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Patient experiences and preferences for advanced HIV disease testing services: a qualitative study in Beira, Mozambique

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ABSTRACT

The decline in HIV/AIDS deaths has been slower than expected, and advanced HIV disease (AHD) remains common. Despite expanded diagnostic services, patient preferences around AHD testing are understudied. This qualitative study explored the experiences and preferences of people living with HIV and healthcare workers to inform patient-centred approaches. In February 2024, purposive sampling identified people living with HIV who underwent testing at three health facilities in poor-urban Beira, Mozambique. We conducted 18 in-depth interviews and 2 focus group discussions (FGDs) with patients, plus 3 FGDs with healthcare professionals. Interviews were recorded, transcribed, translated and analysed using grounded theory. Patient understanding of AHD varied; most reported limited knowledge despite explanations. Healthcare workers noted that some patients struggle with the term “AHD” but view it less stigmatizing than AIDS. Seventy-five per cent of patients disliked the month-long wait for CD4 results and repeated clinic visits, which disrupted their routines and economic activities. Patients strongly preferred decentralized community-based AHD screening. Health professionals perceived community screening with simplified lateral flow tests as highly feasible and likely to improve patient satisfaction and convenience. Our findings suggest that empowering patients and decentralizing AHD screening with rapid tests can enhance uptake, reduce burden and improve care experiences.

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Advanced HIV disease testing; patient preferences; patient experiences; patient empowerment; decentralized testing


SUSTAINABLE DEVELOPMENT GOALS
SDG 3: Good health and well-being

Introduction

Despite the substantial increase in antiretroviral treatment coverage in recent years, HIV/AIDS-related deaths have not decreased as quickly as anticipated. In 2023, an estimated 623,000 people died from AIDS-related causes globally (UNAIDS, 2024). Advanced HIV disease, AHD (defined by a CD4 cell count test result of less than 200 cells per cubic millimeter in blood or a WHO HIV clinical stage of 3 or 4) (World Health Organization, 2024a) is predominantly seen among people living with HIV with poor access to HIV testing, lack early and rapid antiretroviral treatment initiation, interrupt treatment or disengage from care, as well as those who experience treatment failure. CD4 cell count is important as it can help to identify asymptomatic patients with advanced HIV disease who require further screening for opportunistic infections (World Health Organization, 2024a). A CD4 cell count result of fewer than 200 cells per cubic millimeter prompts testing for urinary Mycobacterium tuberculosis lipoarabinomannan antigen (TB LAM) and cryptococcal antigen (CrAg) using point-of-care TB LAM and CrAg lateral flow assays, among other recommendations for the prophylaxis and importance of ART. People with AHD are at high risk of severe illness and death from opportunistic infections (World Health Organization, 2024a).

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Improved access to diagnostics, therapeutic interventions and psychosocial support for HIV and opportunistic infections among people living with HIV, is necessary for reducing AIDS-related deaths, but it is not sufficient. Understanding experiences and preferences of people living with HIV about HIV care services is critical in influencing the uptake of health services including achieving improved treatment outcomes (Tringale et al., 2022). Patient experiences are a comprehensive measure of how patients perceive and interact with healthcare whilst preferences are their individual choices and desires based on their own experiences, beliefs, values and expectations (Oben, 2020). Patients with AHD are often cared for in primary and secondary healthcare settings (Ndlovu et al., 2020; World Health Organization, 2024a) and usually require ongoing diagnostic, therapeutic and psychosocial support which involves frequent interaction with health facilities and health care workers. Qualitative preference research can enhance the understanding of patient journeys (Kerkhoff et al., 2023) as well as obstacles in the AHD diagnostic services, dynamics with health care workers and inefficiencies in the health facility (Burns et al., 2022). This is critical as it can potentially inform improvements for patient-centred care and AHD health services.

Diagnostic testing services have been shown to be the weakest link in AHD management (Ndlovu, Moore, et al., 2025). With the exit of major point of care CD4 testing manufacturers due to low testing volumes, many national programs are relying on a hub and spoke model for CD4 testing in screening for AHD, with the inevitable difficult logistical and infrastructural challenges related to timely transport and delivery of patient samples and results (Nairobi Declaration, 2024; Ndlovu, Moore, et al., 2025). People living with HIV eligible for AHD screening face many complex barriers influencing their healthcare seeking behaviors and disengagement from care is common and is associated with progression to AHD (Burns et al., 2022; Ford et al., 2024). Studies have shown that people living with HIV experience a complex cycle of transitions in HIV care as they engage and disengage multiple times over the course of their lives as their preferences and behaviors change (Burns et al., 2022; Ehrenkranz et al., 2021). Poor access to healthcare facilities, long waiting times at health facilities, as well as psychosocial factors like stigma and discrimination have been shown to contribute to disengaging from HIV care (Burke et al., 2024; Jacob et al., 2020; Sikazwe et al., 2021). Patient perceptions and preferences for HIV services have been shown to be influenced by the quality of care, inefficiencies in health facilities, stigmatizing or discriminatory behaviors from health care workers including the anticipated punitive treatment and negative attitudes of health care workers (Arendse et al., 2024; Beach et al., 2005; Nhemachena et al., 2023).

