AN ANALYSIS OF FACTORS INFLUENCING THE HIV AND AIDS CONTINUUM OF CARE AND TREATMENT IN CHIVUNA, ZAMBIA

BY

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DECLARATION

I, **Harriet Ntalasha-Chipyela** declare that, this dissertation represents my own work and that it has not previously been submitted for a degree, diploma or other qualification at this or any other University.

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CERTIFICATE OF APPROVAL

This thesis by Harriet Ntalasha-Chipyela has been approved as fulfilling the requirements for the award of a Doctorate of Philosophy degree in Sociology at the University of Zambia.

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DEDICATION

This work is dedicated to my mother Miss Margaret Namakama and four other people who have since passed away namely, my late father Mr Simon Shileleki Ntalasha, my two late bothers Mr Burton and Jeff Ntalasha and my sister in-law Mrs Sarah Shakankale Ntalasha. I greatly miss all of you and thank you for everything.

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ABSTRACT

Background: There is still a dearth of literature in Zambia on the factors that influence the HIV and AIDS continuum of care and treatment.

Aim: To explore factors influencing the HIV and AIDS continuum of care and treatment in Chivuna..

Specific objectives. Specific objectives were to: examine the prevailing HIV and AIDS services in Chivuna, explore factors that influence each stage of the HIV and AIDS continuum of care and treatment in Chivuna, determine the factors that permeate through the HIV and AIDS continuum of care and treatment in Chivuna, and suggest measures of addressing the identified influencing factors in order to improve the HIV and AIDS continuum of care and treatment.

Methodology: The study adopted a mixed study design and was guided by the social-ecological model. An exploratory and descriptive study design was used to structure the study design. A total of twenty-four (24) Focus Group Discussions , sixty-seven (67) In-depth Individual Interviews , nineteen (19) Key Informant Interviews were conducted for the qualitative study and 653 respondents interviewed for the quantitative study. Qualitative data was managed and analysed using ATLAS TI version 6 while Special Package for Social Scientists (SPSS) was used for quantitative data.

Results: In relation to objective one the study has revealed that though the HIV and AIDS services were available in Chivuna, most of the departments did not meet the WHO minimum standards. In relation to objective two and three, the study identified several limiting and facilitating factors some of which were specific for each stage while others permeated through the continuum of care and treatment. Among the cross-cutting limiting factors at health facility level were: distance to health facilities, confidentiality concerns for health staff, long waiting times, low staffing levels, inadequate infrastructure while counselling, provision of food supplements and role models acted as facilitators. At structural level cross-cutting limiting factors were: poverty and poor road network and provision of ARVs as the main cross-cutting facilitator. At community level those permeating through as facilitators included positive perceptions about ARVs, supportive social nets which included the family and support groups while, local illness beliefs and HIV and AIDS-related stigma, negative perceptions about ARVs, gender based violence were the main limiting permeated factors. Main negative influencing factors at medicine level were anticipated and actual effects associated with the medicines such as efficacy of medication while side effects acted as limiting factors. At individual level cross-cutting facilitating factors included desire to live longer and seeing someone on ART recover. Factors influencing each stage in the continuum were: for VCT provision of mobile VCT and antenatal services at health facility level as motivating factors while VCT knowledge, perceived risk of HIV infection, health status (persistent poor health and feeling healthy) were the main facilitators at individual level.

For linkage to care main limiting factors were: In effective referral and follow up/tracking system and lack of testing equipment at health facility level while at individual level these included feeling healthy at the time of diagnosis and lack of knowledge on the importance of linkage to care. For ART initiation, main factors were: lack of testing equipment and access to CD4 count results at health facility level while required CD 4 count levels and national guidelines on the initiation of ART were the structural level limiting factors. At individual level limiting factors were depression, fear of life- long treatment and possible side effects. For adherence, readily availability of ARVs was the main facilitating factor at health facility level while forgetting, drug fatigue, lack of health improvement after ART were the main limiting factors at individual level and having reminders while health improvement after ART, sero-status disclosure acted as facilitators at this level. These findings imply the need for strategies that target these multilevel factors.

Thesis: Improvement of health outcomes for PLHIV requires adoption of strategies that target a multiplicity of influencing factors at each stage and throughout the HIV and AIDS continuum of care and treatment from multiple levels of influence as opposed to single level factors.

ACRONYMNS

BCC	-	Behaviour Change Communication
CHAZ	-	Churches and Health Association of Zambia
CDC	-	Centre for Disease Prevention and Control
ECDC	-	European Centre for Disease prevention and Control
DAPP	-	Development Aid from People to People
DOTART	-	Directly Observed Treatment Antiretroviral Therapy
FBOs	-	Faith Based Organisations
FGD	-	Focus Group Discussions
FSP	-	Fertiliser Support Programme
GFATM	-	Global Fund to Fight AIDS, Tuberculosis and Malaria
IDIs	-	In-depth Individual Interviews
IEC	-	Information Education and Communication
KIs	-	Key Informant Interviews
MCH	-	Mother and Child Health
MTCT	-	Mother- to- Child Transmission
NAC	-	National HIV, AIDS and TB Council
NZP$^+$	-	Network of Zambian People living with HIV and AIDS
OPD	-	Out-Patient Department
PEP	-	Post-exposure Prophylaxis
PEPFAR	-	United States President Emergency Plan for AIDS Relief
PLWHIV	-	People Living with HIV
PMTCT	-	Prevention from Mother-to-Child Transmission
RCC	-	Roman Catholic Church
RHC	-	Rural Health Centre
RHF	-	Rural Health Facility
SDA	-	Seventh - Day Adventist
SSA	-	Sub-Saharan Africa

TPH	-	Swiss Tropical and public Health Institute
UNGASS	-	United Nations General Assembly Special Session
UBZ	-	United Bus Company of Zambia
UNAIDS	-	Joint United Nations Programme on HIV and AIDS
VCT	-	Voluntary Counselling and Testing
ZARAN	-	Zambia AIDS and Law Research
ZDHS	-	Zambia Demographic and Health Survey
SEM	-	Social Ecological Model
SNF	-	Swiss National Science Fund

DEFINITION OF CONCEPTS

The different terms used in this study have been defined variously in other studies and academic work. For purposes of the current study, the major concepts are defined as follows:

HIV continuum of Care

A series of HIV care and treatment stages that need to be successfully followed in care and treatment from the time one is diagnosed with an HIV infection so that the goals of ART can be achieved. The stages are VCT, linkage to care, ART initiation and adherence.

Voluntary Counselling and Testing

Voluntary counselling and testing (VCT) is an HIV test that is conducted after the client actively, intentionally and freely chooses to be tested. In this regard, proof of the client's full and voluntary consent must be obtained before the test. This is the first step or entry point onto the HIV and AIDS CoC because a confirmatory HIV-positive test result is required before somebody can be considered for ART and other HIV and AIDS-related services.

Linkage to Care

This is the stage to which a person who has tested HIV-positive, but is not yet eligible for ART needs to move. Also called 'pre-ART' or 'the waiting stage', it is the second on the HIV CoC. This stage is critical because it is during it that HIV-positive people are linked to a healthcare provider who will counsel them on how to live positive positively. The stage is also important for ongoing monitoring of disease progression for ART eligibility and pre-ART counselling.

ART Uptake/ART Initiation

This is the stage at which medication (ART) is prescribed for an HIV-positive person. A person's eligibility to be put on ART is mainly determined by his or her CD4 count level. At the time of the study, the CD4 count required for ART initiation was 350 or less. Once ART is prescribed, ART initiation should be prompt to avoid further disease progression.

Retention in Care

This is continued participation of an HIV-positive person on the CoC once linked. This means that PLHA who join the continuum must receive care and treatment for the rest of their life for them to stay healthy. This is important because there is no cure for HIV at the moment.

Adherence to ART

This is the total compliance of PLHA with the requirements of the medication prescribed for them. It entails that once ARV drugs are prescribed, the PLHA must take the right drug, in the correct doses, every day, at the same time, without skipping doses, and without stopping and restating medication without the healthcare provider’s advice. It also entails making all scheduled clinical visits and going through all the necessary procedures. Adherence to ART is the last stage on the CoC and is essential to attaining viral suppression.

Viral Suppression

This is the lowering of levels of HIV in the blood of PLHA by taking ARVs as prescribed by the healthcare provider, or as per the drug instructions or requirements. Given the fact that HIV and AIDS are currently incurable, the desired outcome of ART is viral suppression. In other words, the whole purpose of ART is to lower the level of the HIV in the bodies of PLHA so that they can live healthier and longer, and be less likely to infect other people.

Influencing Factor

An influencing factor is any factor that either enables or limits people’s entry and retention on the CoCT for the desired outcomes of ART to be realised.

Anti-retroviral Therapy

Anti-retroviral Therapy (ART) is a range of AIDS medicines (ARVs) prescribed for the suppression of HIV and treatment of HIV infections.

Lost to Follow-Up

When PLHA are lost to follow-up (LTFU), it means that they are no longer receiving treatment and care from their care-givers for whatever reason and cannot be contacted, either through visits or by other means of communication, by healthcare providers or community health workers for about six months or longer.

Factor

A factor is any reason or cause that prevents, enables, limits, enhances, slows or accelerates people’s entry and retention on the CoC.

Stigma

Stigma is a label, negative reaction or feelings of disapproval that people may have towards somebody suspected or confirmed to be HIV-positive.

CHAPTER ONE

INTRODUCTION AND STATEMENT OF THE PROBLEM

1.1 Background Information

Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome (HIV and AIDS) pandemic remains one of the major challenges that have affected the world in the past three decades. This led to the United Nations Security Council declaring it a health, development and security issue that primarily affected the developing world. The attention by the UN led to not only the international visibility of the pandemic, but also increased mobilisation of financial, political and human resources needed to eradicate the scourge (Amiga, 2010). As a result, significant inroads have been made, especially in the prevention of new infections, which show a reduction of about 50 per cent between 2001 and 2012, the world over (UNAIDS, 2013). However, the aspect of treatment and care seems to remain a great challenge to worldwide efforts, regardless of the mainstream knowledge, policies, interventions and substantial financial resources that have been dedicated to fighting the pandemic in developing countries. In low and middle income countries, for instance, treatment coverage was only about 34 percent of the 26.8 millions of people living with HIV and AIDS (PLWHIV hence forth) in 2013 and to date, there still remain considerable barriers to universal access to treatment (UNAIDS, 2014).

As the global capacity to combat HIV and AIDS has been enhanced and more resources allocated, policy makers and practitioners have initiated a more integrated and comprehensive response to PLWHIV's needs for care, treatment and support. The HIV and AIDS continuum of care and treatment (CoC), a network of linked and co-ordinated care, treatment and support services for PLHA provided by collaborating organisations (CDC, 2012), is one of the strategies that have been used. Its network consists of the services and the overarching co-ordination framework that makes the impact stronger and more effective than the sum of the individual services (Layer *et al* 2014). It creates linkages among the services provided in homes, communities and institutions, thereby improving access of PLWHIV to the services they need to suppress their viral loads to undetectable levels, which is the overall aim of CoC (CDC, 2012).

The HIV/AIDS continuum of care and treatment is implemented as a series of steps from the time a person is diagnosed with HIV through the successful treatment of their infection with HIV medicines (MoH, 2010 ; CDC, 2012; UNAIDS, 2013). According to CDC (2012, 2014) and UNAIDS (2013), the HIV and AIDS continuum of care and treatment consists of four essential steps required to achieve viral suppression. These include:

(a) The diagnosis of HIV through voluntary counselling and testing (VCT);

(b) Linkage of people diagnosed with HIV to care through access to health care providers who can offer treatment and counselling within three months after a positive diagnosis. This is for purposes of helping them stay as healthy as possible and preventing them from infecting others with the virus. This also involves putting the HIV infected person on sustained and lifelong health and medical care;

(c) Administration of prescribed antiretroviral therapy (ART) upon one's eligibility being determined so as to control their infection (Initiate ART uptake); and

(d) Adherence to medication for viral suppression. This means keeping the amount of HIV in their blood at a low level, a situation that can lead to less morbidity, less mortality and reduced new infections (CDC, 2014).

The stages in viral suppression are viewed as a continuum because each preceding phase has to be completed before the next one is implemented and each subsequent phase depends on the successful completion of the previous one (CDC, 2012). The completion of the stages is essential for optimal health outcomes for PLWHIV (CDC, 2014; Gwadz *et al* 2014). Therefore, one cannot talk about adherence and viral suppression without ART initiation while ART initiation cannot take place without a confirmed HIV test result (CDC, 2012; UNAIDS, 2014). This being the case, any delay in the uptake of one of the phases leads to delays in the commencement and completion of the HIV and AIDS continuum of care and treatment process. The non-completion of any of the stages, on the other hand, leads to the disruption of the process (UNAIDS, 2014).

The focus of the HIV and AIDS continuum of care and treatment is on the HIV positive individuals as they are the ones who need immediate linkage to care, and continued monitoring and retention on the continuum for the achievement of the goal of ART, that is, the suppression of viral loads to undetectable levels (CDC, 2012). In this regard, Sikasote *et al.,* (2011) note that HIV negative are underserved and need to receive more post-test counselling to ensure that they remain negative.

In order to substantially improve health outcomes for PLWHIV and potentially prevent transmission of the virus to others, each of the steps of the entire HIV and AIDS CoC must be implemented (CDC 2012, 2014; UNAIDS, 2014). However, doing that requires the adoption of interventions that address a multiplicity of both barriers and facilitators that influence each stage of the continuum of care and treatment, and the social contexts faced by individuals and populations across each step; a reconceptualization of services to maximise engagement in care; and an ambitious evaluation of programme performance using the all-or-none measurement (McNairy 2012). This can only be possible when the barriers and the facilitating factors at each stage of the HIV and AIDS continuum are known. Understanding the barriers is a precursor to the successful implementation of the HIV and AIDS continuum of care and treatment because it allows for the formulation of policy interventions that are properly targeted at eliminating the challenges in the HIV and AIDS care and treatment continuum in a remote and rural Zambian setting like Chivuna. Knowledge of facilitating factors also allows policy implementers to bolster their work so as to achieve a sustained implementation of the HIV and AIDS continuum of care and treatment.

This study was aimed at investigating the factors influencing the HIV and AIDS continuum of care and treatment. It was prompted by the fact that despite voluntary testing and counselling (VCT) and anti-retrovirals (ARVs) services, which make up the major components of the HIV and AIDS continuum of care and treatment, being provided free of charge, 40 per cent of Zambians have not taken an HIV test (ZDHS 2013-2014) and only about 68 percent of those eligible for ART accessed it by 2009 (MoH 2012). Additionally, data from the Sub-Saharan region, to which Zambia belongs, indicate that only a third of those put on ART were retained in care (UNAIDS 2013). This indicates that some HIV-positive people enter the HIV and AIDS continuum of care late; those eligible for ART delay in accessing it and may only do so when they start feeling sick; and those who start taking their medication do not take it as they are supposed to, running the risk of developing drug resistance and other negative health outcomes (UNAIDS, 2013).

The study identified factors at each stage that either facilitated or limited/delayed the process of people's entry and movement on the HIV and AIDS CoC or made some people drop out along the way. The study's findings will also allow policy makers and service providers to pinpoint the gaps in the linkage between PLWHIV and sustained and quality care, and to implement system improvement and service enhancement measures that will better the lives of PLWHIV as they move from one stage to another on the HIV and AIDS CoC and treatment. Knowing the influencing factors at each stage and having an idea of the stages at which most challenges cause most dropouts for specified populations is vital, as it is the only way of knowing how, where and when to intervene so as to break the cycle of HIV transmission, which is one of the major goals of ART (UNAIDS 2012). In this regard, the study brings an important dimension to the literature on the subject in Zambia because most studies, for instance ,Chopard (2008) ; Grant *et al* (2008); Samuels *et al* (2008); Fox *et al* (2011); Sanjobo *et al (* 2008); Schumaker and Bond (2008); Sasaki *et al* (2012); Musheke *et al* (2013); PEPFAR (2013) and Merten *et al* (2015), have concentrated on either barriers or facilitating factors at each of the treatment phases, that is, VCT, pre-ART, ART initiation and adherence to ARVs, independent of each other. It is hoped that the findings of this study can make it possible to improve health outcomes for PLWHIV.

This study is premised within the subject of sociology in general and medical sociology in particular. It adds to theoretical literature in medical sociology with respect to the long standing debates of the dichotomy of structure and agency. The former, being the influence of societal or macro mechanisms over an individual and the later, being the extent to which an individual is able to exercise his/her freedom and choices amidst the influence of macro social structures (Barness, 2009). The study integrates the elements of both structure and agency by applying the social-ecological model (SEM), to recognize and isolate the influence of a multiplicity of factors which operate at different levels. In this sense, it was possible to investigate individual, community, health system-related, structural and medicine-related factors which influence entry and retention in the HIV and AIDS continuum of care and treatment.

1.2 Global Situation of HIV/AIDS

Since HIV/AIDS was first diagnosed in the early 1980s, it has spread throughout the world, which has led to its being rated the world's third most common cause of human deaths after lower respiratory infections and diarrhoeal diseases (WHO, 2012). Further, it has been estimated by UNAIDS (2010) that in 2001, more than 25.4 million people were living with HIV/AIDS globally. By 2009, the figure had gone up to 33.3 million (UNAIDS, 2010: 23). There were approximately 2.6 million and 3.1 million new infections in 2001 and 2009, respectively. The prevalence rates also went up to 34.2 and 35.3 in 2011 and 2012, respectively (UNAIDS, 2013).

Consequent to the increased prevalence of HIV the world over, countries have up scaled their efforts in the implementation of preventive and treatment strategies. Additionally, HIV and AIDS awareness creation through mass education campaigns predominantly using public media have helped to draw attention to the disease internationally (Alonso 2004). The ABC of prevention, that is, abstinence, being faithful to one partner and correct condom use, have been prominent public health strategies in limiting the further spread of HIV/AIDS. Other important measures have been prevention of mother-to-child transmission (PMTCT), screening of blood before transfusion and promotion of VCT (Connor *et al.*, 1994). Recently the World Health Organization (WHO) added medical male circumcision as an important intervention in the prevention of HIV/AIDS. The successful implementation of the measures above is, however, not guaranteed, as it depends heavily on a particular country's political will, level of economic development and desire to acknowledge HIV/AIDS as a public health, development and security problem. The ability to mobilise resources and availability of international community support are equally significant prerequisites of a successful campaign against the AIDS pandemic.

1.3 HIV/AIDS in Sub-Saharan Africa

Sub-Saharan Africa has always had the largest share of PLWHIV. Extant literature indicates that 95 per cent of PLWHIV live in the developing countries while approximately two-thirds live in sub-Saharan Africa, which constitutes only about 10 per cent of the world population**.** Almost all nations in the region have similar prevalence rates of HIV and AIDS, which range from 6 to 20 per cent of their populations. The number of PLWHIV in South Africa is estimated to be almost one out of five adults (UNAIDS, 2010) while Swaziland, with an estimated prevalence rate of 36 per cent, has the highest number of PLWHIV in the world (MoH, 2010).

However, the latest data from many countries show national prevalence rates either stabilising or declining (UNAIDS 2012). In the Southern Africa region, the prevalence rates vary considerably, but the region is still the most severely affected. With approximately 113 million living in Southern Africa in 2009, there were nearly 31 per cent more PWLHIV than a decade earlier (UNAIDS 2010: 28).

The HIV and AIDS pandemic has also increasingly adopted a female face over time. At the regional level, on average, three women were infected for every two men infected, with the ratio among people between 15 and 24 years widening to 3:1 (UNAIDS, 2006). The majority of new infections are concentrated between the ages of 15 and 24 years, putting this age group at the highest risk, with girls appearing to be more vulnerable to infections (Kalipeni *et al.*, 2006). By 2012, 58 per cent of PLWHIV were women (UNAIDS, 2012: 4).

Globally, HIV is primarily transmitted heterosexually, although risk factors vary within and across populations. In many regions of the world, homosexuals, injection drug users and sex workers account for significant proportions of infections (Jackson, 2002; Mbungua 2006 and UNADS/WHO, 2008). In sub-Saharan Africa, over 80 per cent of infections in adults are through heterosexual transmission while infections due to homosexuality are very low. The second most common means of infection is mother-to-child transmission (Fylkenes, 1999: 286). In Africa, the fact that HIV and AIDS is mostly transmitted heterosexually has led to stigmatisation and discrimination, which have led to complicated prevention strategies and contributed to difficulties in coming up with comprehensive plans to combat the disease (Bongmba, 2007). While the epidemic often has its strongest hold in less developed countries like those in sub-Saharan, the possibility of universal access to effective treatment for the disease in the countries of the region remains remote (UNAIDS, 2012). Where the services may be available, the PLWHIV are often reluctant to seek them, opting to live without support or treatment (Campbell 2003).

1.4 HIV/AIDS Situation in Zambia

The first case of the virus that causes AIDS in Zambia was diagnosed in 1984 (UNDP, 2007: 9). Currently, Zambia is rated one of the seven countries most seriously affected by the pandemic in the world (MoH, 2010). By the end of 2005, 489,330 people were estimated to have died of AIDS-related illnesses while 914,691 were said to be living with the virus and more than 1 million children were orphaned on account of the scourge. Without AIDS, there would only be about 598,934 orphans (UNDP 2007:4) in the country. According to the 2013-2014 Zambia Demographic Health Survey (ZDHS), Zambia's prevalence rate is 13 per cent (CSO *et al* 2014: 233), a decrease from 14.3 per cent, with approximately 1.5 million PLWHIV (CSO *et al* 2010: 2). However, the number of PLWHIV is likely to be much higher because the figures cited only include people who have been tested, yet current statistics show that only about 15 per cent of sexually active adults in Zambia had been tested for HIV by 2010 (MoH and NAC 2010: xv). The 2007 ZDHS, also reports that the prevalence rates and consequent death rates were much higher in the productive age group of between 15 and 49 years (CSO *et al.*, 2009), meaning that AIDS had reduced the average life span of people in the country. Though the actual prevalence rate in this age group has reduced in accordance with the national statistics, the 2013-2014 ZDHS shows that they are still much higher than those for other age groups.

In terms of gender, the available evidence shows that HIV/AIDS infections in Zambia are not gender-neutral (UNDP 2007; MoH and NAC 2008). Like at the global level, the epidemic is increasingly becoming gendered (CSO, 2003). For instance, while 13 per cent of Zambian men aged 15 to 49 years were living with HIV/AIDS in 2001-2002, the number of females of the same age group infected was 18 per cent (CSO 2006: 1). Almost a similar situation prevailed in 2007, in which 16 per cent and 12 per cent of females and males were infected, respectively (CSO *et al.*, 2007: 234). Overall, women accounted for more than 50 per cent of HIV-positive adults (CSO *et al.*, 2007: 2). The available data also indicate that young women are the hardest hit by the pandemic, with those aged between 15 and 19 years being five times more likely to be infected compared with their male counterparts, clearly reflecting a bias towards more female vulnerability in sexual relationships (MoH and NAC, 2010: 34).

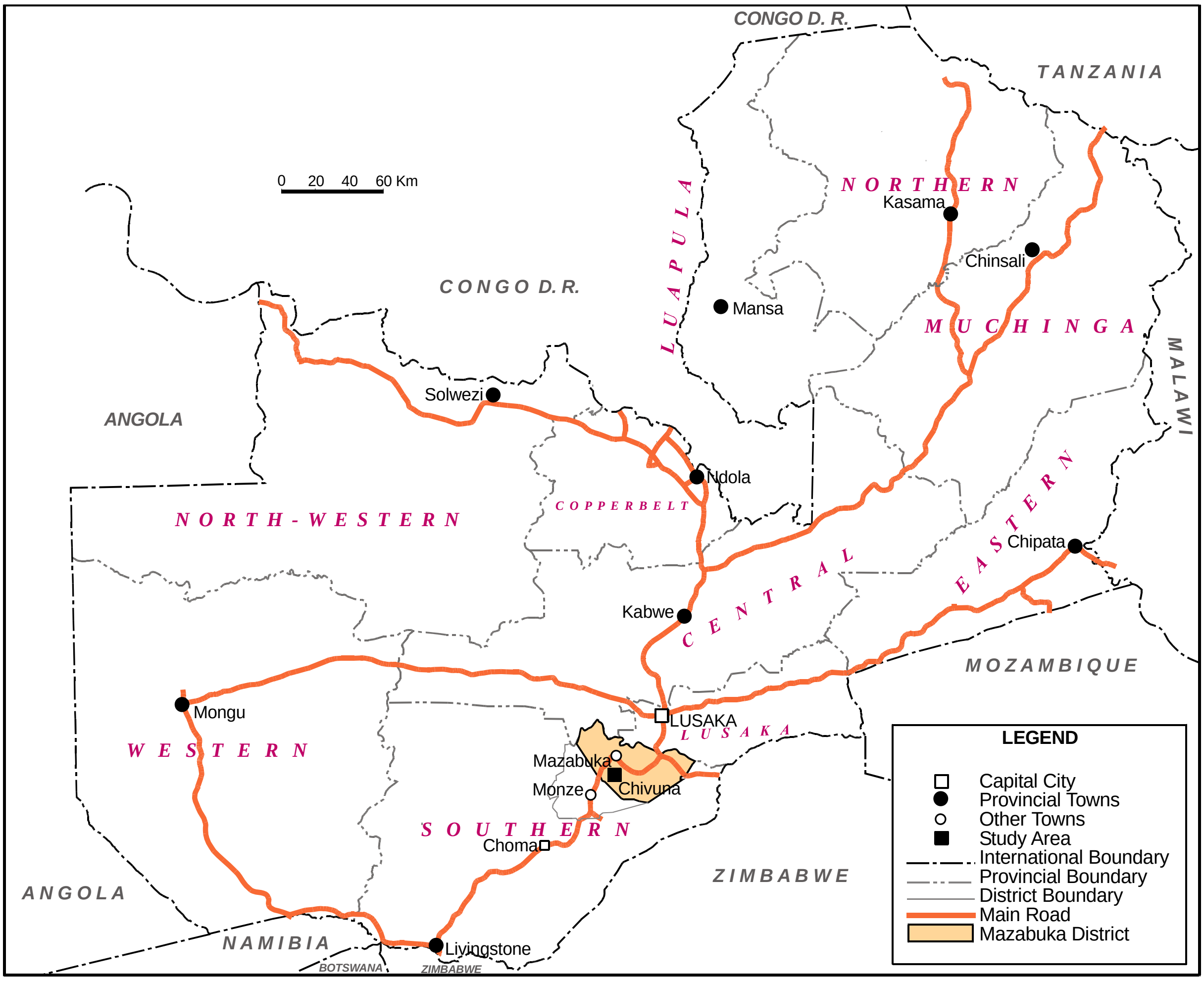
Like women, children have borne the brunt of the HIV/AIDS in Zambia, with about 95,000 of those aged between zero and 14 years being HIV-positive (CSO *et al* 2010: 2). Evidently, though the HIV/AIDS is spread throughout Zambia and in all of its communities, some groups are especially vulnerable. Additionally, in Zambia, like in other parts of the sub-region, HIV prevalence varies across regions and communities. Statistics indicate that urban residents are twice as likely to be HIV-infected as rural residents, with about 10.3 and 9.7 per cent for the urban and rural populations, respectively, aged between 15 and 49 years being infected (MoH 2010: 24). This picture is similar to the one painted by the findings of the 2001/2002 ZDHS, which showed that 23 per cent of urban dwellers and 11 per cent of rural dwellers were infected by the virus. Prevalence rates are also highest in cities and towns that straddle major transport routes, such as Kabwe, Kapiri Mposhi, Livingstone and Ndola (MoH 2005 and UNDP 2007).

Like in other countries in the region, the major mode of HIV transmission in Zambia is heterosexual relationships, which accounts for 78 per cent of the country's infections. This mode of transmission is exacerbated by high-risk sexual practices, poor socio-economic status of women and high prevalence rates of sexually-transmitted infections (STIs). The remaining approximation of 21 per cent of infections is predominantly through mother-to-child transmission during pregnancy, at birth or during breastfeeding. It is estimated that less than 1 per cent of infections result from the transfusion of contaminated blood and blood products, use of sharp instruments and needles, and homosexual relationships (MoH 2008: 3).

1.5 Contextualising the Pandemic in Zambia

Zambia shares borders with the Democratic Republic of Congo (DRC) and Tanzania in the north; Malawi and Mozambique to the east; Zimbabwe and Botswana to the south; Angola to the West; and Namibia to the south-west. Some of the country's neighbours are among the most affected by the HIV pandemic in the region. For instance, Botswana and Zimbabwe have prevalence rates of 24.8 and 14.3 per cent, respectively (UNGASS- Botswana 2010: iii; UNGASS-Zimbabwe 2010: ii). Malawi has a prevalence rate of 11 per cent. Additionally, good railway, road and air networks fan out of the country's heart to other countries in the region, including South Africa, which has a 17 per cent HIV/AIDS prevalence rate and is one of the most affected countries in the region. In other words, Zambia is a transit country that contributes to high cross-border mobility. Consequently, a large number of people are categorised as high-risk persons (UNAIDS, 2010). Figure 1.1 illustrates this information.

Figure 1.1 Map of Zambia, Her Neighbours and the Study Site



Source: Chivuna survey, 2009-2011

According to the 2010 Census of Population and Housing, Zambia had a population of 13 million, of which 60.5 and 39.5 per cent lived in rural and urban areas, respectively, making it the second most urbanised country in Sub-Saharan Africa after South Africa (CSO, 2012: 9). This is particularly significant considering the fact that HIV and AIDS is more prevalent in urban than in rural areas, with estimates putting the rates at 19.7 and 10.3 per cent (MoH, 2008: 24).

The demographic profile of Zambia shows that young people constitute the highest proportion of the population. According to the Sixth National Development Plan (SNDP), 46 per cent of the population is below the age of 15 years, which implies that there is a very high dependency ratio in the country (GRZ, 2011: 6). In addition, 23 per cent of the population were youths aged between 15 and 24 years and they were reported to be the most vulnerable to HIV/AIDS infection. The population has a gender distribution of 51 per cent females, who are also more vulnerable to HIV infections than their male counterparts (MoH, 2008: 3).

High unemployment in Zambia is a serious social problem. Combined with a high dependency ratio, it is a significant challenge to the fight against HIV and AIDS because it has worsened the poverty situation in the country, with 60.5 per cent of the population categorised as poor and 42.3 per cent as extremely poor (LCMS 2012: 181). The relationship between HIV and AIDS and poverty is well established. It is well-known that high poverty levels directly or indirectly promote behaviour that create vulnerability to HIV infection while the pandemic aggravates poverty by putting more pressure on households' limited resources by removing wage earners from employment, reducing the ability of family members of infected people to engage into productive work and causing families to use limited resources for consumption rather than for investment, thereby making the HIV and AIDS problem more complex and reinforcing the relationships between the two (Mutesa and Nchito 2005, UNDP, 2007; MoH 2008 and NAC 2009). The poor are also the people who do not have access to professional care, health information and education, and are unable to secure gainful employment (MoH, 2008).

The available data on poverty in Zambia show that rates are higher in rural districts and much lower in the urban districts on the line of rail (CSO *et al.*, 2012). Thus, people in rural areas have an increased risk of contracting HIV. Additionally, the fact that poverty is more acute in rural areas shapes perceptions of anti-AIDS strategies and the feasibility of ART programmes (Zambia AIDS Alliance 2007). Therefore, if something is not done to fight poverty in rural areas, the people there will have a bleak future (UNDP, 2007). In terms of gender, the majority of the rural poor are women, a fact that makes them more vulnerable to the HIV infection than their male counterparts (GIDD, 2004; Shezongo-Macmillan *et al.*, 2007). Most of the issues identified above were applicable to Chivuna, the study area, because it was a rural area.

1.6 Impact of HIV/AIDS in Zambia

In Zambia, like most countries heavily affected by the HIV/AIDS, the pandemic has become an overwhelming developmental and humanitarian crisis (Shezongo-MacMillan *et al.*, 2007, UNDP, 2007; NAC 2009 and MoH *et al.*, 2006). The available evidence shows that the disease has had a negative impact on the social and economic growth of the country. It has had a devastating effect on individuals and families, and weakened all areas of the public sector, thereby threatening long-term national development (Forgy, 1994, Forster 1994, Ekpo 1999; Kelly, 2000; NAC 2003; Malungo 2003; Chapoto, 2005 and UNDP, 2007).

The AIDS pandemic in Zambia primarily affects the productive age. Therefore, it has negatively affected production and productivity at the household, sectoral and national levels, causing many children to become dependent on relatively fewer productive adults. Ultimately, it has made it difficult for people to have sustainable livelihoods and come out of poverty (Zambia Joint USAID and UNICEF/SIDA Report 1999). Further, the impact of AIDS has gone far beyond the household and community levels, as it has weakened all areas of the public sector and the economy, and stifled national development. Agriculture, from which the vast majority of Zambians earn their living, has also been adversely affected (Kelly 2000), as the loss of workers during the crucial periods of planting and harvesting significantly reduces harvests. In this regard, AIDS is believed to have contributed significantly to the food shortages that the country experienced in 2002 (UNDP 2007), hence the government's designation of the disease as a national emergency (UNDP 2007).

Although the HIV/AIDS infection rates in Zambia show signs of having stabilised, there still remains an urgent need for an integrated response from all sections of the nation, including the government, faith-based organisations (FBOs) and the private sector (MoH *et al.*, 2006). The gloomy picture of the pandemic in the country, as described above, leads to the question: "What is being done to address this situation?" In this regard, the two sub-sections that follow outline the various response strategies being implemented by the Zambian government.

1.7 Response to HIV/AIDS Situation in Zambia

The Zambian government's strategies in the fight against HIV/AIDS can be grouped into two main categories, namely prevention, and treatment and care.

1.7.1 ***HIV Prevention***

Several initiatives aimed at the prevention of HIV and AIDS have been implemented in Zambia, a number of which are being replicated throughout the developing world. This demonstrates the government's high level of commitment to fighting the scourge. Most of the programmes have focused on combating the further spread of the disease, and one of the initiatives was the creation of the National Surveillance Committee (NSC) and the National AIDS Prevention and Control Programme in 1986, barely two years after the first HIV/AIDS case was reported, to co-ordinate anti-AIDS activities. A year later, the National AIDS Emergency Plan for Safe Blood Transfusion was launched (NAC 2003; MoH *et al.*, 2006). In 2002, the National AIDS/STI/STD Council (NAC) was established by an Act of Parliament. The council was legally empowered to apply for funding for its operations and became the sole high-level institution responsible for coordinating the activities of all sectors of the government and society in the fight against HIV/AIDS. At the individual level, the Abstain, Be Faithful or Use a Condom (ABC) Campaign was initiated. Further, the Prevention of Mother-to-Child Transmission (PMTCT) programme was launched in 1995 to fight against the transmission of AIDS from infected mothers to their un-born or breastfeeding babies.

Fighting HIV/AIDS through awareness campaigns began early in Zambia, with much of it involving the distribution of pamphlets and posters warning of the dangers of AIDS and promoting abstinence before marriage. An example was a pamphlet/poster titled, “Sex Thrives, but AIDS Kills”. Over the years, a wide range of media has been used for behavioural change communication (BCC) and carry AIDS awareness raising messages. A number of Anti-AIDS clubs were also formed, of which 1,150 had been registered countrywide by 1992 (htt://www.avert.org/AIDS-Zambia.htm, accessed on 02-04-2009). Despite all these efforts made and HIV/AIDS awareness rising to an estimate of 99 per cent (CSO *et al.,* 2009: 195), the rate of new infections was not declining. For instance, while in 1985 there were only 629 infections, the number of new infections had risen to 44,329 in 2005 and more than 80,000 in 2007. In 2009 alone, nearly 83,000 adults were newly-infected with HIV, representing a rate of about 200 new infections each day. The risk of vertical mother-to-child transmission, which was the second commonest mode of transmission, had also increased, with the number of infants born to HIV-positive mothers increasing from 6,440 in 2006 to 15,630 in 2007 (MoH 2008: 3).

1.7.2 HIV/AIDS Treatment and Care

With the rate of infections showing no signs of declining, the Zambian government thought it necessary to change its approach to HIV/AIDS by not only focusing on prevention services, but also on treatment and care services. In 2004, Mr. Mwanawasa, the late President of the Republic of Zambia, declared HIV/AIDS a national emergency and promised to provide ART to 10,000 Zambians who needed it (AVERT.org, http:/www.avert.org/AIDS-Zambia.htm, accessed on the 02-04-2009). Implied in that commitment was the need to ensure equity in access to HIV and AIDS treatment and care, and improve the uptake of VCT and ART services, and adherence to ART.

The Zambian government was greatly troubled by the continued spread of HIV and AIDS, high death rates and big number of PLHA, and was prompted to also tackle the epidemic from the perspective of treatment and care provision. Specifically, in 2002, the government's goal was to make ART available to every person in need through public health services at a subsidised fee. In 2004, the government announced that ART would be provided free of charge and endorsed the World Health Organisation (WHO) 3 by 5 Initiative, targeting to put 3 million PLHA on ARVs by 2005. The initiative was to be supported by both multilateral and bilateral co-operating partners. The WHO initiative was intended to increase access to ART, particularly in resource-constrained areas of the world (MoH *et al* 2006). By 2005, the Zambian government, with the help of Global Fund to Fight AIDS, TB and Malaria (GFATM), declared that the entire therapy package would be provided free of charge in all public sectors. That made the Zambian ART programme one of the largest in the world (MoH *et al.*, 2006).

Zambia is currently one of the countries with well-funded ART programmes. For example, in 2006, it received US$149 million. By the end of 2009, 68 per cent of the 330,000 Zambians in need of ARVs had been put on ART and a third of all health facilities in the country were providing the service (MoH, 2010). That was made possible by funding mainly from global initiatives of the United States President's Emergency Plan for AIDS Relief (PEPFAR), GFATM and the WHO 3 by 5 Strategy. The provision of ART free of charge was partly informed by consideration of the high poverty levels in the country, which was estimated at more than 64 per cent overall, 80 per cent in rural areas and 34 per cent in urban areas. Further, extreme poverty was estimated at 51 per cent overall, 67 per cent for rural areas and 20 per cent for urban areas. The government was also spurred to complement its effort to prevent the spread of HIV and AIDS with the provision of treatment and care by its commitment to achieving the global and national targets of the Millennium Development Goals (MDGs) (UNDP 2007).

Having realised that VCT is a vital component of ART, the government and various stakeholders, over the past few years, increased their efforts to make the service more accessible by increasing the number of VCT and ART centres countrywide. For instance, the number of VCT centres was increased from about 400 in 1998 to 1,023 in 2007 and that of

ART centres from about 62 in 2005 to about 320 at the end of 2007 and 447 by the end of 2009 (MoH *et al.,* 2007). This means that 115 new facilities were established in 2009 and 20 per cent of health facilities were offering ART by the end of 2009 (Health Institutions of Zambia 2008). The centres were able to either prescribe treatment or provide clinical follow-ups. By the end of 2009, all the 1,563 private and public health facilities in the country were offering VCT services (GRZ 2010). Despite all the efforts made to make ART and related services easily accessible, however, a substantial number of people were not adequately utilising the available services. For instance, despite VCT services being remarkably expanded over the past few years, surveys showed that demand for the service has been disturbingly low. Statistics show that only 15 per cent of the population had been tested for HIV (MoH 2010: xv). The increase in testing facilities has, therefore, not been accompanied by a corresponding increase in the number of people accessing counselling services (NAC 2009). Evidence also shows that a number of those eligible for ART do not start taking it. For example, in 2007 and 2008, only about 40 per cent and 41 per cent of, respectively, of those eligible for ART enlisted for it (WHO 2008). The number rose to about 68 per cent in 2009 (MoH 2012), indicating an increase in the number of people receiving ART over the years. In fact, the figures are said to be among the highest in the region. However, it is clear that a number of eligible clients were not utilising the services, leading one to wonder why, and that was the focus of this study.

1.8 Statement of the Problem

While many studies have been carried out on the HIV and AIDS care and treatment continuum in some countries, for instance, in the United States of America (Bauman *et al.,* 2013; Gwadz *et al* 2014, 2015; and McNairy 2012), the Dominican Republic (Zullinger *et al.,* 2015; Weikum 2015); China (Tan and Huan, 2013), and other countries in the region (Rosen *et al.,* 2010, 2011; Boily *et al.,* 2012; Layer *et al.,* 2014; and Tamori *et al.,* 2014), no comprehensive study had been undertaken on the topic in Zambia. A review of literature had shown that researchers in Zambia had either not studied this topic or had studied single stages, focusing on those related to diagnosis (Denison, 2008; Jurgensen *et al.,* 2012; Sikasote *et al* 2011; Musheke *et al.,* 2013); ART uptake (Murray *et al.,* 2009; Fox *et al.,* 2010) and adherence (Bond *et al.,* 2006; Sanjobo *et al.,* 2008; Fox *et al.,* 2010; Sasaki *et al.,* 2012 and PEPFAR, 2013). The challenge with the single stage approach is that one cannot account for the goal of ART, which is that of suppressing the viral load to undetectable levels (CDC, 2012). The researchers who have attempted to study the CoC in Zambia, for instance, Deo *et al.,* (2012); Topp *et al* (2010) and Topp *et al.,* (2012), all focus on interventions on PMTCT. A qualitative study by Torpey *et al.,*

(2008) focused on the role of community health workers in the CoC while Ogden *et al* (2011) studied the need to remunerate the care-givers in the HIV and AIDS CoC, who are mostly women.

The single stage approach of the studies on the HIV and AIDS CoC in Zambia means that there is still a gap in existing literature on the challenges experienced by people in the HIV and AIDS continuum of care and treatment as a whole. Additionally, the studies, for instance, Torpey *et al.*, (2008), Denison (2008), Jurgensen *et al* (2012) and PEPFAR (2013) all used the qualitative approach. Further, the fact that studies had been conducted on the HIV and AIDS continuum in other settings (Bauman *et al* 2013; Gwadz *et al* 2014, 2015; McNairy 2012; Zullinger *et al* 2015; Weikum 2015; Tan and Huan 2013; Rosen *et al* 2010, 2011; Boily *et al* 2012; Layer *et al* 2014; and Tamori *et al*., 2014) implied a need to replicate them in Zambia owing to the country’s unique geographical, cultural, demographic and political context. It is for this reason that this mixed study was undertaken. It should be conceded, however, that the UNAIDS (2014) study in the region attempted to holistically study the CoC, but was limited in that it did not consider treatment-related factors. It also did not exhaustively look into patient-related factors.

It can be argued, as noted by Bauman *et al.*, (2013) and Gwadz *et al.*, (2014), that VCT uptake, linkage to care services, ART initiation and adherence to medication are phases that do not exist independently of one another. For instance, one requires VCT to know that they need treatment while adherence to treatment is only necessary following commencement of treatment (McNairy, 2012; UNAIDS, 2015). In this regard, the factors affecting each phase of the continuum can only be fully understood when considered within this holistic framework (UNAIDS 2013). The Centre for Disease Control (CDC) also subscribes to this position, positing that understanding the HIV CoC, unlike single stages, is a more reliable way of preserving the health of PLWHIV because it leads to the lowering of their risk of transmitting the HIV virus to others and a reduction of the viral load in their bodies (CDC 2014). ,

Most of the studies conducted in Zambia have not only focussed on VCT, ART uptake and adherence as single entities rather than part of the CoC, but have also mostly been urban-based. For instance, Shezongo-Macmillan *et al.,* (2007); Grant *et al.*, (2008); Murray *et al* (2009) and Musheke *et al.,* (2013). While they have provided significant insight into HIV and AIDS treatment and care, they have not exhaustively explored the facilitating, limiting factors and other experiences of PLWHIV at every stage of the HIV and AIDS continuum of care and treatment. Additionally, they had not undertaken multilevel analyses that would enable the investigation of treatment, individual, structural and socio-cultural factors that, depending on the levels, may negatively influence treatment-seeking behaviour. This is because some factors, for instance, poverty, socio-cultural beliefs and stigma are usually worse and deeper in rural areas than in urban areas, thereby making access to health care more of a challenge in rural areas than in the urban ones (AIDS Alliance, 2007).

Granted, some studies have been undertaken in rural areas of Zambia, an example of which was the one by the Zambia AIDS Alliance (2007) and Samuels *et al* (2008). However, they, too, have focused on single phases of the CoC. Other studies undertaken in Zambia that have similar gaps include Simpson (2010), Fox *et al* (2010) and Juergensen *et al* (2012) (see also Chapter 2). Additionally, most of the Zambian studies that have been cited above for instance Zambia AIDS Alliance (2007); Grant *et al.*, (2008); Samuels *et al* (2008); Simpson, (2010); Sasaki *et al* (2012) ; PEPFAR, (2013) have concentrated on the limiting factors regarding VCT, ART initiation and adherence with little attention to the facilitating factors. This is also true of those studies that have been carried out on the HIV and AIDS continuum of care and treatment elsewhere. For instance, the United States of America ((Bauman *et al.*, 2013; Gwadz *et al,* 2014 and 2015; Mc Nairy, 2012); Dominican Republic (Zullinger *et al.*,2015; Weikum, 2015), China (Tan and Huan (2013) and other countries in the region (Rosen *et al.* 2010 and 2011; Boily *et al.*, 2012; Layer *et al.*, 2014 Tamori *et al.*, 2014), yet the continuum of care and treatment for HIV and AIDS can be influenced either positively or negatively. It is for this reason that this study set out to investigate both the limiting and facilitating factors influencing the entry into and retention in the HIV and AIDS care and treatment continuum in a rural and mission setting of Chivuna in Mazabuka district of Zambia.

The CoC, as a cascade, is an important framework for understanding the status of HIV care and treatment. It was first used in the United States (Cheever 2007, CDC 2012). If not applied in HIV and AIDS service delivery, it would be difficult to ensure equity of access and develop systems for providing humane, effective, high-quality, comprehensive and continuous care to PLWHIV and their families (CDC 2012) in remote areas.

According to CDC (2014) and UNAIDS (2014), a holistic understanding of the HIV and AIDS CoC is important because recent scientific studies have shown that ART and related services do not only preserve and improve the health of PLHA, but also dramatically lower their risk of transmitting the virus to others by reducing their viral load. This is important for a country like Zambia, which has a high HIV prevalence rate.

1.9 Significance of the Study

Zambia is one of the countries most affected by HIV and AIDS. Further, although a lot has been done to fight it, prevalence rates remain quite high. For example, between 2002 and 2007, the prevalence rate only dropped by 1.3 per cent, from 15.6 per cent to 14.3 per cent (CSO *et al* 2009), making Zambia one of the countries with the smallest drop in prevalence rates during that period (MoH 2010: 3). This makes obvious the need for not only the continued upscaling of preventive strategies, but also the intensification of treatment. The latter can only be done by improving entry and retention on the CoC which, in turn, can only be done if those involved have a holistic understanding of the continuum and the various factors that come into play at every stage. Using the social ecological model, this study investigated the multi-level, as opposed to single-level, factors that affect effective service delivery on the HIV and AIDS continuum of care and treatment, thereby painting a more comprehensive picture of the phenomena. It also added a fifth level of investigation to the model, namely the medication level, thereby not only expanding the model, but also contributing to the body of knowledge on HIV and AIDS-related health-seeking behaviour. It further identified the factors limiting entry and retention on the continuum, and some of the mechanisms people use to cope with those barriers. From the literature reviewed, there was no evidence of a similar study having been undertaken anywhere, especially in Zambia.

This study is also significant because it was done in a rural and remote setting in which the provision of quality services is generally more difficult than in urban areas. It has, therefore, contributed to the body of knowledge from that perspective. The study is also unique because Chivuna Rural Health Centre is a mission/church-run facility. Therefore, the study has contributed to the information on the role of churches like the Roman Catholic Church, which is usually critical of HIV and AIDS preventive measures like condom use, in complementing government efforts in the promotion of VCT and ART.

The research is also important because its findings have policy and programming implications. Firstly, the findings may contribute to the development of interventions and programmes aimed at improving the uptake and retention of PLWHIV on the CoC. As stated by Robinson (2008), improving the health of a vulnerable population requires interventions that target multi-level influences by utilising multiple strategies. Secondly, unlike aggregate-level studies, this one was localised. So, its findings will be applicable to localised interventions for the effective management of the pandemic. Thirdly, by investigating local people's perspectives on the factors using a well-formulated questionnaire (see Chapter 3), the study reflected the social and economic context of the study area.

As observed by Vervoot *et al.,* (2007) and Sasaki *et al.,* (2012), this information is critical in the development of culturally appropriate interventions that are, therefore, more likely to lead to successful programmes. Finally, by using both qualitative and quantitative methods, the study generated not only the details of the influencing factors, but also measured the levels and extent of influence of some of these factors on entry and continued participation on the continuum. That knowledge will be important in the determination of entry points for interventions aimed at improving access to and utilisation of lifesaving services. Further, it is also hoped that the findings of this research will stimulate further interest in researching ways of improving access to HIV and AIDS-related services

To the field of sociology, this study has contribution additional knowledge by investigating the episodes of HIV and AIDS using ethnographic, phenomenological and interpretive approaches and the social ecological model. Ethnologically, a people's experiences of living with an incurable disease were explored in a specific cultural context during the researcher's lengthy stay (18 months) in the study area. So, the findings will contribute to an understanding of the role played by cultural frameworks on people's attitudes towards seeking health services. Phenomenologically, the study analysed people's lived experiences and the subjective meanings they attached to their behaviour which, in turn, underpinned their decisions regarding HI and AIDS-related services. So, this study has shown that the pandemic occurs in a social context and that interventions against it must take into account the interactions among the personal and communal factors that make up patients' social environments (Choi *et al* 1998).

1.10 Aim and Objectives of the Study

The study was intended to achieve a specific aim through the attainment of specific objectives.

1.10.1 *Aim*

The aim of the study was to explore the factors that either hinder or facilitate effectiveness of service delivery on the HIV and AIDS Continuum of care and treatment in Chivuna, Mazabuka District.

1.1.1 *Objective*

The specific objectives of the study were to:

1. Examine the available HIV and AIDS services in Chivuna;
2. Explore the factors that influence effective service delivery at each stage of the HIV and AIDS Continuum of care and treatment in Chivuna;
3. Determine the factors that permeated the HIV and AIDS Continuum of care and treatment in Chivuna; and
4. Suggest measures of addressing the identified influencing factors in order to improve service delivery on the HIV and AIDS Continuum of care and treatment

1.11 Research Questions

To achieve its objectives, this study sought to answer the following research questions:

(a) What are the available HIV and AIDS-related services in Chivuna?

(b) Which factors influence effective service delivery at each stage of the HIV and AIDS Continuum of care and treatment in Chivuna?

(c) What factors permeate the HIV and AIDS Continuum of care and treatment Chivuna?

(d) How can the identified factors be addressed in order to improve service delivery on the HIV and AIDS Continuum of care and treatment in Chivuna?

1.12 Conclusion

This chapter first presented the background information to the study. The chapter begun by describing why the HIV and AIDS continuum of care and treatment was important and hence the focus of the study. It went on to give a synoptic view of the HIV and AIDS pandemic globally, regionally and nationally. Indications are that the pandemic has been a global problem. Within Zambia, the chapter also discussed other underlying factors to the pandemic such as poverty in which the scourge has been situated. The discussion has also revealed the feminization of the pandemic.

1.13 Structure of the Thesis

This thesis is divided into 6 chapters. Chapter 1 is an introduction and presents the background information to the study, including an overview of the HIV and AIDS pandemic at the global, regional and national levels, followed by a statement of the problem, the rationale, the aim and objectives, and the research question in the report. Chapter 2 reviews the relevant literature while Chapter 3 discusses the methodology, under fall issues relating to the research design, study site, study population, and sampling and data collection procedures are dealt explained. The different study approaches and instruments used and justification for their selection, data quality controls and ethical issues are also discussed in Chapter 3 while Chapter 4 presents the findings of the research. The fifth chapter discusses the findings while the last chapter draws some conclusions and makes recommendations.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

The study of HIV and AIDS cuts across a variety of disciplines and sub-disciplines, among them, medicine, public health, gender studies, sociology and psychology. That plurality is evident in this study. Therefore, the literature review was a concerted act of interpreting a diversity of both previous studies and general theoretical frameworks relevant to the research. It consisted of an analysis of studies that have attempted to address factors limiting or facilitating the uptake of VCT and ART services on the HIV and AIDS CoC, focusing on the process through which PLWHIV enter and remain on the continuum, specifically the four major components of the HIV and AIDS continuum, namely VCT, linkage to care services, the ART uptake and adherence to prescribed treatment, on which the study focused. The idea was to identify any empirical and theoretical gaps that the current study would address (Kombo and Tromp 2006).

The literature reviewed, which was based on the objectives of the study and relied on databases available to the researcher, such as PubMed, Jstor, Hinnari, Science Direct and Google Scholar, is under the following sub-headings: “The WHO Minimum Standards for the Provision of HIV and AIDS Services”, “the HIV and AIDS Care and Treatment Continuum”, “Factors Influencing the HIV and AIDS Continuum of Care and Treatment”, “Gender Issues on the Continuum” and “Theoretical Framework.

2.2 The WHO Minimum Standards for the Provision of HIV and AIDS Services

In order to assess the HIV and AIDS-related services offered in the study area, it was important to understand the WHO minimum standards or guidelines for the provision of such services so as to be able to measure the provided services against the set standards.

The WHO/UNAIDS 2003 International Consensus Meeting on Technical and Operational Recommendation for Emergency Scaling Up of ART in Resource-Limited Settings and the WHO (2004) Consultative Meeting Report on the Accreditation of Health Facilities to Provide HIV Care specify minimum standards to be met by accredited health facilities in the provision of HIV and AIDS-related services with respect to HIV counselling and testing, human resource, physical infrastructure, supply of ARVs and provision of ART and laboratory management.

2.1.1 HIV Counselling and Testing

The WHO guidelines stipulate that a facility offering HIV and AIDS-related services should have an established and written policy on HIV testing and that the policy should reflect national laws and WHO standards for rapid testing. Additionally, the guidelines demand that all staff be familiarised with the policy.

In terms of counselling, the WHO guidelines are that there should be both pre-test and post-test counselling in an environment that ensures privacy. The testing should be done by individuals trained for the task, but only after the candidate has given informed consent, that is to say, both the test subjects and staff should attest to the voluntary nature of the test. Finally, testing should adhere to the five Cs of consent, confidentiality, counselling, correct results, and connection to care, treatment and prevention services.

2.1.2 Human Resource

In terms of the human resource, the WHO guidelines stipulate that an ART facility should have a permanent ART clinical officer (CO); a pharmacist; two nurses, one for bleeding and the other for adherence; four community adherence supporters; and a data entry specialist/health communication officer. Additionally, all members of staff in the facility should be adequately trained and certified to prescribe ART, undertake clinical follow-ups on recipients and handle HIV and AIDS-related issues and conditions that may confront them, including both adult and paediatric ART.

2.1.3 Physical Infrastructure

A facility offering HIV and AIDS-related services should have, at least, six rooms consisting of a screening room; a registry room with secure and confidential patient record system, and lockable cupboards; a special counselling room; a waiting room, an information room; and a dispensing room with stock control cards and air conditioning to keep the drugs at the right temperature.

2.1.4 Supply of ARVs and Provision of ART

The WHO guidelines stipulated that a facility offering HIV and AIDS-related services should have uninterrupted supply of ARVs to promote patients' adherence to ART. It should also support people being treated so as to facilitate their adherence to the prescribed treatment, and a written protocol to inform decisions on treatment eligibility.

2.1.5 Laboratory Management

The laboratory of a facility offering HIV and AIDS-related services should equally meet national and WHO test norms and guidelines. Such a facility should also facilitate rapid testing and have machines for viral load monitoring (CD-4 count), haematology, and full serum chemistry analysis, and mycobacterial culture analysis, sputum smear microscopy for TB detection, haemoglobin analysis and HIV antibody testing. Additionally, an ART clinic should provide services, at least, five days in a week.

Regionally, a number of studies have been carried out to assess the capacities of and quality of care provided by health facilities accredited to provide HIV-related treatment in resource-limited settings (Landman *et al.,* 2004; Mapunjo *et al* ., 2007 and Mashauri *et al* 2012). In all the studies, the findings have indicated inadequacies in the health delivery system. For instance, there were shortages of personnel adequately trained in HIV and AIDS-related services and ART management, inadequate laboratory equipment for ART monitoring, inadequate physical infrastructure to support confidentiality for counselling purposes, weak information systems, inadequate and erratic supply of ARVs and persistent drug stock-outs (Landman *et al.,* 2004; Mapunjo *et al.,* 2007; Roura *et al.,* 2009 and Mashauri *et al.,* 2012).

2.3 The HIV and AIDS Care and Treatment Continuum

The HIV and AIDS care and treatment continuum, sometimes also referred to as the HIV treatment cascade, is a model that outlines the sequential steps or stages of HIV medical care that PLWHIV go through from initial diagnosis, linkage to and retention in care, ART uptake, and adherence to achieving the goal of viral suppression (CDC, 2012). The continuum is an important framework for understanding the status of HIV care and treatment, and was originally used in the United States of America (Cheever, 2007).

The establishment of continuum of care is important in enhancing the health and wellbeing of PLHA, promoting better adherence to ART, reducing stigma and discrimination towards

PLWHIV, lowering the cost of service delivery and, generally, improving programme outcomes. Therefore, the purpose of the HIV and AIDS continuum of care and treatment is to help deal with HIV as a chronic disease and develop systems that provide humane, effective, high quality, comprehensive and continuous care for PLWHIV and their families (CDC, 2012).

The first stage of the HIV and AIDS continuum of care and treatment, as shown in Figure 2.1, is HIV testing and continues through a number of stages on the path to viral suppression for those initiated on ART (CDC, 2012). Although there are many ways of testing, such as provider-initiated and other diagnostic testing, for instance, through TB treatment centres and antenatal services (Furber *et al.,* 2004), HIV testing, which is the entry point into the CoC, is supposed to be voluntary (WHO 2003 and MoH, 2010). In other words, the clients have to actively and freely take an HIV test at a testing centre and must provide full written or oral consent (MoH, 2010). Additionally, they are expected to voluntarily undergo intensive counselling to prepare them for the result, hence the ‘voluntary counselling and testing (VCT) (MOH, 2010). During the counselling, clients are advised on the steps to take in the event of a positive HIV diagnosis and this is where linkage to a health care provider becomes paramount (MoH, 2010). So, a positive HIV diagnosis is required for one to receive HIV and AIDS-related treatment (Glick, 2005 and Bhagwanjee *et al.,* 2008). In principle, VCT can facilitate behavioural change because the result can encourage a person to take measures to maintain his or her negative status, if negative, or avoid infecting others, if positive, such as using condoms (Bhagwanjee *et al.,* 2008 and Castle, 2003).

Diagnosis and linkage to appropriate medical care during the early stages of HIV infection have substantial clinical and public health benefits. These include decreased morbidity and mortality due to timely initiation of ART, reduced likelihood of further transmission of the virus and promotion of safer sexual behaviour among HIV-infected clients by health care providers (Bhagwanjee *et al.,* 2008, Latkin and Knowlton 2005, and Stringer 2006). Further, VCT is the cornerstone of HIV prevention because when people participate in it, they are acknowledging their vulnerability to HIV infection and taking the first step towards assuming the responsibility to protect themselves and others from infection (UNAIDS, 2003b). In this regard, VCT should be conceptualised as a link on the continuum of HIV prevention, treatment and care rather than as merely a means of screening for treatment and increasing the number of people who know their HIV status (Bhagwanjee *et al.,* 2008). Through VCT, Mother- To-Child- Transmission (MTCT), which is the largest mode of infection for children under the age of fifteen, can be reduced. Therefore, VCT can be an effective way of curbing new infections (Glick, 2005). Low VCT uptake, therefore, has negative consequences for both preventive and treatment efforts (Bhagwanjee *et al.,* 2008).

The second stage of the continuum is the linkage of every person diagnosed with HIV to an HIV health care provider who can treat and counsel them to promote health and reduce the risk of continued transmission of the virus. This should be done within three months of diagnosis (HOPWA, 2007; CDC 2012 and Cheever, 2014). A PLHA needs to be connected to a care provider who can offer him or her treatment and counselling to help him or to stay as healthy as possible and avoid passing the virus to others (CDC, 2012). This stage of the continuum also involves clinical and laboratory monitoring of disease progression on an ongoing basis to determine ART eligibility (CDC 2012). It is, therefore, essential for PLWHIV to enlist for care as early as possible, as this facilitates both early assessment of their eligibility and their access to interventions against the further transmission of HIV and other infections, thereby minimising new infections. With no cure for AIDS currently available, treatment is life long and, to stay healthy, one needs to receive it regularly and remain on care once enlisted (Cheever, 2014).

Once a person becomes eligible for ART, the initiation of medication, which is informed by existing guidelines, is the next step. There is mounting evidence to the effect that ART reduces HIV transmission and prevalence (CDC, 1994; Cohen, 2011; Jia, 2012 and UNAIDS 2013). Antiretroviral are drugs used to prevent retroviruses, such as HIV, from replicating themselves, and are the recommended treatment for HIV infection. ART is treatment using a combination of three or more antiretroviral drugs from, at least, two different HIV drug classes to control the virus (Cheever *et al.,* 2014). The drugs should be taken daily.

Upon initiation of ART, monitoring and counselling of the patient is needed to achieve and maintain viral suppression, which is the health outcome sought for the patient (Miles *et al.,* 2013 and Gwadz *et al.,* 2015). The sensitisation of the patient to the importance of adherence to treatment to avoid drug resistance, ensuring a stable drug supply and keeping in touch with a health care provider is important. It is equally important to encourage the client to develop a good adherence plan that incorporates the family perspective (Miles *et al.,* 2013). This stage also includes ART preparation, which involves discussing with patient the potential side effects, dosing and toxicities associated with the prescribed regime and, finally, dispensing the

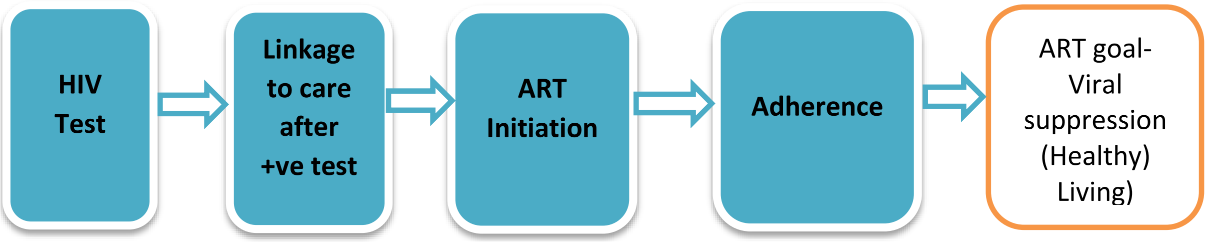
ARVs with clear instructions and verification by a pharmacist that the patient understands the dosing schedule, importance of strict adherence and how to contact the health care facility if potential adverse side effects manifested (MoH, 2010).

Adherence to treatment for viral suppression is the last stage and ultimate objective of ART (CDC 2012). This means taking the correct doses of medicines at the same time of every day in a sustained manner to maintain constant drug levels in the body, avoiding stopping and restarting therapy without medical advice, and adopting good health seeking behaviour. When all these steps are followed, viral suppression can be achieved (MoH, 2010, Bangsberge *et al.*, 2001 and UNAIDS, 2012). Viral load suppression, on the other hand, not only improves individual health, but also reduces HIV transmission at the population level (Das 2010 and Montaner, 2010), as it has been found to reduce the risk of transmitting HIV to others by 96 per cent in the USA (HOPWA 2007).

The importance of adherence to ART cannot be over-emphasised and the best way to live long with HIV is to keep the first ART consummation working for as long as possible. When ART is not taken properly, the virus can evolve, leading to its becoming drug resistant, which is irreversible (MoH, 2010). A person who develops drug resistance can no longer fight the virus in the body, and is at risk of getting sick and dying if he or she does not find another combination of ART. Additionally, it is important to note that the second ART combination usually does not work as well as the first, has more side effects and is more expensive (Bhagwanjee *et al.,* 2008 and MoH, 2010). Without continued non-adherence to treatment, eventually, the patient is at risk of having no treatment options (MOH 2010) and increased chances of transmitting the resistant HIV strain to his or her sexual partners, which becomes a public health problem (Stringer, 2006 and Bhagwanjee *et al.,* 2008). Therefore, a high level of adherence is vital for improved immunological and clinical outcomes, decreased risk of developing ARV drug resistance and reduced risk of transmitting the virus (MoH, 2010 and UNAIDS, 2013).

Once PLWHIV join the continuum, retention is essential for optimal health outcomes. However, retaining people who are not yet eligible for ART and those who are eligible, but have not yet initiated treatment is a big challenge (CDC, 2012). Suffice it to say that it is important to monitor patients during this waiting stage. Below is a diagram depicting the continuum its linkages.

Figure 2.1: The HIV and AIDS Continuum of Care and Treatment



Source: Adapted from CDC 2012 and modified by the author

To improve outcomes in viral load suppression, decreased MTCT and reduced HIV-related mortality, improvements at each step of the continuum must be achieved simultaneously (McNairy *et al* 2012). It is possible to reverse the HIV and AIDS pandemic by ensuring that PLWHIV are aware of their status and receive the treatment they need (CDC 2012). Conversely, failure to enlist and retain people on the continuum can escalate the problem. For instance, 91 per cent of new infections in the USA in 2009 were attributed to PLHA who were not on Medicare and those were infected, but were unaware of their status. In comparison, less than 6 per cent of new infections were attributed to people who were on ART (CDC, 2012). In other words, nine in ten new infections in the USA could have been prevented through early diagnosis, and prompt and sustained care and treatment. Again, this is an indication that timely HIV tests, which are the entry point on the continuum, is a critical step in effective HIV care and prevention because it precedes and enables timely progress to the subsequent stages (CDC 2012, UNAIDS 2013). The available evidence suggests that the rapid up-scaling of quality-assured HIV treatment prevents millions of people from dying, prevents millions of other people from acquiring HIV, saves money and lays the foundation for end the AIDS pandemic (UNAIDS, 2015). This makes early entry and continued participation on the HIV and AIDS CoC and treatment particularly crucial.

The up-scaling of HIV testing, care and treatment across the world and, particularly, in sub-Saharan Africa, which has a large number of PLWHIV, has demonstrated an ability to contribute to the reducing HIV-related deaths, MTCT in high-prevalence countries and a notable decrease in the incidence of HIV in several Sub-Saharan Africa (UNAIDS, 2013). This calls for people to test early, if found positive, to be linked to health care early, start ART as soon as prescribed, consistently take medication and remain on care so as to maintain viral suppression (CDC 2012, UNAIDS 2013). This also helps explain why the focus of the HIV and AIDS care and treatment continuum focuses on the HIV positive people and not on the negative ones.

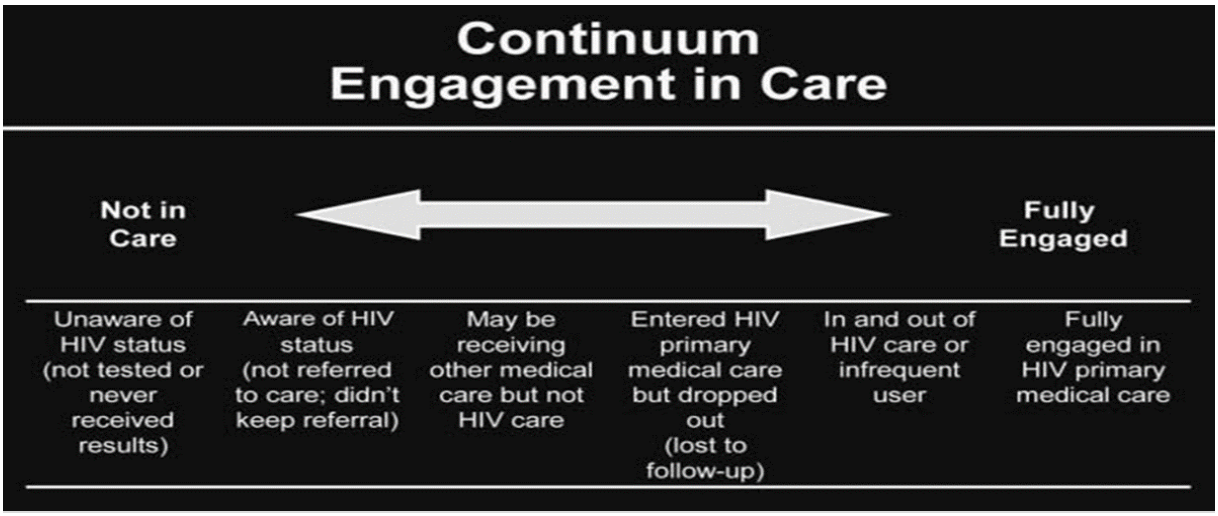
Although the proportion of PLWHIV who enlist for ART in in good time has increased in recent decades, a substantial proportion of them are not doing so (Gwadz *et al.,* 2014 and CDC 2013). When ART is offered, some people do not have access to good ART regimes or discontinue medication and become lost to follow-up (LTFU) because of absence of preventive interventions and support services (UNAIDS, 2012; Burns *et al.,* 2014). In addition, many PLWHIV learn of their infection late, which undermines the effectiveness of treatment and facilitating the continued spread of the disease (UNAIDS, 2012). The grave individual, community and societal consequences of PLHA not gaining access to ART include a high rate of morbidity, reduced quality of life, earlier mortality, viral resistance (when ART is discontinued), increased risk of transmission of HIV to others and high health care costs (Hall *et al.,* 2012). Various studies characterising rates of diagnosis with HIV, linkage to and retention on care, and ART uptake and viral suppression have highlighted the serious problems of PLWHIV (Gwatz *et al.*, 2014).

Although the anti-HIV and AIDS programme has been generally effective and many benefits have accrued to PLHA, it has been undermined by attrition of patients across the care and treatment continuum in both resource-rich and resource-poor settings. For instance, in the USA, only 19 to 28 per cent of PLHA are estimated to achieve viral load suppression (Hall *et al.,* 2014) while only one-third of people who test HIV-positive people in Sub-Saharan Africa are estimated to be remain on medication (CDC, 2013), yet it is important to complete all the stages of the continuum for one to achieve optimal health outcomes (Gwadz *et al.,* 2014).

2.4 Factors Influencing the HIV and AIDS Continuum of Care and Treatment

Some studies have identified both the facilitators and barriers to the HIV CoC. While those focusing on barriers have outlined factors contributing to late testing, delayed or non-uptake of ART and/or discontinuance of ART, those on facilitating factors have concentrated on factors that encourage forward linkages on the continuum. The barriers not only limit, delay or prevent forward linkages for PLWHV and from completing the stages of the continuum, but may also cause patients to keep regressing to earlier stages of the continuum throughout their lives (Cheever, 2007 and McNairy, 2012). The forward and backward linkages are as represented in figure 2.2.

