

**QUALITY OF CARE FOR PEOPLE LIVING WITH HIV/AIDS IN MOROGORO  
MUNICIPALITY**

**BY**

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**A DISSERTATION SUBMITTED IN PARTIAL FULFILMENT OF THE  
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## ABSTRACT

Assessment of the quality of care services provided to people living with HIV/AIDS (PLWHA) was undertaken in Morogoro Municipality whereby a cross sectional survey approach was adopted. Ninety people living with HIV/AIDS (PLWHA) from two NGOs that are well known to support PLWHA in Morogoro Municipality were involved. The two NGOs were namely Faraja Trust Fund (FTF) and Wanaoishi na Virusi vya Ukimwi Morogoro (WAVUMO) which is an association of people living with HIV/AIDS in Morogoro. Data was collected by using a structured questionnaire, which incorporated a care score index that was developed by the researcher, and administered through face-to-face interviews. Descriptive and inferential methods of data analysis were used. Various stakeholders in Morogoro Municipality provided different types of care services to PLWHA. Health services were provided mainly by the Morogoro Regional Hospital and the NGOs of Faraja Trust Fund (FTF) and Wanaoishi na Virusi vya Ukimwi Morogoro (WAVUMO). Counselling and support was being provided by almost all stakeholders mainly the Morogoro Regional Hospital. Families were reported to be the primary care provider in home-based care services. The quality of various care services was determined by using a care score. The highest proportion of respondents (73.4%) reported high quality of care in the home-based care component, while the lowest (7.8%) proportion was in the awareness and practice of PMTCT. Most of the respondents perceived counselling and home-based care services they were getting to be good (43.3% and 70.8%, respectively). Seven variables were tested for important factors determining the extent of care quality among various components of care. Results showed that medical care was significantly influenced by age and education level of respondent. The communication and behaviour change component was affected by age and marital status while counselling and testing

was affected by only duration of living with the virus. The study recommended that, people living with HIV/AIDS should be enabled to improve their economical situation by providing them with low interest loans, training and provisions of social support. Medical services may need to be integrated within the home-based care for ease of accessing.

**DECLARATION**

I, Regina Matern Masako, do hereby declare to the Senate of Sokoine University of Agriculture, that the work presented here is my own creation and had not been submitted for any degree award in any other University.

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Regina Matern Masako  
(MSc. Candidate)

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Date

The above declaration is confirmed

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Prof. John Msuya  
(Supervisor)

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Date

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## **DEDICATION**

This work is dedicated to my beloved parents, Mr. M. J Masako and Mrs. Agatha Makolo Masako, for their tireless support, love, care and excellent parenthood throughout my entire life.



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## LIST OF ABBREVIATIONS

AIDS	Acquired Immunodeficiency Syndrome
AMREF	African Medical Research Foundation
ART	Anti-retroviral therapy
ARVs	Anti-retroviral Drugs
BTC	Belgian Technical Cooperation
CBO	Community Based Organization
CHBC	Community Home Based Care
CMV	Cytomegalo Virus
CT	Counselling and Testing
FANTA	Food and Nutrition Technical Assistance
FAO	Food and Agricultural Organization
FBO	Faith Based Organization
FGDs	Focus Group Discussions
FHI	Family Health International
FTF	Faraja Trust Fund
GDP	Gross Domestic Product
HIV	Human Immunodeficiency Virus
MNRTIs	Non- Nucleoside Reverse Transriptase Inhibitors
MOH	Ministry of Health
MTCT	Mother to Child Transmission
NACP	National AIDS Control Programme
NGOs	Non-Governmental Organization
NRTIs	Nucleotide Reverse Transriptase Inhibitors

OIs	Opportunistic Infections
OPD	Outpatient Department
ORS	Oral Rehydration Solution
PIs	Protease Inhibitors
PLWHA	People living with HIV/AIDS
PMTCT	Prevention of Mother to Child Transmission
RCQHC	Regional Centre for Quality of Health Care
RDA	Recommended Daily Allowance
SPSS	Statistical Package for Social Science
SSA	Sub-Saharan Africa
STDs	Sexually Transmitted Diseases
STIs	Sexually Transmitted Infections
TACAIDS	Tanzania Commission for AIDS
TAS	Tanzania AIDS Society
TB	Tuberculosis
UN	United Nations
UNAIDS	United Nations Programmes on HIV/AIDS
USD	United States of America Dollar
VCT	Voluntary Counselling and Testing
WAVUMO	Wanaoishi na Virusi Vya Ukimwi Morogoro
WB	World Bank
WHO	World Health Organization
ZDV	Zidovudine

## CHAPTER ONE

### 1.0 INTRODUCTION

#### 1.1 Background information

Acquired Immunodeficiency Syndrome (AIDS) is the name given to the fatal clinical condition that results from long-term infection with Human Immunodeficiency Virus (HIV). History shows that AIDS came into public consciousness in early 1980s as a disease that was primarily affecting white male homosexuals in the Bay area of San Francisco (Almond, 1990). Currently, HIV/AIDS pandemic is a world greatest threat (UNAIDS, 1998a), there is an estimated 65 million infections and 25 million deaths are due to HIV/AIDS (UNAIDS, 2006). Deaths are largely among young adults who would normally be in their peak productive and reproductive years (UNAIDS, 2006).

Being infected with HIV does not automatically mean that a person has AIDS or is ill (WHO, 2003). According to MOH (2005) a person will be considered to have AIDS when he/she shows the following symptoms: (i) frequent fevers (ii) persistent cough and/or dyspnoea (iii) oropharyngeal and oesophageal candidiasis (iv) vaginal candidiasis, (v) weight loss, (vi) diarrhoea, (vii) persistent generalized lymphadenopathy (PGL), (viii) skin rashes, sores and generalized pruritis, and (ix) altered mental and persistent severe headache. He/she will also be known as a person who is HIV-positive or seropositive (WHO, 2003). In this case he/she is permanently infected and permanently infectious to others through the several means of transmission. People are infected with virus through sexual, parenteral, and vertical transmission, and a variety of factors increase vulnerability to infection (RCQHC, 2003). Almost 100% of people who contract HIV develop AIDS (Masako, 2002). The period between becoming infected and developing AIDS averages 10

years in adults, similarly infants born with HIV may progress rapidly to AIDS, developing symptoms after four months, or may not develop AIDS for several years (Dossier, 1992). Average adult life expectancy after diagnosis of AIDS ranges from six to 12 months in the developing world and one or two years in the industrialized world (Dossier, 1992). Many other factors may also result in shorter survival of HIV-infected patients in resource-poor settings, including poverty, limited access to health care services, under-resourced medical services, poor nutritional status and the quality of water supply (Bekker, 2006). There may also be considerable regional variations in the prevalence of localised tropical diseases and the spectrum of major HIV-related conditions (Bekker, 2006). The AIDS pandemic continues unabated in poorly resourced countries (UNAIDS, 2002) where there are 65 million people currently living with HIV or AIDS (Global AIDS, 2005), 28.5 million of them in Sub-Saharan Africa alone (RCQHC, 2003). HIV in Sub-Saharan Africa has mostly spread through sex intercourse between men and women (UNAIDS, 1998).

HIV is recognized primarily through testing for the presence of the antibodies formed against the virus (RCQHC, 2003). HIV progressively damages the body immune defence system, preventing the body from protecting itself against infections that it would otherwise render harmless (Dossier, 1992). Over time HIV weakens the immune system to the extent that several opportunistic infections (OI) are present at once (Dossier, 1992). Some opportunistic infections include tuberculosis, *kaposi sarcoma* (a tumour primarily affecting the skin), *pneumocystis carinii* (a form of pneumonia) and diarrhoea (Dossier, 1992). In most cases patients don't die from HIV infection, but succumb to these OI that the HIV induced immune deterioration cannot handle (MOH, 2005).

Appropriate care practices during different stages of HIV are an integral component of the continuum of care for maintaining the health and general well being of people living with HIV/AIDS (WHO, 2003). Many countries have started to outline a care agenda for people living with HIV/AIDS (PLWHA) that includes providing psycho-social care, reducing stigmatisation, food security and ensuring access to essential AIDS medicines, including antiretroviral and treatment for opportunistic infections (WHO, 2003; FAO, 2003). Most appropriate caring for PLWHA is meeting food security, maintaining health and healthy environment. These can be met through ensuring adequate and well balanced diet, appropriate treatment of opportunistic infections, stress management, and physical exercises. Similarly, emotional, psychological and spiritual counselling and support, and balancing these with the needs of other members of the family become necessary (WHO, 2003).

### **1.2 Problem statement and justification**

Tanzania, like other countries in Sub-Saharan Africa, is facing serious health and socio-economic problems of unprecedented nature as a result of the AIDS epidemic (NACP, 1998). The current trend of the spread of the epidemic shows that it will be a pervasive disease for a long time in the country (Kapinga *et al.*, 1993). People living with HIV/AIDS often become frustrated with the disease whereby many are willing to try anything in the hope of staying healthy and living longer (FAO/WHO, 2002). Nevertheless, they go through long, miserable illness, which leads to death in one, or two years after the initial diagnosis of full-blown AIDS (FAO/WHO, 2002). With appropriate care, there is a possibility of increasing the life span of the PLWHA for a number of years. This will reduce the negative impact that the country is facing of losing the educated, trained, productive



manpower and labour force. Most researchers have worked on epidemiological and medical aspects of the HIV/AIDS (Chin and Lwanga, 1989; 1990; Kilewo, 1994 and Kamuzora and Gwalema, 1998). Social science research has focused mainly on means of transmission such as sexual networking (Caldwell *et al.*, 1991) and gender inequality in the risk to the infection (Ngaiza, 1991). Few studies have sought to examine the limits to the support provided by the family or the community (Singhanetra *et al.*, 2001). Therefore, generally little documentation is available associated with care and support to PLWHA.

This study was an attempt to assess the types and extent of care and support given to PLWHA. Results from this study will help policy makers, programme managers and researchers in planning on HIV/AIDS intervention programmes with regard to care and support for PLWHA.

### **1.3 Objectives**

#### **1.3.1 Overall objective**

The general objective of this study was to assess the nature of quality of care services provided to people living with HIV/AIDS (PLWHA) in Morogoro Municipality.

#### **1.3.2 Specific objectives**

Specifically the study thought to: -

- i. Identify the key stakeholders and the most common types of care services provided to PLWHA and characterize the roles they play.

- ii. Develop a care score index and use it to assess the quality of care provided to PLWHA individuals.
- iii. Assess how PLWHA perceive quality of care provided to them.
- iv. Determine the factors that affect the quality of care given to individual PLWHA and to recommend possible measures to take to improve care services.

### **1.3.3 Research questions**

The following research questions were used to guide the study:

- i. What is the extent of care that the PLWHA are receiving?
- ii. Who are the key stakeholders and the most common types of care services they provide to PLWHA and what are the roles they play?
- iii. How do PLWHA perceive the quality of care provided to them?
- iv. What are the factors affecting the quality of care given to PLWHA and what are the possible measures to take to improve care services.

### **1.4 Limitation of the study**

The biggest limit was the fact that only the PLWHA who were members of the two organizations were reached. However, there are others who have not joined such organizations in the Morogoro Municipal. Those ones could not be reached in this study.

### **1.5 Organization of the study report**

The study report is organized in five chapters whereby the first chapter covers the introductory part. The second chapter presents a review of existing literature on care for people living with HIV/AIDS. The third chapter describes the research methodology whereby the chapter covers location and characteristics of the study area, research design,

sampling procedure and techniques, and data collection procedure, which includes construction of care score index. Procedures used in data analysis together with ethical considerations are also pointed out. Research findings and discussions are presented in chapter four while conclusion and recommendations are given in chapter five. Lastly, the references are listed.

### **1.6 Conceptual framework**

The conceptual framework in Figure 1 details the variables that were examined and their expected relationship outlined. The conceptual framework has attempted to group the variables into dependent and independent ones.

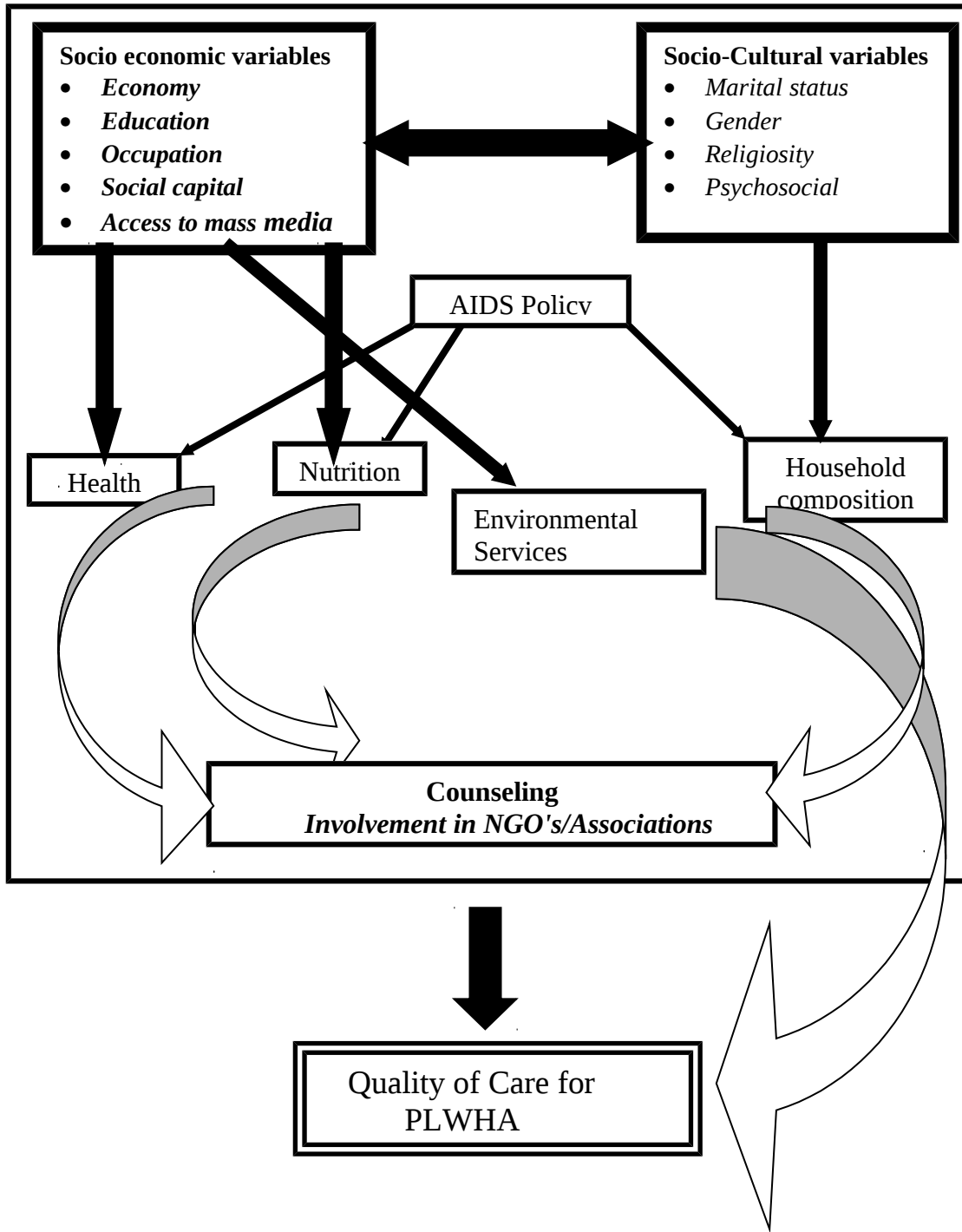


Figure 1. The Conceptual Framework of Quality of Care for PLWHA

## CHAPTER TWO

### 2.0 LITERATURE REVIEW

#### 2.1 HIV/AIDS definition and scope

HIV is an abbreviation representing the Human Immunodeficiency Virus, a retrovirus that causes the underlying damage to the human immune system, which then permits opportunistic infections to cause virulent and fatal diseases to an individual (WB, 1989). Significant evidence now demonstrates that HIV causes AIDS (RCQHS, 2003). Acquired Immune Deficiency Syndrome (AIDS) is used to identify a deadly group of diseases caused by HIV (Cox, 1997). HIV attacks white blood cells, attaching itself to cells with the help of a specific surface protein called CD4 (RCQHC, 2003). This protein is present on white blood cells known as T-helper lymphocytes and macrophages, the T-helper cells help stimulate the production of antibodies and multiplication of other white blood cells (RCQHC 2003). The macrophages help destroy infected body cells. HIV binds itself to the CD4 cell surface, its particles enters cytoplasm of the attached cell. This impairs the functioning of the attached cell, inducing it to make more copies of viral RNA with the help of a virus-specific enzyme called reverse transriptase. As more and more cells are attacked, the body's immunity is gradually weakened. The person becomes vulnerable to a variety of life-threatening illnesses and is said to have AIDS (RCQHC, 2003). Stages of HIV disease according to RCQHS (2003) are: (i) acute infection (2 –8 weeks), (ii) Asymptomatic (2-10 years), (iii) Symptomatic and (iv) Late stage. Diagnosis of AIDS is confirmed if a person with HIV develops one or more of a specific number of severe opportunistic infections or cancers. Such conditions include *kaposis' sarcoma*, *cryptococcal meningitis*, *Tocoplasmosis* and *CMV retinis* (NACP, 2005). People affected with AIDS suffer from various combinations of complications. As this process may take a

long time, PLWHA go through long, miserable illness, which leads to death in one, or two years after the initial diagnosis of full-blown AIDS (Cox, 1997).

