

**FACTORS INFLUENCING ART ADHERENCE: QUALITATIVE  
FINDINGS FROM SELECTED SITES IN TANZANIA**

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## 1.0. BACKGROUND

AIDS was first described as a disease entity in 1981. In retrospect, however, isolated cases occurred during 1970's in the USA and several other areas of the world including Africa. By the end of 2003, the World Health Organization (WHO) estimated that 40 million people had been infected with HIV globally since the outbreak of the epidemic.<sup>1</sup> In the following year (2004), WHO estimated that there were about 14,000 new infections occurring daily around the globe. Majority of the new infections were recorded in the developing countries: Sub-Saharan Africa, Asia and South America. In the year 2003, about 70% (29.4 million) of people infected with HIV lived in sub-Saharan Africa and approximately 3.5 million new infections occurred in the region. HIV infection in this part of the world is largely due to HIV-1 and the predominant mode of transmission is heterosexual contact<sup>2</sup>

In Tanzania, the first AIDS case was reported from the Kagera region in 1983. This case was serologically confirmed two years later (1985). Twenty years after (2003), the overall prevalence of HIV infection among blood donors was 8.8%. Using estimations and projections package (EPP) and the spectrum model developed by WHO, it was estimated that 1,810,000 PLHA in Tanzania. Similarly, it was estimated that only 1 out of 14 AIDS cases was reported. Hence, a total of 187,940 cases are likely to have occurred in year 2003 alone. The estimated annual AIDS-related deaths in Tanzania for the year 2003 were 186,900<sup>2</sup>

Since the advent of Highly Active Antiretroviral Therapy (HAART) in 1996, the overall morbidity and mortality among HIV infected people with access to ARV has markedly decreased.<sup>3</sup> In Tanzania, the availability and use of antiretroviral can be traced back to late 1990s. However, only rich patients – most of whom had relatives/friends abroad or were in contact with local physicians/pharmacists – could access ARVs. Beginning in the year 2000,

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<sup>1</sup>United Nations, UNAIDS/WHO report of 2003. AIDS epidemic update.

<sup>2</sup>Dar es salaam, Tanzania, City of. Ministry of Health GoT report of NACP, HIV/AIDS/STI surveillance, 2001

<sup>3</sup> Palella, F. J, Delarz, K. M, and Moorman, A. C. Declining morbidity and mortality among patients with advanced HIV infection. NENgJ MED. 1998; 338:853 – 860.

the availability of ARVs in the local market relatively increased, coupled with decrease in price and uncontrolled prescriptions.

In collaboration with development partners, the Tanzanian government initiated the scale up of care and treatment for PLHA in the year 2002. Activities included preparation of treatment guidelines, development of curriculum and materials for training of facility-based health care providers, development of facility assessment tool as well as developing the monitoring and evaluation system. Ninety one health facilities at various levels and types were assessed, certified and finally accredited by the Ministry of Health (MoH) [currently Ministry of Health and Social Welfare (MoHSW)] to pilot the HIV and AIDS care and treatment programme. The facilities selected included referral, regional, district, faith-based, military and private hospitals. The first training of health care providers from the first 32 accredited facilities was conducted in October 2004 and started providing ART services in January 2005. By then, the national target was to roll out the programme to all hospitals allowing about 440,000 PLHA accessing ART by the year 2009. The key questions therefore become: 1) what strategies should the program put in place to monitor adherence to ART? 2) How could the program identify factors that influence adherence to ART? And, 3) what could be the subsequent program to improve the adherence among non-adhering ART clients?

Different methods and tools of assessing and monitoring adherence to ART have been in use in different parts of the world. These methods include: patient self-reports, physicians' reports, pill counts, pharmacy logs, direct observation treatment (DOT), medication event monitoring system (MEMS) and antiretroviral drug levels. Most studies of adherence use one or more of these tools. Surrogate markers, viral loads and CD4+ T-lymphocytes count, for instance, have been used to crosscheck the validity of these tools. It is within this context that this study, which is part of a larger project, was developed and conducted.

### **The problem**

One of the envisaged major threats to the programme roll out is the patients' adherence to the treatment. Adherence to the treatment can be defined as the extent to which a patient's

behaviors coincide with medical advice. Factors that influence adherence to ART may be classified into patient factors, treatment regimen, disease characteristics and health system related factors. Patient related factors include socio-demographic such as gender, ethnicity, age, employment, income, education and literacy; and psychosocial factors including substance abuse and social support and stability. Treatment regimen factors include pill burden, frequency of dosing, drug adverse effects and the type of regimen. Prospective studies of adherence to HAART have clearly demonstrated that large number of pills and regimen complexity are much more likely to affect HAART adherence.<sup>4 5</sup> Many ART regimens are comprised of an NRTI backbone (2NRTIs) and either a PI or NNRTI. A study conducted to compare HAART adherence between PI and NNRTI based regimens, showed that rates of non-adherence on PI based and NNRTI based ART were 50.5% and 37.9% respectively, and the difference was statistically significant ( $p=0.004$ ).<sup>6</sup>

Information from a number of sources has documented a direct relationship between levels of adherence and biological and clinical outcomes. Whereas the level of adherence to HAART is closely associated with suppression of the HIV viral load in plasma <sup>7 8 9 10</sup> (non-adherent patients being significantly less likely to achieve viral load less than 500 copies /ml.<sup>11</sup>), a relationship between adherence and disease progression was not established until recently<sup>12</sup>. In long term studies, it has been observed that optimizing early adherence in the early months of treatment is crucial to ensure long-term immuno-virological response in HIV-infected

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4 Gordillo, V, Debamoj, Soriamo, V, Gonyaley, and Lohay J. Socio-demographic and psychological variables influencing adherence to ARV therapy. *AIDS*. Sept 1999;10; 13(13): 1763-9.

5 Sherer, R. Adherence and antiretroviral therapy in injection drug users. *JAMA*.1998; 280-567- 568.

6 Trotta, M. Adherence to HAART is better in pts receiving NNRTI – based regimen than those receiving PI – based regimens. *AIDS* 2003; 17: 1099 – 1101.5

7 Mellors J, Munoz A, Giorgi J. et al. Plasma viral load and CD4+ lymphocytes as prognostic markers of HIV-1 infection. *Ann Intern Med* 1997, 126: 946 -954.

8 Bangsberg DR, Hecht FM, Charlebois ED. et al. Adherence to protease inhibitors, HIV-1 viral load, and development of drug resistance in an indigent population. *AIDS* 2000, 14: 357 -366.

9 Haubrich RH, Little SJ, Currier JS. et al. The value of patient-reported adherence to antiretroviral therapy in predicting virologic and immunologic response. California Collaborative Treatment Group. *AIDS* 1999, 13: 1099 -1107.

10 Paterson DL, Swindells S, Mohr J. et al. Adherence to protease inhibitor therapy and outcomes in patients with HIV infection. *Ann Intern Med* 2000, 133: 21 -30.

11 Molly, S. S, McKenzie, M, Mitty, J. A, and Flanigan, T. P. Enhancing Adherence to HAART: A pilot program of MDOT. *AIDS Read* 11(6): 317 – 328, 2001.

12 Kitahata, M.M., Reed, S.D., Dillingham P.W., Van Rompaey S.E., Young, A.A., Harrington, R.D., Holmes, K.K. Pharmacy-based assessment of adherence to HAART predicts virologic and immunologic treatment response and clinical progression to AIDS and death, *International Journal of STD & AIDS* (2004) 15:803-81.

individuals registered on highly active antiretroviral therapy (HAART) and recommended that priority should be given to interventions aimed to improve adherence in the early months of HAART.<sup>13</sup> It has also been reported that for every 10% decrease in adherence among patients receiving HAART, there is an 18% annual increase in mortality. In a cohort of over 1000 patients followed from the initiation of HAART, adherence (as measured by pharmacy refills) emerged as a major predictor of mortality.<sup>12</sup> The majority of deaths in the entire cohort were in the < 50 CD4 cell strata and occurred almost entirely among patients with adherence levels < 95%. On a more positive note, 50% of patients in the <50 CD4 strata and who were 95% adherent or higher achieved CD4 levels >200 cells/mm<sup>3</sup> after 30 months of follow-up. These data make it clear that adherence directly influences clinical outcome. Similarly, it is clear that even with late presentation of HIV disease, treatment can be effective if excellent adherence is maintained. Non-adherence to ART is likely to cause failure to the first regimen, posing a dilemma in places where options are limited.

