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CHAPTER 1: INTRODUCTION

1.0 BACKGROUND

1.1 The Global HIV/AIDS Impact

According to the UNAIDS 2004 report on the global AIDS epidemic, in year 2003 alone, 5 million people became newly infected with HIV, the greatest number in any one year since the beginning of the epidemic in 1981; with the number of people living with HIV continuing to grow, from 35 million in the year 2001 to 38 million in 2003.

In this period, almost 3 million people were killed by AIDS. Of those newly infected, 3 million are from sub-Saharan Africa – 2.2 million died (75% of the 3 million globally that year). The report further shows that although Sub-Saharan Africa is home to just over 10% of the world’s population, 25 million of those living with HIV are in sub-Saharan Africa (almost two thirds of all people living with HIV); with only 7% of people who need antiretroviral treatment in developing countries having access to ARV’s, estimated at 400,000 at the end of 2003. Without antiretroviral therapy, the report predicts a drop in average life expectancy to below 35 for Swaziland, Zambia and Zimbabwe. In sub-Saharan, an estimated 4.3 million people need AIDS home based care but only 12% receive it (UNAIDS, 2004).

While the worldwide prevalence is still high, there are specific examples of successful interventions, best practices and documentation of impact demonstrated through reduced incidence of the epidemic and overall drops in HIV prevalence in entire populations. There is sufficient evidence to show that countries with different cultures and at different levels of the epidemic can be examples of success, despite the variations.

As shown in Uganda, Thailand and Senegal, strong political commitment at the highest level, multi-sectoral approaches, multi level responses, effective monitoring of the epidemic and risky behaviours, combination of efforts aimed at general population and focus
on groups at high risk, implementation on a large scale and integrated prevention and care are essential features of effective national AIDS programmes regarded as best practice (UNAIDS, 2001).

In 1993 in **Lusaka, Zambia**, HIV rates among young women exceeded 25%, but they have been almost halved in just six years by effective prevention (UNAIDS, 2000).

It’s worth noting from the outset that in terms of treatment, a growing range of infectious diseases cannot be cured by medicine and its ‘magic bullet’. These include viral diseases such as HIV/AIDS, hepatitis B and C, parasitic disease such as new strains of drug resistant malaria and bacterial diseases such a multi-drug resistant TB, among others (Heinman, 2000).

### 1.2 The Alma-Ata Declaration

In 1978, the World Health Organisation (WHO) issued its famous Alma-Ata declaration of ‘Health for All by the year 2000 through the proposed worldwide provision of comprehensive primary health care, which would provide preventive, curative and rehabilitative services at an affordable cost. However, with scarce resources, growing populations and limited manpower the task was almost impossible and has recently become even more difficult due to new disease like AIDS.

One result of this was a fresh look at traditional medicine, redefining it as a potential ally of the medical system rather than an enemy. In 1978, WHO recommended that traditional medicine be promoted, developed and integrated wherever possible with modern medicine but stressed the necessity to ensure respect, recognition and collaboration among the practitioners of the various systems concerned. The manpower resources that WHO hoped to enlist included herbalists, Ayurvedic, Unani or Yoga practitioners, Chinese traditional healers such as acupuncturists and various others. Special attention has been paid to the selection of
traditional birth attendants (TBA’s) who already deliver about two-thirds of the world’s babies (Helman, 2000).

1.3.0 THE HIV/AIDS EPIDEMIC IN AFRICA

1.3.1 Sub-Saharan Africa

According to the UNAIDS epidemic update for year 2004, Sub-Saharan Africa’s AIDS mortality were estimated at 2.2 million, new infections at 3 million and the cumulative number of people living with HIV/AIDS was 25 million, with 57% of PLWHA being women (UNAIDS, 2004).

Projections from African finance ministers, when they met in Abuja during a conference organised by the Economic Commission for Africa, were that the “HIV/AIDS epidemic may cut approximately one percent from African countries’ gross domestic product growth rates”. There are fears that the pandemic could significantly diminish the prospects of realizing the economic expansion necessary to reduce poverty on the continent.

With the foregoing scenario, ministers stressed that additional resources were urgently needed to support Africa’s efforts in confronting HIV/AIDS and urged the World Bank and the International Monetary Fund (IMF) to consider revising the eligibility criteria for assistance to middle income countries afflicted by the AIDS epidemic (The Post, 2003).

The Southern African Development Community (SADC) held an important meeting in November 2002, to critically examine nutritional and health challenges in member countries in the light of the AIDS epidemic. As documented by the regional body (SADC, 2002) the forum looked at, among other things:

(a) The role of nutrition in improving the health of people living with HIV/AIDS.

(b) The role of traditional and indigenous therapies in improving the health of people living with HIV/AIDS.
The range of food supplements and traditional /indigenous herbal products available as immune boosters promoting improved health for the People Living With HIV/AIDS (PLWHA) in member countries of SADC.

The regulations guiding the use of food supplements and herbs to improve the health of PLWHA.

The ways in which food supplements and effective traditional and indigenous herbal medicines can be integrated into the national health delivery systems of SADC member states.

Important recommendations after the meeting included the need for provision of nutrition supplements in the fight against AIDS, investment in nutrition, nutrition education and related programmes for PLWHA in the region.

All the foregoing goes to demonstrate the level of interest in the field of food security at regional level by different stakeholders, a process whose momentum is being facilitated by a robust international community and developed world with potential to support these ambitious programmes (SADC, 2002).

As (DeRose et al, 1999) explain, trends in food production are the worst in Sub-Saharan Africa, where per capita food production has decreased slowly but relentlessly in recent years. Developed countries over this same period were able to increase both food production and production per capita, however, benefiting from advancing technology but also much lower population growth rates than in developing countries.

Also, there has been more focus on food as an important aspect in the lives of PLWHA. Peter Piot and Per Pinstrup-Andersen put it this way, after conducting field visits:
“When you ask people living with AIDS in rural communities in the developing world what their highest priority is, very often their answer is food. Not care, not drugs for medical treatment, not relief from stigma, but food.” (IFPRI, 2002).

The 1996 Zambia Demographic and Health Surveys (ZDHS) reports that about half of the children aged 1 to 4 are stunted in their growth due to malnutrition. (CBOH, 1999) The report further states that women will be increasingly faced with competing demands to maintain crop production, care for family members suffering from AIDS, and protect their own health.

When family members become sick from AIDS, it’s usually the woman who cares for the sick person. Regarding the food requirements, since 1991, Zambia’s agriculture has performed poorly and a number of factors can be highlighted, including inadequate investment in agricultural sector (high interest rates); hasty liberalisation of the sector; unavailable long-term capital for small scale farmers; poor and inadequate rural transport; high input prices; the AIDS epidemic; land degradation; marginalisation of rural farmers and low utilisation of land due to poor land administration (CBOH, 1999).

The problem encountered by Zambia in the process of agricultural liberalisation reflects the political dilemmas associated with dual reform processes, as a former agriculture minister, Dr Scott elaborates:

“...Maize is not only food; it is also a social security card. This is the cash crop which school fees and uniforms have come out of.” (Rakner, 2003).

Accordingly to recent studies by the United Nations Children’s Emergency Fund (UNICEF), the food insecurity in the sub-region coupled with the high disease burden of HIV/AIDS is combining to make the livelihoods coping even more difficult.
The report (UNICEF: 2003) indicates that as many as 14 million people, half of them children have been at the risk of starvation in the six most affected countries namely Zambia, Malawi, Lesotho, Mozambique, Swaziland.

The situation has now stabilised in some countries after the improved rainfall patterns and food aid. The report further states that while the previous 1992 famine was almost exclusively drought related, the high HIV/AIDS situation has considerably reduced agriculture and food security in all the afore-mentioned countries.

For Southern Africa, the AIDS epidemic (UNICEF 2003) has made hunger an even greater peril. An HIV affected household can see its income drop by up to 80% and its food consumption by 15% to 30%. One in four people in the productive age group (15-49) in this region is living with AIDS—this means that fewer adults must support more people and the burden of care shifts to society’s weakest and most marginalized, especially women and girls.

Desperate people adopt damaging and high-risk survival strategies such as selling off land or exchanging sex for food or cash. These strategies undercut people’s abilities to recover and therefore, contribute to long-term poverty.

Other studies widely documented have looked at the impact of sex and gender on vulnerability to HIV infection itself in resource poor settings in different parts of sub-Saharan Africa, (Doyal, L and Anderson, J citing several studies (Baylies & Bujra1999; Jewkes, Levin, Loveday & Penn-Kekana, 2003; Preston-Whyte, 1995; Schoepf, 1998; Wallman & Bantebye_Kyomuhendo, 1996)

Accordingly to a USAID report “Famine has a fuelling factor in the spread of HIV/AIDS. In addition to impairing individual’s level of immunity, it has vector effects, in increased transactional sex activity and labour migration. Improved nutrition can enhance immune system functioning, which is crucial to both prevention and treatment of AIDS. Food security is thus a factor in both mitigation and prevention.
Not all AIDS victims will receive Anti-Retroviral Therapy, but all can receive nutritional support, as a way of buying time”, the report states (USAID 2003).

The United States Agency for International Development (USAID) reports concludes that even under the most favourable scenario, recovery from this crisis will take decades due to the demographic and sociological shift, which changes the profile of rural households and disrupts the transmission of key agricultural and livelihood knowledge when the core productive co-hort of adults is impacted on with AIDS. (USAID, 2003).

The foregoing clearly shows the multiple epidemics, which are impacting countries in sub-Saharan, which includes Zambia. Being dependent on agriculture in the region where droughts are common and AIDS is the single largest development challenge creates a great concern.

1.4 Rationale of the study

In 1998, the estimated HIV prevalence rate for the entire country was 19.7 percent. In urban areas, the prevalence rate among 15 to 49 years olds was more than 28 percent; in rural areas it was 13.6 percent. The overall rate is exceedingly high and shows that Zambia is undergoing one of the worst HIV/AIDS epidemics in the entire world. (CBOH, 1999). By 1999, it was estimated that 1,009,000 persons were infected with HIV in Zambia. However, only 9 percent of these had actually progressed from HIV to AIDS stage.

The National AIDS Council (NAC) in Zambia has various national guiding principles in its work which include: people centred programming, cultural sensitivity in activities, priority centred and integration of programmes, with core objectives focusing on reducing HIV/STI transmission and its impact in social economic terms, minimize mother to child transmission of HIV, making blood transfusion and use of sharp instruments safe, improving the quality of life of PLWHA, improving care and support services for the orphans and other
vulnerable children (NAC, 2002). Also, life expectancy without HIV/AIDS was projected to be 60 years at birth, but it is now projected at 37 years due to AIDS (NAC 2002).

The prevalence of HIV positive results among 15-19 year olds youths indicated a drop over most of the country between 1994 and 1998. In Lusaka, the rate was 28 percent in 1993; it has dropped to 15 percent in 1998. The overall prevalence of positive tests in the country appears to be stable and is not increasing. This has been attributed to behavioural changes. However, the current burden of infection will continue to impact Zambia negatively for many years to come (NAC, 2002).

Key government officials in Zambia are currently in support of the involvement of traditional healers in the vital role of providing health services to communities and steps are being taken to incorporate the practice into the conventional medical system. The Minister of Health (Dr Brian Chituwo) is reported to have said that the task of providing health services to the Zambian people is very big and many of the health workers in health institutions were over-worked; emphasizing that it was impossible to ignore the 40,000 traditional healers that were practicing throughout the country (The Times of Zambia, 2003). The minister, further stated that the task of providing quality health service to the Zambian people could not be left to medical practitioners alone and that Government, through the Central Board of Health (CBoH), was at the moment working out modalities on how traditional medicine could be fused into modern practice, having began with the appointment of the President of Traditional Health Practitioners Association of Zambia (THPAZ) to sit on the CBoH as a board member; while a legal Bill on traditional medicine had been presented to Parliament, now awaiting approval (The Times of Zambia, 2003).
1.4.1 Importance of Study in Zambia

This study will be of particular benefit to Zambia, where multiple health systems are already in existence. However, the interplay among them, extent of collaboration and networking, levels of service utilization by clients, among other factors, still remain sparsely documented, to date. With the financial and technical support of various stakeholders, Zambia’s formal health system has been undergoing reform, an ambitious programme aimed at providing health services as close to the community as possible, in a cost-effective manner.

The provision of health services to PLWHA has been a challenge, given the low rates of people who know their HIV status, the absence of accessible anti-retroviral drugs to treat patients, inability by most patients to access services offered on a cost-sharing basis and the absence of adequate basic health services in some areas. Zambia’s HIV prevalence is high, at the rate of 20% of the adult population, thereby creating a pool of increasing PLWHA, most of who have co-infections of TB. It’s worth noting that recent revisions to the statistics, after reconciling the Sentinel Surveillance Data and Population Based Survey have shown a remarkable difference, with the new prevalence rate at 16% (ZDHS, 2003).

In line with the Alma Ata declaration of 1978, the Zambian government is increasingly making efforts to involve other stakeholders in the delivery of health services, as already acknowledged. Notable among them are traditional Birth Attendants (TBA) non-governmental organizations, community based organizations, including support groups of PLWHA and traditional healers with whom the ministry of health is opening up formal collaborative links to help increase coverage of health provision.

The field of medical pluralism has not been studied extensively in Zambia, more so, the focus on PLWHA. The PLWHA are prioritised on the Zambia National Health Strategic Plan 2001-2005 (NAC, 2002). They are also a critical research priority under the National
Health Research Agenda in Zambia. Existing studies have limited themselves to specific providers within the field of health while the interplay among the different providers and how health seeking is affected in such an environment of plural medicine is under-researched not only in Zambia but many other low-income countries. Reviewed literature in Zambia have mostly looked at health seeking only for other Sexually Transmitted Disease (STD’s) and/or Tuberculosis (TB), while HIV/AIDS research is mainly on PLWHA in relation to stigma and discrimination which consequently influences health seeking.

Clearly, there is a scarcity of adequate evidence based information to facilitate informed decisions by local community based organisations, non-governmental organisations, line government agencies and other international agencies. The following are elements which are possible motivations and the basis for going ahead with a study of this magnitude: The presence of holistic research resources & competences in Norway and Zambia have also encouraged me to undertake this important study which will help to look at the health seeking dilemmas and options of people living with HIV/AIDS in the context of plural medicine in Zambia.

By exploring in-depth, the feelings, opinions and lived experiences of PLWHA using Kleinman (1980) theoretical model with regard to health seeking, a contribution will be made to the body of knowledge at local, regional and international in the field of plural medicine. The opportunities for collaborating and/or networking these various health service providers in order to improve the well being of people living with HIV/AIDS are of the essence.

Resource poor countries in similar circumstances like Zambia will benefit from this study especially those sub-Saharan Africa where the epidemic has the highest impact. By facilitating the illumination of more thematic areas for the Zambian health research agenda in the field of AIDS, TB in relation to medical pluralism, and this will also help inform current theories and practices worldwide on medical pluralism.
1.5 LITERATURE REVIEW

1.5.1 Theoretical Framework

Several studies have clearly documented the multiplicity of options for health seeking and variation in models of health systems themselves. Kleinman (1980) has suggested that in looking at any complex society, one can identify three overlapping and interconnected sectors of health care; the popular sector, the folk sector and the professional sector. Each sector, he explains further, has its own ways of explaining and treating ill health, defining who the healer is and who is the patient, and specifying how healer and patient should interact in their therapeutic encounter.

Strathern and Stewart (1999) explain that: “bio-medicine and indigenous systems are often assumed to be in conflict with another. Indigenous practices may be seen as blocking or interfering with the progress of modern medical treatment regimes. But various contexts exist in which introduced and indigenous medical practices meet different requirements for the population in question. In this instance then, the two systems are seen to be complimentary rather than in conflict.

Further, Strathern and Stewart explain that individuals make decisions when selecting a particular form of medical treatment. These decisions maybe influenced by a consideration of the treatment offered, the relative costs involved, or the religious and political environment in which the person lives. Although there is a universal basis of experience as a biological phenomenon, the perceived causes, treatments, and consequences of the injury or illness are greatly affected by culture.
1.5.2 The Popular Sector

This is the lay, non-professional non-specialist domain of society, where ill health is first recognized and defined and health care activities are initiated. It is also the least studied as compared to others. It includes all the therapeutic options that people utilize without any payment or medical practitioners.

Among these options are:

- Self treatment or self medication (individual based)
- Advice or treatment given by a relative, friend, neighbour or workmate
- Consultation with another lay person who has special experience of a particular disorder or treatment of a physical state.

It’s worth noting from the outset that self-medication and self-prescription is very common in developing countries- this high prevalence is associated with free availability of medicines (Kotwal, 2005). Another study in the Lower Zaire (now Congo DRC) by Janzen...
(1978) have also extensively discussed the phenomenon of what has been referred to as ‘therapy managing groups’ which can be categorised as being in the popular sector as well. Helman (2000) citing Kleinman and Eisenberg, discloses that it has been estimated that about 70-90 percent of health care takes place within the popular sector, in both Western and non-Western societies.

The existence of common understanding in this sector means that, as Helman citing Chrisman (1977):

“This means that both patient and healer share similar assumptions about health and illness, and misunderstandings between the two are comparatively rare”.

Helman asserts that the sector is made up of a series of informal and unpaid healing relationships of variable duration, which occur within the sufferer’s own social network, particularly the family- these therapeutic encounters occur without fixed rules governing behaviour or setting; at a later date the roles may be reversed, with today’s patient becoming tomorrow’s healer, Helman found.

It has also been documented that in general, ill people move freely between the popular and the other two sectors and back again, often using all the three sectors at once, especially when treatment in one sector fails to relieve physical discomfort or emotional distress (Strathern & Stewart, 1999).

Typologies of service providers have been studied in other phenomenon. A. Kowal, citing Reeler (2000), discusses the typologies of providers and prescribers of injections into 3 broad categories namely informal injection providers (including domestic); traditional healers; and the formal injection providers- also, the advantages of lay providers over their other competitors’ are explained as being available all hours, no waiting time for clients, being geographical and socially well accessible, and their ability to simplify bio-medical concepts to
situate injections into a popular disease explanatory system, thereby bridging cultural and social gaps (Kotwal, 2005).

1.5.3 The Folk Sector

Kleinman (1980) defines the folk sector as ‘non-professional, non-bureaucratic, specialist’ which overlaps into the two sectors of the local health system; referring to it as a mixture of many different components-being frequently classified into sacred and secular parts, but this division is often blurred in practice, and the two usually overlap.

In defining this particular sector, Helman adds, explaining that there is a wide variation in the type of folk healer found in any society, from purely secular and technical experts like bone-setters, midwives, tooth extractors or herbalists, to spiritual healers, clairvoyants and shamans. Folk healers form a heterogeneous group, with much individual variation in style and outlook, but sometimes they are organized into associations of healers, with rules of entry, codes of conduct and the sharing of information.

Most folk healers share the basic cultural values and worldview of the communities in which they live, including beliefs about the origin, significance and treatment of ill health. In societies where ill health and other forms of misfortune are blamed on social causes (witchcraft, sorcery or ‘evil eye’) or on supernatural causes (gods, spirits, ancestral ghosts or fate), sacred folk healers are particularly common.

As Helman (2000) further indicates that folk healing offers several advantages over modern scientific medicine. One of these is the frequent involvement of the family in diagnosis and treatment. Because folk healers such as the h’ilo’ol articulate and reinforce the cultural values of the communities in which they live, they have advantages over Western Doctors who are often separated from their patients by social class, economic position, gender, specialized education, and sometimes-cultural background.
As in many other cultures, the doctors tend to tell their patients what has happened, while the healers tell them why. Healers explain ill health in wider, more familiar cultural terms involving the social, psychological and spiritual aspects of their patients’ lives—while doctors’ concentrate mainly on physical diseases and the pathogens or behaviours said to cause them (Helman, 2000). Apart from explaining in a wider context, Janzen (1992) discloses that healers can also engage the patient directly as a ‘participant sufferer’ in ngoma rituals, in order to “come out of his prison” to full self-expression through individualised, yet collective session, through texts, dances and rhymes.

Helman, citing Tessendorf and Cunningham (1997) shows that one study has estimated, for example, that in South Africa almost 1 percent of African nurses also work part-time as traditional healers. However, there are limitations on the incremental gains attained in having folk healers. The use of unsterilised needles by injectionists, for example, may lead to severe skin abscesses, as well as to the spread of hepatitis B or AIDS. It is important therefore to seek folk healers in a balanced way, and to avoid both over-idealisation and over-criticism of them.

It’s worth noting that the folk sector includes both sacred and secular healers. The National Federation of Spiritual Healers (NFSH) define spiritual healing as ‘all forms of healing the sick in body, mind and spirit by means of laying on of hands or by either prayer or meditation whether or not in the actual presence of the patient’. In addition, there are a number of Spiritual Churches and healing circles in Britain that practice spiritual healing through prayer or the laying on of hands; these include Christian Science churches and some Caribbean Pentecostal Churches.

In discussing the Charismatic Catholics, Strathern and Stewart, 1999 states that their emphasis has been on healing since 1973. Pentecostal practices stress speaking in tongues (hence their name, inspiration from the Holy Spirit, and the healing of the sick by means of prayers and the invocation of divine power. Both of these features are exactly the same as leading motifs in charismatic Protestant churches of Petencostal style derivation such as the Assemblies of God. (Strathern & Stewart, 1999).

