

## RESEARCH ARTICLES

# Antiretroviral therapy for all: barriers to achieving universal access in Chikuni Mission in Zambia

K Michelo<sup>1</sup>, K Whalen<sup>1</sup>

1.Chikuni mission Parish

Correspondence: Kelly Michelo ([michelosj@jesuits.net](mailto:michelosj@jesuits.net))

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Zambia has attempted to create universal access to antiretroviral therapy. However, barriers still remain at the individual, institutional and national levels to access ART. The objective of the study was to determine factors related to accessibility to ART by PLHIV in Chikuni Parish in Southern province of Zambia. Out of a total of 1,067 Chikuni Home Based Care clients, 182 filled in the questionnaire: 173 adults, 7 youth aged 15-25 years and 2 children below the age of 15 years. In addition, two local partners implementing HIV and AIDS-related programs were interviewed. Purposive sampling was used to select participants. Out of 182 respondents, 125 (67%) described their condition as of by then to be very good, 44 (24%) as good, and 9 (5%) as not too good. Appointments to collect ARVs were not kept as reported by 43% of the respondents. About a quarter (24%) reported that there was a shortage of ARVs. About 1 in 10 (9%) of the respondents did not take the medication regularly. Access to ART was rated as by 54% of the respondents as good and 45% rated it as fair. Two thirds of the respondents found it hard to reach the facility for treatment; reasons being hospital too far from home, transport too expensive and sometimes transport was not available. On the services received, 56% of the respondents were dissatisfied with the attention and quality of care they received. Challenges of under staffing and self-stigma were some of the barriers to accessing ART. About 1 in 10 (9%) of the respondents did not take the medication regularly. Decentralizing model for ART delivery would improve access to ART.

## Introduction

The prevalence of HIV infection in Zambia is 15.1% among women and 11.3% among males with an overall prevalence of 13.3% among persons of age 15-49 years [1]. Antiretroviral drugs (ARVs) were registered for use in Zambia in 2002, but the drugs were not provided free of cost until June 2004. ART not only prolongs the lives of people living with HIV (PLHIV); it also benefits HIV-negative people by reducing the risk of acquiring infection. Cohen et al [2] found that early initiation of ART (when a patient's CD4 count was between 350 and 550 cells per cubic millimeter) reduced the number of HIV-1 transmissions between discordant couples by 96%. In 2013, the World Health Organization (WHO) recommended that ART should be initiated in all individuals

with severe or advanced HIV clinical disease (WHO clinical stage 3 or 4) and individuals with CD4 count  $\leq 350$  cells/mm<sup>3</sup> and in individuals with HIV with CD4 count 350-500 cells/mm<sup>3</sup> regardless of WHO clinical stage. WHO further recommended initiation of ART at peripheral health facilities with maintenance at the community level between regular clinical visits; trained non-physician clinicians, midwives and nurses can initiate first-line ART and maintain ART; and trained and supervised community health workers can dispense ART between regular clinical visits [3].

Factors associated with accessibility to ART in rural areas have been reported before. Akullian et al [4] found that HIV clients who travelled longer distances to access healthcare were less likely to access ART services in rural Uganda. In rural Mozambique, Schwitters et al [5] observed that barriers to accessing health clinics included transportation and distance-related issues (reliability, cost, and travel time). In a study to compare outcomes for children receiving care in mobile and hospital-affiliated HIV clinics in rural Zambia, van Dijk et al [6] found that access to HIV care and treatment can be increased using outreach teams. A study in rural Nigeria

revealed among factors that fears that free ART will cease was a barrier to access care [7]. In a study in a rural hospital in Zambia among HIV infected children, van Dijk et al [8] reported that most participants had difficulties accessing the clinic due to long travel times including insufficient money, lack of transportation and roads in poor condition. Barriers to accessing ART in rural Tanzania included experienced and anticipated discrimination, among others [9]. Although factors related to accessibility to ART are known, barriers are contextual, cultural and evolving. Hence, the objective of the study was to determine factors related to accessibility to ART by PLHIV in Chikuni Parish in Southern province of Zambia.