Adherence to HAART in Tanzania is not known. However, there are a number of studies elsewhere showing moderate to high adherence. A study conducted in Southern Brazil among adults on ART, only 56.9% reported 95% or more adherence rate.<sup>14</sup> Findings in another study conducted in Spain showed good adherence (more than 90% consumption of prescribed pills) in 57.6% of patients on ART. In the US, it was estimated that the average non-adherence to ART ranged between 50 and 70%.<sup>15</sup>

Increasing or decreasing drug dose, as well as increasing or decreasing dosing interval, may have a major impact on drug interactions. The impact can be significant as most interactions are direct functions of drug concentration over time. This is especially true for metabolic inhibition and pharmacodynamic interactions.<sup>16</sup> In addition; non-adherence may cause

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13 Carrieri MP, Raffi F, Lewden C, Sobel A, Michelet C, Cailleton V, Chene G, Leport C, Moatti JP, Spire B; APROCO study group Impact of early versus late adherence to highly active antiretroviral therapy on immuno-virological response: a 3-year follow-up study. *Antivir Ther.* 2003 Dec; 8(6):585-94.

14 Pinheiro, C. A, Centeno, M.O, Leite, J. C, Drachler, M. L, Silveira, V.L. Self- efficacy expectation and adherence to antiretroviral therapy in HIV infected patients: A cross sectional study in Southern Brazil. *Int Conf AIDS.*2002 Jul 7-12;14:Abstract No. WePeB5846.

15 Chesney MA. Factors affecting adherence to antiretroviral therapy. *Clin Infect Dis.* 2000 Jun;30 Suppl 2:S171-6.

16 Celentano, D. D, Vlahov, D, and Coh, S. Self reported antiretroviral therapy in injection drug users. *JAMA.* 1998; 280:544-546.

unnecessary diagnostic and treatment procedures, produce adverse effects on the quality of medical care, consequently generating additional costs. As HAART is expensive in resource limited settings and has deleterious outcomes both for the individual outcomes (clinical and immunological deterioration) as well as for the community (development of viral resistant strains and an increased viral replication) non-adherence has the serious risk of reducing the public health benefit of HAART.

## **Rationale**

Since 2004, the Government of Tanzania has started implementing an antiretroviral therapy program among patients with HIV and AIDS at national level. While this program is in its infancy but expanding, it is essential to develop a tool that can be used routinely to assess the level of adherence and determine factors affecting adherence among patients on ARVs in the country. The argument is that early detection of poor adherence and associated factors will assist in developing strategies for improvement of adherence to ARV.

The development of interventions and strategies to achieve high adherence levels is not possible if the factors leading to poor ART adherence are not clearly studied in Tanzanian socio-cultural context. There could be many factors affecting adherence to ART including socio-economic, clinical, socially related factors, health system related factors and others. Unfortunately, very few studies have paid attention to this important component in the care and treatment of HIV and AIDS.

The known factors in other parts of the world may not necessarily be the same in the Tanzania settings. The high influence of the informal health sector (including traditional herbal medicine, spiritual healing, homeopathy, Chinese herbal medicine) may play a role to poor ART adherence in this country.

Understanding the level of adherence and the factors affecting adherence among patients on antiretroviral therapy is very important in successful management of HIV-infected individuals.

Identification of these factors and low rates of adherence will be appropriated by urgent measures to improve the level of adherence. The National guidelines for care and treatment of HIV and AIDS do not have a tool to assess adherence. It is expected that the results from this project will facilitate the development of a simple, user friendly and effective adherence measurement tool.

### **Broad and specific objectives of the study**

The broad objective of this qualitative study was to establish and document factors that influence the adherence to ART in Tanzania. Specifically, the study documented the experienced, actual and perceived socio-demographic and clinical factors enabling or limiting adherence to ART.

## **2.0. Methodology**

### **Study Areas**

This study was conducted in eight health facilities conveniently selected from the 91 facilities accredited by NACP to initiate ART care and treatment in Tanzania. The selection of the eight study sites considered the availability of laboratory facilities for patients monitoring including CD4 count and the accessibility of the health facility throughout the year. Similarly, facilities that had participated in a similar study were excluded from this study. In addition, facilities that had just started providing ART services or were not likely to have 70 or more patients on ART were excluded from the study. As a result, Bugando referral hospital, Kahama District Hospital, Oysterbay Hospital, TMJ Hospital, Morogoro Regional hospital, Masasi District hospital, Igogwe Mission Hospital and Muheza Mission hospital were selected as study sites.

Eight research assistants (RAs) competent in conducting qualitative research were recruited and trained for four days. During the training, the RAs were oriented to the study, refreshed on the use of qualitative methods to generate desired data and their responsibilities. Specifically, the RAs collected data from their respective sites: conducted and recorded interviews, FGDs,

and recorded observations conducted at each site. Each RA kept a filed book documenting all activities conducted and recorded emerging issues related to study. During the training, the RAs and the investigators pre-tested and finalized the research tools. The data collection process lasted for two weeks.

## **Methods**

A combination of the following qualitative methods were used to collect data need to meet the broad and specific objectives of the study.

*Focus Group Discussions (FGDs):* The plan was to conduct one FGD with members of the community (male and female adults aged 18 and above) residing within a distance of 5 km from the health facility. The aim was to generate community members KABP-related to HIV and AIDS and some factors that promote or limit adherence among patients on ART in their communities. Where possible, participants identified with assistance from the street or village authorities formed a group for discussion. The discussions were tape-recorded and RAs took notes and wrote expanded notes of each session on the same day.

*In-depth interviewing:* The plan was to interview all (four or five) health workers providing HIV and AIDS-related services at each facility. The interviews explored the health systems-related factors that influence ART adherence among HIV and AIDS patients on: the availability/unavailability of drugs and continuity of supply, staff conduct, presence/absence of other supplies, privacy and confidentiality, presence/absence of stigma, adequacy of pre-, post, and continued counseling and prescriptions, waiting time, health care providers' workload and relationships between the health care providers and the patients. Similarly, 20 patients on ART for more than three months who attended the clinic during the study were interviewed. Data generated from these interviews gave an insight of personal, health system and community-related factors that promote or limit adherence to ART among registered patients. In addition, 10 treatment supporters to patients on ART from each facility were to be interviewed to cross check information obtained from the patients and members of the community for the purpose of gaining a further understanding of some factors that affect adherence among patients on



ART. The interviews were tape-recorded and the RAs wrote a summary each of each session on the same day.

*Observation:* Each research sub-group was supposed to conduct two (one at the beginning and one at the end of the fieldwork) structured observations at each health facility included in this study. The aim of conducting observations was to record some issues that could have been kept a secret or taken for granted by the health care providers interviewed, but have an impact on the patients' adherence to ART. Similarly, data gained from observation helped to guide interviewing and probing during the data collection processes.

### **Problems encountered**

Several obstacles were accounted during the qualitative research process. First, seven days spent at each facility were too short to complete the planned work. For unknown or deliberate reasons, some facility authorities had not made any arrangements for this activity. Authorities for private health facilities in Dar-es-Salaam and Tanga, for example, claimed not to have received information/request from NACP to conduct this study and required more information from the MOHSW/NACP on the purpose of the study and whether they could reveal the sero-status of their clients. Claiming to abide to the National HIV and AIDS care and treatment guidelines, one of the facility administrators recommended to the sub-research team to randomly select HIV-positive patients for interviewing and find a space to conduct interviews. In some cases, some of the patients sent for interviewing had come for their results or had been on ART for less than three months. This situation meant spending a day or two before beginning collecting data and missing the number of intended interviewees.

Second, for the patients' convenience, some facilities do not have HIV and AIDS clinic days. As result, patients on ART walk-in depending on their health needs and their working schedules. Some employed patients, for example, sneak from work to receive treatment thus they had no time to be interviewed. This situation made it difficult for the research team to capture the required number of patients per facility.

Third, many clients had no treatment supporters, which made it impossible for the RAs to interview the pre-determined number of study participants in this category.

