

Barriers and Enablers to Retention in HIV Care and Adherence to Antiretroviral Therapy: Evidence from Dar es Salaam, Tanzania

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Purpose: To explore the enabling factors, barriers, and strategies to improve retention in HIV care and adherence to antiretroviral therapy (ART) among adults (18 years and above) living with HIV in Dar es Salaam, Tanzania.

Methods: We conducted a descriptive qualitative study to better understand and explore enablers, barriers, and strategies to improve retention in HIV care and adherence to antiretroviral therapy (ART) among PLHIV in Dar es Salaam, Tanzania. Focus group discussions (FGD) were conducted with a semi-structured discussion guide between December 2021 and June 2022. A non-random purposive sampling technique was used to select PLHIV and people involved in provision of healthcare and socioeconomic support to PLHIV. Thematic analysis was used to identify and interpret the themes.

Results: Three major themes with 10 sub-themes emerged. Participants indicated that family and partner support, peer-support group/adherence clubs, and healthcare provider counselling on medication adherence facilitated retention and adherence to ART. In contrast, stigma and discrimination, financial constraints, disease outbreaks such as the COVID-19 pandemic, myths and misconceptions about HIV, and side effects of antiretrovirals were mentioned as barriers. Strengthening community and patient education about HIV and ART through peer support groups and financial support for poor PLHIV were the proposed mitigation.

Conclusion: Addressing the challenges to ART adherence may require a more holistic approach. We recommend the implementation of peer support groups and financial support through small microfinance groups as interventions to increase retention in HIV care and adherence to ART in the study area.

Keywords: people living with HIV, peer support group, stigma, SDG 3.3

Introduction

Retention in HIV care and adherence to antiretroviral therapy (ART) are critical elements in achieving viral load suppression among PLHIV.¹ The latter is associated with improved well-being and prevention of disease progression to acquired immune deficiency syndrome (AIDS).² AIDS makes an individual vulnerable to opportunistic infections such as tuberculosis.³ In Tanzania, approximately 1.3 million (76.5%) of the estimated 1.7 million people living with HIV (PLHIV) were receiving ART in 2021. PLHIV who sustainably suppress their viral load have a life expectancy similar to non-infected individuals.⁴

Despite the considerable progress in ART coverage in Tanzania, whereby 82.7% of adults aged 15 years and above know their HIV positive status, 97.8% of those aware with their HIV positive status are on treatment and 94.3% of those on treatment had achieved viral load suppression,⁵ but there is an increasing concern about inadequate retention and adherence to ART.^{6,7} Poor ART adherence leads to virologic failure (7–17%) and increases the risk for acquired HIV drug resistance.^{8–10} Previous quantitative studies^{11–15} have linked socio-economic, cultural, and health system factors to adherence, retention, and viral suppression in sub-Saharan Africa. Furthermore, retention in care and adherence to ART has been shown to be closely associated with optimal individual and public health outcomes and cost-effectiveness.¹⁶ In our qualitative study, we aimed to better understand barriers and enablers to retention in HIV care and ART adherence among PLHIV and their providers of HIV care services and socioeconomic support.¹⁷

Methods

Study Design, Settings, and Population

We conducted a descriptive qualitative study, utilizing focus group discussions (FGDs) to explore the enabling factors, barriers, and strategies to improve retention in HIV care and adherence to ART among adults (18 years and above) living with HIV in Dar es Salaam, Tanzania. The participants were PLHIV from the Dar es Salaam Urban Cohort Study (DUCS) and providers involved in the provision of HIV care and socioeconomic support. The latter groups included clinicians, community healthcare workers, traditional healers, religious leaders, and policymakers. The study was conducted in the Ilala district of the Dar es Salaam region between December 2021 and June 2022.¹⁸ The area has six health facilities that provide care and treatment to approximately 5000–10,000 PLHIV. As of early January 2023, the DUCS platform had registered a total of 136,447 residents living in 25,485 households.