Figure 2.2: Forward and Backward Linkages in the HIV and AIDS Continuum of Care and Treatment



Source: McNairy and El-Sadir (2012)

As can be seen from the diagram, barriers may also lead to some HIV-positive people dropping out of or LTFU as they move along the continuum, which leads to treatment failure, emergence of resistance and the possibility of transmitting resistant virus strains (MOH, 2010).

Most studies focusing on the continuum were undertaken outside Zambia, particularly in the USA, where the concept was developed. One such study is that of Gwadz *et al.,* (2014), a hospital-based quantitative research among African-Americans, which investigated the factors that influenced HIV-positive people's participation at the various stages of the HIV CoC. In particular, it investigated the factors believed to contribute to late testing, delay or decline of linkage to care and discontinuance of ART. The study was based on the theory of triadic influence, a multi-level model that examines three streams of influence on health seeking behaviour, including those related to the individual, social, structural and health systems. At the individual level, the factors that were found to influence ART initiation included poor understanding of HIV treatment; misconceptions about ART, as PLHA did not recognise their need for it, particularly when they felt healthy; fear and distrust of ART, HIV care system and health care providers; fear of side effects; negative outcome expectancies, that is, the belief that ART is ineffective and/or toxic; and low self-efficiency for managing and adhering. Positive outcome expectancies, favourable belief about the personal necessity of ART and positive internal norms, on the other hand, were all positively associated with readiness for ART. The reasons for ART discontinuation included changes in life circumstances, substance abuse, and low level of readiness for ART and side effects at the individual level. At the societal level, the main determinant of late diagnosis and failure to be linked to and retained in care was stigma.

Using the triadic theory, Gwadz *et al.,* (2014) study has outlined multi-level influences on health seeking behaviour for HIV and AIDS-related services. Although this study brought out many issues, one of its weaknesses is that it was restricted to three levels leaving out other factors such as those from health system and medicine-related factors. Additionally, being a purely quantitative study, insights into the influencing factors were not sought. Being a hospital based, the sample was more of a convenient one.

In another study, Gwadz *et al.,* (2015) investigated the strategies for uncovering undiagnosed HIV infection among high-risk heterosexuals and linking them to care with high retention in an effort to seek, test, treat and retain PLHA. Just like the Gwadz *et al.,* 2014 study cited above, the second study was also quantitative and guided by a three-level influence model. Among the barriers identified at the individual level were a lack of awareness of recommended testing frequencies, lower perceived risk of HIV infection, fear of HIV testing and possible consequences of a positive test result, mistrust of the medical environments, substance abuse, competing priorities, which were compounded further by low socio-economic status, such as, mental health problems, unstable housing, and family and child care responsibilities. At the societal level, the barriers identified were fear of potential stigmatisation in an event of a positive test result and peer norms regarding health care, including the idea that regular HIV testing is not necessary. At structural level, poor access to quality HIV testing facilities was identified as one of the barriers. Gwadz *et al.,* (2015) point out that the identified barriers interact to impede access to HIV testing, reduce motivation for people to test, and impede linkage to and retention on HIV primary care among those diagnosed. Gwadz *et al.,* (2015) was limited in a manner similar to the first study, mainly due to the approach adopted.

Blank *et al.,* (2015), in their study of factors associated with retention and viral suppression among women of colour, also identified stigma as a barrier to retention on HIV and AIDS treatment and care. Other factors identified were indecision about seeking HIV medical care while the factors hindering effectiveness in viral suppression included living with others, substance abuse, fair or poor health and hopelessness. Using both qualitative and quantitative approaches, Bauman *et al.,* (2013) studied barriers and facilitators to linkage to HIV primary care in New York City and found that many barriers were in the health care system, especially its complexity, intrinsic delays in care provision, and a lack of patience and friendliness. Delayed linkage to care was attributed to the requirement by HIV care sites of a confirmatory test. The authors further note that delay in linkage was common and partly due to shortages of HIV primary care physicians, system navigation and the long waits for appointments. Typically, clients had to wait between one and three weeks for a new appointment. A patient's first visit was for the blood draw, meeting with a care co-ordinator, and to sort out insurance issues and social service needs. Additionally, a lack of patience and friendliness among the health care staff was identified as a barrier, with many participants reporting that staff at HIV care sites were distant, rude, had bad attitude and unhelpful or disrespectful. Therefore, patients shunned some facilities and demonstrated a preference for patient-friendly ones. Black and others also identified some societal factors hat acted as barriers to patients' entry and retention on the CoC. Among them, stigma was identified as a major barrier to linkage to care, as it caused resistance to testing, secrecy about diagnosis, fear of disclosure, social isolation, reluctance to access medical care when appearing at a clinic would expose their HIV-positive status, and feeling judged by health care staff for suspected immoral behaviour that led to HIV infection.

The strength of the study by Black and others is that it used both qualitative and quantitative approaches and was, therefore, able to facilitate both an in-depth understanding of the issues under study and statistical measure of some of the variables. However, in focusing solely on the health system, it did not explore individual-related, medication and structural factors that, depending on the level of influence, could greatly affect people's entry and retention on the HIV CoC. Additionally, the study only focused on one stage of the continuum.

A study by Agwu *et al.,* (2013) focused on the challenges that PLHA faced in accessing HIV health care. The authors indicate that people who went for health care less often were less likely to enlist for ART. In other words, those with poor access to care were less likely to be on ART. The authors note further that those who did not wish to initiate ART chose to make fewer health care appointments in order to avoid discussing the topic with providers. Other authors, such as Tegger *et al.,* (2008), note competing priorities, primary among them, alcohol and non-injectable drug abuse, as barriers to initiation of ART.

Like contemporary studies, such as Gwadz *et al.,* (2014), earlier studies also acknowledge the role played by society-level factors like fear of HIV-related stigma in limiting people's participation on the CoC. For instance, Stall *et al.*, (1996) and Stone *et al.*, (1998) note that the fear of stigma that might arise if other were aware of patients' HIV diagnosis was a barrier to testing, the entry point on the continuum. The appearance of stigma in both older and contemporary studies indicates that efforts to end the vice have not been successful and that there is a need to enhance the efforts in that regard. The two studies also note that PLWHIV with negative peer norms regarding ART, that is, when their peers tend to avoid ART or consider those on it negatively, are less likely to initiate and sustain medication. They also note that a positive relationship with care providers plays a critical role in facilitating ART initiation.

Kerr *et al.*, (2004) is another American study that investigated the role of individual characteristics on acceptance and initiation of ART or ART uptake. One of the personal characteristic identified as impeding ART uptake was negative perceptions of ART, particularly the fear of side effects. The authors note that the negative perceptions include negative outcome expectancies, that is, the belief that the ART will not be effective. Other studies, such as of Pence *et al.*, (2008), report of low self-capacity for managing and adhering to ART as a demotivating factor to ART initiation.

Some studies have focused on the testing. For instance, Medu *et al.*, (2014) point out that one barrier to testing is stigma. In their systematic review of the effects of rapid HIV testing on HIV incidence and services in populations at high risk of HIV exposure, they found that rapid VCT in health facilities and communities was associated with a large increase in HIV testing uptake and receipt of results. Medu and friends further note that rapid VCT might also prevent human rights violations in marginalised populations where testing might be done without informed consent and stigma might create barriers to testing. They conclude, that rapid testing is one way of encouraging early entry and retention on the HIV care and treatment continuum. Like most other studies, however, the main weakness of the study is that it focused only on one stage of the continuum, yet the other stages are equally important. It also appears to consider individual-level barriers more important than other barriers, as the former were the only category analysed.

Focusing on retention on ART and adherence, Ferro and Weikum, (2015) note that alcohol dependence was a predicator of non-adherence. In their study among sex workers in the Dominican Republic, Zullinger *et al.*, (2015) also found that retention on care was lower among those who reported recent alcohol consumption and higher among women with positive perception of health service providers. In another Dominican Republic study, which focused on people who drop off or are Left-To-Follow-Up (LTFU) on the continuum, in other words, ART interruptions, Zullinger *et al.,* (2015) found that retention and adherence were higher among those with positive perceptions of service and lower among those experiencing stigma and discrimination and those abusing drugs. Butlinger *et al.,* (2014) also observe that those who were enrolled in an ART programmes and receiving transport reimbursement were less likely to drop out of the continuum. Females were also less likely to drop put. Medicine-related factors included the pill burden and complex ARV regimens. Still on LTFU, Tang and Huan, (2013), in their quantitative study in Nanjing, China, attributed high rates of LTFU to lower levels of education.

On linkage of PLHA to care, recent studies, such as Gardner and others, indicate substantial deficiencies on the HIV and AIDS continuum, from testing to care, retention, adherence to ART and viral suppression (Gardner *et al.,* 2011). For instance, it is estimated that viral suppression is achieved in only 28 per cent of PLWHIV in the USA (Gwadz *et al.*, 2014).

In Sub-Saharan Africa, the provision of effective HIV and AIDS-related services is hindered by a multiplicity of challenges, one of which is that of weak health systems. Apart from delay in entering the continuum, a high percentage of people are Left-To-Follow-Up (LTFU) at every stage (Rosen *et al.*, 2011 and Tomori *et al.,* 2014). Thus, some patients, after being diagnosed positive, do not return for results of their initial CD-4 count, some disappear between having an initial CD-4 count check and becoming eligible for ART while others fail to initiate ART after being found eligible for it (Rosen *et al.*, 2011). For example, in 2010, only 49 per cent of those eligible for ART in the region were started on treatment (Iwuji *et al.,* 2013 and Tomori *et al.,* 2014) while as many as 55 per cent of patients failed to receive diagnosis testing for disease staging (Boily *et al.*, 2012). According to Bassett *et al.*, (2009) and Billingsley *et al.,* (2014), the high rate of patient LTFU contributes to high patient mortality rates in resource-limited settings, as those who are LTFU often present later with severe immune suppression and are more likely to die in the first few months of treatment (Brunkof *et al.*, (2009). Early and effective treatment of HIV in resource-limited settings, on the other hand, has led not only to improved patient morbidity and mortality, but also prevention of transmission of the virus among discordant couples (Cohen *et al.*, 2011).

Literature indicates that the majority of patients are LTFU early after HIV diagnosis and many never enlist for treatment programmes (Rose *et al.*, 2011). This is a critical gap in the linkage to care during the pre-ART period, during which there is supposed to be stepwise progression from diagnosis to treatment and usually includes an evaluation for programme enrolment, CD4 testing to determine disease staging and initiation of therapy.

Some studies have investigated the factors that contribute to people delayed or non-uptake of HIV testing and continued participation on the HIV care and treatment continuum in Africa. Layer *et al.,* (2014) undertook a mixed-method study of factors affecting entry and engagement on the continuum in Iringa, Tanzania. The study was a multi-level-analysis focusing on individual, community, and structural and facility levels. At the individual level, the barriers identified included fear of HIV testing, reluctance to test while feeling healthy, fear of repeating the test, distrust of HIV test results and hope based on beliefs in spiritual healing services, that is, the belief in supernatural healing of HIV.

The facilitators of prompt and full utilisation of HIV and AIDS-related services at the individual level were positive perception of the efficacy of ART and its ability to save lives, especially after seeing another person's health improve dramatically after being on ART, increased perceived risk of HIV infection, extended illness, other causes of illness being ruled out, witnessing an AIDS-related death of a spouse or family member, having an extramarital affair and being concerned one might be infected with HIV, recognising one's own high risk of being infected after having unprotected sex with multiple partners. The barriers were seeing no reason for care and treatment while still feeling healthy, not being mentally prepared to accept the test result, denial and bad experiences with a health care provide. Often, patients only go back for linkage to treatment and care later after getting visibly sick.

At facility level, the barriers included inadequate provider-initiated counselling and testing at regular health services and near universal provider-initiated testing for PMTCT. Community-level barriers included beliefs in traditional healers, which was a deterrent for further engagement in HIV services. However, some traditional healers indicated that they encouraged their clients to seek the services of health facilities before resorting to traditional remedies. The facilitators at this level included mass media and community mobilisation activities, PLWHIV and support groups motivating others to test and traditional healers advising their clients to access health care services.

At the structural level, the barriers included widespread and chronic stock outs of HIV test kits and drugs and non-conducive policies, such as those requiring partner testing, passive referral systems, high work-related mobility or migration while due for clinical staging and ineffective systems for CD-4 count testing was the main barrier.

At the facility level, the study found that PLHA struggled to successfully be linked to care when HIV testing and counselling services were differently located, whereby clients were given referral cards and told to go to the nearest counselling centre on their own; being denied services at first encounter; and negative initial interactions with service providers. Same-day linkages from HIV Testing to Counselling services, co-located services and intensive post-test counselling were the facilitators.

Layers *et al.,* (2014) also investigated the influencing factors at the pre-ART stage, which follows clinical staging. During this stage, PLHA are not yet eligible for ART initiation, but are still supposed to be engaged in pre-ART care services until they are eligible to be put on ART. The services at this stage include regular clinical assessments for ART eligibility and consistent HIV care. According to the Tanzanian guidelines, individuals at this stage of the continuum should receive contricozale prophylaxis, a combination of antibiotics used to treat a range of opportunistic infections associated with HIV, free of charge. Clients are expected to visit the counselling centre monthly for monitoring and to receive the medication. Additionally, their CD-4 count should be taken every six months until eligible for ART initiation.

At the individual level, witnessing visible improvements in the health of someone on pre-ART care services was a facilitating factor while frequent stock outs of the required antibiotic prophylaxis was a barrier at the health facility level.

The next stage on the CoC is ART initiation. The Tanzanian national guidelines recommend that ART should be initiated at CD-4 counts of **≤350** or those at an advanced clinical stage. According to Layers *et al.,* (2014), prior to ART initiation, an individual undergoes, at least, three sessions of ART initiation and adherence training often conducted in a group setting. Layers *et al.,* (2014) state that clients needed to continue receiving counselling and education during clinic visits after ART initiation.

The final stage on the CoC is adherence to ART and retention on care. At this stage, the individual-level facilitators include an understanding of the importance of ART and viewing HIV and AIDS as a disease like any other. The barriers include failure to change behaviour, for example, stopping alcoholism, which made people forgetful of some things they needed to do to improve or maintain their health. At the facility level, the barriers included incorrect ART initiation, disrespectful treatment by service providers and challenges with appointment adherence while the facilitating factors were respectful treatment by service providers, good referral/transfer systems and home-based care providers. At the community-level, the main barrier was trust in traditional healers and spiritual healing while the facilitators were social support. Income-generating activities for support groups were the main facilitators at the structural level.

Layers *et al.,* (2014) also identified a number of cross-cutting barriers and facilitators on the continuum. At the health facility, they included a lack of motivation among service providers, a lack of privacy and confidentiality at health facilities, patients not receiving the needed services, poor client-provider communication and long waits/congestion. At the community level, the barriers included stigma and discrimination while co-operation between government officials and traditional healers were facilitators. Long distances to health centres and pervasive poverty were noted as important structural-level barriers.

The research by Layers and others has many merits. Firstly, it used both qualitative and quantitative approaches and, secondly, it used multi-level analysis. As a result, it facilitated the identification of many factors across a number of levels. Finally, it investigated both barriers and facilitating factors. Therefore, it presented a more holistic picture of the influencing factors. The one demerit of the study is that it did not explore medicine-related barriers and facilitators.

In Billingsley and others' qualitative study on barriers to linkage to care in resource-limited settings of Kenya, the main contributing factors identified were complicated systems of care and a lack of human and informational resources while the facilitators were early enrolment, early CD 4 testing and improved time to ART initiation. Drop offs from testing to ART initiation were attributed to a multiplicity of factors that included a proportion of clients opting for alternative health care services (Billingsley *et al.,* 2014).

According to the 2014 WHO Report, among the factors that influence entry, and linkage to care and continued participation on the HIV and AIDS CoC and treatment in low and middle income countries include a lack of integration in health care systems of the various services, from testing to treatment; significant limitations in equipment, personnel and training; stock outs of essential drugs; high transportation and out-of-pockets costs for patients; and social barriers like stigma and a lack of social support (WHO, 2014). While the report is quite comprehensive, it omitted factors that are patient-related and medicine-related. It also omitted cultural factors, such as gender relations, which appear to be very influential in such settings.

In their systematic review of qualitative studies on pre-ART retention on care in Sub-Saharan Africa, Rose *et al.,* (2011) identified several reasons for poor pre-ART retention on care or the failure to link patients from HIV testing to HIV care and retain them on care until they are eligible for ART. They included patients being asymptomatic and, hence, not seeing themselves as requiring medical care; the adoption of the ‘wait and see what happens’ strategy by some patients who lacked resources for transport; the fear of losing employment by taking time off work and being recognised as clients of an HIV clinic; very low CD-4 counts at first presentation for HIV care, patients dying before completing Stage 3; and some approaches to providing care that require multiple visits to clinics, for example, one visit to provide a blood sample for a CD-4 count and another a week later to get the results.

Rosen *et al.,* (2011) point out that without effective retention on pre-ART care, from testing to the first dispensing of ARVs, even patients who have long been aware of their HIV status will access care only when seriously ill, which is often long after treatment eligibility. They conclude that since very little therapeutic care is offered during the pre-ART period, patients must take it on faith that making the effort to go to the clinic for monitoring is worth the effort.

The 2010 WHO/UNAIDS Report recognises identifying people with HIV care needs, timely initiation of ART and provision of life-long care as key elements of the WHO/UNAIDS strategy for achieving universal access (WHO/UNAIDS,2010). However, in its 2013 report, WHO notes that in most countries in the world, large numbers of people go for testing and treatment late, usually when their health is failing, which diminishes the benefits of ART. In addition, there were significant levels of LTFU, particularly in the pre-ART period, due to a lack of structures and services for PLHA during this waiting period. The report identifies long distances to health facilities, advanced illness, alternative health beliefs, shortage of healthcare workers, alcohol consumption, early mortality, self-perceived improvement while on ART, stigma, few CD-4 count testing facilities, poor linkages, overburdened ART facilities, poor treatment preparation counselling, socio-economic issues, such as poverty and loss of income, lengthy waits, unavailability of same-day services, pharmacy overload, work responsibilities, frequent appointments, transport costs, and weak procurement and supply chains (WHO, 2013).

The WHO report identifies poor linkage, nutritional problems, confidentiality concerns, poor staff- patient relationship, poor tracking, inadequate patient monitoring, limited testing and care sites, and inadequate preparation of patients for treatment were some of the major challenges faced by PLHA at all stages of the continuum (WHO, 2013). Specifically for testing, the barriers identified were low suspicion of HIV infection, inadequate counselling, patient perceptions of personal wellbeing, loss of income, a lack of awareness of ART services, absence of symptoms, stigma and difficult of locating the HIV care in the hospital. The reasons for delayed or non-linkage were delayed access to CD-4 test reports due to a lack of adequate CD-4 machines, a lack of financial motivation for staff, poor communication, overburdened health care system and poor tracking system, especially between VCT care and HIV care facility. For ART initiation, the barriers were inadequate pre-ART monitoring, delayed provision of CD-4 results to patients, use of alternative medicines, inadequate post-test counselling, fear of side effects of drugs and patients feeling of healthy. For adherence, some of the reasons were long distances to HIV care facilities, stigma, stopping therapy when symptomatically better, drug stock outs, and lack of support, non-disclosure and undocumented transfers to other ART service providers. The medicine-related barriers were pill burden and treatment fatigue (WHO, 2013).

In Zambia, most of the studies on the HIV and AIDS CoC are on PMTCT, for instance Topp *et al.,* (2010 and 2012). Deo *et al.,* (2012) and Gartland *et al.,* 2013), on the other hand, propose the adoption of integrated modelling of health services to increase uptake and reduce dropout in PMTCT. Other studies equally focus on specific aspects of the continuum. They include Torpey *et al.,* (2008), which was on the role of community health workers on the CoC and Ogden *et al.,* (2011), a study on the need of care for care givers on the continuum, who are mostly women, by remunerating them. These studies, much as they were conducted in Zambia, offer very little insight into people’s general experiences in getting and remaining on life-long treatment. This means that there is still insufficient literature on this subject in Zambia.

Writing on VCT, some authors have associated barriers to testing with the health system (Chopard 2006; MacMillan *et al.,* 2007). Available evidence generally shows challenges in the health sectors of both developed and developing countries. For instance, Schuster and others write of discriminatory attitudes among healthcare providers in the American health care system, pointing out that such attitudes could discourage HIV-infected people from seeking health care, adhering to treatment regimens and returning for follow-up appointments (Schuster *et al* 2005). Other authors who note the existence of discriminatory attitudes towards HIV-infected people in the American health sector include Forrester and Murphy (1992); Annas (1998); Hereck *et al.,* (2002) and UNAIDS (2010), which also mentions negative attitudes on the part of health care workers as a barrier to accessing testing and treatment worldwide.

The literature on resource-poor countries indicates more challenges in the delivery of ART services. For instance, studies in rural Haiti reveal, among the many challenges limiting access to testing and ART services, the cost of medical drugs, erratic supply of drugs, non-integration of HIV testing with primary health care and women's health services, malnutrition and long distances to VCT centres (Mukherjee *et al.,* 1999 and Farmer *et al.*, 2001). The facility-related barriers observed included transport costs, heavy workloads resulting from a shortage of health care providers, non-integration of health services, burnout and inadequate pre-test counselling due to inadequate counselling space, shortage of counsellors against huge numbers of clients to be attended to, a lack of basic counselling skills due to inadequate training among health care providers, low morale among health care providers due to small stipends, which adversely affected counsellor's willingness to do things perceived extra to their job descriptions, a lack of food aid, long distances to testing centres because testing services were offered at selected health facilities that were not accessible to all communities and concerns about a lack of confidentiality (Muula, 2004; Chirawu *et al.,* 2010; Christofides and Jewkes 2010; Medley and Kennedy 2010; Mali and Castle 2003; Chiravu *et al.,* 2010; Day *et al.,* 2003; Matovu and Makumbi 2007; MacPhail *et al.,* 2008; Horwood *et al.,* 2009; Muula 2004 and Kipp *et al.,* 2010). The facilitating factors included free provision of ART, which has been reported to be a driver for VCT uptake (Roura *et al.,* 2009), provision of anonymised convenient rapid testing and same-day result testing (Day *et al*., 2003), wider ART availability (Sweat, 2000), home-based VCT using volunteers and peer educators (Matovu and Makumbi 2006, and Mabunda, 2006) and perceived guaranteed confidentiality (De Paoli *et al.,* 2000 and Kipp *et al.*, 2010).

Like many other countries in Sub-Saharan Africa, Zambia has a weak health sector (Chopard, 2008). Most authors acknowledge that the sector has been equipped for provision of ART, but they also observe that the services are concentrated in urban areas while clients in rural areas still walk long distances to facilities, and have no access to information on available services and home-based care. These are barriers to accessing ART while those that relate to testing include critical shortage of staff, difficulty in accessing CD-4 count testing and a lack of knowledge (Kachimba and Mwaba 2007; Miti 2007; WHO 2008; Chorpad *et al* 2008 and Krebs *et al.,* 2008 and Grant *et al.*, 2008). In addition to inadequacies in the health care delivery system, socio-cultural factors may determine people's treatment seeking behaviour. One such factor, stigma, has been recognised in diverse settings, such as China (Wu *et al* 2007, He *et al* 2009 and Qiao *et al.,* 2015), America (Berger, 2001, Sandelowski *et al.*, 2004 and Schuster, 2005) and in Sub-Saharan Africa (Kalichman and Simbayi 2003; Nakiyemba *et al* 2006; Carr 2007; Meiberge *et al.,* 2008; Mitchel *et al.*, 2007; Kipp *et al.,* 2007, Oneugbu *et al.*, 2013 and Amin *et al.*, 2015), and is a result of the widespread belief that infected people deserve their fate because of their drug-abusing habits or promiscuous sexual behaviour (Kelly 2000). In Zambia, studies that reveal the existence of stigma are Carr and Nyablade (2002); Bond *et al.*, (2003); Bond *et al.*, (2006) ; Grant *et al.,* (2008); Samuels *et al.,* (2008) ; CSO and MoH (2006); Zambia AIDS Alliance (2007), MoH (2008) ; Sanjobo *et al.,* (2008); Fox *et al* (2010) and Fylkesnes *et al.,* (2012). In all these studies, the conclusion is that stigma can dissuade people from testing for HIV, hence delaying them from benefiting from available services. Local ideologies about illnesses, such as beliefs in witchcraft or 'disease of God', usually affect decisions on choice of therapy, with some PLHA opting to consult traditional or spiritual healers before going to the hospital (Golooba and Tollman 2007 and Murray *et al.,* 2009).

Some other factors that have been noted as influencing people's decisions on VCT uptake include persistent sickness; fears associated with testing, namely the fear of blame, accusation, abandonment by spouses and a positive HIV diagnosis; low self-perception of HIV infection vulnerability, perceived risk of HIV infection; declining general health status; ascertaining one's status; and need to protect a baby (Daftary *et al.*, 2007, Grant *et al* 2008; Oshi *et al* 2007; Fyilkesnes and Siziya 2004; Ntozi *et al.,* 1999 and Levy, 2009).

For ART uptake, the barriers identified are inadequate post-test counselling resulting from a shortage of counsellors, which leads to heavy workloads; a lack of adequate counselling space; delays in returning HIV test results; transport costs; a lack of laboratory facilities; hospitals sending away people once they were past a certain illness progression; insufficient numbers of staff amid increasing number of patients; long distances to health facilities; staff trained in ART not being the ones dealing with AIDS patients; a medicine stock outs; counsellors being seen as insensitive; favouritism in ART allocations; a lack of training in ART services; and perceived lack of knowledge among staff was also a concern for clients (Levy 2004, Matovu and Makumbi 2007; Hardon *et al* 2006; Kalipeni 2004; Weiser *et al.,* 2007 and Mitchel *et al.,* 2007). Medicine stock outs and favouritism in ART allocation did not arise in the present study.

From their Kenyan study, Unge *et al.,* (2008) mention six main reasons people do not accept ART. These are fear of taking medicines on an empty stomach due to lack of food, fear of the side effects associated with ART and that the therapy would make them feel more sick, fear of disclosure, possible negative repercussions, concern for continued treatment and care and conflicting information from religious leaders and the community. Other factors identified included opting for alternative care, such as traditional medicine, and illiteracy, which makes patients unable to understand the information given by health care workers and HIV and AIDS related stigma (Unge *et al.*, 2008). Other factors that have been found to inhibit ART uptake are, among others, long clinic queues and insufficient time allocated to each patient; patients' difficulties in finding information about their illness and drugs; patients' beliefs about ART's impact on sexuality and parenthood; inconsistent information from the church, community programmes, health services, home-based care and schools; and a lack of money and hunger (Grant *et al* 2008). At the individual level, physical recovery of those who were once very sick has been noted as one of the facilitating factors for the ART uptake (Mshana *et al.,* 2006; Grant and others (2008).

In adherence, challenges in the health facility system have also come up, including a lack of trust in the health care provider and perceived low quality of the health care facility (Roura *et al.,* 2009). On the other hand, prior experience with the health care sector was found to be important in sustaining treatment (Gilson 2003). The other factors identified were long waiting times and patient-provider relationship (Mshana *et al.,* 2006; Mitchell *et al* 2007 and Meilberge *et al.,* 2008). Conflicting messages from health care providers and religious authorities have also been found to interfere with the desire for testing and adherence (Golooba and Tollman, 2007). Unge *et al.,* 2008 also state that conflicting messages from religious leaders and the community about alternative care do interfere with treatment. Others factors were that rural people saw the hospital staff as being impersonal, difficult to negotiate with and intimidating; corruption and erratic supply of drugs (Mshana *et al.,* 2006).

Sanjobo *et al.,* (2008), in their Zambian study, report of health service-related factors limiting adherence, among them, poor communication between health care professionals and patients, time constraints during consultation, a lack of counselling skills and patient follow-up, a lack of infrastructure for confidential counselling and long distances to health facilities. On the other hand, availability of nutritional support and information were identified as facilitators of adherence. A study undertaken in Chongwe study, a town about 50 kilometres east of Lusaka, the Capital City of Zambia, by Samuels *et al* (2008) also found out that long distances to health care facilities posed a major challenge to patients, and often generated anxieties and uncertainties regarding access to ARVs. The authors further observe that health facility related problems, such as shortage of staff, led to patients waiting very long hours, with some needing three days to access routine reviews because the first and last days were spent travelling to and from the hospital while the other was spent on waiting to be attended.

This report also acknowledges the lack of equipment and limited space at the health facilities covered in the study and suggests that there is a need to increase funding to the health sector in order to reduce such health system-related inadequacies. As Carlucci *et al., (*2008) and Roura *et al.,* (2009) note, sustaining life-long treatment might be particularly challenging for rural residents because they need to travel regularly to major hospitals to obtain pill refills and undergo follow-up checks.

At the community level, provision of ART free of charge, and provision of information to clients and their treatment supporters helped deal with barriers that included scepticism about HIV and ART. This was found to facilitate adherence.

In their studies in three countries, namely Tanzania, Uganda and Botswana, Hardon *et al* (2006 and 2007) tried to gain insight into important factors affecting ART adherence. Among the common constraints identified in all the three countries were transport costs, user fees, long waiting times, a lack of food, stigma and discrimination, a lack of social support, side effects, poor counselling and a lack of equipment, such as CD-4 count machines. Hardon and friends note that, since ARVs were given free of charge, patients mostly incurred on monthly trips to the facilities for drug refills. The authors also note that sometimes, the costs made it impossible for patients to report at the health facility for their monthly refills or the patients got their drugs at the expense of their children's school fees. Similarly, Weiser *et al.,* (2003), in their report on Botswana, note that patients missed their doses due to financial problems. They also point out that monthly visits to clinics to get medication and the long distances involved were a barrier to sustained treatment. At individual level, the barriers identified included forgetting, running out of medication, travel, intolerable side effects and being too busy.

Similarly, in their Ugandan study, Tuller *et al.,* (2008) note that even when patients have a high level of commitment to medication adherence, economic factors, in particular the high cost of transportation for monthly visits to the clinics, were an important challenge to sustained and successful treatment. They note further that the provision of ART free of charge has not eliminated financial barriers to adherence, as the cost of transportation to the clinic to pick up monthly refills continues to be a barrier. They also note that the cost of transportation, relative to income, can be substantial, especially for rural households, and competes with other essential expenses like food, shelter and education.

According to Rosen *et al.,* (2007), transportation costs can impede not only the day-to-day adherence to ART, but also retention in care and lead to significant numbers of patients being LTFU. They further note that most studies on Highly Active Antiretroviral Therapy (HAART) in sub-Sahara African have not included patients Left-To-Follow-Up (LTFU) when determining adherence rates, yet barriers such as high transportation costs can lead to interruption in both treatment and access, and LTFU. Other authors who have identified transportation costs and long distances to facilities as potential barriers to sustained ART include Mshana *et al.,* (2006); Mills *et al.,* (2006) and Roura *et al.,* (2008), who note that the two factors were more of a challenge during severe illness.

Studies have shown that, like transportation costs, a lack of food due to poverty also frustrates patients' determination to take up and adhere to ART because the medication demands that they eat more. In this regard, Mshana *et al.,* (2006) identified the need for ART providers to give patients supplementary food together with the medicines. The authors note that as poverty increases, the tendency for individuals to seek ART decreases and conclude that improvements in the sustainability of care for PLHA can be enhanced by the development of additional social assistance programmes aimed at alleviating poverty among patients in resource-poor countries and empowering them economically.

Crane *et al.,* (2006), in their Ugandan study, suggest that missed doses may be more due to failure to access medication rather than failure to adhere to medication. They also point out that structural rather than behavioural interventions may be the most useful in ensuring optimal treatment response. Oyugi *et al.,* (2004) also write that sometimes access to medication rather than adherence might be the problem. Roura *et al.,* (2008) also attributed challenges in ART adherence to severe poverty, noting that it led to difficulties in procuring transportation to health facilities and conflicted with other priorities in the use of any financial assistance provided through the programme. Similarly, Weiser *et al.,* (2010) also acknowledge the negative role played by poverty and food insecurity in adherence and identify a number of ways in which food insecurity contributed to ART non-adherence or postponement of initiation. One of the ways was that ARVs increased appetite, leading to intolerable hunger in the absence of food. Further, the side effects of ARVs were made worse in the absence of food. Additionally, ART uptake necessitated a patient having a balanced diet. As a consequence, some clients decided not to start at all or skip doses during times they could not cope with the burden of additional nutrition, which competed with other demands that included treatment-related expenses.

In Zambia, like in other countries in the region, poverty has been found to have implications on adherence. For example, the Zambia AIDS Alliance (2007) reveals that paying even small amounts for any AIDS-related treatment would be a burden on family incomes that would put families at risk of failing to meet the costs of other vital needs. Sanjobo *et al.,* (2008) and Grant *et al.,* (2008) also make similar observations. Many other authors acknowledge the importance of patients having adequate food and good nutrition if adherence is to be possible. Additionally, studies have shown that patients on food supplements recovered much faster than those without proper nutrition (Samuels *et al.,* 2009 and Ware *et al.,* 2009) and that poverty and its side effects, such as increased lack of food, made some people stop treatment because they could not bear the hunger resulting from the increased appetite enhanced by ART (Hardon *et al* 2007, Grant *et al.,* 2008, Samuels *et al.,* 2008, Sanjobo *et al.,* 2008, Roura *et al.,* 2008 and Foxy *et al.,* 2010).

As noted in the case of testing and ART uptake, illness ideologies and causation can determine whether people seek alternative treatment. The relationship between local concepts of illnesses and what causes them, on the one hand, and harmful local practices related to HIV and AIDS, on the other, have been documented as common in many African countries (Golooba and Mutebi, 2007). For example, such beliefs have made people on treatment start taking alternative medicines and forgo ARVs or start combining the two. In addition, the belief that it is possible to cure HIV and AIDS through spiritual healing or traditional medicines, which are common in sub-Saharan Africa, can weaken people's confidence in ART (Plummer, 2006 and Roura *et al.,* 2009). Such illness concepts and ideologies are also prevalent in Zambia (Mongensen, 1995; Malungo 2001; Merten 2006 and Murray *et al.,* 2009) and interfere with adherence, as they propagate messages that conflict with the orthodox ones (Murray *et al.*, 2009). In this regard, several authors argue that access and adherence to ART could be improved if traditional health practitioners were used to provide accurate information about ART and HIV and AIDS in general to their patients. For instance, according to findings of a ZARAN research project (ZARAN 2007: 6), about 60 per cent of Zambians received some or all of their medical care from traditional health practitioners, yet few attempts had been made to actively engage the traditional healers in the response to HIV and AIDS. The report notes further that, even in urban areas, where knowledge of HIV and AIDS and its treatment was highest, many patients still preferred to seek care from well-known traditional healers rather than from conventional government or private health clinics. The report, therefore, concludes that the trust that healers inspire in their communities make them potentially valuable channels of accurate information on HIV and AIDS and its treatment, and that they could help to end the misconceptions and stigma around the disease as well as encourage patients to access HIV and AIDS-related services in good time.

The possibility of integrating traditional healers into interventions and using them to provide information on HIV and AIDS and early referrals must be explored in Zambia, as has been done in other African Countries (Munk 1997 and Hatchet 2004). However, there are some concerns and challenges in using traditional healers because, as pointed out by Kalichman *et al.,* (2003), at times, several illness concepts exist for the same affliction, some of which do not follow biomedical reasoning and could negatively affect the uptake of formal HIV-related health care. From a study in a rural Zambian setting, Hojer, (1999) reviews the role of traditional healers in the treatment of regular sexually transmitted diseases (STDs). Among the reasons that led to people consulting traditional healers were perceived lack of privacy in conventional medical facilities, poor quality of health care, bad attitude on the part of health care staff and perceived advantages in combining different types of treatment. The same can be said for conventional HIV and AIDS-related health seeking behaviour, too, and reinforces the idea discussed earlier of some people consulting traditional healers first before seeking conventional health care.

Ndubani and Hojer (1999) and Ndubani (2002) also emphasise the role of traditional healers as potential sources of information for PLHA. Ndubani (2002) also notes further that traditional healers can be a viable supplement to the conventional facilities due to their cultural appropriateness and ease of accessibility to the majority of communities. The World Health Organisation has estimated that more than 80 per cent of populations in low-income countries rely mainly on traditional medicine for their primary health care needs (WHO 1993).

Evidence shows that non-adherence to ART is one of the biggest challenges in AIDS care in Zambia and the world over (NAC 2003). In their study in Zambia, Murray *et al* (2009) mention social factors like ignorance about the implications of having a chronic and potentially fatal disease affects adherence among PLHA. The authors further note that ART has a complicating effect on interpersonal relationships, particularly between husband and wife. A lack of accurate information, depression and hopelessness were also identified as individual factors limiting treatment. In their Zambian study focusing on material features of the drugs or pharmaceutical characteristics, Schumaker and Bond (2008) note that patients become concerned when colours, shapes, size, origin or toxicity differ from expectations. Other concerns were about side effects and rumours about treatment outcomes. Some of these concerns, for instance, size of ARV tablets, side effects and rumours about the treatment, were also noted in the present study. There are some authors, however, who have attributed the lack of adherence among AIDS patients in Sub-Saharan Africa to individual or behavioural obstacles that include forgetting doses, fear of side effects, travelling without medication, stopping drug intake when symptoms disappear or one feels better and wanting a drug holiday (Weiser *et al.,* 2003, Spacek *et al.,* 2006 and Eholic *et al.,* 2007). These factors have also been observed in the Americas. For instance, in their studies on adherence to ART in both developed and developing nations of North America and Sub-Saharan Africa, Mills *et al* (2006) cite fear of disclosure, wanting to avoid medication in public places, depression, forgetting doses, substance abuse, doubts about HIV status, being away from home, being too busy, having no sense of personal worth, seeing positive effects and hopelessness as patient-related barriers to adherence. These factors were also echoed by Unge *et al.,* (2008) and several other authors.

The major factor that has contributed to some patients on ART discontinuing medication is that of side effects (Murray *et al.,* 2009 and Hardon *et al.,* 2007). One side effect, namely increased appetite, discourages adherence because some patients are unable to afford food the required amounts of food (Rosen *et al.,* 2007 and Stevens *et al* 2004). To cope with initial side effects of ART, patients need to be well-informed, which is more challenging to achieve in contexts where illiteracy and a lack of health staff are the order of the day (Hardon *et al.,* 2007, and Aspeling and Whyk, 2008). Among the factors identified as encouraging compliance with treatment at the individual level were feeling and looking better after taking the drugs, ability to look after themselves, support and encouragement from the family members, a desire to see one's children finish school rather than die and leave them young and having a reminder to take medicine (Mshana *et al.,* 2006).

Poor adherence has also been attributed to wanting a drug holiday when feeling fine, fear of taking strong medicine without food, fear of side effects and seeing someone dying while on ART. On the other hand, adherence was most often associated with seeing someone become healthier while on ART (Chesney 2000). In Roura's study (2008), individual level-related factors included individual perception of disease severity and perceived benefits of ART, such as reports of physiological outcomes from treatment and personal persistence. The medication-level factors were pill burden, side effects, type of drugs and poor relationship with health care providers (Chesney 2000). Mills *et al.,* (2006), in their analysis of developed countries that included the USA, Belgium, Australia, Switzerland and the Netherlands, and developing countries in Su-Saharan Africa (SSA), write about medication-related factors influencing adherence, some of which are regimens being either too complicated or too easy to follow, the number of pills to be taken, the size and taste of pills, dosing frequency and pill count (Mills *et al.,* 2006, Ayalu *et al.,* 2010). Schumaker and Bond (2008) also made similar observations, particularly on size, but also added colour and shape. Other medicine-related factors were frequency of dosing, dosage and availability of liquid formulations (Ayalu *et al.,* 2010).

Weiser *et al.,* (2003) write about the importance of disclosure of one's status in adherence. In their study on barriers to ART adherence in Botswana, they note that non-disclosure of positive status to loved ones negatively affects adherence while disclosure facilitates adherence. This is because when they know, loved ones can act as reminders and also give social support. Some authors also reveal that even after taking an HIV test, some people do not disclose to their friends or relatives for fear of stigma, yet, as Mansergh (1998) notes, disclosure of one's positive status is a pivotal step towards getting HIV-related social support, which is critical because it decreases the effects of social stress (Cohen *et al* 1991). Stigma and fear of disclosure cause patients to skip doses, as privacy may be unavailable at scheduled dosing times (Oyugi *et al.,* 2007). Beliefs or perceptions about medication have also been found to limit people's access and adherence to ART. For example, Mills *et al*., (2006) reveal that among such factors were beliefs and perceptions about side effects. The authors also point out that interpersonal factors like discouraging networks, such as those with family members and health care providers may limit people's access and adherence to ART. For example, a lack of trust in health care providers among patients was reported to limit people's access and adherence to ART.

Other studies that have been undertaken on adherence include Farmer *et al.,* (2001) and Mukherjee *et al.,* (2006), which indicate that community health workers' approach to home-based care can improve treatment adherence. Similarly, Mills *et al*., (2008) reveal that adherence can be influenced by patient-related factors like a sense of self-worth, seeing positive results or effects of ART, acceptance of sero-positivity, prioritisation of medication over substance abuse, understanding of the need for strict adherence, using reminders and having a simple regimen. These findings are consistent with those of several other authors. For instance, Aspelling and Wyk (2008) also note that children have a positive influence on adherence, as participants longed to raise their children and ART was perceived as a means to achieving that goal. Additionally, some children also reminded their parents to take their medicine and that, in general, there was value in social support from family members, as they often reminded patients to take their medication. The value of interpersonal relationships was equally referred to by Samuels *et al.,* (2008) and Grant *et al.,* (2008) in their Zambian studies. The authors also note that encouragement and support from the family, such as king medication, and not wanting to leave small orphans behind triggered medication adherence. Individual-related facilitators included having visible reminders, such as putting medication within sight; having clocks/watches; looking better, having hope in the efficacy of drugs and being able to look after themselves.

The literature already reviewed clearly shows the importance of social support in adherence. According to Reynolds, social support, which has been defined by WHO as encouragement from family and friends for patients to co-operate with prescriptions of health care providers, is a strong predictor for adherence (Reynolds 2004 and WHO 2001). The support can come from many sources, such as care providers, family, significant others, peers and networks within the family (Trzynka and Erlen 2004), and can enhance patient motivation for medical adherence (Singh *et al.,* 1999). As will be shown in subsequent sections of this report, the present study shows a close association between one having a reminder and adherence. Roura *et al.,* (2008) refer to social networks' potential to be powerful conduits for support and emphasise the role of the family, other patients and health care providers in providing that support, which can be in form of providing finances to meet the costs related to treatment, collecting medicines on behalf of the sick or helping with household chores. The authors note, however, that the networks can also cause treatment interruptions by being channels for relaying of scepticism towards ART.

Farmer *et al.,* (2003) suggest some ways in which the barriers to access to ART can be overcome. Among the proposals are provision of testing within the context of primary health, offering transport money to patients to minimise transport costs and provision of food supplements. Other remedial measures proposed by other authors include the use of community health workers to administer Directly Observed Highly Active Antiretroviral Therapy (DOT-HAART), (Farmer *et al.,* 2001, Byakika-Tusiime *et al.,* 2005, Weidle *et al.,* 2006 and Mukherjee 2006) and family members as providers of treatment supporters (Nachega *et al,* 2006), implementation of community-based ART clubs (Grimsrud *et al,* 2015), using community-supported models for providing treatment to PLHA so as to lighten the burden of both patients, through reduced travel costs and loss of income, and the health system, through reduced clinic attendance (Bemelmans *et al* 2014) and distribution of ART drugs through self-forming groups of patients (Decroo *et al.,* 2014).

There are some authors who argue that adherence has not been a big problem in Africa. Ware *et al.,* (2009), in their ethnographic study Nigeria, Tanzania and Uganda, reveal that PLHA in Sub-Saharan Africa generally take more than 90 per cent of prescribed doses of ART. The authors note that this level of adherence exceeds that for North America and that it contradicts early scale-up concerns that adherence would be inadequate in settings of extreme poverty. The findings indicate that individuals on ART routinely overcome economic obstacles to ART adherence through a number of deliberate choices to allocate resources in favour of treatment. In addition, adherence was accomplished through the help of treatment partners, family members, friends and health care providers. They observe further that the help is provided on a reciprocal basis, such as people providing help to patients on condition of patients' adherence to ART and making their expectations known to the patients. This made it somehow obligatory for patients to adhere so as to create good will in the helpers, thereby ensuring that the help will continue to be provided. The authors, conclude that adherence in Sub-Saharan Africa is a means of fulfilling social responsibilities and preserving social capital in essential relationships.

Tuller *et al.,* (2009) write of the coping strategies used by some patients to deal with the economic costs of ART. These include saving money despite the resulting deprivation of other necessities, borrowing, and cutting on some expenses, entering into an arrangement with another person on Highly Active Antiretroviral Therapy (HAART) to collect medicines in turns and selling assets to raise money. The authors note, however, that the strategy of collecting medicines in turns has many health implications, such as the one whose turn to collect the medicine has not come missing out on health education and other counselling in that particular month. Roura *et al.,* (2009) note personal persistence as a factor in overcoming obstacles to treatment. Similarly, the present study reveals that people on ART devise a number of mechanisms to overcome barriers to adherence.

The major weakness of the studies reviewed, so far, is that they focused on single phases of the HIV and AIDS care and treatment continuum, most are either clinic or hospital-based, analyse single-level factors and most are qualitative, meaning that they do not provide entry points for interventions.

2.5 Gender Issues in the HIV Continuum of Care and treatment

According to UNAIDS, (2013), challenges to women’s participation on the CoC have been observed in both developing and developed countries, yet the number of women and girls living with HIV and AIDS continues to grow rapidly, with more than 17.7 million living with HIV and AIDS worldwide, over a million more than in 2003. In Sub-Saharan Africa, about 58 per cent of all PLHA are female and a staggering two-thirds of the more than 4,000 people aged 15 to 24 years who become infected with HIV around the world daily are female. In some countries, girls between 15 and 19 years are infected three to six times more than boys of their age. Among the harmful social norms and practices that increase the vulnerability of women and girls to infection are those that restrict women’s access to HIV and AIDS information and services, limitation of women’s control over their sexuality, which makes them vulnerable to sexual violence and abuse, and women’s limited or lack of access to economic resources and rights necessary for them to protect themselves from HIV and AIDS and contribute productively to caring for others affected by the disease. Harmful social norms and practices, such as pressure from peers or others to have multiple sexual partners or transactional sex, can also increase the vulnerability of boys and men to infection (Kelly 2000 and Shezongo-MacMillan *et al* 2007).

Another gender aspect of the HIV and AIDS pandemic is that women carry a disproportionate burden of caring for sick or affected family or community members. The burden often falls on girls and young women, thereby preventing them from obtaining education and denying them the potential for economic empowerment that comes with education. In addition, female care-AIDS patients often face severe stigma. These gender factors in the interaction between gender and HIV and AIDS are complex and, in some cases, vary from one country to another. Therefore, addressing them, which is essential to the achievement of ambitious prevention, treatment and care goals, requires different approaches. Several studies have indicated that gender inequalities weigh heavily on women's access to and experiences of HIV testing and counselling services, and access to antenatal care when pregnant (UNAIDS, 2013).

Gender inequalities play a critical role in determining access to and uptake of HIV testing and counselling as well as disclosure of HIV status. For example, a review of the utilisation of HIV testing and counselling shows that fear of negative consequences of testing and disclosure, such as a breakdown in social relationships; loss of employment, housing and other forms of discrimination, and violence, is a major barrier to uptake. These have been more frequently documented among women, especially pregnant ones. Research in four Asian countries also indicates that while men are test after exhibiting HIV-related symptoms, women are more likely to seek tests after their partners register positive test results. This reflects women’s relatively less amount of control over decisions on their sexuality and health (UNAIDS, 2013). Studies also indicate that outside of prenatal care programmes, women are tested less frequently than men. Therefore, in order to expand services to women outside the context of prenatal care, the use of other entry points, such as family planning services and workplaces, should be explored. These can help to reach young people and men, and counter the view that women bring HIV into families. Other challenges to women’s uptake of HIV and AIDS counselling and testing services include distance to testing centres, poverty and negative attitudes from health workers (http://www.ncbi.nlm.nih.gov/books/nbk/143047).

Violence against women is another barrier to women's access to HIV testing and counselling services, and is now recognised as a public emergency that affects women's health (WHO, 2014). There is evidence that fear of violence is also a major barrier to disclosure of HIV status to sexual partners, as violence is sometimes an outcome of disclosure. Many women may also not want to know their status or results due to fear of stigma and abandonment by their partners, peers, family and the health care establishment (WHO 2015). Other studies that identify violence as a barrier to women's decisions regarding testing for HIV include Maman *et al.,* (2002), Van der Straraten *et al.,* (1998), Dunkle *et al.,* (2004) and Shezongo- MacMillan *et al.,* (2007).

Many studies, particularly those focusing on PMTCT, have identified some challenges faced by women in being linked to care after a positive HIV diagnosis. Some of the challenges are long distances to health facilities, stigma, and a lack of structures for linkage and follow-up mechanisms (Limaye, 2013). For ART initiation, the cited barriers are inadequate post-test counselling, stress, separation of HIV care and treatment services required by HIV-infected mothers and their infants after delivery and health facility visit burden (Chi *et al.,* 2013). In a review of qualitative studies of women living with HIV in America, Sandelowski *et al.,* (2004) show that the women live in fear of the harmful effects of stigma. The effects include social rejection, discrimination and even violence from partners, relatives, friends, employers, co-workers and health care providers. They note further that HIV and AIDS-related stigma was worse for women than it is for their male counterparts (Weiser *et al.,* 2003). Similar observations have been made in the region. For instance, in their study in Kenya, Cadwell *et al.,* (1992) note that often women are infected by their husbands, but blamed and thrown out in a dehumanising manner by their husbands if they are unfortunate enough to develop symptoms first. The Zambia AIDS Alliance (2007) and Grant *et al.,* (2008) have also argued that stigma and discrimination are worse for women and that, as a result, some women do not disclose their positive sero-status for fear of being rejected by their male partners. The mistreatment of HIV-positive women has also been reported in the HIV and AIDS Prevention Strategy (2001) and Unge *et al.,* (2008). As will be shown later, this was the case with some women in the present study.

In their Tanzanian study, Mshana *et al.,* (2006) note that in most cases, men are reluctant to be tested if the initiative came from their wives, as they believed that undermined their authority. They further indicate that when a wife goes for an HIV test before her husband and is found positive, she would be considered responsible for bringing the disease into the home simply because she tested positive first. To some extent, this instils fear in some women who want to initiate the HIV testing even if they feel that they have been exposed to some risk of infection.

In Zambia, HIV and AIDS-related stigma has also been very common and it is very evident that women suffer more stigma and discrimination than men because of their low status in society. For instance, NAC (2003) notes that stigma and discrimination attached to HIV and AIDS affects both sexes, but it is more severe for women, as women risk being beaten and even thrown out of the house by their husbands if their status is revealed. The report further points out that the situation is the same even when the husband is the source of the woman's infection. Therefore, Zambian men and women may face barriers in accessing, utilising and adhering to ART, but women are more disadvantaged because of their inferior socio-economic status, yet they are more vulnerable to infection and have the biggest share of infections (Shezongo-MacMillan *et al*., 2007 and Varga 1999)). The implication is that the provision of free access to ART services is potentially missing its largest potential clientele.

The disproportionate HIV prevalence rates between the genders in Zambia reflect deep-rooted problems, one of which is that of unequal power relations between men and women due to socialisation, cultural beliefs and women's lack of economic empowerment. The unequal power relations are also seen in the society's tolerance for male infidelity and women's limited ability to negotiate for safer sex even when it is clear that they may be at risk of HIV infection (Kelly 2000). In this regard, a Human Rights Watch (2007) report on gender-based abuses and HIV treatment in Zambia notes that human rights activists and policy makers should address the issue of discrimination and violence against women if the world is to combat the AIDS epidemic. The report further notes that treatment policies and programmes should not ignore the connection between domestic violence or women's insecure property rights and their inability to seek access and adherence to HIV treatment. The authors acknowledge that the Zambian government has taken more steps to address violence and discrimination against women, but they also point out that more still remains to be done the legal framework, HIV treatment programmes and support services to address poverty among HIV-positive women. The report states this must be done if HIV treatment is to be provided equitably and women's lives saved. The authors argue that although Zambia is one of the many countries setting ambitious targets for the rapid scaling up of HIV and AIDS treatment and making impressive progress, women’s unequal status in the country gravely undermines their ability to access and adhere to ART.

Human Rights Watch (2007) reveals that the difficulties that women face in their efforts to access HIV and AIDS services have to do with their interpersonal relationships and economic status. For instance, in order for some women to access HIV and AIDS care, they have to fabricate stories for their absence from home during visits to the clinic or support group sessions while others have to hide their medication in pots, holes in the ground or food containers. Others struggle to raise money for food and transport to clinics. The report argues that the situation was usually worse for divorced or widowed women, especially those from whom property was taken away upon being divorced or widowed. Further, some women missed doses in trying to avoid detection by their partners. These issues were also raised in the present study.

Gender-based violence (GBV) and human rights abuses against women have been found to be very high in Zambia (YWCA 1999 and CSO 2006) and these may hinder women living with HIV and AIDS from accessing treatment and adhering to it. Underscoring this point, the Norwegian Council for Africa (2008) reports that women’s unequal status in Zambian society gravely undermines their ability to access and adhere to ART, and that gender-based human rights abuses have had a negative impact on women’s access and adherence to HIV and AIDS treatment; ability to seek treatment, HIV information and testing; and freedom to disclose their status when positive. The situation of women is worsened by misconceptions about HIV and AIDS not only being a result of illicit sex, but an illness for women and, especially, for female prostitutes (Ndubani 2002 and MoH 2007), which implies that women are more promiscuous than men. The misconception is born out of the African idea that promiscuity and infidelity among women is more shameful and intolerable than among men. According to Caldwell (1999), much of AIDS-affected Africa is convinced that there is a relationship between the disease and illicit sex.

Some authors, for instance, Shezongo-MacMillan *et al., (*2007) and MoH (2007), attribute women’s limited access to ART to cultural taboos that do not allow women to discuss sex-related and reproductive health issues openly, which makes women living with HIV and AIDS shy to seek treatment for conditions likely to be STDs. Additionally, because HIV is mainly sexually transmitted, many people believe that women who are infected are promiscuous and that leads to shaming and social seclusion (MoH 2007). It is clear, therefore, that the complex linkages among human rights, gender and HIV and AIDS need to be understood, and that protection of human rights is necessary to reducing women's vulnerability to AIDS infection and increasing their access to ART. Other authors who write about gender imbalances and women's access to HIV and AIDS-related services include Pool *et al.,* (2001), Urassa *et al.,* (2005), Taegmeyer *et al.,* (2005), Daftary *et al* (2007), Mbonye *et al* (2009) and Theuring *et al* (2009). The Lusaka plus News (2004) argues that women are the worst affected in terms of lacking information on HIV and AIDS-related services, which hampers their access to such services.

Gender inequality and culturally norms about masculinity also affect men's vulnerability to HIV and AIDS. For example, in Africa, men are expected to be more knowledgeable and experienced sexually. Additionally, they are supposed to provide for their families, and be self-reliant and strong. Such beliefs and norms hinder men's access to information, and promote experimentation in partnering, stigmatisation of 'effeminate' men and alternative sexualities (UNAIDS 1995). Such norms may not only make men vulnerable to HIV and AIDS infection, but also limit their access to HIV and AIDS-related treatment and care. Additionally, studies have shown that in some cultural settings, there has been feminisation of the health system. In other words, the health system has been made an exclusively women's affair. For instance, in their Ugandan study Larson *et al.,* (2010) note that among the reasons men did not accept couple HIV testing during antenatal was that the clinic environments were not accommodative of men. Therefore, the authors recommend that in order to improve utilisation of such services by men, health staff needed to be sensitised and trained so as to reduce stigmatisation and make the facilities friendlier to male users.

2.6 Theoretical Framework

In exploring the factors that influence people's entry and retention on the HIV and AIDS CoC, the present study was guided by the social-ecological model (SEM), which was adapted from Roura e*t al.,* (2009) and Layer *et al.,* (2014). The Social- Ecological Model is an approach to health promotion that offers a broader perspective because it recognises that most public health challenges are too complex to be adequately understood using single-level analysis (Robinson 2008). It is a more comprehensive approach that investigates multiple levels of influence that impact on health behaviour and, ultimately, health outcomes. The levels of influence are interpersonal factors; community, organisational and institutional factors, and public policies

(Mcleroy *et al.,* 1998). The model looks at organisational structures and processes; community mediating structures, such as schools, churches, neighbourhoods and community networks; social support systems; and power structures, which are not only key components of broader social-ecological perspectives, but essential components of healthcare system and health behaviour (Minkler 1999).

One of the foundations of the SEM is the argument that health promotions programme that focus only on behavioural change through educational activities or other interpersonal-level change strategies often neglect the social and environmental context in which human behaviour occurs and is reinforced. The relevance of the model to the study is its implication that improving the health of vulnerable people requires interventions that target multi-levels of influence and utilise multiple intervention strategies, as it frames human behaviour as a function of personal and environmental socio-economic, political and healthcare system factors (Robinson, 2008; Choi *et al.,* 1998 and Roura *et al.,* 2009). Health seeking behaviour is, therefore, not construed as an exclusive function of the individual, but also as a reflection of wider interactive situational processes because the individual's health-seeking behaviour is located in social, institutional and physical environments (Latkin *et al.,* 2005 and Roura *et al.,* 2009). Thus, individual behaviour is determined, to a large extent, by aspects of the social environment, such as community norms and values, regulations and policies and most good health behaviour results from a combination of efforts at the individual, interpersonal, organisational, community and public policy levels (Mcleroy *et al.,* 1998).

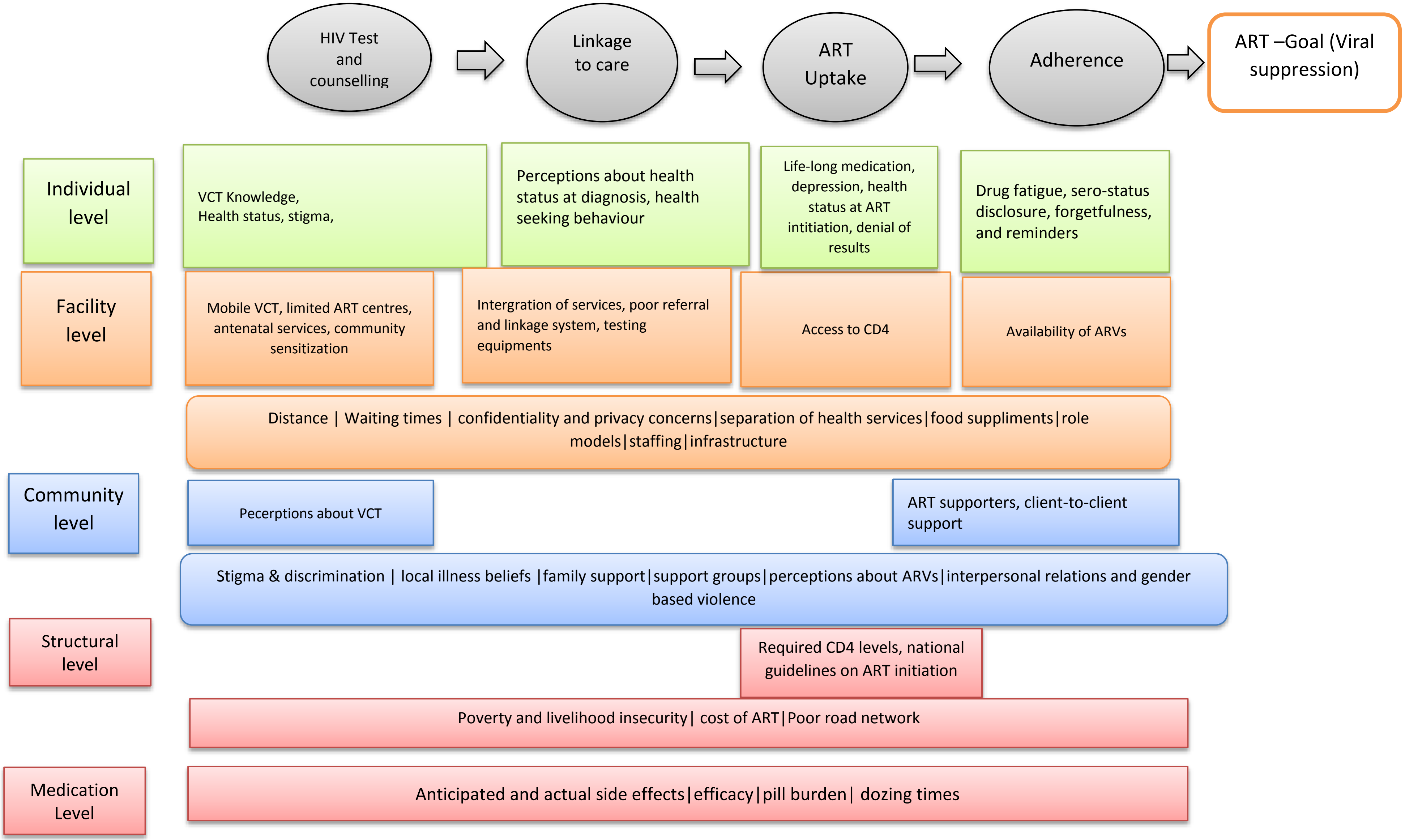
The model situates individuals in a dynamic social ecology in which they adapt their behaviour to their social environment and make decisions based on information, influences and interactions available to them through local social networks, relationships and institutions (Roura *et al.,* 2009). In analysing health-seeking behaviour, the model proposes looking beyond the individuals by considering the social environment in which they exist and the influences that the social world has on them, based on the assumption that the world in which we live influences our behaviour. Health system-related factors are also considered (McLaren and Hawe 2005). So, the approach avoids exclusive focus on any of the individual factors at play. Rather, the model takes into consideration the dynamic interaction between internal/personal and external/non-personal factors in explaining health-seeking behaviour (Choi *et al.,* 1998).

The SEM puts the factors influencing people's health-seeking behaviour into four categories, namely individual, social, programmatic and structural factors (Roura *et al.,* 2009). Structural factors are those over which the individual has completely no control (Parker *et al.,* 2004) and include poverty levels, livelihoods, health policies, laws and the financing of health care systems, all of which are linked to the national economy (Sumartojo *et al.,* 2004). Programmatic factors, on the other hand, are those related to the way health care systems are organised and services delivered, including the availability and affordability of services, attitudes of health care providers, waiting times and distances to facilities (Munro *et al.,* 2007 and Roura *et al.,* 2009). The social factors relate to interpersonal relations, such as those among sexual partners, family members and peers, that affect individual actions (Roura *et al.,* 2009); community-level factors, such as the relationship with and influence of the social systems, institutions like the church, social exclusion, discrimination, stigma, traditional health care systems, local illness ideologies and concepts that are all embedded in people's socio-cultural systems (Musheke *et al.,* 2013); and the relationship between the formal health sector and its professionals, on one hand, and the local people, on the other. These are capable of influencing treatment-seeking behaviour because they are structured by the social order (Duffy *et al.,* 2010). The individual factors are the personal determinants of health-seeking behaviour over which an individual has control, such as personal characteristics, which include perceived severity of the disease, wellness, interpretation of illness and attitudes towards treatment, knowledge, as well as somatic responses to medication (Duffy *et al.,* 2010).

According to the SEM, a more comprehensive approach to health promotion requires changing the practices of social systems that have widespread effects on human health rather than changing the habits of individuals. This framework holds that two or more factors are not only interlinked and interwoven, but also reinforce one another in influencing the individual's treatment-seeking behaviour. While at times the interplay of two factors may be involved, such as reduced waiting times (health sector factor) and motivation to seek treatment (individual factor), sometimes it is a combination of several factors that are involved. For instance, pervasive stigma (social factor) or waiting times at the ART clinic (health related) may reinforce each other and cause a lack of motivation (individual factor) and, ultimately, to attrition from ART care (Musheke *et al.,* 2013). Due to this comprehensive and multi-faceted approach, the model avoids the theoretical divide between individual and structural models by treating both as complimentary paradigms on the same continuum (Roura *et al.,* 2009). Used with modifications, the model was found useful to this study because it facilitated the analysis of the reciprocal interplay between self-regulated and environmental determinants of health-seeking behaviour (Joint United Nations Programme on HIV and AIDS 1999). It also facilitated the study of not only the individual factors, but also others at all levels of the social environment of the subjects.

Using the SEM, the key relational variables under study were investigated at four levels, namely the structural (poverty and food insecurity), programmatic (health system), social (community) and individual (personal determinants). Additionally, the study identified a fifth level, namely the medication level at which the factors included those that related to the characteristics of drugs, such as ARVs not being curative, size of tablets, requirement for ARVs to be taken on a daily basis, the side effects of drugs (Tatabai *et al.,* 2015 and Tuller *et al.*, 2010), availability of liquid formulations, and dosing and pill burden (Chesney 2000 and Ayalu *et al.*, 2014). These variables have been represented diagrammatically in Figure 2.3 below.

Figure 2.3 Factors Influencing the HIV and AIDS Continuum of Care and Treatment



Source: Adapted from Roura *et al*, 2009 and Layer *et al*, 2014 and modified by the author.

The social-ecological factors, being the independent variables, either as facilitators or inhibitors to entry and retention in the HIV CoC, were measured in the five domains illustrated in Figure 2.3. Entry and retention in care, the dependent variables, were measured on a nominal scale for the purpose of identifying their relative importance and specific manifestations study setting (Roura *et al.,* 2009: 204). Therefore, the collection of data was guided by the five categories, namely structural, health systems, social, medication and individual categories. The addition of the medication level was a modification and expansion of the model. Another modification to the model was the transposition of some factors from one category to another for purposes of the study. Specifically, ‘relationships between health professionals and the local people’ was moved from the ‘social’ category to the ‘health system’ because, being the gate-keepers to the health system, health professionals were part of the health system.

These modifications were made in order to make the theory more relevant to the study because, as stated by Chakulimba, (1986), it is necessary to modify theories by either adding to them ideas or variables that may be lacking or leaving out those that may be irrelevant to a given study. Additionally, in the Roura *et al.,* (2009) study, the model was used in an exploration of the barriers to adherence only while, in the present study, the tenets of the model were used in the identification of both facilitators and barriers at all the four stages of the CoC, namely VCT, linkage to care, ART uptake and adherence.

The SEM was used in Tanzania, which is in the same region with Zambia by Roura *et al.,* (2009). However, unlike that study, which was done in a semi-rural setting, the current study was done in a rural and remote area. The two areas, therefore, have varied geographic, demographic, cultural and political settings. It is also worth pointing out that only the levels of the SEM were used in the current study, not its variables (see figure 2.3). That was done because the study was mainly qualitative. Therefore, it had to be anchored on variables emerging from the findings, not predetermined ones.

2.7 Conclusion

This chapter reviewed literature relevant to the present study. As the study was guided by the SEM, its focus was on the individual, structural and community factors; those that related to the system of care; and those that related to the medicines prescribed. The indications of the review are that the effects of many of the factors were consistent across a number of country settings. However, further analysis of the literature also clearly showed that low-income countries, such as those in Sub-Saharan Africa, which are the worst hit by the pandemic, have more barriers to people's entry and retention on the HIV and AIDS CoC. The reason is that in addition to the individual and medication factors, low-income countries also have several problems related to the way the health care system is organised and from the community environment (stigma, local illness ideologies and negative cultural practices). Additionally, structural barriers (poverty and livelihood insecurity) are quite widespread in most resource-poor settings. However, some developed countries like the USA also reported widespread HIV and AIDS-related stigma and discrimination, particularly at the health facility level among health care providers. In terms of gender, the reviewed literature showed that, to some extent, men also experienced barriers to access to HIV and AIDS-related treatment and care services. However, women, who were the worst affected by the pandemic and more vulnerable to infection, faced more barriers to access to HIV and AIDS-treatment and care services. The chapter ends with a discussion of the conceptual framework.

CHAPTER THREE

METHODOLOGY

3.1 Introduction

This study was part of a larger research project called *Improving Equity of Access to HIV Care and Treatment for Adults and Children in Zambia*". The project was funded by the Swiss National Science Foundation (SNF) through the Swiss Tropical and Public Health Institute (TPH) under the University of Basel. Guided by the social-ecological model (SEM), this study aimed at exploring the factors influencing the HIV and AIDS continuum of care and treatment (CoC) among people living with HIV and AIDS (PLHA). It was anchored on the four research questions listed in Chapter One.

Despite this researcher being part of the project design, and data collection and analysis team for the larger project, she conducted this study in a manner that gives it autonomous merit. In other words, the study contributes to a larger project, but it has significance outside the framework of the larger study of which it is a part, and the other smaller components within the larger project. This was partly because it was conducted in an area with a unique social-ecological context. Further, to enhance the uniqueness of the study, the researcher developed her own study tools so as to capture a set of data uniquely different from that used in the main study and other components of the larger project. That notwithstanding, the study benefitted from the larger project in terms of cross fertilisation of ideas and analytical skills; funding for the field work; and sponsorship for the author to spend some time in Switzerland in order to participate in data analysis, gain publication skills, and attend workshops and seminars.

3.2 Research Design

This study used a mixed methods design involving both quantitative and qualitative methods. However, although quantitative data was collected in the study, qualitative component was the more dominant. This was because the researcher desired to have an extensive understanding of the subjects' experiences, which cannot be made from statistical inference. So, the statistical inferences were just used to support the description of a few factors (Creswell *et al*., 2003; Tashakkori and Teddlie, 2003a; 2003b). Therefore, in this study, only a few selected factors, particularly those that were consistently cited by the respondents, such as distance, food supplements, local illness ideologies, stigma and fears associated with testing, were measured quantitatively. This was partly for triangulation purposes and partly for the sake of getting an idea of the extent or level of influence of the factors on the HIV and AIDS CoC. Therefore, the quantitative element was limited to basic statistical measures like frequencies, cross tabulations and statistical tests of selected factors.

This study is premised on evidence of low uptake of VCT and ART services, and adherence to ART. Thus, the study endeavored to investigate the explanatory factors. To that effect, there was a need to explore and describe the main factors involved. Therefore, an explorative and descriptive design that utilised mixed methods was adopted. The choice of research design was deliberate and informed by a slight bias towards qualitative methods because the research sought to explore the limiting and facilitating factors. Further, the study aimed at investigating people's views on and experiences of the HIV and AIDS CoC, making a more descriptive design desirable. As stated by Ndhlovu (2010), descriptive research designs are more ideal for investigating people's views on and experiences of social issues. As noted by Gosh (2003), explorative studies aim at discovering new insights. Meanwhile, Kathari (2004) adds that such studies discover underlying motives of human behaviour and can, therefore, be used to investigate and analyse the various factors that motivate people to behave in particular ways.

