIV in the community for many years and in 2004, with the establishment of the ART clinic, the hospital started to provide ART as part of its range of services. The study looked at barriers and facilitators to adherence among PLHIV. Based on the findings of this study, it is recommended that it's ART facility consider in terms of future planning in relation to ART adherence among PLHIV:

6.2.1. Addressing alcohol abuse among PLHIV on treatment

The abuse of alcohol among PLHIV, and especially men, on medication was identified as an emerging problem within these rural communities. To support adherence, the new ART protocols on Antiretroviral Therapy for Chronic HIV infection in Adults and Adolescents developed by MOH in Zambia (MOH, 2007:15) importantly emphasizes the need to "counsel patients to avoid drug abuse and support patients to refrain from excessive alcohol use". It also emphasizes the need to "identify ways to assist patients overcome obstacles" in relation to treatment and "linking patients to adherence support groups" (MOH, 2007:15).

As there was no counseling programme that was addressing the issues of alcohol and HIV in the community, it will be beneficial for the ART programme to consider developing a programme that can address the specific issues related to the use (and abuse) of alcohol in the community. In addition, the establishment of a support group specifically for those that are on ART and are struggling with the abuse of alcohol would be useful to establish in terms of providing additional support to PLHIV that are likely to also be struggling with issues related to adherence. Possible collaboration between the ART facility at St Luke Mission Hospital and with other agencies and programmes that focus on drug and substance abuse (for example, The Anti-Corruption and Drug Commission in Zambia should be explored so as take advantage of their experience and skill in this area.

6.2.2. Addressing perceptions of ARVs in the community

A number of incorrect perceptions about ARVS and taking ARVS exist within the rural communities where the study was conducted. These perceptions might be acting as barriers to adherence. It is thus recommended that the ART facility regularly update both the content of their community awareness programmes and their training programmes for treatment supporters in order to ensure that some of the negative perceptions held by the community about ART be clarified. Community sensitization should specifically continue to address issues of disclosure, stigma and discrimination to ensure that PLHIV are supported to take their treatment without feeling shy or embarrassed.

6.2.3. Review of the counseling programme

On a number of occasions in the interviews it was noted that women are more likely to face negative consequences in disclosing their HIV positive status and thus require additional support in relation to disclosure. It is thus recommended that the ART facility at St Luke Mission Hospital consider how best it could offer additional psychosocial support to their female clients as they face the significant challenges associated with disclosing their status to their male partners, families and friends.

6.2.4. Strengthening of food security and livelihood opportunities for PLHIV and their families

The Zambia National HIV and AIDS Strategic framework (NAC, 2006: 31) identifies the "promoting of food security, livelihoods and income generation for PLHIV and their caregivers and families" as a key response to support treatment in communities. The role of food in relation to supporting the uptake of ARVs cannot be over emphasized. Increasingly programmes need to ensure that PLHIV are not dependent on hand outs and food parcels for their living. Emphasis by the ART facility at St Lukes Mission Hospital should therefore be placed on making linkages and creating opportunities for PLHIV and their families to have access to sustainable food security and livelihood programmes. For example, more formal linkages with the Ministry of Agriculture and NGOs such as Programme Against Malnutrition (PAM) could be explored.

6.2.5. Caring for treatment supporters

Treatment supporters are the back borne of providing care and support at household and community level. It is therefore important for the ART facility at St Lukes Mission

Hospital to continuously invest in their treatment supporters. In addressing the challenges faced by treatment supporters, the ART facility should explore how it can provide treatment supporters with adequate updated training and the tools for their work (such as providing them with bicycles and HBC kits). Treatment supporters should also have access to sustainable livelihoods opportunities so that they are less dependent on food rations, which are currently being provided as incentives by the ART facility.

6.2.6. Increasing collaborating with churches and traditional leaders

In order to address the specific challenges of Pentecostal churches discouraging PLHIV from taking treatment, the ART facility St Luke Mission Hospital should explore opportunities for using the existing NAC structure known as the District AIDS Task Force, which is responsible for coordinating HIV and AIDS activities within the district. Using this structure, a stakeholders meeting could be held to bring together leaders from all faith based organizations and traditional leaders in the community. This meeting could look at issues of faith, use of traditional medicines and ART, and possibly identify research questions that can be explored further to provide further insights.

It will be important for the ART facility to create a platform where the ART facility, faith leaders and traditional leaders can work together to design appropriate strategies to respond to existing challenges in the community. This will be in line with the National HIV and AIDS strategic framework (May, 2006) that calls for a multi-sectoral response to HIV and AIDS as it recognizes that there are various key players in the HIV and AIDS response and therefore the need to work in a more coordinated way to address HIV and AIDS in communities.