Sampling and Data Collection Process

A non-random purposive sampling technique was used to select PLHIV from the DUCS platform and providers involved in HIV care services and socioeconomic support to PLHIV. The selection of PLHIV was based on these criteria; confirmed HIV and TB diagnosis (whereby TB was a secondary infection after HIV), medical record documentation of poor adherence to ART, and high viral load and/or low CD4 cell count while providers involved in HIV care services and socioeconomic support to PLHIV were selected based on their involvement to the previous study aimed at designing interventions to prevent HIV drug resistance in the DUCS area.⁶

Four FGDs were conducted, three with PLHIV and one with providers involved in HIV care services and socioeconomic support to PLHIV. The number of participants per FGD ranged from 8 to 12, with a mean of 10 participants. Recruitment was discontinued after attaining saturation. The FGDs lasted for an average of 90 minutes.¹⁹ A semi-structured guide was used to conduct face-to-face audio-recorded FGDs. An interview guide was developed following a comprehensive literature review of the field of retention in HIV care and adherence to life-long ART.

The interview guide had topics covering knowledge on HIV/AIDS, adherence, stigmatization, peer support, and strategies to improve CTC services.^{7,11,20} The interviews were conducted in Kiswahili by two authors (GMB and GS), both native Kiswahili speakers.

Data Analysis

Data from the FGDs were analyzed using a thematic approach.^{21,22} The audio-recorded data were transcribed verbatim. The transcripts were read and re-read by two independent authors (GMB and GS) to familiarize themselves with the

content and context before generating a code book. All files of transcripts were transferred to NVivo software for coding and organization.²³ After coding the discussions and organizing them into a manageable format, all codes were shared among the authors for review, and agreement was reached on coded information.²⁴ We continued reading and abstracting the content to more specific and mutually exclusive themes. This process resulted in the refinement of the original tree codes into major themes and sub-themes as presented in the results section. Representative quotes were identified for each sub-theme and then translated into English. The translation of the text was conducted as previously described.²⁵ To ensure the credibility of our qualitative data, we employed several rigorous methodologies. These included triangulation of data sources, member checking, peer debriefing, and maintaining detailed audit trails throughout the data collection and analysis process.

Results

Characteristics of the Participants

In total, 41 participants participated in four rounds of FGDs, averaging 10 participants per FGD. Among the participants 68.3% (28) of participants were females. The median age for all participants was 49 (range: 21–65) years, and 80.5% (33) were PLHIV (Tables 1 and 2). Among the providers of HIV care services and socioeconomic support to PLHIV, the median time they had been working to address HIV care retention and ART among PLHIV was 10.0 (range: 2–29) years. For PLHIV, the median time since they were diagnosed with HIV was 10.5 (range: 2–25) years while the median time of taking ART was 11.0 (range: 2–25) years. The majority 90.91% (30) of the PLHIV participants were receiving combination therapy of Tenofovir, Lamivudine, and Dolutegravir (TLD).

The Emerged Major Themes and Sub-Themes

Three major themes with ten sub-themes emerged as shown in Table 3. The first theme was enablers for retention in HIV care and adherence to ART with three sub-themes: family and partner support, peer-support group use, and healthcare provider counselling on medication adherence. The second theme was barriers to retention in HIV care and adherence to ART with five sub-themes: stigmatization and discrimination, financial constraints, disease outbreak (eg, COVID-19), myths and misconceptions about HIV, the side-effects of antiretrovirals and occurrence of opportunistic infections. The last theme was

Table 1 Characteristics of Participating PLWH

Variable	Category	Frequency (n)
Sex	Male	7
	Female	26
Age (years)	18–25	1
	26–34	4
	35–44	8
	45–55	14
	≥ 56	6
Marital status	Married	11
	Single/Unmarried	9
	Divorced	4
	Widow	9

(Continued)

Table 1 (Continued).

