

**PROVISION OF FREE ARV IN PUBLIC FACILITIES IN TANZANIA:  
'DO THE POOR BENEFIT?'**

BY

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A dissertation submitted to the Health Economics Unit in partial fulfillment of the requirement for the award of a Masters in Public Health (specialising in Health Economics) by the University of Cape Town, South Africa.

**May 2007**

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## DECLARATION

This thesis in its original form is entirely mine and has never been submitted to this University or any other institution of higher learning for any award. It is a product of my original work and the study was done in Tanzania between November 2005 and June 2006. Other sources of data are fully acknowledged and referenced.

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Date: .....

## **ACKNOWLEDGEMENT**

This study would not have been possible without the help of several people to whom I am deeply indebted. I am grateful to my sponsors, the Swedish International Development Agency (SIDA) through the Health Economics and Policy Network (HEPNET) for awarding me the scholarship that enabled me to pursue this course.

I am grateful to the Tanzanian National Institute for Medical Research (NIMR) for allowing me to undertake this training, particularly; Dr. Andrew Kitua, the Director General of NIMR; Dr. Mwele Malecela-Lazaro, the Director of Research and Training; Dr. Sayoki Mfinanga, the Director of NIMR-Muhimbili Research Centre; Dr. Aziza Mwisongo, the NIMR-senior research scientist; and Mr. Mafie, the NIMR-senior Administrative Officer.

I wish to express my deepest gratitude to my supervisor, Dr. Michael Thiede for his tireless effort in giving me valuable and guiding advice throughout the training period. Without his willingness and sense of humour, wise guidance, encouragement, commitment and constructive criticism, I would not have been able to successfully complete this course.

I would also like to thank all my lecturers, especially those in the Health Economics Unit for their great support and encouragement during the period of training.

I also thank my field assistants Victor Mujuni and Furaha George for their contribution in the data collection. Likewise, I thank Mr. Mayunga, Mr. Kalugendo and Mr. Senkoro for data management on my project.

I would like to thank all my friends and student colleagues who supported me in various ways at different stages of the course. Special thanks go to John Ataguba, David Nahamya and Collins Chansa.

I would like to extend my sincere gratitude to my parents Mr. & Mrs. Charles Kahwa, thank you for giving me the support in the world. To my family members, Uncle Jesse Kahwa and my fiancée Milka, I am greatly indebted to you. Your love and support carried me through the most difficult times of the training.

Lastly and most importantly, I owe my deepest gratitude to God for keeping me physically and mentally fit throughout the training.

## **ACRONYMS AND ABBREVIATIONS**

<b>AIDS</b>	Acquired Immune- Deficiency Syndrome
<b>ANC</b>	Antenatal Clinic
<b>ART</b>	Anti-Retroviral Therapy
<b>ARVs</b>	Antiretroviral drugs
<b>CTC</b>	Care and Treatment Clinic
<b>DHS</b>	Demographic Health Survey
<b>EPI</b>	Extended Programs for Immunization
<b>FGDs</b>	Focus Group Discussions
<b>GDP</b>	Gross Domestic Product
<b>GFATM</b>	Global Fund to Fight AIDS, Tuberculosis and Malaria
<b>GOT</b>	Government of Tanzania
<b>HAART</b>	Highly Active Antiretroviral Therapy
<b>HBS</b>	Household Budget Survey
<b>HIV</b>	Human Immunodeficiency Virus
<b>IMR</b>	Infant Mortality Rate
<b>MoH</b>	Ministry of Health
<b>MTB</b>	Mycobacterium Tuberculosis
<b>MTP</b>	Medium Term Plans
<b>NACP</b>	National AIDS Control Programme
<b>NCTP</b>	National HIV/AIDS Care and Treatment Plan
<b>NGO</b>	Non- Governmental Organization
<b>NHA</b>	National health Account
<b>NNRTI</b>	Non-nucleoside Reverse Transcriptase Inhibitors

<b>NRTI</b>	Nucleoside Reverse Transcriptase Inhibitors
<b>PCA</b>	Principal Component Analysis
<b>PEP</b>	Post-exposure prophylaxis
<b>PEPFAR</b>	USA President's Emergency Plan for AIDS Relief
<b>PI</b>	Protease Inhibitors
<b>PLWHA</b>	People Living With HIV/AIDS
<b>PMTCT</b>	Prevention of Mother-to-Child-Transmission
<b>SSA</b>	Sub-Saharan Africa
<b>STI</b>	Sexual Transmitted Infections
<b>TACAIDS</b>	Tanzanian Commission for AIDS
<b>TB</b>	Tuberculosis
<b>TFDA</b>	Tanzania Food and Drug Authority
<b>UNAIDS</b>	United Nations Programme on AIDS
<b>USAID</b>	United States Agency for International Development
<b>VCT</b>	Voluntary Counseling and Testing
<b>WHO</b>	World Health Organization

## **EXECUTIVE SUMMARY**

The impact of the HIV pandemic in Tanzania has been profound and has affected all sectors. Today, HIV/AIDS is recognized not only as a major public health concern but also as social, economic and development problem in Tanzania as in most in Sub-Saharan African countries. With a population of estimated 37 million, Tanzania has an estimated of 2.5 million people infected with human immunodeficiency virus (HIV).

The availability of antiretroviral therapy (ART) which has been defined as the main form of treatment (yet not a cure) for HIV/AIDS showed to significantly prolong and improve quality of life of people infected with HIV.

By and large, the entire range of antiretroviral drugs is available anywhere in the world through private channels. Where resources permit, the supply may be adequate and consistent. Through the public sector, however, and for low-income patients, the choice of drugs may be somewhat restricted. This has implications for decisions such as when to start therapy, which therapeutic regimens to use, and what to do when treatment fails.

The situation requires difficult choices in priority setting, poses serious ethical issues and imposes on government the obligation to scale up programmes in ways that are ethically sound, equitable, beneficial and sustainable as possible (WHO 2004). However in Tanzania, there is no clear policy established on targeting or prioritising specific population groups in order to avoid decision making based on subjective or arbitrary criteria that may lead to discrimination.

The aim of this study was to establish the socioeconomic status of those individuals who benefit most from the provision of free ARV in terms of utilisation in urban and rural settings. It also aimed to identify the criteria used in enrollment of patients for free ARV provision, the barriers for ARV provision and patient's perception on ARV.

A cross-sectional study was conducted to collect the data on the socio-economic status of HIV patients who access antiretroviral therapy in selected ARV clinics in Tanzania. The study was carried out in the urban district hospitals of Dar es Salaam region and the rural district hospitals of Kagera region. Closed-ended questionnaires, focus group discussions (FGD) and key informant interviews were the main instruments. The socioeconomic status of patients receiving free ARV was captured through facility based questionnaires with closed-ended questions about gender, age, education, employment status, living conditions and household assets.

These questions were synchronized with the Tanzania Demographic and Health Survey (TDHS 1999). The questions allowed the comparison of the data set from questionnaires to that from the TDHS for the analysis of the study. Other questions concerning the knowledge, altitude, and practice around ARV were also asked. An asset index was constructed based on information on household ownership of durable goods and housing characteristics using principal components analysis (PCA).

The main findings from this study showed that,

- Overall, the uptake of free antiretroviral treatment in public facilities in Tanzania is relatively higher within the less poor population groups. This pattern is more pronounced in urban areas than rural areas. In Dar es Salaam district hospitals, ART uptake increases with wealth, while in Kagera free ART is skewed towards the lowest and the highest quintiles.
- Yet, those with no education or with only primary education are well represented, relative to the patterns of education reflected in the TDHS. The findings also show a relatively high uptake of ART among the unemployed, among women and within the “productive” age groups. The study, however, could not assess utilisation with respect to health care needs.

Based on the above findings, one can conclude that targeting of free ARV provision in Tanzania should be improved. It is hoped that the findings from the study will help policy makers to set clear policy guidelines, which prioritise vulnerable, poor and marginalised groups of the population.

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## **CHAPTER ONE: INTRODUCTION AND BACKGROUND**

### **1.1 Introduction**

HIV/AIDS is one of the major public health problems with adverse effects on the socio-economic development of many developing countries. Current statistics indicate that over 42 million people are infected with HIV among whom over 27 million are in sub-Saharan Africa (WHO 2004). The epidemic has claimed almost 19 million lives over the past two decades including 4 million children. Further, the epidemic is one of the contributing factors to orphaned children. Studies indicate that HIV/AIDS has left over 15 million children orphaned in its wake (WHO 2004). Sub-Saharan Africa is the world's most severely affected region, with only 10% of the world's population it harbours about two thirds of the global total number of people living with HIV and AIDS (WHO 2004). One in 12 adults in this region is reported to be infected with HIV. According to Laurent et al. (2002), in sub-Saharan Africa, HIV/AIDS is the leading cause of adult deaths. In the year 2000 alone, an estimated 2.4 million out of the global total of 3 million adult and child deaths from HIV/AIDS occurred in the African region.

Tanzania is one of the highly affected countries in Sub-Saharan Africa with about 2.5 million people infected with HIV and an estimated prevalence of 9.6% (NACP 2005). The first acknowledged cases of AIDS were diagnosed in the Kagera region of Tanzania in 1983. HIV/AIDS was initially seen as just a health issue, and the initial response was from the Ministry of Health (MOH). In 1985 the MOH formed an HIV/AIDS technical committee to advice on diagnosis, treatment and prevention of the disease. This resulted into inception of Tanzania's National AIDS Control Program (NACP). The formation of the National AIDS Control Programme (NACP) under the Ministry of Health in 1985 was one of the Government's responses to slow the spread of HIV/AIDS in Tanzania. The NACP started with a two-year phase called Short Term Plan (1985-1986). Subsequent phases were termed Medium Term Plans (MTP) lasting for five-year periods beginning with MTP-I (1987-1991), followed by MTP-II (1992-1996) and MTP-III

(1998-2002) (NACP 2005). All of these phases aimed at developing strategies to prevent, control and mitigate the impact of the HIV/AIDS epidemic through decentralization, multi-sector response and community participation.

The NACP subsequently established District AIDS Coordinators (DACs) in every district in the country. In addition, the National AIDS Advisory Board (NAAB) was established in 1999, and later the Tanzania Commission for HIV/AIDS (TACAIDS) was established on December 1 (World AIDS Day), 2000. TACAIDS was formed by the President and became legally established in November 2001. As the epidemic grew, it was realized that HIV/AIDS was not only a health problem but a wider development problem.

As more sectors realized the importance of the disease in their workplaces and its effect on their development processes, more actors joined to fight the epidemic. In addition, there are a significant number of non-governmental organizations (NGOs) in nearly every district that are playing important roles in combating the HIV/AIDS pandemic. Recent data based on household surveys estimate the sero-prevalence in adults in Tanzania to be 9.6%, with a wide variation across the regions. The disease is the major public health problem and poses a development crisis that affects health, economic and social progress, reducing life expectancy, deepening poverty and contributing to exacerbating food shortage (UNAIDS 2004).

Current age and gender distributions of reported HIV/AIDS cases reveal that the disease has the strongest impact on individuals in the prime of their working and child-bearing years, from 20-49 years, who thus have a limited capacity to make a productive contribution to society. The pattern shows early infection of young women, with reported cases peaking from age 25-34, while in men the majority of cases occur slightly later in life, peaking at 30-39 years (UNAIDS 2004).

These groups are unable to play an active economic role or provide for their families in their advanced stages of the diseases (e.g. WHO stage IV). By 2001 they had left behind an estimated 810,000 children orphaned due to HIV/AIDS,

putting additional pressure on the limited resources of their extended families and communities.

There have been various initiatives to increase access to life saving antiretroviral drugs. In 2003, the Tanzanian Ministry of Health (MOH) in collaboration with other stakeholders, formulated a comprehensive HIV/AIDS policy which sets out the framework for scaling up health sector response to HIV/AIDS and for increasing access to affordable and essential interventions for prevention, treatment, care and support for HIV/AIDS patients (GOT/MOH/NACP 2003).

This study is based on the assumption that socio-economic status is one of the main determinants of exposure to HIV/AIDS with poverty and social inequalities leading cofactors in HIV transmission. Therefore reaching the vulnerable groups (low socio-economic status) for awareness, prevention and treatment of HIV is more than important.

In Tanzania, socio-economic inequalities in utilisation of health care and in health outcomes are large and even within a rural society that might easily be assumed to be uniformly poor (Schellenberg et al. 2003). This suggests that the poor have benefited less than the better off from publicly provided health services due to either some financial barriers or user dissatisfaction. The policy response to this undesirable situation has been to improve the quality of health services provided by public facilities; however it is still not yet clear whether the poor are benefiting or not.

Therefore, this study intends to identify the socioeconomic status of individuals utilizing the free antiretroviral therapy (ART) in public facilities in Tanzania. Its focus is to help answer the question of who are the beneficiaries of the publicly financed antiretroviral programs i.e. whether it is the poor or non-poor. It will also address the question whether the distribution of drugs in public facilities is equitable.

### **1.1.2 HIV transmission**

The HIV infection is acquired through sexual intercourse with an infected partner; exposure to infected blood and blood products; from an infected mother to the unborn child in the uterus during delivery or from breast milk. More than 90% of adults in sub-Saharan Africa acquire HIV infection from unprotected sexual intercourse with infected partners (WHO 2004). Transmission of HIV through body fluids other than blood and genital secretions such as cerebral spinal fluid (CSF), pleural fluid, amniotic fluids is certainly possible. However, to date there are no reported cases of HIV transmission resulting from exposure to saliva, urine or sweat suggesting that the risk of an individual acquiring infection from these body fluids is minimal if any.

Interaction between the viral envelope proteins (gp 120) and receptors on the cell membrane is critical for the HIV to enter and infect the host cell (NACP, 2005). High concentration of the CD4+ molecules and co-receptors has been detected on the surface of T-lymphocytes and macrophages. Other cells that have been found to have CD4+ molecules on their surface include the langerhans cells (found in the skin) and the microglial cells of the brain. Initial infection with HIV is characterized by a relatively brief period of high level acute virus replication. This is sometimes marked by the development of flu like illness with fever, malaise, enlarged lymph nodes, sore throat, skin rash or joint pains. This acute febrile illness (sero-conversion) is accompanied by widespread dissemination of the virus to different tissues especially the lymphoid system that is extensively involved. HIV blood tests that are designed to detect presence of HIV antibodies are usually not yet positive at this point in time. However, such patients are highly infectious although they test negative for HIV using the common test that depend on detection of antibodies against HIV. The high level of viraemia (virus in blood) present at the time of sero-conversion may persist for about three months but eventually stabilizes at an individual set point. The number of RNA copies/ unit volume (viral load) is an indicator of disease activity. Nevertheless most patients

are clinically asymptomatic in spite of this ongoing extensive immunological battle (MOH, 2004)

During this asymptomatic phase of the infection, levels of CD4+ T-lymphocytes, the prime target of HIV gradually decline although the rate of decline varies substantially among patients. Major factors that are known to influence the rate of CD+ T-lymphocytes decline include patient's genetic factors, viral load (number of HIV-RNA copies/unit volume) at the set point, age and viral characteristics. This stage (WHO stage 1) may last for an average of 8-10 years and is free of symptoms although there may be swollen glands (persistent generalized lymphadenopath-PGL).

Over time, the immune system loses the struggle to contain HIV and so symptoms develop. Symptomatic HIV infection is often caused by the emergence of opportunistic infections. The commonest problems include fever, respiratory infections, cough, tuberculosis, weight loss, skin diseases, viral infections, oral thrush, pain and lymphadenopathy. This stage is WHO stages 2 and 3 depending on the particular opportunity infections seen.

The diagnosis of AIDS is confirmed if a person with HIV develops one or more of a specific number of severe opportunistic infections or cancers (WHO stage 4). Such conditions include Kaposi's sarcoma, Cryptococcus meningitis, Toxoplasmosis, pneumocystic carnii pneumonia (PCP) and cytomega-virus reinitis (CMV-reinitis).

### **1.1.3 Impact of HIV/AIDS in Tanzania**

The impact of the HIV epidemic has affected all sectors; hence HIV/AIDS is recognized not only as a major public health concern, but also as socio-economic and developmental problem in Tanzania (NACP 2005).

### ***Health impact***

In many developing countries including Tanzania, the increasing HIV epidemic has impacted significantly on already weakened public health services. The HIV/AIDS pandemic has interacted with other underlying public health problems most notably tuberculosis (NACP 2005). It is now believed that TB is the main cause of death in people with HIV infection because HIV is the strongest factor capable of promoting progression of mycobacterium tuberculosis (MTB) infection to active tuberculosis both in people with recently acquired and latent MTB infections (NACP 2005). This explains why the rate of TB in many African countries has gone up regardless of their well organized TB control programs. In some countries, up to 70% of patients with sputum smear-positive pulmonary TB are HIV-infected (MOH 2005). According to NACP 2005 report, most urban district and regional hospitals in Tanzania report a bed occupancy rate (IP admissions) of up to 50-60% for HIV related conditions. This has led to reduction in resources available for other health problems hence seriously affecting quality of health care services delivered. Also, health care personnel are affected by the pandemic resulting in the shortage of human resource in hospitals.

### ***Economic impact***

The relationship between HIV/AIDS and economic development is complex. HIV/AIDS negatively affects economic growth on the one hand and a weak economy makes it difficult for nations and individuals to mount adequate and comprehensive responses to the epidemic on the other. In addition, reports from UNAIDS 2004, show that poverty is a powerful cofactor to the spread of HIV/AIDS. The economically and socially disadvantaged, women, youth and other marginalized groups in the society, are disproportionately affected by the epidemic. These groups are unable to play an active economic role or provide for their families. By 2001 they had left behind an estimated 810,000 children orphaned due to HIV/AIDS, putting additional pressure on the limited resources of their extended families and communities (UNAIDS, 2004). Ill health and death

due to AIDS are reported to have reduced agricultural labour force, productivity and disposable incomes in many families and rural communities.

There are two major economic effects due to HIV pandemics; reduction in the labor supply and increased costs. In labor supply, it means the loss of young adults in their most productive years affects overall economic output. In terms of increased costs, there is a direct cost including expenditure on health care services, drugs and funeral expenses and indirect costs include lost time due to illnesses, recruitment and training costs to replace workers and care of orphans. These costs lead to a significant reduction in already weakened economic growth.

Data from Kagera, one of the regions most severely affected by HIV/AIDS in Tanzania, indicate that the annual Gross Domestic Product (GDP) declined from USD 268 to USD 91 between 1983 and 1994 respectively (GOT 2002). The report said that, although the decline in GDP was multi-faceted, HIV/AIDS was believed to be a major cause. The similar trends of declining GDP were associated with reduced agricultural population and increase in number of AIDS cases in Tanga region.

### **Social impact**

Studies conducted in Arusha, Kagera and Mwanza regions showed a serious and growing breakdown of social networks, which have hitherto sustained African societies (GOT 2002). Orphans are not only subjected to material, social and emotional deprivation, but also to lack of opportunities for education and health care. It was showed that, an increased expenditures and reductions in income led to withdrawal of children from school in order to reduce education-related expenditures and also to have children help with household chores. The indirect and direct costs due to HIV/AIDS have led to many households to sell their properties in order to pay for these costs. These poor families do not recover to their initial standard of living when productive household members die. Also the study showed that widows and orphans are deprived of their inheritance rights by relatives through the application of outdated traditional practices and customary

laws. The widows are often blamed for the premature deaths of their husbands. However, the above challenges can be stabilized or even reversed given the well organized programs in the country context.

## **1.2 Problem identification**

Evidence on public spending for health summarized by Filmer (2003) shows that the services (loosely categorized as primary health care) which tend to focus on infectious diseases and on other maternal and child health issues that are particularly prevalent among disadvantaged groups favour the better off less than is the case for secondary and tertiary care. But although such services may generally be less pro-rich than others, only rarely are they pro-poor. Additional evidence comes from 45 Demographic and Health Survey (DHS), analyzed by the World Bank (Gwatkin et al. 2000) which indicate that, even services often given high priority in the name of equity (for example oral rehydration for childhood diarrhoea, attended delivery and clinical immunization ) are more likely to be captured by the well off than by the poor.