1.5.4 The Professional (bio-medical) Sector

Kleinman defines this sector as the organized, healing professions, that is, the modern scientific medicine- however; it is also acknowledged that in some societies like the Chinese and Indian, indigenous systems have been professionalised. Further definition is done by Helman (2000) who categorises it as the organised, legally sanctioned healing professions, such as modern Western scientific medicine, also known as allopathy or biomedicine. It includes not only physicians of various types and specialties, but also the recognised paramedical professions such as nurses, midwives and physiotherapists (Helman, 2000).

It has been often argued by several scholars that the professional sector, with the hospital as its main institutional structure, tends to “medicalise” peoples health by among other things, removing ill person from family, friends and community at a time of personal crisis and get care from staff they may have never seen before; then they undergo a standardized ritual of ‘depersonalisation’ by conversion into a numbered case in a ward full of strangers according to gender, age or condition; patients in a ward form a temporary ‘community of suffering’ linked together by commiserisation, ward gossip and discussion of one another’s condition, according to Helman(2000). Over the last century, medicine has largely eradicated the major killer infectious diseases in most Western countries, such as smallpox, diphtheria, polio, tetanus, measles and many bacterial infections. Infant and
maternal mortality has dropped and life expectancy increased. As a result, more people are now living long enough to suffer from chronic diseases—a situation which Tenner (in his article why things bite back) terms ‘revenge of the chronic,’ Helman (2000).

1.5.5 Sectoral-Overlaps

Helman, citing Kleinman notes that traditional medical systems may become professionalised to some extent; examples of this are the Ayurvedic and Unani medical colleges in India, which receive government support. For most patients, illnesses like colds are treated by relatives, supernatural illnesses (such as spirit possession) by folk healers, and natural illnesses by physicians—especially if they are severe.

In this way, ill people frequently utilise several different types of healer and healing at the same time, or in a sequence. This simultaneous use of multiple forms of therapy is very common in most complex societies, especially in the presence of serious illness. Many people diagnosed with cancer, for example tend to change their behaviour and their diets, increase their intake of vitamins, pray more, join self-help group, and consult with alternative or traditional healers in addition to their biomedical treatment (Helman, 2000).

When self-treatment fails, ill people turn to the other providers in the folk, professional and/or the popular sector. Choices made are influenced by the availability of a particular type of helper, whether payment for their services has to be made, whether the patient can afford to pay for these services and the explanatory model that the sick person uses to explain the origin of the ill health. People make choices not only between different types of healer (popular, professional or folk) but also between diagnoses and advice that make sense to them and those that do not (Helman, 2000).
From the outset, it’s worth noting to state that most developing countries are clearly having very fragile or under serviced or ill-equipped biomedical systems of health service delivery.

In sub-Saharan Africa, for example, there is an average of 0.12 doctors per thousand, compared to 0.41 in India, 1.04 in the Middle East, 1.25 in Latin America, 1.37 in China and 3.09 in the Western industrialised countries and 4.07 in the former USSR. In Zimbabwe, for example, 66 percent of the doctors now work in the private sector, while 59 percent do so in South Africa, and 25 percent in Papua guinea as outlined by Helman, citing Benett (1993).

In summing up his study of the quest for therapy in the lower Zaire, Janzen (1978) outlines the major issue facing practitioners, medical institution builders, policy makers; stating: ‘How can the practical responses to physical disease in Western medicine be combined with the deeper, social, emotional, and mystical responses of African medicine, without exacerbating the afflictions to individual sufferers? Janzen recommends that practitioners should refer cases to the appropriate “other” if they are unable to complete treatment. However, other studies discussed the challenges faced in the referral processes.
1.6 Research Questions

- In Zambia's pluralistic health delivery, what are the options and dilemmas for therapy in health seeking, faced by People Living With HIV/AIDS?
- What factors encourage or discourage PLWHA in their quest for therapy given the available options and challenges in Zambia’s plural setting for health systems?
- Are there clear episodes of collaboration and visible examples for networked referrals between and among multiple health service providers for the PLWHA in Zambia?
- How can multiple health service providers’ best collaborate to improve health outcomes for PLWHA?
- To what extents can the theoretical framework by Kleinman (1980) facilitate a common understanding of patient perceptions and expectations on disease, illness and healing thereby deriving a mutually beneficial explanatory model appreciated in all the three sectors?

1.7 GENERAL STUDY OBJECTIVE

1.7.1 To Explore, identify, describe and gain an in-depth understanding of medical pluralism in Zambia in the context of the lived experiences of people with HIV/AIDS in their quest to access and utilise health services.

1.7.1.1 SPECIFIC OBJECTIVES OF THE STUDY

The overall purpose of the proposed study was to investigate the options and dilemmas that PLWHA faced as they sought health services in an environment of multiple health systems and providers in Zambia. The study mainly used purposely-selected informants as a basis for the research. The high prevalence of HIV in Zambia and the increasing number of already infected persons who have limited access to adequate health services and yet faced
with multiple providers, creates challenges in making decisions regarding which providers to consider, coupled with limitations related to poverty, location and other factors linked to access and barriers.

Specifically, the study objectives were:

(i) To identify and describe the characteristics of the known, existing pluralistic health services currently available in Zambia, from the perspective of people living with HIV/AIDS.

(ii) To explore and comprehensively describe the health seeking patterns and matrices as seen from the perspective of people living with HIV/AIDS and/or TB, in selected study sites of Zambia.

(iii) To derive proven insights, which will assist key informants, policy definers and other health practitioners in HIV/AIDS related interventions for the effective, holistic management of TB, HIV/AIDS and other opportunistic infections.

(iv) To gain an in-depth understanding, from the perspective of the health service providers, on their experiences in meeting the health needs of PLWHA and/or TB in selected study areas of Zambia.

(v) To conduct a structured, preliminary findings dissemination forum for stakeholders aimed at identifying existing dilemmas and possible opportunities for shared learning, networking and collaboration to meet the health needs of PLWHA in Zambia.
1.8 Country Profile: Zambia

1.8.1 Geography

Zambia is one of the countries in southern Africa, sharing boarders with eight countries. It is landlocked, covering an area of 752,612 square kilometres (about 2.5% of Africa’s total area), and sub-divided into nine provinces, with a total of 72 districts (see detailed map above). The two predominantly urban provinces of Zambia are Lusaka and the Copperbelt as documented in the ZDHS (2003) citing the CSO (2000).
1.8.2 Population and Demographic characteristics

According to the Central Statistics Office (CSO) in Zambia, the country has a population of 10.3 million people, with an annual growth rate of 2.9 per annum (CSO, 2000). Fertility rate is 2.9 children. By the age of 18, almost half of women aged 15 to 49 have had their first birth. More than 50% of the population is less than 20 years, the most vulnerable to HIV infection. Only 9 percent of women and 14 percent of men know their HIV status (ZDHS, 2003).

1.8.3 Economy and Health

Zambia has a mixed type of economy, with mining being at the epi-centre of economic activity, followed by agriculture. Zambia has been implementing political and economic reforms, resulting is massive privatisation of most of the government owned companies, with foreign investment being at the centre of business activity (the main socio-economic & health indicators are summarised herein).
<table>
<thead>
<tr>
<th>Factor</th>
<th>Value</th>
<th>Year assessed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Annual Growth Rate</td>
<td>2.9</td>
<td>2000</td>
</tr>
<tr>
<td>Life expectancy at birth (years)</td>
<td>50</td>
<td>2000</td>
</tr>
<tr>
<td>Real GDP (per capita) in U$</td>
<td>354</td>
<td>2002</td>
</tr>
<tr>
<td>Domestic Debt as % of GDP</td>
<td>26</td>
<td>2002</td>
</tr>
<tr>
<td>External Debt as % of GDP</td>
<td>190</td>
<td>2002</td>
</tr>
<tr>
<td>Debt service as % of exports of goods &amp; services</td>
<td>13.7</td>
<td>2002</td>
</tr>
<tr>
<td>Human Development Index</td>
<td>0.38</td>
<td>2003</td>
</tr>
<tr>
<td>Human Development Ranking</td>
<td>163</td>
<td>2003</td>
</tr>
<tr>
<td>Population below national poverty datum line</td>
<td>73%</td>
<td>1998</td>
</tr>
<tr>
<td>HIV Prevalence (15-49 year olds)</td>
<td>16%</td>
<td>2002</td>
</tr>
<tr>
<td>Infant mortality (per 1000 live births)</td>
<td>95</td>
<td>2002</td>
</tr>
<tr>
<td>Under 5 mortality (per 1000 live births)</td>
<td>168</td>
<td>2002</td>
</tr>
<tr>
<td>Maternal mortality (per 10,000 live births)</td>
<td>729</td>
<td>2002</td>
</tr>
</tbody>
</table>

1.8.4 Zambia’s Health Care System

Zambia has a health post as the smallest facility. There are also some health centres, clinics, district hospitals, the provincial referral hospital and the national referral one, the University Teaching hospital (UTH). According to (the World Health Report, 2003) the Zambian government expenditure on health as a whole amounts to about 5.5% of GDP.

The Zambian annual health statistical bulletin for the year 2003, released by the Central Board of Health (CBOH) has widely documented various statistics to show aspects of the health system with regard to capacity and service delivery. The newly developed Health Management Information System includes coverage data from traditional birth attendants and community health workers. There is a reported general under utilization of health services in the country. According to the annual health statistical bulletin for year 2003, there has been a high hospital out patient department (OPD) % by-pass first attendance, at an average of 31%. The highest average population per health centre is in Lusaka, at 16,700 per health centre. During the year 2003, on average, 4 out of 12 months experienced some stock out for at least one day during the month. Copperbelt, Lusaka and southern province did not experience stock outs in at least 12 months (CBOH, 2003).

1.8.5 Traditional Healers in Zambia: HIV/AIDS programmes

In Zambia, HIV/AIDS prevention activities by traditional healers were not followed up until 1994 when the Zambia ministry of health traditional medicine unit, supported by the Morehouse school of medicine (USA) developed an STD/AIDS training programme for the healers. After 18 months, 2000 traditional healers were trained together with health centre staff in community education, led monthly follow up meetings- it was also reported that at the time of the mid-term review, 250 trained healers reported selling condoms to patients and community members through a social marketing programme; and that trained healers were
also more likely to have discussed with their clients HIV and STD prevention, HIV testing, condom use and caring for persons living with HIV/AIDS. Most patients to the traditional healers confirmed that their trained healers had taught them basic facts about HIV/AIDS, but they showed poor knowledge about how HIV is not spread, HIV testing, the difference between HIV and AIDS, and AIDS symptoms, UNAIDS (2000) citing Anyangwe, et al 1995. A study in Zambia found that when culturally appropriate exposure to explanations of public health, traditional healers can modify ritual practices (UNAIDS, 2000).

1.8.6 HIV/AIDS Overview

In Zambia, the first case of HIV/AIDS was reported in 1984. By the year 1986, the National AIDS Prevention and Control Programme (NAPCP) was established, which was later strengthened and given a bigger mandate at national level, now referred to as the National AIDS Council, in 1999. The NAC ACT was passed in year 2002 by the Zambian parliament, which ushered the NAC as a legal entity and thereafter, a strategic plan for the period 2002 to 2005 was developed for a multi-sectoral response to AIDS in Zambia.

Among other achievements, Anti-retroviral drugs are being made available in all the provincial hospitals; Voluntary and Counselling (VCT) services in all districts; scaling of Prevention of Mother to Child Transmission of HIV (PMTCT) centres from 6 to 74, support to HBC programmes. (MDG, 2003)

According to the Millennium Development Goals for Zambia (MDG, 2003), The national HIV prevalence rate among the adult population aged between 15 to 49 years has been estimated at 16% with rates much higher among women (18 percent) and then men (13%). The rates are also higher in urban areas (23%) than in rural areas (11%). The AIDS epidemic is at different levels of evolution in Zambia; with urban areas having a stable epidemic while the rural epidemic is yet to stabilise. Almost 50% of adult women in urban
areas are infected with HIV, according to ZDHS cited by the CBOH (2002). The HIV/AIDS mortality rate for Lusaka, Copperbelt and Southern province is the highest, at nearly 60% higher than provinces with the lowest rates namely North-Western, Luapula and Northern.

For TB, Zambia’s TB notification has generally been increasing over time, with case notification in 2003 at over 55,000 cases notified. Sample co-horts; indicate that the cure rate has improved to 64% from 58%. The case detection from all forms of TB is 81%, while the WHO target is 70%. (CBOH, 2003). Its worth noting that due to the health sector reforms which had also changed the way TB was managed, Zambia’s intervention was adversely affected, as reformists did not fully involve TB technocrats and empower (in the reform process

1.8.7 People Living With HIV/AIDS in Zambia

By June 2000 there were 830,000 people over the age of 15 reported to be living with AIDS. Of these 450,000 were women while 380,000 were men. The peak ages for HIV among females is 20 to 29 years while that for males is 30 to 39 years. Young women aged 15 to 19 are five times more likely to be infected compared to males in the same age group. It is estimated that 25 per cent of pregnant women are HIV positive. Approximately 39.5 per cent of babies born to HIV positive mothers are infected with the virus.

HIV/AIDS is contributing to the most profound reversal of development gains made in Zambia over the past 37 years. HIV/AIDS is the most critical development and humanitarian crisis Zambia faces today. Some of the social and economic reversals due to HIV/AIDS epidemic include:

a. Decimating the active age group required for economic growth in the country. This has led to loss of productivity.
b. Life expectancy without HIV/AIDS was projected to be 60 years at birth, but it is now projected at 37 years due to HIV/AIDS.

c. Increasing number of orphans, which were estimated at 600,000 in 2000 but was projected to reach one million by 2002.

d. High burden of disease, which has overwhelmed the health care delivery system.

Further, the report states that (MDG, 2003) the other challenges in the fight against HIV/AIDS in Zambia include, among others: overcoming stigma associated with HIV/AIDS; limited access to care and prevention programmes; human resource constraints; multi-faceted nature of the epidemic; gender inequality and the high cost of ARV’s.
CHAPTER TWO

2.0 RESEARCH METHODOLOGIES, SAMPLE AND SITE

2.1 Research methodology and approach

It has been widely documented that there is no single approach or method that can be said to be more important than others, as seen from the need for contextual relevance and application. The purpose of the investigation itself and other logistical challenges are of the essence, since they may influence the method selected but that should not significantly alter the desired results from the study.

This study was aimed at documenting the lived experiences of people with HIV/AIDS, in their selected pathways to health seeking, considering the health service providers role as a critical input with an effect on the choices or dilemmas that PLWHA may have. Given the nature of this study, it was felt that use of in-depth interviews (using semi-structured guides) with purposely-selected participants would be more desirable to meet the study objectives and get the most out of the data to be collected.

In order to derive detailed information and useful insights, the depth and breadth of investigating phenomenon like that of lived experiences, pathways to health seeking, dilemmas in provider choices and other emerging thematic areas would certainly require the use of a qualitative approach.

The two method research categories are stated as either quantitative or qualitative. Krueger (1988), Creswell (1994) and Fowler (1988) throws light on these differences by stating that while qualitative approaches concentrate on words and observations to express reality and attempts to describe people in natural situations while by contrast, the quantitative approach grows out of a strong academic tradition that places considerable trust in numbers that represent opinions or concepts; more interest in meaning; researcher is the primary
instrument for data collection and analysis; involves fieldwork-observing and recording behaviour in natural settings; study is descriptive; process is inductive in that researcher builds abstractions, concepts, hypotheses, and theories from details (Krueger, 1988) and (Creswell, 1994).

Denzin and Lincoln (1994), explains that qualitative researchers stress the socially constructed nature of reality, the intimate relationship between the researcher and what is studied and the situational constraints that shape inquiry-seeking answers to questions that stress how social experience is created and given meaning.

People living with HIV/AIDS have been widely studied from the context of their general experiences, typical ‘access to services’ studies, stigma and discrimination in general, their involvement in activities meant to prevent further spread as well as gender related investigation of the HIV. Studies on incidence and prevalence of HIV have been common, with statistics being derived in most of the afore-stated instances.

However, in this study, the researcher realised the ‘data gaps’, which would remain unfilled if a typical quantitative approach were used. This study, with its emphasis on community based scenario where most of the data was collected and considering the social, economic, and cultural settings of the participants themselves, the use of qualitative methods was desirable.

As outlined in the fore-going chapter, the main objective of this study was to explore, identify, describe and gain an in-depth understanding of medical pluralism in Zambia in the context of the lived experiences of people living with HIV/AIDS in their quest to access and utilise health services.

In particular, it was found that given the nature of this study, more data would be derived which were more text and less numbers. Most of the participants gave lengthy descriptions of their experiences, defined their process and outcomes of various episodes of
illness and their recovery from the same and how their friends, relations, health service providers and fellow people living with HIV/AIDS helped or were limited to do so for varying reasons.

Triangulation was considered as a possible approach, later adopted after its appreciation grew; with it should be understood that in some instances, a method mix might be more desirable. Creswell (1994), also citing multiple source of experiences documented by Campbell and Fisk (1959); Brewer and Hunter (1989); Denzin (1978); Jick (1979) argue that the concept of triangulation was based on the assumption that any bias inherent in particular data sources, investigator, and method would be neutralized when used in conjunction with other data sources, investigators and methods- these methods may be drawn from “within methods” or “between methods”. It was decided that triangulating within the qualitative methods domain was more desirable, given the nature of the study.

Therefore, an exploratory approach with triangulated methods was considered more desirable to fully investigate the afore-mentioned phenomenon and meet the study aims because as its definition suggests, Kimchi et. Al (1991) in their review of various journal articles and citing Denzin (1970 & 1989) and Browns work (1987), define triangulation as “the combination of two or more theories, data sources, methods, or investigators in the study of a single phenomenon.” the first methods is used to inform the second method; initiation, wherein contradictions and fresh perspectives emerge; and expansion, wherein the mixed methods add scope and breadth to a study (Creswell, 1994).

Qualitative method in itself is very wide, providing various opportunities for informed choices of methods to be employed in the study. Given the study aim and the setting of the participants, an ethnographic approach was considered to be the most desirable, to aid the research process in collecting detailed, relevant, and sufficient data on various phenomenon,
with relevance to what the people living with HIV/AIDS experience in their health seeking journeys in environments of pluralistic health systems, both formal and informal ones.

Collecting data from PLWHA is generally not easy, especially when it also requires that they provide personal information on their dilemmas in typical cultural settings where social constructions of gender may require that some individuals and groups may feel marginalized, including PLWHA. Triangulation of the methods (in-depth interviews, focus groups, participant observation and workshop) helped to gain the required depth and breadth of data, processes, phenomenon, within an ‘emic’ setting, which helped with deriving descriptions, leading to a greater appreciation and understanding of the pathways to health seeking as well as the provider dilemmas and options at the disposal of PLWHA.

It should also be noted that the methods used were informing each other in the whole study process, with one method or data source being consciously considered when using the other methods. Rather than influence the study differently, the researcher found this way of working desirable in helping increase ‘mental alertness’ to inform the next process in the study, thereby understanding some phenomenon being observed or reported.

This form of interdependence and complementary nature of the study instruments helped the furtherance of the research, enabling each process to act as a key informant to the other while retaining its methodological independence as a ‘self-existing’ approach.

Therefore, the outline followed herein where presentation of methods or their discussion are separated is only meant to aid the process of discussing the same, rather than isolation and independence.

While some people living with HIV/AIDS are open about their status, there are still many more who have neither disclosed their status and are unlikely to do so in the foreseeable future, due to their own perceptions of how they expect people to react to their disclosure, or
their own felt need to understand themselves more in their ‘new status’ of living with HIV/AIDS, before attempting to make others understand them.

Even levels of openness within support groups of people living with HIV/AIDS vary, with some more open to disclosure more about their lives than others; some are members who joined much earlier than others. In order to understand more about the afore-stated, the use of in-depth interviews as well as participant observation techniques became imperative.

With such a wide source of data, it was hoped that when methods are triangulated in the most appropriate manner, useful information would be derived; hence the use of in-depth interviews, focus group discussions, participant observation and workshop for selected stakeholders. As Bailey (1996) outlines, the use of multiple methods are common now, with the employment of interactions, observations, interviews, life or oral histories, focus group discussions, analysis of documents and self reported survey data.

Citing Linda Blum and Elizabeth Vandewater (1993) who in interested in changing definitions of masculinity from the view point of middle-class, married women, used participant observation, conducted in-depth interviews and analysed league publications representing the organisations formal ideology (Bailey, 1996). It should also be acknowledged that the main researcher was considerate and respectful to local beliefs and whenever noted, these were presented in their original context, ensuring that the Interpretation and meanings are not lost during translation or other processes in the study (Mill &Ogilvie, 2002).

2.1.1 Summary of data gathering techniques

The whole study was conducted over a period of five months in various districts of Zambia namely Lufwanyama, Chililabombwe, Ndola, Kitwe, Livingstone and Lusaka. All respondents were purposely selected based on the study objectives, theoretical framework being used and the inclusion criteria. As stated earlier, the methods employed in
this study include *in-depth interviews* with 35 participants from among PLWHA, traditional healers, bio-medical health workers and other service providers of PLWHA. Two (2) males living with HIV/AIDS were followed to understand some phenomenon regarding lived experiences in their social context and livelihood; while *focus group discussions* held with people living with HIV/AIDS, traditional healers and bio-medics and ‘EX-TB patients’ totalled 19, had a duo benefit of helping to derive useful information to inform the interview’s depth and breadth of inquiry, while some issues from interviews received their validation from groups who confirmed having had similar experiences. The mini-workshop has 16 participants (see protocols, objectives and invitation letters for workshop).

