

Qualitative Assessment of Health and Care-Seeking Behaviors among HIV-Infected Adults and Health Care Providers in Mozambique

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Received: 03.12.2019

Accepted: 11.12.2019

Published: 28.12.2019

Abstract: Background: From 2009 to 2014, the prevalence of HIV among adults in Mozambique increased from 11.5% to 13.2%. To reduce disease progression and prevent transmission, HIV-infected persons must have access to timely, continuous, high-quality HIV care and treatment services. This study aim to identify the barriers to early diagnosis, access to medical care, ART initiation and adherence. Methods: In-depth interviews were conducted with newly diagnosed HIV-positive patients and health providers in Maputo City and Zambézia Province. Participants were recruited into the study at the time of HIV testing. Interviews were obtained at least 45 days after HIV diagnosis and were conducted in the community where the patients resided. Interviews were recorded, transcribed and translated into Portuguese prior to analysis. A framework approach was used for analysis using NVivo 10.0. Results: Ninety patients and twelve providers were interviewed. Twenty-nine patients (32%) stated that they were motivated to get tested for HIV because they felt they had an unspecified health problem. Among pregnant women, nineteen (44%) were motivated to enroll in care and initiate ART by nurses during their first prenatal visit. Of the 90 newly diagnosed patients, 80% sought care and treatment for HIV after being diagnosed in a health facility. Conclusions: Test-seeking behaviour for persons newly diagnosed with HIV in this study was often influenced by their health status, both for patients accessing voluntarily counselling and testing and for patients who tested in antenatal care settings. Initiation of ART was also strongly influenced by provider recommendation.

Keywords: ART, HIV, behaviour, Mozambique.

INTRODUCTION

With the introduction of the UNAIDS fast-track targets to reach epidemic control through 90% of people living with HIV (PLHIV) diagnosed, 90% of those diagnosed on antiretroviral therapy (ART), and 90% of those on ART virally suppressed, there has been an intense focus placed on increasing the availability of HIV testing services, ART, and HIV viral load testing. Worldwide, about 36.7 million people were living with

HIV and it is estimated that by December 2015, 18.2 million of those who knew their status were on ART. This was double the number on ART five years prior. If these efforts are maintained and expanded, the world will be on track to reach the goal of 30 million people on treatment by 2020 (UNAIDS. 2016).

The effectiveness of ART has transformed HIV infection into a treatable chronic disease, allowing

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DOI: 10.36344/ccijmb.2019.v01i06.003

people who are infected to have the prospect of a prolonged life expectancy and improved quality of life (MISAU. 2010). However, to realize these benefits those who are diagnosed must access HIV care services and adhere to their medication (Rasmussen, D. N. *et al.*, 2013). Factors associated with adherence to treatment are categorized according to patient characteristics, treatment regimen, the patient bond with their care professional, and social inclusion and disease severity (Ickovics, J. R., & Meisler, A. W. 1997),(Høg, E. 2014). While individual, medication-related, and structural factors all affect adherence to treatment, less is known about factors affecting initial uptake to treatment among those recently diagnosed.

In Mozambique, there is a National Strategic Plan for the HIV and AIDS Response, which makes access to antiretroviral drugs a government policy (MISAU. 2010). The plan recommends increased attention and research on adherence to ART, in order to improve understanding of the problem and allow appropriate action by clinical teams in order to ensure good adherence and thus good health and quality of life for PLHIV (MISAU. 2010). As ART coverage increases towards the fast-track target, identifying HIV-infected persons and ensuring they are quickly linked to care has gained importance. One study in central Mozambique found that 43% of patients diagnosed with HIV were not in care within 30 days, and patients often presented with signs and symptoms of advanced disease (Micek, M. A. *et al.*, 2009).

