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Barriers to ARV Adherence among HIV/AIDS Positive Persons taking Anti-Retroviral Therapy in Two Tanzanian Regions 8-12 Months after Program Initiation

Stephen ED Nsimba[1]*, Henry Irunde[2] and Christopher Comoro[3]

[1]The University of Dodoma, Prospective College of Health & Allied Sciences, School of Medicine and Nursing, Tanzania
[2]Ministry of Health (MoH), Tanzania Food and Drugs Authority (TFDA), P.O. Box 77150, Dar-es-Salaam, Tanzania
[3]Dept of Sociology, College of Education, Mkwawa, Iringa, Constituent College of the University of Dar es Salaam, P.O. Box 35043 Dar-es-Salaam-Tanzania

Abstract

The purpose of this study was to measure adherence and to identify specific factors facilitating or constraining adherence to anti-retrovirals (ARVs) among HIV/AIDS patients. A cross sectional study on ARV adherence was conducted in two Tanzanian regions, Arusha and Dar es Salaam, in June and July 2005, involving 7 healthcare facilities in these regions. A multi-disciplinary team of researchers collected the data from two populations: the ARV users and the health care providers. The data was collected from the ARV users through exit interviews, semi structured interviews, adherence measures, focus group discussion and key informants interviews. From the health care staff, the tools used were semi structured interviews, observation of staff conducting consultations, and pharmacy stock check-ups. A total of 207 ARV users were studied, 26 observations were made, 28 health staff were interviewed, 8 focus group discussions and 10 key informant interviews were conducted, and 6 pharmacy stock checks were done in healthcare facilities.

Results from the qualitative discussions, individual as well as institutional factors contributed to non-adherence. For many food, long waiting time, transportation, social supports, lack of education about anti-retroviral therapy (ART) or ARVs, lack or inadequate counseling, drug related side effects, and even knowledge about AIDS were barriers. Structural impediments such as stigma by untrained hospital care workers towards clients, over worked health care staff, and lack of space for confidential consultations, lack of availability of diagnostic and laboratory equipments were also sited as barriers. However, according to health staff, adherence was interpreted to mean using medicines as prescribed, at the right time and at the correct dosage, and attending the facilities as scheduled for follow-up checks.

Many patients are appreciative of the government and of the health care workers involved in the programs. Yet, close attention and adequate supplies and resources to overcome the external barriers and attempts to try to mitigate the internal negative social determinants which prohibit adherence are needed. Unless due attention is paid to the critical issue of adherence, the emergence of drug-resistance will be accelerated and the expected early treatment achievements could be reversed.

Keywords: ARV/ART; Adherence; HIV/AIDS; Food, Hunger; Stigma; Arusha; Dar-es-Salaam; Tanzania

Introduction

In Tanzania, Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS) remains a significant problem with an adult prevalence rate of 8.8%. The concern is not only a major public health issue, but also a socio-economic and developmental crisis that affects all sectors of the population. In light of this, the Tanzanian Government began disseminating free antiretroviral therapy (ART) in 2004. However, there has been no documentation of anti-retrovirals (ARVs) treatment adherence and possible contributing factors to non-adherence. In this study, "adherence" is taken to mean compliance to the demands of ART/ARV. Considering that the drugs calls for routine administration and compliance to be effective, adherence is necessary. Ability of the patients to both consistently take the drugs without fail at exactly or approximately the same times of the day depends on the individuals' frame of mind, his/her family members support, as well as people around them and the community at large. Routinely taking ARVs can be cumbersome and also not easy to live with, follow or remember.

Adherence is described as engagement and accurate participation of an informed patient in a plan of care [24]. The concept of 'adherence' has a broader meaning than compliance which encompasses the extent to which a patient follows instructions, implying understanding, consent and partnership. It also includes entering into and continuing in a programme, or care plan, notably, meeting appointment and tests as scheduled. Adherence to treatment encompasses more than adherence to medications and ARVs [24]. In poor countries adherence can be a problem for a number of reasons. Yet studies have shown no significant difference in adherence between resource-limited and resource-rich countries, which suggests that patients in all environments have trouble taking 100% of their pills. It is therefore recommended worldwide that all ARV programmes should have a concurrent plan for adherence assessment and support [24,25]. 'Near perfect adherence' should be defined as 95% and above adherence. While the government

***Corresponding author:** Dr. Stephen ED Nsimba, DDS, MSc, PhD, Certified in Substance Abuse, Care, Treatment, Prevention & Research Policy, The University of Dodoma, Prospective College of Health & Allied Sciences, School of Medicine & Nursing P.O.Box 259 or 395 Dodoma-Tanzania, East Africa, Tel: 255-713-318113/786-318113; Fax: 255-26-2310005; E-mail: nsimbastephen@yahoo.co.uk

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and other players are determined to increase accessibility to ARVs, specific initiatives to promote adherence to ARVs need to be in place to ensure correct ARV use at all levels, including community levels in Tanzania.