Some participants enlisted for in-depth interviews were purposely selected from focus groups, after taking note of their participation and weighing the possibility of deriving more valuable, in-depth and personal data from them individually, in confidence. This shows the private nature of interviews and public nature of FGD’s (Rosaline & Kitzinger, 1999).

The researcher personally facilitated all discussions except the workshop; with his ability to speak some of the main languages in the 4 different research districts being helpful— the researcher can communicate effectively in Silozi, Bemba, Nyanja and Tonga (some Zambian local languages). This was more helpful among traditional healers and support groups of PLWHA, although it also proved useful when conducting focus group discussions for health workers showed that some older nurses and other individual ones spoke more openly and clearly when some questions were rephrased in local languages— especially for those who were taking a passive role in participation.

It’s worth noting that the interview guides were semi-structured, open ended questions based on pre-designed issues related to the objectives of the study as well as the aspects for consideration raised by the Research Ethical Committee in Zambia (correspondence appended) during the fieldwork.
The final aspect of the study process was the workshop, whose participants were drawn from the same categories where other respondents were drawn in the other approaches. The workshop helped to identify and discuss, collectively, the perceived dilemmas and challenges faced in collaborating and networking the services of various providers, while identifying the opportunities that exist for possible initiation improvement of relations and identified areas for coordinated efforts to better the lives of PLWHA.

2.1.2 Research setting

Participants were recruited from 6 different towns in Zambia namely Livingstone, Lusaka, Ndola, Chililabombwe, Lufwanyama and Kitwe. The study was conducted during the period from July to December 2004. This study was multi-sited, requiring high levels of mobility by the researcher and assistants. The employers for the principal researcher assisted with two research assistants, a vehicle and some fuel to aid the study process. The researcher lived in the riverside area of Kitwe, where his permanent residence has always been, which is about 3 kilometres from the nearest study site for the participant observation and not more than 80 kilometres from the other copperbelt based study sites in Lufwanyama, Ndola and Chililabombwe. Given the study focus on PLWHA and their options and dilemmas, the research team considered them as the ‘primary informants, while the other health service providers were considered as the ‘secondary informants’.

However, the design and work plan of the study was such that it provided a holistic process of establishing a ‘satellite office’ through a particular partner organization(s) whose staff, volunteers or members were to be recruited as respondents. Plans allowed me to spend at least up to 3 weeks in each district; with the study sites being a ½ a days journey between each city to allow for settlement- the first week in each case was mainly spent planning for sessions, recruitment of participants and doing some administrative functions; while the
second week was for interviews, while the last few days were used for summing up and verifications in consultation with research Assistants.

This helped to coordinate the study; cover more work and multi-method used in each particular month when focus was on that particular district. Four of the study sites, namely Lufwanyama, Chililabombwe, Ndola and Kitwe (between 50 km to 100 apart) are within the same provincial government jurisdiction, while Lusaka and Livingstone are about 365 Km away and almost more than 900 Km, respectively, from Kitwe. The researcher commuted on a daily basis to and from research sites in Lufwanyama, Ndola and Kitwe, while temporary residence was taken for studies in Chililabombwe, Lusaka and Livingstone.

The principal researcher was permanently residing in Kitwe, the town where he has always lived and worked in the last 10 years. Research assistants helped with the fieldwork, having been identified from the same districts from which the particular data collection was to be done. The selected towns are also noted in various studies as having high prevalence, being located in provinces with the highest HIV rates; partly explaining why there were reasonable numbers of support groups of people living with HIV/AIDS and initiatives to either prevent and/or provide support in different ways to those already infected with HIV or having AIDS.
2.1.3 [Map of Zambia showing HIV prevalence by Province]

2.1.4 Kitwe study site

Kitwe is one of the selected towns for the study. It is situated in the centre of the Copperbelt province, having access to all the other towns of the province by road. According to the CSO, Kitwe has a population of 417,889 (211,257 males and 206,632) Census of population (CSO, 2003) most of who work in the mining and other related companies. The prevalence rate for HIV is 28.7% based on MOH (1999) estimates.

The research sites in the town were used for pre-testing the interview guides, but also hosted 2 in-depth interviews of faith based leaders as well as the participant observations of 2 persons in the study as well as the mini-workshop which involved stakeholders purposely selected based on the research criteria. As the principal research was resides permanently in this district it was also used as the main administrative centre for planning purposes.

The Copperbelt Health Education Project (CHEP), the employer for the research, a sizeable non-governmental organization working with various CBO’s and other NGO’s and the private sector, through technical support provision of mentoring services is also situated in
Kitwe—part of the logistical support was from the said organization. CHEP’s interventions on HIV/AIDS have been documented by the World Bank, Christian Aid and in the Strategies for Hope series by Action Aid, looking at successful interventions in Africa (World Bank, 2003, Thomas, 2004, & Mouli, 1992). CHEP has been collaborating with various institutions, including the ones which are the subject of this particular study: the Traditional Health Practitioners Association of Zambia (THPAZ), health workers through the board of health, and the PLWHA through their organization, the Network of Zambian people living with HIV/AIDS (NZP+) which whose national chairperson at the time of the study, was an employee of CHEP. It was reasonably easy to coordinate the study through existing networks for joint programmes.

The sites for the participant observations were 2 separate townships.

2.1.4.1 Participant observation Site 1: descriptions

One observation (involving John—not true name) was done in one of the townships in Kitwe. It has housing units built by the local councils, which were later sold to sitting tenants at minimal prices. Most of the houses are covered with iron sheets or asbestos roofing; they also range from 1 to 3 bedroomed houses.

The local council has provided facilities for water supply and the most of the houses are electrified houses and accessible roads between houses do exist. The Bemba, local language is the most commonly used. There are local shops, open markets, taverns and street vendors. Most of the inhabitants are working for mining related companies (some are retirees), and others are in supportive industries, governmental organisations, the private sector or doing personal businesses involving buying and selling of commodities at different markets—people also subsist by doing both formal and informal work.
Backyard gardening is used to supplement monthly incomes. It’s a densely populated with organized housing units and other facilities and services including unplanned open grounds where children play as well as churches and some abandoned welfare centres do not assist. Transport from the centre of town to this township is readily available, mostly by mini-buses. The early evenings are very busy, with many people moving up and about in the streets attending to different things at the markets, in the bars, the bus stops, among other places. Funeral gatherings are a common site, with several homes being inhabited by widows.

2.1.4.2 Participant observation site 2: described

The other participant (Peter- not true name) was observed from another township located within Kitwe district as well. It has housing units self-built by individual owners who obtain plots from the local councils. The houses are not standardised, some are incomplete, with uncoordinated development of structures, which are poorly maintained. Most inhabitants are mostly retirees who have settled there, owners of self-built houses who do private small-scale businesses or individuals renting properties while doing low-income formal jobs.

The place is accessible by public transport, with most roads impassable. Most houses are not electrified, access to treated water is very scarce and most people cannot afford piped water or the high electricity charges- use of candles, lamps and digging of wells is very common. While most houses have several rooms, most tenants live in single room of 2 roomed apartments (mostly partitioned by large curtains to make other rooms) as a family, with most families averaging at least 3-5 persons. Most of the inhabitants use Bemba as the mode of communication. Drinking of illicit brew is common, with most people not able to buy the brew sold in licensed bars and taverns. Incidences of single persons, especially widows are very common.
2.1.5 Ndola Urban study site:

Ndola is the provincial capital of the copperbelt, with a population of 413,969 (208,620 males and 205,349 Females), census of 2000 (CSO, 2003). It has an HIV prevalence rate estimated at 28.4% according to MOH (1999). The mainstay of the people is the remnant industries, which were formed several years ago to support the mining industries. With unstable copper prices, most of these have since been closed, with employees laid off. There are still some few industries involved in copper refinery, cement making, government offices for the province, private initiatives, hotels and trade fairs are held there annually. It has access to local and regional air network.

For purposes of the study, the respondents were from different places around the town, with PLWHA recruited from support groups in the district; traditional healers where from Chipulukusu township while health workers where from clinics being managed by the district board of health. In Ndola, the main contacts were a local NGO, the Health Department of the Catholic Diocese of Ndola (helped facilitate the study among its support groups of people living with HIV/ADS); the THPAZ local branch in Ndola helped coordinate the study among traditional healers most of whom where from Chipulukusu township; and the district health board assisted with the research among the health workers.

2.1.6 Chililabombwe study site:

Chililabombwe is a Zambian district, situated on the boarder with the Congo DRC. It has an estimated population of 77,749 (39,662 Males and 38,088 Females) census 2000 (CSO, 2003) and a prevalence rate of 25.8% according to MOH (1999) estimates. There are a total of 8 health centres, 4 of which are government run while the rest are privately owned, with the mining company being the other main health service provider.
The mainstay of the town is employment related to the mine situated there managed by foreign investors, including subsidiary industries around mine related activities. With copper prices being unstable, investors had conducted large-scale retrenchments, which have affected family livelihood and increased poverty levels. Most of the housing units were built several years ago by the mines and most have now been sold to sitting tenants, some of who are unable to service the units and resort to either selling or renting them while they relocate to neighbouring low-cost, unserviced residential areas which are crowded.

Most of the respondents came from mine areas, including large townships like Kakoso and Lubengele. There are very high cross boarder activities with the Congo, as people buy and sell different commodities. There are occasional large movements of people across borders depending on the socio-economic situation prevailing on either side- with boarder controls very minimal. Trucking activities and commercial sex are common around the boarder area. The district board of health has functioning networks, which were used to recruit respondents for the study. The local branch of the traditional healers association uses the clinic as a meeting place, and some of the support group members who are living with HIV/AIDS are health workers themselves.

2.1.7 Lusaka Study Site:

Lusaka is the capital city of Zambia, where the head of government, parliament, and many other agencies are located. It is considered to be a province in itself; with a population of 1,190,840 (601,523 Males and 589,315 Females) census 2000(CSO, 2003). The HIV prevalence rate stood at 27.2% according to MOH (1999) estimates. It’s highly urbanised, like most other cities in Africa. While, Zambia’s main stay is based in the Copperbelt, Lusaka is the main business centre, with various economic activities being planned and executed from there.
For purposes of the study, there were no Focus Group Discussions held there, except for in-depth interviews among some key informants—most heads of organisations are based in Lusaka. The research among Lusaka respondents was coordinated through the Copperbelt Health Education Project (CHEP) office in Lusaka. The office helped provide a list of potential participants, from which the main researcher purposely selected some of the respondents.

2.1.8 Livingstone Study Site:

The district is a boarder town, with a population of 111,859 (56,037 Males and 55,821 Females) Census 2000. (CSO, 2003). The HIV prevalence rate for the town was estimated at 31%, according to the MOH (1999) estimates. Its Zambia’s tourist capital, having access to international flights directly from the southern Africa region. Mostly, tourist related activities are the main stay of the town, with other income sources being related to agriculture, fishing, and timber business. Livingstone shares boarders with Zimbabwe and Botswana, as well as Namibia through western Zambia. It’s also linked to the trans-route for truckers, with commercial sex being a common phenomenon. Most of the inhabitants also work for some government related organisations, private businesses and small-scale farming. Cross boarder trade by individuals is very common, with several daily crossings being recorded on either side of the boarder in the mentioned countries.

Most residents in the health and teaching profession have migrated to neighbouring countries including Namibia, Botswana, Swaziland, Lesotho, and South Africa in search of higher income earning employment. Due to periodic inflows of incomes from tourist and other subsidiary activities, including incomes from ‘expatriate Zambian workers’, there are some sustained economic booms, the cost of living is one of the highest in the country and housing units are sold or rented at high prices, by local standards.
The research was conducted with the help of a local partner, SEPO centre (SEPO is a Silozi local term which literally means “hope”). The organisation is non governmental, with its focus being on HIV prevention, and support provision through home based care programmes and facilitating the work of people living with HIV/AIDS. The local branch of NZP+ is nested by SEPO\(^1\) centre while they are still developing capacity to get established elsewhere.

Generally, the researcher entered the field through the existing district level networks and organisations, which coordinate the three main categories being studied. District leaders (gate-keepers) for the traditional healers association, people living with HIV/AIDS and the district health boards seconded persons to guide the researcher into the local field scenarios. Some of the gate-keepers were purposely selected as key informants; none participated in the group discussions held due to their ‘perceived superior status’ as leaders which may have affected levels of openness in other focus group members.

Except for Chililabombwe, Livingstone and Lusaka where I lived during the period of the study, the other districts namely Lufwanyama, Kitwe and Ndola were only visited on a daily basis, travelling from Kitwe my place of ‘permanent’ residence. Budget constraints and other logistical reasons influenced the researchers’ decision as to whether to stay in a locality or commute.

\(^1\) SEPO is a local word in Silozi which means ‘Hope’
2.2.1 Inclusion Criteria

- Persons Living with HIV/AIDS who belonged to a support group in the study area.
- Persons with HIV/AIDS who were living “openly” and/ or “shared confidentiality”\(^2\) in their support groups or communities.
- PLWHA, who were not too ill to participate (e.g., having ‘full-blown’ AIDS).
- At least aged between 25 to 49 years old (For health providers and PLWHA in support groups, the age was not very significant in increasing or decreasing the freedom of discussants; however gender proportions were considered when enlisting respondents for both interviews and focus group discussions).\(^3\)
- Those who had episodes of one or more opportunistic infections in the last two years
- Those who had been using at least one health service provider (as defined in Kleinmans’ (1980) theory).

2.2.2 Exclusion criteria

- People who were too ill to participate effectively, especially among PLWHA
- People who were below the age of 25 years or older than 49 years.
- PLWHA who did not belong to a support group in their locality were not included in the group discussions for their category (i.e. PLWHA).

\(^2\) Shared confidentiality in this context means that the person has disclosed their HIV status to at least one other person(s) who may be their own support group or family members or other equally trusted peers; but not yet gone ‘public’ or widely open.

\(^3\) As we learnt from the Pre -test process, ascertaining age or asking potential participants for their ages was problematic for some, experience and judgment was used extensively in those circumstances to benefit from this inclusion criteria.
2.3 DATA GATHERING TECHNIQUES

2.3.1 In-depth Interviews

There is sufficient evidence to show the value added to a study which employs in-depth interviews. Some types of research may require more intensive inquiry into some phenomenon in order to establish reasons why certain things happen in particular ways. This study used interview guides to derive valuable insights and data on the lived experiences of PLWHA as well as the perceptions and experiences of carers in their service provision role.

The benefits of interviewing are widely documented. Irrespective of challenges with interviews, Denzin and Lincoln (1994) citing an article by Fontana and Frey, state that interviewing is one of the most common and most powerful ways we use to try to understand our fellow human beings; it’s a paramount part of sociology, because interviewing is interaction and sociology is the study of interaction (Benney & Hughes, 1956).

The research team interviewed participants some of whom had also been part of some of the focus group discussions, while others were key informants recruited directly from various organizations within the study parameters. Some challenges encountered involved the researcher (based on triangulated methods) having to cope with being part of interviewing, observing and recording the same multiple events, some of which were multi-sited.

The principal researcher observed that there was need to ensure that the role of gatekeepers is well defined and that the research team was taking full responsibility for enlisting respondents for all interviews, based on the research criterion for inclusion and exclusion. Some contact persons who were helping to coordinate the data collection and sources of participants (support groups) had felt that they needed to involve almost all the support group members to maintain group coherence and/or bring new members who had not yet met with visitors to get them ‘exposed’ to such activities!
However, the research team explained the objectives of the study, its limitations in terms of group sizes were also discussed, leading to a common understanding being reached to limit how many people could participate in a session. Not all appointments for interviews where conducted within record time as planned; in some instances, respondents changed appointment dates without notice.

Key informants were the busiest but cost less to host because they were mainly met in their own offices and did not need transport refund or food supplements. Limited respondents were recruited from some of the supports groups from where focus group respondents had been drawn from for purposes of the study.

2.3.2 Focus Group Discussions

Generally, Campbell et al (1999) suggest that FGD’s should be used appropriately, as a compliment rather than an alternative to in-depth interviews, suitable for investigating normative aspects of behaviour. Terrance L. Albrecht et al (1993) citing Shaw (1981) defines a group as two or more persons who are interacting with one another in such a manner that each person influences and is influenced by each other person. As Rosaline et al (1999) outline, focus groups should not be seen as a way to access some static but as yet untapped set of opinions or preferences; participants need to be considered as active subjects, who are involved in constructing social reality through interaction, both in their lives and in the focus group; they possess a dynamic stock of knowledge (Schutz, 1970; Schutz & Luckmann, 1974), which can be mobilised in sensitive and comfortable environments where their views are not implicitly denigrated- participants in a focus group should be treated as citizens, rather than passive consumers.

Morgan (1988) also discusses varying methods, stating that the intermediate nature of group interviewing means that focus groups not only occupy an easily comprehensive
position within the existing set of qualitative methods, but also possess a distinct identity of their own. On the one hand, focus groups cannot substitute for the kinds of research that are already done well by either individual interviews or participant observation; on the other hand, focus groups provide access to forms of data that are not obtained easily with either of the two methods (David, 1988).

In this study, there were participants who did not show up for the focus group sessions (we usually invited at least 2 more persons to provide for that). The break times in between focus group sessions were just as important, as useful insights were collected, later followed up in the full session. As for those who did not come, there were important reasons why some preferred not to show up - ranging from (for healers), due to group leaders not clarifying things correctly, reluctance to discuss what they thought would be session where they would be forced to talk about the herbal combinations they use; some thought it was an indirect way of the government trying to register them and oversee their activities critically.

During the study of the health seeking options and dilemma of PLWHA, I research team carefully thought and reflected on the design of focus groups- Knodel (1993) advises that at one extreme, maximum flexibility maybe desired; the number of groups to be held and even the precise characteristics of the populations to be targeted are decided in a stepwise fashion as the fieldwork progresses-this proved useful for exploratory studies where its helpful to digest the contents of each successive focus group session before deciding if another is needed with any particular target group. Where the researcher already has some substantial background knowledge of phenomenon to be studied, then a detailed design, set in advance is important.

It was easier to involve nurses and other medical personnel and relatively harder to recruit doctors for the focus group discussion (FGD’s). The unfavourable doctor to client ratio may have been an additional factor. Most doctors gave various excuses for not joining groups,
but we also realised that some may have wanted an exclusive setting, a ‘doctors only Group’ composition. However, we still had doctors involved in the study as respondents in in-depth interviews. As for the clinical officers, nurses, environmental health technicians and other para-medics, most of whom maintain regular and direct contacts with clients, data was obtained from them in coordinated, common FGD’s, and despite the difference in professional focus, they easily constituted homogenous groups for discussion purposes.

A focus group discussion of predominantly young traditional healers seemed not to have gone well based on the research team's expectations, with them demanding to be paid for previous studies done in their locality by other researchers. The healers appeared to have been uncomfortable and were not willing to go ahead with the FGD, a position that the researcher team welcomed. However, they later changed their decision, explaining that since the research team was willing to cancel the session, then it interpreted that the team was ‘more genuine than others’ who have abused their trust and confidence- those who had visited them earlier-who did not provide feedback from previous studies; lack of support from government like the one given to their ‘fellow doctors’ in formal government hospitals.

Clarifying research objectives and creating more confidence on ability to provide feedback helped create trust. The research team noted that in this particular instance, the younger healers in the FGD seemed to have been more concerned about their economic livelihood while the older healers were talking more about their work environments and occupational risks in their daily practices, which were disabling factors.

Certain vital issues had to be recorded later, as they came up during a break session or towards the closing periods of the focus group discussions. Some participants informally discussed the phenomenon of the difficulties of abstaining from sex when on TB drugs. Most respondents reported having been given “conflicting information “ on why they should abstain and how long- most concerns were from women that felt that their husbands might
divorce them or get an excuse to go and have sex outside the matrimonial arrangements thereby placing them at even greater risk of HIV infections!

For PLWA, the FGD’s composed of purposely selected members from various support groups from within each district and its zones- in some instances; it was persons from the whole single group who were selected where groups were not very many or levels of openness minimal. The use of the Zambian National directory for PLWHA was useful to locate and identify information for facilitating the recruitment processes for respondents.

2.3.3 Participant Observation

The research team worked with two purposely-selected persons living with HIV/AIDS in one town. Several challenges were encountered in this study process. Ensuring that the 2 participants are “well selected,” observed through participation and various observed phenomenon accurately recorded immediately after each day of being together was not easy to do, being the first time the principal researcher was doing qualitative research at this level.

Having selected only males for participant observation, the main researcher was mindful of the possibility of not getting vital data with gender differentials, had a female participant been recruited as well. Doyal & Anderson (citing Doyal, 1995) acknowledges that women’s capacity for childbearing will have a major impact on their experiences of HIV/AIDS, and alongside these biological differences, the illness narratives of women and men are also shaped by socially constructed gender differences in duties, responsibilities, rewards and entitlements.