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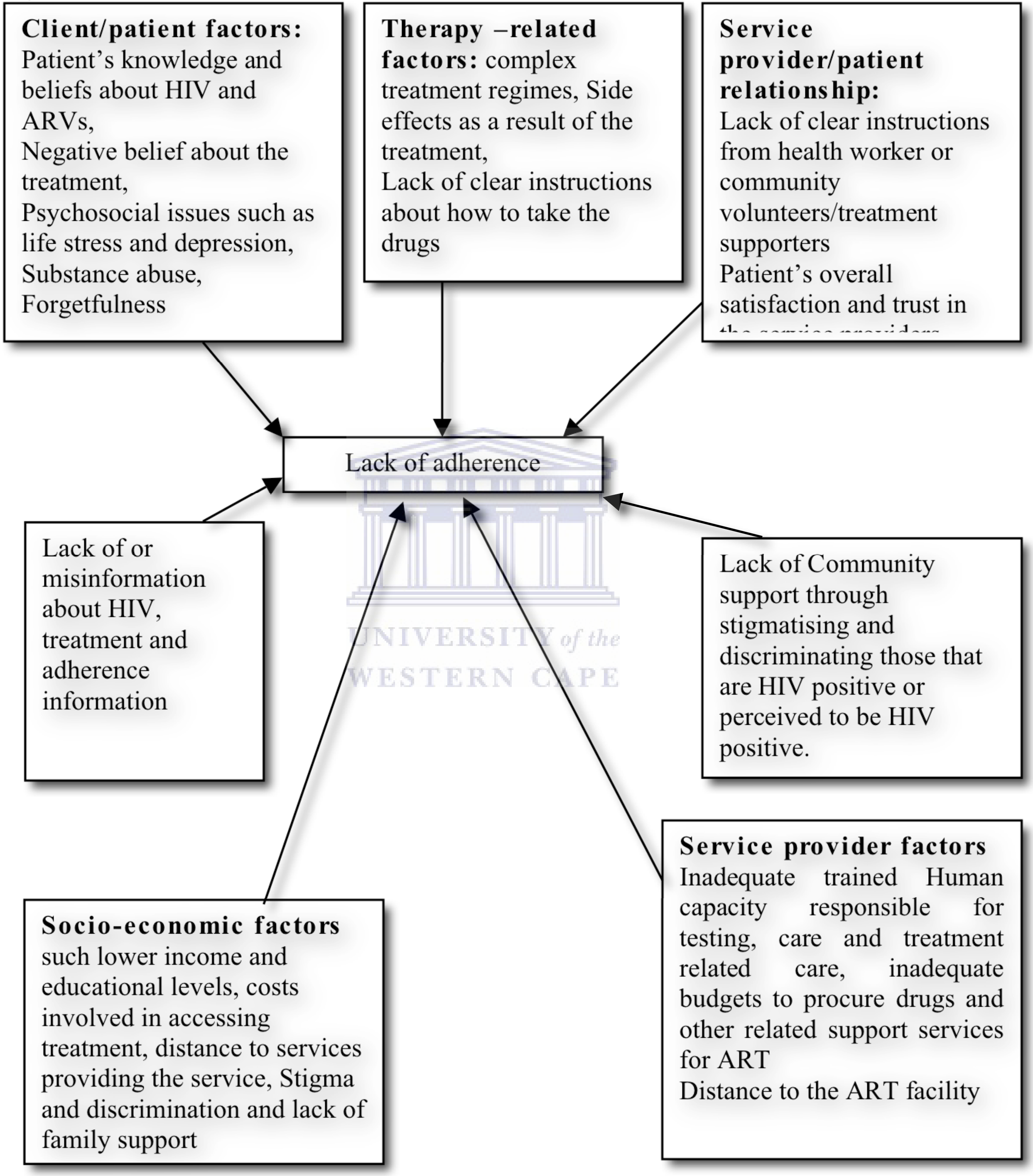
APPENDICES

APPENDIX A: Problem Analysis

Figure 1: Problem Analysis



Client/patient factors: Patient's knowledge and beliefs about HIV and ARVs, Negative belief about the treatment, Psychosocial issues such as life stress and depression, Substance abuse, Forgetfulness

Therapy –related factors: complex treatment regimes, Side effects as a result of the treatment, Lack of clear instructions about how to take the drugs

Service provider/patient relationship: Lack of clear instructions from health worker or community volunteers/treatment supporters Patient's overall satisfaction and trust in

Lack of adherence

Lack of or misinformation about HIV, treatment and adherence information

Lack of Community support through stigmatising and discriminating those that are HIV positive or perceived to be HIV positive.

Socio-economic factors such lower income and educational levels, costs involved in accessing treatment, distance to services providing the service, Stigma and discrimination and lack of family support

Service provider factors Inadequate trained Human capacity responsible for testing, care and treatment related care, inadequate budgets to procure drugs and other related support services for ART Distance to the ART facility

APPENDIX B: Work Plan

Table 2: Work Plan

Research activities	**Months**					
	Year 2008					
	May	**Jun**	**July**	**Aug**	**Sept**	**Oct**
Review of research with ethics committee	▨					
Obtain clearance from the St Luke's Mission hospital	▨					
Piloting and finalizing the research instrument	▨					
Data collection				▨		
Data analysis and report writing				▨	▨	
Submission of thesis for comments and reworking					▨	
Submission of draft to St Luke Mission Management staff					▨	
Finalizing the report and submission to SOPH for submission.					▨	▨

APPENDIX C: Budget

Table 3: Budget

Description	**Unit price (Kwacha)**	**Number of Days**	**Number of Persons/ quantity**	**Total cost (Kwacha)**
1. Stationary				
• Tape recorder and tapes	100,000		1	150,000
• Microphones	50,000		1	50,000
• Note books & pens	5,000		5	25,000
2. Pilot study	20,000	2	5	100,000
3. Allowance for participants and snacks	K30, 000	10	20	600,000
4. Transcribing	K100, 000	5	2	1,000,000
5. Photocopying of consent forms	500		20	10,000
6. Data collection				1,000,000
• Fuel costs				
• Lunch allowance				
7. Photocopying reports	10,000		30	300,000
8. Dissemination meeting	K20, 000	1	30	600,000
Sub total				**3,835,000**
5 % contingency				191,750
Grand total				**K4, 026,750**
Grand total in $				**$1,060**

Budget notes

- Participating clients in depth interviews (3) will be provided with an allowance to provide transport reimbursements
- Two typists (4) will be hired to assist with transcribing from the record tapes.
- Dissemination meeting (8) will be used to present findings to staff of St Luke Mission Hospital and other stakeholders
- Due to do unforeseen circumstances, a 5% contingency has been added to the cost to cushion any unforeseen circumstances
- Current exchange rate is approximately K3, 800 to a dollar.

APPENDIX D: In - depth Interview Guide with PLHIV on ART[11]

Greetings (Good morning or afternoon), my name is Charity Sisya and I am a student of Public Health with the University of Western Cape, in South Africa. Thanks for giving me this opportunity to meet with you. I am interested in asking you a few questions that will assist me to identify the possible barriers and facilitators that might affect the level of ART adherence among people living with HIV/AIDS in rural communities. The information I obtain in this interview and other interviews like this will hopefully be used to support the further development of strategies to support ART adherence in rural areas.