Fourth, some patients on ART were reluctant to be interviewed or recorded, which forced the research teams to spend more time at a facility to get a required number of interviewees at each facility. The RAs were forced to take short notes and write interview full report on the same day. This condition added workload to the RAs that was not in their TORs.

Fifth, some facility authorities did not allow health care providers to be interviewed. This situation limited the number of health providers interviewed per facility. However, interviewing the facility administrators two times provided required information.

The fifth limitation encountered was the language barrier. In some study sites –Kahama and Mbeya, for example, – some of the patients on ART interviewed did not understand Kiswahili. Since the RAs and the supervisors were not conversant with the first languages in the respective areas, translators identified with the support from the health facility managers or local leadership were used to facilitate the interview process.

Finally, the budget set for this part of the major study was too limited. Some of the field activities were not budgeted for. Communication (phone), remuneration for the interviewees, FGD participants and local guides/assistants, are examples of costs that the RAs and supervisors had to cover from their per-diems.

### **3.0. Findings**

#### **Characteristics of the study participants**

Initially, it was anticipated that 4-5 health care providers, 20 patients on ART and 10 treatment supporters would be interviewed. Similarly, it was planned to conduct one FGD with members of the community living within 5 km from the facility and conduct two structured observations at each facility studied. Due to factors like short time to arrange for FGDs, poor cooperation from the facility administration, community members being too busy to attend FGDs (urban

life) and poor cooperation from the local authorities, only four FGDs were conducted. A total of 131 patients on ART (50 males and 81 females), 20 treatment supporters (8 males and 12 females) and 23 health care providers (5 males and 18 females) were interviewed. All participants were aged 18 and above years. Table 1 summarizes the distribution of the study participants.

**TABLE 1: Study participants per site and category**

SITE	PATIENTS		SUPPORTERS		H/WORKERS		FGDs	
	M	F	M	F	M	F	M	F
BUGANDO HOSP	8	12	4	1	1	3	6	6
MOROGORO HOSP	9	11	0	1	0	2	1	5
KAHAMA HOSP	8	12	1	4	1	3	0	0
MASASI HOSP	5	15	0	3	1	6	3	3
MUHEZA HOSP	7	13	2	2	1	1	0	0
IGONWE HOSP	8	12	1	1	1	1	7	3
TMJ HOSP	2	1	0	0	0	0	0	0
OYSTERBAY HOSP	3	5	0	0	0	2	0	0

In total, 208 individuals (80 males and 128 females) participated in this study. All the patients interviewed had been on ART for a period of between 3 and 36 months. With the exception of sites in Dar-es-Salaam (Oysterbay and TMJ hospitals) and to some extent Bugando, all patients started and were getting services from the same station. No patient reported to have been on ART before. Interviewees gave a wide range of interwoven factors that enable or limit patients to or not to adhere to ART that could be categorized in the following sub-groups: the individual, health systems and community as presented below. It should be noted, however, that the magnitude of each factor varies with levels and location/context.

### *The individual level*

The majority of the participants in this study mentioned that patients who have effective treatment supporters are more likely to adhere than those who do not have treatment supporters. The treatment supporters remind the patients to take the ARVs at the right time and consistently even if there are other health problems affecting the patient, prepare food for the patients, going back to the facility for refill or treatment of OIs/other health problems, provide support when the patients fall sick or have other health problems, discourage them from engaging in risk behaviors (drinking, having sex, working too hard or becoming pregnant) that could jeopardize their health and sometimes conducting their economic activities. One patient who has a treatment supporter reported,

My husband knows that I am HIV-positive ... He supports me in several ways ... He is my [registered] treatment supporter ... reminding me to take my medication as suggested by the health workers ... He escorts me to the hospital and takes care of me ... He has assured me that he will not leave me alone (Interview, Igogwe, Mbeya, February, 2007).

Similar views were expressed during the FGD in Masasi, where one of the participants reported that “patients who had disclosed their sero-status had treatment supporters and relatively good social support than their counterparts (FGD, Masasi, February, 2007).

The relationship between the patients and the treatment supporters varied greatly. Some patients mentioned their spouses, friends, uncles, village home-based health care providers, spiritual leaders or a fellow patient on ART to be their treatment supporters.

Interviewees observed that patients who do not have treatment support are less likely to adhere to ART because: once they become weak/sick they fail to follow instructions provided by the health care providers; others become unable to go back to the facility for refilling or treatment of IOs and other health problems or may lack social support that makes them frustrated and finally despair. The majority of the patients on ART interviewed had no treatment supporters, although each patient had someone registered at the facility as his/her treatment supporter. Interviews with the health workers at one of the private for profit health facility commented

that “patients are not required to have treatment supporters to be eligible for ART” (Interview, Dar-es-Salaam, February, 2007).

However, a patient interviewed in Mbeya stated that although she had no treatment supporter, she never misses her dose or engage herself in risky behaviors. She said,

There is no way I can stop taking the ARVs ... I know ‘they [ARVs] are my life’ ... I know that if I don’t take them [ARVs] as instructed or engage myself in risky behavior, I’ll soon die ... I don’t like dieing before my children finish primary school ... I have [an alarm] clock that reminds me when I should take the ARVs (Interview, Igogwe, February, 2007).

Another factor that enables patients to adhere to ART mentioned was the ability of patients to disclose their sero-status. Health care providers interviewed at Morogoro Regional hospital noted that patients who have effective treatment supporters show better adherence than their counterparts. One health care provider explained that “treatment supporters remind the patients to take the drugs or come to the facility for the refill if the patients are unable to ... and provide them with physical, psychological and social support that allow them to abide to ART ... Patients who do not have them [treatment supporters] lack this assistance and are thus less likely to adhere” (Interview, Morogoro, February, 2007).

Poverty was another factor mentioned by the majority of the study participants interviewed. The following quotations suffice to give light on what the study participants meant when they used the term “poverty” or *umaskini* in Kiswahili. A patient interviewed at Kahama District hospital had this to say,

I have seven dependants [children with different fathers] and I’m jobless ... I have to work hard to feed them ... Given that I’m weak, I can not produce enough food ... Sometimes I let the children eat while I sleep on an empty stomach ... The counselors tell us that we should eat before taking the drugs [ARVs] ... In this situation I do not take the drugs ... If I do, I’ll become weak and weaker ... However, whenever I have food, I take the medicine as advised (Interview, Kahama, February, 2007).

One of the FGD participants who is on ART in Morogoro commented,

The major reason why patients do not adhere to ART is the lack of food ... Majority of the patients in this area are unable to get balanced diet as recommended by the health care providers ... The community has no support to PLHA ... The drugs [ARVs] are so strong that you can not take them on an empty stomach ... If one has no enough food, can not take these drugs [ARVs] ... That is why we formed an association to take care of our problems ... We cultivate and sell vegetables ... Each one of us has a share to take home on the daily basis ... We bank the money we get and spend some to take care of our members who are unable to support themselves ... We sometimes foot the funeral and burial costs for our group members (FGD, Morogoro, February, 2007).

Participants in the FGD conducted in Masasi suggested that PLHA should be assisted getting “balanced diet” from locally available foods. One participant observed,

The question of eating enough and balanced food discourages poor patients from using ARVs ... Patients hope that the government or the donors should provide them with balanced diet as the ARVs ... Health care providers and those involved in educating patients on nutrition need to be oriented on how to use locally available foods for balanced diet. Patients need to be educated that what they produce could provide them with balanced food as recommended by the health care providers ... Well trained counselors could resolve this problem ... Once a person knows that s/he is HIV positive, gets confused and despair ... However, the government should provide assistance to PLHV who have spent all their resources seeking for cure so that they could establish income generating activities, which could reduce the orphans burden shouldered by our communities ... Two things are important. One, the government should increase the number of health workers responsible for providing ART services alone at each facility... Two, there is need to introduce stand alone facilities for treating HIV&AIDS related health problems (FGD, Masasi, February, 2007).

A male patient interviewed in Mbeya (Igogwe site) expressed how poverty restricts his adherence to ART in the following manner:

My village is about 18 km from this hospital [Igogwe] ... It costs Tshs 3,000 one way ... That means Tshs 6,000 whenever I visit the hospital for treatment ... Sometimes, I find it difficult to raise this amount, I have to walk [to the health facility] ... It takes me about three to four hours to get here ... When I’m weak or sick I do not show up and thus missing my drugs for some days (Interview, Igogwe, February, 2007).