The main researcher carried out all interviews himself. It was not easy (but possible and manageable) to prevent this ethnographic study of participant “observations degenerating into interview sessions;” also, the need to re-orient my respondents not to feel like they
needed to speak all the time and keep me informed. The researcher decided not to write up anything during the observations but did so immediately after each visit, putting sketchy notes down before arriving home and settling down and typed the scenario of the day into the computer directly from my note guides, later the same day.

It was based on other experiences that the researcher had to find a way of dealing with his own ‘over-consciousness’ of what was felt as being too intrusiveness into the life of the respondent and their immediate families. However, what helped was that the environment was very relaxing, with the family of the observed participant being very informal and participatory. The researcher also pondered on how his regular presence around the respondent would affect his (the respondent’s) way of doing things. Earlier on, the researcher had informed the participant being observed that he needed to be free to go on with his normal daily living with his family, and not to structure things for the researchers sake! The quest to stick to my research protocol and influences of wanting to see my expectations, thereby not seeing what could have, otherwise, been observed and documented, was done away with as the researcher mingled freely, without ‘theoretical limitations due to involvement in the activities of observed participants without hindrance.

In order to cross validate and ensure the reliability of responses from questionnaires used in individual and focus group discussions, there was need to collect additional data through the observed, lived experiences, hence the importance of doing Participant Observation. In this case, physical presence could not be replaced with any other approach in research. The absence of research assistant(s) created a ‘felt difference’ to me as the main researcher, having gotten used to taking notes, facilitating discussions and having the research assistants along, documenting all discussions on our behalf.

Some days went without me feeling satisfied with what I had observed because, in my opinion, they were not as eventful as others had been. One of the respondents appeared to
have needed more privacy since his wife was pregnant and needed his attention at home
more- the levels of openness differed between that found in support groups to a time when the
same respondents now have to be observed over a long period of time in their home setting
and communities, this showed me their typologies of openness, with different depths and
breadth within which people feel comfortable or are willing to share information about their
lives.

I also made sure that they did not feel duty bound to fulfil the whole 3-month period-
therefore, with one participant; we ended within a two-month phase though we kept the
interaction occasionally. Selecting participants from already established groups who were
exposed to the other focus group discussions may introduce a cadre of “prepared participants”
who may introduce elements of being too ready for the researcher! I was conscious of this
phenomenon as I went on with recruitment of respondents.

The strong urge to open up discussions with a view to educate observed participants
was getting strong each time, being a health educator myself. For example, the pregnancy of
one participant’s wife, to me (a typical health educator) indicated ‘non-adherence’ to the use
of condoms or evidence of engagement in unsafe sex, an entry point for health educating the
couple!

I purposely chose my participants on the basis that both where living with HIV/AIDS and that
to create some variations in what type of data I could obtain from each, I chose them from
different locations in the same town- both have their own uniqueness: while one emphasizes
on use of ARV’s, the other participant was more on natural herbal remedies and prayers, due
to his religious orientation.

The use of participant observation as a method helped me cross check through lived
experiences, some of the issues I recorded through in-depth interviews and focus group
discussions- actually, the participant’s movements in search of treatment and support or
provision of the same to other fellow patients was helpful. Also, observing a married man, HIV +ve and whose wife is an expectant mother, showed me how challenging it is to adjust to situations and put health and lives first before the need for the data to be collected.

2.3.4 Workshop for selected stakeholders

This workshop was included as a method, to help gain more insights into the views of various stakeholders regarding the main issues, which help them, network better as well as the existing hindrances to effective collaboration. As defined in the theoretical framework, protocol and methodology documentation, participants were purposely selected (bio-medical personnel, traditional healers, people living with HIV/AIDS and the popular sector, among others) including the groups to which they belong. A total of 16 participants were enlisted for the workshop, which included 4 people living with HIV/AIDS, 5 traditional healers and 5 health workers and 2 others, one from the faith based groups and another from the other non-governmental organisations.

The workshop was held at the premises of a local Non-Governmental Organisations (NGO’s) in Kitwe. There was a research assistant who was taking note of the proceedings of the workshop, which the main researcher, with the help of another co-facilitator, coordinated the process while also taking notes on key issues being deliberated in the group works and the plenary sessions. The data from all the group works and other sessions was compiled and presented in report format by the research team. Before the end of the session, the information in the draft report was disseminated to the group to enable them comment further or correct any statements, which were inaccurate.
2.3.5 Triangulated methods discussed

Conducting the study in a triangulated manner helped enrich the findings and study enjoyable keeping the researcher interested and focussed, while the different methods employed all together in each week appeared to have enabled participants reveal the many choices for health seeking at their disposal.

Each method was valuable as a ‘stand-alone’ as well as part of the other methods employed. In-depth interviews brought out issues which had not been disclosed in focus groups; yet without the group discussions, EX-TB patients who were also HIV positive would not have been motivated to ‘come out’ and ask the research team for separate in-depth interviews, in their ‘new status as PLWHA’.

The immediate benefits of triangulated approaches within a method (qualitative method) were useful. Following up PLWHA in their lived experienced derived data which was more comprehensive, being in a social context where activities of daily living were set in motion and the researcher was given an opportunity to participate, while observing. The contextual clarity was demonstrated in real life processes at family level, with friends, relations and communities as a whole. Yet, participant observation, as a ‘stand-alone’ method would not have been more useful without the data from in-depth interviews, group agreed issues regarding the lives of PLWHA in the focus discussions.

Group discussions helped identify possible participants later enlisted for the in-depth interviews. Finally, the value of the workshop held is seen from a practical context of multi-providers being brought under ‘one roof’ to discuss collaboration and networking was in itself the beginning in coordination among providers. The workshop method was dependent on the data and pre-liminary issues raised in the other data collected in order to discuss in thematic groups and plenary sessions.
The high levels of method inter-dependence and the uniqueness of each contribution to the others demonstrate the incremental benefits of triangulated approaches. The research team saw everything as a matrix of triangulated phenomenon, from multi-sites, varying typologies of health care providers to differentials in clients and methodologies themselves.

2.3.6 Multi-sited research study

This study was undertaken in 6 different districts, purposely selected for varying reasons. Apart from being triangulated, the methods used are also exposed to a multi-sited scenario, where social settings are different but understandably related in terms of relevance and adherence to the study protocol. The data collected is from various sites and different categories as defined in the theoretical framework (Klienman’s), uses method-mixes within the qualitative domain and is multi-sited across pre-selected districts of Zambia, by the main researcher.

Many other qualitative researchers testify about the benefits of using several sites to aid in the research process and derive rich data. Marcus (1995) explains the importance of undertaking multi-sited ethnographic research work, that the world is not the theoretically constituted holistic frame that gives context to the contemporary study of peoples or local subjects closely observed by ethnographers, but it becomes, in a piece-meal way, integral to and embedded in discontinuous, multi-sited objects of study.

Zambia has several tribal groups with varying cultures which entails that studying any phenomenon in depth, especially aspects of lived experiences would be incomplete if not considered in their cultural setting and other related influences around those environments where the study participants were situated and interacting daily. However, it’s worth noting to state that most, if not all the districts involved in the study were places, which have some unique economic activity, attracting different people of varying tribes in search of
employment. But as people move, they also regroup into ‘comfort cultural groups’ of fellow tribe’s persons and involve themselves into their own cultural activities, different from those of the dominant tribes of that district, as was observed by the research team.

Marcus (1998) further argues that ‘Cultural logic’ so much sought after in anthropology are always multiply produced, and any ethnography account of these logics finds that they are least partly constituted within sites of the so-called system. He advises that ethnographers interested in contemporary local changes in culture and society, single-sited research can no longer be easily located in a world system perspective.

2.4.0 Use of information from pre-test data

The study team used FGD’s to pre-test the interview guide as well as expose the team to a typical scenario to be expected in the whole research process thereafter. The interview guide was modified after the pre-testing in Kitwe, in areas and with respondents who were not part of the main study but who possessed similar characteristics in terms of respondents and relationship with the theoretical framework being employed.

Each of the instruments was interpreted into Bemba, the dominant local language in the copperbelt, which the researcher can speak and then re-interpreted back into English to try and gauge whether the same meaning could be derived and where variations occurred, modifications were made to the interview guides. There were separate guides for PLWHA and those for all the other health care providers enlisted for in-depth interviews and group discussions.

The relevant, emerging aspects, which helped improve on the relevance and adequacy of the guide included the use of different languages and their interpretation in focus groups, limitation of individual, lengthy narrations; need to have separate groups for male and female PLWHA, importance of the food poverty in the lives of PLWHA; the perception of PLWHA
being discriminated on account of ‘looking well or being very knowledgeable on health matters’ the emerging role of subsidised ARV’s on PLWHA and their health seeking; the relationship between being seen as a ‘strong person’ and living with HIV/AIDS. The modified guides were used to reinforce the in-depth interviews as well as the focus group discussions and thereby enriching the data based on informed responses.

The length of the discussions and interviews, sequencing and logic or flow of questions also informed and enhanced the quality and usefulness of the data collection instruments and the skills of the research team as a whole. Also, the feasibility of analysis on the pre-tested data collected was considered. The pre-testing helped the research team to have the ‘data transcription and analysis in mind’ while collecting the data, to picture the collection process in the light of how the data will be processed also.

2.5.0 Urban Vs Rural variations

From the outset, it had appeared to the research team that rural based community based organisations had not been able to organise support groups of people living with HIV/AIDS with ease, unlike in other urban communities in the research sites; all the rural based support groups the research team came presented themselves to the researcher as EX-TB patients only, not PLWHA support groups which were the researchers target. However, the principal researcher was able to find participants for in-depth interviews after selected members of one ‘EX-TB’ group (one male and a female) requested to discuss a few things in confidence, at different times. The 2 were able to provide more data after consenting formally- they turned out to be PLWHA, who had not ‘gone public’ but had selectively opened up to the health workers at the local clinic about their HIV status.

Another phenomenon for the rural groups was that word easily went round when the sessions began, attracting a lot more EX-TB patients than we were expecting, and we
therefore had more persons to interview or involve in focus groups than we had planned for. In order to avoid creating ‘divisions’ in small communities and groups the research team and our host (the Rural Health centre) had to agree on holding an extra focus group discussion in order to take care of those who wanted us to “talk to them also.” In each of these instances, research protocols were followed and consent obtained from each individual participant, in case we needed to use the extra data.

The research team conducted studies in the rural area (Lufwanyama district) much earlier, before going to other places to avoid research process disruptions when the rains begin. From experience, most rural households including possible participants would be busy in their fields, clearing in readiness for the planting season. The team resorted to using non peak times when people will have returned to their homes, in the afternoons, as well as going to home settings to reduce their movements. A more reliable form of vehicle had to be used to go through impassable roads and swampy, areas. -This was not a significant phenomenon in the urban research sites.

For rural based sessions of group discussions, with shortages of qualified health workers, retired nurses and other community health workers actively involved in caring and support people living with HIV/AIDS and/ or those providing DOTS for TB were included as participants in the FGD’s for the health workers.

2.6.0 Recording by hand Vs by Tape

Riessman (1993) warns that taping and transcribing are absolutely essential to narrative analysis- students invariably struggle with the issues of how to transcribe the tapes of interviews, which in qualitative interviews are often lengthy.

In this study, most participants, especially for the in-depth interviews of policy makers among some key informants, were very reluctant to allow me to tape record the interviews.
Most said that they ‘did not want to be quoted’ while others simply did not grant consent, without reasons- However, we as a research team also found the use of recorders not giving us additional data we needed, as compared with its relevance in its continued use, so it was not used in most in-depth interviews, but more in the focus group discussions.

But the most interesting scenario and change was with participant observations. On replacing the tape recording and the research assistants with myself doing everything from observations, note taking, discussion and interacting, and listening carefully at all times put a greater responsibility on my newly acquired research skills and coping with changes, some of which meant using all the methods (interviews, focus group discussion and participant observation within a day, each with unique attendant problems).

2.7 Support groups and People Living with HIV/AIDS

The support groups were also categorised differently, with some formed based on the need for HBC and provision of food supplements; others were more inspired in their formative and present stage based on their faith; others are more linked to ARV therapy and other support reasons- education levels and age was not the main factor, though there were far less younger people in various groups which were dominated. By adults

Nichols and Jenkinson (1991) explain that a helping support group comprises people that share some common identified need and will have recognised the existence of that need such that they will be prepared to attend to relevant group as a possible means of dealing with the need. In addition, these people will be capable of giving reciprocal care and mutual help to other members of the group; and where formed on a heterogeneous basis, as long as there is sufficient common ground between members to allow the uptake of a collective task and sufficient experience in common to allow meaningful sharing, empathy and support. Group
members influence each other by responding to ideas and comments in the discussion (Krueger, 1988).

Explaining my presence in some privileged environment like support groups of people living with AIDS was not easy, both for myself and the observed subjects, though the explanations that am also “AIDS-affected” appeared to have helped to create some harmony, including my subjects explanations that am a friend of people living with HIV/AIDS, conducting a research study by following up my subjects wherever they went.

Generally, there was no gender desegregation of participants when dealing with health workers and traditional healers in focus groups- however, for PLWHA, there were separate sessions held for male PLWHA and those of females PLWHA. From the researchers experiences with group discussions among PLWHA, there seemed to have been a difficulty among female PLWHA to assert themselves in the presence of their male counterparts, despite some coming from the same support groups; especially that some issues relating to HIV discussions had deeper gender dimensions which may have affected the discussions.

For newly recruited female or even male PLWHA in support groups, it may not have been easy for them to express themselves openly in a heterogeneous setting because they may still be in a process of negotiation in which they have to decide what to disclose, to whom, when and where to do so.

2.7.1 Support Groups of EX-TB Patients

Some groups were found to have been organised as “Ex-TB patients” support group-based on the need not to impose the “HIV status on the group and force openness, we conducted the focus group discussion as such, referring to the group as an EX-TB patients support group. However, participants discussed equally more on HIV/AIDS just like on TB matters.
Later after the FGD, however, 2 individual members of the group decided to see the main researcher in private for further discussions about their ‘special situation,’ which turned out to be their HIV positive status revealed in confidence to me and our assistants- the nurses at the clinic also knew the AIDS patients who still wanted to remain unknown until such a time that they were comfortable to fully disclose to their spouses and families, before the community knows, we were informed.

Their position was respected and information entrusted to us, secured, based on shared confidentiality. We thus moved from a phenomenon of EX-TB patient, snow-balling into the actual HIV/AIDS clients in-depth interviews- based on their trust and confidence in the research process of the focus group and their quest to “learn more from the research” about their real status for HIV.

2.7.2 Recording the unexpected

The research team was conducting the study, mindful of coming across data and phenomenon, which may not have been expected, while others may already have been encountered in the study process, or was part of reviewed literature.

According to Riessman, transcribing takes considerable time through the scrutinising of the rough drafts of transcriptions, often across a number of interviews before going to the next level-with analytical induction being important at this stage; narrative accounts are jointly produced, with investigators interacting with subjects, analytical ideas change and that as one scrutinises transcripts, features of the discourse ‘jump out’, stimulated by prior theoretical interests and ‘fore-structures’ of interpretation (David, 1988).

Openness levels were also encouraged by the fact that the participants may have seen themselves as being in a workplace environment. The possibility of getting very interesting data from third parties during the researchers interactions as a participant observer had not
been foreseen, (see discussion on participant observations) was educating “complained in a group discussion that their spouses never gave them rest and wanted to have sex with them even when they felt very weak-some had not disclosed that they were HIV positive for fear of victimisation and divorce- HIV according to them, was difficult to use as an excuse for not having sex (the status not known by spouse) except other illnesses like malaria, which they found useful to explain as a reason for not being well.”

Interviewing health workers living with HIV/AIDS as members of a support group at community level was a challenge, especially when seen from the fact that in the discussions, they spoke from all angles as providers, and clients. Observing the HIV+ve health workers in focus groups showed them speaking more as support group members together with other PLWHA but when one was interviewed, she spoke more as a health workers first but also brought out personal matters towards the end of the session.

The phenomenon of possible difficulties in getting PLWHA in the rural district sites to be enlisted as participants both for in-depth interviews and the group discussions had not been foreseen, including the emergence of persons in the EX-TB category disclosing their HIV +ve status later after a group discussion.

2.8.0 My position as a researcher

The researchers role can be describe as that of a person who has worked with, associated and taken keen interest in the lives of people living with HIV/AIDS, for over a decade now. I describe it further as that of an ‘insider’ who knows some phenomenon or certain aspects of PLWHA’s lived experiences but also an ‘out-sider’ because I do not belong to any support group, have not been in contact with groups I was collecting data from. Citing Kvale (1989) discussing the metaphor of ‘miner and traveller,’ as it pertains to the place of the researcher, I can position my self as being an ‘outsider with some basic in-sider information.’
The researcher works for a non-governmental organisation in Zambia, the Copperbelt Health Education Project, (CHEP) which provides technical support to various community based initiatives that need capacity building or strengthening to better perform in their HIV/AIDS interventions. In particular, we also work closely with people living with HIV/AIDS, helping them to support their work in various ways, related to care and support.

The researcher felt encouraged to participate more at community level by knowing his HIV status, having taken some tests before and being ‘AIDS-affected’ because The researcher has personally experienced the impact of HIV/AIDS in his community, among them are friends, relations and family who have died or are still living with HIV- All these experiences have helped the researcher to understand the challenges people living with HIV/AIDS are faced with in their daily lives. The researcher always hoped to understand more about the dilemmas of both (some where PLWHA) clients and their carers (some where staff at CHEP while other are volunteers) in various interventions.

The researcher became more informed, by closely associating with ‘AIDS-competent individuals and their immediate environments,’ learning by asking, seeing and doing. Also, additional studies related to health and social work was undertaken by the main researcher. As a health educator, the researcher has associated with PLWHA and their different health service providers in the last 10 years, but have not methodically and scientifically investigated their lived realities of health seeking in the context of a pluralistic health seeking like exists in Zambia.

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1 This terminology is meant to explain why some communities’ individuals and groups tend to respond better to diseases when infected with HIV infection and/or impacted by AIDS in the social context of the local setting. This typology of resilience is explained as ‘being AIDS competent.”
2.8.1 My own therapeutic encounters - Growing up under plural health settings

2.8.1.1 Remedies I was given

With certain illnesses, I hardly went to the hospital and was rarely admitted because I receive most treatment within the home. My fevers were ‘smoked-out’ by steaming my body under a blanket; I remember that in my childhood, I experienced times when had sleepless nights and very scary dreams which were “stopped” when I was advised to stop taking bubble-fish through the counsel of my a diviner in the locality we lived, the scary dreams ended.

2.8.1.2 Different illnesses, many therapeutic choices:

Malarial attacks were treated when I was subjected to taking particular bitter roots of some flowers- making me vomit forcibly, some yellowish stuff, which signified, according to my mother, the successful recovery from malaria and other fevers. Tattooing and steam smoking helped treat my headaches, were treated with a certain herbal remedy.

I remember having a severe toothache, which was instantly treated by placing some roots of a certain type of flower believed to have medicinal properties- Each time the pain came, I would carefully insert it in some spaces between the aching teeth. I also used to gurgle some water where the same flower roots had been soaked overnight. Visiting the clinic to get painkillers like aspirins and panadols, which I directly inserted around the aching teeth, helped me manage the pains I periodically experienced

2.8.1.3 Typologies of help I got

I would classify the help I got into four sectors namely: the remedies I got within our home; the help I got from friends at school; the visits to the clinic; the self-help I administered on myself; and the faith-based support from the church in our neighbourhood. Depending on

1 Certain type of fish, which buries itself in muddy and very swampy areas of river beds- this fish, has no scales on it.
the type of help I needed, I would decided on where to get treatment or my parents would be involved as well. I felt that it was serious or they observed that I was in pain. I noticed that my mother usually made the decisions when I was a still very young-. Measles in my childhood needed hospital attention and I got admitted in the local hospital, after being referred from the clinic.

My fractured leg (result of injury while doing sports) could only be dealt with at the hospital where my father also worked. I was admitted for more than 3 months and also spent another 3 months at home, recapitulating from the same- prayers from fellow faith based group members helped to enable the healing to be completed. Each affiliation I had whether it is my family, friends, and church had a different influence on my health-seeking pattern with benefits gained.

While my local church always prayed for us to remain in good health for the whole year- thereby preventing many possible illnesses which could have befallen me, my family and other members of the congregation. So, the decision to either treat myself, get help from the hospital or church was dependent on whether my friends advise was inappropriate or the healers has the comparative skill to help better.

2.8.1.4 What I do now

In my adulthood now, I mostly seek treatment from the hospital; my professional bias as a public health educator as well as peer influences has limited my current therapeutic journeys. My faith has a great influence on my belief pattern- my belief that prayer alone can also heal my body when ill; while I also take other bio-medical therapies which my religion has no - objection to. When fatigued, I treat myself with rest- I also take lots of fluids and fruits to boost my immunity- some physical exercises being done during the week, I believe help me to prevent possible illnesses while headaches are dealt with sponging. My own
therapeutic journeys and those of my family influence how we decide where to take our children and what to do when they are ill. Our own belief about what works well and when to seek which help and from which source also influences how we assist our children.

2.8.1.5 What I saw happen in my family

Some of my family members were possessed by spirits, which were believed not to respond to anything else other than some therapeutic dances believed to please the spirits, then they would respond by comforting the dancer- Possessed persons were led to dance, usually for a lengthy period, almost the whole night- Various songs were sang and I was there to observe what was happening. Mostly, these dances took place in a procession with in a group of fellow possessed persons or alone within the confines of our home. In my childhood, I saw this form of therapeutic dance called ‘vimbuza’\(^1\) as a form of entertainment.