The follow-up of patients on ART is complex and requires familiarization of current best practices by motivated and well-trained professional teams. Good follow-up of HIV-positive patients needs to consider other equally important factors such as: distance from the patient's house to the health facilities, HIV-related knowledge, and family support (Conselho nacional de combate ao SIDA. 2009). The Mozambique Ministry of Health had pledged to eliminate vertical transmission, reduce sexual transmission by 50%, increase ART coverage by up to 80%, and reduce tuberculosis mortality by up to 50% by the year 2015. Unfortunately these goals were not achieved and between 2009 and 2015, the prevalence of HIV increased from 11.5% up to 13.2% (INS e INE. 2017). In order to achieve these established goals in the foreseeable future, it will be essential that HIV-infected persons have routine access to comprehensive HIV care services.

METHODS

Study Design

We conducted an exploratory qualitative study based on semi-structured in-depth interviews (IDI) that allowed us to capture perceptions and perspectives of patients and health care providers about the uptake of ART among patients newly diagnosed with HIV infection. The study was performed in one urban high ART-coverage area (Maputo City) and in one

predominantly rural higher HIV-prevalence low ART-coverage area (Zambézia Province), selected purposefully to represent both urban and rural, high- and low-ART-coverage, and high- and low-prevalence areas.

ELIGIBILITY AND RECRUITMENT OF STUDY PARTICIPANTS

Hiv-Positive Adults

Eligible patients were 18 years of age and older, diagnosed with HIV on the day of recruitment, and not previously enrolled in care and treatment (except for prevention of mother-to-child transmission during a previous pregnancy). Recruitment was led by a team of trained researchers in the following health care service delivery points:

- Voluntary counseling and testing (VCT), Tuberculosis (TB) and Antenatal Clinic (ANC) settings in a general hospital, located in Maputo City
- VCT and ANC, both located in a rural hospital in Mocuba District and a primary health facility in community of Mugeba, Zambézia Province.

Ninety adult patients newly diagnosed with HIV were recruited in the three selected health facilities. Consenting participants were asked to provide contact information for follow-up. In order to provide sufficient time for patients to access HIV care, in-depth interviews took place 45 days after recruitment. Fifty interviews were conducted in Maputo City and 40 between the two facilities in Mocuba District).

Health Care Providers

Twelve health care providers, counselors (6), midwives (4), tuberculosis health care providers (2) working in the selected service areas providing HIV-related services were eligible to participate. The eligible criteria for participation were: aged 18 or older, work in the selected service areas providing HIV-related services and being willing to participate in the study.

Data Collection

The team conducted in-depth individual interviews to obtain information about demographics and the health care and treatment seeking behavior of newly diagnosed HIV positive patients. Additionally, health care providers were interviewed in order to capture their experiences of providing care and treatment for patients newly diagnosed with HIV infection. Interviews were conducted in Portuguese or in a local language (Ronga in Maputo or Chuabo in Zambézia) based on participant preference. The interviews lasted approximately 80 minutes for in-depth interviews questions about seeking health care for HIV and barriers and facilitators to care. The questions were asked to explore the personal and structural factors that facilitate or hinder ART uptake.

Data Analysis

All interviews were recorded and transcribed prior to analysis. Interviews conducted in local languages were translated into Portuguese during transcription. Analysis involved thematic charting, which encourages qualitative researchers to identify and summarize common themes arising from the data. Data coding and analysis of themes was done using the NVIVO-10® software (QSR International, Melbourne, Australia) to extract and sort interview text into single-file statements with the same code from all interviews. Some categories were determined prior to data collection by the interview guides, but data analysis was iterative and categories were added, removed and amended during data analysis based on existing findings.

Ethical Considerations

Ethical approval for the study was granted by the Institutional Bioethics Committee on Health of the National Institute of Health of Mozambique and the National Committee on Bioethics in Health of

Mozambique (CNBS). The study was also reviewed according to the US Centers for Disease Control and Prevention (CDC) human research protection procedures and was determined to be research, but CDC was not engaged. All participants provided written informed consent.

RESULTS

Participant Characteristics

Among the 90 participants, 59 (65%) were female, of whom 40 (67%) were pregnant. Fifty-eight percent were married or cohabitating, 19% were either separated, divorced or widowed, and 23% were never married. Sixty percent of the participants were working in the informal sector, 21% were peasant farmers, while 14% reported having a steady job. A low percentage were unemployed (3%) or retired (2%).