A female patient interviewed in Mbeya had another perspective of how poverty limits her adherence to ART. She narrated,

Poverty limits my effort to change my behaviour ... I am used to drinking and having sex with different partners ... That is why I have two children with different fathers ...

One is living with his father ... The other partner refused to take his daughter because he found out that I had sexual relationship with another man ... I have been on ART for two years now ... They [health care providers] advise me not to indulge myself in risky behaviours [drinking and having sex] but I have failed ... I am poor ... I need money to take care of my child and myself ... So, sometimes I drink and sleep away from my house [with *mteja* or sexual customer] without taking the drugs for a day or two ... I appeal to the government to provide PLHA with loans/capital so that we can start small scale business that would facilitates changing our lives and behavior (Interview, Mbeya, February, 2007).

Another factor limiting patients to adhere to ART mentioned was traveling (on business or visiting relatives). Study participants observed that some of the patients fail to carry ARVs with them when they travel or spend longer time out of their station. A health care provider interviewed in Mbeya noted “that they run out of drugs, which makes them not to take drugs as recommended” (Interview, Mbeya, February, 2007).. However, two of the patients interviewed in Morogoro and Mbeya reported that traveling is not a problem; they always carry and take their drugs and make sure that they are back on time for the next appointments.

Some patients who have been on ART for a year and above reported that they have been taking ARVs for a longer time but not cured. Their concern was when will they regain their “normal” health conditions or they should wait for death. “If this is the case, why should we suffer ... These drugs are so strong ... You need to be rich to adhere to the directives they [health care providers] give us ... I am afraid, the drugs will kill us ... not HIV or AIDS ... Sometimes, I give myself a break [not taking the drugs] ... When I find it necessary I take them [ARVs] for some time (Interview, Mbeya, February, 2007).

One of the questions asked to the patients on ART was to what extent does the presence of other people restrict them from taking the ARVs? Patients who had disclosed their status to member of the family, community or were members of PLHA associations reported to have no problem taking drugs even if there were people they do not know. One participant in the FGD conducted in Morogoro confidently stated that “I have declared to the public that I am HIV-positive ... Members of our community know it ... I do not worry about the presence of anybody when I want to take my drugs ... We are encouraging all PLHA to take our example ... They should disclose their status so that they could get support form different sources”

(FGD, Morogoro, February, 2007). However, two patients reported that they fail to take the drugs in the presence of other people whom they would not like to know that they are HIV-positive. A male patient interviewed in Morogoro reported,

One time I had visitors at my house who stayed for three days ... I had a lot of problems taking my medicine [ARVs] ... I hope you know the setting of the rooms we rent ... I have a bed room and a sitting room ... I had no way out ... I skipped a three days' dose (Interview, Morogoro, February, 2007).

Three born-again patients (two females and one male) interviewed in Mbeya reported that they stopped taking ARVs since they joined the Jehovah Church, where, Jesus is perceived/believed the only answer to all problems. A story from a female patient interviewed demonstrates how health seeking behavior and practices limit the adherence to ART. She reported,

I have had serious stomach pain for years ... I underwent medical checkups and received treatment from this hospital [Igogwe] but the problem persisted ... I decided to go to traditional healers [three of them] ... Again, the problem remained intact ... In January 2005, I fell very sick and I lost much weight ... My mother decided to take me to the hospital [Igogwe] ... I was told that I was HIV-positive and qualified to register for ART ... After six months, I recovered ... I was advised by my relatives that I should seek spiritual treatment from a Jehovah Pastor in our area ... We believe that Jesus is the only cure of all problems we face ... Most of the time we pray and fast ... I stopped taking the ARVs for the period I was with this church. However, in December last year (2006), I fell sick ... became too weak to attend church services ... I was admitted at this hospital [Igogwe] for two weeks ... The doctors changed my medication, which I am now taking each day as directed by the health care providers ... I have decided to combine the two treatments [medical and spiritual] ... I have no intention to return to the traditional healers ... They have no cure but stealing people's money ... (Interview, Mbeya, February, 2007).

This quotation suggests that pressure from family members, relatives, church and community members could influence patients' ability and capability to adhere to ART.

Several patients, treatment supporters and health care providers interviewed reported that some of the patients skip doses whenever they get side effects like stomachache, diarrhea, dizziness, loss of appetite or when they are using medications for treating OIs and other health problems. One of the patients recalled that at the beginning of the treatment she lost appetite and had diarrhea after taking the ARVs, conditions that forced her to skip doses until she felt better. A health care provider interviewed in Masasi stated that "some patients fail to adhere to ART



after developing OIs or other conditions like dizziness, mental illness, diarrhea, headache or vomiting, which they associated with the ARVs” (Interview, Masasi, February, 2007).

Stigma is still rampant among members of the community surrounding the health facilities studied, which limits patients’ adherence to ART. Patients identified two types of stigma: from the community members and from the health care providers. On the one hand, patients, treatment supporters and members of the community interviewed had mixed perceptions of health care providers’ stigmatization and discrimination of PLHA. Majority of the informants observed that the health care providers were so friendly and supportive. For example, a patient interviewed in Dar-es-Salaam said that “all health care providers at this facility are supportive and they care for us [PLHA], they listen to us carefully, provide us with enough information that helps us to adhere to the treatment” (Interview, Dar-es-Salaam, February, 2007).

However, a few informants claimed that some of the health care providers stigmatize and sometimes discriminate PLHA. None of the health care providers reported that they discriminate or stigmatize PLHA. For instance, one health care provider interviewed in Muheza emphasized that “we know that PLHA should be handled carefully ... We provide them services in a friendly manner without discrimination” (Interview, Muheza, February, 2007). Another health worker interviewed in Morogoro claimed that “we give our patients proper counseling, some patients have accepted and coped with the disease and ARVs are for free ... These and other factors enable them [patients] to have high adherence rates” (Interview, Morogoro, February, 2007).

On the other hand, all of the interviewees reported that the majority of family and community members still discriminate PLHA. In their perspective, stigma forces individuals not to seek VCT services and those who have tested HIV-positive fail to disclose their status, which interferes with their coping process and hence limiting their adherence to ART. A female patient living with her uncle in Mbeya reported,

My uncle used to support me ...He bought me food, gave me the bus fare to and fro the hospital [Igogwe] and supported me whenever I was admitted ... Three months ago, he told me that I should leave his house and go back to my village ... My mother, a retired civil servant, is poor ... She can not take care of me ... My uncle says he has become

aware that I was *malaya* or a prostitute that is why I have this shameful disease [HIV&AIDS] ...He claims that I have been exhausting his resources and he is ashamed of taking care of me ... In fact, he says I have lowed his dignity among the community members ... (Interview, Mbeya, February, 20007).

The research sub-group that collected data in Kahama noted that some patients and treatment supporters interviewed were unable to speak or understand Kiswahili. The researchers, therefore, used local translators to facilitate the interviewing process. This observation suggests that some patients and treatment supporters who do not understand Kiswahili fail to comprehend messages communicated to them by the health care providers. In turn, patients fail to adhere to ART.

The patient's ability to track the trend of his/her CD4 count was identified as one of the factors that influence adherence to ART. This study, therefore, intended to document whether patients on ART were aware of their CD4 count and what it meant to them. Majority knew their CD4 incremental and decremented changes (good number with increasing CD4 count), which encouraged them to take the drugs as recommended by the health care providers. A patient who has been on ART for two years interviewed in Mbeya quoted earlier reported that her CD4 count was so low (54) when she registered on ART. The counselor told her that she was in a 'danger zone'; she had to start taking ARVs. By the time of this study, her CD4 count had increased to more than 600. She added,

My health has improved tremendously ... As I am speaking to you [the researcher], I have been able to run my business that enables me to take care of my family [a husband and four children] ... As I said earlier, the ARVs are my life ... The problem is the men who want to have sex with me despite my effort to inform them that I am HIV positive ... They are always on my neck ... Could you [the interviewer] advise me on what I could do to avoid them? (Interview, Mbeya, February, 2007.)