2.9 Ethical considerations

The research proposal was submitted to the Norwegian Ethics committee and the Zambian Ethics committee. Additional introductory letters were also written to relevant coordination bodies for sectoral health systems institutions before proceeding with the study. Work commenced upon obtaining clearance from the said committees, taking careful note of any comments or recommendations made on the study. The objectives of the study were explained to all the participants as well as the leaders of the bodies, which represent them (NZP+, THAPAZ, CBOH, etc).

Written permission and informed consent was obtained from every individual respondent (not their group leaders or gate-keepers) for in-depth interviews, ethnographic study and focus group discussions and the workshop. The importance of consent and its extent

\(^1\) This is a therapeutic song and dance done in my tribe, usually by all those who are possessed by spirits. Its closely related to what Janzen refers to as doing *Ngoma*
is well explained by Mauthner et al (2002) who argue that gaining ‘informed’ consent is problematic if it is not clear what the participant is consenting to and where ‘participation’ begins and ends, stating further that ‘consent’ should be on-going and negotiated between researcher and researched throughout the research process; that completing satisfactorily and/or obtaining ethics approval does not mean that ethical issues can be forgotten, rather ethical considerations should form an on-going part of the research and citing Miller (1995 & 1999), they state that another concern involves the ways in which the researcher and any ‘gate-keeper’ influence who eventually become research participants.

Rosaline et al (1999) also explain that group consent to participation is not assumed to represent consent at individual level, and that initial consent is not assumed to represent process consent (citing James and Platzer, 1996) and that participants should be given the right at the end of the session to take back any or all of what they have said (for example, wiping of part of discussion or leaving the same unsubscribed).

The appropriateness of language used to explain the purpose of the study and request for peoples informed consent was done in way understood by all the respondents at all times, and clarifications were made to ensure that the decisions are informed. While the research team was ready to honour those who chose not to participate, non-decided in that way. Participants were informed about their rights to participate or to decide not to participate; that there was no need for them to explain why they had decided the way they did- the withdrawal could be at any level of the interview or focus group discussions. It was also disclosed that their decisions would not affect their relationship with the health service providers or any others-they would continue to access the different services they were getting from their usual providers or carers.

The true identity of the respondents was always held in confidence and true names not used in relation to particular data, unless in a situation where the data was critical for the
report, (policy statements from key informants who did not object) otherwise, the true identity of the specific respondent was always withheld. The researcher took responsibility for data protection, together with the Assistants. Data sources remained anonymised and only unidentifiable names in form of pseudonyms and disguises were used to describe findings. Being at the centre of an HIV/AIDS study, the research team made efforts to conduct themselves in a socially acceptable manner by exhibiting community acceptable behaviour while in the field and away from the project sites.

All those involved in the study in different capacities have been formally acknowledged in the roles played. Also, the limitations of the study in terms of sample size, coverage, and methods used are discussed.

2.10 Analysis, analytical concepts and frameworks

Data analysis is a very important stage in the research process undertaken. As Krueger (1988), citing Yin (1984), defines “data analysis as consisting of examining, categorizing, tabulating, or otherwise recombining the evidence, to address the initial propositions of the study.” The question of validity and reliability will also be discussed interchangeably. Given the varying methods used in this study, data collected was voluminous, hence the need to ensure that it did not accumulate to unmanageable levels before it was inputted, processed on the computer and some basic analytical work of manual processing began, with the main researcher thinking about thematic areas, and how the same would be utilised in the final context.

Field notes from the main researcher were added to the other documents collected from each research assistant. These were discussed with the whole team to ensure that they were understood. Other observed phenomenon were also explained and documented. While a detailed analysis and categorising awaited the entry of data onto the computer (due to data
volume). Data was checked, cleaned and entered using Microsoft word, with files later saved as text only files.

The analytical process used the objectives of the study, the research question and the theoretical framework to evolve relevant thematic areas to help categorise data and aid the report writing process. Sub-themes were also defined and quotes, short narratives of cases written to help with the research process. The discussed and critiqued model of Kleinman was useful in developing the semi-structured interview guides for study the phenomenon of lived experiences of PLWHA, as well as the analysis of the data being aided by the same theory.

The main researcher and the assistants had personal diaries to help separate personal perceptions, emotional reactions, feelings and notes of ideas of what the research personally feels from what the participants are saying as a way of keeping ‘a space between the researcher and the research’.

Also, a verbatim of core statements from key informants as well and focus group discussions was recorded- while the researcher concentrated on documenting core statements, initiating and maintaining the flow of the discussion and reinforcing the same with relevant follow up questions, one assistant was transcribing all the interviews, while another was taking careful notes and documenting participants tonations, emotions and other non-verbal responses and reactions, whether individual and/or group led- this eventually proved useful in ensuring the reliability issues and making overall interpretations of the collected data from the discussions more consistent.

The main researcher basically took responsibility of transcribing all the focus group discussions, participant observation notes and the workshop which was held- he also maintained the role of carrying out all the interviewing process with occasional probes where
necessary, to aid in the clarity aspects of responses. The same interview guide was utilised throughout the interviews, both for individuals and focused group’s discussions.

For each day’s work, the key aspects or statements in the data collected were verified with the groups or individuals before winding up and closing the discussion. Thereafter, the researcher and assistant would meet and summarise the impressions of the meeting, as part of the quality control process for the collected data and also serve the purpose of informing subsequent interviews and discussions to be conducted.

The data collection, analysis and reporting process also helped as other thematic areas emerged, facilitating more literature reviews.

The issue of validity was considered in the report writing process as well, arising from the whole process including methods used, data collecting and analysis. In discussing the area of validity, Jensen’s article featured in Kvale (1989) elaborates that the claim to validity can normally be expressed in the form of a brief result statement, which asserts the explanatory value of the findings; on the other hand; the process of validation involves the application and documentation of analytical procedures.

The method mixes; depth of inquiry involved and the sample sizes and scope of the study itself created a validation process. In-depth content analysis was employed to aid in the accurate interpretation of collected data, with summaries being compared and contrasted among the sectors involved in the study. As discussed herein, Morse (1995) defines reliability as the measure of the extent to which random variations may have influenced stability and consistency of results; while validity is looked at as the extent to which the research findings represent reality and the ability to verify the data.

With appropriately triangulated methods, the research team ensured that all information obtained was verified with the participants, especially core issues on their responses before the end of each session. Also, sessions themselves were planned to be held
in environments which were considered as neutral, especially that we were also dealing with health care system some of which were in ‘conflict with others’ as reviewed in literature and later seen in initial responses.

The FGD’s were used to gain more information based not only on the interview guide, but also the other areas of probe by the main researcher after considering key elements of responses from previous individual interviews carries out. This phenomenon regarding the benefits and value of FGD when used interchangeably to illuminate, give contextual clarity or validate interview responses has been extensively discussed by (Albrecht, Johnson & Walther, 1993).

Group dynamics were important to note, especially in support groups of PLWHA. Having different participants recruited from several support groups as well as sufficient moderation skills for the discussions aided the data gathering process validity as well as resultant findings in the study.

With the current theoretical framework by Kleinman, the study’s focus on multiple health care systems was enhanced in that the theory acted as an aid in the process of arriving at a possible revised theory, as the process allowed for the use of initial theory (Kleinman). For the current investigation and future related ones, the process is helpful in that “researchers can also usefully carry into current studies any theory based on their previous research, provided it seems relevant to these, with the matching of theory against data rigorously carried out (Strauss & Corbin, 1994).

2.11 Data coding Nodes for themes (Using NUDIST- N6).

This study used semi-structured interview guides to discuss various phenomenon regarding the options and dilemmas of PLWHA in their quest for therapy. Using NUDIST version 6, various themes were coded into categories under the ‘tree nodes’ with sub-categories under
most of the codes. *Free nodes* were also created with quotes and general ideas developed and assigned nodes. For purposes of the article submitted as a contribution to the thesis, only selected categories and their data was used in writing the findings of the study and discussing the same. Other categories and their data will be used in forth coming planned articles to be released in other peer-reviewed journals. The whole list of categories included:

- Health seeking pathways (HIV/AIDS diagnoses, prompts for therapy, VCT and gender dimensions).
- Treatment options (ARV’s, herbal remedies and self-treatment).
- Food (food as treatment, well nourished clients and malnourished clients).
- Access to services by PLWHA (affordability, distance, availability, stigma & discrimination and capacity of providers).
- Collaboration (networking, involvement, inclusion, participation, absorption and stand-alone).
- Carer preferences (popular sector, traditional sector, bio-medical sector and other health service providers).
- Policy and practice (coordination, capacity sharing, referral systems, training, legal issues and assessments).
- Carers (working knowledge of HIV, patients as carers, carers own health needs and diagnostic services).
- Proxies for AIDS and TB.
- Poverty
2.12 Limitations of the study

The following may have limited the possibility of getting additional findings or deriving of different ones:

- The used of gatekeepers, networks and other influential people as a gateway to obtain permission to recruit the appropriate respondents.
- To a large extent, the use of support groups limited the recruitment of respondents to people living with AIDS who already belonged to groups while data from those without group membership may have been excluded.
- For participant observations done, there was a sense in which the main researcher felt that he had not reached the ‘point of saturation’ or that of closure (Polit and Hungler, 1995). The time frame and resources were limiting. The fact that the researcher did not live with the participants in the immediate area of observations limited the understanding of other social phenomenon which I could otherwise, have observed.
- The workshop was only held for ½ a day, while participant wanted to discuss some issues further on after developing ‘new ideas’.
- Inability to recruit a female PLWHA as part of participant observations limited gender perspectives of health seeking issues, which may have been observed.

2.13 Dissemination of findings

Some of the core issues regarding opportunities for networking and collaboration as well as dilemmas in the coordination process among differently conceived health care systems with their various explanatory models were initially shared at the workshop held as part of the data collection process. However, upon the conclusion of the study, the findings will be
widely disseminated to various interest groups at local, national and international levels, as listed hereunder:

- The participating Support groups of PLWHA through the Network of Zambian People Living With HIV/AIDS coordinating office.
- The District Health Management Teams (DHMT’s) in each participating district
- The existing Zambia Health Research Agenda Forum for the Central Board of Health, Zambia.
- The existing special stakeholders forum drawing together all the relevant organisations and PLWHA in the Copperbelt Province,
- Publication of the findings on the NORAD Fellows and University of Oslo Websites.
- Depositing of copies of the thesis at the University of Oslo, Mulungushi University, Copperbelt University (CBU), University of Zambia (UNZA) and the Copperbelt Health Education Project (CHEP) Library.
- Dissemination of findings at other relevant local, regional and international conferences
- Publications of papers in peer-reviewed international journals for social medicine and others for HIV/AIDS and TB.

In some way, the dissemination process began during the fieldwork, as the focus group discussions enabled the participants to learn by sharing with others. Most participants reported having learnt more from each other in the Focus Groups.
CHAPTER THREE: ARTICLE FOR THE JOURNAL

MEDICAL PLURALISM IN ZAMBIA:

The health-Seeking Journeys of People Living With HIV/AIDS.

“We have been everywhere, through everything.” –detailed accounts of lived experiences of PLWHA in their search for therapy.

An exploratory study involving 4 districts

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3.1.0 ABSTRACT

This article examines the pathways to health seeking as seen from the lived experiences of people with HIV/AIDS (PLWHA) in Zambia, as they negotiate their livelihoods in pluralistic health care settings. Zambia, together with several countries in sub-Saharan Africa, are undergoing the worst AIDS epidemics in the whole world, with coping mechanisms at national and community levels being stretched to breaking-points.

While several studies have specifically documented general experiences of PLWHA, very few have actually investigated the linkages that exist in the context of pluralistic health delivery systems; with particular consideration of the formal bio-medical system and the traditional healer’s way of working.

The main objective of the study is to explore, identify, describe and gain an in-depth understanding of medical pluralism in Zambia in the context of the lived experiences of PLWHA in their quest to access and utilise health care services. Conducted over a period of 5 months, from July to December 2004, this exploratory study triangulated various qualitative methodologies, which included 35 In-depth interviews, 15 focus group discussions. Participant observation of 2 male PLWHA over a period up to 3 months and later, a half-day stakeholders mini-workshop with 16 participants representing health workers, PLWHA, traditional healers and other relevant organisations. A semi-structured interview guide was used for interviews and FGD’s. The analysis conducted demonstrates how PLWHA negotiate their livelihoods, as seen from thematic areas which include options and dilemmas in health seeking, and pathways to accessing services in a multi-provider setting. The results show the benefits of effective, collaborative and networking interventions by service providers, while revealing the avoidable costs and dilemmas of thinly spread efforts by single providers. There are several qualitative factors that should be critically examined by HIV/AIDS practitioners, PLWHA, and other stakeholders working to improve the quality of life for all PLWHA.

[Key words: PLWHA, Health-seeking, HIV/AIDS, Traditional Healers, Bio-medicine, Pluralism]
3.2.0 Introduction

The field of medical pluralism has not been extensively investigated in Zambia, more so, the focus on people living with HIV/AIDS (PLWHA). The PLWHA have been prioritised in the Zambia National Health Strategic Plan for the period year 2002 to 2005 (NAC, 2002). Although the PLWHA are considered as a critical research priority under the National Health Research Agenda in Zambia, little has been known regarding the study of their health seeking in environments of multi-health systems.

Most of the reviewed studies have focussed on specific providers within the field of health, while the interplay among the different providers and how health seeking is affected in such an environment of plural medicine is under-researched, not only in Zambia but many other low-income countries. Reviewed literature in Zambia has mostly looked at health seeking only for single phenomenon and care providers. Other studies, which have been specific on HIV/AIDS, focussed on issues of participation and involvement of PLWHA, stigma and discrimination, voluntary counselling and testing and other general needs of PLWHA.

The research described in this article utilises several types of qualitative methods, triangulated to help increase data quality and reliability. In-depth interviews, focus group discussions, and participant observation of two PLWHA and an end-of-study mini-workshop meant to help derive data from the core research constituent assisted in shaping the research toward desired goals. The breadth and depth of the study (multi-sited, covering 6 towns with varying demographic settings and sufficient sample sizes) involved purposely selected participants, based on the main theoretical model of Kleinman (1980) and reasonableness of the duration of the study ensured that a holistic picture was developed for the research.

This helped to create an in-depth appreciation and basis for deriving explanatory concepts and ideas which affect and influence pre-selected pathways to health-seeking and
adopted care providers by PLWHA. Carer profiles ranged from the formal biomedicine sector, traditional healers, faith based groups to family and peer support and even self-help itself.

The study examines PLWHA’s opted preferences for health service provider(s), the sequence and matrices of their decision-making and their basis for doing so. Dilemmas both in preferred pathways and their services, as well as perceived or known reasons for not using other services were examined in-depth. Health workers in the bio-medical sector, traditional healers and other providers participated in the study to help understand the options and dilemmas that face PLWHA from the provider perspective.

Factors that affect health seeking patterns, their sustainability, and those that influence choices made were critically considered in the research. Key informants were interviewed to obtain useful insights into policy frameworks, their basis for decision-making and sources of their information in their policy interpretation and definition processes, with respect to PLWHA in a pluralistic health setting.

This study argues that the scarcity of adequate information on plural medicine in Zambia, particularly when seen from the perspective of PLWHA has an adverse effect on the quality of information, decisions made based on the under-researched phenomenon or information and therefore the health outcomes of PLWHA. Among other possible benefits of this study, it’s expected that informed interventions will be initiated and that government health reformists will deeply reflect and consider the findings of this study.

Also, formal and informal health systems and their providers will be expected to learn from PLWHA’s perspectives, and that local communities working within the framework of health systems and livelihood will better their care practices and prioritise the needs of their clients, especially PLWHA.
3.3.0 Background

According to the UNAIDS 2004 report on the global AIDS epidemic, in year 2003 alone, 5 million people became newly infected with HIV, the greatest number in any one year since the beginning of the epidemic in 1981 (UNAIDS, 2004). The number of people living with HIV continued to grow, from 35 million in the year 2001 to 38 million in 2003. Of those newly infected, 3 million are from sub-Saharan Africa – 2.2 million died (75% of the 3 million globally that year). AIDS killed almost 3 million people as already reported in UNAIDS (2004). Currently, there are several initiatives meant to significantly reduce the impact of the AIDS epidemic, namely the 3by5 initiative, the Global fund for TB, AIDS and Malaria, the Millennium accounts as well as debt swaps for AIDS interventions in developing countries (UNAIDS, 2004) and MDG (2003). All these are being implemented worldwide, in areas experiencing epidemic proportions of disease burdens.

The report further shows that although sub-Sahara is home to just over 10% of the worlds population, 25 million of PLWHA are in sub-Saharan Africa (almost two thirds of all people living with HIV); with only 7% of people who need antiretroviral treatment in developing countries having access to ARV’s, which was estimated at 400,000 people at the end of 2003. Without antiretroviral therapy, the UNAIDS predicts a drop in average life expectancy to below 35 for Swaziland, Zambia and Zimbabwe. In sub-Sahara, an estimated 4.3 million people need AIDS home-based care but only 12% receive it (UNAIDS, 2004).

Several studies have clearly documented the multiplicity of options for health seeking and variation in models of health systems themselves. Kleinman (1980) has suggested that in looking at any complex society, one can identify three overlapping and interconnected sectors of health care: the popular sector, the folk sector and the professional sector. Each sector, he asserts, has its own ways of explaining and treating ill health, defining the healer and patient, and specifying how healer and patient should interact in their therapeutic encounter.
Strathern and Stewart (1999) also explain, “biomedicine and indigenous systems are often assumed to be in conflict with another. Indigenous practices may be seen as blocking or interfering with the progress of modern medical treatment regimes. But various contexts exist in which introduced and indigenous medical practices meet different requirements for the population in question. In this instance, the two systems compliment rather than in counter each other. Further, Strathern and Stewart explain that individuals make decisions when selecting a particular form of medical treatment.

These decisions maybe influenced by a consideration of the treatment offered, the relative costs involved, or the cultural, traditional, religious and political environment in which the person lives. Although there is a universal basis of experience as a biological phenomenon, the perceived causes, treatment, and consequences of the injury or illness are greatly affected by culture.

Recent projections from African finance ministers, when they met in Abuja during a conference organised by the Economic Commission for Africa (ECA) indicate that the “HIV/AIDS epidemic may cut approximately one percent from African countries’ gross domestic product growth rates”. There are fears that the pandemic could significantly diminish the prospects of realizing the economic expansion necessary to reduce poverty on the continent. The ministers stressed that additional resources were urgently needed to support Africa’s efforts in confronting HIV/AIDS and urged the World Bank and the International Monetary Fund (IMF) to consider revising the eligibility criteria for assistance to middle income countries afflicted by the AIDS epidemic (The Post, 2003).

According to DeRose et al (1999) trends in food production are the waste in Sub-Saharan Africa, where per capita food production has decreased slowly but relentlessly in recent years. Correspondingly, Peter Piot and Per Pinstup-Andersen put it as such: “when you ask people living with AIDS in rural communities in the developing world what their
highest priority is, very often their answer is food. Not care, not drugs for medical treatment, not relief from stigma, but food." (IFPRI, 2002).

There is a growing body of evidence showing that food, poverty, and HIV/AIDS interplay. In these settings, household incomes usually reduce and the burden of care shifts to society’s weakest and most marginalized; especially women and girls and the core productive co-hort of adults, everyone is then impacted on with AIDS (USAID, 2003). Food security is thus a factor in both mitigation and prevention. Not all AIDS victims will receive antiretroviral therapy, but all can receive nutritional support, as a way of buying time”, states the USAID report.

In Zambia, the 1998 estimated HIV prevalence rate for the entire country was 19.7 percent. In urban areas, the prevalence rate among 15 to 49 years olds was more than 28 percent; in rural areas it was 13.6 percent. This shows that Zambia is undergoing one of the worst HIV/AIDS epidemics in the entire world. (CBOH, 1999). By 1999, it was estimated by the CBOH that 1,009,000 persons were infected with HIV in Zambia while only 9 percent of these had actually progressed from HIV to AIDS.

However, Zambia’s prevalence for HIV has decreased, based on more recent data on HIV testing. National data showed that of the individuals tested, 16% were HIV positive, with women more likely to be HIV positive than men (18% and 13%, respectively) while HIV prevalence was more than twice as high in urban areas than rural areas, (23% and 11%, respectively) as seen from recent data (ZDHS, 2003).

In the current study, four of the 6 research sites (towns) were from the copperbelt province, the main mining region of Zambia. Although visible diversifications are being promoted, like agriculture and tourism, copper mining is still the main stay of Zambia’s economy (now being extended into the North-Western copper-rich province). Copper mining accounts for 95% of export earnings and contributed 45% of government’s revenue during the decade following independence.
Zambia’s population stands at 10.3 million people (CSO, 2000). The copperbelt and Lusaka provinces are the most urbanised and densely populated provinces in Zambia (ZDHS, 2003). Also, it is noted that apart from being economic zones, mining settings often breed high HIV rates, several studies cited by Desmond, Allen, Clift, Plummer, Watson-Jones, Ross, et al (2005) in sub-Saharan Africa have demonstrated (Desmond et al, 2005) citing (Meekers, 1994; Mosha, 1995; Obbo, 1993).