Reasons for Testing

The initial reasons leading participants to seek health facilities for HIV counseling and testing varied by sex and by their entry point for health care access. The main reason for pregnant women seeking testing was antenatal care (Table 1).

Table 1. Reason and Clinical Settings among Patients Accepting HIV testing

| Reason for HIV testing | Male: Female | VCT | ANC | TB | Total |
|-----------------------------------------------|--------------|-----|-----|----|-------|
| Illness/other health issues | 19:10 | 25 | - | 4 | 29 |
| Seeking antenatal services (pregnant patient) | 0:40 | - | 40 | - | 40 |
| Advice of family/friend/neighbor | 3:3 | 5 | - | 1 | 6 |
| Check-up (provider recommended) | 7:5 | 12 | - | - | 12 |
| HIV routine testing | 2:1 | 3 | - | - | 3 |
| Total | 31:59 | 45 | 40 | 5 | 90 |

Notes: VCT: Voluntary Counseling and Testing. ANC: Antenatal Clinic TB: Tuberculosis.

Most participants stated illness or other health problems (32%) as the reason for testing. Patients in the clinic for routine medical care who initially did not intend to get tested for HIV were tested due to a health provider's recommendation.

"I went to HIV test services because I had flu. I went to the hospital but the flu didn't improve and then I went for a TB test and it was positive for tuberculosis. Then I did an HIV test and it was also positive."(female patient).

"The first reason is... I was very sick and my wife also got very sick, she had what is called Night Burn, so one day I went to the hospital for examination. The doctor told me to go and get tested and I said: go to do what? Why did I have to catch this thing..." (Male patient).

"First I had an older brother that became ill and he was hospitalized... the treatment didn't go well and he died. Then I also started to get a little sick, that's when I thought: I have to find out my health status..."(male patient).

"... I went for prenatal care and I was advised to do [the test], and did, and it was positive."(Pregnant female patient).

Twelve of 31 (38.7%) men said that they went to the health facility voluntarily to learn more about their health and get tested for HIV.

Patients tested in VCT were mainly concerned about their health status, while patients enrolled in ANC (40) noted being pregnant as the main reason to perform the screening test.

"When I did the HIV test for the first time I was pregnant. I was pregnant and I was a little scared and asked how can I be infected?" (Pregnant female patient).

Barriers to Timely Enrollment in Hiv Care and Treatment

Issues such as long distances to the health facility, long wait times, lack of access to transport, lack of money and stigma were referred to as critical barriers to timely enrollment in HIV care and treatment after testing.

Most of the participants living in Zambézia stated that they had difficulties accessing the clinic due to distance. In turn, the same participants mentioned long delays before seeing a health provider.

“We were waiting for a long time. But what can we do, if we are already sick we have to wait. We have to accept it. There are even people who do not stand in line to receive pills, others go away, and others do not come here because they know there is always a long queue.” (male patient).

Another barrier to timely seeking of HIV care and treatment was a lack of knowledge about HIV and AIDS treatment. Most of the patients acknowledged that HIV/ AIDS is a deadly disease but only started the medication after some delay.

Patients revealed having some difficulty disclosing their HIV status soon after diagnosis. They also stated that disclosing their HIV status wasn't a simple task because they had to choose people with whom they comfortable to talk about this issue. Most participants disclosed his or her HIV status to only one or two persons.

In most cases, participants disclosed their HIV status to their partners, close relatives (such as mothers, brothers or children) as well as some close friends.

“I told only my husband and my son ... I talked to my son because he's the son of the house” (female patient).

Disclosing a positive diagnosis to partners and family members proved to be a challenge that few could overcome. Many HIV-positive patients stated they intend to keep their status secret, out of fear of discrimination:

“I do not tell anyone ... I'm afraid because they will talk a lot about me.” (female patient).