Qualitative research methods were useful to this study because they generated information from the respondents' perspectives (Vervoot *et al.*, 2007). As noted by Weber (1947, 1964), one of the founding fathers of sociology, to understand human behaviour, there is a need to penetrate the subjective meanings that the people being studied attach to their own behaviour. Weber further argues that the interpretive understanding of social action, which he termed '*verstehen*', was important in gaining explanations of causes and effects. The phenomenological design or an interpretive approach, which is an anti-positivist epistemological position concerned with how individuals make sense of the world around them (Bryman, 2012) was also used. This was to ensure the exploration of the subjects' experiences of HIV and AIDS in specific daily contexts. The flexibility of the qualitative approach also allowed for an in-depth investigation of particular topics because it permitted probing (Kombo and Tromp, 2006:10).

Specific to this study, the phenomenological approach was useful because it enabled the investigation and analysis of issues from the perspective of those being studied. In other words, it enabled the investigation of people's lived experiences and feelings related to entry and retention on the CoC and factors that influence them. In-depth interviews with PLHA, particularly those on treatment, and care-givers also provided some understanding not only of how the various barriers were perceived by individuals, but also how they were experienced and dealt with. Therefore, the interviews provided information on not only the perceived factors, but also the ones actually influencing entry and retention on the continuum, as experienced by the affected and infected people. Through the narratives, it was possible to investigate why some people went for VCT, initiated treatment, dropped out of the CoC or missed doses while others did not. Thus, the approach was good for tapping into the subjective dimension of behaviour (Marsh, 1982, cited in de Vaus, 2001:11), allowing for meaning to be attached to behavioural patterns.

One other advantage of the qualitative approach was that it generated a richer spectrum of barriers and facilitators than a more quantitative approach would have. It was, therefore, more suited for identifying patient-important barriers and facilitators (Mills *et al.,* 2006), such as those that made some people eligible for ART choose to initiate, continue with or adhere to treatment or not (Murray *et al.,* 2009). In addition, the approach facilitated an examination of the dimensions and processes of the subjects' everyday life conditions that made people fail to access treatment even when it was readily available (Thornton, 2008). Within the qualitative approach, the study depended heavily on prolonged observation of ethnographies which, like phenomenology, have roots in anthropology and sociology. This approach enabled the investigation of the role of the cultural framework in people's health-seeking behaviour.

While perspectives are important, the qualitative approach is not able to quantify or measure the level to which something is happening, thereby making it difficult to design interventions. That was where the quantitative approach was brought in, as it facilitated the measurement of the relative impact of the factors that influenced people's entry and continued participation on the CoC by determining their frequency among the population. The factors that occurred more frequently were considered the basis for future interventions aimed at improving access and adherence to ART (Murray *et al.,* 2009). The use of the quantitative approach was also a way of reinforcing objectivity and enhancing data quality, as the researcher's values, interpretation and feelings were not considered (Kombo and Tromp, 2006). Unfortunately, the quantitative approach was unable to add meanings to what was being studied. Fortunately, the qualitative methods did that.

Qualitative data collection techniques included interviews with key informants; focus group discussions whose participants were chosen on the basis of sex, age and other socio-economic characteristics; observations; and in-depth interviews. The research data was collected over a period of one year six months. That much time was necessary, particularly for participant observation, which demanded that the researcher stayed among the study participants for extended periods of time rather than merely visiting periodically.

3.3 The Research Setting

3.3.1 Mazabuka District

Zambia has ten provinces and 103 districts. Chivuna community, the research area, is located in Mazabuka, one of the eleven districts in the Southern Province. Mazabuka district with a population of 230,972 (CSO, 2012), is approximately 120 km South-west of Lusaka on the road and railway from Lusaka to Livingstone, the tourist capital of the country, and across the border into Zimbabwe. The town boasts of large sugarcane plantations, including the Nakambala Estates of Illovo Sugar's Zambia Sugar, which is Zambia's leading sugar producer. Other important economic activities in the district are crop farming and cattle rearing at both the peasant and commercial scales. Mining by the newly-opened Albidon Mine near Munali Hills is also an important economic activity in the district.

Despite the many economic activities in the district, poverty levels are very high, particularly in the rural parts of the district. The high poverty levels have been exacerbated by severe droughts experienced in recent years. To confound the already bad situation, the province has also been experiencing an increased incidence of corridor disease, an incurable cattle disease. The disease is called *denkete*, which means 'falling' in the local language, a reference to the suddenness of the death of infected animals. A healthy-looking, but infected animal can just literally fall dead at any time without warning. The animal diseases have also affected poultry and, to a lesser extent, piggery. Together, the animal diseases and drought have degraded the region from being the maize and animal food basket that it was until the 1990s to one that often depends on government and donor food relief to which the people in the region are not used. As shall be seen later, the high poverty levels have a direct impact on access to HIV and AIDS-related services, treatment and care.

Like most of Zambia, Mazabuka does not have adequately developed infrastructure, such as roads and telecommunications, and some areas of the district are not serviced by public transport. Instead, they depend on small open pick-up vehicles as a means of transport. However, given the high poverty levels in the district, many people cannot afford the fares. So, they just walk the long distances to the nearest points of service. As will be seen later, this has also had an effect on access to health care, in general, and HIV and AIDS-related services, in particular.

Because Mazabuka is on both the railway line and road that lead to Zimbabwe, Botswana and South Africa and Namibia, its residents are prone to catching HIV from people in transit. This vulnerability to infection is partly responsible for the high prevalence rates of the disease in the district, confirming the idea that HIV and AIDS prevalence rates are usually highest in cities and towns on major transport routes due to a heavy presence of truck drivers in such places. The high disease prevalence in the district has resulted in a large number of children being orphaned and various sectors of the district's economy being devastated.

The other factors that have contributed to the high HIV and AIDS prevalence rates in the district included the migrant labourers commonly known as cane-cutters, who go to the district every year to work on sugarcane plantations, and the large number of casual farm workers from different parts of the district and province. The number of casual workers appears to be growing due to the increasingly high poverty levels in the district and the rest of the province. The opening of the Munali Nickel Mine, which attracted people from other parts of the country and all over the world into the district, has also contributed to the high incidence of HIV and AIDS in the district. The large number of people from Chivuna going into and out of Mazabuka Town, where the HIV prevalence is high, make it possible and easier for the pandemic to spread in the study area.

Mazabuka District has 12 health centres, most of which are run by the government. The exception are two of which one is run by missionaries, in Chivuna Clinic and the by Zambia Sugar, a private company. All the health facilities in the district offer VCT services while ART is only provided at selected centres. As will be seen later in the report, that fact has implications on access to AIDS-related services for rural communities like the study area. The district also has two first-level hospitals, namely the government-run Mazabuka District Hospital and run Salvation Army-run Chikankata Mission Hospital. Both hospitals offer VCT and ART services. The District AIDS Task Force (DATF) co-ordinates all HIV and AIDS-related activities in the district through the HIV and AIDS Focal Point Person. The district also has a chapter of the Network of People Living with HIV and AIDS (NZP+) and a number of PLHA groups.

Being a first-level hospital, Mazabuka District Hospital is a referral centre for all health centres and posts in the district. At the time of the study, a plan to turn the institution into a second-level hospital was announced by the Minster of Health. If that happens, the hospital will have specialised departments and, thus, become a referral site for first-level health facilities in the province. At the time of the study, the district hospital had a CD4 count machine and a chemistry analyser, which makes it possible for all sorts of tests, including liver and kidney functioning tests, to be done. Nearly all the health facilities in the district, including Chivuna Mission Rural Health Centre, depended on this equipment. That resulted in too much pressure on the equipment and their consequent frequent breakdowns. That situation, as will be seen in Chapter 4, often contributed to delays in conducting tests, people getting their results and the uptake of ART. Among the HIV and AIDS-related services offered by the hospital were VCT, ART and PMTCT services. The hospital also conducted outreach and mobile services for Mother and Child Health (MCH) and VCT services, sometimes to areas over 50 km away, amid limited financial resources and staff. The hospital also has tuberculosis (TB) and youth-friendly corners.

3.3.2 Chivuna Community

Chivuna community is located in Chief Hanjalika’s area approximately 68 km South-east of Mazabuka Town and 45 km from the main road. It extends over an area of approximately 34 km^2 and is interspaced with hills. The Chivuna Hills on the eastern side are about 1,425 m above sea level. The area is drained by several seasonal streams, most of which lack well maintained bridges. The road network in the area is also very poor, making most parts of the area inaccessible, particularly during the rainy season. The poor state of roads has an implication on the access to health care because most private transporters do not want to travel on bad roads to avoid wear and tear for their vehicles leaving walking to health facilities the only option, including the very sick people. The poor roads, hilly terrain and many unbridged streams have had a negative impact on access to HIV and AIDS treatment and care services because they make it difficult for people to access the points of service or for care-givers to reach their clients. The poor road infrastructure has also had a negative effect on agricultural production, as it hinders the effective distribution of inputs and marketing of produce. In turn, that has reduced the income-earning ability of the people and contributed to the high poverty levels in the area. The seasonal nature of the streams and the animal diseases have implications for the availability of the animal protein that is very important to ART clients.

According to the 2000 National Census, Chivuna had a population of 17,702 while projections indicated that the population would grow to 26,000 and 34,000, by 2020 and 2030, respectively. The main ethnic group in Chivuna are the matrilineal and patrilocal Tongas (Colson, 1962; Chuulu-Bbuku *et al.,* 2001). The traditional administrative establishment divides the area into sixteen zones, which are, in turn, further divided into smaller units called *minzi* (villages). Each *munzi* (village) is headed by a *Sibbuku* (village headman).

Like other Tonga people in the Southern Province, the people of Chivuna are a cattle-rearing group and cattle play an important role in their life as a source of milk, meat and draught power for agricultural production. However, like it has happened in the rest of the province, the numbers of cattle in the area have been decimated by persistent cattle diseases. This has led to a loss of draught power and many people resorting to hoe cultivation, a very limiting farming system. As will be seen in latter chapters, the use of hoes in farming was a severe challenge to most community members, especially to those the sick or convalescent. The animal diseases have often spread to smaller livestock, such as poultry and, to a lesser extent, goats and pigs, thereby exacerbating the already high poverty levels. A number of people have also lost their animals through rampant animal rustling.

The liberalised crop marketing system is another factor contributing to high poverty levels in the area because it has exposed farmers to unscrupulous ‘briefcase’ businessmen who lure them into selling their agricultural produce at unprofitable prices.

All the factors identified in the study area make poverty pervasive there. At the time of the study, the estimated HIV and AIDS prevalence rate for the area was 18 per cent. One of the reasons for the high incidence of the disease was low condom use among casual sexual partners, which is partly attributable to the Roman Catholic Church’s strong opposition to the use of condoms and other contraceptives, and the fact that Roman Catholicism is the main religious influence in the area. Additionally, despite a ban by the area chief, isolated cases of some negative cultural practices like widow inheritance and sexual cleansing persist in some parts of the area. The high poverty levels in the area were also reported to contribute to the bad HIV and AIDS situation in the area because it had led many young women to indulge in illicit sexual behaviour in order to earn a living (transactional sex). The other factor was the large number of people going from Chivuna to Mazabuka and back using pickup vans every day, particularly during the harvest season. These vans took traders from Mazabuka and other parts of the country, where HIV prevalence rates were higher, to Chivuna.

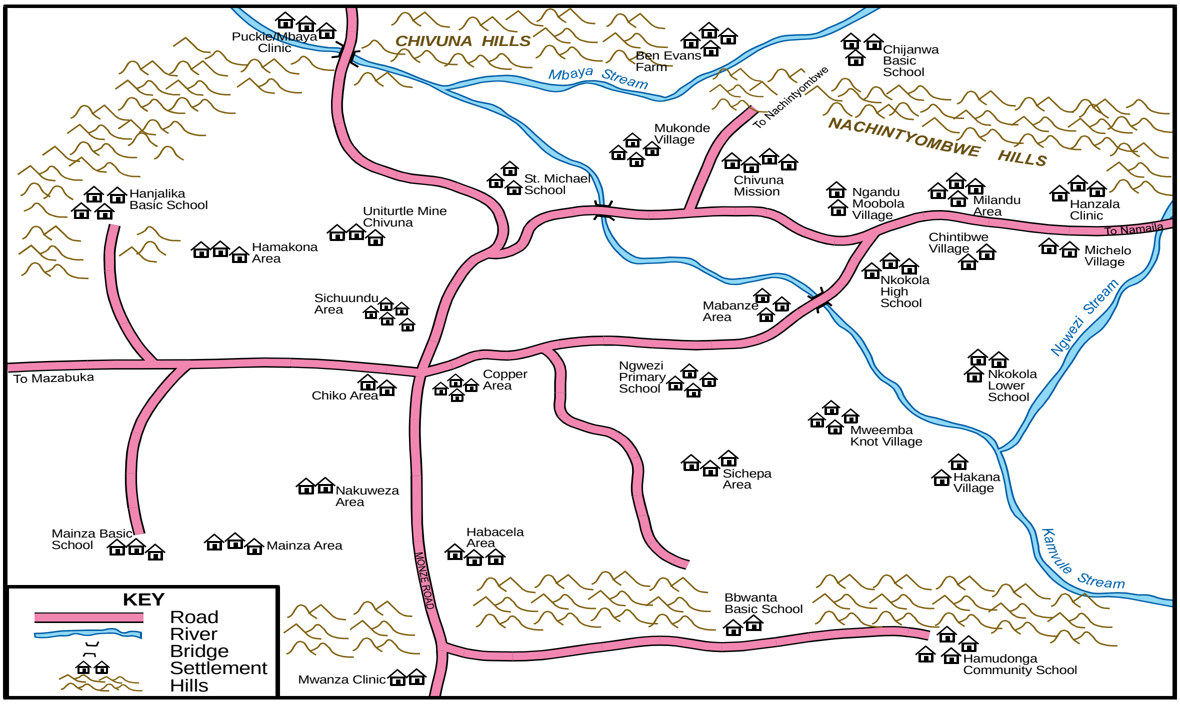
There were, at least, two active HIV and AIDS support groups in Chivuna, namely *Tuyumeyume*, meaning ‘let us be strong’, and *Tukulwaizyanye*, meaning ‘let us encourage one other’. The group memberships consisted of PLHIV, most of whom were women. The groups were involved in activities to raise money to support needy members with fares to the service centres. Some of the money was used to purchase food for those on ART. Support groups also provided members with general moral support and lessons on how to fight the side effects of ARVs. There was also a home-based care (HBC) programme run by the Chivuna Parish of the Roman Catholic Church, which provided basic support to households with bed-ridden patients.

The area has one high school, St Joseph’s Girls High School, five basic schools and a rural health facility. The local people also depend on Mbaya Musuma Rural Health Centre, which is commonly known as Puki and about 28 km away from Chivuna, for HIV and AIDS-related services. In subsequent chapters of this report, there is constant reference to the healthy facility.

The study area has a number of traditional health providers, that is, herbalists, diviners and witchdoctors, six of whom are within a radius of about 4 km from Chivuna Mission Rural Health Centre, which represents a ratio of about six traditional healers to one health facility. As stated already, the main religious influence is the Roman Catholic Church followed by the Seventh-day Adventist (SDA) Church and the Salvation Army.

The map below shows the physical features or topography of Chivuna. As can be seen, the heavily dominated by hills. The hilly terrain is a barrier to access to HIV and AIDS-related services.

Figure 3.1: Physical features of Chivuna



Source: Chivuna survey 2009-2011

3.3.3: Chivuna Mission Rural Health Centre

Chivuna Mission Health Centre was founded in 1951 by the Jesuit Priests (Chivuna Rural Health Centre Annual Report, 2011). Thereafter, it was handed over to a group of nuns, the Sisters of the Holy Spirit of Monze Diocese, who manage the twenty-two bed capacity health facility to this day. As earlier stated, the facility is in Mazabuka District. Therefore, it's administrative and referral centre is supposed to be Mazabuka District Hospital, which is approximately 68 km away. However, because it is a missionary facility and closer to Monze (45 km) than Mazabuka, the facility refers cases to Monze Mission Hospital. The facility is linked to both Mazabuka and Monze district hospitals by gravel roads, which are often impassable, particularly during the rainy season. Mazabuka District Hospital has also been mandated to service health facilities in Monze District closer to its town than Monze Town.

As a mission health facility, Chivuna falls in the category of Mission Hospitals and Clinics located in Rural and Poor Settings. Like other facilities in this category, its operations and interests are coordinated by the Churches Health Association of Zambia (CHAZ), which is also the biggest co-operating partner in the provision of HIV and AIDS-related services. The organisation compliments government efforts in the provision of AIDS medicines, funds and mobile VCT services. As will be seen in Chapter 4, mobile VCT services were preferred by community members for a number of reasons, among them reduced walking distances. Like most missionary entities, Chivuna Health Facility did not get much resources from the government but from CHAZ. CHAZ also runs a HBC programme and subsidies allowances for staff during community-based AIDS-related activities. However, as a Roman Catholic Mission, Chivuna Health Facility neither encouraged nor supported the use of artificial family planning methods, including condoms. That position had negative implications on HIV prevention efforts. CHAZ also provided a 4x4 vehicle and money for fuel specifically for the ART clinic, and nutritional supplements to the facility for people on ART. Food supplementation was identified as an important factor affecting entry and retention on the CoC. At the beginning of the study, support for nutritional supplementation was provided by the World Food Programme (WFP) through Programme Urban Self-Help (PUSH). CHAZ also supplemented government's efforts in the provision of testing reagents, which facilitated access to HIV and AIDS-related treatment and care.

The health facility also worked very closely with Development Aid from People to People (DAPP) through the Total Control of the Epidemic (TCE), a Dutch-funded community-based organisation (CBO). The programme carried out community-based HIV testing through door-to-door voluntary counselling and testing (DDVCT), a strategy even more preferred by the community. By the end of 2010, TCE had carried out more than 900 community-based tests.

Services being provided by the health facility include Outpatient (OPD), Inpatient, Malaria Programmes, TB, Integrated Reproductive Health, Child Care, Environmental Health, and HIV and AIDS-related services including PMTCT, VCT, ART and Home- Based care. The centre has been offering VCT since 2006 and ART services since 2008. By the end of 2011, 1,103 people had been tested and about 784 comprising 489 and 295 women and men respectively were on ART. Out of the total number of people on ART, seventy-one were children below the age of fifteen years, an indication that mother-to-child transmissions were still taking place even when prevention from Mother-to-child (PMTCT) services were available in the area.

3.4 The Rationale for Choosing Chivuna as a Study Area

The study area was chosen for various reasons, one of which was its being a rural setting. This was important in determining how ART services, which were first initiated in the urban areas, had been rolled out in the rural setting. Additionally, the provision of quality health services is generally more challenging in a rural setting than in an urban one. Further, there is evidence to the effect that poverty levels are much higher in rural areas than in urban ones. For Mazabuka District, the estimates are 74 per cent and 55 per cent for overall and extreme poverty, respectively (CSO *et al*., 2006:40). Further, although Chivuna is predominantly a rural setting, it has an influx of traders from Mazabuka urban and other parts of the country, where the pandemic's prevalence rates were higher. That put the residents at a high risk of exposure to HIV infections. Additionally, the mission context of the facility was beneficial to an understanding of the influence and role of the missionaries in complimenting government efforts in promoting access to VCT and ART services. The last factor in the choice of Chivuna as the research area was the researcher's competence in Tonga, the language of the area, and familiarity with the cultural context, which allowed for easy and smooth communication with subjects and contextualisation of cultural phenomena. This was important to the success of the data collection process.

3.5 Sampling Procedure

For the qualitative study, there was a need to identify specific members of the population with specific information of value to the study. With that in mind, a purposive strategy was used to recruit participants. Those selected included key informants like community leaders, traditional healers, leaders of non-governmental organisations (NGOs) and community based organisations (CBOs). Thereafter, the snowball technique, in which the study participants located first were able to identify the next study participants with characteristics desired for the study, was used. Through this procedure, it was also possible to identify participants like PLHIV, ART users and care-givers who, in turn, identified their counterparts. The entry and selection point for the users of VCT and ART services, and care-givers was the ART clinic. Ethical issues were considered at that stage (see sub-section 3.12).

At the health facility level, exit interviews (after purposive selection) were administered on participants as they were leaving the ART clinic after seeking health services. Some of the interviews were also carried out as the users arrived at the clinic. The respondents were selected provided they were youths aged between 18 and 24 years or adults above 25 years and living in the study area. All participation was absolutely voluntary. For the qualitative data, youths aged between 15 and 24 years were also included.

For the quantitative community sampling, a multi-stage approach was used to identify communities and respondents at the household level. Stratified random sampling was used to select communities to be included in the study, classified on the basis of proximity or remoteness to or from the health facility. That was for the purpose of comparing responses. Five communities were selected. Interval systematic random sampling was then used to select 393 households from a list. The probability proportionate to size sampling strategy (PPS) was employed in selecting the sample size for each community. Simple random sampling was, then, employed in selecting the study participants in cases where more than one eligible person was found in a household. Where only one person was eligible, that person was targeted for the interview. Where no eligible person was present at home, appointments were made for interviews to be conducted later. At the health facility level, purposive sampling was the overarching strategy for identification of the samples. Thereafter, randomisation was applied. Two hundred and sixty (260) respondents were selected at the health facility level, taking the number of interviewees to 653.

For the qualitative data, 67 in-depth individual interviews, 24 ten (10-member) focus group discussions and 19 key-informant interviews were conducted.

3.6 Data Collection Instruments and Data Sources

Several data collection instruments were used in this study. This was for the purpose of triangulation, and ensuring validity and reliability of data. This sub-section details the different research instruments used and the rationale for their use.

3.6.1 Qualitative Data Collection Instruments

The collection of qualitative data started on the 22nd September, 2009, and ended in April, 2011. For that purpose, several structured interview guides (checklists) and tape recorders were used. The interview guides and checklists included those targeting key informants (KIs) from the health facility, heads of NGOs operating in the study area and community leaders. Check lists also included those for in-depth interviews (IDI) with community members, ART clients, different categories of focus group discussions (FGDs) and observations. All the interview guides and checklists incorporated the different levels identified in the SEM, such as the health facility, structural, community and individual levels, and the medication level additional added by the researcher. Noting that qualitative research did not approach field work like positivists did (Blaikie, 2000), by teasing out the main constructs from the conceptual and construct questions, this study adopted Husserl's phenomenological approach, an approach in which the researcher brackets experiences, what the literature says and all theories (Husserl, 1962; Smith and McIntyre, 1982). In essence, the approach allows the researcher to get into the field with an open mind like a *tabular rasa*, which paved the way for the construction of interview and FGD questions without the variables in the model.

3.6.1.1 Focus Group Discussions (FGDs)

The focus group discussions (FGDs) solicited for people's views on and perceptions of the factors affecting ART access, uptake and adherence at both the health facility and community level. The FGDs have the advantage of enabling the investigation of a specific topic (Kombo and Tromp, 2006). They are guided discussions and address a topic relevant to the study (Berg, 2001). Hence, they can be used as tools for follow-up and verification on a number of issues. Their advantage over individual interviews is that they provide a greater breadth of ideas, opinions and experiences (Bbuku-Chulu *et al.,* 1988). They were also ideal for collection of information on experiences of PLHA (Shezongo-Macmillan *et al.,* 2007) and possible interventions to improve HIV and AIDS-related treatment and care. As the subject of sex is sensitive, this method was also chosen for its group anonymity factor. It was felt that study participants would be less inhibited in a group setting than in an individual interview (Shezongo-Macmillan *et al.,* 2007; Bryman, 2012).

Another reason for using the FGD technique was the fact that it enabled the collection of a diversity of views and more critical analysis of issues (Bbuku-Chulu *et al.*, 1988). In other words, FGDs can generate a lot of information quickly and are good for identifying and exploring beliefs, ideas or opinions in a community (Kombo and Tromp, 2006:95). In this way, they are less costly and less time-consuming.

In this study, the participants were segregated according to age and sex into 10-member groups. The youth discussion groups were not sex-segregated because young people tend to interact more freely across the sex divide compared with the older generations. So, the sex mix benefitted the discussions rather than disadvantaging them. Among older men and women, it might be a challenge to have a cross-sex group discussion due to entrenched cultural norms. For example, men would dominate the discussions, as breadwinners. Additionally, elderly members of society are more inhibited in speaking about personal and sensitive issues like sexuality than the younger generation. However, a few of the discussions groups were deliberately mixed to allow for the expression of a diversity of views, perceptions and opinions from both sexes in a single group. The face-to-face arguments, accusations, challenges and, at times, clarifications that were made in such groups were all helpful in the verification of data. In that way, the quality of data was augmented (Patton, 2002) and the researcher was able to experience the power dynamics between men and women in the community. All the focused group discussions were facilitated by the principal researcher while two assistant researchers took notes. When permission was granted, the discussions were also tape-recorded, which greatly minimised the possibility of missing any data. The distribution of the FGDs was as indicated in Table 3.1.

Table 3.1: Distribution of Focus Group Discussions

Category	**Clinic based**	**Community based**	**Total**
Young girls and boys aged 15-24	-	5	**5**
Adult males 25 years and above	2	6	**8**
Adult females 25 years and above	2	5	**7**
Mixed adult men and women	2	-	**2**
Support groups mixed adults above 24 years	-	2	**2**
TOTAL	**6**	**18**	**24**

Source: Field work, Chivuna Study 2009-2011

Although FDGs have the advantages already referred to above, they are held in artificial settings because they consist of individuals who may not have interacted outside the context of the arranged meetings (Nkweto, 2011). In addition, the outcomes may be superficial because the facilitator can control the meeting, alter the pace or direction of discussions, or interrupt or stop conversations. The conversations are also not truly natural, as they are stimulated (Nkweto, 2011:55). Conversely, it is, at times, difficult to control some of the participants who tend to hijack discussions while the shy or timid ones speak very little, which might elevate the views of a few individuals above those of the other members of the group, thereby compromising the quality of the data. Additionally, despite the group anonymity factor, some people still feel uncomfortable to discuss sensitive personal issues like sexuality in public. Twenty-four (24) FGDs were facilitated in this study.

The demerits of methods justify the use of other methods because, as Mushaukwa (2011:45) notes, “The advantage of additional data collection methods is that any gap that may have been left by one method will be quickly filled up by another." Therefore, in this study, another method, in-depth interviews, was employed.

3.6.1.2 In-Depth Individual Interviews (IDIs)

These were interviews targeting purposively recruited ordinary community members who included people on ART and their care-givers and PLHIIV who were not on any HIV and AIDS medication.

The advantage of using in-depth interviews (IDIs) is that they enable the researcher to investigate issues or events in-depth and in detail (Orodho and Kombo, 2002 cited in Kombo and Tromp, 2006: 10). They also help the researcher to obtain both specific and general information, and gain a range of insights on specific issues (Corbetta, 2003). In this way, the researcher gets a complete and detailed understanding of the issues under investigation (Kombo and Tromp, 2006). In this study, the method enabled the researcher to get as much narratives as possible because it allowed the interviewees to tell their stories in their preferred order and words (Bbuku- Chulu *et al.,* 1988).

Through the narratives, it was possible to get people's views on the episodes of the illness. The researcher was also able to gain a deeper understanding of the contexts and situations in which treatment-seeking behaviour took place, and had an opportunity to share her understanding of the different issues and check it against the perspectives of the subjects. In-depth interviews were, therefore, used to conduct a more detailed investigation of PLHIV's unique personal experiences of living with the disease, uptake of VCT and ART, and adherence to treatment *vis-à-vis* the barriers and facilitators. Most of the information on personal experiences solicited in the IDIs would be difficult to solicit in FGDs.

The researcher made an effort to ensure representation of both sexes. However, that was a challenge because, generally, women were more available, open and willing to be interviewed. Sixty-seven (67) people were interviewed in this study, as shown in Table 3.6.1.2.

Table 3.2 Distribution of in-depth Interviews

Category	**Community Based**	**Clinic Based**	**Total**
Male and female users aged from 15 years	46	15	61
Care givers	2	4	6
TOTAL	**48**	**19**	**67**

Source: Fieldwork Chivuna study, 2009-2011

Much as IDIs generate in-depth and detailed information and presents the issues under study from enriched perspectives, they also have some weaknesses. As stated by Kombo and Tromp (2006), some of the weaknesses emanate from the fact that respondents are supposed to be allowed to narrate their life histories without much interruption. In this way, they may provide too much irrelevant and too little useful information. Additionally, the respondents may become emotional, repetitive or take too much time talking about one thing, thereby wasting time (Kombo and Tromp, 2006). Such demerits can only be compensated for by the use of other methods of data collection. In this study, key informant interviews were also conducted.

3.6.1.3 Key Informant Interviews

Key informants are people whose special positions in the community give them access to information not be readily available to the other community members (Bbuku-Chulu *et al.*, 1988). In this study, they were selected purposively (see Sub-Section 3.5) from among people who occupied certain positions within the community, those involved in the HIV and AIDS fight at the community and health facility levels. They included traditional healers, traditional leaders (chiefs and village headmen), church leaders, ART clinic workers and managers of NGOs and CBOs doing AIDS-related work. Of the nineteen key informants selected, three were traditional leaders, three were traditional health practitioners, two were church leaders, three were managers of NGOs and eight were health care providers (see Table 3.6.1.3.

Table 3.3: Key Informants

Traditional Leaders	Traditional Healers	Church Leaders	Managers of NGOs	Health Care Providers	Total
3	3	2	3	8	19

Source: Fieldwork Chivuna study, 2009-2011

In the three methods so far discussed, the researcher relied on information provided by respondents. To authenticate the responses, the researcher had to adopt the role of an observer.

3.6.1.4 Participant and Non-Observations

These observations were carried out at both the rural health facility and in community and focused on determining how well the health facility was equipped with HIV and AIDS prevention materials, basic, but essential equipment like blood pressure machines, scales and thermometers, and treatment guides. The availability of medicines; storage and administration of medicines; and patient-health care provider and patient-patient interactions and relationships were also observed. The observations also focused on routine follow-up of patients on ART, health education and counselling sessions, including the counselling environment (privacy, conduciveness, adequacy of space for all the different activities at the ART clinic, attitude of health care providers and time taken for each counselling session). The times the workers reported for work and closing times for the ART clinic were also observed. At the community level, headmen's courts and the daily activities of the people were observed.

This method was chosen because it helps a researcher to have an *emic* Pike (1966) or insider's perspective of issues under investigation instead of entirely depending on information provided by respondents. It is, therefore, an important method for triangulation and validation of information collected using other methods. The researcher was also actively involved in the daily life of the community under study and was, therefore, able to examine the different dimensions of living in the community. The researcher was also able to understand why people behaved the way they did, making it possible for her to understand the meanings that people attached to their own actions, which either motivated or demotivated them from making certain decisions like deciding to go for an HIV test, start taking ARVs and/or to adhere to treatment. For instance, by participating in community events like funerals, it was possible for the researcher to understand the beliefs that contributed to delays in the uptake of VCT and ART, and hindered adherence. Through interactions with some women in the area, particularly those who had been divorced for seeking AIDS-related services against their husbands' consent, the researcher was also able to understand the fears that prevented women from seeking such services. Additionally, the extended periods of interaction with study participants allowed observation of participants in natural settings, which reduced the incidence of what Payne *et al* (2004) referred to as the Hawthorne Effect or reactivity, that is, the chances of people acting in a particular way when aware that they were being observed was minimised because it is difficult for people to continue altering their natural behaviour when being observed for a long period. The language competence of the principal researcher, a Tonga, and the whole study team was a great advantage especially in this method, but also in the other methods generally because it allowed for easy communication. Having gone to school in the study area for five years and worked there in a similar study for six months, the principal researcher had a lot of knowledge about the area, which enabled her to contextualize the familiar cultural aspects.

Observations at the household level helped the researcher to better understand the contexts in which everyday decisions were made. They provided an understanding of intra-household power relations and dynamics and division of labour, and how these affected decision-making in relation to health-seeking behaviour at the household level. The researcher observed study participants as they engaged in their everyday activities like cooking, washing, drawing water, collecting firewood and preparing meals. Patterns of waking up, retiring to bed and eating in the household were also observed too. Before any household was put on the observation list, the permission of the head of the household was obtained by the researcher. The observations were made over a period of 18 months and a diary was kept in which all the field observations, personal reflections and perceptions of the different situations observed, and informal conservations were recorded. All the observations were done by the principal investigator.

Participant observation is not without weaknesses. Among its notable weaknesses is the possibility of study participants altering their natural behaviour upon realising they are being observed (Payne *et al*., 2004). That was possible in this study, particularly at the beginning, as the researcher went into the study area openly as a researcher. However, as already mentioned, this possibility was minimised by the extend duration of the observation. Conversely, the researcher’s extended stay among the subjects, as stated by Nkweto (2011), inevitably made her more of a sympathetic and, therefore, biased and subjective, member of the community, thereby compromising her chances of remaining an objective researcher. These weaknesses in this method necessitated the use of other methods, including those already discussed.

3.6.1.5 Tape Recording

After getting informed consent and permission, interviews were tape recorded. This method was important in capturing the responses verbatim. To avoid loss of any data, the tapes were transcribed immediately after each interview and translated from Tonga into English. For further triangulation, social mapping was also used.

3.6.1.6 Social Mapping

A social mapping exercise was conducted with local community members consisting of five males and five females of all age categories. This exercise was intended to provide an idea of what the people considered the main physical features of their community and how those may impede or facilitate the uptake of HIV and AIDS-related services. The map also showed places that were perceived to be high-risk places for HIV infections. Prominent among the features were the main roads, bus stations, drinking and shopping places, streams, hills, places of worship, water points, schools and the health facility (see social map in Chapter 5).

3.6.1.7 Document Reviews

In this process, the principal researcher participated in a systematic review of ethnographic studies on barriers and drivers of adherence to ART in various cultural settings in Sub-Saharan Africa. The review led to a publication of a Meta-Ethnography titled, *Patient-Reported Barriers and Drivers of Adherence to ART in Sub-Saharan Africa*.

3.6.1.8 Other Sources of Qualitative Data

The other sources of qualitative data included television, newspapers, community radio stations, informal observations and discussions with community members. A camera was also used to take photographs of less sensitive materials, such as the road network, modes of transport and buildings. In addition to qualitative data, quantitative data was also collected.

3.7 Quantitative Data

Survey data collection was done between September, 2010, and February, 2011, using questionnaire. The questionnaire was chosen because it could be presented to each respondent in exactly the same way to minimise the role and influence of the interviewer. Its use also enhanced objectivity, reliability and validity of findings and conclusions (Ndhlovu, 2010).

After the qualitative data was collected, it was subjected to preliminary analysis for identification of major emerging themes, which were, then, compiled and used by the research in developing a well-informed questionnaire. This means that the questionnaire was based on the respondents', not the researcher's, perspectives and experiences of the factors influencing the uptake of VCT and ART, and adherence to treatment and these were further investigated in the survey. In a way, as stated by Mills *et al* (2006), this avoids biasing the investigation with *a priori* assumptions about what factors may be important to a particular issue in a given population.

Starting with a qualitative research allowed the local people to tell the researcher what they believed to be important factors, rather than the reverse. Using questions developed in economically or culturally foreseeably different settings causes surveyors to force respondents to answer potentially irreverent questions (Mills *et al.*, 2006). The local people's perspective of the factors, however, reflected the socio-economic and cultural conditions of the study area. The knowledge gained thereby would be essential to the development of culturally appropriate and effective interventions that, in turn, were more likely to lead to successful and sustained programmes (Vervoot *et al*., 2007 and Sasaki *et al.*, 2012).

3.8 Selection and Training of Data Collectors

Prior to the field work, workshops were conducted for the assistant researchers. For the qualitative study, two Tonga-speaking residents of the area, one male and one female, were recruited and trained as data collectors for four days. For the quantitative study, a seven-day workshop was organised for eleven Tonga-speaking data collectors in August, 2010. These data collectors had participated in several earlier health surveys conducted by the Ministry of Health (MoH) and Central Statistical Office (CSO).

3.9 Pilot Study

A pilot study is a small-scale replica and a rehearsal of the main study and is meant to identify any administrative and organisational challenges to the main study and respondents (Sarantakos, 1993). It helps to test the effectiveness, appropriateness, reliability and validity of the data collection instruments (Bbuku- Chulu *et al.*, 1988). The pilot study is conduct in a setting similar to that of the actual study. In this this study, two pilot studies were conducted to test both the qualitative and quantitative research instruments. The studies also assisted in the refining of the main research plan in terms of the personnel, finance and time frame. They also helped to acquaint the data collectors with the conditions in the study area, which was necessary to their preparation for the main study. The data collected during the pilot study was analysed and the lessons learnt were documented, and used to further modify and refine the data collection instruments. Additionally, the sharing of experiences also helped in clarifying some issues in the questionnaire and other research instruments.

3.10 Data Collection Process

Before commencing the field work, permission was obtained from the Permanent Secretary, Ministry of Health. Permission was also obtained from the district and local leaders, both the political and traditional ones. In addition, an initial two-day visit was made to the study site by the principal researcher for initial introductions to and familiarisation with the community leaders, who included the area chief, and to secure accommodation.

Except for those involving health care providers and managers of NGOs, all the interviews were conducted in Tonga. Further, all FGDs were facilitated by the principal researcher with the help of two trained research assistants. The appointments for FGDs and IDIs were made with study participants a few days in advance. That was done to minimise inconveniences to the participants, especially given the fact that some of the interviews were conducted during the peak of the rainy season when most of the people were busy working in their fields. The questionnaire was administered by the eleven trained research assistants under close supervision of the principal researcher.

3.11 Data Analysis

Data analysis is the examination of collected information and making of inferences (Kombo and Tromp, 2006). All the data collected using qualitative techniques were analysed using qualitative approaches. The recordings of all interviews, FGDs and IDIs were, firstly, transcribed verbatim and, secondly, translated into English from the local language. The interview transcripts were, thereafter, processed according to thematic fields using ATLASTI Version 6 software. The data were grouped into the four major themes of the study, namely VCT, linkage to care, ART uptake and adherence. Like in the case of Roura *et al* (2009), the social-ecological framework was used as a further guide for classifying the data into the five broad categories of ‘individual’, ‘health system’, ‘medication’, ‘social’ and ‘structural’ factors. After that, a detailed thematic content analysis and coding was conducted for identification of themes and sub-themes. The codes were, then, compared for similarities and differences and, thereafter, grouped into sub-categories of similar codes. That process involved reading and re-reading the text to highlight key quotes and indicate emerging themes. To enhance the quality of that analysis, the principal researcher had been trained for two days in the use of ATLASTI. As is usually the case with qualitative data, collection and analysis were done simultaneously. For example, every day, the researcher went through that day’s interviews to identify any gaps in the data that would require filling up or clarification.

The observational notes were manually analysed to identify broad themes that best captured the study setting and described the livelihoods and treatment experiences of PLHA. The observations also helped in the triangulation of the data collected using other techniques, such as IDIs.

Quantitative data were analysed using descriptive statistics at the univariate and bivariate levels. Frequency listings were obtained to determine the counts and proportions of selected variables and cross-tabulations were done to ascertain associations between variables. The extent of the associations among variables was measured using Chi-square. The Statistical Package for Social Sciences (SPSS) was used to process and analyse the data. Only selected factors relating to barriers and facilitators under each stage and those permeating the stages were selected for analysis.

3.12 Reliability and Validity

Research reliability is basically concerned with the extent to which the results of a study will be consistent if replicated by another researcher under similar conditions (Yin, 2003). To ensure that the data collected was reliable, there was a deliberate effort to cross-check and compare data from different sources using multiple methods of data collection. The reliability of the data was further enhanced by respondent validation or verification of results with the respondents.

While reliability is about consistency in measurement, validity is about the degree to which the research methods and tools used correctly measures what they are intended to measure (Nkhata, 1997). It is also the degree of accuracy with which the findings of a study represent the studied phenomenon, such as the views of respondents (Ndhlovu, 2010). Much as it is not possible to attain perfect validity in social research, in this study, some measures were put in place to minimise enhance validity. For example, where a factor was seen to be behind some identified phenomenon, an effort was made to eliminate all other possibilities of causation. Further, to reduce the threat of other events taking place at the same time or “history”, the study was conducted within a specified 18-month period. Additionally, results from one group of respondents were compared and cross-checked with other sources using different instruments for verification and validation purposes. This process continued until a saturation point was reached. As stated by Yin (2003), triangulation removes inconsistencies, thereby making data valid and reliable. Payne and others (2004) note that the more extensive the triangulation, the more confident people can be about the findings. To further enhance the quality of qualitative data, a deliberate effort was made to ensure as much representativeness as possible by interviewing, in addition to people who lived near the health facility, those from communities, at least, 20 km away from the facility in all the four directions.

Maturation, that is, the normal process of change to which all human beings are subject in the course of their developmental process, including the natural process of growing up of the people being studied (Nkhata, 1997), was minimised by not prolonging the research period beyond one and half years. In the same vein, experimental mortality did not arise because this study was not a longitudinal one with special cases that needed tracking over a long period of time. Indeed, respondents died during the study, but those were not unique cases needing follow ups.

To enhance the representativeness of the sample, the study employed a multi-staged randomised sampling technique, starting with the community, moving to the households and ending with the individual respondents. That was done to minimise selection bias.

There is another kind of validity called external validity, which refers to the degree to which the findings of a study can be generalised to other settings in the real world in processes similar to the adopted investigation process (Nkhata, 1997). It has to do with the 'generalisability' of the findings. So, external validity is the extent to which results from a study can be generalised beyond a particular study or respondents (de Vaus, 2001 and Corbeta, 2003). However, because the present study was localised, its findings can only be generalised to similar settings with similar characteristics.

Other mechanisms put in place to enhance data quality included use of trained, experienced and highly competent Tonga-speaking data collectors, a number of whom had participated in earlier national studies; pre-testing of all data collection instruments; and translation of the questionnaire and background information into Tonga.

3.13 Ethical Considerations

As a general principle, the right to knowledge must be balanced against the rights to personal and community integrity and privacy. This need for balance places limits on where, when and how research can be conducted, although the main areas of concern vary from one type of research to another (Peil, 1982:18). Considering the fact that the topic under investigation was a sensitive one, there was a greater need to abide by the necessary ethical requirements. As a component of a bigger research project, the study was first approved by the Ethics Committee of the State of Basel (EKSB) and, later, by the University of Zambia Humanities and Social Sciences Research Ethics Committee. Clearance was also obtained from the Ministry of Health, at national and district levels. Further, before commencing actual field work, permission was sought from the local political and traditional leadership in the area.

In social science research, because of its nature, ethical issues arise in many ways, such as in conducting the research, gaining access to information, getting co-operation from participants, ensuring that the after-effects are not damaging to study participants and the use of data collected (Peil, 1982:18). Therefore, at the individual level, further ethical considerations were made. As clearly stated by Homan (1991 cited in de Vaus, 2001:83), regardless of the research design, social research should conform to four broad principles, namely informed consent, voluntary participation, no harm to participants, and anonymity and confidentiality.

3.13.1 Voluntary Participation

From the start of the interviews, participants were informed that their participation in the study was entirely voluntary. They were also informed that they had the right to withdraw from the interview at any time and that they were not obliged to answer any question would that would make them feel uncomfortable in any way. Additionally, the study participants were assured that their withdrawal from the study would not jeopardise their relationship with health care staff or use of the health facility in future. Further, they were informed that they were not to be paid for their participation in the study. All these assurances were necessary because, as clearly stated by de Vaus (2001), a well-established principle of social research is that people should never be led to believe that they are required to participate in a study.

After informing the study participants of their conditions of participation, there was also a need for them to be provided with adequate information about the study so that they could make an informed decision on whether or not to participate in the study.

3.13.2 Informed Consent

Informed consent is a “close cousin” of voluntary participation (de Vaus, 2001:84) because the two are interlinked and very interrelated. Consent, in research, demands that all participants be provided with information about the study, its purpose, how it will be carried out, and its direct risks and benefits to participants (Chilisa and Preece, 2005). Therefore, in the present study, all the participants were informed about the identity of the researcher, the sponsor and the participant selection process.

For all the individuals above 18 years who took part in the study, informed consent was obtained while assent was obtained for respondents below 18 years. The general purpose of informed consent was to ensure that the respondents’ decision to participate in the study was made from an informed perspective, voluntary and without undue expectations of reward. The need to uphold informed consent was stressed to all the data collectors, who were required to ensure that all potential study participants understood exactly what they would be signing up for if they decided to participate in the study and signed the consent form.

The procedure for obtaining informed consent was that the data collector explained to each potential participant the purpose of the study, its potential risks and benefits, duration of the interviews and how the data would be used. The data collectors were also required to explain to each potential respondent that their participation in the study was purely voluntary. Further, the respondents were informed that they had the right to stop the interview, refuse to answer any question that made them feel uncomfortable or completely withdraw from the interview at any time if they so wished. In this way, the important ethical concern for violation of privacy was addressed. Further, with adequate information about the study provided, there was no room for deception in the study.

Prior to their signing of the informed consent form, the potential participants were asked to repeat to the data collector what they understood about what they had been told about the research. That was done to ensure that each potential participant was aware of the contents of the consent form. If satisfied that the potential participant understood the implications of their proposed participation in the research and still chose to participate, the data collector asked the potential participant to sign the consent form. All the study participants who could not sign were made to stamp the forms with their thumb prints.

3.13.3 Confidentiality and Protection of Respondents

According to Winner and Domink (1994 cited in de Vaus, 2001), “The principle of confidentiality and respect for respondents is the most important ethical issue requiring compliance on the part of the researcher.” Maintenance of confidentiality for respondents is important, at least in part, for purposes of protecting potential respondents from any future adverse repercussion of their participation. As rightly stated by de Vaus (2001), failure to do so is an obvious way in which participants can be harmed because social research frequently entails the collection of personal information which, if made public, could be embarrassing, humiliating or cause harm to study subjects in one way or another. One way of complying with this important ethical requirement was to avoid the use of individuals’ names in the report and, where necessary, the use of pseudonyms. So, each participant was assured of confidentiality and anonymity. The participants were also assured that the research data would not be accessible to anybody outside the research team. To that effect, the data collectors were repeatedly cautioned that any of them who would divulge any information would be dismissed from the research team instantly. Additionally, the team was often reminded of the legal repercussions of failing to maintain the highest levels of confidentiality.

The protection of confidentiality in research is important not only for ethical reasons, but also for methodological ones because if potential participants have the assurance of confidentiality, they are likely to divulge even private and personal matters (de Vaus, 2001). The selected participants would also most likely give honest answers (de Vaus, 2001:86) if their confidentiality is assured. Peil (1982) writes that once confidentiality is maintained, potential harm to respondents is minimised

3.14 Limitations of the Study

This research was a case study conducted in a rural and peculiar mission setting. That makes the findings generalisable only to similar settings with similar characteristics. Further, for comparative purposes, it would have been desirable to conduct another study in another area, preferably in another province. However, this study was confined to one locality. It should be noted, however, that, as pointed out by Ritchie and Lewis (2012), localised studies are important because they generate contextualised and culturally appropriate localised interventions for the effective management of the research problem.

Although frantic efforts were made to ensure equal representation of both sexes in the sample, that could not be done because, generally, women were more available for interviews. For instance, while women were usually found at home during the interview period, some male participants with whom appointments had been made for them to be interviewed were away from home for extended periods.

Despite the study having the mentioned limitations, its findings were validated and found to be consistent with both the local and global literature on the subject.

3.15 Conclusion

This chapter discussed the methods employed in the study. For the purpose of ensuring data quality, multiple data collection instruments were utilised, among them FGDs, IDIs, observations and key informant interviews. Others were tape recorders, social mapping, and document analysis. For quantitative data, a questionnaire was used. The chapter also described the composition of the sample, the sampling procedure and how the data collected was analysed. The study’s handling of ethical issues has also been discussed.

CHAPTER FOUR
RESEARCH FINDINGS

4.1 Introduction

The findings are organised according to specific study objectives. Before presenting findings directly linked to the objectives however, findings on the socio-economic and demographic characteristics of the respondents are presented first. This was important because these findings would be useful in the presentation of findings related to the objectives. The chapter therefore, focuses on the following sub-headings: the socio-economic and Demographic Characteristics of respondents, available HIV and AIDS-related services in Chivuna, factors influencing the HIV and AIDS continuum of care and treatment at each stage and those that permeate through this continuum of care and treatment.

4.2 Socio-Economic and Demographic Characteristics of Respondents

The main characteristics considered in this study include sex, age, educational levels, and marital status, religion and livelihood sources. These variables were chosen because as shall be seen in later, some of these factors have some influence on entry into and retention in the HIV and AIDS continuum of care and treatment. The main sub-topics in this sub- section include the socio-economic and demographic characteristics of respondents who made up the qualitative and the quantitative sample.

4.2.1 Description of Respondents who Participated in the Qualitative Research

The qualitative sample had a mixed sample consisting of individual users of health care services, conventional health care providers, managers of HIV and AIDS related organisations, traditional healers and leaders. Table 4.1 gives a distribution of the characteristics of the respondents categorised as users and shows that a total of sixty-seven (67) individual interviews were conducted. Out of these, most of them, (60 percent) were women and the remainder twenty-seven (40 percent) were males. In terms of age, Table 4.1 further shows that a large number of individual users were between the ages of 25 to 49 (46 percent) followed by the ages of 50 to 69 and 70 to 80 years old, 24 percent and 16 percent respectively. The age group 15 to 24 had the smallest number of respondents, (14 percent). The data in the Table also indicates that the majority of the respondents were at the time of the interview married (72 percent) with 4 percent of the respondents having never been married before. Table 4.1 further shows that widowhood was quite high among respondents with 15 percent of the respondents having lost their spouses. This is followed by either divorced or separated (9 percent). Further perusal of data also revealed that women made up a larger number of those widowed (not in table). This is also observed in the quantitative data below.

Discussions with respondents revealed that there were a number of factors at play for the striking differences observed between men and women in terms of widowhood. One explanation given was that in this community, men tended to re-marry early after the demise of a spouse than women who usually had to wait for another man to approach them for marriage.

Further analysis of data presented in Table 4.1 shows that educational levels were quite low with more than half of the respondents, (57 percent) and fifteen (22 percent) being between primary level and no education, respectively. Only eleven, 16 percent and 5 percent of the respondents had attained secondary and tertiary education, respectively. Low educational levels as will be discussed later, were found to be one of the factors influencing the HIV and AIDS continuum of care and treatment.

Table 4.1 further shows that a larger proportion (46 percent) of respondents belonged to the Roman Catholic Church followed by 36 percent for Seventh-day Adventists (SDA). This was followed by 13 percent for Salvation Army while 5 percent represented other religious denominations. If SDA members, Salvation Army and other religious affiliations were to be grouped together as Protestants then, Protestants were more at 54 percent compared to 46 percent for Roman Catholic.

All the individual users were Tonga speaking and all of them involved in agricultural production as a source of livelihood. A few combined small businesses such as trading in beer with selling of groceries, running of grinding mills and selling of food stuffs at the market including the small market at the ART clinic. A few of them also combined farming with working either at the Mission School, or the health facility. A small number of the respondents also owned cattle while small livestock like chickens, goats and pigs were owned by nearly all the respondents. These were often sold for income. However, both agricultural and livestock production were reported to have been negatively affected by several factors.

Table 4.1: Socio-Economic and Demographic Characteristics of Respondents who participated in the Qualitative Study.

Background Characteristics	No	%
Age group		
15-24	09	14
25-49	31	46
50-69	16	24
Above 70	11	16
Total	**67**	**100**
Sex		
Male	27	40
Female	40	60
Total	67	100
Educational level		
No education	15	22
Primary	38	57
Secondary	11	16
Tertiary	03	5
Total	**67**	**100**
Marital status		
Married	48	72
Single	03	4
Divorced/separated	6	9
Widowed	10	15
Total	**67**	**100**
Religion		
Roman Catholic	31	46
SDA	24	36
Salvation Army	09	13
Other	03	5
Total	**67**	**100**

Source: Field work, Chivuna study 2009-2011

In terms of key informants eight were health care providers categorised as four males and four females. All the health care providers' interviewed had attained tertiary education. In addition, to their salaried jobs, two of the male health care providers also carried out farming on a large scale. More than half of the health care providers were Tonga. Those who were not Tonga had worked in the study area for over four years and were thus fluent in the local language.

Three traditional leaders and three traditional healers were also interviewed. Out of the three healers, only one was female. In terms of educational attainment, all of them had very low educational attainments with all three of them falling within the category of none and primary school level. Farming and charges raised from administering their medicines were their main sources of livelihood. All the traditional leaders were males and only one had attended tertiary education. The senior most traditional leader, i.e. .the chief was in addition to farming also on a monthly government salary. Three managers of NGOs and one CBO were also interviewed out of which two were males and one female. All of them had attained tertiary education.

As mentioned above in Chapter 3, the study also collected quantitative data. Hence, the next sub-section provides characteristics of study participants relating to the quantitative sample.

4.2.2 Description of Respondents who Participated in the Quantitative Research

As in the case with the qualitative sample above, key background characteristics i.e. sex, age, marital status, main source of livelihood were considered. Table 4.2 presents the distribution of all the key background characteristics of the respondents covered in the survey. Similar with the qualitative sample, the data shows that more than half of the respondents (58.2 per cent) were females with males representing 41.8 per cent. For women, largest proportion of the respondents fell in the age group 45 years and above (25.8 per cent) while that of the males was in the age group 35 to 39 (27.8per cent). On the overall, a high proportion of the respondents (25 per cent) fell in the age group 35 to 39 followed by 24.7 per cent in the age group 45 and above. The other age groups are represented by 13.8 per cent and 13.3 per cent for age group 30-34 and 20 to 24 years old respectively.

In terms of educational attainment, Table 4.2 shows that on the overall, the respondents had low educational attainment with more than 60 per cent falling within the category of no education and primary, 15 per cent and 63 per cent respectively. The table further shows that 20 per cent of the respondents had attained secondary while only 1.2 per cent had gone beyond secondary school. Further analysis of the table shows that compared with women, men had higher proportion of respondents with secondary education at 22.7 per cent and 18.7 per cent for men and women respectively. The trend is however, slightly different at tertiary level with females and males being represented by 1.3 and 1.1 per cent respectively.

Such low education levels as alluded to above and as will be seen later, had negative implications for adherence.

Table 4.2 further shows that more than half of the respondents (57.3per cent) were Protestants followed by Roman Catholic (42.7 per cent). Further analysis also shows that a large proportion of women (56.6 per cent) and men (58 per cent) were Protestants as compared to 41.8 per cent and 43.5 per cent Catholics for men and women, respectively.

In terms of marital status, the majority of the respondents (71 per cent) were married followed by widowed 13.5 per cent. The single and divorced and separated categories were each represented by 7.8 per cent. The data further shows a higher proportion of men being married than women, 80 and 64.5 per cent for men and women respectively. A different trend is observed when the other marital statuses are taken into consideration, with the biggest difference being in widowhood 17.4 per cent for women compared with 8.1 per cent for men. Further, the data show that 10 per cent of the female and 4.8 per cent of the male respondents were either divorced or separated. Further analysis of the table also shows that 7.3 per cent and 8.2 per cent of the men and women respectively, had never been married before.

Out of those married (not in the table) 72.8 per cent were in monogamous unions while the remainder 27.2 per cent were in polygamous relationships. When a comparison between sexes is made, the data in the table shows that the proportion of female respondents in polygynous unions were much higher than that of their male counterparts, 32.7 per cent, for females and 21.1 per cent for males. When residence at marriage is considered, over 83 per cent of the respondents settled with the relatives of the man with only 14.9 per cent and 1.9 per cent of the respondents settling with the wife’s relatives and in a new place respectively. This is a reflection of the typical patrilocal type of residence practiced in the study area. This means that generally, in the event of a marriage being irretrievable, women were more affected by the cost of losing relationships with the husband’s relatives and that of re-establishing their lost natal relationships.

Table 4.2: Socio-Economic and Demographic Characteristics of Respondents who participated in the Quantitative Research.

	SEX					
	Male		Female		Total	
	No	**%**	No	**%**	**No**	**%**
Age Group						
18-20	2	.7	8	2.1	10	1.5
21-24	39	14.3	48	12.6	87	13.3
25-29	33	12.1	46	12.1	79	12.1
30-34	33	12.1	57	15.0	90	13.8
35-39	76	27.8	87	22.9	163	25.0
40-44	27	9.9	36	9.5	53	9.6
45+	63	23.1	98	25.8	161	24.7
Total	**273**	**100**	**380**	**100**	**653**	**100**
Education						
None	28	10.3	70	18.4	98	15
Primary	180	65.9	234	61.6	414	63.4
Secondary	62	22.7	71	18.7	133	20.4
Tertiary	3	1.1	5	1.3	8	1.2
Total	**273**	**100**	**380**	**100**	**653**	**100**
Marital Status						
Married	218	79.9	245	64.5	463	70.9
Single	20	7.3	31	8.2	51	7.8
Divorced/Separated	13	4.8	38	10.0	51	7.8
Widowed	22	8.1	66	17.4	88	13.5
Total	**273**	**100**	**380**	**100**	**653**	**100**
Religion						
Catholic	114	41.8	165	43.4	279	42.7
Protestant	159	58.2	215	56.6	374	57.3
Total	**273**	**100**	**380**	**100**	**653**	**100**

Source: Field work Chivuna Survey 2009-2011

An assessment of respondents' sources of livelihood was also made. Data pertaining to this are presented in Table 4.3. Respondents were asked a number of questions to elicit the main economic activity or income generating activity of the head of household at the time of the survey. The Table shows the percentage distribution of respondents according to current main source of livelihood. Farming is the most common economic activity with a distribution of more than 42.4 per cent farming with and without cattle put together (33.4 per cent and 9.0 per cent respectively). As seen in Chapter 1 farming had been threatened due to many factors and thus rendering most of the people poor. This is as shall be seen later in this chapter had negative implications on access to HIV and AIDS related services.

Farming is followed by piece work 13.3 per cent. The table shows that 6.6 per cent of the respondents were self-employed. Unskilled permanent and skilled permanent employees had a per cent age proportion of 4.7 per cent and 2.9 per cent respectively. The proportion for housework or unpaid was 21 per cent and was the domain of women. The least proportion was for those studying with 0.2 per cent.

The data shows that there were some respondents who were skilled and permanently employed in the sample. This can be explained by the fact that one of the randomly selected communities also covered the residential area for both the high school and health facility employees and hence this outcome. The unskilled permanently employed were mainly community members working either at the health facility or the high school as classified daily employees (CDEs).

Table 4.3: Source of Livelihood for Respondents of the Quantitative Research

Livelihood source	**Male**		**Female**		**Total**	
	No	%	No	%	No	%
Permanent skilled	12	1.8	7	1.1	19	2.9
Permanent unskilled	21	3.2	10	1.5	31	4.7
Piece work	48	7.2	39	6.0	87	13.3
Farming with no cattle	17	2.6	42	6.4	59	9.0
Farming with cattle	137	21.0	81	12.4	218	33.4
Fishing	1	.2	0	0.0	1	.2
Self employed	7	2.6	36	9.5	43	6.6
Unemployed	14	5.1	27	7.1	41	6.3
House work	-	-	137	36.1	137	21.0
Studying	1	4	0	0.0	1	.2
Retired	15	5.5	1	.3	16	2.5
Total	**278**	**41.0**	**380**	**58.2**	**653**	**100**

Source: Field work Chivuna survey 2009-2011

4.3 Prevailing HIV and AIDS-related Services in Chivuna

In relation to objective one which was to examine available HIV and AIDS related services in Chivuna, this sub-section addressed questions such as: what services were offered and where were they located, when were they administered, who was in charge of the administration and under what conditions. Focus is also on the infrastructure, staffing levels, training of those who are supposed to administer ARVs, the availability of essential drugs, reagents and equipment such as CD4 count and liver functioning machine. The examination was done in comparison with the WHO minimum standards for the provision of HIV and AIDS services. This investigation was necessary because partial social and health ethnographers tend to profile the setting at the outset to show what structures of the services are before they get the people's experiences. This is done with a view to triangulate findings.

4.3.1 VCT and ART Services Provided

Chivuna Rural Health Facility offers both VCT and ART services. The facility has been providing VCT and ART services since 2006 and 2008 respectively. These services were provided three times per week on Mondays and Thursdays, with Wednesdays being restricted for paediatric ART. VCT and ART were not integrated into general health services but was separated from the rest of the services. This practice was to some extent viewed with mixed feelings by some clients. While some felt that it exposed them to finger pointing, others felt it was better as it gave them an opportunity for interaction and share experiences with fellow positive people. Such experiences were viewed as facilitating factor for use of available HIV and AIDS-related services. There was a TB and youth-friendly corner though at the time of the study, the youth friendly was not yet in operation. This seemed to create a lot of challenges for youths who were visibly missing from the facility.

People entered into the ART clinic from various points which include PMTCT, TB corner, other diagnostic procedures, VCT centre and mobile VCT services. At the time of the study there were 1,148 registered clients with 855 on ART. Out of the total number on ART, 489 were women, 295 were men and 71 were children. The ART coordinator explained that there was a lot of swapping of clients between Mbayamusuma, another health facility which offered ART in the area and Chivuna Rural Health Facility as some people from Chivuna preferred to go to Mbayamusuma and vice-versa as a way of avoiding stigma in their communities.

Chivuna Health Facility was also involved in provision of community services. Among these services were mobile VCT and community sensitisation. This was done in order to provide services to many remote communities, which were still affected by long distances to health centres where VCT and ART services were being provided.

These mobile services were provided with the support of CHAZ and Total Control of the Epidemic, (TCE) a Danish funded NGO. TCE also referred clients to the ART clinic. The main services offered under the mobile services were PMTCT, under five clinic, antenatal clinics, community sensitisation, family planning and VCT. CHAZ had also bought the health facility a 4x4 vehicle specifically for mobile VCT. However, provision of these community-based activities was at times not consistent due to inadequate and erratic funding as well as shortage of staff. For instance, although the health facility had more than two vehicles, with one vehicle specifically for the ART clinic, the whole facility only had one driver for all the duties at the centre. At times fuel was also not available.

The hilly and rugged terrain of the area and generally the poor state of the road network made some communities inaccessible particularly during the rainy season. For TCE, this was confounded by the use of bicycles as the main mode of transport. However, even when a 4x4 vehicle was available; some areas were still not accessible by such kind of vehicles. As part of community services, the facility also provided sensitisation on HIV and AIDS. However, being run by the Roman Catholic Church, the facility did not distribute condoms.

For follow ups, the facility depended on community treatment supporters. The study discovered that this mechanism had a lot of challenges particularly, for remote communities due to lack of transport. However, there was optimism among staff that the mechanism would improve as the facility was in the process of acquiring bicycles for treatment supporters covering hard-to-reach areas. The poor follow up mechanism was also attributed to what one care provider referred to as, “Allowance syndrome” making some health staff and community health workers not being interested in any extra work without pay.

4. 3.2 VCT and ART Physical Infrastructure

Although the building was specifically built for the ART clinic, the space was clearly inadequate, leading to congestion. The building had three rooms consisting of a waiting room, registry, a consultation room and a tiny corridor with a sitting capacity of about ten people. Inadequate rooms, as will be seen later had negative implications on counselling.

The waiting room, which was also the group counselling room, could only accommodate about twenty people at a time. According to health care providers working at the clinic, this made group counselling, which was supposed to be conducted on each ART day difficult.

Yet clients saw group counselling sessions as very important in encouraging to enter and continue participating in the HIV continuum of care. Study participants testified how they were encouraged to test for HIV, be linked for care, start taking medication and also continue taking medication once they started as a result of experience sharing through such sessions. The photograph below shows part of the ART building with an unfinished structure.

Figure 4.1: Part of the ART Clinic with an Unfinished Structure

Source: **Field work Chivuna survey, 2009- 2011**

The study discovered that, though very critical, special private counselling rooms were not available. The screening and dispensing of drugs were done in the same room while the registry was also the counselling room. Clients waiting to see the clinical officer and those collecting files waited in the small corridor which was very close to the counselling room. It was observed that due to the corridor being too small, some clients sat right in front of the room where counselling was taking place. This required both the counsellor and the client to speak in low tones knowing that there were people sitting right in front of the room. The data/health communication room was also lacking.

It was found out that inadequate space was a problem particularly during the rainy season when several clients queued to be attended to. Some of the critically ill patients lied down either on the small veranda or on the grass in front of the ART building as they waited to be attended to. The health staff, however, was optimistic that congestion at the facility would end soon with the completion of another building which was under construction with funding from CHAZ. The new building was expected to have a laboratory, counselling rooms and a separate office for the clinical officer. However, the completion pace was not very impressive in that the structure was found at roof level when the study began more than one year ago and was still at the same level at the end of the study. Limited funding was cited for the slow progress.

Observations and discussions with health care providers revealed that clients' records were kept on open shelves yet the WHO guidelines recommend that such records should be kept in lockable storage for confidentiality purposes. However, the dispensary had an air condition as per WHO minimum standards**.**

4.3.3 VCT and ART Staff

There were no permanent staff at the ART clinic, staff from the main facility worked at the ART clinic on rotational basis. Among the reasons given for this were the inadequate staffing. Inadequate staffing was also cited as partly the reason why the clinic was held only twice in a week. Secondly, it was learnt that there was need for all staff to have experience in providing ART services. Another reason given was to enable all staff working at the facility have a share in the allowances which were provided by CHAZ for the ART clinic.

Consultations with health providers revealed that, on each ART day, there were supposed to be a clinical officer, registered nurse, a pharmacist, a nurse for bleeding, three to four counsellors for adherence and an information officer. However, this was not always the case due to understaffing at the facility because the additional services of VCT and ART had been introduced without increasing the number of health workers. For instance, at times only one to two staff were found at the ART centre to conduct all the procedures. Additionally, the facility was supposed to have two clinical officers but only had one to attend to the Out Patient Department (OPD), In-Patient Department (IPD) and ART clinic. As a result, the clinical officer had to first do the rounds in the wards and attend to any emergencies at the OPD before going to the ART clinic. On some ART days, only one nurse was found running the whole ART clinic.

Generally, most of the members of staff at the facility complained of being over-worked since the introduction of VCT and ART services. It was pointed out the new services were being offered in addition to the other duties yet the number of member staff remained exactly the same. This was a great constraint and affected service delivery to people intending to access HIV and AIDS related services in many ways. Firstly, it was observed that because of inadequate staffing, people waited for a long time before being attended to. The fact that the whole facility only had one clinical officer told the whole story of what people were subjected to. The Clinical Officer was required to start with general health service delivery and was only able to go to the ART clinic after 10:00 hours yet some clients came as early as 05:00hours. Secondly it was discovered that counselling sessions were much shorter than they were supposed to be. For instance, one of the health care providers informed the researcher that these counselling sessions were supposed to last not less than 20 minutes but because the counsellors were not enough, counselling time was much shorter. These deficiencies imply that the quality of services delivered was greatly compromised. However, in addition to conventional health staff, the health facility had a number of community health workers who worked on rotational basis as peer educators, as well as ART and adherence supporters.

4.3.4 Training in HIV and AIDS-Related Services

Only the clinical officer (CO) and the ART Coordinator were found to have official training in ART services while the rest of the staff did not and all of them complained of being inadequately trained in HIV and AIDS-related services and yet they were expected to carry out these services. These services consisted of adult ART management, paediatrics and VCT diagnostic and counselling. It was revealed that nine health care providers were trained in counselling with only one nurse having been oriented to carry out all the requirements for dispensing of ART.

The training was provided by CHAZ. However, the study discovered that even when a nurse had been fully oriented in all the areas of ART services, she could not initiate treatment because this was not allowed by the national guidelines if the clinical officer or doctor was around.

All the community cadres who included peer educators, HIV medics, treatment and adherence supporters, were found to have only done some basic orientation to ART services for a week. In the actual fact, nearly all the community cadres complained of the training received not being adequate. Most of them stated that the training they covered in one week should have been done in three months, implying that most of the training material was left out. The fact that staff worked on rotational basis at the ART clinic also had negative implications. Firstly, it meant that there was no continuity in terms of experience yet ART provision is supposed to be a specialised field. Secondly, it was viewed by some clients as compromising confidentiality. As shall be seen later, both the above mentioned scenarios came up as being some of the barriers to accessing available HIV and AIDS-related services.

4.3.5 VCT and ART Equipment

In terms of laboratory management the only equipment that the facility had was as sputum smear test machine for diagnosis of latent TB. Reagents were also always available through the involvement of both the Government and CHAZ in the distribution of these items. At times Total Control of the Epidemic (TCE), a cooperating partner in VCT, also provided testing reagents. This made basic testing such as rapid testing always possible. However, major equipment such as CD4 count machine for viral load monitoring, hematology and, hemoglobin machines, full serum chemistry analyzer and antibody test machines were all lacking.

Samples for liver and kidney functioning were being sent to Mazabuka District Hospital because the facility lacked a chemistry analyzer and CD4 count machine. This was done two times a month. There was much concern by health care providers over the lack of these basic but essential testing machines because this required that all samples delivered to Mazabuka District Hospital located more than 60 km away. This was a big challenge particularly during the rainy season as the road connecting the two health facilities was at times impassable. At times the health facility also experienced logistical problems. All this meant re-taking blood samples, a situation that sometimes raised suspicions and resistance from some of the members of the community who suspected some health care providers of being involved in Satanism, thereby using their blood for rituals. This resulted into reluctance on the part of some potential users and dissuaded some of those believing such allegations from HIV testing, and consequently limiting the access to ART.

Lack of testing equipment was reported to lead to delays in getting test results and consequently caused delays in linking positive clients to care and initiating treatment for eligible clients. Some health staff expressed how frustrated they felt at times when they were unable to initiate treatment due to delayed test results even when some clients would be showing signs of deteriorating health status. It was further reported that in the past, a CD4 count machine was allocated to the facility by CHAZ. This equipment had since been transferred to Chikankata Mission Hospital, a much bigger health facility located about more than 50 kilometres away. In addition to this, the facility also lacked many other equipment required as minimum standard for a faculty offering HIV and AIDS-related services. These included a full serum chemistry analyser, haemoglobin and haematology machines and an HIV antibody testing machine.

4.3.6 Supply of HIV and AIDS Drugs

All the drugs required for the administration of ART were provided by both CHAZ and government through medical stores. The facility had never experienced any drug shortages and had in stock both first line and second line ARVs. All clients except one were still on the first line medicines. There was Post- Exposure Prophylaxes (PEP) only for members of staff. However, at the time of the study, incidences requiring these services such as accidental needle pricking of staff had never occurred at the facility. Antibiotics which were necessary for Pre-ART were also available. The readily availability of ARVs encouraged people to cover the long distances to the health facility and was hence a facilitator for adherence. Antibiotics for prophylaxis were also always available.

4.3.7 The Nutritional Food Supplements

The healthy facility also provided nutritional supplements for those on ART as a way of supporting them to encourage adherence. This nutritional support comprising of HEPS, cooking oil, mealie meal, beans, groundnuts and Kapenta was provided through CHAZ. At the beginning of the study, WFP also did provide food supplements but the support was stopped in early 2010. No specific reason was given but there were insinuations of irregularities at the point of distribution as being one of the reasons why this support ceased. There were 145 beneficiaries of the nutritional support. The criterion used was vulnerability i.e. the very old, very sick, very poor, not improving on CD4 count in three months and orphans between the ages of 0-14 years old. However, the supply was reported to be inconsistent and at times, the food package was not provided in full. As shall be seen later, availability of nutritional support was a big motivator not only for adherence but for testing and ART uptake and adherence as well and hence one of the cross-cutting influencing factors in the HIV continuum of care.