Psychological factors, including drug abuse, alcohol addiction and mental health problems such as depression, have been associated with low adherence in HIV positive adults and adolescents as have other psychological variables such as perception of one's ability to follow a medication regimen, or self efficacy [7,20,27,28] . Beliefs about health and illness, in particular about the necessity of medication towards the illness and concerns about its potential adverse events, have been found to be influential in both HIV and other disease areas [9,10].

ARVs are only effective if the patient adheres strictly to the regimen. Medications must be taken everyday for the rest of the patients life and the correct dose must be taken. Normally a patient takes 2-3 drugs in daily dose in order to avoid developing resistance to one single drug. Alcohol not only reduces the effects of medical treatment but also puts individuals at risk of contracting and/or fuelling HIV and AIDS. It is not easy to understand that alcohol consumption may influence negatively a person's capacity to follow up a strict medication regimen. Intoxication be it on single occasions or regularly, leads to reduced self-control and difficulties to follow-up on routines and duties. Furthermore, heavy drinking is often associated with a less regular life style and problems to follow up daily care, resulting in bad nutritional state and poor sanitation etc [30].

Thus, AIDS remains a significant factor in the social and economic development of many countries, specifically many in Sub-Saharan Africa (SSA). In Tanzania, East, the burden of HIV is second only to malaria with an estimated prevalence rate of 8.8% among adults [5]. Tanzania also has a significant antiretroviral therapy (ART) program. Because adherence to treatment is a critical factor in the success of ART, attention to all factors, such as external, structural factors and cultural, as well as internal behavioral and individual factors which could prevent adherence should be identified and addressed.

Study area

The study was conducted in two major commercial and urban areas of Tanzania: Arusha and Dar-es-Salaam. Arusha and Dar-es-Salaam regions were chosen because they had already been providing ARVs for at least 3 months at the time of the study. Moreover the two selected regions are located in different geographical areas. Arusha is situated in the north of Tanzania and has a population of 1,292,973. It also has a temperate climate. In addition, Arusha is a major tourist city attracting foreigners from Europe and America. It is nicknamed as the "Geneva of Africa" because it is the seat of many national and international conferences and meetings. Dar-es-Salaam is the current capitol of Tanzania and is in the coastal region with a population of 2,497,940 [22] Dar-es-Salaam is a coastal area that has a hot and humid climate. Of these two cities, Dar- es Salaam is a major commercial city in the country attracting many people from upcountry and outside Tanzania.

As of the early 2000s, Tanzanians living with HIV/AIDS have had increased accessibility to suppression of their virus through anti-retrovirals (ARVs). Many non-governmental organizations (NGOs) and the government are involved in providing thousands of free ARV medications. As of 2006, there were 25,300 people on ARVs treatment. As the country began to initiate a wider treatment effort, there has been a need for monitoring the level of adherence and maintenance of viral suppression. Patients on anti-retroviral therapies have been strongly encouraged to perform maximum, optimal adherence, at least 95% [8,23] because less than optimal adherence may result in medication viral resistance, thus causing decreased quality of life and progression to AIDS and death. Subsequently, patients will require regimen change which also increases treatment costs [2].

Figure 1: ARV adherence study sites shown by arrows and Map of Tanzania showing the study areas of Arusha and Dar-es-Salaam. Source of this map: Nsimba's PhD thesis, Karolinska Institutet, Stockholm, Sweden, Nov, 2003.

The importance of adherence and monitoring of levels in a population can not be more emphasized. It has been observed that medication non-adherence has been associated with increased secondary bacterial and parasite resistance in Sub-Saharan African countries. Studies have reported that many species of bacteria have developed resistance in developing countries where antibiotics are often freely available without prescription and often with uncertain or incorrect diagnosis [13].

In order for medications to have maximum beneficial therapeutic effects, adherence and proper patient prescriptions are key issues. The concept of 'adherence' has a broader meaning than compliance and encompasses the extent to which a patient follows instructions, implying understanding, consent and partnership. It also includes entering into and continuing in a program, specifically, attending scheduled appointments and tests.

In poor countries adherence can be a problem for a number of fully defined reasons listed in the research literature, i.e., lack of transportation, lack of food, and co-morbidities [11]. However, as later experience with antibiotics demonstrate, low adherence is not restricted to certain social classes but is widespread and unpredictable [12]. Research in the HIV field supports this perspective. Moreover adherence rates vary not just between individuals but also within the same individual over time [3] .Adherence is therefore best thought of as a variable behavior rather than as a constant characteristic of

an individual. Most people will exhibit low adherence some of the time [11].

