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FACULTY OF SOCIAL SCIENCES

**NUTRITIONAL SUPPORT AND CARE SERVICES FOR URBAN ADULT PEOPLE
LIVING WITH HIV/AIDS: A CASE STUDY FROM DAR ES SALAAM, TANZANIA.**

By

MWAPILI NEEMA JOSHUA

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*For My Husband Peter and
Our Sons Henry and Ronny*

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Abstract

It is well known that nutritional status plays an important role in preventing opportunistic infections as it improves immunity system. Not so much is known about how people living with HIV/AIDS manage their nutrition and the difficulties encountered in accessing support and other services necessary for maintaining their nutrition and health and improve quality of life.

In this study, persons with HIV/AIDS were asked to tell about nutrition support and care services provided by both formal and informal institutions in the society. Using a semi-structured interview guide in this study, the author conducted in-depth interviews with ten interviewees of both men and women. Information was also obtained from informants from relevant organisations especially AIDS Service organisation (ASOs), and departments in ministries. Thematic approach was employed in data analysis. The categories identified to explain the problems of the HIV-positive persons in managing their nutrition and health included **Nutrition perception and knowledge, source of income and stigma related to HIV/AIDS**. Others were **adherence and access to medication and medical monitoring, gender related cultural practices in the society, support from informal and formal institutions, and challenges for NGOs in providing services**.

The findings from this study showed that a large number of people living with HIV/AIDS rely on AIDS organisations for support services they need. Access to services in public institutions like government hospitals was difficult. The findings also show that support for people living with HIV/AIDS from relatives was limited and this could be due to stigma attached to the disease and difficult economic situation whereby relatives have little resources for their own families. In addition, challenges to meet basic life need for themselves and their families were found to be important concern for interviewees.

This study calls for more research on nutrition and experiences of people with HIV/AIDS about their health and nutritional management. This will give understanding on how already infected individuals and affected families can be supported in order to live as long as possible without progressing into AIDS disease.

Key words in information retrieval of this document are **Tanzania, Dar es Salaam, nutrition, care, support services and PLWHA**.

ACRONYMS AND ABBREVIATIONS

AIDS	-	Acquired Immunodeficiency Syndrome
ACC/SCN	-	Administrative Committee on Coordination, Sub-Committee on Nutrition (of the United Nations)
AMREF	-	African Medical Research Foundation
ANSA	-	Association of Nutrition Service Agencies
ART	-	Antiretroviral Treatment
ARV	-	Ant-retroviral Drugs
ASOs	-	AIDS Service Organisations
CD4	-	Cluster of Differentiation found on a subset of T-lymphocyte
CDC	-	Centre for Disease Control and Prevention
COUNSENUITH	-	Centre for Counselling, Nutrition and Health care
FAO	-	United Nations Food and Agriculture Organisation
FANTA	-	Food and Nutrition Technical Advisory Project
FHI	-	Family Health International
GDP	-	Gross Domestic Production
HIV	-	Human Immunodeficiency Virus
ILO	-	International Labour Organisation
MDAs	-	Ministries, Departments and Agencies
NACP	-	National AIDS Control Program
NDD	-	Nutrition Development Division
NGOs	-	Non Governmental Organisations
PASADA	-	Pastoral Activities and Services for People living with AIDS in Dar es Salaam
PLWHA	-	People Living With HIV/AIDS
PRB	-	Population Reference Bureau
REACH	-	Rapid and Effective Action Combating HIV/AIDS
SHDEPHA	-	Service, Health and Development for People living with HIV/AIDS
TACAIDS	-	Tanzania Commission for AIDS
TB	-	Tuberculosis
TFNC	-	Tanzania Food and Nutrition Centre
UNAIDS	-	United Nation Program on HIV/AIDS

UNICEF	-	United Nations Children's Fund
USAID	-	United State Agency for International Development
URT	-	United Republic of Tanzania
WAMATA	-	Walio katika Mapambano na AIDS Tanzania
WHO	-	World Health Organisation

CHAPTER ONE: INTRODUCTION

1.1 Introduction

“The nutrition voice needs to be heard louder and stronger in the HIV field.....”care” has somehow been narrowed to the cost of anti-retroviral and this is counter productive.”
(UNAIDS Director) (ACC/SCN, 2001)

Providing sufficient nutrition to meet people’s needs for health, growth and development has been a long standing challenge for African countries. This challenge is further exacerbated by the emergence of HIV/AIDS. At family level the HIV epidemic has weakened societies and economic status making it even more difficult to ensure food security, education and other basic services. The HIV/AIDS epidemic remains the greatest threat to health and socio-economic development in the world. Despite decreases in the rate of infection in certain countries the overall number of people living with HIV has continued to increase in all regions of the world except the Caribbean (UNAIDS, 2005). Globally there was an additional of five million new infections in 2005. The number of people living with HIV globally has reached its highest level with an estimated 40.3 million people, up from an estimated 37.5 million in 2003. More than three million people died of AIDS-related illnesses in 2005.

In Africa, the Sub-Saharan region is the worst affected having about 25 to 28.2 million people living with HIV/AIDS and by the end of 2003, AIDS claimed about 2.2 to 2.4 million lives of Africans (UNAIDS, 2003 cited in TFNC,2003:1). In Tanzania, the rate of HIV infection was found to be high in adult people where by 9.5 percent were infected in the year 2003. The National AIDS Control Programme (NACP) estimates that, there were 1.8 million adults living with HIV/AIDS by the end of the year 2003. However, in the same year 186,900 people died of AIDS and NACP estimates that only one out of five AIDS cases is reported (NACP, 2003:1. This implies that the number of AIDS deaths can be higher than the known figures. Although the current statistics shows about 7 percent of adults in Tanzanian mainland are living with HIV, in cities and towns HIV prevalence averaged 11 percent, almost twice the levels found in rural areas (UNAIDS, 2005).

Nutrition is a phenomenon that is a basic life process. It refers to a basic activity of nursing because all human beings must receive some type of nourishment or sustenance to remain alive. The word nutrition is derived from the Latin verb ‘nutrire’ meaning to feed, foster or cherish (Simpson and Weiner, 1989). Nutrition also refers to nutrients that the body ingest and to the sum of the processes that take in and utilize the nutriments through ingestion,

digestion, absorption and assimilation. Another word closely related to nutrition and derived from the same Latin root is nourishment. In health care, these two words are often used interchangeably, although nourishment may encompass other forms of support such as educational or spiritual in addition to food substances.

The interaction between HIV/AIDS and nutrition has been defining characteristics of the disease since the early years of epidemic. HIV/AIDS are associated with poor nutritional status and weight loss. Despite recent developments and improvements in medical treatment, nutrition has remained one of the key components in the care of HIV disease. Moreover, nutrition is intrinsically linked to immune function. It is well documented that provision of proper nutrients can support an already compromised immune system and that lack of even one essential nutrient can have especially deleterious effect. Malnutrition, weight loss and wasting continue to affect patients at all stages of HIV infection. Studies show that both macronutrient and micronutrient deficiencies contribute to immune dysfunction and can lead to disease progression. A weight loss of as little as 5% can significantly increase morbidity and mortality (ANSA, 2004). Nutritional strategies including food choices appropriate for the individual medication schedule can improve adherence and enhance the effectiveness of drug therapies. This linkage suggests that nutrition have an important role to play in slowing progression of the disease and contributing to successful antiretroviral therapy. In other words, knowledge about nutrition is important thus it is necessary to understand the specific constraints people living with HIV/AIDS (PLWHA) face in accessing food and other care services including nutrition information and help identify alternate, feasible options on these constraints.

1.2 The Research problem

Nutrition status is important in preventing infection, in supporting the immunity thus delaying the progress of HIV disease. It is also known to affect the immune system in sepsis and in chronic diseases (Huang et al, 1988). Maintaining good nutrition also helps to reinforce the effectiveness of medicine taken by the HIV-positive individuals including the antiretroviral therapy. Adequate nutritional support is essential to all human beings, but it is particularly essential to persons infected with the human immunodeficiency virus (HIV). In HIV infection, Kotler et al (1989) found that the timing of death may be more closely related to depletion of body cell mass than to infection. However, nutritional problems in Tanzania especially undernutrition has been a major problem. According to United Nations Food and

Agriculture Organisation (FAO) Food Balance sheet for Tanzania -2001, the average energy intake of an adult Tanzanian was 1997calories (TFNC,2003) which is below 2400calories; the recommended average per day depending on the physical activities (FAO,2004). This shows that the energy requirements for most Tanzanian are not met. On the other hand, causes of nutritional problems in Tanzania for some years have been inadequate food intake, frequent infections, household food insecurity, inadequate basic services, poor economic situation, traditional customs and practices and more recently HIV/AIDS.

Since nutrient requirements are increased for people living with HIV/AIDS, it can be argued that these people are definitely more prone to undernutrition. It is therefore important to ensure adequate nutrition to meet their body requirements, strengthening immunity and complement the drug treatment; all aimed at improving their health, nutritional status and mitigating the effects of HIV/AIDS condition. Limited education of HIV positive people and their families about beneficial health measures and nutrition may be a problem if they are poorly informed about ways to maintain and optimize their health status. This includes measures to improve nutrition, early detection and treatment for opportunistic infections and adherence to antiretroviral drug treatment. With respect to nutrition, in some circumstances people who are poor can not obtain sufficient quantities of nutritious food. However, some patients can have access to natural foods including locally grown fruits and vegetables but they may choose processed foods which are not nutritious and also expensive because of low knowledge about their nutrition.

Prior research indicates that good nutrition status is important in preventing opportunistic infections and probably delaying the progress of HIV infection to AIDS. Person living with HIV/AIDS have identified that they want support and information about building their immune systems. Therefore, strengthening education for HIV-positive people and their families can help them to adopt better ways to optimize their care and improve nutrition. Other strategies should also be explored to provide health and nutrition information and support for HIV infected individuals. This include working with NGOs and other community-based organisations that provide counselling and support for HIV infected individuals as well as those working with high risk population (which presumably include large number of HIV infected persons). Although nutrition has been reported to be very important in preventing infection and maintaining the immunity, little has been done about this phenomenon of nutritional support and care services for people with HIV/AIDS.

As part of this Master thesis work, an exploratory qualitative study will be conducted to investigate the nutritional support and care services for people living with HIV/AIDS. Specifically, the researcher will explore, analyse and explain about how HIV-infected persons manage their nutrition and health with focus to problems they face in accessing nutritional support and other support services they need. The researcher chose to use this approach because there is little or no knowledge about the phenomenon of how HIV- infected persons manage their nutrition and health.

1.3 Significance of the study

In this study of nutritional support and care services for people living with HIV/AIDS in Dar es Salaam, the researcher will both explore and explain what can be done to help to sustain Tanzanian people living with HIV/AIDS in good health as long as possible and prevent progression of HIV infection to AIDS stages. This study is one of the ways to create awareness about the problems faced by HIV-positive individuals in relation to their nutrition and health care management. The study has implications for the social welfare provision and public health care providers to support people living with HIV/AIDS in maintaining the quality of their life and delay the progression of HIV infection to AIDS. The study also has significance for social workers and policy makers. The findings can be used by these audiences to design intervention programs aimed at sustaining PLWHA in good nutritional status and health, thus helping them in adherence to antiretroviral therapy and prevention.

1.4 Objectives of the Study

The main purpose of this study was to explore, analyse and explain the nutritional support and care services for people living with HIV/AIDS in urban areas. Specifically this study was aimed to enable each participant to tell about their nutrition and health management focusing on the difficulties they face in accessing support services and other needs necessary to curtail progression of HIV infection to AIDS stages and improve the quality of the life. The researcher encouraged the participants to explain in their own words the experience they have in maintaining their health since it was discovered that they were HIV-positive. Understanding of the support services provided by AIDS Service Organisations (ASO) which is a non-governmental organisation and the challenges they face was another aim of the study, since most of the support services for PLWHA are provided by AIDS organisations.

In order to address the main purpose of this study, four specific research questions were proposed for the study.

- What problems are faced by HIV-positive people in relation to their nutrition?
- What services are provided by ASOs for people living with HIV/AIDS?
- How do people infected with HIV/AIDS get information about their nutritional care?
- What problems are faced by ASOs in providing nutrition support and services for people living with HIV/AIDS?

1.5 Study participants

Ten individuals participated in the interview for this study. Six women and four men were interviewed in their homes. The selection of respondents was based on the age, duration they have been living with HIV and habitants of urban- Dar es Salaam. Their age ranged from 34 to 45 years. Five women were widows and one divorced, one man lived with a spouse and five children while the other men were separated. Their education level was mostly elementary (primary) school education with only two men who had reached ordinary secondary school education. None of the participants had formal employment and they live on petty trade/business like selling fresh fish, food produces such as maize, beans, rice in the markets; selling clothes, beads, earrings and selling of cooked foods in small canteens. The participants were financially not secured as their income was determined by how much they sell per day, however they averagely earn about Tsh.1000 to 1500 (1 to 1.5 USD). Two widows lived in houses left by their husbands and other respondents depend on renting a room to live with their children. The number of children they live with ranged from 2 to 5 children of age between 9-15 years.

1.6 Study area description

Dar es Salaam is the capital city in Tanzania. It lies adjacent to Indian Ocean. The city has an estimate population of 2.5 million. Three municipalities that constitute the city of Dareslaam i.e. Ilala (637,573), Kinondoni (1,088,867) and Temeke (771,500) make a total population of 2,497,940 (Dareslaam Municipal Council Difluca Program, 2003). The city is highly populated due to rural- urban migration and migration from other towns. It is one of the most affected parts of the country with adult HIV prevalence range of 10-15 percent (NACP, 2003:15). Due to wide spread poverty (Lugalla, 1997) urban life is as hard as rural life for people living with HIV/AIDS (PLWHA) in Tanzania today.

Moreover, despite the many organisations that have been addressing AIDS issues at national level (Mhamba&Titus, 2001) nutritional support and care services have not been systematically provided for people living with HIV/AIDS. Even where services have been available, few people have information about them or are guided on how to access these services. The organisations which have been dealing with AIDS include African Medical Research Foundation (AMREF), National AIDS Control Programme (NACP), Pastoral Activities and Services for people living with AIDS in Dareslaam (PASADA), Tanzania Commission for AIDS (TACAIDS), Centre for Counselling, Nutrition and Health care (COUNSENUH), Services, Health and Development of people living with HIV/AIDS (SHDEPHA) and WAMATA (Walio katika Mapambano na AIDS Tanzania, meaning "Those in Struggle Against AIDS in Tanzania (Mhamba&Titus, 2001 in Kaijage, 2004:34).

Furthermore, each of the three municipalities of the city oversees one public hospital. The hospitals are Amana (150 beds) for Ilala, Mwananyamala (160 beds) for Kinondoni and Temeke (120beds) for municipality of Temeke. The three hospitals have an average of up to 100,000 out-patient visits per year (Dareslaam Municipal Council Diflucan Program, 2003). For people who are employed by the government and private sector, some work sites have health clinics that serve as a point of entry into formal health care system or they have health insurance for their workers. As for unemployed among the city's population there are public and private dispensaries in each of the city's administrative wards. However, since the 1990s when in the name of cost-sharing, user fee were introduced as part of health sector reform, most people use these health care facilities only in case of medical emergency (Kiwara, 1995). Thus people with HIV/AIDS depend on such AIDS organisation like SHDEPHA, WAMATA, PASADA and similar organisations for most of their health care services. Most of the AIDS service organisations (ASOs) are non-governmental organisations. As will be discussed later in chapter 3.3, some of ASOs are religious or faith based organisation but majority are established without religion basis.