Others indicated that although they had not disclosed, they intended to do so:

“...not yet. But I will tell my mother and my husband.” (Female patient).

Nevertheless, patients who disclosed their HIV status confirmed that family support helped them cope with the disease. Thus, there was a close relationship between disclosure of HIV status and obtaining emotional support for treatment.

“She liked it, said it is a good idea to treat it well. So when I told her that today I will go to the hospital she said yeah. When we woke up she said `friend go to the hospital, you cannot be late.’” (male patient).

Both health care providers and patients agreed that care and treatment and retention is complex. Antiretroviral treatment was considered complex and patients associated treatment failure with difficulties in taking medication for a long period of time along with maintaining a balanced diet.

Slightly more than half of the survey participants cited stigma or negative attitudes from community members as a factor preventing them from seeking health services for HIV care and treatment.

Facilitators to Timely Enrollment in Hiv Care and Treatment

One of the facilitators for timely enrollment in HIV care and treatment was having the enrollment take place the day after diagnosis.

“I got there, it did not take long after we opened the medical record and the next day I started to collect the tablets” (male patient).

Family support associated with knowledge about HIV/AIDS was described as a factor leading to early ART initiation. Thus, having family support, and being accepted by others, created an environment where PLWHIV can openly express feelings and emotions.

Patients reported that feeling good while taking the medication is one of the factors that most contributed to retention on ART.

“... I know that taking antiretroviral, which are the pills I'm taking, I may fall ill in the beginning, but I have to take the prescribed time and not stop, so that things go well. You cannot contract the times, not abuse much, no drinking, no smoking and in particular respect the schedule for taking the pills” (female patient).

“... I felt dizziness and deep headaches in the first days after starting to take antiretrovirals because I used to take it before going to work ... now I take the pills before going to sleep... it's cool not feeling dizziness anymore because after taking the pills I just sleep” (female patient).

Some patients reported that receiving encouragement from social network (of other PLHIV) and the desire to feel healthy helped them adhere to treatment.

“Now I'm fine, I do not do anything. I see people who are here with me, I see teachers, nurses, orderlies, many people who are coming are right here receiving treatment like me, so it's not worth sitting at home sad while I see many people who are here to get these pills and I'm also starting to take these pills...” (Female patient).

Reactions to Being Told They Have Tested Positive

The patients experienced two types of reactions after receiving their HIV diagnosis: some stated that they were waiting for a positive result while others did not imagine themselves as HIV-positive.

Pregnant patients who learned of their status stated they already suspected the diagnosis, or expected a positive result due to their partner's sexual behavior.

Most HIV-positive results were from participants who were recruited during ANC at the three health care units included in the study. Some patients felt relieved as they were experiencing symptoms of advanced disease and required treatment.

"... When I was tested I already knew, had some symptoms that I felt, I took the test again and it came back positive, then I started to do treatment." (female patient).

Some Patients Blamed His/Her Partner For Their Infection:

"It was the ignorance of trusting someone who I married three years ago. I heard that the woman who was with him before he married me also was sick ..."

(female patient).

Some patients felt victimized, because they were infected during consented sexual relations by their partner.

Other Individuals Blamed What They Perceived As Their Own Carelessness Or Irresponsibility:

"I picked it up for playing badly. When I was alone I played a lot with women, even my brother also told me, but I did not want to hear..." (Male patient).

Health care providers from one health center informed researchers that after receiving their diagnosis most patients tended to accept it well, though felt unhappy with the result.

"The person usually feels healthy before the diagnosis and they take time to believe that they are infected..." (provider).

Hiv-Related Knowledge

One of the most important factors related to adherence to HIV treatment was one's knowledge of HIV and general health concepts. Most of the patients demonstrated basic knowledge about HIV (testing, modes of transmission, advantages and disadvantages of ART).

"I just know that to do the test is good, and is good for your health, because HIV/AIDS is a disease that has no cure, and those with AIDS have a few days of life left, you see. One also has to do the test to know

the situation and deal with it, and many young people are afraid to do the test" (female patient).