According to many studies conducted on ARV treatment in developing countries, the majority of patients usually start ARV treatment at an advanced stage of HIV disease. In one treatment centre in Ivory Coast, 55% of patients were in CDC category 3 (advanced disease) at the start of treatment, in Senegal this proportion was 75%, while 68% of the patients at the Mildmay centre in Uganda had advanced disease at the start of therapy (WHO,2004). This is due to a combination of factors such as late care seeking through fear or denial, a lack of accessible counseling and testing services so that many people are unaware of their HIV infection and the high cost of the drugs which leads to treatment being deferred.

By and large, the entire range of antiretroviral drugs is available anywhere in the world through private channels. Where resources permit, the supply may be adequate and consistent. Through the public sector, however, and for low-

income patients, the choice of drugs may be somewhat restricted. This has implications for decisions such as when to start therapy, which therapeutic regimens to use, and what to do when treatment fails (WHO 2004).

One of the goals of the Tanzania Care and Treatment Five-year Plan (NCTP 2003) is to “increase access of ARVs to HIV patients, provide quality, continuing care and treatment to as many HIV positive residents of the United Republic of Tanzania as possible, building on the careful planning already completed by the Ministry of Health and the Tanzania commission for AIDS” (GOT/MOH 2003:21).

The plan recommends that the treatment be made available through established care and treatment clinics. It further proposes maximal integration within the existing healthcare infrastructure, local planning, efficient use of available resources, increasing the number of VCT centres, fast creation of PMTCT programmes in all antenatal clinics, and an expansion of routine counselling and testing of all patients in the healthcare system regardless of their reason for entry (GOT/MOH 2003).

The total budget to implement the plan is estimated at USD 539 million over 5 years, with most of the cost (68%) occurring in the final two years of scaling up. However, so far the government has been unable to raise the amount necessary to ensure that the target will be reached (GOT/MOH 2003). Currently, it is estimated that only 13,000 HIV patients are on the public ARV provision programme with 96 sites which provide the services in the country (MOH 2004). This is a small number compared to the HIV positive population, but due to financial constraints, government is unable to expand the programme.

The Government of Tanzania, with donor support, has a plan of putting more than 400,000 people living with HIV/AIDS on antiretroviral (ARVs) within a five year period, of which 65,150 will be treated by the end of 2005 (GOT/MOH, 2003). Furthermore, the Tanzania Food and Drug Authority (TFDA) registered more than 50 antiretroviral formulations enabling private pharmaceutical

companies and hospitals to stock and sell ARVs (TFDA 2004). This indicates the commitment of the Government and other stakeholders to increase access to ARVs for people living with HIV in Tanzania.

The situation requires difficult choices in priority setting, poses serious ethical issues and imposes on government the obligation to scale up programmes in ways that are ethically sound, equitable, beneficial and sustainable as possible. One way to address this challenge is to set criteria to decide who to receive these life saving medicines. Some of the criteria are clinical features, such as a CD4 count below 200 cells/mm<sup>3</sup>, World Health Organisation stage 4, and the patient's willingness, readiness and ability to adhere to ART (MOH 2005; WHO 2004). However in Tanzania, there is no clear policy established on targeting or prioritising specific population groups in order to avoid decision making based on subjective or arbitrary criteria that may lead to discrimination.

According to WHO 2004, special care has to be taken to ensure and monitor access for the vulnerable, poor and marginalized populations. The Tanzanian Household Budget Survey 2002 confirms that income poverty is high and social indicators are usually poor. It also points to large gaps between different groups and the biggest gap is between rural and urban populations i.e. rural households are much poorer than their urban equivalents in almost all aspects. However, the need to focus on reducing poverty in rural areas remains compelling. For example, in rural Tanzania, 75% of the population live below the poverty line, and hypothetically these are the ones who suffer more with HIV/AIDS because they lack the necessary information on HIV transmission as they are illiterate and have no access to all services provided by government including proper use of condoms, existence of ARV, and different health education programmes through the media regarding dangers of high risk behaviour. This is reflected in the statement by the ART-LINC Study Group (2005) that the inverse equity hypothesis applies, which stipulates that health inequities will get worse as effective new public health interventions initially reach those of higher

socioeconomic status and only later the poor may therefore be borne out in the case of HAART in resource-poor setting.

It is therefore important to understand how health providers are deciding who should receive treatment and who are the socio-economic groups actually benefiting from free/ subsidized ARV provision through public health facilities in Tanzania.

### **1.3 Rationale/ justification of the study**

This study is clearly important in a developing country where the HIV epidemic is expected to have a dramatic impact on life expectancy and lead to early mortality for a large proportion of the population. Average life expectancy in Sub-Saharan Africa is now 47 years, when it could have been 62 years without the AIDS pandemic (WHO 2004).

Highly Active Antiretroviral Therapy (HAART), a combination of at least three drugs has substantially improved the prognosis of HIV-infected patients in industrialized countries. In resource –poor setting in Africa, Asia and South America where 90% of people with HIV/AIDS live, access to HAART continues to be limited. It is estimated that one million HIV-infected individuals presently receive HAART in low and middle income countries which represents only 15% of the 6.5 million people urgently in need of such treatment in these settings (ART-LINC Study Group 2005). Currently, there are no fixed dose combination for second line therapy ( patients move from one pill twice a day up to 15 pills daily) and the price can be as much as 10-20 times higher than a generic first line regimen. For example in Cameroon, the first line therapy costs US \$ 277 per year while the second line therapy is over US \$ 4000 (Calmy et al. 2004). The treatment of children poses a particular challenge. Because of lack of commercial interest (few paediatric cases in western countries), some manufacturers of ARV drugs do not produce paediatric formulation at all (Calmy et al. 2004). Some molecules are marketed without even having been tested for

use in children (e.g. tenofovir) and those paediatric formulations that are produced are generally more expensive. While the fixed dose version for adults is available for about US \$ 200 per patients per year, the best price for the same drugs in paediatric formulations is about US \$ 1300 (oral solutions and syrups).

The “3 by 5” initiative launched by the World Health Organization (WHO), the joint United Nations Programme on HIV/AIDS, including the Global Fund to Fight AIDS, TB and Malaria (GFATM), and the US President’s Emergency Plan For AIDS Relief (PEPFAR) provide additional hope that millions of people with HIV/AIDS will have access to life saving treatment in the coming years (WHO 2004). Within this initiative free ARVs would be provided through public health care institutions ensuring that not only will the poor not be excluded from the scaling up of ART, but also priority will be given to them by making drugs available and affordable.

Although ART has been shown to be effective in poor settings (Laurent et al. 2002) and poor HIV patients have demonstrated their potential to be adherent to therapy, there has been very little primary research on how the poor benefit from the ART provision. Specifically in Tanzania, there are no studies been done to find out how these poorest of the poor do benefit from ARV provisions in public facilities.

The purpose of this research is to fill this gap. Specifically, there is a focus on the socio-economic status of those accessing ARV drugs in terms of perception of ARV provision, the productivity gain after taking ARV and the barriers to ARV provision. The findings of this study will help policy makers in Tanzania to set clear policy guidelines, which prioritise vulnerable, poor and marginalised groups of the population.

## 1.4 Study objectives

The main objective of this study is to determine to what degree poor and vulnerable groups in Tanzania benefit from the provision of antiretroviral treatment.

The specific objectives are:

- I. To evaluate the criteria considered by managers and providers for eligibility to access antiretroviral treatment free of charge.
- II. To establish the socio-economic and demographic characteristics of those utilising the free ARV drugs.
- III. To compare the socio-economic and demographic characteristics of those utilising free ARV drugs to those of the overall population and the respective utilisation rates.
- IV. To determine whether the poor have enough information about ARV on side effects, appropriate doses and time to start ART (knowledge and attitude towards ART)

Table 1 provides an overview of the study objectives, data or information that were needed and the source of the data/information for each objective

**Table 1: Study objectives, Data Requirements & Sources**

<b>Objectives</b>	<b>Information/ data needed</b>	<b>Tool/source</b>
1) To evaluate the criteria considered by providers for eligibility to access ARVs free of charge	Objectives of ARV roll- out	Interviews with key informants (MOH, TACAIDS, NACP and other local NGOs)
2) To establish the socio-economic characteristics of those utilising ARV drugs.	Asset-based index including: Location Source of drinking water Availability of electricity Sanitation facilities Building materials Possession of valuable and Durable goods	Interviews with key informants (MOH, TACAIDS, NACP and other local NGOs). Structured questionnaire interviews with HIV patients on ARVs.
3) To compare the socio-economic status of those utilising ARVs to those of the overall population and to determine the respective utilisation rates.	Asset-based index including: Location Source of drinking water, Availability of electricity, Sanitation facilities, Building materials of dwellings, Possession of valuable and durable goods. The following socio-economic variables will also be captured: Occupational history (employment), Education, Geographical location (Urban-rural residence).	Structured questionnaire interview with HIV patients on ARVs. Tanzania Demographic and Health Survey (TDHS 1999)
4) To determine how the poor perceive provision of ARV	Qualitative data on the knowledge levels and attitudes towards ART. Quantitative data to compare the perception of the poor vs. the perception of the community as a whole.	Interview with patients on ART based on a structured questionnaire; focus group discussions.

## **CHAPTER TWO: ANTIRETROVIRAL TREATMENT IN TANZANIA'S PUBLIC SECTOR**

### **2.1 Overview**

This chapter will provide the Tanzanian context, including the demographic and socio-economic structure of the country. The health structure within the country and the health status of the population will be described. Lastly, the ARV programmes, types of antiretroviral treatment available in the public sector in Tanzania and the World Health Organization (WHO) recommendations will be discussed.

### **2.2 Country context**

The United Republic of Tanzania, situated in East Africa, has an area of 945,087 sq km, divided into 26 regions, and has a total population of 36,977,000 with the annual population growth rate of 2.5%. Each region has at least four districts. The GDP per capita is International \$ 630 (NHA, 2002).

According to the latest Household Budget Survey (HBS) 2001/2002, there has been a modest improvement in economic growth. The economy has diversified and household consumption has increased. The proportion of the population that is poor has fallen slightly, although the absolute number has risen due to the population growth (Demombynes and Hoogveen 2002). The improvements have been concentrated in urban areas particularly Dar es Salaam while they have been more limited in rural areas where the majority (about 75%) of Tanzanians live. There is a concern that the rapid growth may not be substantially reducing poverty and rather is associated with rising inequality where about 87% of the poor in Tanzania live in the rural areas. This is supported by the Household Budget Survey (HBS) 2002, which shows a rise in Gini coefficient from 0.34 in 1995 to 0.35 in 2002. Poverty levels are strongly related to the education of the head of the family. The survey showed that, some 51% of individuals are poor if the head has no education compared with only 1 % when the head is educated

above primary education level. The percentage of adult literacy is 71% where 29% can neither read nor write. Very few adults in rural areas have been educated above primary education level. (Household budget survey (HBS) 2001/2002). The inequality also exist in education among men and women, where women are about twice as likely as men to have no education and 41% are unable to read and write (HBS 2001/2002). The rise of the private sector in Tanzania has caused a drop in government and parastatal employment from 5.2% to 2.5% of adults (NHA 2002).

However the HBS 2001/2002 show the large gap between the above different groups, the biggest gap is obvious between urban and rural populations. To fill this gap, the sustained growth in rural GDP and reduction in the rate of population increase is highly required.

### **2.3 Health system and health status in Tanzania**

The health system in Tanzania has a pyramidal pattern of a referral system recommended by health planners, which is from dispensary to consultant hospital. It is structured at various levels of health care delivery and services as follows: Village health services form lowest level of health care delivery and services can be offered in homes. The dispensary services cater for between 6000 to 10000 people while the health centre services cater for about 50000 people. Each district has at least one district hospital and every region has a regional hospital with specialist in various fields and offers more services than district hospital. The referral consultant hospital is the highest level of hospital services in the country and there are 4 referral hospitals in the country, which caters for all zones, Eastern, Northern, western and Southern zones.

Generally, the health status of the people in Tanzania is poor. The infant mortality rate (IMR) is 99 per 1000 live births, the under-5 mortality rate is 160per 1000, the maternal mortality rate is 800 per 100,000 births, and the average life expectancy is 48 years (WHO, 2004). However, 71% of children between 12-23 months are fully vaccinated (EPI, 2004). Contraceptive prevalence remains very

low in Tanzania, which causes the annual population growth rate (2.5%) to be one of the highest in Africa (Government of Tanzania 2002). About 7% of married women overall use modern methods of contraception which compares with rates of 28% and 36% for Uganda and Kenya respectively (WHO 2004).

Like other sub-Saharan countries, malaria, HIV/AIDS, Tuberculosis, diarrhoea contribute to high morbidity and mortality figures in Tanzania. These problems are unevenly distributed between urban and rural populations, between children and adults and between well-educated and non-educated citizens. The most affected are the majority of the total population, which is the rural citizen (75% of the total population), children under 15 years (47 % of the population) and none educated citizens (56% of the total population) (World Bank 2003).

As it was stated above, the level of poverty (illiteracy, unemployment) hypothetically is the underlying reason of the burden of the disease. Also the quality of health facilities is often poor due to lack of trained/motivated personnel, lack of drugs, and lack of functioning equipments, even if the number of facilities is not low (Munish et al. 2001).

The total expenditure on health as a share of GDP is 4.9 percent and per capita expenditure on health is international dollars 31 \$. 83% of private expenditure on health is out of pocket (NHA 2002). This figure implies a financing system that is overall regressive.

#### **2.4 ARV programme in Tanzania**

One of the most effective interventions currently available for people living with HIV/AIDS involves the use of various combinations of highly active antiretroviral therapies (HAART). However, the high costs of these drugs and the infrastructure needed to monitor their use have so far put these medications beyond the reach of most PLHA in Tanzania.

The Government of Tanzania adopted the National HIV/AIDS Care and Treatment Five Year Plan (NCTP) in October 2003. The implementation of the plan is ongoing. Strengthening the health infrastructure is one of the four key goals of the plan. The NCTP describes a strengthening and certification procedure in order to assess, upgrade and certify facilities, to have them become ready for quality HIV/AIDS care and treatment.

Minimum criteria were identified and a site assessment tool was developed in order to assess whether or not a facility is ready for HIV/AIDS care and treatment. The tools were developed in a collaborative effort of representatives from the Ministry of Health/NACP and from several national and international partner organisation working with HIV/AIDS care and treatment programs in Tanzania (NACP 2005).

During the first year (2004/2005) of the plan, 96 health facilities were selected to start with HIV/AIDS care and treatment. A care and treatment team of all these facilities received one week training on HIV/AIDS care and treatment. Assessment visits and re-assessment visits have been performed to 96 facilities in order to assess the quality of HIV/AIDS care and treatment services at the facilities. All the 96 facilities have received anti-retroviral drugs (NACP 2005).

In the second year (2005/06), another 104 health facilities have been targeted to start anti-retroviral therapy.

### **Scope of Care and Treatment at the Care and Treatment Clinic (CTC)**

People suffering from HIV related illnesses, may attend a wide variety of services at different levels of the health care system in Tanzania. These services range from a public or private multipurpose clinic or health centre and a home based care program to antenatal clinics and the prevention of mother to child transmission of HIV program (PMTCT). Furthermore there are Voluntary Testing and Counselling (VCT) sites, Tuberculosis (TB) or sexual transmitted infections

clinics (STI), a general outpatient department unit (OPD) or an inpatient ward prepared for patients with HIV/AIDS (NACP 2005).

#### **2.4.1 ARV Treatment in Tanzania**

After a decade of slow progress in the treatment of HIV infection, the last few years have seen dramatic advances in the development of antiretroviral drugs (ARV). They have been defined as the main form of treatment (yet not a cure) for HIV/AIDS (WHO 2002). This now offers extended patient survival and improved quality of life. Various new medications (such as protease inhibitors (PIs) and non-nucleoside reverse transcriptase inhibitors (NNRTIs), when combined with other older nucleoside reverse transcriptase inhibitors (NRTIs), have the potential to reduce HIV replication by crippling enzymes that are crucial in the replication of HIV. When a patient with HIV starts taking these drugs, the concentration of the HIV viral load drops rapidly. It is estimated that within three to four months of treatment, an initial HIV concentration of 100,000 copies per millilitre of blood can be reduced to a level below that of detection allowed by current technology. However, on stopping ARV treatment, HIV replication resumes and the viral load rapidly reverts to what it was prior to treatment. The circulating virus starts to weaken the immune system as reflected by the progressive fall in the CD4 lymphocytes count which increases the rate of occurrence of opportunistic infections.

Theoretically, the multiple steps in replication of HIV provide opportunities for intervention. Therapeutic regimens may be directed at one or several of the following stages essential for viral replication.

- Attachment of HIV to host cell
- Reverse transcription of viral RNA to DNA
- Integration of pro-viral DNA into host genome

- Expression of the viral gene after it has been integrated into host cell DNA including the process of transcription of more viral RNA and the translation of viral proteins
- Processing and post-translational modification of protein products of the virus

## **2.4.2 Types of Antiretroviral Drugs**

The existing antiretroviral drugs fall into three main categories

1) Nucleoside reverse transcriptase inhibitors (NRTIs): This class of drugs was the first group of drugs to be used and was the mainstay of antiretroviral therapy for the last 13 years of the AIDS epidemic. The primary mechanism of action of this class is inhibition of viral RNA-dependent DNA polymerase (reverse transcriptase) enzyme.

2) Non-nucleoside reverse transcriptase inhibitors (NNRTIs): Similar to NRTIs, this class of drugs acts by disrupting the reverse transcription of viral RNA into DNA which is then incorporated in the cell's nucleus. However, unlike the NRTIs, they are not directed incorporated into the viral DNA but instead inhibit replication directly by binding to the enzyme reverse transcriptase. The resistance to these drugs however, develops rapidly especially when used alone.

3) Protease inhibitors (PIs): These drugs competitively inhibit the HIV protease enzyme whose activity is critical for the terminal maturation of infectious virions and this inhibition prevents the maturation of virions capable of infecting other cells.

Currently, there are only two combinations of three drugs (regimens) that can be used sequentially and be effective in suppressing viral replication. These are often termed as 1<sup>st</sup> line and 2<sup>nd</sup> line regimens. When resistance to the second line regimen develops, theoretically the increased viral replication leads to a progressive loss in CD4 lymphocytes and eventual progression to AIDS and

ultimately death. However, patients are encouraged to remain on the regime in spite of failure as there is some evidence that the resistant virus is less fit than in the absence of ARV. WHO recommends that, if a patient needs to change from 2<sup>nd</sup> line regimen, he or she should be referred to a specialist physician for individualized care (WHO 2003).

#### *ARV first line regimen:*

The drugs recommended by (WHO, 2004) for a first line regimen in adults and adolescents include one of the four possible combinations listed below.

d4T (stavudine) +3TC (Lamivudine) +NVP (Nevirapine)

ZDV (Zidovudine) +3TC (Lamivudine) +NVP (Nevirapine)

d4T (stavudine) + 3TC (Lamivudine) + EFZ (Efavirenz)

ZDV (zidovudine) +3TC (Lamivudine) +EFZ (Efavirenz)

#### *ARV second line regimen*

The second line regimen recommended by WHO (WHO 2004) for adults and adolescents includes the following drug combinations:

1) Abacavir 300 mg twice daily/ lopinavir / ritonavir 133.3/33.3mg (Katera) 3 tablets twice a day and didanosine 200mg two tablets a day on an empty stomach

2) Abacavir 300mg twice daily/ saquinavir/ritonavir (SQV 5X 200 mg or 100 mg bd plus RTV one mg cap bd) and didanosine 20mg two tablets a day.

#### *Monitoring patients on ARV therapy in Tanzania*

In Tanzania, according to the NACP (NACP 2005), CD4+ T-lymphocyte count is the gold standard method used to determine the time for initiation and change of therapy. Each patient should have a baseline CD+ T-lymphocyte count (and viral load where possible) done before initiating treatment. CD+ T-lymphocyte count should then be repeated at least every 6 months. It was found that, initial

immunological and virological response as reflected by CD4 count and viral load, were the most important factors in prediction of progression to AIDS or death over subsequent years. In patients with HIV-1 who are starting Highly Active Antiretroviral therapy (HAART), prognosis is strongly associated with CD4 cell count at baseline. High levels of HIV replication at baseline, older age, a history of AIDS and infection through injection drug use are also associated with increased rates of clinical progression (Egger 2003). Patients' characteristics at the time they start HAART, can thus be used to predict their probability of disease free-survival, and overall survival. Treatment in most cases be associated with weight gain and reduced morbidity from opportunistic infections, or lack of weight gain, may indicate treatment failure and so the need to consider changing regimens.