Here is an information sheet about the research I am conducting. We can read it together - and I can answer any questions that you might have.

Note: ***Refer to the participant information sheet, read it in the local language for those that cannot read. Give an opportunity for questions.***

I just want to re-emphasize that if you would prefer NOT to take part in this research study it will not affect you in anyway – and particularly not in terms of the quality of support that you receive from the ART clinic.

Note: ***Once it established that the person has no further questions, then ask the following:***

I would like to know if you are willing to participate in this interview?

If the potential participant says NO:

Thank you very much for taking the time to listen to me, I wish you the best.

---

[11] The questionnaire was adapted from the International HIV/AIDS Alliance study of the experiences of treatment users and health care workers, 2004 and WHO research *From access to adherence: the challenges of antiretroviral treatment, studies from Bostwana, Tanzania and Uganda*, July 2006.

If the potential participant has agreed to be interviewed, then proceed with the following:

Thank you again for accepting to be interviewed. This interview will take only about 1 to 2 hours. But before we start the interview, I would like us to go through the informed consent form (*the consent form to be read in the preferred language of the participant*),

Note: emphasize the following

- *The interview process (i.e. what it will involve)*
- *The participate can with draw at any stage or chose not to answer any questions that makes them uncomfortable*
- *Issues of confidentiality*
- *Explain why I want to use a tape recorder – and request permission to do so.*

Ensure that the consent form is signed by both participant, or consent is given on tape and the person conducting the research.

Thank you again, I just want to assure you that everything discussed here will be used solely for the purpose of my studies and the overall findings (from *all* the interviews I conduct) will be reported back to St Luke Mission Hospital. Your name will not however ever be included in the research report or referred to during the report back process.

First I would like to find out some background information about you:

1. Demographic information

1.1 Sex (to be noted by the interviewer)

1.2 What is your marital status (*Probe if married, single, divorced, widow, widower and cohabiting)*?

1.3 How old are you?

1.4 What level of education have you attained? *(None, primary, secondary)*

1.5 What do you do for a living?

1.6 Do you belong to a support group for people living with HIV?

1.7 How do you travel to the ART clinic? *Probe (taxi, bus, walk)?* How long does it generally take you to get to the clinic?

2. Knowledge and perceptions about ARV treatment

2.1 I would like to understand what you know about ARVs. Can you explain to me what the **purpose** of taking ARVs is?

(Probes: what are they meant to do in relation to your health? What is their expected benefit?)

2.2 What particular ARVs are you **taking** at the moment?

(Probes: do you know the names of the ARVs you are taking – or if not, what do they look like)

2.3 What do you understand that you have to do in terms of **taking** the medication for it to be effective?

(*Probes: How long do you have to take them for? How often do you have to take them? In what combination?)*

2.4 Before starting on ARVs where did you get information about ARVs?

(Probe: Reading materials such as posters, books; friends; the HIV support group, HBC, through the counselor at the health facility, church, medical personnel, other sources – and if so, ask them to specify)

3. ARVs and adherence to treatment

3.1 How long have you have been on ARV treatment?

3.2 Besides ARVs are there other medications you are taking? For what? When did you start taking this medication? When do you have to take this medication *(Probe: daily basis or not? Forever or not?)*

3.3 People have various experiences with ART – some of them good and others not so good. Can you explain to me *your* experience of being on ART. Lets first focus on the **positive experiences** you have had. Can you tell me what some of your positive experiences have been in starting ART (in other words the positive changes that you have experienced)?

(Probe: difference made to their physical health, and mental health/sense of general well being, difference in terms of primary relationship (e.g. partner))

3.4 Now lest focus on the **negative or difficult experiences** – what have you found to be difficult or a challenge about starting and now being on ART?

(Probe: experiences of stigma associated with taking ART, experience of side effects, difficulties in accessing the drugs, difficulties in having to take them, their lack of knowledge about things that come up and they don't know what to do, lack of food to support ART up take, lack of money, distances to the clinic,)?

I am particularly interested in looking at some of the ways ART patients are dealing with having to take medication each day. As I had said earlier at the beginning of our discussion, what ever you say to me is anonymous, your name is not being recorded – so I hope that you feel comfortable enough to share with me some of your real experiences – The information you are sharing with me will be used to help gather information that can help others on ART adhere to their treatment particularly in rural areas.

3.5 Have you perhaps missed a dose in the last day, 4 days, one-week or month?

This is a very important question. I appreciate how difficult it is to take medicines daily. If you do miss a dose, please can tell me the reasons for missing the doses? Please give me an example or two

Probes: simply forgot, lack of food, use of alcohol, feeling better or well, busy doing other things, being away from the place of residence, distance to the health facility, fear of stigma and discrimination, depressed, experiencing side effects, waiting times at the clinic, drugs have finished or any other reasons,

3.6 What do you think happens in your body if you skip or forget to take your ARVs

3.7 Lets now talk about the things that **help you take your pills** regularly and on time?

Probes: (e.g. buddy, relatives, clock, cell phone, children, acceptance of the HIV status, disclosure, beliefs about the value of treatment, feeling better and others)?

3.8 Have you **disclosed** your HIV + status to someone close to you (like your partner, someone in your family, your close friend)?

(Probes:

DISCLOSED: Who have you disclosed to? Do they know that you are on ARVs? And if so, do they help you to take your pills? Does this help you or make things more difficult in terms of taking your pills?

NOT DISCLOSED: How does this affect you taking your pills?

4. Discussing ARVs and adherence with the clinic staff

4.1 What would you do if you were feeling sick after taking your medications?

(Probe: would you tell your doctor or nurse? When would you tell them (at next clinic visit, go especially to the clinic)

4.2 What would you do if you have forgotten to take your medication over the last period from one clinic visit to the next?

(*Probe: would you tell your doctor or nurse*? *why is this so?)*

4.3 With your experience of taking ARVs, what would you tell someone as the most important things they need to know to help them take their pills every day?

4.4 If the clinic asked you how you think they and their staff could offer 100% support and information to keep ART patients adherent - what would you tell them?