## Methods

The study was conducted in Chikuni Mission which is a Jesuit mission located in the rural areas of Zambia's Southern Province, approximately 30 km southeast of the nearest town of Monze. Chikuni Parish extends up to 50 km away from the mission in all directions and is comprised of 21 outstations. Chikuni Parish Home Based Care (HBC) is a project run by the parish that strives to alleviate the suffering of those infected and affected by HIV. HBC has approximately 1,000 clients, most of whom access ART from Chikuni

Mission Hospital at the centre of Chikuni Parish.

This was a cross sectional study. The distance some PLHIV cover to come to the health facility determined the sample size. All the respondents cover at least 40-50km from the homes to Chikuni Mission Hospital. The study considered to interview the following PLHIV: 173 adults, 7 youth aged 15-25 years and 2 children below the age of 15 years. Since the study was qualitative, purposive sampling was used in order to cover the full range of issues that was covered in the questionnaire.

Interviews were conducted with PLHIV when they were accessing services at Home Based Care outreach visits or ART clinic at Chikuni Mission Hospital. In addition, interviews were conducted with two local partners implementing HIV and AIDS-related programs, namely: coordinator at the District AIDS Task Force, a government institution fighting HIV and AIDS and a nurse from Chikuni Mission Hospital.

### **Ethical clearance**

Before conducting the study permission to conduct the study was sought from Chikuni Mission Hospital Administrators and District AIDS Task Force (DATF) staff in Monze. Prior to the interview, the questionnaire was explained to the interviewees. It was

emphasized that the interviewer should confirm with the interviewee that it is agreeable to having the interview. It was important to re-affirm and re-establish consent. All the persons interviewed did so freely, knowing how the information they gave was going to be used and for what purpose. Privacy is always a concern, especially when disclosing an individual's HIV status. To ensure privacy, no names were taken of the interviewees.

## **Results**

The results are presented in two sections: people living with HIV and institutional interviews:

### **People living with HIV interviews**

Out of a total of 1,067 Chikuni Home Based Care clients, 182 filled in the questionnaire of which 74% were female. Most (95%) respondents were aged more 25 years or older and on ART (96%). The majority of the respondents generated income by farming on their land (46%) followed by casual labourer (31%). These results are shown in Table 1. All the respondents went to Chikuni Mission Hospital for follow-ups and medication. Only 12 (7%) out of 182 respondents came from other health facilities: Monze Mission Hospital, Choma General Hospital and Namwala Hospital.

Table 1: Age distribution of respondents (Total=182).

Factor	n (%)
<b>Age (years)</b>	
<15	2 (1)
15-25	7 (4)
>25	173 (95)
<b>Source of income</b>	
Farming on own land	84(46)
Casual labourer	56 (31)
Farming or breeding livestock on someone's land	22 (12)
Business*	13 (7)
Fixed employment	2 (1)
Involved in an income generating activity run by an organization#	2 (1)

\* Business included cutting and selling grass, making and selling baskets, making and selling buns

# Organizations included the Chikuni Home Based Care

The average number of follow-up visits per year was 3.3. Most (73%) of the respondents thought that the frequency for appointments in a year given to them for regular medical follow-ups was frequent enough.

Tests that were conducted at Chikuni Mission Hospital found that almost all (99%) respondents reported that they had CD4 count done. About a third (38%) reported that viral load determination was done, although this test was not done in the hospital. Cholesterol test was done in 96 (53%) of the respondents. These results are shown in Table 2.

Altogether, 96% of the respondents took ARVs. All the seven respondents who did not take ARVs indicated that they did not take ARVs because, according to the healthcare staff, they did not need ARVs yet. Out of 182 respondents, 125 (67%) described their condition as of by then to be very good, 44 (24%) as good, and 9 (5%) as not too good.