Treatment is to be considered successful if the viral load decreases by 1 to 2 logs (10 to 100 folds) from the baseline level. However in most cases, CD4+ will be used instead of viral load thus a rise in CD4+ T-lymphocyte count will indicate success. Treatment failure on the other hand is indicated by a viral load increase of 0.3 to 0.5 logs or a 30% fall in CD4+ T-lymphocyte count.

### **2.4.3 WHO recommendations on ARV treatment**

Treating AIDS in the developing world means working in a context of poor health care infrastructure and limited financial and human resources, most of which are concentrated in capital cities. Health care providers in the developing world are faced with patients who have different characteristics to those seen in clinics in western countries: half of all cases in developing countries are among women of child bearing age; there are much higher proportions of children affected; patients tend to be more in critical conditions as they are diagnosed late in the course of the disease; and they are commonly afflicted with one or more complex co morbidities, such as tuberculosis and malnutrition (Calmy et al. 2004).

The WHO recommends that before the treatment starts in a resource-limited setting, the following should be taken into consideration: documentation of past medical history, identification of current and past HIV-related illnesses, identification of other medical conditions that might influence the timing and choice of ART and current symptoms and physical signs of other medical conditions such as TB and pregnancy (Avert 2005). This assessment will help to identify the stage of HIV disease the person has.

According to the WHO, all HIV patients having WHO stage IV disease, should start treatment. However, the decision on whether other people should start depends also on the laboratory tests that are available especially the person's CD4 cell count. A CD4 test measures the number of CD4 or T-helper cells in a patient's blood. The more CD4 cells in blood, the stronger is the immune system, and the better the body can fight illnesses (WHO 2003). WHO recommends that a person should start treatment when one is in WHO stage IV disease regardless of CD4 count, WHO stage III disease taking into account if the person has a CD4 count less than 350 and WHO stage I and II disease with a CD4 count less than 200 (WHO 2003).

The increase in the affordability of, and financing for, ARV has resulted in a rapid expansion of programmes providing ARV and of countries planning to introduce or scale-up access to ART (Picazo 2003). Whilst global organizations, such as the WHO and the International Human Immunodeficiency Virus (HIV) Treatment Access Coalition are supporting country efforts to increase access to treatment through a series of regional consultations exploring opportunities for scale-up and lessons learned from pilot initiatives (Kapp 2002), there is a lack of clear evidence-based information to guide policy makers and planners in resource-poor countries.

## **CHAPTER THREE: LITERATURE REVIEW**

### **3.1 Overview**

This chapter provides a review of the studies on the extent of HIV/AIDS pandemics in Africa, the socioeconomic status of individuals with HIV and their utilisation of public facilities. It includes affordability and sustainability of antiretroviral drugs in the context of limited resource settings. The related international research and the methodological approaches will be discussed. Finally, equity concepts regarding the distribution of ARV will be explored.

### **3.2. Introduction**

HIV/AIDS is considered one of the most threatening diseases in the world today (WHO 2004). Life expectancy and child survival rates have declined tremendously in some of the worst affected countries and the disease is today having a major impact on social and economic development not only in health but also in education, agriculture, transport, industry, human resources and the economy in general. Sub-Saharan Africa is one of the regions that has been hit hardest by the HIV/AIDS epidemic. In this region alone, about 29.4 million people were estimated to be living with HIV in 2004 with approximately 3.1 million new infections having been anticipated to have occurred (UNAIDS,2004).

In Sub-Saharan Africa, the national HIV prevalence rates vary greatly between individual countries. There is empirical evidence that in some African countries, the epidemic is still growing while others face an increasing danger of explosive growth. In Cameroon, for example, there was a sharp rise in HIV prevalence (more than doubling to over 11%) between 1998 and 2000. In Somalia and Gambia, the prevalence is estimated to be fewer than 2% of the adult population while in South Africa and Zambia around 20% of the adult population is infected (Avert 2004). However, in some of the Southern African countries, the national HIV prevalence rates for the adult population exceed the rates for South Africa and Zambia e.g. Botswana (37.3%), Swaziland (38.8%), Lesotho (28.9%) and Zimbabwe (24.6%) (Avert 2004).

In West and Central Africa, the infection rate is still relatively low although in some countries the prevalence rates are creeping up. The HIV prevalence rate is estimated to exceed 5% in a number of countries including Cameroon (6.9%), Central African Republic (13.5%), Cote d'Ivoire (7.0%) and Nigeria (5.4%) (Avert 2004). On the other hand, HIV infection in East Africa varies between adult prevalence rates of 2.7% in Eritrea to 8.8% in Tanzania. In Uganda the countrywide prevalence among the adult population has declined from 9% and is estimated at 4.1 % (Avert 2004).

### **3.3 Socio economic status in relation to HIV/AIDS and ARV treatment**

It is believed that poverty and illiteracy raise the probability of HIV infection. This is possibly due to the fact that people with low income and little education are less able to afford condoms and may also have less access to information about dangers of high-risk behavior (Cowan et al. 1994; Krueger et al. 1990; McCoy et al. 1996). However, at least in the first decade of the HIV/AIDS epidemic in Africa, HIV infection did not follow this pattern (Ainsworth and Semali 1998).

Pilot studies have demonstrated the clinical feasibility and effectiveness of highly active antiretroviral therapy (HAART) in a range of resource-poor settings, including Cameroon, Cote d'Ivoire, India, Kenya, Malawi, Senegal, South Africa and Uganda (Attawell and Mundy 2003). Patients have demonstrated good adherence, and there is limited evidence of the development of resistance (Attawell and Mundy 2003). Mascoloni (2002), in an article presented at the Barcelona AIDS Conference, identified factors contributing to effectiveness as careful preparation and counseling of patients prior to starting treatment, training family members to support patients, local government and community support, and recovery from AIDS illnesses, which strengthens patient commitment.

Antiretroviral drugs for HIV positive patients have been found to be effective in prolonging the lives of HIV patients and reducing incidence rates of opportunistic diseases such as Tuberculosis (TB) (Forsythe 2002). Studies conducted about the effects of ARV in New York and France found that associated health benefits

included a 41% drop in hospitalization, 41% drop in new AIDS cases and a 69% reduction in death from AIDS (Forsythe 2002).

Studies have shown that ART reduces the risk of tuberculosis (TB) by as much as 80 percent. For example, in Brazil, TB incidence of 8.4 per cent was reduced by 80 percent in patients with CD4 counts below 200. In South Africa, TB incidence was reduced from 17 per cent to 3 per cent in a group of patients with CD4 counts below 200 (WHO 2004). However, evidence from countries including Thailand, Botswana and South Africa, shows that HAART alone will not prevent a rise in TB cases among people with HIV. For example, in Botswana, a combination of HAART with a well-managed DOTS programme that has achieved 90 percent treatment completion rates, TB remains the leading cause of death among people with HIV (Attawell and Mundy 2003).

Developing countries, including Tanzania, are facing challenges of ensuring equitable access of antiretroviral treatment to people living with HIV/AIDS. Where the need and demand for ART exceeds the current ability to deliver, some people will receive treatment and others will die. Such a situation poses serious ethical issues for governments, international agencies, non-governmental organisations (NGOs), health care institutions and workers (WHO 2004).

According to WHO (2004), with some exceptions such as Brazil, where ARV is provided at no cost within the public health sector, "ability to pay" is determining access to drugs in many low and middle-income countries. The drugs themselves may be obtained privately and medical care as well as related services such as laboratory monitoring is often provided through the private sector. The public/private distinction is however blurred by the fact that private patients who can pay for the drugs are often treated and monitored in "centers of excellence" (e.g. the teaching hospitals of major cities) which themselves are publicly funded.

A few patients in developing countries receive drugs at subsidized cost through donor supported projects such as the UNAIDS Drug Access Initiative in Ivory Coast. Similarly, in Senegal, less than one hundred patients are being treated with antiretroviral drugs, through an initiative supported by the National Aids Control Programme, Agence Nationale de Recherche sur le SIDA - France, Institut de Médecine et d'Epidemiologie Africaine - Paris and Fondation d'Espoir - France. However, Attawel and Mundy (2003) found that even with subsidized cost, treatment may not be affordable for the poorest. Experience outside of large-scale national programs indicates that the poor are the least likely to access anti-retroviral therapy (ART). For example, in the Drug Access Initiative (DAI) in Cote d'Ivoire, despite efforts to ensure equitable access, poorer people were less likely to access treatment than those who were better off (Attawell and Mundy, 2003).

A minority of people living with HIV/AIDS (PLHA) receive free treatment through participation in clinical trials which may be externally and/or nationally funded. This is the case in Thailand, where patients are receiving drugs through the HIV-NAT clinical trials conducted in 19 hospitals around the country (WHO 2004).

The proportion of people with symptomatic HIV infection who are receiving ART ranges from small to insignificant. It is estimated that, less than 8% of people who require antiretroviral (ARV) treatment can access these medicines in developing countries. For example, in Uganda, probably less than 1% of people with HIV related illnesses are receiving ART. In Thailand, nearly 10% of people eligible for treatment were being treated through the Ministry of Public Health (MOPH) programme in 58 hospitals, but that proportion has substantially decreased since then. In Brazil, however, nearly 100,000 out of 530,000 people with HIV infection are receiving ART following a presidential decree, in November 1996, that access to antiretroviral drugs be made universally available through the public health system (UNAIDS 2004).

The high price of many of the HIV-related medicines and diagnostics offered by common suppliers - especially antiretroviral medicines - is one of the main barriers to their availability in developing countries. There are several other important barriers, including a lack of the basic components required for care, treatment and support of people living with HIV/AIDS, such as trained staff in health facilities, constant availability of laboratory equipment and supplies, sufficient funding, efficient pharmaceutical services, strong political will and government commitment. Wider availability of information on prices and reliable sources of medicines improves decision making processes in the context of procurement (UNAIDS 2004).

Various countries, organisations, researchers and practitioners are proposing various criteria for ensuring equity in access to ARV in resource limited settings. Loewenson and McCoy (2004) indicate that explicit patient selection criteria or the involvement of communities in decisions about selecting patients can enhance equity and prevent the development of patronage or corrupt practices around treatment.

### **3.4 Limitations on greater access of ARV in limited resource settings**

Antiretroviral drugs (ARV) started to be used in western countries with the launch of zidovudine in 1987 while highly active antiretroviral therapy (HAART) has been in widespread use in these countries since 1996. In developing countries, the widespread treatment of ARVs became a realistic goal in early 2001, when companies producing generic drugs reduced the price of treatment by announcing they could provide triple therapy at an annual cost of US\$ 300 (Calmy et al. 2004). However, it was clear that it would not be possible to replicate the western approach if large numbers of patients were to be reached due to the limited human resources, limited availability of drugs and lack of access to monitoring tools. Through practical experience and operational research, Medecins Sans Frontieres (MSF) and ministry of health partners have been moving towards a rationalization of available resources and simplification of

strategies. This process has focused on patient entry criteria, choice of therapy, drug supply management and delivery of care.

With respect to antiretroviral therapy (ART) in lower income countries, the ART-LINC Study Group (2005) observed that only 39% of the participating clinics were publicly funded, indicating that the private health sector, profit-oriented or not, plays an important role in the delivery of HAART in lower income countries. Determined to find out the long-term sustainability of these treatment programmes the authors found that among the centers charging patients for care, the median cost per year of treatment represented a substantial proportion of the per capita income in low-income countries. The baseline data also indicated important differences between patients with and without follow-up information, and with and without baseline CD4 count, in terms of the type of clinic accessed (public or private) and the socio-demographic and clinical characteristics of the patients.

In moving towards providing sustainable access to treatment for the majority in the developing world, Calmy et al. (2004) suggested that models of care must be adapted to the realities of these regions. Current treatment models have been developed in Europe and North America, and are based on the availability of more than 20 ARV drugs, decentralization of treatment, the routine use of sophisticated laboratory tools by specialists, and tackling of viral strains that predominate in wealthy countries (Calmy et al. 2004). In the context of the developing world, the simplification and decentralization of treatment are crucial for successful strategy to extend ARV therapy, facilitating adherence and optimizing the chances of sustainability and long term success. This includes the whole process of providing ARV drugs, inclusion criteria, management of side effects, choice of a drug regimen (first or second line), when to start therapy etc. In developed countries, simplification of the drugs is the most crucial component in ARV therapy (Calmy et al. 2004).

Apart from the complex ethical dilemmas, equity issues have to be taken into consideration in order to achieve fairness in health care financing. In addition, some other practical constraints in setting inclusion criteria in resource-poor settings have been identified. For example, access to free public health care through health insurance schemes that could help in paying the cost involved in accessing health care services is not common in developing countries and therefore, the cost for accessing health care is significantly out of pocket. In this case, the best solution is to offer free access to ARV drugs by prioritizing the medical criteria rather than ability to pay i.e. putting those with greatest risk of death (people living with HIV/AIDS) would greatly promote the notion of fairness.

Another constraint that Calmy et al. (2004) observed was that the laboratory tests that are routinely used before putting patients on HIV/AIDS treatment in wealthy countries are inaccessible to most people in developing countries. Until accessible and affordable means of measuring CD4 cell count (or proxies such as total lymphocyte count) and viral load become widely available, the decision to start treatment must rely on clinical staging, which means prioritizing symptomatic (WHO stages III and IV) patients. Other than the doctors, this task can be done by clinical officers and nurses provided that they are sufficiently trained.

In order to achieve good adherence, the affordability of ARV drugs by ensuring that treatment is provided at lowest cost as possible is very important. However, the continued political pressure to block the use of patented medicines threatens to stifle progress in making simple and affordable treatments more widely available (Calmy et al. 2004). The simplicity of fixed-dose triple combinations makes them attractive for both developed and developing world settings, but patent holders are unwilling to cooperate in producing these combinations, and they are only available through generic producers to developing countries.

Another constraint is assessing clinical treatment failure timely. This is also critical because waiting for clinical failure before changing drugs allows increase in viral load and decrease in CD4 count, hence the higher failure rates. Therefore, a simple and inexpensive rapid test to detect early virological failure and to optimize the alternative therapy is also needed. Also, it is important to monitor toxicity and support diagnosis of opportunistic infections. For example, it is difficult to diagnose tuberculosis depending on the number of specimens examined i.e. Ziehl–Nielsen detects 30–60% of the culture-positive tuberculosis suspects (Calmy et al. 2004). Moreover, as the degree of immunosuppression increases, the frequency of extrapulmonary tuberculosis and mycobacteremia also increases, leading to difficult diagnostic challenges in places where culture and biopsy are not readily available (Calmy et al. 2004). In pediatrics, there is also no easy means of diagnosing tuberculosis in HIV-positive children so the clinicians have to rely on a combination of clinical score and radiography to diagnose pulmonary tuberculosis.

With regard to the high prevalence of tuberculosis among HIV infected people, there is a need to integrate ARV treatment within tuberculosis treatment programmes. For example in Malawi, Calmy et al. (2004) found that the tuberculosis programmes are mostly decentralized while ARV treatment initiation and follow-up is often still very centralized, resulting in relatively low uptakes for ARV treatment among HIV-positive patients with tuberculosis (WHO stage III or IV). It was also found that most patients with tuberculosis who are also HIV positive are too weak and cannot afford to return for additional consultations for ARV treatment initiation and follow-up while taking tuberculosis treatment. Therefore, there is a need for new models where ARV treatment and follow-up is integrated into tuberculosis programmes and gradually decentralized. Calmy et al. (2004) suggests that, in order for the ART scale-up to be successful, treatment programmes must be decentralized from urban centers to the community primary health-care setting. Patients cannot be expected to travel tens of kilometers every month to receive life-long treatment, and ARV drugs

have to be delivered as close as possible to where people live in order to ensure good adherence. Even in resource-poor and understaffed settings, this could be implemented at least for the follow-up of stable patients who have initiated ARV treatment in clinics. However, a critical barrier to scaling-up is lack of human resources. This is because most resources are focused in the cities, leaving the great responsibility to the less qualified medical staff in rural areas.

A study by Kabugo et al. (2002) showed that the fee-for-service HIV clinic providing ARV treatment had successfully operated and managed patients living with HIV/AIDS. Those who survived and remained on therapy derived long-term virologic and immunologic responses to ARV drugs in a manner similar to those observed in industrialized countries. Therefore, strategies to reduce the financial burden and other barriers to uninterrupted care as well as incentives to increase such practice models should be further explored in the African context.

### **3.5 Related international research on ARV provision**

There have been some efforts made by policy makers in some developing countries to set criteria that will sound more ethical in prioritizing the vulnerable and the least disadvantaged groups regarding equal access to ARVs. For example, a pilot study in Senegal was used to set criteria to offer ARVs. The first criterion was patient's residency followed by clinical status based on biomedical data. The patients in the study were assessed on the set criteria and if the patient passed the first two criteria, a third criterion of social profile was used. The social profile was aimed at assessing patient's capacity to adhere to treatment and ability to pay for ARVs (Bennett and Chanfreau 2005).

In Uganda, a national policy for ARV expansion was developed in 2003 which among other issues defines criteria to determine who should receive treatment and a hierarchical system is used to determine eligibility. The first two criteria are clinical and adherence considerations. The next step is to categorize patients into

either a priority or an ordinary group. Priority eligibility is granted to patients who require treatment immediately while ordinary eligibility is granted to patients who will receive ARV in the future. Patients in the priority eligibility group include pregnant women who are HIV positive and these are considered under the Prevention of Mother to Child Transmission programme (PMTCT), post exposure prophylaxis for health workers and rape victims, children, HIV/AIDS activists and participants in research projects already on ARV. These criteria are prevention-driven and some reflect the social and economic benefit which may be derived from a certain group (Benett and Chanfreau 2005).

In Mexico, after the introduction of free ARV, the first priority was given to patients who were already on treatment and those who met explicitly clinical criteria. A waiting list was also created for each state depending on the stage and severity of the disease (Bennett and Chanfreau 2005). Clinical related criteria take on an important role, whereby the gold standard is the CD4 count. However, this requires modern laboratory equipment. Unfortunately, many health care facilities in developing countries are not equipped with such testing equipment, and in most settings the application of these criteria is limited to urban areas. This may create room for inequities, as the relatively more wealthy dwellers in urban areas have better access to CD4 testing equipment as compared to their rural counterparts (Muula 2004).

To eliminate inequities and to make the health system function effectively, it is essential to address the growing shortfall and maldistribution of personnel and resources in various regions. Jones (2004) proposes increasing the availability of health services, to improve financial, geographical and cultural accessibility of health services, and to improve the quality.

A study on the socio-economic patterns of service uptake focusing on public sector programmes for voluntary counseling and testing (VCT) in South Africa showed that the two upper wealth quintiles were under represented while the second lowest was best represented (Thiede et al. 2005). In specific terms, the

low-income groups of people accessed more of the general services and utilised VCT at public sector facilities than the well off. The overall findings showed that socioeconomic groups were not evenly represented in clinic attendance and more especially exaggerated when it came to undergoing VCT. The least well-off quintiles among the townships' population appeared to take up the services more than the others as a result of various issues around the perceived quality of public sector services. This study made use of several household asset questions from the South African Demographic and Health Survey (DHS) in order to allow comparison with the DHS data set during the analysis phase of the study.

### **3.6 Methodological approaches**

Several studies to examine the disparities in a particular health variable (e.g. usage of health services or health status) across people with different standards of living have been done. Even so, the question still remains on how best to measure living standards. Two approaches are prevalent in literature and these focuses on whether to use direct measures such as income, expenditure or consumption while the other one is concerned with the use of a proxy measure by making use of the best available data. Gwatkin et al. (2005) tried to make the distinctions between these approaches as follows.

