WORKING PAPER

Attrition from HIV Care and Treatment Services in Tanzania

Magnitude and Reasons

August 2018

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CONTENTS

TABLES

ABBREVIATIONS

ART	antiretroviral therapy
ARV	antiretroviral
CHMT	council health management team
CTC	care and treatment clinic
HAART	highly active antiretroviral therapy
LTF	lost to follow-up
NACP	National AIDS Control Program
PLHIV	people living with HIV
RHMT	regional health management team
WHO	World Health Organization

EXECUTIVE SUMMARY

Background: HIV still ranks as the greatest public health challenge in the world. Treatment with highly active antiretroviral therapy (HAART) improves quality of life and reduces death among people living with HIV (PLHIV). Retention in HIV treatment is extremely important because it enables continued antiretroviral therapy (ART), diagnosis of antiretroviral drug (ARV) toxicities and treatment, and diagnosis and treatment of ART failure. Retention also allows continued social support and health education, helping people cope with the chronic illness and improving their adherence to ART. Because sustained participation is necessary for HIV treatment to be effective, understanding factors that govern participation—or lack of it—is vital to the work of MEASURE Evaluation, which is funded by the United States Agency for International Development (USAID) and the United States President's Emergency Plan for AIDS Relief (PEPFAR), to improve site-level health services.

Objective: This study aimed to determine the magnitude of attrition for PLHIV from ART, determine common types of attrition, and document reasons for poor retention in ART services—all to improve retention of PLHIV in ART. Note that "attrition" refers to anyone who is not retained in ART. Learning more about attrition is important for preventing it and increasing retention. By addressing this knowledge gap, this research contributes to USAID's goal of controlling the HIV/AIDS epidemic.

Methods: This study used retrospective record review and a cross-sectional study design involving PLHIV enrolled in treatment between 2006 and 2014 in two high-volume care and treatment clinics (CTCs) in MnaziMmoja Hospital (Ilala District, Dar es Salaam region) and Mkuranga District Hospital (Pwani Region).

Data analysis was done using the software STATA 13. Descriptive data analysis was used to determine the magnitude of attrition among PLHIV from ART and to describe baseline characteristics of the study population. Factors associated with attrition, and confounding factors, were explored through descriptive data analysis.

Findings: A total of 5,499 PLHIV initiated on ART in the two health facilities during the study period, January 2006 through December 2014. Most of those who initiated on ART were women (68% in Mkuranga District Hospital and 76% in Mnazi Mmoja Hospital) and were 15 years old or older (93% in Mkuranga and 91% in Mnazi Mmoja). Attrition was 0.9 percent in Mkuranga District Hospital and 19 percent in Mnazi Mmoja Hospital. "Lost to follow-up" (LTFU) was the most common cause of attrition cited in Mkuranga District Hospital (84%), whereas in Mnazi Mmoja Hospital, the most common cause of attrition was death (62%). The magnitude of attrition among PLHIV who initiated on ART gradually increased as the time after initiation on ART increased; 2011 had the highest attrition of all of the follow-up periods. Attrition was 26 percent at six months and 41 percent at 12 and 24 months. In both health facilities, the most common reason for stopping ART (among PLHIV on ART who were traced to their homes) was stigma at the clinic or community (37% in Mkuranga District Hospital and 64% in Mnazi Mmoja Hospital). Religious belief was the least common reason (5%) in Mkuranga District Hospital and lack of food (3%) was the least common reason in Mnazi Mmoja Hospital.

Conclusion: Attrition from ART among PLHIV is still a public health problem in the two health facilities where the survey was conducted in Tanzania. Death and LTFU are the most common types of attrition, with stigma mentioned most commonly by PLHIV as a reason to stop ART services. A robust vital registration system for death registration, a robust tracking system for LTFU, and interventions to address stigma are needed to improve retention.