## **2.2 HIV/AIDS situation**

### **2.2.1 Situation worldwide**

Since the first cases of Acquired Immunodeficiency Syndrome (AIDS) were reported in 1981, infection with human immunodeficiency virus (HIV) has grown to pandemic proportions, resulting in an estimated 65 million infections and 25 million deaths (UNAIDS, 2006). Sub-Saharan Africa is the world's most severely affected region (NACP, 2005). Approximately 10% of the world's population lives in sub-Saharan Africa, but the region is home to approximately 64% of the world population living with HIV (UNAIDS, 2006). The number of women infected exceeds that of men (Piwoz and Bentley, 2005). A recent national survey of 15 to 24 years old adults in South Africa reported that the HIV prevalence rate in females was 3 times higher (15.5%) than the rate in males (4.8%) (University of Witwatersrand, 2003). One of the major factors that play a role in the dynamics of HIV infection is the level of empowerment. The low level of education, especially in women and patriarchal system puts women in a subservient position. Consequently, women have lesser control over their own bodies and lack negotiating skills for their protection (Moore and Williamson, 2003; Gangakhedkar *et al.*, 1997). In 2003, young people (15-24 years old) accounted for half of all new infections worldwide (UNAIDS/WHO, 2004). During 2005 alone, an estimated 2.8 million persons died from AIDS, 4.1 million were newly infected with HIV, and 38.6 million were living with HIV (UNAIDS, 2006). It is well known that HIV/AIDS is spreading rapidly in several parts of the world, but the most striking observation is that the move appears to be

moving towards Asia (Bloom and Godwin, 1997). HIV continues to disproportionately affect certain geographic regions (e.g Sub-Saharan Africa and the Caribbean and subpopulations (UNAIDS, 2006).

### **2.2.2 Situation in Africa**

Africa remains the continent by far the most affected by HIV/AIDS. A continent has about 28.5 million people living with HIV/AIDS as compared to 65 million globally, which is home to only 11 percent of the world's population (UNAIDS, 2006). Of the 19 million deaths that occurred globally in 2003 resulting from AIDS, 83 percent (16 million) had occurred in Sub-Saharan Africa (RCQHC, 2003). The estimated number of deaths in 2001 alone in the region was 2.2 million (UNAIDS, 2002). All countries in the region except Angola have an estimated adult (i.e. aged 15-49 years) HIV prevalence exceeding 10% (UNAIDS, 2006). One in 12 adults in this region are reported to be infected with HIV (NACP, 2005). Transmission is primarily through heterosexual contact and more women are HIV infected than men (UNAIDS, 2006). Mother-to-child transmission of HIV occurs in 30-45% of cases in the region (Fawzi *et al.*, 2005). Further, Sub-Saharan Africa accounted for about 90% of orphaned children by AIDS (Fawzi *et al.*, 2005). Southern Africa is the epicentre of the AIDS epidemic whereby in Botswana, Lesotho, Swaziland, and Zimbabwe, the estimated adult HIV prevalence exceeds 20% (UNAIDS, 2006). South Africa, with an HIV prevalence of 18.8% and 5.5 million persons living with HIV, has, along with India, the largest number of persons living with HIV in the world (UNAIDS, 2006). It is further articulated by UNAIDS (2006) that though recently, declines in adult HIV prevalence have been observed in Kenya, Uganda, Zimbabwe, and urban areas of Burkina Faso but AIDS death rates continue to rise. The pandemic has swept African

countries, particularly in Sub-Saharan Africa, due to the presence of aggravating circumstances that favour the transmission of the virus, circumstances that vary from country to country (Willis, 2002). HIV has spread in Africa because, as Lindenbaum (1997) notes, of an interruption of an international political economy with its cavernous inequalities in economics, health care, diseases and suffering.

### **2.2.3 Situation in Tanzania**

Since 1983 when the first cases of AIDS were reported in Tanzania, the HIV epidemic has spread rapidly to all districts and communities affecting all sectors of the society. A total of 18, 929 AIDS cases were reported to the NACP from the 21 regions during the year 2003. This resulted into a cumulative total of 176,102 reported cases since 1983 when the first three cases were identified in the country (NACP, 2005). In 2003 over 1.8 million persons were estimated to be living with HIV and AIDS and close to 800,000 cumulative AIDS cases. The overall prevalence of HIV infections among blood donors during 2003 was 8.8%. Recent data based on household surveys estimate seroprevalence among adults in Tanzania to be 7%, with a wide variation across the regions (NACP, 2005). The highest HIV/AIDS prevalence (10-16%) occurs in Mbeya, Iringa and Dar es Salaam. The lowest is in Manyara and Kigoma where HIV/AIDS prevalence is about 2.2%. Most infections are transmitted through sexual intercourse and hence the populations most affected are the sexually active individuals between 15 and 49 years of age whereby women have a higher risk to become infected than men (NACP, 2005).

### **2.3 The social– economic impact of AIDS in African societies**

Health wise, the HIV/AIDS pandemic has interacted with other underlying public health problems, notably tuberculosis, which remains one of the principal causes of death in



persons with HIV infection worldwide (NACP, 2005). Most urban districts and regional hospitals in Tanzania report a bed occupancy rate of up to 50 – 60 % for HIV related conditions. The pandemic has reduced resources available for other health problems thus adversely affecting quality of health care services delivered in the African countries. In addition, health care personnel are affected as well by the pandemic resulting in human resource crisis in hospitals at a time that more resources than ever are needed to start care and treatment programmes with ART (NACP, 2005). Government income used for the treatment and care of the HIV/AIDS patient in hospitals is enormous where the number of patients in hospitals is increasing due to more people falling sick as a result of weakened immunity within the community (NACP, 2005). There is also increasing mortality especially among children 1-5 years old, which contributes to falling life expectancy (RCQHS, 2003).

According to NACP (2005), the relationship between HIV and AIDS and socio-economic development is complex. On one hand, HIV and AIDS negatively affect economic growth and on the other hand the weak economy makes it difficult for nations and individuals to mount adequate and comprehensive responses to the epidemic. In addition poverty is a co-factor to the spread of HIV and AIDS. Deaths due to AIDS have reduced agricultural labour force, productivity and disposable incomes in many families in rural communities. In Kagera one of the regions most affected by AIDS, annual Gross Domestic Product (GDP) declined from USD 268 to 91 between 1983 and 1994 respectively (NACP, 2005) whereby AIDS was believed to be a major cause. Similar trends of declining GDP were associated with reduced agricultural production and increase in number of AIDS cases in Tanga region in Tanzania. HIV/AIDS also leads to reduced capacity to deliver social responsibilities because of illness (RCQHS, 2003).

Socially, death of a young adult often means loss of a father or/and mother who are the main family's income earners. This tends to increase poverty and food insecurity within the family whereby orphans not only get deprived of material, social and emotional privilege, but also lack the opportunities for education and health care. Widows and orphans are deprived of their inheritance rights by relatives through the application of oppressive traditional practices and customary laws. The widows are often blamed for the premature deaths of their husbands and spread of disease to their infants (NACP, 2005). Women are shouldering the burden of HIV infection in the developing world in terms of their numbers and in their responsibilities for providing food and care for orphans and other family members who become sick or ill of HIV/AIDS (Piwoz and Bentley, 2005).

#### **2.4 HIV/AIDS care and support**

Due to the many problems that PLWHA may encounter, a definite care and support at different levels need to be provided to them. PLWHA have a variety of needs beyond the mere provision of clinical care. These needs include psychological, spiritual, nutritional, educational, economic and legal support. The care provided to AIDS patients in their homes and communities must therefore address these needs not only among the patients but also their caregivers at home and in the community (MOH, 2002). Successful linkages with a variety of partnering programmes and care sites are encouraged at all levels. Partnership between care and treatment organizations and support programmes in the community need to be established in order to ensure a continuum of care through functional referral mechanisms (NACP, 2005). A continuum of care is defined as a care delivery approach which links health, medical and social support services within a defined geographical area to meet a wide and evolving range of needs over time comprehensively

(NACP, 2005). Specific care and support needed by PLWHA according to WHO (2003) include counselling and testing (CT), food and nutrition, home-based care, eradication of stigma and discrimination and spiritual support. Others include sexually transmitted infections (STI) treatment and prevention and provision of HIV/AIDS antiretroviral drugs (ARVs). Similarly, the other care and support services are traditional healers and medicine, family, orphan and social support, prevention of mother-to-child transmission (PMTCT) and end of life care.

#### **2.4.1 Counselling and testing**

HIV infection affects all dimensions of a person's life: physical, psychological, social and spiritual. Counselling should consider both the physical and mental well being of a person. Voluntary HIV counselling and testing (VCT) plays a key part in HIV-related prevention and care. It is particularly important as a starting point for the access of other HIV/AIDS-related services (WHO, 2001). If a person does not know he/she is infected, he/she can't get any treatment or care. It is widely recognized that knowledge of the HIV infection can help a person to stay healthy for longer as well as preventing new infections (WHO, 2001). In many places people are diagnosed with HIV when they are already seriously ill whereby at this point, there are fewer opportunities for cost-effective interventions, which can improve their quality of life. VCT also provides benefit for those who test negative because it may result in a change of behaviour (WHO, 2001). Counselling is primarily directed at meeting the psychological and social needs of the infected individual (MOH, 2002). Ideally, care for PLWHA should start with voluntary counselling and HIV testing. However, only 10% of people who need testing in low and middle-income countries have access to counselling and testing services (Harding, 2003). According to NACP (2005), the Tanzania national target was to have six VCT centres per district, each with at least

two full time counsellors by 2006. Whether freestanding or hospital based, public or NGO sponsored, VCT centres will continue to play a crucial role in identifying PLWHA by confirming HIV infection, and therefore be a critical source of patients to the HIV and AIDS treatment programmes.

Counselling should inform people about the facts of HIV infection. Correct information helps to dispel myths about HIV and AIDS. In some countries e.g South Africa, many myths about HIV exists such as 'virgin cure' (UNAIDS, 2000). The "HIV/AIDS virgin cure", sometimes known as the "virgin cleansing myth", is the belief that having sex with a virgin will cure and/or prevent a person from developing AIDS (UNAIDS, 2000). Counselling is also crucial to the success of any medical treatment. It is important that the person understands why and how illnesses related to HIV should be treated. The person should also be informed what treatment and care services are available locally and how they can be accessed. Even in very resource poor countries with minimum infrastructure, some treatment can be made available (UNAIDS, 1997).

In some countries, VCT programmes are few and recent. In Malawi, for instance, anonymous testing occurs in selected antenatal clinics for surveillance data (Chimwaza and Watkins, 2004). Some largest hospitals may test for HIV when the symptoms suggest AIDS (i.e. in the late stages) and the results may be kept secret from the patient's relatives, perhaps because of confidentiality, which is very common among health facilities in sub-Saharan Africa (Nkowane, 1993; Ndaba – Mbatax and Seloibe, 2000; Uys, 2000). Follow-up counselling can help HIV positive persons to understand, cope with, and accept their HIV positive status (UNAIDS, 2000).

Behaviour change counselling is one of the services provided to PLWHA. There are two aspects to behaviour change counselling. One is to encourage persons who have tested HIV negative to adopt behaviours and lifestyle patterns that may be less risky than those practiced before the test. The other is to encourage persons who have tested HIV-positive to adopt behaviours and lifestyle patterns that enhance their own health status and that prevent further transmission of HIV (RCQHC, 2003). In Asian countries, HIV infection is attributable primarily to various high-risk behaviours such as unprotected sexual intercourse with sex workers, and injection-drug use (UNAIDS, 2006). Important aspects of counseling and patient education include stabilization of psychosocial issues and prevention of HIV transmission through behaviour change counseling (Khalsa, 2006). The most important prevention approach is education and behaviour modification (Gallant, 2004) whereby emphasis should be on behavioural intervention strategies that focus on interpersonal prevention skills rather than just patient knowledge is paramount. Positively reinforcing incremental changes toward safer behaviour, and addressing how to disclose HIV-seropositive status to a sex or drug partner is also important (CDC, 2003). However, other studies (Goldschmidt, 2004; Bryson, 1996) have documented the safest sexual practices for PLWHA to be abstinence followed by monogamy. For patients who are neither abstinent nor monogamous, the physician should convey the following infection prevention messages: consistent and correct condom use; sex only while sober; reduced number of sex partners; and less mucosal trauma. For patients who use intravenous drugs, physicians should recommend cessation of illicit drug use or, if this is unlikely, using sterilized or new needles and not sharing needles.

### **2.4.2 Food and nutrition**

Appropriate dietary and care practices during different stages of HIV are an integral component of the continuum of care for maintaining the health and nutritional status and general well being of PLWHA (WHO, 2003). Despite its significance in health, nutritional care for PLWHA had not received adequate attention. Food can neither cure nor treat HIV/AIDS, but eating well is essential to maintain and improve the performance of the immune system (TAS, 2005). Nutrition is therefore an essential part of any HIV care package (FAO and WHO, 2002). The food must be adequate in quantity and quality. The effectiveness of antiretroviral drugs (ARVs) are less known in people with poor nutritional diets than in people with good nutritional diets (WHO, 2002). The type of food to PLWHA is also important because it has association with the ARVs. For instance, *Lopinavir-ritonavir's* one of the ARVs absorption is increased if taken with food high in fat (FAO and WHO, 2002). Poor nutrition and HIV disease are part of a vicious cycle that contributes to further deterioration of the health of patients and that ultimately leads to mortality (Fawzi *et al.*, 2005). Deficiencies of vitamins and minerals, such as vitamins A, B-complex, C, E and Selenium and Zinc, which are needed by the immune system to fight infection, are commonly observed in people living with HIV/AIDS in all settings (Kupka and Fawzi, 2002). HIV affects nutrition through increases in resting energy expenditure, reductions in dietary intake, nutrient malabsorption, and loss; and complex metabolic alterations that culminate in weight loss and wasting common in AIDS (Melchior *et al.*, 1998). People living with HIV/AIDS (PLWHA) have additional energy needs because of the extra energy used by HIV infection and opportunistic infections, nutrient malabsorption and altered metabolism. In the absence of AIDS symptoms (WHO stage 1), HIV infected persons should increase energy intake by 10 percent over the level of energy intake recommended for healthy non-HIV infected persons of the same age, sex and

physical activity. In the presence of symptoms (WHO stage 2 and above), all HIV infected persons, should increase energy intakes by 20–30 percent over the level of energy intake recommended for healthy non-HIV infected persons of the same age, sex and physical activity. PLWHA do not require additional protein than the level recommended for healthy non-HIV infected persons of the same age, sex and physical activity. Micronutrient requirements are recommended to reach recommended daily allowance (RDA) levels (NACP, 2005). This can be achieved by consuming a variety of foods. In case of deficiency, supplementation may be necessary. However, there is evidence (Abrams *et al.*, 1993) in an observational study among HIV-infected men in the United States, daily use of a multivitamin supplement was associated with a significant reduction in the risk of progression of AIDS by 10% and a significant reduction in the risk for low CD4+ counts. In another study, among HIV-infected men in the United States enrolled in the multicentre AIDS cohort study, a U-shaped relation was noted between vitamin A intake (from diet and supplement) and risks of progression to AIDS and death (Tang *et al.*, 1993; Tang *et al.*, 1996). It was further noted that higher intakes of niacin, vitamins B-1, B-2, B-6 and vitamin C were associated with slower progression to AIDS and with 40-60% reduction in the risk of death after 8 years of follow up (Semba *et al.*, 1996; Tang, 1997). Short-term micronutrient supplementation has been shown to improve body weight and body cell mass (Shabert, 1999) to reduce HIV RNA levels and to improve CD4 cell counts (Muller *et al.*, 2000) and to reduce the incidence of opportunistic infections (Moocchegiani, 2000). A nutritious diet can help maintain the proper functioning of the immune system and provides needed energy, protein and micronutrients during all stages of the infection. This can be obtained through a balanced diet (NACP, 2005). Nevertheless, improved nutrition is not enough in itself to permanently keep people healthy and survive. History provides evidence of this, as in the late 1980s many people with HIV in the United States and other

countries, developed opportunistic infections, progressed to AIDS and died, even though they had an excellent diet. Thus, good nutrition may help to prolong the period of time between HIV infection and the onset of opportunistic infections. Nutritional care and support includes many components, and particularly when a person is asymptomatic, it must include giving an adequate quantity and quality of food. With regard to vitamins and minerals, it is unclear to what extent these are helpful in the early stages of HIV infection (FANTA, 2004). Several studies have been published on the role of vitamins and minerals in HIV disease progression and mortality (Kantar *et al.*, 1999; Coodley *et al.*, 1996; Allard *et al.*, 1998, Jiamton *et al.*, 2003 and Fawzi *et al.*, 2004).