Several factors have been attributed to low adherence, in particularly behavioral and psychological factors, including mental health problems such as depression. In many Sub-Saharan African countries even the perception of one's lack of ability to follow a medication regimen, or self efficacy affects outcomes [7, 20, 27, 28] . Moreover, cultural beliefs can also affect a person's adherence. In some instances, beliefs about health and illness, particularly about the necessity of medication to ward off illness and concerns about its potential adverse events have been found to be influential in both HIV and other disease areas [9,10]

The purpose of this study was to explore and examine behavioral and psychological factors related to adherence and non-adherence to ARV medication with the view of suggesting possible intervention measures to sustain or improve adherence. The study has thus targeted facilities where ARVs are known to have been provided for at least the past three months through various facilities.

Health care facilities

Seven healthcare facilities were chosen including public, and private/faith-based facilities which provided ARVs at least 3 months previously. In Arusha, four healthcare facilities were studied. These were Selian, St. Elizabeth hospitals (faith-based facilities), Mount Meru and Arumeru hospitals (public facilities). Selian is operated by the Lutheran Church and St. Elizabeth is run by the Roman Catholic Church. Both hospitals are located within Arusha City and are beneficiaries of the President's Emergency Plan for AIDS Relief (PEPFAR). The Selian hospital started the ARVs programme earlier in 2003, while St. Elizabeth started the programme in early 2005. Selian has already registered a total of 535 ARV users, of whom 353 were female and 182 were males. At St. Elizabeth hospital there were 299 (215 female and 84 male) ARV users. Community counselors were helping ARV users in Selian and St. Elizabeth hospitals. Mt. Meru, which is a Government regional hospital is located in the heart of Arusha City, while Arumeru hospital is located 15 kilometers out of the city and serves as a Government district hospital. While Mt. Meru had registered 344 (212 female and 132 male) ARV users, Arumeru had only registered 87 (42 females and 45males) ARV users. Both started ARVs program late in 2004 and are funded by the Government of Tanzania and the Global Fund. Some facilities in Arusha were not operating on a daily basis, leading to time constraints for the research team as well as for ARV users.

In Dar-es-Salaam, three healthcare facilities were studied, Mwananyamala, PASADA and Hindu Mandal hospitals. Mwananyamala is a public district hospital, located in Kinondoni municipality. PASADA is a faith-based hospital run by the Roman Catholic Church and is located in Temeke municipality, while Hindu Mandal is a private hospital located in the heart of Dar es Salaam, in Ilala municipality. It is owned and run by Tanzanians of Indian origin. PASADA and Mwananyamala started their ARV programmes in 2003 and 2004 respectively, while Hindu Mandal hospital started in 2002. Mwananyamala is a beneficiary of both the Government and the Global Fund, and is also a beneficiary of an HIV/AIDS project run jointly by three institutions: Muhimbili University of Health & Allied Sciences (MUHAS), Dar es Salaam City Council and Harvard School of Public Health (known as the MDH project) (Table 1and Table 2). Funding of study facilities is shown in table 2 below. In Mwananyamala hospital, the total number of registered ARV users were 1791 (females 907 and males 884). PASADA had registered 508 ARV users (364 females and 144 males) and Hindu Mandal had 178 ARV users attending.

Study Design

This was a cross sectional study design using rapid appraisal data for collecting both qualitative and quantitative techniques The study was conducted in 7 healthcare facilities in Arusha and Dar-es-Salaam in June and July 2005. A multi-disciplinary team of researchers collected the data from ARV users through semi structured interviews, adherence measures and focus group discussions. Key informant interviews were also collected as well as data from health care staff using semi structured interviews, observation of staff conducting consultations and pharmacy stock check-ups. However, sadly we never asked or collected important information related to mental illness; co-morbid drug and alcohol addiction among HIV infected patients and who were on ARVs in these 2 regions.

Study population

At the time when the study was conducted, it was estimated that 25,300 patients were receiving anti-retroviral therapy in Tanzania and now they should be more than that number. The study population included current ARV users who had been on ARV treatment for at least 3 months in two regions. Our sample was recruited from ARV users who were on treatment for three or more months in the 7 facilities from the two study regions. Thus, a total of 207 persons who were on ARV and who consented both verbally and in writing were included in the study. Furthermore, our study population also included few selected staff at healthcare facilities who were counseling, prescribing, and administering ARV drugs, such as nurses, doctors, and the pharmacists who were dispensing and stocking drugs. In addition, key informants were identified from communities where the ARV users were drawn and interviewed. Key informants included HIV/AIDS activists from non government organizations (NGOs), coordinators of HIV/AIDS programmes and representatives from local government.

Data collection tools

A combination of data collection tools were used to gather the information in this study. Tools used for data collection for ARV users were exit interviews, semi-structured questionnaires, adherence tool and focus group discussions (FGDs). These tools were originally developed at a multi-country workshop. Qualitative data were obtained using an observation checklist, focus group discussions (FGDs) and interviews with key informants. Adherence tools are instruments or equipments which were used to measure or collect different information related to patients ARV drug a intake on regular

Cadre of Staff (N = 70)	Nos. of patients who consulted with this category of health worker	Percentage (5%)
Counsellors	15	21%
Nurses	20	29%
Doctors	68	97%
Pharmacists	54	77%

Table 1: Shows different cadres of health workers consulted in the facilities for the 2 study regions as reported by ARV users during exit interviews.