4.4 Factors that Influence the HIV and AIDS Continuum of Care and Treatment.

Guided by the Social-ecological model, this study aimed at investigating factors that influence the HIV and AIDS continuum of care and treatment. This sub- section of the report will, therefore, present findings on the second objective that explored the factors that influenced each stage of the HIV and AIDS continuum of care and objective three which was to determine the factors that permeated through the HIV and AIDS continuum of care and treatment. As noted in Chapter 1, the first stage of the continuum involves one being diagnosed with HIV by taking an HIV test. After which those diagnosed positive are supposed to be linked to a health care provider who can offer treatment and counselling as soon as possible after learning that they are positive. This is also the stage where ART eligibility is determined (and usually this was reported to be based on the CD4 count cells). After one is found eligible for ART and treatment prescribed as the third stage, there is need to get and stay on ART and hence the need for them to be linked to ART provision so that they can start taking medication immediately. The last stage is adherence to prescribed treatment so as to achieve viral suppression and healthy living.

The study found out that there were both facilitating and limiting factors. While the facilitating factors enabled the early entry and continued progression of HIV positive people along the HIV and AIDS continuum of care for desired outcomes, the limiting factors either made people decline or delay entry and also limited their progression along the HIV and AIDS continuum of care for desired outcomes of achieving the goal of ART. The study also found out that while some of the influencing factors were specific to each stage in the continuum of care, others were common or permeating through the HIV and AIDS continuum of care and treatment. Additionally, the study also established that there was an interplay between these factors where by two or more would interact to either facilitating or limit achievements of the HIV and AIDS continuum either at each stage or throughout the HIV and AIDS continuum of care and treatment.

4.4.1 Factors Influencing Each Stage of the HIV and AIDS Continuum of Care and Treatment

4.4.1.1 Stage One: VCT (HIV Testing- Entry into HIV Continuum)

This sub-section of the report presents findings in relation to the second study objective which was to explore factors that influence each stage of the HIV and AIDS continuum of care and treatment. As indicated earlier, the HIV and AIDS continuum of care and Treatment is made up of four distinct but related stages which include HIV testing, linkage to care of those that are found HIV positive, ART initiation upon one being found eligible for ART and adherence to prescribed treatment. Therefore, findings relating to the first stage that is, HIV testing which is the entry point into the HIV and AIDS continuum of care and Treatment are presented first.

It was reported that for one to enter the HIV and AIDS continuum of care and treatment, there was need for a confirmed positive HIV diagnosis. This was only possible by one taking an HIV test through Voluntary Testing and Counselling (VCT). This makes VCT the entry point into the continuum of care and treatment. This study found several limiting factors as well as facilitating factors that influenced entry into the HIV and AIDS continuum of care and treatment. While the limiting factors negatively influenced the continuum of care and treatment by delaying people to go for VCT, the facilitating factors encouraged testing and hence entry into the HV and AIDS continuum of those that were found HIV positive.

Key findings are presented throughout a multi-level continuum of care framework. Influencing factors are presented for each stage of the continuum of care that is, VCT, linkage to care, ART uptake and adherence and those permeating through all the stages of the HIV and continuum of care.

4.4.1.2 Health Facility Level: Facilitating Factors

The Health facility level is one of the five levels of influence of the social ecological model which guided this study. The rest are community, structural, medication and individual levels. According to the social-ecological model, health system-related factors are those that are related to the health system and basically relate to the way health systems are organised and delivered including availability and accountability of services, attitudes of health providers, waiting times and distance to the health facilities, staffing levels, equipment and how these either facilitated or limited the HIV and AIDS continuum of care and treatment. The findings presented in this sub-section relate to how the health facility –related factors influenced the HIV testing or VCT which is the entry point into the continuum of care and treatment.

At health facility level, several factors were identified as positively influencing an individual's ability to access and participate in HIV care and treatment services including provision of mobile VCT and community sensitisation.

(i) Provision of Mobile VCT and Community Based Sensitisation.

Provision of mobile VCT was one of the themes identified at health facility level as facilitating VCT uptake. As a way of increasing access to HIV and AIDS related services and enhance HIV testing, the health care providers embarked on providing of community based services such as mobile VCT and sensitisation activities. Therefore, mobile VCT services facilitated the VCT uptake. In this study, many key informants and community discussants particularly those from distant communities emphasised the need to increase access to VCT centres. Provision of mobile VCT services was seen as an immediate strategy to reduce the problem of distance and related costs affecting people from remote communities. As a result, health care providers reported that attempts were made to alleviate the distance barrier by providing mobile VCT services to remote communities. The response was overwhelming whenever mobile VCT services were provided as conveyed by the statement below:

> *"Yes, these services [mobile VCT services] do encourage people to be tested because one of the major barriers is distance to the health facility, so when you take the service closer to their homes more will come forward for testing. So yes we always see more people coming forward for testing each time we go out in the community"* (Male health care provider).

Mobile VCT services were seen as a way of reducing distances to VCT not only by healthcare-providers but by several respondents from the community. Therefore, whenever the question, "How can access to VCT be improved for remote communities?" was asked during discussions particularly, with community members from distant areas, the common answer was: "*The government should provide mobile VCT services.*"

Apart from reducing distance, study participants pointed out that mobile VCT services were preferred because the people tested did not have to wait for a long time for the results. To some extent, mobile VCT service reduced suspicions of Satanism because blood was not taken away in bottles as was the case with conventional testing. However, the method used by TCE seemed more preferred because in addition to addressing all concerns raised above, its home-based aspect addressed the issue of anonymity. During one of the male clinic based focus group discussions, a male ART user who was tested by TCE while supported by other participants elucidated:

> *"I was tested by people from TCE. With them they do not get a lot of blood for the test, I got my results the same day. And then unlike the clinic where so many people would be present, TCE people come to our homes and so other people in the community do not see you testing. When you come to ART clinic it is clear what you have come here for, the way people look at you, you know, they are imagining about your test result. On the way to the ART clinic sometimes you meet people you know and they will ask you where you are going to or coming from, you do not know what to tell them. But when it is done at home all this is not there."*

Similar views were raised by health care providers themselves as one of them stated:

> *"The issue of anonymity is very critical for people to come forward for testing because even when we say that stigma has reduced in the community because of our community sensitisation, the fact is that it has not been wiped out completely. When we go out for mobile VCT we conduct it at some central place accessible to the people in a particular locality but for TCE, the field officers follow people to their homes and so people can test without being noticed by other community members, that is the difference"* (Male health care provider).

Generally, there appeared to be less scepticism and doubting of test results with the mobile VCT services. This was mainly because many study participants felt that the possibility of the test results being mixed up was minimised with the mobile testing since the testing was done in the presence of the client and results given immediately.

In addition to the mobile VCT services, the health facility carried out sensitisation massages through the use of role models particularly on major occasions like World AIDS day. This was reported to have helped a lot in terms of motivating people to go for testing, starting medication because they would also want to be healed like them.

It was further reported that the facility had received a lot of support from CHAZ in terms of transport by providing a 4x4 vehicle with fuel and by subsidising staff allowances for these community based activities. Additionally, the facility also cooperated with TCE. Despite all these efforts put into such community programmes however, reports were that there were still a lot of challenges. Among those repeatedly mentioned were limited financial resources due to the huge size of the catchment area. Other equally notable challenges included shortage of staff and the poor road network. Limitations relating to shortage of staff were ably presented by one of the male health workers found working at the ART clinic when he elucidated:

> *The available number of staff is at times inadequate to go out in the communities to carry out outreach programmes such as community sensitisation and mobile ART services because we now have two clinics to run yet the number of staff has remained the same. The same members of staff who work at the ART clinic also conduct general health services. We are also supposed to have two drivers but we only have one at the moment, so it is quite difficult for us even if we have a vehicle specifically meant for the ART clinic. Sometimes you find that you arrange to go out for sensitisation or to do mobile ART services, but in the meanwhile there are other operations somewhere that need a driver or maybe there is an emergency. This means that we have to abandon whatever other activities we had planned.*

It was reported that inadequate funding affected services in a number of ways including inability to fund transport costs for out-of-station activities and recruitment of support staff such as an additional driver. This also demotivated health staff from being involved in additional work outside their normal working hours. Therefore, in a related interview, another key informant from the health facility lamentably stated:

> *"Lack of funding has made it difficult to effectively implement these communities based ART services, we have four vehicles but we can't employ an additional driver because there is no money, at times we have no fuel, and then we are not able to buy bicycles for our ART supporters. It is also difficult to motivate our staff to participate in these activities because remuneration is either poor or unavailable. This is compounded by the "allowance syndrome" which makes both community health workers and regular health staff not to be willing to do any voluntary work"* (Female health care provider).

The poor state of the road was also found to have hampered the effective delivery of mobile ART services to remotely located communities (see figure 4.1). The need for the government to work on the roads and maintain bridges was repeatedly mentioned by many informants and community discussants. It was pointed out that this was the only way the provision of mobile VCT services to the hard-to-reach communities would be possible.

The many challenges in the provision of community based VCT services were ably summed up by a female key informant from the health facility:

> *"What encourages people to come for VCT is the reduced distance. For example when we carry out mobile VCT services, you see more people coming for testing. However these mobile services are usually hampered due to lack of financial resources for fuel and manpower. With such constraints, it is usually difficult to say or plan the number of visits we are going to do per month, it is not frequent, so we*

> *only do it as and when the resources are there. Then we have the poor road network, in some places, roads do not exist, we have a 4x4 but we can't still reach certain places."*

It was revealed that despite the health facility being involved in community based HIV and AIDS related service, being a Faith Based Organisation (FBO), its Anti-AIDS campaign messages were limited. For instance, the health staff were unable to fully implement the ABC (Abstain, Be faithful and use a Condom) campaign because as an FBO in a mission setting, the facility could not promote the use of condoms and hence removing the C in their campaigns.

(ii) Antenatal Care Services

Antenatal services and the desire to have a healthy baby also facilitated testing. A number of respondents particularly women, mentioned that they were tested for HIV as a requirement for antenatal (*chipimo cha mada/chipimo cha ba makaintu or women's clinic).* They explained that they were encouraged by health staff to test for HIV in order to protect their unborn babies. While the PMTCT programme compelled every pregnant woman to be accompanied by their partner for the HIV test, some women complained of resistance from their partners who refused to accompany them for antenatal clinic. Therefore, requirement for pregnant women to be accompanied by spouses was a barrier. The men stated that they were reluctant to do so because as noted in some men's' focus group discussions, their view was that *"basankwa taba miti bamakaintu mbobamita"* (Men do not carry the pregnancy only women do). Hence, antenatal services were generally referred to as *chipimo Chamada or chabamakaintu (*women's clinic) and therefore, shunned by many men. Some men who were willing to accompany their wives were at times reluctant due to fear of ridicule from friends within the community because this was viewed as a sign of "*kukomwa kumukantu",* (Being under the control of the wife).

However, most of the women were convinced that this service would enable an HIV positive woman give birth to a healthy baby. As a result, some women with resisting partners went to an extent of requesting either a male friend or relative to accompany them to the health facility for the sake of accessing the service. Some women explained that they had witnessed the suffering which some of their colleagues who had given birth to HIV positive babies went through. This experience prompted them to go for testing to avoid going through a similar experience. Apart from resistance from some partners, the other limitation women faced was the inconceivably long distances to testing places which some pregnant women were required to cover. Additionally, observations revealed that most of the pregnant women going to the health facility carried babies on their backs, adding to the challenge of accessing the services.

4.4.1.3 Liming Factors

(i) Limited ART Centres

The fact that ART services only existed at selected health facilities in the area such as Chivuna was an issue negatively influencing HIV testing. It was found that VCT services were available at all health centres in the area such as Hanzala, Nkonkola and Mwanza which were located much nearer to some of those communities affected by long distances to VCT services at Chivuna health facility. However, it was found that some people were reluctant to test at these health facilities despite their proximity. It was indicated that this was because VCT services were not accompanied with treatment. This meant that in the event that one was found positive and needed further investigation, they were referred to Chivuna Health Facility where repeated tests would be carried out.

This concern was raised in many discussions involving community members. For instance, during a focus group discussion with ten women aged between 25-76 years from a community located approximately 20 km west of Chivuna rural health facility, most of who were not yet tested, a middle aged woman expressed concern for repeated testing and while supported by all her friends said that:

> *"Some of us from distant villages like ours are usually discouraged to go to either Nkonkola health facility or Hanzala which offer VCT although these facilities are located close to us for fear of repeated collection of blood because when you are found positive you are sent to Chivuna Health Facility where some blood is drawn from you again."*

In another interview, a male health care provider also pointed out that:

> *"There is usually delay among people coming from distant communities in accessing VCT services even when these services are available at all these other rural health facilities because they also want to access treatment in case they are found positive. I have seen this happening here at Chivuna health facility from the time treatment was introduced in 2008, the number of people coming for testing has also gone up."*

Offering of ART services at selected facilities also made linkage of those found positive to a health care provider from remote communities a challenge. This was mainly because some of these may not see the need of covering long distances to Chivuna ART centre particularly when one was still feeling healthy. The possibility of losing some of HIV positive after testing was quite high because of this arrangement.

4.4.1.4 Community Level: Facilitating Factors

This is another level of influence of the social –ecological model and the findings presented under this sub-heading relate to social or community factors influencing the HIV and AIDS continuum of care and treatment. Community factors include community perceptions about VCT and treatment, interpersonal relations such as those between married partners, family members that in turn affect individual actions. Community level factors also include social exclusion, discrimination, stigma, traditional health care systems, local illness ideologies and concepts which are all embedded in people's socio-cultural systems.

(i) Community Perceptions about VCT

The study found out that many study participants had positive perceptions about VCT. The people perceived VCT as good because it enabled one to know to know their status and get medicines if found sick". Various reasons and advantages were identified for this perceived "goodness of VCT". The most frequent mentioned was the possibility of accessing life prolonging medicines if found positive and be able to prolong one's life. This view appeared to be shared by different segments of the community as is evidenced by the variety of quotes presented below:

> *"The people at the clinic can test your blood using their machines, as traditional healers we do not have these machines. If somebody is tested it helps a lot because they can know their status. The people at the clinic can also advise you on the type of food to eat and sometimes if the clinic has food, you can be given some. From time to time, one can be treated and given check-ups"* (Traditional healer).
>
> *"VCT is good because you can know your status. If I am found positive I would be given medicine and if I am not found positive, then I will follow the instructions of how to prevent myself from contracting the virus"* (Middle aged tested woman, community based female FGD).

From the statements above, there is no doubt that most study participants perceived VCT as an entry point to HIV and AIDS related treatment and care. The statements also indicate that most study participants were of the view that early testing was good as this enabled one to access treatment early, "before one became too sick".

From experience, many study participants were able to attest that if one delayed in going for VCT and taking medication, which unfortunately was found to be the case with many people, recovery usually took longer. It was also clear that many study participants were aware that VCT was not only important for those who tested positive to help access treatment but even for preventing infection among those who tested HIV negative. It was reported that once found negative, one would take measures to protect one self. Expressing her views, a male ART supporter stated that:

> *"There are a lot of benefits in VCT that I can mention. One thing is that you know whether you are positive or not. The other thing is that when you are found positive you can be given instructions how to live, they can check your CD4 count where they will determine whether you can start medication or not. And of course if you are found negative that means you can start taking care of yourself so that you do not indulge yourself in unprotected sex"* (Community based KII).

For some study participants VCT was good not only as a way of preventing infection at a personal level but also as a way of preventing the further spread of the disease. This is mainly because they felt that when one was found negative, then they would be given instructions by health care providers concerning how to protect themselves from infections. Additionally, if found positive they would be advised on how to prevent further spread of the virus to other people.

While concurring with the above views, some study participants were, however, quick to mention that this was only possible among "caring people". Though not very common, some respondents argued that some people used their knowledge of their positive status to deliberately spread the disease to other unsuspecting community members because they "would not want to die alone". One of the male ART supporters narrated how one man who after being diagnosed positive, deliberately went on a "rampage infecting women". He narrated further that, thereafter the same man proudly went around telling other community members how much he had spread the disease saying*: "But I have spread the disease, we shall die many".*

Similar remarks were reported at one the women's community based focus group discussion when one of the women remarked:

> *"We hear some women taking ARVs saying it proudly that, 'Ino tulabamana' (We shall finish them)"* [referring to men they went out with].

For some study participants having known their status helped them to plan and hence gave them a second chance to work and save something for their children, as one of the female ART users running a small business poignantly stated:

> *"VCT has really helped some of us, knowing that you are positive means that your days are numbered so there is need to work hard and at least leave something for your children. This is why I said that the government should assist us with small loans which we can use for meaningful income generating activities"* (42 year old female ART user community based IDI).

Most of those who had experienced the benefits of VCT ridiculed those who were still afraid of going for VCT. They attributed this fear to lack of knowledge of the benefits of early VCT and ART uptake. From most of the responses above it is quite clear that people's positive perception of VCT was linked to the availability of ARVs and in particular the free provision of ARVS. It can therefore be stated that there had been a transformation of people's perception concerning VCT because of free provision of ARVs. It was revealed that before the availability of free ARVs, the most common view concerning testing was, "What is the point of testing when nothing can be done even if one was found HIV positive". Sharing his experiences, a male health care provider explained that:

> *"Unlike in the past when VCT was viewed negatively, now it is viewed more positively because of the free medicines, you find some people coming early for testing because they want to access medicines before they become too sick."*

A female health care provider also shared her experiences and challenges when she recalled that:

> *"People were a problem at that time [referring to the time before the introduction of free ARVs] because of fear, you would hear them saying or asking you questions like: After you have tested me and if you find me positive, there is no help that you will give me, all that will follow for me will be worries of dying, so there is no benefit in knowing my status. Even for us as health care providers it was a big challenge at that time because you start wondering what to do if you test somebody and they test positive. In fact sometimes you start praying hard that somebody is not found positive because we knew that after testing; there was nothing we could do apart from giving them health education say on nutrition. Then even on that one, you ask them if they have a garden for green vegetables or groundnuts they would say they did not have. So it was really a big challenge for us. But now when one is found positive there is no problem, it is less challenging because help is there*".

In the same vein, the availability of free ARVs led to some changes in the meaning of a positive result. A number of respondents indicated that had they tested positive before the free ARVs were provided, the view of their results would have been different. This is reflected in some of the statements as the one below:

> *"I was not terrified when I was told that I was positive and have this disease because I knew that something could be done at the health facility, unlike in the past when there was nothing, besides I have seen so many people on drugs get better so I also had hope of getting better one day"* (31 year old male ART user clinic based IDI).

From the quote above it is clear that positive perception of the medicines played a role in encouraging people to go for testing. As a result, many participants indicated how they were encouraged to test because they saw someone who was on ART get better and hence enhancing their belief that ARVs were effective. Therefore, seeing someone who was critically ill recover because of ARVs, made people believe in the effectiveness of ARVs. This consequently motivated them to take up an HIV test so that they could access medication.

In terms of disadvantages, the most frequently mentioned was the possibility of stigma and discrimination from the community. It was reported that this made life unbearable for the person involved. This fear of stigma was elucidated by a statement from one of the female ART users when she noted that:

> *"The only disadvantage is stigma from the community. Once you are known that you are positive people start seeing you differently, like you are no longer part of the community anymore. This prevents some from going for VCT; they think of what will happen to them if found positive"* (37 year old ART female user, community based IDI**).**

For some, the concern was not only being known that one was positive by other community members but also fear of the positive HIV result and inability to handle the positive status. As a result, some study participant explained that they feared to test because they were worried of testing positive as "they would end up dying early". They narrated that they would be preoccupied with the thoughts of being positive and hence comments like, "It is better not to know" were common. For some, this worry would still be there even when they knew that medicines were there. For instance, during one of the community based individual depth interviews, a polygamous middle age man, who boasted of having worked for several AIDS related organisations but had not yet decided to test, shared his fears when he expounded as:

> *" If found positive you can die early because VCT makes you know your status, and so if found positive I would be worried most of the time and I can end up dying early. In short, VCT is bad because it brings worries and early death".*

In a related interview, another male narrated:

> *"VCT has both advantages and disadvantages. If you found positive you develop worries and lose concentration on whatever you are doing because you will be thinking to yourself, I may die any time. If were tested and found negative, I would rejoice and I can even go to my kraal to have a cow slaughtered and eat offals and my plans would prosper"* (45 year old not tested male, community based IDI).

These sentiments were reiterated by a middle aged polygamous man, when he stated that:

> *If I am found negative I would be very happy and can avoid any more infection and become productive to accumulate more wealth. If I am found positive, I think I would die because I have big plans which I need to accomplish, if I test positive that would be the end of me. I always advise my wives to be faithful because what they do affects me as well (Middle aged man, community based male FGD).*

For some categories of the community members, such as the youths and the very old, particularly old women, their feelings were that testing was good and that what was bad was the location of the testing facilities. This was because to some extent it was telling the rest of the community that they were promiscuous. Some youths explained that just by being seen at the VCT centre was an indication that they had "already been sexually active at their age". As a result, very few youths were found at the VCT centre. However, from interviews and discussions with health staff, it was revealed that the youths did go for testing and got ARVs from the health facility secretly.

While for the youths being spotted at the clinic would be telling the whole community that they had started indulging themselves in sexual activities, for the aged, particularly old women, being seen at the VCT centre meant that they were still indulging themselves in sexual activities at their age. It was reported that this caused a lot of embarrassment on the part of some elderly women. To some extent, such feeling of embarrassment did force some to stay away from either being tested or from taking the medicines. For instance, an elderly woman who was tested and found positive in early 2010 refused to start taking medicines and was reported saying, *"This is a disease for young ones, I can't start queuing for ARVs with the young ones, it is better I just die".* She passed away in May 2011.

Negative community talk about the medicines and VCT did exist and circulated within the community. Such talk re-enforced the misconceptions of both VCT and ART, thereby acting as added barriers to accessing available services. For instance, although not very wide spread, it was found, as noted above that, there was talk among some community members that some uncaring nurses deliberately injected some people with the virus. This was believed by some community members to be the reason why some people tested negative the first time and positive after three months. There was also talk about Satanism. Negative talk about the medicines was also common. All these though not very wide spread, were reported to be deterrents for some of those intending to use the available VCT and other related services.

4.4.1.5 Individual Level: Facilitating Factors

This as explained above is another level of the social ecological model. Individual level factors are the personal determinants of health seeking behaviour over which an individual has control. Such personal characteristics included knowledge, fears associated with testing and fear of life-long medication, fear of medication side effects, having no symptoms of ill health, perceived risk of HIV infection and wanting to avoid stigma. Facilitating factors are dealt with first.

(i) Perceived Risk of HIV Infection

At individual level, several factors were identified as influencing testing positively including high perceived risk of HIV. In this study, this was found to come in many forms among them poor health which included persistent or chronic illness, death of sexual partner including co- wives and chronic illness and death of one's young children. This can be illustrated by responses in relation to the question, "What prompted you to go for VCT?" as quoted below:

> *"Kuchiswa ciswa sunu ehh mutwe, ehh kusomoona, ehh maulu. Limwi ndati ndikapimwe ndibone cilubide" (Persistent illness, today headache, diarrhoea, pain in the legs, so I said let me go and be tested so that I know what was wrong with me)"* (47 year male ART user, clinic based IDI).
>
> *"As I told you that I was in a polygamous marriage. Then my husband and the other wives died. I had no hesitations but to believe that it was this disease that had killed them though they were not tested"* (Middle aged widowed ART user clinic based female FGD).

Perceived unfaithfulness either of self or of a sexual partner also did trigger the need to test for HIV. For instance, a 46-year old polygamous male who tested negative explained how he had several times been encouraged to go for HIV testing because he was married to two women who he suspected of being unfaithful. Additionally, he stated that at times, he was also tempted to be involved in sexual relationships with other women and all this made him feel that he was at high risk of HIV infection and hence the need for him to take an HIV test.

Similar views were expressed in several other related interviews as can be illustrated from the quote below:

> *"I was very promiscuous, I had more than 70 girl friends when I was working at the farms in Mazabuka, so I thought of all this and said to myself this was not a normal sickness let me test)"* (37 year old male ART user who confessed to have had more than 70 girlfriends, Community based IDI).

Because of the assumption that they were already HIV positive, perceived risk was also a barrier to testing. It was also found that at times perceived risk of infection did not always encourage people to go and test. This had to do with self-awareness of promiscuity in the past. As a result perceived did either prevent or delayed some people from taking up an HIV test on the premise that they were HIV positive. The usual answer for most of those found in such a situation, was, "K*uyoowa kujanika abulwazi inga kwayindilila"* (perceived risk and self-awareness of risk worsened the fear of having a positive HIV test).

While it has been noted above that high perceived risk of HIV infection was a predictor for testing, low perceived risk of contracting the virus dissuaded some people from taking up VCT even when facilities were located nearby. This is illustrated from the quotes below:

> (Laughter first) *"I stopped doing those things a long time ago, why would I go for testing for such diseases? How can I get those diseases?"* (About 70 years-old woman, clinic based IDI).

> *"I haven't sacrificed myself to go for VCT because I still feel very healthy and my former husband still looks healthy too. I have never had any other relationship with another man apart my former husband, I am still fat and I feel that I am okay*," (27 year-old divorced untested female, community based IDI).

(ii) VCT Knowledge

Having knowledge about VCT, its advantages and where to test was another factor identified as facilitating HIV testing at individual level. The majority of respondents expressed knowledge about existing facilities and also knowledge about what VCT was all about, including its benefits. This knowledge was attributed to community based sensitisation activities carried out by the health facility in conjunction with other NGOs and community radio stations such as Radio Chikuni. Sensitisation was also reported to be done through health education sessions conducted by the health facility on each ART day. Some of those who had been tested for HIV categorically stated that this knowledge helped them access the services and enter the HIV and AIDS continuum of care and treatment.

The perceived role of knowledge in facilitating VCT can be illustrated by the quotes below:

> *Having knowledge is very important), that is why as someone said, community sensitisation is very important, this has helped a lot because the more people come to know about VCT and the benefits, the more they come forward for testing. All of us here decided to test because we had some information about testing and its goodness"* (Middle aged female ART user, clinic-based female FGD).
>
> *"Having knowledge about the value of VCT is very important. It can even reduce the many rumours about the medicines and VCT which go round in the community. You hear somebody who has never even taken ARVs talking about the medicines, eh they are too big, like tablets for cows, eh, alapa kusondoka (ARVs can make you ran mad), but if the health care providers came into our communities to teach us, all this cannot be there. There is a lot of cheating each other in these villages where we live due to lack of knowledge)"* **(**74 year **ol**d male ART user, clinic based IDI).

This also applied to knowledge concerning where to go for testing as shown in Table 4:4. The data in the table indicate that on the overall, all the people who tested knew where to go for testing. These results show that knowledge about where to go for testing plays an important role in the people's uptake of VCT. From this table, it can be derived that knowledge about where to test was significant in motivating people to test, at P value .000. It was found out that in when compared with other sources of information such as the radio (in particular Radio Chikuni a Roman catholic radio station), the school and church gatherings, the health facility was viewed as one of the most important sources of knowledge.

It is worth mentioning that at 20 per cent, as shown in Table 4.4 on the overall, the level of the study participants not having knowledge about where to test was high enough to be of concern. This calls for the need for stepping up activities aimed at providing the community with information on testing and where to test.

Table 4. 4: Association between Knowledge of where to test and HIV testing

	Yes		**No**		**Total**	
HIV Testing	**No**	**%**	**No**	**%**	**No**	**%**
Yes	519	100.0	0	0.0	519	100
No	0	0.0	134	100.0	134	100
Total	**519**	**80.0**	**134**	**20.0**	**653**	**100**

Source: Field work Chivuna survey, 2009-2011. $\chi^2 = 38.853$, $P<0.000$.

Those participants who lacked knowledge categorically stated that, they either did not test or had delayed to do so due to lack of knowledge about the availability and benefits of VCT service. Many participants narrated how the lack of knowledge about benefits of VCT negatively affected them by delaying them go for VCT as conveyed by the statement below:

> *"Lack of knowledge was the greatest hindrance that prevented us from going for VCT; I personally lacked the knowledge to fully understand what VCT was all about. So even when I came for testing I did not know anything, I just came to the clinic because I was not feeling well but not for VCT. When I explained to the nurse what happened that was when I was tested. Even after three of my young children died, I did not think about VCT, because I could not connect the deaths to HIV and AIDS" (M*iddle aged female ART user, clinic based female FGD).

Lack of knowledge undoubtedly affected the distantly located communities more than those who lived near the health facilities offering ART services. This was partly attributed to the limited sensitisation activities that such communities were exposed to. Health workers had made frantic efforts to reach these remote communities through community based activities but had a lot of challenges as expressed in the following statement:

> *"Then the other factor that prevents people from coming for testing is lack of knowledge, this still is the case with so many people out there because we have not reached some communities, particularly distant ones due to a lot of challenges. So when we go out for our outreach or mobile activities we usually start with community sensitisation and this helps a lot. You have some people even confessing after the test that they had not tested much earlier due to lack of knowledge about VCT, but as I said when we met last time there are a lot of challenges in implementing the mobile services"* (Female health care provider).

This situation was also elucidated by the area chief when he stated:

> *"People lacking knowledge about VCT are still very many because my chiefdom is very big up to Shanamodonga, Namaila (located approximately 60 and 50 km respectively), and up to near the border with Zimbabwe.So these people have not been reached in terms of sensitisation, they know nothing about VCT and still believe that the medicines are killer drugs."*

At times having accurate knowledge about symptoms of HIV and AIDS was also found to be a barrier to the early uptake of VCT. It was reported by several key informants that some of the people who possessed this knowledge were able to relate their health conditions to the symptoms. This led to anxieties, fear and consequently delays in the uptake of VCT. This was reported to be more among the educated people such as teachers and worse still among the health workers themselves. Health care providers working at the ART clinic narrated that in most cases, when such people decided to take up testing; they did not go to the local health facility but instead went to other facilities with some of them going as far as Lusaka located more than 100 km away just to avoid being spotted at the local health facility. This led to delays in testing and consequently delays in accessing treatment and care services even when they were located nearby.

(iii)To Avoid HIV- Related Stigma and Discrimination

Some participants reported that they took up testing early simply because they did not want to waste time and be associated with HIV and AIDS and avoid possible negative reactions in the community. For instance, during one of the community based female focused group discussions, one middle aged woman, who, when trying to answer the question, "What are some of the factors that encourage people to go for VCT?" noted that:

> *"Kutayanda kuhibwa kuti ulachiswa,nkaambo kuti wafwambana kunwya musamu,inga kunyina ukonzya kuhiba kuti ulaciswa, inga akusilima taaku (Not wanting to be known that you are sick, because if you start taking medicines early no one can know that you are sick, you won't even lose weight "* (Middle aged woman, Community based FGD).

Reiterating these sentiments, another participant from the same group of almost the same age stated that:

> *"Ino kuti walala mubulo a kusilima kwanjila, amana waneneya, kwamana boonse bantu bahiba kuti ulatopinga" (Now, if slimming comes in and then you gain weight, everyone will know that you are topping-up),* (taking ARVs).

According to the health care providers, this was a new trend that had come with the evolution in perception of the efficacy of ARVs and their free availability. Expressing this view, 36 year-old female health care provider shared her experiences when she explained that:

> *"Most people now want to be tested early and get medicines, you find when you tell them about their CD4 count being too high and that they would get medicines later, they start complaining saying: 'Sister that will be too late, I want to start taking medicines immediately,' Some do not want to fall sick or start losing weight so they want to test early and start taking medicines as soon as possible to avoid suspicion. People are now in a hurry to test and get the medicines as soon as possible before they become sick."*

4.4.1.6 Limiting Factors

(i) Absence of Symptoms of ill Health.

Among the limiting factors identified was one having no signs of ill health. This acted as a barrier as some people saw no need of testing for HIV when they were still feeling healthy and with no symptoms of ill-health. A relationship was sought between feeling healthy, low perception of risk and testing and testing. Results are presented in Table 4.5. The results in

Table 4.5 show the extent to which low perceived risk and still feeling healthy both dissuaded people from going for testing or delayed testing.

The results show that more than 60 per cent of strongly agree and agree put together of those not tested did not do so because they still felt healthy while feeling not at risk of HIV infection was at 49 per cent. The significance for these factors is P=0.00. Some people also cited one being too sick or severe illness particularly those from remote communities as one of the reasons why they were unable to test or delayed to test. Other factors at individual level were low perception for severity of the sickness and seeing someone on ART die.

Table 4.5: Association between Individual-Related Reasons and HIV Testing

	Strongly Agree		**Agree**		**Somewhat Agree**		**Disagree**		**Strongly Disagree**		**Total**	
Reason for not testing	No	%	No	%	No	%	No	%	No	%	No	%
No symptoms of ill health	26	19.4	60	44.8	18	13.4	16	11.9	14	10.4	134	100
Perceived risks	13	9.7	53	39.6	17	12.7	23	17.2	28	20.9	\ 134	100

Source: Field work: Chivuna survey 2010, χ^2 = 5.910, P<*0.000.*

Because of high poverty levels, some study participants also strongly indicated that they were encouraged to for HIV testing hopping that they would test positive and be given free food by the health facility. For this reason some people tested several times hoping that one day they would test positive and be able to access food supplements. For instance, an ART supporter explained how some people went for testing many times each time hoping that they will test positive and be given free food. He narrated:

> *"You hear them saying 'Tiimwapima kabotu bulwazi nkobuli mumubili oyu" (You did not conduct the test properly, I am sure the disease [referring to HIV and AIDS], is there in my body" (*ART supporter, Community based KII).

Therefore, in answering the question relating to why they decided to go for testing, comments like *tuli bachete*, (We are poor) or "I wanted to have access to free food", were common.

(ii) Fears Associated with Testing

These fears made people either decline or delay taking up an HIV test and consequently delayed those who were found HIV positive to enter the HIV and AIDS continuum of care and benefiting from health care services. Study participants also strongly pointed out that they delayed or declined to test because they were afraid of receiving positive test results. They noted that this fear was as a result of other fears including, fear of taking drugs for life if found positive, fear of side effects , fear of gossiping and finger pointing and generally fear of being stigmatized by the community if found positive. They pointed out that these fears were also because of the fact that despite the availability of ART, positive HIV test diagnosis was associated with death and illicit sexual behavior. Table 4.6 illustrates the levels of influence of the various fears on testing among those who had not tested.

The results show that fear of gossip was the highest at 97 per cent followed by fear of divorce at 94 per cent. This finding signify the levels of stigma and gender based violence in the area. This was followed by fear of side effects from the medicines and fear of taking medicine for life, 50 and 48.5 respectively. Fear of living with HIV and AIDS was the lowest at 47.1 per cent. The significance level for all the factors in Table 4.3 is P=0.000, showing a significant correlation of these factors with testing.

Table 4. 6: Association between Fears of Testing and HIV Testing

Fears of	**Strongly Agree**		**Agree**		**Somewhat Agree**		**Disagree**		**Strongly Disagree**		**Total**	
	No	**%**	**No**	**%**	**No**	**%**	**No**	**%**	**No**	**%**	**No**	**%**
Divorce	126	94.0	8	6.0	0	0	0	0	0	0	134	100
Living with HIV and AIDS	12	9.0	51	38.1	8	6.0	61	45.5	2	1.5	134	100
Taking medicines for life	9	6.7	56	41.8	7	5.2	34	25.4	28	20.9	134	100
Gossip	130	97.0	4	3.0	0	0	0	0	0	0	134	100
Side effects.	10	7.5	57	42.5	5	3.7	31	23.1	0	0.0	134	100

Source: Chivuna survey 2009-2011, *$P<0.000$, for all the fears*

The Stage One facilitating and limiting factors described are presented in Box 1.

Box 1: Factors influencing VCT by Level

Facilitating Factors

Health Facility
- Mobile VCT and Community Based Sensitisation
- Antenatal Services

.**Individual**
- High Perceived risk of HIV infection
- To Avoid HIV- Related Stigma and Discrimination
- Having Knowledge about VCT
-

Community
- Positive perceptions about VCT

Limiting Factors

Health facility level
- Limited ART centres

Community
- Negative Community Perceptions about VCT

Individual
- Low Perceived Risk of HIV Infection
- No symptoms of ill health
- Fears Associated with Testing

Source: Field work Chivuna survey, 2009- 2011

After a confirmed positive test results, there was need for the HIV positive person to be linkage to care services for continued counselling and pre-ART monitoring.

4.4.2 Stage Two: Linkage to a Health Care Services after a Positive Test Result

This is the second stage in the HIV and AIDS continuum of care and treatment. It was reported that after one was diagnosed HIV positive, he or she was required to link with a health care provider as soon as possible in order to enrol in HIV care services and be able to receive the necessary care. This stage was important for monitoring and pre- ART counselling so that HIV positive people know how to live, especially avoiding reinfection for them to live as healthy as possible while they waited for eligibility to ART. It was also reported that the counselling HIV positive people received in this pre- ART period although this was not always the case, was meant to avoid the positive people infecting other people.

This stage was also important for laboratory monitoring for disease progression for ART eligibility. In this stage those, who were not yet eligible for ART initiation were required to continue engaging in pre-ART care services until they were eligible to initiate ART. During this stage HIV positive people were also expected to receive septrin so as to treat any possible opportunistic infections associated with HIV, free of charge. Clients were expected to return to the health facility monthly for monitoring and to receive medication and were expected to receive CD4 testing every six months until eligible for ART initiation. It was also revealed that once one was linked to care, there was need for them to be retained in care throughout the continuum as there was no cure for HIV and AIDS.

At Chivuna Health facility, HIV positive people were linked from various entry points which included PMTCT, TB corner, and other diagnostic procedures, VCT centres outside Chivuna Health facility and within the ART centre. For those patients tested outside Chivuna health facility, they were given referral forms from the VCT centre to Chivuna ART centre which would facilitate their linkage with a health care provider. For those tested at Chivuna VCT/ART centre, these forms were not necessary as ART services were located in the same building and conducted by the same health workers that offered VCT services. Referrals to the ART clinic were however, required for pregnant women and those diagnosed through other entry points within Chivuna health facility. Interviews and discussions with health care providers particularly the ART coordinator and the communications officer indicated this was the most challenging stage where a larger proportion of HIV positive people dropped out and were lost to follow up in the continuum. This study found the following limiting and facilitating factors that influenced one's linkage to a health care provider after being diagnosed HIV positive at different levels at this stage of the HIV and AIDS continuum of care and treatment.

4.4.2.1 Health Facility Level: Limiting Factors

(i) Lack of Integration of HIV and AIDS services and Poor Transfer System to other Points of Care

As noted above, at Chivuna health facility, HIV related services except for PMTCT were located in the same facility and same building. This facilitated linkage of those who tested HIV positive to a health care provider immediately or the same day after testing. It was noted however that, problems existed in linking PMTCT clients as these services were located in another building and this required a pregnant woman diagnosed with HIV to spend additional time at the health facility as they needed to join another queue at the VCT/ART clinic away from the antenatal clinic. Some women were lost to follow during these internal transfers. In fact, observations revealed that these women were not accompanied by any staff at all to ensure that they did reach the ART clinic and linked to a health care provider at the ART clinic. Similar challenges were faced by those clients who were referred from other entry points such as TB corner and diagnostic procedures.

Worse challenges in linkage to care were however for those that tested at health facilities that did not have ART services as they needed to travel to Chivuna Health facility. These needed to cover long distances to Chivuna health facility and so some dropped out at this stage. Some of these challenges were ably elucidated by the health communication officer when he explained:

> "*.....for people that test here, being linked for care is not really a big problem because all the services are located in the same place, but for those who enter the ART clinic through PMTCT or other entry points other than VCT experience some problems because they usually have to start the whole process all over again as these services are separated from ART services. Some of these clients may decide to come back another day but in the process fail to do so, so some drop off while others come back but late just like that. For those from very remote communities it is also due to lack of money for transport and food."*

He explained further therefore that those tested in other VCT centres where there was no ART were less likely to be linked to care because of the distances, related costs and the long ques at Chivuna facility.

Discussions with the other health care providers and in particular the ART coordinator revealed other bottlenecks within the health system. For instance, she noted that there was no effective system for transferring people who were tested and referred from other centres. She noted further that like for intra-facility transfers, those being referred for linkage from other facilities were not accompanied by any staff from the referring facility and also that there was no proper monitoring system to ensure that those engaged in care were retained, as she narrated:

> *"......another problem is lack of an effective system for transferring people across different points of care because even when we talk about people tested at other centres being given transfer forms to come to Chivuna ART clinic once they are found*

> *positive, there is no proper monitoring to ensure that they actually do so. For instance, they are not accompanied from the referring centre to the ART clinic. This also applies to monitoring those who get linked to care to ensure that they remain in care, follow up and tracking is equally poor, we have tried through community workers such as adherence supporters but the system is not very effective because of the distances and logistical problems."*

She further pointed out that the health facility was in the processing of putting in some effective system which would enhance linkage of those tested outside Chivuna health facility. One such structure was to visit all VCT centres through mobile ART services at least once a month so as to identify all those who need linkage to care. She elucidated:

> *"At the moment there was no structure in place to follow up all those who test HIV positive to ensure that they are all linked to care but we are in the process of putting up something. For instance, since Chivuna ART centre is the Zonal centre, we want to start visiting all VCT centres at least once a month so as to identify all those who are supposed to be linked to care."*

However, she was quick to mention that the only challenge with this would be the very challenges affecting mobile VCT services of inadequate staffing, inadequate financial resources and poor road network leading to some of the referring centres and communities being inaccessible. She also noted that there was need of stepping up measures which would ensure that those that were engaged in care were retained so as to avoid drop outs and lost-to- follow up. She explained that the community based approach of using community based health cadres for follow ups and tracking would work but that this needed a lot of financial support so as to provide transport and financial incentives for the workers involved in such activities. Further , she noted that these community health workers also needed to be adequately trained in counselling so that they could be able to provide adequate counselling particularly, on the importance of those who test positive to be linked to a health care and also to remain in care even when they were still feeling healthy and not yet on ART.

(ii) Lack of Testing Equipment

It was learnt that for a positive person to be linked to care, there was need for them to have their CD 4 count cell levels assessed. In addition to this, there was also need for monthly monitoring and assessment of disease progression for health staff to determine ART eligibility. This required laboratory services that met the WHO minimum standard. It was learnt that the only equipment available in the laboratory was a sputum smear microscope for detection of latent TB. Reagents were also always available through both the government and CHAZ. At times Total Control of the Epidemic (TCE), a cooperating partner in VCT, also provided testing reagents. This made basic testing such as rapid testing always possible. However, major equipment such as CD4 count machine for viral load monitoring, haematology and haemoglobin machines, full serum chemistry analyser and antibody test machines were all lacking.

Because of such inadequacies, the process of one obtaining these major results was a challenge for the majority of the clients. For instance, it was revealed that there were a lot of delays in people getting the results for CD4 count because the nearest CD4 count machine could only be found at Mazabuka District Hospital located more than 60 km away. This meant that tests were sent to Mazabuka Hospital. It was reported further, that this machine was sometimes not in working condition and often broke down due to too much pressure as all health facilities in the area including Chivuna depended on it. This delayed results subjecting tested people to come to the health facility to check for their results several times. This was a big challenge particularly for those clients coming from remote communities as they were required to cover the long distances and incur travel costs to the health facility, many could not afford following their results several times. It was reported that this led to delays in linkage while some of such clients never came back for their results and in the process never linked to care and lost at this stage of the HIV and AIDS continuum of care and treatment. This implies delays in clients getting such results and consequently causing delays of HIV positive people in using the available services.

Many health care providers were cognisant of such challenges and acknowledged that they lead to drop outs as one of them observed:

> *".....before our CD4 count machine was taken to Chikankata Hospital things were much better. We have lost some patients in this manner. You have been to Namaila yourself madam [referring to the researcher], how many times do you think one can come here to follow results? They may come one or two times but that is already too much. Some patients after coming for their results a number of times and they do not find them, they get discouraged. In fact there was one man who came from Nadongo, (located about 50 km from Chivuna health facility) he came here about two times without getting the results because of the same delays we are talking about, after coming two times without finding his results, he has not come back. May be he is dead or maybe he decided to go Pucky clinic we do not know. I just hope that he has done so because unfortunately he was one of those who tested positive"* (Male health care provider.)

Further discussions and observations also revealed that because all other testing major equipment were lacking, procedures required in this stage which would enable HIV positive move to the next stage and be able to benefit from available services were all adversely affected. For instance, monthly monitoring for disease progression which was necessary for ART initiation was a challenge and this meant that patients had to go through the same waiting process because such tests had to be sent to Mazabuka district hospital. Individual level factors influencing linkage to care were also identified.

4.4.2.2 Individual Level: Limiting Factors

(i) Feeling Healthy at the Time of diagnosis

It was found out that some study participants who at the time of testing or after the diagnosis were still feeling healthy saw no immediate need of seeking further Medicare. This mainly applied to those who tested at other health facilities and referred to Chivuna health facility. It was reported that some of these saw no need of covering the long distances and that they would only turn up much later when they started feeling sick from advanced HIV . On the other hand it was found out that those who had advanced illness at the time of testing linked to care almost immediately. This is explained by one of the health care providers when he narrated:

> *"If one was still feeling healthy at the time of diagnosis, linkage to a health care provider is usually delayed and some may only come back for linkage when they have become very sick., but you find those who are seriously sick at the time of being diagnosed wanting to be linked almost immediately, also for those who tested outside Chivuna health facility and were too sick at diagnosis to cover long distances on foot also delayed to be linked."*

Not believing positive HIV results was another factor identified as delaying people's decision to be linked to care.

(ii) Denial of Positive HIV test Result

A number of study participants reported that at first they did not believe their positive test results. This disbelief was partly associated with beliefs in other causes such as witchcraft. Because of these beliefs some people reported delaying going back to the health facility after the positive diagnosis but instead went to either traditional or spiritual healers whom they believed would give them the correct medicine. This is clearly shown in Table 4.19 which shows that even though most of the people (66 percent) went to a health care provider after a positive HIV test diagnosis, the number of those who went to alternative health care providers (at 33 percent) was also considerable and of concern.

Some study participants also reported of doing their tests more than once because they did not believe their results and had to undergo several tests because of denial. This denial of positive test results was associated with the fact that despite the availability of medicines, HIV and AIDS was still viewed as a fatal condition. Some study participants even reported of going to other health centres with the hope of being given the correct test result which would be negative. All this inevitably led to such clients delaying in being linked to care and hence missed out on the benefits of such linkages, despite some of them having tested early.

(iii) Lack of Knowledge on the Importance of Linkage to Health Care Services.

Perhaps due to inadequate post-test counselling, most clients did not seem to know the importance of linkage to care other than ART treatment. In fact the common answer when asked on the importance of linkage to care before being ART initiation was *I do not know*. What most of them seemed to understand was the importance of being on ART. As shall be seen below, inadequate counselling was linked to other health system related factors such as lack of special counselling rooms and inadequate human resource. This as indicated by most of the health care providers, was further complicated by some individual-factors such as low educational levels among most of the clients which made assimilation of information very complicated.   The stage one limiting factors are depicted in Box 2.

Box 2: Factors Limiting Linkage to Care of HIV and AIDS continuum of care and treatment by Level

Limiting Factors
Health Facility
• Lack of integration of Services and Poor Transfer System to other Points of Care • Lack of Testing Equipment
Individual
• Lack of Knowledge on the Importance of Linkage to Health Care. • Denial of positive HIV test results

Source: Chivuna Survey 2009-2011

4.4.3 Stage Three: Initiation of ART (ART Uptake Stage)

This is the third the major stage of the continuum which an HIV positive person is required to pass through and it involves an HIV diagnosed person to start taking ARVs after determination of ART eligibility. ART up take after ART eligibility was reported by health care providers as required so as to control the HIV infection and that this was to be done timely once prescribed. It was found out that some people delayed to do so while others did so immediately. The following limiting as well as facilitating factors were identified at different levels at this stage of the continuum of care.

4.4.3.1 Health facility level: Limiting Factors

(i) Lack of Testing Equipment and Access to CD 4 Count

Due to lack of major testing machine (observed in the second stage), ART initiation was also affected because before ART was initiated, there was need for the health care provider to assess the CD 4 count levels. Like for linkage to care, the lack of testing equipment locally caused a lot of delay in obtaining such results from the District Hospital. This consequently delayed commencement of ART. Some of these concerns are conveyed in the quotes below:

> *"We were given a CD4 count machine by CHAZ but this was taken to Chikankata Mission Hospital and so we have to take blood samples to the District Hospital twice a month. The frequency of transporting blood samples increases depending on the 4.4.3.1number of people queuing up for testing in a particular month. The problem is that sometimes the machine breaks down on the day the samples are taken due too much pressure because we are not the only health facility that takes samples there. When this happens, blood samples have to be retaken because we cannot keep them beyond 24 hrs before testing. This leads to delay in initiating patients on medication because there is a requirement that results are known before a client can be put on drugs"* (Male health care provide).
>
> *"Some testing machines should be acquired because that is one thing that delays people to start medication, some die while waiting for test results because our blood has to be taken to Mazabuka and then sometimes we are told that there was need for fresh blood and tests to be repeated meanwhile the patient keeps waiting for results without any medication even when one could be very ill" (Middle aged* female ARV user, clinic based FGD).
>
> *"If only the samples could be tested here [at Chivuna health facility] it would have been better but now patients have to wait for samples to be taken to Mazabuka and then results to come before somebody can be given the drugs, this causes a lot of delay, some of our colleges have died in the process of waiting"* (32 year old male on ART for 3 years, clinic based IDI).

The delay caused a lot of concern among some health workers as it was clear to them that there was a possibility of some clients dropping out at this stage due to the delays caused. To some extent, the delays and the re-taking of blood samples lead to mistrust and suspicions of some health care providers. It was also suspected that repeated taking of blood samples was to enable some health care providers use the collected blood for satanic rituals. Like with linkage to care stage discussed above, it was revealed that some eligible clients were in the process of waiting for test results lost. One ART client stated that:

> *"That happens a lot [referring to retaking of blood samples], like for me, they had collected blood more than two times from me. Because of drawing blood from you on a daily basis in the end, they can even drain the last of drop of blood from you, sometimes you start thinking of possibility of other things happening, we do not know what happens maybe our blood is being sold"* (Female ARV user, mixed clinic based FGD, amid agreement from other participants).

Such concerns were confirmed by some health care providers as some of them stated that:

> *There is some talking about that [repeated blood taking]. Some clients have even approached me jokingly asking about where we take their blood and whether we sell it. They have heard about Satanism yes and so they ask such questions. This is made worse by the re-taking of blood samples we have talked about. And then results do delay sometimes because of not having our own machines here.*

Some structural factors were also identified as either limiting or delaying ART initiation.

4.4.3.2 Structural Factors: Limiting Factors

Structural factors are those over which the individual has completely no control. These factors include poverty, livelihoods, health policies and the financing of health care systems all which are linked to the national economy.

(i) National Guidelines on Initiation of ART

National guidelines on the initiation of ART was identified as negatively influencing ART uptake and hence disrupting the linkage between linkage to care and ART uptake because these guidelines did not allow commencement of ART when neither a clinical officer nor doctor was around. Therefore, in the event that the only clinical officer was not available, no new clients could be initiated on the medicines no matter how desperate the situation could be. Such a scenario undoubtedly led to delays in initiating patients to ART and consequently leading to other related problems yet some of these clients would have gone to the health facility early enough.

(ii) Required CD 4 Count Levels

Another barrier for ART uptake was requirement for CD4 count to be at a 350 as was the requirement at the time of the study. Some respondents desperately complained about the delay to start taking medication because of their CD4 count being still high often leading to desperation, anxieties among such clients and some dropping out at this stage of the continuum. For instance, a woman in her early thirties had travelled from Lusaka, the capital city (located more than 150 km away) to the study site for an HIV test. She lamentably narrated that she had been tested more than once in Lusaka and that each time she was told that her CD4 count was "still very high" yet she was feeling very unwell. She was hopeful she would be given a different result which would enable her start taking medicines because, "she really envied those who were taking their medicines". It was indicated that such clients eventually stopped visiting the ART clinic because they could not understand why they were not given medicines when they were very sick yet some of those who did not look sick were given medicines.

Some of the study participants and respondents were also sceptical about government continuing with the supply of free ARVs. This was more so with the increasing number of people on ART. This created fears and anxiety, prompting others to be either reluctant or avoid taking ARVs. Therefore, in answering the question, 'What would you do if there was no more supply of free ARVs? The common statements were, '*Mpooanya awo mpoya kumanina musinzo wesu aawo'* (That would be the end of our journey), "*Banji besu balimuminzi bayakufwa, inga tatuyuuli misamu nkaambo tulibacete* (Most of us rural people would die as we can't afford to buy the medicines because we are poor).

People's concerns about future availability of ARVs are also reflected in Table 4:11 below. The results show that more than 80 per cent of those who had not commenced taking medicines gave concerns of future supply of ARVs as one of the reasons why they had not done so.

4.4.3.3 Individual level: Limiting Factors

(i) Fear of Life-Long Medication and Forgetfulness

Fears of taking drugs every day of one's life until death were reported by both ART clients and health care as a contributing factor for the non-uptake of ART. Most respondents recognised the challenge involved in one taking medicines every day for life. Therefore, a number of people confessed to hesitating in starting medication even when they were required to do so because of fear that one day they may forget. Fear of forgetting was compounded by beliefs such as if you forget even for a day you die. Such fears are elucidated by the quote below:

> *"No, I did not start taking medicines immediately, I was very afraid to get the medicine. I was actually given some time (kuliyeeya) to think about it. I was afraid of taking medicines daily and forgetting so I kept on thinking to myself "what will happen to me if I forget even for one day since people say that you can die if you forget even for a day?" The doctor really encouraged me and my neighbour also encouraged me. Other people are scared just like I was afraid myself, when they just think of taking medicines every day and then what they have heard people talk about the medicines it really scares them"* (41 year-old widow and ART user, clinic based IDI).

During another clinic based In Depth Interview (IDI) an elderly widow, who reported that she kept the medicine for three months after collecting it from the health facility without taking it, also shared her initial fears as she recollected:

> *I first wondered how life was of taking ARVs. I stayed three months with the drug without taking it. The more I ignored taking the drug the thinner I was growing. I was scared of taking the medicine for life, I was afraid that if I forget even for a day as we used to hear I would die. So because of this fear, I delayed in starting medication.*

In answering the same question, similar sentiments were expressed by several other ART clients as illustrated by the quotes below:

> *"Then there was the taking the medicine for the rest of my life, I wondered how life would be of taking tablets every day till I died, it was hard, I preferred to die than suffering taking tablets for the rest of my life"* (50 year old widow, ART user community based IDI).
>
> *Problem one was the thought of taking the medicine for life and every day because once you start you have to take every day otherwise you die, so I had these questions If I start, will I manage to take them for life and every day of my life? It really sounded very impossible (*44 year old male ART user, clinic based FGD).

(ii) Depression after HIV Positive Test Result

There were also reports of possibility of depression among some clients after being informed of their sero-positive status. This was partly as a result of the difficult that came with coming to terms with a positive diagnosis. There were also some clients who reported of crying, being mentally disturbed and acting like they were mad upon receipt of the positive diagnosis, an indication of not being mentally prepared to accept a positive diagnosis. For instance a middle aged woman reported of continuously crying after learning of the results. She stated that at first, she could not believe the results, so she had to test several times hoping to be given a different result. Another female respondent reported of being in a state of confusion and that for days she could not sleep and started acting like a mad person subsequent to her being told of the results. Some of these experiences can be illustrated in the quote from a female ART in her late forties when she narrated:

> *"Upon getting my results, I cried a lot, I kept on thinking I was dreaming and I would wake to be told that it was not true, I remember the day I was given the results, I failed to sleep and I started acting like I was mad,….. I could not stop crying"* (38 year old Female ART client, community based IDI).

It was reported that this affected and consequently delayed their linkage for the required Medicare after being diagnosed HIV positive because when all this was going on, such clients were not in position to start taking medication even when it was prescribed. All this could be signs of denial and depression which could hinder one from ART up take and hence the need for adequate post-test counselling.

To measure depression, those respondents who tested positive were asked to state how they felt upon being told of the positive result. The results are contained in Table 4.7. The results show that 44 per cent and 24.4 per cent of the respondents indicated strongly and quite strongly feeling depressed respectively. This means that 68.4 per cent (about two- thirds) of the respondents felt some kind of depression upon receipt of their positive result, that is depressed and quite depressed put together.

Table 4:7 Feelings of Depression after an HIV Positive Test Result

Levels of depression	**No**	**%**
Very strong	139	44.0
Strong	77	24.4
Quite strong	6	1.9
Not strong	17	5.4
Not very strong	77	24.4
Total	**316**	**100.0**

Source: Field work Chivuna survey, 2009-2011

Several key informants from the health facility and the church also did report of cases of depression and confirmed that this did hinder ART uptake among such clients. They did acknowledge the possibility of depression among people who tested positive. They reported that it was possible among such people to refuse taking medication and instead go to either a traditional healer or a faith healer due to deep denial. Hence, the need for adequate and intensive post-test counselling. However, this was not possible in this study because of several health system-related barriers including low staffing levels, inadequate physical infrastructure and limited training in HIV and AIDS–related services. Inadequate post-counselling was a barrier to linkage to a health care provider and ART uptake as it contributed to HIV positive people not being mentally prepared to accept a positive diagnosis.

As in linkage to a health care provider stage, it was revealed that feeling healthy at the time of ART eligibility and not believing a positive diagnosis made some ART clients to either delay or decline ART uptake. The stage three factors described are presented in Box 3

Box 3: Factors Influencing ART Initiation of HIV Continuum of Care and Treatment by Level

Limiting Factors
Health Facility
• Lack of Testing Equipment
Individual
• Fear of life-long medication and forgetfulness
• Depression after a positive HIV result
• Health status at time of initiation-still feeling healthy at the time of ART eligibility • Not believing the positive diagnosis
Structural
• Required CD4 Count levels
• Guidelines on Initiation of ART

Source: Chivuna survey 2009-2011

4.4.4 Stage Four: Adherence to ART for Viral Suppression

This is the fourth major and last stage of the continuum. Adherence to ART was reported to be important so as to maintain viral suppression. It was reported that since there was no cure for AIDS, once one starts taking ARVs, there was a requirement for them to consistently continue taking them for life so as keep the viral suppression low and avoid being sick. The study found the following limiting and facilitating factors that influenced people’s adherence to prescribed treatment at different levels at this stage of the HIV and AIDS continuum of care and treatment.

4.4.4.1 Health Facility Level: Facilitating Factors

(i) Readily Availability of ARVs

While free provision of ARVs influenced the whole HIV and AIDS continuum of care and treatment, readily availability of ARVs was one of the factors identified by many respondents facilitating retention in care and treatment and consequently led to viral suppression. No study participant reported of any shortage of ARVs. The consistent availability of ARVs was therefore , identified as one of the factors that facilitated treatment compliance and retention in care and treatment, an assertion verified by all sources, including physical checks on all ART days. This included availability of both first line and second line drugs and Post Exposure Prophylaxis (PEP). It was reported that the availability of drugs was partly attributed to CHAZ complimenting supplies of drugs, because at the time of the study, there were reports from some government run-facilities about shortage of ARV drugs. This prompted people on ART to protest against the government. The consistent availability of drugs motivated clients to walk unimaginably long distances to the health facility because they were sure of finding them each time they went there.

4.4.4.2 Community Level: Facilitating Factors

(i) Treatment Supporters.

These were community members helping with adherence almost on a voluntary basis. They were recruited by the health facility with financial assistance from CHAZ. As adherence supporters, their role was to ensure that those on ART adhered to their medication by providing them emotional and social support during visitation. They also facilitated retention in care and treatment by helping ART clients to keep their appointment dates by reminding them through follow-ups. If any clients were too sick to walk to the health facility for medical refills, adherence supporters would collect medicines on their behalf. They also sensitised other community members on the importance of testing early and hence facilitated entry into the continuum.

All ART clients who had an opportunity of interacting with ART adherence supporters reported that they had been motivated to consistently take their medicines because of the support that they received. Sharing her experiences, a widow who usually lived alone stated:

> *"My children are not with me, I usually stay alone as a widow, when my grandchildren come to visit they remind me but, I am lucky to stay near an adherence*

> *supporter, he usually comes to remind me about the importance of taking medicines daily. He also gives me a lot of encouragement. Some times when I am feeling unwell and it is time to take medicines from the clinic he gets them for me. This has really helped"* (52 year old widow, ART user, community based IDI).

In a related interview, during one of the focus group discussions, another female ART user noted:

> *"The other thing is also the ART supporters. They are doing a good job and have really helped my life to keep on going. Every time I am visited by an ART supporter I have observed that it has helped and encouraged me to continue taking my medicine, these people are very important because they are saving people's lives"* (female ART user, clinic based female FGD).

One of the female health care providers also acknowledged the role of these supporters when she elucidated:

> *"These are effective community volunteers; some are professional and have gained respect from the community. These are helpful and are able to encourage other people from the community to adhere to treatment. For a client to be able to keep appointments is another challenge. This is where community based volunteers come in because these help prepare clients for review."*

Notwithstanding perceived important role by ART clients, it was reported that ART supporters worked under very difficult conditions. For instance, in one meeting consisting ten of them, it was revealed that most of them lacked transport. This precluded them from reaching remote areas and also reduced their frequency of monitoring their clients, yet this was critical for adherence. They also complained about what they referred to as meagre allowances which were not enough for them to adequately support their families. According to them, this led to them having divided commitment particularly, during peak periods as they had to work on their farms in order to sustain their families.

Home-Based Care (HBC), which was directly supported by the Roman Catholic Church, though was found to be in existence, was reported not to be very active. One of the reasons given was that the roles of HBC, which among others were to render palliative care to people in advanced stages of AIDS and attend to their domestic chores, were no longer desirable because with the coming of ART, most of the ART clients were no longer bedridden. However, it was reported that some of the care givers mostly men, had been taken on as adherence supporters. Interaction between clients was also reported as a facilitator for adherence.

(ii) Client –To –Client Support

Having interaction with other people living with AIDS was another factor that was reported as a driver for retention of ART clients in care and treatment and consequently viral suppression. Most of the respondents explained that through this interaction, they were able to share personal experiences and hence cope with the side effects. It was also reported that this interaction was a source of emotional and social support for each other as people on ART. For instance, during a mixed clinic-based focus group discussion in answering the question, "How have you benefited from the interaction with other people living with AIDS, a middle aged widow on ART for close to two years shared her experiences when she narrated that:

> *"We talk about how each one of us is feeling these days, we do tell each other about our experiences with the drugs and how the medicine has helped us. You find that other people who started taking medicine earlier also have similar problems like what you are having and this encourages many to continue taking the medicine and we laugh a lot when we remember how we used to be before we started taking the medicines. When we meet here we say we have come to the garage for repairs"* (Middle aged widow, mixed clinic based FGD, amid support and laughter from other discussants).

In a way, this also contributed to the creation of new social networks. For instance, some respondents explained that they felt closer to some of the fellow clients than some of their own blood relatives. They stated that they often visited each other while some of those coming from distant places preferred to spend nights at fellow clients' residences even when they had relatives living close to the health facility.

Therefore, in answering a question on how he had benefited from such an interaction, a man in his late thirties who had been on ART for about one year shared his experiences when he reported that:

> *"It has encouraged me very much, I feel am not alone and we also come to know some things that we didn't know. We learn from each other's experiences and this really keeps us going, when you hear your friends' stories then you feel encouraged because you discover that your friends experience is worse than yours, so you say then I am better. We continue supporting each other in the community, because we have become friends with some of the people that we meet at the clinic and we find ourselves visiting each other, because we have something in common, they say a problem shared is a problem solved"* (48 year Male ART user community based IDI).

Client-to- client interaction came up prominently during group counselling sessions because it facilitated sharing of experiences among clients some of whom had been on medication for a long time.

4.4.4.3 Individual Level: Facilitating Factors

(i) Having Reminders

At individual level, several factors were identified including one having a reminder. Many respondents reported that having reminders helped them take their medicines every day and on time. These included having someone to remind them such as family members. Those who had disclosed to their partners mentioned that their spouses were important reminders. Their usual comments were: *"Kubaa ukuyeezya na chikuyeezya cilagwasya maniningi kuti utalubi kunya musamu)* (Having someone or something to remind you helps a lot in ensuring that you do not forget to take medicines).

The results in Table 4.8 show the role of one having a reminder in adherence showing that all those people with reminders never missed taking their drugs.

Table 4.8: Association between having a Reminder and Adherence to ART

Longest period of time ever missed taking ARVs	**Yes**		**No**		**TOTAL**	
1-2 Weeks	3	60	2	40	5	100
2-8 Weeks	28	52.8	25	47.2	53	100
More than 2 Months	0	.0	1	100	1	100
Never Missed	213	100	0	.0	213	100
Total	**244**	**89.7**	**28**	**10.3**	**272**	**100**

Source: Field work, Chivuna survey 2009-2010, $\chi^2 =$ 115.980, *P<0.000.*

The above findings reflect a very close association between adherence and one having a reminder. Instead of depending only on human reminders, some ART users mentioned physical reminders among which were: use of wrist watches, setting cell phone alarms and use of radios. However, some respondents complained of having experienced negative reactions from some community members for putting on wrist watches because as narrated during a focus group discussion, "These days whoever wears a wrist watch is associated with ARVs". This was linked to the new type of stigma that was associated with ARVs.

Some clients reported putting medicine bottles in certain positions as noted by a 37 year - old female ART user when she stated that:

> *"Every evening after taking the medicines, I put the bottles on top of the table and after taking the pills every morning, I put the bottle under the table. So depending on where the bottle is, then I know I have already taken or not taken the medicine."*

Although many study participants mentioned the value of using a watch/clock, radios and cell phone alarms, because of high poverty levels in the area, a number of study participants explained that they were not able to afford most of these dependable reminders. As a result, some mentioned that they were forced to inform say a neighbour who owned either a radio or cell phone to tell them when it was time for taking medicines. This of course often led to involuntary disclosure of one’s status. Some resorted to using shadows and shades. Concern over use of such time telling devices were that they were unreliable because at times they would be unavailable. For instance, on a cloudy day one would not use shadows to determine time. Also use of radio was not reliable as a radio announcer may be carried away with the presentations and forget to announce time.

(ii) Sero-Status Disclosure

Disclosure of one’s status to either close family members or ones close associates was also reported to be an important facilitator for retention in care and treatment while non-disclosure was a predictor for non-adherence. A number of those who decided to disclose stated clearly that they did it as a way of having a reminder to avoid forgetting. Forgetting, particularly in the early stages of treatment, was seen by many clients as big challenge in taking drugs every day. Additionally, for many of the respondents, disclosure was a form of mobilizing emotional, social and material support which helped reduce worry and stress that came with one knowing that they were living with an incurable disease. Those who had decided to disclose thus, were able to attest of the benefits from disclosing their HIV status to both family members and close associates as illustrated by quotes below:

> *“I should say that having disclosed to my family has really helped a lot, before I did so, I used to feel as if I was carrying something very heavy but after I told them about my status and that I was taking ARVs everything just changed) because my family members are very supportive and sometimes we even joke about my status, sometimes when I am almost forgetting you hear of my children shouting, ino mwa topinga kale MTN? (Have you already recharged with MTN?). And we laugh about it”* (43 year old male ART user, clinic based IDI).
>
> *“Disclosure is good because even food and transport money your family members and others close to you can assist you if they know about your status but if they do not know, they cannot do it, some even escort their sick to the health facility, even when we go out visiting we should tell those we are visiting so that they know in case of emergency”* (Elderly man, clinic based men’s FGD).

Health care providers and care givers also did acknowledge the role of self-disclosure in ensuring that somebody took medicines accordingly. For instance, a female health care worker reported that people handled a positive result differently, with a possibility of some of them going into depression. She stated that this could lead to treatment interruptions and hence the need for emotional support from family members. She alluded further, to other challenges like forgetting that many clients encountered particularly in the initial stage of their treatment. Therefore, in sharing her experiences she explained that:

> *"I think the other thing is disclosure of one's HIV status to close family members and other close associates. I have heard of many clients confessing that life became much easier after they told their family members that they were positive and were taking medicines because then they are supported emotionally. You know some people go into depression after being told of their status and they may not be able to take their drugs daily if there is no support and encouragement, they may just give up everything and say let me just die. When beloved ones know there are so many other things that they can do to ensure that one takes the drugs accordingly, it may be lending transport money, providing food, or even travelling to the health facility to collect medicines on behalf of the patient and so forth. Then there is the issue of forgetting, many clients have told me that they used to forget a lot when they started taking their medicines but were always reminded by their family members because they had disclosed to them that they were taking ARVs."*

It was reported however, that many people who decided to disclose to some and not to others or used selective disclosure. For instance, many respondents said that they disclosed to their close family members and that within family members they decided to disclose to adults and older children because these could understand what was going on. One female client reported not disclosing to her aged mother because, "She was not strong enough to handle the news" and did not want her to be worried. Within sexual relationships, some women decided not to disclose to their spouses for fear of violence and abandonment. Other respondents also stated that they only selected to disclose to those they knew would keep secrets.

Those who had decided initially not to disclose narrated the disadvantages of non-disclosure as they shared their experiences. For instance, a 40 year old male ART user narrated how one day, he could not take his drugs because he failed to do so in the presence of his friends who he had not disclosed his status to. He thus, recounted:

> *"I used to miss especially those days when I was still hiding. One day when I was with my friends it was time for me to take drugs and then the conversation became so interesting. If my friends went to their homes 20 minutes past the time I was supposed to take drugs, then I would take them but they did not go and by the time they left, it was too late. I could not take the drugs in their presence because I did not want them to know"* (40 year old Male ART user on ART for almost 4 years, community based IDI).

There were reports of people who decided not to disclose their status and ended up dying in the process due to lack of encouragement and support. For instance, in one community located about 20 km west of Chivuna Rural Health facility, a man was reportedly to have been travelling to Chikankata Mission Hospital located approximately 50km for ART instead of Chivuna health facility located nearby. His family members reported that they did not know, though they suspected their relative of being on ART, until they discovered what was termed as a big bundle of ARVs under his bed after he died. All the community members were very positive that this could not have happened if he had disclosed his status to his family members because he would have been given moral support that was required in such a situation.

In general non-disclosure was attributed to anticipated negative reactions. Many married women strongly pointed out that they were afraid of disclosing their results to their spouses because of possible negative reactions. They reported that non-disclosure of their status to their spouses was what helped them to adherence to medication. They stated that for them to take the drugs they had to hide them to avoid trouble. One woman narrated that she tested first before her husband and only disclosed to a friend in the neighbourhood because she was not sure how her husband would react. She stated that she also had to keep her medicines with the same friend and was only able to disclose to the husband after he tested positive. She explained further that if she had disclosed first, there was a possibility of her being blamed for the infection. Several women who did not disclose their positive status mentioned fear of victimisation, rejection and infidelity accusations as some of the reasons for not doing so.