#### ***Income approach***

This approach is straightforward and appealing because respondents are asked a simple question along the lines of how much their household income in the past year was and the respondents are expected to place their estimated annual income in a bracket rather than report the exact amount. However, practical and conceptual issues arise. For example, the respondents may not respond truthfully, especially if they think their answers may leak back to the authorities. It is also not easy to be able to recall accurately all household members' incomes from all sources, for the past year. Questions concerning labour income and unearned income, including transfers, in-kind income such as gifts of food from

neighbours should be treated differently. It is also not clear whether income should be measured before or after taxes. If the expenses associated with running the family business are to be deducted from income to derive net income the emerging question is how to collect the data on such expenses. For example, it is not clear how expenses associated with a piece of equipment such as a tractor should be handled.

The information collected to date on household income in developing countries is typically of poor quality, not least because of these problems. A study done by Gasparini and Panadeiros (2002) on assessment of changes in the distribution of benefits from health nutrition policies in Argentina provides an example of a useful income approach to measurement when neither expenditure nor consumption data are available. The authors utilise two large living standards surveys to obtain data on utilisation of targeted health and nutrition programs in Argentina. Although these surveys do not provide insight into expenditure, the authors estimated household welfare using household income and adjusting for household size applying an equivalence scale. Utilisation rates for the programs were then analyzed across the distribution of this adjusted income measure. However, conceptually it is not clear whether income is the best measure of living standards, because it merely captures how much money is coming into the household. As such, it may not give an accurate picture of the household's living standard. Taking the case of pensioners, for example, in the developing world pensions are likely to be small and people may subsidise their living standards by using up their own savings.

### ***Expenditure approach***

Under the expenditure approach, respondents are asked about household spending patterns which are aggregated to a spending figure. However, again some technical and conceptual issues arise. For example, it is not explicit whether it is sufficient to measure expenditure over a specific time period (week, month or year) or whether to concentrate on the type of purchase during a given

time period. In addition, it is not clear how “lumpy” purchases, such as a car or a television set, should be handled.

In developing countries, the major problem with the expenditure approach is that many households grow a great deal of food for subsistence purposes which constitute a large fraction of their total consumption. As such, a household may look poor from an expenditure standpoint because it gets its food from its own plot and yet it may be actually enjoying a reasonable standard of living. Another problem is that subsidies may give a distorted picture of living standards. For example, one household may be able to live rent free because the head of the household is a doctor at the village clinic or a state-enterprise worker. Judged by expenditure, the household would appear poor because it pays no rent, but this would be the wrong inference.

### ***Consumption approach***

This approach has been used frequently by the World Bank, particularly in the context of Living Standards Measurement Studies (LSMS) (Deaton and Zaidi 2002). A household's food consumption is defined as the sum of its own produce and any produce that it buys from others or is given by others. However, this approach also has certain problem regarding how to treat consumption. For example, if a household has a small business producing handicrafts and keeps some for its own use, these products are counted as consumption while the proceeds from the sale of the remaining products show up in the household's consumption of other items (for example, school uniforms bought from the proceeds). The consumption approach only measures expenditures on consumption goods and does not attribute these expenditures to the use value of each good. The use value of a good, however, depends on the purchase price as well as the expected life of the good.

Further, the consumption approach does not look at the amount of rent a family pays for its accommodation but at the imputed rent—the amount it would have

had to pay had it rented its accommodations at the market rate. Everyone, whether living in a rent-free government house, personally built house, or a rented house, is assigned a positive imputed rent. However, the approach is complex and time consuming especially when if the assessment of living standards are not the main goal of the exercise.

Due to the above and some other related shortcomings, large-scale household survey exercises such as the Demographic and Health Survey (DHS) have eschewed the consumption approach. In fact, the DHS, somewhat surprisingly, has eschewed *all* approaches to measuring living standards, leaving researchers in the frustrating position of having excellent household data on maternal and child health variables but no income, expenditure, or consumption data that would, for example, allow them to compare immunization rates among the poor with those among the better off. This situation led researchers to look at the non-health information collected in the DHS and asked whether it could be used to construct an ad hoc proxy measure of living standards. The conclusion was to the affirmative (Filmer and Pritchett 2001).

### ***The asset index approach***

The asset index approach, deriving an index of household wealth based on household assets with the help of principal component analysis (PCA), is often used to measure living standards. Some of the studies utilise actual DHS data to which the asset index approach is applied, while others compute living standards measured by applying the asset index approach to data sets other than those produced by the DHS. One such study that used DHS information was conducted by Thiede et al. (2005) who explored the use of voluntary HIV/AIDS counseling and testing in South Africa. Another study was conducted in Kenya by Montagu et al. (2005) who looked at the use of reproductive health services through the private sector in Kenya.

A study done by Barros et al. (2005) focused on the question whether health and nutrition programs are reaching the neediest used a non-DHS data set. The inequality was measured by applying PCA to both the Brazil DHS and data from regional surveys to construct an asset measure. In addition, a study done by Schwartz and Bhushan (2005) assessed the effectiveness of contracting out primary health care delivery by constructing a household wealth index using PCA that was applied to baseline and follow-up surveys in Cambodia. The other example is a study on reproductive health among Nepalese adolescents where the asset index approach was applied to baseline and end line surveys of urban and rural communities where a targeted, community-based, participatory health programme had been initiated for disadvantaged youths. The resulting asset measures were used to assess inequalities in the effectiveness of the youth programmes. Peters et al. (2005) also utilised the PCA-based asset index approach to construct a socioeconomic status indicator from a family health survey in Uttar Pradesh State, India. Yet another application of the asset index approach was done by Anwar et al. (2005). In this instance, the PCA was applied to the 1996 census data collected from a rural area of the Ganges-Meghna Delta in Bangladesh.

Given the diversity of data and research questions addressed above, the PCA approach to living standards measurement appears to be reliable. This approach to living standard measurements, in contrast to the income, expenditure, and consumption approaches, does not produce a cardinal measure of living standards, let alone a monetary one. However, this approach cannot be used to determine whether people are poor in the sense that they live on less than a given monetary poverty threshold. In addition, it is not possible to make comparisons across countries because it is incorrect to say that a household with a score of  $-0.75$  living in Tanzania is poorer than one with a score of  $-0.25$  living in Botswana. The PCA only makes it possible to rank households within a specific context, and we can say that within a specific sample a household with a score of  $-0.75$  is poorer, according to this measure than one with a score of  $-0.25$ .

From the point of view of capturing inequalities between poor and less-poor people, the approach seems to work reasonably well because the program administrators could organize an exit survey of users and ask them about their dwelling type, their ownership of household durables, the water supply they use, and so on. Armed with these data, the administrator could apply the PCA weights from a national survey (for example, the country's DHS) and generate for each user of the program's facilities a score on a proxy wealth index. From the national survey, the administrator will know the cut-off points on the wealth index that separate the poorest quintile from the second poorest, the second poorest from the middle quintile, and so on.

### **3.7 Related international research using asset indices**

A number of studies have been undertaken to investigate whether publicly funded programs reach the poor people. These studies are relevant to my study since they also used PCA to establish the socioeconomic status of people accessing health services in a particular country. Filmer and Pritchett (2001) conducted a study to estimate the relationship between household wealth and children's enrollment in India. They used a proxy indicator of wealth by constructing a linear index from asset ownership indicators using PCA to derive the weights. To validate the method and to show that the asset index predicts enrollments as accurately as expenditures or more so, they went further by using the data set from Indonesia, Pakistan and Nepal that contain information on both expenditures and assets. The results showed large, variable wealth gaps in children's enrollment across Indian states.

Another study done by Grabowsky et al. (2005) was done in Ghana and Zambia on achieving equity in the distribution of insecticide treated bed nets (ITNs) through links with the measles vaccination campaign. The wealth index was measured by asking the head of households' questions on household assets. A scoring system was drawn from the DHS as developed and reported by the World Bank (Gwatkin et al. 2000). The scores were summed by household and

individuals were ranked according to the total score of the household in which they resided. The sample was then divided into population quintiles i.e. five groups with approximately the same number of individuals in each. The study found a substantial increase in the ratio of ITN ownership between the poorest households compared with the least poor. Although the study was looking at ITN provision, it is very relevant to our study because of the similarity in methods used to identify the poor people accessing health services.

In Tanzania, a study done by Schellenberg et al. (2003) on health care for children in rural southern Tanzania showed that care seeking behaviour was worse in poorer than in relatively rich families even within a rural society that might be easily assumed to be uniformly poor. A baseline household survey was undertaken, focusing specifically on the extent to which care's knowledge of illness, care-seeking outside the home, and care in health facilities were consistent with Integrated Management Of Childhood Illness (IMCI) guidelines and messages. They used PCA to develop a relative index of household socio-economic status, with weighted scores of information on income sources, education of the household head and household assets.

In conclusion, there is no single ideal approach. Some studies are using benefit incidence analysis (BIA) to calculate the benefits associated with the program and see how they are distributed across the population, paying particular attention to the distribution between the poor and the better off. Benefits, usually expressed in monetary terms, are based on records of service utilisation. For example, if the programme in question is the government's entire spending program for the health sector, the study would ask how many primary care visits, how many hospital outpatient visits, and how many hospital inpatient days each individual or household had in the period covered by the study. Each of these would then be converted to a monetary amount by multiplying the number of visits or days by the amount of government spending or subsidy involved. This may vary from one individual to the next—for example, from the poor to the rich.

As shown above, majority of publicly funded programmes discussed showed successful efforts at reaching the poor. However, none of the studies focus on the socioeconomic status of patients receiving ARV in the public facilities i.e. whether these services are reaching poor people infected with HIV. This study aims at filling this gap.

### **3.8 Equity Principles**

In this section, several ethical principles and equity principles that can potentially be applied to guide decisions in choosing scheme for fair ARV provisions will be discussed. This will provide an overview of criteria decision makers can apply in a particular country to set priorities for the provision of free ARV with regard to the eligibility of different socio-economic groups.

Equity is a broad concept that is related in some way to the idea of a fair distribution of something or the other across different individuals and groups in society (Mooney 1983). It is important to distinguish between equity and equality within concepts of a fair distribution. Equity is about fairness, and it may be judged fair to be unequal in some instances. For example, in health care it may be judged equitable to have unequal access to services in a sense that groups who are more likely to be ill (elderly people, children under five years and pregnant women) should perhaps be given greater access to health care services than those who are less likely to be ill because the chance that they might fall sick is higher as compared to young people. Thus, equity can only be achieved if resources are allocated in a fair or just way within each society (Van Doorslaer et al. 1993). However, it should be noted that fairness is a value judgment. This therefore implies that an equity goal adopted in one health system may not necessarily be the same in another health system.

Logically, equality of health cannot be achieved since there are many factors that influence the health of individuals including genetically inherited conditions, natural deterioration in health over time, age, gender and the individual's perception on their health. Considering these factors, it is unlikely to have equal health for all. Donaldson and Gerard (1993) argue that attempting to achieve good health may be seen as elitist in the sense that informed individuals are prevented from choosing their own level of health which may be somewhere below "good health". For example, a person may choose not to give up smoking. Such a goal would bear negatively on the quality of life on a community. The objective for equity should be provision of opportunity, which is about health care rather than health itself.

Equity can be viewed in two broad aspects: horizontal equity and vertical equity. Mooney (1983) defines horizontal equity as equal treatment of equals and vertical equity as unequal treatment for unequals. Therefore, horizontal equity means those with the same health conditions should get the same treatment in all aspects while in vertical equity means unequal treatment for unequal need.

In terms of ARV treatment, horizontal equity could mean that those patients with a CD4 below a certain threshold be given the same equal opportunity to access similar health care. Also, individuals living in different geographical areas of the country should receive the same treatment regimes for the ART programmes and also use the same services equally.

In terms of HIV/AIDS, the vertical equity principle means that patients who are in stage 1 of their disease would not necessarily be given the same measure of treatment and care as those ones in stage 4 of AIDS disease since they would have different symptoms of the disease. Also, in health care financing, If ART are funded by the government through taxation, then vertical equity principle would mean that, the rich should pay a high proportion of their income in order to cross-subsidize the poor and that will reduce the burden to the government on providing the drugs to the poor.

However, dilemmas are still on how to assess equity among social groups (rural vs. urban, men vs. women, rich vs. poor). Evans et al. (2001) argue that in comparing men and women, one may question how to weigh the fact that women often tend to have longer life expectancy but higher morbidity as compared to men. This is because there are no standards or obvious criterion that explain this and even if the criterion exist, one could still argue that the norms of health that were developed for men do not apply to women (Evans et.al 2001)

The following three particular theoretical concepts dealing with equity will be discussed in order to explain their useful as regard to equal utilisation of free ARVs provision in Tanzania.

#### *The utilitarian principle*

In general terms, the utilitarian principle calls for maximising the overall societal benefits. In terms of the health sector, the utilitarian principle means to maximize the overall health benefits of the society as a whole and thus to maximise the sum of individual well-being. Although the utilitarian principle has been understood to embrace considerations of justice, it does not provide a basis for choosing among the eligible groups in the most equitable manner. A common critique of utilitarianism is its inability to address issues of distributive justice (McGuire et al. 1988). Utilitarianism has a strong focus on efficiency, while equity is about a fair distribution of resources and not necessarily maximization of utility. In the context of ART, the strict application of utilitarian principles means to preferentially treat those patients whose health improvement would be greatest, i.e. whose medical conditions have greater chances of survival and the expected remaining life expectancy is greatest. Compelling to this principle, one might possibly argue that those with an advanced state of HIV would benefit less from ARV provision because giving priority to the sickest will reduce the chances of success of treatment. However, experience has shown that even severely sick patients can benefit from a significant increase in life expectancy. Again, this would oppose the equity principle that requires fair chance of treatment to

everyone regardless of the overall health outcome and could have implications for policy issues.

### *The egalitarian principle*

According to the egalitarian principles of justice, the emphasis lies on the equality of outcomes. According to Evans et al. (2001), the egalitarian principle in health sector could mean equality in health outcome. Evans et al. (2001) argue that egalitarianism in the context of health requires that people be given an opportunity to have equal health status, hence the authors stress the equality of opportunities, which entail equal access to health care. However, justice in health may also be interpreted as the equality of health care resources. This would call for distributing resources equally among persons or distributing goods, such as health care services, equally among different groups. This does not automatically capture the existence of different health care needs. People suffering from TB or malaria in addition to HIV/AIDS have greater health needs than people living only with HIV/AIDS. Aiming at equalising health care would lead to a diversion of resources to interventions that produce very small benefits for people and inhibiting the people who require enormous resources to obtain any benefit at all (Macklin 2004).

### *The maximin principle*

Under this principle, which is based on Rawls (1971), those who are worst off are given priority, i.e the maximum of good should be directed at those with minimal endowments. In the health care delivery context, this usually refers to those who are worst off in terms of health status. However, Macklin (2004) urges that the maximin principle could be also applicable to the most vulnerable e.g. orphans, marginalized or discriminated groups, poorest and sickest. In broad terms, it means that the highest priority should be given to the least economically advantaged individuals because they are more likely to have poor health status and yet can not afford to access health care services. With regard to the provision of ART, this implies that the least advantaged group and the sickest

(clinically advanced stage) should be prioritized regardless of how much they would benefit from ARV. However, the maximin principle conflicts with principle of utilitarianism because the interpretation would be to divert resources from those who could benefit more from the treatment.

### *Access vs. utilisation*

Equal utilisation for equal need requires conditions whereby those who have an equal need for health care make equal use of health care (Oliver and Mossialos 2004). Compared with equal access for equal need, equal utilisation may require more efforts by policy makers, and would require that potentially acceptable reasons for unequal use of healthcare services (by those in equal need) be overridden. These acceptable reasons should not be confused with unacceptable reasons for differential use of health care. For example, some individuals (or groups of individuals) may be better informed and more adept at accessing—and making full use of—health care than others. Differences in lifestyle preferences and/or levels of risk aversion may lead to differences in the utilisation of health care, but the principle of equal utilisation for equal need does not allow for these considerations (Oliver and Mossialos 2004).

Equal access for equal need seems to be the most appropriate principle of equity for the healthcare policy maker to pursue, because (1) it is specific to health care and does not require that we discriminate between people who are already ill purely on the basis of factors that are exogenous to their health, and (2) it respects acceptable reasons for differentials in health care utilisation by those in equal need.

### *Need vs. utilisation*

According to Oliver and Mossialos (2005), need is defined along the following four dimensions (1) normative need, in which an expert, professional administrator, or scientist defines need by laying down their desired standard and comparing it with the standard that actually exists; (2) felt need, in which need is equated with want, and is assessed by simply asking a person or population if they feel they need a service; (3) expressed need, where felt need is turned into action; (4) comparative need, where the characteristics of a population who receive a service are ascertained, and where people with similar characteristics who do not receive the service are adjudged to be in need.

### *Supply and Demand of Health Care*

In general, supply maybe seen as the only relevant consideration for securing equal access for equal need. However, it is also important to consider demand-side aspects, such as the individual's ability to pay for health care. For example, in developing countries user charges are increasingly being used as a method of cost-sharing and to quell the demand for health care, but there is some evidence that user-charges have a negative impact on the demand for health care in lower income groups than in higher income groups. Assuming that the suppressed demand in the face of user-charges is for needed health care (and that access to health care is not currently favourably biased towards the poor), the increase in or introduction of general patient user-charges may well have a detrimental effect on the principle of equal access for equal need (Oliver and Mossialos 2004).

Moreover, the geographical proximity to healthcare services varies quite considerably within many countries and there will always be some acceptable variations in the supply of health care services, especially specialist health care who cannot be allocated entirely equally across all areas. However, efforts have to be made to ensure that all areas/regions are equally serviced by the range and quality of health care specified by the policy maker. According to Oliver and Mossialos (2004), these efforts can be met by ensuring the following. Firstly,

healthcare resources must be distributed to regions according to population size, local input costs (for example, labour and capital), healthcare needs, and the income mix within each regional population, rather than any historical pattern of distribution towards relatively wealthy regions (subject to specific targeting of resources to supra-regional centers of excellence). As a consequence, the local purchaser and provider use of healthcare resources must be monitored to ensure that the resources are used in a manner that is consistent with promoting equal access for equal need. Secondly, efforts ought to be made to overcome any "inequitable" capacity constraints in "disadvantaged" areas, to ensure that there are incentives/directives for sufficient facilities and staff to locate and retain within these areas.

On the demand side, there are some important factors such as knowledge, information, cultural beliefs, indirect financial costs (for example, travel costs), the opportunity cost of patients' time (for example, foregone wages), and their preferences that may contribute in equal access to health services. There is a need for more research to ascertain the relative extent to which any observed income related differentials in healthcare utilisation (and non-utilisation) are either the consequence of differential opportunities, or differential preferences. In addition, cultural factors may influence an individual's willingness to access health care across different groups in a particular community, (for example women may feel uncomfortable with the idea of visiting a male general practitioner). This issue may even be more relevant when considering groups defined by income, social class, etc.

Since utilisation is easier to observe, most research on equity of access has so far used utilisation to approximate access to health services. However, as discussed earlier, the principle of equal utilisation for equal need does not account for acceptable variations in the use of health care, and consensus is required in defining the reasons for these acceptable variations. Moreover, there are some unacceptable reasons for variations in the use of healthcare use that have to be addressed both from the supply and demand sides.

## *Conclusion*

The above theories show that the strategies for equity in health care in a particular country depend on normative argument. It is unlikely to find only one proper theory of social justice prevailing in a particular country.

In Tanzania, it is not clear which ethical and equity principle applies to the provision of ARVs in public facilities. There are some guidelines provided by Ministry of Health on the criteria used to provide ARV as discussed earlier, however, there are no clear indications on whether provision of free ARV is equitable or not. This study aims at filling this gap.

## **CHAPTER FOUR: RESEARCH METHODOLOGY**

### **4.0 Overview**

This chapter provides a detailed description of the methodology used in this study to collect both quantitative and qualitative data. The sources of data and the analysis of data obtained will be described. The chapter will also explain the methods used to evaluate information on the socio-economic status of those receiving free ARV in relation to the socio-economic indicators from the 1999 Tanzania Demographic Health Survey (TDHS 1999). Particularly, principal components analysis (PCA) as an approach of choice will be discussed. Lastly, the limitations of the study will be highlighted.