Although some efforts have been made to characterize and incorporate preferences of people living with HIV for AHD diagnostic testing services, into global guidance (World Health Organization, 2024a); there remains a significant gap in literature, with lack of published studies specifically investigating patient preferences for AHD testing services within health facilities in high AHD burden settings. Furthermore, national clinical guidelines seldom include patient preferences for ADH diagnostic testing (Ndlovu, Assane, et al., 2025). In addition, less is known about the perspectives of HCW on AHD diagnostic testing services. The aim of this qualitative study was to explore the experiences and preferences of patients and health care workers in AHD diagnostic testing services. The goal is to contribute to future policy and strategies for improving patient-centred care for AHD testing services.

Methods

Study design

This was a descriptive qualitative study using in-depth interviews (IDI) and focus group discussions (FGDs) among patients as well as FGDs among health care workers. The social practice theory was utilized (Chenail, 2014; Spaargaren et al., 2016) to assess how patient behaviors, experiences and preferences are also shaped by their routines and social norms including health care system structures.

Study setting

Since 2012, Doctors Without Borders (Médecins Sans Frontières (MSF)), in collaboration with the ministry of health of Mozambique, has been implementing different catalytic interventions in Beira to reduce sexual reproductive health and HIV/AIDS related morbidity, mortality and incidence among key and general

population (Medecins Sans Frontieres, 2024). In 2022, MSF commenced a decentralization program of AHD management to 10 primary health clinics, in Beira, to improve early diagnosis and quality of care through a mentorship program. In the clinical mentorship program, trained mentors (clinicians with expertise in AHD care) regularly supported mentees (doctors and consulting nurses) through a combination of on-site, side-by-side mentorship (clinical case reviews, joint patient consultations, supportive supervision) as well as remote support, for 3 months. The mentorship program also included provision of commodities for AHD testing (CD4 cell count instruments and CD4 advanced HIV disease lateral flow tests, cryptococcal antigen lateral flow tests, urine *mycobacterium tuberculosis* lipoarabinomannan tests) to some of the health facilities.

This qualitative study was conducted in selected health facilities that had undergone AHD clinical mentorship and these included Munhava, Manga Loforte and Chingussura health facilities. These 3 health facilities are located within poor-urban settings of Beira. The 3 study sites were purposively chosen as they had ongoing MSF AHD activities including clinical mentorship support and 2 health facilities (Munhava and Manga Loforte) had onsite AHD tests (CD4 cell count, urine *Mycobacterium tuberculosis* lipoarabinomannan antigen and cryptococcal antigen test) and Chingussura had none, Table 1. Munhava is a referral clinic that also receives patients eligible for AHD screening, referred from lower-level primary health facilities. These patients included those initiating antiretroviral treatment, individuals with high viral load, patients who were non-adherent, those returning after disengagement, and those experiencing treatment failure for other reasons.

Selection and recruitment of study participants

- (a). Patients were purposively recruited in 3 health centers (Munhava, Manga Loforte and Chingussura)
- At Munhava and Manga Loforte health facilities, patients were considered for inclusion if they had just completed having a clinical consultation related to AHD and had their blood and or urine samples collected for AHD testing (because they were either initiating antiretroviral treatment, or had a high HIV viral load or if they were non-adherent to antiretroviral treatment and or returned to care after a period of disengagement). Patients referred from other health facilities to Munhava for further AHD screening and management were also invited. This sampling approach allowed us to select individuals who were most likely to provide valuable and relevant information for the study.
 - At Chingussura health facility, patients were considered for inclusion if they had just completed having a clinical consultation related to AHD and were due to be referred (or their blood sample) to Munhava health facility for further AHD screening and management.
 - In all the 3 study sites, patients were identified with the help of the facility health care workers, who assessed their eligibility to potentially participate in the study based on the set criteria. Patients were included in the study if they gave written informed consent and if they were older than 18 years. Patients were excluded from the study if they were seriously ill and needing immediate medical attention.
- (b). HCW selection: consenting counselors, nurses and doctors, directly involved in the provision of AHD services at the 3 study sites were purposively recruited into the study. HCW participants were eligible if they had at least one year's experience in AHD patient management. Researchers contacted HCW directly and consenting HCW were interviewed.

