

Factors influencing adherence to antiretroviral therapy from the experience of people living with HIV and their healthcare providers in Sierra Leone: A qualitative study

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Abstract

Background: Antiretroviral therapy is the main drug for the treatment of Human Immunodeficiency Virus, slow disease progression, and reduce the spread of infection. HIV treatment is also known to require high level of adherence of over 90% to achieve good treatment outcomes and viral load suppression. In Sierra Leone, it is estimated that about 70% of PLHIV are non-adherent in their first year of treatment. Understanding the reasons behind this high-rate of non-adherence is critical for the development of strategies to improve adherence. This study identifies the barriers and facilitators influencing adherence to antiretroviral treatment in Sierra Leone.

Methods: A qualitative study design using in depth interviews was conducted in two districts in Sierra Leone – Freetown and Bo. In-depth interviews were conducted with 4 health care workers and 16 people living with HIV.

Results: Several facilitators and barriers to Antiretroviral therapy(ART) adherence at the personal, community, and health system levels were identified. The facilitating factors included perceived benefits of ART, family support, having a treatment partner, receiving free ART medicines and belonging to peer support groups. The barriers included denial and non-disclosure of HIV status, frequency of medication, use of traditional medicine, lack of money for food and transport, stigma and discrimination, work barriers, lack of medicines and test kits, limited health workers and long distance to clinics.

Conclusions:

The key emerging themes arising from different health system level in this study include Support from families, treatment partners and the need for peer support groups. Understanding the facilitators and barriers to antiretroviral therapy identified in this study can improve adherence and provide relevant information for more responsive and equitable program implementation in low and middle-income countries. There is the need for implementing adherence augmentation programs with implementation of activities that will improve community knowledge for prevention and reduction of stigma and the need for integrating HIV treatment services close to communities.

Background

The global commitment to Fast-Track the HIV response and end AIDS by 2030 is not on track(1). There were almost 700,000 deaths from AIDS-related causes and 1.7 million people with new HIV infections in 2019 (2). In Africa, despite improvements in HIV prevention, testing, and treatment, HIV/AIDS remains one of the leading causes of mortality, with more than 400,000 deaths on the continent in 2019. Of the estimated 25.8 million people in Africa living with HIV in 2019, 4.3 million were not diagnosed, and a further 3.4 million were not receiving antiretroviral treatment (ART) (1). In Sierra Leone in 2019, an estimated 78,000 people were living with HIV (PLHIV), with only 48% knowing their status and only 43% receiving ART (1).

The mainstay for treatment of people living with HIV/AIDS is a combination of antiretroviral drugs. ART stops HIV from multiplying and can suppress HIV to undetectable levels in the blood, allowing a person's immune system to recover, overcome infections, prevent the development of AIDs and reduce the risk of HIV transmission (2). Adherence describes how a person uses and receives treatment according to medical recommendations, including timing, dosing, and consistency. HIV treatment requires a high level of adherence of over 90% to achieve good treatment outcomes and viral load suppression (3)(4). Adherence can be challenging for example, in one hospital in Brazil, under 20% of people living with HIV did not stay on ART(5). There are many barriers and facilitators to adherence. Barriers include medication and health concerns, stigma, family responsibilities, and problems with schedule and routine(6). People with better socioeconomic status related to income, education, and employment status were more likely to adhere to

treatment than patients with poor socioeconomic status(7). Expansion and decentralization of HIV/AIDS services allowed for implementation at the community level and increased collaboration through task sharing between health professionals, thereby increasing timely access to treatment for patients and overcoming limited human resources in hospitals (8). Interventions that focus on early ART initiation and groups of people who are more likely to drop out of treatment, can improve adherence(9).

There are many challenges with ART services in Sierra Leone. In 2011, a study revealed that 70% of people living with HIV remain on treatment for less than one year after initiation of ART with an estimated survival rate of 92%, but this study did not follow non-adherent patients and could not identify the factors affecting adherence to ART(10). A cohort study at the main tertiary hospital in Sierra Leone showed that 62% of eligible ART patients stopped care before initiating ART(11). The study also identified the main barriers to adherence to ART as a lack of understanding of the importance of treatment adherence due to poor relationships and communication between people living with HIV and healthcare professionals. The study recognized the need for context-specific interventions to support adherence that considers access to medicines, care, and support for people living outside the capital city of Freetown.

