

RESEARCH

Open Access



Hospitalized with HIV in Zambia: individual and system factors driving the high burden of admissions and post-discharge mortality in the era of HIV epidemic control

Chiti Bwalya^{1,2*}, Kirsten Stoebe², Godfrey Muchanga¹, Mwangala Mwale¹, Choolwe Maambo¹, Swamie Banda¹, Palicha Halwiindi¹, Linah K. Mwango³, Caitlin Baumhart^{6,7}, Nyuma Mbewe⁴, Mundia Mwitumwa⁴, Priscilla Mulenga⁵, Manhattan Charurat^{6,7}, Wilbroad Mutale⁸, Michael J. Vinikoor^{4,9†} and Cassidy W. Claassen^{1,4,6,7†}

Abstract

Background Despite progress towards HIV epidemic control, people living with HIV (PLHIV) in Zambia continue to face high mortality during and especially after hospitalization, with suboptimal post-discharge care leading to poor outcomes. We conducted a qualitative study to better understand factors influencing post-discharge engagement in care for HIV and associated comorbidities.

Methods We conducted in-depth interviews with 16 recently discharged PLHIV, seven caregivers, and two doctors; and three focus group discussions with inpatient doctors ($n=8$) and lay counsellors ($n=16$) at two tertiary hospitals in Lusaka, guided by the social-ecological model. Data were audio-recorded, transcribed verbatim, managed with *Atlas.ti* 9, and thematically analyzed.

Results Individual and household-level barriers to post-discharge care for PLHIV included HIV status denial and stigma, limited disclosure, and limited social and emotional support. Health-related barriers included concomitant treatments for TB, HIV comorbidities, and behavioral health issues like depression and alcohol abuse. Health system barriers included limited confidentiality during admission and poor communication between healthcare providers and between facilities aftercare transitions following discharge. Social-economic factors included economic shocks of hospitalization and post-discharge recovery, which compounded pre-existing poverty and high transportation and food costs. Conversely, disclosure of HIV status, better social support, a financially stable household, and hospital follow-up appointment reminders facilitated better post-discharge care.

Conclusion After hospital discharge with HIV, system and individual challenges exacerbate pre-existing interpersonal, health, environmental, and system-related factors to cause poor outcomes. Holistic community-based

[†]Michael J. Vinikoor and Cassidy W. Claassen Shared senior co-authors.

*Correspondence:
Chiti Bwalya
Cbwalya@mgic.umaryland.edu

Full list of author information is available at the end of the article



© The Author(s) 2024. **Open Access** This article is licensed under a Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International License, which permits any non-commercial use, sharing, distribution and reproduction in any medium or format, as long as you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons licence, and indicate if you modified the licensed material. You do not have permission under this licence to share adapted material derived from this article or parts of it. The images or other third party material in this article are included in the article's Creative Commons licence, unless indicated otherwise in a credit line to the material. If material is not included in the article's Creative Commons licence and your intended use is not permitted by statutory regulation or exceeds the permitted use, you will need to obtain permission directly from the copyright holder. To view a copy of this licence, visit <http://creativecommons.org/licenses/by-nc-nd/4.0/>.

interventions to facilitate these patients' re-engagement in care after discharge could help HIV programs reach the last mile in epidemic control.

Keywords ART, HIV, Hospitalization, Post-discharge engagement, Qualitative research and mortality

Background

Despite progress towards HIV epidemic control, people living with HIV (PLHIV) in Zambia face high mortality during and especially following hospitalization. Zambia has an ongoing generalized HIV epidemic with a prevalence of 11.0% [1]. Zambia adopted the test-and-treat guidelines in 2016 with the goal of identifying and linking all PLWH to HIV care and treatment [2]. Individuals who test positive for HIV are immediately initiated on anti-retroviral therapy (ART), regardless of CD4 count. More than 1.2 million PLWH are currently receiving ART [3]. According to a recent population-based survey, 88.7% of PLWH in Zambia know their HIV status, of whom 98% have started ART, and of these, 96.3% have an HIV RNA level < 1000 copies/ml [1].

Despite this remarkable progress in scaling up ART, HIV-related morbidity continues to be a major risk factor for hospitalization and premature death in Zambia [4]. Individuals with HIV who are hospitalized face an increased risk of death during hospitalization and even more so in the post-hospital period. Furthermore, HIV-positive status is associated with an increased risk of readmission after discharge, accompanied by further increases to their mortality risk [5–7].

In Zambia, the prevalence of HIV among hospitalized people is persistently high, up to 50%, with inpatient mortality rates ranging from 20 to 30% [4]. Furthermore, an estimated 40–50% of PLWH who are hospitalized and then discharged die within six months, a trend also seen in other African countries [4–6, 8, 9]. Lower CD4 counts, discharge against medical advice, and failure to link to care within one month after discharge have all been linked to higher post-discharge mortality rates [6, 8].

Hospitalized PLWH in Zambia tend to have history of long-term ART use of more than five years, as well as poor care retention and viral suppression, with frequent disengagement from care [10–12]. Studies from across the region have found that poor treatment outcomes and mortality following hospitalization may in part result from low engagement with the healthcare system following discharge; or patients' inability to follow and act on medical advice, appointments, and prescribed treatments following hospitalization [6, 8]. For many patients, poor re-engagement in care results in a 'revolving door' of re-admissions. This cycle of multiple readmissions can result in poor treatment outcomes and even mortality despite multiple engagements with the healthcare system [13].

Prior literature has described various barriers to HIV treatment access and retention across many contexts in sub-Saharan Africa (SSA), including clinic-based stigma and poor clinic infrastructure [14–16], geographical distance to clinics and hospitals [17, 18], lack of psychosocial support [19], inadvertent disclosure of HIV status [12, 14, 15] and comorbid mental health conditions like depression [20]. However, a comprehensive understanding of the facilitators and barriers to post-discharge engagement with local community HIV clinics and discharging hospitals among PLWH following hospitalization in Zambia remains lacking. Given high mortality rates observed in the six months following hospital discharge [4], it is critical to understand the barriers that prevent optimal re-engagement in care as well as clinical outcomes during this important post-discharge period.