A model of nutrition care as a form of physical support has been illustrated by O'Hare *et al.*, (2005) in Kampala on home-based care for orphaned children infected with HIV/AIDS. Low vitamin A is associated with the acute phase response to infection (Baeten *et al.*, 2004). Mebendazole was given after every three months together with oral rehydration solution (ORS) and anti-pyretic medication (O'Hare *et al.*, 2005). Each visit involved providing nutritional advice and particular emphasis on the value of using local produce. The provision of vitamin A and mebendazole was meant to improve nutrition status of orphans and hence reduce the rate of opportunistic infections. The people caring for the orphans living with HIV/AIDS were well trained and educated on HIV occurrence, transmission and prevention (O'Hare *et al.*, 2005).

Nutritional effects are normally observed that could be related to malnutrition (FAO, 2005). In fact, in Africa AIDS was initially known as 'slim disease' because of the wasting syndrome typically experienced by people with the disease. Research suggests that malnutrition increases the risk of progression of HIV infection, and it may also increase



the risk of HIV transmission from mother to baby. In turn, HIV infection makes malnutrition worse through its attacks on the immune system and its impact on nutrient intake, absorption and the body's use of food (Fawzi, 2003). Malnutrition associated with HIV infection has serious and direct implications for the quality of life of people with HIV/AIDS. Weight loss is often the event that begins a vicious circle of increased fatigue and decreased physical activity, including the inability to prepare and consume food and reduced work productivity. In people with symptomatic HIV condition there are likely to be several overlapping processes taking place (FAO, 2005).

### **2.4.3 Home- based care**

The family, household and community have often been identified as having a crucial role to play in HIV/AIDS related care in developing countries (Singhanetra *et al.*, 2001). Yet few studies have sought to examine the limits to the support that such institutions can provide (Singhanetra *et al.*, 2001). Hospital based care offers primarily medical service only to a very small number of people. Currently, patients suffering from HIV/AIDS related conditions occupy 50% of the hospital beds in urban areas in Tanzania (MOH, 2002). This justifies the extension of institutional care of AIDS into their communities (MOH, 2002) hence the home-based care. In rural sub-Saharan Africa, most care for patients with AIDS are provided at home by relatives (Chimwaza and Watkins, 2004). Home-based care despite its limitations and lack of additional support has become the most important source of care and support for PLWHA in Northern Thailand (Singhanetra *et al.*, 2001). Families provide sympathy and care as well as emotional and financial support. However the nature of care provided varies between the rich and poor and between household types. More affluent people, for example, seek medical care from different hospitals and clinics as well as herbalists, willing to spend considerable amounts

on medical care, which they believe, might prolong their lives. Home-based and formal health care links are necessary in order to make home-based care effective (NACP, 2005). Home based care programmes are providing comprehensive care and support within the household level and this include physical care, hygiene care, nutrition care and support, exercises and shelter. Others are clinical care such as preventive therapy, simple medications and adherence to a long-term treatment, psychological support, family planning access, emotional support, social support, spiritual support, legal support, and economic support (NACP, 2005). Efforts to care for PLWHA at household level have been largely left to NGOs, which are limited in their resources, and services they provide (Singhanetra *et al.*, 2001). Poverty, misunderstanding, misinformation and stigmatisation all contribute to PLWHA to be cared at home (Singhanetra *et al.*, 2001).

#### **2.4.4 Stigma and discrimination eradication support**

HIV/AIDS is an illness that not only has no cure, but also is stigmatised and the prevalence rates make it potential catastrophe for population and health service (Uys, 2003). Stigma is the process of devaluation of people living or associated to with HIV/AIDS (Sharma, 2003). Since HIV is a potentially life-threatening illness, coping with social stigma is the first issue addressed (New York State Department of Health AIDS Institute (2004) and Gallant (2004). Stigma and discrimination associated with HIV and AIDS are one of the greatest barriers to preventing further infections, providing adequate care, support and treatment and alleviating the impact of HIV/AIDS (NACP, 2005). The same author also argues that stigma and discrimination are triggered by many factors, including lack of understanding of the disease, myths about how HIV is transmitted, prejudice, lack of treatment and social fears. Depression is a common reaction to a life

threatening and stigmatised diseases such as HIV and AIDS. It is often precipitated and maintained by economic stressors and social upheavals of which persons with AIDS are exposed to (NACP, 2005).

Stigma and discrimination can prevent people from getting tested, contribute to infecting others and prevent people who are infected from receiving adequate care and treatment (Panos, 2005). Wider access to VCT can lead to greater openness about HIV/AIDS and to less stigma and discrimination. Seeing other people speaking out about their infection status can then encourage other people to come forward for testing. If people get tested and speak out when they are not seriously ill, this can change the image of HIV/AIDS from illness, suffering and death to living positively with HIV (UNAIDS, 1997). WHO asserts that access to ARVs will rapidly reduce stigma (WHO, 2003) and this is true at the global level and, to an extent, at individual level. The disappearance of AIDS symptoms such as body marks, slimness or *kaposi sarcoma* is felt as a real relief (Kitahata *et al.*, 2002) and that could reduce stigma.

#### **2.4.5 Spiritual support**

Many people find great comfort from spiritual leaders during chronic illness, even if people have not been actively involved with a church or religious groups, (WHO, 2002). Addressing spiritual needs is an important aspect in any aspect of care. Chronically ill patients often lose hope and reason to continue to live, which is often relieved through reassurance and spiritual care. Spiritual needs of the patient must be determined and attended to appropriately thus the need to involve faith-based organizations (NACP, 2005).

#### **2.4.6 Sexually transmitted infections (STIs) treatment and prevention**

Untreated STI can increase both the acquisition and transmission of HIV by up to tenfold. This suggests that STI control has the important role in the reduction of sexually acquired HIV transmission. If an HIV positive person has an untreated STI, the potential to spread their infection grows. A person who is HIV positive and also has an STI may also progress to AIDS quicker. Therefore, treating an STI during the symptomatic stage of HIV is important, since this can keep the person healthy for longer (UNAIDS, 2002). The increased risk of HIV transmission due to elevated HIV viral concentrations in genital tract secretions during acute HIV infection (Pilcher, 2004) and episodes of STIs underscores the importance of early HIV detection and screening and counseling in the context of sexually transmitted infections or risk factors (Sexually transmitted diseases treatment guidelines, 2002).

#### **2.4.7 Provision of HIV/AIDS Antiretroviral Drugs**

Recently, after a decade of slow progress in the prevention of HIV infection dramatic advances in the development of antiretroviral drugs (ARVs) have been achieved. This now offers extended patient survival and improved quality of life (NACP, 2005). Various new medications such as protease inhibitors (PIs) and non- nucleoside reverse transcriptase inhibitors (MNRTIs) have been developed. (MNRTIs) when combined with older nucleoside reverse transcriptase inhibitors (NRTIs), have the potential to reduce HIV replication (NACP, 2005). The provision of antiretroviral drugs, sometimes called antiretroviral therapy (ARTs), is just one part of the treatment and care that needs to be provided for HIV positive people. ARV's are expensive, thus, inspite of great efforts being made to provide ARVs for resource poor communities, the reality is that for many communities it will take sometime before ARVs are made available (UNAIDS, 2006). In

the meantime there are many other things that can be provided, but these will not exclude the provision of ARVs when they are available. Indeed, when ARVs do become available the availability of these other services will make the provision of ARVs both easier and quicker (WHO, 2000).

During 2003-2005, substantial gains were made in the number of persons receiving ART in resource-limited countries (UNAIDS, 2006). The "3 by 5" initiative, a strategy of the World Health Organization and UNAIDS, sought to provide treatment to 3 million persons (50% of those in need of treatment worldwide) in low- and middle-income countries by 2005. By December 2005, 18 countries had met their "3 by 5" target, and the number of persons receiving ART had increased from 400,000 in December 2003 to 1.3 million (UNAIDS, 2006). By the end of March 2006, about 561,000 persons in 15 countries were supported (PEPFAR, 2006).

In sub-Saharan Africa, 17% of the estimated number of persons in need of ART received it in 2005 (UNAIDS, 2006). Brazil provides free ART to all in need of treatment, and approximately 83% of HIV-infected persons receive therapy (UNAIDS, 2006). The Caribbean is the second most HIV-affected region of the world whereby like sub-Saharan Africa, HIV transmission is largely heterosexual. Approximately, 68% of persons in need of ART received it in 2005 (UNAIDS, 2006). In the United States, 55% of persons in need of ART received it in 2005 (UNDP, 2005).

Despite the gains in ART, only 20% of persons in need of treatment in low- and middle-income countries were receiving it in December 2005 (UNAIDS, 2006). ARVs are given to PLWHA under several conditions. Moreover, the issue of ARVs depends on the availability of CD4 tests facilities. WHO recommends that ARVs be made available to asymptomatic person, if they have a CD4 count of less than 200 cells per mm<sup>3</sup>. If CD4s tests are not available WHO recommends that ARVs be not provided even for people who are asymptomatic (WHO, 2002). Several guidelines (DHHS, 2005), New York State Department of Health AIDS Institute, 2005) for antiretroviral therapy concur that treatment is for patients who are symptomatic (e.g have thrush, fevers, thrombocytopenia, or wasting); have AIDS (CD4+ cell counts of less than 200 cells per mm<sup>3</sup> or AIDS-defining conditions); and who are pregnant (to prevent perinatal transmission). As documented by Khalsa (2006), a normal CD4+ cell count is roughly 1,000 cells per mm<sup>3</sup> ( $1,000 \times 10^9$  per L) for a non-HIV individual. Early symptoms may begin when CD4+ T-lymphocyte cell count levels drop below 500 cells per mm<sup>3</sup> ( $500 \times 10^9$  per L). AIDS-related opportunistic manifestations usually do not occur until CD4+ counts are below 200 cells per mm<sup>3</sup>, with a subset of more serious complications at CD4+ cell counts below 50 cells per mm<sup>3</sup> ( $50 \times 10^9$  per L). The author however noted that, it is common for patients to remain asymptomatic (or unaware of mild symptoms) even with CD4+ cell counts below 200 cells per mm<sup>3</sup>. CD4+ cell counts typically decline at a rate of 50 to 100 cells per year.

Patients on ARV treatment are strongly encouraged to identify an adherence assistant (NACP, 2005). The adherence assistant is a person identified by the patient to help him/her with ART medications, e.g a family member, friend, colleague, or community member. When necessary, patients with special needs can be assisted by counsellors and

social workers (NACP, 2005). ARVs should be taken at the same time of the day always and it is a continuous process. Regardless of the disease stage or need for therapy, a patient's readiness, willingness, and ability to adhere to therapy are key prerequisites for treatment success (DHHS, 2005).

The use of single drug in the treatment of HIV infection by using ARV is not recommended in Tanzania, instead antiretroviral therapy both in naïve patients and those who had received treatment before, involves the use of combinations of drugs. A triple therapy consisting of 2 NRTI + NNRTI or 2 NRTI + PI is recommended (NACP, 2005). In ARV adherence care, some contraindications relative to initiation of ARV are also considered, such as if compliance is not assured, if the patient refuses to give consent, in the first trimester of pregnancy and if there is liver or renal failure (NACP, 2005). This dramatically increases the importance of alternatives of such as home-based care (Russell and Schneider, 2000).

#### **2.4.8 Traditional healers and medicine**

Traditional treatments for HIV/AIDS can be attractive as they are accessible, culturally appropriate and acceptable and may be more affordable in resource poor countries (WHO, 2003). Traditional medicine differs greatly from region to region and is often very specific to a location. People with HIV/AIDS as they become frustrated with management of their disease they are willing to try anything in the hope of staying healthy for longer, thus they consult traditional healers as well (WHO, 2003). There is little evidence that such therapies are safe or effective in treating HIV infection. Whilst some of the traditional treatments may be helpful, others may do more harm than good. Traditional medicine

should not replace more proven modern treatments if they are available (UNAIDS, 2000). However, in the absence of such treatments, traditional medicine can be a feasible option if it relieves pain and makes the patient feel better (UNAIDS, 2000).

#### **2.4.9 End of life care**

WHO (1995) describes palliative care as the active total care of patients whose disease is not responsive to curative treatment. The goal is quality of life. It further describes important elements that include pain and symptom management, the holistic approach, and support for families through the course of the illness into the bereavement period. All persons with terminal illness need end of life care. Towards end of life care it is essential that the patient and the family have social, emotional and spiritual support (SAT, 2003). In palliation in terminal illness one attempts to allow the patient to die with dignity and relieve him/her of distressing symptoms. Palliation also offers support to help the patient live as actively as possible until death enables the family to cope with their loved-one's illness and with their own bereavement (NACP, 2005). Terminal care is the care given around the period of dying (SAT, 2003). In many resource poor countries, the existing health infrastructure is inadequate to provide in-hospital care for terminally ill people (Singhanetra *et al.*, 2001). Often, the Reference only option available for care of people with AIDS is care at home. Even when hospital care is available this is often not what people want (Singhanetra *et al.*, 2001), and is indeed not necessary, because usually no more medical care other than pain relief can be provided. Although it can be distressing to discuss these issues, making plans can reduce anxiety. Making a will can also prevent family conflict and ensure that partners and children are not left destitute. This is particularly important where 'property grabbing' is common (UNAIDS, 2000).



#### **2.4.10 Family, orphans and social support**

The need to offer counselling to partners and families following the death of a family member or friend is often overlooked, particularly in resource poor countries (SAT, 2003). Counselling can help a person to discuss their loss and to mourn appropriately. The family members may have unresolved fears about HIV infection for themselves, and can be helped to come to decisions about HIV testing. The process of grieving may last many months, possibly even years. However, for some people a single counselling session may be sufficient to clarify their thoughts and feelings, and to reassure them that they are coping as best as they can under the circumstances. Other people may need several sessions, and some people never completely come to terms with a loss, particularly that of a child (van Dam *et al.*, 2002). Caring for orphans from HIV/AIDS and who are often affected by HIV/AIDS requires action at all levels. In the countries hardest hit by HIV/AIDS, care for orphans lies often with their extended families or communities (van Dam *et al.*, 2002). In Uganda there is a programme that provide social economic support by supporting the income-generating projects by giving small loans to carers, therefore allowing carers, widow/widower/orphan or those caring for them to invest in projects e.g. setting up a stall to sell cooked food, and thus to support their families in sustainable manner (O'Hare *et al.*, 2005). Psychological support through counselling is as well provided to the orphan children, this support comes by virtue of a team well known to the family. Such support is also available when the child is admitted to hospital or when the child dies. Knowing that someone cares has been the most frequently quoted benefit of this support (O' Hare *et al.*, 2005). Social support to PLWHA and their families is the other kind of support that PLWHA should be given. In Thailand, for example, there are funeral associations belonging to the community welfare programme since 1974 (Singhanetra *et al.*, 2001). A member of household pays 20 Baht for each death and

receives 10,000 – 15,000 Baht when a member dies. This helps to cater for the funeral costs that could have added more pain to the family if it is not available (Singhanetra *et al.*, 2001). The author noted that increasing number of deaths from HIV/AIDS has led to many village households applying for membership of several associations as a form of security. However increase in number of deaths from HIV/AIDS imposes a burden on households as they try to maintain their membership of several different funeral associations (Singhanetra *et al.*, 2001).

#### **2.4.11 Prevention of mother to child transmission (PMTCT)**

Programmes directed at preventing mother-to-child transmission (MTCT) are increasing throughout the world (Piwoz and Bentley, 2005). These programmes are offering HIV testing and counselling to women as part of their antenatal care, which include decisions to take HIV tests and to disclose the test results (be it positive or negative) to another family member or a partner and there is a decision to breast-feed, for how long, or not to breast-feed at all. There are also decisions for the future, including how women may care for themselves and provide for their children (Piwoz and Bentley, 2005). Vertical transmission from mother to child can occur in utero, during labour and delivery, and through breastfeeding. In sub-Saharan Africa the risk of transmission through these means ranges between 10 and 30 percent (RCQHC, 2003). Transmission of HIV from an infected mother to her infant during breastfeeding ranges from 0.01- 0.04% per day of breastfeeding depending on the mother's health status and HIV viral load (Richardson *et al.*, 2003). By 2000 an estimated 5 million children had been infected by HIV through mother to child transmission and increases in child deaths of more than 100 percent are projected by 2010 in the most-affected regions of the world (UNAIDS, 2002). The joint UN programme on HIV/AIDS estimates that about 600,000 children under 15 years of age

were newly infected in the 2000 alone (UNAIDS, 2002). Ninety percent were infected through mother -to- child transmission (MTCT), and 90 percent of the infections occurred in sub-Saharan Africa. In some sub- populations, more than 30 percent of pregnant women are HIV infected (RCQHC, 2003). In developed countries, MTCT rates have fallen to as low as two percent of births among HIV-infected mothers in recent years with the introduction of HIV counselling and testing, short-course zidovudine (ZDV or AZT) prophylaxis, elective caesarean delivery, and the safe use of infant formula instead of breastfeeding (McIntyre, 2000). In Africa, however, where these interventions have generally not been available, and where prolonged breastfeeding is the norm; about 25–35 percent of HIV-infected mothers pass on HIV to their infants (Dabis *et al.*, 1993). Recent analysis of antenatal care data in Dar-es-Salaam region has revealed a decline in the HIV prevalence between 1995-2003 (TAS, 2005). Despite a 5-year scale-up of interventions to prevent mother-to-child transmission (PMTCT) of HIV, approximately one in 10 pregnant women were offered PMTCT services, and fewer than one in 10 HIV-positive pregnant women received ART prophylaxis for PMTCT worldwide (UNAIDS, 2006). In a study conducted in Tanzania, antenatal pregnant women were randomised to daily vitamin A (preformed vitamin A and B-carotene) and/or multivitamins (vitamins B-complex, C, and E) resulted in about 40% reductions in the risks of fetal loss, low birth weight and severe prematurity (Fawzi *et al.*, 1998). The same was reported by Villamore *et al.*, (2002) to a significant increase in weight gain during pregnancy.