HIV/AIDS research in Sierra Leone has mainly focused on describing ART adherence, and in one hospital, with little attention given to exploring the health systems and socioeconomic factors affecting adherence to ART.

There is a gap in the evidence about the barriers and facilitators around adherence to ART in Sierra Leone. Understanding this from both people living with HIV and health care providers is critical to developing interventions that support adherence to ART. This study will provide relevant information for decision-makers, public health professionals, and clinicians on implementing more responsive and equitable ART programs that will improve adherence and the quality of life of people living with HIV.

Methods

Study Site

The study was conducted in the two main referral hospitals in Sierra Leone: Connaught Hospital in the capital city of Freetown and the Bo government hospital in Bo, the second major city in Sierra Leone (see Fig. 1).

Freetown and Bo districts were deliberately chosen as they are the two districts with the highest prevalence of HIV/AIDS in Sierra Leone, with rates of 2.7 and 1.8 in Freetown and Bo, respectively(12). Connaught hospital is a 300-bed hospital that houses an HIV/AIDS clinic and ward and serves as the main referral center for adult HIV/AIDS care in Freetown. Bo government hospital is a 500-bed hospital with a clinic and ward for people with HIV/AIDS.

Study design and sample

A qualitative study design employing in-depth interviews was used to explore the barriers and facilitators to adherence to and provision of ART (13). Qualitative interviews generate in-depth and contextual information about an individual's experiences, beliefs, perceptions and explore reasons behind their answers through probing questions (14). In-depth interviews with four (4) healthcare workers and sixteen (16) people living with HIV were employed to explore the complexities of the issues related to adherence to ART. The research adapted a triangulation strategy by comparing patients' and healthcare workers' views to enhance the integrity of the findings (15).

Purposive sampling was used to select participants based on features or characteristics that will enable a detailed understanding of the topic (16). In each hospital, the list of people living with HIV was reviewed to select patients that are adherent or non-adherent to treatment, who were receiving ART treatment and care at the health centre for at least

one year and attended the clinic at the time the research was conducted, was aged 18 years and above and spoke English or Krio. Healthcare workers (medical doctor, community health officer, the counsellors, and the nurse) involved in the care of people living with HIV were selected.

Data collection

Interviews with people living with HIV were conducted by the lead author, in Krio language, in a private room in the HIV clinic at Connaught Hospital and the Bo Government Hospital and lasted between 45 and 60 minutes. A topic guide was used to explore the background of participants, their experiences with ART, barriers and enablers to using ART services, and concerns about taking ART and other services related to ART. The lead author interviewed the health workers in English in the hospitals' offices and lasted up to 60 minutes. Using a topic guide these interviews focused on the background of participants, their roles and responsibilities in ART provision, their perceptions and experiences of people's adherence to ART, and their role in improving adherence to ART.

Data analysis

The recordings were transcribed verbatim. Where necessary, the recordings were transcribed in the local language (Krio) and then translated into English; and a sub-set was checked against the recordings for quality of transcription and translation. The interviews were analyzed using thematic framework analysis(15), and data were managed using NVivo 11 programme. A coding framework was developed based on themes emerging from the data. The coding framework was applied to transcripts of all interviews, charts were then developed for each theme, and these charts were used to describe the themes.

Results

Participant characteristics are included in tables 1 and 2. Sixteen PLHIV were interviewed – 8 from Bo and 8 from Freetown. The majority were female (11), adherent to ART (9) and employed (9). Four health workers were interviewed with two from each study site. Three health workers were female.

Table 1

characteristics of PLHIV in the interviews

More female in Bo population than in Freetown and more employed participants in Freetown than Bo and more female among the Bo participants than in Freetown.