Challenges	Number of respondents	Percentage (%)
Lack of incentives	26	93
Heavy workload	23	82
Inadequate training	20	71
Long waiting time for patients	12	43
Too few staff to attend these patients	11	39
Becomes too exhausted/tired	5	18
Seeing difficult clients or non compliant ARV users	3	11

Table 2: Challenges most frequently mentioned by health workers in the study facilities within the 2 regions (N = 28) when interviewed.

basis as prescribed or directed by a health staff. These instruments which were used in this study to measure adherence and how they were used are as described in annexes 1-5 and included:

- A two-day recall period, this measured the consistency of times respondents took their medicine over the previous two days using sun and moon charts.
- Visual analogue, whereby ARV users were asked to pour beads from one glass into another to indicate the number of pills they would have taken in a month. The remaining beads in the first glass were deemed to be the pills ARV user forgotten to take during the course of the month. Adherence was recorded based on the line marked from 0-10 on the first glass.
- Pill count method undertaken by the dispensing pharmacist. Numerator being pills supposed to have been taken subtracting missed pills and denominator being pills supposed to have been taken.
- Health workers assessment: They were asked to estimate the percentage of adherence of their ARV users in a period of not less than 3 months.

Data collection and analysis

Data was collected by the research team and research assistants. Research assistants administering the adherence measurement tools and exit interviews were trained and supervised by the study investigators. Research team members conducted 207 semi-structured interviews with ARV users, 28 staff interviews (5 medical doctors, 3 of them were managers; 9 nurses, 5 counselors, one of whom was also a social worker; 6 pharmacists, 1 dietician, 1 lab technologist, and 1 receptionist; 8 focus group discussions, 10 key informant interviews, 26 observations of consultation and 6 pharmacy stock checking. Review of meeting notes to share the daily experiences were conducted each evening. In addition, the principal investigator checked the completeness of the collected data every day. In order to maintain consistency, the same team collected data in both Arusha and Dar-es-Salaam regions.

Analyses were undertaken using both MS Access and EPI Info 2000. Descriptive analysis was done for the basic demographic characteristics. Means and standard deviation were calculated for quantitative data. FGDs were tape recorded and also hand notes were taken during the discussions by two MA students in their final year (second year from the University of Dar-es-Salaam). The discussions took place in a conducive friendly environment in which rooms were provided at health facilities and allowed the discussions

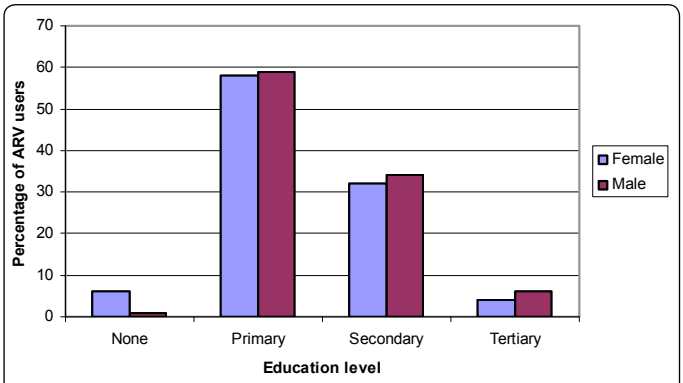

Figure 2: Sex distribution of the ARV users by level of education.

to be conducted peacefully and smoothly. These discussions were led and moderated by Dr Comoro (an experienced Social Scientist from the University of Dar-es-Salaam). In the two regions FGDs took between 60-90 minutes. For qualitative data, coding was done and was organized into different themes, and finally the data were summarized using themes. Furthermore, both translation and transcription of qualitative data was done by our experienced social scientist (Dr Comoro) where similarities and differences were elicited and captured. Methods used for estimating adherence included both ARV users` self assessment, health workers` patient assessment, pill count and visual analogue.

Results

Demographic characteristics consisted of 139 (67%) females and 68 (33%) males all were aged 18 years and above. The sex distribution of ARV users by level of education are presented in Figure 2. The majority of them (both sexes) had primary education around 58% and secondary education about 32% respectively. Of 139 females interviewed, 37% self-reported that they were not employed and 35% were business women and 28% were civil servants. Similarly, among the 68 males interviewed, the most prominent occupations reported were private employee and business owners, each of which constituted to 40% and the remaining 20% were civil servants.

The adherence practices or behaviours as reported by participants who were on ART /ARV to health workers of their routine taking medications at home is shown in Table 1. Furthermore, they reported use the following methods to remind them taking ARV medications as prescribed by clinicians which included: watches, radios and alarm clocks to remind themselves of medication times. There were few people who reported (n = 35/207) not take their medication at the correct times or as prescribed by clinicians/health staff. One Focus group participants described the behavioral problems associated with medication adherence as follows:

"These is a problem of adhering strictly to time and if you forget, it is a problem. (Female FGD, Selian Hospital, Arusha).