For the Zambian socio-economic scenario, unpredictable copper prices have led to unstable mine operations, with different investors divesting and re-investing in various mines, thereby affecting expansion plans, national income levels as well as disrupting local socio-economic livelihoods. Most retrenchment mineworkers end up living in the poor outskirts of the mine facilities, with little or no source of alternative disposable incomes. A recent Christian Aid report discusses issues of short-term poverty in Zambia as being a permanent condition when HIV is present; the report also documents how disrupted economic activities around the mining communities increase both poverty and HIV/AIDS (Thomas, 2004).

### 3.4.0 Research Setting

The research was conducted in 6 different towns namely Lusaka (the capital city of Zambia), Livingstone and 4 other Copperbelt based towns namely Ndola, Chililabombwe, Lufwanyama (rural) and Kitwe.

### 3.4.1 Research Objectives

Specifically, the objectives of the study were to:

1. Explore and comprehensively describe the health seeking patterns and matrices as seen from the perspective of PLWHA and/or TB pre-selected study sites of Zambia.
2. Gain an in-depth understanding of the different health service provider perspective and experiences in meeting the health needs of PLWHA and/or those with TB in pre-selected study areas of Zambia.
3.4.2 Study design and methods

The study was conducted during the period from July to December 2004. The study was exploratory in nature, employing mainly triangulated qualitative methods to achieve the afore-stated objectives. Thirty-five (35) in-depth interviews and 15 Focus Group Discussions (FGDs) were conducted. Specially designed semi-structured interview guides were used to collect data from purposely-selected respondents. Additionally, two purposely-selected participants were observed in an ethnographic sub-study for a period up to 3 months. At the end of the data collection phase, a study workshop involving 16 participants was convened and co-facilitated by the main researcher to discuss collaborative possibilities in multi-health services to PLWHA. In the workshop, similar categories of respondents were invited and the main researcher presented some of the ‘preliminary findings’ and other issues which were identified in the study as either enabling factors or disabling for networking and partnering purposes. The participants used different methods, which included group work in homogenous settings as well as plenary sessions to express and present their views. While there were no intentions to generalise the findings, critical results and the repetition of responses helped to document common experiences and phenomenon being studied to be more useful for stakeholder reliance. On average, about one month was spent in each area, allowing for study preparatory works, data collection, data cleaning and transcription works, all done in liaison with the research assistants.

The main researcher conducted all the interviews himself at all times, with assistants being available (one male assistant was used in the 4 copperbelt districts while 3 others assisted in Livingstone and Lusaka) at all times, except during the ‘participant observation’ methodology. For participant observations, short notes were taken immediately after leaving the study site and/or subject and more detailed ones written afterwards each evening.

Depending on the nature of the respondents, different languages were used to collect data (the researcher and assistants were able to speak and write in at least 3 of the local
languages and at most 5 main different languages spoken by most of the respondents in the research sites, (namely, English, Bemba, Nyanja, Silozi, and Tonga). All members of the research team had lived in particular towns were the study was being done and were competent in using local languages, having lived for more than 15 years in those towns, using local languages.

The most common language was used, with the ‘minority’ speakers of other languages informed periodically about the other discussants contributions. Although minority speakers felt that they had difficulties using the most common language, they understood most of the discussion elements ant its process. The research assistants involved were three social workers and one teacher and a psychosocial counsellor; all had appreciable experience in doing research works related to HIV/AIDS but needed additional support to enhance their skills in conducting qualitative studies.

The researcher spent one week on a pre-study training of research assistants (mainly in qualitative methods) before and during the pre-test process, before the study commenced. Special care was made to avoid working with assistants who may fall under one of the sampled categories-The study had possibilities of generating ‘confronting views’ especially between the bio-medical group and the traditional healers. The researcher and the assistants lived within easy reach of each other, an aspect that helped us provide time for discussing and reconciling data from each day’s sessions.

When conducting the focus group discussions and interviews, only key words were mastered and questions phrased accordingly by the researcher. The FGD’s held in Kitwe were used to help pre-test the interview guides and illuminate on contextual issues among all the categories of clients and service providers. Both interview guides for use among PLWHA and other key informants were field-tested with respondents who possessed similar characteristics; all these being in sites were the main elements of the study would not be conducted. Where
necessary, appropriate changes were considered before the research instruments were finally used.

The main researcher visited all venues for appropriateness for each category of respondents. The site for the end of study mini-workshop had to be a neutral venue, since it involved different service providers as categorised in the research process who already had perceptions towards each other’s profession and its acceptability (lessons learnt from pre-test sessions).

The local networks of Zambian People Living With HIV/AIDS (NZP+) the bio-medicine associations (Medical Council of Zambia), Zambia Nurses Association (ZNA), the Central board of health (CBOH) and the traditional healers and practitioners associations (THAPZ), among others, either helped coordinate the administrative processes of identifying contact persons in each district of study and/or provided respondents.

Based on the inclusion and exclusion criterion (despite working with gate-keepers) the main researcher and his assistants ultimately decided as to whom of those identified would be invited to participate. Some individual respondents from the focus group discussions were invited to participate in subsequent in-depth interviews if it was felt necessary by the research team, hoping they may provide more valuable, additional responses. Other in-depth interview participants were enlisted irrespective of involvement in focus groups.

For the FGDs, the size ranged from 7 to 10 persons. The PLWHA were put in FGDs which were gender-specific, while health workers and traditional healers had common focus group discussions irrespective of their sex, since that aspect seemed not to influence levels of openness and freedom to discuss issues which may be considered personal or uncultured (work experience of the main researcher in liaison with health workers, healers and PLWHA led to this decision).
The inclusion criteria for HIV+ participants were:

- They should belong to a particular support group in the study district;
- They should be living “openly” and/ or within ‘shared confidentiality’, at least in the support groups they belong to;
- For PLWHA, They should also not be too ill to participate (e.g., having full-blown AIDS and being bedridden);
- At least aged between 25 to 49 years old

For health providers (both bio-medical health workers and traditional healers), experience had shown that there was need to look at the FGD with greater flexibility- all respondents were grouped together ‘as professionals’ irrespective of age, gender or specialisation (e.g., health workers included nurses, clinical officers, pharmacists, environmental health technicians; while traditional healers included herbalists, bone-setters, diviners, spiritists and witch finders)- some had two or more specialisations.

There was a participant categorisation challenge, especially in instances where PLWHA belonging to a support group were health workers and church leaders. One respondent was a pastor and belonged to a support group as a PLWHA. These overlaps were expected, as the model Kleinman (1980) provides for that, with another example where we had a health worker from one local hospital, was also a member of a community based support group for PLWHA and leader in a faith based group.

3.4.2 Data collection

For each interview or focus group discussion, permission to use a tape recorder was sought. The use of note books and tape recorders was explained and permission obtained from each individual participant for their use, even for FGD’s. The research team was not allowed to use tape recorders in 3 particular FGD’s and 10 interviews (lack of consent from
one participant was enough to discontinue the use in FGD’s); reasons for disallowing tape recording were (due to group variations in levels of openness; still unconvinced with how the raw data would be discarded and previous experiences of non-researchers who visited PLWHA groups and abused the hospitality extended to them in the past through extensive publicity of photos and audio-visual data collected). All data transcriptions and translations were either done in English or another local language and later translated into English, if necessary.

Privileged information was safeguarded, to which the confidentiality and consent criteria were strictly adhered. Coded names (which were serially linked) instead of true ones were used to maintain anonymity of respondents. Questions from participants were answered before commencement of the study. The researcher secured data collected. Respondents were informed that they could still withdraw the information if and when they felt like so at the beginning, within the session or at the end of the interview or discussion, even if they had earlier consented and signed to grant permission.

The researcher used a personal diary where personal perceptions, emotional reactions, and feelings about what the participants are saying were kept. Verbatim reports were created from each day’s interview and discussions held every evening, with core issues being presented to the informants for their validation before concluding the day.

Subsequent interviews were improved upon after re-listening to tapes, re-reading notes, diaries and discussing the data as a research team; as the main researcher and assistants met and summarised the impressions of the meeting(s), as part of the quality control process for the collected data and also for the purpose of informing subsequent interviews and discussions to be conducted.

The collected data were transcribed and typed on a regular basis (research assistants for interviews and main researcher and one other assistant for FGD’s. The data was then coded, categorised and analysed using NUD*IST 6 software (QSR International Pty, Ltd, Melbourne, Australia) as discussed by Barry (1998). The data indexing was done with
reference to the identified thematic areas related to the research questions, study objectives, and theoretical framework (Klein man, 1980). Later, printed copies of the summaries and categorised data (which included sub-categories in some instances) were manually organised and further coding and categorisations done, to aid the interpretation process.

Citations were also coded in the computer and used appropriately to ensure their relevance in various thematic areas and contextual clarity of the core statements made. Indexed categories were created and the data coded on the basis of each paragraph. Construction of narratives, stories and citations in local languages (to be translated into English) were also done.

3.5.0 Results

The findings of the study have been put under headings, though there are many cross-cutting issues and responses, whose presentation and discussion is overlapping, just like the subject of investigations itself. This aspect applies to all irrespective of the categories of respondents, given the nature of the topic, which was documented by the research team with the discussion following a similar pattern. It should be noted that 2 of the respondents for in-depth interviews were categorised as ex-TB patients (they belonged to the ex-TB patients support groups).

These particular ex-TB patients ‘turned out to be’ PLWHA, (in addition to their TB status) who did not want to be identified as the latter but were willing to be interviewed separately after the ex-TB patients FGD. Both of them were rural based, from places where the research team and its gatekeepers could not identify existing, visible support groups or individuals who could be said to PLWHA, considering the study inclusion criteria as well.

The dilemma of reporting findings based on a setting with overlapping service providers, as well as clients seeking multiple care services entails that putting definite,
literally designed categories for reporting findings and discussing them may be very challenging- an attempt has been made to do so despite this perceived limitation.

3.5.1 Health-seeking ‘Triggers’ and diagnostic dilemmas

Several participants categorically explained how they came to begin to feel that they needed more help. There were different experiences based on individually felt bodily manifestations of ailments and/or those of a spouse, sibling or other sexual partner.

As one narration of a male participant (ex-TB patient) in a focus group discussion put it this way:

“The problem started in 1996 with my first wife. I had herpes zoster (which later got treated and I got cured) and my wife was pregnant; she started suffering from kidney related problems in 2001; I took her to the hospital where she got admitted and later was discharged and referred to another special hospital, where we were told the disease had no medicine. Later, my wife died and no one told me the truth about her status. In 2003, I re-married but my second wife also died, after complaining of a headache- I was later diagnosed with TB and was put on treatment…”

The advice of closely respected peers and relations, when combined with lived experiences of personally coping with diseases or helping others cope seemed to have an emotive effective which prompted PLWHA to consider their own health critically. Most participants agreed that the death of a close relation had a ‘trigger effect’ in initialising the quest for diagnoses and treatment.

Providers were also asked to share their experiences in diagnosing their clients and how they finally arrived at a particular conclusion to categorise illnesses as HIV and/or TB. There were varied explanations and differentials even in carers in the same category of health service provision as defined in the theoretical framework.
While some involved specifically pre-designed tests of a standard nature, especially in the bio-medical setting, others were completely different, dependent on whether one was consulting a herbalist, spiritist, faith healer or diviner.

Traditional healers seemed to mix up the diagnosis or even the naming of AIDS itself, using the words interchangeably for TB as well, which they referred to as Ntanda Bwanga. The healers had several names and terminologies to describe AIDS and other STI’s or other illnesses similar to them. Words and terms like Kalaye Noko; Kapokota; Akapopo were frequently used by traditional healers in most sessions held for them, both in-depth interviews and focus group discussions.

For faith healers, they explained that they were mainly dependant on ‘the spirit to lead them to the diagnosis’ before they could help any further- not every member of the faith could be shown what the problem a patient has, except the ‘apostles’ as the respondent referred to them. Except for two healers who claimed to have cured AIDS patients (their claims were immediately disapproved by fellow healers in 2 separate focus groups), there was unanimity on the lack of a cure for AIDS but unanimous agreement on the existence of treatment for the related illnesses. A male pastor in an interview also reported that God could cure AIDS patients through prayer.

The area of HIV/AIDS diagnosis seemed to be the domain of the bio-medical sector, as most healers reported that they referred all cases for HIV testing if they realised that the illness appeared to be incurable and had symptoms of HIV/AIDS.

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2 AIDS is called by this name because most of the time when a person is sick (some patients from the urban areas) they tend decide to be taken to their village(s) ‘to die honourably’ under the care of their mothers, or other parents.

3 A disease similar to AIDS; a ‘slimming’ disease that is believed to turn the eyes to a yellowish colour.

4 Swollen Lymph nodes believed to be a result of having sexual contact with a woman who has had an abortion.
Coping with newly diagnosed HIV was seen as a challenge among several PLWHA, some of whom were hurried through the testing procedures, told their results, then the results of partners, in some cases, their partners will have already died. Others were ‘pushed into knowing their own status’ based on that of a spouse who has already died.

One male PLWHA was visibly sad as he narrated his own experiences, which drew the empathy of other group members. In his own words, he reported that:

“…. One day a nurse called and advised me to go for VCT (was counselled and then tested for HIV). This was the time the nurse revealed to me that ….. ‘we tested your wife before she died, her condition was not good.’ Later she told me that my own results were also HIV +ve, and that I should look for money and start taking ARV’s.”

PLWHA reported that the post diagnosis period seemed to be the worst, with some having to wait for a long time, documented as between two to four months before they could be put on treatment or other forms of support in home care programmes and hospitals. This ‘long wait’, coupled with the knowledge of their diagnosis, seemed to affect most PLWHA.

Traditional healers, in the same workshop setting also discussed the need for ‘user-friendly HIV testing’ for themselves and asking the bio-medical group to help ‘make it easy’ for them to get tested and receive counselling in VCT centres.

In a workshop meant to discuss possible areas of collaboration among the healers and bio-medics, it was documented that diagnostic equipment and services were not sufficient to meet the increasing need for them from PLWHA and other clients. The experiences of PLWHA respondents in a FGD revealed that while some appreciated the provision of ARV’s, there was limited support for their other needs for post-test counselling as part of a continuum of care, during the treatment process. As expressed by one participant:
“...We need access to nurses to talk about our situation, our feelings on drug reactions, among other things... but if you question them (nurse) you are told, oooohhhhh, so you have now become a doctor, eeehhhh? Treat yourself then!”

[Interview, Male PLWHA].

Another male participant (health worker) in a FGD referred to a phenomenon of there being lack of ‘wellness clinics apart from the usual VCT to ARV route!’

Further probes in the in-depth interviews also showed the psychosocial needs of PLWHA, beyond drugs being administered. There was a concern that:

“Long histories of multiple complaints should be cared for. It’s important to sit us down and discuss, even before the VCT stage, its better to do it early,” reported one male PLWHA in an interview.

Responses from the faith-based position showed that there does not seem to be a holistic policy for VCT in their groups, mostly promoting and limiting their spiritual and social services for members to pre-marital counselling. The need to fill the gap like the foregoing was alluded to in the workshop setting, where it was stated that improving the quality of already existing VCT services was important in the process of helping PLWHA.

3.5.2 In search of best therapy: ‘We have been everywhere!’

When asked to account for their lived pathways to health seeking, especially for the treatment of opportunistic infections, different experiences were shared but the most common factor was the multiplicity of providers who were consulted, for either a single aliment or several manifestations of diseases. Among the main reasons for particular choices of health provider or carer, only one explicitly stated that they had decided on their own to treat themselves on herbal remedies. In three FGD, there was greater consensus that friends and
relatives played a greater role in the choice of particular service providers, with the first preference being that of traditional healers.

There was little disagreement on the understanding that some cases had to be referred to the hospital after realising that the clients were not getting any better. Other experiences involved what was referred to as ‘round-trips to and from’ meaning journeys made to consult healers and the hospital interchangeably, with both providers being equitably visited and treatment obtained from them. However, some participants felt that some healers took advantage of them and were even charging higher fees than the ones obtaining in the hospitals and other clinics.

Among respondents who preferred traditional healers, their main reasons were the low cost of services, greater attention and support, more time spent per patient seen, and what was described in a FGD as ‘understanding our situation.’ Looking at providers from a vertical perspective, it was agreed by several participants in at least three of the FGD’s that clinics provided better services than hospitals, based on experiences related to lower fees and more attention being granted per visit made.

On home-based care (HBC) services, a concern was registered by PLWHA (in two FGD’s and one in-depth interview) regarding the need to expose most carers to new knowledge and skills on the best caring practices. This was emphasised as a need because most of the carers were ‘retired nurses’ who may not have been exposed to more recent ways of thinking and working in the field of HIV/AIDS, especially when it came to treatment.

As one participant explained,

“…These nurses who mostly help us in the HBC are retirees; the latest drugs for HIV treatment elude them....”
The sense of feeling helpless after having undergone multiple sicknesses and not being cured was acknowledged by various PLWHA in several focus group discussions, with some clients having even gone to neighbouring countries in search of what was perceived as more effective treatment, especially where it involved traditional medicines. As one participant put it, “I have gone through different diseases, like coughing, and fever. This was coming several times, I could be okay for few days but it was reoccurring; I have even been to the Congo..........” [Ex-TB Patient, FGD].

One respondent ended up being laid off from employment after over-staying at home without renewed sick leave. Some respondents reported that they did not prefer any of the providers but relied on themselves and their knowledge of herbs from books and friends, with the hospital costs being the greatest hindrance to their choice of formal care. Most respondents did not feel that they received enough help from relatives, as one PLWHA reported in his own words that ‘relatives only help when you are very sick!’ Another ex-TB patient gave a full account of his lived experiences and dilemmas with the diagnosis process, the different health service providers who assisted him and the critical pathway to accessing services in a FGD.

As he put it, “...I sold all my property in order to pay for all my treatment with traditional healers in Zaire. I was diagnosed and then told that I had been bewitched. I came back from Zaire without money; I was finished. I then started thinking carefully to say, why should I be going to traditional healer? I had different herbal remedies in my house, which did not help me. One day, I saw a vision, and then I felt that I just needed to pray. I was so thin, weak and lonely. I went to see the local priest to repent all my sins. I remember having had sex with many different women, I knew myself very well. When I told the priest that I was very sick, he
felt sorry for me and gave me money to use to pay for hospital expenses, including an X-ray. *The X-ray was very bad…*

This narration documents the sequence of health seeking and its pathways, with each provider and the client having a particular explanatory model of what the illness and problem is all about.

There seemed to be different explanations to typologies of coughs, which were discussed by ex-TB patients. A particular type of cough was referred to as “*Ichifuba icha Amankowesha*”⁵. Other terminologies used by the traditional healers for typologies of coughs included *NtandaBwanga*⁶. The other type of cough was acknowledged as the TB related one which can be treated and cured at the hospital. This was generally the view held by all different health service providers and their clients namely the bio-medics, traditional healers; ex-TB patients support groups and those of PLWHA. As the healers in a FGD it was expressly said that:

“This Amalwele yantambi, ba hospital tabaishiba”- Ifibanda nafifula sana!  . Ifiwa efikoselepo, Bantu baleipyan⁷.

In an FGD of health workers, two respondents summed up the experiences that their own relatives and friends have had, as well as what their own clients reported experiencing ……

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⁵ A type of cough which was said to come as a result of someone—especially a man sleeping with a woman who has not been ‘cleansed’ after the death of a spouse, or a consequence of a man sleeping with a woman who has had a miscarriage, abortion or is menstruating. Diseases that were associated with promiscuity and adulterous behaviour by husband or wife, which resulted in the child becoming sick and thin or man developing an unexplained, prolonged cough.

⁶ Disease or illness that is mysterious and hard to treat or diagnose even by witch doctors themselves. This word was commonly used because they could not understand the aetiology of some coughs, which other healers felt could have been TB. Therefore, they associated it to witch craft.

⁷ ‘Traditional or cultural diseases’ diseases cannot be handled by the bio-medics; doctors cannot treat because they do not understand them, they should refer to us! Many People are spirit -possessed and because they avoiding ‘cleansing’ and as a results they are dying and killing others due to failure to be traditionally ‘cleansed’ in the proper manner.
“Some PLWHA waste time by going to traditional healers, while some mix the herbal remedies with bio-medicines. In the morning, they will be at the clinic and later in the evening, they will be with a traditional healer. ...Some will start with healers and when they are getting worse, then they come to the hospital.”

Another female health worker (FGD) reported that:

“Most client see traditional healers and us health workers in a sequence. When ‘you’ go to see a traditional healer, you maybe made to dance and you feel tired but the next morning, you are at the clinic!”

While referring to experiences of others, some appeared to actually refer to their own experiences when they visit traditional healers, as health workers. Traditional healers confirmed having treated several health workers and their family members on several occasions. Clients who belonged to faith-based groups were also reported to have visited healers, except that, as it was reported:

“They don’t want their priests and pastors to know they are coming to see us, so they end up coming very late in the night when they could have easily come during the day....”

[Interview, male Traditional Healer].