Study site	Adherence to ART		Gender		Age (years)			Work		Total
	Adherent	Non-adherent	Female	Male	24-35	>35-45	>45	employed	Unemployed	
Bo	5	3	7	1	3	3	2	3	5	8
Freetown	4	4	4	4	4	3	1	6	2	8
Total	9	7	11	5	7	6	3	9	7	16

Table 2

characteristics of health workers in the interviews

Study site	Type of health worker		Gender		Age (years)		Total
	Clinician	Counsellor	Female	Male	20-30	30-40	
Bo	1	1	2	-	1	1	2
Freetown	1	1	1	1	-	2	2
Total	2	2	3	1	1	3	4

Facilitators and barriers to adherence to ART

The study revealed several facilitators and barriers to ART adherence at person, community and health system levels (Figure 2).

Person level

Perceived benefits of ART

Most participants were positive about the effects of ART especially when they were able to take the medication as prescribed and had regular appointments for follow-up. They explained that HIV care had improved their quality of life and health status.

"I felt very good when I started taking the medicine at the time I was confirmed HIV positive. Currently, I'm not feeling good and I am losing weight[...] I was informed at the treatment centre that my blood is low and I believe it happened because I missed my appointment for medicine pick up. Now I have started treatment and I'm beginning to feel great again". (Non-adherent Female, Bo)

Family Support

Support from family members is essential in providing hope for survival of PLHIV as highlighted by a healthcare worker:

"so if there is strong support from the family, it will be very good. We need to pass the message to the family and relatives so that they will be able to support these people. If you stigmatize PLHIV, they will lose hope for survival. That's why family is more important because they spend about 90-95 percent of their time with them" (Male Health worker, Freetown).

A patient also noted that it was important to have a treatment partner that will provide additional support for adherence to ART medication.

"I informed my small sister that the medication am using is for prevention and she must remember me in the morning and at night to take my medicine. She has been informing me on a daily basis."

Denial and non-disclosure of HIV status

Many PLHIV reported that they were frightened of disclosing their HIV status to their partners for fear of their relationship ending. One woman explained that her husband gave her money and sent her back to her village:

“My husband is a soldier so I was taken to the hospital where he works. He received the test and informed me that I am HIV positive. I did not believe him initially. He said we cannot continue the relationship. He informed me that it is possible that I may have contracted the disease from my work as a hairdresser (used needle and comb). He therefore asked me to return to Bo and gave me Le150,000 (£15 or \$19) as hospital cost. At the hospital, I was tested and confirmed again to be HIV positive. I was encouraged to commence medication and advised to meet the requirement of monthly appointment”

(Adherent Female living with HIV, Bo).

Many PLHIV reported not disclosing their status to other members in their family. Others spoke about being told not to speak about their HIV status with anyone as this would result in being harassed or ostracized.

“you know as for our own health condition people normally hide it. It’s not like headache that you will easily disclose. It has to be kept secret. We were advised not to disclose it to anyone because if you disclose it to people they will start pointing fingers at you that you are HIV positive. That’s why we are always advised not to disclose our status and to continue taking our medications” (Adherent Female living with HIV, Bo)

Health workers also reported that many PLHIV do not disclose their status in families, and some go to the extent of losing all their medication to keep their status a secret from their partner.

“Most of our patients do not give us the correct information about their partner [...] they usually say, my husband is not here, my husband has travelled[...]someone who is married and does not disclose their status to their partner [...] when it is time for that person to take their medication it becomes a problem” (Female Health worker, Freetown).

Medication issues

Some PLHIV reported that the taste and size of the medicines deterred them from keeping to the treatment regime. Healthcare workers expressed concerns about the frequency of ART leading to difficulties in adherence to the regime.

“it’s difficult to take a drug every day of your life especially with the kind of pills and the daily intake that is required coupled with other additional blood medicines” (Female Health worker, Bo).

“For me it is the big tablet [...] when I started taken the medicine at first, because of the taste I usually vomit” (Adherent Female living with HIV, Bo)

Use of herbal medicines

Some PLHIV reported feeling better and stopped taking their ART with the belief that traditional herbal medications will help provide long-lasting solution but eventually became seriously ill.

“It was last year that I stopped taking the medication. This year I was asked to take HIV test again when I started feeling sick. I informed the healthcare professionals that I was using herbal medication to treat HIV” (Non-adherent

Male living with HIV, Freetown).