INTRODUCTION

HIV still ranks as the greatest public health challenge in the world. By the end of 2014, an estimated 36.9 million people were living with HIV globally, with about 90 percent residing in sub-Saharan Africa. In Tanzania, the first case of AIDS was reported in 1983 from the Kagera region, and by 1986, AIDS cases had been reported in every region (National AIDS Control Programme [NACP], 2012). Tanzania was gripped by the HIV epidemic during this time of accelerated HIV transmission. However, with the advent of HAART in 1996, the overall morbidity and mortality among PLHIV on ART has decreased markedly (Mukadi, 2001).

Using the 2011 and 2012 prevalence as the authentic source of HIV burden in Tanzania, the prevalence of HIV infection in adults 15–49 years of age in Tanzania was 5.1 percent (6.2% among females and 3.8% among males), a slight decrease from the previous 5.7 percent (6.6% in females or 4.6% in males) as reported in the HIV and Malaria Indicator Survey conducted between 2007 and 2008 (National Bureau of Statistics, 2012).

The Plan for HIV/AIDS Care and Treatment for Tanzania mainland was launched in October 2003. Actual implementation started in October 2004 with the aim of providing quality care and treatment for all PLHIV in the country (NACP, 2003). As a result, CTCs have been set up in public and private hospitals, health centres, and dispensaries throughout Tanzania (Ministry of Health and Social Welfare, 2004). Owing to a strong national response, the number of clinics providing services, and subsequently the number of people accessing services, has increased tremendously from 2004 to 2014.

By the end of 2014, a total of 1,301 CTCs were providing HIV/AIDS care and treatment services, and over one million PLHIV were already enrolled in and had initiated ART (NACP, 2014). This corresponds with the national cohort analysis, which reported that an estimated 21 to 30 percent of the approximately 1.2 million PLHIV in the country had been registered at care and treatment facilities (NACP, 2012). This aligns with World Health Organization (WHO) guidelines that indicate about 15 to 20 percent of all PLHIV in the advanced stages of AIDS require HAART.

Because Tanzania has implemented HIV care and treatment services for more than a decade, efforts to understand the dynamics of retention in ART are of great importance. Retention in ART determines the effectiveness of the HAART program owing to the threat of resistance arising from high attrition rates. Good retention in HIV treatment is important because retention leads to continued ART, diagnosis and treatment of ARV toxicities, and diagnosis and treatment of ART failure. Retention is also important for continued social support and health education to cope with the chronic illness (Geng, et al., 2010).

However, knowledge related to the magnitude of attrition from ART, associated factors, and reasons for attrition is scarce and quickly becomes outdated owing to shifting cultural dynamics and changing lifestyles, in general.

This study aimed to determine the magnitude, common types, associated factors, and reasons for attrition from ART services in order to improve retention of PLHIV in ART.

Research Questions

This study sought to answer the following questions:

1. What is the magnitude of attrition among PLHIV from ART at 6, 12, and 24 months after beginning ART?
2. What is the magnitude of various reasons) for ART attrition (LTFU, died, informal transfer to another CTC, stopped coming for other reasons, or unknown category)?
3. What are the reasons for ceasing to attend a CTC?

METHODS

Study Design

The study used retrospective record review and cross-sectional survey designs in a consecutive manner. The study was conducted for a period of twelve months.

Study Area and Study Population

The study was implemented in two large-volume CTCs, one in Mkuranga District Hospital (in a rural area) in Pwani region and one in Mnazi Mmoja Hospital (in an urban area) of Dar es Salaam region. All patients enrolled in ART from January 2006 through December 2014 were eligible for the study. The national HIV care and treatment database, located at NACP headquarters, was used to produce a list of rural and urban CTCs that reported the largest number of patients enrolled in ART during the study period, to allow a minimum of 24 months after enrolment in ART.

Data Collection

Patients receiving HIV and AIDS services are monitored through a standardized data recording and reporting system. This system, which is used in all ART providing health facilities, captures important data regarding the status of the patient's follow-up once enrolled in CTCs. Client-level data are collected using a standard national patient monitoring form known as CTC2, which is kept at the clinic.

