

## Antiretroviral therapy clinic attendance among children aged 0-14 years in Kahama district, Tanzania: a cross-sectional study

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### Abstract

**Background:** Efforts made to scale up care and treatment for HIV in Tanzania have started to pay off. The number of people living with HIV (PLHIV) who are on antiretroviral therapy (ART) has massively increased owing to an increase in investment made. However, this is not reflected in all populations, especially children living with HIV. This study, therefore, aims to determine the magnitude and factors associated with ART uptake among children living with HIV in Kahama district, Tanzania.

**Methods:** This cross-sectional study was conducted among pairs of children aged 0-14 years and their caregivers. A total of 423 randomly selected caregivers of HIV-positive children were interviewed using a structured questionnaire. The outcome variable was ART uptake while independent variables constituted of socio-demographic, health facility, and systemic factors.

**Results:** A total of 132 (31%) of all caregivers reported to have missed at least one clinic visit for their children during a period of three months before the survey. Of them, one in four missed at least two clinics. Caregivers cited factors such as lack of transport fare and distance to the health facility as barriers to attend the planned clinics. After adjusting for the important confounders and other covariates, factors associated with ART uptake were being divorced/widowed (AOR= 0.57, 95% CI; 0.33-0.97) and having primary education or more (AOR 0.30, 95% CI 0.11-0, 82).

**Conclusion:** One in every three HIV-positive children miss their scheduled routine ART clinics in Kahama, Shinyanga. Tailored interventions should target caregivers of such children who are divorced or widowed and those with low or no education while addressing distance and transportation challenges in this and other areas with similar contexts.

**Keywords:** HIV/AIDS, antiretroviral therapy uptake, factors, Tanzania

### Introduction

Efforts to reduce the burden of HIV/AIDS has led to massive reduction of new infections, HIV related mortality, and improved life expectancy of People Living with HIV (PLHI) in Tanzania (THMIS, 2013). Such efforts include scaling up of care and treatment of HIV using antiretroviral therapy (ART), strategies to prevent mother to child transmission (PMTCT), advocacy, and other behaviour modification interventions (UNAIDS, 2014b,c). The prevalence of HIV among adults aged 15-49 in Tanzania has declined from 7.0% in 2004 (THMIS, 2004) to 5.3% in 2012 (THMIS, 2013) and 4.7% in 2015. Moreover, the incidence of the disease has also declined to below 1% of the general population (Wang *et al.*, 2016). This has been partly due to increased ART coverage, where the cumulative number of people on ART in Tanzania increased by 50% between 2011 to 2012 (THMIS, 2013). By 2015, about 47.6% of people living with HIV (PLWHIV) were on ART (Wang *et al.*, 2016). In 2014, a total of 1,209 health facilities in Tanzania were providing ART to both adults and children, while 1,446,916 people living with HIV were enrolled into care and 567,892 on ART of which about 7% were children less than 15 years (PEPFAR, 2015).

Despite the notable gains in Tanzania, children are left behind and therefore jeopardizing national and global efforts to attain the 90-90-90 goal (UNAIDS, 2014a). In this, UNAIDS calls on countries by 2020 to reach 90% of people living with HIV diagnosed; having 90% of diagnosed people on ART; and having 90% of people in treatment with fully suppressed viral load. While the UNAIDS estimated a total of 130,000 children and adolescents are in need of ART in Tanzania, only 26.5% children had been on ART by the end of 2013.

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Evidence for factors associated with low uptake of ART among children suggest that weak integration of PMTCT services within the child immunization clinics and other child programmes; low coverage of early infant diagnosis (EID) services; low levels of provider-initiated testing and counseling (PITC) for children presenting to healthcare facilities; frequent stock outs of HIV testing kits; and weak linkages to care and treatment services for children identified as HIV positive could be affecting ART clinic attendance and therefore ART uptake (NACP, 2012; Kimani-Murage *et al.*, 2013). Moreover, Tanzanian regions also vary significantly geographically and culturally, which can also contribute to varied factors. Such evidence, however, is lacking in the context of Tanzania. This study therefore aimed to determine the magnitude of missing ART clinic attendance in which children gets ART refill. Moreover, we sought to examine factors associated with missing the ART clinics among children 0-14 years in Kahama, Tanzania.