Money for food and transport

Many PLHIV reported that they found it difficult to continue working and earning money when they were ill. This impacted on their ability to buy food which they need when they take ART and pay for transport to get to the health facilities. They relied on friends or relatives to provide food and help with transport, but often felt embarrassed to ask for help.

"The little money I had is no more and there is nothing left at the moment [...] if they will help with supply or money [...]so that when I regain my health i will be able to start my business and support my children" (Non-Adherent Female living with HIV, Freetown).

Healthcare workers also indicated that many PLHIV did not continue their treatment because of lack of food or money for transportation. They also reported that food was only provided for PLHIV who were underweight.

"I'm not taking the medications because I do not have food [...] others will say i do not have transport [...] we have a system for providing food for people with low body mass index and that is all at the moment" (Female Health worker, Freetown).

Community level

Treatment partner

Many PLHIV and healthcare workers recognized the importance of having a treatment partner to help with adherence to ART: *"it is good for someone living with HIV to have a treatment partner" (Female Health worker, Freetown).*

Health workers and PLHIV also recognized the importance of acceptance of partner status and prescription refill by the treatment partner.

"imagine the man is negative and the wife is positive but yet still he is here to collect the medication for the wife" (Female Health worker, Bo)

"so my daughter normally comes for my medication" (Female Health worker, Bo)

Stigma and discrimination

Many PLHIV reported experiencing stigma and discrimination because of their HIV status from family, friends and community members. They explained that HIV/AIDs is still regarded as a taboo subject, that stopped them disclosing their status, discussing care and treatment and getting help.

"Yes, initially I was staying with my husband's relatives[...]when they discovered that I had the virus [...] they started laughing at me [...] they started throwing provocative words at me, they don't even give me food to eat and they finally asked me out of the house (crying) [...] Just look at me, my hair is not even neat because I don't have someone to do it for me". (Adherent Female living with HIV, Bo).

Some PLHIV stated that frequent ailments and weight loss is associated with HIV by their community, and when they start ART and put weight on they are accepted, as one person explains here:

“Initially when I got the disease, my friends were not talking to me properly because I was constantly losing weight but now they feel free to talk to me and they come closer to me. Thanks to God for that [...] I didn’t inform them about my condition [...] they would have been afraid of me if I had informed them earlier of my status.” (Adherent female living with HIV, Bo).

PLHIV also reported fear of discrimination in the workplace, and therefore did not disclose their HIV status to their employer or colleagues, and changed their times for medication:

“initially I was taking my medication at 9 O’clock but then I noticed that it will give me problem at my work place [...] I decided to take it before leaving my house.” (Non-adherent Female living with HIV, Freetown).

Health care workers also reported many examples of PLHIV experiencing stigma and discrimination such as lack of support, fear of death and not sharing toilets and items such as cups and cutlery. This influenced how PLHIV were able to access and adhere to ART, as well as having profound effects on their mental health.

“Look at this lady for example she came this morning crying [...] she is staying with her mother. This is what she said, my mum said I’m going to die soon. She came crying and I told her to wait for me for a while and all these days she has been coming here saying that her mum hasn’t been supportive to her [...] She said If my mum is not ready to support me how will I survive?” (Female Health worker, Freetown).

Work barriers

Most participants reported improvement in their health when they were taking their medication. However, many found it difficult to take the drugs regularly when they were working and often missed their medication during work hours.

“well the medication is good because if you are on medication for a certain illness and you see improvement then it’s good [...] I miss my medication when I go out for work” (Adherent Female living with HIV, Bo).

PLHIV faced discrimination in the workforce (as described above) and a woman spoke about losing her job because her employer observed her taking medication at the same time every day.

“when I am taking the drug, they are watching me [...] I was informed that If I know that I have a disease and I am taking a drug let me be careful [...]so when it’s time to take the drug, I would think of my life and my only daughter [...] So, I would usually take the drug. Later I was then dismissed from my duty” (Non-adherent female living with HIV, Freetown)

Health system

Free medicines

Healthcare workers emphasized received ART free and also mentioned the importance of ensuring that ART continue to be free for PLHIV in LMIC, as the high cost of these drug would prohibit uptake by PLHIV.