CHAPTER TWO: BRIEF OVERVIEW OF LITERATURE

Introduction

This brief overview of literature about HIV/AIDS will explore about HIV history in Tanzania, development of HIV infection in adult person, nutrition in HIV/AIDS and the impact of the disease at families or households.

2.1 History of HIV/AIDS in Tanzania

The first cases of AIDS were reported in Tanzania in 1983, and from there HIV epidemic has spread rapidly to all districts and communities affecting all sectors of the society. According to Nguma, (1992) the history of AIDS begun in the north western Tanzania, where AIDS first took its toll on young men and women involved in illegal trade with Zaire, Rwanda and Burundi (Nguma,1992 cited in Kaijage 2004). Here the trade flourished on illegal buying and selling of currency, minerals, alcohol and basic commodities that were in short of supply in Tanzania, especially after the war with Uganda in late 1970s. People began to die in great numbers (Mann et al., 1992) and symptoms were so mysteriously similar that, witch craft was the only explanation that the community could offer. They believed that witch craft was the main cause of these deaths and that those dying were been witched.

According to National AIDS control program (NACP, 1989), the first cases of AIDS were identified in 1983 in Kagera region. However by 1986 all the regions in Tanzania Mainland had reported AIDS cases. In the year 2003 (NACP, 2003) a total of 12,675 AIDS cases were reported to the National AIDS Control Programme from the 21 regions. This resulted into a cumulative total of 785,865 reported cases since 1983 when the first cases were identified in the country (NACP, 2003). The recent data based on household survey in Tanzania show that, (NACP, 2005:2) the rate of HIV transmission estimate in adults was 7 percent with wide variation across the regions. Most HIV infections are transmitted through heterosexual intercourse; and the population most severely affected are sexually active individuals between 15 and 49 years of age.

In looking at Nutrition support and care services among adult ambulant people living with HIV/AIDS in Dareslaam, Tanzania, we can first look at the history of HIV/AIDS in Africa starting with examination of literature. In 1982 (Ankrah1993, Museven, 1991) only one African country; Uganda had an estimated HIV prevalence rate more than two percent (Ankrah1993, Museven, 1991 cited in Kaijage, 2004:2). However by 1990s (Akukwe and Foote, 2001) some people were beginning to fear for the future of Africa. Africa is the

continent hardest hit by HIV/AIDS and it is a continent that account for more than two thirds of all HIV/AIDS population in the world although it comprises only ten percent of the entire global population (Akukwe and Foote, 2001 cited in Kaijage, 2004:3). Lack of resources at individual and national level to cope with the infection for those already affected can be the reason why Africa is more affected by HIV/AIDS. But on the other hand poverty trap, stigma related to HIV and lack of adequate education and information about HIV transmission and AIDS disease in African societies contributes to the spread of infection.

Furthermore, provision of sufficient food to meet people's needs for health, growth and development for African countries including Tanzania has been a long standing problem. The situation is further exacerbated by the emergence of HIV/AIDS which is hard hitting the continent. HIV epidemic has weakened families, societies and their economic status making it even more difficult to ensure food security, education and other basic services. As soon as a member of the household starts to suffer from HIV-related illnesses, loss of income of the patient and increased expenditures for medical expenses follows. However, death results in permanent loss of income, less labour on the farm resulting to less food to feed the family.

Although people may live happier and healthier lives when they have access to rich, rewarding and supportive social relationships (Cvitanic, 1993), empirical research is needed to provide data on how social support applies to the African experience of HIV/AIDS. In addition, there is also increasing inability of relatives or community to support vulnerable groups thus (Tibaijuka & Kaijage, 1995) explain this as symptomatic of change in family concept such that, family responsibilities are increasingly confined to nuclear than extended relations.

2.2 HIV/AIDS in Adults

Adult Development is the time after adolescence. On adolescent transitions into emerging adulthood there are three distinct stages; Early Adulthood, Middle Adulthood, Late Adulthood. Early Adulthood takes place between the ages of 20-30 and during this period individuals are; physically the healthiest, cognitively grown to make life decisions, and socioemotionally take on new roles. Middle Adulthood takes place between the ages of 30-60. During this period individuals can struggle with generativity versus stagnation. However, late adulthood takes place around age of 60 years (CTER,2006).

However, adult people living with HIV/AIDS with regard of this study will refer to a person with age above 20years who are infected with HIV. Further more; Ambulant People living with HIV/AIDS in this study will refer to people who are HIV positive but the condition has not progress to full AIDS blow. They are people at asymptomatic and early symptomatic stages of HIV infection (according to WHO classification). They are not considered as sick on bed and they are able to carry out their daily life activities. In Africa, HIV transmission in adults occurs most commonly through heterosexual intercourse. After it is transmitted, Bartlell and Finkbeiner, (1998) HIV infection generally follows a common pattern in all regions of the world although the interval between phases may be shorter in developing than developed countries (Bartlell and Finkbeiner, (1998) in Piwoz and Preble, 2000:3).

In acute infection, the first phase HIV causes symptoms such as fever and body ache that clears up spontaneously, generally within 1 to 6 weeks after infection. At this time, concentration of virus in the blood also known as viral load is high. If a woman is pregnant or breastfeeding at this time of infection the risk of transmitting virus to the baby is greater due to high viral load. At this time the body has not yet produced antibodies to the virus and a person is tested, the standard HIV antibody test will be negative.

In the next phase; seroconversion, the body begins to produce antibodies to HIV. The seroconversion phase generally takes place 6 to 12 weeks after HIV infection and at this time HIV antibodies can be measured through blood test and a positive antibody test confirms that adults are HIV infected (Piwoz &Preble, 2000:3). On the other hand, infants born to HIV-infected mothers carry their mother's antibodies even if infants themselves are not infected. These maternal antibodies may remain in their bodies for 15 to 18 months, thus standard HIV antibody test cannot confirm HIV infection in infants younger than 18 months of age (NACP, 2005:40)

Asymptomatic period is usually a prolonged period of several years when an infected person feels well and has no symptoms of infection. During this period (Piwos and Preble, 2000) the immune system of infected individual is gradually affected by the disease and CD4 T-Lymphocyte cell counts gradually decline. The effect of HIV on nutrition begins during this asymptomatic period, thus literature suggests that nutrition care should start at this stage because timely improvement of nutritional status can help to strengthen the immune system hence delay the disease progression (FANTA, 2004). Literature says that, in early symptomatic period, the first symptoms of a weakened immune system occur and common

conditions include fungal infections of the mouth and other mucosal surfaces, bacterial pneumonia, tuberculosis, chronic fatigue, fever and weight loss. These conditions tend to persist for several weeks or months in people living with HIV.

Late symptomatic infection phase is advanced stage of HIV/AIDS and it is defined by a blood test that confirms a low number of immune cells (ie.CD4 T-Lymphocyte cell count less than 200) or by presence of various other severe complications (TFNC, 2003:13). The amount of virus (HIV viral load) is high during this stage because the immune system is not able to control the infection, thus weight loss or wasting of muscles becomes a serious problem. At this stage a person may be seriously sick, working ability become weak and need some one to help.

In developed countries, the average length of time between HIV infection and AIDS diagnosis can be as long as 8 to 10 years (Grants et al 1997), however in poor countries like Tanzania, this period and the time between AIDS diagnosis and death may be shortened by exposure to infectious diseases, poor nutrition and health care like accessibility of antiretroviral drugs and treatment of opportunistic infections. Research does suggest that the chance of HIV-infection might be reduced in individuals who have good nutritional status; and the onset of the disease and death might be delayed where HIV-infected individuals are well-nourished. It is also likely to be many years until antiretroviral drug (ARV) are widely available in Africa, therefore it is important everything that can be done and should be done to provide care and support for people living with HIV/AIDS before they reach the stage of need of antiretroviral drugs. For example, many of the common HIV-related opportunistic infections are fairly easy to prevent and treat. The prevention and treatment of opportunistic infections can result in significant gains in life expectancy and quality of life among people living with HIV.

2.3 Nutrition in HIV/AIDS

Nutrition and HIV are linked, thus adequate nutritional support is essential to the well-being of people living with HIV/AIDS. Any immune impairment as a result of HIV/AIDS can contribute to malnutrition if not well managed. However, malnutrition leads to immune impairment, worsens the effects of HIV, and contributes to a more rapid progression of the disease. Therefore malnutrition is both contributing and is a result of HIV disease progression. According to NACP (2005) a person who is malnourished and then acquires HIV is more likely to progress faster to AIDS because the body is already weak and cannot fight co-

infections particularly without access to antiretroviral therapy and prophylactic medications, while a well nourished person will have a stronger immune system for coping with HIV and fighting illnesses.

FANTA, 2004) explain that, nutritional care and support can be effective especially for those HIV-positive individuals who have not yet progressed to the stage of requiring antiretroviral treatment. This is because timely improvement of nutritional status can help to strengthen the immune system, thereby reducing the incidence of infection, preventing weight loss and lean body mass and delaying disease progression. On the other hand, nutritional care and support helps people living with HIV/AIDS to manage HIV-related complications, promotes good response to medical treatment, and improves the person's quality of life by maintaining strength, comfort, level of functioning, and human dignity. Kotler et al., (1989) comment that, early attention to nutritional intake may delay the progression of HIV infection to AIDS and maintain an improved quality of life. Therefore nutrition counselling should begin at the time persons are informed they are HIV-positive.

At the same time, it is recommended that FANTA, (2004) a person living with HIV/AIDS requires the consumption of an adequate amount in the appropriate proportions of macronutrients (e.g., proteins, carbohydrates, fats) and micronutrient (e.g. vitamins and minerals). In the absence of AIDS symptoms, HIV-infected persons should increase energy intake by 10 percent over the level of energy intake recommended for healthy non-infected persons, while in presence of symptoms they should increase energy intake by 20-30 percent over the level recommended for healthy non-infected person of the same age, sex and physical activity level. These recommendations are for HIV-infected persons, including those taking antiretroviral drug. Despite this, it is important to remember that many people in resource limited settings like developing countries are experiencing pre-existing malnutrition and that HIV will worsen the situation and this implies the progression of HIV infection to AIDS and death in poor settings is likely to be rapidly than in developed countries.

As for HIV-positive individuals, TFNC, (2003) nutritional support need to include food support, nutrition education, and information about food requirements, healthy life style, HIV and nutrition relationship, food and water safety and hygiene and interaction of food and medications such as antiretroviral drugs. It also includes nutrition counselling to enable people infected with HIV make appropriate food, behavioural and other social choices in various situations. However, due to scarcity of food in much resource limited settings, people

with HIV/AIDS may be unable to follow recommendations to manage the effect of food-medications, thus NDD (2004) suggest that health workers or nutrition counsellors should involve PLWHA in identifying feasible options for the nutritional management of food and drug interaction which may also contribute to maintaining drug adherence by create interest in continuation of the treatment.

2.4 Impact of HIV/AIDS on Households

HIV/AIDS is wide spread in both urban and rural communities and mostly affected persons are at the peak of their sexual and economic activities. Death of a young adult often means loss of a father or/and mother and family income generator. Studies conducted in Arusha, Kagera and Mwanza regions show a serious and growing breakdown of social network which have previously sustained African societies (NACP, 2005:3). Individualistic practices are on the increase, which means that, orphans are not only subjected to material, social and emotional deprivation, but also lack of opportunities for education and health care. This will have grave social consequences for the future generations. Results of studies conducted in western regions of Tanzania (Rau, 2001) have shown that many relatives refused to take responsibility for orphaned children, and many of those who did were unable to adequately look after the children.

As has been found in Tanzania, Thailand and Uganda, grand parents are most likely to take responsibility in orphans but they are also likely to be poor and unable to offer substantive material support to children. Tibaijuka & Kaijage (1995) explain that, this increasing inability of relatives to support orphans may be seen as symptomatic of change in the concept of family. Under economic pressures, related to a combination of recession and unemployment, structural adjustment reforms, drought and HIV/AIDS, family responsibilities are increasingly confined to nuclear rather than extended relations. Since in most African societies families and relatives are the major form of social security system, the increasing change in concept of family is likely to worsen the impact of HIV at individual and household level and increase social deterioration, therefore other strategies need to be sought in supporting vulnerable groups in the society.

The impact of HIV/AIDS on household begins as soon as a member of the household starts to suffer from HIV-related illnesses. Loss of income of the patient (who is frequently the main breadwinner), and household expenditures for medical expenses may increase substantially.

However, death results in a permanent loss of income from less labour on the farm or from lower remittance, funeral and mourning costs and removal of children from school in order to save on educational expenses and increase household labour, resulting in a severe loss of future earning potential. A study of adult mortality (Ainsworth et al, 1996) found that 8 percent of total household expenditure went to medical care and funerals in households that had an adult death in the preceding of 12 months.

When husbands die from AIDS, their widows suffer from lack of cash, since men are the main income earners. Thus a study (Toupozis, 1998) found that the most pressing need for widows was credit to begin cash-generating projects. Another study (Rugalema1998) found that households in Tanzania were using a variety of mechanisms to cope with HIV/AIDS. Some households cut back on meals, some sold agricultural produces and others sold off assets like house furniture to raise money to pay health cost. Also some used child labour extensively to perform domestic and agricultural activities which was associated with reduced school attendance.

World Bank, (1997) comments that, the impact of HIV/AIDS on household can be reduced to some extent by publicly funded programs to address the most severe problems. Such programs have included home care for PLWHA, support for basic needs of the households, foster care for AIDS orphans, food support and support for educational expenses for children. Such programs can help families survive some of the consequences of adults AIDS death when the families are poor or become poor as a result of HIV/AIDS.

CHAPTER THREE: HIV/AIDS EPIDEMIC IN TANZANIA

3.1 Information about the country.

Tanzania is one of the East African countries, others being Kenya and Uganda. The neighbour countries include Rwanda and Burundi in the west, Mozambique, Zambia and Malawi in the south and Kenya and Uganda in the north, while Indian Ocean borders in the east. According to population census of the year 2002 (URT, 2002; 2003) the total population was 34,443,603. Males were 16,829,861 and 17,613,742 females. The annual growth rate was found to increase from 2.8 percent per annum during intercensural period of 1978-1988 to 2.9 percent per annum during the period of 1988-2002. Basing on this high growth rate Population Reference Bureau (PRB, 2005) estimated that population increased from 34,443,603 in August 2002 to 36,481,000 in mid-2005. At the same time, the World Bank data on Tanzania show that, the fertility rate (births per woman) was 5.0 in the year 2003, while infant mortality rate (per 1,000 live births) was 104.0 in the same year and the mortality rate for children under five years was 165 per 1,000 children. Further more, data from the Population Reference Bureau (PRB, 2005) also show that, the life expectancy for Tanzanian was estimated to be 43 years for men and 45 years for women.

The sub Saharan African countries including Tanzania have high population growth rate compared to economic growth (Jay Cox, 1988). The population growth has impact on economic growth and other sectors especially in providing services to people such as health, education, employment, water etc. This implies that when population increases and economic is low or remain the same, the economy will not be able to serve the increased population. However, about 30 percent of the population live in urban areas while 70 percent of population in Tanzania are peasants who depend on agricultural activities and they live in rural areas where access to most of social services may be more difficult than in urban places.