Variable	Category	Frequency (n)
ART using	TLD	30
	ABC + 3TC + ATV/r	2
	TDF + FTV + ATV/r	1
Economic activity	Entrepreneur	15
	Peer educator	4
	Technician	3
	Community Healthcare Worker	2
	Peasant	1
	Cleaner	1
	Unemployed	4
	Driver	1
	Volunteer	2

Table 2 Characteristics of Participating (Providers of HIV Care Services and Socioeconomic Support to PLWH)

Variable	Category	Frequency (n)
Sex	Male	6
	Female	2
Age (years)	18–25	0
	26–34	0
	35–44	2
	45–55	3
	≥ 56	3
Job title	Community Healthcare Worker	2
	Traditional Healer	1
	Clinician	3
	Policy marker	1
	Religious leader	1
Role when working with PLHIV	Community education	3
	Management of PLHIV	3
	Policy marker	1
	Spiritual leader	1

Table 3 Major Themes and Sub-Themes for Retention in HIV Care and Adherence to Antiretroviral Therapy

Themes	Sub-Themes	Codes
Enabling factors	<ul style="list-style-type: none"> Family and partner support 	<ul style="list-style-type: none"> Reminded to take medicines. Reminded to keep clinic appointments. Not hiding taking their ART Getting partner support Getting family support
	<ul style="list-style-type: none"> Peer support group 	<ul style="list-style-type: none"> Provided education about HIV infection. Sharing the health benefits of taking ART Sharing life experiences and fighting HIV stigmatization and discrimination
	<ul style="list-style-type: none"> Healthcare provider counselling on medication adherence. 	<ul style="list-style-type: none"> Provided counselling to PLHIV. Provided close follow-up to PLHIV. Motivate PLHIV by sharing the health benefits of taking ART. Help PLHIV deal with ART side effect
Barriers	<ul style="list-style-type: none"> Stigmatization and discrimination 	<ul style="list-style-type: none"> Attending care and treatment clinics at a distant facility to protect their confidentiality. Skipping medication due to lack of privacy when taking ART Asking someone to collect your ART on behalf. Missing appointments due to lack of privacy at the care and treatment clinics Hiding their ART from people
	<ul style="list-style-type: none"> Financial constraints 	<ul style="list-style-type: none"> Lack of transport fee for ART refills or attending the clinic regularly Food insecurity Lack of hospital fees for treatment of opportunistic infections
	<ul style="list-style-type: none"> Disease outbreaks, eg, the COVID-19 pandemic 	<ul style="list-style-type: none"> Disruptions to care and treatment clinic services due to the COVID-19 pandemic Community and government shifted attention (eg, resources and clinicians) to COVID-19 pandemic response
	<ul style="list-style-type: none"> Myths and misconceptions about HIV 	<ul style="list-style-type: none"> Being treated by a traditional healer Beliefs about using prayers to treat HIV. Superstitious beliefs
	<ul style="list-style-type: none"> Occurrence of side-effect of antiretrovirals 	<ul style="list-style-type: none"> Insomnia Nausea Fatigue Weight gain Discontinuing ART to treat opportunistic infections
Strategies	<ul style="list-style-type: none"> Strengthen community education and awareness about HIV/AIDS and patient knowledge about ART 	<ul style="list-style-type: none"> Patient education about HIV/AIDS and ART Community education about HIV/AIDS to reduce stigmatization and discrimination. Strengthening the teaching about HIV/AIDS at all education levels
	<ul style="list-style-type: none"> Economic empowerment for PLHIV 	<ul style="list-style-type: none"> Forming microfinance groups Providing loans to PLHIV Providing entrepreneurship skills to PLHIV Compensating peer-educators Providing health insurance coverage to PLHIV

strategies to improve retention in HIV care and adherence to ART with two sub-themes: community education about HIV/AIDS and antiretroviral therapy and economic empowerment for PLHIV.