To conduct a retrospective record review, data were extracted from the HIV and AIDS Patients Monitoring Form, which is a medical record kept at all CTCs. By using ART registers and the CTC2 databases, a list of all PLHIV on ART who had missed their three appointments was established. Files of PLHIV on ART who were identified as missing were separated from other files. Patient-level data about the PLHIV on ART identified as missing were retrieved from the CTC2 databases. The study included data from the time the facility began providing services up to June 2015. To maintain anonymity, individuals were identified by their unique CTC numbers. Forms were designed to extract data on whether the patients were classified as LTFU, dead, stopped, or transferred to another CTC. The extraction of data for the retrospective phase of the study was done by a team of three trained data collectors in each clinic. The period of data collection for the baseline survey was two months. During the data collection period, the coinvestigators conducted random checks on the data recording process to ensure data quality.

Retrospective analysis involved all patients who were initiated on ART any month from January 2006 through December 2014. This period was chosen so that patients who were enrolled on ART any time between January 2005 and December 2014 would have been on ART at least 24 months, the minimum to be included in the study.

The second part of the study involved tracing the patients categorized by attrition from ART. This information was obtained from the CTC2 databases and ART registers. Interviewers followed up with a total of 138 patients at their households, collecting information on causes of attrition using a structured questionnaire. This was done by two research assistants: one facility home-based care coordinator and one community volunteer. The data collectors used a tracking form designed to catch all indicators important for tracing the defaulters. During the cross-sectional surveys to follow up on people categorized under attrition, the co-investigators conducted random checks on the data-recording process to ensure data quality. This process was complemented by direct supervision by the study team every two weeks. Attrition was defined as missing an appointment for three or more months after ART initiation.

Training

A three-day training was conducted for the data collectors on research ethics and data collection tools. The purpose of the training was to field test the tools (identify areas needing improvement and ensure a common understanding of the variables and indicators of the study). Data collectors were medical personnel.

Data Analysis

Data abstracted from ART registers and CTC2 database (patient-level data) and data from the cross-sectional survey were entered into a database created using Microsoft Access. During data entry, multiple checks were inserted into the database. The data, once entered, were randomly checked by the coinvestigators by cross validating with the paper records to ensure the reliability of data recorded. The data from the paper-based patient records on the CTC2 form and the cross-sectional survey data were merged with the patient-level data from the electronic CTC2 database to make one database with each study participant identified by their unique CTC number.

Data were analysed using STATA 13 software. Descriptive data analysis was used to determine the magnitude of attrition among PLHIV in ART, to describe baseline characteristics of the study population and to determine the reasons for attrition among PLHIV.

Ethical Considerations

The first part of the study involved record review. Permission to use the data was sought from the Ministry of Health, Community Development, Gender, Elderly and Children and Center for Disease Control and Prevention/Tanzania, through the signing of a data transfer agreement. The National Institute of Medical Research provided ethical clearance to conduct the cross-sectional surveys. Informed consent was sought to interview PLHIV or relatives and friends at their residences.

Limitations

The study facilities were not randomly selected nor were they nationally representative. However, with one of the selected facilities in an urban area and the other in a semi-urban area, they are reflective of where most facilities in the country are located.

Retrospective data were collected through routine clinical service records. This data is usually incomplete; however, multiple data sources were used to assess the status of the patients' ART attendance such as CTC2 and ART registers. This reduced the magnitude of data incompleteness.

Specific Plans for Data Dissemination and Use

The study findings will be disseminated to key stakeholders at the national and subnational levels to advocate for national research of a similar nature. Regional health management teams (RHMTs) and council health management teams (CHMTs) can use the findings to develop an action plan with the technical working groups at the regional and council levels to improve the quality of care provided to PLHIV in their area and address attrition from ART. The dissemination to RHMTs and CHMTs will be done during NACP's regular meetings. This would allow regions and districts to use the findings for quality improvement initiatives at CTCs in their respective regions and councils such as verifying those lost to follow-up, updating the attendance status of their patients, and updating the true lost to follow-up (defaulters).