The rate of spread of HIV infection in major city like Dar es Salaam has been very high. One of the reports by National AIDS control program (NACP, 2002:7) indicated that from July 1998 to June 1999 AIDS and Tuberculosis (TB) ranked as the number one causes of death for both men and women aged 15-59 years. However, Dar es Salaam reported higher rates of HIV infection than any other part of the country, with infection rate ranging from 10-20 percent. With a population of about 36 million at present, (CDC, 2002) it is estimated that over 2 million people in Tanzania are infected with HIV/AIDS; 70.5 percent of whom are in the age of 25-49 and there are more than one million children who have lost one or both

parents due to AIDS. According to recent data (UNAIDS, 2005) the prevalence of HIV infection among adults in Tanzania was 7 percent, but in cities and towns the rate was higher 11percent, almost twice the levels found in rural areas. Notwithstanding the high rates of infection, (Setel and Lewis, 1999:35) Africa has been able to keep on surviving mainly because people in the communities that have been hit hardest by HIV/AIDS have relied on each other for support to sustain their morale in battle against the AIDS epidemic.

At the same time, various clinical and social efforts have been undertaken to address the HIV/AIDS problem in Tanzania. The efforts have been directed towards behavioural change to prevent transmission, treatment of opportunistic infections and currently use of antiretroviral drugs to prolong the lives of the infected individuals. Furthermore, in the year 2004, the Government started the antiretroviral drugs (ARV) programme in Referral hospitals as pilot sites and there was a plan to expand the programme to all hospitals in the country to enable more patients to access this service. However, experience from other countries in the world (TFNC, 2003), show that, good nutrition has a role to play in HIV/AIDS. It strengthens the body immune system and thus decreasing the vulnerability to opportunistic infections. These in turn, improves the quality of life of the individual and delay the process of HIV progression to AIDS. Maintaining good nutrition also helps to reinforce the effectiveness of medicine taken by the individual including the antiretroviral drug. Therefore maintaining adequate and nutritious food consumption to meet the special needs the disease generates is critical for all people living with HIV/AIDS.

Furthermore, nutritional problems in Tanzania especially undernutrition has been a major problem. The Food balance sheet for Tanzania-2001 indicated that, (TFNC, 2003) the average energy intake of an adult Tanzanian is 1997calories which is below 2400calories the recommended average of per day depending on the physical activities (FAO, 2004). This shows that the energy intake is not sufficient to meet their body requirements. In addition, the causes of nutritional problems in Tanzania have been inadequate food intake, frequent infections, household food insecurity, inadequate basic services, poor economic situation, poor eating patterns related to traditions, customs and practices and more recently HIV/AIDS.

3.2 Impact of HIV/AIDS in Tanzania

HIV/AIDS is a major development crisis that affects all sectors in Tanzania that the country is facing a major threat to the survival of its people and the development chances of the nation from a concentrated and generalised HIV /AIDS epidemic. It is estimated that (TACAIDS, 2003) more than two million people including children were living with HIV/AIDS in 2002. During the last two decades the HIV/AIDS epidemic has widely spread affecting people in all walks of life and decimating the most productive segment of the population particularly women and men between the age of 20 and 49years. AIDS has a potential to create severe economic impacts in many African countries including Tanzania. On the other hand, HIV/AIDS is different from other diseases because it strikes people in the most productive age and is essentially 100 percent fatal. Although it is difficult to establish the impact of HIV / AIDS in different sectors of society, economy or for the overall development, there is evidence that the impact of AIDS is already felt in many public sectors of the society, and also private and business enterprises feel the impact due to higher morbidity and mortality among their workforces.

The major economic effects are reduction in the labour supply and increased costs. AIDS-related illness and deaths to employees affect a firm by both increasing expenditures and reducing revenues. On the other hand expenditures are increased for health costs, burial fees and training and recruitment of replacement employees. Revenues may decrease because of absenteeism due to illness or attendance at funerals and time spent on training new staff. This was revealed by a study (ILO,1995) in eight organisations in Tanzania which found that medical costs associated with AIDS-related diseases for the workers increased over one year time frame from Tsh.2.8million in January to Tsh.4.6million in December, almost 63% increase. Other impacts include lowering of life expectancy, reduction in productivity, increasing poverty at individual, family and national level, raising infant and child hood mortality and growing numbers of orphans. For instance in 2004, UNICEF estimated that (Charwe et al., 2004) there were 980,000 orphans in Tanzania whose one or both parents had died of AIDS; however this number was expected to exceed one million by 2005, constituting 58 percent of all orphans in the country.

One of the most shocking markers of the demographic effect of AIDS mortality (Epstein, 2005) is life expectancy at birth i.e. the estimated average number of years a person could expect to live if age-specific death rates prevail throughout his or her life. In developing

countries life expectancy was chronically low mainly because of high infant mortality. Once measures were taken to alleviate the common causes of infant mortality, life expectancies began to climb. However, life expectancies in many sub-Saharan African countries including Tanzania are now estimated to be low because of AIDS mortality among adults. The life expectancy is estimated to be 45 in presence of AIDS; but adult people could live for more than 55 years without the existing AIDS disease.

The HIV/AIDS epidemic is a serious threat to the country's social and economic development and has serious and direct implications on the social service and welfare. The overall impact of AIDS on macro-economy may be small at first but increases significantly over time. A macroeconomic simulation model (Cuddington, 1993) estimated that the impact of AIDS on the growth path of the Tanzanian economy would reduce GDP by 15-25% by the end of 2010, and reduced per capita income by 0-10%. However, the levels of per capita income here are not affected much as the GDP because population is expected to be less due to deaths from AIDS. The model includes consideration of increasing morbidity and mortality from AIDS which in turn affect labour productivity, higher health care spending and lower saving rates leading to lower investment levels. On the other hand, (Epstein, 2005) as mortality rates are rising, the fertility rates are expected to decline by the year 2015 since fertility rates will tend to be lower for HIV-infected women than for uninfected. In addition, approximately one-third of children born to HIV-positive mothers are infected and unlikely to reach child bearing age themselves. HIV/AIDS also may reduce birth rates indirectly through its impact on sexual behaviour whereby women may reduce risky sexual practices by increasing abstinence and condom use.

Findings from a study (ILO,1995) suggests that the size of the labour force will decrease by 20% by the year 2010 due to the impact of HIV/AIDS, and there will be decreases in production as younger, less experienced workers replace those who have died. Further more, it is estimated that providing triple combination antiretroviral therapy to HIV-positive adults in Tanzania would cost 15% of the GDP (Hogg et al, 1998). However at the moment the Tanzanian government is collaborating with international donor organisations in procurement of antiretroviral drugs.

3.3 AIDS Service Organisations (ASOs)

In most developing countries like Tanzania, provision of most of social services is both public and market oriented system. This in turn has encouraged the introduction of volunteer sector under the banner of Non Governmental Organisation to dominate the provision of social service (Gomez, 1999:109). Tanzania has undergone rapid political and economic change over the last two decades. The process of economic and political liberalization upon which Tanzania embarked during the mid 1980s signalled huge transformations for the non-state sector, which has since burgeoned (Gibbon 1995; Kiondo, 1993; 1995). NGOs are working on a diversified range of activities in many parts of Tanzania. These activities are aimed to improve livelihood of people including care and support for people living with HIV/AIDS.

Non governmental organization (NGO) can be described as established group of people targeting to address a specific problems using a clear and defined strategy. The beneficiaries of the NGO are usually specific target population. However, according to NGO Policy (1999), NGO is: ... *a voluntary grouping of individuals or organizations, which is autonomous, non-political and not-for-profit sharing, organized locally at grassroots level, nationally or internationally, for the purpose of enhancing the legitimate economic, social and/or cultural development or lobbying or advocating on issues of public interest or interest of a group of individuals or organization* (URT, 1999:9)

Furthermore, the number of NGOs in Tanzania is increasing rapidly. According to Fredrich Ebert stifling Foundation (FEF, 2000), between 1961 and 1980 there were only 25 registered Non Governmental Organizations. However by 1990 the number raised to 41, then between 1990 and 1993 the number went up to 224 and according to the Registrar of Societies, Tanzania had 8499 NGOs as of September 1998. (Vice Presidents' Office, NGO Calendar).

Across Africa, (FHI/USAID, 2002) the 1980s marked the beginning of mushrooming of support groups and AIDS service organisations (ASO), non-governmental organizations (NGO), and community based organizations (CBO) involved in AIDS care advocacy. The Ugandan AIDS Support Organization (TASO), the Salvation Army AIDS Project in Zambia (Chikankata), and WAMATA (Walio katika Mapambano na AIDS Tanzania, meaning "Those in Struggle Against AIDS in Tanzania") began to make an impact on the care and support of AIDS affected families and people living with HIV/AIDS. Further more (Hartwig, 2001) these groups also began to form linkages with similar organizations in other countries. The London Lighthouse, the International Coalition of AIDS Services Organizations (ICASO),

and the AIDS Coalition to Unleash Power (ACTUP), were some of the partners that influenced the work of the African organizations.

Locally, too, they began to influence change thus by late 1980s and early 1990s a number of non-governmental organizations including community based organisations, AIDS service organisations, Faith-based organizations (FBOs) have been involved in care and support for people living with HIV/AIDS. In early 1980s and 1990s most of the governments in developing countries including Tanzania were undergoing structural adjustments which led to privatization of most social services for their people. Life became very hard for low-income and poor people when the state introduced policy of cost-sharing for every service people needed. In addition, during that time there was little knowledge and education about HIV/AIDS in the society such that care and management of the disease at individual and community level was limited. According to a joint report by (FHI and USAID, 2002), some of the pioneering AIDS care programs included those by WAMATA, Pastoral Activities and Services for people living with AIDS in Dareslaam (PASADA), SHDEPHA in Dareslaam, the Anglican Church in Dodoma and both the Evangelical Lutheran (ELCT) and the Catholic Church in Kagera and Arusha. Service Health and Development for People Living with HIV/AIDS (SHDEPHA) organisation was started in the early 1990s.

Like elsewhere in sub-Saharan Africa (Mesaki, 1993), every family in Tanzania has lost someone either in kinship relations, at work, or in the neighbourhood, where funerals are held each day. Unlike the biomedical explanations witchcraft beliefs in the society did not induce the fear of contagion that has led to the stigmatization of HIV-positive people. Witchcraft was believed to affect only the person to whom it is directed or intended, where as contagious disease can affect all with whom the infected person has contact. Thus with knowledge that AIDS is an incurable sexually transmitted disease, families began retreating from the tradition of caring for members who had been diagnosed with AIDS. As some authors on AIDS in Africa have suggested, (Thindwa, 2002) compassion needed to be restored in the African family, which historically had maintained a tradition of supporting its most vulnerable members (Thindwa, 2002; Mesaki, 1993 in Kaijage, 2004:6)

By the early 1990s (Sangiwa et al, 2000) WAMATA and other ASOs had begun to provide alternative care for AIDS patients at home. Hence the value of family was restored and home care encouraged. All these helped to bring about positive changes in the society and African community response to HIV/AIDS slowly emerged. With availability of antiretroviral

therapy that is helping the people with HIV/AIDS to live longer, Cvitanic, (1993) there is a need for interventions to promote health and prevent further HIV transmission. It is important therefore to combine all efforts to sustain PLWHA in good health as long as possible at the same time preventing further risks of transmission to self and others. According to (NACP, 2002:30) the Tanzania programs by AIDS Commission (TACAIDS), the NACP of the Ministry of Health, professional associations, and a variety of non-governmental, ASOs and private organizations have played a big role in mobilizing the public to access available treatment and also to prevent further spread of HIV/AIDS. The major mobilization tool has been media, especially the radio, unlike television and newspapers which serves mostly the affluent population.

3.4 Government strategies in abatement of HIV/AIDS

HIV/AIDS was declared as a national disaster in Tanzania in 1999 by the Third phase President, Honourable Benjamin William Mkapa. According to (National multisectoral strategic framework on HIV/AIDS, 2003-2007) HIV/AIDS is discussed as a major hindrance to development and is among the government's top challenges, together with poverty alleviation, improving social sectors and other development problems. Since 1987, HIV/AIDS intervention programmes have been coordinated and directed by the National AIDS Control Programme (NACP) under the Ministry of Health. The country response took the form of a Short –Term Plan (STP) where as, in the first phase; the Ministry of Health implemented a two-year Short Term Plan (1985-1986). The main aim of the Short Term Plan was to mobilize and train health care workers about the disease and to develop blood transfusion safety standards. During the subsequent phases, five-years Medium Term Plans I, Medium Term Plan II and Medium Term Plan III that ended in 2002 were developed and implemented. These plans treated HIV/AIDS mostly as a health challenge, with little emphasis on mitigating its effects on other sectors. However, the National AIDS control program mainly concentrated on monitoring, research and prevention.

Furthermore, a new National HIV/AIDS Multisectoral Strategy Framework (NMSF) was formulated in 2001 in line with the National Policy on HIV/AIDS. The policy on HIV/AIDS was a multicultural response in which Tanzania Commission for AIDS (TACAIDS) became operational in 2000. Essentially, its role was to facilitate strategic leadership and multisectoral coordination, monitoring and evaluation of national responses. The commission was given the task of assisting every sector in planning, budgeting and mobilizing financial and human

resources for its own HIV/AIDS-mitigating and control programmes. This would involve all government and private sectors, the bilateral and donor community NGOs, local government councils who would in turn coordinate and involve the public and private sectors, NGOs and religious groups in the fight against HIV/AIDS. In addition the objective of the new policy were to strengthen sectoral roles, ensure political and government commitment in the prevention of the spread of infection, encourage voluntary HIV testing and increase care for PLWHA and their families. Other objectives were to enhance research efforts, ensure the revision and creation of legislation regarding legal and ethical issues on HIV/AIDS (Tanzania Policy on HIV/AIDS, 2001)

Despite the above mentioned efforts and the large numbers of people affected (ILO, 2004) the fight against HIV/AIDS has so far been very much a Ministry of Health responsibility. However, Ministry of Education and Culture (MOEC) and the Education department work together on HIV/AIDS. The education sector in Tanzania works within the framework of education policy of 1995. This policy guides the provision of education in Tanzania and focuses on increasing enrolment, quality improvement, equitable access and optimum utilization of available resources. The policy however, seems not to take into account aspect of HIV/AIDS. Currently, HIV/AIDS activities/ interventions are based on two non-formal policy documents supported by the National Policy on HIV/AIDS of 2001 that focus on school youth and adults and MOEC guidelines on AIDS Education and Life Skills.

Through National multi-sectoral strategic framework, the multisectoral AIDS Project has being implemented with support from the World Bank. The project aims at financing national programs on HIV/AIDS for both the Mainland and Zanzibar Government, non-government, civil society and community organisations. To this end, the project components will mobilize communities to expand, and strengthen activities to be funded within the full spectrum of HIV/AIDS responses for prevention, care, and support, as well as mitigation of socioeconomic impacts of the epidemic. The conceptual basis for this component is that, the factors determining the spread of HIV are to a limited extent under the influence of the Government; thus civil society has to play an important role as a partner responsive to the epidemic. Another component of the project will provide funds to strengthen prevention, care, and mitigation of the epidemic through public sector programs, by supporting the Ministry of Health in the HIV/AIDS work-plan that includes medical interventions, procurement of commodities and services, and awareness campaigns; also support other ministries,

departments, and agencies (MDAs) to implement their own comprehensive work-plans, addressing both the internal, and external impacts of the epidemic in the specific ministries relative to their work. On the other hand, capacity building, information education and communication campaigns, and impact studies will be supported. Further more, the project will support TACAIDS in fulfilling the HIV/AIDS coordination mandate, i.e., its advocacy, providing leadership responsive to the epidemic, and monitoring and evaluation responsibilities, including institutional strengthening, and core functions related to the commission's mandate.