4.5 What type of support do you think the support groups of PLHIV need for them to be most helpful for people taking ARVs to help them stick to their treatment?

5. Cost Considerations

5.1 How much do you have to pay to cover your travel expenses every time you visit the clinic?

5.2 Do you incur any other costs as a result of taking ARVs? *(Probes: increasing food costs, costs associated with tests at the facility, reduced income due to side effects)*

5.3 Do you lose income as a result of your coming to the clinic for reviews or refills?

I would like to thank you for taking time to answer to my questions. As I had mentioned at the beginning of the interview, I would like to re-assure you again that whatever we have discussed here will be solely for the purpose of fulfilling my studies and help develop strategies that can support ART adherence in the rural areas. The information provided will

be treated with strict confidence and your name will be not included in the report or other interviews.

Do you have any questions that you would like to ask me - or would you like to tell me anything else?

I would like to thank you again for your time and the information that you have shared with me and I wish you the best.

Note: if issues of further referral have been identified during the interview then refer participant to the relevant support structures within the health facility

END OF INTERVIEW

APPENDIX E: Interview Guide for Health Workers at the ART facility

Greetings (Good morning or afternoon), My name is Charity Sisya and I am a student of Public Health with the University of Western Cape, in South Africa. Thanks for giving me this opportunity to meet with you. I am interested in asking you a few questions, that will assist me to identify the possible barriers and facilitators that might affect the level of ART adherence among people living with HIV/AIDS in rural communities. The information obtained in this interview and other interviews like this will be used to support the further development of strategies to support ART adherence in rural areas.

Here is an information sheet about the research I am conducting. We can read it together and I can answer any questions that you might have.

Note: ***Refer to the participant information sheet. Give an opportunity for questions. Once it established that the person has no further questions, then ask the following***

I would like to know if you are willing to participate in this interview?

If the potential participant says NO: Thank you very much for taking the time to listen to me, I wish you the best.

If the potential participant has agreed to be interviewed, then proceed with the following:

Thank you again for accepting to be interviewed. This interview will take only about 30 minutes to 1 hour. But before we start the interview, I would like us to go through the informed consent form, *(Give the participant the consent form and read it with them)* emphasizing the following

- *the interview process (i.e. what it will involve),*
- *The participate can with draw at any stage or chose not to answer any questions that makes them uncomfortable*
- *Issues of confidentiality,*
- *Explain why I want to use a tape recorder and request permission to do.*

Ensure that the consent form is signed by each participant, or consent is given on tape and the person conducting the research.

Thank you again, I just want to assure you that everything discussed here will be used solely for the purpose of my studies and overall the findings from all the interviews I conduct will be reported back to the St Luke Mission Hospital. Your name will not however be included in the research report or referred to during the reportback process.

First I would like to get some back ground information from you

1. Background information

1.1 What is your role in the ARV programme at St Luke Mission Hospital?

1.2 What is your Profession?

1.3 How long have you been **involved** or working **in the area of HIV/ART related health care delivery**, 1.4 How long have you been **working** in particular **this** facility?

2. Training

2.1 What specific training have you received for this job in relation to the ARV programme: can you tell me about the focus or content of the training (eg. counselling, clinical care, HBC etc), and how long the training was for?

Probe: Counseling skills, any training related to ART delivery, or did you get readings about it.

2.2 How long was each of these training courses?

2.3 How much discussion or input was given on **adherence** specifically?

(*Probe: how many training sessions/days focused on this issue; what key issues related to adherence did they focus on; or if not received – how did they access information on adherence?)*

3. ART and adherence to treatment

3.1 What is the proportion of patients that are considered to be adherent to ART at this facility?

3.2 What do you use to determine adherence in this facility? (*Probe: appointments, irregular attendance at the hospital, refills?*

3.3 In your opinion and based on your experience what assists someone to be adherent? What are the characteristics of a patient or the characteristics of their circumstances that helps them be adherent?

Probes: the support they have around them, whether they have disclosed or not, education, Knowledge of ART and the belief system in the value of the ARVs?

3.4 Similarly, what do you believe prevents patients from taking ART regularly? Are there characteristics in a patient – or associated with their context - that leads to them to be non-adherent?

Probes: costs to patients, lack of food, distance to the health facility, side effects, not having a treatment supporter, use of alcohol, fear of stigma and discrimination, feeling well?

3.5 Currently what type of strategies or support are you offering ARV patients to keep them adherent to their drugs?

Probes: Adherence counseling, ART outreach, community involvement etc

3.6 From your experience what do you think are the particular challenges working in a rural area for keeping people on adherent on ART the particular challenges were working in a rural area for keeping folk adherent to ARTs?

3.7 What do you think you need to do *more* of so as to support adherence to ARTs in this facility. In other words, what do you think you need to do more of so as to increase the level of adherence - and the number of patients that are adherent?

3.8 What specifically do you think you need to do or put in place to support non-adherent patients?

3.9 What support would you need as a health worker to provide the additional type of adherence-related support or interventions for patients that you have just shared with me?

I would like to thank you for taking time to answer to my questions. As I had mentioned at the beginning of the interview, I would like to re-assure you again that whatever we have discussed here will be solely for the purpose of fulfilling my studies and help develop strategies that can support adherence in the rural areas. The information provided will be treated with strict confidence and your name will be not included in the report or other interviews.

Is there anything else you would like to tell me or ask me? If not, thank you again for participating in this interview and wishing you the best.

End of the interview

APPENDIX F: Guide to conducting focus group discussion with PLHIV support group members

Introduction

Greetings (Good morning or afternoon), My name is Charity Sisya and I am a student of Public Health with the University of Western Cape, In South Africa. Thanks for giving me this opportunity to meet with you all. I am interested in asking you a few questions, which are part of my student research, but will also assist me to identify the possible barriers and facilitators that could affect the level of ART adherence among people living with HIV/AIDS in rural communities. This hopefully will be used to support development of strategies that can support ART adherence in rural areas. To help me explain in detail, please here is the information sheet that we can read together and I can answer any questions that you might have.