#### **2.4.12 Treatment of opportunistic infections**

There are many laboratory non-infectious comorbidities commonly seen in patients with HIV (Aberg *et al.*, 2004; New York State Department of Health AIDS Institute, 2004) They include anaemia (caused by chronic disease, malnutrition, or quiescent

mycobacterium infection), thrombocytopenia (related to chronic liver disease), leukopenia and lymphopenia (reflective of immunosuppression), hypergammaglobulinemia (caused by overall dysregulation of the immune system), hypoalbuminemia (caused by malnutrition or liver disease), transaminitis (caused by viral hepatitis) and proteinuria (caused by HIV-associated nephropathy, most often in blacks). Patients with HIV also have typical health care needs beyond conditions related to HIV (Aberg, 2004; New York State Department of Health AIDS Institute, 2004). These include the need for routine, age-appropriate health-maintenance screening for cardiovascular health and for cancer (e.g., breast, prostate, colorectal). Thus, extra preventive focus at baseline is increasingly important for these patients. That is to say PLWHA need baseline evaluation in health maintenance interventions, opportunistic infection prophylaxis and antiretroviral therapy (Khalsa, 2006). One component of health maintenance in patients with HIV is routine vaccinations such as for tetanus and diphtheria (Kaplan *et al.*, 2002). The overall goal of antiretroviral therapy is to convert HIV infection into a chronic disease by suppressing viral replication to arrest or revert immunodeficiency progression and preventing opportunistic complications. With this goal in mind, therapy is desirable for patients who have or are near to having AIDS, based on symptomatology or CD4+ cell counts (Khan, 1998). However, more recent studies (Kaufmann *et al.*, 2004) have shown that these benefits are lost after discontinuation of therapy, thus necessitating lifelong therapy after such early initiation.

## **2.5 Key stakeholders and the roles they play in provision of care for PLWHA**

Services provided to PLWHA are coordinated and delivered by a broad range of stakeholders (Global Fund, 2004). This is because there are various factors likely to affect the provision and quality of care (NACP, 2005). These stakeholders include (i) the patient (PLWHA), (ii) the family and caregivers, (iii) the community HBC provider, (iv) the

Government, (v) local and international organizations or group (NGOs, CBOs, FBOs), and (vi) religious leaders. Others include social workers, reproductive health programmes and private institutions.

### **2.5.1 The PLWHA**

The PLWHA are themselves the main stakeholders to their care as they are supposed to accept and cope with their condition, thereby maximizing on their emotional health. Individuals living with HIV/AIDS are the primary caregivers to their health (AMREF, 2005). They should take their medicines accordingly and report any complication accordingly (NACP, 2005). PLWHA individuals are supposed to participate in the care process by making decisions on their own welfare (AMREF, 2005). They are supposed, if possible, to give consent on caregivers and where the care will be provided for example home or hospital especially during the terminal phase of the disease (AMREF, 2005). Health care providers can change the experience of illness and death for PLWHA through adequate counselling, palliative care and terminal care that meet professional standards (Uys, 2003). The individuals living with HIV/AIDS should also prevent transmission of their infections to others (NACP, 2005; MOH, 2005).

### **2.5.2 The family and caregivers**

The family also is one of the stakeholders in provision of care for PLWHA, which strengthens the PLWHA sense of belonging to their social groups (AMREF, 2005). Caring for the PLWHA helps the family to accept the condition and reduce stigma (AMREF, 2005). This is mostly done under home based care which make it easy to provide care and support to the client while attending to other responsibilities and also to be present at the time of death (AMREF, 2005; NACP, 2005). Learning to consult individuals living with

HIV/AIDS on matters concerning their care is one of the roles to be played by the family, whereby the family is also supposed to involve PLWHA in all care activities and any other family activities without discrimination (AMREF, 2005). The family needs to learn to accept and adjust to the situation, including that of terminally ill people with AIDS. The family is also supposed to collaborate with other care providers, such as religious institutions, support groups, health and social institutions. This becomes shared responsibility on issues of referral and networking (AMREF, 2005; MOH, 2005). The need to prepare for death as inevitable and sensitive, the family and caregivers should emphasize this to a family member living with HIV/AIDS. They should sensitise about the importance of ensuring the continuity of care of family members who are left behind. The family should also encourage PLWHA to write a will. Remembering that being present is a major support is one of the family roles towards care and support (AMREF, 2005).

### **2.5.3 FBOs, NGOs and CBOs**

According to NACP (2005), faith based organizations (FBOs), non governmental organizations (NGOs) and community based organizations (CBOs) that have interest in providing care to PLWHA especially the chronically ill patients are encouraged among other support services to provide care according to the national guidelines for home-based care. The NGOs, FBOs and CBOs also link the health facility to HBC for referrals. They also provide counselling and spiritual support to patients/families and communities.

### **2.5.4 The community**

The community also is a stakeholder towards provision of care to PLWHA, the community should accept the situation of the PLWHA and learn to collaborate and work with agencies around such as religious groups and other social agencies to meet the needs

of those infected/affected (AMREF, 2005). The community should also help the knowledge of HIV and to correct the myths and misconcepts about HIV/ AIDS prevention care and prevention (MOH, 2005). Other community roles are to identify own spiritual/pastoral needs, be open to the caregiver and share any worries and also advocate for behaviour change (AMREF, 2005). The community also helps to promote awareness about prevention of HIV/AIDS. Likewise by providing care it helps community members to understand the nature, counteract myths and misconceptions and holds the community morally together (AMREF, 2005). In order to eliminate stigma and provide appropriate support to the PLHA, the community should have adequate knowledge on HIV transmission, prevention and other crosscutting issues related to HIV/AIDS. It is therefore, imperative that each community takes an active role in addressing the issues of both HIV acquisition and its management (Parry *et al.*, 2004).

### **2.5.5 The Government**

The Government is one of the major stakeholders in provision of HIV/AIDS care and support. It is the one to create a supportive policy environment. It also develops policies and guidelines (AMREF, 2005). The government has a role to develop and maintain standards, to provide and coordinate training, to provide or subsidize drugs and commodities and help in the formation of support groups, which in turn would lobby and advocate for the rights of the PLWHA (AMREF, 2005). The health care system is one of the government sectors in provision of HIV/AIDS care and support; optimal adherence requires full participation by the health care team (MOH, 2005). The objectives of clinical care are to ensure care and treatment (MOH, 2005). Since HIV/AIDS opportunistic infections take long to heal therefore prolonged hospital stays are inevitable (AMREF,

2005). There is increased risk of acquiring other infections within a hospitalised setting because of their lowered immunity (AMREF, 2005). This can be avoided if the hospital stay is limited and continuous care is provided at home (AMREF, 2005; Uys, 2003).

Tanzania government has organized several programmes for the purpose of confronting the pandemic (TACAIDS, 2003). The Tanzania Commission for AIDS (TACAIDS) is the leading and an inclusive, multisectoral process to develop and apply national guidelines for providing nutritional care and support to PLWHA. The general purpose is to provide policymakers, programmes, caregivers and PLWHA with sound guidance to improve the nutritional status and well being of PLWHA. Being a governmental programme, TACAIDS multisectoral response to HIV/AIDS mission includes:

- to develop a strategic framework and national guideline to supporting planning, coordination and implementation of the national multisectoral strategies at all levels
- to develop and facilitate implementation of the national strategy for mobilization and utilization of resource for HIV/AIDS
- to establish and strengthen partnership of expanded response among all stakeholders in government departments, PLWHA, NGOs, FBOs, CBOs, private sector and religious leaders
- to promote research of HIV/AIDS and to find linkage with other institutions
- to develop effective mechanisms for monitoring trends of HIV/AIDS epidemic and the impact of the interventions
- to establish sustainability and effective management capacity at TACAIDS level.



### **2.5.6 Religious leaders**

Religious leaders are often called upon to provide guidance; counselling and spiritual support to HIV/AIDS patients and families but are asked by the government to refrain from claiming to cure AIDS through prayers (NACP, 2005). Spiritual needs of the patient must be determined and attended to appropriately thus the need to involve in FBOs (MOH, 2005).

### **2.5.7 Other stakeholders in provision of HIV/AIDS care**

The reproductive health programmes, private institutions and social workers are also stakeholders in the provision of HIV/AIDS care and support (Global fund, 2004).

## CHAPTER THREE

### 3.0 METHODOLOGY

#### 3.1 Overview, location and characteristics of the study area

This chapter presents the methodology of the study. It describes the approach that was used in conducting the research. Respondents for this study came from two NGOs. These are WAVUMO (Wanaoishi na Virusi vya Ukimwi Morogoro), which means an association of people living with HIV/AIDS, and Faraja Trust Fund. The two NGOs are non – profit offering a wide array of services to people living with HIV/AIDS including testing, counselling and medical services in Morogoro Municipality and its suburbs.

The study was conducted in Morogoro Municipality, which is the regional headquarters of Morogoro Region. Morogoro Municipality has a total land area of 260 sq.km. It is one of the oldest towns in the history of Tanzania established in the 18<sup>th</sup> century. Arabs used Morogoro as a stop over and route for slave caravans from the hinterland to the coast before shipping them to the Far East through the Indian Ocean (Morogoro Municipality, 2006). The population of the Municipal stands at 228 863 in the ratio of 50.35% women and 49.65% men according to the national population census of 2002. The population growth rate in the Municipal is 4.6% per annum and the average income of a person per year is Tshs 185 000/=.

The total average annual rainfall ranges between 821mm to 1,505mm. Long rains occur between March and May and short rains occur between October and December. Major economic activities include industries of primary and secondary level, subsistence and commercial farming, small-scale enterprises and commercial retail as well as wholesale.

The main agricultural crops are sisal, rice and maize, which are grown in the neighbouring districts and the periphery of the Municipality. Other crops include vegetables, fruits and yams.

Morogoro Municipality has HIV/AIDS prevalence rate of 6.7% (NACP, 2005). The prevalence rates for Morogoro region in 2002 were 8.6%, 8.9%, and 8.4% for 15-24 years, 25-34 years, and 35 years and above respectively. There were 7,073 AIDS cases reported by the year 2003 (MOH, 2003). There are two organizations in Morogoro Municipal that are well known for working to support people living with HIV/AIDS (PLWHA). The two organizations are Faraja Trust Fund (FTF) and Wanaoishi na Virusi vya Ukimwi Morogoro (WAVUMO). The two organizations are the ones that were used in this study.

### **3.2 Faraja Trust Fund (FTF)**

Faraja Trust Fund (FTF) is a non-governmental organization established in 1991, situated in Morogoro Municipality, which deals with several developmental issues and has been in the frontline in war against HIV/AIDS. FTF provides a number of services to PLWHA including counselling and home care programmes, coping support, income generation activities and preventive health education. A specialist medical doctor in psychiatry and public health founded it. FTF has a total of 200 active members PLWHA.

### **3.2 Wanaoishi na Virusi vya Ukimwi Morogoro (WAVUMO)**

“Wanaoishi na Virusi vya Ukimwi Morogoro” (WAVUMO) is a non-governmental organization of PLWHA. It is situated in Morogoro Municipality having a total of 50 active members PLWHA. WAVUMO provides a number of care and support services to its PLWHA members, including; counselling and testing, home-based care programmes,

nutritional support, medical counselling and support, provision of seminars on HIV/AIDS and end of life care. The organization was established in year 2000 having only 16 members. The organization aims at lengthening the lives for PLWHA in Morogoro region.

### **3.3 Research design**

This study adopted a cross-sectional design. The design allows data collection at a single point in one time (Babbie, 1990). The design is useful for description purposes as well as the determination of relationships between variables. Limited resources and time also justified the use of this design.

### **3.4 Sampling procedures**

#### **3.4.1 Population and sample**

The population from which the sample for this study was drawn involved people living with HIV/AIDS (PLWHA) who were members of WAVUMO and Faraja Trust Fund organizations. Data on type and quality of care provided to PLWHA were obtained.

#### **3.4.2 Sample size**

The sample consisted of 90 people living with HIV/AIDS (PLWHA) who were selected for interview. They included 40 respondents from FTF and 50 respondents from WAVUMO. Two groups of Focus Group Discussions (FGDs) of PLWHA were also organized for discussion in each organization, each group comprised of 4 members. Also, 2 key informants who were members of management team from each organization were interviewed. Other stakeholders such as collaborating NGOs, Morogoro Regional and District Medical Officers, Morogoro Regional and District AIDS Coordinators were consulted.

### **3.4.3 Sampling technique**

Purposively the 90 individuals living with HIV/AIDS were selected ensuring desired representation of specific subgroups of males and females, adults, elderly and youth. Purposive sampling technique was used to select the 4 members for FGDs and the 2 key informants for in-depth interview from each organization. One FGD was for men and one for women. The other stakeholders that deal with HIV/AIDS those who were at the top management level were also interviewed.

### **3.5 Data collection procedures**

A specially designed questionnaire was used to collect data from people living with HIV/AIDS (PLWHA) through face-to-face interviews. Each interview was accompanied by the introductory remarks pertaining to the purpose of the study, and the respondents' cooperation was solicited. In order to be able to hold focus group discussions with all 2 purposively selected groups, each group on gender bases was held separately. This encouraged group members to speak more freely about the subject without fear. This complies with observations by Morgan and Kreguer (1993). Prior to focus group discussion, the objectives were explained to the respondents in order to make them aware. Focus group guide was used to guide the discussion on various aspects and it was composed of open-ended questions as shown in appendix 4. The information from the other stakeholders consulted was obtained by use of a checklist as shown in Appendix 3.

#### **3.5.1 Development of research instrument for assessing the quality of care:**

##### **Construction of care score index**

In order to assess quality of care provided to PLWHA, a score index was developed with respect to various caring parameters. Such parameters included counselling and testing

services, medical care and home based care rendered by care providers. Others were care awareness and practice about prevention of mother to child transmission (PMTCT) and communication and behaviour change for PLWHA. A panel of relevant experienced experts and practitioners from Sokoine University of Agriculture and TACAIDS were consulted to suggest the important parameters to be included. A draft was compiled and given to the experts for comment before the index was used to collect data. Details of the score index are given in Appendix 1. Ruel and Purmima (2002) used a similar approach of scoring system to quantify child-feeding practices and used the score to examine associations between child feeding practices and nutrition.

### **3.5.2 Pre-testing of research tools**

Prior to data collection, the survey instrument was submitted to some members of staffs in the Department of Food Science and Technology at the Sokoine University of Agriculture to check for content validity. Pre-testing was then done under field conditions whereby five respondents were randomly selected from a group of people living with HIV/AIDS in Temeke, Dar-es-salaam. The area was not part of the study area. The aim of pre-testing was to check if the questions were clear, specific and pertinent to the study objectives. The questionnaire was then revised and used for data collection.

### **3.5.3 Types and sources of data**

#### **(a) Primary data**

Primary data were obtained through structured questionnaire for sampled individuals PLWHA (Appendix 2). The questions focused on the information of socio-demographic and care aspects with regard to testing for HIV/AIDS, medical treatment of opportunistic

infections, knowledge and services of PMTCT, behaviour change communication, and home-based care. General discussion guide and eliciting details through probes was done through focus group discussion (FGD) guide (Appendix 4) for individuals PLWHA to get detailed qualitative information. Other information was obtained from selected key informants from management teams of WAVUMO and FTF through a checklist (Appendix 3). Other stakeholders dealing with HIV/AIDS were also consulted. They included Morogoro Regional and District AIDS Coordinators, Morogoro Regional and District Medical Officers. Others were National AIDS Control Programme (NACP), Family Health International (FHI), Pathfinder and Tanzania Commission for AIDS (TACAIDS).

### **(b) Secondary data**

The main sources of secondary data for this study included WAVUMO and FTF, Ministry of Health and its departments, Tanzania Commission for AIDS (TACAIDS), UN Agencies, collaborating NGOs and Regional and District Medical Offices. Others were published and unpublished research reports from various sources.

### **3.6 Data analysis**

The collected data were coded and where applicable data from open-ended responses were sifted and categorized for further analysis. All quantitative analyses reported in this study were conducted using the computer programme Statistical Package for Social Sciences (SPSS) version 11.5. Descriptive statistics, which included means, frequencies and percentages, were computed to describe quality of care provided to PLWHA. Inferential statistics were computed to show linkages between dependent and independent variables. They included cross-tabulations with chi-square ( $X^2$ ) and t-test statistics. Responses of the

focused group discussion were recorded and data from each group was summarized and broken down into smaller meaningful units of information.

### **3.7 Ethical considerations**

Ethical considerations were abided to throughout this study. Consent was obtained orally after a participant was given all the information about the project. Confidentiality of the information provided by the respondents and the organizations was ensured.



## **CHAPTER FOUR**

### **4.0 RESULTS AND DISCUSSION**

#### **4.1 Overview**

This chapter presents the research findings. It is divided into four sections. The first section of this chapter describes the demographic and socio-economic characteristics of the respondents; while section two discusses the stakeholders and the types of care services they provide to PLWHA. In section three results on the care score index that was constructed to assess the quality of care provided to PLWHA are presented and the fourth section discusses how people living with HIV/AIDS perceive quality of care that is provided to them.