Therefore, asked about disclosure, the majority of the respondents, more than 60 per cent stated that they decided not to disclose their status to any one (Table not indicated). Of those who did disclose, about 49 per cent disclosed to their partners while the majority 51 per cent disclosed to either relatives in the household or friends outside the house hold. The fact that most people decided not to disclose to their spouses who are supposed to be their closest associates meant depriving themselves of the much needed support. This also reflects the interpersonal challenges involved with matters relating to HIV and AIDS particularly among sexual partners.

In fact, a number of those who disclosed their status complained of having experienced negative reactions. Some of the negative reactions experienced by those who disclosed their status are presented in Table 4.9. These results are a clear indication that stigma and discrimination levels against somebody known to be living with the virus were high at more than 90 percent for all the above categories.

Table 4. 9: Experiences of HIV and AIDS- Related Stigma and Discrimination

	Yes		No		Total	
	No	%	No	%	No	%
Not allowed to touch some one	99	96.1	4	3.9	103	100
Asked not to touch some one's child	101	98.1	2	1.9	103	100
Blamed	101	98.1	2	1.9	103	100
Being avoided	101	98.1	2	1.9	103	100

Source: Field work Chivuna survey 2009- 2010

(iii) Personal Perceived effects from the Medicines.

The effects included both positive effects and side effects. While perceived positive effects or efficacy from medicines such as one feeling better, increased body energy, physical body changes (such as increased body weight, beautiful skin in women) encouraged HIV positive people to continue taking medication, the side effects acted as a predictor for non-adherence. Among the most commonly mentioned were persistent headache, nausea/ vomiting, heart palpitations, dizziness, partial blindness, increased hunger and appetite, body rashes and un proportional body weight(such as big belly, small legs, big muscular hands).

Those who experienced side effects narrated how they either stopped or tempted to do so, to postpone and dread dosing times of "the terrible side effects". Many of them pointed out that they had to be strong for the purpose of feeling well again and also wanting to live longer. Some of these experiences are illustrated by the quotes below:

> *"For me I had so many problems just after starting the medicine, sometimes I could not open my eyes, sometimes it was terrible headache like it was splitting into two, even becoming deaf, na imwi yakali nzala , citankaamo ndakali kuunya musa kakunnyina chakulya himwi hiindi (I do not know whether it was hunger because sometimes I would take them without any food), ah if you are not strong you can give up, but I thought about my children, I would say to myself, who will look after them, their mother is dead, this encouraged me to continue taking the drugs,"* (Widower father of six young children, community based IDI).

> *"When I started taking the drug, I felt more sick than before. My body became so weak; I used to feel dizziness after taking the drug. Sometimes I used to feel and behave like somebody who was drunk with beer because I would fail to find the door. I had bad effects from the medicine. So when it was time to take the medicine ndakali kuliyeeya maningi, ndakali kuti ndinywe na ndilekele biyo kunwa musamu ooyu (I*

> *used to think to myself should take it or I just stop taking this medicine)"* (46 year old male ARV user, community based male IDI).

Health care providers and care givers were also cognizant of the difficulty that people on ART had to go through because of side effects as conveyed by the following quotes:

> *".......and then there are some clients who develop bad side effects, a number of people just give up, we really have to work hard to encourage them, but again the distances are a problem so some people may not come to seek more information, and so some start thinking what they have been hearing about ARVs being killer drugs is true so they abandon the medicines"* (Health care provider).
>
> *"The only problems I have seen are the side effects, in the beginning he [referring to the husband] used to complain a lot after taking the medicines. He used to have headaches most of the time and he also used to complain about cizyungu boombe, (dizziness), and I had to force him to take the medicine" (42 year old Female* care giver, married to an ART client, community based IDI).

A number of ART users and some key informants from health related background reported that the many side effects from ARVs were one of the reasons why some patients opted for traditional medicines as these did not have any side effects.

4.4.4.4 Limiting Factors

(i) Forgetfulness

Forgetting was one of the factors that was repeatedly reported as causing ART clients to miss their drugs. Many study participants attested to facing this barrier especially in the initial stages of treatment. During a mixed group discussion, participants were emphatic on forgetting as a barrier to adherence as can be illustrated by the statement below:

> **"***Yes, 'kuluba nkokupati, (forgetting is the major problem), especially when you are just starting sometimes you are supposed to take at 8 and you remember at 09:00 hours. I used to forget a lot at the beginning but with time I have become used now"* (Elderly male, FGD).

In another interview, a 71 widow also shared her experience when she noted:

> *"Sometimes I forget on time, you will find that by the time I realise that I have not taken the drug its two hours or four hours later.I have seen it a problem for adherence"* (female ART user, community based IDI).

Some study participants reported of putting measures such as those under reminders to ensure that they did not forget. So for instance, some reported of disclosure to say a family member who would act a reminder.

A number of key informants and discussants during focus group discussions mentioned, *kukolwa makoko,* (too much beer drinking) as one of the reasons why some people skipped their doses. Forgetting because of being too busy with other activities, especially those relating to livelihoods, such as looking for food for the family was also raised in some discussions, especially with women discussants. Some study participants also mentioned of not taking their medicines because they had travelled to some distant place without them, or as a result of hoping to get back home early but end up being delayed.

Many study participants who had been taking ARVs also attested that forgetting reduced with time. Other participants said that with time they had "developed certain feelings" that usually reminded them of not having done something very important. They narrated that, taking medicines became something they did automatically like eating or putting on clothes. Therefore, sharing her experiences a 60 year old widow who had been on ART for more than three years, elucidated that:

> *"Yes it is there [forgetting] but with time it lessens, taking ARVs becomes like eating nshima na kusama cisani (like eating nshima or dressing up), you never forget to eat, when it is time to eat you remember or when it is time to dress up you do so, in fact we eat our food almost at the same time every day, immediately it is time to eat you feel the hunger, so it is the same with these medicines, you get used with time. Even with clothes no one ever forgets to put on something when they are going out, they become part of you. For me sometimes I feel heavy and strange, I feel as though there something I have not done then immediately, I remember I have not taken my medicine*" (Widowed female ART user, clinic based IDI).

These experiences were reiterating to by several other ART users who had also been on treatment for some time as shown by statements below:

> *"Every time it is about time to take the medicine, I hear a bell in my ears reminding me to take the medicine. It is like going to school. Every school girl or boy wakes up early and prepare to go to school on time. They fear of being punished if they are late, same it is in ART taking"* (Man in early thirties on ART user for almost 2 years, mixed clinic base FGD, amid support from other participants).
>
> *"Yes moyo inga ulabwaluka" (heart beats faster) then you know there is something you have not done, so you know it is your medicine you have not taken"* (Elderly female, mixed clinic based FGD).

After one was on medication for some time, they started feeling better again. So feeling better influenced people to either stick to medication or not as discussed below.

(ii) Health Improvement while on ART

Feeling better and disappearing of symptoms was reported to be both a driver and barrier for adherence. Some of those who had recovered were reported to continue taking their medication as they did not want to fall ill again. They pointed out that they remembered how sick they were before starting ART and felt proud of their good health. They felt good that they were able to work for themselves again instead of depending on other people. Others said the drugs gave them a second chance to work and be able to leave something for their children when they die. Sharing her experiences, a 33 year old female ART user for three years noted:

> *"After all the side effects stopped, I feel much better now and I would not want to fall sick again and so I make sure I take my medicines accordingly. I have grown fat as well and I am very proud of the way I look and feel. I used to forget but now am proud because I just find reminding myself due to the way I am feeling. I hope to work hard for my children,"* (33 year old Female ART user, clinic based IDI).

Same views were expressed during focus group discussions as is illustrated by the quote below:

> *"Also feeling better does encourage a lot, for me I used to have boils all over my body including buttocks but now all that is over and I would want to continue feeling healthy okay"* (Elderly male, clinic based mixed FGD with ART users).

Some respondents reported that because they were healthy again, they were tempted to discontinue with ARVs as they started doubting whether they were ever suffering from AIDS. For instance, during one of the clinic based IDI, a 40 year male ART user for three years noted:

> *"Ahh sometimes, feeling healthy again can make you stop taking the medicines, there have been times when I feel and start thinking that maybe it is not really AIDS that was troubling me. Look at me, are there any signs that I was once very ill? I am just following instructions from health care providers that is all because I do not feel any more pain in my body.*

These sentiments were reiterated during a mixed focus group discussions with ART clients when one of the male discussants, while being supported by fellow discussants retorted:

> *"Kulinvwa kabotu akuyeya kuti ndayumwa, cipa kuleka kunya musamu" (Feeling better and thinking that I am healed can make one stop taking the medicine)"* (Elderly male discussant, amid agreement from other discussants, clinic based mixed FGD).

These views were also expressed by some care givers. A 45-year old female, who once had to care for her husband when he was bedridden, for instance, narrated how her husband who had fully recovered was reluctant to take his medicines because he was, "feeling better".

A number of study participants also gave one being too sick or severe illness, particularly those from remote communities as another factor which made replenishing of drugs difficult. It was further noted that at times one being too sick also made it difficult for one to take the medicines even when they were available, especially those who lacked social support to ensure that they took their medication accordingly.

(iii) Drug Fatigue

Though they were very grateful that drugs were available, some of those on medication for some time indicated that they were tired of taking medication every day. Thus, while being on the drug for a long time did help in adherence, at times it also acted as a barrier because of what some participants referred to as being tired of taking medicines every day or drug fatigue. This was so particularly when there were no signs of one recovering after being on medication for a long time. Comments like, "*Twacinvwa kunya musamu abuzuba"* (We are tired of taking drugs every day), were quite common particularly from clients who had been on ART for some time. Speaking from personal experience, one of the male ART clients who had been on ART for more than two years elucidated:

> *Feeling well again really encourages us to take these drugs but we are just asking the scientists at least to manufacture an injection or a table drug to be taken every 6 months instead of the way we take these drugs every day. Twachivwa basa kunwa musamu a buzuba limwi inga wati ndipumune kwa mazuba mashoonto biyo, (We are tired of taking drugs every day, so sometimes you may say let me rest for a few days (male ART user on ARVs for more than two years, clinic based IDI).*

These sentiments were reiterated by several other ART users and care givers as can be seen from the following remarks:

> *"I can tell you my sister (referring to the researcher), temptations to stop are there because you get tired of taking tablets every day of your life, more than two years of taking medicines every day is not a joke but when I think about the illness in the past, how sick I was, I tell myself, I have to continue taking these drugs"* (Male ART user in mid-forties, community based FGD).
>
> *"Then the taking of medicines every day is also a problem as some people would want to give themselves some days off especially when they start feeling well, my husband sometimes becomes reluctant to take his medicines, but I am always on him because I suffered a lot to look after him when he was very sick"* (Care-giver of husband who was once bedridden, Community based IDI).

There were some study participants reported that they were almost stopping or actually did so because of unbearable side effects such as too much hunger and appetite in the absence of food. Others cited were dizziness, headache and partial blindness. Box 4 presents the stage four factors described above.

Box 4: Factors Influencing Adherence to Prescribed Treatment) by Level

Limiting Factors

Individual Level

- Drug fatigue
- Forgetfulness
- Health improvement while on ART
- Fear of side effects

Facilitating Factors

Individual level

- Having reminders
- Sero status disclosure
- Health improvement while on ART
- Perceived effects from the medicine

Health Facility Level

- Availability of ARVs

Community level

- Treatment supporters
- Support from fellow ART Clients

Source: Field work Chivuna survey, 2009- 2011

4.4.5 Factors permeating through the HIV and AIDS Continuum of Care and Treatment

In relation to the third objective, the study found out that in addition to the factors identified which corresponded to specific stages of the continuum, there were several factors that permeated through the HIV and AIDS continuum of care and treatment. These influenced entry, retention and engagement in HIV services at nearly all the stages throughout the HIV and AIDS continuum of care at and treatment. This study found limiting factors as well as facilitators permeating throughout the HIV and AIDS continuum of care and treatment at various levels of influence.

4.4.5.1 Health Facility Level Factors: Limiting Factors

(i) Distance

Several factors were identified at health facility as influencing entry, progression and retention in care and treatment continuum. The study found that one of the cross cutting influencing factors to the various stages of the continuum was distance to the health facility and related cost. For study participants that lived within the vicinity of Chivuna health facility, many of them repeatedly mentioned reduced distance to the health facility as one of the facilitators that encouraged people to enter the HIV continuum by taking an HIV test and progression through the continuum of care and treatment. This included HIV testing, linkage of those found positive to a health care provider and being retained in pre-ART Medicare, determination of ART eligibility and ART initiation and complying with medication for viral suppression. This is mainly because in relation to these services, they were located at the same health facility.

Many of the study participants from both the community and health facility were grateful that the government had set up such services in their area and could therefore not hide their happiness. Expressing her sentiments during one of the focus group discussions with people on ART, a middle aged female discussant living less than 500 meters from Chivuna health facility, jubilantly narrated that:

> *For us who are close to ART centres have no problem with distance when one wants to go for testing, it is only our friends who come from places like Hanzala, Namaila (located about 25 and 50 km from Chivuna Rural Health Centre respectively) who still experience such problems. In the past, people from here used to go to Monze and Mazabuka for testing"* (Female ART user, clinic based female FGD).

Expressing similar views, a female health care provider also noted:

> *"Yes the distance factor is one of the most mentioned barriers limiting access to ART services here in the rural areas. With the setting up of Chivuna ART centre the people living in the nearby communities no longer experience this problem. In the past people from here used to spend nights at Puck clinic. So yes the people around here may experience other barriers like stigma as they try to go for testing but definitely not distance and transport costs. I would say the distance factor is still there for those coming from remote communities like Nadongo, Nachintyombwi and Namaila, but even for them, it has reduced a bit. This has helped a lot in encouraging people to test.*"

Many still remembered the hardships they went through in the past before Chivuna VCT and ART centre was established in their efforts to access the various services of the HIV continuum of care and treatment. It should be noted that reduced distance did not always guarantee uptake of the available HIV and AIDS services. This is mainly because there were several other factors at play such as HIV and AIDS stigma, confidentiality concerns, gender-based violence and long waiting times due to low staffing levels. It was common therefore, to find people who were very close to the health facility who had not entered the continuum or delayed in doing so and those who could not continue moving along the continuum because of all these barriers.

Although distance was found to have reduced for communities near to Chivuna health facility however, it was found out that there were still many communities where distance factor still remained a big challenge. Thus, long distances to health facilities was identified in this study as one of the health system- related factors that came very prominently from all sources as limiting nearly all the various stages of the continuum. As a result, long distances dominated nearly all discussions particularly, from distant located communities. This means that long distances either delayed or limited people from being tested, those found HIV positive from being linked to heath care providers soon after testing. For instance it was reported by key informants from the health facility that because of long distances, some people including those who tested positive did not go back to the health facility for their results. This meant that these people could not be connected or delayed being connected to a health care provider for pre-ART care and counselling, depending on whether they did go back later for their results or not. Such delays consequently negatively or delayed initiation of ART for those found eligible and also from adhering to medication and consequently limiting or delayed the desired outcome of viral suppression.

For instance, Namaila and Nadongo were located approximately50 and 60 km from Chivuna ART centre respectively while in some instances people travelled close to 100 km on foot to the health facility for them to access these HIV and AIDS- related services. Therefore, when responding to the question, "What would discourage someone to go for either VCT or collect medicines?" The challenge of covering long distances to ART centres was frequently raised by many informants and discussants, particularly with respondents from remote communities. This was literally put as, *'Musinzo wa kuunka ku Mission ndempenzi pati', (*The long distance to the Mission is the biggest problem). When asked to rank the major barriers to ART, *Musinzo (*distance) to the health centres was usually ranked as number one by most people from the distant communities. Study participants described a range of experiences they had to encounter so as to reach the distant VCT and ART centres. For instance, during one of the male group discussion with a community located about 20 km from the facility, a middle aged male discussant lamentably narrated that:

> *"Distance is problem number one for us. Muyeeye biyo namwatola ciindi chilamfu buti kusika kuno kuhila ku Mission, ino nywebo mwalikwenda amotokala, ino muntu uchisidwe musinzo wakuhila ku Mission inga wakwanishya buti? (Imagine how long it took you to travel here from the Mission and yet you came by a vehicle. Can a sick person manage to cover such as distance?"* (Un-tested male discussant, Community based FGD).

Discussions with study participants who were affected by distance clearly showed how much delay was caused to access HIV and AIDS –related services such as VCT due to distance:

> *"It took about two years for me to go for testing; I used to have rashes on the whole body. Some people advised me to go to Puckie [another health facility also known as Mbayamusuma] but it was too far and I had no transport money. The rashes persisted, so when Chivuna ART centre was opened, I decided to come here for testing and they told me that I had the virus in my blood"* (Elderly female ARV user clinic based FGD).
>
> *"For me it took me more than six months of just thinking about the distance to the Mission to go and test because at that time I was feeling very ill and did not have the energy to walk from Nachintyombwi to the Mission. It takes more than seven hours to walk from my village to the Mission"* (39 year-old Male ART user IDI).

To measure the extent of the influence of the distance factor and related cost of travelling to a health centres for the various services that made up the components of the HIV continuum, study participants were asked a number of questions. For instance, those not tested were asked to state to what extent they either agreed or disagreed with the two statements such as: *"I have not tested because the testing centre is too far and, I have not tested because had no money".*

The data in Table 4.10 show that a substantial number of study participants agreed with both statements, more than 30 per cent (for strongly agree and agree put together). Further analysis of the table reveals that the proportion of those agreeing was also statistically significant at P Value 0.00 significant level. This is a typical example of how distance and related costs negatively influenced people's entry and progression along the HIV continuum of care and treatment.

Table 4.10: Association between distance to ART centres and testing

Reasons	**Strongly Agree**		**Agree**		**Somewhat Agree**		**Disagree**		**Strongly Disagree**		**Total**	
	No	%	No	%	No	%	No	%	No	%	No	%
Had no money for transport	3	2.2	32	23.9	13	9.7	39	29.1	47	35.1	134	100
Testing place was too far	6	4.5	41	30.6	6	4.6	29	21.6	52	38.8	134	100

Source: Chivuna Survey 2009-2011, $\chi^2 =$ 28.0094, $P<0.000$.

Because all the services were basically located at the same health facility, long distances and related costs to ART centres were also cited as being a barrier for those who tested HIV positive from being linked to health care provider for continued pre-ART Medicare and also negatively influenced their decisions to start taking medication and also retention in care and treatment. And consequently had a negative implication for viral suppression. Therefore, the access factor came up very strongly in these stages of the continuum as well. For instance Table 4.11 presents data on distance and related costs to ART facilities and how they influence the ART uptake.

The results in Table 4.11 indicate that for those who did not start taking medication, both ART centre being too far and having no money to follow treatment were given as reasons for not doing so with as many as 94 per cent and 90.4 per cent respectively, (strongly agree and agree put together). The association is also very significant. This is another typical example of how distance and related costs limited people's entry and continued retention in the continuum of care continuum.

Table 4.11: Association between Reasons for not Starting ART and ART initiation

	Level of Agreement											
Reasons	Strongly Agree		Agree		Somewhat Agree		Disagree		Strongly Disagree		Total	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
ART centre too far	46	74.2	12	19.4	4	6.5	-	-	-	-	62	100
No money to follow treatment	52	83.9	4	6.5	6	9.7	-	-	-	-	62	100
Worried about sustainability of treatment	6	9.7	46	74.2	1	1.6	6	9.7	3	4.8	62	100

Source: Chivuna survey 2009-2011. *P<0.000, for all the reasons*

For adherence, the distance factor was even more challenging because of the continuous and repeated need for medical refills and other appointments. Many participants pitifully recounted the anxieties and agony they experienced each time they were required to go for their medical refills for the lifelong medication. They were aware of repeated travelling to the health facility and the troubles of finding transport money many could not afford. As a result, most of the people from distant communities wanted ART services to either be extended to nearby health facilities or made available through mobile services and satellite clinics.

Sharing her experiences, a female ART user who was also a widow and from a community located about 40 km from the ART centre narrated that:

> *"Ino basa musinzo wakuboola ku Mission abuzuba kubweza musamu watujaya, mbulwazi buti oobu butanvwi musamu (The journey to the Mission to get medical refills is really killing us, what kind of disease is this that cannot be treated?). Can't they make the medicine available at our nearest clinics like Hanzala or deliver them the way they do for under-five? Some people get discouraged to go to the clinic when they think of walking the long distances all the time"* (67 year old widow and ART user, mother of six, clinic based IDI).

Expressing similar sentiments, during one of clinic based a mixed group discussions and amid agreement and support from other participants, another elderly woman from an equally distant community recalled:

> *"Distance is too much for some of us, it could be better if the medicines were made available where we live, if the clinic people were bringing the medicines in the communities for those who come from distant places. There are times some people become very sick and if there is no one to send to get medicine on your behalf then you have to wait until you feel better because you are unable to travel the long distance , meanwhile you miss taking your medicines because you have nothing"* (Elderly female ART user, clinic based mixed FGD).

The distance factor was also acknowledged by all health care providers as expressed by the following statement from one of them:

> *"Yes the distance factor really affects adherence and this is even worse in the initial stage of drug initiate because when they are just starting, a client is first given drugs for two weeks for monitoring purposes ,then after that they are given for another two weeks. After that if the client experiences no major side effects, the period is increased to 1 month. If the client still experiences no major problems, then they are given drugs to last for 2-3 months. Now you find that some fail to turn up because of distance. The initial stage is crucial because this is also the time when most patients may start feeling worse because of side effects and that is where effective follow-ups are important to avoid patients dropping out"* (Health care provider).

The distance factor was compounded by travel related costs. Key informants from the health facility and community did recognise the problems experienced by clients as a result of repeated visits to the health facility, particularly, those who were coming from very remote communities. Appeals for drugs to be made available nearer to the community were repeatedly made so as to reduce anxieties and worries experienced each review date by those affected. Expressing his concerns, one of the traditional leaders, explained:

> *"Some is again the distance and transport costs to the health facility that hampers adherence, the situation in some of the households is really bad, for one to raise some money to continuously go to the clinic is just impossible."*

These concerns were shared by several other key informants from the health facilities, as summed up in the quotation below:

> *Those in distant communities still face the problem of distance because even with the setting up of Chivuna ART there are still a lot of people coming from distant places may be 62 kilometres and some fail to turn up for review when they are feeling unwell because they fail to raise transport money and they may be too weak to walk.*

Therefore, while appreciating the service, many, study participants bemoaned the time spent away from their livelihood activities. This was so especially during the rainy season because of long waiting times to see health care provider each time they went for review. For those coming from remote areas, the time spend away from livelihood activity was even more because some were reported to travel from their homes a day in advance as one of them poignantly narrated:

> *"Then distance to the health facility is a big problem, but if you want life what can you do? As for me I always start off from my place on a Sunday and spend nights with one of my relatives who live near the Mission so that I can be at the clinic early enough and go back home the same day. Sometimes I make it to go back home the same day but like last time I came for review I was not feeling too well and I kept sleeping along the way and I had to spend a night on the way, and then the hunger, I was feeling very hungry but you see I could not ask for food from the people who gave me where to sleep because I felt embarrassed, I had carried some chibwantu [local non-alcoholic brew] ,but it got finished, so I slept hungry and continued walking the following day"* (33 year old Male ART user, clinic based IDI).

Long distances were compounded by conditions of poverty and at times extreme poverty in some households which made securing of transport fares a big challenge. Given the above scenario, many respondents pointed out that they depended on walking when going to health facility irrespective of distance because they were unable to raise the money required to meet transport costs. Therefore, whenever the question, "How do you get to the health centre?" was asked, the usual response was, *'Kweenda amaulu',* (walking on foot). Emphasising how poverty had negatively impacted on the local people, a male informant from the community who was also an ART supporter narrated that:

> *The poverty levels in this area are quite high, some of them fail to raise even a small amount of money for them to be able to reach the ART centre and may be they would not even have any food in the household, so how do they come to the clinic? The situation is usually worse during the rainy season when most people have completely nothing in their households.*

Similar sentiments were echoed by another key informant from the health facility who was also a coordinator for PMTCT when she said that:

> *"Some people even fail to raise a mere K1, 000 (less than 20 cents) so paying for the transport to go for VCT when they are not sick is usually the last thing that they can ever think of"*

These assertions were consistently reiterated by many community members themselves who were equally concerned about distance to the health facility. During a focus group discussion with men from a community located approximately 18 kilometres north-east of Chivuna Rural health facility one of the men remarked that:

> *"We depend on walking even if transport may be available because we can't afford transport costs of K5, 000 [about one dollar] one way, so we walk most of the time."*

The distance factor was more challenging for the physically challenged, aged and the very young. For instance, for the children, the long distances meant that they always needed somebody to travel with each time there was need for reviews and collection of drugs. Therefore, in answering a question related to the challenges of being on ART, some of the children on ART most of whom were also orphans narrated how difficult it was for them to travel on their own to the health facility as some of their guardians may at times either unwilling or unavailable to accompany them.

Related costs in adherence were also more challenging because in addition to transport costs, there was need for one to have money to purchase food while away from home attending reviews and medical refills to enable them take their medicines. Counselling was another factor identified as influencing all the stages of the continuum.

(ii) Waiting and Opening Times

Inadequate staffing was also mentioned by both health care providers and users as being a barrier to quality of services provided in general and length of time taken for one to be attended to by a health care provider. Almost all the health care providers interviewed complained of increased workload with the introduction of the ART clinic. They noted that ART services were introduced while numbers of staff remained the same. Consequently, long queues were usually a common sight at the ART clinic with some people waiting as long as five hours before they could be attended to. On some ART days, the visibly tired health care workers struggled to attend to all the clients by extending working hours, exhibiting a lot of commitment towards their work.

Many study participants, users in particular also complained about the limited opening days and time of the ART clinic and long waiting hours while waiting to be attended to by the health staff, in particular, the only clinical officer. They noted that most of them spent very long hours waiting even when they came very early in the morning, with some of them reaching as early as 05:00 hours. This was with the hope of being attended to early so they could go back home in time to attend to their livelihood sources. However, most of them were only able to leave the health facility after mid-day. This was also confirmed by several observations. Study participants in particular key informants from the health facility attributed all these problems to inadequate staffing.

The staffing situation was ably summarized by one health care provider when she narrated that:

> *"The ART clinic was introduced without any changes in the number of staff. This has led to increased work load for the few staff available. For instance, the full establishment for the health facility even without the ART clinic is two clinical officers but we only have one. So on each ART day, the only clinical officer has to first do the rounds in the wards and attend to any emergencies at the OPD before going to the ART clinic. This contributes to long queues and long waiting times that clients are subjected to. Not having enough staff is also partly the reason why the ART clinic is limited to only two days in a week."*

Similar sentiments were expressed by several community members as illustrated by the following remarks:

> *"The attitude of most health care providers is just okay but the problem is that the doctor (referring to the clinical officer) is just alone and patients are just too many and no one to help. Some people can wake up around 04:00hours and they are here by 0600 hrs and they would be number 3 or so but the doctor only comes around 0900hrs. The doctor has to work at OPD and wards and after she has finished, that is when she attends to patient patients at ART. Even if you were the first one to arrive, you will go home around 13:00hours. The workload is just too heavy for one person, if the government could at least send one or two more doctors so that they can assist each other"* (ART user a mid agreement and support from other discussants, female community based FGD)

Some health staff complained of the trauma and emotional attachment that they developed towards some of their clients, particularly those who were already too sick, aged, the very young and those they had been interacting with for a long time. Some of them also mentioned stress arising from dealing with large numbers of clients in a day.

(iii) Lack of Trust and Confidentiality Concerns About Health Staff

Partly because high levels of HIV and AIDS related stigma and discrimination in this community, many study participants were concerned health care providers, some of whom knew them personally would divulge their positive status to other members of the community. Seen within this context therefore, confidentiality and privacy was were valued as very important factor facilitating entry into the continuum, engagement and retention in care and treatment. Lack of confidentiality was therefore, another factor that emerged as an issue negatively influencing access and utilisation of the available VCR and ART services and hence either delaying or limiting the desired linkages in HIV care continuum. Because of such concerns, some users feared that health staff would inform other people in the community about their positive status if they went to the health facility to access HIV and AID related. It was reported that at times, people preferred to go to far off VCT and ART centres for VCT and ART services leaving Chivuna which was close because of confidentiality concerns thereby causing a lot of delay in accessing HIV and AIDS-related services. For instance, it was revealed that there was a lot of "swapping" of clients between Chivuna and Mbayamusuma rural health facility that offered ART in the area as some clients living near Chivuna rural health facility preferred to go to Mbaya rural (Puki) health centre and vice versa. One of the health workers explained that this was very common and that at times those clients who could afford transport costs from Chivuna travelled as far as Lusaka located more than 100km away for their VCT and ART services because of the same concerns.

Confidentiality concerns came up from both health staff and ART users. Sharing his experiences, a male ART user, who was tested and commenced taking his drugs in the capital city before him retiring from a government department, remarked:

> *"Some [health care providers] do keep secrets, others do not because people are different, some people complain about the issue of confidentiality among some of the health care providers who work at the ART clinic. I think these people need more training so that they can know how to handle such issues of confidentiality. You know at Chelstone clinic (referring to health facility in an urban setting of Lusaka the capital city of Zambia), where I started from, health care providers are better trained to handle such issues, you do not find people complaining,"* (63 year old male ARV user, clinic based IDI).

Similar concerns were expressed by several other ART users. For instance, during one of the community-based in-depth interviews, a 59 year old female ART user poignantly stated:

> *"Then you also have some health care providers who do not keep maseseke (secrets) and they go and publish what you have shared with them to everybody out there, sometimes you are just the two of you and then after some time you hear your issue being talked about at Copper (referring to a popular drinking place in the area) and then you start wondering how did these people come to know about it? Some people do not come here because of this behaviour of some of the health staff"*

Some health care providers admitted that some of their colleagues did not always maintain confidentiality with regard to HIV status of their clients as explicitly noted by one of them:

> *"Another thing is that some people do not have confidence in us as health care providers. I have heard some people say "people who work at the clinic do not keep secrets, you would share something with say an ART supporter or health care provider and the next day you hear about it in the community. So I think we need to work on confidentiality if people have to come and utilise these service and stop shunning them"* (Male health care provider).

Because of these confidentiality concerns, some people said they avoided certain health staff they did not trust selecting to see those they could confide in. They would only approach the un- trustworthy staff if they had no option and were totally stranded and convinced that their confidant was not going to be in the clinic on that particular day. This was clearly conveyed by the statement from one of the male ART clients when he recalled:

> *"For me there is one counsellor [named counsellor], I trust a lot but sometimes I go there I do not find him and I keep hesitating going in the counselling room thinking that he will come but you find that he is not coming and then I just force myself going inside and see whoever is there"* (39 year old Male ART user, clinic based IDI).

This statement was echoed by one of the male health- care providers when he noted:

> *"Clients do choose who to confide their secrets with, I have seen this, when a particular clients sees that the health care provider they trust is not there you just see them just loitering outside, hoping that the particular person would come, they will only go into the counselling room when they are convinced the health care provider they would be waiting for was not coming on that day."*

Some participants were also of the view that not having permanent staff based at the ART clinic compromised confidentiality (as staff worked at the ART clinic on rotational basis). Generally, they felt that when too many health care providers were involved; keeping of secrets was not guaranteed as a young female ARV user stated:

> *"Then also at our clinic here it is not like at Mbaya where you find the same people all the time you go to the ART clinic, here they keep changing so it is difficult to confide in so many health care providers, a friend of mine who started with Mbaya has continued going there despite Chivuna ART centre being opened nearby for the same reason, she tells me there you find the same nurses each time you go there"* (Young female ART user, FGD with support group, community based).

There was also a preference for fellow positive people to be the ones to work as ART supporters. These were viewed as more understanding, more caring, non-judgmental, supportive and trustworthy than the non-HIV positive ones, as expressed by the statements below:

> *"That is why even ART supporters should be people who are also on medication because they at least have experience with the medicines and also they are more understanding. Again fellow positive ART supporters are better because we have something in common with them. Even in terms of encouraging people for ART they are better because they speak from personal experiences and they also keep secrets, you see some people are forced to go to health facilities elsewhere for the sake of not wanting to have their status revealed in the community"* (25 year old Male ARV user, clinic based IDI).

Apart from lack of confidentiality among some health staff, some participants accused certain health- care givers of being fond of blaming clients, non- empathetic, uncaring, un-kind, rude and fond of using unpalatable language to clients. They pointed out that their condition as people living with *(eechi chilwazi),* this illness (i.e. HIV), required being treated with understanding, kindness and care. A number of study participants attested to having bad encounters with some of the health staff, including nonverbal reactions as some of them shared their experiences:

> *"Some [health care providers] are very bad the way they treat patients, they like telling off patients and pass comments like: Tiitwakaliko nomwakali ku bweza bulwazi, (We were not there when you were getting infected with the disease) yet they know that us patients are short tempered). You know this disease is a complicated one, patients require people who are kind and understanding)"* **(**42 year old male ARV user, clinic based IDI).
>
> *"Some of those nurses do stigmatise a lot, you see them not wanting to sit close to you, especially if you are coughing, inga balatantamuka, (They discriminate), sometimes you even hear some of them saying, ma inga bwakutambukila bulwazi (You can end up being infected too)"* (middle aged female ART user, community based FGD).

Due to lack of understanding of the window period, some study participants also reported that some health care workers could not be trusted and hence capable of deliberately infecting people with the HIV virus. According to them, this explained why some people tested negative on the first visit and positive during the second one. Some of the health workers were also accused of being careless and that as a result mixed up blood samples and hence giving wrong results.

Separation of VCT and ART services from general health services also emerged as a concern.

(iv) Separation of Health Services

The study found out that at Chivuna health facility ART services were separated from the general health services. This was a problem because it exposed those who attempted to use these services to finger pointing and gossip. As a result, it limited or delayed people in coming forward for testing, from being linked to a health care provider, initiation of ART and also caused treatment interruptions. It was reported that this was one of the reasons why clients requested for a separate gate away from the main gate. This was to enable them enter and exit secretly without them being seen by the other people attending general health services. This concern came out clearly in number of interviews and discussions. For instance, expressing her views during one of the community based focus group with women, one of the discussants noted:

> *"I heard that at the hospital there are segregated areas where the ART patients get their drugs. As a result, people easily notice them that those are HIV positive. Most of those on ART fear to go for refills because of not wanting to be seen by other community members. This is bad because eventually some of them do not go to collect their medicines and shortly one dies. We have seen such cases in the community"* (Not tested female community member, community based female FGD).

However, other respondents were of the view that the separation was good because it made it possible for those affected interact with each other. This is can be seen from the statement from one of the health care providers as he stated:

> *"Personally, I feel the separation is good because enables them open up to each other since they all know that they are there for the same problem. At OPD this would be problem because it would be difficult to know what the person standing next to them on the queue would be suffering from, it could be malaria. At the ART clinic you find that people just open up and start talking to each other, sharing experiences about the medicines, distances they cover and so forth. So I think the separation of services is quite helpful."*

Several ART clients also seemed to share this view. Another cross-cutting factor identified was provision of food-supplements.

4.4.5.2 Facilitating Factors

(i) Provision of Nutritional Supplements

Nearly all respondents including health care providers, ART clients and community members strongly felt that availability of food supplements, provided by CHAZ, was a potent motivator not only for testing, but for ART up take, retention in care and treatment. Many attributed this to the poverty levels in the area which generally affected the food security for many households. It was reported that at times, the situation was so desperate that a positive HIV test result was preferred as it was viewed as a way of having access to food. The statements below show the perceived role of nutritional supplements in the various stages of the continuum:

> *"But madam, (referring to the researcher), the food issue has a very important role to play in motivating people to go for VCT and adherence to medicines. Sometimes people even prefer to be found positive so that they can have access to food and become very annoyed when they are found negative. You hear them saying 'Tiimwapima kabotu bulwazi nkobuli mumubili oyu" (You did not conduct the test properly, I am sure the disease [referring to HIV and AIDS], is there in my body"* (ART supporter, Community based KII).

The views on the need for food were not confined to women. Men who are traditionally expected to provide all the basic needs, were equally concerned about food.

> *"If somebody has no food there is no encouragement to go for VCT. Most people have heard about the increased appetite and hunger problems arising from taking these drugs, so they get demotivated from going for VCT because they will start worrying where they would get food from should they test positive and required to start taking medicines"* (un-tested 34 year old male, community-based male, IDI).

Some of respondents stated that some people who tested negative came repeatedly in the hope that they would be positive and have access to the most required commodity. Health care providers were also cognisant of the role food supplements played in HIV-testing and therefore, lamented that such packages were no longer provided for all their clients due to insufficient supply and the increasing number of clients requiring them.

It was reported that the food situation usually became desperate particularly in the months of December and January because this was the time when most households ran out of food and the crops for that particular season were not yet ripe. Many ART clients narrated how some community members teased them and called them all sorts of names each time they saw them carrying food from the clinic but at the same time envied them. This is elucidated by the quote below:

> *A number of those who are not on ART laugh at us and call us all sorts of names but at the same time they envy us as we carry our food from the clinic, they would have nothing and some come secretly to beg from us, you can really see the envy in their eyes and we see some of them coming to test* (Male ART user, clinic based male FGD, amid agreement and support from other participants).

Even after testing for HIV, the issue of food insecurity haunts the poor people. This of course affects decisions of those eligible for ART to start taking medication and also the levels of adherence during treatment. This means that nutritional support does not only influence people's willingness to test for HIV but also their decision to start and continue taking the life prolonging medicines. To a great extent, at ART uptake stage, this fear was due to anticipated side effects associated with the drugs as they had heard drugs from those who were already on the drugs, as shown in statements from one of the ART users who stated that:

> *"The other problem that troubled me was lack of food because at the time that I was tested, we were told there was no food at the clinic. So I started thinking to myself, if I am tested and found positive and required to start taking the ARVs, how will I manage without food because I used to hear from those who were taking them complain about too much appetite and hunger as a result of the medicines. So I was worried"* (65 year old Male ART user, clinic based IDI)**.**

For those already on medication, the worry was with the actual side effects as they were able to personally experience them. For instance, during one of the community based in-depth individual interviews, a 55 year old female ART user noted:

> *Number one is the food that I get from the clinic. I am a poor person, without this food I do not know how I could have managed because the drugs cause a lot of appetite and if you do not have food, you can cause other problems in your body. Then two, I really need life, I want to prolong my life so that I can work for myself as I used to do before and see my children grow before I die.*

These views were reiterated by several other community members and health care providers working in the area. Several factors were mentioned for this scenario among them persistent cattle diseases. As a result, many were found to have resorted to cultivating their fields using hoes. This kind of cultivation is very limiting in farming. Use of hoes is very common but has severe challenges among most communities and worse among those who were sickly or just recovering from some illness.

The other contributing factor mentioned to the rising poverty levels in the area was the lack of access to the market as a result of the liberalised market economy which exposed many small-scale farmers to unscrupulous briefcase businessmen. The scenario was worsened by the poor road network in the area. The connection of these rural economic hardships to food supplements is that such unprecedented collapses in both crop and animal agricultural systems have stressed the rural villagers to a level of envying food provided at the AIDS-related programmes.

Additionally, many ART clients mentioned that they had become poorer after being bedridden for a long time with some reporting that while they were not able to engage in meaningful agricultural production during the time they were sick, they used up whatever small savings they had accumulated for consumption.

It was also revealed from different sources that although free ARVs were available, a number of people still delayed to go for testing due to the various barriers they faced. This meant that they only accessed ART when they had already become too sick and were therefore off production for some time leading them to rely on food supplements as they began the treatment.

Some respondents also reported that before the medicines were made available for free, some people would want to deliberately use up all their savings be it cash or animals thinking that, "I will die soon and leave all these properties for other people to inherit, so let me use up everything so that "*bagunywe bayanda kukona"* (to shame those who want to inherit my property because I will leave nothing for them). This also exacerbated the poverty levels.

Many key informants particularly from the health facility were aware of the difficulty situation that those once bedridden were in and were expected to fend for their families almost from the scratch. However, they lamentably pointed out that they did not have the capacity to assist them in anyway.

Viewed within the context of poverty therefore, most respondents strongly felt that provision of food supplements was critical to facilitate adherence. However, many respondents were quick to mention the challenges involved in providing food supplements amid an increasing number of ART clients. They therefore emphasised the need to give the clients who recover some sustainable source of livelihood in order to reduce the dependence on food supplements from the health facility. This was elucidated by one of the male health care providers when he narrated that:

> *"Provision of food supplements is very important for people taking medicines, it encourages them to take their medicines consistently otherwise they may stop because of the side effects. Many of them have experienced increased appetite especially when one starts feeling better. You see one of the biggest challenges we have in this area is poverty and when we talk about poverty we mean that most of the people in this area are very poor here. This means that nearly all of them need food supplements*

> *and we are not managing. The situation for us has even been worsened by the withdrawal of WFP and so we have just remained with the food from CHAZ which is not enough. This is why for me, I feel that giving these people hand-outs is not really helping the situation, I think for those who recover should be supported in some kind of income generating activities".*

Study participants on ART equally shared the view about sustainable assistance for a number of reasons. Firstly, many of them were aware that they were not the only ones in need of food nutrients. Secondly, they appreciated the difficulty faced by the health facility in providing food supplements for an increased number of ART clients. Lastly, they wanted to get out of the shame and embarrassment that came with free food which made many of them have some feelings of change in their social status from that of self-reliance to that of being "beggars". They stated that they longed to be able to take charge of their lives and be able to fend for their families again.

While being supported by all the group members, an elderly male support group member, who was also the chairperson for one of the support groups, expounded his views:

> *"We appreciate the food the government is giving us, but at times it is very embarrassing and dehumanising for big people like us to be lining up for food, we have become beggars or like small children who are unable to look after themselves. We need fertilizer and seed so that those of us who have become stronger can be able to grow food for ourselves instead of government continuing to giving us food, you can imagine carrying these (pointing at a 2.5 litre container) for cooking oil each time we come here, if we grow enough food for ourselves we can be able to sell part of it, buy ourselves cooking oil and all the nutritious food we need. Only lazy people would want to continue getting free food even after they have recovered. We formed a support group but we do not have enough capital to start a meaningful income generating activity"* (Male discussant, community based FGD with support group).

While low agricultural production was generally reported for most parts of the area, a group from Namaila, one of the remotest areas boasted of having plenty of food in their area. However, they instead lamented over lack of access to markets to enable them sell their produce due to poor state of road network. Furthermore, they stated that if there was accessibility to the markets, they would expand their production and have money needed to buy themselves nutritious foods necessary to go with the medicines.

In order to have a typical measurement of the role of food supplements on the continuum, the study investigated the extent to which food supplements influenced adherence. The results are presented in Table4.12. The results show that most of those who received food supplements (88.7 per cent) never missed taking their medicines. This shows that there was a relationship between one having access to food supplements and adherence, typically showing how the supply of food supplements was influential in the continuum of care in this limited resource setting. The relationship was significant at P=0.00 as indicated below. On the other hand, 87.5 per cent of those not receiving food missed taking their medication for more than two weeks.

4.12: Association between Food Supplements and Period ever Missed Taking ARVs

Received Food Supplements	**Period ever Missed taking ARVs**									
	1-2 Weeks		**2-8 Weeks**		**More Than 2 Months**		**Never Stopped/Missed Medication**		**TOTAL**	
	No	**%**	No	%	No	%	No	%	No	%
Yes	4	1.8	21	9.5	0	0.0	197	88.7	222	100
No	3	9.4	28	87.5	1	3.1	0	0.0	32	100
	7	**3.0**	**49**	**19**	**1**	**0.4**	**197**	**77.6**	**254**	**100**

Source: Field work Chivuna survey 2009- 2011, $\chi^2 = 24.0033$, $P<0.000$.

As can be seen from the P value, this association is very significant. Many study participants on ART lamentably explained how difficult it was to take the medicines without food. A widow in her late sixties who was on ART and not a beneficiary of food supplements remarked:

> *"Lack of food has been the major barrier for me. You know these medicines are very strong so you take them without food in the body you feel like you are running mad. Some of our friends are lucky because they have continued getting food from the clinic, some of us have nothing, at least those getting food from the clinic do not have to worry about food to take with their medicines"* (Female ARV user , clinic based IDI).

These sentiments were also reiterated by a female health care provider when she remarked:

> *Then there is the issue of nutrition, this is very important because the medicines are very strong, without food the patients feel weak and become discouraged from taking them every day. So the programme on food aid is a motivator for adherence.*

Although availability of nutritional food was reported by all respondents in general as a motivator for nearly all the stages in the continuum, there were reports of inconsistencies and inadequacies in the supply of this most wanted commodity. For instance, it was reported that sometimes the nutritional support did not come on time while at times it was not enough to cater for everyone who was eligible. This made it difficult at times for the health care providers to register new people into the programme even when they desperately needed the food.

It was also reported that community support for the sick was no longer there because of the dying spirit of giving among members of the community. This social support spirit was reported to have been eroded away by the high poverty levels affecting the area. This meant that in the event that one was too sick to provide for oneself, there was no guarantee of getting any assistance from other members of the community and hence the much reliance on the food from the health facility.

Whenever it was mentioned during the interviews and group discussions both within the community and at health facility as shown in the sentiments below, the issue of food supplements usually raised a heated debate. According to some study participants particularly, ART clients and others from the community, the inadequate supply of food nutrients was at times artificially created. They stated that the food received was enough to go round for most of the clients in need had it not been for what they referred to as some "greedy health care providers". It was reported that some of these greedy health staff were fond of getting food meant for ART clients for their own families while others were reported to be selling the food. These sentiments were raised in various interviews and discussions as can be seen from statements from one of the focus group discussions with community members from central part of Chivuna when a participant stated that:

> *"Some of those nurses are really benefiting from that food; some of them even refuse to be transferred to other health care facilities. Sometimes you find them at one of the food containers sharing the food. There is one nurse who was supposed to be transferred to Hanzala health centre but she declined to go because of the same benefits"* (Middle aged male discussant, community based men's FGD).

Other concerns raised as regards the food nutrients were the long distances clients were required to cover in order to access the food and carry it home on their heads. Discussions, repeated observations and interactions with some of the clients revealed that some of these clients came from communities located over 50 km away from the food storage facilities and some were either too sick or too old to carry the food on their heads. For instance, on one of the ART days, the researcher observed a sickly looking old woman who after getting the food remained at the facility for hours. The research team had no option but to drive her to her home village located more than 20 km away. The old woman narrated that in most cases she spent a night at the facility if there was no "Good Samaritan" going in her direction while at times she had to depend on the Parish priest to give her a ride on his way back from his outreach programs.

Another concern raised was the location of the food containers being in front of the out-patient department (OPD). According to study participants, this exposed the beneficiaries to embarrassment, ridicule and begging from other members of the community. This was worsened according to some of clients by the "deliberate loud calling of names by some nurses such that all passers-by and those at the OPD could hear so as to embarrass the recipients". The clients proposed that the containers be moved to the ART building away from the main facility building to reduce gossip and finger-pointing.

(ii) Use of Role Models and Positive Living

It was reported that as part of community sensitisation, health care providers used some of the willing ART users for some time as role models. Usually, these would tell their stories and experiences of how sick they were before they went for testing. They also narrated their personal positive living experiences with ARVs. This was done either during community-based sensitisation or during HIV and AIDS day commemoration in December which was organised and celebrated at the health facility every year. This was done through sketches and drama. Such activities contributed to the individual motivation of going for HIV testing on the basis of *kubona wakali kunywa musamu wakapona,* "seeing someone on ART get better."

(iii) Counselling and Psychosocial Support

Counselling was found to be another cross cutting enabler for testing, linking HIV positive people to health care provider and also to continue moving along the continuum. This included pre-test, post-test/pre-ART and continued counselling. Therefore, pre-test counselling was reported to be a very strong facilitator for testing while post-test and pre-ART counselling were important to link people to a health care provider and also encouraged people start taking ART once found eligible while continued counselling enabled and encouraged those on ART to continue taking medication despite the barriers that they were facing. This was clear from the sentiments from community members in general and those who had an opportunity to be counselled in particular. A middle aged widow on ART who was once bed-ridden and after her recovery decided to work as a volunteer adherence supporter shared her experience when she stated that:

> *"One day on my way to the clinic I met a young man from TCE. He talked to me about the goodness of testing early and starting to take the medicines before it was too late. He reminded me about my children and how they would suffer if I was to die like my husband had. All this encouraged me to go for testing and after a week I was tested and was found HIV positive. Before that, it took me almost two years of feeling unwell without going for a test"* (Female ART user, clinic based IDI).

Expressing similar sentiments a male health care provider noted that:

> *"Without pre-test counselling, people usually delay to come forward to test because of fear. Even when they come to the clinic, you see some reluctance, but after you explain to them the advantages of VCT and the medicines then you see them changing their mind almost immediately. The only problem is that sometimes the time for intensive counselling may not be there because of time constraints."*

Many participants in the study also acknowledged the encouragement and support that they received from some health care staff. They narrated how they were encouraged to go for testing by health care providers whom they interacted with at the time. During one of the mixed focus group discussions with some ARV users, the following views were expressed:

> *"For me sister Mooba has been really encouraging. Inga ndaamba kuti Sister Mooba ngo Leza wangu nkaambo nindalifwide" (I would say that Sister Mooba is my god because had it not been for her, I would have been dead by now). When some of us were going for testing, Chivuna ART centre was not there; my wife became very ill after delivery, and I was required to take her to Monze hospital but I had no transport money. So she assisted me with transport to Monze, my wife was tested positive there. When I saw this I was also encouraged to test and found positive too. So as my colleagues have said some health care providers are really encouraging and helpful"* (Middle aged male ART user, mixed clinic based FGD).

To some extent, the sentiments from the quote above also indicate the importance of a cordial relationship between patients and health care providers in encouraging access and utilisation of HIV and AIDS-related services.

Discussions with those on ART revealed the critical role played by post-test counselling in the subsequent stages of the continuum after a positive HIV test result. They narrated that acceptance of a positive HIV test result and hence acceptance to live with a chronic illness and dependence on medicines for life was a complicated process. It involved firstly, acceptance of the HIV positive result and secondly, seeing oneself around the new status of living with the virus. Acceptance was at times further complicated by community talk and negative beliefs about the medicines. In order to accept the new status and its implications, adequate post-test counselling was identified as one factor that encouraged those who were found positive to see the need for being in touch with a health care provider who would offer them pre-ART Medicare and support. Similarly, pre-ART counselling acted as a predictor for those who were eligible for ART to start taking the medicines as during this period HIV positive were counselled on the benefits of ART and starting taking ART as soon as the prescription was done. For instance, several study participants on ART who had the privilege of being counselled adequately shared their experiences of how, amid several other factors, post-test counselling helped them start taking drugs. This can be seen from the statement below:

> *Yes I did, I think because I was properly counselled. I was informed that my CD4 count was very low and that it could be lower than that if I did not commence taking drugs immediately, which would have been too risky. But when I was given my results, I could not believe it. I used to cry lot at first. Later I felt better because I knew at least I could be treated. I think this was all because of the counselling that I got, otherwise it was very difficult for me to accept at first before this counselling* (33 year old female ART user, community IDI).

Sharing her views and experiences on the importance of adequate counselling from working with pregnant mothers in antenatal clinic, a female health care provider noted:

> *"Some people are reluctant to start taking medicines due to deep denial and poor counselling. Counsellors deal with many people, so some people would not be satisfied with the counselling because the counsellors get tired at some point. The main problem is staff shortage. This is critical, you find that you have forty mothers and you are just alone, yet there is need for adequate time for a positive mother to go thorough adequate counselling after testing."*

When asked what motivated them to continue taking the lifesaving drugs, most study participants reported that they were encouraged to do so because of continuous encouragement, emotional support and counselling from health staff. Some of them stated that they almost stopped taking their drugs because of the side effects and were encouraged to continue by the counselling and support received from the health staff and community based health workers as narrated below:

> *"Then we have encouragement from the health staff, some of them are really helpful and this has kept some of us going and made us continue taking the medicines. Without this kind of support one would just give up because it is not easy being on these drugs. They are very encouraging and always continue advising us. There were times when I was feeling like stopping because of the way I used to feel each time I took the medicine but the nurses kept on counselling and encouraging me"* (**24 year old M**ale ARV user, clinic based IDI).

> *"It was after three months after taking ART when I developed kasinga, (side pain) in my chest. It was very painful especially when I was trying to do some work. The pain*

> *was there for two weeks and it was terrible and I almost stopped taking the medicines. I went back to the clinic where I was advised by one of the nurses that all would be well after sometime, they told me that I was to keep on taking the medicine and that I would be okay. That is how I continued and now everything is over"* (Female ARV user clinic based male FGD).

Other categories of people who played a role in this process were support groups and community health workers such as adherence supporters. These followed those that had tested and found positive to ensure that they accessed a health care provider for pre-ART Medicare and professional counselling, encourage those eligible for ART to start taking medication and also adherence to medication for viral suppression.

Despite counselling and psychosocial support being an enabler of people's entrance and continued movement along the continuum, it was found to be limited and hence inadequate and this was due to several other health system and individual factors. This made counselling inadequate and less intensive. Inadequate counselling was a barrier to all the stages of the continuum in that it delayed or prevented people from entering the continuum, being linked and ART uptake as HIV positive may not be mentally prepared to accept a positive diagnosis and link further for care and treatment. Inadequate continue counselling also led to treatment interruptions as people need continued counselling for them to cope with living with an incurable health condition.

One of the factors limiting counselling was shortage of space. Several participants strongly felt that the available space was inadequate to accommodate all the services that were being offered. Therefore, much as the health staff could be aware of the need for privacy in counselling in ART services, the available space did not allow the kind of privacy that was desired for proper counselling environment. This was seen as negatively impacting on the quality of counselling. For instance, due to limited space at the ART clinic, the room where counselling was conducted was also the place where patients' records were kept. This situation raised concerns among both key informants and community members who viewed it as compromising privacy and confidentiality required for counselling.

These concerns can be illustrated by the following quotes:

> *"We also need a bigger building so as to accommodate all these services that we are providing. For counselling we need privacy so that patients can be free and comfortable. At the moment this is lacking and as a result clients are limited as to how much they can share with the counsellor because instead of having only 2 people in a room there are usually more than two people in the same room because registry is also the counselling room. So even when they happen to have questions about their treatment and condition, some may not say anything"* (Male health care provider).
>
> *"The rooms are not enough, you find in the room there are many of you, maybe more than three yet you are supposed to be only two of you with the counsellor, there is no privacy at all. Most of the time as you are talking to the counsellor there is another nurse giving out cards and people keep coming in and going out of the same room and you get distracted"* (male ARV user, male clinic based FGD amid agreement and support from other discussants).

In addition to privacy concerns, some study participants expressed fears of cross infections due to congestion. To some extent, such concerns also imply that some ART users were aware of their susceptibility to infections as a result of their low immunity which further precluded them from using the limited infrastructure. The assertions made by the study participants were verified through repeated observations.

Another factor raised for inadequate counselling was understaffing amidst increasing patient levels with the introduction of ART, was viewed by many health care providers interviewed as negatively impacting on quality of services that they ultimately delivered. Therefore, while adequate pre-test, post –test and continued counselling were crucial for encouraging people enter and continue moving along the HIV continuum, many health care providers and users expressed a lot of concerns over its quality. These concerns can be elucidated by the view of some of the health care providers when she stated that:

> *"Even counselling if it has to be adequately done, we need more counsellors. This is considering the numbers of patients that we deal with. We are supposed to be with one patient for at least not less than 20 minutes but because sometimes there would be a lot of people to be seen and just a few of you to attend to them, this becomes very difficult. And also because many of them cover long distances to reach the clinic, you try to squeeze in as many as possible to ensure that all are attended to and by the end of the day you are completely exhausted. This also affects the way some health staff behave towards patients because they are human beings and they get tired."*

For community based community workers and support groups, their main limitation was lack transport yet they were expected to cover long distances so as to reach some of their clients. They also complained of meagre allowances they were getting which were not enough to carter for their families. According to them, this forced them to have divided loyalty particularly during the peak periods as they needed to provide for their families.

Another factor linked to inadequate counselling was limited training in HIV and AIDS-related services. Nearly all the health care providers, lay counsellors, and volunteers ART and adherence supporters interviewed indicated the need for further training in ART delivery and counselling services. They noted that the training that they had received was not adequate to enable them deal with all the aspects of HIV and AIDS. For instance, only the clinical officer and ART Coordinator had official training in ART services. It was also reported that about eighty-seven ART supporters and nine of the health care providers had been oriented to counselling, with only one nurse having been oriented to do all the requirements for dispensing of ART. Thus, expressing concerns about training needs, a male lay counsellor remarked:

> *"We definitely need further training in ART delivery because so far we have just been oriented for one week, under normal circumstances, the course we did should have been done in two months but it was compressed and so we covered it in one week. Though we were trained in both counselling and palliative care, this is still not enough. We need more training in all areas of ART."*

In a related interview, a female health care provider noted:

> *"All members of staff need more training so that they can be competent in ART delivery, at the moment only the CO and the ART coordinator have had official training in ART services, the rest of the staff have only undergone orientation for one week and this is not enough to enable them adequately handle all the issues that relate to provision of ART services."*

It was also revealed that at times health care providers who were adequately trained in ART delivery were not always working at the ART clinic. In essence, this compounded the inadequate training of staff in ART delivery. Gaining experience from working in the ART clinic would have been a cushion for inadequate training. For instance, it was found that the only nurse who had been oriented in all the areas of ART delivery and once coordinator for the ART clinic was at the time of the study, no longer working at the ART clinic but at the OPD. This did not only disrupt continuity in experience but was also a clear misplacement of training and experience yet both were very essential for a specialised field like ART delivery. At individual level, high illiteracy levels made counselling a major challenge. Many health care providers explained that this made counselling complicated as the level of understanding was very low.

4.4.5.3 Structural Level: Facilitating Factors

(i) Government Policy of Free Testing and ARVs.

Nearly all the ARV users interviewed explicitly stated that they were encouraged to go for testing because they only saw the point of doing so with the availability of free provision of ARVs. It was pointed out clearly, that in the past, people were not willing to test because they could not afford to buy the medicines. Similarly, free provision of ARVs was cited as the motivating factor for ART uptake and also for complying with medication.

Many participants were happy with the government for the free ARVs which most of them could not initially access due to the direct cost that was attached to them. They indicated that in the past only those with money accessed ARVs, presently both the rich and the poor could access the medicines. In fact for most participants, including some of those who were gravelly affected by the distance factor, free ARVs were viewed more important in enhancing access to ART services than reduced distance. Some of the views in connection with the free provision of ARVs were illustrated by the following statements from some of the ART users when they explained that:

> *"Free provision of medicines encouraged many of us to come forward for HIV testing because unlike in the past now all one needed to do is kulyaaba (decide) and do the test and the medicines are there. In the past people used to fear testing because the medicines were only for the rich but now any one can get the medicines. So that is why we say that the government should never stop providing us with these medicines because most of us will die, we can't afford buying ARVs. We really thank the government for these medicines, many of those who should have died a long time ago are still alive and looking after their families because of these same medicines"* (Elderly female amid agreement from the others, clinic based female FGD)**.**

Reiterating similar views, a male health care provider noted:

> *"Yes the provision of free ARVs has really motivated many people to do their HIV testing. Unlike in the past when people were given prescriptions to go and buy ARVs from pharmacies, now as long as they reach the health facility, they are assured of getting the medicine."*

Concerning linkage to a health care provider and ART uptake, many study participants who were on ART explained that they were encouraged to be linked to a health care provider and also start taking ARVs because they were being provided freely. They explained that many of them would not have been able to do so had they been required to buy because they were poor people. Therefore, there were comments such as, 'Free provision of the medicines made it possible for me to start taking the drug and because we are not to buy the medicines any more'. These sentiments were reiterated by many key informants.

Free provision ARVs also was repeatedly reported to have encouraged many ART clients to continue taking their medicines and hence also facilitating viral suppression. Study participants were aware of how difficult and impossible it would have been to have these lifesaving drugs had they not been provided free. They repeatedly and emphatically mentioned that without this service, most of the people were not going to afford buying the life prolonging dugs. Expressing her views, one of the female ART users explained:

> *"I have never missed taking the medicine and I am always going for reviews because I have accepted my position and also because I know that the medicines are there free of charge. If we were required to buy, how many of us were going to manage to buy? We were just going to be dying in our houses. The government has shown that it cares for its people, we are really thankful; many of us have been saved from dying early. Because even going to test, many of us have done so because now we know that help is there, the drugs are free and there is no need of one wasting time*" (52 year old Female ART user, clinic based IDI).

Reiterating the similar sentiments, a health care provider also stated:

> *"Yes free provision of ARVs is really one of the biggest motivators for adherence; there is no doubt about that. Most of the people do not have money and so they cannot afford buying the medicines. I think this is the same even in the urban areas but poverty is worse here in the villages because of lack of employment opportunities."*

To some extent it was not only the mere free availability that encouraged people but it was also to do with the positive perception that people had with the drugs. This positive perception has evolved overtime as more people were able to experience the efficacy of the AIDS drugs. Perceptions and how they have evolved over time will be discussed later below.

4.4.5.4 Limiting Factors

*(*i) Poverty and Livelihood Insecurity

Poverty levels were reported to be high in the area, nearly by all sources. Although a few people were reported to be doing well, evidenced by the buying of open vans used for transport, most people were reported to be generally poor and hence faced extreme economic hardships. As a result, many respondents talked to particularly those from remote communities, complained of lack of money to access health facilities or delayed in doing so as a result of having no money to travel to the health facility for testing, being linked to a health re provider and continue seeing a care provider, start taking medication and continue collecting medicines. Therefore, finding extra money to pay for transport to attend HIV and AIDS related services and to buy food during visits was a big challenge and hence one of the major reasons for no- engagement, delayed and lost to follow from care. This was mainly because most of the people in the area depended on farming which has been under threat from so many negative factors. Extreme poverty had also eroded the spirit of giving, a form of social security system that existed in the area and cushioned the sick and the elderly, exposing the needy even to more risks.

Even mere observations were enough to tell how perverse poverty was in some parts of the study area. For instance, Namaila (literally meaning a place of abundant sorghum), there was indeed abundant agricultural produce due to the many perennial streams in the area but the place was completely cut off from markets due to the deplorable state of the roads. This left the people with completely no access to liquid cash which they badly needed for transport to health facilities. In the rest of the study area, the common song was *denkete*, (animal disease*)*, lack of draught power, erratic rain patterns, lack of markets and deplorable road network.

To measure poverty levels, respondents were asked a self-perception question about how they considered their own households in comparison with most households in the community. The options were much richer, a little richer, same, and slightly poorer much poorer, and much poorer. The results are contained in Table 4.13.More people, approximately 48 per cent considered their households to be poorer (Slightly and much poorer, 27.3 and 20.4 per cent respectively put together). About 31 per cent perceived their households to be a little bit wealthier while only 2.3 per cent perceived themselves to be much wealthier.

Table 4.13: Self-wealth Perception of poverty

Self-Perception	**No**	**%**
Much wealthier	15	2.3
Little bit wealthier	201	30.8
Same	126	19.3
Slightly poorer	178	27.3
Much poorer	133	20.4
Total	**653**	**100.0**

Source: Field work Chivuna survey 2009-201**1**

As a follow up question, respondents were asked to state their level of worries about food availability in the home. Respondents were asked four questions as presented in Table 4.14. In response to the first question, as many as 45 per cent of the respondents indicated that their households were sometimes worried of their households running out of food and 23.6 per cent were often food insecure while 32 per cent stated that they never worried of food running out. Further analysis of Table 4.14 also shows that on the overall, most of the respondents indicated that they were food insecure, 68 per cent (sometimes and often put together) against those who felt they were always food secure, 32 per cent. The results in the table show that the scenario is quite similar to when the respondents were asked whether they had ever eaten less than they wanted to with 42.1 per cent and 23 per cent for sometimes and often eaten less respectively, representing 65 per cent. On the other hand, less respondents, 35 per cent indicated that they had never experienced any food shortages. These results indicate that food insecurity was quite a big problem in the study area and that it negatively influenced the HIV and AIDS continuum of care and treatment.

When respondents were asked about whether they knew that their children were hungry but did not have enough money to buy food, 43.2 per cent indicated that this was never the case in their households while 35 per cent and 22 per cent had experienced such a scenario either sometimes or often, respectively. This means that those who did experience some food shortages accounted for as many as 57 per cent. In answering the last question about buying nutritious food, again most of the respondents indicated that they were unable to buy nutritious food for their children, either some times, 41 per cent or often, 22 per cent representing 63 per cent. On the other hand, 37 per cent indicated that they had never failed to provide a balanced diet for their children.

Table 4.14: Levels of worrying about Food insecurity

	Levels							
Worries	**Sometimes**		**Often**		**Never**		**Total**	
	No	%	No	%	No	%	No	%
Running out of food	292	44.7	154	23.6	207	31.7	653	100
Eaten less than wanted	275	42.1	151	23.1	227	34.8	653	100
Knew that children were hungry but could do nothing	227	34.8	144	22.1	282	43.2	653	100
No money to buy nutritious food for the children	267	40.9	143	21.9	243	37.2	653	100

Source: Fieldwork, Chivuna survey data; 2009-2011

Because food security did come out strongly from the narratives as influencing testing, ART uptake and adherence, a typical relationship was sought between testing and food insecurity. Table 4. 15 presents results on food security and testing. The results show that more people 44.per cent, who never experienced food insecurity went for testing compared to 26 per cent from the same category that did not test. The results also show that 34.8 per cent of those who sometimes and 39 per cent of those often experiencing food shortages had not tested.

On the overall, these results show that food security was a predictor for testing with significance P value of 0.000 which typically shows the extent of the influence of food security on people's entry and continued participation along the continuum of care continuum.

Table 4. 15: Association between Experience of Food Insecurity and HIV Testing

	Experience of food insecurity							
	Sometimes		**Often**		**Never**		**Total**	
HIV/Test	**No**	**%**	**No**	**%**	**No**	**%**	**No**	**%**
No	47	34.8	53	39.3	35	26.0	134	100
Yes	192	37.1	98	18.9	228	44.0	519	100
Total	239	36.6	151	23.1	263	40.3	653	100

Source: Fieldwork, Chivuna Survey, 2009-2011, $\chi^2 = 28.0094$, $P<0.000$.

Therefore, like for VCT, there were a number of respondents who because of poverty and food insecurity reported having delayed to start taking the medicines. They were concerned about anticipated side effects if they took the strong medicines on empty stomachs. For instance, a 56 year old ART user who had been a widow for ten year and delayed to start taking her medicines for a year lamented that:

> *"Alimwi ndakanyina chakulya, ndakali kuyoowa kufwa akaambo kakubula chakulya ceelede mumubili, ino inga chakulya ndacijana kuli mebo ndimuchete, eechi chakandipa mizeezo minji nkaambo wanywa musamu kakunyina chakulya mumubili inga waliletela bulwazi bumbi, (In addition, I did not have any food, I was afraid of taking the medicines because I was scared of dying since I did not have the proper food to go with the medicines, where can a poor person like myself get food from? This gave me a lot of worries because I used to hear from those who were on ARVs that if taken without food, the medicines may lead to other unknown health problems)."*

This was also observed by many health care providers as illustrated by this statement that:

> *"In fact ARVs are perceived as being linked to food availability because some people feel that if one has no food then you should not think of taking them because of what they have heard about side effects from the drugs. You even hear some saying where do I get food from if I start taking ARVs, so it is better I do not just start taking them"* (Male health care provider).

Therefore, when asked about the role of food security on ART up take, many study participants did indicate that without food it was difficult for one to do so because of the worry of where to find food once on drugs. They noted that they had heard about side effects arising from taking ARVs without proper nutrition from those who were on ART. Results for food security and ART uptake are presented in Table 4.16. The data show that more respondents 73 per cent who never had food security were not motivated or delayed to take their medication followed by 16.5 and 10.3 per cent of those who often and sometimes had food security respectively.

Cursory examination of Table 4:16 shows that more than 50 per cent of those with food security, (57.3 per cent, sometimes and often put together), did start taking their medication compared with 43 per cent of those with no food security. The results also show that 73 percent of those without food security did not start taking medication. The data shows that the relationship between food security and ART uptake was very significant at 0.000 P. Value. This finding typically, further confirms the extent and level of influence that food security had on the whole continuum of care.

Table 4. 16: Association between ART Uptake and Food Security

	Have food security							
	Sometimes		Often		Never		Total	
ART Uptake	**No**	**%**	**No**	**%**	**No**	**%**	**No**	**%**
No	10	10.3	16	16.5	71	73.2	97	100
Yes	114	41.9	42	15.4	116	42.6	272	100
Total	124	33.6	58	15.7	187	50.7	369	100

Source: Chivuna Survey 2009-2011. $\chi^2 =$ 34.4677, $P<0.000$.

While poverty was found to impact negatively on VCT and ART uptake, its impact on adherence was found to be even more because of the need of repeated visits to the ART centre for reviews and medical reviews. Poverty was also found to be confounded by long distances to health facilities still being experienced by many communities. Additionally, most households were also found to be experiencing food insecurity. This forced some to depend on food supplements from the health facility which was also not enough for every one on ART. As will be seen below, many study participants narrated how difficult it was for them to continue taking medicines without adequate food and what they termed as terrible side effects arising from the use of ARVs without food.

Because of generalised poverty and food insecurity experienced in the area, Comments like "*musamu ulakola kuti ko nyina chakulya, nkaambo ooyu musamu ulaanguzu maningi"* (The drug can make you feel as you have taken alcohol if you take them without food because it is very strong), *bamwi besu inga balayoowa kunya musamu akaambo kakuti musamu ulapa nzala akulya maningi,* (Some of us are scared of taking medicines because of increased appetite and hunger arising from taking ARVs). Cases of people not taking their medicines and those tempted to stop taking the drugs due to hunger were therefore, quite common. Some of the lamentations over food insecurity and the challenges of taking ARVs without food are expressed in the quotes below:

> *The only problem with ARVS is the diet; you need to have good food like milk, meat and eggs, cooking oil, where does a poor person like me get the money to buy such foods? Then there is hunger, you feel like eating all the time and where does one that food to eat all the time come from? This has caused a lot of problems* (43 year widow ART user, community based FGD).
>
> *"These drugs are helpful and effective but they do give a lot of side effects especially hunger, I really have to struggle, to find food for my grandchildren that I am caring for because their appetite has really changed from the time they started taking these medicine. They need a lot of food. Sometimes they have to take the medicines without any food. I have heard elderly people on ART complain about bad side effects if drugs are taken without food, I know my grandchildren do feel them also, but what can I do?"* (Grandmother caring for two small orphaned boys on ART IDI).