According to Health sector's HIV/AIDS strategy 2003-2006, Ministry of Health has a comprehensive and developed strategy on HIV/AIDS. As HIV/AIDS become the major cause of adult morbidity and mortality in Tanzania, its serious impact on the health services has affected the quality of care and led to an attrition of the work force. The Ministry feels that the implementation of a comprehensive health sector strategy will assist in the future process of priority-setting and resource mobilization. As in the past, the priority HIV/AIDS interventions planned is in the areas of preventions, care and support and impact mitigation. A run through the Ministry's strategy showed that most of the activities planned are in areas such as training, home-based care, counselling, psychological support and palliative care, comprehensive management of opportunistic infections, nutrition and integrated HIV/AIDS/TB care. On the other hand, in Antiretroviral Treatment (ART) programme which started in 2004, the government aimed to put 65,000 patients on treatment by end of the year 2005. However, according to (TACAIDS,2005) until December 2005 about 96 sites were providing ART and number of people receiving the treatment increased from 2,000 people at the beginning of 2005 to over 22,024 by mid December of the same year.

In summing up, the Tanzania government response to the AIDS for a long period has primarily focused on containing and preventing the disease. In order to slow the spread of the disease in already affected areas, the government work with NGOs to establish condom distribution programs and educational campaigns designed to change people sexual behaviours. Although containment and prevention efforts could play an important role as part of overall strategy for combating HIV/AIDS in Tanzania, they have not been overly effective by themselves.

As it is argued that HIV/AIDS is rooted in problems of underdevelopment such as poverty, food and livelihood insecurity, socio-cultural inequalities and poor support services and infrastructure; AIDS specific responses alone are unlikely to contain the spread or mitigate the impact of the epidemic. Therefore all sectors including Ministries, Departments and Agencies policies need to have approach that address broader developmental problems across sectors, highlighting the specificity of HIV where necessary. On the other hand official formulated policy documents should be made aware to the implementers and the public as whole since there is perception that some policy documents may exist but the relevant departments and other implementers are not aware of the document.

Further more, media organizations as a sector must be educated and empowered to provide accurate coverage of HIV/AIDS issues and events because media play a pivot role in reflecting the policies environment and in defining and influencing it. However, the general public have not been educated enough about the need to respect human rights of people with HIV/AIDS and this has permitted HIV-related prejudices to flourish and has driven HIV/AIDS patients underground in an effort to avoid stigmatization associated with the disease. However, closer examination of relevant laws or regulations and their enforcement concerning human rights and the stigma of HIV should be considered. Thus, majority of people do not know their HIV-status although they may be already infected, and spreading of the disease is carried forward.

3.5 Determinants and Dynamics of the HIV Epidemic

Tanzania is faced with a generalized and concentrated HIV /AIDS epidemic which has reached over 10 per cent of the sexually active population and continues to rise in most parts of the country. HIV transmission is estimated to be about 80 per cent through heterosexual contacts; less than five per cent is attributed to mother to child transmission; less than one per cent related to blood transfusion. Other transmission routes like intravenous drug use, professional accidents or through traditional skin practices are rare. Although most people have heard about AIDS and know how HIV is transmitted (TACAIDS, 2003) widespread gaps and uncertainties in people's mind on HIV transmission continue to exist. Despite prevention efforts in the last 16 years, there is little sexual behavioural change. Although most people are personally affected in one way or other by HIV/AIDS, large portions of the people seem not feeling the risk.

In addition to programme issues which impact on the dynamics of the epidemic, the main factors determining and driving the spread of HIV in Tanzania are the prevailing sexual relations especially involving young persons and underlying social and cultural factors like polygamy, widow inheritance and stigma towards HIV/AIDS in the society. Sexuality is still largely a taboo subject in families, schools and in public education /information. The construction of sexual relations in the society and among different population groups is still poorly understood. Traditional male dominated gender relations and poor economic opportunities impact negatively on the capacities of girls and women to be in control of their sexual relations, thus making them more vulnerable to HIV infection. Moreover, cultural practices like widow inheritance in some ethnic groups, customary laws which do not allow property inheritance for women and gender inequalities in many societies compounds the spread of the disease especially in women. Most women face problems in accessing and owning property and other valuable belongings of their husbands after death.

Furthermore, poverty in all its facets reduces the capacity of the public and private sectors to provide quality services in education, health and social security for responding to the threats of the epidemic. It also limits the capacities of individuals, families and communities to access existing services. Poverty at individual, family, community and national levels is considered to be the major determinant of spread of the epidemic, whereby HIV/AIDS is creating a vicious cycle by increasing the level of individual and family poverty thus more vulnerability to HIV infections.

CHAPTER FOUR: METHODOLOGY

Introduction

In this chapter method, techniques and procedures followed in the field will be discussed. Essentially, the chapter will focus on description, explanation for research design and justification of research method used, sample selection, respondents' demography, techniques used to generate data, and the analysis. Others themes are reliability and validity of data, ethical issues considered, and difficulties encountered in designing the study and carrying out field work.

4.1 Study Design

Social science research is a process of trying to gain better understanding of the complexities of human interactions through systematic means (Marshall and Rossman, 1989). In the most elementary sense, the design is the logical sequence that connect the empirical data to a study's research questions and ultimately to its conclusion. Research design can be described as the plan that guides the investigator in the process of collecting, analysing and interpreting observations. It is a logical model of proof that allows the researcher to draw inference concerning causal relations among the variables under investigation (Nachmias, 1992 cited in Yin, 2003:21). This logical plan is as blue print of research, and it should address some questions like what to study, what data and how to generate them, how to analyse the data and reach the conclusion.

Qualitative and quantitative are frequently used to identify different modes of approaches to research. Quantitative research presents its results statistically by numbers or figures. On the other hand, qualitative research data and results are presented by words or narrations. The two research approaches differ in their assumption about reality, research purpose, methods or process, researcher's roles and importance of the context (Mc Millan and Schmacher, 2001). However, Ragin provide a key difference by mention that, quantitative research work with few variables and many cases where as qualitative researchers rely on a few cases and many variables (Ragin, 1987 cited in Creswell, 1998:15).

Designing a qualitative research is an ongoing process that involves tackling back and forth between the different components of the design, assessing the implications of goals, theories, research questions, methods and validity of one another. It does not start from a predetermined starting point or proceed through a fixed sequence of steps, but involves interconnection and interaction among the design components (Maxwell, 2005:3). On the

other hand, Creswell defines qualitative research as an inquiry process of understanding based on distinct methodological traditions of inquiry that explores a social or human problem. The researcher builds a complex, holistic picture, analyzes words, reports, detailed views of informants and the study is conducted in natural settings (Creswell, 1998:15).

In this thesis, an exploratory qualitative research study of nutritional support and care services for people living with HIV/AIDS was conducted. Qualitative methods are appropriate when a complex social phenomenon is to be studied (Guba & Lincoln, 1981; Marshall & Rossman, 1989). Qualitative approach was used for this study because there is little or no knowledge about the phenomenon of how HIV- infected persons manage their nutrition and health. An ordinary or natural inquiry provides the most comprehensive understanding of the phenomenon of nutritional support and care services for HIV infected individuals and their perspectives. Merriam (1988) points that a case study is an exploration of a bounded system or a case over time through detailed, in-depth data collection involving multiple sources of information rich in context (Merriam, 1988 cited in Creswell, 1998:61) More over, case study method is selected for this research as it provides an opportunity to get into deep insight of a phenomenon and its context and also retain the holistic and meaningful characteristics of real life.

The qualitative approach in this study consisted of interview and observation. As for this study in particular, in depth interview was conducted and this was face- to- face or one- to - one interview. Through this method interviewer managed to extract more information from the individual because of the flexibility of the interview itself. Judd and colleagues, (1986) explains that, the flexibility of the interview if properly used helps to bring out the effective and value-laden aspects of respondents responses to determine the personal significance of their attitude.

On the other hand, observation has ability to describe naturally occurring events in natural settings. It provides the opportunity to document activities, behaviour and physical aspects without having to depend upon people's willingness and ability to respond to questions (Taylor-Powel and Steele, 1996). Thus observation may be particularly informative about activities that can not be talked about because of ignorance, inability (such as non verbal behaviours), fear or embarrassment. During interview, direct observation of non-verbal body language expressions was recorded in field note as they also express people's feelings and emotions about the point in conversation. Taylor and Bogdan (1998:90) note that, "no other

method can provide the depth of understanding that comes from directly observing people and listening to what they have to say at the scene". Observing the living conditions of the respondents at their homes also helped to complement and enrich of data obtained.

4.2 Sample selection

In qualitative research, the typical way of selecting settings and respondents is neither probability nor convenient sampling, rather, it falls into another category termed as purposeful selection or by another term purposeful sampling (Patton 1990, Light et al 1990 cited in Maxwell 2005:88). Purposeful sampling was used to identify respondents from HIV-positive individuals who were members of the AIDS Organisation; SHDEPHA meaning Service, Health and Development for people living with HIV/AIDS. It is merely a Tanzanian NGO and also a non religious based organisation which was formed by a group of HIV-positive individuals on September 1993 after deciding to mobilize their resources to fight the stigma and discrimination of people living with HIV/AIDS. This organisation started operating since November 1994 and it has since then expanded nationally with 103 branches currently operating throughout the country and it has been funded by various international organisations including UNDP,UNAIDS,UNICEF, USAID and CARE-International. It also receives funds from the government through NACP and TACAIDS.

Purposeful sampling is a method of selecting the best informant who is able to meet the informational needs of the study (Morse, 1989:117). Respondents chosen in this way are theoretically representative of the culture, role and position needed for the study (Brink1989:157). With the help of the organisation program coordinator who was familiar with members of the organisation, the researcher selected potential respondents to interview about their backgrounds, nutrition, health, sources of information about nutrition and their health and helping institutions.

Selection criteria were age should be between 25-45 years, duration they have been living with HIV should be not less than five years, and they should live in Dareslaam. This age group was selected for this study because it is active adult age group which is considered to be much affected by HIV/AIDS. No one respondent selected refused to be interviewed. The purpose of the interview was explained and consent form translated in Swahili language for the participants, and they said they are satisfied with the explanation of the interview purpose. They were told that interview would last for an hour or more. Participation was voluntary that

participants were free to choosing not to participate or for discontinuing participation at any time. Data generation took place in November and December 2005.

4.3 Interviewee

Six women and four men were interviewed at their homes. Their ages ranged from 34 to 45 years. Five women were widow and one divorced, three men were separated and one man was living with a spouse. As a group the respondents were low educated as two men had secondary school education while others had elementary (primary) school education. The respondents were active in their daily life activities during the study, although they had been hospitalized sometimes for opportunistic infections particularly tuberculosis and herpezotzer, and malaria (frequent recurring). They were financially not secured as no one respondent had formal employment. They all live on different petty businesses like selling fresh fish, food produce such as maize grains, beans, and rice in markets; selling clothes, beads, earrings, necklaces and selling cooked foods in small canteens. Two widows live in houses left by their husbands while other respondent depend on renting a room to live with their children. All women interviewed live with their children (2-4 children) aged 9-15 years. One man lived with his five children and a spouse, while the separated men were not living with children.

4.4 Data generating technique

Data generation methods are the means to answering the research questions (Maxwell 2005:92). Method selection depends not only on the research question but also on the actual research situation and on what will work most effectively to give data needed. Primary data for this study was generated through in-depth interview of the people living with HIV/AIDS and administrators in the NGO which provides services for people with HIV/AIDS in Dareslaam. A semi-structured in-depth interview was used to gain a perspective of the HIV-infected individuals about nutritional support and care services. The interview was one-to-one interview in respondents home. One of the most important sources of case study information is the interview. However, Marshall and Rossman (1989) define interview as a method of data collection that may be described as an interaction involving interviewer and interviewee with the purpose to obtain valid and reliable information. At the same time, observation of the living condition at interviewees' homes was recorded in the field note.

An interview guide (see appendix II) was used to obtain information and to guide the interview. Subsequent questions or comments like "tell me about.... or give me an example

of..., encouraged the respondent to expand their explanation and express more issues about the themes of discussion. Phrasing of the interview question was reworded as necessary to elicit more information during the interview process. Moreover, Bogdan and Biklen, (1982) noted that the respondent might be self-conscious initially. They state that the interviewer must support and assure respondents that the content of the interview is important and that their perspectives are valuable.

The interviewer attempted to be flexible and spontaneous in responding to the immediate interview content. Interviews were audiotaped and field notes were maintained through out the interview to record gestures, body language and observation of living condition at respondents home. Field note book was frequently used to record some information which did not need tape record. These field notes were useful in the later analysis of data and for cross-reference throughout the process of interpreting and analysing the data. Informants' responses were also recorded in the field note. The informants were administrators and programme officers and were used to express themselves so it was easy for a researcher to take notes. The interview with informants was conducted in office to minimize interference of other people.

At the same time, questions from respondents relating to the appropriateness of health or food and nutrition practices were answered if in the questions were within the researcher's expertise. In the response to this, researcher attempted to avoid contaminating the research setting with advice or suggestions that might have affected the interview flow and time. Using grand tour questions (e.g. can you tell me.....) in the interview guide and contrasting questions for more explanation helped to avoid leading the respondent, thus enhance the validity and reliability of the study. In conducting interview the researcher used Swahili language, which is the national language of Tanzania. All people participated in the study could speak and understand this language. As suggested by Silverman (2000), "data analysis does not come after data gathering" If you have one interview or recording or set of field notes, go through it and start transcribing and reviewing your data in the light of the research questions. Thus during field work, record of daily field activity was kept in the field diary and this included reflection ideas on the day's work and preparation for the next day.

In addition, informants from various institutions provided information for this study. Informants were from government and non government organisations addressing issues of HIV/AIDS. These include National AIDS Control Programme (NACP), Tanzania Commission for AIDS (TACAIDS), WAMATA ("Those in struggle against AIDS in

Tanzania”), SHDEPHA(Service, health and development for people living with HIV/AIDS) and CONSENUTH (Centre for counselling, nutrition and health care). Ministry of health and social welfare provided useful reports and documents. Other important materials were from Tanzania Food and Nutrition Centre (TFNC) library, WAMATA, CONSENUTH, and internet websites such as United Republic of Tanzania Government, UNAIDS, WHO and FANTA.

4.5 Data Reliability and Validity

Right from the early stages of writing research proposal one need to consider the quality of the work because this is the basis on which your work will be judged. Reliability and validity are the important criteria used in judging the quality of the research. Maxwell (1996), Kvale (1996) and Silverman (2001) promote the value of applying reliability and validity benchmarks to qualitative research. They argue that these offer the most effective means of evaluating the quality of research; despite the fact that reliability and validity are measurements of objectivity which is a central research issue in quantitative research. However, qualitative researchers appreciate that, Blaxter et al, (1999) research is not a wholly objective activity carried out by detached scientists. It is a social activity powerfully affected by the researcher’s own motivations and values. It also takes place within a broader social context, within which politics and power relations influence what research is undertaken, how it is carried out and how it is reported and acted upon (Blaxter et al., 1996 in Christine and Immy, 2002)

Reliability refers to consistency in the data. If another researcher with similar background were to interview persons with HIV infection, the data should show similar content and yield the same codes and categories. Information obtained from each interview should show the logical progression of ideas about the topic (Brink, 1989). In this study, reliability was enhanced by prompt transcription of audiotapes with additional notes from the field notes including body language of the respondent and from the field diary that incorporated feelings of the interviewer and reflections. Controlling bias due to interviewer fatigue by scheduling one interview per day and allowing the interviewee to decide for the time and place they want to conduct the interview also aimed at enhancing data reliability. Further more, preconceived ideas or theories were avoided to prevent a mind-set towards the interview or respondent. In addition, (Leinenger, 1985) validity in qualitative research refers to the truthfulness and understanding of the data. On the other hand, Maxwell (1996:87) maintains that it is credibility of description, conclusion, explanation, interpretation or other sort of account.