RESULTS

A total of 5,499 PLHIV initiated ART in the two health facilities from January 2006 through December 2014. In both facilities, the majority of PLHIV who initiated ART were women; 68 percent in Mkuranga District Hospital and 76 percent in Mnazi Mmoja Hospital. Most of those who initiated ART in both health facilities were 15 years or older (93% in Mkuranga and 91% in Mnazi Mmoja), had a walking functional status (75% in Mkuranga and 67% in Mnazi Mmoja), and had a body weight of 55 kgs or less in Mkuranga and above 55 kgs in Mnazi Mmoja. The number of PLHIV in both health facilities increased gradually from 2006 to 2014, with the highest number of PLHIV who initiated ART in 2014 for both health facilities (17% in Mkuranga and 27% in Mnazi Mmoja) (Table 1).

Table 1. Baseline characteristics of PLHIV who were initiated on ART in Mkuranga and Mnazi Mmoja Hospitals through December 2014

Baseline characteristics	Mkuranga District Hospital	Mnazi Mmoja Hospital
	Frequency (Percent) ***n*=1723**	**Frequency** (Percent) ***n*=3776**
Sex		
Male	545 (31.6 %)	894 (23.7%)
Female	1178 (68.4%)	2882 (76.3%)
Missing	-	1 (0.0%)
Age group		
<1	23 (1.4%)	88 (2.3%)
1–4	45 (2.6%)	75 (2.0%)
5–14	59 (3.4%)	187 (5.0%)
15+	1596 (92.6%)	3427 (90.7%)
Year ART started		
2006	44 (2.5%)	-
2007	188 (10.9%)	85 (2.3%)
2008	229 (13.3%)	267 (7.1%)
2009	188 (10.9%)	366 (9.7%)
2010	151 (8.7%)	391 (10.4%)
2011	166 (9.6%)	402 (10.6%)
2012	217 (12.5%)	627 (16.6%)
2013	246 (14.3%)	636 (16.8%)
2014	294 (17.3%)	1003 (26.5%)
Functional status		
Working	1285 (74.6%)	2528 (63.6%)
Ambulatory	402 (23.3%)	9 (0.2%)
Bedridden	36 (2.1%)	16 (0.4%)
Missing	-	1424 (35.8%)
Baseline weight (Kilograms)		
<45	634 (36.8%)	464 (12.3%)
45-<55	615 (35.7%)	509 (13.5%)
55+	446 (25.9%)	1716 (45.4%)
Missing	28 (1.6%)	1088 (29.8%)

The magnitude of attrition among PLHIV who initiated ART increased with time in ART; the proportion of those who were no longer in ART (attrition) increased gradually from six months to 24 months after initiation of ART. For Mkuranga District Hospital, the differences in attrition are bigger between a six-

month follow-up and one-year follow-up compared with a one-year and two-year follow-up. 2011 had the highest attrition of all the follow-up periods; 26 percent at six months, 41 percent at 12 months and 24 months.

The trend of increasing magnitude of attrition over time was not as consistent at Mnazi Mmoja Hospital. In some years, the magnitude of attrition remained the same or decreased with increasing time after ART initiation (Table 2).

Table 2. Magnitude of attrition among PLHIV initiated on ART in Mkuranga District Hospital and Mnazi Mmoja Hospital

Health facility	Year initiated in ART	Magnitude of attrition of different follow-up durations after ART initiation		
		6 months	12 months	24 months
Mkuranga District Hospital	2010	25%	29%	30%
	2011	26%	41%	41%
	2012	18%	31%	40%
	2013	16%	22%	26%
	2014	24%	27%	41%
Mnazi Mmoja Hospital	2010	24%	25%	33%
	2011	45%	41%	39%
	2012	41%	40%	41%
	2013	17%	20%	18%
	2014	9%	13%	13%

PLHIV who stopped ART represented the lowest proportion in both health facilities (0.9% in Mkuranga District Hospital and 19% in Mnazi Mmoja Hospital). The most common category of attrition among PLHIV in ART was LTF (84%) in Mkuranga District Hospital and death (62%) in Mnazi Mmoja Hospital (Table 3).