Many health care providers also reported of how challenging it was for them to talk to clients about health education and good nutrition when they knew that most of them could not even afford a simple meal. As a result, study participants from the health facility repeatedly mentioned the need for nutritional support. This is as illustrated by the following statement:

> *"The problem with this area is that there no sources for natural body building foods, there is no river following throughout the year where people could get fresh fish from, then they do not grow beans, only cow peas and ground nuts which do not go to the end of the year, in most cases by June-July or august they have run out of such food stuffs. So, for one to start ART without proper nutrition is a big challenge. Even where adherence is concerned, without proper nutrition it is big problem because people fear side effects from the drugs taking the medicine on empty stomach, so they skip. So yes lack of food can lead to treatment interruptions even when someone believes in the medicines" (Male health care provider).*

Lack of food was also reported to have contributed to challenges in the implementation of PMTCT program. Several cases of women who failed to follow instructions on PMTCT were reported. For instance, during one of the clinic based IDI, one of the female ART clients reported how she could not wean off her baby despite being advised to do so by health care providers due to inability to afford a balanced diet. She pointed out that she was convinced the baby got sick during breastfeeding.

Because of these high poverty levels, food supplements provided by the health facility were seen as a very important predictor in the continuum. However, as noted above, food supplements were not enough due to limited supplies and big numbers of people in need.

Rising poverty levels were also confirmed by several key informants some of whom had lived or worked in the area for many years. These were able to attest to the changes that had occurred in the livelihoods of the local people as seen from the quotes below:

> *"Then poverty levels in these same places are quite high, even when transport was to be available they cannot afford transport costs to the health facilities because they do not have the money, poverty is there because people especially this side (pointing east wards) where the roads are bad cannot access markets for their agricultural products, people have also become poorer because of denkete (foot and mouth disease), most people now use hands to till their land instead of draught power and this has affected production"* (Traditional leader).

These sentiments were reiterated by a traditional leader, an ex-teacher, who when referring to the challenges people would face if the government were to withdraw free provision of ARVS stated that:

> *"Ino aawo mpochiti kashupile, nkaambo kuya kuba mpenzi pati kuti akamane naaba nfulumende bakatalike kuulishiya mu samu ooyu nkaambo banji omuno mumizi mba cete, bantu banji baya kufwa, ino mali manji inga bajana kuli? Taaku, nkokuti bayanda kujaya bantu kuti ba fulumende bachita boobo nkaambo mbuli buchete buli muminzi muno, cita! (That would be the beginning of problems, if the government stopped providing these medicines free of charge because most of the people are poor, a lot of people will die, because where will people find money to buy the*

> *medicines? It means the government wants to kill people if it does that because poverty levels here in the villages are very high).”*

As a result, distance, lack of money to travel to a health facility and lack of food to take with drugs if found positive were repeatedly and consistently mentioned by many respondents as being some of the major factors that hindered them from accessing HIV and AIDS related services.

Poverty was reported to be deeper among women due to intra-household gendered unequal access to and control of resources. Many study participants attested to women still lacking control of resources within the home. For instance, during one of the community based IDI, one polygamous man in his early thirties who referred to himself a modern man and one of the few who seemed to be doing quite well confirmed this. He stated that he did consult his two wives over how the income realised from the sale of maize was to be used. He was however, quick to mention that in most cases, he bulldozed in decision making because according to him: *“Because I have big plans, for instance, I may want to buy a tractor”.* He pointed out further, that his wives only controlled money from the sale of food crops like groundnuts because according to him:

> *“In Tonga there is a saying that, (Mukaintu tapegwi lubono lunji kaambo inga wakutwangila) A woman should not be allowed to control huge sums of money because she can become proud and have no respect for the husband.”*

Poverty was also reported to be worse for women and in particular, widowed and divorced women as most of them were reported to have lost nearly everything upon being divorced or widowed and expected to go back to their *mukowa* (maternal relations), without anything. Therefore, the most common response from such women to the question, “What did you inherit from your late husband or upon divorce?” was, ‘Nothing’. This had lot of implications on the access to HIV and AIDS related services for women.

In reference to this situation, a religious leader expounded that:

> *“The other problem is poverty because generally they [women] are poorer, those married to rich men have no control on whatever wealth that is available, so those who are in remote places can’t travel to the health centre to test because they are not able to raise money for transport, then those who are widowed or divorced they become poorer because according to the Tonga culture a woman loses nearly all major property upon divorce or being widowed.”*

It was also found out that generally, there were more divorced and widowed women than men, due to the fact that they remained in that status for longer periods than their male counterparts who tended to re-marry early.

In addition to poverty, the poorly developed road network was also a big challenge for people to access the HIV and AIDS-related services. Poor road networks made private transport owners in the absence of public transport services; shun reaching some communities as they did not want to risk their vehicles on the rugged roads. This meant that even in the unlikely event that one managed to raise a bit of money to cover the transport cost, there was no vehicle under whatsoever which would possibly pass by. This meant that walking, even for the seriously ill and the aged was the only option.

Commenting on the bad state of most roads in the area, a female health worker noted that:

> *You have places like Chijanywa, [located about 20 km from Chivuna Health facility], where the only time you see a vehicle is once a year and that is when Ministry of Education is delivering examination papers. Even by use of 4x4 vehicles one has to struggle to reach some of these places.*

During a social mapping exercise done in the central part of Chivuna, a heated discussion erupted over the state of the roads in the area when an elderly man in his late fifties, while vigorously using both of his hands to express his point and unanimously supported by all the other group discussants, expounded that:

> *"The roads in this area are really bad especially when you go this side [pointing in the south-east direction], beyond the Mission, I think the last time these roads were graded was after independence in 1964, bridges are not maintained, in fact beyond the Mission there aren't even any roads to talk about. No vehicles can travel on these roads, not even a scotch cart only chilayi (sledge) can go there, and now imagine you are carrying a patient."*

Another middle aged man amid laughter and applause from the other participants retorted:

> *"Those ministers should not just sit in their nice offices getting fat and developing big tummies; they should come here and see some of these roads we are talking about."*

The picture below depicts part of a rugged road that passed over a stream without a properly maintained bridge.

Figure 4.2 A rugged road with an un maintained Bridge

.

Source: Field work Chivuna study: 2009-2011

Lack of maintenance of bridges usually worsened the situation particularly during the rainy season making it literally impossible for people from certain communities to reach the health facility for all the services.

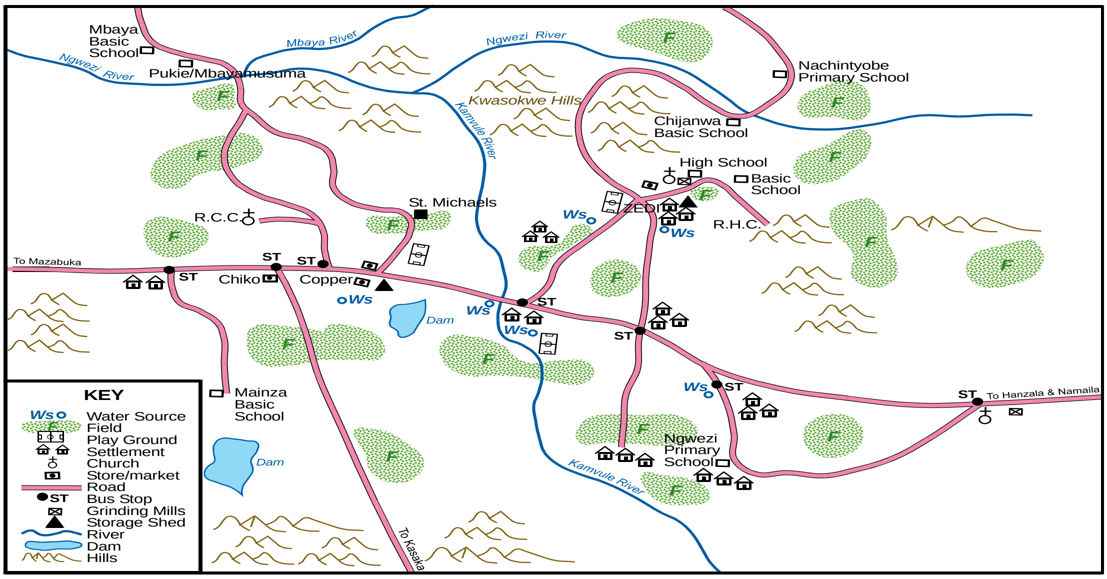
An oxcart was used as alternative mode of transport especially for carrying the very sick and so was the bicycle.

Figure 4.3: An Ox-cart as an Alternative Mode of Transport

Source: Field work Chivuna study 2009-2011

However, the hilly terrain usually made the use of these two alternative means of transport limited. These factors were also identified during the social mapping exercise as shown in the social map given below.

Figure 4.4: Social Map Showing Factors Limiting Access to the Health Facility as Perceived by the Community



Source: Field Chivuna study, 2009-2011

In addition to structural factors, community factors were also identified.

4.4.5.5 Community Level: Facilitating Factors

(i) Perceptions About ARVs

Perceptions have an important role in determining people's behaviour including treatment seeking behaviour. It is therefore, important that they are addressed in order to improve uptake of VCT and ART services and adherence. In addition, people are the beneficiary and hence key stakeholders of every health intervention. Therefore, investigating, understanding and addressing their perceptions are critical for the successful implementation of any health intervention. In this regard, the way the people perceived existing VCT and other ART services is crucial in achieving equitable access to AIDS related services. Undoubtedly, the way they will perceive them will influence their uptake of the services and adherence.

To investigate the role of perceptions in the continuum, respondents were asked about what they knew or heard about ARVs. Many of them were able to attest to the efficacy of the

ARVs. This was based on either their personal experience or from the physical recovery they had seen occur among those who were on ARVS within the community. For others, it was based on community talk or what they had heard being said about the life prolonging drugs by other community members.

Positive perceptions about the ARVs were reported to facilitate people's decisions to take up an HIV test, being linked to a health care provider, commencement of ART uptake once eligible and also contributed to avoiding of treatment interruptions once one had commenced medication. For many, this was as a result of seeing some of their colleagues who were once bedridden but had since recovered. For others it was also a combination of what they had personally witnessed and messages received about the efficacy of the ARVs from other community members. As a result, many community members had positive perceptions about the medicines as they viewed them as highly efficacious and this prompted them to take an HIV test, to be linked to a health care provider after testing HIV positive, start taking medication once prescribed and also continue taking medication. This can be seen from the statements indicated below**:**

> *"People used to die before the introduction of ARVs. After the introduction of the ARVs, the beds were empty at Monze hospital. That is how we thought of starting ART services at Chivuna clinic. Even here in the villages burials were a weekly thing but now we go for months without hearing of a funeral in the community, there is no doubt ARVs are working. This has encouraged many people to accept taking medicines once eligible"* (Female health care provider).
>
> *The benefit of taking ARVs is to reduce the impact of the AIDS, but I don't know if the drugs could cure the disease completely. The other benefit is that all problems related to HIV and AIDS would be cured. In addition, we also hear that the drugs can make the virus sleep. We have seen a lot of people on their feet again after taking the ARVs, So the benefits are there, as some people say ,they are miracle tablets because they have managed to bring people back from the graves" All this encouraged me to start taking these medicines, (*Middle aged male, clinic based mixed group discussion).

Many key informants from the health facility also explained that positive perceptions that people had about ARVs also encouraged those that were found HIV positive be linked to a health care provider for continued health care services. According to them, this was because they were aware that it was the only way they could access the drugs which they viewed as lifesaving.

The survivors often commented that, '*Twakali bafu, nitwali mubulongo sunu abwizu nobwalilampide a zyuumbwe zyesu* (We were dead, we would have been part of the soil and grass would have out grown on our graves by now).' During a focus group discussion with members of a support group, a middle aged widower amidst laughter and agreement from the other participants poignantly narrated that:

> *"I started taking the medicine, I became fine and very strong. I was very sick and my voice was so faint that for one to hear what I was saying, there was need to bring their ear close to my mouth. I would call for "keele" (porridge) in a very faint voice (laughter from other participants). But now as you can see, I am okay, at that time even lifting a small container of water was a very big problem. It is only unfortunate we have no photographs of how we were before we started taking drugs you could have seen now some of us who are here used to look like. I wish we were like white people who do keep photographs. If you were to see those photographs, you would not believe it is us seated here speaking to you. "Twakali zyumbwe zyeenda." (We were moving graves).Those who saw us then and see us now really get encouraged to accept the medicines."*

Views on the efficacy of ARVs were also expressed by several care givers. Sharing her experience, a female care giver who took over care of an HIV positive granddaughter after the death of her daughter from AIDS noted that:

> *"My daughter (referring to the researcher), these drugs are really effective. You should have seen how this girl was looking before she started taking drugs she was completely finished and she had lost so much weight. "Uyo mwana ngomubona wakalicisidwe basa, wakali, manide" (This child you see here was very sick, she was finished). But shortly after the medicines she became okay. You can see how she is looking; you do not have to be told. "Ndaupa bulemu oyu musamu mukali" (I have come to respect this medicine. It is really effective)"* (Grandmother and care giver to an orphaned 4 year-old girl).

Another care giver retorted:

> *"This boy was very ill but now he is very strong,* mbobajata mapulawu *(He is one of those holding ploughs),"* (Uncle to an HIV positive nine year old boy orphaned by AIDS).

Sharing her experiences, an elderly woman who took care of her son who relocated from one of the urban areas when his health deteriorated, abandoned by the wife and later died, poignantly stated that: *"I am sure if these drugs had come earlier my son wouldn't have died".*

There is no doubt that all such positive perceptions of ARVs alluded to above encourage those requiring to start taking medication to do so. Many of the health care providers also explained that people's perceptions about the drugs had evolved over time because of what people had witnessed. One health care provider stated that in the past, people used to view them as killer drugs. He recalled that:

> *"In the past people used to think of ARVs as killer drugs because a number people actually used to die upon starting treatment. This was because, maybe because of the cost that was attached to the medicines, a number of the people used to start taking medicines very late. Adherence was also very difficult because of the same cost. But this is no longer the case, yes people may still face other barriers but at least the cost of medicines is not there anymore"* (Male health care health care provider).

Apart from encouraging people to start taking their medication, positive perceptions equally motivated people to consistently take their medication and hence remain in care and treatment. This was because of the positive conviction that people had in the efficacy of the drugs. This was even much so especially for those who had tried other remedies without any improvement. When asked what they thought about the medicines, a common response, particularly among users was, *"Ma RVs (or ma RR,* as they were usually referred to by the elderly*), mbobuumi bwesu"* (ARVs are our life).

Perceived efficacy of the medicines was not only held by the direct beneficiaries but was a commonly held view even among community leaders. Referring to what motivated people to adhere to ARVs, the area chief had this to say:

> *"Belief in the effectiveness of the medicine actually encourages many to continue taking them because they are able to remember how they were before started taking them. Some of them were as good as dead, but immediately they started taking the medicines they recovered completely. Many actually do believe that ARVs are their life."*

These views were also shared by many other key informants, particularly those from the health facility who also had an opportunity of directly interacting with people on ART

The actual beneficiaries most of who had been on medication for a long time, also shared their experiences as reflected from the statements below:

> *"For me it was like you were almost in the grave and then somebody just comes to take you out, it is really a second chance to live, that is why even when some people call us names eh banwya eh balaabuumi bwakutonkatonka, na balaabumi mutubbodela mebo nkunya" (those who depend on medicines or those whose life was in the bottle, I have continued taking my medicines"* (58 year old female ART user clinic based IDI, on ART for more than 3 years).

Another male ART user recalled:

> *"Number one is feeling better, if you used to be bed-ridden and sickly most of the time and then you feel better. Many of us are convinced that these medicines are the ones that have made us feel the way we are feeling now and so we have agreed to continue taking them for life"* (Middle aged man, male clinic based FGD)**.**

This conviction was even re-enforced further among those who had tried other remedies which never brought any health relief. This was the case with those who had once sought consultation with some healers. Some of the sentiments are reflected in the statements below:

> *"I find VCT to be good to me because I was always sick and thought that I have been bewitched. I would take the traditional medicines but still no improvement. I went for VCT and after being tested I was given medication. Within a short time I was able to start doing minor jobs which I couldn't before and eventually I became strong and healthy again"* (Elderly male ART user, Clinic based Male FGD).

> *"From the time I started taking the medicine; I started feeling better by the day; now I can walk again. "Ino basa ndakashoma kuti musamu oyu ulaponya," (I believe that this medicine works), when I remember how I was, because I was as good as dead. I consulted so many traditional doctors who used to tell me that I had been bewitched but immediately I started taking these drugs I got better. Now I even think of my money I used to give those traditional healers because since now I have a good appetite, I could be buying myself food using that same money"* (**20 year old** Female ART user, community based IDI).

As a result, there were frantic efforts to adhere at whatever cost, including disclosure so as to avoid treatment interruptions. This was some form of coping strategies as will be discussed in details later in this chapter and as reflected in the statement below:

> *"Some are afraid of taking medicines for life, and others are afraid of forgetting to take the tablets. But forgetting cannot be there because like myself naturally I am very forgetful but not with these medicines, I have never forgotten because I take them as my life. Whenever I go visiting, I always carry my medicines with me, in fact that is the first thing to be packed. I also remember to carry my card in case I become ill where ever I am going to visit. I also make sure I inform the people I am visiting that I do take medicines, you know just in case something goes wrong or I forget, they can remind me"* (54 year old female ART user, clinic based IDI).

Experienced efficacy of ARVs had also undoubtedly changed perceptions of some of the traditional healers. For instance one of them who was also on ART narrated that he respected ARVs because they had helped him. He pointed out that from *the time he started taking them, he had realised that his body became much better*. He explained that he started with by taking my own medicines but they did not work and that from then he knew that this disease could only be treated by medicines from the hospital. He noted that all those [traditional healers], still claiming that they can cure it are just liars; they just wanted to eat people's money. He explained that referred all the people who came to consult with him to the clinic so that they can first be tested for HIV.

Nearly all study participants were also of the view that ARVs could allow positive women give birth to healthy children as reflected in Table 8.4 below. As a result, despite the many barriers they experienced in accessing PMTCT most women embraced it.

Because most people understood that the medication was for life, they were concerned about sustainability of supplies in terms of both manufacturing and continued free provision by the government. Because of their knowledge about adherence, most of those on ART could not imagine a life without the medicines. They therefore, hoped the government would continue with the free supply of the medications because they were poor people who could not afford buying medicines.

Therefore, referring to the possibility of government withdrawing free provision, common statements were: "*Mpotuya kufwida awo, inga musinzo wesu mpo uyokumanina awo"* (That is when we shall all die, that will be the end of our journey), "*nkaambo aaya mapillusi mbobuumi bwesu"* (Because these medicines are our life). Concern about future sustainability of medicines is also reflected in Table 7.1 above with more than 80 per cent expressing this concern.

Additionally, it was found out that ARVs had changed the way an HIV positive person was viewed in the community. It was reported that in the past an HIV positive was viewed as dying. As a result, some people were reluctant to lend them money for fear of them getting too sick and dying before they could pay back. This change was summarised by one of the PLWHIV who was also the Chairperson of one of the support groups when he stated:

> *"ARVs have changed people's attitude towards us. Before ARVs came some people would not even dare lend money to somebody who was suspected to be an AIDs patient for fear that they would die before they paid back. Even the way people now treat to somebody who is sick is very different because now everyone knows that you still have a life ahead of you even if you are HIV positive. In the past people would just wait to die. The sick also have also had a different approach towards life now because in the past some people would even want to commit suicide once pronounced positive while others would squander all their property knowing that they were going to die anytime but now all this has changed."*

Likewise, ARVs had changed the way many HIV people viewed themselves as most of those on ART no longer considered themselves as dying instantly though HIV was still linked to death. This was a major shift in thinking compared to the time before ARVs.

It was also reported that some local terms had been coined to refer to ARVs, some of which reflected the efficacy of the medicine and hence acted as drivers for ART uptake and adherence. However, others were derogatory. The derogatory ones precluded eligible users from accessing and using the medicines as they just managed to re-enforce the level of stigma which still existed in this community. Among the positive concepts were *musamu* (the medicine), m*apilusi* (the tablets) and *mukabuumi* (Life giver). The ones meant to ridicule those on ART included, *Tonka-mazuba*, (prolonging days or adding days), MTN top-up, (like recharging the cell phone with units without which the phone cannot work) and *mpoka* (big corn). Those on ART were also referred to either as *balabuumi bwakutonkatonka* (those with life depending on medicines) *or balabuumi bwamumabbodela* (those whose life was in the bottle) and *ba topinga*, (recharged life).The HIV and AIDS was referred to as *bulwazi* (the disease), *malwaz*i *akaboola ino* (these diseases of these days) or *chilwazi catumana eechi* (the disease that has finished us). To some extent these terms also reflected the perceived magnitude of the disease.

Because of the evolution of people's perception concerning the medicines, it was reported that people wanted to test as soon as possible and avoid becoming sick and associated with a deadly disease. According to the health care providers, this was a new trend that had come with the evolution in perception of the efficacy of ARVs and their free availability. Expressing this view, 36 year-old female care provider shared her experiences when she explained that:

> *"Most people now want to be tested early and get medicines, you find when you tell them about their CD4 count being too high and that they would get medicines later, they start complaining saying: 'Sister that will be too late, I want to start taking medicines immediately,' Some do not want to fall sick or start losing weight so they want to test early and start taking medicines as soon as possible to avoid suspicion. People are now in a hurry to test and get the medicines as soon as possible before they become sick."*

To measure people's perceptions of ART, respondents were first asked whether they had heard about ARVs. As many as 97.2 per cent answered in the affirmative while only 2.8 per cent had not (table not reflected). As a follow-up, respondents were asked about their perceptions on ARVs. Table 4.17 shows the respondents' various perceptions and beliefs about ARVs.

As can be seen from Table 4. 17 the results show that more than 90 per cent believed that ARVs could allow a woman give birth to a healthy child. This is an indication that most of the respondents had positive and correct perceptions about ARVs while fewer harboured negative ones. These positive perceptions encouraged them to go for testing VCT which would enable them access ARVs and also continue taking them once they were prescribed. However, the negative perceptions are also notable with that of infertility, being at approximately 14 per cent. The results also show that as many as 9.8 per cent still felt that ARVs could kill somebody. These results mean that misconceptions about ARVs were still of concern and were high enough to negatively influence utilization of available ART services and adherence.

Table 4. : 17 People's Perceptions about ARVs

Perceptions	**Yes**		**NO**		**Total**	
	No	**%**	**No**	**%**	**No**	**%**
Allow women give birth to healthy children	589	90.2	64	9.8	653	100
Make one feel more sick	64	9.8	589	90.2	653	100
ARVs can cause impotence and infertility	89	13.6	564	89.4	653	100
ARVs can kill	64	9.8	589	90.2	653	100

Source: Field work Chivuna survey 2009-2011

These findings are an indication that despite the many benefits from ARVs and also the evolution of perceptions from negative ones to positive ones, negative perceptions had not been completely wiped out. Many key informants from both the community and the health facility affirmed that misconceptions were still prevalent mainly in some of the very remote communities where community sensitisation was still limited as elucidated by the statements below:

> *There are still many people lacking knowledge because of the size of the chiefdom and some communities being very remote. Some of the people in these remote communities know nothing about the medicines. And also you find that very few people are on medicines in such communities and behave not seen any one taking ARVs so they do not know the effectiveness of these drugs. Those who have seen people recover, some of whom were almost dying do believe that ARVs are very effective because they have seen it with their own eyes. So for these people*

> *when they are advised to start taking ARVs they immediately do so because they do believe in the medicines working.*

In a related interview, a male health care provider, with reference to the same lack of knowledge in distant communities elucidated:

> *"I think nearly everyone now sees them as important. But of course there is still the problem of distance, you have communities where we have not yet been, so there people are still very ignorant about the medicines, they still perceive ARVs as poisonous and causing other health problems because of lack of knowledge."*

She continued:

> *Such messages are coming from the community itself; there is a lot of cheating each other in the community. Such talk is there. To combat this, we have continued with community sensitisation. The only problem again is the distances and inadequate resources for us to spread the news to the remote parts of the area; I tell you some places we have not reached. CHAZ is assisting with some finances for allowances and fuel but the problem is vast because the area is too vast, we need more support if we have to reach all these remote places.*

However, it appeared that even communities that were not really remote per se were still entrenched in some of these misconceptions which could dissuade those intending to continue accessing and utilising ARVs from doing so. This contributed to delay in testing, starting taking ARVs upon ART prescription and also treatment interruptions. For instance, in one of the community discussions in a community a few metres from the health facility, the child bearing issue came out quite strongly. Some of the women in this community were convinced that the" effect of ARVs was much stronger than that of family planning pills", and that if ARVS were taken while a woman was using family planning pills, family planning pills would not work and she would end up being pregnant. Whenever this question was asked, some women were emphatic as they explained that, "*ma mapilusi a family planning inga alazundwa ku ma ARVs,"* (Family planning pills become non-effective because of ARVS). The concern of ARVs causing impotence and infertility also came up from a number of group discussions.

In one community located about 20 kilometres north of Chivuna health facility; concerns for the manufacturer came out quite strongly during a focus group discussion with female community members. Expressing her concerns, amid support from the rest of the group, one of the discussants who was also an adherence supporter expounded:

> *"What we think sometimes is that the white man who is providing these medicines will one day just stop manufacturing them so as to wipe out all the Africans so that they can come and occupy land. This discourages some people who want to continue taking these medicines as some may say there is no need of continuing with the medicines anyhow. In fact this why we think white people are also giving us condoms infected with the virus so that we are all infected and end up taking the medicines and then when they stop making them, we all die."*

In adding her voice to the discussion, another discussant narrated:

> *"Yes as my friend has said, we hear that white people will one day deliberately stop making the ARVs drugs so as to wipe out the black race from the earth and then they can come and occupy our land, you know we hear such stories."*

Key informants were emphatic that on the basis of such misconceptions, a number of people still delayed in testing and consequently delayed people in accessing the other services that came after one being found HIV positive.

It was clear that the accuracy of the information that people have about VCT and ART in general was equally vital as inaccurate information contributed to people having negative perceptions about a particular service and consequently its low utilisation. For instance, it was found that the community talk about the bad side-effects of the medicines and negative attitude of the health care staff did exist even among those who had not visited the health facility. Some of the respondents, particularly the men noted that in most cases women were the ones involved in such community talk, referred to as *misalo* when they met at water points. Existence of such *misalo* was clear from people's answers to questions such as: "How do you view your health care providers?" "Or how does the community view ARV?"

During a mixed focused group discussions with community members, a female discussant amid agreement from the rest of the participants remarked that:

> *"Yes we also hear that some of them (health care providers) are rude to patients. We also hear they like calling those who are found positive all sorts of names. Some people have also complained about their secrets being revealed to other people in the community because some of them have no confidentiality. Such stories discourage some people from going to the clinic for testing because you start thinking this can happen to me also."*

In clarifying about such talk in the community, a male health care provider expounded his views when he narrated:

> *"Yes the problem is that such information circulates in the community because people are always interacting. So some people who heard about such stories or anything bad about the health facility do not come for testing. Sometimes you find some people from here going to Mbaya for testing and for collection of medicines and those who live near Mbayamusuma coming here because of the same stories they have heard about health providers not keeping secrets. So you find people going to far off health facilities where they are not known and in the process they delay in accessing treatment."*

Similar sentiments came up from other sources. For instance, during one of the male community based FGDs with a community very close to health centre, a middle aged man expounded:

> *"People's views about the medicines are changing because a lot can see what these medicines can do but sometimes you still hear,bantu bamwi baamba kuti eh ma RR alajaya, ehh inga wasondoka, inga wafwa kuti waluba kunwnwa olo buzuba bomwe. Bamwi bantu ba shoma inga balayoowa kuunka ku cibbadela kukupimwa (Some people say ehh RR {referring to ARVs} can kill you, ehh they can make you mad, you can die if you forget to take your medicines even for one day. Those who listen to such stories are discouraged from taking the medicines even when they are advised to do so after being tested"* (Male discussant, male community based FGD).

Community talk about the side effects from the medicines including those relating to child birth and fertility in general were mentioned by some study participants. These concerns are measured in Table 4.18. The results show that approximately 14 percent of the respondents believed that ARVs could cause impotence and infertility while belief that ARVs can kill and make one more sick was each represented by 9.8 per cent. Such concerns can preclude some eligible clients from ART uptake.

Despite the evolution in people's perceptions that has been observed above, it was reported that there were still some negative perceptions and misconceptions about ARVs. Though they only came up in isolated discussions, most of the misconceptions emanated what was referred to as *misalo* or community talk and rumours that circulated in communities. Some of the talks were about the bad side effects, ARVS being poisonous, the size and the length of the drugs, (with some of such comments coming from people who had not even seen how ARV s looked like).

It was also clear from the reports that AIDS in these communities was still linked to perverted sexual activities even when other modes of transmission were well known. Viewed this way, ART was therefore directly linked to a disease for sexual perverts. This appeared consistent from all sources including youths. For instance, during one of the community based youth focus discussion with youths aged between 15-24, when the question what they thought of HIV positive people in their community, nearly all of them bluntly stated *buhuule,* (prostitution) and that, “Even for the babies which are positive we say, *Bamazhali babo bakali bahuule,* (Their parents were prostitutes).

A number of those who had tested and in particular women, confessed of, “I had to first think about it before going for testing, I was fearing embarrassment in case the disease was found because this disease causes embarrassment.” To some extent this indicates that HIV positive status was still negatively and lowly perceived. This was confirmed further by the reported reluctance among some community members to openly talk about HIV and AIDS. So even when it was clear that either one had AIDS or died from AIDS, nobody would dare say it publicly.

(ii) Support Groups and other supportive Social Nets

These included support groups, the family, community health workers and local transporters. Support groups encouraged and facilitated testing, linkage to care, ART uptake and adherence to ART. Support groups were a community initiative mainly consisting of people living with HIV (PLWHI). Social support from these groups was reported to come in form of emotional, psycho-social support through experience sharing. This helped members to cope with stigma and discrimination which some ART clients attested to as still being present in the community. The groups were reported to deal with stigma and discrimination through community sensitization. Using their personal experiences they also taught the community members the benefits of early HIV testing, importance of seeing a health care provider once tested positive, remaining in care once engaged, starting medication early and also adherence and hence motivated people to enter and be retained in the continuum of care. Some of them were reported having to physically link friends and other community members to health care providers for further HIV care and treatment. The groups were reported to be involved in income generating activities (IGAs) such as gardening and poultry. Some of the money realized was used to support members particularly those who failed to raise transport money to travel to and from the health facility for reviews. Part of the money was used to buy food for members who were still very sick and unable to work for themselves. This food helped to avoid treatment interruptions.

However, most of the group leaders complained of the inability to engage in more meaningful and gainful IGAs due to lack of funds for expansion. For instance, the chairperson for one of the groups narrated the challenges the group was facing. He noted that despite the large number of members of more than 50, membership fee which was one way of fundraising was too low to support a sustainable economic venture. In addition, most of the members were too poor to pay even the same minimal fee. Summing up his experience of heading such a group, he explained that:

> *"That money [referring to the money raised from different ventures by the group] is usually given to our members, say if they are required to go to the hospital and they have nothing, we give them, because some of them may be too sick to cover the long distances on foot, and then some may need food. Poverty is the main problem, the group is big but most of them are too poor to pay membership fee, not even the smallest amount, most of them are widows, and when you talk about assistance, nearly everyone needs help because they are all poor. Like that young widow I told you about the other time we met, she has completely nothing, nothing and when you reach her home, you do not have to ask about how they are living because you can see it just by looking. When you visit her to remind her about the importance of adherence, the first question she is asking you is about food to take with the medicines."*

To measure the role of support groups in ensuring access and continued participation in care, and treatment, a typical relationship was sought between support groups and adherence. Results are in presented in Table 4.18. The results show that most of the respondent on ART who belonged to support groups (83 per cent) never missed taking their medicines. The significance value is at P value =.000.

The results in the Table 4.18 indicate that support group membership was a predicator for adherence because as seen from the qualitative data, members were able to get material and psycho-social support, which enhanced adherence. Typically, this is an example of how support groups facilitated access and retention in care and treatment.

Table 4. 18: The Relationship between membership in Support Group and period ever missed taking ARVs

Longest period of time ever missed taking ARVs	**No**		**Yes**		**Total**	
	No	**%**	**No**	**%**	**No**	**%**
1-2 weeks	3	60.0	2	40	5	100
2-8 weeks	53	100	0	0.0	53	100
More than 2 months	1	100	0	0.0	1	100
Never stopped taking medicines	36	16.9	177	83.1	213	100
Total	93	34.2	179	65.8	272	100

Source: Chivuna survey 2009-2011. $\chi^2 =$ 133.7139, $P<0.000$.

However, as revealed in the narratives, most of the support groups were limited as to how much material and financial assistance they could render to their members due to financial difficulties. This was confounded further by wide spread poverty, meaning that the number of members in dire need of help was too large. The role of these categories of people was limited by a number of limitations including lack of transport for remote places. Support rendered by local transport was also reported as having facilitating testing, engagement and retention in care for those people coming from distant communities.

Despite some negative reactions reported about the community therefore, it was reported that community members often came together to offer support for those who were sick, particularly, in ferrying the very sick to the hospital. It was reported that if one community member had an ox cart and another had a pair of oxen, they would put their resources together so as to take the sick to the clinic. Many ART clients attested to having benefited from support from the community in form of transport, either borrowing an ox-cart or bicycle to transport them to the health facility because they could not walk. Some mentioned the possibility of borrowing money from say a friend or a neighbour for transport in order to attend clinic reviews and medical refills. Therefore, statements about borrowing an ox-cart or a bicycle from a neighbour to transport the critically ill were very common. This came out clearly during one of the clinic based mixed focus group discussions as reflected from the statements below:

> "Yes*, in fact in most cases we ask from those who have. Like for me when I was brought here last year August, I could not walk so my children had to ask for an oxcart from our neighbour to bring me here".*
>
> **"** *That is true today I borrowed a bicycle from my neighbour because I am not feeling too well to walk, I could not walk from Kasaka"* (located about 15 km from the health facility).

Similar sentiments were expressed from a community based female focus group discussion where it was claimed that nearly the whole village had tested due to the encouragement offered to each other. Thus, in responding to the question on community support, one discussant stated that:

> *"Just like the family, the community can do the same, offer transport and take the sick to the hospital. Some communities are not supportive, they are not cooperative. But, in a village like ours here, we do cooperate a lot and all of us would be going to visit the sick person. Nearly everyone has tested in this village because we support each other as a community"* (tested elderly woman, community based female FGD).

In some instances, the community was even reported to facilitate adherence by encouraging some uncaring family members to take care of their sick or unwell relatives. In this way the community ensured that a community member on ART did not miss taking drugs as indicated in the statement below:

> *"I saw someone who was critically ill and there was no one to get the drugs for him and he almost died because the drugs finished and he could not continue. As a community we persuaded his relations to go and get the drugs for him because he was not able to walk. So there are such cases and the community has to come in and help because some families can be so unsupportive"* (Middle aged woman, amid agreement and support other study participants, community based FGD).

Many respondents who once benefited from the support of the community did testify of the support from the community. However, some study participants pointed out that there was still a lot of finger pointing and negative reactions from some members of the community indicating a need for increased community sensitisation. Social support was also reported to be in form of one being a member of a support group.

Supportive social networks were also reported as coming from local transporters in form of offering either free transport or the possibility of one paying later. This enabled those without money; particularly those who were too sick to walk to health facilities access the much needed heath care. Family support was repeatedly mentioned as an encouraging factor for entry into the continuum and continued progression along the continuum.

The family or *ba mukwashi* particularly, immediate family members were consistently and repeatedly mentioned by nearly all sources as being helpful in encouraging sick family members to go for testing, access Medicare, start taking ART and also to continue taking medication. Almost like the community at large, they were reported to assist sick family members in many ways. One way was to physically support the sick by escorting them for testing while others would borrow scotch carts for transport if the relative was too sick to walk to the health facility. Sometimes the family assisted sick family members by helping them with house chores such as cooking, cleaning the surroundings and fetching water for them. Lending and providing transport money to enable a sick relative access testing services was also common.

To measure the extent of family support in this community, respondents were asked to state to what extent they felt they were supported by their families. The results in Table 4.19 show that about 39 per cent and approximately 25 per cent of the respondents stated that they felt very much supported and quite supported by their families respectively. Another14 per cent said they felt little supported followed by 3.5 per cent of those who felt somewhat supported.

The data in the Table 4.19 reveal that 19 per cent of the respondents felt unsupported by their family members. Basically, these results show that the perception of family support was quite high among the majority of the respondents. If the two categories of responses (feel very supported and supported were to be put together) they account for 64 per cent. These results show that family support in this community was still dependable suggesting that it can be used not only to encourage people to go for VCT but also to avoid treatment interruptions.

Table 4:19 Levels of Family Support

Levels	No	%
Feel very much supported	255	39.1
Feel supported	161	24.7
Feel somewhat supported	23	3.5
Feel little supported	93	14.2
Feel not supported	121	18.5
Total	**653**	**100.0**

Source: Field work Chivuna survey, 2009-2011

In order to measure the role of family support on the whole continuum, a typical example was sought from the measurement between family support and testing as shown in Table 4.20. The results show that more people (82 per cent, very supported and supported put together) who felt supported by their families went for testing and only 7.4 per cent (for very supported and supported put together) did not go for testing.

These results confirm that there is a close relationship between testing and family support with a significance level at P= 0.00 providing a typical example how family support facilitated the desired linkages and outcomes in the HIV continuum of care and treatment.

Table 4.20: Association between Levels of Family support and testing

	Levels											
	Very supported		Supported		Somewhat supported		Not supported		Not very supported		Total	
Testing	**No**	**%**	**No**	**%**	**No**	**%**	**No**	**%**	**No**	**%**	**No**	**%**
No	4	3.0	6	4.4	9	6.7	77	57.0	39	28.9	134	100
Yes	245	47.3	179	34.6	18	3.5	3	0.6	73	14.1	519	100
Total	**249**	**38.1**	**185**	**28.3**	**27**	**4.1**	**80**	**12.3**	**112**	**17.2**	**653**	**100**

Source: Field work Chivuna survey 2009-2011, $\chi^2 = 384.4087$, $P<0.000$.

Unlike for VCT, linkage to care and ART uptake, the support by the family in adherence becomes even more critical because of the need for one to be constantly available for one on ART. The support was reported to be in many ways including, emotional support and practical support such as collecting medicine for the very sick, acting as reminders, lending or providing transport money to facilitate going for reviews. Family members also acted as reminders, provided food and offered general care for those who may be too weak to do anything for themselves. This support gave people encouragement to take their medicines as required as illustrated in the statements below:

> *"One, just knowing that you have a family or children is encouraging, because you want them to assure you that they will be there for you. Then two, family support is very important, for instance, they are able to remind you. I am able to take all my drugs because my children and husband do remind me. I have a watch for taking the drugs but my family is also very supportive and they remind me a lot of times, this is why it is important to disclose your status to close family members so that they can be able to support you and remind you because if they do not know about your status, there is no way they can remind you. So it is very important to let the people you live with know about your status"* (65 year old female ART client clinic based IDI).
>
> *"The family members also do render financial support. Like today, I was given transport money by an uncle of mine to enable me come and collect my medicines because I was feeling too sick to walk here"* (Young man, mixed group discussion clinic based FGD).

Acknowledging the importance of the family in adherence, a health care provider stated:

> *"Family involvement acting as reminders and supporters is very important. In addition to that, family can bring their sick relatives to the clinic by escorting them and sometimes they would come to collect medicines on their behalf if they are too sick to walk. They can also monitor them taking of medicines because they are the closest.*

In order to further measure the role of family support on the continuum, a measure between family support and adherence was sought. In this regard, respondents on ART were asked how much they felt supported by their family members and how this support helped them take their medication. Results are contained in Table 4.21. The results show that those respondents (80 per cent) who felt supported and 79 per cent who felt supported by the family never missed their medicines while more than 80 per cent of those who never felt supported stopped taking their medication for more than two months.

The P value is at .000, indicating that family support was very important in adherence. The data in this table typically further shows the role of family support in the continuum of care. It was also reported that the level of support needed in adherence differed from that required in encouraging one to go for VCT, being linked to care and encouraging one to start taking medicines, as there is need for someone to be consistently available to monitor the taking of drugs. Family members can be the best option for the DOTART. Family support should be harnessed because family members are the closest to the individual on ART.

Table 4.21: Association between Family Support and Period ever stopped taking ARVs

	Period Ever Stopped Taking ARVs									
Levels of Family	**1-2 Weeks**		**2-8 Weeks**		**More than 2 months**		**Never Stopped**		**Total**	
Support	**No**	**%**	**No**	**%**	**No**	**%**	**No**	**%**	**No**	**%**
Very Supported	1	.8	26	20.5	0	.0	100	78.7	127	100
Supported	1	1.1	17	18.2	0	0.0	75	80.7	93	100
Somewhat Supported	0	.0	5	83.3	1	16.7	0	.0	6	100
Never Supported	3	6.5	5	10.8	38	82.7	0	0.0	46	100

Source: Field work Chivuna survey 2009- 2011. χ^2 = 70.3032, *P<0.000.*

While immediate family members were generally reported to be supportive, some close families and other relatives were reported to be unsupportive. A number of respondents narrated how they were discriminated against after they were known to be HIV positive by their own close family members. For instance, during a community based mixed group discussion consisting of ten youths (6 females and 4 males), aged between 15 and 24, discussants stated:

> *But some families are not supportive, they even refuse to eat with the patient saying "inga bwatutambila bulwazi" (We can also end up being infected by the disease). Even bathing, they will say let her use her own bathing materials".*

Reiterating this sentiment, another participant from the same FGD retorted*:*

> *Some families would start calling you names and will use bad language like "mutakapi chakulya katulemya kuyola tubyabi olo ati, nookali kujana mali wakali kulya olike ino watushupa kulwazya."(Don't give her food, we are tired of cleaning her, when you were making money you were eating alone, now that you are sick you want us to suffer looking after you).*

Similar views were expressed from related discussions with youths. For instance during a focus group discussion with 5 girls and 5 boys aged between seventeen and twenty-one years, while supporting and applauding each other, similar views were expressed as illustrated below:

> *Yes, they will start calling you names and they will say "kalasampuzya aka kala abulwazi, aka kahule" (This prostitute is embarrassing the family), your friends bring money and you only managed to bring HIV and AIDS. (***Girl)**

Reiterating this view another participant stated:

> *Some will say, "Twakali kukwambila tookali kunvwa (We used to tell you, you never listened to us) like that song which is always being played at Copper". Some youths even end up committing suicide by taking some poison because of the way some parents react" (Boy)..*

Reiterating these sentiments, a female health care provider also remarked that:

> *"But there are those clients where may be the families are not very supportive so the risk of non-adherence is very high as their visit to the clinic is not so regular because sometimes they may be too sick to come for medical refills on their own."*

Therefore, although family support was critical in encouraging people's entry and progression along the continuum, not all families were supportive. This is also reflected in both Table 4.21and Table 4.52 above. Table 4.25 shows that about 19 per cent of the respondents did not feel supported while Table 6.3 shows that 29 per cent of the respondents who did not feel supported in any way by their family members did not take up testing. This calls for sensitisation of the family so that they can see the need to offer support to ailing family members to enable them test early enough. Medication-related factors were also mentioned.

4.4.5.6 Limiting Factors

(i) Local Illness Ideologies and Illness Explanation

In relation to local illness ideologies, the present study sought to investigate and establish firstly, to what extent such beliefs still exist in a rural area like Chivuna. Secondly, to explore the actual role or impact of such beliefs could have on people's decision making in relation to entering the continuum and be retained in care and treatment. In order to investigate this, in addition to the ordinary members of the communit**y,** those community members who had knowledge on local health systems were interviewed. These included elderly community members, community leaders, traditional healers, health care providers and heads of NGOs and CBOs.

Respondents were asked whether witchcraft did exist in the area and how common it was. They were also asked what other illness concepts existed in the local area. It was generally reported by nearly all sources that beliefs in witchcraft were common and that witchcraft was still being practiced in the area. Therefore, in answering the question, 'How common is witchcraft in this area?' Many informants and discussants answered in the affirmative and actually attested to its existence. For instance, a male key informant from one of the local church organisations who had worked in the area for many years recounted that:

> *"Yes aah beliefs in witchcraft, they are there and they are the majority. People have strong beliefs in it and they practice it, you see most of the people are outside the church and what do you think they are doing out there? Witchcraft is also found in churches because churches have become place where people hide their evil dealings. So, witchcraft is there even in the church, witchcraft is one of the foods of the evil ones"*

These views were reiterated by many other informants as. For instance, a female health care-provider who had worked in the area for more than four years and also educated there recalled:

> *"Witchcraft is still very common here because even when people are admitted in the wards you hear their talk, you hear them telling each other stories about witchcraft. I think it is still very strong in this area."*

In emphasising that witchcraft was still being practiced in the area, many community members narrated their personal encounters and experiences with witchcraft. These views came from both the young and the elderly.

Participant observations during the funeral of one of the community leader's wife, who died two days after being admitted to the local health facility, also confirmed the existence of such beliefs among the people of this area. During the whole period of mourning the talk among the women who the researcher interacted with was, *'Bakabajaya biya, inga muntu wafwa buti kuchiswa kwamazuba obile, bantu mbabi, oobu mbulozi*'. (They killed her because how can one die after being ill for two days only, people are bad this was definitely witchcraft).

Discussions held later with one of the health care providers, however, revealed that, the deceased actually had complications with her intestines and that there were delays in seeking health care from the health facility.

Asked whether HIV and AIDS could be caused by witchcraft, a number of the respondents answered in the affirmative. According to them, it was possible for witches to 'send' any kind of illness to a targeted person including HIV and AIDS. It was believed this kind of AIDS would be difficult to handle by hospital people because diseases caused by witchcraft could not be detected by hospital machines. Additionally, such a condition could not be treated by *misamu ya makuwa* (medicines for white people) but only by *chi* Tonga medicines. Asked whether HIV and AIDS did exist, however, nearly all study participants did state that they believed HIV and AIDS did exist. Among other local illness concepts identified were *cibinde, kafungo, luo, mashabe and masoto.* All these were reported to be different conditions from different causes and according to them, all these could only be handled by traditional medicines or spiritual healing (especially in the case of *luo* and *mashabe*).

However, reports showed that there had been some evolution in understanding between *kafungo* and AIDS. This was because even though most of the respondents were still adamant on similarities of symptoms, they stated clearly that the two were different health conditions. In addition, reference was repeatedly made to HIV and AIDS by most respondents as, "*Malwazi aaya akasika", (*These new diseases), *malwazi aaya ngeenya atumana*, (These same diseases which have finished us) indicating that HIV and AIDS was viewed as a totally different and new type of health condition.

Nearly all the respondents were emphatic that, all the conditions identified could only be cured using traditional medicine. This was risky because as long as the people were convinced that it was one of the above mentioned conditions, conventional medicine would not be sought. Emphasising the need to use traditional medicines for the mentioned ailments instead of modern medicine, one of the elderly women interviewed in connection with local illness ideologies, while smiling, stated that:

> *"Inga wahimana hibbadela nkaambo oonse aya malwazi apona biyo a misamu ya chitonga (You can go to as many hospitals and you would not find a cure because all these diseases can only be treated by Tonga medicines)."*

Discussions with other categories of respondents established that, there was a lot of delay among some people in accessing VCT and consequently subsequent services as a result of such beliefs. It was reported that even after one was tested positive, these alternative treatment ideologies and beliefs were still at play. Several cases were cited of people who because of such beliefs, opted to first go to consult a traditional healer, some of those tested positive opting to first consult a traditional healer, a spiritual healer instead of immediately going to see a health care provider for linkage to care. In the same vein, some positive people on ART opted to drop out and go for these alternative remedies. Where testing is concerned for instance, during one of the community- based focus group discussions, a young man in his early thirties reported of a friend who nearly died while trying to consult a traditional healer. He stated that his friend had gone to several traditional healers but all in vain and that he only recovered after being put on ART.

Similarly, several discussions with people living with AIDS and on treatment also showed the amount of delay caused as a result of people believing that they had either been bewitched or as result of other locally explained causes. This can be illustrated by the narrative below:

> *I first felt my feet paining and then I felt as if the pain was coming to my heart, after which I would collapse. I thought I was bewitched so I then went for divining where I was told that I was bewitched for turning down some man's proposal and I was given some medicine but I did not get well. I then decided to go and see another diviner where I was asked to pay K15, 000 and a black chicken. I went to another one [traditional healer] the third one I think, How many have I mentioned so far? Because I went to three of them. The rituals were performed again but I was getting worse and worse, I started collapsing anyhow. I went to the last traditional healer who also told me to pay a K 15,000 and a chicken. He made several tattoos on my body and also gave me some herbs which I was told to smear on my body. I did that for a month but the illness was becoming worse (52 year-old female ART client, community based IDI).*

Asked how long she took before going for VCT, the same woman cited above continued:

> *"It took me a long time; it took me about one year six months [going from traditional healer to another]. That is when the idea came of going to the hospital, so I asked one of my cousins to escort me to Kabwe General Hospital."*

Answering a similar question, another woman recalled that:

> *"I never believed or thought that I could be HIV positive, all I believed it was in witchcraft. I used to go and consult traditional healers every time I was unwell. Traditional healers are more interested in money; they used to tell me that it was mashabe (demons). I tried to follow their advice but nothing helped me. It took me four years meanwhile my health was becoming worse. Friends could come to advise me, but all their advice were not useful to me because to me only being bewitched was in my mind"* (Widow in early seventies, clinic based IDI, ART user).

These revelations were reiterated by some key informants living in the area. During one of the key informant interview, a young male church leader from one of the local church organisations said that:

> *"Yes that one is really there in these communities (referring to beliefs in other causes), from the way they talk no doubt you know that they have these beliefs. As a result when one is sick the first thing that will come to their mind for some of them is being bewitched and so they go to traditional healers looking for healing while they delay in accessing medication that can help them."*

This was sometimes compounded by claims made by some healers that they were able to both detect and cure HIV and AIDS, "as long as they were consulted early before the disease invaded the whole body", as claimed by one of them. The same healer further narrated that:

> *"When a patient comes to me and is suffering from AIDS, I develop a strange feeling different from the one I have if one is suffering from malaria and other diseases, "Nkaambo inga ndilausama mubili wamulwazi" (Because I am able to take on the patient's body), [and start feeling the way the patient is feeling]."*

The above statement also reflects a serious lack of knowledge about the condition of HIV and AIDS that still exists among some of the traditional healers.

Narratives by some community members also indicated that some people did believe that some traditional healers could cure HIV and AIDS. During a focus group discussion among women from a village located very close to the Mission health facility, the women emphatically narrated that there was one traditional healer in the area whom they knew of being able to cure AIDS. They stated that, some patients who had consulted him had become healed. They wondered why government had not allowed such medicines to be used openly.

Community leaders were well aware that such claims did impede the uptake of formal HIV related health care. During a meeting with a group of ten village headmen, stress was made on the delay cause by such claims, when one of them, while being supported by all his fellow headmen explained that:

> *"Then you have those traditional healers and spiritual healers who would tell some patients that they can treat them. These traditional healers would refute the test from the hospital and may start telling patients that they are being attacked by "basangu" (ghosts) So you find instead of one going to the health facility to test and start taking the medicines, they start taking traditional medicines or going for prayers to get rid of the ghosts."*

Several other Key informants equally confirmed and bemoaned the amount of delay emanating from such beliefs and use of traditional medicines and remedies illustrated by the following quote:

> *"Yes such beliefs are there in this area and as long as one is convinced that the cause of a health condition is say, mashabe or luo, they may not come to the health centre for testing. This does happen; they will want to try their own medicines which they believe will sort out the problem. When it fails that is when they will come to the hospital and sometimes you find they come to the hospital when it is too late"* (Male health care provider working in the area for more than 5 years).

Therefore, because of the belief that some health conditions could only be cured using traditional remedies and not modern medicines, as indicated above, consultation with other health service providers was also common. Respondents were therefore, asked with who they felt more comfortable with to consult each time they had a health problem. Results relating to people's health seeking pattern are reflected in Table 4. 22. The results show that while the majority of the respondents 66.2 per cent indicated that they felt more comfortable to go to the health facility whenever they had episodes of illness, a substantial number of them felt comfortable to either consult a faith healer or traditional healer, 17.2 and 12.9 respectively. Other health service providers consulted were herbalists 2.8 per cent, pharmacists 6 per cent and home remedies as being the least consulted, .5 per cent.

These results indicate that while most of the respondents indicated being more comfortable with the health facility, consultation with non-conventional health practitioners, representing about 33 percent, is noteworthy. This is an indication that the delay in seeking evidence based treatment and care did occur. Another notable revelation by these results is that in the qualitative study, apart from reports of such cases coming from key informants, very few respondents attested to consulting either a faith healer or a priest for healing. On the contrary, the quantitative results show that a very prominent number of people did consult faith healers for various health conditions.

Table 4. 22: Health Seeking Patterns of Respondents

Feel comfortable to consult	No	%
Traditional Healer	84	12.9
Priest/Faith Healer	112	17.2
Herbalist	18	2.8
Clinic/Hospital	432	66.2
Pharmacist or Friend	4	.6
Relative or Friend/Home Remedies	3	.5
TOTAL	**653**	**100.0**

Source: Fieldwork, Chivuna survey 2009-2011.

Despite the general belief in witchcraft and traditional medicine in the area, some people particularly those living with AIDS and were on ART with the experience of seeing traditional healers, no longer had confidence in such practitioners and their medicines. They explicitly stated that there was no link between witchcraft and AIDS. They vehemently refuted claims that traditional medicine could cure AIDS. Undoubtedly, the view of most of the ART clients was as a result of the perception these people had concerning ARVs emanating from their experiences of using the medicines.

After getting an HIV test result, it was reported that because of such beliefs some those who tested positive consulted alternative health care providers instead of going to the health facility for linkage to care. This made it difficult for these people to be connected to a health care provider soon as after getting their results. According to some of them, this action was taken because they first had doubts in their test result as they thought of other causes. They reported that this made them embark on alternative treatment despite the need for to see a health care provider. An elderly widow narrated that:

> *"The other big problem that I had was belief that it was not HIV, I thought it was "zyinjilwa" (demons) as the traditional healers told me, so it took me time to accept the test results because my mind was convinced that it was zyinjilwa. All this made me delay in accepting the results and the drugs. Then you also have people talking in the community, you hear some saying eeh so and so used some herbs like mubala and they were healed of AIDS, some talk of Back to Eden, using a tree called neem-tree, I said may be I try them and see what happens"* (Elderly widow on ART, Community based IDI).

To measure the influence of local illness ideologies on linking HIV positive people to a health care provider after testing, respondents who had tested positive were asked who they consulted after testing. The results are contained in Table 4.23

The results in Table 4.23 show that although the majority of respondents, 85 per cent went to the health facility, consulting traditional healers after testing was quite common (15 per cent).

Table 4.23: Health Care Provider Consulted after Testing

Type	**Yes**		**No**	
	No	**%**	**No**	**%**
Traditional healer only	40	14.7	0	0
Priest/Faith healer only	2	0.7	0	0
ART centre only	230	84.6	0	0
Total	**272**	**100**	**0**	**0**

Source: **Field work, Chivuna survey 2009-2011**

Relatedly, those who had not started taking their medicines stated that they chose not to because they were taking alternative remedies such as traditional medicines and going for prayer sessions as shown in Table 4.24. The results in the Table show that of those who decided not to start taking their medication after testing, the majority agreed to taking traditional medicines and going for prayers (84 percent for both, strongly agreed and agreed put together). The results are significant at P= 0.00. All the three tables above are clear indication of how local illness explanations and beliefs in alternative remedies influenced people’s entry and retention in the continuum of care.

Table 4.24: Association between Local illness Beliefs and ART Uptake

	Level of agreeing and disagreeing											
	Strongly Agree		Agree		Somewhat Agree		Disagree		Strongly Disagree		Total	
Beliefs	**No**	**%**	**No**	**%**	**No**	**%**	**No**	**%**	**No**	**%**	**N**	**%**
I take traditional medicines	51	82.3	1	1.6	1	1.6	6	9.7	3	4.8	62	100
I go for prayers	51	82.3	1	1.6	1	1.6	3	4.8	0	0.0	62	100

Source: Field work, Chivuna survey 2009-2011, χ^2 *= P<0.000 for all the factors.*

Health care providers also reported how local beliefs precluded some eligible ART clients from taking medicine early enough. This can be conveyed by a statement from a male health care provider who had worked in the area for more than five years as he explained:

> *"You know this side (pointing south eastwards) where we have not reached for community sensitisation because of distance and the bad roads, such beliefs are still very strong, one may be tested and given medicines but in their mind they may still have doubts about the cause of their problem because they may feel that they have been bewitched or that there could be another cause like say mashabe and not AIDS. They may get the medicine from the hospital but not take it there and then till the problem persists."*

Such beliefs made some people not only doubt the positive test result but interfered with continued taking of medicines. It also resulted in some people either combining ARVs with other remedies or abandon ARVs for traditional medicines which were believed would handle a particular health condition. It was revealed that such practices were still quite common. Key informants also revealed that the belief in other cause of illness that local people still held on to added to the problem. Therefore, in answering the question, "Is it common for people to start taking ARVs and then stop for other medicines because of such beliefs? A female health care provider, who had been working in the area for more than three years, explained:

> *"Yes that is quite common especially the some distant places. If a health problem persists after being on ART for some time, they may say may be it is not AIDS, it could be say luo, mashabe, witchcraft or whatever they would believe in and so they may stop taking ARVs and try some traditional remedies, some may even decide to combine. Then there is also the problem of community talk, some may say so and so tried this or that medicine and they got healed, now there is the famous mafuta a chiwena (crocodile fat) curing AIDS, one may want to try it while on ART or even stop taking ART because they are convinced from what they have heard that it cures AIDS and most times such beliefs affect the remote places more because they have not been sensitised."*

There were examples of healers who advised their clients to discontinue taking ARVs while others encouraged them to combine for better results as illustrated by a statement shown below:

> *"Combining is very common; those who combine want fast results. Some even stop taking ARVs after visiting a traditional healer. There is one traditional healer this side in Mabanze (pointing southwards). What he does is that when a patient on ARVs goes there, ulasonda, (divines) without being told, he will tell you that "I know you are on ARVs." Then he will tell you to stop taking the ARVs while he starts giving you his herbs and then after a certain period he would tell you to go for a test. A lot of people have been found negative after taking his medicine. May be the government needs to see him so that they can get his medicine to make treatment for AIDS. There is one woman who went there to that traditional healer and is now negative but she has continued coming to the hospital for food aid. I asked her what she does with the*

> *medicines she gets from the hospital and she told me that she throws them away"* (Middle aged woman; community based female FGD amid agreement from other participants).

Health care providers were also aware of the impediment caused by such beliefs in ensuring that ART clients stuck to their medication. Sharing her experience, a female health care worker narrated that:

> *"Some of their beliefs are positive, there are some traditional healers who would say may be for this sickness there is need for an HIV Test, then they would refer that person to the clinic. Some of whom I have interacted with them have done that. But others do not allow anyone who goes to them to take any other medicine. So you find there are those traditional healers who recommend patients to stop taking ARVs for their medicines. Such cases are there."*

Apart from beliefs in other causes of illness, it was also revealed that some patients particularly those on treatment for a long period without improvement, were driven into combining ARVs with alternative remedies. Others either abandoned ARVs for alternative treatment, or tempted to do so due to the belief that traditional medicine can relieve HIV and AIDS symptoms and at times cure them permanently. At times, people combined the two due to desperation for healing. In one such a case, a 35 year old man who had just relocated from one of the urban areas where he was working decided to come back to the to the study area which was his home area due to poor health. At the time of the interview, he had just decided to stop taking ARVs and started taking, *"mafuta achiwena,*" (crocodile fat) because it was believed that it had much more efficacy than ARVS. He explained that he had been on ARVs for a long time without any positive results. In addition to this, he pointed out that he had also been to see a traditional healer who gave him some herbs. On the day of the interview, the man looked quite tired forcing the researcher to request for a call back which could not take place because he died two days later.

Sharing her experience, a single female ARV user on medication for two years, and one time tempted to combine ARVs with alternative medicines also explained that:

> *"No I have not (never combined with other remedies) but when I was still very sick there were times when I would think of combining so that I could feel better fast, I was very desperate for healing, but now I do not even think about it because I have seen how effective these medicines are (ARVs), many of us who should have been in the soil by now have all become strong and healthy again"* (38 year old ART user, clinic based IDI).

These views were expressed by several key informants as illustrated by statements below:

> *"Let me say that people may do this [combining] for many reasons, one could be desperation for healing, say you are on ART for some time and there is no improvement, you may want to try other medicines also including going for prayers. I think this is normal"* (Male church leader).

> *"Believing in witchcraft is still very strong in these people and this makes some people stop taking medicine and go for traditional medicine. Some would even combine the two for quick recovery"* (Female health care provider).

Those study participants who did combine ART with other forms of treatment were asked what they combined with. Table 4.24 presents results on the extent of combining ART with either traditional medicine or prayers.

Results further show that combining ART with faith healing was very high at 66 per cent while combining with traditional medicine accounted for 19 per cent. On the overall, these results show that the practice of combining ARVs with either prayers or traditional medicine was very high. Such practices can undoubtedly interfere with ART up take and adherence and hence the need for them to be addressed.

Table 4.25: Combining of Other Remedies with ART among ART clients

Combination	**Yes**		**No**		**Total**	
	No	**%**	**No**	**%**	**No**	**%**
Combined ART with traditional medicine	53	19.5	219	80.5	272	100
Combined ART with priest/faith healer	179	65.8	93	34.2	272	100

Source: Field work Chivuna survey, 2009-2011

Answering a question related to faith healing, a church leader elucidated:

> *"There are some church organisations that claim to be able to pray for some body and get cured of AIDS. There is a woman in Nkokola area who was advised by a Mizimo church to stop taking drugs after the pastor prayed for her, this woman is now dead. I think this is misleading people. For us as a church we just give moral support and even material support for the sick and not to tell them that we can cure AIDS, no. Of course when one is sick they need spiritual support so that they can accept their situation but we never claim we can cure AIDS no."*

In an earlier interview with a group of ten headmen, before the same woman reported above died, a senior headman stated:

> *"And then in these communities there are churches that cheat people telling them to throw away their medicines because they will pray for the sick and they will be fine. It has happened in this village. One woman was on ARVs and then she started going for prayers and stopped taking her drugs, now as we are talking she is in problems, she is very sick.*

Health care providers repeatedly mentioned long distances that some of their clients were required to continuously cover to health facilities as a contributing factor to abandoning ART for alternative remedies. It was reported that such scenarios, "forced" some people to resort to other remedies as the only option available for them. Thus, referring to the distance factor, a male health care provider remarked:

> *"Also the fact of distance to health facilities and if one has a problem while on ART, they may decide to see a traditional healer or herbalist nearby instead of travelling a distance of 60 km, especially if one is feeling un well, because how would one make it from say Nyeezi which is more than 50 km to Chivuna walking? So as I have mentioned before, sometimes it is not a matter of choice but a matter of what is available in some of these place"s.*

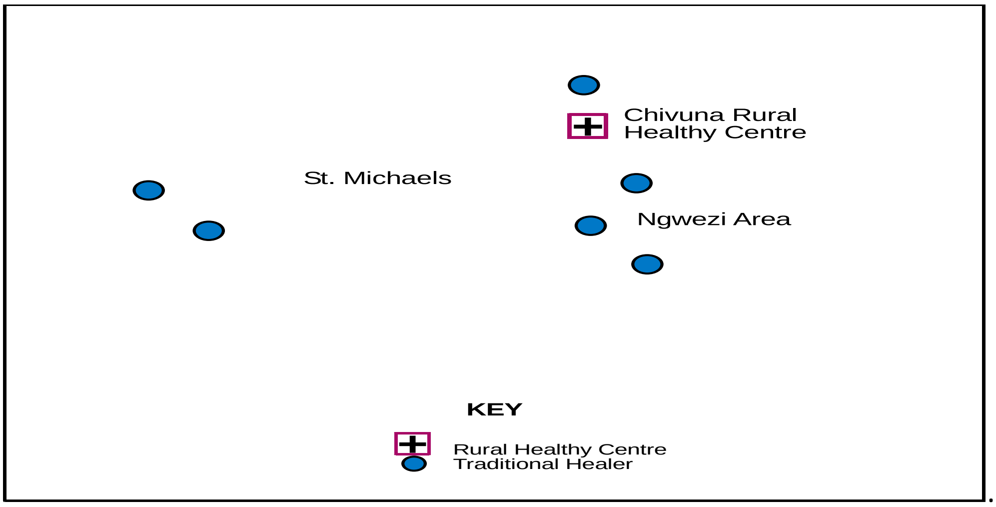
As was the case with VCT and ART uptake, HIV and AIDS related stigma and discrimination was another factor alluded to by many study participants as contributing to treatment interruptions.

It was also revealed that the use of traditional herbs was not always a matter of choice or belief as at times it was the only option available particularly, for remote communities. Sharing his experiences, for instance, a male key informant from the health facility elucidated that:

> *"Like last week one woman came for antenatal with a small child walking from Syanamudonga and the child was crying, I think she was tired and hungry. So I just had to request for the ART vehicle so that we could carry this woman back to her home. We discovered the place was really far from here, may be close to 60km and there you find that people know nothing about VCT or ART at all. That is where you find people really believing in witchcraft, they know nothing about VCT and people still claim that they can treat AIDS, people there are still very far in terms of knowledge. And again the problem is that for these far off places traditional healers are the most accessible so they are the first contact in case of any ailment. So sometimes consulting a traditional healer may not be as a matter of choice but could be the only option available."*

The availability of traditional medicine versus modern facilities is also reflected in Figure 4.5 below. This distribution was for a radius of about two kilometres from Chivuna health facility.

Figure 4.5: Traditional and Modern Health Care Systems in Chivuna



Source: Field work Chivuna study, 2009-2011

The implication of this finding is that traditional healers were more wide spread than modern health care facilities. There is no doubt that this scenario could be worse in more remote communities.

Although nobody was interviewed directly in connection with prayers, there were reports concerning churches particularly one known as *mizimo* which was cited as praying for people with various ailments and would be healed. Leaders from this church were also reported to be advising those on ART to stop taking the medicines. When asked about the existence of AIDS however, nearly all the respondents answered in the affirmative.

It was also reported that at times, it was common for one to be taken to a traditional healer by family members without their consent particularly when one was too sick to resist such a move.

In addition to local illness causations, existence of HIV and AIDS-related stigma and discrimination within the community was also emerged as another factor influencing the desired linkages in the continuum.

(ii) HIV and AIDS-Related Stigma and Discrimination

These were also found to be very common themes throughout the continuum and did impede an individual’s ability to access and participate in HIV prevention, care and treatment continuum. Some study participants narrated how travelled very long distances to go places where they were not known for HIV and AIDS –related services so as to avoid being seen by people they knew at their local health center. It was reported from some sources that negative reactions towards people suspected or confirmed to be HIV positive was reducing in the area. This was attributed to what health care providers referred to “aggressive community sensitization and awareness creation. “It was also reported that HIV and AIDS was increasingly being perceived as a common disease like “malaria” and ARVs like “Panadol,” a common pain killer in that it had become common.

Notwithstanding these reports however, a number of people reported to have either not having gone for testing or delayed to be tested, not being linked or to a health care provider or delayed, delaying to or not initiating ART and having treatment interruptions for fear of possible negative reactions from the community at large and at times from family members and close associates. They explained that they did not want to be spotted at local VCT centre as this culminated into involuntary disclosure and consequently gossip, blame and finger pointing from other community members. Many of them narrated of the fears that they had including fear of being laughed at and judged by other community members if seen entering the VCT/ART building as they would be labelled positive.

Therefore, although stigma was reported to be reducing, fear of stigma was reported as one of the major reasons why people delayed or declined being tested, being linked a health care provider, initiating and being retained in ART for desired outcomes of HIV continuum. Many respondents claimed to have experienced it at a personal level. For instance, a female ART client in her early forties narrated how her cousin and his wife made her eat alone and also not allow her to use any of their cooking and eating utensils. She further explained that one day, she heard her cousin’s wife telling her children not to accept any food she had handled. She narrated that on a number of occasions, she witnessed her sister-in-law beat up her smallest child who from time to time violated these instructions. She lamented that after the rainy season, she was planning to build her own house at a distant place from her cousin’s house se because she was convinced that all this was happening due to her condition.

Similar sentiments were expressed by a number of other ARV users as shown from the statement below:

> *Ah! Yes, stigma is there in this community. I have experienced it several times. At times, you are walking and people start pointing fingers at you saying "ulya ulaabulwazi" (That one has the disease) and you over hear them. So what I do sometimes is to answer back so that "bagunywe" (to embarrass them). So I would say, "Yes I am sick so what is your problem?" Then they keep quite they do not say anything again because they get embarrassed. Sometimes even the way people look at you, you can tell that probably they know something about you, for why would somebody stare at me with curiosity? There is a young man who every evening passes through the road close to my home running and when he is near my home he starts shouting saying: "Heee chasika ciindi ca kutopinga" (Hee it is time to top-up),* (47 year old male ART user, clinic based IDI).

Because of stigma which was reported as still present and precluding some people from taking their medication as prescribed by the health care providers. Fear of stigma and its implications can be illustrated by the quote below:

> *"For me at the funeral, I just stand up as if I am going to the toilet, I go behind some house and throw my tablets in the mouth and then come back pretending as if I just want to drink water and that is it because I would not want other people to know that I take ARVs, there is too much gossip"* **(**25 year old female ART user community based IDI).

While being on ART complicated social interaction for some respondents, especially young women, it appeared not to bother some respondents, particularly elderly ones , may be because they were no longer concerned about sexual relationships , as is clear from this statement:

> *I travel with my medicine and take it publicly, I would say [basa amundipe meenda ciindi casika], (Please give me some water, it's time for me to take medicine), even at funerals in full view of every one (Elderly male, mixed FGD amid laughter from the rest of the discussants).*

Expressing the level of stigma in the community, when the question, "How can the community help you with adherence?" was asked during one of the clinic based female group discussion, a middle aged female participant propounded:

> *Ohh now those [referring to other community members] are not even supposed to know because from the day you disclose to them, which would be your new name. Do not even ever pick a quarrel with one of them because if you do, you would hear them saying anwebo no munwa ninzi ncowamba, (hey you who is on drugs what can you tell me), so as to shut you up. Omuchaangu nkwile kumuuna Nkoyoowa kuti masampu inga ayindilia (Poor you, you just shut up for fear of further embarrassment).*

Reports also showed that women and in particular elderly women faced more challenges where negative reactions from the community were concerned. This can be elucidated by the statement below:

> *For old women like myself "insoni" (embarrassment) is there, it's worse for an old woman like myself because people will look at you with those querying eyes, even fellow patients, it is like they are asking the question old woman how did you get it [AIDS] at your age. Those were the obstacles that I faced when coming to get medical refills. But I really do not mind, I am already in this situation and so there is nothing I can do apart from coming here. I come here for treatment, and this is what I tell the nurses, to treat me. The situation is of course really embarrassing for an old woman like me to be found with the disease of the young people. You see it is very clear anybody who comes to this place here is taking AIDS medicines, even the food that we get from the container there; it is people like me on the medicines who get. So, one cannot hide at all. Everyone knows. But as I have mentioned people look at me when they find me here at the clinic, or even at the container there, I see questions in their look, I see it in their eyes, they do not say anything but just stare at me* (About 80 year-old Female ART user, Clinic based IDI).