Table 1. Characteristics of study facilities.

Health facility	Estimated cohort size (in year 2023)	Patients eligible for CD4 cell count testing in Q1 and Q2 2023			Standard of care for CD4 testing at the health facility (2023)
		HVL*	New ART [∞] initiation	Poor ART [∞] adherence	
Munhava health center‡	12,831	262	626	112	2 PIMA CD4 instruments (laboratory) and pilot use of Visitect CD4 LFA
Manga Loforte ‡	3,311	143	361	**	Pilot use of Visitect CD4 LFA
Chingussura‡	1421	82	198	**	Samples referred to testing hubs †

Key: * HVL: high HIV viral load. [∞] Antiretroviral therapy. ‡ Primary health care facility. ** This historical data were not available from facility databases. † Hub is a central testing health facility, and a spoke is a peripheral referral health facility.

Sample size for estimation

Among patients, a preliminary sample size of 20 individual interviews and 2 FGDs (each with 3–6 participants), for a total of 26–32 patients; was initially proposed; based on the principles of qualitative research (Vasileiou et al., 2018). However, the final sample size was determined and adjusted primarily by the achievement of data saturation, aiming for an in-depth exploration of patient perspectives and comprehensive coverage of emerging themes. A purposive sampling approach was used to select patients, which included their reasons for AHD screening and gender-balanced considerations to assure a range of perspectives and experiences. Furthermore, pragmatism was considered in sample size estimation, particularly in relation to time and project resource constraints.

The intervention

In the study sites, the study nurse and or study assistant approached eligible patients after they had completed all the routine AHD clinical engagement (with the doctor, nurse, social worker or counselor) and they introduced themselves as well as explained the study to the patients. Potential patients were assured that non-participation was not going to impact their future healthcare access, or work in the case of health care workers. Interested patients were taken to a private room for further details about the study and consenting patients were asked about their preference for an individual interview or in a group. Patient enrollment into the study followed their own will, written voluntary consent to participate as well as permission to audio record the interview.

Health care workers were selected directly at the clinic by personally asking if they had the time and interest to participate in an interview. Due to known professional hierarchies, health care workers were stratified into three homogenous groups (counselors, nurses and doctors/clinical officers) per health facility, to generate comprehensive discussions in the focus group and shared knowledge. We aimed to conduct at least 1 FGD per facility for either professional group. In total, we estimated to have a minimum of 3 FGDs among HCW.

IDIs and FGDs were conducted within the health facility, but in quite and private rooms which were a distance from the busy routine-consultation and patient waiting area. The interview rooms were also deemed appropriate by the interviewees. IDIs were chosen to ensure maximum confidentiality for the people living with HIV to discuss potentially sensitive information whilst FGD were used to enable collective views of the group participants, while also allowing individual opinions.

After the interviews, patient participants were provided with a light refreshment.

Data collection

Semi-structured interview guides with open-ended questions were developed based on the constructs of the social practice theory and literature review (Chenail, 2014; Elliott, 2008; Spaargaren et al., 2016). The semi-structured interview guide had four question domains which sought to explore the patient's: (1). general understanding of AHD (aetiology, diagnosis, prognosis), the associated opportunistic infections as well as the point-of-care tests, (2). experiences from interactions with health care workers and health facilities' services whilst undergoing AHD testing services, (3). balance of economic productivity and health facility visit (4). as well as their preferences for AHD testing services. Patient experiences were defined as a comprehensive measure of how patients perceive and interact with healthcare whilst preferences are their individual choices and desires based on their own experiences, beliefs, values and expectations (Oben, 2020). Interview guides were developed for patients and health care workers (see appendix file 1 and 2). Feedback from research team and experts was sought for content validity and clarity of the questions.

Four experienced researchers, from Mozambique, were trained on study data collection tools and methods, for 3 days. The study interview guides were piloted among 5 people living with HIV undergoing AHD screening and 3 health care workers at Munhava health facility. The pilot interviews, simulating the real process including consent, were conducted whilst also paying attention to clarity of questions, flow, timing and participant understanding. The interview guides were revised based on pilot feedback and validated.