## **Materials and Methods**

### ***Study design and settings***

This cross-sectional study was conducted in Kahama district in Shinyanga Region, Tanzania. The health system in Tanzania follows a pyramidal shape design whereby starting from national apex the areas are divided into regions, districts, divisions, wards and finally to broad base villages. The Kahama District was purposefully selected because of the following reasons. First, the district was included within a wider integrated maternal, new-born and child health programme of the Ministry of Health and Ariel Glaser Paediatric AIDS Healthcare Initiative (AGPAHI) that started in 2014. Second, the district had a higher burden (8.3%) of HIV in the region (NACP, 2009; UNAIDS, 2014c). Third, Kahama district has a highly dispersed population with challenging infrastructures especially in its rural areas. Fourth, the ART coverage and retention to care were low in the district.

In Kahama district, only 808 HIV-positive children were enrolled in care and treatment clinics in 2014. Among them, only 744 were already initiated on ART. CTC data suggested that only 7% of children in need of ART were reached (AGPAHI unpubl.). In Tanzanian context, ART is only provided in ART clinics also known as Care and Treatment Clinics (CTCs).

### ***Study population, sample size and sampling***

This study included caregivers of HIV positive children aged 0-14 years attending care and treatment clinics at health facilities in Kahama district. Caregivers with very sick HIV positive children and those with HIV positive children initiated on ART less than three months prior to the study were excluded. The study estimated a sample that was representative of caregivers seeking ART for children living with HIV at health facilities in Kahama District at 95% confidence level. Since there was no documentation of proportion of children aged 0-14 years keeping clinic appointments, 50% was adopted. The desired level of absolute precision was 5%. The estimated minimal sample size was therefore 384, and after adjusting for non-response (10%), a total of 423 caregivers were targeted for the study. All public CTCs were included in this study. A sampling frame was made out of the list of children and their caregivers attending the facility on the day of data collection. An assumption was made that 30 children would attend a clinic in a given day. A simple random sampling was used to choose participants.

### ***Data collection***

A pre-tested questionnaire was used for data collection. Data were collected using a face to face interview using a pre-tested structured questionnaire. The dependent variable for the study was uptake of ART among children living with HIV. This was defined as attending care and treatment clinics according to appointments for nutritional assessment, consultation, ARV refill and related health services. The proportion of children 0-14 years living with HIV keeping clinic appointments was determined by asking the caregivers the number of times they missed bringing their children to the clinic in the past three months as well as looking at children's facility records (CTC2 cards). The clinic appointments for children are scheduled monthly as per current National HIV and AIDS

guidelines for all the CTCs that were involved in the study. The responses of study participants were categorized as either never missing a clinic appointment or missing at least one clinic appointment in the past three months.

The independent variables included individual socio-demographic factors (age, sex, education, marital status and family size), caregiver's relation to child, and perceived benefits of ART to children and utilization of ART services by caregivers. Other independent variables included system factors such as time required to access the nearest ART clinic, finances, transport and waiting time and health facility factors such as attitude of service providers, availability of service providers, service providers' support, availability and frequency of services, availability of ART and education on ART for children. In assessing perception of caregivers on ART for children, the Likert scale was used, i.e., 1=strongly agreed, 2=agreed, 3=disagreed and 4=strongly disagreed. Responses were coded, the numbers cumulatively added and summarized by merging the median value for the scores. The highest scores from median 1-2 were grouped as "agreed", and the median score 3-4 were grouped as "disagreed".

### **Data analysis**

Data was rechecked for completeness and consistency of information on daily basis. Coding of open ended questions was done and thereafter, data was entered for analysis using SPSS version 15 software. Data was analysed using descriptive and multiple logistic regression analyses. Descriptive analysis was conducted to compare the characteristics of the population using Chi-square test and  $p < 0.05$  was considered statistically significant. Multiple logistic regression was used to assess contribution of independent factors associated with ART uptake after controlling for covariates and other confounding variables.

### **Ethical consideration**

Ethical approval to conduct this study was obtained from Research Ethics Committee, Muhimbili University of Health and Allied Sciences. Permission to conduct the study in Kahama district was obtained from the District Executive Director while permission to carry out data collection was obtained from the in-charge of selected facilities. Before the interview, participants gave a written consent to participate.