It was also becoming widely accepted among community members that if one were of poor health and suddenly put on weight then they were taking ARVs. This is also applied to wearing of wrist watches. It was insinuated that such wrist watches were used as reminders of when to take the drugs.

To some extent, these sentiments were an indication that a new type of stigma was emerging in the community which had to do with one being on ARVs. There was a strong view that unlike in the past, ARVs had made it difficult to identify the sick. In addition, claims were that, most of them particularly; women had even become more beautiful and attractive than those not taking ARVs and hence luring men into sexual relationships. Sharing his views a traditional leader observed that:

> *"The only observation that I am seeing with ARVs now, which might be a problem is that some people view ARVs as making it difficult to see who is sick, in the past before these medicines came you could clearly see those who were sick which is not possible now. You hear people saying that these ARVs will finish people because now you can't tell who is sick, the women on ART now even look more beautiful than those who are not sick".*

To measure levels of HIV related stigma in the community, respondents were presented with five statements to which they were asked to state their level of either agreement or disagreement. The results are contained in Table 4.25. The results show that in relation to the first statement that: AIDS suspects lose respect in the community, most of the respondents approximately 68 per cent agreed with the statement, (36 and 32.2 per cent strongly agreed and agreed respectively, put together). For the disagree category, approximately 17 per cent of the respondents disagreed and 15.3 per cent strongly disagreed, with the two put together accounting for approximately 32 per cent.

On the second statement that: if a family member was to be infected with HIV I would keep it as a secret, the results were quite similar to the previous statement. The results show that strongly agree and agree put together accounted for 68 per cent (strongly agree 57.7 and agree, 10.3 per cent) while that of disagree was at 32 per cent (strongly disagree and disagree, 25 .9 per cent and 6.1 per cent respectively put together).

In responding to the third statement which read: ‘In this community, HIV positive people fully participate in social events’, the results in the table above show that most of the respondents, 68 per cent indicated that they strongly disagreed while 20 per cent and 12.3 per cent agreed and strongly agreed with the statement respectively. The results in the table further show that about 42 per cent and 20.4 per cent of the respondents strongly agreed and agreed respectively, with the fourth statement that: ‘HIV positive children were bullied by other children in the community with the two responses strongly agree and agree put together accounting for more than 62 per cent and about 68 per cent if the somewhat agree category is added. On the last statement: No mother would allow their children to play with an HIV child, the results show that about 35.5 per cent strongly agreed while 32.5 per cent of the respondents agreed (with the two categories adding up to 68 percent. Those who disagreed accounted for 16.7 per cent and the strongly disagreeing, 15.3 per cent with the two adding up to approximately 32 percent. On the overall, these results clearly show that stigma and discrimination levels in the community were very high reflecting and confirming the concerns from the narratives.

Table 4. 26: Perceived Levels of HIV and AIDS-related Stigma in the Community among Respondents

	Strongly Agree		Agree		Somewhat Agree		Disagree		Strongly Disagree		Total	
	No	%	No	%	No	%	No	%	No	%	No	%
AIDS suspect lose respect in community	234	35.8	210	32.2	-	-	109	16.7	100	15.3	653	100
Would keep HIV status of a family member as a secret	377	57.7	67	10.3	-	-	40	6.1	169	25.9	653	100
HIV positive participate fully in social events	80	12.3	129	19.8	-	-	-	-	444	68.0	653	100
HIV positive children are bullied by other children	276	42.3	133	20.4	35	5.4	109	16.7	100	15.3	653	100
Mothers do not allow their children to play with HIV positive children	232	35.5	212	32.5	-	-	109	16.7	100	15.3	653	100

Source: Field work Chivuna survey 2009-2011

It was clear from the reports on stigma that anticipated stigma was a very common one as illustrated by the quotes below:

> *There is also fear of fellow human beings. Speaking for myself I was afraid of being laughed at by fellow community members, I used to think if I am tested and I am found positive people will start laughing at me , ndakalikutibantu inga banditatamuka (I used to think to myself that people may start discriminating me)* (64 year old female ART user, clinic based IDI).
>
> *"I used to think to myself, all the friends that I associated with no one had talked about going for VCT where do I start from alone? I had a lot of questions. I started thinking to myself; What if am positive what would be the reaction of my friends towards me? How about my parents? Will they accept me as their daughter? How is life living on ART? How do ARVS look like? How many tablets do people take a day? Am I going to manage to be in a circle of those taking ARVs if test positive? Yoonse eeyi mibuzyo yakali kweenda mumizezo mbuli meenda amumulonga, (Different types of questions were flowing in my mind like water in a stream). Tears came down as I asked myself questions which had no answers. I said to myself, at my age are there many people who are on ART? How would the community regard me? How will people in the community look at me if found positive and start taking the drugs"?* (19 year old female ART user, community based IDI).

Stigma precluded people from the uptake of VCT even where VCT centres were locally available. This also applied even in many instances where people perceived themselves to be at high risk of HIV infection. For instance, a female ART user in her mid-thirties from a polygamous union who was also an ART supporter living approximately 3km from the ART centre narrated how she delayed to go for VCT. This was despite perceiving herself to be at risk of HIV infection and also possessing knowledge as an ART supporter. She pointed out that her co-wife died after being sick for a long time prior to losing two of her babies. She attested that she did not go early for VCT because of fear of being laughed at by community members. She recalled:

> *"I delayed going for VCT because I used to fear* the result from VCT, *I was afraid of being laughed at if found positive .Ndakasanguna kuliyeeya kwamazuba manji," (I had to do a lot of reflecting about VCT for a number of days before going there)"* (42 year old ART **su**pporter and ART user Community based IDI).

In a related interview another young woman who had not yet gone for testing despite living very close to the health facility but instead contemplating to go to a VCT centre located about 25 km away east of Chivuna health facility stated:

> *" At this clinic you may meet somebody who knows you, and they may start telling other people .In addition to that some of those people who work at the ART clinic live with us here in this community we know each other, that is a big problem)"* (Community based IDI).

There is also no doubt that stigma was largely due to the fact that HIV and AIDS was still perceived in this community as a disease linked to promiscuity as illustrated by the following statements:

> *"You know the negative reaction from people towards people like us is mainly because even though people are aware of other modes of transmission; sexual intercourse and promiscuity are still very prominent, this is the problem. Eechi ncendatakali kuunkila ku kukupimwa nkaambo ndakali kulisenda, nakalikuti inga bantu bandibona buvuule. This is why I had problems with going for VCT, because I always thought that people would see me as a very promiscuous woman; I used to feel ashamed,"* (53 year-old female, community based IDI).
>
> *"This is also the problem because a lot of people just think of one mode of transmission, yet there are so many and they think of us who are positive as being very careless with our lives. Speaking for myself I have had only known two men in my life yet I am sick"* (Female ART user in early forties, community- based FGD).

The fact that HIV and AIDS was still linked to perverted sexual activities compounded stigma for HIV positive women and even worse for elderly women because being an old woman added to the stigmatisation. The level of stigma in this community was also quite clear from many interactions with the people. This was also explicit during a social mapping exercise when every participant insisted that an HIV positive person be placed at the edge of the map and the negative one in the centre. This was mainly because according to them an HIV positive person was an important member of the community while a positive one was there and at the same time was not there. According to them this meant that the AIDS patient was not really part of the community because he was waiting for death. It was pointed out further that such a person would be expected to die any time, he is a moving corpse and that because of this HIV positive people were at times not involved in some work.

It was also reported that self-stigma was worse among community leaders like church leaders who were expected to be role models and of high moral standing in the community. For instance, a health care provider narrated how one church leader refused to start medication even when his CD4 count was as low as 50 because of his concern about how his family and the whole community would think about him.

(iii) Interpersonal Social Relationships and Gender-based Violence

Concerns for social relationships and in particular sexual relations as undermining one's decision making in the entry and engagement in HIV testing were also reported. It was found out that though these concerns were universal for men and women, they were more associated with one's age, gender and marital status. Many female study participants narrated their experiences and challenges in trying to go for testing, being linked to a health care provider and in consistence taking their medication due to fear of violence and abandonment from their partners. As a result, number of study participants, particularly young married women, reported either having delayed to take up VCT or not having done so, delayed initiating medication and also having problems with adherence due to fear of possibilities of violence, abandonment and even divorce in the event of them testing positive. As a result, after testing, most of the women did not disclose their status to their spouses for fear of violence. This complicated adherence.

Similarly, unmarried study participants and youths in particular, were concerned about future relations and inability to secure future partners in case they were spotted at a VCT or ART centre as this entailed involuntary disclosure of one's positive HIV test result. Therefore, comments like, *"kuyoowa kulekwa'* (fear of being divorced) and, "if seen at a VCT or ART VCT securing a sexual relationship would be difficult", were common among the married were men and young respondents respectively. Such concerns interfered with people's access and utilisation of the HIV and AIDS services and thus limiting or delaying the desired linkages and outcomes. For instance, while answering as to why they delayed to go for an HIV test, a single 40 year old female ART client confessed:

> *"I was also scared of being laughed at by people after knowing my status, you know people around here have coined certain names to refer to the sick, people no longer want to associate with you, even kushabwa (getting a boyfriend) becomes a problem, basankwa inga balatatamuka, (men keep a distance),even some family members and so you find yourself lonely"* (community based IDI).

These concerns were expressed and reiterated by different sources. For instance, when asked the question, "Have you heard about some cases where people have been divorced because of going for VCT?" this was clearly attested to during one of clinic based focus group discussions, as illustrated by the statements below:

Eecho chilachitika maningi (That happens a lot).

Another participant retorted:

> *"Chasing of wives is there. Like one woman in our village was chased by her husband for going for VCT. After the woman became okay, the husband came back again for the wife".*

Many community leaders were well aware of such practices and how they impeded access to available HIV and AIDS related service. As a result, they were emphatic on the need, in an era of HIV and AIDS, to do away with such negative cultural practices.

Concerns about negative cultural practices were expressed by several other key informants as evidenced by the statements below:

> **"***Yes that is very common, and when the man refuses it means the woman cannot go even if she perceives herself to be at risk because the man is the head of the household. But some are flexible while others are very rigid. I also know of women who have gone against their husbands will and do the test and some of these women have now lost their marriages especially those who were found positive because they were blamed for being unfaithful. This discourages a lot of women from going for testing. But what I have seen is that the situation is worse in polygamous marriages because each woman would want to protect her marriage and so you find none of them wanting to be the first one to have a test for fear of being blamed and losing their marriage in the process"*(Church Leader).

Actual cases of women being divorced, threatened to be divorced and other forms of violence for either insisting on testing or testing positive were very quiet common. For instance, a 36 year old woman initially from a polygamous union narrated how after testing positive she was subjected to prolonged mental and verbal abuse from her husband. She explained that, she had invited her husband to attend the ante-natal clinic, as per clinic requirement but declined. After the test which unfortunately turned out to be a positive test, problems started and that the husband did not want to have anything with her. She pointed out that her husband then started blaming her for having brought the disease into the union. At the time of interview, she was living with one of her maternal aunties with all her four children, one of whom was HIV positive and on ART. In her own words she lamentably narrated that:

> *"I was tested in 2009 and I was found positive. I saw that he [husband] had nothing to do with me. Each time I prepared food for him he would not eat it but instead he would go to his first wife to ask for food. He even stopped sleeping in my bedroom saying, 'how can I sleep in a bedroom where there is a deadly disease'. And each time he came back from his drinking spree he would wake me up and demand that I narrate to him how and where I got the deadly disease from because as far as he was concerned he and the other wife were not sick and that from the time he started having affairs with women he had never slept with an HIV positive woman. Sometimes he would tell me, 'you already infected me and am just a moving grave, because you as my wife you have killed me already'. He had never beaten me but he mistreated me through the way he was speaking to me. I saw that his actions were to chase me away from his house and that is how I left to come and live with my aunt here, as they say, 'Actions speak louder than words'. From the time I came here he has never come to see me or render any assistance to the children"* (36 year old ART user, separated from husband, Community based IDI).

Narrating a similar experience, during one of the clinic based women's focus group discussions, another woman in her mid-forties stated that:

> *"I went for testing while my husband was not around because he used to refuse me, each time I talked about it he would threaten me saying when you go there do not even think of coming back, you can go and get married to your doctor. So one day when he was not around I decided to go secretly. I was tested from Puky Clinic. When my husband returned and saw my ART card, he asked me what the card was about. I told him that my sickness troubled me and I went for testing, and got the card. When my day came for me to go to the clinic, I asked him where it was and he told that he burnt it. From that time I differed with him. At that time I also realised that I was pregnant and so I decided to leave for my village to enable me have access to the medicines and protect my baby. The baby is now more than six months and he has never come to see her, we are still separated and I do not care."*

Notwithstanding the concerns about loss of sexual relationships being more common among women than men, there were also instances of men harbouring such fears. For instance during one of the clinic based IDIs a middle-aged male narrated that:

> *"I feared my wife. I thought to myself, if am positive is she going to stay with me? Many women had divorced because of the same disease, I told myself, No I won't go. If I lose this woman, how would people regard me in the community? My name will be spoiled. It takes a minute to spoil a name and takes years to build it. Fear of*

> *divorce had been a bad barrier going for VCT. One day, as I was chatting with her I asked her to go for VCT with me, her answer was why? Where did we get the disease from? You are not honest, because the only man I know and sleep with is you. If you are HIV go and test but do not tell me the results when you come back. I am not interested in such stories. I looked at her without a word. As we went to bed to sleep, I had a sleepless night. My mind started thinking about the conversation that I had with my wife. I started thinking, if she can answer me like that and we have not tested, if am positive is she going to take care of my children? Definitely she will run away. If she runs away, am I going to manage to stay alone with the children? Those barriers troubled me a lot. I said to myself, I have been in marriage with her for so many years and a disease to separate us. People say, the devil you know is better than the one you do not know, so I said to myself I am not ready to marry someone else anyway."*

Relatedly, two other male ART users also shared their initial fears:

> *"Alimwi ndakayowa kulekana abakaintu (The other thing is I was scared that my wife would divorce me)"* (Midddle aged male ART user, clinic based FGD, amid laughter from other participants).
>
> *"The other worry was about my wife, I wondered what was going to be her reaction if am found positive. Is she going to accept my status? What if she divorced me, who will look after me and am I going to manage to look after my family. Those were the questions that troubled my heart"* (61 year-old male ART user, clinic based IDI).

As a result of the fears identified above, many respondents gave fear of divorce as a reason for not testing or delaying to test. Table 4.6 shows that more than 90 per cent of those who did not test gave fear of divorce as one of the reasons for not doing so and the significance at P value= 0.00, a typical example of the role of such fears on people's entry and retention in the continuum of care.

Cases involving women, who could not be consistent with taking their medication or stopped completely for fear of violence, were quite common. The women also reported that being on medication as generally straining their relationships. For instance, a divorced female ART user in her late thirties narrated how she stopped taking her medicines because she was looking for somebody to marry her. She stated that she had relocated to the village from Lusaka, where she was also working as a house maid after her first marriage failed. Upon reaching the village, she got into a relationship with a man who she hoped would marry her. Further, she explained that problems started when the man decided to live with her, making it difficult for her to continue taking the medicines as she did not want him to know that she was on ARVs. She thus, stated:

> *"I did not want the man I had a relationship with to know that I was on ART because I was looking for someone to marry me. Ndakali kuyoowa kuti inga wanditatamuka" (I was afraid that he would abandon me). I think this was one of the major reasons*

> *for missing ART that time. I used to take ARVs and I stopped taking them for similar reason"* (32 year old Female ART user, community based IDI).

In a similar interview, a 40 year female ART, a widow also narrated:

> *"The main challenge was the thought of being detected by my late husband because at first he did not want us to talk about testing even when so many of co-wives had died, he always spoke of witchcraft, so I was thinking what of if he sees me taking the medicine what will be his reaction, he may even chase me. So at first I was hiding it with my neighbour the one who advised me to go for VCT* (female ART user, community based IDI).

The same woman above revealed that this was a challenge for her becaus**e** it meant that each time she had to wait for her husband to move out of the premises before she could go to the neighbour's home because she did not want to be frequenting her neighbours home and be suspected of anything.

These sentiments were also expressed during one of the community based focus group discussion with women when one of the discussants, amid agreement and support from the other participants elucidated:

> *"Some men throw away medicines, even for pregnant mothers who want to protect the unborn baby, others even when the baby is born and is supposed to take the medicine given at the health facility, they would throw it away saying, "In my house I do not want anybody taking this medicine, and as long as this is my child you shall not give him this kind of medicine. So these women have to take medicines secretly, they can't even dare disclose to their husbands that they are on ART"* (Elderly female, community based FGD).

There is no doubt that these experiences interfered with people's entry and progression along the continuum and consequently limiting or delaying the desired linkages and outcomes of the continuum.

4.4.5.7 Medicine- related factors

These basically had to do with anticipated and actual possible effects or efficacy associated with ARVs. This included seeing someone on ART get better. People wanted to test so that if found positive they could access the ARVs and feel better as well and the observed/anticipated efficacy of the ARVs also encouraged those who were found positive to start taking medication. Many study participants therefore, indicated that they were prompted to go for testing, start taking the ARV drugs either after seeing or hearing how others had recovered because of taking ARVs. This was facilitated further by role models.

Among these was the actual efficacy or positive effects associated with the medicines. This included either seeing some body on ART get better or one feeling better, (increased energy, physical body changes such as putting on weight) after being on the medicines for some time. For, instance those who started taking medication became strong and healthy again, gained weight. These can also be linked to positive perceptions about the medicines. Some clients even claimed that those who were on ARVs looked healthier than those who were not, with such women becoming more beautiful with long hair and smooth skins. All this acted as predictor for testing, ART initiation and adherence.

While anticipated and actual effects of the medicines facilitated entry and movement along the continuum, negative possible effects and other medicine related issues acted as barriers. The most frequently mentioned medication-related concern was the need for ARVs to be taken for the rest of one's life once tested and found positive and ARVs not being curative. A number of study participants wished that curative medications could be provided as opposed to life-long ARVs. This was attributed to the fact that most people have known medicines that cure and to be taken only for a short period and not for life. Another concern that was raised in connection with ARVS were the side effects that arose from using them. The concerns about the medicines can be deduced from the individual fears associated with the medicines shown in Table 4.26. The results in this table show that concerns among those who had not tested were very highly represented at 48 and 50 per cent for taking medicines for life and side effects from medicines respectively.

Some of these side effects reported as being associated with ARVs were, headaches, increased appetite and intolerable hunger, drowsiness, swollen legs, vomiting, heart palpitations, nausea and generalized skin rashes. However, at the stage of testing, these were mere anticipated concerns mainly derived from what people that had either used these medicines in the past or heard about them medicines from other people. It is noteworthy that their association with testing was very significant at P=000.Therefore, these anticipated side effects and concerns about the need to take medicines for life once initiated did interfere with one going for testing and also initiating ART.

Therefore, because of these anticipated side effects, comments like, *"ndakalikuyoowa musamu nkaambo ulakola (*I was afraid of the negative side effects*), musamu upa kuchiswa* *kwiindilila, “*The medicine can make you more sick”, were quite common in both testing and ART uptake as being the reason why people delayed or had reservations for testing and ART initiation. There were also those who talked about seeing some people who were on ART developing unproportioned weight gaining, such as big chest and small legs. Such negative side effects did cause delay in initiation of ART among some would be ART clients. Therefore, comments like, ‘*ndakasanguna kuliyeeya nkaambo ndakali kuyoowa kusekwa’* (I delayed in starting to take medicine because I was afraid of being laughed at, ‘if I were to start taking medicines and developed such body changes’, were also common.

In adherence, most of these issues were no longer anticipated concerns but as experienced by those on ART. Some study participants narrated that some of these side effects were so serious that they either almost or actually stopped taking their medication. Those who experienced the negative ones narrated how they either stopped or tempted to stop taking ARV, to postpone and dread the dosing times because of these “terrible side effects”. Many pointed out that they had to be strong to continue taking ARVs” for the sake of feeling well again, and wanting to live longer. Some of these experiences are illustrated by the quote below:

> *“For me I had so many problems just after starting the medicine, sometimes I could not open my eyes, sometimes it was terrible headache like it was splitting into two, even becoming deaf, na imwi yakali nzala , citankaamo ndakali kuunya musa kakunnyina chakulya himwi hiindi (I do not know whether it was hunger because sometimes I would take them without any food), ah if you are not strong you can give up, but I thought about my children, I would say to myself, who will look after them, their mother is dead, this encouraged me to continue taking the drugs,”* (Widower father of six young children, the oldest 17 years old and the youngest 8 years old community based IDI).

When I started taking the drug, I felt sicker than before. My body became so weak; I used to feel dizziness after taking the drug. Sometimes I used to feel and behave like somebody who was drunk with beer because I would fail to find the door. I had bad effects from the medicine. So when it was time to take the medicine I used to think to myself should take it or I just stop taking this medicine) (46 year old male ARV user, community based male IDI).

Health care providers and care givers were also cognizant of the difficulty that people on ART had to go through because of side effects as conveyed by the following quotes:

> *“And then there are some clients who develop bad side effects, a number of people just give up, we really have to work hard to encourage them, but again the distances*

> *are a problem so some people may not come to seek more information, and so some start thinking what they have been hearing about ARVs being killer drugs is true so they abandon the medicines"* (Health care provider).
>
> *"The only problems I have seen are the side effects, in the beginning he [referring to the husband] used to complain a lot after taking the medicines. He used to have headaches most of the time and he also used to complain about cizyungu boombe, (dizziness), and I had to force him to take the medicine"* (Female care giver, married to an ART client, community based IDI).

A number of ART users and some key informants from health related background reported that the many side effects from ARVs were one of the reasons why some patients opted for traditional medicines as these did not to have any side effects.

Other concerns raised over the medicines were the requirement for the medicines to be taken on a daily basis and for life. Study participants narrated that they were not used to take medicines that were to be taken for life because all their lives, medicines were supposed to handle a particular health condition. Therefore, comments like "Musamu *ulabeleka, ino pesi twacinvwa kunya mapilusi a buzuba", Tulombozya musamu unwigwa amwaka komwi, olo kuubika munyeleti".* (This medicine works, but we are tired of taking tablets every day. We are wishing it could be taken at least once per year or be made into injection form). Some wished ARVs could be made in liquid form for easy swallowing. Though not generalised, some study participants talked of the size of the tablets as being too big particularly for younger clients. For instance, a male adherence supporter elucidated:

> *"There is need for the manufacturer to consider the younger clients because the tablets are too big, so you find that care givers are required to start crushing the tablets because these young people on ART fail to swallow them."*

Some of the clients also complained about the, size of medicine bottles, number of bottles one was given to take particularly, if one was given a course for a number of months was also an issue. This was because according to them, "It was not possible to hide them when coming from the health facility and everybody along the way would see that one was carrying the medicine". This, to some extent, just reflected the level of stigma in this community. For some of the participants, the number of pills to be taken per day and number of times the drugs were to be taken was another issue. For this reason, many proposed that the drug be provided either in injection form or reduced to say once every after six months. This was also to reduce possibility of one forgetting to take medication.

4.4.5.8 Individual- Level: Facilitating Factors

(i) Seeing Someone on ART Recover

Among individual reasons were seeing one on ART recover. ART clients reported that they were encouraged to go for testing, start taking their medicines and also continue doing so because they had earlier seen somebody who was very sick get better after taking ARVs. This was through use of role models – people who were seen by the whole community as bed ridden and dying who had fully recovered and became very strong again. Apart from physical recovery, participants also made mention of other positive effects such as long hair, nice smooth skin and general beauty as illustrated by the quotes below:

> *"I was encouraged because of my friends whom I saw, who were bedridden and the moment they started taking drugs they became strong and healthy and some of them looked very beautiful with nice smooth skin and long hair, (ndakati ma andime ndisole) (So I said let me also try"* (41 year-old female ART user clinic based IDI).
>
> *"I was encouraged to start taking my medication when I saw those who were on ART getting better. They look healthy and they were strong, some of them even looked much healthier than those who were not sick, this really encouraged me"* (61 year old (Male ART user Community based IDI).

Other individual-related facilitators identified and found to run throughout the continuum of care were desire to live longer, seeing someone recover while on ART

(ii)Desire to Live Longer

Desire to care for one's family or children and in particular young children, came up several times as a driver for entry and continued participation along the continuum. Many said that they had seen orphans suffering in the community and they did not want their own children to be found in a similar situation. This is clear from statements below:

> *"Then for my children, to continue caring for them, since their father is dead who would look after them, this really troubled me, if I died no one would look after them, many orphans are suffering in our communities and I did not want this to happen to my children"* (Middle aged widowed mother of 3, community based IDI).
>
> *"I think being sick or not feeling unwell is what prompted me to go for VCT, another thing was that I was worried about my children because they were still very young. So I would say to myself "Ino bana bangu ndibasiye shuwa (How can I surely die and leave my children)"* (37 year old male ART user, father of 4, clinic based IDI).

This desire to continue caring for one's children was so strong that it was enough to overcome HIV and AIDS related stigma as is shown in a statement from a 58 year old woman:

> *"The feeling of shame is always there, that feeling was there but when I thought about my children, I put it aside"* (Female ART user, community based IDI).

In addition to caring one's children, there was also some sense of wanting to be independent of other people so as to take charge of one's own life and responsibilities as the same woman cited above continued and said:

> *"I was tested because I wanted to be given medicines and be healed so that I could continue working for myself and my children, now I can weed my groundnuts, otherwise I was not going to be able to do that, may be would have even been dead by now. I am looking after five of my own children and three of my nieces whose parents died."*

It was also common to hear people having gone for testing so as to access treatment in order to avoid dying early not necessarily for anybody else but for themselves because they just wanted "to stay alive". Such comments were also common for one's decision to start taking medication and also to consistently and continuously taking medication. So comments like *"buumi mbubotu",* (Life is good), *kuyanda buumi*, *kutayanda kufwa kufwambaana,* (wanting to stay alive and not wanting to die early) were also common as a reason for testing. While some did it for their own sake, for others it was because they wanted to live longer for the sake of their families, particularly those with very young children. Others were seeing someone on ART get better. Results are contained in Table 4.26

The results in the table show that all the mentioned individual factors played an important role in facilitating adherence, with all of them being above 80 per cent (very strong and quite strong put together), typically showing the role of all individual reasons on the continuum of care. The significance is also very high at P=0.00.

Table 4. 27 Individual-related reasons and levels of Agreement

Individual factors contributing to adherence	Levels of agreement and disagreement Very strong		Quite strong		Somewhat strong		Not strong		Total	
	No	%	No	%	No	%	No	%	No	%
Seeing someone on ART recover	218	85.8	15	5.9	20	7.9	1	.4	254	100
Desire to support one's family	130	51.2	123	48.4	1	.4			254	100
Desire to live longer	210	82.7	22	8.7	22	8.7	0	.0	254	100

Source: Field work, Chivuna survey 2009-2011, χ^2 *= P<0.000 for all the factors.*

Some participants also indicated that the perceived severity of the illness and too much pain, what some referred to as *chilwazi chilatuma cheni, the* illness and pain itself will force you to go for testing, be linked to a health care provider, start taking medication and also consistently take medication at individual level. At times severe illness was also seen as preventing people to access services particularly, those from very distant communities. Low perceived severity of the illness also dissuaded people from accessing and being retained in HIV related services and hence having a negative implication on viral suppression.

4.4.5.9 Limiting Factors

(i) Low educational levels

Educational levels in the study area were said to be quite low. Many key informants particularly, from the health facility, observed that this scenario contributed to treatment interruptions. It was reported that because low literacy, levels of understanding were equally low, making it difficult for clients to assimilate information. Sharing his experiences, a male health provider narrated:

> *"Then you have the problem of high illiteracy levels, if you were to check the files, most of them have only gone up to grade 5, so understanding this pandemic is poor and then for the same reason many have problems with reading which means they only have to depend on the health care providers to give instructions but as I have said level of understanding is also low, even understanding simple instructions is a problem so you have treatment interruptions in that way."*

These sentiments were similarly expressed by some illiterate ART client themselves. Referring to her inability to read and how it affected her taking of medicine, a 48-year- old widow who was unable to read and write elucidated:

> *"Then I have the problem of being uneducated, if I forget what the nurse has told me I am unable to read the instructions. It becomes a problem because it means going*

> *to the Mission (Chivuna rural health centre) to ask the nurses again, this is difficult looking at the distance coming here to the Mission. However, the problem is reducing since I have been on the same drug for some time and so I know how to take my medicine"* (Female ART user, clinic based IDI).

Relatedly, another elderly female ART client who was equally unable to read and write, amid laughter from other discussants, lamented:

> *"You see not being able to read is also a problem, at times I get angry with my parents for not sending me to school. At the clinic they give you instructions on how to take the medicines and if you are able to read you can do so even if you forgot the instructions, now for some of us who can't read, you find yourself in problems"* (Female discussant, clinic based female FGD).

Some study participants also cited one being too sick as a barrier for adherence as it would be difficult to travel to the health facility for medical reviews and refills especially in situations where one had no one to send for collection of medicines. Box 5 presents factors that permeated throughout the HIV and AIDS continuum of care and treatment.

Box 5: Factors Permeating the HIV and AIDS Continuum of Care by level

Limiting Factors
Health Facility
• Long distance to heath facilities and related costs, • Low staffing Levels
Medication • Side effects. • Pill burden
Structural • Poor road network • Poverty and livelihood insecurity
Individual • Severe illness • Low educational levels
Facilitating Factors
Health facility • Counselling and psychological support. • Provision of nutritional supplements
Community • Supportive Social networks • Family, support groups
Individual • Seeing someone on ART recover • Desire to live Longer
Structural • Government Policy of free ARVs

Source: Field work Chivuna survey, 2009- 2011.

The study also established that the different factors identified above were interlinked and interwoven and hence reinforce each other in influencing the PLHIV individuals along the continuum of care and treatment. Therefore, while at times the interplay of two factors may be involved such as reduced distance to the health facility (health sector factor), may for example encourage an in individual to go for VCT through motivation to seek treatment (individual factor), sometimes a combination of several factors may be involved. For instance, some study participants cited pervasive stigma (social factor) or waiting times at the ART clinic (health related) which all reinforce each other leading to lack of motivation (individual factor) and consequently resulted into a negative influence on the HIV and AIDS continuum of care and treatment such as one not presenting themselves on time for VCT, not being linked to care services, not starting ART or even attrition from ART. The opposite was also possible.

As such there were a number of respondents who lived very close to the health facility who had not tested, or had tested but could not continue going to the health facility for the required health services and hence not being retained in the continuum once found positive for desired outcomes of ART. For instance, at the beginning of the study four women in a polygamous union and living in close proximity to the health facility had not tested for HIV. A check on them at the end of the study two years later, they still had not tested. Asked why, they all cited concerns about lack of trust and confidentiality of health staff (health system related factors) and fear of being rejected by their husband and blamed if they tested positive (social factor). On the other hand some people from distant communities came for services at Chivuna despite the long distances due to other factors such as free HIV services, need for food (because of pervasive poverty), and encouragement from the family/support groups and also their personal desire to live longer.

In the same vein, it was also reported that some of those who possessed knowledge about the advantages of VCT had not tested. For instance, one female ART user who was also an adherence supporter and living only about 2 kilometres from the health facility narrated:

> "It *took me several months before I could decide to be tested despite me having the knowledge about the advantages of VCT and where to test. This was because I was afraid of possible negative reactions from my husband"* (Adherence supporter, KII).

Other ART user in their frantic efforts to access and comply with treatment, some clients went to the extent of preferring to attend a far off located health facility where they felt confidentiality would be maintained. However, such avoidance and selective strategies often worsened the situation as they led to either delay or complete non utilisation of available services. For instance, when asked why she continued going to a far off facility instead of transferring to Chivuna, a nearby ART centre, a widowed mother of five in her late forties stated:

> *"I can never transfer to Chivuna rural health facility because the nurses there like gossiping a lot. I do not trust them at all. The only problem is that sometimes when I am too sick I fail to go to Pucky to collect my medicines because it is very far and so I have to wait until I am feeling much better, at times I run out of drugs completely and so I miss"* (46 year old Male ART user, community based IDI).

All this shows that the factors did not exist in isolation but that they interacted with one another to either negatively or positively influenced the achievements of the HIV and AIDS continuum of care and treatment. Some study participants also reported that severe illness particularly when there was no helper also prevented people from entering and continue participation in the HIV and AIDS continuum of care and treatment.

The study findings also revealed that the influencing factors at times caused the individual living with HIV to return to earlier stages of the continuum and hence causing backward linkages. For instance, it was reported that there were some people living with HIV who became very sick after they stopped taking medication upon feeling better from being on medication for some time because they believed that they had been healed

To deal with the barriers identified above, study participants were found to have adopted various copying strategies so as to be able to access treatment and adhere to it, showing a lot of determination to enter and remain in the continuum of care and treatment. This was possible by adopting a variety of strategies. These included travelling in advance and sleep in nearby communities, ignoring possible negative reactions, begging or borrowing transport money from friends, relatives and neighbours, begging for free transport from transporters or pay later and begging for food to be taken with medicines. These also included avoidance of certain people and places so as to escape stigma, travelling with food or food money when going for reviews to enable them take their medicine, *kuliyumwa, kunya musamu kakunyina cakulya naukola* (being strong and take medicines on an empty stomach despite the side effects), priotising their health at the expense of household needs (such as using school money for transport), borrowing medicines and taking reduced dosages. Others were disclosure to someone they trusted so they can act as reminders.

There was also disclosing to family members, religious leaders, fellow church members, close friends or confidants for material, financial and emotional support required to cope living with a positive result. Some disclosed to traditional healers because they were believed to keep secrets.

In addition to this, some had physical reminders such as buying a wrist watch, use of cell phone alarms, putting drug bottles in certain positions and use of radios for time telling. Non-disclosure was another mechanism devised. This was done so as to avoid violence, abandonment, stigma and discrimination. Non-disclosure was also done so as to avoid isolation, economic, psycho-social and emotional sanctions, particularly for women. Seeking alternative treatment and remedies, combining ART with other remedies and abandoning treatment when they fail completely were also improvised. At group level, people on ART had set up support groups. These groups aimed at reducing stigma in the community through community sensitization. Additionally, support groups also provided social and emotional support to group members through experience sharing. Further, support groups provided financial and material for group members so as to facilitate adherence.

Among the related costs were shame, loss of self- esteem and embarrassment associated with begging and disclosure. Others were isolation and abandonment particularly for women. Some ART clients also reported of delay due to avoidance of certain health care providers who were believed as lacking confidentiality. This was partly because, there was often need for more investment as more money and time may be required to travel to alternative facilities. Because some study participants preferred certain staff they could trust, the result was longer waiting hours. There were also worries and anxieties of having to cover long distances, finding transport and food money and being away from home for long periods. Then there was the cost of losing relationships and having to establish new ones. These relationships could be ordinary, mutual friendships, marital and family relationships. For example, after divorce in a patrilocal set up of the study area, it meant that the women were the ones who were usually affected, as they were expected to move from man’s relatives back to one’s natal family. There were also health risks due to possibilities of taking wrong drugs and wrong dosages as a result of begging for drugs and reducing dosages. Health risks would also arise from use of alternative remedies or combining ART with other remedies and abandoning treatment.

In addition, there were opportunity costs due to being away from an income generating activities (IGAs) and livelihood sources resulting from frequent travelling to health facility and long waiting times at the health facility. This also included cost of using alternative remedies from traditional healers as these were never free. Additionally, there were travelling costs to reach the healers as some of them were located very far.

4.5 Conclusion

In relation to objective one, the study found out that though HIV and AIDS services were available at Chivuna Health facility, but were a number of gaps as the available services did not meet the WHO minimum guidelines for the provision of HIV and AIDS services.

For the second and third objectives, both cross-cutting and specific factors corresponding to each stage in the continuum were identified. Among the cross-cutting factors at health facility level were: distance to health facilities, counselling, and provision of food supplements and confidentiality concerns of health staff At structural level these were: provision of free ARVs, poverty and poor road network while at community level these were supportive social nets, gender- based violence, local illness beliefs and HIV and AIDS-related stigma. Main influencing factors at medicine level were anticipated and actual effects associated with the medicines. At individual level main factors included desire to live longer and seeing someone on ART recover.

Factors corresponding to specific stages in the continuum were: for VCT: mobile VCT at health facility level, perceived risk of HIV infection, persistent poor health, and feeling healthy at individual level. For linkage to care main factors at health facility level were: In effective referral and follow up system and lack of testing equipment locally while at individual level these included feeling healthy at the time of diagnosis and lack of knowledge on the importance of linkage to care. For ART initiation, these were: lack of testing equipment, while required CD 4 count levels and national guidelines on the initiation of ART were the structural factors. At individual level these were depression, fear of taking medication for life and possible side effects. Readily availability of ARVs was the main influencing factor at health facility level for adherence while forgetting, drug fatigue, having reminders, feeling better , disclosure, non-recovery after being on medication for some time were the individual level factors.

In to limiting factors, the study found out that despite the many barriers that HIV positive people experienced, they adopted various mechanisms to ensure that they accessed the lifesaving services and also navigate through the various stages of the continuum for desired outcomes.

CHAPTER FIVE

DISCUSSION OF FINDINGS

5.1 Introduction

The aim of this study was to explore factors influencing the HIV and AIDS continuum of care and treatment. This chapter discusses the major findings from the study and it is premised on the specific research objectives. This study was prompted by the dearth of literature in Zambia concerning the factors that may either positively or negatively impact linkages at each of the stages of the HIV and AIDS continuum of care and treatment. Understanding factors that either motivate or prevent people with HIV from engaging in and adhering to care at each stage along the continuum is critical to successful treatment and prevention efforts (Layer *et al.,* 2014).

5.2. Prevailing HIV and AIDS–Related Services in Chivuna.

In line with the first objective: to examine the prevailing HIV and AIDS related services, the study found that generally these services were available. However, a number inadequacies were found when compared with the WHO minimum guidelines in the provision of VCT and ART services and these affected the effective operations of the facility. These gaps did exist in nearly all the key departments of VCT and ART delivery. For instance in laboratory management, the CD4 count, the haematology machine and chemistry analyser were lacking. In terms of the physical infrastructure, instead of at least six rooms for counselling, screening, record keeping counselling, waiting room, dispensing and data room, the health facility only had three rooms, leading to the combining of services in one room. This also meant that some of the services provided were not as effective as they were expected to be. For instance, due to lack of specific private counselling rooms, the quality of counselling was compromised because of confidentiality concerns as the counselling room was also the registry.

Additionally, the shortage of health staff also impacted negatively on counselling, waiting and opening times. Earlier studies from other countries within the region (Landman *et al.,* 2004;Mapujo *et al.,* 2007; Libamba *et al.,* 2007; Somi *et al.,* 2007; Schouten *et al.,* 2011; Mashauri *et al.,* 2012), have also observed inadequacies in many health institutions accredited to provide HIV and AIDS –related services. However, unlike other studies (Harriers *et al.,* 2007; Van- Rensburg, 2008; Roura *et al.,* 2009; Mashauri *et al.,* 2012; Layer *et al.*, 2014; WHO, 2414), Chivuna health facility had sputum machine, always had reagents, and never run out of ARVs both for first line and second line and the required antibiotic prophylaxis drugs. This could be attributed to the involvement of CHAZ in the provision of ARV drugs and reagents. Despite this however, it is very clear from the findings that the inadequacies in the health delivery system affected the smooth delivery of HIV and AIDS-related services and hence negatively influenced entry and retention in the HIV continuum of care and treatment of PLWHIV.

In relation to objectives two and three, the discussion is guided by the social-ecological model. Hence, the discussion is based on a multi-level analysis intended to reflect how the linkages are impacted on at all the four stages along the continuum thereby giving a multi-level understanding of the factors that influence entry and retention in the HIV and AIDS continuum of care and treatment. This is also an effort to show how the factors from the different levels interact in influencing an individual to enter into and continue progressing along the continuum and also to show why it is important to adopt multiple strategies from multi-level of influence if desired linkages and outcomes are to be achieved. In this regard, the findings are presented and discussed according to the different levels of influence of the model that guided the study namely: health facility, structural, community, medication and individual.

5.3 Factors that Influence the HIV and AIDS continuum of Care and Treatment Continuum

In line with objectives two which sought to explore the factors that influence each stage of the HIV and AIDS continuum of care and treatment and objective three which was to determine factors permeating through the HIV and AIDS continuum of care and treatment, findings are discussed according to different levels of the social-ecological model. The study at a general level shows that there were both limiting and facilitating factors at each stage of the HIV and AIDS continuum of care and treatment at different levels of influence (Boxes 1-4). Within these limiting and facilitating factors, there were those that permeated through the HIV and AIDS continuum of care and treatment as well as specific ones for each stage in this continuum (Box 5). While limiting factors delayed entry and also caused disruptions in linkages along the HIV continuum, the facilitators enhanced entry and smooth participation of PLWH along the HIV and AIDS continuum of care for desired outcomes of ART. At each level of influence (health facility , structural, community, medication and individual levels), themes that permeate throughout the continuum of care and treatment are discussed first after which the specific ones for each stage in the HIV and AIDS continuum of care and treatment are dealt with as follows:

5.3.1. Health Facility Level Factors

At health facility level, study participants from Chivuna raised a wide range of issues which influenced an individual's decision and ability to enter into and be retained and continue progressing throughout the HIV and AIDS continuum of care and treatment. One factor raised at this level, was distance to VCT and ART centers and related costs. It was reported that for communities that were close to Chivuna health facility, distance had reduced and this was found to be one of the motivating factors for people to take up HIV testing, be linked to care and be engaged, retained in care and continue progressing throughout the continuum. Several other studies in the region have also shown that reduced distance to health facilities can be a predictor for the uptake of HIV and AIDS –related services (Angoti *et al.,* 2006; Roura et al.,2009, Sasaki et al., 2012, UNAIDS, 2013).

However, findings from the present study show that there were still many people from distant communities who were still affected by the distance factor and related costs of transport, a finding that is not only unique to the study area but in many other countries within the region as well (Hardon *et al.,* 2006 and 2007, Botswana, Tanzania and Uganda; Angoti *et al.,* 2009, Malawi ; Roura *et al.,* 2009, Kenya; Medley and Kennedy, 2010, Uganda; Rosen *et al.,* 2011 ; Layer *et al.,* 2014, Tanzania) and Zambia (Carlucci *et al.,* 2008; Samuels *et al.,* 2008; Sanjobo *et al.,* 2008; Sasaki *et al.,* 2012, UNAIDS, 2013). As in the present study, all this literature shows that long distance to health facilities and related costs has been one of the major barriers limiting people from accessing, entering into and retention in the continuum. For instance for VCT, interviews and discussions with people from such communities clearly demonstrated the amount of delays that occurred from the time one started thinking about going for testing and the actual day of testing and hence late entry into the continuum. The same contemplation due to distance also lead to delays in linkage to care and progression along the continuum because all these services were basically located at the same facility. Therefore, as noted by Tuller *et al.,* 2009, even when ART were now provided free in most parts of the SAA, treatment- related costs are still there, and hence still a big barrier to people's entry and retention in the continuum of care and treatment. Findings from this study confirm this.

So, as noted by Nuwaha *et al.,* (2002), close proximity to health centers can without doubt be one of the enablers to the uptake of HIV and AIDS –related services and can therefore enhance people's entry into and continued participation in the HIV and AIDS continuum of care and treatment. It should also be noted however, that at times even some of those who were closely located to the health facility did not adequately utilize the available HIV and AIDS –related services. This was mainly because as we shall be seen later, there was an interplay of several other factors from a multiplicity of levels including HIV and AIDS-related stigma, fear of gender based violence, confidentiality concerns and local illness explanations.

Another factor found to be influential throughout the continuum was counselling and psychosocial support from health care providers. This counselling was reported to encompass pre-test, post-test/pre-ART and continued counselling, support and encouragement. Many study participants who had benefited from adequate counselling at all stages explained how helpful it was for them in entering, being linked to care and continued participation in the whole continuum. This finding is consistent with several other studies from within the region like (Samuels et al.,, 2008;Rosen *et al.,* 2011; UNAIDS, 2013; Layer *et al.*, 2014)and elsewhere (Bllingsley *et al.,* 2014;Blank *et al.,* 2015; Bauman et al.,2013;Gwadz *et al.,*2014;

While adequate counselling at the various stages was found to play a pivotal role in encouraging people to engage and continue participating in the continuum, study participants from Chivuna community reported that in most cases it was not adequate. As has been found to be the case with earlier studies (Hardon *et al.,* 2006; Layer *et al.,* 2014, WHO,2014) a number of reasons were cited for this scenario including low levels of staffing, and lack of conducive counselling environment in that proper counselling rooms were lacking due to limited physical infrastructure. Many authors (Grant *et al.*, 2007; Levy, 2009; Bagwanjee *et al.,* 2008) have also shown the negative implications of inadequate counselling in the uptake of HIV and AIDS- related services. For instance, as noted by Bagwanjee *et al.,* (2008) when pre-test was lacking or inadequate, clients from this study also reported of delay in going for testing and those who did test HIV positive either delayed or declined to get their test results after a positive diagnosis.

Inadequate post- test and pre-ART counselling made some clients fail to come to terms with the positive test result and hence found linkage to care and accepting to start taking medication difficult even when it was prescribed because of likely mental disorders such as depression associated with positive HIV diagnosis (Grant *et al.,* 2008). Similarly, Layer *et al.,*(2014) note that those patients without adequate post-test counselling were mentally un prepared for linkage to care while others did not see the need of linkage to care especially if they were still feeling healthy at the time of the diagnosis. In the same vein, Jackson (2002; WHO/UNAIDS 2010; Rosen *et al.,* 2011) emphasize the need for adequate on- going counseling and not to limit it to testing so as to avoid treatment interruptions.

Therefore, inadequate counselling at all the stages in the continuum (pre-test, post-test, pre-ART and continued counselling) may lead to people's late entry into the continuum of care. In the same vein, it led those diagnosed with HIV dropping –off or being lost to follow up at any stage of the continuum and hence unable to successfully progress along the continuum of care and treatment and also fail to achieve viral suppression.

Although counselling was cited as important in the throughout the continuum of care and treatment, it was reported to be more critical in the stages after testing particularly at linkage and ART initiation as these stages required that an HIV positive diagnosed person is mentally prepared for the positive test result for them to be able to accept the new status. Thus as pointed out by Jackson (2002), post-test counselling was more important than pre-test counselling because before the test, the possibility of a positive result may seem unlikely and hence difficult for people to take counselling seriously around a theoretical framework outcome. When given a positive result, however, disbelief and denial may continue for some time after the test and hopelessness arise for most people. Confirmed by results from this study, without adequate post-test counselling, HIV positive people failed to accept their results and hence delayed in linking to a health care provider and also in starting ART even when it is prescribed. In this study, a finding that has also been reported elsewhere (Yu et al., 2005) and within the region (Starace., 2002), many study participants reported of crying, acting like they were mad and being depressed after being told of their positive test results, indicating the need for adequate post-test counselling so as to adequately mentally prepare those who have been diagnosed HIV positive.

Waiting and opening times were another factor raised as being influential throughout the continuum of care and treatment. As observed before by many studies from within the region, (Hardon *et al.*, 2006 and 2007; WHO, 2010; Layer*et al.*, 2014) and within Zambia, (Sanjobo *et al.*, 2008; Musheke *et al.* 2012; UNAIDS, 2013), most of the study participants from Chivuna complained about long waiting and limited opening times. They explained that they spent long hours at the health facility to be attended to by a health care provider, spent long hours walking to the health facility instead of them being involved in a livelihood or income generating activity, with some particularly those from remote communities, spending approximately on average about three days away each time they were required to travel to the health care facility for HIV and AIDS-related services. For instance, similar to Samuels *et al.,* (2008) those study participants from remote communities reported that they spent on average 3 days away from their homes because the first day was spent walking to the health facility and spent a night in nearby communities, the second day was spent at the health facility while the third day was spent walking back to their homes. If they were seen earlier, they may start their journey back home on the second day. However, many explained that even if that was possible, they still needed to sleep on the way because of the long distances. This means that they still could only reach home on the third day. For those that were seriously sick, the fourth day was spent resting. Unique to this study, limited opening times was another barrier raised and was also reported to contributing to congestion and long ques at the facility. As was the case with inadequate counselling noted above, long waiting times was attributed to inadequate staffing, a situation that has also been observed in other settings (Chopard; *et al.,* 2008; Krebbs, 2008; Samuels et al., 2008; WHO, 2010; UNAIDS, 2013). Limited opening times observed in this study was also attributed to low staffing levels.

Earlier qualitative studies from elsewhere (Bauman *et al.*, 2013; Gwadz *et al.*, 2014), other countries within the region (De-Poli et al., 2004; Angotti et al., 2009; Larson et al., 2010; Layer *et al.,* 2014) and within Zambia (Grant *et al.,* 2008; Samuels *et al.,* 2008; Musheke *et al.,* 2013) found deep rooted distrust of health care providers in charge of the ART delivery. This distrust and lack of confidentiality of health staff seemed to negatively influence treatment seeking in the present study with many study participants in this study also complaining about lack of trust and confidentiality of some of the health staff. Because of the lack of trust, it was believed that some nurses deliberately infected some people with the virus and to them, this explained why some body would test negative on the first visit and positive during the second one. Perceived lack of confidentiality and trust for health staff was a big barrier mainly because of high levels of stigma in this community and therefore an important barrier to people's participation in the HIV continuum of care and treatment. As a result, many study participants reported travelling long distances to other far off health facilities, where they were not known so as to avoid being seen at the local health facility, a situation referred to as "mobile patients" by Samuels and others (2008).Within the facility, some study participants reported being selective of health care providers they could trust. All this led to delay in people entering and also negatively affected the continued participation of those diagnosed HIV positive. Other qualitative studies have shown that many people nonetheless preferred to opt for alternative therapy such as traditional healers and faith healing in which they confided (Hatchet *et al.*, 2004; Musheke *et al.*, 2013).

Some health care providers were also reported of having negative attitude, rude, being judgmental attitude towards HIV positive patients. This also reduced people's motivation to enter into and continue participating in the continuum of care and treatment. Such attitudes were barriers to people accessing and continued participation in the continuum of care and treatment because as stated by Apelling and van Wyk (2008; Christopholous *et al.*, 2015) patients prefer a health care provider who is available, confidential, kind, approachable, non-judgmental, encouraging and supportive. This finding shows the importance of good patient- provider relationship in facilitating the uptake of HIV and AIDS related services. Health care providers are the gate keepers to the health care system and hence the entry point to the health system. In their Mozambican study Posse and Bautussen (2009) put the role of health care providers in adherence at 79 per cent.

Because of all these concerns, many HIV positive study participants preferred fellow positive person for the role of counsellor and ART supporter. According to them, these were more understanding, trusted and non-judgmental because they were in a similar situation. Besides as noted by Kato *et al.*, (2011), through their own experiences, people living with HIV were able to understand the conditions of others living with the disease and can thus be effective HIV counsellors.

The way health services were organized was another issue raised. It was found that at Chivuna health center, HIV and AIDS-related services were separated from the general primary care services. This was a challenge because it exposed those wanting to use HIV and AIDS related services to stigma and discrimination, a finding that is common and observed in earlier studies (AIDS Alliance, 2008; Grant et al. 2008).

However, in Chivuna, there appeared to be some variance over this issue among ART clients in that while some of them harbored mixed feelings over this arrangement, others favored it. The latter category felt that the separation was good because it gave them an opportunity to interact with those of their kind, which they found to be beneficial for their entry and participation in the continuum. To our knowledge, this observation is unique to Chivuna and Zambia as a country.

Consistent with other studies within the region (Roura *et al.,* 2009; Sanjobo *et al.,* 2008; Chirawu *e t al., 2009*) and elsewhere (Mukherjee *et al.,* 2006, Haiti) another factor identified was provision of food supplements by the health facility. This was reported to be a motivation factor in the whole continuum, but more frequently mentioned for entry, ART initiation and retention in care. Many study participants narrated how they were encouraged to take up an HIV testing in the hope of accessing food with some of them even preferring to be found positive for the sake of accessing food, how they were encouraged to start taking ARVs after being given food and how this encouraged them to continue taking medication as they did not have to worry about side effects associated with ARVs. This was a clear reflection of high poverty levels in this part of the country.

Much as food supplements played a pivotal role in the whole continuum, gaps existed in the sense that food was limited. Again this was partly because of pervasive poverty in the area which rendered nearly every in need of food supplements. Another gap was in the frequency of supply as at times it was delayed. There were also some bottlenecks in the actual distribution itself in that it was reported not to reach the intended beneficiaries as some health care providers were reported either selling some of the food stuffs or keeping it for their families.

Despite CHAZ offering some training to health staff, limited training in HIV and AIDS –related services was also reported as a barrier to provision of quality HIV and AIDS –related services. Most of the health care providers actually complained of not having adequate training in the work that they were doing and yet ART provision was supposed to be a specialized field. According to them, this negatively impacted on the quality of the service that they delivered. Hardon *et al., (*2006) ; Shezongo-MacMillan *et al .,(* 2007); Layer *et al.,* (2014) also report of negative impact of lack of/ inadequate training of health care staff in charge of HIV and AIDS –related services.

While the study found cross-cutting themes observed above, a number of factors corresponding to each stage in the continuum were also identified at health facility level. In VCT or entry stage, provision of mobile VCT and community based sensitization activities, antenatal care services, limited ART centres and antenatal services. Positive issues like bringing testing services closer to the community such as through mobile VCT, another finding that is not unique to this study (Makumbi and Matovu, 2007; Angotti *et al.,* 2009; Chirawu *et al.,*2009; Grable *et al.,*2010) was another factor found to be reported as enabler of HIV testing. This was for many reasons including reduced distances and related costs, anonymity factor and prompt receipt of test results. In the study area, provision of Door- to Door- testing (DDT) organized by TCE, one of the cooperating partner was even more preferred to mobile testing. As noted above, however, in Chivuna provision of these community based activities was limited by so many challenges ranging from an interaction of other health system –related factors such as inadequate staffing to structural factors including inadequate financial resources and poor road network in the area.

Many study participants, women in particular, reported that the requirement for pregnant mothers to test for PMTCT during pregnancy enabled them to take up an HIV testing were encouraged to go for HIV testing. This was enhanced further by other health system –related factors which included counselling on the importance of PMTCT by health staff and individual factor of desire to have a healthy child. This was precipitated by the experience of seeing another woman giving birth to a sick child in the past and the suffering they would have to go through.

However, it was found that the requirement for all pregnant mothers to come for testing with their partners was a barrier. This requirement, a finding not only reported in China but in other settings as well (Layer *et al.,* 2014), limited many women from accessing and using the services and benefiting from the PMTCT program because of resistance from their partners. In Chivuna community, because most women were aware of the risks of not doing so, they were reported of circumventing this requirement by going to the health facility either with a male relative of friend for the sake of accessing these lifesaving services.

It was also found that ART centres were limited and Chivuna Health facility was the only facility offering both VCT and ART services while the rest of the facilities only offered HIV testing. This proved to be a challenge in that in the event that one tested positive, they were required to travel to Chivuna ART center for further investigation and hence need for repeated tests. This repeated testing precluded many from testing at other VCT centers an indication that people preferred a full package comprising of both VCT and ART and not only one component. This is another observation which to our knowledge is unique to the study area.

For linkage to care and ART initiation, the main issue raised at health facility level were to do with testing equipment. It was reported that blood samples for CD4 count had to be transported to Mazabuka District Hospital once a week; a frequency which was not guaranteed as it depended on the availability of fuel. Additionally, the only CD4 count machine was not always reliable due to constant break down arising from too much pressure. This delayed HIV positive people's linkage to care and ART initiation as both of the stages required these further investigation to be carried. Many study participants particularly, those on ART expressed the challenges that they had to go through before getting their CD4 count results and the consequent delay in accessing the treatment they so much desired. Additionally for Chivuna, the other machines except the sputum smear test machine for detection of latent TB were all located at Mazabuka District Hospital. These findings are consistent with earlier studies from the region (Rosen *et al.*, 2011; 2013; Layer *et al.*, 2014).

Another major challenge identified in this study for linkage to care services at the health facility level, an observation which has also been made by other studies (UNAIDS, 2013; Layer *et al.*, 2014; Rawizza *et al.*, 2015) was the lack of effective referral, monitoring and tracking system for HIV positive people. For instance, those diagnosed from other centers and other departments within Chivuna Health facility were not accompanied by any health worker to ensure that they were actually linked to a health care provider. Additionally, due to shortage of staff and other logistical challenges, follow- ups were not effective.

It was found that at Chivuna health facility, both VCT and ART services were located in the same building. This was found to facilitate enrollment of those found positive and also linkage to care the same day, an observation also made by (Layer *et al.*, 2014). Challenges were, however, faced by those who were tested in PMCT and other diagnostic procedures which were located away from the VCT and ART clinic as these needed to be referred to the ART clinic for enrollment and linkage. This meant starting the whole procedure of seeing a health care provider all over again including the long clinic queues. The situation was, however, worse for those diagnosed outside Chivuna ART clinic because in addition to being subjected to long clinic queues, they were also required to cover long distances, incur costs of transport and food while away from home. These challenges made some people delay, decline or drop off at this stage of the continuum. Therefore, the people diagnosed from other VCT centers were the less likely to be linked to care because of these additional challenges.

For adherence and viral suppression, one main enabler raised in this study and unique to this study, was the readily availability of ARVs. This availability which made possible partly because of the involvement of CHAZ encouraged people to walk inconceivably long distances to the health facility because they were confident that each time they went there, they would find the ARVs. Unlike other studies (Grant *et al.,* 2008; Samuels *et al.,* 2008; Levy, 2009; Kennedy and Medley 2010) this study did not report of shortages of ARVS and testing reagents yet at the time of the study there were reports of shortages particularly of ARVs in other public health institutions in other parts of the country.

A limitation that did not exist in the current study but observed in other settings (Hardon *et al.*, 2006) was corruption and favoritism in the allocation of ARVs. Cost of ARVs which has been reported in other similar settings (Weiser *et al.*, 2003) and within Zambia in earlier studies before the introduction of free ARVs (Grant *et al.,* 2008) was also not reported in the current study.

5.3.2. Structural Level

Consistent with findings from other settings, (Mshana *et al.,* 2006; Roura *et al.,* 2009;Tuller et al., 2009; Geng *et al.,* 2014) poverty and livelihood insecurity was another influential factor throughout the continuum. Because of pervasive poverty, many study participants pointed out that they had challenges in securing money for transport to go to VCT and ART centers, forcing many to resort to covering long distances on foot. Lack of food also demotivated people from taking an HIV test for fear of anticipated side effects arising from taking ARVs on empty stomach if found positive, delayed ART initiation because of the same anticipated side effects and also negatively impacted on consistence in taking drugs due to experienced side effects related to ARV drugs.

High poverty levels could be linked to the Structural Adjustment Programme (SAP) which was introduced by the then Government of the Republic of Zambia in the early 1990s (UNDP, 2007). This saw the withdrawal of Government aided crop marketing organization the introduction of liberalized market economy which exposed many small scale farmers to unscrupulous briefcase businessmen. Peculiar to this region of the country was also the persistent and disease and droughts in recent years which has transformed the once bread basket region of the county to one depending on food handouts.

Though some people in this area were reported to have been beneficiaries of the Fertilizer Support Programme (FSP), the later situation has often thrown back most people into low crop yields, a situation that has created a vicious circle of poverty and poverty trap. This has been exacerbated over the years particularly before the introduction of free ARVs, to the loss of able bodied members of household to AIDS, a situation which is not peculiar to Zambia but common to several other countries in the region. Still viewed within the context of HIV and AIDS, even with the free provision of ARVs, some people were reported to be still gaining strength as they were still in the recovery stage.

While commenting on poverty and HIV and AIDS , it should be noted that a number of micro and macro studies (Mutesa and Chito, 2005; UNDP, 2007; MoH, 2008) argue that there exists an interlinkage between poverty and HIV and AIDS while other authors (Hargreaves, 2013; Mufune, 2014) note that the fact that many of the countries severely affected by HIV and AIDS are also in the southern part of the globe and poverty stricken, this does not necessarily mean that poverty leads to HIV infection. This means that a relationship between HIV and poverty remains mixed and hence the need for further research around this area (Mufune, 2014). However, in the present study, this linkage seemed to some extent exist.

Another finding apparently peculiar to Chivuna was the negative impact created by poor road network on the continuum. It was reported that because of poor road network and in the absence of public transport services, at times even when one managed to raise some money for transport to travel to the health facility for HIV and AIDs-related services there would be no motor vehicle to get on. This was mainly because the rugged roads discouraged most private transporters. This equally forced people to cover the long distances to VCT/ART centers on foot, a situation which was very challenging particularly for the aged, physically challenged and the very young. In the same vein, poor road network limited the provision of several other community based HIV and AIDS-related activities which would act drivers for people to enter early into and be retained in the continuum of care.

As noted by other authors (Roural *et al.,* 2009) free testing and no cost associated with ARVS was another factor identified as predictor of entry into and continued participation the continuum. This was attributed to Government policy of free testing and free ARVs intended to encourage people take up HIV testing. Nearly all study participants narrated how free testing and free provision enhanced their entry and continued participation in the continuum respectively. They explained that as poor people, they would not have afforded the costs of testing and worse still to be on the lifelong saving treatment and were grateful to government for this provision. While free testing and free provision of ARVs was an indication of government commitment, the main gap identified in this provision was the long distances that many people still needed to cover for them to access these free services.

Challenges specifically for ART initiation at this level were the national guidelines on the initiation of ART and the required CD4 count levels for one o be considered eligible for ART. At the time of the Zambian National guidelines stipulated that only a doctor or clinical officer could initiate ART. In Chivuna community this proved to be a challenge because of the fact that there was only one clinical officer in charge of both the OPD and the ART clinic. In the event that the clinical officer was not around particularly at month ends when she was required to go to Mazabuka for her banking services, no one would be initiated on ART on that particularly day. Meanwhile some people would have covered long distances to the health facility. This is another finding that seems peculiar to Chivuna community.

Many study participants also complained about the required CD4 cell levels before one could be eligible for ART initiation. At the time of the study, the National Prescribed CD4 count level was 350. This meant that even if one was feeling unwell, as long as the CD4 count was above 350, ART initiation could not be done. Some study participants on ART narrated their experiences at this stage of the continuum. Key informants from the health facility also did note that some people were lost to follow up at this stage with some resorting to other remedies as they saw no need of continuing coming to the health facility when they were "denied" treatment. Other authors (Layer *et al.,* 2014) have also acknowledged this requirement as being a barrier to early initiation of ART. Because the issue of CD 4 count has emerged as a limiting factor even in earlier studies, there are considerations of abolishing its requirement for ART initiation (CDC, 2012).

5.3.3 Community Level

At community level, study participants raised a range of challenges which reduced people's motivation in entering into and progressing along the continuum. These included HIV and AIDS related stigma and discrimination, negative perceptions of ARVs and VCT. Others were local illness, concepts about illness causation and gender based violence. Facilitators included social nets such as membership in support groups, client to client interaction, community health workers and support from the family.

In Chivuna community, it was widely acknowledged that stigma and discrimination was reducing in this community. However, many HIV positive study participants reported of a range of experiences of negative reactions at personal level after being diagnosed positive. Fear of stigma and discrimination has been discussed as one of the major barriers for the uptake of HIV and AIDS-related services in diverse settings, elsewhere (Bauman *et al.,* 2013; Gwadz *et al.,* 2014; Medu *et al.,* 2014; Blank *et al.,*2015; Zullinger *et al.,* 2015) from other countries within the region (Kalichman and Simbayi, 2003; Mitchel *et al.,* 2007; Miller *et al.,* 2010; Rosen *et al.,* 2011) and within Zambia(Grant *et al.,* 2008; Sanjobo *et al.,* 2008, Fox et al., 2010; UNGASS-ZAMBIA, 2010; Fylkesness *et al.,*2012). Many study participants in this study narrated how they delayed to go for HIV testing, how they avoided being sported by other community members frequenting the VCT/ART clinic for fear of negative reactions. Fear of stigma was an important barrier to accessing and participation in HIV and AIDS related services because as noted by Goffman (1963), one of the early sociologist, stigma contributed to spoiled image or identity. In the study area this spoiled image was mainly because HIV and AIDS was still linked to perverted sexual behavior, a belief that led to the HIV positive people to be judged for their condition. In fact, the statistical measurement of stigma shows that the levels of stigma in this community were still very high. As noted by Merten *et al.,* (2015), it was plausible that people would want to protect themselves from discrimination and marginalization, as it was stated in many narratives. Fear of stigma jeopardized health seeking and disclosure to persons who might otherwise provide material and social support. As observed by earlier authors and confirmed by results from this study, the connotation of immorality and death linked to HIV because of the life threatening character of the disease (Niehaus, 2007; Meiberg *et al.*, 2008), blaming person with HIV for their infection (Meiberg *et al.,* 2008) are the core and hence the most important determinants of HIV-related stigma.

Another factor identified as influential throughout the continuum of care at the community level and also common in many other earlier studies from the region (WHO, 2010; UNAIDS, 2013; Layer *et al.,* 2014) was local illness explanation and beliefs about illness causation. In Chivuna, it was widely reported that local illness beliefs such as witchcraft or spirits being able to cause illness including HIV and AIDS existed. Such beliefs discouraged people from entering into and progressing along the continuum as they would feel that their health condition could only be addressed by traditional healers, spiritual healers and other non-conventional remedies. Additionally, some people believed that even HIV and AIDS could be cured by these alternative remedies. Such beliefs made people delay entry into the continuum, delay linkage to a health care provider, made people delay or decline ART initiation and also caused treatment interruptions. Ultimately, this negatively impacted on viral suppression and healthy living and the desired outcome of ART treatment.

Except for Aspelling and Van Wyk (2008) who report that traditional beliefs and customs did not interfere with adherence, several studies from the region (Hatchet, 2004; Plumer, 2006; Roura et al., 2008) and within Zambia (Mongesen, 1995; Malungo 2001; Merten, 2006; Roura *et al.,* 2010) have reported the negative role of such beliefs on people's access to and utilization of HIV and AIDS-related services. This calls for interventions aimed at sensitization of people against such beliefs so as to ensure people's early entry into and successful progression throughout the continuum. As observed by other authors (Golooba and Mutebi, 2007; Musheke *et al.*,2012), because of these beliefs, some people, those who believed in illness as an act of God or caused by evil spirits reported embarking on prayers or faith healing. This also caused delays because as noted by Vermeulem (2011), insisting on accessing conventional medical care would imply that one did not believe in the power of prayer. As noted by Musheke *et al.*, (2012), as a corollary, the perceived efficacy of alternative treatment and faith healing needs to be challenged through sensitisation targeting patients, religious leaders, faith healers and herbal medicine providers.

Perceptions of ARVS was another factor identified at this level as influencing people’s entry and successful progression along the continuum. In this study, it was reported that much as perceptions about ARVs were evolving from negative to positive ones, negative ones had not completely been wiped out in this community. A growing body of knowledge has shown that negative perceptions about ART has the potential of demotivating people from being engaged in HIV and AIDS related services (Kerr *et al,* 2004; Gwadz *et al*, 2014 ; Layer *et al.,* 2014). However, because of this evolution, most of the people in the community strongly believed in the efficacy of ARVs as lifesaving drugs. This motivated many of them to go for testing so that if found positive, they could access the medicines and avoid early death. This positive belief of ARVs equally encouraged people to continue taking these medicines.

In line with findings from other studies conducted in the region (Shezongo- Macmillan et *al.,* 2007; Taegmeyer *et al.*, 2009; Theuring *et al.,* 2009; WHO, 2014) gender based violence and its outcomes precluded some people in this study particularly, married women from participating in HIV and AIDS-related services. Many women reported of fear of being abandoned, being accused of infidelity and at times physical harm if seen either at a testing center or being found with ARVS. Thus, reports of women being divorced and abandoned for insisting on being tested for HIV or found HIV positive and in possession of ARVs were quite common in the study area.

Supportive social networks such as the family and support groups was another influential factor identified at this level. This membership was reported as motivating a person’s decision to enter into and be retained in the continuum. Others were community health workers, client to client interaction, community at large and the family. Except for client to client, which was more frequently mentioned for adherence, all the factors identified above were reported as playing a role in encouraging people to test, be linked to care, ART initiation and also adherence.

For instance, membership in support group and community health workers, through their counselling, psychosocial support, sensitisation against stigma and discrimination in the community encouraged people to have HIV testing, get linked for care, ART initiation and also to be retained in care. Consistent with other studies in particular in relation to support groups (Roura *et al.,* 2009) they provided social, emotional and material support. The statistical measurement at P value 0.00, suggests a very close association between adherence and one being a member of a support group, which is a typical example of the role of support group on encouraging people to participate in HIV and AIDS –related services. However, in this study, support groups were found to be operating under very difficult conditions. For instance, they lacked transport to enable them access some of the clients, which affected their frequency in the visitations and monitoring of some of the distant located clients. Additionally, while support groups provided members with money for transport and food, which encouraged uptake and retention in HIV and AIDS services, their capacity to do so was limited due to lack of financial capital to enable them be involved in meaningful income generating activities. Community health workers also had logistical problems which equally hampered their work. Additionally, both categories of community workers were very poorly remunerated.

Support from the family was also cited as a major facilitating factor throughout all the stages in the HIV continuum and a very close association was established between family support and adherence at P value 0.00). This is another typical example of the role of family support in the HIV continuum of care and treatment. This finding is similar to earlier studies elsewhere (Farmer *et al.,* 2001) and within the region (Nachega *et al.* 2007, Posee and Bautussen, 2009; Sasaki *et.al*, 2012). It should be noted however, that in this study despite existence of high levels of family support, some families were not supportive and so some study participants complained about lack of support and discriminatory attitudes from their close family members.

As in some studies (Roura *et al.,* 2009) client to client interaction was reported to be applicable specifically for adherence. As a result, many study participants explain how they were motivated to take their medication through experience sharing facilitated by this interaction.

5.3.4 Medicine-Related Factors

The main factors raised at this level were anticipated in the first three stages and actual positive and negative effects of ARVs in the last one. Among the most frequent mentioned positive effects were seeing someone on get better after being sick for a long time making people believe that ARVs were effective in saving lives, actual physical recovery after being on ARV for some time. All this encouraged those who had not tested to test so that they could also access the medicines and feel better again start taking ARVs and also continued taking medicine believing that they would also one day get better.

Negative effects were mainly associated with the many anticipated and actual side effects associated with the medicines (vomiting, headache, nausea, dizziness, increased hunger and appetite). The anticipated side effects made people delay to go for HIV testing for fear of a possible positive HIV test result which would require them to start taking the ARVs. The anticipated negative effects of ARVs equally contributed to those found positive to delaying in accepting to start taking HIV medication while the actual negative effects caused treatment interruptions and drop offs or lost to follow up along the continuum of care and treatment. These findings are consistent with findings from elsewhere (Kerr *et al.,* 2004; Musheke *et al.,* 2012; Gwadz *et al.,* 2014) and from within the region (Schumaker and Bond, 2008; Tabatabai *et al.,* 2015). This, as rightly noted by (Butler *et al.,* 2014) indicates the need for adequately counselling at all the stages of the continuum to ensure that people understand these issues so they can manage the fears of side effects and side effects themselves in the event that they are found positive.