Lack of transport especially from remote areas was an additional challenge as expressed by one male:

"I once missed my scheduled appointment for refill because there were no buses or lorries coming or going that way and I waited on the bus stop for many hours but could not and decided to go back home" (Male FGD, Mount Meru Hospital-Arusha).

However, problems persisted in Tanzania even when treatment centres were locally close-by as explained by one respondent from Selian Hospital-Arusha:

"I was initially registered at KCMC in Moshi to start my ART. At that time there was no ART clinic near-by my home. Now there is one clinic nearby my home but I am denied to be transfered from KCMC to my nearby home clinic. Sometimes, I don't have the money to pay for my bus fare to go to KCMC which is located more than 170 kms".

The problem of long waiting time was cited as a major challenge to adherence in Tanzania. The mean time spent at the clinic was six hours. About half (12/28) of the health care providers interviewed reported long waiting times as a problem.

Food was cited as a problem among ARV users, although it did not significantly affect adherence. Both male and female patients said that drugs were increasing their appetite and they did not

have enough food. A male patient at St. Elizabeth hospital made the following comment,

"The problem I have with ARVs is related to food, I have no money and ARVs increases my appetite, I am not capable of buying food."

One key informant in Sinza, Dar es Salaam, said that some patients were selling freely obtained ARVs for food. According to FGD participants, lack of food was said to disrupt one's schedule of taking drugs, affecting adherence. Information related to food problems among users of ARVs was also corroborated by staff interviewed in health facilities. A male doctor in Arumeru hospital observed that:

"Food is a big problem, patients are getting appetite when they use drugs, but have not stopped using medication."

Another female FGD participant cited food as a factor for adherence. She observed that some patients take their doses at night because it is the time when they get food. This implies that food shortage can be a major drawback to adherence. As a result of this lack of food some patients reported to taking their ARV medications only once a day in the evening (instead of twice daily), because that is the only time they have food.

Participants also reported Stigma as one of their negative experiences they were facing including discrimination and lack of social support. Furthermore, some ARV users reported that after disclosing their HIV-positive status, they lost their jobs, some were abandoned by their families/relatives or were badly treated by their partners. As a result, some study participants often decided to hide their HIV status from colleagues, friends, relatives, neighbours and other peers and stated like this:

"I cannot take drugs when people are looking at me. I always go and hide when I take them, because once people see you taking ARVs they start whispering about you all the time".

The side effects most frequently reported by ARV users were body rashes, nausea, vomiting, headache, increased heart rate, diarrhea and swelling of legs. This occurrence of side effects was mentioned as an important reason for skipping ARV doses as quoted below:

"I had side effects and decided to take medications only once per day (Male FGD, St Elizabeth-Arusha)".

Although there were differences among the study settings, generally there was no difference in perceptions about HIV/AIDS between the different groups of informants. Key informants working in the community commented that ARV adherence was most threatened by lack of ARV knowledge. According to key informants, counseling was important to prevent attrition and enhance medication adherence. Although some key informants noted that beliefs of witchcraft associated with HIV/AIDS infection still prevail and reliance on traditional healing occurs, people have started gaining trust in ARV medicine and many patients are now attending clinics despite the crowded conditions.

One male patient from Arumeru said that he did not receive any counseling. Another male patient from Mt Meru hospital who claimed to have received some counseling but he could only remembered taking medication "due to fearsome instructions" he got from a Doctor that is "if you don't take medications as prescribed you will die". A female patient from a faith-based facility in Arusha reported that she was not told what would happen if she stopped taking regularly or as prescribed by doctors ARV medications. In Arusha, FGD participants expressed similar concerns on the frequency and quality of counseling. Participants at one male FGD reported that:

"You find 25 patients and only one person attending all these patients and he/she just tells you to go and collect your medication because she/he has no much time to spend explaining properly to you as others are also waiting to be served". (Male FGD participant, Selian, Arusha).

Heavy workload was mentioned by health care providers as one factor affecting adherence and quality of counseling provision since the scaling up of ART in Tanzania had occurred without any increase in manpower to cater for the increasing numbers of patients who are supposed to be on ARVs (Table 2). As a result health care providers are clearly overworked as they struggled to cope with the larger number of patients on clinic days. As some health workers said:

"You get overworked like this and you even don't get time to take a cup of tea (no time for tea break), as there are too many people coming to the clinic and yet we are very few".

Apart from health workers, none female participant FGD also commented on the large number of clients attending ART clinics as follows:

"If the situation remains like this, doctors and nurses will get tired and the last patient receives poor attention or gets no proper attendance".

Issues of disclosure and social support system

Out of 100 ARV users interviewed [exit interviews (70) and semi-structured interviews (30)], only 8 were living alone in a household. It was found that 94% of the 30 semi-structured interviewees who were on ARVs had disclosed with 83% of them receiving assistance on use of drugs, e.g. transport support, food and reminders to take drugs.