However, patients who had been on ART for a period of between three and eight months or less had checked their CD4 count only once, thus were unable to respond to this question. Majority of the patients and their treatment supporters were unable to respond to this question because they did not know their/patients' CD4 levels. It suggests that the patients and their treatment supporters were unaware of this important element of ART. This is a red flag to the effectiveness of communication between health care providers and their clients.

### *Health systems-related factors*

The study participants were asked to mention some of the health systems-related factors that promote or limit adherence to ART. On the average, public health facilities provide HIV&AIDS related services two days per week (Tuesdays and Thursdays) from 8.00 am to 2.00 pm. However, all health providers interviewed reported that often the facilities remain open till 6.00 pm depending on the number of clients seeking services. It was noted that private facilities allow walk-ins (without appointment) while public facilities are strict to the fixed timetable. It was reported by health care providers that clients who experience health problems were free to seek the doctor on any day. Similarly, it was reported that patients who show serious conditions are given priority; they do not have to wait in a queue – the emergency triaging and treatment (ETAT). One patient interviewed in Mbeya observed that this was a good practice and an indicator that the health care providers care for them. She said,

We are very thankful to our doctors and the nurses ... They are so considerate in their work ... A patient in serious conditions will be taken right away to the doctor's room ... Majority of us feel relieved when this happens ... However, some of the patients do not like it ... They complain that they have similar problems and have been waiting for long time ... In their perspective, they want a 'first in, first saved' approach should apply ... You know that we are not all the same (Interview, Mbeya, May 2007).

Health care providers were asked a question “what happens if patients’ appointment (treatment or refill) falls on a public holiday?” All health care providers interviewed reported that they use a calendar to eliminate the problem of patients coming to collect medications on such days.

Patients, treatment supporters and health care providers interviewed reported that client flow at the facilities depends on the number of patients at the facility, the availability of health care providers (who have to fulfill their regular responsibilities before serving in the HIV&AIDS clinic) and the health condition the patient is in. Patients with OIs or other health conditions spend more time at the facility than those who do not have such problems. On the average, the reported time spent at the facility ranged from 10 minutes and several hours. One patient interviewed in Mbeya, reported that “the time I spend at the facility varies with visits ... On some days, I spend about 15 minutes and on other days it may take up to 7 hours or more (Interview, Mbeya, February, 2007).

The study participants reported that the duration on ART was a factor contributing to the longer time spent by the patients at the health facilities. Beginners were reported to spend longer time than their counterparts at every point in the clinic. Patients observed that the longer the time the patient spends at the clinic had a negative impact to their adherence to ART. Majority of the interviewees recommended that the government should allocate sufficient health care providers responsible for providing ART services at each facility.

Shortage of ARVs, OI treatment drugs and other supplies (laboratory reagents, for example) were reported to be common among the public facilities than the private sites studied. Clients served by private facilities reported that there has been no shortage of ARVs, OI treatment drugs or other supplies. Public health facility managers interviewed in Morogoro, Masasi and Kahama stated that they order supplies from the Medical Stores Department (MSD) through the district authorities as recommended by MoHSW. The problem is that in most cases, MSD, the only government trustee to import and distribute health-related supplies in the country, runs out of stock of supplies ordered. To get the supplies, therefore, the district has to re-order, which leads to delays and unnecessary shortages at the region, district and facility levels. In their opinion, the government should allow districts to identify and use alternative supplier(s). One facility manager remarked “we are in the era of free trade and globalization ... For MSD to function effectively, it should compete with other suppliers” (Interview, Kahama, February, 2007).

Assurance of privacy (physical, visual and audio) and confidentiality to the patients increases chances of good adherence to ART. The interviewees were asked to evaluate the capability of the health facility and health workers on these issues. Majority of the interviewees, the patients and the treatment supporter in particular, were comfortable with the privacy and level of confidentiality at their respective facilities. One patient interviewed in Masasi, for example, stated,

We are satisfied with the level of privacy and confidentiality at this facility ... Everything concerning our treatment is kept a secret between the patients and the doctors [doctors and nurses] ... We follow the same procedures [for example, same reception and pharmacy, recording weight] like other outpatients, we have separate doctor's room(s) and we are attended by health care providers who are so friendly (Interview, Masasi, February, 2007).

A health care provider interviewed at the private facility in Dar-es-Salaam confidently reported “patients’ information is a top secret at this facility. Only the health care providers dealing with HIV&AIDS have access to the patients’ record” (Interview, Dar-es-Salaam, February, 2007). An administrator of another private health facility in Dar-es-Salaam claimed that the MoHSW’s guidelines for ART recommend that HIV&AIDS care and treatment providers should ensure privacy and confidentiality to their patients. In the facility administrator’s view, the researchers’ request to interview patients on ART would mean that the health care providers have disclosed their status, which would compromise with their professional ethics. She, therefore, recommended that the researchers should pick interviewees randomly until they got a number of interviewees need for the study.

Data from observations conducted at the private health facilities in Dar-es-Salaam show that although the facilities provide HIV&AIDS-related services two days a week, the majority of the patients come at their convenient time. The health care providers at these facilities interviewed said Dar-es-Salaam residents have different lifestyles and working schedules that would make them unavailable for the treatment/consultations on Tuesdays and Thursdays. This arrangement, therefore, is meant to increase adherence among patients on ART served by these facility.

However, a few patients and members of the community were suspicious that some of the health workers leak patients’ information. During the FGD conducted in Morogoro, one participant reported that he had witnessed a health care provider revealing identities of patients he had attended on that day. Adding, “Although I do not claim that all health care providers do so, it is true that some of them disclose patients’ sero-status that could lead to stigmatization, separation and discrimination” (FGD, Morogoro, February, 2007).

Similarly, during the FGD conducted in Masasi, participants observed that there is no confidentiality at the health facility because it treats all types of venereal diseases (gonorrhoea and syphilis), cancer and HIV, which paves way for patients not on ART to recognize PLHVA. One participant was concerned that some of the health workers leak their sero-status adding,

“Health care workers at this facility talk about their patients’ information that make us feel scared of testing ... I’d better go to a facility in Dar [Dar-Es-Salaam] or Arusha rather than testing here [Masasi] (FGD, Masasi, February, 2007). A patient interviewed in Mbeya observed that “everyone knows the location of the doctor treating HIV&AIDS-related health problems ... Hence, it is easy for the people to know that you are suffering from HIV or AIDS if you are queuing to enter that room or when you are walking out” (Interview, Mbeya, February, 2007).

Observation data collected at Mwananyamala (during the pre-testing of tools in Dar-es-Salaam) and one private health facility in Dar-es-Salaam, show that files for patients on ART have a different color (yellow) from those of other outpatients’ files. Hence, curious people could associate the file color and the location of the doctor to be seen with the health problem facing the patient. A patient interviewed at one facility in Dar-Es-Salaam stated “the level of privacy and confidentiality is so poor ... One can conclude on your sero-status just by the color of the file ... Why don’t they use files of the same color for all patients?” (Interview, Dar-Es-Salaam, February, 2007).

Health care providers observed that the room allocated for their activities are so small, few unfurnished, too old, not soundproof and very few. In this situation, it is easy for other people to overhear and even see what is going on in the doctors’ and counseling rooms. A private health facility studied in Dar-es-Salaam, for instance, had no specified room for the counselor! Similarly, it was observed at two public health facilities studied that at some point there were two doctors or counselors in one room. In addition, it was observed at all facilities studied that the level of interference (physical or phone calls) during counseling or consultation sessions was high. In a combination with other factors, this situation compromised privacy and confidentiality, which contributes to the low quality of services provided.

Many of the health facilities studied did not have CD4 count machines. Facilities that had the machine it had low capacity, with technical problems or had broken down. In this situation, the health workers have to send blood samples to the nearest facility that has the CD4 count machine. Health care provided caught in this situation reported that it takes about a week or so

to get the results, which creates delays in registering qualifying patients on ART. A health worker interviewed in Kahama commented, “Some patients fail to understand why we do not give them ARVs on the first day ... As a result, they do not come back for the results and some either die as they wait or seek alternative healing services” (Interview, Kahama, February, 2007).

As stated earlier, the some of the patients interviewed who have been on ART for more than six months knew their CD4 incremental and decremented changes (a good number with increasing CD4). Those who have been on ART for less than six months had checked their CD4 level only once. A few said that they were waiting for the second test results.

