

# PERCEIVED BARRIERS TO ACCESSING AND ACHIEVING ADHERENCE IN ANTIRETROVIRAL THERAPY AMONG HIV PATIENTS AT A RURAL MISSION HOSPITAL IN ZIMBABWE

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## Abstract

**Introduction:** Globally, efforts are in place to enhance accessibility to antiretroviral therapy (ART) for people living with HIV. However , many eligible HIV patients in low and middle income countries fail to access ART and when they do, issues of poor adherence emerge as a major drawback to achieving disease control. **Background:** Bonda is a mission hospital in Manicaland province in Zimbabwe. Reports from the ART clinic revealed that a significant proportion of patients were not adhering to follow-up dates for resupply or getting entirely lost to follow up. **Study Purpose:** The study aimed to capture the views of patients receiving ART from this rural setting regarding some of the institutional, socioeconomic, religious and cultural factors which may serve as barriers to accessibility and adherence to medication. **Study methods:** A descriptive cross-sectional study in which qualitative in-depth interviews were carried out to elicit these perceived barriers in a convenience sample of 28 HIV patients accessing services at the centre and a purposive sample of 3 nurses employed in the OI/ART clinic. **Findings:** Distance and economic constraints particularly related to transport costs were documented to be the major challenges to access and adhering to ART schedules and regimes. Institutional issues such as long waiting times and inadequate levels of staffing were reported but were not perceived by respondents as contributing much to adherence to ART resupply schedules. Also social issues such as religion, culture and stigma were reported to contribute to a marginal extent as barriers to ART access and adherence.

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**Keywords:** Barriers, Antiretroviral therapy, Access, Adherence, Rural

## **Introduction:**

HIV is incurable but anti-retroviral drugs (ARVs) delay progression of HIV to AIDS thereby improving the quality of life of those infected and affected by HIV. Once a patient has been commenced on treatment the individual receives the treatment for life in order to benefit from the therapy. Interruption in drug adherence results in treatment failure and drug resistance.

The evident benefits of ARVs quickened global efforts to enhance accessibility of anti retro viral treatment (ART). In 2000, 189 governments worldwide committed to the Millennium developmental goals (MDGs). Target 6b focused on achieving universal access to ART to all those who needed it by 2010 (UN General Assembly, 2000). This commitment culminated in governments either offering ARVs for free or ARVs at subsidized rates leading to the establishment of Opportunistic infections/ Antiretroviral therapy (OI/ART) clinics. By the year 2005 however, it was espoused that 93% of those needing ARVs still could not afford the treatment (Amaral, 2005). Thus the World Trade Organization (WTO) made amendments of compulsory licensing in the Trade Related Intellectual Property rights (TRIPS) agreement to resolve the financial barrier to accessibility of ART. This resulted in the prices of ARVs plunging from between USD 10 000 - 15 000 per year in 2001 to USD 350 per year (Chirac, 2002). Thus ARVs became cheaper, more available and theoretically, more accessible.

In spite of these global efforts to enhance accessibility of ARVs treatment coverage for middle and low income countries have remained low as indicated in **Table 1**.

**Table 1. Regional ART Coverage in LMICs<sup>a</sup>, 2010<sup>b</sup>.**

Region	ART Coverage		
	<i>Estimated number of people needing ART</i>	<i>Estimated number of people on ART</i>	<i>%age Coverage</i>
Eastern & Southern Africa	7,700,000	3,203,000	41%
Western & Central Africa	2,900,000	709,000	25%
Latin America & the Caribbean	950,000	478,000	50%
East, South & South-East Asia	610,000	114,000	19%
North Africa & the Middle East	100,000	12000	11%

a. Low to middle income countries

b. Source: WHO/UNAIDS/UNICEF (2010)

Though the number of patients on ART in Zimbabwe has been rising steadily, the treatment coverage is not satisfactory in comparison with the global efforts invested in the accessibility of ART. In 2007 treatment coverage was 7% primarily as a result of the majority of Zimbabweans not knowing their HIV status (ZNASP, 2006-2010). The Review of the National HIV and AIDS Treatment and Care Programme for the period between 2004-2007, indicated that ART coverage increased from about 5,000 to over 100,000 (29%) by December 2007. Findings of this review led to the development of the Plan for the Nationwide Provision of Antiretroviral therapy. The numbers of adults and children accessing ART was 148 144 (39.7%) in December 2008 and 215 109 (56.8%) in November 2009 (UN General Assembly, 2010). By the year ending December 2010, 347 172 of 593 168 eligible patients (58.5%) were on ART (Kuchera, 2010). Although there has been debate regarding the authenticity of these figures (Physicians for Human Rights Report, 2009), what is apparent in Zimbabwe is that the roll out of treatment coverage has been slower than hoped for and barriers exist which are interfering with accessibility of ART to eligible candidates (ZNASP, 2006-2010).