### **4.1 The Tanzania Demographic Health Survey (TDHS 1999)**

The Tanzania Demographic Health Survey (TDHS 1999) was undertaken in November 1999 and it was the fourth in a series of national sample surveys. The first was the 1991-1992 TDHS, which was followed by the Tanzania Knowledge, Attitude and Practices Survey (KAP) in 1994 and then by the 1996 TDHS.

The primary objective of the 1999 TDHS was to collect data on at the national level (with breakdowns by the urban- rural and Mainland-Zanzibar residence wherever warranted) on fertility levels, nutritional status of young children, childhood mortality levels, knowledge and behavior regards HIV/AIDS, and the availability of specific health services within the community. Related objectives were to produce these results in a timely manner and to ensure that the data were disseminated to a wide audience of potential users in governmental and non-governmental organizations within and outside Tanzania.

The ultimate intent was to use the information to evaluate current programs and to design new strategies for improving health and family planning services for the people of Tanzania. The survey was undertaken by the Tanzanian National Bureau of Statistics (NBS) in collaboration with other stakeholders. The 3,826 households were selected for the sample, out of which only 3,677 were occupied.

Of the households found, 3615 were interviewed representing a response rate of 98 percent.

## **4.2 Study design**

A cross-sectional study was conducted to collect the data on the socio-economic status of HIV patients who access the antiretroviral therapy in selected ARV clinics in Tanzania.

Cross-sectional data included socio-economic indicators and demographic characteristics of those patients receiving ARV. The information regarding the socioeconomic status of the patients receiving ARVs was obtained through a structured questionnaire administered to those patients that requested the Source of drinking water, availability of electricity, sanitation facilities, building materials of dwellings, possession of valuable and durable goods. Also the following socio-economic variables were captured: Occupational history, employment, education and geographical location. To be comfortable and avoid noise, the interviews were administered in the waiting room of each facility. Information relating to knowledge, attitudes, practice of ARV, barriers to access ARV was obtained through focus group discussions composed mainly of community leaders, religious leaders, staff and other local community groups. The Information regarding the criteria and eligibility to be involved in the ART programmes was obtained from key informants (programme managers and heads of each ARV clinic visited).

## **4.3 Study population**

The study population comprised all adult HIV patients accessing free ARV drugs in hospitals, primary health care facilities or in ARV clinics run by local NGOs in Tanzania. Because of limited resources, it was impossible to conduct the study across the entire population. The sample was taken from two regions, namely Dar es Salaam and Kagera.

It should be noted that the ARV programs in Tanzania are still in their infancy and hence the drugs are available mainly to the region and district hospitals. Hence only district hospitals from the selected regions were chosen for data collection i.e. Dar es Salaam urban district hospitals and Kagera rural district hospitals. The reasons for choosing these districts were as follows:

- The study compares the rate of ART utilization between groups of different socio-economic status and contrasts the findings for a rural and an urban study setting.
- Dar es Salaam is the commercial city of Tanzania. This means that the well established health care facilities are situated there, while Kagera is one of the first regions in Tanzania to have an ART programme in the rural areas.
- These regions can be considered to have rather well established ARV programmes that had been in place for the last one year at the time of the study.
- Comparing to other regions providing ARVs, these regions were easily accessible within resource constraints.

There were three health facilities selected from Dar es Salaam and other three facilities selected from Kagera, which are discussed in detail later. Therefore, the sample included patients from six facilities in total.

**Inclusion criteria:** All adults with 18 years of age and above, receiving free ARVs. The patients should have been on these drugs not less than two months and had to be going only to these selected facilities to access the drugs.

**Exclusion criteria:** All patients (less than 18 years), patients served by community based care and all patients with mental disorder.

It is estimated that about 400,000 patients in Tanzania require ARVs but only 13,000 HIV patients access free ARVs. The sample size of 300 patients on ARVs was obtained randomly and then 150 patients per region were chosen.

#### **4.4 Sampling strategy**

By using the list of health facilities in Tanzania that offer ARV programmes, the following steps were taken: By using purposive sampling, two regions were purposively selected, one from rural and one from urban areas. Dar es Salaam was selected as the urban setting and Kagera was selected as the rural setting. By considering some of the criteria including well established programme, a sufficiently large number of patients attending the facility, easier accessibility to the facility and staff cooperation, these facilities within the regions were also purposively selected. Three different facilities were selected in Dar es Salaam and data were collected directly from these hospitals. In rural Kagera, one mission hospital and two public facilities were selected. Systematic random sampling in each facility of people waiting in the queue to receive ARVs was used in conducting the questionnaire interviews until the sample size was achieved. This means that, every fourth person waiting in the queue was approached and asked whether he/she would be willing to be interviewed. Focus group discussions were arranged on the basis of purposive sampling to select focus group representatives, while a snowballing method was used to identify the key informants.

#### **4.5 Data collection sites**

In Dar es Salaam, the facilities selected were Mwananyamala Hospital, Amana Hospital, and Temeke Hospital. In Kagera, the facilities selected were Ndolage Designated District Hospital (DDH), Rubya Mission Hospital and Nyakahanga Hospital. All hospitals were well organized and ART programmes began in early 2005. These ART programmes are funded by different donors through the Tanzanian Government. Although all the facilities mentioned above seem to be funded mainly by international organizations, some of the funds come from the

government line ministry- Ministry of Health under the Multi-country AIDS Programme in Africa (MAP). Data were collected from 24<sup>th</sup> November 2006 through 21<sup>st</sup> December 2006.

#### **4.6 Data Collection instruments and methods**

Closed-ended questionnaires, focus group discussions (FGD) and key informant interviews were the research instruments. The socio-economic status of patients receiving free ARVs was captured through facility based questionnaires with closed-ended questions about gender, age, education, employment status, living conditions and household assets. Many of these questions were synchronized with the Tanzania Demographic and Health Survey (TDHS 1999). The questions allowed the comparison of the data set from questionnaires to that from the TDHS for the analysis of the study. Other questions concerning the knowledge, attitude, and practice around ARVs were also asked.

A two days piloting study was conducted in order to pretest the tools that were to be used to make sure all questions were clear to interviewers and interviewees. This tool pre-testing study was conducted at two hospitals, namely Aghakan and Tumbi located in Dar es Salaam and Coastal regions respectively. Immediately after the piloting study, all necessary corrections including language, type of questions were made before the actual study began.

Since the questionnaires were developed in English, the translation was made to Swahili (local language) because the majority of Tanzanians especially in rural areas can hardly communicate in English. However, it was again translated back to English to ensure the quality of translation. Two research assistants were employed to administer the questionnaires, and the main selection criterion was that they had to be university graduates with previous experience in data collection. There was a one-day training workshop for the research assistants to ensure the quality of the fieldwork. The training ensured that both research assistants understood ethical issues, the content of both the English and Swahili

questionnaire and also allowed for joint practice in order to develop skills for time management for administering the questionnaire.

In-depth interviews with key informants and FGDs with community representatives were also conducted. Four key informant interviews with ARV programme managers (site managers) at the selected facilities were conducted. The reason for the FGDs was to establish the perception of ARV in the community and also to identify the barriers to access free ARV. The reason for in-depth interview with key informants was to evaluate the criteria considered for eligibility to access free ARVs in public facilities.

The FGDs were divided into single sex groups. Five Males and five females were interviewed independently to avoid conformity because of the social interaction between males and females. Stewart and Shamdasani (1990) emphasise differences in ideas of males and females which in some contexts suggest gender separation in the context of FGDs. Five discussion groups were formed. Three FGDs were conducted in Dar es Salaam and two in Kagera. The FGDs comprised of six to nine people with common interests and experiences. The FGD and interview with key informants was only conducted by the principal investigator and the interview was tape recorded while research assistants helped to write filed notes.

#### **4.7 Ethical issues**

As discussed earlier, research assistants were trained to explain all the important issues before they began the interview. Issues to be explained were the purpose of the study, voluntary participation on the study and that the participant is free to withdraw from the study at any time they wish to and thus will not have any effect on their ARVs receiving.

##### **4.7.1 Consent form**

A consent form was given to all interviewees and they had to sign it before the start of the interview. Participants were free to accept or refuse to sign it.

Participants were also told to ask any question whenever they wish to. The consent forms were in Swahili and there was not undue influence to the participants.

#### **4.7.2 Confidentiality**

Both quantitative and qualitative questionnaires were kept anonymous. Also there was no personal information collected, such as personal identity. All necessary information was kept by using a coding system. Efforts were made to ensure total confidentiality. During the research process, completed questionnaires were kept in a secure place, only accessible to the research team. The study had no harm, risks, pains or any other inconveniences to the subjects since it was the interview based study.

Participants were told that all result findings obtained from the study will be disseminated to interested parties and stakeholders. Results/feedback will be distributed and discussed with relevant and interested bodies. These include representatives of relevant HIV organizations, policy makers in the Ministry of Health and other stakeholders. The results of the research will be made accessible to interested patients and the community through the facilities.

#### **4.8 Nature and Sources of Data**

- A total of 300 interviews were conducted, 155 from the Dar es Salaam region and 145 from Kagera. Data obtained from the questionnaires referred to the socio-economic status of those subjects receiving free/subsidized ARVs.
- The Tanzanian DHS 1999 data on socio-economic status of the populations was used to compare with the socio-economic status of individuals obtained from the questionnaires. Access to the dataset was granted by Measure DHS. The TDHS 1999 was conducted by the Tanzania National Bureau of Statistics (NBS) and a total of 3615

households were surveyed. The TDHS was used as baseline data for the generation of an asset index and the establishment of socio-economic quintiles.

- Through in-depth interview and focus group discussions, qualitative data were obtained. To ensure the quality of the data obtained, the interviews were recorded, transcribed and analyzed into codes and themes.

#### **4.9 Data analysis**

Data were entered manually from questionnaires into a master spreadsheet. Data were checked and cleaned by a system of double entries into twin spreadsheets for each questionnaire by separate members of the research team. After data entry completion these spreadsheets were compared and cross-checked. The software packages used were EPI Info for data entry and STATA 8.0 for data analysis. Focus Group Discussions were conducted by the principal investigator with the help of two research assistants. Key informant interviews and FGDs were tape recorded and field notes were written.

##### **4.9.1 Quality control**

The interview setting and conduct were synchronized to avoid any differing responses. Closed rooms were used to avoid noise and other inconveniences to ensure the privacy and confidentiality.

*Face validity* was assessed by using a pilot study. 20 questionnaires were administered before the beginning of the main study.

In case of any problems with the questionnaire, e.g. ambiguous questions, time length for one interview etc. were revised immediately after the pilot.

*Content validity* was addressed through clarity of definition and terms.

*Reliability* was accounted for by using the standardised questionnaire and interview guidelines, ensuring that tools in local language and English have the

same meaning. A one-day training workshop was also organized for all research assistants in order to ensure that the quality of the fieldwork was good.

#### 4.10 Constructing an asset index using principal component analysis

An asset index was constructed in STATA 8.0 using principal component analysis. The asset index for individual  $i$  is defined as

$$A_i = \sum_k \left[ f_k \frac{a_{ik} - \bar{a}}{s_k} \right]$$

Where  $a_{ik}$  is the value of asset  $k$  for a household  $i$ ,  $\bar{a}_k$  is the sample mean,  $s_k$  is the sample standard deviation and  $f_k$  is the score factor.

Principal component analysis (PCA) is a popular approach used to construct an index of wealth from information on household ownership of durable goods and its housing characteristics. It seeks to describe the variation of a set of multivariate data in terms of set uncorrelated linear combinations of the original variables, where each consecutive linear combination is derived so as to explain as much as possible of the variation in the original data, while being uncorrelated with other linear combinations. The asset index is typically assumed to be the first principal component i.e. the first linear combination (more details on PCA are in the literature review section).

The data from the Tanzania Demographic Health and Survey (TDHS 1999) was used for comparison. In order to permit a comparison with DHS data, the list of household assets and characteristics were chosen to get a close an overlap between the two surveys as possible. Asset variables within the questionnaire matched with the respective DHS variables.

This approach made it possible to compare the socio-economic status of patients who access free or subsidized ARVs with the socio-economic status of the rest of

the population. The study population in both regions was divided into five socio-economic quintiles. Weights were calculated for urban and rural data separately and TDHS households were allocated to separate quintiles for rural and urban.

#### **4.11 Limitations of the Study**

- The first concern is that the DHS data are relatively old and asset ownership patterns in Tanzania could have changed since we used the 1999 Demographic Health Survey (TDHS 1999).
- The second concern is that there were resource and time constraints as well as some bureaucratic hurdles put in place by various organisations that impacted on the fieldwork. Also due to some unavoidable circumstances, the FGDs in some facilities could not be interviewed separately. However, most of the bureaucratic at some facilities were sorted out that led to conduct five FGD comprising of both staff and patients. The idea was to interview them independently as these two different groups of people have power imbalances. This therefore could have introduced some sort of bias in the study because patients are not free to speak out their ideas and problems in fear that their treatment could be jeopardized.
- The third concern is that the research relies on the answers from patients only, since the interviews were facility- and not household-based. This could have introduced some sort of bias in the study because the patient's assets ownership could be different from what the patient reported. Patients may not reveal their true asset ownership in order to avoid showing that they are not poor/ rich or vice versa depending on the circumstances.

## **CHAPTER FIVE: RESULTS**

### **5.0 Overview**

In this chapter the criteria considered by providers for eligibility to access free ARV treatment in Tanzania will be evaluated. The comparison of socioeconomic characteristics of people accessing ART to those of the overall population i.e. gender, age, education attainment, employment status, head of household in both rural and urban settings with respect to their utilisation rates will be established. In addition, knowledge, attitudes towards ARV and barriers to access free ARV among community members in both settings will be analysed. Finally, the socioeconomic status of people receiving ARV in terms of household asset possession will be described.

### **5.1 Criteria considered by providers for eligibility to access free ARV in Tanzania**

The clinical condition of the patients and the level of CD4 count were the main criteria for eligibility. There are three classes of individuals who are clinically eligible to begin treatment and include; all those clinical criteria regardless of CD4+ cell count. Also the eligibility includes those patients that fall in WHO stage 3 with their CD4+ cell  $<350/\text{mm}^3$  and all who have a CD4+ count  $< 200$  cells/ $\text{mm}^3$ , regardless of their symptoms. Beyond clinical eligibility, it is important to assess and address the patient's willingness, readiness and ability to be on ART adherently.

Psychological consideration (not exclusion criteria) therefore needs to be evaluated before initiation of therapy during several (three to six) pre-treatment visits i.e. the patient has attended three or more scheduled visits to an HIV clinic and concluded that there is no active alcohol or other substance abuse that could affect adherence and there is no untreated active depression. It is also strongly recommended that clients have disclosed their HIV status to at least one friend or family member who will become the adherence assistant and if possible should

join support groups. In addition, clients need to have accepted their HIV positive status, and have insight into consequences of HIV infection, the role of ART and the very real need to adhere strictly before commencing therapy. Finally, the patient has to be able to attend the CTC on a regular basis (transport may need to be arranged for patients in rural areas or for those coming from remote site) or have access to services able to maintain the treatment chain. The following are some quotes from the key informants regarding the eligibility criteria.

“Okay, the main thing we are looking at of course is WHO clinical stage 3 and 4 and the level of CD4 count less than 200 as it is shown in this guideline. Those are the main criteria. But you see, again we don’t want to force the patients to come for the treatment and that’s why we have our counselors here as you may see that room. They counsel patients, advise on the role of ARV and their side effects and make sure they consent themselves or their close relatives before they start getting treatment.” (Key informant from the National AIDS Control Programme (NACP)).

“Here the social criterion is the fundamental thing we are looking at because it is crucial as far as adherence is concerned. So we make sure the patient has disclosed his/her HIV status to at least one of his member family or close friend so that the patient can get the support of course financially and morally. The financial support is important because so far the government has no any transport arrangements for the patients who can not afford to pay for the transport costs every time they come here.” (Key informant from Kagera region)

“You see, the important thing we are looking at here is the condition of the patients and level of CD4 count. So long as the CD4 count is below 200, immediately the patient will start drugs. We make sure the patient attend the VCT before starting drugs so that they know the importance and the effects of the drugs. So we follow what the guidelines say and there is nothing much I can tell you.” (Medical Doctor from Dar es Salaam region).

However, there are could be potential gaps between official and actual criteria as discussed above. For example, officially there maybe no discrimination on the basis of SES but in practice providers may ration drugs away from poorer patients if they perceive them to be less able to comply , or may ration them towards their friends and family.

## 5.2 Socioeconomic characteristics of people receiving free ARV in Tanzania.

The comparison between the socioeconomic characteristics of the people receiving free ARV to the overall population using TDHS 1999 was made and the following results were observed;

**Figure 1: Provision of free ARV by gender**

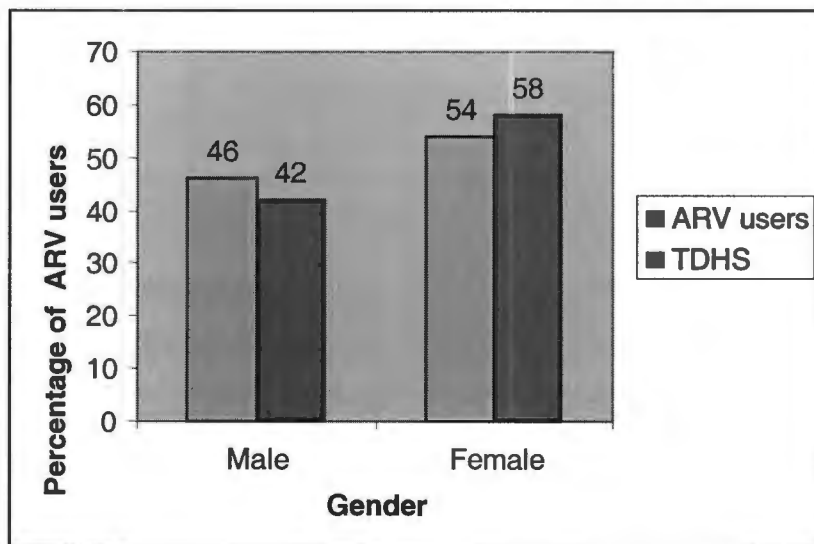
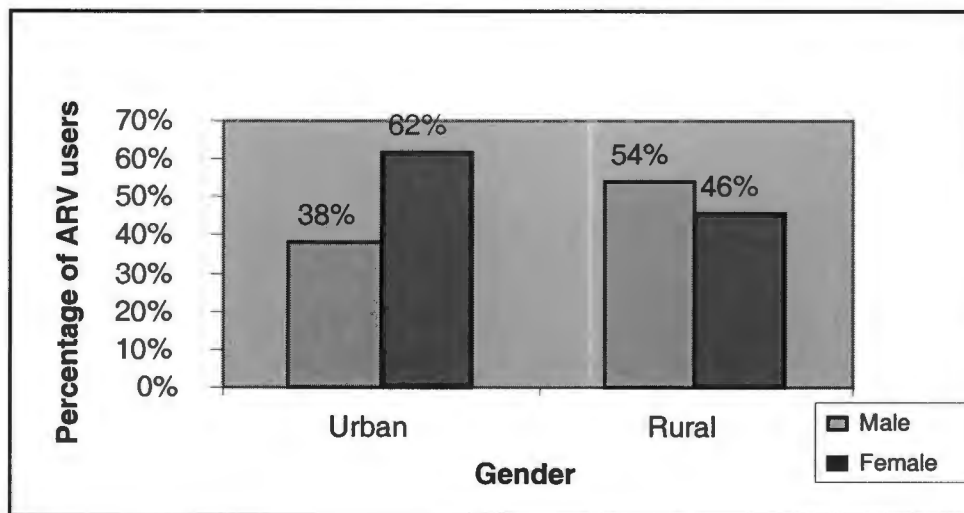


Figure 1 clearly shows that, in absolute terms, women utilise free ARV more (54%) than men (46%) in all facilities. When the data was stratified in rural and urban (as shown in Figure 2), it was found out that in urban areas women had higher utilisation (62%) of free ARV than men (38%). In rural areas men had higher utilisation (54%) of free ARV than women (46%). Three reasons can

explain these findings. Firstly, the data from the TDHS (1999) showed that there are more women than men, with women constituting 58 % of the total population and men constituting 42%. However, it was found that the sex composition of the population does not show significant variation by urban-rural residence. Secondly, in urban Tanzania, women are more affected by HIV than men while in rural areas there are slightly differences of the rate of infections between men and women (NACP 2005). Thirdly, it is assumed that women are more sensitive to their health than men so that they can take care of their children so probably they respond more positively on the call for ARV than men. However, in rural areas, the majority of women are unemployed and decisions on their health care depend on their husbands. This could possibly explain the reason of relatively small percentage of women in rural areas utilising ARV.