The primary objective of this study was to conduct formative work to identify factors that influence re-engagement in HIV care following hospital discharge that would be amenable to improvement through a community-based intervention. We sought to explore how patient-level factors, situated within broader healthcare and socioeconomic determinants, influence healthcare utilization and subsequent health outcomes after hospitalization among PLWH, as well as potential interventions to avert death and improve HIV re-engagement in care following hospitalization in Zambia.

Methodology

Study design and setting

We conducted a qualitative study in Lusaka, Zambia to better understand the determinants of post-discharge engagement in care, as part of a formative phase of a hybrid implementation-effectiveness study testing the feasibility and acceptability of a community health worker-delivered intervention for PLWH following hospitalization. For this study, we define "post-discharge engagement" as a complete set of decisions and actions necessary to ensure a discharged patient has access to and is both capable of and willing to act on medical advice including keeping doctors' appointments, linking with a local clinic for ART support, and post-discharge disclosure of HIV status.

From March to June 2022, we recruited patients with HIV at the time of discharge from one of two large tertiary care hospitals in Lusaka, the University Teaching Hospital (UTH) and Levy Mwanawasa University Teaching Hospital (LMUTH) who had HIV and were admitted for any reason, including opportunistic infections

and non-communicable diseases. After at least one month following hospital discharge, we interviewed the patients, their caregivers, professional and lay health workers involved in care delivery and hospital and program administrators. These hospitals are the largest in the country, with the most well-trained staff, and provide services to patients with the most advanced HIV disease from across different socioeconomic backgrounds and communities throughout Lusaka, including many high-density, predominantly low-income urban communities. Socioeconomic status and housing structures in these communities where these patients come from are mixed, with most residents working either in the informal sector or in low-paying jobs in the public and private sectors [21]. Health services in every community are provided by government level 1 hospitals, and any patients with serious illnesses related to HIV are referred to UTH and LMUTH.

Positionality statement

This work was carried out by a team of experienced Zambian and U.S. researchers including U.S. clinicians practicing HIV medicine in Zambia and the U.S. All members of the research team have experience working with PLWH in community settings. Zambian researchers include social scientists and clinicians, all with prior qualitative research experience in HIV prevention and treatment, fluent in English, Nyanja, and Bemba, the three relevant study languages. The U.S. researchers include infectious disease physicians who have many years of experience practicing medicine in Zambia and leading HIV prevention and treatment programs in clinical and community settings; and a social scientist with extensive qualitative research experience in HIV prevention and treatment in SSA.

During data collection and analysis, we used reflexive practices and a member-checking participatory workshop to improve the rigor of our work. We addressed the role of our qualifications, social positions, and work experience to consider how our respective backgrounds, beliefs, and assumptions influence analysis and interpretation through explicit discussions. We used weekly research team meetings to peer debrief and compare interpretations of our findings. These steps increased the trustworthiness and credibility of this research, ultimately contributing to a more comprehensive understanding of the factors influencing post discharge engagement.

Theoretical framework: the social-ecological model

We used the social ecological model (SEM) framework to help identify and understand the factors influencing HIV care engagement among PLWH following hospitalization [22]. The SEM model proposes that an individual's health

behavior is influenced by multi-level, interdependent factors including those at the individual, household or interpersonal, community and broad society or system levels [22]. Efforts to change health behavior must take these multiple complex levels of influence into account [22].

In this study, we focus on the health system at the broader system level. Further, we apply the SEM across three distinct stages of care considering factors that influence utilization of and engagement with HIV care before hospitalization, during hospitalization, and finally post-hospitalization.

Recruitment of participants and data collection

Data collection activities included focus group discussions (FGDs) and in-depth interviews (IDIs) and were carried out by a small team of trained qualitative researchers fluent in languages predominantly spoken in Lusaka (English, Nyanja, and Bemba). Several participant groups were included. First, we recruited adult PLWH ($n=16$), both men and women, who were admitted, treated, and discharged from either UTH or LMUTH. Patients were eligible for recruitment if they were HIV+, 18+ years, >1 year on ART, admitted and discharged from study hospital, resident in Lusaka, and had evidence of sub-optimal HIV control, as evidenced by HIV viral load >1,000 copies/ml and/or CD4 count <100 cells/mm³. Study participants were purposively selected using eligibility criteria. To identify eligible hospitalized participants for the study, research assistants reviewed files of all admitted patients to identify those with a positive HIV test to then identify those who met other eligibility criteria. Participants were identified during admission and invited to participate in interviews one to three weeks post-discharge.

When recruiting PLWH during hospitalization, we also asked if they had a caregiver involved in their care whom we could interview, when applicable and with the participant's permission, we approached caregivers for interviews ($n=7$). Interviews were typically conducted from the participant's/caregiver's home, or occasionally at the hospital at the time of a post-discharge follow-up visit. Typically, we interviewed individuals with HIV and their caregivers sequentially on the same day. The main interview themes focused on reasons for hospitalization, hospitalization experiences and the post-discharge phase, barriers to accessing ART, and clinic or hospital services after discharge.

Both hospitalized participants and their caregivers were asked about the hospitalized participant's experiences with staying on treatment, their support system since diagnosis, and their interactions with the health-care system since discharge.