Access in this context is defined beyond just the initial opportunity to be commenced on ART services but is extended to apply to the enablement to continue on the prescribed drug regimens. In addition to advocating for the establishment of treatment centres, there is need to explore and filter out the issues that make it difficult for ART patients to remain adherent to ART once commenced.

### **Study Background**

Bonda Mission Hospital is a rural secondary health centre in the eastern highlands of Zimbabwe that has been designated to provide ART initiation and follow up services. Information from the institution indicates

that not all patients registered in the ART program are getting their drugs as scheduled and a significant proportion miss their scheduled appointment dates for review and drug resupply while some eventually become lost to follow up. The study was carried out in order to establish barriers in the accessibility of ARVs at Bonda Mission hospital and make recommendations on preventive measures. Specifically, the study aimed to determine the institutional, social and economic factors that the affected population of HIV infected patients at the centre perceive to be contributing to the poor access and adherence to ART.

### **Methodology**

A qualitative descriptive cross-sectional design was used to facilitate the eliciting of an in depth view on barriers to accessibility and adherence to ART among the study population. The study population comprised of patients registered to receive ART at Bonda Mission Hospital, and the nurses working at the OI unit. Convenience sampling was used to select study participants from the population of patients by selecting every other patient who visited the clinic in February 2012 and taking them through an in-depth interview. A total of 28 patients were enrolled into the study. Purposive sampling was done to identify 3 health workers employed in the OI/ART clinic for interviewing purposes using an interviewer administered questionnaire. Analysis of qualitative data from interviews was performed using the ‘thematic content analysis’ framework which consists of reading and re-reading the field notes and transcribed texts, manual coding in the margins and synthesizing and grouping data in relatively exhaustive categories. Ethical clearance to carry out the study was received from the Medical Research Council of Zimbabwe, and permission was provided by authorities at Bonda Mission Hospital. Informed consent was sought from clients prior to participation.

### **Findings**

The patients involved in the study had been commenced on ART in the period ranging from July 2006 to March 2012. **Table 2** shows the general characteristics of the study interviewees. None of patients involved in the study had been placed on waiting list before ART commencement. The study captured the issues considered by patients and health workers to contribute to non adherence to ARV drug resupply scheduled dates.

**Table 2. General characteristics of study interviewees (patients enrolled in the OI/ART<sup>a</sup> clinic) (n=28)**

Characteristics	Frequency
AGE (Years)	
25-35	10
36-45	10
46-55	4
56-65	3
66-75	1
SEX	
Male	6
Female	22
MARITAL STATUS	
Single	0
Married	21
Divorced	4
Widowed	3
EDUCATION	
Primary	10
Secondary	17
Tertiary	1

a. OI/ART Opportunistic Infection/Antiretroviral therapy

### **Drug Supply scheduling**

Of the 28 participants, 17 expressed satisfaction with the ARV monthly resupply schedule. On the other extreme, 7 patients expressed discontent with the procedure of having to report to the clinic for resupplies on a monthly basis. Three main issues were cited for this discontent. Firstly, participants felt that this resupply schedule left them with a short space of time to save money to cover transport costs. For those clients who resorted to walking due to inability to access transport options, the long journey to and fro the clinic on foot was noted to be painful. The third point raised was that participants earned their livelihoods through self-employment efforts and saving a whole day off every month interfered with this effort.

Four of the interviewees (14%) admitted to ever missing a scheduled appointment for ARV drug resupplies.

The nursing staff interviewed presented the following as the most common reasons why patients failed to meet scheduled resupply appointments: financial problems which translated into lack of bus fare, illness, attending funerals, forgetfulness as patients do not consult their hand held cards to check on review dates, and preference to attend to their work.

### **Clinic based Transfer & Referral systems**

Some participants reported barriers encountered with the referral system within the ART programme when they had travelled outside the catchment area of the host clinic. Below is a list of some of their experiences;

“One time when I had travelled the nurses insisted that they would not give me a resupply unless I produced a referral letter first. They eventually gave me the drugs but only after some serious groveling.”

“When I travelled I discovered that there was no OI clinic anywhere near where I was living. In the end I had to travel a distance of 180km back to Bonda to get a resupply.”

“I earn a living through selling goods from South Africa in the different rural areas and in these places where I go to do business there are no OI clinics such that I have to send my hand held out-patients department (OPD) card with the prescription using the buses so that my relatives can go to the centre to collect drugs on my behalf. They then send the drugs to me using the bus.”