“I think when it comes to the fight of HIV, I think the medication should be free. So, if the medication is free it will help most of our clients[...]the cost of their medication is too high” (Female Health worker, Freetown).

Good relationships with health workers

PLHIV reported the existence of good interaction with healthcare workers involved in their treatment. They mentioned that health workers encourage them to take their medications attend clinic and reassure them to take their medication to maintain good health and wellbeing.

“They treat me well and they also encourage me. The first day that I came to the hospital I was so discouraged but the nurse talked to me and really encouraged me” (Adherent Female living with HIV, Bo)

Limited numbers of skilled health workers

Healthcare workers expressed concerns about the burden created by the small number of health staff working with PLHIV. They mentioned that this will allow them to spend more time in reviewing the wellbeing of patient, while allowing other staff to focus on drug-therapy related issues.

“I will love to have another staff that would help us to assess patient (Female Health worker Bo).

Lack of medicines and tests

Healthcare workers reported a lack of ART medicines and test kits that are used in caring for PLHIV. They explained that drugs and test kits are provided by donor organizations, and that there are frequent delays in procurement.

“...in terms of HIV care you go anywhere there is the issue of drug stock out and [...]test kits shortage are all the problems we encounter” (Female Health worker, Bo).

Distance to health facilities

PLHIV reported that they had long distances to travel to the ART clinics. In Bo, people would travel at least 30 minutes, and this would cost about £1. In Freetown, people would travel for an hour to reach the clinic, which would cost them about £2. The average weekly wage in Freetown is about £3.4 for workers that participated in this study or nothing for those without a job. They requested for ART services to be closer to their homes.

“They need to bring the health facility closer to my community, if it is possible because there is no health facility where I live” (Adherent Female living with HIV, Freetown).

Discussion

The study revealed several facilitators and barriers to ART adherence at the personal, community, and health system levels. The facilitating factors included perceived benefits of ART, family support, having a treatment partner, receiving free ART medicines, and good relations with health workers. The barriers included denial and non-disclosure of HIV status, frequency of medication, use of traditional medicine, money for food and transport, stigma and discrimination, work barriers, lack of medicines and test kits, limited health workers and long distance to clinics. Here we discuss three key areas that have emerged.

Support from families, treatment partners and peers is needed

Most healthcare workers and PLHIV revealed that support from close family members and having a treatment partner was very important in improving adherence among people living with HIV/AIDS(PLHIV). The likelihood for adherence and improvement in quality of life was more prominent among patients who informed their spouses of their status. Other studies revealed that non-disclosure of positive HIV-status can lead to HIV transmission, treatment discontinuity, poor health outcomes and difficulty in HIV prevention and control(17)(18)(19). Other studies clearly indicated the importance of including family members and other treatment partners in adherence augmentation programs by providing enough information that could aid long-term adherence(20)(21). Healthcare workers and patients also confirmed that the feeding program was available in communities among peer support groups to encourage patient interaction and adherence. Other studies also reaffirmed the importance of implementing adherence program for PLHIV in peer groups other than as individuals(22)(23). Therefore, it is important that adherence augmentation programs are implemented in communities as a means of ensuring that communities understand the management of HIV/AIDs also inform communities of their responsibility to their HIV spouses.

Community support to people living with HIV

In addition, the participants expressed concerns of community stigmatization in which healthcare workers were involved in handling complaints from PLHIV against close family members and other community members. The study revealed several issues of stigmatization among couples, in-laws and close family members with divorce, house expulsion of a widow and provoking words from close relatives respectively. This showed the existence of stigmatization irrespective of the advice from healthcare providers to community members for acceptance of PLHIV. Other research findings suggested that there is an existing gap in perception between PLHIV, healthcare professionals and community individuals and emphasised the need for improvement of such interactions(24). Such can also be improved further by using the stepping stone approach in communities where PLHIV are being stigmatized. Some recommendations for the prevention and reduction of stigma in the community include the improvement of the knowledge of the community, mass media campaigns and direct contact or testimonies from PLHIV(25)(26).