In addition, we also interviewed healthcare workers to gain their insights on the barriers to re-engagement

in care for hospitalized HIV patients. We conducted three FGDs with healthcare workers: one with a purposive sample of inpatient physicians at discharging facility ($n=8$), and two with lay counsellors ($n=16$), stratified by those providing services to patients at the two hospitals ($n=8$), and providing services at community clinics to patients after discharge ($n=8$). We also conducted IDIs with two infectious diseases doctors managing the HIV programs at the two hospitals. Interview questions focused on providers' perceptions of patient experiences with ART, the inpatient hospital system, and discharge procedures. Additional questions included support and follow-up systems, referral mechanisms between hospitals and clinics, difficulties with retention, linkage, and reasons for disengagement.

Data management and analysis

All audio recordings from FGDs and IDIs were transcribed verbatim and those conducted in local languages were translated simultaneously into English during the transcription process by research team members. All transcripts were then imported into *Atlas.ti* 9 and coded iteratively by Zambian and U.S.-based researchers using a thematic analysis approach [23]. Following transcription,

Table 1 Characteristics of PLWH and caregivers that participated in the study

Characteristics	PLWH	Caregivers	Total
Sex			
Women	10	5	15
Men	6	2	7
Age (years)			
18–34	5	1	6
35–44	6	5	11
45–54	6	1	7
>55	1	0	1
Household income			
Low-income	11	6	17
Middle income	4	0	4
High income	0	0	0
Education level			
No education	1	1	2
Primary education	8	2	8
Secondary education	6	4	10
Tertiary education	2	0	2
Status of HIV disclosure			
Disclosed to family members	12	N/A	12
Not disclosed to family member	4	N/A	4
Timing of HIV diagnosis			
Before hospitalization	12	N/A	12
During hospitalization	4	N/A	4
Time on ART			
< 5 years	10	N/A	
6 to 10 years	1	N/A	
>10 years	3	N/A	

the team read through a subset of transcripts, then developed and defined an initial code list informed by the data, the interview guides, the conceptual model, and our initial understanding of key topics. The analysis team met weekly to refine the coding scheme, adding inductive codes that captured more analytic concepts and topics emerging as of importance across interviews. To ensure the team understood the codes in the same way, in addition to weekly meetings used to discuss the codes and their application, the team conducted an intercoder reliability check on one hospitalized participant's transcript using the finalized codebook. Once a final codebook was developed and codes defined, we coded all transcripts using *Atlas.ti* 9.

Next, two team members (BC and KS) assessed the relationships between codes and identified and named resulting themes related to factors influencing post-discharge disengagement and framed around the different factors identified in the model (e.g., individual, interpersonal) experienced at different times (e.g., prior to hospitalization, post-discharge).

Finally, we used member-checking strategies to ensure our key findings resonated with our study population. Study participants (both clinicians and hospitalized PLWH) attended participatory workshops where we shared key findings and sought additional feedback.

Ethical considerations

Ethical approval for this study was obtained from the University of Zambia Biomedical Research Ethics Committee (Ref-1346-2020) and the University of Maryland Institutional Review Board (Ref: HP-00094612). Additional approvals were obtained from the Zambian National Health Research Authority, and the Ministry of Health at both provincial, district, and clinic levels. Written informed consent was obtained from all participants as per the local Research Ethics Committee guidelines.

Results

Social and demographic characteristics of participants

The majority of PLWH were women (10/16, 62.5%), with ages ranging from 35 to 55 years old. Most PLWH were from low-income families, with many having only completed primary school; additional details are presented in Table 1. Most caregivers were wives, followed by husbands, or siblings of the hospitalized participant. Caregivers were typically 45 to 54 years old and mostly female (5/7, 71.4%),

The social-ecological influences on HIV care engagement

Our focus toward intervention development was the post-discharge period, however, we found that some of the barriers to re-engagement in care stemmed from long-term issues affecting participants' ability to engage

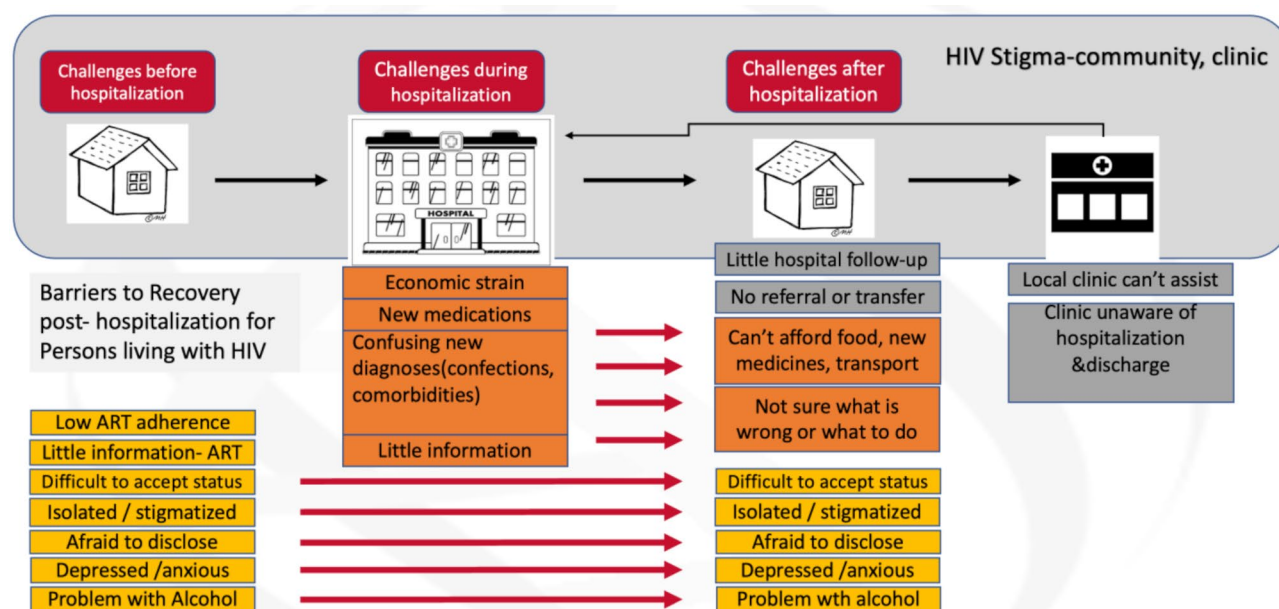


Fig. 1 Factors influencing engagement in medical care for people living with HIV following hospitalization