**Figure 2: Provision of ARV by gender in rural and urban facilities**



**Figure 3: ARV utilisation vs. educational attainment**

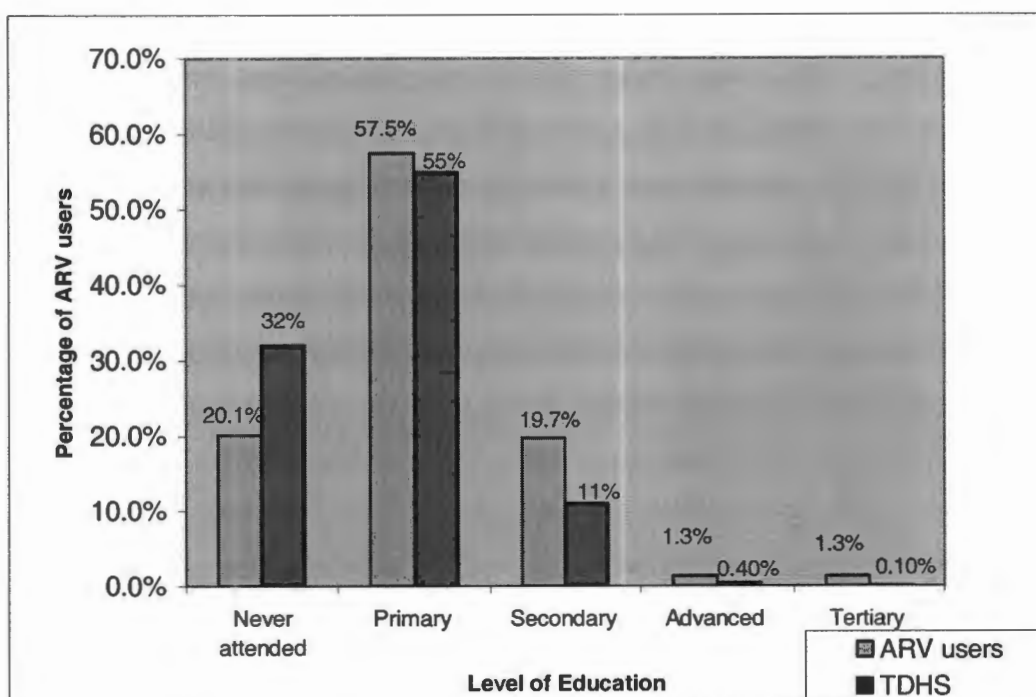
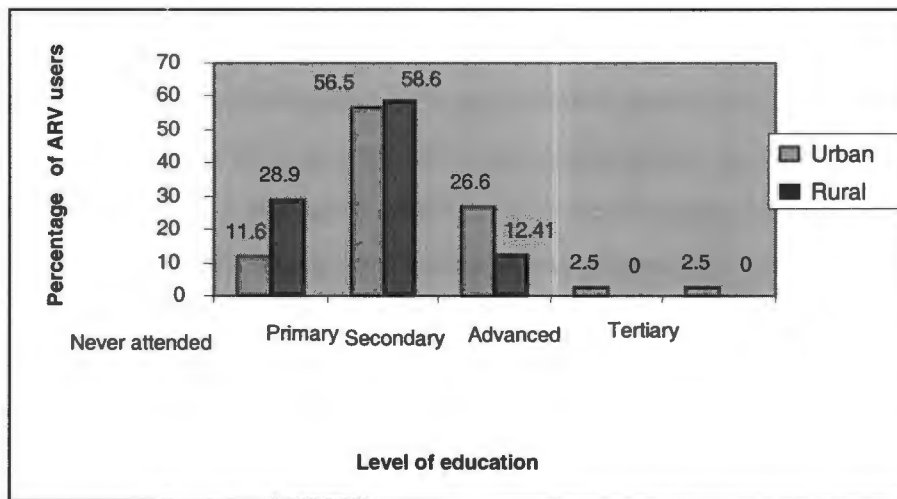


Figure 3 shows the overall utilisation of free ARV according to patients' educational attainment. According to Figure 3, the majority of patients accessing ARV have primary level education (57.5%). Those with secondary level education (19.7%) had almost similar access compared to those who never attended school (20.1%). Those with advanced and tertiary level education had the lowest level of utilization of ARV with only 1.3% each. The results were not surprising because there were some reasons explaining this trend. Firstly, the data from DHS (1999) shows that the majority of people in Tanzania (55%) have only primary education followed by non-education (32%), secondary education (11%), advanced (0.4%) and those with tertiary education (0.1%). Secondly, many studies in Tanzania have shown that the HIV pandemic affects individuals with no education or only primary education to a higher extent (MOH, 2005). Maybe this is because of lack of awareness of risky sexual behavior or because of limited access to condoms. Thirdly, all study sites were public facilities. People with higher education who tend to be economically better-off do not attend public facilities to the same extent and rather prefer private hospitals, where the perceived quality of healthcare services is higher and confidentiality

usually guaranteed. However, as compared to the DHS, it is obvious that the non-educated utilising ARV are underrepresented while those with secondary education and higher are slightly overrepresented. This could be also because of their differences on information and awareness of the existence of the drugs. The primary level refers to primary school education that takes seven years before entering secondary education. Secondary education takes four years and prepares a student to enter into advanced school. The advanced education takes two years and prepares a student to enter into university or other higher learning institutions (tertiary education).

**Figure 4: ARV utilization by level of education in rural and urban settings**



Interestingly, the results are similar, even when the data are stratified into rural and urban facilities, as shown in Figure 4. However, those with no education in rural areas make up a higher percentage of ARV users than their urban counterparts. This could probably be due to the fact that there is a higher percentage of a non-educated person in rural areas than in urban areas. The opposite pattern is shown for those with secondary education and above, whereby urban individuals have a higher level of utilization of ARV than rural counterparts, which again could be due to the fact that a relatively small percentage of educated people lives in rural areas. The rural sub-sample did not capture a single person with advanced or tertiary education. The argument, however, can not be conclusive, as it was difficult to relate the findings to the prevalence of education levels in rural and urban areas due to lack of information.

**Figure 5: ARV utilization by age group**

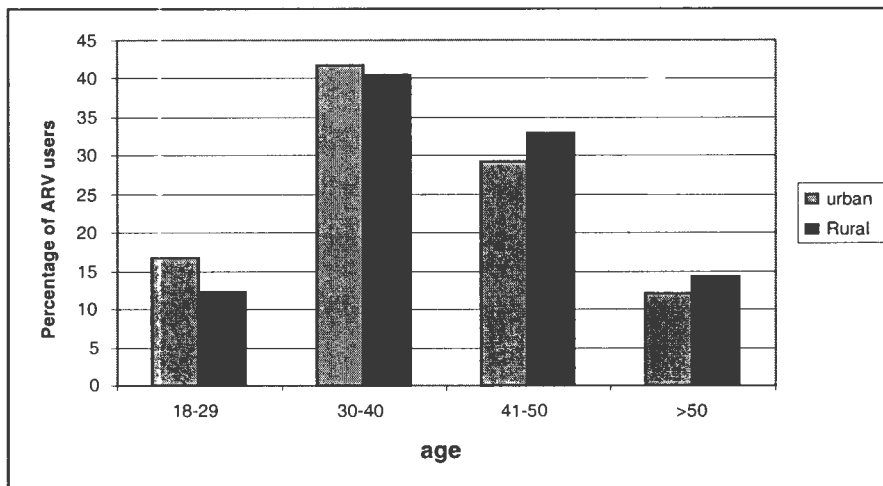
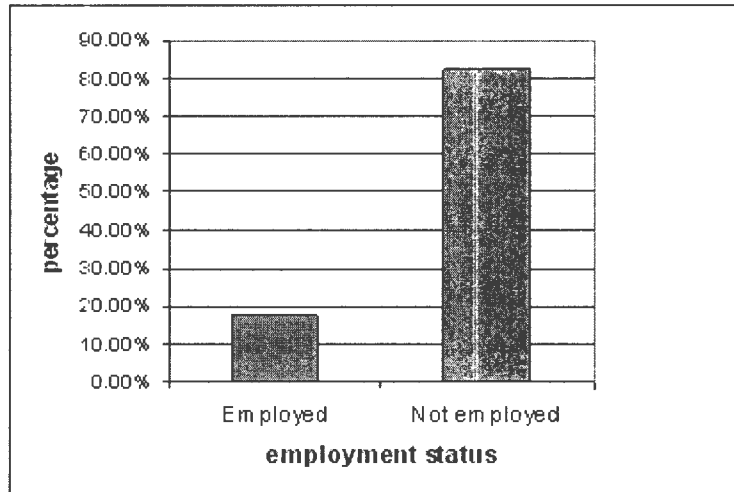


Figure 5 shows ARV utilisation according to the age of patients. As it is shown, there was no big difference of age of patients receiving ARV even when the age was stratified into rural and urban. The age group between 30-40 years was utilising ARV more (40%) than other groups. This probably means that the most affected age group in both urban and rural settings was the 30-40 age groups. The findings by UNAIDS (2004) show that the pattern of early infection among young women peaked among the age group 25-34, while in men the majority of cases occurred slightly later in life, peaking at 30-39 years. These groups are mostly unable to play an active economic role or provide for their families.

The results show that the majority of patients receiving ARV especially in urban areas have to travel for more than one hour to reach the hospital. Most of the respondents (90%) pay up to 400TSH (0.45 USD \$) for the return ticket. Interviewees stated that it is not always affordable to pay for the transport every time. When asked what they do in cases when they had no money for transport, up to 80% said they borrow from either relatives or friends. In rural areas, 99% of the patients walked long distances (more than one hour) to reach the facilities.

**Figure 6: Employment status of the patients utilizing ARVs**



As it is shown in Figure 6, only 18% of the patients utilising ARV are employed. The majority of patients utilising ARV (82%) are not employed. It was difficult to make a comparison with the general population because there were no data in TDHS 1999 showing the overall employment status in Tanzania. However, the findings shown above could be misleading since in developing countries like Tanzania, self-employment and informal economic activities are more common than formal employment. When asked how they make their living, most of the respondents stated that they were either self employed or ran small businesses.

**Figure 7: Head of Household**

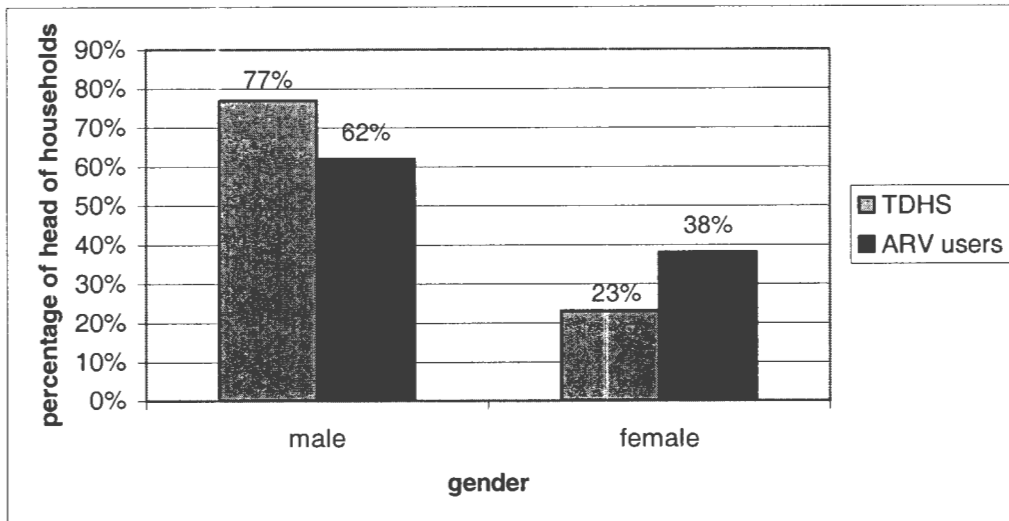


Figure 7 shows the distribution of gender of households heads across ARV users and TDHS respondents. The results show that the majority of households (62%) of patients on ART were headed by males as compared to females (38%). However, across the general population (TDHS sample) relatively more households were headed by males (77%). When the heads of the households were stratified into rural and urban settings, the picture remained the same, as shown in Figure 8 and figure 9 below. However, the gender pattern seems to be more prominent in rural areas than in urban areas. This may be explained by the fact that women in urban areas are able to run their own families without depending on men because some are more educated, availability of more employment opportunities and adoption of western culture of living. Also divorce is more common in urban than in rural because of the same reasons of education and more employment opportunities.

**Figure 8: Head of Household in both settings (rural/urban) for ARV users.**

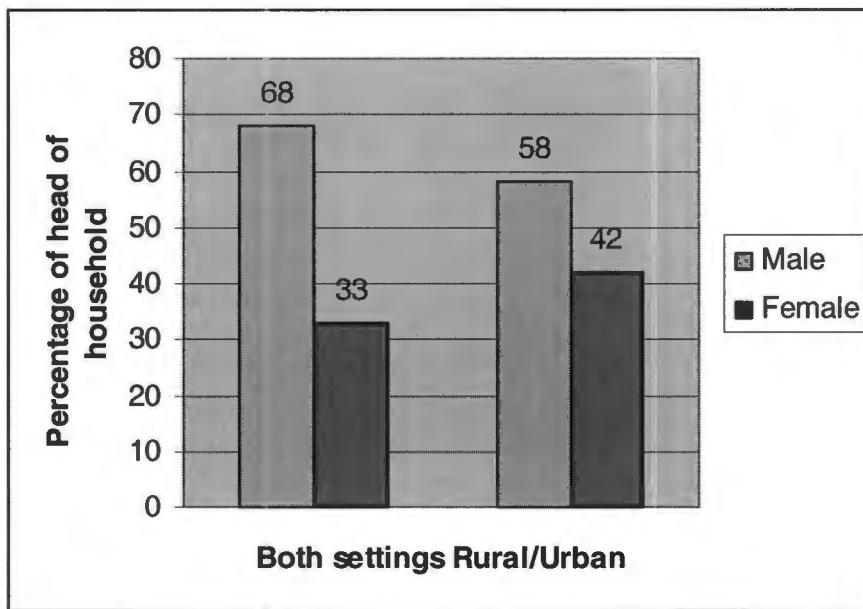
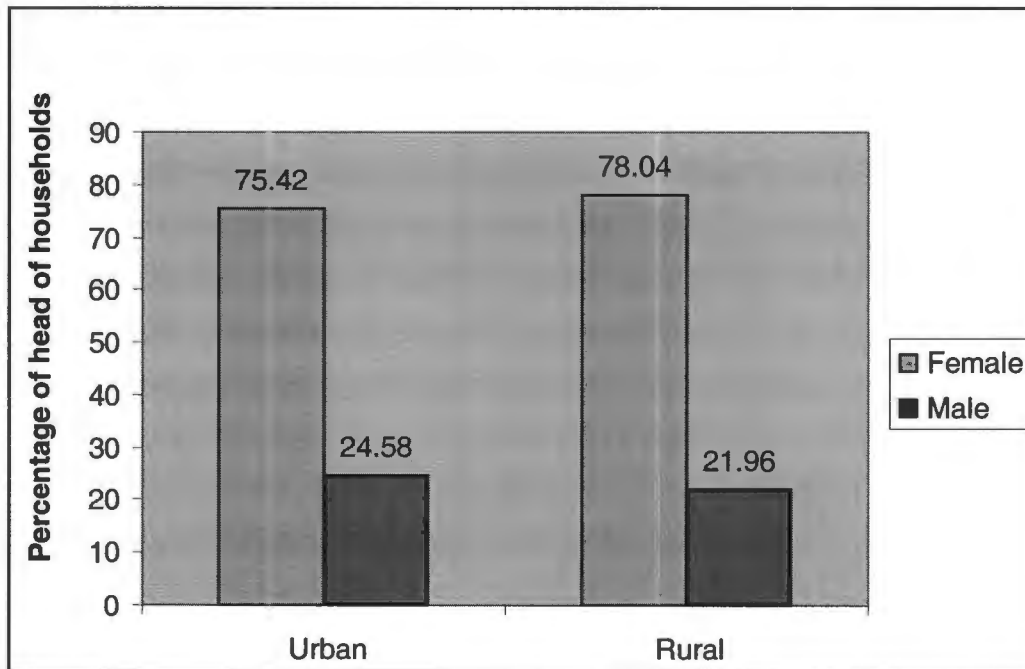


Figure 9: Head of Household in both settings (rural/urban) from DHS 1999



From these findings one could conclude that the gender of the household head plays a role in determining utilisation ART by household members.

### **5.3 The knowledge and attitude of HIV patients towards ARV in Tanzania**

The facility based questionnaire was used to ask respondents about sources of information on the provision of free ARV drugs and its perception. It was found that the majority of the participants (98%) had heard about free ARV provision either from clinic personnel, community health workers or family and friends. The probable reason is due to the fact that most of the patients, as discussed previously, start receiving drugs when they are already in the advanced stage of the disease with other co-morbidity factors. This means that they will start ARV after being advised by clinical personnel or family members to test for HIV since their conditions are worsening.

Media sources such as newspapers, leaflets, radio and television were not a common source of information about ARV with the exception of only 1% of the respondents with higher socio-economic status. From this information, one can therefore argue that either public sensitization of ARV through the media is still inadequate or that probably many people who need such information do not have access to the media due to financial constraints. It is evident however, from the TDHS that the possession of radio and television is exclusively associated with the high socioeconomic status.

In the case of ARV perception, respondents were asked to talk about what they knew about antiretroviral drugs for HIV/AIDS. Most of the respondents said that the drugs are useful in prolonging life because they had improved their health making it possible for them to resume work and gain confidence. However, some respondents from the rural setting said that the drugs give them appetite to eat more than normal and that is why some of the people are scared to start drugs because they do not have enough food. The following are some quotes taken from the respondents.

“Oyo (wow), these drugs are good because they help in extending our life. When I started taking them, I started eating normal, gained energy, and I don’t have any complains at the moment. Look at me now (smiled a bit), if I meet a person who saw me three months ago, he will not believe”. (Woman in the FGD from Dar es Salaam region).

“I know that these drugs do not heal completely but thanks to doctors who found these drugs and I always pray for them so that God will give them idea of getting drugs that can heal completely. What I know is that if I was to die today then I will die after ten years. So don’t you see that it helps to prolong life and we will be able to take care of our children”? (Man in the FGD from Kagera region).

“You see, when someone starts using the drug, the virus is paralyzed and it can no longer multiply at the rate it used to before the antiretroviral drugs. This therefore reduces the opportunistic diseases that were so common and a person is able to live longer. So, although it does not mean that the person is cured completely but his/her life is extended”. (Community leader in the FGD from Dar es Salaam region).

“My friend had lost weight, was not feeling comfortable going out with us and his family was suffering because they were depending on him. Then we heard of ARV and advised him to come here and start ARV. I can tell you that, if you see him now, you can’t believe that the guy is HIV positive and he is back to work“(Man from Kagera region)

“This drug is very useful if is used accordingly but the problem is that, some patients do not follow the instructions. We tell them that don’t ever miss to take the drug and stop drinking alcohol but when we visit them, you find them drinking alcohol sometimes. I think it is because of the psychological problems. But for those who follow the instructions, they are improving and they look great. I think you can see some of them here (Laughter at the back)”. (Medical Doctor from Dar es Salaam region)

“The problem with these drugs is that you have to eat too much. When you start these drugs you eat two times more than normal. So my friend stopped taking drugs because he could not get food for him and his family. But you see now, he died last month and left the wife with four children” (Man from Kagera region).