Patients and their treatment supporters were asked to comment on the usefulness and effectiveness of the information provided by health care providers regarding ARVs ad ART. Data collected show that the health care providers communicate verbally to the patients and the treatment supporters. Information provided includes the importance of consistently taking medication on the right time without fail, the number of pills to be taken each time, taking ‘balanced diet’, date and time for the next appointment or refill and the likelihood of developing side effects. In addition, the health care providers remind their clients that they should come back to the health facility whenever they experience any health problem(s). The interviewees were satisfied with verbal information provided. However, one patient who has been on ART for two years observed,

At the beginning of the treatment doctors provided me with written information that enabled me to adhere. Nowadays, they give us information verbally ... Sometime, I forget what the health care providers tell me, which makes me fail to take the drugs effectively ... I am sure that written information would help me to remember the doctors’ instructions (Interview, Mbeya, February, 2007).

A health care provider interviewed in Masasi put it clear that,

We provide written information to patients recently registered on ART ... We communicate verbally with patients who have been on ART for sometime ... This information includes facts on the effectiveness and ‘strength’ of the medication, when to take the drugs and the need for completing the dose after CD4 checkup ... Medicine containers are labeled ... indicating name of the drugs and time to take them (Interview, Masasi, February, 2007).

Patients on ART and their treatment supporters were asked a question: “which additional information about ARVs and ART do you need?” On the one hand, patients who had been on ART for less than one year were concerned with the short time they spend with the doctors and the counselors such that they have no opportunity to ask questions they have regarding ARVs and ART. An observation made by a patient interviewed in Bugando suffices to represent other patients with similar views. She said,

You know [the interviewer], this facility serves many patients ... Our doctors often attend more than 100 patients a day ... They get tired ... In this situation, we spend short time with the counselors and the doctors ... we have no time to ask question ... We listen to what they have to tell us ... I would be glad to be able to ask as many questions as I could every time I go to the health facility (Interview, Bugando, February, 2007).

On the other hand, patients who had been on ART for more than one year asked, “How long will it takes to get cured”? (Interview, Masasi, February, 2007). “For how long shall we have to take these medications?” (Interview, Bugando, February, 2007). “Why do side effects vary among patients?” (Interview, Morogoro, February, 2007). “What health problems are likely to affect an HIV positive female who becomes pregnant?” (Interview, Mbeya, February, 2007).

All of the health workers, the counselors in particular, interviewed complained of the heavy workload they shoulder at their respective health facilities. A counselor interviewed at Muheza hospital, for example, said, “We attend 70-80 patients on clinic days ... sometimes more than a hundred” (Interview Muheza, February, 2007). A nurse/counselor working in the HIV&AIDS clinic interviewed in Mbeya reported that the health workers at that facility are required to fulfill responsibilities in their respective units/wards beginning at 7.30 until 9.00 am prior to attending patients in the HIV&AIDS clinic. Adding,

By the time I get to the clinic [HIV&AIDS care services], I am already exhausted ... The patients are already on the queue for some hours waiting for our services ... Sometimes, the patients and their treatment supporters fail to understand why we do not start offering services at 7.00 am ... Our clinic is open till 3.00 pm ... However, my experience has been that we often work until 6.00 or 7.00 pm ... We are currently receiving patients who have different counseling needs beyond our training ... We often find it difficult to counsel patients like the drug addicts, prostitutes or alcoholics ... We need refresher trainings to cope with the changing nature and needs of the clients we attend ... In the past, we had frequent supportive supervisory visits from the NACP and the regional level ... The frequency of their visits has been so low such that



we have no one to present our complaints to ... We are experiencing burnout due to various factors ... The facility administration considers counseling a secondary responsibility ... I'm not remunerated for HIV&AIDS counseling ... The administration declared that 'counselor' is not a staff cadre in the health system [MoHSW] (Interview, Mbeya, February, 2007).

A quotation above supports the observations made at every facility that all health care providers in the HIV&AIDS clinic were recruited from different departments at the same site. This means that working in the HIV&AIDS clinic is an additional workload to the already overburdened health workers. In addition, it was reported and observed that the majority of the counselors experience different levels of burnout, which need to be established through research and hence, develop intervention programs to control this problem that jeopardizes the quality and equity of HIV&AIDS services provided in the country.

This study sought to understand the extent to which the training on HIV&AIDS facilitates or limits the provision of quality and equitable health care. All health workers interviewed had undergone training (at different times and duration) conducted and funded by the MoHSW through the NACP, among other things, the training focused on topics like the health care provider-patient relationship (the does and don'ts when attending HIV&AIDS patients), type of medicine to administer to each case and information to provide, counseling (for counselors) for behavioral change and coping with the health problem, testing for HIV, the importance of referral service and the overall management of the HIV&AIDS services. All the health care providers admitted that the trainings they underwent were very useful; enabling them to work confidently.

However, the health workers had some reservations regarding the training programs offered in their fields. A nurse/counselor interviewed in Mbeya quoted earlier, commented as follows,

As you might be aware [the interviewer], ART services have scaled up ... to groups and sub-groups that had not been identified when we were trained ... the prostitute, drug addicts, discordant couples, children, the disabled ... other groups will surface, seeking for our services ... the homosexuals and lesbians, for example ... We have no skills to attend such people ... However, we use our working experience to face this problem ... It is sad to mention that the 'technical know who' approach is often used to select who goes to which training! Non qualifying personnel are selected to attend such trainings ... I get surprised to hear that someone [fellow employee] is attending a certain training, which I qualify and should be attending ... We have health workers at

this facility who have two traveling bags ... they are always away attending seminars, workshops or meetings of all kind even if they do not qualify ... If you are not one of those ... you never get an opportunity to advance your skills ... I don't know if NACP is aware of this situation ... (Interview, Mbeya, February, 2007).

Generally, the health care providers interviewed recommended that the MoHSW and the NACP in particular, should ensure that eligible health care providers attend these trainings and not otherwise.

Health care providers, who participated in this study, were asked “to what extent do you perceive yourself to be at risk of being HIV infected in the course of providing services to your clients?” A majority of the participants reported that they take precautions and operate very carefully. They do not perceive themselves to be at risk because they are trained on how to protect themselves. Whenever they have doubt, they use preventive creams, prophylaxis or take post prophylaxis exposure drugs. Reporting on what happened to one of the health workers at Bugando hospital, an interviewee said,

One nurse accidentally pricked her finger while attending a patient who had all symptoms of HIV&AIDS [had developed OIs] ... She was very scared ... She used prophylaxis; but she was not contented ... She tested for HIV ... Thank God, results showed that she was negative. She is waiting to have a second test next month ... She always reminds us to be careful so that we do not experience the hard time she is currently going through (Interview, Bugando, February, 2007).

Another health care provider interviewed in Masasi observed that “We [health care providers] are at risk of getting infected because one might have bruises on the hands ... as you attend the client you might get infected. There should be a system that allows us to test our sero-status every three months and the government should pay us risk allowance” (Interview, Masasi, February, 2007).

### *Community level*

Each participant in this study was asked to discuss some of the socio-cultural factors existing in their communities that promote or hinder adherence among patients on ART. The majority observed that stigma, which is still rampant among community members is the major factor

limiting PLHA from adhering to ART. Further analysis of interview and FGDs data collected on this issue; indicate that fear for stigma could be understood at three levels: the individual, the family and the community levels.

a) *Community level*: most members of the community know that AIDS has no cure and that it takes a long time to “kill” (reducing him/her to a skeleton) an infected person. As such, AIDS is a stress to the sick person, relatives, and health service providers. Sometimes, some care givers argue that it is a waste of resources caring for a person who will eventually die (Barnett and Blaikie, 1992). Data from in-depth interviews and FGDs conducted for this study show a similar pattern in the studied areas. A female patient interviewed in Mbeya and comments from FGDs conducted in Morogoro and Masasi, for instance, indicate that in the early days of the outbreak of HIV/AIDS, members of the communities perceived and labeled PLHA “deviants” from the traditional and religious sexual norms and their treatment a waste of meager resources available. Many of the community members used to claim that “they [deviants] had to shoulder their own burden; “paying the cost of their unaccepted sexual behaviors and practices” (FGD, Masasi, February, 2007). As a result, some members of these communities isolated, rejected or segregated PLHA, which had two implications. On the one hand, fear of being stigmatized by the society restricted individuals from seeking VCT services available in their areas, which caused delays in registering eligible patients on ART. On the other hand, individuals who had tested HIV-positive kept it a secret, which led to the lack of social support (treatment supporters, for example), effective follow-up by the health system and the rapid spreading of the disease within and among communities.