in care well before their (observed) hospitalization. Our main findings are summarized in Fig. 1, where we depict the major factors that influence engagement in HIV care over time across three stages: pre-, during, and post-hospitalization. We identified three main themes: (1) at the individual level, HIV stigma and disclosure as well as health co-morbidities complicate engagement over time; (2) at the household level, hospitalization acts as an economic shock with consequences for engagement; and (3) at the health system level, factors such as inadequate healthcare worker (HCW)-patient communication, confidentiality concerns, and limited discharge support impair post-discharge follow-up.

Long-term personal and individual factors

PLWH and their caregivers spoke of a number of long-standing factors that had been impacting their engagement in care before hospitalization and continued or worsened as contributors to poor outcomes post-discharge. These included: (1) fear of disclosure of HIV status; (2) HIV-related stigma; (3) concomitant treatment concerns; (4) burden of substance abuse and mental illness; and (5) competing concerns/complications of co-morbidities.

The long reach of HIV stigma and fear of HIV status disclosure

For many participants, learning about their HIV infection was a psychological shock, often accompanied by refusal to accept their HIV status and thus leading to delayed ART initiation, with some only starting ART when they were very sick and required hospitalization.

Others mentioned going for months without starting to take their medication despite being advised to do so. As this 27-year-old woman who had been diagnosed during hospitalization explained:

I felt upset, and the doctor encouraged us to...start treatment, but this was not easy for us to do so we [patient and husband] just decided to sit just like that. ... went home and never started taking any drugs and it went on like that for months. (IDI, 27 year female participant)

HIV-status disclosure for many patients was limited to a few close family members such as spouses, siblings, and, in some cases, parents. Most participants feared being ostracized and stigmatized. Failure to disclose one's status posed difficulties for both healthcare providers in the hospital and patient caregivers at home. Participants described how lack of disclosure generated barriers for treatment adherence in multiple ways: first, fear of being 'found out' prevented some patients from taking their ART at home. Second, healthcare workers noted that lack of disclosure often result in missed appointments. Lay counselors narrated stories of patients who were unable to come to the hospital because they were too ill to travel on their own or because the one person to whom they had disclosed their status was unavailable. Lack of disclosure further made it difficult for healthcare providers to engage families without involuntarily disclosing their patient's status.

There are certain patients that can be referred here in the hospital and when you visit them in the wards and ask their family if the patient is on any medication (ARVs)... that patient is unable to talk and you ask the caregiver if the patient is on any medication; they (caregiver) will say they are not aware So, if you ask the caregiver if the patient is on ARVs.... Like that people (patients) get disturbed because you would have disclosed the status to the caregiver. Some patients do not want to disclose their status to their caregivers. (FGD with lay counsellors)

By contrast, when disclosure did occur, it acted as an enabler and facilitated engagement into care. For example, lay counselors suggested that having someone to support them at home assisted the patient in returning to the hospital and taking their medications. Once discharged, many participants recounted the various forms of support they received from family (e.g., financial support, reminders to take medication and attend follow-up appointments, emotional support and encouragement).

I went to the farm to tell my elder sister about it. She comforted me and told me that this happens to a lot of people..."there are many people that are sick (with HIV) and I should not worry too much... this is common just as malaria, just start taking ARVs and continue taking your drugs" My sister told me. ...My young brother also told me to continue with his medication and that we should take care of each other by reminding each other. (IDI, 54 year male patient)

Infectious and non-infectious HIV co-morbidities are commonly diagnosed during hospital admission and complicate ART adherence and engagement in HIV care over time

Concerns about taking multiple medications at the same time were frequently cited as a barrier to adherence, for both ART and other medications. For some participants, taking ARVs was not difficult, and they reported not experiencing any side effects. However, difficulties were reported when patients were asked to take multiple medications simultaneously, including after discharge. This was especially common with TB medication, as participants often believed that a person taking TB medication was too sick to withstand both TB and HIV treatments at once. As one 28-year-old woman who was managing both HIV and TB explained:

Then they also told me that I had TB, and I collected the TB medication as well. But the TB drugs have given me challenges. When I take them, I start feeling sick and sometimes my legs get affected and I even fail to walk. You find that my joints become

weak, but the legs do not get swollen. (IDI, 28 year old female patient).

A number of participants also reported having a non-communicable disease (NCD), such as heart disease or diabetes, in addition to HIV. For some of these participants, their NCDs were their primary concern as they found managing their NCDs more difficult than managing HIV. For others, this comorbidity contributed to their inability to stay in HIV care or get to the hospital for further management due to the prohibitive cost of medications for NCDs. Unlike ARV, medications for NCDs were rarely free, and their costs further depleted the finances of families who had already lost income due to the illness or hospitalization of their family member.

I have been having challenges because I now have 3 things; I have HIV, I have sugar (diabetes) and I have BP. I have to take medication for HIV, I have to take medication for BP, and you'd find that this hospital will have HIV drugs but no medication for diabetes and sometimes they don't have even for BP. I have to buy (diabetes medicine) if I don't take medication, my BP will shoot up (IDI, 50 year old female patient)

Disability caused by NCDs, particularly heart disease and stroke, were also cited as a very common barrier that makes it difficult for some patients to travel to their clinic or hospital appointments physically. Lay counselors from the local clinic related instances of patients who were assumed to be lost to follow-up, but when home visits were made, they found some patients had cardiac and/or neurologic issues, resulting in impairments that made it difficult for them to come to the hospital or clinic.