Note: ***Refer to the participant information sheet, read it in the local language for those that cannot read. Give an opportunity for questions.***

I just want to re-emphasize that refusal or with withdrawal from this process will not affect you in anyway – and particularly not in terms of the quality of the care or the support that you receive from the ART clinic.

Once it established that each person in the group has no further questions, then ask the following

I would like to know if you are willing to participate in this focus group discussion (FGD)?

If the potential participant says NO: Thank you very much for taking the time to listen to me, I wish you the best.

If the potential participant has agreed to be part of the FGD, then proceed with the following:

Thank you again for accepting to be part of the FGD. This FGD will take only about 1 hour to 2 hours. But before we start the FGD, I would like us to go through the informed consent form *(refer to the consent form and use appropriate language),*

Note: emphasize the following

- *the interview process,*
- *The participate can with draw at any stage or chose not to answer any questions that makes them uncomfortable*
- *Issues of confidentiality,*
- *why a tape recorder will be used during the process.*

Ensure that each participant signs the consent form, or consent is given on tape

Before we begin the FGD, can we reach a consensus on the group rules for the FGD. As a group what would you like us to have as ground rules?

As a group we also need to ensure that what is discussed here remains here.

Thank you again, I just want to assure you all that everything discussed here will be used solely for the purpose of my studies and the findings will be reported back to the St Luke Mission Hospital. Your names will neither be included in the research report nor referred to during the interview process.

1. Knowledge and perceptions about ART

1.1 What do you know about ARVs?

1.2 How should the ARVs be taken, for example how often should the medicines be taken and for how long?

2 ART and adherence

2.1 When people start ARV treatment, what stops them from continuing it or taking doses as prescribed?

Probe: too expensive, time consuming, stigma and discrimination, denial of their status, lack of food, lack of employment, use of traditional medicines, being away from home, use of alcohol, distance from the facility, side effects, clinic waiting times being too long and others.

2.2 From your experience, what do you think can help or helps people on ART remain adherent?

Probes: knowledge of the ARVs medicines, disclosure, having social support, belief in the treatment, feeling well or better and others

2.3 What support is given by the health workers to help people on ART to better adhere to their medication?

2.4 What can be done by the PLHIV, support groups, family members, health workers and the community to support people on ART to remain adherent?

2.5 What type of support do you think support groups or caregivers need for them to be most helpful for people taking ARVs to help them stick to their treatment?

I would like to thank you all for taking time to answer to my questions. As I had mentioned at the beginning of the interview, I would like to re-assure you again that whatever we have discussed here will be solely for the purpose of fulfilling my studies and help develop strategies that can support ART adherence in the rural areas. The information provided will be treated with strict confidence and your name will be not included in the report or other interviews.

Is there anything else you would like to tell me or ask me? If not thank you to all you all for participating in the FGDs

Note: if issues of further referral have been identified during the FGD then refer participant to the relevant support structures within the health facility.

End of Focus Group Discussion

APPENDIX G: Guide to conducting focus group discussion with caregivers (ART treatment[12] supporters)

Introduction

Greetings (Good morning or afternoon), My name is Charity Sisya and I am a student of Public Health with the University of Western Cape, In South Africa. Thanks for giving me this opportunity to meet with you. I am interested in asking you a few questions, which are part of my student research, but will also assist me to identify the possible barriers and facilitators that could affect the level of ART adherence among people living with HIV/AIDS in rural communities. This hopefully will be used to support development of strategies that can support ART adherence in rural areas. To help me explain in detail, please here is the information sheet that we can read together and I can answer any questions that you might have.

Note: ***Refer to the participant information sheet, read it in the local language for those that cannot read. Give an opportunity for questions.***

I just want to re-emphasize that refusal or with withdrawal from this process will not affect you in anyway – and particularly not in terms of the support that you receive from the ART clinic.

Once it established that the person has no further questions, then ask the following

Having read, I would like to know if you are willing to participate in this Focus group discussion (FGD)?

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[12] The questionnaire was adapted from the International HIV/AIDS Alliance study of the experiences of treatment users and health care workers, 2004 and WHO research *From access to adherence: the challenges of antiretroviral treatment, studies from Bostwana, Tanzania and Uganda*, July 2006.

If the potential participant says NO: Thank you very much for taking the time to listen to me, I wish you the best.

If the potential participant has agreed to be part of the FGD, then proceed with the following:

Thank you again for accepting to be part of the FGD. This FGD will take only about 1 hour to 2 hours. But before we start the interview, I would like us to go through the informed consent form *(refer to the consent form and read in appropriate language),*

Note: Emphasize the following

- *the interview process,*
- *The participate can with draw at any stage or chose not to answer any questions that makes them uncomfortable*
- *Issues of confidentiality,*
- *why a tape recorder will be used during the process.*

Ensure that each participant signs the consent form, or consent is given on tape

Thank you again, I just want to assure you all that everything discussed here will be used solely for the purpose of my studies and the findings will be reported back to the St Luke Mission Hospital. Your names will neither be included in the research report nor referred to during the interview process.

1. Back ground information

1.1. What is your role as caregivers or treatment supporters?

1.2 How many PLWHIV do you support as a care provider?

2. Training

2.1. Have you undergone training to support you in being a caregiver or treatment supporter? *Probes: Type of training such as Home Based Care skills, Treatment supporter, Counseling skills and others*

2.2. How long was the training?

3. ART adherence issues

3.1. From your experience as a caregiver or treatment support what keeps patients from taking ART regularly?

Probes: age socioeconomic status, lack of Information (knowledge), beliefs, depression, distance to the facility, disruption of daily activities stigma and discrimination.

3.2. In your view, what do you think helps patients take their medicines as instructed?

3.3. What is currently in place at the facility and in the community to help people on ART to adhere to their medication?