#### **4.2 Demographic and socio – economic characteristics of the respondents**

The aim of this section is to describe the demographic and socio – economic characteristics of the respondents. The characteristics described include age, sex, marital status, education level and main occupation.

##### **4.2.1 Age distribution**

The distribution of respondents according to their age is shown in Table 1. The respondents are grouped in 6 age groups. Most of the respondents (36.7%) were between 31-40 years of age. It was observed that 28.9 %, 18.9 % and 7.8 % were in the age groups of 41–50, 21–30, 51-60 years respectively. It is further shown that very few (2.2%) respondents belonged to 61 years and above. The respondents' age ranged between 16 and 68 years of age. The mean age for all respondents was 37.81 whereby the mean for females was 36.4 years and for males was 38.4 years.

**Table 1: Age distribution of respondents**

Age group in years	Percent		
	Male (N=26)	Female (N= 64)	Total (N=90)
Age groups			
10 – 20	7.7	4.7	5.6
21 – 30	19.2	18.8	18.9
31 – 40	38.5	35.9	36.7
41 – 50	30.8	28.1	28.9
51 – 60	3.8	9.4	7.8
> 60	0%	3.1	2.2
<b>Total</b>	<b>100</b>	<b>100</b>	<b>100</b>

#### 4.2.2 Gender composition

Distribution of the respondents by gender included 28.9% males and 71.1% females (Table 1). The striking imbalance of males and females respondents can be explained by the fact that many men were not willing to open up themselves to people especially those who were not members of the NGOs they were enrolled in. Female-headed households made up 50% of the 90 households of the respondents interviewed while male-headed households made up 48.9 and there was one child headed household. Among the respondents interviewed 61.1% were heads of their households.

#### 4.2.3 Marital status

Marital status was categorized as single, monogamous and polygamous marriages, divorced, widow, separated, and cohabiting. Distribution of the respondents according to their marital status is summarized in Table 2. Given the nature of the sampled respondents (i.e. PLWHA), it is not surprising that 37.8% of the respondents were widows or

widowers. Few females (4.7%) were cohabiting (i.e. living with male partners without formal marriage) despite knowing their seropositive status. Much of the prior research on care giving has focused on cohabitation as the primary caregiver as often found to be associated with informal care provision (Biegel *et al.*, 1991 and Pearlin *et al.*, 1994). The majority of the male respondents (34.6%) were monogamous married.

**Table 2: Marital status of respondents**

Marital status	Percent		
	Male (N=26)	Female(N= 64)	Total (N=90)
Single	30.8	17.2	21.1
Monogamous married	34.6	14.1	20.0
Polygamous married	7.7	3.1	4.4
Widow/widower	19.2	45.3	37.8
Separated	3.8	9.4	7.8
Cohabiting	0	4.7	3.3
Divorced	3.8	6.3	5.6
<b>Total</b>	<b>100</b>	<b>100</b>	<b>100</b>

#### 4.2.4 Level of education

About 67% of respondents completed primary education and 10% attained secondary education (Table 3). Others had informal education, higher education, adult education and none.

**Table 3: Education level of respondents**

Education level	Percent		
	Male (N=26)	Female (N= 64)	Total (N=90)
Few years in primary school	19.2	7.8	11.1
Completed primary school	65.4	67.2	66.7
Few years in secondary education	1.1	3.1	3.3
Completed secondary education	3.8	12.5	10.0
Higher education	0	1.6	1.1
Informal education	0	3.1	2.2
Adult education	3.8	1.6	2.2
None	3.8	3.1	3.3
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

#### 4.2.5 Occupation

As presented in Table 4, petty trade, which included food vendors and kiosks, was the main activity for the respondents, accounting for 32.2% of them. This was followed by agriculture (16.7%), and self-employment (12.2%). Less reported types of occupations included casual labourer (2.2%) and formal employment (2.2%). This low percentage of the formal employment could be due to low level of specialization, which is attributed to low level of education among the studied individuals living with HIV/AIDS.

**Table 4: Occupation of respondents**

Occupation type	Percent		
	Male (N=26)	Female (N= 64)	Total (N=90)
Formal employment	0	3.1	2.2
Self employment	15.4	10.9	12.2
Casual labour	0	3.1	2.2
Petty trade	30.8	32.8	32.2
Agriculture	23.1	14.1	16.7
Student	7.7	0	2.2
None	23.1	35.9	32.2
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

#### 4.2.6 Household composition

Table 5 shows that most of the households of the people living with HIV/AIDS (48.9%) had between 5-8 persons followed by 42.2% who had 1-4 members. The overall mean of household size was 5.2 people. Family size observed in this study is similar to other studies conducted in Tanzania (Mkunda, 2005). According to population census of 2002, the average of 5.2 household size observed in the study complies with the district average of 5.2 (NBS, 2002). Number of people per household ranged from 1 to 15 persons.

**Table 5: Household composition of respondents**

Household size	Percent		
	Male (N=26)	Female (N= 64)	Total (N=90)
1 – 4 persons	48.0	40.6	42.2
5 – 8 persons	48.0	50.0	48.9
9 and above persons	4.0	9.4	8.9

#### **4.3 Key stakeholders involved in the provision of care for PLWHA**

Stakeholders in provision of HIV/AIDS care and support were all those involved in care and had a role to play in the delivery of various services (AMREF, 2005). In this study, different types of stakeholders were identified dealing with care giving to PLWHA in Morogoro Municipality. These included governmental organizations/institutions, non-governmental organizations (NGOs), faith-based organizations (FBOs), community based organizations (CBOs), the PLWHA themselves and the families. Some specific aspects of the roles were unique to the specific players, but others were overlapping to some extent. Every stakeholder was found to be important and making vital contributions to the total care system. Through focus group discussions and key informants, three categories of care services for PLWHA were identified to be provided by various stakeholders. The three

categories included health services, counselling and testing and home-based care. Each of the categories is described in the next sections.

#### 4.3.1 Health services

Different health service providers were identified in Morogoro Municipality, which included hospitals, health centres, dispensaries, and pharmacies as indicated in Table 6. It is emphasized by the Ministry of Health, 2005 that health care facilities are required to make proper diagnosis, initiate the right treatment and provide appropriate counselling services. According to the National Policy on HIV/AIDS of 2001 all HIV positive people should benefit from early counselling and prophylactic treatment against opportunistic infections, and continue to lead normal and productive lives. Some organizations, including FTF and WAVUMO, were also providing modern medicines as well as alternative medicine services from traditional healers.

**Table 6: Health facilities in Morogoro Municipality identified to provide services to PLWHA**

Category of service	Owner				Total
	Govt	Private	Parastatal	Others	
Dispensaries	11	14	02	06	33
Health centres	03	04	01	02	10
Hospital	03	0	0	0	03
Pharmacies [PtI]	0	12	0	0	12
Pharmacies [PtII]	0	118	0	0	118

**Source:** Municipal Health Office (2005)

Key: PtI = Pharmacies

PtII = Medical stores

#### **4.3.2 Counselling and support**

Counselling and support was being provided by almost all stakeholders; governmental organizations, non-governmental organizations (NGOs) and faith-based organizations (FBOs). Government hospitals including Morogoro Regional Hospital and Nunge Hospital mainly provided counselling and support services. Sokoine University of Agriculture (SUA) provided nutrition education. The NGOs that provided counselling and support services in Morogoro Municipality were Faraja Trust Fund (FTF), Wanaoishi na virusi vya UKIMWI Morogoro (WAVUMO), AMREF and ANGAZA. FORD foundation provided assistance to support PLWHA groups and for WAVUMO office coordination. In this study, it was observed that 71.1% of the respondents received pre-test counselling and the remaining 28.9% did not receive pre-test counselling, while 81.1% received post-test counselling and the remaining 18.9% did not receive post – test counselling (Table 7). Counselling before testing was provided to individuals who were considering having an HIV test. Counselling is done with information on basic technical aspects of screening and the possible personal, medical, social, psychological and legal implications of being diagnosed either positive or negative (MOH, 2005). It is worth noting that quality of counselling is very important as from this point is when the person living with HIV/AIDS can live positively and get assisted to work through particular problems she/he faces (SAT, 2003). Counsellors encourage people having HIV to recognise and develop ways in which they can deal more effectively with the problem (SAT, 2003). The fact that 28.9% and 18.9% of the respondents did not receive pre-test counselling and post-testing counselling respectively is a reason for concern. Effort is thus needed to ensure that pre and post-test counselling is available to all people who need it. The results of counselling services have similar findings to that of Harding (2003), that only 10% of people who

need testing in low and middle-income countries have access to counselling and testing services.

**Table 7: Distribution of respondents according to their responses of receiving counselling service**

Response	Pre-testing counselling		Post-testing counselling	
	Frequency	Percent	Frequency	Percent
Yes	64	71.1	73	81.1
No	26	28.9	17	18.9
<b>Total</b>	<b>90</b>	<b>100.0</b>	<b>90</b>	<b>100.0</b>

#### 4.3.3 Home-based care

Since patients suffering from HIV/AIDS-related conditions occupy about 50% of the hospital beds in urban areas in Tanzania, most patients are cared at home (MOH, 2002). The family was reported to be a primary care provider in this study (Table 8) where it was observed that the key caregivers in the family with regard to home-based care were relatives (37.8%), followed by an older child (27.8%). The findings of this study are contrary to what Biegel *et al.*, (1991) found on family care giving in chronic illness. Pearlin *et al.*, (1994) reported cohabitation to be the key way of care giving in their communities. The respondents who reported to have had no one to care for them at home in this study were 2.2%. It is worth noting that some of the respondents did not wish members of their households to know about their HIV/AIDS status. The majority of those who disclosed their status did so to only one member of the family and those whose primary caregivers were neighbours did disclose to the neighbours and not to the family members. Results show that 74.4% of the individuals living with HIV/AIDS had told their households' members the truth about their status and 25.6% did not have any household member knowing their HIV/AIDS status. A study conducted by Kapata (2004) on



caregivers of AIDS patients in rural Tanzania reported that the majority of the care providers were family members of the PLWHA and these care providers received very little or no support from the community and the households were stigmatised. Home-based care services were also being provided by non-governmental organizations (NGOs) from the community based home care providers. However, 42.2% of respondents stated not to be visited by the community home-based care (CHBC) providers. Distribution of the respondents according to the frequencies of visits from care providers is summarized in Table 9. Low level of frequency of visits was contributed by a few number of home-based care (HBC) providers who have to attend to all 19 wards of Morogoro Municipal as reported by the FTF and WAVUMO key informants. This was also reported by the respondents during focus group discussions to be a problem and they stated that this lead to the home-based carers to loose track of patients' progress and their immediate needs. For HBC to be functional, it is vital that good lines of communication be developed and maintained between the different levels of patient care (MOH, 2005). Economic support is one part of the home-based care. The respondents obtained economic support through their organizations. The reported type of support, which were funded by SAT and FORD Foundation were in form of loans and some working devices like wheelbarrows, bicycles, food and clothes.

**Table 8: Reported caregivers in the family**

<b>Caregiver</b>	<b>Frequency</b>	<b>Percent</b>
Parents	15	16.7
Relative	34	37.8
Older child	25	27.8
Wife/husband	9	10.0
Neighbours	5	5.6
None	2	2.2
<b>Total</b>	<b>90</b>	<b>100.0</b>

**Table 9: Frequency of visits by care providers from CHBC**

<b>Frequency of visits</b>	<b>Frequency</b>	<b>Percent</b>
None	38	42.2
Annually	5	5.6
Monthly	20	22.2
Fortnight	7	7.8
Weekly	20	22.2
<b>Total</b>	<b>90</b>	<b>100.0</b>

#### **4.3.3.1 Provision of medical support at home**

Table 10 shows that nearly 65% of the respondents obtained medical support at home. The policy of MOH states that at the time of leaving the health facility, patients should be given adequate discharge summary information to enable the next care provider to take over efficiently. Patients are supposed to take such information to a health facility nearest to their place of domicile or to the community HBC provider. This is so done to ensure the continuum of quality health care from the health care facility to the household (MOH, 2005).

**Table 10: Respondents provision of medical support at home**

<b>Response</b>	<b>Frequency</b>	<b>Percent</b>
Yes	58	64.4
No	32	35.6
<b>Total</b>	<b>90</b>	<b>100.0</b>

#### **4.3.3.2 Family support on using medication and ARV**

The results showed that merely 31.1% were using ARVs, while the rest (68.9%) were not yet on ARVs treatment. Half (54.4%) of the respondents acknowledged getting support from their families on the use of medications including ARVs, while 45.6% did not get support from their families. Since there is no cure for HIV/AIDS or vaccine to prevent HIV infection, ARVs can help to prevent, treat, or even cure many of the opportunistic infections and relieve the symptoms associated with HIV/AIDS, which include fever, coughing, itching, poor appetite, difficulty breathing or swallowing and chronic diarrhoea. ARVs are a group of drugs that directly attack the HIV virus and significantly reduce the replication rate of the virus on the body of the HIV infected person. These drugs can decrease the viral load and slow down the progression of HIV disease (FANTA, 2004).

#### **4.3.3.3 Training of home care givers**

Table 11 shows that only a moderate proportion (36.7%) of home caregivers received training on care for people living with HIV/AIDS. According to NACP guidelines for home-based care services, the family is required to choose among themselves at least one person who would be trained on specific elements of care for their patient. However, the guideline further states that it is essential that more than one family member knows about the general care of the patient so as to support each other and assure continuity of care in case the primary care giver is absent. Home care is pursued, not as a way to divert the

burden of chronically ill AIDS patients from hospitals to the community, but to provide the same care in a different environment (NACP, 2005). Home-based care is the one way of ensuring that PLWHA receive quality care beyond the health facilities (TAS, 2005). Home-based care is therefore an important link between health facilities and home or community for providing support, follow up and monitor compliance and adherence of those on ARVs (TAS, 2005).

**Table 11: Member of family reported to have received training on caring for PLWHA**

<b>Response</b>	<b>Frequency</b>	<b>Percent</b>
Yes	33	36.7
No	57	63.3
<b>Total</b>	<b>90</b>	<b>100.0</b>

#### **4.4 Extent of care for PLWHA: Results of care score indices**

Appendix 1 displays a care score index that was developed in order to assess quality of care provided to PLWHA. It included five components which are (i) counselling and testing services, (ii) medical care services, (iii) home based care rendered by care providers, (iv) awareness and practice about prevention of mother to child transmission (PMTCT) care and (v) communication and behaviour change services for PLWHA. In order to allow for comparisons, scores were converted to percentages of the maximum possible score. Therefore each parameter had 100 as the maximum score and 0 as the minimum score. Scores were categorized as very low quality of care (0-20), low quality of

care (21-40), moderately high quality of care (41-60), high quality of care (61-80) and very high quality of care (81-100).

#### 4.4.1 Counselling and testing

Results of the extent of care in counselling and testing are summarized in Table 12. Forty percent of the respondents received high quality of counselling care while 23.3% received moderately high quality of care. Only 4.4% acknowledged receiving very high quality of counselling care.

**Table 12: Quality of care in counselling care component**

<b>Category of care quality</b>	<b>Mean score</b>	<b>Frequency</b>	<b>Percent</b>
Very low quality of care	4.13±6.73	23	25.6
Low quality of care	29.58±5.10	6	6.7
Moderately high quality of care	52.26±4.87	21	23.3
High quality of care	72.36±5.38	36	40.0
Very high quality of care	86.88±2.39	4	4.4
<b>Total</b>		<b>90</b>	<b>100.0</b>

##### 4.4.1.1. Factors that determine the extent of care in the counselling component

T-tests for mean values of various variables were conducted to determine factors that influence the extent of care in the counselling component. The variables tested included duration of living with HIV, age, gender, occupation, marital status, type of household head, and level of education. Results of each of the variables tested are described in the following sections.

### (a) Duration of living with HIV

The findings revealed that there was significant difference in quality of counselling between the respondents who have lived with HIV for 0 to 2 years and those of 3 to 4 years ( $t = 2.251$ ;  $p \leq 0.05$ ) (Table 13) whereby the former scored higher than the latter. Other groups have shown no significant difference in their mean values. The plausible reason could be that the PLWHA who have lived for a shorter time with their serology tend to attend and adhere more to counselling than those who have lived longer with their positive serology. It can further be explained that perhaps messages that are provided during the counselling are the same so much that PLWHA are not motivated to continue receiving the service.

**Table 13: Quality of counselling and duration of living with HIV/AIDS**

Duration category	Mean score	t	Significance (2 tailed)
0-2 Years	51.7614	2.251	0.028*
3-4 Years	35.4348		
0-2 Years	51.7614	-0.003	0.997
5-18 Years	51.7857		
3-4 Years	35.4348	-1.798	0.079
5-18 Years	51.7857		

Key: \* indicates  $p \leq 0.05$

### (b) Age of an individual PLWHA

The study results revealed that, there was no significant difference in quality of counselling among various age groups at  $p \leq 0.05$  (Table 14). The reason could be that counselling was equally provided to all the individuals despite of their age differences.