Coming from a financially stable household thus was an enabler of engagement as it allowed some patients to stay engaged with the healthcare system following discharge and overcome the challenges of an NCD comorbidity. Participants who had financial resources were also able to afford transportation to the health center, and more easily obtain all of the necessary drugs. Participants indicated that their spouses, siblings, nephews, and other family members helped them meet their hospital needs as well as other needs post-discharge. This included paying for food and rent, as well as transportation and medicines.

Symptoms of mental illness and unhealthy alcohol use

Long-standing symptoms of mental illness (such as depression and anxiety) and substance use (such as alcohol) affected participants' ability to attend medical appointments and take their HIV medications as recommended following discharge. Narratives from patients

and caregivers suggested that some patients were dealing with undiagnosed mental illnesses. Caregivers described how their relatives were struggling with “thinking too much and stress” and how this was affecting their treatment journey. One caregiver described how her sister (the patient) often expressed feeling sorry for herself because she assumed she had become a burden to others because of her sickness. Other patients described broken relationships due to their HIV status alongside other mental health concerns. As a 41-year-old woman whose partner had left her for another woman explained:

It was really a hard time for me, it wasn't easy. At that time even for me to start getting sick, it was depression. My husband had left me, so I started to gradually feel sick So even for me to just accept it became very difficult for me and ...after that then the lay counselor] sat me down and told me that it happens. (IDI, 41 year old female patient)

Lay counsellors also highlighted how PLWH who struggled to accept and disclose their HIV status, or who disclosed and then experienced stigma from their family, felt socially alienated, helpless, and unhappy, and sometimes had suicidal or parasuicidal thoughts.

The thing is that these people are ... not airing out what they are feeling inside. It just eats them up inside, that is why they reach an extent to say, they should just stop taking the drugs or commit [] suicide. ... When you live with people who don't care about you... These are the people who reach a point of depression, and they want to die. Some families say bad things like, “Eh, you are troubling us, just drink your medicine.” (FGD, hospital lay counselors).

To cope with this situation, especially among men, some patients turned to alcohol. Heavy alcohol misuse contributed to poor medication adherence and in some instances missed appointments as one participant narrated.

Yes, I have seen this with my friends, they stopped drinking medication, they continued drinking beer, thinking they can clear their mind. (IDI, 50 year old male patient)

Household Level: economic shocks, poverty, and food scarcity

Hospitalization as an economic shock

While many of the individual-level factors influencing re-engagement in care were longstanding issues; at the household level, we found concerns around the period of hospitalization particularly important—specifically, the

hospitalization itself represented a significant economic shock. Particularly for lower-income households, illness and hospitalization, exacerbated the economic vulnerability of the household, which then negatively influenced post-discharge engagement in care. The most significant example of this was when the primary breadwinner in the family became ill, as this greatly reduced the family's income. Hospitalization not only led to a loss of employment/income for the patient and/or their caregiver, but also increased expenses due to the cost of labs, medications, and scans, which further pushed families further into poverty. One 28-year-old woman describes the challenges her husband, and therefore, her household, were now facing:

He is also not doing anything; he lost his job during the time that I was in hospital because he was the one who was taking care of me. I had no other person to look after me while in hospital. (IDI, 28 year old Female patient)

Unplanned expenses that arose from hospital admission, such as new prescribed medications and transportation to and from the hospital for the caregiver and other family members, further contributed to the depletion of household resources. When the hospitalization involved comorbidities, such as diabetes, this caused extra economic burden on families due to additional resources spent on “special food” to address recommended dietary requirements, additional testing that was rarely free (unlike those for HIV), and new medications. Some families reported that these costs, particularly those related to medications, forced them to choose between treatment and food.

I usually see my medication finishing but like I was saying, in my case I have get on two buses ... So, most of the times when you think of that, ahhh! ... for me I don't even have a small amount, so that my children eat nshima or porridge. So, I would rather let my children eat with little I have then I stay back home [than come to the hospital]. (IDI 54 year old Female patient).

Counsellors told stories about participants who stopped taking their medications because they didn't have enough food, or because they perceived they did not have enough “good” (i.e. nutritious and healthy) food.

If we go to a patient and find out why they are not taking their medications correctly, then they will say, 'I have a problem finding food. Look at me I have TB and HIV, and all these things so you find that when I take my drugs, they just work on me on an empty

stomach and sometimes I feel like I am going mad so it's the lack of food that's making me not take my drugs.' (FGD, lay counsellors).

Health system factors: HCW-patient communication, staff and caregiver attitudes, confidentiality concerns, discharge instructions and fragmented referral system

In addition to individual and household-level factors influencing engagement in care following hospital discharge, participants described a number of challenges they faced with navigating the healthcare system.

HCW-patient communication

During hospitalization, communication gaps were reported at several levels, the first of which was inadequate communication between clinicians and patients. Many participants said that they were not told or do not recall being told (as perhaps they were very ill at the time) why they were hospitalized, or why laboratory tests were being performed on them. They complained that clinicians did not adequately explain their condition. One 54-year-old male participant who was admitted for pain claimed that he was not explicitly told what he was suffering from, as he explained:

They didn't tell me anything, when they came, they will just come to write in the file, run some tests and they go and then those who give medicine come and just like that. (IDI, 54 year old male patient)

Participants further expressed concerns about inconsistency in the medical plans provided by the clinical teams at the hospital. One caregiver narrated a story of how one junior doctor prescribed a certain drug for their relative that the family had to buy in the morning, only to be told in the afternoon by the senior doctor (i.e., supervisor) that it was not the appropriate drug. At that point the consultant doctor prescribed another drug that the patient had to buy to replace the drug earlier prescribed, despite having already depleted his limited financial resources. Others complained about doctors changing medicines more than once for patients during the course of admission, and then asking them to buy all new prescribed drugs. Finally, gaps in communication sometimes resulted in caregivers procuring the wrong medication.