All interviews (IDI and FGD) were conducted in local Portuguese, and participants were also allowed to express themselves in other local languages (Sena or Ndau). The trained researchers were paired with the gender of the interviewees to stimulate unlimited discussions, and this was potentially culturally appropriate. Interviewers worked in pairs, with one person taking notes and observing non-verbal communication and the other asking questions. All participants completed a short socio-demographic questionnaire prior to participating in the interview. Each FGD was also conducted by two researchers to ensure that reliable notes were taken whilst ensuring the full involvement of all participants. IDIs and FGDs were conducted until data saturation was reached, in which no new findings were revealed. The interviewer and note taker agreed on interview data saturation. Each IDI was audio-recorded and lasted 20–30 min. FGDs were also audio recorded and lasted about 30–45 min. After each interview, patient/s were also briefly educated by research staff about AHD and the associated diagnostic tests, as well as the need for increased individual-level awareness and demand for AHD testing services. The MSF project psychologist was available on standby in cases of psychosocial care and support needs for study participants.

After each interview, the facilitator completed a debrief report summarizing key points, participants' openness and/or group dynamics. Daily reviews of the conducted interviews and debrief reports were done with the research team.

Data management and analysis

A unique study identification number was generated for all participants, whilst unique personal identifiers were not collected. All audio-recorded IDI and FGDs were transcribed verbatim, translated into English and the audio recording was verified with the transcription by two independent Portuguese-speaking translators (MIA and MGG). Interview transcripts were analysed through manual thematic analysis, combining deductive and inductive steps (Braun & Clarke, 2019). Two team members, ZN and MGG, who did not conduct the KII/FGDs, led the detailed reading of the full-length transcripts and manually developed an initial codebook. Codes were analysed to generate themes and subthemes, and their respective frequencies were noted. The codebook was shared with the study team for review and input, and a meeting was convened to discuss initial ideas generated, which were presented in tables. Themes emerging during the participant interviews and observations, as well as themes pre-identified by the study team, were also discussed. Meticulous and systematic cyclical reading and coding of the transcripts was done to refine the analysis as well as explore for any emergent categories and themes. Qualitative findings were analysed and reported following the COREQ checklist (Tong et al., 2007). Themes were identified at the individual level, organizational and systemic, as well as interpersonal levels.

The primary outcome was the qualitative descriptions of experiences and preferences for AHD diagnostic testing services among patients and HCW.

Researcher positionality

The research group consisted of international and local individuals (Mozambicans), employed by MSF, except for a few. Some of the researchers were trained healthcare providers, whilst others are qualitative and quantitative researchers. The teams' experience in HIV studies, clinical practice and in-depth local knowledge of Mozambique benefited this study; however, the research teams' roles and identities could have influenced study data collection, analysis and interpretation. To mitigate such influence, the interview guides were developed in conjunction with a representative of the local community group (LB), not employed by MSF and who has extensive experience working in the local settings as well as collaborating with community members who have recovered from AHD. Also, a Mozambican researcher not employed by MSF (MIA) was also involved in data management and analysis. Further, all interviewers were fluent in local languages (Portuguese, Sena and Ndau), and this facilitated communication in the participants' preferred language. For data analyses, ZN took an etic view while MGG took an emic view, and all team members helped with interpretation. To strengthen the study's methodological rigor and transparency, meetings were held with the research team to reflect on the iterative process of data review, including preliminary results and discussion. Reflections were also made to assess how individual perspectives may have influenced data collection, analysis and results reporting.

Ethical considerations

The study was approved by the MSF ethical review board committee (2156), the Mozambique National Committee on Bioethics for Health (85/CNBS/22) and the Stellenbosch University Health Research Ethics Committee (S23/11/298). All methods were carried out in accordance with relevant guidelines and regulations.

Potential study participants had the study explained to them, including its purpose, risks and confidentiality. Patients provided written consent to participate and be audio-recorded, whereas HCW provided oral consent. All FGD participants signed confidentiality agreements not to share information discussed outside the group and permitted to have the sessions audio recorded. A stipend was provided to all patient participants in accordance with the recommendations of the local ethical review board.

Results

Characteristics of patient study participants

From 12th to 29th February 2024, a total of 18 patient IDIs, 2 patient FGDs and 3 FGDs for HCW (1 for nurses, 1 for counselors and 1 for doctors) were conducted in Beira (Mozambique). Only 3 patients opted not to participate in the study as they were in a hurry to leave the health facility. Among all the 24 patient study participants, the median age was 32.5 years [IQR: 30–39]. Most participants had completed primary school as their highest level of education (13/24; 54%) and 79% were engaged in informal trading (19/24), [Table 2](#). The majority of participants were undergoing AHD screening because of high HIV viral load (14/24; 58%) and the median time on ART was 33 months [IQR: 15–93].