#### **5.4 Factors that contribute to the utilization of free antiretroviral drugs in public facilities in Tanzania**

Respondents were asked the factors constraining utilization of these drugs for those who need them. Most of the reasons given by respondents were that, people are scared of testing for HIV due to stigma, discrimination and alienation. In addition, some of the respondents indicated that they were not aware of the availability of free ARV drugs. However, it was pointed out that, some who are aware of these drugs feel shy to stand on queue waiting for the drugs because of the fear of being recognized by other people. The other reason hindering utilisation was that people could not afford to travel to health facilities more especially those that were residing in remote areas.

As regard to the availability of ARV, most of respondents say that the drugs were available in most hospitals. However, those in urban areas complained about the transport cost they incur while in rural areas, individuals complained about the long distance they had to cover by walking to the hospitals. The following statements from the focus group discussions underline the concerns:

“Sometimes I decide not to go because I don’t have 800 shilling (USD 0.85) for the return ticket and when you go there, you have to wait for more than 5hours so you will have to buy food so I can not go there everyday and you see I am not working.” (Woman from Dar es Salaam region).

“I walk for about one and half hours to reach the hospital. I used to have a bicycle but now my uncle took it. I have got no alternative, I have to go and take drugs otherwise I will die. Thanks God that I have strength to walk that long distance. But now imagine people who are seriously sick here in the village and can not

walk. There is no way they can go there and sometimes they have to go weekly, it is impossible. (Man from Kagera region).

“We have tried to ask them (medics) to put the patient on the same day for ant-TB drugs and ARV but they don’t want to listen so you find a person traveling twice in a week to the same hospital while he/she should have gone once, this is burden to the patient.” (Health care provider from Dar es Salaam region)

“Patients have to walk a long distance for these drugs and some of them are weak so there are some other days they decide not to go because they can not walk for such a long distance.” (Community member from Kagera region).

“Sometimes even your friends/ neighbors get tired of helping us because you keep on borrowing money everyday and you can not pay back so sometimes you go and ask for the money from your relatives. Sometime the relatives don’t offer money on the actual day and they tell you to go there next week because they know you will go there again.” (Woman from Dar es Salaam region).

“Some people do not go for ARV because they are not aware of the availability of these drugs. Some who are aware of these drugs feel shy to stand on queue waiting for the drugs because other people will know them when they see them.” (Man from Kagera region).

The reason for choosing the above quotes was because they were commonly repeated by most participants in the FGD.

### **5.5 Household assets ownership among patients receiving ARV**

Since the aim of the study was to identify the socioeconomic status of those accessing ARV, household asset ownership was used as a criterion to differentiate socio-economic quintiles. By using principal components analysis (PCA), the weights of asset variables were generated using the reference sample. Quintiles were generated on the basis of the asset scores. This section

specifically looks at asset ownership among ARV patients and their household characteristics, given their categorization into quintiles determined on the basis of the reference sample.

As it may be expected, asset ownership differs between the rural and the urban sample. The data presented in Table 2 & 3 indicate that urban and rural households have almost the same percentage of radio ownership. However, more than half of the households of urban patients own televisions as compared to only 4% of the rural sample. Also, refrigerators are uncommon in rural areas. Bicycles are more common in rural areas compared to urban areas, while cars and motorcycles are almost exclusively owned by urban households. The percentage of households with access to piped water is much higher in the urban areas (83.76 percent) compared to the rural areas (0.68 percent). The traditional pit latrines are commonly used in both settings with 84.2% in rural areas and 63% in urban areas. Flush toilets are almost exclusively owned by urban households. The type of toilet facility has implications on the household's health status. It is important to note that, households without a proper toilet facility are exposed to the risk of diseases including dysentery, diarrhea and typhoid fever.

The common type of floor materials in rural areas was earth/sand/dung with almost 85% comparing to only 4.5% urban counterparts. Most of urban households (76%) have floors made of cement. Table 2 shows the five quintiles in ascending order from the lowest to highest quintiles i.e. Q1-lowest, Q2- low, Q3-middle, Q4-high and Q5-highest.

**Table 2: Household assets ownership in urban districts (Dar-es-Salaam region)**

Variable	Q1	Q2	Q3	Q4	Q5	Total
Have flush toilet	0.0%	6.3%	0.0%	16.02%	63.4%	37.01%
Have traditional pit latrine	100.0%	93.75%	100.0%	84.01%	36.66%	62.98%
Have cement floor	100.0%	75.0%	3.4%	4.0%	0.0%	10.4%
Have ceramic tiles	0.0%	25.0%	96.5%	96.0%	75.6%	76.6%
Have earth/sand floor	8.5%	0.0%	0.0%	0.0%	0.0%	4.5%
Have other floor materials	0.0%	0.0%	0.0%	0.0%	15.8%	8.4%
Have piped water in residence	0.0%	68.7%	93.0%	88.0%	84.0%	83.76%
Have public tap	100.0%	18.75%	6.9%	12.0%	9.7%	11.7%
Have protected well in residence	0.0%	12.5%	0.0%	0.0%	6.0%	4.54%
Have car_ truck	0.0%	0.0%	0.0%	0.0%	18.3%	9.74%
Have motorcycle	0.0%	0.0%	0.0%	0.0%	14.63%	7.79%
Have bicycle	0.0%	6.25%	0.0%	8.0%	8.53%	6.49%
Have electricity	0.0%	6.25%	10.3%	84.0%	97.5%	68.18%
Have Television	0.0%	0.0%	0.0%	20.0%	89.0%	50.64%
Have radio	0.0%	12.5%	44.8%	84.0%	100.0%	76.62%
Have refrigerator	0.0%	0.0%	0.0%	0.0%	73.2%	38.96%

Table 2 (ARV patient data) shows that, in the urban setting, the main type of toilet facility in the highest quintiles is the flush toilet (63.4%). Households from the highest quintile have ceramic tiles (75.6%). Piped water in residence, as a source of drinking water is associated with the highest socioeconomic group and it concentrates more in Q3, Q4 and Q5. Individuals from the highest quintiles possess more cars/trucks and motorcycles compared to the rest of the wealth quintiles. Possession of bicycles, refrigerators, televisions, radios and electricity is also highly associated with the highest income group.

It is also important to observe that the type of toilet facility in the low and lowest quintiles is mainly traditional pit latrine (94% and 100% respectively) and their houses are mainly cement rather than tiled floors. None of the patient from the lowest quintile had electricity and the main source of drinking water was public tap (100%). None of the households from the low and lowest quintiles possessed cars/trucks or bicycles. Only 6.25% of households from the low quintile had a bicycle. None of the households in the lowest quintiles owned a refrigerator, television, or radio. However, 12.5% of individuals from the low quintile owned radios.

**Table 3: Household assets ownership in rural districts (Kagera region)**

Variable	Q1	Q2	Q3	Q4	Q5	Total
Have flush toilet	0.0%	0.0%	0.0%	0.0%	4.5%	2.05%
Have traditional pit latrine	100.0%	100.0%	100.0%	100.0%	65.7%	84.24%
Have ventilated improved latrine	0.0%	0.0%	0.0%	0.0%	29.8%	13.69%
Have cement floor	0.0%	0.0%	0.0%	0.0%	1.49%	0.68%
Have ceramic tiles	0.0%	0.0%	0.0%	0.0%	31.3%	14.4%
Have earth/sand floor	100.0%	100.0%	100.0%	100.0%	65.7%	84.24%
Have other floor materials	0.0%	0.0%	0.0%	0.0%	1.5%	0.68%
Have piped water in residence	0.0%	0.0%	0.0%	0.0%	1.49%	0.68%
Have protected well in residence	0.0%	0.0%	0.0%	0.0%	67.16%	38.82%
Have public tap	100.0%	100.0%	100.0%	0.0%	28.3%	67.12%
Have rain water	0.0%	0.0%	0.0%	69.64%	1.5%	0.68%
Have car_ truck	0.0%	0.0%	0.0%	0.0%	1.49%	0.68%
Have motorcycle	0.0%	0.0%	0.0%	0.0%	1.49%	0.68%
Have bicycle	0.0%	100.0%	0.0%	100.0%	38.8%	28.76%
Have electricity	0.0%	0.0%	0.0%	0.0%	19.4%	8.90%
Have television	0.0%	0.0%	0.0%	0.0%	54.54%	4.10%
Have radio	0.0%	0.0%	100.0%	100.0%	88.0%	78.76%
Have refrigerator	0.0%	0.0%	0.0%	0.0%	2.9%	1.36%

Table 3 shows that only 1.49% of ARV patients from the highest quintile in the rural setting had cars/trucks/motorcycles. The main type of transport in the rural setting is bicycles and these are mainly owned by individuals from low and higher quintiles. However, the ownership of bicycles is also associated with higher socioeconomic status because as it is shown above, none of individuals from lowest quintiles had a bicycle.

The possession of durable goods like refrigerator, television is exclusively associated with the highest socioeconomic group. However, lowest and low quintiles did not have radios while the possession of a radio in middle quintiles was 100%, higher quintiles (100%) and highest quintiles (88.0%). None of the households in the lowest, low, middle and higher quintiles had electricity; however it was relatively common in the highest quintiles with almost 19.4%.

Piped water in the residence as main source of drinking water was exclusively in the highest quintile with only 1.5% of the households accessing piped water while for the open public, the well was the main source of drinking water in all quintiles. Traditional pit latrine and improved ventilated latrines were the most common toilet facility in all quintiles while flush toilets were exclusively for the highest quintile with only 4.5%. Cement floor materials were exclusively for the highest quintile with only 1.5%, while the earth/sand was the main floor material in most households across the quintiles.

### **5.6 Utilization of ARV by different settings (urban vs. rural)**

The utilization of ARV by different quintiles (socioeconomic status) in rural and urban settings is shown below in Figures 10 and 11 below. This presentation ultimately reflects the socio-economic structure of ART patients in the rural and urban settings. The results reflect the degree to which the poor benefit from the free provision of ARVs in public facilities.

**Figure 10: Percentage of people on ARVs by different settings and wealth quintiles**

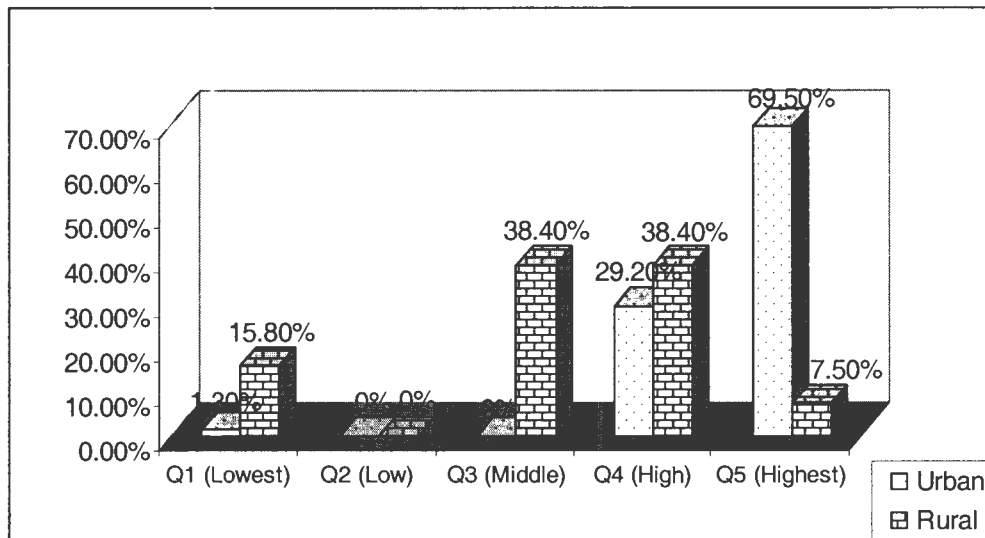


Figure 10 shows that there are extreme differences in the socio-economic structure of ART patients between the two different settings. The findings show that socioeconomic groups are not evenly represented in free ARV utilization, especially in urban districts. In rural districts, the ARV utilization is concentrated in the middle or third quintile (38.40%) and high or fourth quintile (38.40%). In the rural sample, there was no individual belonging to the second quintile utilizing ARV. ARV utilization in urban districts is concentrated in the two upper quintiles i.e. the fourth or high quintile (29.20%) and fifth or highest quintile (69.50%).

The above results indicate that free ARV provisions in urban districts may be less equitable compared to rural districts in terms of socioeconomic status because those with higher socioeconomic status are more favored than their counterparts. However, in rural districts, the findings show that ARV provision caters not only for individuals from the highest quintiles but also those from lowest quintiles i.e. Q1 (15.80%). However, those in higher quintiles especially in the middle and higher quintiles have higher utilization rate than those in lowest quintile in rural districts. Overall findings in both settings show that those in highest quintile have higher utilization rate of free ARV than those from lowest quintiles. It should be noted however that lacking information on need according to the socioeconomic

status of individuals could make these findings not conclusive. The results reflected in Figure 10 may overstate inequities in the provision of ART, as the socio-economic quintiles were constructed on the basis of the reference sample at the national level. The extreme results suggest that it may be more appropriate to calculate separate asset indices for Tanzania's rural and urban areas.

In order to avoid the misleading results based on existing different lifestyles between the two settings and also to make the results more precise, two separate rural and urban indices have been calculated, as the socio-economic structures of rural and urban differ dramatically and thus asset ownership. Separate quintiles were formed accordingly. The categorization of the patient samples into these revised socio-economic groups are shown in Figure 11 below. This presentation avoids the bias that occurs because of the differences in living standards between urban and rural individuals.

**Figure11: Percentage of people on ARV by different settings and wealth quintiles using two separate indices for rural and urban settings**

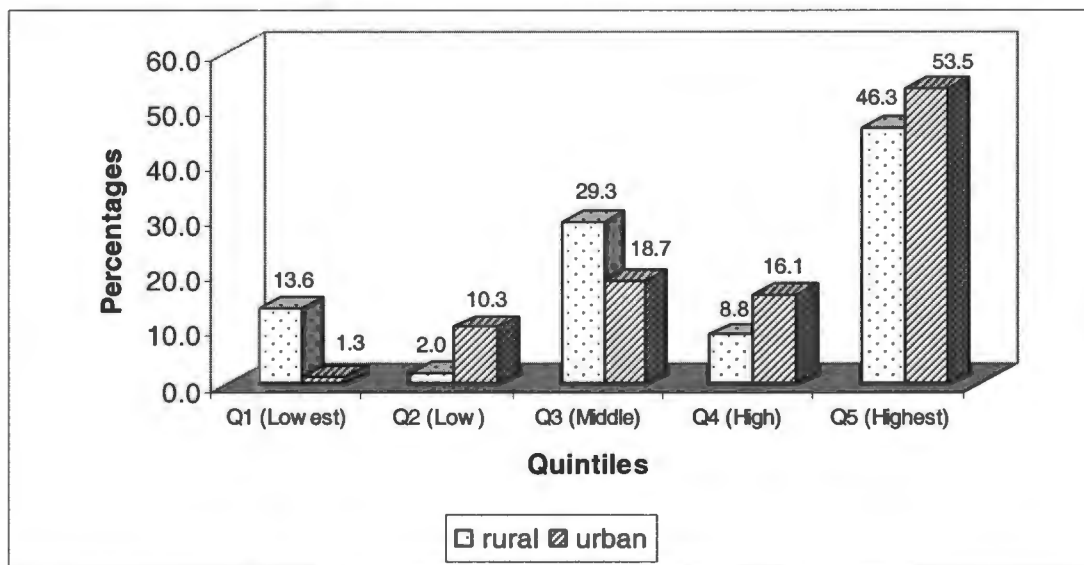


Figure 11 shows that still ARV utilization in urban districts follows an ascending pattern from lowest to highest quintiles while rural districts caters not only

individuals from the highest quintiles but also those from lowest quintiles have higher utilization rate (13.6% of ART patients fall into the first quintile) despite of the split into two different indices. However, as compared to the lowest quintile, patients in the middle and highest quintiles are overrepresented in rural districts. The findings still show that socioeconomic groups are not evenly represented in free ARV utilization, especially in urban districts. However, in urban districts, there are some patients who belong to the first (1.3%) and second (10.3%) quintiles who are utilizing free ARV. The third and fourth quintiles have almost similar are almost evenly represented with 18.7% and 16.1% respectively. However, 53.3% of all ART patients in the urban sample belong to the highest quintile. In rural districts, the ARV utilization is also concentrated in the highest quintile with 46.3%, which in terms of living standards is now different from the highest quintile in the urban setting. 29.3% of ART patients are from the rural third quintile. It is interesting to observe again that based on the rural asset index the individuals from the lowest quintiles still seem to underutilize free ART services (13.6% of patients fall into the first, 2.0% into the second quintile).

Overall, findings from both settings show that there are relatively more individuals from the better-off socio-economic groups in the specific settings who benefit from the provision of free ARVs. Since the sample size was relatively small, the overall findings can not be conclusive, however.

**Table 4: Different facilities in urban setting by different wealth quintiles based on pooled urban data**

Quintiles	Amana Hospital	Mwananyamala Hospital	Temeke Hospital	Total
Q1	0 (0%)	0 (0%)	2 (4%)	2 (1.3%)
Q2	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Q3	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Q4	9 (16%)	21 (41%)	15 (32%)	45 (29.2%)
Q5	47 (84%)	30 (59%)	30 (64%)	107 (69.4%)
<b>Total</b>	<b>56 (100%)</b>	<b>51 (100%)</b>	<b>47 (100%)</b>	<b>154 (100%)</b>

Table 4 reflects the findings based on a national-level asset index for the study sites in the urban area. The two patients from the sample who fall into the lowest socio-economic quintile were treated at Temeke Hospital. The utilization of ARV facilities is associated with higher socioeconomic status.

**Table 5: Different facilities in rural setting by different wealth quintiles based on pooled rural data**

Quintiles	Ndolage Hospital	Nyakahanga Hospital	Rubya Hospital	Total
Q1	8 (17%)	9 (20.5%)	6 (11%)	23 (15.75%)
Q2	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Q3	20 (43.4%)	15 (34%)	21 (38%)	56 (38.35%)
Q4	15 (32.6%)	18 (41%)	23 (42%)	56 (38.35%)
Q5	3 (6.5%)	2 (4.5%)	5 (9%)	11(7.5%)
<b>Total</b>	<b>46 (100%)</b>	<b>44 (100%)</b>	<b>55 (100%)</b>	<b>146(100%)</b>

Table 5 indicates that the distribution of access to free ARV in rural facilities also caters for individuals from lower socioeconomic status. However, the percentage of individuals utilizing free ARV increases with the high socioeconomic status especially in the middle and higher quintiles. These findings again support the results shown in Figure 10 that, the individuals from higher socioeconomic status have higher utilization rate of ARV provision comparing to the low counterparts. The pattern is consistent across the three facilities.

**Table 6: Percentage of patients on ARVs by gender pattern and wealth quintiles based on pooled rural and urban data**

Quintiles	Urban (Dar es Salaam)		Rural (Kagera)	
	Male	Female	Male	Female
Q1 (Lowest)	1 (1.7%)	1 (1.1%)	11 (14%)	12 (18%)
Q2 (Low)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Q3 (Middle)	0 (0%)	0 (0%)	28 (35%)	28 (42%)
Q4 (High)	12 (20.3%)	33 (34.7%)	33 (42%)	23 (34%)
Q5 (Highest)	46 (78%)	61 (64.2%)	7 (9%)	4 (6%)
<b>Total</b>	<b>59 (100)</b>	<b>95 (100)</b>	<b>79 (100)</b>	<b>67 (100)</b>

Table 6 presents the socio-economic pattern of patients on ARVs in the rural and urban facilities by gender. Despite the overall higher share of female patients in the urban setting and male patients in the rural setting there is no consistent gender pattern across socio-economic quintiles in either the rural or the urban sample.

The detailed results show that ARV provision in all facilities in both settings favour the better-off in society.

## **CHAPTER SIX: DISCUSSION**

### **6.1 Overview**

This chapter discusses the findings around the socio-economic structure of patients utilising ARV in public facilities in Tanzania. The summary of the findings will be presented. The application of principles of equity will also be briefly discussed in this chapter.