Still, from the interviews with key informants and focus groups participants, it was clear that stigma is still prevalent in society. There is stigma in homes affecting infected family members, as well as in places of work. This could affect both disclosure and adherence. According to a participant in a female FGD (Selian, Arusha)

"My utensils were put separate, including my spoon. All your belongings are not touched and you feel bad."

The situation for those employed in the private sector was worse as seen below:

"I was a driver, I lost my job when my relative went to tell my boss that I was HIV positive." (Male FGD Mwananyamala, Dar es Salaam).

"I lost my job after my boss noticed that I was positive." (Female FGD Selian, Arusha).

"I work in a drug store, I am told not to touch medicine because my hands have black spots and have been told that if customers notice, they will stop buying medicine from our store." (Female FGD Mwanayamala, Dar es Salaam).

"If I disclose I will be stigmatized, they look at us as if we are prostitutes. We are treated like leprosy patients." (Male FGD Mwananyamala, Dar es Salaam).

"Disclosure brings problems, you can lose business. Sometimes I am not invited to attend ceremonies because I have disclosed." (Female FGD, Sinza, Dar es Salaam).

At the other hand, some of the respondents indicated to receive some support as a result of disclosing:

"I have told my family and if the time of taking medication comes they remind me." (Male-FGD, Selian, Arusha).

"My husband knows my status and we are helping each other. We cannot disclose in a workplace." (Female FGD, Mwananyamala, DSM).

Lack of space for confidential consultations was also mentioned to be inadequate especially in Arusha facilities. However, one public hospital in Arusha had no separate rooms for consultation and thus, no confidentiality. At that time of the study, 3 doctors at this facility were sharing a single room and consulting with 3 different ARV users at the same time.

Three options for HIV/AIDS treatment mentioned were; traditional healers, religious healing and the use of ARVs. In spite of widespread information about the AIDS pandemic, the idea of be-witchment was still reflected in the perception of some patients. A few of them thought that AIDS was inevitable and that potentially every one was at risk of infection. In their perspective, someone with AIDS was destined to die.

Discussion

This study was conducted in order to identify possible barriers (factors) which constrain or facilitate (enhance) adherence to ARV treatment among HIV/AIDS patients and possible ways to improve adherence.

The study examined several factors (barriers) affecting adherence to ARV medications by interviewing ARV users, health staff, and key informants. Some of the factors mentioned to constrain adherence include stigma, poor social support, wrong beliefs on HIV causation, lack of food, side-effects, inadequate counseling, long waiting time, costs related to transport and long distance to the facility. Factors promoting and / or facilitating adherence include adherence counseling, disclosure to the family members, social support, religion, good chain of drug supply, information and education.

Despite obstacles to the implementation of comprehensive HIV treatment programs in Tanzania, the results of this survey indicate that there are so many factors which the National Aids Control Program (NACP) within the Ministry of Health has to consider them and take necessary actions when scaling up country wide ART for all persons to be recruited or who qualify to receive ARV drugs so that these people adhere strictly to medications as prescribed and dispensed to them for use in their homes. However, there was no self-reported differences in adherence to taking ARV medications as prescribed or required between males and females in our study groups or between the two regions. Similar observation was noted by DiMatteo in 2004, that adherence was generally unrelated to gender, education or socio-economic status

The relatively good adherence to ARTs reported in this study are possibly attributed to by initial efforts made by the Ministry of Health when they started training staff to run ART clinics before starting rolling out of the ART program country wide, free availability of ARVs, motivated staff and users, especially in these early days of rolling out. Rolling out of the programme by phases and availability of donor funds such as GFATM and PEPFAR have contributed to these early success.

However, there were serious concerns (barriers) which could lead to non-adherence to ARTs. For example some of the healthcare facilities we studied did not ensure adequate confidentiality for patients. The worst situation was where three doctors were sharing one consultation room. In situation like this, patients were less likely to communicate freely or even attend consultation visits. Also a major issue was waiting time. Patients spent an average of eight hours waiting for services. Long waiting time could have adversely affected clinic attendance and adherence. Having a more efficient appointment scheduling process and more available trained staff to balance the increasing workload would shorten waiting times. Many ARV users continue using drugs without proper checking of their CD4 counts, as well as liver and kidney function. Availability of laboratory services is important to monitor treatment response and adjust medications accordingly. Having to rely on other laboratory services meant patients had to return to the clinic for an extra visit, which only added to the clinic workload, long waiting times and costs the patients money in terms of bus fare, food and to some few patients who do not have relatives they need to have money for accommodation in hotels or guest houses within that region as they come far away. That means by the time they receive treatment or see a clinician most buses have left. Consequently, they are forced to spend a night in town.