Probes: Family, HBC support, support groups

3.4. What do you think should be done or put in place at the facility to support PLHIV to adhere to ARVs?

I would like to thank you all for taking time to answer to my questions. As I had mentioned at the beginning of the interview, I would like to re-assure you again that whatever we have discussed here will be solely for the purpose of fulfilling my studies and help develop strategies that can support ART adherence in the rural areas. The information provided will be treated with strict confidence and your names will be not included in the report or other interviews.

Is there anything else you would like to tell me or ask me? If not, then thank you again and wishing the best in your work

End of the FGD

APPENDIX H: Participant Information Sheet for Individual Interviews

UNIVERSITY OF THE WESTERN CAPE
SCHOOL OF PUBLIC HEALTH
Private Bag X17 ● **BELLVILLE** ● 7535 ● South Africa
Tel: 021- 959 2809, Fax: 021- 959 2872

October 2008

Dear Participant

Introduction

Thank you very much for providing me with an opportunity to explain to you in detail about the research. I am Charity Sisya, a student at the SOPH, University of the Western Cape. As part of my Masters in Public Health I will be conducting a research to enable me complete my Masters degree.

Purpose of the Research

The purpose of the research is to identify possible barriers and facilitators that could affect the level of ART adherence among people living with HIV/AIDS (PLHIV). The findings of this research will contribute to understanding barriers and facilitators among PLHIV in rural areas and therefore assist the health facilities to develop strategies that can support ART adherence

Interview process

As part of the data collection process I would like to request that you participate in an individual interview. The individual interview will take about 1 to 2 hours. A tape recorder will be used during this exercise. You are free to withdraw at any stage of the interview or discussion. You are free not to answer any questions that you are uncomfortable with you. Please note that refusal or with withdrawal from this process will not affect you in anyway.

Confidentiality

The information you provide during this process will be kept confidential. You will be referred to with codes such as a number or letters and your name will not be disclosed. Issues around confidentiality will be discussed before you sign the consent form or give verbal consent. Information collected both on tape and written down will be locked away at all times. All information collected will be destroyed as soon as the final research report is written up.

Benefits and Costs[13]

You will not receive any direct benefit from participating in this study, but you will receive a transport reimbursement of K10, 000. Your participation in this research will benefit others in providing understanding of the barriers and facilitators to adherence and therefore contribute to improving support for people on treatment in rural areas.

Informed Consent

Your verbal consent or signed consent is required before you take part in the interview. I will read the consent form with you and answer any of the questions you have.

Questions

For any questions, or if you need additional information, you can contact me on:

Charity Sisya
Cell phone: 097 7 474739
Email address: charity.sisya@vsoint.org
Telephone at work 260-1- 224469

I am accountable to Ms. Nikki Schaay, my supervisor at UWC. Her contact details are as follows:
Phone (South Africa) 084 211 5544/021-788 4186

Email at schaay@mweb.co.za

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[13] This section of the information sheet will be adapted for health workers – who will not be paid any reimbursement for their participation in the study.

APPENDIX I: Participant Information Sheet for Focus Group Discussions

UNIVERSITY OF THE WESTERN CAPE
SCHOOL OF PUBLIC HEALTH
Private Bag X17 ● **BELLVILLE** ● 7535 ● South Africa
Tel: 021- 959 2809, Fax: 021- 959 2872

October 2008

Dear Participant

Introduction

Thank you very much for providing me with an opportunity to explain to you in detail about the research. I am Charity Sisya, a student at the SOPH, University of the Western Cape. As part of my Masters in Public Health I will be conducting a research to enable me complete my Masters degree.

Purpose of the Research

The purpose of the research is to identify possible barriers and facilitators that could affect the level of ART adherence among people living with HIV/AIDS (PLHIV). The findings of this research will contribute to understanding barriers and facilitators among PLHIV in rural areas and therefore assist the health facilities to develop strategies that can support ART adherence

Interview process

As part of the data collection process I would like to request that you participate in a focus group discussion (FGD). The FGD will take about 1 to 2 hours. A tape recorder will be used during this exercise. You are free to withdraw at any stage of the interview or discussion. You are free not to answer any questions that you are uncomfortable with you. Please note that refusal or with withdrawal from this process will not affect you in anyway.

Confidentiality

The information you provide during this process will be kept confidential. You will be referred to with codes such as a number or a letters and your name will not be disclosed. Issues around confidentiality will be discussed before you sign the consent form or give verbal consent. Information collected both on tape and written down will be locked away at all times. All information collected will be destroyed as soon as the final research report is written up.

Benefits and Costs

You will not receive any direct benefit from participating in this study, but you will receive a transport reimbursement of K10, 000 and some snacks during the research process. Your participation in this research will benefit others in providing understanding of the barriers and facilitators to adherence and therefore contribute to improving support for people on treatment in rural areas.

Informed Consent

Your verbal consent or signed consent is required before you take part in the interview. I will read the consent form with you and answer any of the questions you have.

Questions

For any questions, or if you need additional information, you can contact me on:

Charity Sisya
Cell phone : 097 7 474739
Emial address: charity.sisya@vsoint.org
Telephone at work 260-1- 224469

I am accountable to Ms. Nikki Schaay, my supervisor at UWC. Her contact details are as follows:
Phone (South Africa) 084 211 5544/021-788 4186

Email at schaay@mweb.co.za

APPENDIX J: Informed Consent

UNIVERSITY OF THE WESTERN CAPE
School of Public Health

Private Bag X17 ● **BELLVILLE** ● 7535 ● South Africa
Tel: 021- 959 2809, Fax: 021- 959 2872

Thank you for agreeing to allow me to interview you. What follows is an explanation of the purpose and process of this interview. You are asked to give your consent to me on tape or in written form when we meet to conduct the interview.

Information about the Interviewer
I am Charity Sisya a student at the SOPH, University of the Western Cape. As apart of my Masters in Public Health, I am required to conduct a research. I will be focusing on adherence issues among ART users. I am accountable to Ms Nikki Schaay who can be contacted on schaay@mweb.co.za, or by calling (South Africa) 084 211 5544/021-788 4186

Purpose of interview
To learn about some of the experiences people living with HIV/AIDS have in being adherent to ART.