Yes, we bought medicine we were prescribed from that pharmacy (pharmacy just outside the hospital) we bought almost k320 (about 20 \$USD), they wrote it for us then this doctor came and said not this medication. (IDI, 44 year old caregiver).

Patients and caregivers further expressed frustration with doctors who were too busy to fully engage with them,

often delegating this task to nurses or lay counselors, who they perceived to have less information on the medical plan. "To be honest, there is no doctor that I sat with to talk about this while I was there" stated one 49-year-old female patient. Without adequate information, it was more difficult for patients to understand the reasons for ongoing hospitalization, the steps necessary to get better, and the importance of follow-up clinical visits.

Staff attitudes during hospitalization

Participants also reported mixed experiences with the attitudes of staff at the hospital. Some reported that providers did not seem to care or pay attention to their needs. Participants attributed this behavior to high staff-to-patient ratios and overload (too much to do at any given time).

On the other hand, positive experiences with HCWs were said to positively influence post-discharge engagement. Some participants appreciated the help they received from the hospital. "Well, I really got a lot of help, because after I was given like more than 10 drips, I felt much better.... I really was taken good care of." stated one 37-year-old male patient. Lay counsellors were a source of support for PLWH as they provided adherence support; they encouraged PLWH to go to the local community facility for their ART refill appointments, provided PLWH with information on how to take their medications, and reminded patients about their hospital appointments.

It was helpful in the sense that, they were encouraging us not to miss even a day. It was encouraging because they will tell you, 'If you do this and that, you will be fine, just continue taking medicine.' ... they even used to call to ask about how we were feeling... Sometimes they would even remind us not to forget to go back. (IDI, 27 year old Male participant)

Confidentiality concerns

The hospital has open patient wards with curtains that offer limited privacy. This created a significant challenge to provision of HIV counseling, as the wards were often congested with many patients and their caregivers, especially at the time of discharge. Patients reported feeling uneasy receiving counseling about HIV and associated conditions in an open room with other patients and family members nearby, even if the curtain was closed. Lay counselors and other staff therefore had to provide, in patients opinion, suboptimal information to patients. These patients tended to have challenges understanding their condition and what was expected of him/her post discharge.

I wanted to say that the other problem is that there is no confidentiality in the wards when it comes to counseling patients. You will find the beds are closely put together, so you have no choice but to make it short and fast so that other people do not know what is really going on. (FGD, Lay counselors)

Discharge instructions

Patients and their caregivers described the hospital discharge process as unstructured with minimal/no documentation provided for the patient, which created challenges for both the providers during patient follow-ups, and for patients once they were at home and expected to return to the hospital.

Patients reported that their healthcare providers did not provide them with clear, understandable, and adequate information at discharge. As a result, some patients left the hospital with a poor understanding of their diagnosis and the purpose of new medications.

The information they told us ... it's like we didn't hear it clearly because of not knowing it well. I don't know how I can say it, but I don't know if it's the time they didn't have to say things in detail? However, when I came back, I was like, 'Eish!' Not telling me was a mistake because I wondered why I was again getting sick like it was when I went to the hospital. That made me complain and I wasn't happy with it. (IDI, 27 year old Male patient)

Some participants did not know when to return to the hospital. In some cases, this was because they were given a verbal follow-up appointment date. A verbal appointment also made it difficult to know who to see when patients returned to the hospital. Others said they were sent to a counselor within the hospital shortly before discharge (for those new on ART or those with mental health challenges who needed more counseling), but a counselor was not always available, so they were told to return another day. Missing a counselor at discharge and being asked to return to the hospital for the missed appointment required the patient to travel back to the hospital, incurring additional travel costs, particularly for patients too sick to use public transportation.

The timing of patient discharge by doctors was also erratic and this also contributed to challenges that patients faced with getting back to the facility. Patients stated that they could be discharged at any time, including when no lay counsellors were available to give them information on their next hospital appointment or when they would receive follow-up support from the lay counsellors.

Fragmented referral systems

Once discharged, patients faced additional challenges because of a breakdown in communication between the patient, the discharging hospital, and the local clinic or outpatient department where follow-up was supposed to occur. Whereas most participants were given a formal referral letter, containing information on diagnoses and medications, when their primary/local clinic transferred them to LMUTH/UTH, at discharge, patients were rarely, if ever, given a referral letter back to a nearby clinic and/or a discharge note with information about their previous admission and treatment received to give to a doctor at their next appointment. As one 59-year male patient exclaimed:

There was no referral, but this is why I am saying that, had they known, they should have given us one so that in case of any problems we easily run to our local clinic. (IDI, 59 year old male patient)

In addition, while in many cases it is advised that the patient returns to the hospital for review, especially for those with complicated health cases, patients often struggled to make it back to the hospital. Lack of information on why they were admitted and what was their discharge diagnosis and plan undermined patient motivation to return to the discharging hospital, particularly in light of transportation costs. Further, they were often unable to follow-up the discharge at the local community clinic, which patients reported was less equipped to help them. Sometimes, after hearing about the recent admission, the local clinic doctor referred the patient back to the original hospital.

Doctors in group discussions confirmed that whereas the process to transfer a patient to a higher level of care (i.e., from the local clinic to the hospital) was in place and widely followed, including with structured paperwork and training, the transition of care back to the local clinic post-discharge was mostly on the shoulders of the patient and his/her caregiver. The referral form (initiated by the local clinic when proposing to hospitalize a person) had a section at the bottom for the admitting hospital to give a discharge plan to be followed up by the referring facility, but this was not used by discharging doctors. The admission records stayed at the admitting facility and the 'discharge slip' given to patients only contained the date of discharge and timing of follow-up at most.