Another major challenge with the ARV drugs was the fact they were not curative and for life. This concern came mainly because traditionally, people were used to medicines that cure health conditions. Therefore, as rightly observed by Murray *et al.,* (2009), there was need for a new cultural framework around illness given local expectations that medicines are normally thought of as curative and therefore temporary. As observed by Schumaker and Bond (2008) and Ayalu *et al.,* (2012; Zullinger*et al.,* 2015), characteristics with the ARVs of taste, size of tablets, not being in liquid form and many dosing times were also of concern in this study.

5.3.5. Individual Level Factors

At individual, many factors influence a person decision and ability to enter into and be retained in the continuum of care and treatment were identified. One factor raised in this study and reported to be influential in all the stages throughout the continuum, a finding that is not unique to Chivuna but to other settings in the region as well (Nuwaha *et al.,* 2007,Unge, 2008) was desire to live longer. This desire was reported to be for either personal reasons because life was good or for the sake of other people such as one’s family particularly for those that had very young children. Severe illness or advanced illness observed in this study has been acknowledged in earlier studies within the region also (WHO, 2013).

Another cross-cutting theme mentioned at this level and also associated with the medicines as noted above was seeing someone who was once very sick get better. So people tested so that they could access ARVs if found positive, while those that were prescribed medication were also encouraged to start taking medication and once prescribed ARVs encouraged to continue taking them and retained in care. This finding is consistent with those of (Kerr *et al.,* 2004); WHO (2014); Tuller *et al.,* (2014). Fear of side effects was another cross-cutting theme for testing, ART uptake and adherence to medication, a factor also linked to the medicines. Though side effects were mentioned in the three stages, they were however more frequently mentioned for adherence and this is mainly because, in both testing and ART initiation, the fears were only anticipated while as in adherence, they were as actually experienced by those taking ARVs.

Factors corresponding to specific stages at this level were also identified. For testing, those similar to other studies included perceived risk of HIV infection (Fyilkesnes and Siziya, 2004) persistent illness (Ker *et.al.*, 2004; Oshi *et al.*, 2007; Grant *et al.*, 2008; Blank *et al.*, 2014*)* and the many fears associated with testing(Grant, *et al.,* 2008; Blank *et al.*, 2014; Gwadz *et al.*,2015). A unique finding to this study was people testing because of wanting to avoid stigma and discrimination. This was a reflection of high levels of stigma in this community because people wanted to test early and access the medicines so as to void being sick and be suspected of being HIV positive. For linkage to care specific factors and observed by other studies included not seeing the importance of linkage (Billingsley *et al.*, 2014; Layer *et al.,* 2014) health status at the time of the diagnosis and not believing positive HIV test result or denial (Alvarez*et al.,* 2013; Parchure *et al.*, 2015). According to the sociologist, Kubler-Ross (1969), these were common in patients diagnosed with terminal illness. She notes that denial acted as a coping mechanism while depression could not be avoided in such patients. Another specific factor for testing was knowledge. It was that all tested knew where to test indicating that knowledge was very important predictor for people to take up an HIV test and enter the continuum if found positive. The P value was 0.00, suggesting a very close association between testing and one knowing where to test. The importance of having knowledge, awareness of existing HIV and AIDS –related services and the benefits of testing in testing has been reported before within the region (Nuwaha *et al.,* 2002, Theuring *et al.,* 2009) and elsewhere He *et al.,* 2009). The gap here however, was that, there were still many community members particularly from remote communities who still lacked the knowledge which would enable them enter and be retained in the continuum of care. This was mainly because, of an interplay of several other factors such as low staffing levels required to do the job of community sensitization, lack of financial resources and poor road network. For linkage to care, specific factors were ones health status at the time of diagnosis and lack of knowledge on the importance of linkage to care services and denial of positive test results.

For ART uptake, findings from the present study that have also been noted by other authors were depression after a confirmed positive HIV test result (Roura *et al.,* 2009) fear of life –long medication and fear of forgetting (Kerr *et al.,* 2004). These fears expressed in this study are consistent with Bandura's concept of self- efficacy which says that people with low-self efficacy are more likely to view difficult tasks as something to be avoided rather than to be mastered because it makes people believe tasks to be harder than they actually are (Bandura, 1977). According to Bandura therefore, low self-efficacy strongly influences both the power a person actually has to face challenges competently and the choices a person is most likely to make and that these effects are particularly apparent and compelling with regard to behaviors affecting health. Hence we see in this study that because of low self –efficacy, some people were less likely to take action as they developed feelings of helplessness in that they viewed the task ahead of them (of life –long medication) as being too difficult and un manageable.

For adherence, specific factors were forgetfulness (Barfod *et al.,* 2006), forgetting due to being drunk (Parhure *et al.,* 2015) recovery after (Weiser*et al., 2003*; UNAIDS, 2013); having reminders (Mshana *et al* 2006; Grant *et al.,* 2008). Others were disclosure of one's sero-status, drug fatigue (UNAIDS, 2013); (Chesney et *al.,* 2000; Murray *et al.,* 2009). Consistent with findings from other studies from within the region (Nachega et al., 2007), findings from this study show that the longer the duration of treatment, the more adherence will decline. But unlike such earlier studies, this study also showed that adherence increased with duration of treatment and hence the longer one was on medication, the easier it became for them to adhere to prescribed treatment.

It is also should also be noted that some of the cross-cutting influencing factors noted above were more influential in some of the stages along the continuum than others. For instance, food supplements were more important in adherence because all the side effects associated with taking ARVs without food were no longer anticipated in this stage but actual and as experienced. This also applies to the many other anticipated medicine- related side effects. Similarly, long distances to health facilities were more of a challenge in adherence because of the frequency of travel and related costs required for medicine refills and other monthly appointments. Post-test and pre-ART counselling was also more important than pre-test counselling because there is need for HIV positive people to see themselves around the new status and accept the living with a chronic disease for them to be able to continue participating in the continuum of care for optimal benefits from ART.

Additionally, some of the factors identified above were complicated further by socio-economic and demographic factors of the respondents such as gender, age, marital status, educational level and. For instance, although poverty was wide spread, it was much more extreme and deeper among the aged, female divorcees and those that were widowed. Meaning that the issues of entry and being retained in the continuum and viral suppression, were more of a challenge among this category of clients. HIV and AIDS-related stigma and discrimination was worse off for women, particularly the aged and the youths, fear of gender based violence and its outcomes was also more among women than their male counterparts. Similar, long distances to health facilities were felt more among the aged, the very young and the physically challenged.

It should also be noted that the factors noted above did not exist in isolation but that they were interlinked and therefore interacted with each other in either negatively or positively influencing the HIV and AIDS continuum of care and treatment. Hence, as noted by Roural et al., 2009; Musheke et al., 2013), while at times the interplay of two factors may be involved for example to encourage an in individual to go for VCT, sometimes a combination of several factors may be involved. As a result, in this study some study participants cited pervasive stigma (social factor) or waiting times at the ART clinic (health related) which all reinforced each other leading to lack of motivation on the part of the individual and consequently resulting into a negative influence on the HIV and AIDS continuum of care and treatment such as one not presenting themselves on time for VCT, not being linked to care services, not starting ART or even attrition from ART. Hence as seen from the findings, some people close to Chivuna health facility had not utilised the available services despite reduced distance because of other factors that acted as barriers while some from distance communities travelled to the health facility because of other factors that acted as motivators. All this shows that the factors did not exist in isolation but that they interacted with one another to either negatively or positively influence the achievements of the HIV and AIDS continuum of care and treatment. The fact that some people for example from distant places travelled over long distances to access care is also an indication that some of the factors were overriding over others. Hence, despite the long distance, the need to live longer could be an overriding factor and influenced people to attend health care while stigma could be an overriding factor and prevented those that were close to the health facility from accessing and using the available services.

By application of the social-ecological model, this study has revealed as assumed by the model that an individual's health seeking behavior is located in social, institutional and physical environment and consequently behavior shapes and is shaped by social environment (Roura *et al.,* 2009). Thus, individual treatment seeking behavior for HIV and AIDS related services of VCT, ART uptake and adherence is determined to a large extent by the social environment which includes community norms and beliefs such as local illness ideologies and interpersonal relations. The physical environment also includes health system factors (including negative attitude and lack of confidentiality of health staff) and public policy or policies which include policy on financing of health, for example, free provision of ARVs and testing. In addition to the physical environment are individual factors such as feeling better, fear of side effects, illiteracy and depression.

Therefore, the resulting health seeking behavior would be a combination of efforts at all of the levels, for example, individual, interpersonal, community. Thus, through the application of the social-ecological model, this study has been able to investigate and show as stated by Roura and others (2008) that individuals are located in a dynamic social ecology in which they adapt their behavior to their social environment and make decisions based on information, influences and interactions available through local social networks, relationships and institutions. All this is a clear indication that the theory was very useful for the study.

5.4 The Meaning of the Study in the Context of Sociology and Its Contribution to the Field of Medical Sociology

This study used the social-ecological model (SEM) from study conceptualization to data analysis and discussion. The SEM is embedded in a protracted sociological problem of structure and agency. It was chosen in recognition of the influence of broader structural factors over individual actors and the inadequacies of individual factors in explaining social phenomena. Since the study found that entrance and retention in the HIV continuum of care is influenced by a multitude of factors operating at health facility, community, structural, medical and individual levels, it confirms the importance of considering multiple factors in understanding illness and disease and also the influence of macro structural factors outside the individuals themselves.

The study for instance indicates that, the community and structural level contains factors which possess as a threat to the individual's entrance and retention in the HIV continuum. These factors include poverty, food insecurity, stigma and local illness explanations. This means that the agency of an individual actor is constrained by the community and society at large making him fail to seek proper treatment. Giddens in his 1984 structuration theory book intimated the failure by people to act in their own interests in the face of structural fundamentals. Additionally, people's experiences of illness in a specific cultural context such as living with a health condition and in particular an incurable one is also brought out by the use of the SEM. This model has therefore, contributed to understanding and explaining the role played by a particular cultural framework on people's health seeking decision in relation to entry into and retention in the continuum of care.

This is mainly because as pointed out by some sociologists (McLaughlin and Braun, 1998) all cultures have systems of health beliefs to explain what causes illness, how it can be cured or treated, and who should be involved in the process. Therefore, societies which see disease as a result of natural scientific phenomena, advocate medical treatments that combat micro-organisms or use sophisticated technology to diagnose and treat disease. Other societies as seen in this study believe that illness is the result of supernatural phenomena and promote prayer or other spiritual interventions that counter the presumed disfavour of powerful forces. This is what has come out from this study in that because local illness explanations did exist in the study area, these influenced their health seeking decision pattern. As long as a health condition was seen as caused by witchcraft for instance, traditional and not conventional medicine was sought.

Cultural issues play a major role in patient compliance. As has been seen, the Tongas of Chivuna as an ethnic group have their own perspectives and values for the health care system, and their health care beliefs and health practices differ from those of another traditional health care system. Therefore, as seen from this study, cultural differences affect patients' attitudes about medical care and their ability to understand, manage and cope with the course of an illness, the meaning of a diagnosis, and the consequences of medical treatment (Mc Laughlin and Braun, 1998). At individual level, some of the concepts identified by the study were denial and depression, which according a renowned sociologist Kubler-Ross (1969) were common as coping mechanisms for patients diagnosed with terminal illness.

By using the multilevel model, the study has also contributed to a broader understanding of people's health seeking patterns, because as stated by Choi *et al.,1998*, the investigation , analysis, and explanation of health seeking behavior requires taking into consideration the interaction of both individual and the social environment in which an individual is located. And therefore, efforts to improve health seeking patterns require interventions targeting both individual and external factors. The use of this approach has also demonstrated that, to ensure people's early entry and continued participation in the continuum for the ultimate goal of ART (viral suppression for less morbidity, less mortality and less transmission of new infections), there is need to adopt multiple strategies targeting multi levels of influence.

Max Weber's concept of verstehen (Coser, 1977), was useful for this study because it focuses on peoples lived experiences and the subjective meanings and views they attach to their behavior. In this way it was possible as indicated by (Goshi, 2003) to discover people's motives for their behavior patterns. In this regard, this study has contributed to understanding people's health seeking behavior in particular in relation to one's decision to enter into and be retained in the continuum or continue progressing along the continuum for viral suppression, a desired outcome for ART. In the same vein, the study has contributed to understanding the motives why some people delay, decline to enter and still others enter but drop off along the way. Meaning, people's decision to enter into and be retained in the continuum, delay to enter into, decline and drop off can be said as being partly to be dependent on their subjective interpretations of their perceived illness. Additionally, sociology is about understanding human behavior (Giddens, 2009). By studying people’ s health seeking behavior in relation to HIV and AIDS –related services, using the above model, this study has contributed to understanding the pandemic and related services from a social point of view requiring not only medical interventions but also social interventions.

To sociological theory, the study has added a fifth level of analysis to the model used. In this way, the study has expanded the model and its level of investigating and analyzing health seeking behavior. Therefore, future sociologists intending to investigate health seeking behavior can use the five levels of analysis instead of the original four.

CHAPTER SIX
CONCLUSIONS AND RECOMMENDATIONS

6.1 Summary and conclusions

The aim of the study was to explore factors influencing the HIV and AIDS continuum of care and treatment. In pursuit of the aim, the study utilized the social -ecological model which analyses health behavior from multilevel of influence namely: health facility, community, structural and individual levels and an additional one i.e. the medication level which emerged from the present study at pilot stage. This model was found useful for this study because of its broad approach in analyzing individual health seeking behavior in that it takes into consideration of both personal and non- personal external environmental factors in explaining an individual's health seeking behavior. By using this multilevel analysis and mixed study methods, the study has revealed that there were limiting and facilitating factors on the continuum of care and treatment some of which were specific for each stage along the HIV and AIDS continuum of care and treatment while others were influential throughout the continuum of care and treatment from different levels of influence. Among the specific facilitators for VCT, which is the entry point into the HIV and AIDS continuum of care and treatment, were having knowledge about the advantages of VCT and where to test, provision of mobile VCT, positive perceptions of VCT, antenatal services and persistence illness while limiting factors were negative perceptions about VCT, fears associated with testing and having no symptoms of ill health.

For the second stage of the HIV and AIDS continuum of care and treatment, that is, linkage to care services, limiting factors included lack of testing equipment locally, lack of an effective referral system, separately located services, denial of positive HIV test result, one's health status at the time of diagnosis and lack of knowledge of the importance of linkage to care. Location of all HIV and AIDS related services in one building, as was the case at Chivuna ART clinic, was the main motivating factor at this stage. For ART initiation limiting factors were lack of equipment and feeling healthy at the time of eligibility for ART initiation. Others were required CD4 count levels and the national guide lines on the initiation of ART which at the time of the study stipulated that only either a doctor or clinical officer could prescribe ART. Meaning that in the absence of these two, clients eligible for ART could not be initiated on ART thereby delaying ART up take and consequently disrupting the desired linkage at this stage of the continuum of care and treatment. For adherence, facilitators included readily availability of ARVs, having a reminder, support from fellow ART clients, ART supporters and fear of side effects, forgetfulness and alcohol abuse as limiting factors. The major limiting factors that permeated through the continuum of care and treatment were distance to health facilities and related cost, waiting times and limited opening hours, confidentiality concerns and lack of trust of health staff and lack of integration of health services. Other cross- cutting limiting factors were poverty and livelihood insecurity, stigma and discrimination, local illness ideologies, negative perceptions about ART, poor road network while provision of food supplements, positive perceptions about ART, provision of free ARVs, counselling, supportive social networks such as support groups and the family were the major facilitators.

These findings indicate that the HIV and AIDS continuum of care and treatment is influenced by a multiplicity of factors at each stage and throughout the continuum of care and treatment. Hence the need for the consideration of these factors both at each stage and throughout the continuum of and treatment. This can help improve PLWHIV participation in the HIV and AIDS continuum of care and treatment and achieve the desired out comes of ART.

This study contributes to the needs of men and women who are living with HIV and AIDS in terms of accessing and utilising health services in the HIV and AIDS continuum of care and treatment. First, it used the social ecological model to determine a comprehensive list of facilitators and barriers as indicated above which influenced the HIV and AIDS continuum of care and treatment in a primary health care unit of Chivuna in the Southern Province of Zambia. This list on the continuum of care (Box 1-5) can provide valuable insight to social ecological factors that researchers looking at HIV and AIDS care programmes ought to consider addressing if they are to improve care and render the required services. From the many factors identified, it can also be stated that through the use of the social ecological model, this study has demonstrated that an HIV positive individual's decision to enter into and progress along the HIV and AIDS continuum of care and treatment is influenced not by personal factors only but an interaction of several factors from multilevel of influence. These include from those from personal level and external no-personal environmental factors such as those coming from the community, structural, health facility and medication levels. Some of these factors correspond to each of the stages in the HIV continuum while others cut across all the stages of the continuum. This implies that to achieve the desired outcome of the HIV and AIDS continuum of care and treatment which is to keep the viral load to undetectable levels, there is need to adopt multiple strategies targeting multiple factors from level of influence. This will involve addressing barriers at each of the levels and stages throughout the continuum of care so as to decrease the barriers to HIV and AIDS-related care.

This, as assumed by the model, suggest that improving equity of access and utilisation of HIV and AIDS related services, (in the case of this study entry into and continued participation in the continuum), requires interventions that target multiple levels of influence and also utilise multiple intervention strategies (Minkler,1999). Secondly, this study revealed a new component on the continuum, that is, medication level which shows that there were aspects of HIV and AIDS treatment such as side effects from ARVs and efficacy of ARVs which could either negatively or positively influence the HIV and AIDS continuum of care and treatment respectively. This in essence improves the existing model by adding an extra concept and future researchers intending to use this the model can apply the mode with the five levels as opposed to the original four.

The practice implications of adopting a broader social ecological perspective to address barriers and enhance facilitators shifts the field of HIV and AIDS care and programming from thinking about individual interventions to how individual interventions may be augmented or supported by interventions at various levels of influence. The results point to emphasising the potential benefit of adopting a multilevel intervention approach. This calls for combining interventions that could produce synergies that are greater than interventions that only utilize one level of influence (Weiner et al., 2012). Adopting a more ecological approach requires careful analysis and planning to identify key leverage points at each level that may exhibit interdependence with determinants at other levels (Stokols, 1992; 1996; Choi et al., 1998; Roura et al., 2009), the use of health promotion planning models (Green et al., 2005; Bartholomew and Robinson, 2008). Therefore, consideration of the theoretical mechanisms underlying the desired outcomes that could guide the logic for particular strategies within Chivuna would be ideal. As elicited from the interviews, this will likely require collaboration among multiple fields of expertise in health policy implementation at local, community, health facility, medication and individual levels.

It should be noted that the field of health care programming is witnessing a shift from a focus on individuals to a broader health system perspective that brings attention to the accessibility of health materials and tools, the communication skills of health professionals, and the institutional characteristics that support the active engagement of PLWHIV and their families. As this shift occurs, greater attention in Chivuna will need to be placed on how to create more comprehensive interventions, prepare healthcare professionals, educate and prepare the community, and build both healthcare systems and public health infrastructures that foster and support this shift. In turn, as shown by the results, this change can help create environments that reduce barriers, provide information, foster dialogue, and ultimately encourage engagement of PLWHIV and their families.

6.2 Implications for policy

If the barriers identified by this study were addressed, findings from this this study can contribute to future HIV and AIDS related programmes aimed at improving the health outcomes of the HIV and AIDS continuum of care and treatment. Secondly the broad perspective provided by this study through the use of the social ecological model can lead to formulation of more broad based policies and programmes that can make a difference not only for the people of Chivuna but in the lives of many other people.

6.3 Recommendations

In relation to the last objective, the following are some of the suggested measures aimed at improving the HIV and AIDS continuum of care and treatment:

1) Improving capacity and effectiveness of HIV and AIDS related service delivery: Government should ensure that health facilities accredited to deliver HIV and AIDS –related services meet the WHO minimum standards so as to enhance people’s early entry and progression along the HIV and AIDS continuum of care and treatment for desired outcomes of ART. For instance CD4 count machines should be available at time of testing so as to enhance linkage to care services immediately after one tests HIV positive.

2) Community- centered interventions: The health facility should build capacities for community- based organisations like support groups through training, resource generation and mobilisations. Through such interventions it can also be possible to

combat HIV related stigma, negative local beliefs, gender based violence and other practices that hinder the uptake of VCT/ART-related services. Alternative treatment and faith healing can also be challenged through sensitization targeting patients, religious leaders, faith healers and herbal medicine providers. Challenges relating to distance and indirect costs can be addressed by bringing services closer to the communities through introduction of community- based approach in the distribution of HIV–related services. This can reduce the indirect cost for people living with the virus and their families to deal with distance to health facilities and hence positively influence the HIV and AIDS continuum of care and treatment.

3) Provision of food supplements and free ARVs: Viewed within the context of high poverty levels, there is need to continue with free ARVs and provision of food supplements to be part of the package of ART.

4) Address poverty among people on ART: This can be through social protection by Government for vulnerable people, as is already the case currently, but needs to be expanded so that more vulnerable people, particularly, those on ART can be reached. To avoid perpetual dependency on handouts, government could consider giving some vulnerable but viable community members (particularly those on ART) some soft loans in form of agricultural inputs and also re-stocking of cattle. To avoid past failures of such programs, better monitoring mechanisms should be put in place.

5) Need for information, education and communication through health communication: Through such activities, health care providers and other stake holders can be able to provide adequate and updated information about ARVs so as to create demand for HIV and AIDS service throughout the HIV and AIDS continuum of care and treatments, address harmful and positive practices and perceptions about ARVs so that many can know that these medicines were a source of *buumi* (life) and not killer drugs. Such information would also address individual factors such as one still feeling healthy, low perception of HIV infection, fears associated with testing and side effects from ARVs. In this way, people can have proper information about side effects; the need to test even when they were feeling healthy or have low self-perception of HIV risk. In the same vein, people can have understanding that one can only start taking medication at a certain level of CD4 count level.

6) Need for the local health facility to reorganising the system by separating appointments for clinical assessment from those visits to pick up medication so as to reduce waiting times at the health facility

6.4 Future Research

A number of issues arose in the course of the present study which prompted the need for further research. Therefore, it is proposed that future studies could focus on the following:

1) Investigating the actual proportions of people dropping off at each stage of the continuum.
2) Exploring the challenges of health care providers in providing HIV and AIDS –related services.
3) More broadly, this study has generated facilitating and limiting factors on the continuum of care using a social-ecological model. The factors could take the position of variables in a quantitative study within Chivuna. The variables could enable clarification of influences on programme implementation at each level. Therefore, development and testing of predictive models in social-ecological studies of this nature are imperative and would provide useful guidance for understanding in greater detail and to generalise the findings.

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APPENDICES

Appendix 1

General Information/Introduction

Greetings! I am __________________________ and I am *working/studying* at the University of *Zambia/Basel.* We are also collaborating with ZAMBART (Zambia AIDS Related TB Project), an organization, which is aiming at improving the quality of life of persons affected with TB or HIV.

We are conducting a research project aiming at improving the health care services. The study has two main objectives. First, we would like to explore what a person usually does when he or she is sick and needs treatment. Some people may face problems like a lack of money, or a lack of support in the family. Sometimes health care services may not be able to respond to particular health problems.

Second we are interested whether there are special concerns as regards HIV related health services. We would like to know how you have been informed about HIV testing and treatment options and whether you have ever made use of such services, or intend to in future. Today an HIV infection does no longer signify death. Medication has become available also in Zambia. If this medication is taken regularly it can improve survival and the wellbeing of a person with HIV. However, still many persons do not consult HIV related services. They may fear the reaction of their families and the community. There might be other reasons. Also, of those who are participating in an ART program, some stop going there. It is therefore important to know more about people's views on HIV related health services to improve health services.

This interview is part of the first phase of the study. We plan to interview 25 households in the Districts of Monze, Namwala, and Mazabuka, and in Lusaka. The purpose of this interview is to learn about households concerns with healthcare and treatment seeking.

Confidentiality

We will ask several persons the same questions. We will not tell any names to anyone. Everything you say will be treated highly confidential. The results of this research will be written down in a report where no names will be mentioned.

Study Team

This study is led by UNZA and the University of Basel, Switzerland, and their collaborating institution ZAMBART. Responsible persons are Dr. Jacob Malungo, UNZA, and Dr. Sonja Merten, University of Basel, Switzerland.

The following persons are part of the Chivuna Team ***Dr.Jacob Malungo, Ms Harriet Ntalasha, Obvious Michelo and Pamela M***

The interview will take no longer than 1 hour. Your participation in this interview is completely voluntary. Any question you feel uncomfortable about, please feel free not to answer it. Your names and other information that may identify your household will be kept confidential. The results of this research may be published but your identity will be protected.

There may be unexpected concerns arising during your participation in this study. Some questions may make you uncomfortable. If so, you are not obligated to answer them and we can move on or stop the interview.

We will not provide money for this survey. There are no direct benefits associated with participation in this survey but may be indirect benefits for your community in the future. The information gained in this study may help organizations design future interventions.

If you have further questions about this research, you may contact the following persons:

Dr. Jacob S. Malungo
The University of Zambia,
School of Humanities and Social Sciences
Social Development Studies Department
Demography Division
P.O.Box 32379, Lusaka, Zambia
Tel/Fax: 260-1-290320
Cell: 097805997
Email: shakumenzya@hotmail.com.

If you have any questions about the ethics of this research, please contact the Chairperson of the Research Ethics Committee at UNZA, PO Box 50110, Lusaka. Telephone +260 1 256067.

Dr. Sonja Merten
Institute of Social and Preventive Medicine at the Swiss Tropical Institute, an associated institute of the University of Basel, Switzerland
Steinengraben 49
4051 Basel
Tel: +41 270 22 22 / 0975 792714
Email: Sonja.merten@unibas.ch

We are asking you for written consent to take part in this discussion. Could you please read (or have read to you) this consent form and then sign it if you agree?

Date: Signature PI:

Appendix 2: Consent Form

Interviewer : ☐ ☐☐☐

You understand that your participation in this study will not benefit you directly, but it may benefit others in the future.

You understand that your participation in this study is voluntary. You will be free to decline if you wish. If you agree to participate, you can decide not to answer certain questions and can stop the interview at any time.

You understand that you are free to ask questions before signing this form and that if you have further questions about my dissertation research, you may contact Dr. Jacob S. Malungo, The University of Zambia

Tel/Fax: 260-1-290320. If you have any questions about the ethics of this research, please contact the Chairperson of the Research Ethics Committee at UNZA, PO Box 50110, Lusaka. Telephone +260 1 256067.

You have been provided with this information in writing and/or had it read to you by a researcher from the study.

Consent statement for signature

YES, I have read this entire consent form, or had it read to me, and any questions have been answered to my satisfaction.

YES, I have been informed by the interviewer in oral or written form about the aims of this study, and about the ways how the information I will provide can be used.

I’ve had enough time to take my decision. All questions I have regarding the study have been answered satisfactorily.

YES, I agree that the responsible researchers, and representatives of the ethical committee can obtain insight in the transcripts of the information I provide, however under strict confidentiality.

YES, I confirm to participate in this study out of my free will. I know that I can withdraw my consent at any time. I can keep a copy of this consent form.

Consent
I agree to participate in this study
☐ no
☐ yes
☐ I need more time to decide, another contact time agreed: ______________________________

Recording
Tape recording allows us writing down literally everything what you said. We will not give the tapes to anyone outside the study group. Your name, or any other names you mention, will not be appearing in written form.

I agree that the interview is recorded on tape
☐No

☐Yes

Study participant:
Date:____________ Location: _______________ Signature:_______________
Interviewer:
I confirm that I have explain the participant the aims and contents of the study. I will comply with all the requirements of this study as mentioned above. In case I become aware of any potentially negative effects on the study participant I will inform him/her immediately and not influence him or her in his decision.

Date:_____________ Location: ________________ Signature:_____________

Appendix 3: English Questionnaire

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Appendix 3
Questionnaire
I. Location
Town
Area/village---------------------------
Community/clinic-----------------------

II. Interviewer visits------------------
First visit----------------------------
Second visit---------------------------
Date-----------------------------------
Interviewer code---------------------------
Record the time -----------------------------------
Result of the vist*---------------------------------
Day month year_----------------------------------
Day month year-------------------------------------
Name of interviewer-------------------------------
Hour/ minute--------------------------------------
*Result codes--
01= Completed--
02= Not at home--
03= Postponed---
04= Refused --
05= Partly completed-----------------------------------
06= Incapacitated
07= Other
Supervised by:____________________________________
Name: ____
EDITED BY: ____
DATE ____________________ DATE _______________________

SECTION 1. DEMOGRAPHIC INFORMATION

1= MALE 2= FEMALE
Q.1 Sex of the Respondent
Q.2 How old are you?
Age in completed years
Q.3 What is your nationality?
Q.4 What tribe do you belong to?
Q.5. What is the highes level ofeducation you have completed?
1= None
2= Primary
3= Secondary
4= Tertiary
97= Don’t know
98= Refused to answer
Q. 6 Up to which Grade?
Q. 7 What is your religion?
1= Christian: Roman Catholic
2= Christian: Protestant
3= Animist
4= Islam
5= Buddist
8= Ancestor spirit worship
9= Hindu
10= Judaism
11= Other, specify: ______________
12= No religion
6= Zionist (Protestant) Church 98= Don’t know
7= Confucian (Chinese religion) 99= Missing/No response/refused
Q. 8 How religious do you consider yourself to be?
Read options: this is respondent's self assessment
1= Not religious
2= Not very religious
3= Average religious
4= Very religious
97= Don’t know
98= Refused to answer
Q. 9 How regularly do you attend religious services?
1= Every week
2= About once a month
3= Less than once a month
4= I don’t attend services
97= Don’t know
98= Refused to answer

97= Don’t know
98= Refused to answer
99= Not applicable

Q. 10 Do you participate regularly (at least once a month) in other community group activities?
1= Yes
2= No

Q.11 What is your civil status?
1= Mafried and skip to Q.14

Q.12 What is your marriage type?

Q.13 Where did you settle after getting married?
2= Single
Skip to Q. 13
3= Divorced or separated
4= Widowed
98= Refused to answer
1= Polygamist
2= Monogamist
97= Don’tknow
98= Refused to answer
1= Woman moved to the man’s homestead
2= Man moved to the woman’s homestead
3= We settled in a new place
97= Don’t know
98= Refused to answer

Q.14 Are you in a stable relationship with a man/woman?
1= Yes
2= No
98= Refused to answer
99= No Applicable

Q.15 Do you live with your husband/wife or primary partner?
1= Yes
2= No
98= Refused to answer
99= Not Applicable

Q.16 For how long have you been in a relationship with your husband/wife or primary partner?
1= Less than 1 year
2= 1-5 years
3= More than 5 years
97= Don’t know
98= Refused to answer
99= Not Applicable

SECTION 2: FOOD SECURITY

Base all responsences for (Q 31-34) on these below:
Sometimes
Often
Never
Refuse

Q.17 Do you worry that your family may run out of food before you have money to buy again?

Q.18 Have you ever eaten less than you wanted because you don't have enough money to buy food?

Q.19 Do you know that your children are hungry but you just do not have enough money to buy food?

Q.20. Do you not have enough money to buy healthy and nutritious or balanced food for your children?

SECTION 3: HEALTH SEEKING STRATEGIES

Now, I will ask you some questions about your health status and about what do you do when you are sick or concern about your own health.

Q.21 When was thelast time you were ill?
1= Within the past 6 months
2= 1 year ago
3= More than one year ago
4= Never
97= Don’t know

98= Refused to answer

Skip to Q.25

Q 22 What kind of illness, problems or concerns did you have?

Q.23 How would you rate the severity of the ... (illnes in Q. 36), from your point of view?

1= Very severe
2= Severe
3= Average
4= Little
5= Not severe
97= Don't know
98= Refused to Answer

Q.24 At the time you were ill with ... (name illess from Q.36), who did you consult for treatment?

After the first answer, ask if he/she consulted anyone else; read all the options and check all tha apply, up to 3 responses.

1= Traditional healer
2= Ppriest/Faith healer
3= Herbalist
4= Clinic/Hospital
5= Pharmacist
6= Relative or friend/home remedies
97= Don't know
98= Refused to answer

Q.25 When you felt ill with ... (illness from Q.36), how long did you wait until you consulted someone or treatment?

1= Several days
2= 1-2 days
3= Immediately
4= I never consulted someone
97= Don't know
98= Refused to Answer

Q.26 How would you rate your personal health now?

1= Very good
2= Good
3= Average
4= Poor
5= Very poor
97= Don't know
98= Refused to Answer

Q 26 In general, when you are sick or have concerns about your health, who do you feel more comfortable with toconsult for? Read all the options. Multiple answers are possible.

1= Traditional Healer
2= Priest/Faith Healer
3= Herbalist
4= Clincic/Hospital
5= Pharmacist
6= Relative or Friend/ Home Remedies
97= Don't Know
98= Refused to Answer

Q 27 When you are sick, who usually decides which practitioner you should consuld for treatment?

1= My Partner/Spouse
2= Dughter/Son
3= Sibling
4= Parents
5= Friend
6= Parent in-law
7= Other Relative
8= Myselt
9= Me and my Partner/Spouse (Jointly)
97= Don't Know
98= Refused to Answer

Q.28 When you are sick, who usually pays for the related health treatment costs?

1= My Partner/Spouse
2= Daughter/Son
3= Sibling
4= Parents
5= Friend

6= Parent in-law
7= Other Relative
8= Myselt
9= Me nd my Partner/Spouse (Jointly)
97= Don’t Know
98= Refused to Answer

SECTION4: PERCEPTIONS AND BELIEFS

We have heard a lot about you and your family and about what do you do when you are ill. Now, I would like to continue talking to you about HIV and AIDS.

Q 29 Have you heard about Antiretrovirals? Skip to Q.30.

1= Yes
2= No
98= Refused to Answer
99= Not Applicable

Q.30 I am going to read you some statements about ARVs, please tell me if you are Agree or Disagree.

A-ARVs allow women to give birth to healthy children
A- ARVs make you sick
B- ARVs are not good for children
C- ARVs can make you impotent/infertile
D- ARVs can kill you

Q.31 Now, I am going to read you some beliefs that people have about HIV and AID. To what extent do you Agree or Disagree with them? USE PICTOGRAM 2.

Stronlgy agree
Agree
Somewhat agree
Disagree
Stronlgy dis agree
Don'tKnow
Refused to Answer
Not Applicable

A- People who are suspected of having HIV and AIDS loose respect in this community
B- If a member of my family got infected with HIV, I would want it to remain a secret
C- In this community, people with HIV fully participate in the social events
D- Children who are HIV positive are bullied by other children
E- No mother would let their children play with children who are HIV positive
F- Tradtitional medicines can relieve the symptoms of HIV andAIDS quicker than ARVs
G- Tradtitional medicines can cure HIV andAIDS
H- Treatments with traditional medicines are easier to follow than with ARVs
I- It is easier to access to traditioanl medicines than to ARVs
J- HIV and AIDS can be caused by withcraft
K- HIV and AIDS has been released in purpose to eradicate the black race
L- People who take ARVs are guinea pigs for the governments and other agents. HIV andAIDS has been

Now I would like to know more about the role that HIV/AIDS plays in your own life.

Q. 32 Do you perceive that HIV and AIDS is a problem in your life?

1= Very big problem
2= Rather a big problem (USE PICTOGRAM 1)
3= Somewhat a problem
4= A Minor problem
5= Not a problem
97= Don’t know
98= Refused to answer

Q.33 How often do you think about HIV and AIDS?

1= Always/ Everyday
2= Often/Every week
3= Sometimes/Not every week
4= Rarely/Not evern once a mont
5= Never
97= Don’t know
98= Refused to answer

Q.34 The Orange Circle represents your person. I am going to ask you how close do you feel are these sicknesses from you? Can you locate them on the table? cm cm (Use prism)

A.- Brain Tumour
C.- Malaria
cm cm

B.- Syphilis
- HIV and AIDS

SECTION 5: HIV VOLUNTARY COUNSELING AND TESTING

I would now like to continue talking about you. I will ask you some questions about HIV testing and counseling. What we will discuss during the rest of the interview depends on whether you have been tested or not. Like all the other answers your answers to these questions will be kept confidential and will not be revealed to anybody. We need this infomration to understand the circumstances surrounding health seeking strategies.

Q35 Do you know any place where you can go for HIV testing?

1= Yes
2= No
98= Refused to answer

Q36 Have you ever been tested for HIV?

1= Yes
2= No
97= Don’t know
98= Refused to answer

Skip to Q.90 – questions applicable for respondents who have been tested

Q.37 How did you get tested the first time?

1= I went for VCT
2= Antenatal care
3= Testing during under five check up
4= Referred during another diagnosis process
5= TB corner
97= I don't know
98= Refused to answer
99= Not Applicable

Q 38 I am going to read some reasons that people have for going to be tested. Think about your own reasons and tell me to what extent do you Agree or Disagree with them. USE PICTOGRAM 2.

Stronlgy agree
Agree
Somewhat gree
Disagree
Stronlgy disagree
Don't know
Refused N/A

A- I got sick and I was worried that I might have
B- My sexual partner was sick
C- I suspected my partnre to have other sexual partners
D- I knew that I had taken some risks
E- I wanted to know my status
F- I wanted to get married
G- I plan to have children
H- I only went for testing because it was compulsory

Q.39 Many people experience fears before going for HIV testing, how strongly have you experienced the following fears? USE PICTOGRAM 1.

Very Strong
Quite Strong
Somewhat Strong
Little Strong
Don't Know
Refused to answer
NotApplicable

A- Fear of loosing the main partner(divorce/abandonment)
B- Fear of loosing friends
C- Fear of damaging the family reputation
D- Fear of being rejected by potential partners to get married
E- Fear of taking medication forever
F- Fear of not being able to have children
G- Fear of being rejected by sexual partners to have sexual intercourses
H- Fear of gossip and finger point in the community
I- Fear of ARV side effects
J- Fear of not managing to handle the consequences of living with HIV

Q.40 From the time you started to think about going for a test, how long did it take you before you actually went for the test?

Years

Months
Write number
Weeks
Days

Q. 41 Did you consult anyone before going for HIV testing?

1= Yes
2= No
97= Don’t know
98= Refused to answer
99= Not Applicable

Skip to Q. 43

Q.42 Who did you consult? Read all the options. Multiple answers are possible.

Spouse/partner
Household relatives
Close relatives (not living in my household)
Co-wife/Co-wives
My friend(s)
Other sexual partners
Don't know
Refused to answer
Not applicable

Q.43 Did he/she/they agree with your intention to go for testing?

1= Yes
2= No
3= Only some of them
97= Don’t know
98= Refused to answer
99= Not Applicable

Q.44 Some people have fear to consult their partner(s) before going for HIV testing.
How strongly have you experienced the following fears? USE PICTOGRAM 1.

Very Quite strong
Somewhat strong
Little Not strong
Don't Refused N/A

A- Fear that she/he would not allow me to go for testing
B- Fear of being abandoned
C- Fear of being accused of misbehavior
D- Fear of violence (physical and/or verbal)

Q.45 Before testing, how strong did you have problems with ...? USE PICTOGRAM 1

Very Quite strong
Somewhat strong
Little strong
Don't know
Refused to answer
Not Applicable
A- Drinking Alcohol
B- Having sexual affairs
C- Misusing money

Q.46 Before testing, how strong did those issues mentioned in Q. 71 cause problems in your household?

Very Quite strong
Somewhat strong
Little strong
Don'tkn know
Refused to answer
Not Applicable
A- Drinking Alcohol
B- Having sexual affairs
C- Misusing money

Q.47 Think of your relationship before you went for HIV testin. To what extend do you
Agree or Disagree with the following statements? USE PICTOGRAM 2.

Strongly
Agree
Somewhat
Disagree
Strongly
Don't know

Refused N/A
A- I could turn to my spouse/partner for support in times f crisis
B- My spouse/partner and I got along well together
C- I trusted my spouse/partner

Q 48 Do you still have the same sexual partner now than before going for testing?
1= Yes
2= No
97= Don’t Know
98= Refused to answer
99= Not Applicable

Q.49 How did the relationship with your sexual partner change after you went for testing?
1= I was abandoned
2= It deriorated
3= It remained the same
4= It improved
97= Don't know
98= Refused to answer
99= Not applicable

Q.50 Before testing, have you ever been separated from your spouse because of conflict within the marriage?
1= Yes
2= No
97= Don’t Know
98= Refused to answer
99= Not Applicable

Q.51 Have your current sexual partner(s) been tested in the last year?
Yes
No

Q.52 Do you know the HIV status of your current sexual partner?
Yes
No
97= Don’t know
98= Refused to answer
99= Not Applicable

Q.53 How many times have you been tested for HIV? Write number: _________

Q 54 How long ago did you do your first HIV test?
1= Within the last year
2= 2-3 years ago
3= Less than 10 years ago
4= More than 10 years ago
97= Don't know
98= Refused to answer

Q 55 When did you do your last HIV test?
1= Less than 6 months ago
2= 6-12 months ago
3= 1-2 years ago
4= 2-3 years ago
5= More than 3 years ago
97= Don't know
98= Refused to asnwer

I would like to ask you to share your test results with me; You don't have to. If you do it, you can be sure that this infomration swill be kept condiential and that they will not be revealed to anybody.

Continue next question

Q.56 What is your HIV status?
1= HIV Positive
2= HIV Negative
98= REFUSED TO ANSWER

Skip to Q.60

APPLICABLE FOR RESPONDENTS HIV +

I would like to continue to talk to you about your reactions when you were told that your results were positive. As for the questions before, all your answers will be kept confidential and will not be revealed to anybody. It will help us to understand the ciurcumstances surrounding health seeking strategies related to HIV/AIDS.

Q.57 I will now read you some reactions and feelings that people may have when they are told they are HIV positive. How strongly have you felt about them? USE PICTOGRAM 1.
Very strong

Quite strong
Somewhat
Little strong
Not strong
Don't know
Refused to answer
Not Applicable

A- I felt very depressed
B- I felt ashamed of having the disease
C- I felt I could continue having a normal life as planned and I could handle my positive status
D- I wanted to keep it secret
E- I feared of a near death
F- I felt that I brough a lot of embarrasment to my family
G- I felt relieved because I could start the medicationand avoid of being sick/weak during long time
H- I could plan realistically for the future of my family
I- I felt I brough a lot of financial problems to my family

Q.58 After a all this time, do you think there are more advangtages or disadvantages of knowing your HIV positive status?

1= All advantages
2= More advantages than disadvantages
3= Some advantages and some disadvantages
4= More disadvantages than advantages
5= All disadvantages
97= Don't know
98= Refused to answer
99= Not Applicable

Q.59 How comfortable do you feel now as a person living with HIV?

1= Very comfortable
2= Comfortable
3= Same as before of being diagnosed
4= Uncomfortable
5= Very uncomfortable
97= Don't know
98= Refused to answer
99= Not Applicable

NOTE FOR THE INTERVIEWER: SKIP TO Q. 70 to continue the interview APPLICABLE FOR RESPONDENTS HIV NEGATIVE

I would like to continue to talk to you about how do you think people react when they are told that their test results are positive. What do you think about it will help us to better understand the circumstances surrounding health seeking strategies related to HIV/AIDS.

Q.60 I will now read you some reactions and feelings that people may have when they are told they are HIV positive. Try to assume that you had been found HIV positive, how would you have felt? USE PICTOGRAM 1.

Very Quite
Strong strong
Somewhat strong
Little strong
Not strong
Don't know
Refused to answer
Not Applicable

A- I would have felt very depressed
B- I would have felt ashamed of having the disease
C- I would have felt I could continue having a normal life as planned and I could handle my positive status
D- I would have wanted to keep it secret
E- I would have feared of a near death
F- I would have felt I brought a lot of embarrasment to my family
G- I would have felt relieved because I could start the medicationand avoid of being sick/weak during long time
H- I would have felt relieved because I could plan realistically for the future of my family
I- I would have felt I brough a lot of financial problems to my family

Q. 61 Do you intend to go for testing again?

1= Yes
2= No
97= Don’t Know
98= Refused to answer
99= Not Applicable

NOTE FOR THE INTERVIEWER: SKIP TO Q.140 AND FINISH THE INTERVIEW QUESTIONS APPLICABLE FOR RESPONDENTS WHO HAVE NOT BEEN TESTED

Q.62 I am going to read some reasons that people have for not going to be tested. Think abouto your own reasons and tell me to what extent do you Agree and Disagree with them.

1= Stronlgy Agree
2= Somewhat Disagree
3= Stronlgy
4= Don't know
5= Refused to answer
97= Not Applicable

A- I don't know anything about testing
B- I am not at risk
C- I feel healthy therefore I don't need to be tested
D- I am not interested to know my status
E- I don't know where to go
F- The testing place is too far
G- I would not have the money to follow the treatment
H- I know that the status of my sexual partner is positive

Q. 63 Many people experience fears related to obtaining an HIV positive result. I will now read you some of these fears. How strong have you experienced them? USE PICTOGRAM 1.

Very Quite strong
Somewhat strong
Little strong
Not strong
Don't know
Refused to answer
Not Applicable

A- Fear of loosing the main partner(divorce/abandonment)
B- Fear of loosing friends
C- Fear of damaging the family reputation
D- Fear of being rejected by potential partners to get married
E- Fear of taking medication forever
F- Fear of not being able to have children
G- Fear of being rejected by sexual partners to have sexual intercourses
H- Fear of gossip and finger point in the community
I- Fear of ARVs' side effects
J- Fear of not managing to handle the consequences of living with HIV

Q.64 Have you talked gto your spouse/partner about going for HIV testing?

1= Yes
2= No
97= Don’t know
98= Refused to answer
99= Not Applicable

Q. 65 (b) If not why?

A- Fear that she/he would not allow me to go for testing
B- Fear of being accused of misbehavior

Q. 66 Some people have fear to consult their partner(s) before going fro HIV testing.
How strongly have you experienced the following fears? USE PICTOGRAM 1.

1= Very strong
2= Quite strong
3= Somewhat strong
4= Little strong
5= Not Don't strong
6= Refused to answer
7= Not Applicable

Q. 67 Has your spouse/sexual partner been tested in the last year?

1= Yes
2= No
98= Don’t Know
99= Refused to answer
99= Not Applicable

Q. 68 Do you know the HIV status o your spouse/sexual partner?

es
No
98= Refused to answer
99= Not Applicable

Q. 69 I will now read you some reactions and feelings that people may have when they are told they are HIV positive. Try to assume that you had been tested and found HIV positive, how strongly would you feel about them? USE PICTOGRAM 1

Very Quite strong
Somewhat strong
Little strong
Not strongly
Don't know
Refused to answer
Not Applicable

A- I would feel very depressed
B- I would feel ashamed of having the disease
C- I would feel I could continue having a normal life as planned and I could handle my positive status
D-I would want to keep it secret
E-I would fear of a near death
F-I would feel I brought a lot of embarrasment to my family
E- I would feel relieved because I could start the medicationand avoid of being sick/weak during long time
F- I would feel relieved because I could plan realistically for the future of my family
I- I would feel I brough a lot of financial problems to my family

Q. 70 Do you intend to go for testing in the future?

1= Yes
2= No
3= Don’t know
4=
98= Refsued to answer
99= Not Applicable

NOTE FOR THE INTERVIEWER: SKIP TO Q.130 AND FINISH THE INTERVIEW

SECTION 6: DISCLOSURE – (only for HIV +)

I would like to continue talking to you about DISCLOSURE. I would like to know whether you have talked to anybody about your HIV status and about the treatment with ARVs. This information will help us to understand the circumstances surrounding the access to the HIV and AIDS related services. As before, all your answers will be kept confidential and will not be revealed to anybody.

CONTINUE WITH NEXT QUESTION

Q 71 Have you shared your HIV positive test results with anyone outside the Clinic?

1= Yes
2= No
98= Refused to Answere (SKIP TO Q.108)
99= Not Applicable

APPLICABLE FOR RESPONDENTS WHO HAVE DISCLOSED

Q.72 Who have you shared your HIV positive status with. Read qll the possible options.

Multipl3 answers are:

Co-wife (ves)
Spouse/partner
Spouse/partner
Household relatives
My friend(s)
Other sexual partners
Don't know
Refused to answer
Not applicable
Close relatives (not living in my household)

Q.73 To whom did you disclose first your HIV positive status?

Household relatives
My friend(s)
Other sexual partners
Don't know
Refused to answer
Not Applicable
Close relatives (not living in my household)
Co-wife (ves)

READ ALL THE OPTIONS. CODE ONLY ONE RESPONSE

Q.74 How long did it take you to first disclose your HIV positive status?

1= Within a day after knowing my results
2= Within 1 week
3= Within 1 month
4= More than 1 month
5= 1 year or more after knowing my status

97= Don't know
98= Refused to answer
99= Not Applicable

Q.75 Why did you disclose? I am going to read some reasons that people who are HIV positive may have to disclose their status. Think about your own reasons and tell me to what extent do you agree or disagree with them.

Stronlgy
Agree
Somewhat
Disagree
Stronlgy
Don't Refused N/A

USE PICTOGRAM 2

A- To get support from my family
B- To get support from my spouse/partner
C- To avoid re-infection
D- To encourage my spouse/partner to go for testing

Q.76 Some peole have fears related to disclosing their HIV positive status. I will now read you some of these fears, how strongly have you experienced them?USE PICTOGRAM 1

Very Quite strong
Somewhat strong
Little strong
Not strong
Don't know
Refused to answer
Not Applicable

A- Fear of being abandoned by my spouse/partner
B- Fear of being rejected by my family and friends
C- Fear of being blamed
D-Fear of violence (physical and/or verbal)

Q.77 In the last 12 months, have you ever found yourself avoiding or isolating yourself from friends or family because of your HIV status?

1= Yes
2= No
97= Don’t know
98= Refused to answer
99= Not Applicable

Q.78 How much negative reactions from others do you feel in your day-to-day life? USE PICTOGRAM 1.

1= A lo
2= Rather
3= Some
4= Little
5= None
97= Don’t know
98= Refused to answer
99= Not Applicable

Q 79 How would you rate the severity of stigma, which is any negative reactions towards any HIV positive person in this community? USE PICTOGRAM 1.

1= Very severe
2= Severe
3= Average
4= Little severe
5= No severe
97= Don’t know
98= Refused to answer
99= Not Applicable

Q.80 I will now read you some negative reactions from other people that many people living with HIV experience. Have you ever felt them?

Yes
No
Don’t know
Refused to answer
Not Applicable

NOTE FOR THE INTERVIEWER: SKIP TO Q. 85 to continue the interview
APPLICABLE FOR RESPONDENTS WHO HAVE NOT DISCLOSED

Q.81 I will now read some reasons and fears that people with HIVE + may have to do not disclose their status to anyone. Tell me how strongly do you feel about them?

Very strong
Quite strong
Somewhat strong
Little strong
Not strong
Don't know
Refused Not Applicable

USE PICTOGRAM 1

A- I am afraid of being abandoned by my spouse/partner
B- I am afraid of being rejected by my family and friends
C- I am afraid of being blamed
D-I am afraid of violence (physical and/or verbal)

Q.82 Do you intend to disclose your HIV positive status to anyone in the future?

Yes
No
Dont’t know
Refused
Not Applicable

Q.83 To whom would you disclose your HIV positive status?

READ ALL THE OPTIONS. Multiple Answers are:

Household relative
Close relatives
Possible
Spouse/partner
Other sexual partners
Co-wife (ves)
My friend(s)
Don't know
Refused to answer
Not Applicable

Q84 How would you rate the severity of stigma, which is any negative reactions towards any HIV positive person in the community?

1= Very severe 5= Not severe
2= Severe 97= Don’t know
USE PICTOGRAM 1
3= Average 98= Refused to Answer
4= Little severe 99= Not Applciable

A- I was asked not to touch someone's child
B- I was asked to leave because I was coughing
C- I was called bad names
D- I was told that I would die anytime
E- I was made to eat alone
F- Iwas blamed for my HIV status
G- People avoided me

SECTION 6: TAKE UP OF HIV TREATMENT -(Applicable only for respondents HIV +)

I would like to continue talking to you about your experience with the HIV/AIDS related treatment. This information will help us to understand the circumstances surrounding the the access to the treatment and the difficulties that people have to take it up. As before, all your answers will be kept confidential and will not be revealed to anybody.

QUESTIONS APPLICABLE FOR RESPONDENTS HIV + ON ART

Q. 85 Are you currently on HIV and AIDS treatment (Antiretrovirals Therapy)?

Yes
No

Q.86 For how long have you been on treatment?

1= Less than 6 months
2= 6 - 12 months
1= Yes
2= No
97= Don’t Know
98= Refused to Answer
99= Not Applicable
99= Not Applicable

Skip to Q.92
Continue with next question

Q 87 When did you start taking ART?

1= Immediately after knowing my test result
3= Since 1 - 2 years
4= Since 2 - 3 years
5= Since more than 3 years
97= don't know
98= refused to answer
2= Within the first 6 months
3= Within 1 year after
4= Within more than 1 year after
97= Don't know
98= Refused to answer
99= Not Applicable

Q.88 I am going to read some reasons why people decide to start to take ART. Think about your own reasons and tell me to what extent do you Agree or Disagree with them.USE PICTOGRAM 2

Stronlgy agree
Agree agree
Somewhat agree
Disagree agree
Stronlgy agree
Don't know
Refused to answer
Not Applicable

A- I had to do what I was told at the clinic/hospital
B- I just wanted to stay healthy
C- I wanted to support my family
D- I was encouraged by my spouse/partner
E- I was encouraged by my frriends
F- I saw someone on ART recovered, that motivated me

Some people say that it is good to take other treatments, such as herbs. Others consult a priest or a faith healer. I would like to know whether you have ever made use of such treatments. It is important that you are open about this, even if you were told at the clinic that you should not use such treatments. All what you told to me will be kept confidential and it will not be revealed to anybody.

Q.89 After knowing your positive HIV test results, who did you consult first for treatment?

1= Traditonal Healer
2= Priest/Faith Healer
3= Herbalist
4= ART Centre
97= Don’t Know
98= Refused to Answer
99= Not Applicable

Q. 90 Have you ever consulted for treatment related to HIV and AIDS a ...?

Yes
No
Don't know
Refused to Answer
Not Applicable

Q.91 Have you ever combined ARVs with

A-Traditional medicine
B- Spiritual practices
D- Herbs

NOTE FOR THE INTERVIEWER:
Skip to Q. 95 to continue the interview
QUESTIONS APPLICABLE FOR RESPONDENTS HIV + NOT ON ART

Q.92 When was the last time that your CD 4 counts were taken?

1= Less than 6 months
2= 6 -12 months
3= Since 1 -2 years
4= Since 2 -3 years
5= Since more than 3 years
6= CD4 counts never taken
97= Don't know
98= Refused to Answer
99= Not Applicable

Q.93 What was the result of your CD 4 counts?

1= Below 200

2= Between 200-300
3= 350 and above
97= Don't know
98= Refused to answer
99= Not applicable (CD4 counts not taken)

Q.94 I am going to read some reasons that people who are HIV + may have not to take up treatment (ART). Think about your own reasons and tell me to what extent do you Agree or Disagree with them. USE PICTOGRAM 2

Stronlgy agree
Agree Somewhatagree
Disagree
Stronlgy disagree
Don't know
Refused to Answer
Not Applicable

A- ARVs are not available in my area
B- I feel healthy
C- I don't believe the result
D- I don't believe ARVs work
E- I am worried about the sustainability of ARV's supply
F- I take traditional medicines
G- I go for prayers
H- My family would not support me if I take ARVs
I- My spouse/partner does not want me to take ARVs
J- The ART centre is too far
K- I do not have the money to go for treatment
L- I have seen many people on ART dying

NOTE FOR THE INTERVIEWER:
Skip to Q.130 and Finish the interview

SECTION 7: ADHERENCE TO ART; (only for HIV + ON ART)

I would like to continue talking to you about your experience with ARVs. I would like to know whether you have or have had difficulties to follow the prescriptions with ARVs. This information will help us to understand the circumstances surrounding the treatment. As before, all your answers will be kept confidential and will not be revealed to anybody.

Q. 95 For how long have you been taking your medication?

1= 1-3 weeks
2= 1-3 month(s)
3= 3-6 months
4= 6-11 months
5= 1 year or more
97= Don't know
98= Refused to answer
99= Not Applicable

Q.96 Have you ever received any food supplement because you were on ART?

1= Yes
2= No

Q. 97 If Yes, for how long have you receicved the food supplement?

Q. 98 Do you participage in any support group for people living with HIV and AIDS or doing things for HIV and AIDS-related issues?

Q. 99 How often do you participate?

1= Up to 1 month
2= 2-3 months
3= More than 3 months
4= Since I started ART
97= Don't know
98= Refused to answer
99= Not Applicable

Q 100 Do you have some one close to you who encourages/reminds you to take the medication (ART)?

1= Yes
2= No
97= Don’t Know
98= Refused to Answer
99= Not Applicable

Q.101 If Yes, Who?

1= My Partner/Spouse
2= Daughter/Son
3= Brother/Sister
4= Mother/Father
5= Friend
6= Family in-law
7= Uncle/Aunty
97= Don’t Know
98= Refused to Answer
99= Not Applicable

8= Neighbour
9= Traditional Healer
10= Faith Healer/Priest
15= Someone else
1= Yes
2= No
97= Don’t Know
98= REFUSED TO ANSWER
99= N/A

Q.102 How satisfied are you with the support you received from them?
USE PICTOGRAM 1
1= Very Satisfied
2= Rather Satisfised
3= Somewhat Satisfied
4= Little Satisfied
5= Not Satisfied
97= Don’t know
98= Refused to answer
99= Not Applicable
Yes
No

Q.103 Has someone ever discouraged you to take the HIV treatment (ART)?
1= Yes
2= No

Q.104 If a relative of yours became sick with HIV and AIDS, would you encourage him/her to take ?
1= Yes
2= No

Q.106 Think about what help you need to take the medication. I will now readyou a list of factors that help people to follow the ARVs regimen. Tell me how strongly these reasons help you.

Very strong
Quite strong
Somewhat strong
Little strong
Not strong
Don't know
Refused to answer
Not Applicable

USE PICTOGRAM 1
A- Desire of live longer
B- Desire of caring of my family
C- Being reminded by someone
D- Having a reminder such as an alarm watch, etc
E- Seeing someone on ART who recovers
F- Having the support of my spouse/partner
G- Having the support of my family and close friends
H- Having health care providers in the cinic who care about me

Many people find it difficult to take all their ART as prescribed. We would not be surprised if you have missed taking some of your medication over the last few days. We are trying to find out how difficult it is for patients to take their medication. Please asnswer these questions as honestly as you can. All the information that you provide us will be kept confidential and will not be revealed to anybody.

Q.107 In the last month, for how long have you been missing your medication (ARVs)?
Never
1 DAY
2-3 days
1 week
2-3 weeks
More than 3 weeks
Don’t know
Refused to answer
Not Applicable

Q.108 In the last month, how often have you not been able to take your medication at the right time?
1 day
2-3 days
1 week

2-3 weeks
More than 3 weeks
Don’tknow
Refused to answer
Not Applicable

Q.109 In the last month, how often gave tiy bit been able to take your medication in the correct dosage?

Never
1 day
2-3 days
1 week
2-3 weeks
More don’t know
Refused to answer
Not Applicable

Q.110 Including before the last month, what is the longest period of time that you have ever

1= 1-2 weeks
2= 2-8 weeks

Missed or stopped the medication-ARVs?

3= More than 2 months
4= Never stopped/missed medication
97= Don’t know
98= Refused to Answer
99= Not Applicable

Q.111 Have you re-started again?

YES, I am still on treatment
YES, but I stopped again
NO, I didn't start ARVs again
Not Applicable

Q.112 People may miss taking their medication for various reasons. I will now read some of the reasons why you may have missed taking any medication within the past month. Tell me to what extent do you agree or disagree with them.

Stronlgy Agree
Somewhat Agree
Somewhat Disagree
Stronlgy Disagree
Don't Know
Refused to Answer
Not Applicable

USE PICTOGRAM 2

A- I was busy with other things
B- I simply forgot
C- I had too many pills to give to the child
D- I did not want others to notice
E- I felt like the drug was making me sick
F- I fall asleep through the dose time
G- I did not have transport to go to the clinic for refill
H- I saw someone on ART who die
I- `The medication was not available in the clinic
J- I did not have the food to take with the medicines
K- I didn't have the money to afford the treatment
L- I was told to stop by traditional healer, witch doctor.

END OF THE INTERVIEW

Q. 130 We have compleyed the Questionnaire. Before we conclude the interview, do you have any questions or additional comments you would like to share with me? Write the comments.

Record the time of completing the interview
________________ Hours __________________MINUTES

THANK YOU VERY MUCH FOR YOUR COOPERATION

Appendix 4 : Interview Guides

Interview guide for the Health Care Provider

1. Sex
Male [ ]

Female [ ]
2. Age…………………………………………
3. Educational level…………………………………………………….................
4. Type of specialised training………………………………………………....
   ………………………………………………………………………………………
5. Current position……………………………..
6. How long have you been in current position?...
   ………………………………………………………………………………………
7. How long have you worked at the Health Facility?...
   ………………………………………………………………………………………
8. Do you think your training is adequate to handle your current position?.(probe any HIV and AIDS related training)................
9. If no, what kind of training would you require?..
   ………………………………………………………………………………………
10. When did this health facility start providing ART?..
   ………………………………………………………………………………………
11. What other ART/AIDS related services does the facility provide?..........................
12. What other services does the facility provide?...
   ………………………………………………………………………………………
   ………………………………………………………………………………………
13. What is the catchment area for this facility?...
   ……………………………………………………………………………………… How far is the furthest HH from the facility?..
14. Does the health facility provide mobile VCT/ART services? ....
15. How often?...
16. Are training kit/guidelines available?..
17. Number of trained health care providers?...
18. If VCT is available, how many people have been tested so far (from 2008)?
   Females [ ]
   Male [ ]
19. Do they all collect their results? ....
20. What percentage of those tested do collect their results? ....
21. Who do you think have been more affected? ....
22. Since the services started, how many people have started treatment? ....
23. How is the adherence like? ....
24. Who adhere more to treatment? ....
25. Is Post Exposure Prophylaxes (PEP) available at the facility? ....
26. Who can access it? ....
27. Are the drugs (ARVs) including PMTCT, always readily available at the facility?.................
28. Who are the major providers of the drugs? ....
29. What are some challenges faced by people intending to go for VCT in this area?.......
30. Challenges for those who want to start ART(probe for all the levels) ....
31. Challenges for sustaining ART treatment? ...(probe for al l the levels)..
32. How can access and adherence to ART be improved?..
   ……………………………………………………………………………………....
   ……………………………………………………………………………………....

Interview Guide for ART Clients

1. Sex
   Male [ ]
   Female [ ]
2. Age………………………………………..
3. Educational level ....
4. Marital status ....
5. Type of marriage ....
6. Religion…………………………………………………………….................
7. Number of own children below 15 years..
8. Number of other children living with you below 15 years......................................
9. Status of other children living with you...
10. How long have you lived in this community?...
11. Major source of income/livelihood..
12. How far is the nearest VCT center?...
13. How far is the ART center?..
14. Are there any mobile services provided in this area?..
15. When did you know that you were HIV positive?..
   ………………………………………………………………………………………
16. How did you know that you were HIV positive?...

14. What prompted you to go for VCT?...
15. From the time you decided to go for VCT how long did it take you before you actually went for the test?...
16. What challenges did you face before going for VCT? (Investigate at all levels)..................……………………………………………………………………..........
17. What encouraged you to go for VCT?..(investigate at all levels).........................
18. After knowing your status, did you disclose to anyone?...
19. If Yes, to whom and why ? ....

……………………………………………………………………………………..........

20. If No, why?...
21. How long did it take before you could disclose and why?.....................................
22. How did your family members react when they knew you were positive?............

....

23. How long have you been taking ARVs?...
24. What are some of the challenges you face in accessing ARVs at facility level?
25. What challenges do you face at community level?
26. How would you prefer to get your medical support?
27. How long do you usually wait before you see your health care provider?

………………………………………………………………………………………

28. Why do you think you wait such long (if wait for along time?)
29. Do you trust your health care provider?
30. How comfortable are you to take your drugs in public?
31. Are you a member of any support group?
32. If yes, what kind of assistance do you receive?
33. Have you ever skipped or stopped taking your drugs?

    If yes, what were some of the reasons?

34. f you have never stopped or skipped, what have been some of the [ ]
35. Are there any costs involved for your treatment?

    If yes please specify the costs...

    What have you heard about ARVs?...

    ……………………………………………………………………………..................

36. Do you think that your health provider has given you enough information about your condition?
37. If yes what information do you have?

    If No, what information do you require?...

38. What do you think should be done to encourage PLWA to go for VCT,start treatment and be able to continue?

    At Individual level……………..................….............……..................................

    At community/family level……………………………..

    At health facility level...........................………...... …………..................……..........

    At structural level……………………………….……......…………................

    Medication level………………………………………….......................................

    ……………………………………………………………………………………..........

Interview guide for household head

1. Sex
    Female [ ]
    Male [ ]
2. Age…………………………………………………………….......................................
3. Educational level………………………………………………….............................
4. Source of Income/livelihood……………………………........………….................
    ………………………………………………………………………………………
5. Religious affiliation………………………………………………….....................
6. Marital status
7. Type of marital union
8. Number of children below 15 years
9. What do you know about HIV/AIDS?
10. What do you know about about ARVs?
11. Have you ever been tested for HIV/AIDS?

Yes [ ]
No [ ]

12. Did you collect your results?
13. If yes, what prompted you to go for a test?
14. If No, why?
15. If any of your household members were sick, would you encourage them to go for VCT?
16. If they were found positive, what would you do?
17. Do you think that traditional medicine can cure AIDS?
18. What do you think of ARVs?
19. How do you think t spiritual support can help HIV/AIDS patients?

Key Informant Interview Guide

HEALTH FACILITY

- Main difficulties faced by patients on ART in the area.
- At individual level, community family level, health facility level?
- Views on ART
- Views - working with AIDS patients.
- Challenges in working with AIDS patients.
- How can these challenges be minimised?
- What has been your experience in working with PLWHA?
- Is there any change in people's willingness to test now that medicines are available free of charge?
- How is AIDS viewed by the community members?
- What community based organisations do you work and are some of the benefits/challenges working with these organisations? e.g. NGOs, Church, Home Based care Providers
- How do you think access ad adherence to ART can be improved?
- What are your views on ARVs?
- What do you think the community thinks about ARVs?
- What do you think of spiritual healing, traditional healers and HIV treatment?
- Challenges/ barriers for people intending to go for VCT,start taking ARVs,avoid treatment interruptions at health facility level, structural,community,individual, structural and medication levels?

Interview Guide for ART Client

- From your personal experience, what are the challenges in accessing and adhering to ARVs at Individual level, community/family level, health facility level?
- How have you managed to overcome or handle these challenges yourself?
- What do you think of VCT?
- What have you heard of ARVs?
- From whom?
- What do you personally think about ARVs?
- Who has given you support to continue with your treatment?
- What do the community members say about ARVs?
- What do traditional dealers, the church say about ARVs?
- What do your health care providers say about ARVs?
- What do you think are the barriers/ facilitators for VCT/ ART uptake and adherence at ART?
    - (i) At individual level
    - (ii) At community/Family level
    - (iii) Health Facility level
    - (iv) structural
    - (v) Medication

K I Informants
NGOs/Church

- For how long has your organisation been working in this community?
- What kind of AIDS related services is your organisation providing?
- When did it start providing this service(s)?
- What do you think of VCT, ARVs?
- What do you think of AIDS patients?
- How has been your experience in working with people who are HIV positive?
- What challenges do if you think people face in decisions to test, ART uptake and adherence at:
  - (i) Individual level
  - (ii) Community/family level
  - (iii) Health facility leve
  - (iv) Structural
  - (v) Medication
- How can people be encouraged to go for a test? Start treatment and adhere to it?
- What is your organisation doing to help alleviate some of the challenges faced by PLWHA?
- What have been your challenges to your organization in working with PLWHA?
- What other services would you want to provide?
- Do you think you are doing enough? If not why not?

Traditional Healer
Interview Guide

- Any training/sensitization on HIV/AIDS?
- What do you know about HIV/AIDS?
- If someone came to you with it symptoms of AIDS related disease or what advice would you give them? And why?
- Are you able to detect HIV and AIDS?
- Do you think traditional medicine can cure HIV/AIDS?
  Give an explanation for your answer.
- What is your opinion on ARVs?
- What do you think of VCT?
-

FOCUS GROUP DISCUSSION WITH COMMUNITY MEMBERS
Interview Guide

Community knowledge on AIDS, ARVs, VCT,
Barrieres /facilitators for VCT/ ART uptake and adherence at all levels- individual, health faccilty level, community/family/ Structural and medication level
Community perceptions on VCT, ARVs, AIDS Patients,
Views on health care providers, Quality of care,
Challenges faced PLWHA at all levels/ community, health facility, structural, individual and medication.
How these challenges can be overcome
Local community illness beliefs

Key Informant-Home Based Care

Interview guide
Main services given.
Challenges of working with HIV/AIDS patients
Oher constraints they face in their work

Life history

Please tell me about your self from the time you were born up to today.

Appendix 5: Names of Zones/Communities in the Study area.

Name of Zone	**Name of Senior Headman/Chairman**	**Location**
Zone 1:	Senior Headman Nyambe	Chitonga area
Zone 2:	Senior Headman Nyambe	Hanjalika school
Zone 3:	Senior Headman Kasanda (Emson Mandanda)	Mainza area
Zone 4:	Senior Headman Ngandu Malambo(Peter Ngandu - Julu)	St. Micheal's area
Zone 5:	Senior Headman Fabian Chintibule	Nkonkola area
Zone :6	Senior Headman Chikanda Muncile (Mr Sofas Mbozi)	Hanzala area
Zone 7:	Senior Headman Chiginga	Namaila school
Zone 8:Dumba –Magoye Research	Senior Headman Hangoma	Magoye Research school
Zone 9: Ngwezi blocks and Chiimba settlement	Chairman Nyambe	Matimbya area(near the chiefs place)
Zone 10: Ngwezi settlements extensions A and B	Chairman Hatwembe /Mr Nkumba	Mweemba area
Zone 11:Ngwezi settlements extension D	Chairman Mr.Aaron Namanje	Opposite Kagila(Between Chivuna and Mazabuka)
Zone 12: Musuma settlement	Chairman Chitatu/Adria Ngandu	Puky area
Zone 13:Mbaya Musuma	Chairman Andrew Ng'andu	Bbaale farms (after Mbaya Musuma
Zone 14: Kaleya small holder Co.	Chairman Goodson Hambizya	Kaleya small holdings – sugar
Zone 15:	Rotty Mweemba	Mabwe Tubwa-towards ChikankantaaaNo , between Chief Mwenda and Hanjalika
Zone 16:	Senior headman Mukonde- Paul Mweemba	Chivuna