With the exception of communities in Morogoro, which have allocated land for PLHA groups to grow vegetables for their consumption and generating income to supplement treatment costs, none of communities studied had formal support to PLHA. One participant in the FGD conducted in Masasi claimed “we know there are people on treatment [ART] ... However, we do not know their treatment needs ... It is a secret to their families and friends” (FGD, Masasi, February, 2007). Another participant made it clear that “we are all poor ... We can not afford two meals a day for our families ... How do you expect us to support other families’ members!

... In my view, the government should provide patients on ART with enough food ... otherwise their ability to adhere will remain questionable” (FGD, Masasi, February, 2007).

Deeply-rooted religious beliefs among some communities, in Mbeya in particular, were reported to limit patients from adhering to ART. Interviewees and FGD participants reported that some of the religious groups – that have mushroomed in the region – perceived HIV&AIDS to be a punishment from God due to their wrong behaviors that violate God’s commandments. In their view, God is the only solution to every problem, including HIV&AIDS. Hence, turning to God for the cure is mandatory. In the same perspective, individuals who suffer from HIV&AIDS should be “born again”, “fast” and “repent” as a curative process.

As indicated by some interviewees and FGD participants, the wide spread religious beliefs have resulted into two points that are crucial to this study. On the one hand, some potential patients for ART decide to seek spiritual healing before seeking VCT services. They do so when they are too weak to recover. Once such patients die, it justifies the “claim” that ARVs can not cure AIDS. In the case of patients who recover and return to their respective Churches, the claim remains the same “Jesus has the power over all powers” (Interview, Mbeya, February, 2007). On the other hand, patients on ART may be pressurized by family members, friends or religious leaders/staunch followers to abandon ART and seek spiritual healing, which could result into non-adherence-related problems.

It is known that traditional healers (THs) continue to play a big role in providing health care among African societies. This is true because few Africans have access to quality (western) medical services (Fako, 1985) and that some “perceived” illnesses have no biomedical explanations or cure (Kamazima, 2003). With this information in mind, interviewees and FGDs participants were asked to explain the role of THs in their respective communities regarding the treatment and cure of HIV&AIDS.

Data from in-depth interviews show that some patients on ART and other members of studied communities seek treatment of HIV&AIDS and other health problems from the THs, a

reflection of different health seeking behavior and KAPB on HIV&AIDS. They do so for two main reasons. First, “they perceive sorcery a cause of the ‘health problems’ facing them ... not HIV&AIDS,” claimed a health worker interviewed in Mbeya. In her view, “Problems perceived to be caused by sorcery are attended by the THs ... not the medical doctors” (Interview, Mbeya, February, 2007). Second, data from interviews suggest that there are THs who claim to have cure for AIDS. “They advertise their services on the radio, road signs, and newspapers ... some live as far as Dar-es-salaam ... which attracts people who are desperately looking for a solution to their health problem(s) (Interview, Mbeya, February, 2007).

However, majority of the interviewees and FGD participants observed that the situation has gradually changed. FGD participants in Morogoro, for example, observed that there is light at the end of the tunnel! The outbreak of HIV/AIDS and its impact to the society has forced individuals, families, groups and communities to have open discussion on sexual behavior and practices. This is reflected by the perceived changes in sexual behaviors and practices of most members of the communities. A treatment supporter interviewed in Kahama observed that “There are very few people in this area who still believe that THs could treat HIV or AIDS ... They assist us solving other problems but not this one [HIV&AIDS]” (Interview, Kahama, February, 2007).

b) *The family level*: It is scientifically known that the main mode of HIV transmission in Africa is through sexual intercourse. Hence, most members of the society conclude that individuals (the adults) who have AIDS committed adultery or had sex before marriage (FGD, Morogoro, February, 2007). The fear to be associated with deviant sexual behaviors in the family and the community, limits some individuals from seeking VCT services. At the same time, those who have tested HIV positive keep the results a secret from their spouses/partners/significant others for fear of separation or marriage brake-ups. A female patient interviewed in Mbeya quoted earlier stating that her partner had run away from her after finding out that she was HIV positive and on ART, is a vivid example. It further suggests that patients on ART may fail to disclose their status to family members, which could deny them important social support needed for ART adherence. In addition, the fact that health seeking behavior is greatly influenced by the context within which the decision is being made, pressure from family

members who perceive spiritual or traditional healings to be important, might force eligible or patients on ART to go for alternative treatment approaches. In the due course, patients on ART might fail to adhere.

c) *Individual level*: Fear of being rejected, joked or labeled “unfaithful in the marriage/relationship”, “a sex maniac/promiscuous” or the one who “brought” HIV&AIDS in the family/community, limits some individuals from seeking VCT services available in their areas. At the individual level, there are two sub groups that could be distinguished as: 1) patients who tested HIV-positive and, 2) those who have not sought VCT services. On the one hand, some individuals who have tested HIV-positive and are on ART struggle to cope with the situation and the reactions they receive from members of the communities and families. A patient interviewed in Morogoro quoted earlier reporting that he had problems taking ARVs in the presence other people, sheds light on this struggle. In addition, patients who had not disclosed reported (and were reported) to fail taking medication when unfamiliar people were around.

On the other hand, individuals who have not tested fear being marginalized, discriminated, divorced (for those married) or rejected by their families and members of the society once they tested HIV positive. In the view of one of the health workers interviewed in Mbeya quoted earlier, the failure to seek VCT causes delays in registering eligible patients on ART, which could lower the level of adherence.

#### **4.0. Discussion**

Findings from this study show that there are a number of factors that in a combination of some sort enable or limit the patients from adhering to ART. The influence of any factor could vary with individual patients, level of support received, location and time. Patients who report that lack of bus fare to and from the health facilities, hence missing appointments; would overcome this problem if quality HIV&AIDS services were provided at the nearest health facility in their areas. A use of mobile centers could assist health care providers to reach patients in the rural and hard to reach areas. Similarly, clear instructions/communication from

health care providers to the patients regarding the treatment regimen and nutrition are important in supporting adherence. For example, the issue of “balanced diet” needs to take into consideration locally available foods. Patients should be informed how they could get balanced diet from locally grown and available foods rather than imported food. This could improve the level of adherence among patients who perceived that to be “poor” to buy “recommended” diet and thus not taking the ARVs as prescribed. In addition, the provision of written information and in first languages where clients and treatment supporters cannot comprehend Kiswahili, could contribute to adherence among clients on ART.

Patients’ demographics – gender, level of education, income and personality – did not seem to have significant influence on adherence. In other words, patients in all categories reported to adhere or not to adhere. This observation concurs with the evaluation of findings from studies conducted on adherence that attributed non-adherence to one or more of these characteristics, “but in fact the accuracy of predictions based on these variables is no better than chance” (APA, October 30, 1997; HRSCareAction, May 2005). The point here is that professionals and health care providers should never attempt to predict which patient will adhere to the ART regimen and who will not. On the one hand, patients judged by health care providers unlikely to adhere to their medications (the substance abusers, alcoholics, MSMs, lesbians and prostitutes, for instance) would receive services of low quality. On the other hand, health care providers are likely to overestimate adherence to ART of patients they judge to be compliant. In turn, such patients out of a desire to please health care providers would over-report adherence (HRSCareAction, May 2005; Poppa *et al.*, 2003).

The National HIV&AIDS treatment guideline recommends that for a patient to be registered on ART, s/he should have a treatment supporter. It was envisioned that choosing a treatment supporter would enable the patient to disclose and have social support that would increase adherence to the medication. However, this study found out that majority of the patients had no treatment supporters; others had names and addresses of persons (some who did not exist) registered at the facility but did not support them at all and very few patients had treatment supporters functioning as recommended. This situation was reported and observed at all facilities studied. Two observations could be made. First, the health facilities’ administration

do not abide to the HIV&AIDS treatment guidelines, which opens room for non-adherence to the whole process of HIV&AIDS care and treatment at the facility level as indicated in this report.