Table 2. Characteristics of patient study participants.

Variable	Proportion, n (%)
Total	24
Sex	
Female	13 (54.2)
Male	11 (45.8)
Median age (years) [IQR]	32.5 [30–39]
Marital status	
Single	12 (50)
Married	10 (41.7)
Widowed	1 (4.2)
Other	1 (4.2)
Highest education	
No school	2 (8.3)
Primary school	13 (54.2)
Secondary school	9 (37.5)
Tertiary school	0
Occupation	
Unemployed	3 (12.5)
Student	1 (4.2)
Domestic	6 (25)
Informal trader	13 (54.2)
Formal salaried	1 (4.2)
Reason for AHD testing	
High HIV VL	14 (58.3)
Return after disengagement	4 (16.7)
Poor ART adherence	5 (20.8)
Time on ART (months)	
<12	0
12–24	6 (27.2)
24–36	8 (36.4)
>36	8 (36.4)
Median time on ART (months) [IQR]	33 [15–93]
Health facility	
Munhava	14 (58.3)
Manga LoForte	4 (16.7)
Chingussura	6 (25)
Referral	
Yes	4 (16.7) *
No	20 (83.3)

Key: *From Mafambone and Matadoro health posts to the Munhava health facility.

Central themes from patient experiences and preferences

These study findings were synthesized into five primary themes, which include (1) general knowledgeability about AHD and the POC diagnostic tests; (2) interpersonal communication environment in health facilities; (3) efficiency in the health facility; (4) competing priorities and life's trade-offs whilst accessing AHD testing services; (5) preferences for AHD testing services.

Theme 1: knowledgeability about AHD and the associated diagnostic tests

Patients described a limited understanding of AHD, especially its definition and associated diagnostic tests even though most of them stated that this was explained to them.

the nurse explained what AHD is, but I have forgotten. IDI, male, 42years; IDI, female, 40years; IDI, male, 32 years.

the nurse collected blood from me and said it's for CD4 testing, but I don't understand what CD4 is. But I think that CD4 can only be something to control my own health. FDG, female, 37 years.

Patients also expressed limited knowledgeability of other associated point-of-care tests for AHD. Patients spoke of merely following the instructions of doctors and nurses on tests to be done and highlighted that they must oblige and follow what they are told to do, as failure can result in health deterioration.

the doctors know what tests need to be done on us and they have the power. IDI, female, 28 years.

Patients expressed the desire to be better empowered to understand AHD and associated tests, which could help them to make informed decisions concerning their treatment, condition and future care needs. Respondents emphasized that more detailed infographic education material could be useful to empower them to understand AHD, and this could also be discussed with peers and within community differentiated HIV service delivery groups.

One female patient explained her desire.

in the community, everyone has this blue-tooth music playing devices and why can't they also send us some information on AHD in these other types of devices like phones and radio. FGD, female, 46 years.

Theme 2: interpersonal communication environment in health facilities

Patients expressed quite differing views and opinions regarding the atmosphere that makes them feel comfortable speaking up, asking questions and being actively involved in discussions with HCW about their health. Some patients described feeling rushed in most consultations, with limited desire from HCW to understand their needs and perspectives.

sometimes I find the doctor with a face that scares me and I cannot ask any questions and the consultation finishes quickly. IDI, female, 36 years.

Other patients appreciated the time and effort they received from health care workers and highlighted the importance of health care workers showing concern, respect and a non-judgmental attitude, especially as patients can contribute to their healthcare. Patients described this as empowering and encouraged them to be open.

initially, I was even afraid to come here to the hospital because I had stopped taking the medicine. But when I got here, they welcomed me well and explained to me the dangers of stopping the medicine. Nobody shouted at me. I liked it. I am not going to stop taking my medicine again. IDI, male, 56 years.

One male participant characterized nurse providers by noting that, "they warmly welcome us, they are happy and interested in us". IDI, male, 38 years.

Theme 3: efficiency in the health facility

Concerns regarding the long turnaround time for AHD test results (which took a month or more) were very common, with nearly all patients being unhappy with the delays and the need to come back for further

testing. The uncertainty of “not knowing” when one’s AHD screening results will be issued was perceived as a threat and resulted in feelings of fear, as illustrated by this quote:

I am always worried about my health status and scared of the likely outcome of test results, especially as the outcome comes after a month. I am anxious not knowing what type of medication they will give me. Right now I am taking medication every three months in the facility and I don’t know if they will change that and make me come here everyday for medication. IDI, female, 33 years.

Some patients described many service points that people living with HIV must navigate, making it difficult to quickly move through the health facility.