## **Results**

### **General characteristics of study participants**

Data of 423 caregivers of children aged 0-14 years living with HIV were available for analysis. About 81% of the interviewed caregivers were females and about 64% aged above 30 years. More than three quarters of the interviewees were the biological parents of the children attending CTCs. About two thirds of the participants had completed primary education. Almost three-fourth of the participants were themselves living with HIV and taking ART (Table 1). The mean age of the children was  $6.2 \pm 3.2$  years with majority (42.1%,  $n=178$ ) of them aged between 4-7 years.

### **ART clinic appointments and barriers to keeping appointments**

The results indicate that about 31% of the caregivers missed clinic appointments at least once in the during three month period before the survey. Among the 132 caregivers who reported not bringing their children to the clinic at least once in the three months, 72.7% had missed one clinic visitation, 24.2 % missed two visitations, and 3% missed three or more CTC clinic visitations. Lack of money for transport was reported by 24% as reason for missing. About 33% reported other reasons including attending a funeral, forgetting the clinic date, sickness, child being in school, child having remaining stock of ARV, and flooding of rivers making it difficult to reach the clinic (Table 2).

**Table 1: characteristics of study participants--caregivers (N=423)**

Characteristic	Response	n (%)
Sex	Male	78 (18.4)
	Female	345 (81.6)
Age group (years)	15-24	63 (14.9)
	25 - 29	82 (19.4)
	≥ 30	278 (64.7)
Marital status	Single	69 (16.3)
	Married /Cohabiting	240 (56.7)
	Divorced /Widowed	114 (27.0)
Education	None/ Incomplete primary	151 (35.7)
	Completed primary education	250 (59.1)
	Secondary education or more	22 (5.2)
Occupation	Unemployed	19 (4.5)
	Formally employed (Public and Private)	8 (1.9)
	Self-employed (farmer, petty trader)	396 (93.6)
Sero-status	Unknown	79 (18.8)
	Negative	35 (8.3)
	Positive and on ART	307 (72.9)

**Table 2: Reasons for missing child's clinic appointment**

Variable	Response	Proportions (%)
Reason for missing clinic appointment (n=131)	I had other work at home	29(22.0)
	Lack of money for transport	32 (24.2)
	The child was too sick	27 (20.5)
	No reason	44 (33.3)
	Sub-Total	132 (100)
Other reported reasons (n=44)	I had a funeral	3 (6.8)
	Forgot the date	2 (4.5)
	Caregiver was sick	24 (54.5)
	Child was in school	7 (15.9)
	Child had ARVs stock	1 (2.3)
	Flooding of rivers	7 (15.9)
	Sub-Total	44 (100)

**Access to health facilities offering ART services**

A total of 200 (47.3%) and 223 (52.7%) of the participants reported <1 hour and >1 hour as the time taken to travel to a CTC clinic, respectively. Of those living near CTC clinics (<1hr), 149 participants never missed clinic attendance while 38.6% missed the clinics at least once. Among those who were living far from CTC clinic (>1hr), 49.8% (142) never missed while 61.4% (81) missed their clinics appointment at least once. Furthermore, about 49% caregivers reported using Tanzania Shillings 1000 (US\$ 0.5) or more to access a CTC for their children. There was no significant difference in missing clinic appointments reported by caregivers not incurring travelling costs and those incurring travel costs (p=0.435).

**Perception of caregivers on ART for children living with HIV**

Almost all caregivers agreed that it is important for their children to be on ART. Increased survival of the children on ART was one of the most frequently cited perceived benefit of ART. Others included improvement of immunity and decreasing frequency of illness (Table 3). On ART initiation, 79% of caregivers agreed that ART should be provided to the child as soon as they are found to be

HIV positive, in line with the current national guidelines. Almost all of the caregivers agreed that they can recommend ART to another caregiver with an HIV positive child.