Most (96%) respondents reported that ARVs were free of charge. Out of 182 respondents, 78 (43%) reported that the number of times that they agreed with the medical attendants to be collecting the ARVs in a year was not followed as per agreed schedule.

When the respondents were asked if they experienced any shortage of ARVs supply when their day for collection was due, 24% of the respondents said there was a shortage of ARVs. For the 24% of respondents who had experienced ARV shortages, 92% of them said it happened only sometimes, 5% said it happened frequently and 3% said they usually found what they needed. When there was a shortage, most clients still received ARVs but fewer of them. Chikuni Mission Hospital usually gave out ARVs for three months at a time, but when there was a shortage, PLHIV only received a one-month supply of drugs. The majority of the respondents indicated that the supply of ARVs was improving.

When the respondents were asked if they ever shared the medication with family members or friends, 177 responded to the question of which 175 (99%) said they did not share ARVs with anyone. When they were asked if healthcare staff ever advised them to share medication with others, 26% of the

respondents said they were advised to share medications.

Table 2: Laboratory tests done on follow-up (Total=182)

Test	n (%)
CD4 count	180 (99)
Viral load	70 (38)
Cholesterol	96 (53)
Chest X-ray	17 (9)
Other sexually transmitted infection	12 (7)

When they were asked if there was a time when they stopped taking ARVs, 3% admitted to having stopped taking the drug. About 1 in 10 (9%) of the respondents did not take the medication regularly. Most of those who did not take it regularly gave the reason that they were forgetting to take medicine.

A question was asked to the respondents on how they would rate their access to ART. About half (54%) of the respondents rated it as good and 45% rated it as fair. Nobody said his or her access to ART was bad or very bad. Overall, 120 (66%) respondents found it hard to reach the facility where they received treatment. Of the 120 respondents who indicated that the hospital was not in easy reach, 108 (90%) said that the hospital was far from home and it took them many hours to get there, 66 (55%) indicated that transport was too expensive and 46 (38%) reported that there was no transport available at all. On the services received, 56% of the respondents

were dissatisfied with the attention and quality of care they received.

### **Institutional interviews**

Two local partners implementing HIV and AIDS-related programs were interviewed, namely: coordinator at the District AIDS Task Force, a government institution fighting HIV and AIDS and a nurse from Chikuni Mission Hospital. The following challenges were expressed by the DATF: (a) Due to distance some clients failed to reach the hospital on the day that they agreed with the medical staffs hence defaulting. It was even worse during rainy season; (b) There were families that were critically lacking food to eat and the district did not provide food. Therefore, poor nutrition also caused some clients to refrain from taking ARVs since ARVs cannot be taken without food; (c) Some church pastors were preaching to the people that they were healed and the virus was no more. Therefore, no need of taking ARVs when one is healed. This lead to default hence causing the patient to die early or recommended to move to another stage of treatment that might have been difficult to get; (d) Mixing alcohol with ARVs caused some people to default; (e) The challenge of under staffing in the Ministry of Health affected the service delivery; and (f) Self-stigma among clients themselves. Some even

reached the extent of paying some people to collect drugs on their behalf.

The challenges expressed by the nurse from the Chikuni Mission hospital were as follows: (i) Mixing alcohol, traditional herbs with ARVs led most of the clients to develop kidney problems; (ii) The nurses were overloaded with work. There were so many clients against very few medical officers; (iii) There was no nutrition support to help the clients who were critically stricken by hunger; and (iv) Most of the clients came from far places. Others even spent night on the way before they got to the hospital.

## **Discussion**

Overall, it appeared that nearly every HIV-positive person who was eligible for ART (i.e., has a CD4 count below 350 cells/mm<sup>3</sup>) received it. Of the 4% of respondents who did not receive ART, all indicated that it was because they did not qualify for it yet, indicating that their CD4 counts were above the threshold defined by Zambia's ART protocols [10].