Sometimes I must go through a lot of rooms (in the health facility) and in all those rooms, I must follow queues. I end up leaving at 2 pm since morning. ID1, female, 39 years.

I always come with my mind prepared for these delays and disappointments that I will face, especially as I may lose the whole day being here. FGD, male, 27 years.

Some patients described health facilities misplacing their healthcare files, as illustrated by the below quote.

today I was very confused and angry when I arrived. I did the tests last month hoping to see the result today. Its been a couple of times now that when I arrive, they tell me they cannot find my file and they end up having to generate me a new file. IDI, female, 38 years.

Patients felt that doctors and nurses should articulate the available options for AHD testing so that patients could come to an informed decision as to which testing options could be convenient and acceptable to them.

I don’t know what PIMA CD4 instrument is, but I already know about Visitect CD4 test as I saw it earlier. I liked Visitect (CD4 lateral flow test) because it’s a little bit fast, it doesn’t make me stay for a long time at the clinic. It will be good if doctors always tell us about testing options that can help give quick results. IDI, male, 35 years.

Some patients described being referred to other health facilities as an inconvenience

I leave home at 5 o’clock in the morning to go to the clinic, then when I got there, I was referred to another clinic. Being referred means I must skip work. I end up being lazy and stop taking treatment and tests. I prefer to have everything in the clinic next to my place. IDI, male, 39 years.

Theme 4: competing priorities and trade-offs in accessing AHD testing services

Patients reported that regular visits to health facilities disrupt their daily routines and negatively impact their economic productivity, especially when they have to spend nearly an entire day at the facility and sometimes leave without receiving the help they expected from HCW. This is highlighted by the following quotes.

I must come back several times for my medication, which is tiring and costly. I spend the whole day at the hospital waiting, which makes it hard to manage my other responsibilities. FGD, female, 44 years.

this requirement for repeated and frequent visits is a problem for me. I prefer going to the clinic that is close to my home because I can quickly get back to work. FGD, male, 29 years.

Participants said that the travel time and costs associated with visiting the health facility were also a burden in their lives.

some of us struggle to find money for transport to the clinic. IDI, female, 38 years.

Theme 5: preferences for AHD testing services

In the IDIs and FGD, patients expressed the challenges of accessing “traditional AHD testing” models and expressed their personal preferences. The remarkable preference by patients was the desire to have access to AHD screening in the communities using simplified tests, and this was particularly among patients with prior experience with ART.

If this portable CD4 test (Visitect) can be usable in the community, it can help because we suffer by walking too much coming to the health facility and sometimes, we don't have the money for the chappa (taxi). IDI, female, 32 years.

Preferences also included improved ways of communication and education about AHD.

I would like to hear about AHD in the radio, or even television too, for everyone to listen and know what CD4 is. FGD, female, 38 years.

I would like that when people come to health facilities, they leave happy, not sad. IDI, male, 41 years.

Central themes from health care worker interviews

The FGD among counselors had 3 males and 1 female, whereas the FGD for nurses had 5 nurses (3 females and 2 males). The FGD for doctors had 2 males and 4 females. One was a doctor, and 5 were clinical officers (assistant medical officer (diploma). Two FGDs were conducted at Munhava health facility (doctors and counselors), whilst one was conducted at Manga Loforte (nurses). All participants were between 25 and 53 years old and had 1–6 years of experience in AHD-related work.

Three primary themes emerged, and these include: (1) AHD workload for health care workers (2). Patient's knowledgeable and uptake of AHD services (3). HCW preferences for AHD services

AHD workload for HCW

In the FGD, doctors described seeing an estimated 10 patients per day, per doctor, for AHD screening and or management and that each patient consultation lasted about 15–20 min. However, doctors described that for newly diagnosed HIV patients and clinically unstable patients with AHD, the consultation could last between 30 and 45 min and that they request urgent testing results for these patients.

Most providers (92%) confirmed they receive significant numbers of patients for AHD screening and management referred from different PHCs but felt that most of the patients could be managed at the referring PHC.

clinical mentorship together with AHD tests should be provided to lower tier health facilities so that they can manage most of the AHD patients. FGD, male, 44 years.

A HCW recounted one patient explaining how his life is made difficult by these referrals to a higher-level health facility, which is far from his home.

Patient uptake and knowledgeable on AHD services

HCW, especially counselors and nurses, expressed the difficulty that people living with HIV have in processing the word "AHD" when told about the stage of their disease.

speaking about AHD is usually a sensitive topic. The mere mention of the word "advanced" makes many patients scared but they seem to ultimately understand that it really means a serious illness. So, it is very important for us to explain and educate them about AHD. FGD, female, 36 years.