**Table 3: Perception of caregivers on ART for children living with HIV**

Perceived statement	Number (%) agreed
Important for child being on ART	412 (97.9)
<b>Perceived benefits of ART to children</b>	
Prolongs survival of the child	153 (36.2)
Improve immunity and prevents opportunistic infections	124 (29.3)
Decreases the chances of the child being frequently ill	130 (30.7)
To prevent the child dying from HIV related illness	16 (3.8)
<b>Initiation of ARVs to children</b>	
As soon as they are found to be HIV positive	334 (79.0)
When the caregiver is ready for their child to start ARVs	50 (11.8)
As per doctor's advice	31 (7.3)
When the child has low CD4 count	8 (1.9)
<b>Recommend ART to another care giver with an HIV positive child</b>	<b>420 (99.3)</b>

#### **Determinants of ART services uptake among children living with HIV**

In the univariate analysis, ART uptake was associated with caregiver's education level, occupation, reported sero-status, and the unit/point of service at which caregivers spent most time waiting to access services were independently associated with uptake of ART among children. We conducted multiple logistic regression analyses to examine independent association of these factors after adjusting for other confounders and covariates.

**Table 4: Factors associated with uptake of ART services**

Variable	Response	Bivariate logistic regression		Multiple logistic regression	
		OR (95% CI)	P-value	AOR (95% CI)	P-value
Sex	Male	1		1	
	Female	1.64 (0.93-2.92)	0.088	0.57 (0.31-1.03)	0.064
Age group	15-24	1		1	
	25 - 29	0.87 (0.45-1.72)	0.703	1.16 (0.53-2.53)	0.715
	≥ 30	0.58 (0.33-1.03)	0.062	0.82 (0.40-1.67)	0.586
Marital status	Married /Cohabiting	1		1	
	Single	1.53 (0.89-2.66)	0.127	1.52 (0.86-2.69)	0.148
	Divorced /Widowed	0.62 (0.37-1.07)	0.074	0.57 (0.33-0.97)	0.034
Education	Secondary or university	1		1	
	Never been to school/incomplete primary	0.43 (0.17-1.07)	0.071	0.63 (0.23-1.71)	0.362
	Completed primary education	0.22 (0.91-0.55)	0.001	0.30 (0.11-0.82)	0.017
Occupation	Formally employed	1		1	
	Unemployed	0.16 (0.03-0.97)	0.047	0.24 (0.03-1.79)	0.164
	Self-employed	0.27 (0.06-1.15)	0.076	0.54 (0.10 -2.80)	
Sero-status of caregiver	HIV Positive and on ART	1		1	
	Unknown	1.29 (0.76-2.19)	0.340	1.52 (0.84-2.78)	0.17
	Negative	2.09 (1.03-4.26)	0.041	2.00 (0.89-4.51)	0.095
Reported Long waiting time	Triage	1		1	
	Counselling	2.02 (0.67-6.12)	0.214	2.16 (0.67-6.98)	0.196
	Consultation	5.02 (2.13-11.8)	0.001	3.91 (2.04-7.5)	0.001
	Pharmacy	4.16 (1.76-9.87)	0.001	3.05 (1.56-5.89)	0.001
	Registration	2.69 (0.94-7.64)	0.064	2.24 (0.92-5.49)	0.076

In the adjusted analysis, caregivers who were either divorced or widowed were found to be 43% less likely to bring their children for ART uptake compared to married caregivers ( $p=0.034$ ). Also, caregivers with primary education were 30% less likely to miss ART clinics for their children compared to their counterparts with secondary or university education ( $p=0.017$ ). Caregivers who reported to spend more time waiting to access consultation services at CTC were four times more likely to miss bringing their children to the clinic at the last visit than those reporting less time spent waiting for services (AOR= 3.91, 95% CI; 2.04-7.5,  $p=0.001$ ). Caregivers reporting spending more time waiting for pharmacy services had three times higher odds of missing bring their children to the clinic than those waiting for triage services (OR= 3.05, 95% CI; 1.56-5.89,  $p=0.001$ ) (Table 4). Triage services include checking for vital signs, opportunistic infections, and other health conditions that may require specialized clinical care.

## Discussion

Evidence generated by this study is unique, done in Tanzania, and can inform the current test and treat strategy to ensure that the country is in line with the 90-90-90 UNAIDS goals (UNAIDS, 2014a).