Thus, characteristics of the interview, interview techniques, the interview guide, method of sample selection and data analysis can affect the validity. As for this study, validity was enhanced by conducting the interview in respondents' home; avoid leading questions, transcribing audiotapes promptly and accurately, identifying missing information and revising the interview guide, field notes and memos was necessary through out data analysis.

4.6 Difficulties encountered and strength for the study

The research method approach (qualitative approach) used for this study was appropriate regarding the sensitivity of the study itself and the general concerns in HIV/AIDS. The case study approach on the other hand, and the interview technique was helpful in reaching the insight of individual case. One-to-one interview, use of open-ended questions and use of Swahili language enabled interviewee to express more information during the interview. The study was very useful to my profession of nutrition in the way that it enhanced my understanding on the complexity of HIV/AIDS and nutrition especially for the population represented by the participants of this study.

Despite the strengths mentioned above, there were some dilemmas and hard choices to make during the field work as they were important determinants of the success of the work which was ahead. As for this study, it was necessary for the interview to be conducted at the respondents' home. During the interview there was some interference of neighbours or visitors and we had to stop our conversation for a while until the visitor left the place. At last the interviewee managed to explain to the visitors to come in later after finishing the interview. However, in overcoming this problem the interviewee were asked to choose for a suitable place and time for the interview in order to avoid these interferences. In some circumstances, interview was conducted in late evening time so as to minimize interference and maintain confidentiality.

In addition, the participants of this study were living in very long distance from one another and mostly in outside the city centre and peripherals of the three municipalities in Dar es Salaam. It was really difficult to make appointment with the participants because they were occupied in their daily activities, thus they had mandate to decide for the date and time they felt was convenient for meeting. Due to this scattering of the interviewees' homes it was difficult to conduct more than one interview per day. Travelling from one participant's home in the peripheral of one municipality to another point also outside the city centre was not an

easy work. In ensuring that no time was wasted on waiting for appointment, the researcher used other time of a day to meet with informants in relevant offices and departments and get some documents that provided information needed.

Further more, the language used for interview was Swahili. Therefore translation of all scripts into English language was another extra work. The researcher managed to translate the scripts while maintaining the meaning of the words, sentences or phrases of the interviewee. It was also difficult to get literature materials and studies related to this topic as very few researches have been conducted focusing specifically on nutritional support and care services for people living HIV/AIDS. Most of the studies available are medical researches on nutrition in HIV which are focused upon individual nutrients and biological parameters but not the complex phenomenon of how people with HIV cope with the disease with regard to nutrition and other care services. However, through reading different publications collected from different sources, using internet websites and Bodø University library data base, the researcher obtained some information for literature review of this study.

Time and finance as important resource was limited for this study and the process of transcribing and translating the scripts demanded a lot of time and concentration. Financially, the study was not funded hence more constraints especially the travelling costs to the participants home and bus fare for the participants as well.

4.7 Ethical considerations

A number of basic ethical principles provide benchmarks against which to judge the study as one move through the stages of planning, implementing and outcome of the research. These include the right of free and informed choice, protection from the harm to individual and equipment and principles of privacy, autonomy and honest. In this study, a researcher attempted to ensure that some ethical issues were maintained. These were:

- Obtaining permission from the Regional Commissioner to conduct the research in Dar es Salaam city.
- Informed consent form was prepared and given to research participants to sign after a clear oral explanation of the research purpose and process that will be involved.
- Participants were informed about the right to withdraw from the study at any time during the process.

- Confidentiality of all information from the participants and anonymity were highly maintained throughout the study and findings writing and presentation.
- Participants list, scripts, tapes and transcripts were securely stored and thereafter be destroyed.

4.8 Data Analysis

Data analysis is the process of bringing order, structure and meaning to the generated information using a planned procedure. In this study data analysis followed the bottom-up approach as the process of analysis i.e. starting from raw data, then breaking them into units of practical meaning that led to emerge of themes and lastly core categories where description and critical analysis and discussion begin. Strauss and Corbin, (1998); Coffey and Atkinson, (1996) explain analysis as the interplay between researchers and data. It is both a science and art. It is a science in the sense of maintaining a certain degree of rigor and by grounding analysis in the data. The analytic procedures that underpin coding procedures establish links of various sorts, thus coding links different segment or instances in the data. The fragments of data are brought together to create categories of data that are defined as having some common property or element, link all the data fragments to a particular idea or concepts.

In practice, coding can be thought as a range of approaches that aid the organization, retrieval and interpretation of data. Huberman, (1994) suggests that coding constitutes the “stuff of analysis” allowing one to differentiate and combine the data you have retrieved and reflections you make about the information (Huberman1994 in Coffey and Atkinson, 1996). In another way, segmenting and coding data enable the researcher to think about and with the data. Data interpretation and analysis for this study employed the thematic analysis procedures. Thematic analysis is part of early procedures of data analysis in grounded theory, but grounded theory goes beyond thematic analysis (Ezzy, 2002:87).

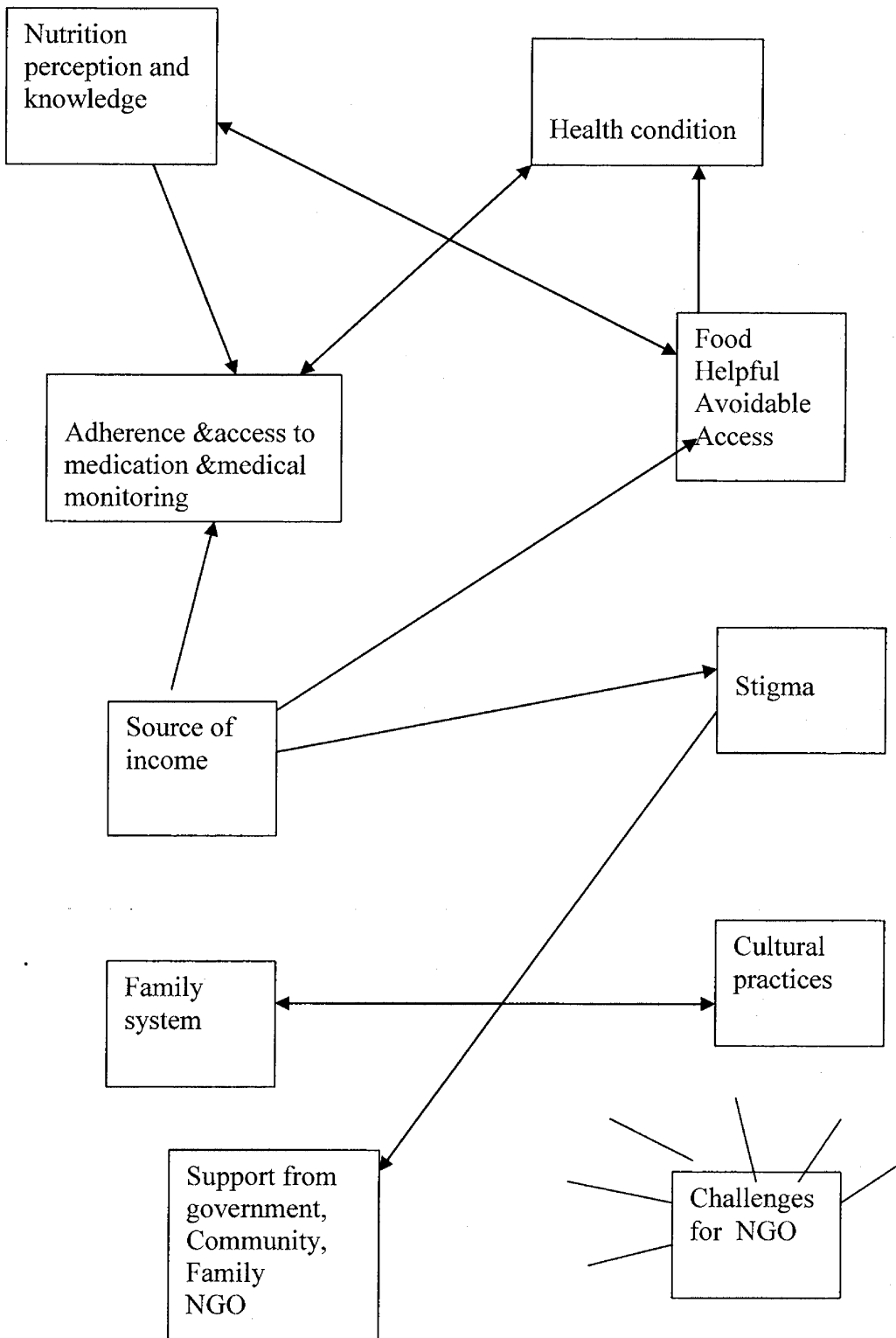
Data from the tape were transcribed, and both transcribed data and data from the field note book were translated into English ready for analysis. Open coding by reading each interview transcripts line by line or word by word, looking for meaningful concepts, in-vivo codes; terms used by respondents was done. This process made the researcher more familiar with the data. Open coding was done in order to reduce the data in to small pieces which are more useful. Giving names for the concepts, writing memos on the names were to and fro process.

Coding is the process of defining what the data are all about (Charmas, 1995 cited in Ezzy, 2002:86) also it is a process of identifying themes or concept in the data. During coding the researcher attempts to build a systematic account of what has been observed and recorded. Glaser described open coding as a way to generate emergent set of categories and their properties (Glaser, 1978 cited in Ezzy, 2002:88). More specifically, Strauss and Corbin describe open coding as the part of analysis that pertains to the naming and categorizing of phenomena through close examination of data (Strauss and Corbin, 1990:62).

During open coding the researcher attempted to find out the meaningful concepts or codes from the text. The themes which emerged were: Accessibility to food, perception and knowledge about nutrition, adherence to treatment [Tb and ARV], Stigma hinder support from relatives and community, access to care services [ARV and monitoring of CD4 counts], lack of formal employment [only petty business], family system [widow, single man], most important support services needed [food support, education support for children, facilitation to run their life], inadequate resources in NGO to meet people needs, dependency on donors. Others were difficult access to resources from government, diversion of fund to other purposes, lack of human resources in NGO, no overall national coordinating body for HIV/AIDS organisations.

The next step in coding is described as axial coding. This involves specifying a category in terms of the conditions that give rise to it, the context in which it is embedded, managed, carried out and the consequences of those strategies (Strauss and Corbin, 1990:97). The aim of axial coding is to integrate codes around the axes of central categories. In axial coding the researcher looked for relationship between the themes emerged in open coding so as to form categories. The categories emerged were also interrelated in forming a common pattern of problems related to nutritional support and care services for people living with HIV/AIDS. The categories were: **Nutrition perception and knowledge, adherence and access to medication and medical monitoring; cultural practices; health condition; source of income, family systems, stigma, support from family, community and NGO; foods helpful, access; NGO challenges.** These categories are presented in the diagram below and relationship is indicated by arrows.

Analytical Categories



Key:

- One way related themes
- ↔ Two ways related themes
- Related to all

The diagram above illustrate the general picture of the findings and it can be noted that nutrition perception and knowledge and income influence adherence to medication. Income was also found to influence access to food and stigma, where as this stigma also affected access of support from the family and community. Categories which were found to have similar discussion from the interviewees were merged together. However, Challenges for NGO was found to be related to all categories since PLWHA in this study rely on this organisation for support and care services.

The final stage in coding (Strauss and Corbin, 1990) is selective coding. This involved the identification of the core categories on which the analysis focuses. At this stage the researcher attempted to focus attention on the key components, the most significant categories and concentrate her efforts for discussion and critical reflection about the phenomenon in the study. The significant categories emerged were: **Nutrition perception and knowledge, Source of income, Stigma related to HIV/AIDS, Adherence &access to Medication and medical monitoring, Gender related cultural practices in the society, Support from Formal and Informal institutions, and Challenges for NGOs in providing services.**

These categories formed the main findings of this study and will be discussed in chapter five of this thesis.

CHAPTER FIVE: MAIN FINDINGS AND DISCUSSION

5.1 Introduction

Nutrition is important in preventing infections and maintaining the immune system. Kotler et al (1989) found that poor nutritional status as defined by loss of body cell mass was the life-limiting factor for persons with AIDS. Increased metabolism as a result of HIV infection may compound the problem (Hommes et al, 1990). For people living with HIV/AIDS, food impacts the quality of life by providing body mass, energy and immunity against opportunistic infections. However, persons who maintain their weight appear to live longer after HIV diagnosis.

This chapter explores and describes problems related to nutritional support and care services for people living with HIV/AIDS based on interviews conducted during field work. The analysis highlighted the most important concerns that were expressed by the participants. The findings are organised in themes or categories as highlighted in chapter 4.9 of this thesis. However, the themes are strongly linked and cut across each other as such; some repetition of key points in discussion is inevitable.

5.2 Nutrition perception and knowledge

Food habits are among the self-behavioural changes among people with HIV/AIDS after diagnosis. More often, (Derdiaria & Schobel, 1990) changes occur in stamina, relationships, sexual function, rest and recreation and dependence. Specific dietary behaviours that were altered and how the subjects decide to make the changes were not explored. However, eating enough and balanced meal that include protein, energy, fat, vegetables and fruits was explained as one of the dietary change people made by respondents. It was observed during the interview that respondents believed that nutrition is important for their health, but for their case they feel that they do not get satisfying nutrition, thus they do not meet their body requirements.

*“Nutrition gives me strength to do my daily life activities and keep me in good health”
(35years widow)*

“Sometimes I have nothing to cook for me and my children because of difficult life here in town, so if we get small food we just eat to survive but not satisfying” (40years widow)

Belief in the use of nutritional supplements is prevalent in HIV-infected persons. In this study, it was found that respondents had the same perception about nutritional supplements but they admitted the high cost of supplements compared to natural home prepare food. This is supported by (Abrahams, 1993, Bandy et al, 1993) as they found that vitamins, minerals, and traditional Chinese medicines preparations and healthy food products such as pollen, amino acids, and cod liver oil are used as complementary health care modalities.

“The nutritional supplements are for rich people, but for me I need food which I can share with my children because they depend on me” (45years man)

Among the identified causes of nutritional problems in Tanzania (TFNC, 2003) these include poor food intake related to traditions, customs and practices. This has led to ignorance about nutrition in the society. The respondents in this study showed their concern that with the current situation of HIV infection; nutrition can be one of the strategies to cope with the epidemic since no curative treatment is available at present. The antiretroviral drugs are not meant to cure the disease, but to minimize the multiplication of the virus by improving the body immunity. On the other hand, locally available foods including fruits and vegetables might be more affordable than processed foods. Therefore; nutrition counselling should begin at the time persons are informed that they are infected. Furthermore, health workers at places where HIV testing is done could assist in these educational efforts. Nutrition education and counselling with respect to context can help to change the perception and improve knowledge and practices of people living with HIV/AIDS.