Table 3. Magnitude of various categories of ART attrition by December 2014 in Mkuranga District Hospital and Mnazi Mmoja Hospital

Category of ART attrition	Mkuranga District Hospital		Mnazi Mmoja Hospital	
	Frequency	Percentage	Frequency	Percentage
Stopped	7	0.9%	92	19.0%
Died	118	15.1%	300	62.0%
LTF	640	84.0%	89	19.0%

A total of 765 in Mkuranga District Hospital and 481 in Mnazi Mmoja Hospital met the definition of attrition. Of these, 115 (15%) in Mkuranga District Hospital and 96 (20%) in Mnazi Mmoja Hospital were successfully traced when followed up. Among those reached, 75 (67%) in Mkuranga and 63 (66%) in Mkuranga District Hospital were interviewed (Table 4).

Table 4. Proportion of PLHIV reached and interviewed among those experiencing attrition in Mkuranga District Hospital and Mnazi Mmoja Hospital

Health facility name	Attrition (N)	Reached (*n*; %)	Interviewed (*n*; %)
Mkuranga District Hospital	765	115 (15%)	75 (67%)
Mnazi Mmoja Hospital	481	96 (20%)	63 (66%)

In both health facilities, the most common reasons for stopping ART among PLHIV in ART (after being traced at their respective homes) was stigma at the clinic or community (37% in Mkuranga District Hospital and 64% in Mnazi Mmoja Hospital). While religious beliefs were the least common reason (5%) in Mkuranga District Hospital, lack of food (3%) was the least common reason in Mnazi Mmoja Hospital (Table 5).

Table 5. Reasons for attrition among PLHIV on ART who were traced in Mkuranga District Hospital and Mnazi Mmoja Hospital

Reasons for attrition among PLHIV in ART	Mkuranga District Hospital (*n*=63)		Mnazi Mmoja Hospital (*n*=75)	
	Frequency	Percent	Frequency	Percent
Transport costs to facility	8	13%	7	9%
Long waiting time at clinic	12	19%	2	3%
Stigma at the clinic/in the community	23	37%	48	64%
Family pressure	3	5%	0	0%
Lack of food	4	6%	2	3%
Religious beliefs	3	5%	7	9%
Traditional beliefs	10	16%	9	12%

DISCUSSION

Although the number of PLHIV who were initiated on ART increased gradually during the study period, the overall proportion of HIV-positive children who were initiated on ART was lower than the proportion of adults. To respond to this finding, interventions to increase ART uptake in children must be scaled up. This could include improvements to HIV testing and linkage to ART services. On the other hand, HIV prevention among pregnant women is also an effective tool. However, a robust method to determine the burden of HIV for both adults and children is needed, together with design methods, to evaluate the impact of the interventions to prove if they are effective.

Our study observed that most of those who were enrolled in care and later initiated on ART were females. This aligns with data from the Tanzania HIV and Malaria Indicator survey 20111/12, which found that nearly twice as many women are HIV-positive as men (Tanzania Commission for AIDS, 2013). Females, particularly women of reproductive age, have more opportunities to get tested, because of higher rates of attendance at reproductive and child health clinics than males. Males also have poorer health-seeking behaviour compared to females (Galdas & Marshall, 2005).

We also observed that most of the study participants had good body weights and ambulatory functional status implying that people sought medical services before becoming seriously sick. PLHIV with unfavourable functional status have advanced low immunity and are prone to opportunistic infections (Tachbele, 2016).