Enabling Factors for Retention in HIV Care and Adherence to ART

Participants highlighted that the use of different alert systems and family support has improved their adherence to medication as quoted below.

I set an alarm every day for the quarter to eight and the alarm reminds me. But, four minutes before that time my twenty-year daughter also reminded me by sending a phone message using a special and unique language we only understand: mum, time is makangarawe (Individual living with HIV (ILHIV), aged 64 years old, widow)

Some participants acknowledged that support from their partners helped to improve adherence to ART through being reminded to medicate, for example, one had this to share:

.....my husband also reminds me by using a unique phrase *Diamondi karanga zimeshafika* meaning “it is time to take your medications, he sends this message five minutes before time. (ILHIV, aged 50 years old, married woman)

Participants also acknowledged that engagement in peer support groups has facilitated their adherence, since through peer support groups PLHIV educates and encourages each other by sharing life experiences and on matters relating to proper use of medication and adherence. Quoting one of the participants.

Home visits have yielded results as we understand each other which is very easy for counselling on the proper use of medication and frequent refilling of the medication. (ILHIV, aged 34 years old, unmarried woman)

Healthcare personal counselling was also mentioned as among the factors that facilitated adherence. This counselling mainly focuses on the proper and timely use of medication to prevent viral multiplication and the importance of retention in ART services.

Also, when we have already been identified as PLHIV, we need counselling from doctors on the proper use of the medication, (ILHIV, aged 50 years old, widow)

Barriers to Retention on HIV Care and Adherence to ART

Participants expressed concern about stigmatization both at the family and community level. Some PLHIV were hesitant to attend clinics close to their residences or ask someone to collect their ART on their behalf for fear of being recognized. They even refused a family visit or any refill program that would reveal to others that they are receiving ART.

There was a time when we started a community refill program for the youths and adolescents, the program aimed to bring medication refills close to their living places, but with time the number of refill patients decreased, and when we asked for the reasons, they said they were hiding from being known that they are taking antiretroviral drugs..... we had to stop this program..... (Clinician, aged 53 years)

Another participant had this to share:

For example, you have already tested and disclosed your HIV status within the family. This connotes a sacrifice; you have sacrificed yourself because each household member will take it differently. Some will accept the situation and support you in medication issues, and others will discriminate against you and inform other people around you about your status. (ILHIV, aged 47 years old, widow)

Financial instability was reported as a major driver of food insecurity and made covering transportation costs for clinic visits a challenge. Both factors make it difficult for PLHIV to take their ART and visit their clinic to collect their prescribed medication refills. For instance, one participant commented:

Due to financial difficulties that we experience, we fail to buy food, something which discourages us from sticking to our medication properly as we are advised by doctors as you cannot take them when you are hungry. (ILHIV, aged 48 years old, unmarried woman)

Shifting priorities over time was also mentioned as an important barrier. For instance, as COVID-19 spread globally, many countries, especially those with weak healthcare systems and limited resources, including Tanzania, shifted their priorities and attention toward responding to the COVID-19 pandemic. For example, one participant explained that:

The COVID-19 pandemic is now considered to be bigger than other diseases including HIV. Most people talk more about COVID-19 than HIV, even posters along the main roads are all about COVID-19. This situation will have negative consequences in the future regarding HIV, as there will be insufficient public awareness about HIV. (Community healthcare worker, aged 60 years old)

Another participant further commented that:

For example, during the first wave of COVID-19 in Tanzania, people living with HIV were shifted from every month to six-month clinic and they were given drugs for six months, regardless of the client's adherence and health status and some of the patients were re-allocated from the regular clinics to elsewhere. (ILHIV, aged 45 years old)

Participants commented on the myths and misconceptions perpetuated by some religious leaders. PLHIVs sometimes are told to stop their medications because God will cure their HIV.