To a large extent, responses from the health workers corroborated with the above reports. At the study setting, whenever a client presents themselves from another centre, staff insist on a transfer letter first and may only provide a drug resupply for up to one month without this document. Nursing staff interviewed pointed out that the system was meant to safeguard drug abuse whereby one patient may end up collecting ARV drugs at many centers. The system also serves to curb against loss to follow up and treatment default as the patients have to confirm the availability of their treatment cocktails prior to transfer .

In addition patients are obliged to visit the clinic they want to be transferred to so that they establish rapport and confirm that their prescribed drugs are in stock in that prospective centre. Second line drugs for example, are a privilege for patients registered to receive ART at certain bigger sites like Bonda, but may not be in stock in the other ART centres. One nurse elaborated that this situation can be disheartening because patients are made to believe ARVs are everywhere but when they seek transfers they then realize that the drugs may not be as readily available. Work done in the Zambian copper belt in 2008 also revealed the non availability of OI/ART clinics in certain settings to be a substantial barrier to ART access and continuity of care within the referral system (Grant et al, 2008).

#### **Perceived quality of service delivery in the clinic**

Most (27 of 28) participants expressed satisfaction in the way staff at the OI/ART clinic served them. Nineteen (19) indicated that staff was friendly, 4 described staff as ‘approachable’, one pointed out that they had a positive attitude, another stated that they were always happy, one indicated that they were always helpful and one went further by elaborating that, “it is because of their good care that we come to the OI clinic”. The staff generally thought themselves helpful to their clients. One nurse did confess however that patients complain indirectly about the slow rate of service delivery.

The OI clinic operates during the week for 8 hours. It closes during weekends and public holidays. The shortest waiting time that any participant admitted to have experienced from the time of registering at the entrance to being served was indicated to be 5 minutes and the longest mentioned was 4 hours. The average waiting time was calculated to be 59 minutes (median = 30 minutes; mode = 30 minutes). Some participants indicated that the time varies with the number of patients in the queue arguing that “if there are less people we wait less time and if there are more people we wait more time” and others confessed that they do not keep track of time. One nurse revealed that patients wait longer time on days that they collect blood for CD4 cell count because they only write the ART prescriptions after they have collected blood for CD4 cell count so patients have to wait a little longer. None of the participants interviewed had failed to attend the OI clinic because of the long waiting time. One patient was frank to point out that “I want to live that is why I have to endure the long queues though it is painful to wait and disheartening if there are many patients to be attended that day”. These findings are contrary to those documented in 2013 in Malawi and in 2010 from a Ugandan setting where long waiting time was reported to be a barrier in the accessibility of ART [Mbirimtengerani et al, 2013;Kunihira et al, 2010]. In the Ugandan study, the minimum waiting time was 7 hours and maximum 10 hours, (median 9 hours; mean 8 hours 36 minutes).

Another participant hinted that at they do not wait as long for services in the OI clinic as they do in the out patients department to get their cards stamped or in the pharmacy dispensary to collect prescribed drugs together with the rest of the clients accessing services other than OI clinic related at the institution.

One nurse admitted that the time is not enough because they do their work hurriedly thus compromising quality and do not have room to attend to offer psychological support that patients may require during consultation. Another confessed that there were too many patients to be attended by 3 nurses as they consult over 70 patients on busy days. Paper work was a burden because though they book patients, many patients do not respect their review dates and it was a hassle to retrieve their files. Related to this is the issue of a lot of hard copy filing and completion of ART programme papers for monitoring and evaluation purposes. In addition few nurses have knowledge of managing patients on ART and as such few shoulder the burden of caring for patients on ART. One pointed out that inadequate staffing compromised quality of care rendered because the focus would be on dispensing drugs than attend to the holistic needs of patients and also working under pressure was likely to predispose them to burnout. These findings are similar to those documented in South Africa in which members of staff confessed to being over worked and inadequate to man the OI clinic

(Padarath et al, 2006). In addition it was established in Uganda that inadequate staffing compromised quality as it translated into long waiting time for patients (Kunihira et al, 2010).

### **Distance and transport costs as barriers**

The range of distance that participants reported travelling from home to hospital was 5km to 200km. The average distance was 31km (mode 20km ; median 20km). Of the 28 participants interviewed, 21 commuted to the hospital, 3 walked and 4 either walked or commuted depending on availability of commuter fares. The longest distance walked reported in the study was 30 km. It was hinted that walking to hospital was difficult as the terrain was mountainous and some roads were rocky and had galleys. A female patient reported that one patient had been robbed on the same route she uses and she was afraid that she will eventually suffer the same fate. Nursing staff admitted that some patients sometimes miss appointments due to distance.