Counseling was an important requirement for successful ARV adherence. At the initiation of treatment, patients receive the most intensive counseling. However once they were on treatment there was less counseling conducted unless there was a problem. Since is well recognized by Horne and others that adherence declines over time (Horne et al, 2001). Counseling should be conducted whenever patients visit the clinic. Thus, providing proper ARV counseling and support should be an integral part to adherence to medications. When patients come for medication refills, counselors are in a good position to evaluate medication adherence via pill counts and inquire about any problems. For patients with less than optimal adherence, counselors can advise patients on using various tools to remind them when to take their medications. Using alarms or having a "buddy" to remind the patient are possible solutions. If the patient has not disclosed that they are on treatment with ARVs, the counselor could suggest approaches to disclosing or assist with finding a treatment supporter.

Poverty in Tanzania is a serious problem that adversely affecting adherence. Many patients complained that the cost of food often precluded then from taking their medicine.

Some key informants, as well as ARV users themselves, confided that many patients on ARVs complained that these drugs cause hunger. Food shortages in the general population are therefore a serious setback. For instance, it has been reported that some patients are selling their ARVs for food. In some situations, patients were taking their ARVs only in the evening when they consumed their only meal. It would be important for clinics to collaborate with agencies that donate or make provisions for food supplementation.

Although ARV users received medicines free of charge, additional costs prohibited them from visiting the health facility for follow up and medication refills. These costs included travel costs, user or registration charges at health facilities and money spend on food while attending appointments. Other patients had to travel long distance to attend their appointments, and sleep near ART clinic, hence paying for the accommodation while waiting the clinic day. The costs associated with the ARV treatment far exceed the resources of ARV users. Eliminating or minimizing such barriers should be a routine part of the treatment package.

As general knowledge about HIV/AIDS prevails among ARV users, some patients apparently have none. As stated by a key informant:

"Education about HIV/AIDS is lacking in our society as some people don't accept even if they are found to be positive, they believe themselves to be bewitched". This view is supported by a similar contention, that: "Less educated people perceive the disease to be due to witchcraft".

Beliefs of being bewitched or of having a spell cast on them or of being afflicted by an AIDS devil/spirit (a 'jini') are commonplace, and they inhibit adherence to ART. More efforts are still needed to educate both community and ARV users on HIV/AIDS to eliminate those beliefs. For ARV users, adherence counseling is necessary for each visit to the clinics. Correcting misconceptions regarding HIV/AIDS can reduce stigma and thus, possibly create a more supportive environment for HIV status disclosure. Patients living in a more supportive and accepting family household and community are more likely to be adherent.

A study conducted by Sheri Weiser et al (2003), indicated that side effects did not pose a large barrier to adherence, 51% experienced some side effects but less than 10% of them reported side effects as a significant barrier to treatment. This was also noted by Akam AW et al [1]who found that very few side affects were noted or cited as cause of poor adherence (5%). In this study for a few patients, side effects did seem to affect adherence. For this reason, being informed about the side effect profile at the initiation of treatment, how to better manage them and the fact that they subside over time would be important information to communicate to patients.

There were some limitations in this study. Since most of the assessments were self report, observer or interviewer bias might have led to inaccurate reporting. The method of determining adherence rate in this study included self-assessment of ARV users and the literature suggests that patients tend to overestimate adherence (Chesney, 2000). Due to financial, logistic and laboratory constraints, we were unable to compare adherence rates with viral loads and CD4 cell responses. However, the strength of this cross sectional study was the use of a combination of different approaches (qualitative and quantitative) including respondents who were ARV users, health care staff and key community informants. Hence, these approaches are complex and makes interpretation of the data difficult and taking a long time. Furthermore, interpretation of these data needs to be carefully undertaken before arriving at particular conclusions because of the sample size and some differences in geographical locations between the two Tanzanian regions.

However, sadly this study never asked or collected important information related to mental illness; co-morbid drug and alcohol addiction (how many used alcohol while on ARTs) among HIV infected patients and who were on ARVs in these two (2) regions. As mental illness, co-morbid drug and alcohol addiction affects (compromises) seriously adherence among patients who are on ARVs leading to them skipping doses or not taking the drugs at all (poor adherence to ARVs). Hence worsening the prognosis of the diseases condition in AIDS patients as they require medication assisted treatment and or counseling. Not asking or collecting these important parameters (information) was because we faced both time and financial constraints which blinded us.

Despite the above cited study limitations, our study has strengths too. For example using a combination of different methods/approaches of data collection (i.e. FGDs, interviews, observations and key informants etc) and respondents permitted extensive triangulation of these methods which gave us more comprehensive type of results.

Conclusion

Despite barriers to ARV adherence, the overall self-reported adherence among recruited persons who qualified to receive ARV drugs in the two areas surveyed is encouraging. However, more effort is needed to achieve optimal adherence. Challenges such as lack of food, stigma and other operational limitations such as distance, bus fare, few ARV clinics, long waiting times, unreliable supply of ARVs in some facilities, staff shortages and low incentives for staff must be addressed. Provision of support to ARV users, including food, monetary supplements to offset the costs affiliated with ARV treatment and community education to reduce stigma. Continued and more intensive training for ART clinic staff is needed to more effectively manage ARV patient treatment. Furthermore, disclosure had both negative and positive effects on adherence.