People who claim that they were HIV positive give testimonies that their viruses were cleared following prayers received from pastors, so they encourage people to visit their churches for the same service and after receiving prayers they are encouraged to stop taking antiretroviral drugs (Traditional healer, aged 35 years)

Also, there was a comment on superstitious beliefs:

Some patients will stop taking their antiretroviral after being told by the witch doctors that they are suffering from a disease caused by being bewitched and he/she will cure the disease. (ILHIV, aged 51 years old, widow and peer educator)

Participants spoke about how ART side effects deter them from regularly taking ART. One participant commented that:

The side effects of ART affected my husband's sexual performance because before started using this medication my husband and I enjoyed our marriage very well but after started using this medication he experienced the problem of male impotence. Sometimes we can't meet without using male enhancement drugs. (ILHIV, aged 52 years old, married woman)

Strategies to Improve Retention on HIV Care and Adherence to ART

Participants reported that they believe community education will help minimize the problem of stigmatization, even for those with self-stigma, and that they can accept their status. They further elaborated that those people who are HIV positive and adhere to their medications can be used as a witness and to educate others in society. For example, one had this to share:

It is important to continue providing education to the community, first the education on how to accept their HIV situation to the extent that it will eliminate the self-stigmatization before being discriminated against by other people but also, for those who will adhere to their medication. (Religious leader, aged 64 years old)

Another participant further commented that:

You know, the Government made great efforts to provide medications for HIV and education about HIV, but more education is needed at the lowest level, in rural areas as you cannot identify a person with an infection by looking at him or her but AIDS affects every day. (ILHIV, aged 50 years old, married woman)

Participants also advised that peer education can be employed to address the problem of stigmatization. People with similar health status can counsel their colleagues. Quoting one of the participants:

She tells me not to be afraid, since she got HIV a long time ago and she is still surviving, and if she was scared, she would not have survived all this long, she would have died a long time (ILHIV, aged 50 years old, married woman)

Another participant further commented this on peer support,

From my experience, there are PLHIV who are used to counselling new patients who tested HIV positive before starting medication. This old patient makes a follow-up to this new one at least for three or six months, this approach has helped to reach those whose status are remained undisclosed due to fear of stigma (Clinician, aged 37 years old)

Participants further explained that microfinance groups have the potential to help PLHIV in many ways such as the provision of HIV-related education and counselling, entrepreneurship knowledge, and skills to enable PLHIV to gain financial stability and long-term productivity. For example, one participant opined:

I propose to have microfinance groups for the people living with HIV. These microfinance groups are helpful through members contributing small amounts of money weekly and being allowed to take loans with small interest from the same group. The money which will be gained can be used to buy food to stay healthy. (ILHIV, aged 43 years old, married woman)

Participants proposed that for those who are unable to participate in microfinance interventions, the government and other participants should offer partial financial support, food, and transport refunds, especially on HIV clinic visits or soft loans as start-up capital. Regarding financial assistance, one participant gave testimony of how a PLHIV was supported through the Tanzania Social Action Fund (TASAF) program. He reiterated that the program managed by the Tanzania Commission for AIDS (TACAIDS) aimed at alleviating poverty among poor people in Tanzania. Quoting one of the participants:

The government through TASAF provided financial assistance to adolescents living with HIV from poor families every month to support them in buying exercise books for those who are at school. Those who are out of school were financially supported through their proposals which they wrote to start small businesses. For those groups whose proposals met the required criteria, then they are given sixty percent (60%) of the amount requested and they are given the remaining forty percent later depending on the progress. (Policy maker, aged 49 years)

Participants also mentioned that the government should take strong action to address the churches that mislead the community and PLHIV.

In this, the government should look seriously and take strong action where possible; we do not discourage religious prayer but get them and continue using the medication. And for the church leaders who keep on telling the patients to throw away their medication after receiving a word of GOD as they call "should stop this". (ILHIV, aged 21 years old, female)

Discussion

This qualitative study revealed critical factors for improving retention in HIV care and adherence to ART. Strengthening community education, encouraging family and partner support, and economic empowerment for PLHIV were reported to be the enablers and strategies that can be employed to reduce stigmatization and mitigate the problem of poor adherence and improve the retention in HIV care.