Another Participant Said:

"Well, I knew of HIV/AIDS, so there was talk of HIV and AIDS being two different things, HIV is just the virus, and when they do not treat it you can have AIDS, which is the same disease. So, it is transmitted through sexual intercourse, blood transfusion, a blade, or by cutting things..." (male patient).

Patients who demonstrated basic knowledge about HIV underlined the importance of taking medication to stay healthy.

On the other hand, some participants appeared to have low HIV-related knowledge, even though they knew that HIV was a serious illness:

"Nothing ... I did not know anything. Only that it's a disease that kills" (female patient).

Many patients (n 20) were not registered in an HIV care program and were not enrolled into ART 45 days after being diagnosed as HIV-positive:

"I never been, but I will do it, I'm going back with my lady because its soon, I'm still not sick yet I am well, and we expect to start there together" (male patient, not enrolled in ART, 45 days after being diagnosed HIV positive).

This comment shows that both the knowledge of HIV concepts, HIV status and the notions of "sick" or "healthy" are crucial for adherence to treatment. We also observed that timely treatment is linked to knowledge of HIV.

Health Provider's Perceptions About Demand For Treatment

Timely enrollment in HIV care and treatment after receiving a diagnosis is linked to barriers related to access to the health facilities and ART services. According to the health providers, there are more barriers to HIV treatment initiation among those newly diagnosed.

Health providers stated the main enabling factors for patient enrollment in care and treatment are the lectures given daily at public health facilities. These lectures provide basic knowledge about HIV and help patients feel confident about their health.

One healthcare provider reported that some patients only seek out HIV testing when they have signs and symptoms of advanced disease.

“Patients appear here only when they are already sick, and others come in the same situation... already at an advanced stage of the disease ...” (Health provider).

Health providers also stated that the demand for treatment by patients is strongly linked to the availability of HIV and CD4 testing.

The other crucial factor influencing demand for HIV treatment services is distance from the patient’s residence to the health care units. Many patients have to travel distances ranging from 20 to 30 kilometers to reach a health facility. Two of the most commonly reported difficulties are the lack transportation and the difficult access to roads, especially during the rainy season. For example:

“One of the things that maybe make the patient give up is the distance. We see that most of these patients live... about 30 kilometers away, then suppose you have no transport, no money to get transport wherever it is.” (Health provider).

“The problem is that to come here many people have to walk far. And others have to cross the river.... But when the water is high because of the rain they do not cross, so they give up on treatment and only come here when the disease is already advanced.” (Health provider).

Providers mentioned that some patients complain that long waiting time for consultations was a principal cause for delay in HIV care. The waiting time for follow-up appointments are positively related with the number of HIV-positive patients with a scheduled appointment for the same day and time. Treatment initiation delays were also strongly related to difficulties in acquiring the patients CD4 test results on time, as many of those tests results were usually given three days after the diagnosis, and at the time of the study, treatment initiation was dependent on clinical and immune status.

Delays in scheduling treatment tend to lead to giving up appointments by some patients as illustrated by the following quotes:

“... delay in getting appointments makes them give up ... others say that they don’t appear for their appointments because it coincides with the day they work and they do not want to lose their job...” (Health provider).

DISCUSSION

The sample was diverse due to having been selected in three different types of health facilities in both urban and rural areas.

Among those not tested in ANC, the health status of the patient was the primary motivator to get tested.

This study also illustrated the level of knowledge related to HIV and the benefits of treatment were both facilitators and barriers to ART adherence. Lack of HIV knowledge and an understanding of the benefit of early treatment was a barrier for patient linkage to care and timely initiation of ART. Many study participants identified as peasants (21%) or domestic workers (19%) implying lower levels of education. Rasmussen *et al.*, (2013) showed that a low level of education can influence the information level and this level of information can negatively affect adherence (Rasmussen, D. N. *et al.*, 2013).