Adequate adherence to ARV medications is very important for patients who are on ARTs. Without adequate adherence support, ART programmes will be faced in the near future with a high proportion of treatment failure and development of drug-resistance, together with a related increase in demand of second-line treatments which are more than 10 times more expensive than first-line treatments. Global donors, and governments/ministries through their national programmes need to emphasize the importance of treatment effectiveness and adherence in order to ensure that sustainability of current efforts to scale up access and availability of ART. Also future studies are needed to explore more about ART adherence among Tanzanian patients countrywide and should consider including mental illness, co-morbid drug and alcohol parameter assessments.

Our study examined several factors/barriers which could affect adherence. Some of the factors mentioned to constrain and/or complicate adherence include stigma, poor social support, wrong beliefs, lack of food, side-effects, inadequate counseling, long waiting time, costs related to transport and long distance to the facility. Factors promoting and/or facilitating adherence include adherence counseling, disclosure to the family members, social support, religion, good chain of drug supply, information and education.

Tanzania has made a good start in rolling out ARVs since October, 2004. By the end of 2006, the National Aids Control Program (NACP) within the Ministry of Health had already covered all 21 regions and 132 districts in Tanzania. There is wide-spread appreciation for the Government and health workers involved in the programme. The Government has established ambitious targets to be achieved or realized. However, unless due attention is paid to the issue of adherence, resistance to both first-line and second-line drugs will develop or be inevitable and this will reverse the expected early treatment achievements.

Based on the study findings here are some recommendations:

- **Institute pill counting**. Pill count will help to clear doubt that some patients are selling their drugs. However, be it may difficult to know whether they are throwing away the drugs instead of swallowing them. But still this is such an important adherence tool. In many facilities this system is not used. Public facilities in Dar es Salaam have started using it but the system is still weak, as many patients do not bring their drugs for counting on clinic days.
- **Employ adequate numbers of well trained staff**. More trained staff are needed to cope with increasing workloads in ART clinics. This will also help clients by reducing waiting times.
- **Increase the access to ART clinics**, as well as improving facility

infrastructures and laboratory services. This can be done both by increasing the frequency of opening of existing clinics and opening new clinics closer to where people live. Such clinics might be used to review patients who have initiated treatment at a larger hospital facility.

- **Establish reliable drug supply**. There were some feelings that drug supply is not yet reliable. Reliable drugs supply needed to be instituted as well as educating clients and providers that the supply chain is stable.
- **Create proper referral networks of ARV users between facilities**. Such a referral and transfer network should allow patients to be treated as close to their homes as possible with minimum waiting times and travel costs.
- **Train staff on adherence counseling and update** their HIV/AIDS knowledge continuously. This implies that not only pharmacists and dispensers have a responsibility for adherence counseling. Every one from clerk to nurse to doctor to counselor has a responsibility to encourage full adherence, recognizing how difficult it is for patients to maintain full adherence.
- **Train and support community** counselors who operate from their home (as seen in Arusha) The use of community counselors has been shown to be effective in other countries and in Tanzania. Creating training opportunities for such councilors and involving them in follow up and support of ARV patients should occur at every ART facility.
- **Prepare IEC material focusing on adherence to ARVs, stigma and disclosure**. These materials should emphasize that patients on ARVs need support to be fully adherent and that patients on treatment can be healthy and fully able to work or be employed.
- **Waive registration/consultation fees**. Registration and consultation fees should be waived for HIV/AIDS patients.

INTERVENTION	SPECIFIC TARGET	METHOD OF EVALUATION
Managerial	Institute drug counting Employ adequate staff Have reliable drug supply Initiate NGO for loans Increase ART clinics Improve transfer of users to nearby ART clinic Open clinics early and minimize clients' waiting time Avail more confidential consultation room	Number of clients bringing drugs for counting. Number of new staff employed. Availability of stable chain of drug supply. Number of NGO established Number of new ART clinics Number of users transferred to nearby ART clinics Number of clinics open on time Number of clinics with confidential consultation rooms
Educational: Training of provider	Update knowledge of staff Train on adherence counseling (emphasize on initial side effects) Training supportive staff to minimize stigma to clients	System to update staff knowledge in place. Number of staff trained on adherence counseling Number of supportive staff trained
Educational: Training of the public	Train community counselors who operate from home in Arusha Prepare IEC materials focusing on promoting disclosure and stigma reducing Conduct education through radio, TV and Newspapers	Number of community counselors trained Number and types of IEC materials prepared. Number of programs produced.

Table 3: The followings are the proposed interventions from this study.

- **Conduct intervention studies**. Intervention studies are recommended in order to sustain and promote adherence to ARVs. It is the wish of this research group to continue with intervention studies if funds are made available.

We finally proposed the interventions in Tanzania based on this small but very important study findings (Table 3).

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