**Table 14: Quality of counselling and age**

Age group	Mean score	t	Significance (2 tailed)
Young (16-30yrs)	47.0455	-0.765	0.447

Adults (31-45yrs)	52.6630		
Young (16-30yrs)	47.0455	0.901	0.373
Old Adults( $\geq$ 46yr)	39.3182		
Adults (31-45yrs)	52.6630	1.693	0.095
Old Adults( $\geq$ 46yr)	39.3182		

### (c) Gender of the respondent

The results show that there was no significant difference in quality of counselling between male and female respondents at  $p \leq 0.05$ . However, the females appeared to have higher scores than males ( $t = -1.060$ ;  $p = 0.292$ ). The possible reason to this could be that women are more forthcoming than men.

### (d) Occupation of the respondent

There was no significant difference in the mean score of quality of counselling among the various categories of occupation at  $p \leq 0.05$  (Table 15). Those with informal/self-employment, however, scored higher than the other occupation categories.

**Table 15: Quality of counselling and occupation**

Occupation category	Mean score	t	Significance (2 tailed)
Self/Informal employment	55.9091	1.323	0.194
Petty trade	43.1250		

Self/Informal employment	55.9091		
Agriculture	45.8333	0.869	0.393
Self/Informal employment	55.9091		
None	55.3448	0.059	0.953
Petty trade Agriculture	43.1250 45.8333	-0.288	0.775
Petty trade None	43.1250 55.3448	-1.658	0.103

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**(e) Marital status**

Results in Table 16 show that there were no significant differences in mean scores among the different categories of marital status at  $p \leq 0.05$ . However, the married/cohabitating couples scored higher. The most likely reason to this could be due to their responsibilities which they feel to each other, and therefore push them to seek more information on different aspects with regard to their care.



**Table 16: Quality of counselling services and marital status**

Type of marital status	Mean score	t	Significance (2 tailed)
Single	43.4211	-1.491	0.143
Married/cohabiting	55.3846		
Single	43.4211	-0.590	0.560
Divorced/Separated	50.2273		
Single	43.4211	-0.097	0.923
Widow	44.2647		
Married/cohabiting	55.3846	0.515	0.610
Divorced/Separated	50.2273		
Married/cohabiting	55.3846	1.477	0.145
Widow	44.2647		
Divorced/Separated	50.2273	0.538	0.594
Widow	44.2647		

**(f) Type of household head**

Those who were household heads scored higher than the ones who were not, but the difference was not significant ( $t = 1.076$ ;  $p = 0.874$ ). The results further show that the heads of households who were female scored slightly higher (49.1) than the male ones (48.1) but again the difference was not significant ( $t = -0.159$ ;  $p = 0.874$ ).

**(g) Level of education**

Among various education categories, there was no significant difference in the mean scores (Table 17) at  $p \leq 0.05$ . Nevertheless, those with no formal education scored the lowest while those with secondary and above education scored slightly lower than those

with primary education. It appears that the primary education was the most favourite level for counselling services, something that may require further investigation.

**Table 17: Quality of counselling services and level of education**

<b>Education category</b>	<b>Mean score</b>	<b>t</b>	<b>Significance (2 tailed)</b>
Primary and adult education	49.1667	0.259	0.797
Secondary education and above	46.9231		
Primary and adult education	49.1667	1.065	0.290
No formal education	34.5000		
Secondary education and above	46.9231	0.745	0.467
No formal education	34.5000		

#### **4.4.2 Medical care**

Results of the extent of care in the medical care component are summarized in Table 18. Most of the respondents (68.9%) fell in low quality care category while 12.2% were in very low quality. Only 12.2% were able to score very high quality of care. People suffering from HIV related illnesses, may attend to a wide variety of medical services at different levels of health care system. These services may range from public and private multipurpose clinics, health centres, home-based care programmes, antenatal clinics, to PMTCT programmes. Others are VCT centres, TB clinics, STI clinics, general OPD unit, and inpatient ward (NACP, 2005).

**Table 18: Quality of care in medical care component**

<b>Category of care quality</b>	<b>Mean score</b>	<b>Frequency</b>	<b>Percent</b>
Very low quality of care	15.76±5.39	11	12.2
Low quality of care	34.52±4.76	62	68.9
Moderately high quality of care	47.08±1.67	16	17.8
High quality of care	73.33±0.00	1	1.1
Very high quality of care	15.76±5.39	11	12.2
<b>Total</b>		<b>90</b>	<b>100.0</b>

#### 4.4.2.1 Factors that determine the extent of medical care component

The same seven variables that were considered in the counselling and testing component were also tested. Results for each of the variable are present in the following sections.

##### (a) Age

The respondents in various age groups were found to score significantly different values of quality of medical care (Table 19). Old adults scored the lowest quality of medical care and this may be explained by the fact that most young people and adults are more economic independent and thus tend to have more access to medical care. Adults who scored the highest were probably more responsible to themselves and to their families and hence tend to seek whatever medical care they could obtain.

**Table 19: Quality of medical care and age**

<b>Age group</b>	<b>Mean score</b>	<b>t</b>	<b>Significance (2 tailed)</b>
Young(16-30yrs)	35.4545	-0.823	0.414
Adults(31-45yrs)	37.5362		
Young(16-30yrs)	35.4545	2.154	0.037*
Old Adults(≥46yr)	28.7879		

Adults(31-45yrs)	37.5362	3.482	0.001***
Old Adults( $\geq$ 46yr)	28.7879		

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Key: \* indicates  $p \leq 0.05$ ; and \*\*\* is  $p \leq 0.001$

### **(b) Gender**

The study results revealed that male and female respondents scored almost the same quality of medical care, 34.87 and 34.90 respectively ( $t = -0.010$ ;  $p = 0.992$ ). This indicates that medical care services in the families and community were equally provided to men and women.

### **(c) Occupation**

Results show that in various categories of occupation there was no significant difference in mean score medical care (Table 20) at  $p \leq 0.05$ . It might be that most of the respondents were depending on the free services that were provided to them through the public health facilities. It is likely that they could not afford extra medical services that are available in the market.

**Table 20: Quality of medical care and occupation**

<b>Occupation category</b>	<b>Mean score</b>	<b>t</b>	<b>Significance (2 tailed)</b>
Self/Informal employment	34.5455	-0.436	0.665
Petty trade	35.9524		
Self/Informal employment	34.5455	0.069	0.946
Agriculture	34.2222		
Self/Informal employment	34.5455	0.403	0.689
None	32.8736		
Petty trade	35.9524	0.717	0.477
Agriculture	34.2222		
Petty trade	35.9524	1.342	0.186
None	32.8736		

**(d) Marital status**

The study results reveal that, there was no significant difference in quality of home-based care and different categories of marital status at  $p \leq 0.05$ . However, the married and cohabitating couples scored higher in quality of medical care as displayed in Table 21. The reason to this could be that the married/cohabitating couples tend to remind each other on their medical care and in case there are some medicines prescribed or adherence treatment, the partners remind each other to go to the hospital for the treatment.

**Table 21: Quality of medical care and marital status**

<b>Marital status category</b>	<b>Mean score</b>	<b>t</b>	<b>Significance (2 tailed)</b>
Single	34.3860	-0.850	0.400
Married/cohabiting	37.4358		

Single	34.3860	-0.186	0.854
Divorced/Separated	35.1515		
Single	34.3860	0.435	0.666
Widow	33.1373		
Married/cohabiting	37.4358	0.580	0.565
Divorced/Separated	35.1515		
Married/cohabiting	37.4358	1.621	0.110
Widow	33.1373		
Divorced/Separated	35.1515	0.668	0.508
Widow	33.1373		

#### **(e) Type of household head**

There was no significant difference in mean scores of respondents who were households' heads and those who were not at  $p \leq 0.05$ . Similarly, quality of care was almost the same for male and female households (mean of 35.45 for the male-headed and 34.67 for the female-headed households). The likely reason to this could be that it didn't matter what sex of the head of household was, they all obtained the same type of medical care since this type of care was obtained from the health facilities and not within the household settings.

#### **(f) Education level**

The results show that, there was a significant difference in mean scores among the various categories of education (Table 22). Primary/adult education level scored higher in quality of medical care than those with secondary education and above ( $t = 2.157$ ;  $p = 0.034$ ). It is likely that most of the educated individuals living with HIV/AIDS tend to shy away to be seen that they are infected. They therefore tend to miss some of the very important services including the medical services. Free medical services for PLWHA were only

provided to individuals who have declared their status and who were willing to attend in person.

**Table 22: Quality of medical care and education level**

<b>Education category</b>	<b>Mean score</b>	<b>t</b>	<b>Significance (2 tailed)</b>
Primary and adult education	35.9259	2.157	0.034*
Secondary education and above	29.2308		
Primary and adult education	35.9259	0.276	0.783
No formal education	34.6667		
Secondary education and above	29.2308	-0.896	0.384
No formal education	34.6667		

Key \* denotes that  $p \leq 0.05$

#### **(g) Duration of living with HIV/AIDS**

Results in Table 23 reveal that there was no significant difference in quality of medical care among individuals with varying duration of living with HIV/AIDS at  $p \leq 0.05$ . The probable reason to this could be that because most of the medical care services for PLWHA were provided free of charge, respondents were willing to continue receiving them even at extended durations.

**Table 23: Quality of medical care and duration of living with HIV/AIDS**

<b>Duration category</b>	<b>Mean score</b>	<b>t</b>	<b>Significance (2 tailed)</b>
0-2 Years	61.8902	-0.711	0.479

3-4 Years	65.3765		
0-2 Years	61.8902	-0.646	0.520
5-18 Years	65.2730		
3-4 Years	65.3765	0.018	0.986
5-18 Years	65.2730		

#### 4.4.3 Home based care

Nearly 57 % of the respondents received high quality of home-based care and 16.7% reported very high quality of the same (Table 24). Home care draws on the strength of families and communities (WHO, 2001) whereby families are the central focus of care and form the basis of community home based care (CHBC). The goal of CHBC is to provide hope through good quality and appropriate care that helps patients and families maintain their livelihood and have the best possible quality of life. From various studies (WHO, 2000), it is clear that most people would rather be cared for at home and that effective home care improves the quality of life for chronically ill people and their family caregivers. A well functioning CHBC programme provides a continuum of care for persons with chronic illnesses from a health care facility to the home environment. Inputs from families, communities and health care systems are essential for any result-based CHBC programme. Community home-based care is defined as any form of care given to chronically ill people in their homes. Such care includes physical, psychological, social and spiritual activities (WHO/GPA in NACP, 2005). Since most terminally ill patients prefer to die at home, there is a need to bring hope to all of them in more friendly and familiar environments (NACP, 2005).

**Table 24: Quality of home-based care in home-based care component**



<b>Category of care quality</b>	<b>Mean score</b>	<b>Frequency</b>	<b>Percent</b>
Very low quality of care	16.46±3.16	6	6.7
Low quality of care	29.87±5.16	6	6.7
Moderately high quality of care	50.91±6.18	12	13.3
High quality of care	70.52±4.84	51	56.7
Very high quality of care	83.25±2.82	15	16.7
<b>Total</b>		<b>90</b>	<b>100.0</b>

#### **4.4.3.1 Factors that determine the extent of Home-based care component**

T-testing of the mean scores of quality in home-based care among the various categories of seven test variables indicated that none was significant different at  $p \leq 0.05$ .

#### **4.4.4 Awareness and practice about prevention of mother-to-child transmission**

##### **(PMTCT)**

Awareness and practise about PMTCT component of care was only assessed among the female respondents (n=64). Table 25 summarizes the results. About 67% of the female respondents scored very low quality of care. Only few (4.7%) of the female respondents reported high quality of PMTCT care. This finding is not surprising because it is estimated that approximately one in 10 pregnant women do get PMTCT services, and fewer than one in 10 HIV-positive pregnant women do receive ART prophylaxis for PMTCT worldwide (UNAIDS, 2006). It is estimated that globally only 5% of pregnant women attending antenatal clinics have access to PMTCT services (Global HIV Prevention Working Group, 2003). A study conducted in eight African countries on the cost-effectiveness of *Nevirapine* to prevent mother-to-child transmission revealed that there was an average of 1898 averted infant HIV infections (Michael *et al.*, 2004). HIV/AIDS is said to have the face of a woman. The vulnerability of women and girls to HIV is increased by biological, economical, social and cultural factors (RCQHC, 2003).

**Table 25: Quality of care in Prevention of mother-to-child transmission (PMTCT) practices care component**

<b>Category of care quality</b>	<b>Mean score</b>	<b>Frequency</b>	<b>Per cent</b>
Very low quality of care	0.00±0.00	43	67.2
Low quality of care	25.00±0.00	16	25.0
Moderately high quality of care	50.00±0.00	2	3.1
High quality of care	75.00±0.00	3	4.7
<b>Total</b>		<b>64</b>	<b>100.0</b>

#### 4.4.5 Communication and behaviour change

Results of care quality scores for the communication and behaviour change care component are summarized in Table 26. The results show that respondents were in favour of this component of care because a total of 65.5% fell in the high and very high quality of care categories. Among core elements of care and treatment that need to be established at the care and treatment clinics include education about behaviour change to reduce transmission of HIV (NACP, 2005). The prevention of HIV emphasizes on behavioural intervention strategies that focus on interpersonal prevention skills. Positively reinforcing incremental changes toward safer behaviour, and addressing how to disclose HIV-seropositive status to a sex or drug partner is also important (CDC, 2003).

**Table 26: Quality of care in communication and behaviour change component**

<b>Category of care quality</b>	<b>Mean score</b>	<b>Frequency</b>	<b>Percent</b>
Very low quality of care	<b>18.18±0.00</b>	1	1.1
Low quality of care	33.77±4.44	7	7.8
Moderately high quality of care	51.78±4.28	23	25.6
High quality of care	66.80±4.38	46	51.1
Very high quality of care	83.92±3.99	13	14.4
<b>Total</b>		<b>90</b>	<b>100.0</b>

#### 4.4.5.1 Factors that determine the extent of communication and behaviour change care component

Among the test variables that were considered, only those categories of age and marital status were significantly different in the way in which they were related with communication and behaviour change care component at  $p \leq 0.05$ . These are described in the next sections.

##### (a) Age

The study results reveal that old adults (46 years and above) scored the highest and this was particularly so as compared to young respondents at  $p \leq 0.05$  (Table 27). The reason to this could be that the old adults are a group that is having a lot of responsibilities on matters concerning their lives and possibly their marriages and also is an age group that cares for a number of people (dependants). Therefore this age group is likely to seek for more information and be willing to change behaviour than the younger age groups.

**Table 27: Quality of communication and behaviour change care and age of respondent**

Age group	Mean score	t	Significance (2 tailed)
<b>Age</b>			
Young(16-30yrs)	56.6116	-1.744	0.086
Adults(31-45yrs)	63.2410		
Young(16-30yrs)	56.6116	-2.140	0.038*
Old Adults( $\geq 46$ yr)	66.1157		
Adults(31-45yrs)	63.2410	-0.819	0.416
Old Adults( $\geq 46$ yr)	66.1157		

Key: \* denotes  $p \leq 0.05$

**(b) Marital status**

Table 28 shows that there is a significant difference in mean score between single and the married/cohabitating couples ( $t = -2.838$ ;  $p = 0.007$ ) whereby the latter group scored higher than the former group. The possible reason could be that, the married/ cohabitating respondents tend to support each other and hence give each other some useful information regarding their care. Likewise, being a couple they might be having some responsibilities to their children or relatives hence could be trying to search for more information with regard to their care so as to stay healthy for longer. Significant difference is also noted between the single and widowed respondents at  $p = 0.009$ , with widows showing higher scores. Having lost their spouses, the widows are more likely to accept behaviour change than the singles.

**Table 28: Communication and behaviour change and marital status**

<b>Marital status category</b>	<b>Mean score</b>	<b>t</b>	<b>Significance (2 tailed)</b>
Single	54.0670	-2.838	0.007**
Married/cohabiting	66.4334		
Single	54.0670	-0.936	0.357
Divorced/Separated	59.5041		
Single	54.0670	-2.704	0.009**
Widow	64.7059		
Married/cohabiting	66.4334	1.350	0.186
Divorced/Separated	59.5041		
Married/cohabiting	66.4334	0.501	0.618
Widow	64.7059		
Divorced/Separated	59.5041	-1.114	0.271
Widow	64.7059		

Key: \* \* denotes  $p \leq 0.01$

#### 4.5 How PLWHA perceive quality of care provided to them

Four aspects of care were considered in assessing how the PLWHA perceived the quality of care provided to them. The four aspects included, counselling, home based care, availability of health services and cost of health services. Five-point scale was mostly used to assess the perception. Each of the aspect is discussed in the next sections. However, it is important to keep in mind that perceptions of satisfaction and quality are often based on comments from friends, neighbours, and family or interpersonal, rather than technical or skills of service providers (Pathfinder, 2002).

##### 4.5.1 Quality of counselling

Most (43.3%) of the respondents rated counselling services they were getting to be good (Table 29). Using chi-square statistic testing the table also shows that no significant differences in perceived quality of counselling by people living with HIV/AIDS between males and females at  $P < 0.05$  were noted. Most people in this study obtained their counselling services from VCT Centres (63.3%), while the rest obtained their services from hospitals (25.6%), and through the community workers (2.2%).