3.5.3 PLWHA and their preferred health service providers

When asked to outline their basis for preferring a particular health service provider to another, PLWHA have different explanations for the choices they had actually made in their lives, mostly shaped and influenced more by others than themselves. The use of multiple health services, provided by both traditional healers and the formal bio-medical sector, was common among PLWHA.
There was no specific pattern observed as to which one was more preferred than the other, although different clients preferred one to the other depending on their socio-economic position, spirituality, cultural orientation, and the influences of their peers, relatives, and spouses. The disease and the actual stage of the disease appeared to be great determinants for which services to access.

A participant in a discussion explained the context of being everywhere:

“We have challenges when faced with opportunistic infections and one has to move from one provider to another. We have been everywhere, through everything! The healers will do their part, the hospital takes over at some stage- but when it comes to TB, the hospital takes too much time to detect TB.”

[Interview, Female PLWHA].

For participants who had accessed TB treatment with the traditional healers, they reported that it took less time for healers to detect it and the treatment did not take too long. Even for HBC programmes, which are perceived to be community based and more accessible, participants in an FGD agreed that it took too longer to be registered and then begin to access services.

One male PLWHA reported:

“It normally takes up to three months to get registered into the programmes and start benefiting. By the time they are included, some will have already died- there is no early response in the HBC system.”

In several focus groups, it was generally felt by PLWHA that it helps to have early diagnoses; access to treatment, and adherence to prescribed treatment regimens both for TB and HIV/AIDS therapy. In explaining the dilemmas identified in accessing services among healers and the bio-medical providers, one participant was quoted as having said that:
“Can a traditional healer give you [a] blood transfusion? The answer is no! but even if we want to rely on hospital services, they are not only expensive but [also] limited facilities for CD4 count, viral load checks, and for the drugs, you pay not less than K50, 000 (about 10USD) per month for a dosage of combination therapy…”

This seemed to have been a generally accepted phenomenon in the group, with most participants contributing that each provider had their own comparative advantage as well as disadvantages.

Ex-TB patients had similar experiences when it came to making choices for providers. One respondent in an in-depth interview expressed less confidence in the potency of some herbal remedies, which had been recommended to her.

“When friends of my relatives saw that I was sick, they had advised her-my mother, to use herbal remedies to treat me…” reported a female ex-TB patient. In this particular case what is noted is that the sequence of advice and recommendations maybe long, the treatment option being reinforced at several categories of influence before the ultimate decision is made, ‘from friends to relations then the mother’s final action’ seals the patients need for the treatment.

Other respondents, both in interviews and FDG’s for PLWHA, disclosed that when very ill, the likelihood of being consulted was minimal, with patients being taken anywhere and everywhere in search of what could work best for them.

In the directly observed therapy (DOT) for the treatment of TB cases, a health worker discussed the need to involve traditional healers in the treatment support process, since they were the patients’ own choice of preferred health system.

3.5.4 The food-factor in health seeking by PLWHA

In all the triangulated methods used for purposes of deriving data to illuminate the challenges faced by PLWHA in their quest for therapy, one theme which has repeatedly cross-cut every discussion has been the issue of food. In the interviews, (more often than not)
clients, without being prompted, mentioned the food factor in all the related discussions, especially with regard to treatment of TB and HIV/AIDS. Food was mentioned repeatedly as the single most important basis for initiation, continuity and possible stoppage of drug intake (both for anti-TB drugs and ARV’s) in all the towns where the study was done.

For PLWHA, having to decide whether to belong to support groups or remain in homes to be visited and provided with food supplements was a challenge. In some HBC programmes, to which some sampled participants belonged, there seemed to exist some care structures that were perceived as being inflexible. This was because of their inability to allow for provision of similar services for home-based PLWHA and those who form and belong to support groups, regularly attending group sessions away from home.

As a whole group in a focus discussion highlighted their dilemmas, saying:

“Once you get into the support group organised by the HBC, you are excluded from the food scheme given in communities- therefore, people opt to go back to the homes and not be members of the support groups; people do not eat information.”

[Male PLWHA, FGD]

An in-depth interview with an HBC provider disclosed later that the reasons for excluding the PLWHA from the food distribution list was mainly because they (support group members) were considered to have benefited from food supplements which were cooked during their sessions each day at the centres.

In referring to the dilemma of being excluded from food supplementation, one male PLWHA respondent, in an interview, stated that:

“…. Before they can provide you with food and other help, they want you to really look sick and in need. It’s like you still need to do something in order to confirm your HIV +ve status by behaving sick.”
The foregoing phenomenon was said to be common to almost all PLWHA in the communities they live, which are serviced by different HBC team, most of whom are faith-based. Irrespective of HIV status in some cases, it was reported in at least two FGD’s that completion of TB treatment might also mean that one is removed from the list of food supplement beneficiaries.

As one male participant explained his own experience in an interview, before he joined the support group:

“when you finish your TB treatment, you also get removed from the food distribution list. They say we are many in the community. If there is less food, for us all, why are they still recruiting orphans and vulnerable children to receive food?”

Another female respondent, later in a FGD stated:

“When you gain weight and look well, you won’t get food; home support visits to you are either removed altogether or reduced.”

The food factor appeared to have been the most emotive aspect in several of the sessions held, both for in-depth interviews and FGD’s. A female group discussion (who were members of support groups) had another dimension to highlight regarding their vulnerabilities in relation to the food needs.

They expressed deep concerns for their own situation and surrounding circumstances, which affect their daily lives. As they explained:

“The HBC feeds us here at the centre when we come, but our children remain home having nothing…most of us are widows. This hunger can drive us into all sorts of life-styles (mu bulalelale)\textsuperscript{8} to help survive as HIV +ve women, it’s not easy.”

They reported the food issue with visible agreements being emotionally expressed. Food insecurity seems to be the very reasons why some respondents (PLWHA) reported that

\textsuperscript{8} Having multiple sexual partners (bemba terminology for sexual promiscuity)
they had even liquidated their land assets to get some money for food. In expressing their willingness to earn their living, the women in their FGD explained that:

“We may be sick but we can work and feed ourselves—we have no fields to grow food, all were sold...we need to pay money to rent fields in which we can plough in each rainy season.”

From ex-TB patient’s perspective, food was considered critical in their quest to help to increase adherence to TB treatment through the DOTS strategy. In an FGD (rural setting) they expressed their limitations in reaching out to help TB patients, reporting that hunger was one of the reasons for clients stopping to take the TB drugs, that...

“The food factor is a common problem—we have buried many clients prematurely. We can help with their house chores but if we can’t feed them, they remain helpless.”

When prompted to list a catalogue of things that they felt would improve the livelihood of PLWHA, the health providers’ and clients’ workshop reported, among other things, that nutrition was highly prioritised in the ‘needs hierarchy’ and where poverty was mentioned, it related mainly to food poverty. Food poverty was seen both as a primary and a secondary barrier to effectively referring clients between the different models of service provision.

For traditional healers, their encounters with PLWHA and other clients provoked a feeling of both helplessness and hopelessness (tatukwete naifwe ifya kulya pakutila tupele abalwele, elyo tatwakakwate) when it came to providing food to those were brought sick and were from poor families. The traditional healer’s dilemma was that some of the herbal remedies they gave their patients who were PLWHA increased appetite but in the absence of food, the treatment would be incomplete. Healers viewed food as part of the treatment, which did not make things easy when it came to treating clients, most of who were said to be poor.

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9 We do not have food to give to our patients now, and we are not likely to have in the near future, either (English translation of bemba)
As one female traditional healer described it in an interview:

“Our patients come from very far away, I do let them stay in our home but the problem is related to food. Some clients come without money while others promise to pay only when they get well.”

Helping their patients by giving out their own food was said to have adverse implications on the healers and their families, making them poorer. A Christian Aid study in the Copperbelt province cited a key informant as stating that “poor people get HIV and become poorer. (Thomas, 2003). For people living with HIV/AIDS, one of the leaders of their national network of Zambian people living with HIV/AIDS (NZP+) acknowledged that:

“for those members not taking ARV’s and are not going to afford them for consistent consumption, we encourage the use of herbal remedies- they can also see traditional healers where appropriate- you see, these high costs of tests and treatment adversely affect our poor members in the network.” [Interview, Male key informant NZP+].

3.6.0 Discussion
The numbers PLWHA are still on the increase worldwide, with annual increases in those newly infected still high despite several efforts to fight the epidemic. Therefore, there will always be the need for providers to care for PLWHA, in the bio-medical care sector, traditional healers, and other practitioners.

The theoretical framework by Kleinman, which has been extensively used in this study, may have focussed the scope of the study to a pre-determined categorisation of health providers. The selection of respondents from support groups of PLWHA may have had some influence on group responses, since they may have had ‘group-led’ views on particular issues being discussed. The findings also confirm that the health systems and care-seekers categories (as outlined by Klienman) are not linear and some health service providers or PLWHA themselves may also belong to more than one category.
This study has attempted to demonstrate that the clients’ perceptions and those of their peers, relatives, workmates, and others they interact with affect their decisions regarding which services to access and at what stage. Janzen (1978) discusses the role of therapy managing groups when it comes to supporting clients- these, he explains, play a brokerage role between the sufferer and the specialist, irrespective of model.

Most PLWHA were also concerned about the lack of visible, additional support beyond and apart from VCT services and help related to ARV’s treatment. It was felt that the bio-medical setting did not meet the needs of PLWHA who may fall outside the VCT-ARV sphere, as most were not able to pay for the expensive, though subsidised treatment, more so, with the pre-ARV tests being beyond the reach of many PLWHA. The absence of this continuum of care beyond these formal stereotypes of organising counselling and testing services seemed to affect and limit alternative care mechanisms to support clients who tested positive and did not yet need to be on ARV’s or those who could not afford them.

Several experiences were shared on challenges faced by PLWHA, as seen from the provider perspectives. The differentials, both within sectoral providers and among the others, seem to have added more dilemmas for some PLWHA, while it appeared to have provided more options for others, who saw variety to mean their span of choice making had increased.

TB and HIV diagnosis was explained differently among traditional healers, while biomedicals had a common model based on rigorous laboratory examinations, clinical diagnosis and formal treatment (cure line of drugs for TB), making ARV’s available for opportunistic infection treatment and immune boosting. While healers were said to diagnose TB early enough and treat it within a period of not more than 4 months, the bio-medical sector had treatment protocols which some traditional healers perceived as being too long, taking up to 8 months.
PLWHA also felt, in some situations, that it took too long to be attended to at the hospitals as well as what they described as ‘the long wait’ to be enlisted by HBC teams. The herbal treatment remedies for the healers were said to have been shorter and perceived to take less time to arrive at a cure. For the hospital bio-medical treatment, it was said to take longer due to the pre-determined standard diagnosis and treatment procedures.

Faith groups saw themselves as one of the ‘last resort’ providers as clients exhausted all alternatives for therapy and then ‘turned to God.’

It appeared that most healers did not distinguish between treatment and cure, when it came to the management of HIV/AIDS, emphasising that they told their clients that ‘there is no cure for AIDS, while others preferred to refer to HIV by another name to stop their patient worrying, it was reported.

Most PLWHA and TB patients described their health-seeking pattern as either specific to one model (either self treatment with herbal remedies, traditional healers, or bio-medical carers). Prior to deciding on a specific provider themselves, there were several examples of ‘journeys in health seeking’ which made them move from one provider to another, aided by the advise of either friends, relatives, peers and others in their circle of influence and decision making. Some PLWHA obtained bio-medical diagnosis, others went to see their faith healers or self-treated, while still others felt that their disease was as a result of witchcraft and they immediately sought help from traditional healers.

Most of the round trips among different providers appeared to have been costly, forcing some to sell their properties in order to better finance both their health seeking journeys and the resultant treatment. Based on the comparatively more acceptable explanatory model, the care-seeker or those who influenced them explained the aetiology of the illness;
the preferred provider would be a particular one, for that moment, subject to changes when it was perceived that the client was not improving.

Some of the ‘round trips’ within a particular care provider model or among different models would entail going to neighbouring countries in search of ‘the truth’ about their illness in order to be treated early, or follow up other peers knowledge of what worked in their particular situation. Janzen found similar settings; especially where clients felt that witchcraft was responsible, then they would immediately seek specific help from healers alone. It’s the explanatory model, which matters the most.

There was a sense of ownership among some providers, with both traditional healers and bio-medics referring to the other providers as ‘delaying our patients’ when a client is being treated elsewhere. The question as to ‘whose patients are they’ may affect client’s freedom to go for alternative providers after treatment failures or the need for additional help. The presence of visible tattoos made by traditional healers on a PLWHA would attract more scrutiny and an open rebuke from most bio-medical carers, for having ‘wasted time’ going to see traditional healers.

The resulting effect of care providers influences and feeling of ownership, while not explicit, was also seen among faith groups whose members preferred to see their traditional healers in the night to avoid being seen by their fellow faithful and church leaders- as going against the teachings of their faith to seek healers help instead of their God.

However, one of the leaders for the traditional health practitioners association in Zambia was supportive of those clients who use multiple options, saying: ‘those who try both are better than those who go for single therapy.” The sense of being ‘everywhere’ was not limited to clients but healers who became ‘clients’ also. Most traditional healers reported going to the hospital when ill, with only a few stating that they had seen fellow healers the
phenomenon of healers not ‘trusting each other has been known to relate to possible jealousy or suspicion that the other healer may weaken their powers.

The cases of self-treatment were not only common among PLWHA, but also the biomedical providers. PLWHA self-treated partly due to their faith convictions and the teaching of spiritual leaders; dissatisfaction with other provider or access related challenges they faced. Most bio-medics reported ‘applying first aid’ on themselves. Several healers reported seeing fellow healers or coming to the hospital depending on the explanatory model behind their illnesses. Among the faith groups, cases or referrals were common, as most home care programmes were managed by faith based groups.

Some faith groups had internal referral systems to their ‘superior spiritual priests or chief apostles’ in other towns if and when they failed to treated their members spiritual healing. Most PLWHA felt neglected whenever they were referred to another provider or whenever they could not reach their destined points of referral. This was due in part because they lacked the means to access the services in the place of their referral.

Even just going to the place was difficult; raising the issue of whether or not, (the poor, as most PLWHA stated they were) could afford to be referred to other providers without a clear mechanism as to their capacity to access those services. Most PLWHA appeared not to have the ability to take advantage of the referrals to access alternative services due to expensive ‘gateways to accessing free or subsidised ARV’s and/or TB drugs.

Food was widely identified irrespective of provider model and also by all clients (PLWHA and TB patients) to be one of the single most important aspects in the health-seeking pathway, more so when it came to treatment options and dilemmas. Several studies have documented the importance of nutrition for PLWHA or other vulnerable communities, asserting that ‘poverty fuels HIV/AIDS and that HIV/AIDS can and does fuel poverty in turn.’ (UNAIDS and World Bank, 2001; Thomas, 2004). Having looked at lived realities of
PLWHA, this study may help inform and operationalise ‘the good intentions’ and policies of various agencies involved in food provision as well as drug therapy.

In particular, food poverty, as it is commonly referred to, was reported to have been the reason why PLWHA sold their pieces of land (the very assets they desperately need for long term survival) in order to buy food and meet immediate nutritional benefits needs. The sale of assets by the poor and ill is a common phenomenon when affected by droughts, hunger and starvation (UNICEF, 2003).

These multiple vulnerabilities and consequential impacts on the social structures in entire communities seemed to manifest itself in form of food insecurity and malnutrition. Similar experiences have been reported in Southern Africa (UNICEF, 2003; USAID, 2003; UNAIDS and World Bank, 2001; Thomas, 2004).

Care providers (HBC) who also help provided food supplements and their clients, PLWHA, faced increased impacts of the HIV/AIDS epidemic from several social structures at community level, the ‘food baskets’ have to feed more people, as more Orphans are also factored in. Most PLWHA felt discriminated against when some HBC providers excluded them (those who o belonged to support groups or those who looked well, or had completed TB treatment). While there are other incremental benefits for belonging to a support group (Nichols & Jenkinson, 1991) food therapy should also be seen as important for the immediate survival of PLWHA.

Food was seen as a treatment option in itself, with some preferring it to other services, including ARV treatment. Some PLWHA were fed from support group venues for their meetings, but this was not considered helpful by many who wanted food instead to be delivered to their homes so they could share with their families-other studies and meetings have documented and evolved plans around these nutritional factors, like USAID (2003) and SADC (2002) reports.
For most women, they felt vulnerable, as the possibility to engage in risky behaviours (sentiments of some widows) was high, in order to ‘feed our children.’ Doyal & Anderson (2005) reported in their study of African women in London that the experiences of mothering with HIV were complex and contradictory- the women reported that they had to be everything to the kids, being single mothers. There was a felt need for more food to be provided, even for those PLWHA who were using herbal remedies from healers or self-prescribed ones on the shelves of supermarkets or herbalists. Some herbs were not only immune boosters but also multi-vitamins, which made most PLWHA hungrier and in need of food immediately, which healers were unable to provide. Interviews with traditional healers showed that most of them were in need of food themselves.

3.7.0 Case studies

CASE STUDY A:

Peter is 34 years old, living positively and openly with HIV. His wife is pregnant and due to deliver twin babies soon. Her recent HIV test was negative. The family lives in a high-density suburb of his town, mostly inhabited by retirees or those retrenched from the mining companies and other subsidiary businesses. The family can be classified as being in the low-income group, living on a less than $50 per month budget. They live in an electrified, rented one-roomed house, sub-divided as living room and bedroom. They have communal water well next to their house, shared among neighbouring homes. They live with a little girl, a niece to his wife who helps with several house chores. Peter intends to bring his son from his first wife to join them soon.

Having been diagnosed with pulmonary tuberculosis, he later decided to take an HIV test, which came out positive. Before then, his relations had already gotten worried and were suspecting witchcraft. During his treatment, his first wife is reported to have divorced him, remarrying another man in the village, while he was taken on and care for by his sister. His brother-in-law reportedly chased him away from the same home in the year 2000, when he
became open about his HIV status to the public. Support from his faith based network continued, with prayers and visits.

Peter seemed to be a persuasive, self-motivated person, has pioneered the formation of a network of support groups to help others living with HIV/AIDS. He occasionally escorts people from his network to the hospital for VCT and registration for commencement of ARV treatment. Peter conducts open lectures on HIV/AIDS to outpatients. Peter explains the use of herbal remedies with clarity. He helps refer those who need ARV’s to the local hospital and others to his faith-based healers who promote the exclusive use of herbal remedies. Peter seemed to dwell more on the side effects, cost and other limitations of ARV’s when teaching fellow support group members, with some sense of preference towards use of herbal remedies. The herbal remedies cost less than ARV’s, but were not necessarily cheap to buy.

**CASE B: John:**

John is a 37 years old male, living positively and openly with HIV/AIDS. He is married to a health worker who lives in the same locality, a short distance away, together with their matrimonial children. John previously worked with a mining company upon graduating from the university. He has a history of repeated TB attacks, one of which resulted in him being discharged on medical grounds by employers. The retirement package he got was used to establish some small-scale businesses and bought at least two houses from which he gets rental incomes.

His children seemed to interact fairly well with Peter, discussing issues regarding their school requirements quite openly. Friends and relations frequently visited him, some of whom he considered as dependants, including his wife and children who live in another home. Peter feels he needs to help his wife ‘for the sake of the children,’ the same reason for being together as husband and wife.’ He plays a lead role in explaining his personal experiences with ARV’s to his group members, some of who know little about ARV’s.

He seemed to have a wider collection of other literature and is now stocking other materials on AIDS related issues in one of the rooms. He takes his ARV’s timely with strict scheduling- he has food readily available in his home and makes efforts to cook and eat well at every opportunity. He also ‘reluctantly’ promotes the use of herbs for those in his support group who cannot afford to consistently buy and take ARV’s.

He showed me a small building he owns from which the group wants to start a drug store to sell herbal and other pharmaceuticals which do not require licensing for members and other community beneficiaries who may need help. Later, he asked me to accompany him to the home of a female member of his support group who was unwell, living with her elder sister in the same township.

**3.7.1 Discussion of cases**

The main researcher has no previous experience in participant observation. He learnt how to do field research by doing field research with the two male PLWHA being observed (Bailey, 1996). The two case studies involving Peter (not true name) for the observed person A and John (not true name) for observed person B, helped inform the study and validate some phenomenon which had been discussed but were not seen from lived experiences.
Both persons are HIV positive but living and responding differently; the same disease but varying ways of coping with it. John is a former university graduate, he previously had a good job with the mines before retirement (family lifestyles had to be adjusted considerable when he was laid off on medical grounds), and while Peter was also relived from employment after being too ill beyond the prescribed sick leave days.

However, both have a history of having TB before they knew their HIV status, with varying levels of openness. John invested his money into properties, which are earning him incomes for now, while Peter has no formal source of income, he keeps a dependant, his wife is expectant and he appeared to have many dilemmas on how to sustain them-still he thinks about adding on his son, born from his first wife who is in the village with him.

Peter can be classified as being poor, while John is not- while peter receives fewer visitors, John is frequented by his children and wife who is living separately after discovering that he was HIV positive- but she still needs his support and she comes to ‘see’ him and get necessary supplies for her children- Johns wife works for health service organisation.

The case studies reveal fundamental differences in ‘levels and depth of disclosure’ regarding Peters and Johns health-seeking pathways- these variations relate to what is said in a group setting and what is not disclosed.