### **6.2 Provision of free ARV policy in Tanzania**

The main reason for providing free ARV in public facilities in Tanzania is to improve the quality of life of those living with HIV/AIDS. This is reflected in a statement by the Tanzanian government. One of the goals of the Tanzania Care and Treatment Five-year Plan is to “increase access of ARV to HIV patients, provide quality, continuing care and treatment to as many HIV positive residents of the United Republic of Tanzania as possible, building on the careful planning already completed by the Ministry of Health and the Tanzania commission for AIDS” (GOT/MOH, 2003:21).

The study revealed that all HIV/AIDS patients on ARV in Tanzania are on first line regimen. This is due to the fact that the free ARV roll-out policy in Tanzania began late 2004 and according to WHO recommendations, a standard combination of drugs known as first-line should be given to those who have just started on the ARV treatment. In Tanzania’s policy, before treatment failure is presumed and a particular regimen discarded, every effort should be made to rule out causes other than drug resistance. Patients should be evaluated for correctable factors such as inappropriate dosing schedules, drug interactions that may reduce the efficacy of some of the ARV drugs, non-adherence due to side effects and evidence of mal-absorption (NACP 2005). Since it takes time to take all these factors into account, this could explain the reason why the majority of ARV users are on first line regimens. Also, one could think of the higher costs involved to purchase the second line drugs in developing countries as discussed

previously. The criteria for eligibility to access the free ARV in Tanzania are clearly outlined by the Ministry of Health and reflected in the key informant interviews as reported above. However, the socioeconomic status of patients receiving ARV is not one of the criteria for eligibility, which results in an over proportional share of patients from the higher socio-economic strata. Also the criteria for disclosure i.e. to disclose their HIV status to at least one friend or family member before starting the treatment could cause the barrier to utilise the ARV to some patients who are not ready or feel shy to disclose their HIV status to avoid the alienation.

### **6.3 ARV utilisation by gender in Tanzania**

Findings from the study showed that women utilise free ARV more (54%) than men (46%) across all study sites visited, even though there is a different pattern between the rural and urban sites. Probably this is due to two reasons: Firstly the HIV infection rates in Tanzania are higher among women than among men (NACP 2005). Also women are more sensitive regarding their health than men, so probably they respond more positively on the call for ARV than men. These findings are supported by the studies conducted by Barongo et al. (1992) and Berkley et al. (1990). It was found that the factors contributing higher risk of HIV among women in Tanzania includes the low social status of women and economic dependence on men and these factors affect women's capacity to determine their sexual lives with sexual decision making being constrained by coercion and violence (MOH 2004). However, there are no biological factors which make women more susceptible to HIV infections. Another study done by NACP 2005 revealed that women are more likely to go for voluntary counseling and testing (VCT) than men, hence are more likely to utilise free ARV, as VCT is a prerequisite for access to free ARV. The reason for women to have higher utilisation rate could be also due to the fact that while men experience stigma of exposing their HIV status more, women get scared of HIV infection because they

fear to leave their children orphaned, so they opt to test for HIV and start ARV early so that they can live longer and take care of their children.

The discussion above implies that the free ARV utilization in Tanzania is relatively equitable from a gender perspective.

#### **6.4 ARV Utilization by age in Tanzania**

The findings from the study show that the age group between 30 and 40 utilizes ARV more than other age groups. This applies to both rural and urban settings. The reason could be the fact that in Tanzania the most affected age group in both setting was age of 30-40 with more than 40%. These findings tie in with the UNAIDS findings which showed that the pattern shows early infection of young women, with reported cases peaking from age 25-34, while in men the majority of cases occur slightly later in life, peaking at 30-39 years (UNAIDS, 2004). These groups are unable to play an active economic role or provide for their families.

One can argue that the free ARV provision in Tanzania with regard to age groups is relatively efficient because this age group has the largest and most productive segment of the labor force. Hence by having higher utilization rate of ARVs on this age group will have implications for the labor force supply as well as the Tanzanian economy in general.

#### **6.5 ARV Utilization by educational level in Tanzania**

The majority of those utilizing ARV (almost 60%) in the study had primary education. Those with no education (never attended school) and with secondary education had almost similar level of ARV utilization while those with tertiary education were the least. When comparing the educated (all levels of education) and non educated (those who never attended school) participants it becomes obvious that the educated ones are utilizing more ARV (almost 80%) than the non- educated ones (20%). Note that the educated and non educated ones in Tanzania regardless of their level of education are 87% and 13% respectively. The possibility for the non-educated being overrepresented among ARV patients

compared with the general population is not excluded. These findings remained consistent, even when the results were stratified into rural and urban settings. This could be due to the differential access to information between the groups, as reflected by access to magazines, newspapers and other news media. However, evidence from the focus group discussion (FGD) indicated that those with a university degree may not feel comfortable standing on the queue waiting for drugs, so they prefer to go to the private facilities. Also they may have well-paid jobs and therefore can afford the private sector. The confidentiality in public facilities may also not be guaranteed.

With regard to whether the provision of ARV by education level is equitable or not, the study results imply that it is relatively equitable because the majority of those utilizing free ARV services are those with either primary education or with no education. This mirrors the statistics from NACP 2005 which showed that the majority of people with HIV are non-educated especially those in rural areas. However, one cannot derive an ultimate conclusion because, as discussed earlier, the utilization pattern may just reflect that those with higher education opt to attend the private facilities.

### **6.6 ARV utilization by employment status**

As it was shown in the previous chapter, only 18% of the patients utilising ARV were employed. The majority of patients accessing ARV (82%) are not employed. The unemployed who are also more infected with HIV diseases make their living by running their small business, which are not always sustainable. Some patients are unemployed so they are totally depending on their relatives (NACP, 2005) and the situation was worse in rural areas where more than 95% were unemployed. The findings matched with NACP 2002 which show that majority of HIV patients in Tanzania are unemployed. The reason could be that they have ample time since they have no serious issue keeping them busy. Also the unemployed ones have financial constraints so they might not have money to

buy condoms and other contraceptives and do not access information on HIV because they do not have TV, Radio and do not know how to read and write.

With regard to whether the ARV provision by employment status is equitable or not, one could argue that it is equitable since the majority who do not have steady income to pay for their drugs have higher utilization rate of ARV than their employed counterparts.

### **6.7 ARV utilization in both settings (urban vs. rural)**

As shown in the previous chapter individuals from the higher socio-economic status form a bigger share of ARV users than individuals from lower socio-economic strata. However, the relation between these settings and their needs were not analyzed in this study so any equity judgment derived from this study can only be based on a very general notion of social justice according to socio-economic status.

Based on the data obtained from the study sample, it was found that the individuals with primary education and those with no education have the higher level of utilizing ARV among the population. This study due to some limited information was based on the assumptions that those with no education represent individuals from lowest quintile and those with primary education represent the lower quintiles and from that assumption, one can conclude that free ARV provision is more equitable in rural districts comparing to the urban counterparts. Another argument is that individuals from the lowest quintiles are economically disadvantaged and vulnerable to diseases. These groups also have lower health status compared to those from highest quintiles. This implies that the principle of vertical equity is not achieved because these vulnerable groups are underserved. One could also think of the maximin principle of social justice and conclude that ARV provision in both settings is not fair since it is clear that those who are most disadvantaged in terms of health status and socio-economic status are not prioritized.

However, the purposive selection of facilities could have induced any bias because the study areas are not really representative of the average rural and urban populations in Tanzania.

## CHAPTER SEVEN: CONCLUSIONS AND POLICY RECOMMENDATIONS

While the provision of ART has substantially improved the prognosis of HIV-infected patients in industrialized countries, in resource poor settings in Africa, Asia and South America where 90% of people with HIV/AIDS live, access to ARV continues to be limited.

The study intended to help answer the question of who are the beneficiaries of the free antiretroviral provisions in public facilities in Tanzania in relation to socioeconomic groups in rural and urban settings, i.e. “do the poor benefits?”

The study has found that non-educated individuals and those with primary education, unemployed individuals, and age groups between 30-40 years have higher utilization rate of ARVs compared to their counterparts. Furthermore, the comparison among these groups was done in relation to their relative occurrence in the overall population using the TDHS 1999 and the underlying reasons for the greater access among these groups are discussed in previous chapter.

However, in rural settings it was found that some percentage of individuals from the lowest quintile are benefiting from the ARV provision compared to urban settings where there were no representatives from the lowest quintile. It can be concluded that those from the lowest socioeconomic group in urban settings may only start benefiting after those from the highest socioeconomic group have benefited.

However, the information received from the focus group discussions showed that not only do the supply factors influence the degree of equality in the utilisation of free ARV drugs in Tanzania but also there are crucial factors from the demand side that play a big role in the distribution of these drugs. For example, some patients were scared to take ARVs because they increase the patients' appetite and thus tend to increase food expenditure. Also some patients believed that

they have been bewitched so they would rather opt for traditional healers than taking ARVs.

Regarding to the above findings, one can conclude that the utilization of free ARV provision in Tanzania does not reflect the level of need and thus should be judged unfair in terms of vertical and horizontal equity. Also, in the light of the maximin principle of social justice, the utilization pattern would be judged unfair, because the least economically disadvantaged and vulnerable are not prioritized.

In summary, the study has the following policy recommendations,

- The standard assumption that the poor are always the principal beneficiaries of publicly funded health services is clearly incorrect and must be replaced by vigilance to ensure that the traditional pattern of higher service coverage among upper income groups does not continue.
- There is need for improving the free ARV programmes in favor of the poor and least economically disadvantaged and thus for improving vertical and horizontal equity in ARV provision in Tanzania.
- More research is needed to clearly establish the relationship of socioeconomic characteristics of those accessing ARV and improve the understanding of service provision in urban and rural settings. This information will help policy makers to improve the effectiveness of ARV programmes aimed at reaching the poor, not only in terms of treatment but also prevention of HIV/AIDS. Also, the resource allocation formula can be used to design a policy in such a way that ARVs are provided fairly across the societies.
- The government also needs to sensitize the public about existence, importance and the availability of antiretroviral drugs widely. The findings of this study showed that the majority of patients (90%) knew about existence of ARV through clinical personnel and only few patients (less

than 1%) had learned about the programme from radio, television or leaflets.

- There is a need for the government, whenever necessary and especially for those who can not get food, to support the provision of food and basic services. This is most important in rural areas where people can hardly afford to buy food and yet are receiving ARV. The response from one participant in the focus group discussion in rural areas said that other patients are scared to take ARVs because they increase appetite.
- The government should initiate national campaigns against HIV stigma all over the country through national celebrities and popular people who are HIV positive and are already on ARV treatment to give their views on the disease and its treatment. This will reduce stigma in the context of HIV/AIDS and will improve the utilisation of voluntary counseling and testing for HIV. Similarly, the government should alert the public especially in the rural areas on the key aspects of HIV transmission and promote the incorporation into behaviour and practices.
- There is a need for the government to ensure that the ARV programmes work according to the set priorities. This can be achieved by developing tools that help in constantly monitoring and evaluating the programs to inform policy makers whether the least economically disadvantaged and vulnerable are reached.
- Further studies have to be conducted to determine why some socioeconomic groups are not utilizing free ART services that are available in their area.

In Tanzania, the provision of free ARV is still in its infancy and the need for scaling-up is as urgent as ever. The need to set priorities that will allow easier accessibility of these drugs in such a way that will target and reach the least disadvantaged groups is highly needed. Macklin (2004) also concluded by

insisting that making decisions in priority setting should take into consideration all relevant ethical and equity principles to ensure that all human rights obligations are respected, protected and fulfilled.

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## **APPENDIX A: Consent letter for Key Informants**

Dear interviewee,

You are requested to participate in a study about who benefits from free/subsidized antiretroviral drugs in Tanzania. The information provided by you will be taken as confidential. Your participation is entirely voluntary and you have the right to withdraw from the process of the interview whenever you wish to. The information provided will only be accessible to responsible persons and no personal information will be required from you.

The aim of the study is to fulfill the requirements for my Master's degree in Public Health. It will also help to provide information to policy makers on how to develop suitable guidelines on improving access and fairness in the provision of antiretroviral medicine.

### ***Declaration***

I have read and understood the nature of the study in which I am participating. I therefore agree/ do not agree to participate. I also give / not give permission for this interview to be taped by the interviewer

Signature of respondent: \_\_\_\_\_

Date: \_\_\_\_\_

## **APPENDIX B: Key Informant Interview Schedule**

Which type of ARV programmes are you involved in?

Are the ARV drugs provided free or on a subsidized basis?

When were these programmes started?

Please explain what are the objectives underlying the provision of free or subsidized ARV drugs?

What are the criteria for eligibility to access free ARVs?

What groups of people are these ARV programmes mainly targeting?

How do you know that those who are accessing the drugs are target people and how do you maintain it?

What do you think are the barriers to all eligible for free/subsidized treatment not accessing ARVs?

How can these barriers be removed?

## **APPENDIX C: Informed Consent form for Study Subjects**

My name is Amos Kahwa, a Master's student at the University of Cape Town (UCT) in South Africa. I am conducting a study to evaluate who benefits from free antiretroviral drugs in Tanzania. This is to fulfill the requirements toward the award of Masters of Public Health. It is also my hope that the study will have necessary information to policy makers who may in turn improve the services you are receiving. The findings of this study will also be provided to you.

The information you are giving me will be treated as confidential and will have no any impact on the treatment you are receiving at this facility. The completed questionnaires will be accessible to responsible persons. By assuring you the confidentiality, there are will be no names or any other personal identification requested from you. In this study, you have the right to agree to participate or not to participate. You also have the right to withdraw from the study at any stage whenever you wish to.

**Consent:** I agree to participate in the study.

Signature:..... Date.....

## APPENDIX D: Study Questionnaire

### Part A

ID Number: \_\_\_\_\_

Name of facility: \_\_\_\_\_

District \_\_\_\_\_

URBAN	1
RURAL	2

PLEASE INDICATE BY TICKING THE APPROPRIATE ANSWER WHERE APPLICABLE.

### PART: A

#### 1. Gender

MALE	1
FEMALE	2

2. Age \_\_\_\_\_

#### 3. Level of Education: *Please tick appropriate box*

Never attended school	1
Primary level education	2
Secondary level education	3
Advanced secondary school (High Level)	4
Tertiary education, including undergraduate and diploma level	5
Higher advanced learning = masters and PHD programmes	6

4. Where do you live? \_\_\_\_\_

5. How do you come to the clinic/ facility/Hospital?

1) Walking

2) Traveling

6. How long do you take to reach this clinic/ hospital /facility?

Less than 15 min	1
15-30 minutes	2
30 mins to one hour	3
Over one hour	4

7. This is applicable, if Q 5 above is traveling. Do you travel by public or private means?

Private	1
Public	2

a) If public how much does it cost you to travel here? (Amount in TSh) \_\_\_\_\_

b) Is it affordable to pay for the transport every time you need to come for treatment? Yes/ No

c) If No, what do you do if it happens that, you don't have money for transport? \_\_\_\_\_

8. Question

a) Are you employed?

Yes	1	Go to questions 8b and 8c
No	2	Go to question 9

b) Where do you work? \_\_\_\_\_

c) What is your position there? \_\_\_\_\_ Go to question 10

9. In the past 7 days have you had any work for pay?

Yes	1	Go to question 10
No	2	Skip to question 11

10. What kind of work was it? \_\_\_\_\_ go to Q. 13

11. When was the last time that you worked for money?

Within the last month	1
Within the last 3 months	2
Over six months ago	3

13. In the past 10 days have you had money available from other sources than work?

Yes	1	Go to question 11
No	2	Skip to question 12

14. What are the sources \_\_\_\_\_?

15. What is the number of people living in the household (excluding visitors)? \_\_\_\_\_

16. Who is the head the household? Male or female \_\_\_\_\_

17. What is the main source of drinking water for members of your household?

Piped	1	→	In residence	1	Outside residence	2	Public tap	3
Open well	2	→	In yard/plot	1	Outside yard	2		
Protected well	3	→	In yard/plot	1	Outside yard	2		
Borehole	4	→	In yard/plot	1	Outside yard	2		
Spring water	5							
Rain water	6							
Tanker truck water	7							
River, canal or surface water	8							
Bottled water	9							
Water from gravity flow scheme	10							

18. What Type of toilet does your household have?

Flush toilet (own)	1
Flush toilet (shared with other household)	2
Traditional pit toilet/ latrine	3
Ventilated improved pit latrine	4
No facility/ Bush/ Field	5
Other : Please specify _____	6

19. Please indicate by ticking if your household has:

Electricity	1
Radio	2
Television	3
Telephone (fixed ) /( mobile)	4
Refrigerator	5
Lantern	6
Cupboard	7

20. What is the principal flooring material in your house?

Earth/ dirt/sand/dung	1
Cement	2
Vinyl or asphalt tile	3
Ceramic tiles	4
Parquet or polished wood	5
Other, please specify _____	6

21. What is the main material in the walls?

Thatched	1
Mud and pole	2
Un burnt bricks	3
Burnt bricks with mud	4
Burnt bricks with cement	5
Timber	6

Cement blocks, bricks, concrete walls	7
Stone	8
Other, please specify _____	9

22. What is the principal roofing material in your house?

Thatched	1
Iron sheets	2
Asbestos	3
Tiles	4
Tin	5
Cement	6
Other, please specify _____	7

23. Does any member of your household own.....?

A bicycle	1
A motorcycle or motor scooter	2
A car or truck	3
A boat or canoe	4
A donkey	5

24. What do you use for lighting?

Electricity	1
Biogas	2
Kerosene	3
Charcoal	4
Dung	5
Others please specify _____	

25. Would you say that people in your household often, sometimes, seldom or never go hungry?

Often	1
Sometimes	2
Seldom	3
Never	4

**PART: B**

26. How did you know about provision of free ARV's

<i>Friends/family</i>	1
<i>Posters at clinic</i>	2
<i>Newspapers</i>	3
<i>Leaflets</i>	4
<i>Clinic personnel</i>	5
<i>Community health worker/health educator</i>	6
<i>Radio</i>	7
<i>TV</i>	8
<i>Other, please specify _____</i>	

27. How were you enrolled on this programme? \_\_\_\_\_

28. When did you start receiving treatment on this programme? \_\_\_\_\_

29. Do you think these ARV drugs help? Yes/ No

If yes, why do you think so? \_\_\_\_\_

If No, why do you think so? \_\_\_\_\_

30. How many times do you come to receive drugs at the facility?

Once a week	1
Once in a fortnight	2
Once a month	3

31. Are you the only one receiving free drugs in your household?

Yes	1	Skip to qn 30
No	2	Go to qn 29

32. How many other people in your family are receiving free ARVs? \_\_\_\_\_

33. Are you the only one who needs these drugs in the household?

Yes	1	Skip to 32
No	2	Go to Qn 31

34. What do you think could be the factors constraining accessibility of these drugs for members of your household that need them \_\_\_\_\_

35. What are the benefits you get from these programmes? \_\_\_\_\_

36. Do you incur any costs in accessing these drugs?

Yes	1	Go to qn 34
No	2	Skip to 35

37. What are the costs?

Consultation fee	1
Payment for drugs	2
Laboratory test fees	3
Other costs, please specify _____	

38. Do you think that whoever needs these free drugs get access to them?

Yes	1	End
No	2	Go to On 39

39. What do you think are the factors that constrain others from accessing the drugs?

\_\_\_\_\_

## **APPENDIX E: Focus Group Discussion (FGD)**

There will be discussions with representatives of the communities within selected areas. It is expected to discuss with religion leaders, community leaders and other representatives in case of any other available groups in the selected areas.

A brief introduction about the research project will be given to the group discussion and the verbal consent form will be obtained from all participants

### **Suggested Questions:**

What do you know about antiretroviral drugs?

What benefits do you think are obtained from receiving antiretroviral drugs?

Do you know whether ARVs are provided free or at a low cost in any facility in your community?

Who do you think is eligible to access free or low cost ARVs?

Which groups of people do you think benefit more from these services? Why?

Do you think whoever need to use ARVs can access them?

What factors do you think would encourage or discourage people from accessing antiretroviral drugs?