**Table 29: Perceived quality of counselling services**

<b>Response</b>	<b>Male (%) n=26</b>	<b>Female (%) n=64</b>	<b>Total (%) n=90</b>
Very poor	34.6	21.9	25.6
Poor	3.9	6.3	5.6
Fair	11.5	23.4	20.0
Good	42.3	43.8	43.3
Very good	7.7	4.7	5.6

Chi-square value = 2.985;  $p = 0.56$

##### 4.5.2 Quality of home based care

Majority of people living with HIV/AIDS rated the quality of home based care provided to them as good (70.8%) while none rated it as very good (Table 30).

**Table 30: Perceived Quality of home-based care services**

<b>Response</b>	<b>Frequency</b>	<b>Percent</b>
Very poor	10	11.2
Poor	6	6.7
Fair	10	11.2
Good	63	70.8
Very good	0	0.0

#### 4.5.3 Quality of health services

A significant proportion of respondents rated quality of health services provided to them as fair (42.2%), while 26.7% rated it as good and 17.8% rated it as very good (Table 31). Further analysis reveal that majority of respondents (76.7%) reported to get health services whenever they needed while only 23.3% failed to obtain health care at least once (Table 32). When the respondents were asked to give the reasons for missing the services, majority of them (86%) indicated lack of enough drugs to be the main reason. Others indicated lack of health workers (4.5%), lack of HIV testing services (4.5%) and not willing to pay for the services (4.5%).

**Table 31: Perceived quality of health service received**

<b>Response</b>	<b>Frequency</b>	<b>Percent</b>
Poor	12	13.3
Fair	38	42.2
Good	24	26.7
Very Good	16	17.8
<b>Total</b>	<b>90</b>	<b>100.0</b>

**Table 32: Frequencies of missing health services when needed**

<b>Extent of missing</b>	<b>Frequency</b>	<b>Percent</b>
Once	3	3.3
Twice	9	10.0
Thrice	2	2.2
More than four times	7	7.8
None	69	76.7
<b>Total</b>	<b>90</b>	<b>100.0</b>

#### 4.5.4 Cost of care

There was only a total of 16.7% respondents who indicated to have incurred some money costs for health services provided to them, especially on medical care (Table 33). On the other hand, the majority of the respondents (83.3%) did not incur any money cost. This observation is due to the fact that all the two NGOs where the respondents were members were providing free health services for PLWHA. Similarly, all the PLWHA were supposed to receive free medical treatment in government hospitals as stipulated in the National HIV/AIDS Policy of 2001.

**Table 33: Perceived cost paid for health services**

<b>Response</b>	<b>Frequency</b>	<b>Percent</b>
High	7	7.8
Fair	8	8.9
Have incurred no cost	75	83.3
	<b>90</b>	<b>100</b>





## CHAPTER FIVE

### 5.0 CONCLUSIONS AND RECOMMENDATIONS

#### 5.1 Conclusion

The general objective of this study was to assess the nature of quality of care services provided to people living with HIV/AIDS (PLWHA). The work involved developing a care score index for assessing the quality of care provided to PLWHA. The approach involved distinguishing care for PLWHA into five components for the sake of analytical convenience. The five components were namely: (i) counselling and testing, (ii) medical care, (iii) home-based care, (iv) awareness and practice about PMTCT, and (v) communication and behaviour change. Other objectives were identification of key stakeholders and assessment of PLWHA perception of quality of the care services they get as well as to determine the factors that affect the quality of care given to individual PLWHA. The major reason for conducting this study was based on the need to have clear understanding of the type of care and support provided to PLWHA so as to fill the existing information gap. Data were collected through structured questionnaire from a purposive sample of 90 respondents from two NGOs, which are well known to support PLWHA in Morogoro Municipality. Descriptive and inferential methods of data analysis were used.

The following are major conclusions drawn from the findings of this study:

Various stakeholders in Morogoro Municipality provided different types of care services to PLWHA. Different health service providers were identified which included hospitals, health centres, dispensaries, and pharmacies. They included governmental organizations/institutions such as the Morogoro Regional Hospital and Nunge Hospital. Non-governmental organizations (NGOs) were those of Faraja Trust Fund (FTF) and

Wanaoishi na Virusi vya Ukimwi Morogoro (WAVUMO) where the PLWHA were the members and some faith-based organizations (FBOs) like St. Mary Hospital.

Counselling and support was being provided by almost all stakeholders; governmental organizations, non-governmental organizations (NGOs) and faith-based organizations (FBOs). Government hospitals including Morogoro Regional Hospital and Nunge Hospital, which provided mainly counselling and support services whereas Sokoine University of Agriculture (SUA) provided nutrition education. The NGOs that provided counselling and support services were Faraja Trust Fund (FTF), Wanaoishi na virusi vya UKIMWI Morogoro (WAVUMO), AMREF and ANGAZA.

Families were reported to be the primary care provider in this study in home-based care services. Results show that majority (74.4%) of the individuals living with HIV/AIDS had told their household members the truth about their status. Home-based care services were also being provided by non-governmental organizations (NGOs) from the community based home care providers. These were mainly those of WAVUMO and FTF organizations.

The quality of various care services was determined by using a care score index developed by the researcher. The highest proportion of respondents (73.4%) reported high quality of care in the home-based care component, while the lowest (7.8) proportion was in the awareness and practice of PMTCT (Table 34). Other components of care that seemed to be favoured were communication and behaviour change (65.5%) and counselling and testing (44.4%). On the other hand, medical care was among the less favoured (13.3%).

**Table 34: Reported extent of high quality care among various components of care for PLWHA**

<b>Component of care</b>	<b>Percent</b>
Counselling and testing	44.4
Medical care	13.3
Home-based care	73.4
Awareness and practice about PMTCT	7.8
Communication and behaviour change	65.5

Most of the respondents perceived counselling and home-based care services they were getting to be good (43.3% and 70.8%, respectively). A moderate proportion (42.2%) of respondents perceived quality of health services provided to them as fair while a few (17.8%) perceived it as very good. Further analysis revealed that majority of respondents (76.7%) reported to get health services whenever they needed while only a few (23.3%) failed to obtain health care at least once. Only a total of 16.7% of the respondents indicated to have incurred some money cost while the majority (83.3%) did not incur any money cost for health care services.

Seven variables were tested for important factors determining the extent of care quality among various components of care for PLWHA. The variables were: duration of living with HIV/AIDS, age, gender, occupation, marital status, type of household head and level of education. Results showed that medical care was significantly influenced by age and education level of respondent (Table 35). The communication and behaviour change component was affected by age and marital status while counselling and testing was affected by only duration of living with the virus. Home-based care component was affected by none of the seven variables.

**Table 35: Factors determining extent of care quality among the various components of care for PLWHA**

<b>Component</b>	<b>Important factors</b>
Counselling and testing	-Duration of living with HIV/AIDS
Medical care	-Age
Home-based care	-Education level
Communication and behaviour change	-None
	-Age
	-Marital status

## 5.2 Recommendations

Based on the finding of the study, the following recommendations are pertinent in ensuring high quality of care for people living with HIV/AIDS:

- (a) People living with HIV/AIDS should be enabled to improve their economical situation by providing them with low interest loans for expanding their petty businesses since most of them were already in this informal sector.
- (b) Since the majority of respondents had low levels of education, there is a need for training of PLWHA to acquire skills for better and reliable livelihood. With more skills they can be in better position to fight poverty by engaging themselves in different income-generating activities.
- (c) The fact that the PLWHA have already lost some of their working capacity, provision of support in terms of relief of food items, clothing, working tools and other support for their families such as school fees and uniforms for their children will help them to sustain their living.

- (d) Since PMTCT services were found to be poorly provided, extension of the services to reach more women of reproductive age appear to be necessary, and the training should be part of the sex education provided.
- (e) Medical services should be integrated within the home-based care whenever possible, for ease of accessing since home-based care is mostly provided at household level.
- (f) Counselling should be strengthened as a support for other services provided to PLWHA since it is a cross cutting type of service involving medical, home-based care, PMTCT and communication and behaviour change.
- (g) Further research is needed to determine the predictors of quality of care and needs of people living with HIV/AIDS in order to improve their quality of life and improve their survival.

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## APPENDICES

### Appendix 1: Variables and scoring system used to create the care index for people living with HIV/AIDS (PLWHA)

#### I. Variable and scoring system for counselling and testing

<b>Variables</b>	<b>Coding</b>
Availability of pretest counselling	Yes = 2 No = 0
Quality of pretest counselling Waiting time before consulting the counsellor Duration of consultation with the counsellor Clarity of information received from the counsellor Quality/depth of information received from the counsellor Usefulness of information received from the counsellor An opportunity to ask questions during the consultation	For each sub-parameter; Poor = 0 Fair = + 1 Good = + 2 Very good = + 3 Excellent = + 4
Availability of posttest counselling	Yes = 2 No = 0
Quality of pretest counselling Emotional support given by counsellor Easiness of making new appointments Overall quality of counselling session	For each sub-parameter; Poor = 0 Fair = + 1 Good = + 2 Very good = + 3 Excellent = + 4
<b>Maximum/ Minimum</b>	<b>40/ 0</b>

## II. Variable and scoring system for medical care for PLWHA

<b>Variables</b>	<b>Coding</b>
Quality of services received from health facility	For each sub-parameter; Poor = 0 Fair = + 1 Good = + 2 Very good = + 3 Excellent = + 4
Payment of health facility services	Yes = 2 No = 0
Cost that is paid at the health facility	High = 1 Fair = 2 Low = 3 Don't know = 0
Failed to get health services at least once	Yes = 2 No = 0
Frequency of missing health services	None = + 4 Once = 3 Twice = 2 Thrice = 1 > Than 4 times = 0
<b>Maximum/ Minimum</b>	<b>15/0</b>

### III. Variable and scoring system for home based care for PLWHA

<b>Variables</b>	<b>Coding</b>
Disclosure to a family member (s)	Yes = 1 No = 0
Training of home carer	Yes = 1 No = 0
Getting medical support at home	Yes = 1 No = 0
Missed medical support at home when actually needed it	Yes = 0 No = 1
Get psychosocial support at home	Yes = + 1 No = - 1
Getting enough food per day at home	Never = 0 Sometimes = 1 Usually = 2 Always = 3
Number of meals per day	Once = 0 Twice = 1 Thrice = 2 > Than 4 times = 3
Number of days taken balanced diet in the last seven days	0 – 2 = + 1 3 – 4 = + 2 5 – 7 = + 3
Support from family members for taking medications	Yes = + 1 No = 0
Getting consideration for food support as prescribed to suit condition	Yes = 1 No = 0
Frequency of visits by a care provider from CHBC programmes	None = 0 Annually = 1 Semi annually = 2 Monthly = 3 Fortnight = 4

	Weekly/Daily = 5
Services provided by home based care provider that is seen on regular basis by an individual living with HIV/AIDS; Listens to me Cares about me Answers my questions Spends enough time with me Involves me in decision about my care Respects my choices Deals with my problems Engages me in my care Is helpful to me Respects me Supports my decisions Sees me when I ask Provides me information	For each sub-parameter; Never/No experience = 0 Sometimes = 1 Usually = 2 Always = 3
General hygiene	Poor = 0 Fair = 1 Good = 2 Very good = 3 Excellent = 4
Emotional support from family	Poor = 0 Fair = 1 Good = 2 Very good = 3 Excellent = 4
Suffer loneliness and neglect from family, neighbours or community members	Never = 3 Sometimes = 2 Usually = 1 Always = 0
Involvement in faith based organization	Yes = 1 No = 0
Availability of spiritual care	Yes = 1

	No = 0
Legal aid information	Poor = 0 Fair = 1 Good = 2 Very good = 3 Excellent = 4
Number of days participated in exercises (at least 30min) in the last seven days	0 – 2 = 1 3 – 4 = 2 5 – 7 = 3
<b>Maximum/ Minimum</b>	<b>82 / 1</b>

**IV. Variable and scoring system for awareness and practice about PMTCT care for PLWHA**

Awareness of PMTCT	Yes = 1 No = 0
Utilization of PMTCT services	Yes = 1 No = 0
Services provided at PMTCT services	
- Counselling on Breastfeeding	Yes = 1 No = 0
- Counselling on ARV utilization	Yes = 1 No = 0
<b>Maximum/ Minimum</b>	<b>4/ 0</b>

**V. Variable and scoring system for communication and behaviour change care  
for PLWHA**

Awareness of importance of behaviour change	Yes = 1 No = 0
Have you opted changing your sexual behaviour Yes, already Have started I don't think I will Have no plan for that	Yes, already = 3 Have started = 2 I don't think I will / Have no plan for that = 0
Perceived level of HIV/AIDS	I have received enough information = 2 I have not received enough information = 1 Not at all = 0
Services obtained on behaviour change	
Training	1
Meeting	1
IEC	1
Media	1
PMTCT	1
<b>Maximum/ Minimum</b>	<b>11 / 0</b>

## Appendix 2: Questionnaire for people living with HIV/AIDS (PLWHA)

Questionnaire No: |\_\_|\_\_|

|\_\_|\_\_| |\_\_|\_\_| |\_\_|\_\_|\_\_|\_\_|  
Date      Month      Year

### 1.0 INTRODUCTION

Good morning/ Good afternoon,

My name is \_\_\_\_\_ from the Department of Food Science and Technology, Sokoine University of Agriculture, Morogoro. I am carrying a study in the district with the aim of assessing the quality of care provided (given) to PLWHA which involves, looking into the effectiveness of Government strategies to safeguard the rights and needs of PLWHA. Recommendations from the study findings are expected to contribute towards improving lives and minimize stigma of PLWHA. You have been selected among the PLWHA from which data will be collected. I assure you that all the information provided during this interview will be treated confidentially and be used for the purpose of this study only.

### Section one: Socio-demographic data

The first section will enquire about your personal information

1.Name of the Hamlet..... Street ..... House No.....

2.Name of the respondent.....

3.Age: (*in years*) |\_\_|

4.Gender: (*Please observe*)

1= Male; 2= Female |\_\_|

5.What is your current occupation?

1 = Formal Employment; 2 = Self /Informal employment; 3 = Casual labourer

4 = Petty trade; 5 = Agriculture; 6 = Student; 7 = = None |\_\_|



6. What is your marital status?

1 = Single; 2 = Monogamous married; 3 = Polygamous marriage;  
 4 = Divorced; 5 = Widow/Widower; 6 = Separated;  
 7 = Cohabiting; 8 = Other (*specify*)..... |\_\_|

7. What is the type of your household?

1 = Male headed household; 2 = Female headed household;  
 3 = Other (*please specify*)..... |\_\_|

8. Are you the head of household?

1 = Yes; 2 = No |\_\_|

9. What is your religion?

1 = Christian; 2 = Moslem; 3 = Traditional;  
 4 = No religion; 5 = Other (*specify*). ..... |\_\_|

10. What is your highest level of education attained?

1 = Few years in primary school; 2 = Completed primary school;  
 3 = Few years in secondary education; 4 = Completed secondary education  
 5 = Higher education; 6 = No formal education; 7 = Student  
 8 = Other (*specify*) ..... |\_\_|

### Section two: Testing for HIV/AIDS

*Thanks, let us now discuss about testing for HIV/AIDS since ideally, care for PLWHA start with counselling and testing.*

11. How and when did you find about your HIV status?

1 = During pregnancy .....years, months, weeks ago  
 2 = During an illness ..... years, months, weeks ago  
 3 = After a partner tested HIV positive..... years, months, weeks ago  
 4 = After an insurance application..... years, months, weeks ago  
 5 = When taking voluntary/routine testing of health status ..... years, months, weeks ago  
 6 = Other (*please specify*)..... |\_\_|

12. Did you receive any pre-test counselling?

1 = yes; 2 = No (*If no go to question 20*) |\_\_|

13. If yes, would you please tell where did you receive pre-test counselling?

1 = VCT centre; 2 = Hospital based; 3 = Community workers  
4 = STI clinic; 5 = Antenatal care

14. How would you rate the waiting time before consulting the counsellor?

1= poor; 2 = fair; 3 = good; 4 = very good; 5 = excellent

15. How would you rate the duration of consultation with the counsellor?

1 = poor; 2 = fair; 3 = good; 4 = very good; 5 = excellent

16. How would you rate the clarity of the information you received from the counsellor?

1 = poor; 2 = fair; 3 = good; 4 = very good; 5 =

17. How would you rate the quality, the depth of information you received from the counsellor?

1= poor; 2 = fair; 3 = good; 4 = very good; 5 = excellent

18. What was the usefulness of the information you received?

1= poor; 2 = fair; 3 = good; 4 = very useful; 5 = excellent

19. Did you have an opportunity to ask questions during the consultation?

1 = poor; 2 = fair; 3 = good; 4 = very good; 5 = excellent

20. Did you receive post-test counselling?

1 = Yes; 2 = No (*If no go to question 23*)

21. How would you rate the emotional support given by counsellor?

1 = poor; 2 = fair; 3 = good; 4 = very good; 5 = excellent

22. How was the easiness of making new appointments with the counsellor?

1 = poor; 2 = fair; 3 = good; 4 = very good; 5 = excellent

23. What was the overall quality of the counselling session?

1 = poor; 2 = fair; 3 = good; 4 = very good; 5 = excellent

**Section Three: Health Facilities for Treatment of Opportunistic Infections**

*Let us now discuss about availability and adequacy of health facilities at your area.*

25. Is there any health facility within your area?

1 = Yes; 2 = No |\_\_|

26. Have you ever utilized the health facility?

1 = Yes; 2 = No |\_\_|

27. If no why? .....

.....