This study found that one third of children attending CTC in this context missed at least one clinic visit scheduled for their ART appointment and ARV refill and jeopardizing adherence to treatment and therefore risking their drug sensitivity. ART coverage is low among children aged 0-14 years in Tanzania, and even worse in Kahama district. Only 7% of children in need of ART have been reached by 2015 (AGPAHI unpubl.). This alarming clinical and programmatic challenge needs to be addressed in order to reach the national and global targets (UNAIDS, 2014a). Keeping a clinic appointment is crucial in ensuring uptake of ART (White *et al.*, 2008). In this study, all of the children were HIV positive and on ART which is in line with the 2015 national HIV and AIDS guidelines (NACP, 2012, 2017).

Caregivers cited several factors for missing appointments. The common factors included lack of money and being tasked with other domestic activities. The financial barriers are not uncommon among HIV-positive caregivers and constitute one of the most common socio-demographic disadvantages (Sunguya *et al.*, 2011, 2014; Weiser *et al.*, 2011). Other studies conducted in other regions in Tanzania have shown that caregivers of HIV-positive children also succumb to food insecurity, poverty (Anema *et al.*, 2009, 2100; Sunguya *et al.*, 2011, 2014). Similar to other contexts, the current study has also demonstrated long travel time to facility contributed to missed appointments (Bilinski *et al.*, 2017). Despite the decentralization of health services in Tanzania, there are still fewer facilities offering ART services as compared to the numbers of existing health facilities in the country. Some of the facilities offering ART services are located far away from residences of individuals requiring the services (NACP, 2009). Moreover, the majority of the caregivers in rural areas required 30 minutes to two hours to walk to the main road before accessing a vehicle to take them to the clinic (Ezekiel *et al.*, 2012). Caregivers having more than one HIV positive child also face greater challenges with the difficulty of carrying the children to the clinic without any help (Ezekiel *et al.*, 2012).

HIV-positive caregivers succumb to a number of socio-demographic disadvantages including loss of loved ones (Weiser *et al.*, 2011). These create further economic and social challenges. In this study, divorced or widowed caregivers were more likely to miss appointments compared to those living with a spouse. This may complicate treatment outcomes. Similar to other studies (Kubai, 2011; Foresto *et al.*, 2017), the current results suggest higher odds of missing appointments among caregivers with higher compared to that of lower education level. In our study areas, people with less education are mainly farmers and not in a formal sector. Therefore, they may have time to take their children to hospitals compared to those under formal employment. In this study, long waiting time during accessing consultation and pharmacy services at health facilities offering ART was associated with missing clinic visit. Lack of integration of services within the CTC could help to explain these differences in waiting time and association with missed clinic opportunities. Comparable to this study, findings from a study in Kilimanjaro, Tanzania

revealed that a clinic appointment was reported as a whole day affair and valuable time was wasted waiting at different service points (Ezekiel *et al.*, 2012).

The current study has demonstrated that most of the caregivers perceived ART to be beneficial to children living with HIV, reporting that ART prolongs child survival and decreases the chances of a child being frequently ill. Such positive perception may be attributed to experience of ART benefits themselves or from counselling when attending CTC (Ezekiel *et al.*, 2012). Furthermore, the majority of the caregivers agreed that ART initiation to a child living with HIV should be as soon after diagnosis of HIV which is in line with Tanzania national HIV and AIDS guidelines recommending all children below the age of 15 years to be initiated on ART immediately after being diagnosed HIV positive (NACP, 2009, 2012, 2017).

Unprecedented proportion of children missed their ART clinic appointments in Kahama. One third of caregivers enrolled in this study missed at least one ART clinic for their children in during a three-months before the study. Efforts are therefore needed to address this programmatic and clinical challenge in view of striving to attain the 90-90-90 UNAIDS goal and the nation's strategy of test and treat all (UNAIDS, 2014a). In addressing the missed clinic visit, there is a need to address factors associated thereof in Kahama.

In conclusion, one in every three HIV-positive children miss their scheduled routine ART clinics in Kahama, Shinyanga. Tailored interventions should target caregivers of such children who are divorced or widowed and those with low or no education while addressing distance and transportation challenges in this and other areas with similar contexts.

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