Second, it is clear that the condition that requires patients to have treatment supporters to qualify for ART is important but not sufficient to predict high levels of adherence. The argument is that the National AIDS policy, HIV&AIDS treatment and care guidelines, the health system and care providers should be able to establish and pay attention to factor(s) influencing or impeding adherence for each patient rather than making generalizations. Patients should be provided with all necessary information including benefits of disclosing to enable them to make informed choice whether to or not to disclose. Certainly, this approach might seem to be difficult to achieve in terms of time, personnel and money that will be needed. However, if this approach is integrated into the HIV&AIDS care and treatment system it could improve patients' adherence to the regimen.

Similarly, the majority of the health workers interviewed observed that patients who disclose their sero-status are more likely to adhere than those who do not. However, data collected for this study do not support this claim. Some patients who had not disclosed reported to adhere and vice versa. Again, this observation calls for the consideration of multi factors that influence adherence among patients on ART. Stigma and discrimination was cited as one of the hindrances to adherence that both health care providers and community need to address. The patients feel being discriminated by the health care provides while health workers deny it. Education on stigmatizing actions and language is important for both groups. Patients reported that they feel free to take their drugs in an environment where they are accepted and supported. In addition, further research is needed to identify types and levels of stigmatization and discrimination among health workers and members of the community toward the PLHA.

As indicated earlier, HIV&AIDS are stressful diseases. Patients who have been on ART for a long time reported to have been tired of taking the drugs and wanted to know how long will it take them to get cured. This finding signals the fact that living with HIV can interfere with adherence to therapy and other health promotion behaviors. In fact, other studies have shown



that “individuals who are experiencing depression or psychological distress tend to be less compliant with treatment” (APA, October 30, 1997). This study, unfortunately, could not establish the level of stress among the interviewees. Therefore, there is an importance of conducting a study to determine whether psychological stress or depression contribute to non-adherence among patients on ART in Tanzania. It suggests that there is a need to review the process of preparing patients for ART. A patient who expects to be cured after a certain period might not perceive ART as a life long treatment.

Health seeking behavior and practices of PLHA is a result of several interwoven factors: the individual patient, family members, relatives and the environment within which the decision is made. Pressure from family members, the community, peers or personal choice play a big role in the course of medication patients on ART choose to undergo. As indicated by findings from this study, by virtue of their choices or pressure from community members, some patients combine ART and other alternative healing services – spiritual and traditional, for instance – available in the community, which in turn interferes with the adherence to ART. In addition, it is clear from this study that the perceived ineffectiveness and the experience with the health system in the study areas adds salt to the wound, providing a justification for some patients not adhering to ART.

Several studies on knowledge retention, performance and the ability of trained health care providers to abide to the working guidelines have concluded that heavy workload, poor supportive supervision (Ozek, et al, 1998; Latman, 2004; Chaudhary, et al, 2005); poor motivation (Valadez, et al, 1997); lack of drugs and other supplies, lack of retraining (Woollard, 2006) and lack of continuing education/communication among trained health influence the health care providers’ ability to offer quality and equitable health care services. This study captured similar factors. HIV&AIDS activities are shouldered by already overburdened health care system. Whenever there is a big number of clients, health workers are forced to spend less time with the clients, which some patients perceive as discrimination or poor client-practitioner relationship. Lack of drugs and other supplies causes delays in providing services to potential clients, increases unnecessary referrals, which increases the ART-related costs and may force clients to seek alternative healing services that could

compromise their adherence to ART. Lack of training and refresher courses on new developments in the HIV&AIDS care and treatment denies health care providers confidence when performing their duties. However, improved follow-up/supportive supervision, reliable supply of drugs and other supplies, frequent trainings and feedback to all levels could help keeping the health care providers motivated and facilitated to perform their duties as expected.

## **5.0. Conclusion**

Indeed, it is clear from this study that factors influencing patients' adherence to ART in Tanzania are interwoven and should not be taken as a one-to-one function. In other words, health care providers should not judge their patients' ability to or not to adhere by certain characteristics. For example, it should not be taken for granted that a well-off appearing patient will adhere to the regimen than a patient who appears to be poor. Likewise, a patient who has a registered treatment supporter (who may not exist or is ineffective) may have low adherence than a patient who has none. Having other mechanisms, an alarm clock, for instance, to remind the patient when to take the drugs could facilitate adherence among the patients on ART.

Similarly, the effects of each factor seem to vary with an individual, location, context and time. In this context, some patients and members of the community reported poverty to be a limiting factor among the majority of the patients. However, the meanings of "poverty" in this context vary with individuals and communities. To some, poverty means the lack of "enough food" let alone "balanced diet." Other patients and members of the community describe poverty to be the inability to meet treatment-related costs like faire to and from the health facility, time spent walking to the health facility or time spent at the health facility and in most cases on empty stomach. Yet, others interpret poverty as the lack of money to meet other needs for an individual person and immediate dependants.

In addition, it should be noted that an enabling factor to one patient could be a limiting factor to others. The ability to note changes in one's physique, health conditions and being able to continue with income generating activities, for example, was reported to be a factor that encourages some patients to adhere. However, to some, an improvement in health conditions

warrants them to return to their lifestyles – alcohol drinking or having sex – which jeopardizes their adherence.

Finally, it is vivid that some behavior-related factors would take a long time to change for the effective adherence to ART among registered patients. There is a need to conduct more research works on each agenda that seems to limit adherence and find client-friendly means to reinforce positive behaviors and practices with regard to adhering to ART. However, health system-related factors documented in this study could be rectified and have a positive influence on adherence. The following section provides some recommendations made based on the study findings and experience from other parts of the globe.

## **6.0. Recommendations**

1. Further research is need on some issues emerging from this study. Information to be generated could facilitate Phase III (Intervention) of this project:

- a) The increasing stigma towards PLHA by the health care providers and its impact on adherence to ART.
- b) Strategies to reduce waiting time at the clinic. That is, how to increase client flow at the ARV outlets? Negotiating with the clients on ART appropriate time for refill or for next appointments could be one of the approaches.
- c) What strategies could be used to keep health workers providing HIV & AIDS-related services motivated as a mean to reduce the level of burnout observed among them and movement from the rural and hard-to-reach areas of this country?
- d) Determining the types and levels of stigma among the community and health workers towards PLHA.
- e) Establishing strategies of appropriate and effective way of coordinating HIV&AIDS activities at all levels to reduce confusion and workload currently shouldered by HIV&AIDS health care providers.

2. Evaluation of the messages and models used in training health care workers and counseling PLHA on the ‘nutritional food’ to be taken by patients on ART. It appears the messages

models present “balanced food” food as understood by medical practitioners, eating the whole fish or half a kilogram of meat, one liter of milk and vegetables. The messages and models used therefore, should be in patients context and communication materials be localized rather centrally produced. In turn, this approach could overcome the perception of lack of quality food due to poverty as a hindrance to ART adherence. Patients should be encouraged to identify nutritional food from the locally grown crops.

3. Effort should be made to make ARVs available to patients in the rural and hard to reach areas of this country. The assessment of health facilities in rural areas for refills is highly recommended. Village health workers or community/home based care workers could be trained to provide refill services in their areas. Furthermore, equipment need for the provision of HIV&AIDS-related services – the CD4 count machine for instance – should be made available to the district facilities. This strategy would reduce the waiting time ART potential clients have to wait before registering.

4. Frequent supportive supervision visits should be implemented at all levels. NACP staff should be able pay one supervisory visit to each facility at least twice in a year. These visits should be used to identify factors enabling or limiting the provision of quality and equitable ART services as per guidelines. Supportive supervisors should give feedback to all levels, which should, in turn, be used in the planning for future activities.

5. NACP should plan and conduct training programs (initial and refresher trainings) for health workers providing HIV & AIDS-related services. Whenever possible, training curricula should include new developments in the HIV & AIDS care and treatment – handling the most at risk groups, discordant couples, overcoming burnout and counseling patients who have been on ART for more than one year. It should be mentioned here that qualifying staff should be given a priority to attend these training programs. Follow-up supportive visits should be conducted regularly to ensure quality control.

## References

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