A counselor further expanded that the term "AHD" is less stigmatizing and less synonymous with death as compared to using the word "AIDS" but still clarifies the urgency of care needed and the high risk of death.

AHD is more appropriate a term to use to describe the patient's condition than AIDS and patients seem to understand that their HIV stage is now critical and needs urgent medical management. FGD, female, 36 years.

Most HCW, especially counselors and nurses, insisted that most people living with HIV still did not understand what AHD is and the associated point of care tests, as the following quote highlights.

Most patients don't understand firsthand what is AHD, and that is where our role as counsellors comes in. It's our mission to make them really understand and the steps that will be taken. We use posters that illustrate the stages of HIV. We can even explain in local dialect languages, especially to the elderly who have difficulty communicating in Portuguese. FGD, female, 33 years.

majority of the patients don't understand the associated diagnostic tests for AHD. We explain these and the benefit of doing these tests and people living with HIV end up understanding. FGD, female, 39 years.

HCW preferences for AHD services

In the opinion of health care workers, use of POC tests with immediate issuance of results could improve patient satisfaction and convenience for AHD diagnostics and services, as illustrated by the following quotes.

true point-of-care testing for CD4 can help improve satisfaction of patients for AHD services. In health facilities that have PIMA CD4 instrument in the laboratory, just like here in Munhava, the result flow is still not fast enough because most patients that have blood samples collected to do the CD4 cell count test, have to come back a month later for their results and other tests like Mycobacterium tuberculosis lipoarabinomannan antigen, but some patients do not come back again. FGD, male, 44 years.

A counsellor in the FGD added that “the Visitect CD4 test is better performed by us as well as other AHD tests (urine Mycobacterium tuberculosis lipoarabinomannan antigen and cryptococcal antigen). We are already trained in conducting all of them. As the colleague was saying, our patients are special. So, it would be very practical for us, because we already know the patients and we are working with them. FGD, female, 33 years.

According to HCW participants, a decentralized AHD screening model in the community could include distribution of simplified CD4 lateral flow tests within differentiated service delivery models or via peers or community health workers.

we need to think about how we can actively find people who need AHD screening rather than waiting for them to come to the HIV clinics on their own. FGD, male, 44 years.

Discussion

This study assessed experiences and preferences of patients when engaging in AHD testing services, and the study findings suggest that significant numbers of people living with HIV, within the poor-urban setting, have limited knowledgeability about AHD but desire to have AHD screening tests in the communities. The implementation and provision of AHD testing services should include enhanced patient empowerment as well as considerations for decentralization of simplified AHD screening tests into communities. This could strengthen approaches for person-centred care in screening for AHD, improving patient convenience, and addressing access barriers.

Many patients had limited knowledgeability about AHD, a finding consistent with results from another study (Pita et al., 2025). Nonetheless, most expressed a desire to be better informed to make decisions about their healthcare, while others preferred a more passive role, relying on healthcare workers' guidance. The term AHD was introduced in 2017 by the WHO (World Health Organization, 2017), and it may not have effectively reached communities, resulting in poor understanding and subsequently low demand for AHD-related interventions. Unlike the extensive campaigns for HIV viral load testing (Activist toolkit: campaigning for routine HIV viral load test, 2016; Hans et al., 2023; The South African National AIDS council), we could hardly find large campaigns promoting awareness of AHD and CD4 testing. AHD programs should invest in meaningful empowerment of people living with HIV through a multi-channel approach of information, education and communication, combining print, interpersonal (through peers), digital and multimedia; tailored to local context and languages. Studies have shown that involving patients in their own care has many benefits, including increased patient empowerment and satisfaction (Birkeland et al., 2022; Sikombe et al., 2025).

A healthy patient – health care worker interpersonal communication was experienced by some patients through gestures of genuine care and receptiveness by health care workers. This meaningful presence of health care workers has been recognized in other studies. For example, Carol D Rose *et al.* demonstrated that respectful provider-patient relationships where providers listen to and validate patients' experiences, led to greater trust, better engagement and improved outcomes (Dawson-Rose et al., 2016). Also, as most patients undergoing AHD screening are receiving ART (Stelzle et al., 2025), health care worker training on empathy and respectful relationships is still necessary, as studies have shown that clinic staff attitude can influence health outcomes (Burns et al., 2022; Loveday et al., 2024).