28. What kind of services do you receive at the health facility that you attend? (*With probing to obtain the response, tick all that was obtained*)

1 = Drugs for prevention/treatment of infectious disease |\_\_|

2 = Pain relief medications |\_\_|

3 = Medications for opportunistic infections |\_\_|

4 = Drugs for Tuberculosis (TB) treatment |\_\_|

5 = ARV services |\_\_| go to 29

6 = Nutritional care and support |\_\_|

7 = Other (*Please specify*) .....

29. What assistance do you receive when receiving ARV treatment?

1 = Drugs; 2 = Nutritional care and support;  
3 = Food assistance; 4 = Adherence counselling; 5 = None |\_\_|

30. How do you rate the service you received from the health facility?

1 = Poor; 2 = Fair; 3 = good; 4 = very good; 5 = excellent |\_\_|

31. Did you pay for the service you received?

1 = Yes; 2 = No (*If no go to question 33*) |\_\_|

32. How do you rate the cost you paid?

1 = High; 2 = Fair; 3 = Low; 4 = Don't know |\_\_|

33. Are there times that you needed services and you failed to obtain them?

1= Yes; 2 = No (*If no go to question 36*)

34. If yes, how many times?

1= once; 2 = twice; 3 = thrice; 4 = more than four times; 0 = none

34. Would you please mention if any, reasons for the missed service?

1 = Absence of health worker 2 = Refusal of health worker; 3= Insufficient drugs;  
4 = Other (*please specify*) .....

36. Donor funds meant to support PLWHA are supporting well the PLWHA?

1 = Strongly agree; 2 = Agree; 3 = Disagree;  
4 = Strongly disagree

#### **Section four: Knowledge and services of mother- to – child transmission (For women of childbearing age**

*Let us now discuss on PMTCT. Current strategies on HIV/AIDS are geared towards improving the health of HIV – infected mothers and reducing the transmission of the virus to their children during pregnancy, labour, delivery, and post-delivery through breastfeeding as outlined in the National Policy on HIV/AIDS, 2001.*

37. Are you aware of PMTCT services?

1 = Yes; 2 = No

38. Did you ever-attended PMTCT services?

1 = Yes; 2 = No

39. What services did you receive in PMTCT services?

1= Counselling about breastfeeding; 2 = ARV services

3 = Counselling about mother-to-child transmission;

4 = Counselling on healthy baby feeding options or practices

**Section five: Behaviours change communication**

40. When one is aware of his/her HIV status, is encouraged to adapt healthy sexual behaviour so as to live positively with HIV/AIDS as well as reducing the chance of infecting the other partner. Were you informed about this important need?

1 = Yes; 2 = No |\_\_|

41. Have you opted changing your sexual behaviour?

1 = Yes already; 2 = Have started;  
3 = I don't think I will; 4 = Have no plan for that |\_\_|

42. What services have you obtained on behaviour change in the last twelve months?

1 = trainings .....no. of trainings;  
2 = Group meetings.....no of meetings;  
3 = IEC materials (flyers and posters). .....no. of flyers and posters;  
4 = Media source (radio, T.V, newspapers, pamphlets/posters, T-shirts, painted walls, road signs, meetings, plays, stickers);  
5 = PMTCT related trainings .....no. of trainings;  
6 = Other (*Please specify*) ..... |\_\_|

43. Would you say you have enough information about HIV/AIDS?

1 = I have received enough information; 2 = I have not received enough  
3 = Not at all; 4 =I don't know |\_\_|

**Section six: Home-based care for PLWHA**

44. Do any member of your home know your HIV status?

1 = Yes; 2 = No |\_\_|

45. Did any member of your home receive training on caring for PLWHA (or home – based care)?

1 = Yes; 2 = No |\_\_|

46. Do you get (provided with) medical support at your home?

1 = Yes; 2 = No |\_\_|

47. Is there any time that you missed medical support at your home when you actually needed it?

1 = Yes; 2 = No |\_\_|

48. Have you ever been referred to clinic or health facility?

1 = Yes; 2 = No |\_\_|

49. Do you get psychosocial support (e.g. supportive counselling) from your home members?

1 = Yes; 2 = No |\_\_|

50. How many household members do you live together currently? .....

51. What is the age profile of your household members?

Member	Age	Member	Age
1		6	
2		7	
3		8	
4		9	
5		10	

52. Within the household, who provide most care especially when you are sick?  
 1=Parents; 2 = Relatives; 3 = Older child; 4 = Wife/husband; 5 = Others (*please specify*) ..... |\_\_|

53. Do you get enough food from your household?  
 0 = Never; 1 = Sometimes; 3 = Usually; 4 = Always |\_\_|

54. How many times per day do you take food?  
 1 = Once / day; 2 = 2 times / day; 3 = 3 times / day; 4 = 4 times / day; 5 = more than 4 times/ day |\_\_|

55. How many of the last seven days have you taken a balanced diet with all six food groups?  
 (I.e. carbohydrates, proteins, fats, vitamins, minerals and water)?  
 1 = 1 – 2; 2 = 3 - 4; 3 = 5 – 7 |\_\_|

56. Do you get support from your family members for taking your medications, including taking life – long medications such as, ARVs? (for those taking ARVs, TB medications).  
 1 = Yes; 2 = No |\_\_|

57. Do you get consideration in food (quality) support from the family to ensure adherence of preventive therapies, to ARV and other prescribed medications to suit your condition?  
 1 = Yes; 2 = No |\_\_|

58. What is the frequency of visits by a care provider from community home – based care programmes?  
 0 = None; 1 = Annual; 2 = Semi – annual; 3 = Monthly;

4 = Fortnight; 5 = Weekly/Daily

59. How can you rate on service provided by the care provider who you see on regular basis? Could be at home, a nurse practitioner or a physician.

(a) My care provider listens to me

N/a = no experience; 0 = Never; 2 = Sometimes; 3 = Usually; 4 = Always

(b) My care provider cares about me

N/a = no experience; 0 = Never; 2 = Sometimes; 3 = Usually; 4 = Always

(c) My care provider answers my questions

N/a = no experience; 0 = Never; 2 = Sometimes; 3 = Usually; 4 = Always

(d) My care provider spends enough time with me

N/a = no experience; 0 = Never; 2 = Sometimes; 3 = Usually; 4 = Always

(e) My care provider involves me in decisions about care of my HIV status

N/a = no experience; 0 = Never; 2 = Sometimes; 3 = Usually; 4 = Always

(f) My care provider respects my choices

N/a = no experience; 0 = Never; 2 = Sometimes; 3 = Usually; 4 = Always

(g) My care provider deals with my problems

N/a = no experience; 0 = Never; 2 = Sometimes; 3 = Usually; 4 = Always

(h) My care provider engages me in my care

N/a = no experience; 0 = Never; 2 = Sometimes; 3 = Usually; 4 = Always

(i) My care provider is helpful to me

N/a = no experience; 0 = Never; 2 = Sometimes; 3 = Usually; 4 = Always

(j) My care provider respects me

N/a = no experience; 0 = Never; 2 = Sometimes; 3 = Usually; 4 = Always

(k) My care provider supports my decisions

N/a = no experience; 0 = Never; 2 = Sometimes; 3 = Usually; 4 = Always

(l) My care provider sees me when I ask

N/a = no experience; 0 = Never; 2 = Sometimes; 3 = Usually; 4 = Always |\_\_\_|

(m) My care provider provides me information

N/a = no experience; 0 = Never; 2 = Sometimes; 3 = Usually; 4 = Always |\_\_\_|

60. How do you rate care on hygiene practices (e.g. oral, skin, hair and environmental care (toilet facilities) at your home?

1 = Poor; 2 = Fair; 3 = Good; 4 = Very good; 5 = Excellent |\_\_\_|

61. How do you rate the emotional support from the family members especially during times of any chronic illness?

1 = Poor; 2 = Fair; 3 = Good; 4 = Very good; 5 = Excellent |\_\_\_|

62. Are there times that you think you suffer from loneliness and neglect from your family, neighbours or community members?

0 = Never; 1 = Sometimes; 2 = Usually; 3 = Always |\_\_\_|

63. Are you involved in any faith – based dominion /organization?

1 = Yes; 2 = No |\_\_\_|

64. Do you obtain spiritual care from the faith- based organization you are involved?

1 = Yes; 2 = No |\_\_\_|

65. How do you rate how you obtain information about where to get legal aid that you may need (e.g. areas such as inheritance, writing of wills and human rights, join PLWA support groups)?

1 = poor; 2 = fair; 3 = good; 4 = very good; 5 = excellent |\_\_\_|

66. On how many of the last seven days did you participate in at least 30 minutes of physical activity? (Total minutes of continuous activity, such as walking, swimming, biking) other than you do around the house or part of your work?

1 = 1 – 2; 2 = 3 - 4; 3 = 5 – 7 |\_\_\_|

67. Have you experienced changes in living standards after being living with HIV/AIDS?

1 = A lot of change; 2 = Moderate change; 3 =Very little change;  
4 = No change; 5 = It is too early to comment |\_\_\_|



68. What are the major constraints you encounter in your everyday life (after been living with HIV/AIDS). Rank according to importance e. g if food security is the most pertinent constraint then let it be no. 1

- 1. ....
- 2. ....
- 3. ....
- 4. ....

69. In your opinion, what aspects should be considered in provision of care given to PLWHA?

- 1. ....
- 2. ....
- 3. ....
- 4. ....

*THE END*

*THANKS FOR YOUR COOPERATION*

### **Appendix 3: Checklist for key informants (in depth Interview)**

#### **A. NGOs**

1. What services are you offering to people affected and infected with HIV/AIDS
2. What are your sources of funds?
3. What are the problems facing you in delivering services to people living with HIV/AIDS?
4. Do you receive any assistance from the government? If yes, which assistance?
5. In your opinion, what aspects should be considered in assessing the quality of care given to people living with HIV/AIDS.
6. What are your plans for improving care for people living with HIV/AIDS

#### **B. NACP/TACAIDS/Ministry of health**

7. What services are you offering to people/Organizations taking care for people affected and infected with HIV/AIDS
8. What are your sources of funds?
9. What are the problems facing you in delivering services to people living with HIV/AIDS?
10. In your opinion, what aspects should be considered in assessing the quality of care given to people living with HIV/AIDS.
11. What are your plans for improving care for people living with HIV/AIDS

#### **C. Regional and District aids coordinators/ Regional and District medical officers and collaborating NGOs**

12. What services are you offering to people/Organizations taking care for people affected and infected with HIV/AIDS?
13. What are your sources of funds?
14. What are the problems facing you in delivering services to people living with HIV/AIDS?
15. In your opinion, what aspects should be considered in assessing the quality of care given to people living with HIV/AIDS?
16. What are your plans for improving care for people living with HIV/AIDS?

#### **Appendix 4: Guideline for focus group discussion (FGD), on quality of care for people living with HIV/AIDS (PLWHA)**

Welcome to our focus group. We are here today to talk together about quality of care for people living with HIV/AIDS (PLWHA) in Morogoro Municipality. You should feel free to participate and you are also free not to speak. Please be comfortable in deciding what you wish to share with the group.

We are trying to explore about quality of care for people living with HIV in your community. In this discussion there will be 4 subsections named as, Situation of the disease, Availability of care, Quality of care and Suggestions for improvement.

##### **1.0 Situation of disease**

- 1.1 What do you think is the situation of HIV/AIDS in your municipality?
- 1.2 Do you think the campaign to fight HIV/AIDS is working or not?

##### **2.0 Availability of care**

- 2.1 What aspects of care do you consider to be important in your area?  
- *Use them to assess the situation / quality of care they are getting*
- 2.2 How can you describe the availability and accessibility of care in your area?  
- *Probe to obtain the ones they are getting e.g among the aspects mentioned which ones are you getting here?*  
- *Probe about various health and other facilities and if there is cost involved*

##### **3.0 Quality of care**

- 3.1 How can you rate the quality of care provided by various stakeholders in your Municipality? If possible give examples.
- 3.2 In your opinion, what factors are affecting quality of care for people living with HIV/AIDS in Morogoro Municipality?
- 3.3 In your opinion, what aspects should be considered in assessing the quality of care given to people living with HIV/AIDS?

**4.0 Suggestion for improvements**

4.1 In your opinion, what should be done to improve the quality of care provided to people living with HIV/AIDS?

**Appendix 5: A care score index for assessing how PLWHA Perceived quality of care provided to them**

**1.0 Quality of HIV/AIDS testing Scale**

**Pre-testing**

1.1 How would you rate the waiting time before consulting the counsellor?

1 = poor; 2 = fair; 3 = good; 4 = very good; 5 = excellent

1.2 How would you rate the duration of consultation with the counsellor?

1 = poor; 2 = fair; 3 = good; 4 = very good; 5 = excellent

1.3 How would you rate the clarity of the information you received from the counsellor?

1 = poor; 2 = fair; 3 = good; 4 = very good; 5 = excellent

1.4 How would you rate the quality, the depth of information you received from the counsellor?

1 = poor; 2 = fair; 3 = good; 4 = very good; 5 = excellent

1.5 What was the usefulness of the information you received?

1 = poor; 2 = fair; 3 = good; 4 = very useful; 5 = excellent

1.6 Did you have an opportunity to ask questions during the consultation?

1 = poor; 2 = fair; 3 = good; 4 = very good; 5 = excellent

**Post-test counselling**

1.7 How would you rate the emotional support given by counsellor?

1 = poor; 2 = fair; 3 = good; 4 = very good; 5 = excellent

1.8 How was the easiness of making new appointments with the counsellor?

1 = poor; 2 = fair; 3 = good; 4 = very good; 5 = excellent

1.9 What was the overall quality of the counselling session?

1 = poor; 2 = fair; 3 = good; 4 = very good; 5 = excellent

In each sub – parameter, the highest score is five (5), and the lowest score is 1. Therefore in this category of counselling and Testing, the highest score is 45 and the lowest score is 1.

### Scoring the scale

Add the score for all 9 questions,

Divide the scored total by overall total of nine questions, which is  $5 \times 9 = 45$ , and then all response formats multiplied by 100 to get the percentage score for ease interpretation.

### Score classification

0-20% -Very poor

21-40% -Poor

41-60% -Fair

61-80% -Good

81-100% -Very good

### Section 3. Home- based care testing scale

How can you rate on service provided by the care provider who you see on regular basis?  
Could be at home, a nurse practitioner or a physician.

(a) My care provider listens to me

N/a = no experience; 0 = Never; 2 = Sometimes; 3 = Usually; 4 = Always

(b) My care provider cares about me

N/a = no experience; 0 = Never; 2 = Sometimes; 3 = Usually; 4 = Always

(c) My care provider answers my questions

N/a = no experience; 0 = Never; 2 = Sometimes; 3 = Usually; 4 = Always |\_\_\_|

(d) My care provider spends enough time with me

N/a = no experience; 0 = Never; 2 = Sometimes; 3 = Usually; 4 = Always |\_\_\_|

(e) My care provider involves me in decisions about care of my HIV status

N/a = no experience; 0 = Never; 2 = Sometimes; 3 = Usually; 4 = Always |\_\_\_|

(f) My care provider respects my choices

N/a = no experience; 0 = Never; 2 = Sometimes; 3 = Usually; 4 = Always |\_\_\_|

(g) My care provider deals with my problems

N/a = no experience; 0 = Never; 2 = Sometimes; 3 = Usually; 4 = Always |\_\_\_|

(h) My care provider engages me in my care

N/a = no experience; 0 = Never; 2 = Sometimes; 3 = Usually; 4 = Always |\_\_\_|

(ii) My care provider is helpful to me

N/a = no experience; 0 = Never; 2 = Sometimes; 3 = Usually; 4 = Always |\_\_\_|

(j) My care provider respects me

N/a = no experience; 0 = Never; 2 = Sometimes; 3 = Usually; 4 = Always |\_\_\_|

(k) My care provider supports my decisions

N/a = no experience; 0 = Never; 2 = Sometimes; 3 = Usually; 4 = Always |\_\_\_|

(l) My care provider sees me when I ask

N/a = no experience; 0 = Never; 2 = Sometimes; 3 = Usually; 4 = Always |\_\_\_|

(m) My care provider provides me information

Aspects that are included for assessing Home –based care, with respect to care provider and patient relationship involve thirteen (13) sub-parameters; of which each sub –parameter have four (4) as the highest score and 0 as the lowest score. Therefore in this category fifty- two (52) is the highest score and 0, the lowest score.

**Scoring the scale**

Add the score for all 13 questions,

Divide the scored total by overall total of nine questions, which is  $4 \times 13 = 52$ , and then multiply by 100 to get the percentage score.

**Score classification**

0-20%        -Very poor

21-40%       -Poor

41-60%       -Fair

61-80%       -Good

81-100%      -Very good

**Reliability of scale**

Reliability analysis was done to test reliability of scales used for assessing quality of care for people living with HIV/AIDS. Reliability for scores used for assessing home-based care obtained from the caregivers that the individuals living with HIV/AIDS see on regular basis was Cronbach's alpha 0.9669. Resulting Cronbach's alpha for assessing quality of counselling and testing was 0.7908.