Attrition increased with increasing time in ART in Mkuranga District Hospital. In most years in Mnazi Mmoja Hospital, attrition decreased with increasing time before follow-up. The trend in Mnazi Mmoja has been reported by others in the past (Nuwagaba-Biribonwoha, et al., 2015). The scenarios in the two study sites convey different messages; Mkuranga District Hospital implies ineffectiveness of retention interventions for LTFU at the health facility and community levels. The scenario in Mnazi Mmoja Hospital implies a functional tracking system capable of bringing back those who became LTF. The scenario in Mnazi Mmoja can also be explained by the fact that, over time, people die or move and go to another clinic. It can also be explained by the fact that Mnazi Mmoja is in an urban setting; a higher proportion of people in urban, versus rural, areas have mobile phones, making them easier to track (Tweya, et al., 2014). These scenarios illustrate the differing capacities of health facilities to track clients who miss appointments or become LTFU.

Death and LTFU were the most common types of attrition found in the study. Presence of an ineffective community health system, with the capacity to track clients and referrals, and a deficient vital registration system, to document death at the community level, may have played a big part in this. Unreported death has also been associated with LTF in other studies (Geng, et al., 2011). However, sometimes those classified as LTF or dead may have self-transferred to other health facilities. Similarly, there might be underreporting of death events because there is no functional vital registration system in the country.

Most of those who were categorized as "attrition" (15% in Mkuranga District Hospital and 20% in Mnazi Mmoja Hospital) were not reached with tracing. It is common in urban areas for PLHIV to seek care and treatment services far from where they live, making them difficult to track; however, in our study we found this to be the case in both urban and rural areas. In a study conducted in Malawi, few individuals who were LTFU were traced in the community. One of the observations in the Malawian study was that clients provided false physical addresses and phone numbers (Tweya, et al., 2014), making it difficult for the clients to be tracked either physically or through the phone.

The study documented that stigma in the health facilities by health care providers, as well as in the community by community members, was the most common reason PLHIV stopped ART. Stigma has also been found by others as a reason for attrition from HIV care and treatment services. Attrition has been

shown to greatly affect uptake of HIV services (Katz, et al., 2013). Addressing stigma would thus improve retention in HIV care and treatment.

Subjects also mentioned lack of food and religious beliefs as reasons for stopping ART. Lack of food may cause some clients to use most of their time looking for food, rendering them unable to attend clinics regularly. Beliefs, such as some religious leaders can cure HIV through prayers, are another reason for stopping ART.

RECOMMENDATIONS

Based on our findings, we developed the following key recommendations:

- Reliable estimates of the number of HIV-positive children must be established. Interventions to offer HIV testing and link children to ART services should be improved to increase the number of HIV-positive children receiving care and treatment. It is also good to have accurate estimates of the HIV burden to evaluate the effectiveness of different interventions.
- Male health-seeking behaviour needs to be improved for them to access HIV care and ART services. Hence, there is a need for interventions that are specifically designed to increase male health-seeking behaviour.
- Measures to improve retention in ART should be enhanced. These include ongoing counselling during clinic appointments, health education for PLHIV during clinic visits, and a functional community health system to track PLHIV at the community level and link them to other CTCs as needed.
- To improve record keeping, there should be a robust vital registration system to ascertain deaths in the community. Using patients' unique identification number, the Tanzanian health information system must be improved to allow individuals at different health service points to be traced. This will help reduce the number of PLHIV labelled as LTF when they have self-transferred to other health facilities.
- Even after a decade of HIV, stigma is still one of the most common reasons people stop ART services. Continuous counselling and health education must be enhanced to reduce stigma associated with HIV.

CONCLUSION

Attrition among PLHIV from ART is a public health problem in the two study areas in Tanzania. Death and LTF are the most common types of attrition, and stigma was the most common reason mentioned for PLHIV to stop ART services in the two health facilities. A robust vital registration system for death registration, a robust tracking system for LTF, and interventions to address stigma are necessary to improve retention.

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