Health systems support

This study emphasized the need for improving adherence among PLHIV by ensuring the recruitment of additional skilled and motivated staff that can support treatment by providing interventions that will help improve drug therapy problems faced by PLHIV. Several studies have shown that Pharmacist intervention through appointments was vital in the prevention and reduction of drug related problems and in improving patient adherence to ART with subsequent increase in CD4 count(27)(28).

The study also confirmed the need to ensure that medicines and test kits are free and always available for PLHIV. This would ensure patient confidence and reliance in the health sector so that patients do not miss doses or travel from long distances to get medications that may not be available at the health facilities. A study in Uganda also revealed that there was a significant association between missing doses and missing appointments. Therefore, it is important to ensure that strategies are designed that will help improve adherence to ART medications among PLHIV. Key to any strategy is to ensure that ART medications are free and available at all times considering the fact that about 60% of the population in Sierra Leoneans are poor(29) and may not be able to pay for treatment or ART medications. Adherence to ART can be improved by integrating treatment services by using accredited pharmacies(30) and clinics(31) close to communities. This will help reduce spending in transportation for PLHIV, reduce hospital visit for medication refill while improving adherence, monitoring, interaction and collaboration between the primary healthcare facilities and hospitals.

Limitations

It was a sensitive topic to explore, especially in an environment where stigma and discrimination towards PLHIV are common, and PLHIV may have been reluctant to express their ART experiences. By establishing a good rapport and sensitive questioning, we hope to have minimized this. In addition, PLHIV may have concealed information related to adherence because the interviews were conducted at the HIV clinic where they also receive treatment. This was minimized by ensuring that no one entered the room during the interviews and removed all personal identifiers from the transcripts and reports.

Conclusions

Our study revealed that several factors influence adherence. The factors identified as facilitators are the perceived benefit of ART by PLHIV, family support, treatment partner, free medicine, and good relations with health workers. The barriers include denial and non-disclosure of HIV status, frequency of medication, traditional medicines use, lack of money for food and transport, stigma and discrimination, lack of medicines and test kits, limited healthcare workers (medical doctors, pharmacists, and nurses), and the distance of PLHIV to the health facility. Strengthening the support from families, communities and the health system will help PLHIV to continue with ART and prevent or reduce stigmatization in the community.

Abbreviations

PLHIV: People living with Human Immunodeficiency virus

HIV/AIDs: Human Immunodeficiency Virus/Acquired Immunodeficiency Virus

ART: Antiretroviral therapy

CD4: Cluster of differentiation 4

LMIC: Low and middle-income country

Declarations

Ethics approval and consent to participate

HIV/AIDS is a sensitive area of study, and people living with HIV are often stigmatized within their communities and were sometimes reluctant to talk about their illness and treatment. Several approaches were taken to support participation: building rapport with participants, sensitive probing, showing empathy and providing support if upset, ensuring private place for interviews, assuring that participation is voluntary and can withdraw at any time without fear of repercussion to treatment and care. Confidentiality of participants was vital for such a sensitive study and participants were informed to sign a consent form prior to participating in this study. All audio recordings and transcripts were coded and stored in a safe location. All methods were performed in accordance with the declaration of Helsinki and the study was approved by the Sierra Leone Ethics and Scientific review committee of the Ministry of Health and Sanitation.

Consent for publication

Not applicable

Availability of data and materials

All data and materials are available, and can be provided upon reasonable request to the corresponding author.

Competing interests

The authors declare no competing interests whatsoever.

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Authors' contributions

All authors have read and approved the manuscript. ML and JR developed the concept and proposal of the study. ML, JR and ST provided guidance on research methods. ML, JR and HRW analysed the dataset. ML and JR prepared documents and framework for ethical approval and consent for the study. ML, JR, HRW, SL, ST, MHS and POE provided expert review. ML trained the study assistants on use of the study and on transcribing for data collection and prepared the write-up. ML and ST and JR finalised the manuscript.

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Authors' information

Not Applicable

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Figures



Figure 1

Map of Sierra Leone showing the selected study sites

Figure 2

Facilitators and barriers to ART adherence (+ indicates facilitators; - indicates barriers)