In this study, nutrition information was found to be very important among people living with HIV/AIDS as it helps them to manage the symptoms and make themselves feel better. Respondents explained that they need information about foods that are helpful in different complications they face and how to prepare these foods. They need to have knowledge of what foods to buy when they have some money. People were explained that they would like to eat something which can help their bodies. Straus et al., (1984) suggest that, the use of special foods and supplemental nutrients may be common in persons living with HIV/AIDS. Therefore managing dietary intake to control their disease may become a serious occupation for HIV-positive persons who use all available resources to determine what they should eat to protect their health. The interviewees explained their experience with foods which they find helpful in situations when they have complications as result of HIV infection.

“If I don’t eat vegetables for long time like one week, I get skin problem like rashes and itching. Also eating fruits after meal helps me to feel comfortable and satisfied with the amount I eat because since I started the ARV ; I eat much.” (40years widow)

“Usually I feel stomach pain when I eat beans, and soft drinks (like soda) are not good for me because they increase the fungal infection I have in my reproductive parts but fruit juice has no problem if I drink it” (38years woman)

Since people infected with HIV may be receiving nutrition information from various sources like group meeting, friends, radio programmes and from the NGOs, we can see how networks play role in information transferring. However the information messages need to be correct so as to help in management of their health. Anderson et al, (1993) noted that people living with HIV/AIDS more often obtain information about nutrition from friends than from health professionals. Group net-works are used by HIV-positive for social interaction whereby sharing of ideas, knowledge and experiences takes place.

“We learn from each other when we meet in our monthly meetings because people feel much free so they tell much about their experiences and management of some complications or symptoms when we meet” (42 years widow)

Almost all respondents reported that they had received nutrition information from the NGO; the SHDEPHA, group member, seminars and rarely from radios and reading materials. On the other hand, Lovejoy et al, (1988) found that HIV-infected people preferred to obtain information about managing their diseases from nurses, physicians and other health professional rather than from pamphlets. The reasons for this as explained by respondents were not having the radios, they live in houses without electricity and some lack time to listen to radio because they are busy in their daily works. Therefore interviewees’ nutrition knowledge was more influenced by learning experiences from themselves in group discussions and friends. In addition, attending seminars organised by the organisation help them to learn how to take care of themselves with regard to the disease.

5.3 Source of income

Care and support needs of HIV-positive people are considered poorly understood and poorly met due to lack of resources in most of poor countries. People living with HIV/AIDS need access to appropriate treatment, care and support including income support to meet their basic life needs. Lack of formal employment or reliable source of income was found to affect the ability of households to acquire enough and nutritious foods for healthy lives. Households are said to be food secured when there is food availability, accessibility, stable supply and quality food.

For rural areas, the availability and quantities of nutritious foods depends on production activities in the family. However, food purchase by urban dwellers depends on the household income. Petty trading was found to be the most source of income for people in this study. The activities involved selling of fresh fish, clothes (used clothes), beads earrings and necklaces and selling foods in small canteens. Due to small capital they have their businesses are also small thus little earnings. Selling of belongings like household furniture was one of the means used by most of people to get some money to buy food before joining the AIDS organisation to get loans. Others also sold their furniture and other valuable belongings in order to get money for starting small business to enable them to buy food and other basic requirements.

“I started selling my furniture one by one until they were all finished, so I was stuck until I joined this NGO; it is helping me very much” (39years widow)

The source of income here seems to be not reliable because their business activities are not stable due to loss of capital when the business is not successful and time they have to these activities is also limited in circumstances when they are sick, also they are forced to spend the little money they have without earning.

*“My business is now stopped because I was admitted in hospital last month and I used all the money when sick so I’m now requesting for another loan to start it again” 34years man
16/11/2005*

This cumulative insolvency increases people living with HIV vulnerability and become dependent on support from relatives, neighbours or community and NGOs. Lack of government support for households affected by HIV/AIDS exacerbates this situation, threatening the life of many poor people infected with HIV and their children. Other studies have indicated that increasing economic hardship is associated with disease progression and

appears to be a consequence of both increased expenses (Bowie et al., 1996; Cunningham et al., 1995), and decreased likelihood of employment. Stress and depression faced by people living with HIV/AIDS as a result of difficult life they live was explained to make their life more short.

“If you have food in the house, even if you don’t get money in the business you are sure of something to eat with your children. But now I woke up in the morning with nothing in the house and no money to buy food; I feel sad and much thinking of what to do” (45years man)

Food safety and hygiene is very important for people living with HIV/AIDS because they are more vulnerable to infection as their immune systems have already been weakened. Proper handling of food and water is especially important to avoid infections caused by bacteria and viruses in contaminated foods and water. Maintaining the hygiene standards was observed to be low in interviewees’ home as they lived in one room with children and individual possessions and this made it more difficult. Supply of clean water for drinking was also a problem, thus people need to treat water for drinking by boiling. This on the other hand was not affordable by everybody, although it jeopardise the health of people living with HIV/AIDS.

“I can’t afford to buy charcoal or kerosene for cooking food and boil some water for drinking. I have also to buy the water for everyday use and all this need money. So, I just trust the water we get from the tape although is not clean.” (40years widow)

Income support for people living with HIV/AIDS is important to enable them to meet their basic life needs including food for themselves and their families. However reliable income source or support is also crucial to support their children who depend on them for other important needs like school needs. Although primary school tuition in Tanzania is free, children are required to provide writing materials, text books, and school uniforms as well as to bring food and pay for travel expenses. These are often beyond the means of families. This problem becomes worse once the children reach secondary school where fees are charged. At public school annual fees are Tsh 40,000 (40 US dollar) in addition to transport, food, uniform, text books and exercise books. In private schools the fees are much higher depending on the school status. Orphans and children of people living with HIV/AIDS can only afford this with the support from the NGO. However the NGO have no capacity to support all children due to lack of adequate resources. Furthermore the NGO is supporting

orphans for education in public schools, thus this seem to be irrelevant for the AIDS organisation to pay for an orphan education in government school.

Unless people living with HIV/AIDS are actively supported to meet their basic needs and their families, the families and communities will fall into more poverty than the existing one, thus the impact of HIV/AIDS will not be abated. This is because the spread of HIV is likely to continue if poor women opt to have a relationship with men in order to get support to meet some basic needs. It was disclosed by the interviewee that the support they get from the NGO is making them independent and manage their basic needs; otherwise women have to find some men partners for support. This in turn put them in to risk of contracting more virus perhaps of another HIV-type and also spread of infection to other people.

“A woman may choose to have a man who can help her because she don't have any means to help her self and the children, but if you are managing your life.... you don't need to sell your body to get money. Also we know that if we avoid sex we can live longer because we don't get more viruses” (40years widow)

Women's economic dependency to men increases their vulnerability to HIV. After the loss of a husband, a HIV-positive woman in certain social situations may have to find an income or secure financial and social security through another relationship. Research has shown that (Elias and Heise,1995) economic vulnerability of women make it more likely that they will exchange sex for money or favours, less likely that they will negotiate safe sex and less likely that they will leave a relationship that they perceive to be risky. Therefore empowering women and guaranteeing them their economic and social rights should not be an option because failure to meet the life basic needs among person infected with HIV including women was found to be a big life challenge. On the other hand this may become a hindrance in success of intervention programs aimed at preventing spread of the disease.

5.4 Stigma related to HIV/AIDS

Stigma and discrimination are global problems which hinder control and prevention efforts as they increase denial about the issues of HIV/AIDS in many societies. Provision of services and care support for infected individuals and affected families is also hampered by stigma since prejudice against people with HIV/AIDS exists in most societies although not shown publicly. Stigma and discrimination are closely related although stigma is often referred to undesirable attitudes that are incongruous with our stereotype of what a given individual

should be (Goffman, 1963). Likewise, discrimination focuses on the actions, treatment and policies that arise from such attitudes which may violate the human rights of people living with HIV/AIDS and the ones close to them (UNAIDS,2000).

Although society has greater information and understanding of the transmission mechanisms and effects of HIV, the problem of prejudice still exists. Indeed, recent research still identifies the ways in which society can reject the needs for services for those with AIDS and (Takahashi, 1997) the “Not in my back yard” syndrome still exists. Death, although not a taboo, it retains fear for many people in many societies. AIDS confronts the non-infected people with the reality of death that they are reminded about their own mortality; this challenge engenders a distancing- stigmatising response (Mason et al., 2001). Stereotyping also highlights prevailing societal prejudices and greatest prejudice is often shown towards sufferings from an infectious illness that primarily affects marginal persons (Dukes and Denny, 1995).

The tendencies to view HIV/AIDS as something which happens to other people and particularly to people who are different in behaviour can lead to stigmatising response by the society. In Tanzania HIV is mainly transmitted through heterosexual intercourse. The means of contracting HIV, the spread of the disease and the media portrayal of it as affecting marginal groups like sex workers or drug users lead to an infected person facing stigma in more than one way. It was disclosed by the interviewee during interview that people in the society have negative attitude towards HIV infected individuals. Although this is not shown publicly, PLWHA are looked by other people in the society with different perspectives. They are considered as promiscuity people to their partners, sinful people and they are generally thought to have adultery behaviour which made them contract HIV.

“We are regarded as people who have deviant behaviour, adulterers, prostitutes, no future life and careless people in the society. People say we are just like moving dead bodies”
(38years woman)

Sociologists have also highlighted societal responses which have led to the search for scapegoats and thus to a distinction to be drawn between the innocent and the guilty (Paicheler, 1992) the later being those people infected by virtue of their own sexual or drug related behaviour. However, biophysical changes in the HIV disease trajectory is usually the same that one can not draw a distinction between the innocent and the guilty, thus the innocent victims also experience stigma. The interviewees in this study commented that

people living with HIV/AIDS face stigma regardless of the circumstances they acquire the infection.

“My husband’s relatives abandoned me completely after he died and they kept on accusing me for bringing death to their son” (43years widow)

Although there are varieties of diseases which are stigmatising, it is important to distinguish the case of someone stigmatised for a purely physical traits such as facial disfigurement from that when the stigma accompanies with judgements which are related to a stereotype. The HIV-positive person may be stigmatised not solely for being positive but also for assumptions regarding their sexual life style and other stigmatising characteristics such as drug use. Most adult HIV infection in Tanzania is associated with sexual life style, alcoholism and drug use. However, people can contract HIV by other means including infected blood products or blood transfusion. On the other hand rich and poor people experience stigma differently. Studies have shown that (Nyblade et al., 2003) poor individuals with HIV/AIDS experience greater stigma because they have the fewest resources to cope with and resist it. The rich can afford to get care from outside the community, even abroad, ensuring that no one in the community will learn their HIV-positive status. In contrast, poor people are often forced to disclose their status to family and relatives in order to access services and benefits, but this on the other hand makes them more vulnerable to stigmatization by people in the family, relatives and the community they live.

Stigma and discrimination are likely to be higher and the level of care is less for poor versus rich people with HIV. At most basic level this is simply because the poor can not afford health care or equally good health care as the wealthy. At the same time it was mentioned in the interviews that poor people with HIV are stigmatized precisely because they are poor and marginalized and that the rich get better care in health system in the community because of high social status that their wealth bestows on them. However, stigma from health care providers was not explored in this study and according to respondents most of rich people with HIV were known to get services from private hospitals.

The data also highlights that stigma towards people infected by HIV/AIDS is manifested in differential treatment, gossip, loss of identity or role and loss of resources and livelihood. Nyblade et al., (2003) noted that people living with HIV/AIDS internalize the negative views of them, leading to feelings of guilt, self-blame, inferiority, and self isolation, and despair, loss of hope and abandonment of life aspirations. The stigma associated with HIV/AIDS can

have effect of polarising individuals within families into those who accept the HIV- positive person and those who reject them (Powel-Cope and Brown, 1992). People with HIV/AIDS complained being stigmatised at the family level and then community levels, thus hindering support and care for them. During the interview it was revealed that stigma may originate from the family members while at the same time it is difficult to conceal the situation because one need support to manage the life as well.

“I had no place to stay after my husband died, and my brother’s wife rejected me with my children to stay in their house. I walked around looking for place to stay with my children but no body helped me until when I come to this NGO and they helped me with some money to rent this room I’m living now” (35years widow with infected children)

Social exclusion usually manifest itself as the reduction of daily social interaction with relatives or neighbours, exclusion from family and community events and shunning or turning away by the public. During the interview, respondents described how are ashamed by the people and distancing where friends and neighbours no longer visit or visit less often. They also reported being excluded from family and community special events and gatherings like wedding ceremonies, family councils or meetings.

“People just decide not to bring you invitations to participate in events like weddings because they assume you can’t afford to contribute so they see you just like not existing. So you need to compel this interaction by showing eagerness to contribute and participate, otherwise you are likely to be isolated; but again you should have something to contribute!”

(43years widow)

Promoting deeper understanding of HIV and AIDS to the public will reduce people stigmatizing and discriminatory actions against people living with HIV/AIDS. Data from this study show that the knowledge of HIV/AIDS is limited, thus society need more information. Lack of in-depth knowledge about HIV and AIDS among the people in the families, neighbours, relatives and the society in general may contribute to stigmatization. Although people may know how HIV is transmitted, (Nyblade et al., 2003) more detailed information of other aspect of HIV and AIDS are incorrect or missing together. People need to understand the difference between HIV and AIDS, how the disease progress and the longevity of a person with HIV.

5.5 Adherence, access to medication and medical monitoring

Access to antiretroviral drugs (ARV) is increasing among people living with HIV/AIDS in developing countries as a result of local, national and international efforts. However, all respondents in this study reported they had started using the antiretroviral treatment. During the interview they explained that their health has improved after they begin using the ARV treatment.

“My health is somehow good now compared to last year. I have gained weight from 50 to 60kg now, also every day illnesses are not coming to me, I can stay more than a month without getting malaria, fever, etc. I would like to maintain this health if I could manage” (35years widow)

Uncertainties about sustainability of the treatment and possible long- term side effects were also concern of respondents during the interview. Some interviewee reported having problems like taste changes, nausea, dizziness, and numbness in finger tips and toes after they started the treatment. The side effects of some medications (FANTA, 2004) can lead to reduced food intake or reduced nutrient absorption that exacerbate the weight loss and nutritional problems experienced by people living with HIV/AIDS. However, the prevalence, frequency and severity of side effects vary among the ARV drugs, and among individual patients. Most of the interviewee reported to have increased appetite and, they feel to eat more frequently than before.

“Since I started this treatment...I eat much and I feel hungry every time; you know I eat like a baby,... eating several times a day” (40years widow)

Issues related to antiretroviral treatment (ART) in resource limited settings have become increasingly relevant to people living with HIV/AIDS, care givers, service providers and programmers. Interaction between treatment and food and nutrition can significantly influence the adherence to drug regimens, and nutritional status of HIV- infected people. In resource limited settings many people with HIV/AIDS lack access to sufficient quantities of nutritious foods, which may pose additional challenge to the success of the antiretroviral treatment. Obtaining sufficient good quality food was reported to be difficult by all interviewees. This was considered important for sustaining general health and aiding recovery from common infections they get, but also to maintain regular meal times and take ARV as prescribed was related important. They mentioned their difficulties to coordinate their regular doses when they are not certain of having some food to eat.