Discussion

To inform the development of interventions to reduce post-discharge deaths and non-viral suppression in hospitalized people with HIV, we conducted a formative, qualitative study to understand barriers and facilitators to care engagement following hospital discharge. Based

on the social-ecological model, three levels of factors – individual, household, and health system -- influenced health behavior related to care engagement following hospitalization. While some critical factors identified were not unique to the post-discharge period (HIV stigma, disclosure, etc.), we generated novel information on unique factors that impact post-hospital engagement and how pre-existing issues are worsened by hospitalization and discharge.

We also found that post-discharge re-engagement in care was influenced by factors along the cascade of care. For many participants, long-term barriers to engagement in HIV care (such as anticipatory HIV stigma) were also barriers to post-discharge re-engagement in care. As we depict in Fig. 1, ART adherence challenges stemming from anticipated HIV stigma contributed to the likelihood of hospital admission and undermined post-discharge care transitions and engagement. While the impact of stigma on the HIV care cascade is well-known [24], it is important to highlight in this study as it holds implications for post-discharge engagement in care. We found that fear of HIV status disclosure due to HIV-related stigma resulted in inadequate social support for medication adherence and compliance with post-discharge clinical appointments and other clinical instructions. Patients who disclosed their status to supportive family were able to access more comprehensive social support, which facilitated adherence to treatment requirements, post-hospital care instructions, and hospital appointments. Others have also found similar findings with disclosure playing a key role in improving the acceptability of ART adherence, retention in care, and reduction in stigma leading to slower disease progression, higher odds of viral suppression, and reduced hospitalization risks [25–27].

Mental health concerns also served as long-term factors that frequently constrained post-discharge. As in many other settings, patients with depression had challenges with ART adherence resulting in poor treatment outcomes [28–30]. These findings suggest that improving mental health screenings for admitted patients is critical for diagnosis of mental health issues, as well as referral to counselling services, and that an integrated approach to HIV/NCD and mental health is needed for improved patient care. Such integrated approaches have been shown to improve NCD control, patient retention, and viral suppression [31, 32].

Challenges associated with treatment regimens for comorbidities, both for TB and many NCDs, were exacerbated during admission and in the post-discharge period. For some, this reflected concerns about taking multiple drugs. ART has transformed HIV/AIDS into a manageable chronic condition that allows PLWH to live longer and more fulfilling lives [33]. However, living longer with

HIV presents unique risk factors related to aging and NCDs. Many of the patients in this study were middle-aged and had both HIV and an NCD, particularly high blood pressure and diabetes, similar to other settings [34]. Patients in this study found managing HIV easier than NCDs, which demonstrates how far ART has come. NCDs such as diabetes necessitate dietary changes and costly medications; patients believed they needed expensive food for their medication to work. Hypertension required daily medications, which were not always provided by the health system and required that patients pay out of pocket. These concerns were exacerbated in poor households, many reeling from the economic shock of illness and hospitalization. Cash transfers at the time of hospital discharge could be an important strategy to incorporate into interventions in the post-discharge period; as they may enable family members to invest in the patient's recovery directly through better nutrition or access to necessary more costly medications, or indirectly, through investments in capital toward re-engagement in income-generating activities.

In the case of low-income households, limited access to food, paired with misconceptions about drug interactions and the perceived need for expensive food for medications to be effective, may have made patients reluctant to take their drugs [35]. Further, the impact of pill burden and side effects on treatment adherence has been extensively studied [36]; patients associated a high pill count for TB, HIV, and other infections with potential harm and an increased risk of drug intolerance [35]. Further support and education are needed for patients with comorbid NCDs and HIV to support medication adherence. Addressing medication costs is also critical; affordability and accessibility of NCD treatments should be improved to increase patient access. Healthcare workers including lay counsellors should thoroughly explain drug interactions and food requirements particularly for HIV and TB comorbidities. Addressing misconceptions, impacting information on side effects, pill burden, timing of ART with TB medication, and their impact on other diseases such as meningitis and NCDs is crucial for improved treatment outcomes post discharge. Additionally, beliefs about food quantity and quality should be addressed to improve treatment adherence and outcomes.

Healthcare system challenges amenable to intervention

Importantly, the study health system level barriers to engagement in care following discharge that may be amenable to change. Barriers included communication gaps between patients and health care workers during hospitalization, perceived poor staff attitudes, patient and provider concerns about lack of confidential hospital space for patient counselling, poor discharge instructions, and

fragmented referral systems between the hospital and the local clinic.

Patient-provider communications have been highlighted in various contexts, including SSA, as a crucial factor influencing treatment adherence and retention in care, with poor communication often leading to suboptimal treatment outcomes, poor adherence, patient dissatisfaction, and inefficient use of health system resources [37–40]. Similarly, our study found inadequate and poor communication between clinicians and patients, with perceived inconsistent medical plans resulting in patients not fully understanding their treatment plan or follow-up appointment schedules or value. Communication gaps were also extended to the hospital discharge process, whereby inadequate discharge instructions made it difficult for patients to engage with the local community-based clinics or return to the discharging hospital for follow-up care. Having too many patients being admitted and discharged from these two understaffed facilities may explain the lack of structure and adequate information during the discharge process. These findings suggest that enhancing clinical staff's skills in effective communication and relationship-building may improve patient retention and engagement in HIV care [39]. Holistic approaches such as Patient Centered Care (PCC) could improve communication between clinicians and patients as well as patients' experiences with the healthcare system [41].

In this study, patients had mixed interactions with hospital staff: positive experiences facilitated post-discharge engagement. Hospital staff, particularly lay counsellors, were frequently described as a vital source of support for patients, especially in providing adherence counselling for post-engagement in care, as noted by others [42, 43]. Lay counsellors, who are cheaper to hire and train, can play an important role in relieving clinical staff's role of providing psychosocial support and thus improve communication with patients and help the hospital provide a structured discharge process with all the information patients need once discharged [44]. To strengthen the role of lay counsellors as well as communications across all hospital staff, PCC training should also be extended to lay counsellors, as they play a key role in supplementing the efforts of overburdened clinical staff.