Patients identified several key factors that contribute to inefficiencies within the health facility, and these include prolonged lead-time for AHD test results, multiple service-points, long queues and occasional referrals to other health facilities. Despite these challenges, patients' engagement in AHD testing services also

appeared to be shaped by competing life priorities, with survival and economic productivity sometimes taking precedence over healthcare needs. Although not examined in depth during the interviews, it is evident that for people living with HIV in impoverished settings, the immediate struggle to secure economic survival can often overshadow concerns about AHD, which may be deprioritized amid daily life hardships. This finding is consistent with other studies that have shown that daily survival activities (market trading and other informal work) can take precedence over healthcare visits, as lack of income can immediately disrupt their critical livelihood (Mwamba et al., 2018; Poudel et al., 2017). The welcome back package campaigns, which provide non-judgemental supportive return for people living with HIV who have interrupted treatment (Arendse et al., 2024; World Health Organization, 2024b), have been shown to increase retention and treatment acceptance for re-engaging patients. Applying such friendly “welcome package” strategies, not only to those disengaged from care, but also to people living with HIV with AHD could improve demand for screening and health outcomes.

The strong willingness for decentralized AHD screening tests, particularly among patients with prior experience in ART, suggests that familiarity and experiences with the health facilities may be key to this desire. To reach more persons eligible for AHD screening and diagnose them sooner, it may not be enough to wait for them to come to health facilities for testing, future studies should explore pilot introduction of simplified POC CD4 tests within differentiated service delivery models for ART in the community. Such testing could be focused on identifying a few who may be clinically unwell, or with virological failure, or those likely to disengage or with a history of disengagement, among other reasons. Such studies could also explore the willingness of people living with HIV to be tested in the community without any increased risk of harm, even though studies focusing on HIV self-testing in the community showed that risks were no greater compared with other HIV testing services (Pasipamire et al., 2020). CD4 testing in the community could be through differentiated HIV service delivery group leaders, peers or community health workers, and this can help to identify patients eligible for further care at health facilities. While not explored, simplified tests for CD4 count in the community, can be based on skin prick, with no specialist equipment to administer or interpret and these could be similar or better than the Visitect CD4 lateral flow assay (Ndlovu, Masquoui, et al., 2020, 2025).

Health services, designed for AHD screening and management, risk failing to achieve maximal impact if they do not take the patients’ considerations into account, particularly in poor settings where people living with HIV are mostly in “survival mode”, and may be considered “outlier patients’ who fall through the cracks.

Findings in context

Study findings suggest that significant numbers of patients are not knowledgeable about AHD and that the implementation and provision of AHD testing services are incomplete without enhanced patient empowerment and considerations for decentralization of testing services into communities. There is a need to explore possibilities of non-health facility-based testing modalities for CD4 measurement using simplified lateral flow tests to screen for AHD in the communities. Considerations should be made on how this intervention can be integrated within existing HIV differentiated service delivery models for HIV, many of which involve infrequent interactions between patients and health facilities. This could be crucial in strengthening approaches for person-centred care in screening for AHD, improving patient convenience as well as addressing access barriers, especially as majority of patients with AHD are already on ART. Community advisory boards and other civil society advocacy groups in local settings can be engaged to advise on AHD testing in the community. Our findings highlight the importance of providing AHD testing services in ways that encourage patients to engage in earlier diagnosis.

Limitations and strengths

All patients were from a poor urban setting, less likely to have a tertiary education, and mostly employed in the informal sector, which may limit the generalizability of our findings. The study also failed to have more than 1 FGD per health care worker professional group due to the limited number of health care workers in health facilities. There was a potential loss of nuance in translating FGDs and IDI recordings from

Portuguese to English; however, we tried to minimize this with the involvement of a native Portuguese qualitative researcher who cross-checked the translations. The main strength of this study is that it has helped to provide an understanding of the patients' preferences for AHD testing services. The flexibility of purposive sampling and qualitative data collection helped to provide detailed and rich preference perspectives from patients.

Further research studies could explore pilot implementation of community-based AHD screening using simplified CD4 lateral flow tests. Future studies can also explore how preference research findings are translated into national policy/guidance and how HCWs practically integrate experiences and patient-centred preferences into clinical care for individual patients.

Conclusion

The study shows the complex realities faced by people living with HIV when engaging in AHD testing services, and findings highlight the need for enhanced patient education and empowerment, as well as considerations for decentralization of AHD screening test services into communities. Researchers, implementers, and policy makers should consider integrating patients' experiences and preferences into global and national AHD implementation practise and guidance, which so far has been limited.

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No potential conflict of interest was reported by the author(s).

Data availability statement

The dataset used for the current study will be available from the corresponding author upon reasonable request.

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