“Some weeks ago, I was down with malaria and I could not go out to the market for my business to get money for food, so I had to stop taking my medicine because this drug makes me feel more weak if I don’t eat” (34years man)

Moreover, on receiving the ARV, people are usually advised to eat balanced diet but, they had no detailed information as to what this should be. Although access to ART in developing countries is expanding, the majority of people living with HIV/AIDS still do not have access to antiretroviral treatment (WHO, 2003). In this study, almost all interviewee were getting treatment from the NGO, not from the government health centres. They commented that, in order to be eligible for the government scheme for antiretroviral treatment one should do tests like CD4 T-cell count, viral load, liver function and others associated with starting and monitoring antiretroviral treatment. The cost for these tests is so expensive that low income people can not afford them. Furthermore; the interviewee explained that they face a lot of bureaucratic procedures in public hospitals, and find it more convenient to use the NGO. According to ART guidelines in Tanzania (NACP, 2005), all patients with CD4 T-cell counts less than 200 and those at AIDS stage 4 (WHO classification) are clinically eligible to begin the treatment. However, some patients get this service at very late stages, thus a possible effect is not seen before they die.

“Some people (especially those very sick) are dying before they get confirmed to start the treatment because it takes long time to get results for all the tests in public hospitals. But also they can not afford to go to private hospitals, so they just wait and die before they get the service” (45years man)

For HIV-positive persons, monitoring of immune system function after a given period of time is considered very important so that people can take measures to improve their health and maintain the quality of life. The CD4 T-cell counts test is usually recommended for people living with HIV/AIDS to monitor their immune function and mark the progression of HIV infection. Low CD4 T-cell counts are associated with a variety of conditions, including many viral infections, bacterial infections, parasitic infections, sepsis, tuberculosis, malnutrition, psychological stress and social isolation (Info,2006). However, normal T-cell counts are between 500 and 1500 CD4 T-cells per microliter. As mentioned before that tests like CD4 T-cells count are expensive, people with HIV have less access to this service and this contribute to deterioration of their health because knowing the immunity status could help them to take measure to improve or maintain it.

Given the level of HIV-related illness and strong sense of urgency about treatment, it might be expected that adherence would be at high level. However, there was little indication that interviewees were informed of specific strategies to enhance adherence to treatment. They explained that they usually take medicine after meal or some minutes before meal. On the other hand this is challenging when a person has no food to eat when the time for taking the medicine comes. Ensuring a diet with sufficient quantities of nutrients-rich foods is crucial for people living with HIV/AIDS, and nutrition is an integral component of care and support for HIV-positive persons under any condition. People should understand that antiretroviral can reduce the viral loads and contribute to improve health status, but also can create additional nutritional needs and dietary constraints that work against the positive outcomes if not well managed. With regard to this, nutrition needs to be an integral part of HIV/AIDS treatment programs to ensure success in antiretroviral programs in the country.

5.6 Gender related cultural practices

“Our poverty and inequalities in the societies also limit our access to health care and nutritious foods which is not only needed to maintain good health but also affects the possibility of taking up antiretrovirals” (two women complained)

For many women in AIDS affected household, losing a husband is the first of many other losses she may face in her life. Widows in most of the developing countries are generally the poorest and least protected by the law because their lives are likely to be determined by local patriarchal interpretations of traditions, customs and religion. Unmarried women are the property under the control of their fathers; married women belong to their husbands. Women interviewed in this study, most of them being widows commented that being financially dependent and responsible for the care of their families is not a new attribute of their lives but is made more difficult by being HIV-positive. Life is found to be more difficult because they need to keep themselves in health condition, getting all the important foods that can help to minimize the impact of HIV in the body, at the same time working in limits; not to exhaust the body and lose strength and the children are also depending on them. Therefore, their HIV situation makes them different from other healthy individuals.

Furthermore, traditional paying of bride price which used to be modest gift intended to promote links between families is now seen as income-generating opportunity by families with girls. This on the other hand is contributing to lack of respect to women and especially the transfer of assets to the husbands' family on his death serve to devalue women lives and

put them in danger of abuse and poverty. Legal assistance for low-income families can help to ensure that widows inherit property and not pushed further into poverty after the death of their husbands.

When women lack title to land, housing and other valuable assets, they face a narrowed choice of economic options. They have to deal with homelessness, poverty and violence and this contribute to impoverishment of both themselves and their children. However, under customary law, all meaningful property like land, house and other valuable assets are owned by the husband. Women are often reduced to the status of property-less dependents that have to submit to the will of their husbands in order to survive. The customary law on matrimonial property perceives a married woman as unpaid servant of her husband. She works for him, looks after his family, acquires and preserves property for him. On the other hand, lack of knowledge among women and access to formal court systems, lawyers and other legal resources can make the matter worse.

Furthermore, loosing properties and belongings after the death of husbands can unravel the whole fabric of the family, limiting access to health care services, adequate nutritious foods, and forcing children out of school into employment. As discussed earlier in chapter 3.5, customary laws on inheritance rights can make women more vulnerable to infection.

“After my husband death, relatives went to the house we lived while I’m in the village mourning and they took out all furniture and house ownership papers. They wanted me to stay in the village but I knew life could be more difficult than here; now you can see I’m renting this room to live with my three children,.....it has no even electricity! I have a friend in our group but she is better because she lives in her house left by husband and she also gets some money from renting rooms to people” (37years widow)

In many cases properties are grabbed from the widow on the pretext of safe-keeping, to prevent widows from getting them. Though property grabbing is stealing (Bunch, 1995) police are reluctant to intervene thus public and private distinction is used as a cover to prevent state involvement in situation threatening the life of widows. The death of a husband is not considered to terminate a marriage under most customary laws in African societies. As a result, avenues are made for continuing a marriage even after death of the man either for the widows own protection or as a means of making use of her reproductive capacity to reproduce more children for the lineage. This may be a common practice in rural areas than in urban places. Property grabbing after the death of a husband was experienced by almost all women

interviewee including the divorced where the husband remain with all assets. The interviewee commented that many women face violence, loss of access to assets, children and homes; and this is particularly if they are HIV-positive and after the death of husbands. As husband dies from AIDS, relatives assume the woman will also die soon therefore they grab all the property including children in some situations.

In addition, oppression against women in societies in most of developing countries may have a great impact in increasing vulnerability of women to HIV/AIDS. Maman et al., (1999) found that there were gender differences in the decision- making that led to the use of HIV voluntary counselling and testing services. While men made the decision to seek voluntary counselling and testing independent of others, women felt compelled to discuss testing with their partners before accessing the service, thus creating a potential barrier to access services. Inheritance and property ownership rights for women need to be strengthened especially in this era of HIV/AIDS. In addition, to advocate strategies to empower women will enable them to decide themselves for life affairs including their health.

5.7 Support from formal and informal institutions

Formal institutions here are referred to those institutions in the society that use written laws and regulations in their daily activities. This includes Government institutions, Non-Governmental Organizations (NGOs) and private organisations. However, also informal and social networks like family, relatives and community net works at certain levels are important in managing problems in the society.

5.7.1 Informal institution.

Informal and social networks are the typical features of most African societies including Tanzania. In societies, people cooperate and assist each other in various activities like building houses, farming, caring for the sick and sharing food with those who do not have. However, this depends on tribe, class and location. In rural areas this can be more possible than in urban areas. Family and community networks have been important institution in supporting its members in different ways like caring for sick including people living with HIV/AIDS. Today the sheer magnitude of the impact of AIDS has stretched these social networks and mechanisms to the limit, reducing their capacity to fulfil their traditional roles. Further more, the stereotypes and stigma related to AIDS have also led to people living with HIV/AIDS being excluded from these social networks in both rural and urban societies.

In urban areas, the social networks are mainly between HIV-positive individuals themselves and the NGOs providing services. In this study support for people living with HIV/AIDS from the relatives was found to be limited. This could be due to stigma attached to HIV and difficult economic situation where by relatives are also poor or have very little resources for their own families. It was revealed during the interview that people at family and community level are not supporting their relatives that are HIV-positive.

“Sometimes even if the relatives are aware of your HIV status, they are not ready to give support instead they say; you should go to your NGO to get assistance” (35years widow)

5.7.2 Government organisations

The government is one of the formal institutions responsible for protection and welfare of its people. Such protection is provided in different ways like social welfare provision including services for people living with HIV/AIDS. Pervasive poverty at the local, regional and national level is perceived to hamper all attempts to control the AIDS epidemic and mitigate its impacts. Despite well intentioned national policies, the lack of decentralized funds, low accountability and poor local capacity for implementation lead to poor quality service delivery. In this study, inadequate infrastructure such as poor roads, water supply, and electricity in urban areas was cited as some of the factors hampering the lives of poor urban dwellers including people living with HIV/AIDS. The main objective of care for people living with HIV/AIDS as explained in the National AIDS policy is to:

Promote appropriate nutritional, social and moral support to HIV-positive individuals to enable them to enjoy a quality of life, remain productive and live much longer with the HIV/AIDS. Another objective is to provide adequate treatment and medical care through an improved health care system which aims at enhancing quality of life (TACAIDS, 2001:26)

Although through this policy the government is expressing a lot of concern about services for people living with HIV/AIDS, the effect is not felt by this group of people. People do not see any support from the government. During the interview most people expressed their feelings about the bureaucratic system associated with accessing health services in public hospitals.

“Last month I was suffering from malaria therefore admitted in public hospital and they denied giving medicine without money despite showing them my identity card for free treatment and they said only the bed is free” (34years Man)

At the same time, people living with HIV/AIDS are among the group of individuals that are exempted from paying health costs in health cost sharing system according to a directives of

Ministry of Health and Social welfare. Others are old age people, children under age of 5 years, pregnant women, and people with disability and chronic diseases. However there has been no follow up of the nature of exemption, resources for treatment, drugs supply and enforcement of the directive, thus the directive is interpreted to different things in different areas.

5.7.3 Non-governmental organisations

In Tanzania, NGOs operate in a diversified range of activities in different sectors. These include sectors like health, education, child care, agriculture, water supply and sanitation, environment conservation and HIV/AIDS which is considered to be a crosscutting issue in almost all organisations. Besides providing services, NGOs are also involved in building capacity of local communities and other stake holders as a way to ensure and expand service delivery to the people and improve their livelihood. AIDS organisations (ASOs) like SHDEPHA among others were found to be very supportive for the people living with HIV/AIDS in Dar es Salaam. As pointed out in its brochure, the mission of this organisation is:

“To advocate for the basic rights and protection of people living with HIV/AIDS and provide them with essential basic services. It aims to empower People living with HIV and to address the stigma and discrimination they face.”

The services provided by this organisation include home based care for people that are bed ridden, counselling for HIV testing, human and legal rights advocacy, community education about HIV. Others services are basic needs support for widow and orphans, loans for income generating activities to help HIV-positive individuals and orphans to get their basic needs. As stated by respondents during interview, they only rely on the NGO to get loan and credit because they have no access to government and other private credit and loan institutions because they have no assets for mortgage and formal employment. In addition, care and health services like treatment of opportunistic infections and provision of antiretroviral drugs are among the services provided. Informal institution support was observed to be weak especially in urban areas due to stigma related to HIV as well as economic stress in families, and this applies also to societies in rural areas. This however necessitates the formal institutions to collaborate and strategise more on how to support people living with HIV/AIDS in order to keep them productive as long as possible in the society.

5.8 Challenges for NGO in service provision

Since the beginning of the HIV/AIDS, local national groups have been at the forefront of taking action; in some communities they have been the major players in taking actions to mobilize communities in tackling the HIV/AIDS epidemic. Local non-governmental organizations, faith based organizations and community-based organizations have been at the centre of the response to the HIV/AIDS. In many countries, they have been responsible for the majority of the resources reaching individuals and have played a leading role in developing and implementing strategies to mitigate and prevent HIV/AIDS. However, in most of the developing countries NGOs are often more efficient and effective at providing services than state agencies because they are connected to people, thus local NGOs have shown an important ability to organise people and resources.

It is not surprising that in many parts of the world (REACH, 2005) where governments are characterized by lack of popular representation and failure to provide adequate services, private foundations and donor agencies are simultaneously turning to local NGOs to lay the ground work for expanding civil society and promoting socioeconomic development. It was learned that, the strength of the organization contributes significantly to their success and the sustainability of their activities can be derived in one way or another from the close connection that the organization have with the population they serve.

Local NGOs are uniquely positioned to initiate and establish close working relationships with other locally based groups in the public, private and voluntary sectors. Partnership and collaborations among different institutions allow local organization to focus on more specialized programmatic areas and enhance their ability to increase referrals to other NGOs and government services. These partnerships also encourage networking, sharing best practices and mentoring, thus encouraging more local ownership of the project. Many of the AIDS organisations like SHDEPHA employ individuals who have been personally affected by the disease. On the other hand, this enhances direct connections between the organization and the populations they serve, thus producing strong incentives to carry out activities in a transparent and responsible fashion. Their commitment to making a difference is apparent in their passion and degree of involvement.

In order for local organisations, particularly the AIDS organisations to achieve effective service delivery to people living with HIV/AIDS in the community they need to overcome the major challenges they are facing in providing service to the people. AIDS organization such

as SHDEPHA has inadequate capacity to provide to the people due to lack of enough resources. The number of people who need services is extremely high while the resources are few. It was explained by the organisation administrator that funding and other resources for service delivery to people depend largely on external donors. However some donors have their areas of interest and priorities that it becomes difficult for the organisation to address specific problems in the community. For instance, according to the administrator the organisation was receiving funds for treatment and education support for orphan education. But the organisation would like to address other problem of the people like providing loans for income generating activities so that they can meet some of their basic needs including food.

International donors or organisations inherently have greater access to resources than most of the national and local organisations and this access can give them the luxury of becoming strategically focused and donor-specific. Local and national organisations on the other hand often hop from project to project, frequently with different objectives and approaches, to keep the revenue flowing (REACH, 2005). This can limit their ability to focus and concentrate on becoming institutions of excellence in a particular service delivery area. The potential is for an organisation to spread itself too thin by attempting to work in too many different areas in which it often does not have technical experience or expertise. When it comes to employing expertise, most of the organisations are known to rely primarily on the voluntary as opposed to paid staff as their financial capacity does not allow employing highly paid staff.

Access to funds and other resources from both the government and external donors was explained to be a problem for AIDS organisations. The reason for this can be weak administrative capacity of the organisation. Most of the local organisations come to the attention of donors because of their effective programming and achievements. It is the financial management capacity of many local organisations that raises obvious concerns for any donor. However, many local organisations may not have the rigorous accounting procedures and systems that donors and potential collaborators consider a minimum standard, and do not have the resources to invest in improving administrative procedures when scarce resources available are prioritised to relieve suffering in the community.

"We write many proposals requesting for funding from the government and other international donors but we face a big challenge because competition is very high to get your proposal successful" (NGO program officer)

In addition to financial management limitations, lack of competence in human resource management, organizational planning and fund raising, proposal writing, monitoring and evaluation was explained to be obstacles for accessing funds from the government and other donors. It was also disclosed by the organisation program officers and administrators that funds from external donors through the government for the purpose of AIDS epidemic containment are sometimes diverted to other economic activities in the government. The reason for this may be lack of main or the overall national coordinating body for HIV/AIDS projects and activities of the AIDS organisations. Lack of the overall coordination has also resulted in the emergence of many organisations, but not sufficient services for reaching the people. It was revealed by interviewee that there is a duplication of services and each organisation is trying to work on many areas of the HIV/AIDS problem but inefficiently.