Lessons from the fore-going case studies demonstrate that is no such thing as being totally on herbal or ARV remedies- different manifestations of illness may demand alternative treatment, though the index, mostly preferred option may either be herbal or ARV’s.

Peter and John present an interesting phenomenon in the study of medical pluralism in that the participant observation showed that one is celebrated, (John) the other is (Peter) seemed to be tolerated! It may appear that the socio-economic status of both affected how their relations, friends and immediate families related with them. Irrespective on ones AIDS status, being financially independent seemed to bring respect, social acceptance and attracted incremental
visits to the patients- with the patient playing the role of provider to the extended family, friends.

Variations noted between the two relate to numbers of visitors received; clinical appearance (Peter looked visibly and relatively unwell; both of them tended to influence their peers (especially in support groups where they belonged and other meetings of PLWHA) towards their own adopted mode of therapy; John appeared to be critical in his health seeking, asking his providers to explain terms and possible effects of taking various remedies.

While both lived openly with AIDS, only John opened his house to meetings for his fellow persons with AIDS-practically, he seemed to have more room to himself, being in a 4 roomed house while Peter lived in a one roomed house, with his family size likely to grow as they expected a child, were already keeping a dependant and he (John) was already thinking about his son in the village to come to town and join them-this latter thought may not have been discussed with the wife.

These two cases depict a scenario where educational level, faith based influences, location of residence, socio-economic position, nutritional status, marital status and level of openness tend to influence ones livelihood as a PLWHA. Being poor and ill seemed to have a sense of being tolerated, while those with money maybe more celebrated- more visits, interaction, being accepted and easiness of associations. It should be noted that Peter was chased by his brother in-law from their matrimonial home in circumstances he believed were due to his initial TB diagnosis and illness.

The HIV status or label seemed to be immaterial in a context where the PLWHA is independent, a provider of income or other resources. Peter seemed to have spent more time to help others, it also looked like a way of gaining acceptance- the nature of discussions he participated in a community level were more on social issues and community problems, difficulties with rental payments and possibilities of being moved out of the house; while John
focussed more on reading books, discussing business plans and looking at future educational prospects for his children.

The aspect of Peters’ lived experience was that he is industrious, easily available to help others and appears to look after his wife well, within his means. Peter seemed to be less open on some phenomenon—his wife may not have been aware of his plans to ‘bring his son’ from the village.

The participant observation helped the main researcher look at the benefits and costs of ARV’s, as well as herbal remedies and the explanatory models John and Peter (and their own therapy groups). John’s wife and other friends he has are medical staff while Peter is very pro-faith, usually leading church meetings and teaching others to follow the doctrinal teachings of the faith, being one of the leaders himself.

These observations showed the main researcher that PLWHA are people like any others, first and foremost. While HIV adds a challenge to them, other ways of doing things and relating with people are the same— they marry, get divorced, have children, look after the extended families and they also belong to therapy managing groups which can influence other PLWHA as well as other communities members even on non HIV related illnesses or other phenomenon.

Typologies and comfort zones (and their variations) with regard to openness and disclosure were noted in the changes in speech, behaviour and attitude in different situations, a phenomenon observed in both Peter and John. Mobilisation skills learnt from the AIDS domain appeared to be useful to both Peter and John, who were able to discuss and influence other community members to consider deepening a well in the neighbourhood (for Peter) and open a shop to sell drugs and other remedies (for John). Although he took the ARV path, John seemed to be considerate of other group members with him who needed to access
cheaper herbal remedies—\(he\) was ready to help start a drug store to operate on a cost recovery basis to subside their costs.

Support groups of PLWHA usually share vital information on treatment and self-care, creating a structure of therapy managing in itself, with occasional direct influences from family members, as was observed. Each was very competent in explaining how to use the therapy of their choice, ARV’s for John and Herbs for Peter (Observing the two when they were part of other meetings of PLWHA, they defended their choice of treatment in very passionate ways. In one meeting, most of the participants who were not on ARV’s were taking herbal remedies because they could not yet afford the drugs, which at that time where costing 12 USD for a one-month dosage. This was understood as most poor people live on less than a dollar a day (UNDP, 2003) and there is more evidence to show that HIV makes poor people get poorer while ARV’s and TB drugs tend to boast appetite, which is a problem in environments of food poverty, UNAIDS (2001) and Thomas (2004).

The two case studies helped inform the other data collecting methods by giving additional information, clarity on already collected data and context to various phenomenon in the whole study—participant observations should be considered are part of other methods, used to inform each other, like was the experience in this study.

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CHAPTER 4: RECOMMENDATIONS

4.1.0 Recommendations

Based on the findings of this study which have been discussed in the context of other findings and theories in the similar field of medical pluralism, the following are recommended as critical ideas and issues to consider in future studies as well as answering the research questions and meeting the study objectives.

4.1.1 Collaboration of different health systems

(a) The most useful way of networking various service providers like the ones identified in this study, is by ensuring that each is seen to be respected in its own right, without any single system being considered more superior than others.
(b) Each health system has its own strengths and weaknesses, which should been seen as opportunities for creating partnerships leading to better service deliveries to PLWHA. Formal referral systems may only work in an environment where explanatory models and ways of thinking and working are seen as important values which clients understand, hence their preferences. Janzen (1978) emphasises that there is need for referrals from one health system to other (which he calls the ‘significant others’).

© Absorption of one system by another, especially tokenistic intentions may not prove helpful in forging long-term relationships for better health. Testing of herbal remedies under a typical bio-medical model or attaching traditional healers to formal health systems which makes them delink themselves from their own models need to be examined critically and done differently.

4.1.2 Improving health service for people living with HIV/AIDS.

(a) People living with HIV/AIDS should been seen as key informants, policy definers and active participants in the process of providing care to them. PLWHA can be traditional healers, bio-medical health workers and faith leaders, as this study found out. They must be treated as informed clients who need help from fellow care providers, not as passive receivers of drugs, information and care.

(b) The food element in the quest for therapy should be considered as important. In situations where ARV’s are still not enough to meet the needs of all those who require them, food plays a mitigating role in reducing the impact of AIDS on families. Promotion of affordable, locally available foods for PLWHA and their families should be a priority.

© Given the multiplicity of preferences by PLWHA in their health seeking, there is need for government and other stakeholders to look at the health systems in a holistic way, providing the much needed support to traditional healers and other non-traditional carers apart from the bio-medical fraternity alone. Traditional healers need specific forms of support, which are
cost-effective and sustainable, given the simplicity of their work environment and the nature of their operations. Improved support to traditional healers, home based care teams and others will also positively impact on the quality of care and support passed on to the PLWHA themselves.

4.1.3 Interventions in Health education

(a) There should be a deliberate approach to ensure that every intervention to meet the needs of PLWHA should also factor in and reach the *therapy managing group*, as described by Janzen. They are very influential on the ultimate decisions regarding PLWHA’s health seeking patterns and the explanatory model they adopt.

(b) Interventions should not reinforce stereotypes and some attitudes and information, which consolidate the social exclusion of PLWHA, but rather, all educational materials and ways of working should accommodate all the different health systems, ensuring that PLWHA are reached through various media.

© Prevention strategies for STI’s, HIV and TB should apply anthropological perspectives to their approaches. All planned prevention strategies for diseases that are seen as contagious should build on existing indigenous etiological belief systems. With the fore going in consideration, the ‘indigenous contagious theory’ needs to be extensively applied (Green, E.C., 1999). Therefore, all interventions should factor in the local beliefs about the aetiology of diseases, with all IEC materials and outreach programmes considering the explanatory models in the folk and popular sectors.
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Annex: A

*In-depth Interview Guide* For Key Informants (PLWHA)

Interview no_________   Location________________

**Introductions:** Explain the purpose of the interview, make the respondent relax, assure confidentiality of information they provide and thank them for their time. Make them feel that the information they are going to provide is important for the furtherance of the study objectives which are of mutual interest.

1. **CURRENT AND PAST OPTIONS & DILEMMAS FOR HEALTH SEEKING**
(A) Please tell me more about your experiences of living with HIV/AIDS

(Lived experiences)

(B) Please tell me more about your options and dilemmas for health seeking:

(Health seeking options & dilemmas)

© What has been your personal experience in your quest for help from your health provider(s). (Pathways to Providers)

2. EXISTENCE OF PLURALISTIC HEALTH DELIVERY SYSTEMS

(A) What are the various types of health service providers you are aware of? (Catalogue of Providers)

(B) Please tell me more about the ones you have been able to access as at now. (Therapeutic encounters)

(C) Please describe more, the levels of accessibility to particular therapeutic options related to your health seeking. (Accessibility & Health-Seeking)

3. MOTIVATING FACTORS FOR ADOPTING/MAINTAINING PROVIDER (S)

(A) Please describe your decision path when adopting a health provider (Process of adopting Providers)

(B) What do you consider as important when deciding to maintain a health service provider (maintaining a preferred provider)

© Please tell me more about the role of your preferred providers in your health seeking endeavours (Role of provider in health seeking)
**Closing Remarks:** Thank the respondent/Group for their views, interest in the study and re-assure confidentiality of information they provided and thank them for their time, effort and commitment. Cross-checks the documented citations or quotes and other key statements from individuals or the group, as a true reflection of what respondents actually said. Reassure them of their privileges and rights in relation to the information they provided for the study and that they will be considered as important beneficiaries during the dissemination of the final report of the study.

**Annex: B**

*In-depth Interview Guide* For Key Informants

(SERVICE PROVIDERS)

Interview no_________ Location________________

**Introductions:** Explain the purpose of the interview again, make the respondent relax, assure confidentiality of information they provide and thank them for their time. Make them feel that the information they are going to provide is important for the furtherance of the study objectives which are of mutual interest.

1. **CURRENT AND PAST SERVICES PROVIDED TO PLWHA**

(A) Please tell me about your experiences in serving clients known or clinically suspected to be living with HIV/AIDS?

(Providers experiences in serving PLWHA)

- Please explain how you have served people living with HIV/AIDS differently from other clients without HIV/AIDS.
• How do you explain the effect of serving people with HIV on your ways of working and planning in your workplace environment?

• What difference does it make when one’s status has been disclosed and when the status is withheld but you clinically suspect an HIV case?

(B) What do you consider to be the most common diseases among your clients living with HIV/AIDS?

• How do these different diseases influence the way you support people living with HIV/AIDS?

• What challenges do these diseases bring to the way you would better care for people living with HIV/AIDS?

• What are the main misconceptions clients come with regarding HIV related complexes and symptoms?

• Explain how the different clinical presentations of HIV and their stages towards full blown AIDS influence your services to people living with HIV and/or AIDS.

(Common disease of PLWHA)

(C) Given opportunities, what do you consider doing differently for your clients who are PLWHA?
(Different/ Additional services)

(D) In what particular ways are your services different from other service providers for PLWHA?

(Uniqueness of services).

(E) Please explain the lessons you have learnt in your interactions with PLWHA?

(Lessons Learnt/ Working with PLWHA).

2. **EXISTENCE OF PLURAL HEALTH SERVICE DELIVERY SYSTEMS**

(A) Please briefly describe an average daily work schedule in your practice

(Regular work schedule).

(B) Kindly itemise the other health service providers known by you.

(C) In your past experiences, how have you dealt with a situation where you felt that another service provider could support your client additionally and differently?

(Referral to other providers)
(D) As a service provider, could you please tell me more about your personal health service providers?

(Providers own therapeutic options)

3. MOTIVATING FACTORS FOR ADOPTING/MAINTAINING PROVIDERS

(A) Please describe any experiences you have in serving a PLWHA referred to you by another health service provider?

(Serving referred clients)

(B) What role have you been playing in the health seeking decisions made by your clients?

(Providers role in clients’ opted carer).

(C) Please describe what you feel helps you keep your clients? (Client maintenance factors)

Closing Remarks: Thank the respondent/Group for their views, interest in the study and re-assure confidentiality of information they provided and thank them for their time, effort and commitment. Cross-checks the documented citations or quotes and other key statements from individuals or the group, as a true reflection of what respondents actually said. Reassure them of their privileges and rights in relation to the information they provided for the study and that they will be considered as important beneficiaries during the dissemination of the final report of the study.
Annex C:

PROTOCOL FOR OBSERVATIONS (PERSONAL GUIDE)

PREPARATIONS BEFORE FIELDWORK:

1. Reflect on previous visit, read through notes taken.
2. Remember to carry note book and diary
3. Call the participant if prior arrangement was not made for particular date
4. Allow more time in between different methods being used in one day
5. Dress appropriately and use ‘right’ mode of transport.
6. Avoid going for fieldwork in the company of other friends, peers and other uninvited participants for the purpose of the study.

WHEN IN THE FIELD:

1. Be a participant who observes, with limited influence in the participants daily life
2. Consider clients needs for privacy and his own health first.
3. Be observant and avoid stressing up the participants with multiple visits, allow some days between.
4. Avoid being ‘a health educator while in the field’
5. Be sensitive to client’s environment and be ready to terminate the study if clients feel uncomfortable with the situation of observation.
6. Allow clients their own time to be ‘on their own’ by observing their need for that.
7. Be considerate and imagine how it feels to be observed over a period.
8. Not to record any information while in the field but do so on my way back before reaching home. Record notes in shorthand, reflect on the day’s events and observed phenomenon critically.
9. Participate in activities involving third parties, if and when allowed.
AFTER FIELDWORK:

1. Use the field shorthand write-ups to record detailed account for the day.
2. Reflect on what I feel I did well and what I feel could have been done better
3. Reflect on the different observed phenomenon and consider the findings from the other participant being observed.
4. Learn from the participant observation and reflect on what is being reported in interviews and focus group discussion.
5. Begin to develop discussion point on the triangulated methods.
6. Consider whether enough data had been collected and if no new phenomenon coming, up, considers possibility of early termination of the 3 month planned observation.
7. Prepare myself to ‘leave the field and the client’ for research purposes, though communication between us may continue informally.

Annex D(i):

(INFORMATION SHEET: INFORMED CONSENT FORM)

We hereby request you to participate in this study, which involves research, looking at the health seeking options and challenges of people living with HIV/AIDS in Zambia, given that we have various health delivery systems available, both formally and informally.

Zambia is one of the countries in sub-Saharan Africa with a high prevalence of HIV/AIDS. With a growing population of people living with HIV/AIDS, it is important to gain an understanding of the role played by various health care systems in the country in the process of meeting the health needs of people living with HIV/AIDS. Of equal importance is the perception of people living with HIV/AIDS as they access services from different medical
systems. This research will help in providing more information to enable people living with HIV/AIDS and their service providers to informed assistance when needed and this is also likely to help with uniting care providers to better meet the needs of people living with HIV/AIDS.

We would like to find out a number of things from you concerning your opinions and experiences on this subject. The information, collected through audio tapes and note books (after obtaining permission from every participant) will only be serially linked by codes and not real names; all data collected and the instruments used will only be accessed by the researcher and his assistants—all information obtained will be handled confidentially and shall not be used for any other purpose other than for the production of the report. I realize that your views are important to help us in the way the country’s different health systems and providers respond to the needs of People living with HIV/AIDS.

Participation in this study is voluntary, with no consequences for not being involved. Therefore, if you do not wish to participate in the study, be rest assured that this will not affect your ability to access the usual services you currently get or expect to obtain from your health provider now and in the future. In the event that you agree to participate, you are also free to end your involvement at any time of your choice, if you feel like doing so. We do not expect additional costs arising from this study. However, the researcher will cover all expenses related to your participation. This research will not involve the use of drugs or other medicines, as the methods for getting information are only through the use of interview guidelines as well as observations, which are well defined. The interview is expected to take about 45 minutes or so. For those to participate in Focus Group Discussions, the expected
time is about one hour and thirty minutes. Kindly sign here if you have no objections to participating in this study.

My Physical address (the principal investigators residence) is: Plot Number 2047B, Fyalipwa Close, Riverside, KITWE. I can also be contacted on phone numbers: (Home) 02-222315 and (Cell) 096901965 in Zambia.

Annex D (ii):

INFORMED CONSENT FORM

I understand the purpose of this study and have accepted to participate on my own accord, without being forced to do so.
ANNEX: E

WORKSHOP DESIGN AND PARTICIPANTS INVITATIONS

Workshops, when used appropriately, have been known to have (among other things) helped inform interest groups and individuals, derive, consolidate and even evaluate the effectiveness of methods used in health interventions and other approaches. This particular study seeks to benefit from this proven process by bring together all the stakeholders (particularly the different health service providers and people living with HIV/AIDS). This workshop meant to cover a half-day period, is expected to involve 20 persons and three (3) co-facilitators led by the principal investigator.
OBJECTIVES OF THE WORKSHOP

1. Share the preliminary findings of the study for purposes of initiating critical discussion regarding PLWHA and health service provider’s strengths, opportunities, challenges and limitations.

2. Critically discuss the experiences of participants in current collaborative initiatives as well potential for enhanced pathways to networking.

3. Draw lessons from PLWHA on their therapeutic encounters as a basis to inform, lobby and engage policy and decision makers, health systems reformists and different health service providers.

WORKSHOP METHODOLOGY

There will be equitable participation from the groups involved in the study, as defined in the theoretical framework, protocol and methodology documentation (bio-medical personnel, traditional healers, people living with HIV/AIDS and the popular sector, among others).

The facilitation team will mainly use participatory approaches and other methodologies, including preliminary key note presentations on the findings; homogenous and heterogeneous group work, group presentations, plenary and close with a summary presentation of the discussion to allow for further inputs from participants.

EXPECTED OUTCOMES

1. The structured, purposive sessions will have helped illuminate and consolidate the findings of the study through guided, critical reflections on the interaction involving PLWHA and health systems/providers in Zambia.
2. Create a possible working, multi-disciplinary team of stakeholders who will work within their existing structures to continue relating and promote local-level dialogue, respect and mutual understanding among the various stakeholders.

3. Useful information, ways of thinking and mutual understanding will be derived and expected to be disseminated to relevant interest groups to help re-activate existing activities related to lobbying and advocacy for inclusion, improved networking, collaboration and mutual respect among various health service providers and PLWHA in Zambia.

4. Health reform strategists and policy makers and implementers will be able to better appreciate how the different health service delivery systems in Zambia can mutually bring incremental benefits to PLWHA.

DRAFT PROGRAMME FOR THE WORKSHOP

DATE:  
DAY:  

VENUE:

<table>
<thead>
<tr>
<th>TIME</th>
<th>ACTIVITY</th>
<th>FACILITATOR (S)</th>
</tr>
</thead>
<tbody>
<tr>
<td>08:30 to 09:00</td>
<td>Registration of participants &amp; introductions</td>
<td>The Research Assistants</td>
</tr>
<tr>
<td>Time</td>
<td>Activity</td>
<td>Facilitator</td>
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<td>----------------------------------</td>
</tr>
<tr>
<td>09:00 to 09:30</td>
<td>Dissemination of preliminary research findings</td>
<td>The Principal Researcher (Alick Nyirenda)</td>
</tr>
<tr>
<td>09:30 to 10:00</td>
<td>Group Work</td>
<td>Self-Group facilitation</td>
</tr>
<tr>
<td>10:00 to 10:15</td>
<td>Tea Break</td>
<td>Self/Group facilitation</td>
</tr>
<tr>
<td>10:15 to 11:30</td>
<td>Group Work Presentations</td>
<td>Group Representative</td>
</tr>
<tr>
<td>11:30 - 12:00</td>
<td>Plenary Session/Discussion</td>
<td></td>
</tr>
<tr>
<td>12:00 - 12:30</td>
<td>Summary of outputs &amp; way forward</td>
<td>The Principal Researcher (Alick Nyirenda)</td>
</tr>
<tr>
<td>12:30</td>
<td>END OF WORKSHOP</td>
<td></td>
</tr>
</tbody>
</table>

**Draft Letter of invitation to participants**

(Date/ Address/ Contact information)

Dear Sir/ Madam

**RE: DISSEMINATION OF STUDY FINDINGS & DISCUSSION**

Further to the discussion we held with you regarding your possible participation at the planned workshop, I would like to formally request for your involvement at this forum. As you may already be aware, we will be discussing the preliminary findings of the study, so as
to help facilitate a mutual understanding of the various critical aspects of the study findings documented through individual interviews and selected group discussions.

The objectives of the workshop, expected outcomes, programme and a guide on the geographical location of the venue for the workshop are hereby attached to this letter. Please feel free to seek further clarification on what will be expected of you during the session.

In appreciation of your expected involvement, we have planned to ease your participation by doing the following:

(a). Your transport costs from your home to the venue will be refunded, based on the public transport rates prevailing. Should you have a different need for other forms of transport, kindly contact us on the stated contact address and phone numbers so that we can consider your special requirements.

(b). A basic lunch allowance will be provided to all participants, based on the prevailing local rates in an average restaurant for a wholesome but reasonably priced meal.

©. The organisers are unable to provide any other allowances, except the ones explicitly stated herein. All the participants are considered as important stakeholders in this study, likely to benefit directly or indirectly from the findings of this study and the possible implementation.

We would like to thank you most sincerely for accepting to participate at this forum and earnestly look forward to seeing you soon. Please contact us if you will need additional information from us.
Yours sincerely

Alick Nyirenda

Researcher

STUDY ON PLWHA & DIFFERENT HEALTH SERVICE PROVIDERS

UNIVERSITY OF OSLO,

DEPARTMENT FOR GENERAL PRACTICE & COMMUNITY MEDICINE

NORWAY.