Some participants blamed their partners for infecting them, linking it to partner infidelity. Not unexpectedly, for some client’s first learning they were HIV infected and considering disclosure of their status to others caused major psychological stress, anxiety, and uncertainty (Micek, M. A. *et al.*, 2009),(Auld, A. F. *et al.*, 2011). On the one hand, keeping one’s HIV diagnosis secret exacerbates feelings of insecurity in marital and family relationships potentially leading to isolation and social exclusion. On the other hand, disclosure of HIV-positive status does not guarantee social support and empathy or lead to happiness or increased security.

The fear of discrimination appears to play a dominant role in discouraging visits to a health facility. Rasmussen *et al.*, (2013) mentioned that many patients reported a lack of confidentiality during clinic visits with many consultations held in open rooms in the presence of other patients (Rasmussen, D. N. *et al.*, 2013).

We observed that some patients sought HIV care in a timely manner while others did not. We also observed that timely uptake of care and treatment was strongly linked to becoming symptomatic. These data are corroborated by Micek *et al.*, (2009).

A national evaluation of the HIV treatment program in Mozambique also found that patients take a long time (approximately 15 days) to enroll in HIV care services after diagnosis (Auld, A. F. *et al.*, 2011).

Several studies have described that the distance to access HIV care services were considered as key barriers to starting ART among people living in rural areas (Mshana, G. H. *et al.*, 2006),(Cataldo, F. *et al.*, 2017). Our results show that the distances patients must travel to the health facility, combined with poor infrastructure and lack of access to transport were important barriers to access. Other studies also report extended distance from patient residence to health facility as a structural barrier to uptake of services (Cohen, M. S. *et al.*, 2011). We also found that newly diagnosed patients living in rural Zambézia faced difficulties in accessing health facilities due to long distances.

CONCLUSIONS

Our findings demonstrate that health seeking behavior is often influenced by patient health status both in terms of seeking voluntary counseling and testing as well as for screening in antenatal services. A patient's limited general knowledge of HIV and AIDS was seen as the main challenge to be addressed in the development of an effective approach to the early diagnosis of persons living with HIV and uptake of HIV treatment.

Although there were variations in seeking HIV treatment among the participants of the two provinces, distance to health facilities was considered by the participants of Zambézia province as a major cause for the delay. Health providers also recognized this as one of the major reasons for delayed enrollment in HIV care services.

Non-disclosure of HIV status, was associated with fear of social exclusion. Our results suggest the disclosure of HIV status in both provinces proved to be a challenge for the majority of participants.

List of abbreviations

| | |
|------|---------------------------------------------------------|
| AIDS | Acquired Immune Deficiency Syndrome |
| ART | Antiretroviral Therapy |
| CD4 | Cluster of Differentiation |
| CNBS | National Committee on Bioethics in Health of Mozambique |
| CDC | Centers for Disease Control and Prevention |
| DNSP | Direção Nacional de Saúde Pública |
| HIV | Human Immunodeficiency Virus |
| IDI | In-depth Interview |
| INS | Instituto Nacional de saúde |
| TB | Tuberculosis |
| VCT | Voluntary counseling and testing |
| ANC | Antenatal Clinic |

INS Scientific Publication Disclaimer

The findings and conclusions in this paper are those of the authors and do not necessarily represent the views of the National Institute of Health.

Cdc Scientific Publication Disclaimer

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the funding agencies.

Competing Interests

Authors declare no competing interests.

Pepfar Publication and Attribution Language Funding

This research has been supported by the President's Emergency Plan for AIDS Relief (PEPFAR) through the U.S. Centers for Disease Control and Prevention (CDC) under the terms of cooperative agreement GH000080.

Authors' Contributions

The study was conceptualized by FB, JF, YP, NH and CB. AM and GT contributed to data collection, and data analysis was performed by AM, CB and RC. The first draft of the manuscript was written by AM. All authors reviewed the final article.

Acknowledgements

The authors would like to thank the Mozambican Ministry of Health (MISAU), National Institute of Health and CDC Mozambique. The authors would also like to thank the health facilities which took part in this study, the in-charges and all facility staff involved, as well as all research participants who took part in this study.

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