“Some people are establishing NGOs just because they have access to funds from the external donors, but not because of motive from the problem of HIV/AIDS itself” (NGO administrator)

AIDS organisation may tend to follow funding streams without assessing the fit with their philosophical missions. This in turn may create a competitive and even hostile landscape with other organisations and government-supported activities. For instance, the mission of the SHDEPHA is: *“to advocate for the basic rights and protection of people living with HIV/AIDS and to provide them with essential basic services, And it aims to empower people living with HIV/AIDS and to address the stigma and discrimination they face.”*

However, since its inception the organisation has been more involved in fighting stigma in the society. One of the strategies used to reduce stigma is through creating awareness by providing education and information about HIV transmission in the community, encouraging people for voluntary HIV testing and transparency to the public through television and newspapers about their HIV status and the benefits of early detection of the infection in management and cope with the disease. It is envisaged that all these efforts may help to break the silence about HIV/AIDS in the communities, thus encourage discussions that contribute to behavioural change and attitudes toward HIV/AIDS and people who are already infected.

According to the organisation leader, providing the people with essential basic services including nutrition support remains a problem because of limited resources they have. The organisation also provides the service of antiretroviral treatment for PLWHA. However, the provision of antiretroviral drugs could be done under the government supported activities so

that AIDS organisation can concentrate on home-based care services for AIDS sick people at homes and empowerment of others to meet their essential basic needs and their families, and support services for orphans. However, donors are interested on antiretroviral treatment thus AIDS organisation have to implement this program to maintain flow of funds and other support from donors. Edwards and Hulmes,(1997) argue that, the structures and values of NGO can come to mirror those of the donor, and NGO can face pressure from the donor to conduct a project in a manner that would compromise the organisation principles. At the same time, relying only on ASOs to provide services for people living with HIV/AIDS may not be a reasonable solution because the population to be served is growing as the time advance and the spread of infection is continuing while resources are not adequate to match with the problem magnitude. Therefore more strategies like collaboration between the government and ASOs are needed to support already infected individuals while efforts to prevent spread of infection are on progress.

5.9 Summary

The purpose of this study was to understand the people living with HIV/AIDS perspectives of nutrition support and care services for managing the disease and maintaining their health and quality of life. A qualitative approach was used to explore their experiences and the difficulties they face in coping with the HIV infection. Through the interview with people living with HIV/AIDS, different concerns were expressed. The analysis of findings was presented in themes as shown in analytical categories in chapter 4.9 of this thesis. However, the themes were strongly linked and some cut across each other. Nutrition perception and knowledge, source of income, stigma, access and adherence to treatment were closely interlinked themes regarding nutrition and care services for people living with HIV/AIDS.

My findings show that, nutrition was an important part of shaping the interviewee trajectory in HIV/AIDS. People see nutrition to be important for their health but they don't get satisfying nutrition due to difficult food accessibility resulting from low income they have. Lack of adequate knowledge of what foods may be helpful in managing disease complications was also observed in this study, thus nutrition counselling and education need to be incorporated in any HIV/AIDS interventions related to prevention and management of the infection.

At the same time access to food had an impact to adherence to medication as people were aware that they need to eat enough and balanced meal to enhance the efficiency of the treatment. There is a need to be food secured for one to continue with the treatment because they feel weaker when they take medicine without eating enough food. Furthermore, socio-cultural issues including stigma in the society, gender inequalities and lack of HIV education may contribute to life problems of people living with HIV/AIDS. According to interviewees in this study, stigma related to HIV infection is still a major challenge and this may have a serious implication for carrying out effective prevention efforts. Stigmatization of people living with HIV/AIDS still exists in the society in different ways although publicly not shown. Moreover, ability to have sufficient food and other basic needs for themselves and their children was critical concern in this study. However, challenges to meet basic needs (Weatherburn et al., 2003) have been also documented for Britain's HIV-positive Africans immigrants, thus this may be particularly acute for PLWHA in poor country like Tanzania where the capacity of the state to provide for its people is very low.

My analysis shows that, support services from both formal and informal institutions are important for vulnerable members in any society. However, it was the NGOs as one of the formal institution that was found to provide support for people living with HIV/AIDS. Access to services in Government institutions like public hospitals was difficult due to bureaucratic procedures and lack of follow up and enforcement of the government policies and directives. In addition, HIV/AIDS stigma at families, relatives and the community in general was found to limit the social support net-works in the society. The support for PLWHA from the relatives was explained to be low and this could be due to stigma related to HIV/AIDS and difficult economic circumstances that, relatives also have little resources to provide for their own families. However, relying on the NGOs for support services needed by people with HIV can not be a sustainable solution for this particular problem because these organisations also depend on donor funds, and resources available are not adequate to serve big population considering the current situation of HIV infection rate. Therefore, linkage between the government and the NGOs especially AIDS service organisations (ASOs) is crucial so that through these already established institutions the government can provide support to people and families affected by HIV/AIDS.

The findings presented by this study however, are confirmed by conclusion of other studies (Weatherburn et al., 2003) which suggests that health interventions related to HIV/AIDS

must focus on income-generation and other basic needs, and improve access to health services and information for people living with HIV. Intervention programs need to include the broader context of individuals and families' survival like access to food and other basic needs. The findings from this study can assist in understanding from the perspectives of HIV-positive persons the effect of nutritional support and care services upon their health status, and efforts towards control and prevention of HIV.

CHAPTER SIX: CONCLUSION

Prior research indicates that nutritional status is important in preventing opportunistic infections and probably in delaying the progress of HIV disease. Maintaining good nutrition also help to reinforce the effectiveness of medicine taken by the HIV-positive individuals including antiretroviral treatment. Persons living with HIV/AIDS have identified that they want information about building their immune systems. However, information has been sparse about how PLWHA in Tanzania manage their nutrition including their perception, information source and problems they encounter in managing their nutrition and health.

An exploratory qualitative study has been conducted to investigate the nutritional support and care services for people living with HIV/AIDS in urban Tanzania. This approach was used because there is little or no information about the phenomenon of how individuals infected with HIV/AIDS manage their nutrition and health. The lack of data about nutritional status of PLWHA, their household food security and other support and care services for themselves and their families means that little is known about the real life of HIV-positive persons both men and women in urban and rural communities. A case in point here is the national HIV surveillance data which concentrate more on infection rate and medical management of the infection thus little information is available about how the already infected and affected individuals and families can be supported in managing their nutrition and health to enable them to live as long as possible without progressing into AIDS stages. By delaying the progress of HIV infection into AIDS, the infected person can continue being productive to the society and managing their families. Thus this may help to minimize the problem of orphanage in the society. Nutritional problems in Tanzania, particularly undernutrition, is a major problem due to many reasons including inadequate food intake, frequent infections, household food insecurity, poor economic situation and recently HIV/AIDS. Since nutrient requirements are increased for people living with HIV/AIDS, they may be thought to be more prone to undernutrition and this has more impact on the disease progression.

This study was conducted with the purpose to explore, analyse and explain the nutritional support and care services for people living with HIV/AIDS in urban areas and with a specific aim to enable participants to tell about their nutrition and health management focusing on the difficulties they encounter in accessing support services necessary to cope with the infection and improve the quality of life. A qualitative approach was used to explore their experiences and difficulties they face in coping with the HIV infection. An in depth interview with people living with HIV/AIDS was conducted at their homes. In addition, observation of the living

condition was done to enrich the information obtained and help in more understanding of the real life. Interview with AIDS organisations that provide services for people with HIV/AIDS was also conducted to gain more about the problems they have in providing support services to this category of population in the society. A total of ten people were interviewed; six women and four men. Information was also obtained from informants in various organisations, departments and ministry relevant to the study.

Furthermore, the analysis of the data in this study employed a thematic approach and it highlighted the most important concerns that were expressed by the participants during interview. Coding of the materials was done in different steps from open coding, axial and selective coding as suggested in thematic and grounded theory analysis procedures. The findings were organised in themes or categories and these were the basis for analysis and discussion. The major themes which came up from the data analysis were nutrition perception and knowledge, source of income, stigma related to HIV/AIDS, adherence and access to medication and medical monitoring. Other categories were gender related cultural practices, support from both formal and informal institutions and challenges for the NGO in providing services.

The findings show that, people perceived nutrition to be very important for their health, but they lack food accessibility due to poor income they have and to take into consideration that they don't grow foods in urban areas. There was lack of sufficient knowledge about foods which may be helpful in managing disease complications. On the other hand, this necessitates that nutrition counselling and education need to be incorporated in any HIV/AIDS interventions related to prevention and management of the infection. Information about nutrition was mainly obtained from group discussion or meetings and sharing experiences from friends and other members of the organisation. Through nutrition education and counselling, correct and more useful information are likely to be conveyed among the people living with HIV/AIDS.

Access to health services in public hospitals emerged as chief concern for all respondents in this study. According to the government directives health services for HIV-infected individuals are supposed to be free, but in practice treatment in public hospitals is not free for PLWHA and high proportion of low-income and poor including HIV-positive person have insufficient money to access the service. In addition, the cost of laboratory tests and transport to clinics compounded the problem. Treatment need be accessible to PLWHA and if possible

to all people in the country. This will include antiretroviral treatment, associated laboratory tests and other costs of treatment in public hospitals. In addition to this, nutritional support to assist recovery and support treatment adherence need to be provided as part of treatment thus these need to be incorporated in the current antiretroviral programme. Furthermore, there must be clarity and transparency about cost-sharing exemptions because government directives and policies seem to be not enforced and often interpreted differently in different areas.

Socio-cultural issues including stigmatizing HIV-infected individuals in the society, gender inequalities and poor HIV education contributed to life problems of people living with HIV/AIDS. In addition, some studies have shown increased changes in the concept of family in parts of the country whereby responsibilities are more confined to nuclear family rather than extended relations. This implies that historical tradition of supporting the vulnerable groups in the society is deteriorating. Thus other strategies must be employed to help the needy people in the society. Stigma related to HIV infection was a major challenge to the life of HIV-positive person and has serious implications for carrying out effective prevention efforts. People at risk and HIV-infected individuals who fear stigmatization or being labelled as part of a stigmatized social group may be reluctant to admit risk behaviours, to seek relevant prevention information and to obtain HIV-antibody testing. On the other hand, they may also be reluctant to access health care services. These in turn can increase the likelihood of continuing risk behaviours, becoming infected and transmitting the virus to others.

Some progress has been made in reducing AIDS stigma in the society particularly providing education and understanding on HIV transmission among the people in the society. However, more detailed information of other aspects of HIV/AIDS are missing as people need to understand the difference between HIV and AIDS, how the disease progress and the longevity of infected persons. Promoting deeper knowledge of HIV/AIDS will reduce stigmatizing and discriminatory actions to people with HIV/AIDS. Therefore, there is a need to increase awareness of the disease to all sectors of the society emphasising that "HIV is not a death sentence" thus normalizing the treatment of HIV as other chronic conditions like diabetes, asthma, etc.

The core support services identified by PLWHA in this study include food, health services, and schooling support for their children and access of loans and credit for income earning activities to enable them to meet life basic needs. However, at present they rely only on AIDS

organisation to get loans since they have no access to other credit facilities like banks and private organisations. Looking at this broadly, relying on the ASOs alone for support services for PLWHA will not be a sustainable solution because these organisations also depend on donors to get resources and at the same time they are not sufficient. Thus strengthening the link between ASOs and the government is important so that through these already established institutions the government can provide support to people living with HIV/AIDS.

This Master thesis has attempted to answer the questions posed before conducting the study in such a way that, problems faced by HIV-infected people were explored and explained. Among others, low income and stigma they face were major problems. At the same time lack of nutrition knowledge to cope with the nutritional and health complications related to HIV infection was another major problem because they need to maintain their nutritional status in order to curtail the progression of the disease.

Moreover, services provided by the NGO included loans for income generating activities, treatment, education support for orphans whose parents died of AIDS and home based care for bed ridden patients who can not visit the organisation for services. However, the NGO was found to face many challenges including insufficient resources to serve the people in need and other administrative capacity problems which in turn lead to difficult access of funds from both international donors and the government.

It is worth here to suggest that understanding and policy making surrounding HIV prevention and treatment must include the broader context of families' survival and security needs like access to health care, food, shelter, employment or income generation for the HIV affected individuals and families. The findings presented in this Master thesis can be used by policy makers in designing better programs aimed at sustaining people with HIV in good health as long as possible. As commented by the Prime Minister (The Guardian, 22nd May 2005) that supplying PLWHA with anti-retroviral drugs without giving them food is not enough, thus there is a need to join efforts in providing support for HIV patients because they need adequate and proper food as part of the treatment. Improved nutrition support and care services may lead to greater longevity with fewer hospitalization and improved quality of life.

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APPENDICES

Appendix I

NUTRITIONAL SUPPORT AND CARE SERVICES FOR URBAN ADULT PEOPLE LIVING WITH HIV/AIDS.

Participants Consent Form

The purpose of this study is to explore, analyse and explain the nutritional support and care services for people living with HIV/AIDS in urban areas, focusing on the difficulties they face in accessing support services they need to cope with the disease.

The following information is provided to you to decide whether you would participate in this study.

Data collection will involve one-to-one interviews, transcription of interview and observation notes. This work will be done by myself. No names or other identification possibly will occur on the transcripts and the tapes will be destroyed soon after the completion of the research. Anonymity will be maintained in the whole process.

Do not hesitate to ask any questions about the study either before participating or during the time that you are participating. I, **Neema M. Joshua** would be happy to share my findings with you after the research is completed. However, your name will not be associated with the research findings in any way, and your identity as participant will be known only by myself.

The expected benefit for participating in this research is that, the report may be used by the government or NGOs in designing and implementing community and home-based care program that will address the needs of the families and people living with HIV/AIDS.

Please sign if you agree to be interviewed in this study.

You should be aware that you are free to decide not to participate or to withdraw from this study at any time in the process.

A copy of this consent form will be given to you to keep.

Signature of Participant

Date.

NUTRITIONAL SUPPORT AND CARE SERVICES FOR URBAN ADULT PEOPLE LIVING WITH HIV/AIDS.

INTERVIEW GUIDE.

General information

Interviewee No.....

Age.....

Sex.....

Marital status.....

Religion.....

Education level.....

1. Background information.

How many people are in the family that you are living?

How many work and what support they give to the family?

How do you support yourself?

Are you employed? Please tell me more about the economic activities you do to earn a living

Do you have a spouse –is she/he living with you

Is your spouse working? What activities she/he is engaged on to earn?

2. About Nutrition

Can you tell me how many meals you eat per day?

How are they different? What amount you eat?

Can you tell me other foods you eat apart from the family food?

When do you eat that food and what amount

How do you get such a food?

Tell me the problems you face regarding your nutrition

Physical, financial, knowledge

3. About Health

Can you tell me how do you feel about your health?

What medicine do you usually take and how you get them

How do you maintain your health for the whole time?

What information about nutrition are given about use of this medicines

How nutrition is helpful to your condition

4. About information

Tell me how you get information about your nutrition and health

What are the limitations that you face in implementing advice you get about your nutrition and health

Tell me about the services you get from the NGOs, and in what ways they are helpful

What other services would you need them to be provided?

5. About other helping institutions

Tell me about support or assistance do you get from the community - neighbours and friends

What do you think people say about PLWHA in your community?

What health services do you get free in case you get sick and where do you get them

What other institutions provides services for you?

What specific and important services would you need to satisfy your nutritional needs?

Where and how do you think you can get them?

What make these services accessible for you and what prevent you from getting them

How do your expenditure before and after knowing your HIV status differ

6. About the NGOs - (for administrators)

Tell me about this NGO-

The mission, Role, and Number of professional staff

Relation ship to the government, other NGOs - Referral system

What services do you provide for PLWHA

How the services reach the clients and what make them fit for clients

How do you get feedback from clients?

What are the challenge do you face in providing services for PLWHA

How do you meet these challenges?

What are future plans to improve the services?

Do you have some thing you would like to underline regarding this topic we have talked about