Interview process
As part of the data collection exercise you are being requested to be a participant in a focus group discussion or an individual interview. The interview process will take between 1 to 2 hours. A tape recorder will be used during this exercise. You are free to withdraw at any stage of the interview or discussion and you may chose not to answer any questions that make you uncomfortable. Please note that refusal or with withdrawal from this process will not affect you in anyway – and particularly not in terms of the quality of the care or the support that you receive from the ART clinic.

Confidentiality
The information that you discuss with me during this process will be kept confidential. You will be referred to with codes such as numbers and letters when I write up my report. All information collected from these interviews will be destroyed after the research is completed.

AGREEMENT
I have read /or the information about this research has been read and explained to me.

I have understood the purpose and I have had an opportunity to ask the questions and my questions have been answered.

I voluntarily chose to participate in this research and I consent to be interviewed.

Interviewee code………………………………………………………………………

Participant Name (printed)…………………………………………………………………

Participant Signature & Date ……………………………………………………………

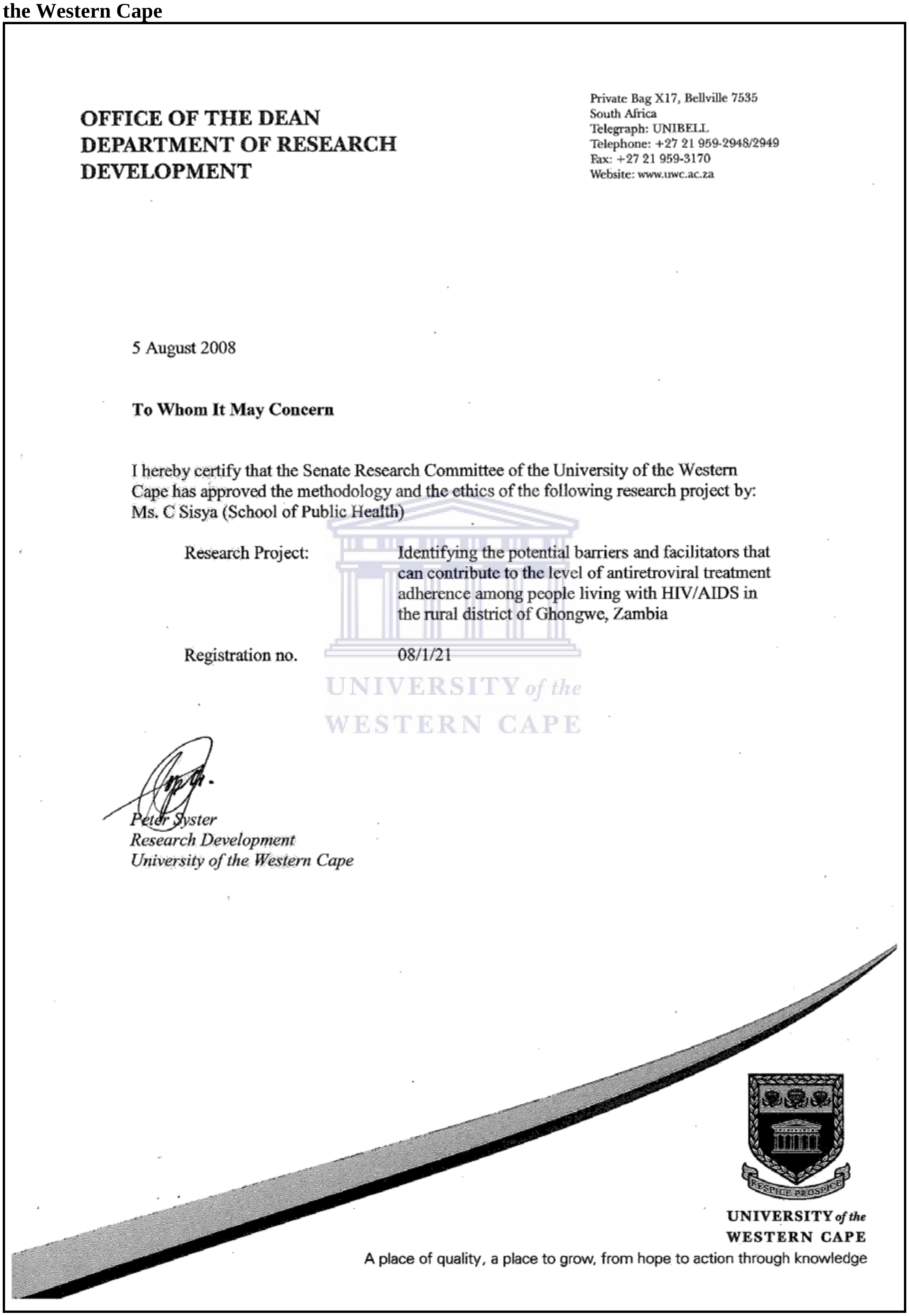
Name of Researcher conducting the interview & obtaining informed consent………
……………………………………………………………………………………………

Researcher signature……………………………………………………………
(To accommodate those participants that might not be able to write, this signature will also certify that verbally consent has been given by the interviewee)

Date

APPENDIX K: Ethics Committee approval letters

Figure 2: Ethics Committee approval letter, Department of Research Development—University of the Western Cape



OFFICE OF THE DEAN
DEPARTMENT OF RESEARCH
DEVELOPMENT

Private Bag X17, Bellville 7535
South Africa
Telegraph: UNIBELL
Telephone: +27 21 959-2948/2949
Fax: +27 21 959-3170
Website: www.uwc.ac.za

5 August 2008

To Whom It May Concern

I hereby certify that the Senate Research Committee of the University of the Western Cape has approved the methodology and the ethics of the following research project by: Ms. C Sisya (School of Public Health)

Research Project:	Identifying the potential barriers and facilitators that can contribute to the level of antiretroviral treatment adherence among people living with HIV/AIDS in the rural district of Ghongwe, Zambia
Registration no.	08/1/21