Additionally, our findings showed that interventions such as peer support groups, microfinance, and financial support to PLHIV might help in reducing stigma and increasing adherence to ART and retention to HIV care. Our findings correlate with previous studies that showed microfinance interventions improved the adherence, viral suppression, and livelihood of PLHIV in general.²⁶

Peer support groups can help newly diagnosed individuals cope with their disease and offer support from PLHIV who struggled with and overcame prior poor ART adherence and retention in HIV care and who have faced community and self-stigma. Through these peer support groups, PLHIV encourage each other by sharing their lived experiences coping with HIV, ART, stigma, and life in general. Through sharing the stories, those who had suffered from stigma and had

poor adherence often learn to improve their adherence and how to live with the disease accordingly. Our findings are in line with previously reported studies.^{27,28}

Additionally, microfinance groups may serve as a platform for the provision of peer education, counselling on psychological issues such as depression, anxiety and entrepreneurship skills.²⁹ A transdisciplinary study conducted in Dar es Salaam³⁰ suggested combining microfinance and peer support groups, and through these groups, education on HIV and HIV drug resistance, stigma reduction, the benefits of adherence, and entrepreneurship knowledge and skills can be offered.

PLHIV also reported that the COVID-19 pandemic affected adherence and retention in care. In particular, the first wave of COVID-19 in Tanzania caused some disruptions to CTC services, such as extended HIV clinic visits and re-allocation of patients from their usual clinics (unpublished data). The shifts in governmental attention, resources, and educational campaigns away from HIV during the COVID-19 pandemic were also mentioned by participants and PLHIV. More public advertisements, interventions, and public awareness campaigns targeting the COVID-19 pandemic are thought to have led to a neglect of other diseases, including HIV. Global health leaders advised the best way to deal with both pandemics is to tackle COVID-19 and HIV together.³¹

Limitations

We acknowledge that our study site was limited to urban settings in Dar es Salaam and the participants' age was skewed to older individuals.

Conclusion

In conclusion, our study suggested that family and partner support, peer-support group use, and healthcare provider counselling on medication adherence are factors that facilitate adherence to ART among PLHIV. Conversely, stigmatization and discrimination, financial constraints, pandemic response, ART side-effects, and misconceptions about HIV are factors that hinder adherence to ART. Increasing public knowledge about HIV, economic empowerment to PLHIV, and implementation of evidence-based interventions such as financial support through small microfinance groups and peer support groups are likely to improve the well-being of PLHIV and lead to increased adherence to ART and HIV care retention. Therefore, we recommended the implementation of evidence-based interventions for improving retention in HIV care and adherence to ART in the study area. Also, we recommended that more studies, especially from semi-urban or rural settings, be conducted to identify interventions to improve ART adherence and care retention in those settings.

Data Sharing Statement

Data used to draw this conclusion are available from the corresponding author upon request.

Ethical Approval and Informed Consent

The study was approved by the Muhimbili University of Health and Allied Sciences Institutional Ethical Review Board (Ref No. MUHAS-REC-12-2021-921) and the National Committee on Medical Research Ethics (Ref No. NIMR/HQ/R.8c/Vol.1/1870). Written consent to participate, record the interview and publication of anonymized responses was obtained prior to data collection. This study complied with the Declaration of Helsinki for medical research involving human subjects. Furthermore, we adhered strictly to ethical guidelines to safeguard the privacy and confidentiality of our research participants. This involved obtaining informed consent, anonymizing sensitive information, and storing data securely with restricted access.

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Author Contributions

All authors made a significant contribution to the work reported. All authors contributed to data analysis, drafting or revising the article, have agreed on the journal to which the article will be submitted, gave final approval of the version to be published, and agree to be accountable for all aspects of the work.

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