Bus fares reported in the study ranged from US\$1-US\$16. Members of staff made estimates of transport costs in the range of US\$4 to US\$12. Two of the participants interviewed admitted that at one occasion they had failed to access their drugs at the scheduled time because of lack of funds to cover transport costs. Of the 26 patients who had never missed appointments because of lack of bus fare, 23 reported that they struggled to get money for transport. They indicated that they borrow and engage in piece jobs to return the money, sell assets to raise the money as well as depend on well wishers. One patient said that in order to cut on travel expenses she liaised with OI staff so that she and her husband get resupplies on the same day so that one of them could come and collect both their drugs. Clients raised the issue of delayed results and numerous additional review dates as an important issue, “When they take your CD4 count then you have to return again the next week for the result and then they say come again next time for sputum and come again next time to see clinical officer. I wish everything could just be done the same visit because where does the bus money come from?”

Findings of the research affirm that being from a low socio economic status can act as a barrier in the access to ART. Similar results were established in research done in Botswana, Tanzania and Uganda, were patients of a low socio economic status failed to get money to cover additional cost of accessing ART such as transport costs, in spite of ART being given for free (Hardon et al, 2006). Anneli revealed a similar issue in a study in India where financial struggles with ART related costs like transport and food were seen to hinder adherence to ART (Anneli, 2007).

### **Religion & Culture**

None of the participants interviewed admitted to have any cultural beliefs and practices that were a barrier in the accessibility of ART. Nursing



staff revealed incidents in their experience in which cultural beliefs and practices proved a barrier in the access of ART. Sometimes husbands had refused to allow their wives to be commenced on ART and this was only possible because of the patriarchy prevailing in the community. Another common example cited is that partners in polygamous marriages were sometimes tempted to hide their HIV status from each other to the extent that they may stop accessing their drugs.

All but one participants interviewed were Christians and testified that their religion encouraged them to seek and access ART. One patient was not a member of any religious grouping but it did not deter him from accessing ART. Health workers acknowledged that some of the members of conservative African apostolic churches did not adhere to ART regimens because their doctrine was against health seeking behaviour at formal medical institutions. In addition, nurses had encountered isolated cases where patients had stopped taking ARVs as a result of a belief in spiritual healing. One nurse testified of parents who initiated their child on ART but distanced themselves from the program because of their religion. In keeping with this view another study carried out in Malawi pointed out that harboring a strong religious belief that God has supernatural powers and heals HIV and AIDS was strongly associated with non adherence to ARV drugs among women in Malawi (OR 5.37; CI (3.16 ± 7.36); p (0.004) (Mbirimtengerani et al, 2013).

### **Social support structures and stigma**

All of the participants pointed out that they received varying degrees of family support in accessing ART. Only 1 patient revealed that she had lacked support in the early stages; she said “they segregated me because I was ill but now they have accepted me”. Nursing staff noted that some patients especially widows were bitter about being HIV positive and deaths of their spouses and not optimistic about being on ART so that the nurse feared that their hopelessness would eventually choke them out of the program.

Twenty-seven participants reported that they have not been victims of stigma with 5 confessing that they were not visibly ill and that no one except their nuclear family knew about their HIV status. A 70 year old participant, a victim of stigma, indicated that people were spreading gossip concerning her status but this had not deterred her from accessing ART. One nurse acknowledged that stigma was a barrier in the accessibility of ART in that some patients who resided in areas with OI clinics nearer than the host centre refused to be transferred because they did not want to be seen by people who knew them joining the queue for OI clinic patients.

### **Conclusion**

Some issues of note emerged as being possibly associated with the

reduced quality of maintenance of access to ART in this qualitative exploratory study. A more detailed analytical study is recommended in order to confirm the extent to which these issues are truly related to the reduced adherence to review dates and eventual loss to follow up experienced in the ART programme at the study site.

One of the important issues raised is that long distances travelled to access services as well as the associated high transport costs. Decentralization of ART services to some of the smaller clinics (primary health centres) would aid in alleviating this challenge. This move would have to be coupled with intensive capacity building for health workers employed in these units in the form of training as well as mentoring opportunities so that the concept of nurse led ART initiation and maintenance becomes achievable. Increasing the workload of nursing staff through such task sharing initiatives will also call for supplementing the levels of staffing in these centres. Long waiting queues and lack of holistic care provision would also be alleviated by increasing the human resources workforce.

Another recommendation aimed at catering for the distance issue is the introduction of more mobile outreach services where the ART clinic staff at the central site actually make a provision to review and manage clients from their local clinics or using a mobile unit.

In the long term more development oriented interventions are encouraged as a means for these low socioeconomic populations to improve income generation which is the underlying problem feeding the poor access to health services delivery in general.

Excessive paperwork was documented by staff as adding to their already heavy workloads and therefore impeding the swift efficient delivery of quality ART services. Computerization of OI units and use of health information systems would facilitate the management of input, processing, analysis of data and output of data facilitating easy storage and quick retrieval of information.

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