Peter Syster
Research Development
University of the Western Cape

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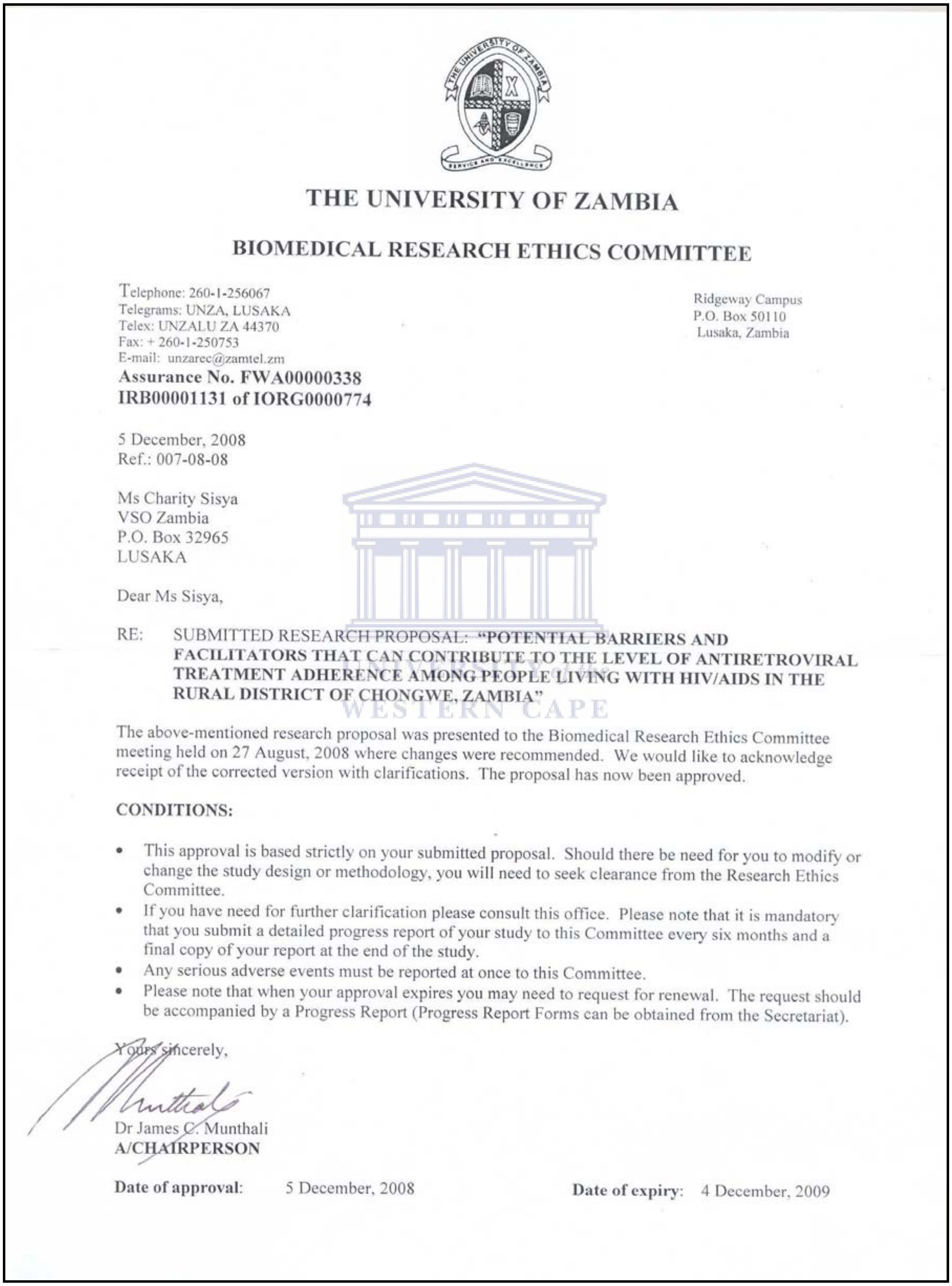
WESTERN CAPE
A place of quality, a place to grow, from hope to action through knowledge

Figure 3: **Ethics Committee approval letter, Biomedical Research Ethics Committee—University of Zambia**



THE UNIVERSITY OF ZAMBIA

BIOMEDICAL RESEARCH ETHICS COMMITTEE

Telephone: 260-1-256067
Telegrams: UNZA, LUSAKA
Telex: UNZALU ZA 44370
Fax: + 260-1-250753
E-mail: unzarec@zamtel.zm

Ridgeway Campus
P.O. Box 50110
Lusaka, Zambia

Assurance No. FWA00000338
IRB00001131 of IORG0000774

5 December, 2008
Ref.: 007-08-08

Ms Charity Sisya
VSO Zambia
P.O. Box 32965
LUSAKA

Dear Ms Sisya,

RE: SUBMITTED RESEARCH PROPOSAL: **"POTENTIAL BARRIERS AND FACILITATORS THAT CAN CONTRIBUTE TO THE LEVEL OF ANTIRETROVIRAL TREATMENT ADHERENCE AMONG PEOPLE LIVING WITH HIV/AIDS IN THE RURAL DISTRICT OF CHONGWE, ZAMBIA"**

The above-mentioned research proposal was presented to the Biomedical Research Ethics Committee meeting held on 27 August, 2008 where changes were recommended. We would like to acknowledge receipt of the corrected version with clarifications. The proposal has now been approved.

CONDITIONS:

- This approval is based strictly on your submitted proposal. Should there be need for you to modify or change the study design or methodology, you will need to seek clearance from the Research Ethics Committee.
- If you have need for further clarification please consult this office. Please note that it is mandatory that you submit a detailed progress report of your study to this Committee every six months and a final copy of your report at the end of the study.
- Any serious adverse events must be reported at once to this Committee.
- Please note that when your approval expires you may need to request for renewal. The request should be accompanied by a Progress Report (Progress Report Forms can be obtained from the Secretariat).

Yours sincerely,

Munthali

Dr James C. Munthali
A/CHAIRPERSON

Date of approval: 5 December, 2008 **Date of expiry:** 4 December, 2009