The drug shortages that were reported to be particularly acute in urban, government-run facilities appeared to have been less severe at Chikuni Mission Hospital. PLHIV had never been unable to collect drugs from Chikuni Mission Hospital; they just received a reduced amount and had to return to collect

more. While PLHIV had basic access to ART, there were still barriers related to ease of access and quality of care. According to the findings, barriers to ART were identified at three levels: individual, institutional, and national.

Individual barriers were found at the household level and affected an individual person's ability to access ART. The individual barriers varied from person to person, but two typical barriers emerged from the study: physical distance and opportunity costs. Because Chikuni Parish was a rural area and clients came from over 50 km away to reach the ART clinic at Chikuni Mission Hospital, physical distance was the major challenge that individuals faced when accessing ART. The difficulties of distance disproportionately affected women, children, and the elderly. Women were less likely than men to own a bicycle, and children – especially young children – and the elderly were not strong enough to cycle long distances.

The physical barriers identified in the current study are consistent with factors cited in literature. Roura et. al [11] conducted a study in semi-rural Tanzania to evaluate attrition in the country's ART program. They found that distance to the clinic was as a barrier to clinic attendance. The majority of respondents in

their study indicated that ART services should be brought closer to the clients, and this is in line with the WHO's 2013 recommendations that ART services be decentralized [3].

Related to the barrier of distance and the time it takes to reach the treatment facility is the barrier of opportunity costs. Opportunity costs have a variety of implications on the economic and educational aspects of people's lives. An opportunity cost is the opportunities foregone when choosing one expenditure over another. In the case of PLHIV, one of the opportunity costs of traveling long distances to access ART is the loss of one (or two or three) days of work. Over half (59%) of the respondents relied on agriculture as their main source of income, and presumably more relied on it as a secondary or supplementary source of income. Agriculture is labour-intensive work, and spending up to 10% of the month accessing ART (3 days out of 30) can have a serious impact on income generation.

For children accessing ART, the opportunity costs include missed days of school. This can have a serious impact on student achievement, especially if the child's appointment at the ART clinic is on a critical learning day, such as a test day.

Finally, widows and single parents face the opportunity costs of the risk of leaving children at home alone and unattended while the parent goes to the ART clinic. If the adult is fortunate, a relative who lives nearby or a friendly neighbour can watch the children. However, there are also cases where the children are left at home without adult supervision. The parent must prepare food in advance and hope that nothing happens to the children while he or she is away.

Other studies found similar barriers and outlined the effects of poor service delivery. Gourlay et al [12] reviewed literature regarding the barriers to uptake of ART for PMTCT. Of 23 studies, 52% of the studies included staff shortages as a barrier. Staff shortages have huge impacts on the quality of care PLHIV receive from treatment facilities. In addition to staff shortages, drug shortages are other problems that affect individuals accessing ART at local health facilities. Drug shortages not only have the potential to do serious physical harm to people who rely on the drugs for survival. The shortages also cause mental anguish for PLHIV. They know their life depends on their ability to get the drugs, so a shortage raises concerns that one day the drugs may become unavailable. While access to ART has given PLHIV hope for their future, they also see instability in the

situation and worry that their health - and life - is at risk.

Because of the sampling method, there might have been significant selection bias. Chikuni HBC is located in a rural area, and clients live too far apart to visit in their homes. Additionally, only the clients' villages are known, not the specific location of their house. Thus, random sampling could not have been possible because it was difficult to construct a sampling frame. Instead, participants were sampled in a place where many people had gathered during HBC outreach visits or follow-up visit days at the hospital. The challenge with this sampling method, however, is that the people interviewed were already accessing services. There might have been people in the communities who could not have accessed services at all and the findings might have been biased against them.

Though there is widespread ART coverage in Zambia, PLHIV still face many challenges when accessing ART. Barriers at three levels – individual, institutional and national – hinder people's attempts to access ART and following them in their own centres (outreach) could improve accessibility to ART.

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