Implications and recommendations

While the vast majority of HIV human and financial resources are spent in outpatient and community settings, as the prevalence of NCDs among PLWH increases with age [34], hospitalization provides a critical and largely neglected opportunity for screening and treatment for NCDs and re-engage people with HIV in care after periods of challenge. As advised by WHO [45], all admitted patients should be screened for NCDs

including mental health issues and substance abuse, and provided with counselling support and appropriate treatment. Community-based support, through the use of lay counsellors as cited in other settings [46–49], can act as a bridge between health facilities and the community, while also providing all post-discharge support such as adherence, re-enforcing messages from clinicians, and ensuring that patients are supported to return to a facility for treatment when necessary. Lay counselors can also be used to address home-based stigma through family counseling and help improve disclosure and social support [49]. Similar to provision of ART, PLHIV (and others) in SSA need additional support with free or low-cost drugs for NCDs as most can't afford these medications. National programs and hospitals should consider stocking drugs for NCDs in addition to HIV medication. Moreover, the provision of nutritional support and food supplements will further help many patients, especially those living in poverty exacerbated by loss of income due to hospitalization. Community referrals to social welfare programs and community education about nutrition can also play key roles to support those experiencing food insecurity. To improve communication among health care workers, hospital policies governing treatment and discharge protocols should be revised and information flow should be strengthened. For example, a simplified patient card that includes all information about the patient, such as prescribed drugs and clinical appointment dates, could significantly improve clinician and patient communication. Lay counselors working with the hospital should have their roles expanded to include them providing additional patient navigation services to support patients during admission and ensure that patients fully understand reasons for their admission, treatment plans and also help transition the patient from in-hospital admission to clinic-based ART programs [50]. Additional research is needed to understand the need and effectiveness of HIV-NCD care integration in Africa and how this can be linked to inpatient settings, as well as evidence-based interventions to support people with HIV and comorbidities following hospitalization.

Strengths & limitations

This study has multiple strengths, foremost that it is based on the actual lived experiences of PLHW discharged from the hospital and their caregivers. The hospital to community discharge transition is frequently neglected in Africa, including in the HIV health system. Our study findings are supported by data collected from clinicians and lay counsellors as well as patients and their caregivers. Data triangulation facilitated a holistic understanding of patients' experiences, while considering the challenges that providers and caregivers face when supporting them. Furthermore, interviews with

community-based lay counsellors provided perspectives on patient experiences in both inpatient and outpatient health facilities, allowing an understanding of discharged patients' experiences when navigating local community clinics after hospitalization. Furthermore, interviewing patients within one month of discharge improved the credibility of their stories as memories of their hospitalization were still recent.

It is important to note that the perspectives and experiences were gathered from a carefully selected small group of participants with either very low CD4 count or poor viral non-suppression. Therefore, our findings may not accurately represent the perspectives of all patients with HIV who are hospitalized, especially for non-HIV-related reasons, such as surgery, pregnancy complications, or orthopedic conditions. While this represents a small proportion of PLWH in Zambia, they are at high risk for post-hospital mortality. Understanding and addressing the challenges faced during and post-hospitalization for PLWH is critical to reduce morbidity, mortality, and meet the ambitious goal of zero new transmissions by 2030.

Conclusions

Inpatient settings provide a compelling yet neglected opportunity to re-engage PLHIV with care while improving viral suppression, managing comorbidities, and lowering mortality. Persistent challenges after discharge, such as interpersonal issues, health concerns, environmental factors, and systemic issues, exacerbate existing barriers to effective treatment and re-engagement in care. To effectively reach these individuals, HIV programs that aim for epidemic control should consider holistic community-based interventions to mitigate the many factors that act as barriers for patients and support better treatment outcomes.

Abbreviations

PLWH	People Living with HIV
ART	Antiretroviral therapy
FGD	Focus group discussions
IDIs	In-depth interview
SEM	Social Ecological model
SSA	Sub-Saharan Africa

Acknowledgements

The authors would like to thank everyone who helped with this research. This includes clinicians at UTH and LMUTH, lay counsellors and their supervisors, as well as nurses working in the hospitals who helped with patient recruitment. We also want to thank the social science research assistants, for collecting and transcribing all the qualitative data. Finally, and most importantly, we would like to thank the all the participants and their caregivers who agreed to participate in the qualitative data collection activities. The views expressed in this article do not necessarily represent the official views of NIMH, who funded this work.

Author contributions

MM, GM, CH, SB, and PH collected and transcribed all the data. CB, WB, and KS collected some of the data with clinicians and supervised all data collection activities. CC and MV provided overall supervision and technical support for the data collection. CB, KS, MM, GM, CH, SB, and PH carried out the

data analysis. CB wrote the first draft of this paper. KS, MV, and CC reviewed and edited the first draft, and thoroughly reviewed and edited the second draft. LKM, NM, MC and WB reviewed the paper and provided critical feedback. All authors were involved in the design of the main study and helped write the paper. All authors have read and approved the final manuscript.

Funding

This Research was supported by a Grant from the United States National Institute of Health (NIH) (R34MH122265-01). The funding body however had no role in the study design, data collection, analysis and interpretation and in writing the manuscript.

Data availability

No datasets were generated or analysed during the current study.

Declarations

Ethics approval and consent to participate

Ethical approval for this study was obtained from the University of Zambia Biomedical Research Ethics Committee (Ref-1346-2020) and the University of Maryland Institutional Review Board (Ref: HP-00094612). Additional approvals were obtained from the Zambian National Health Research Authority, and the Ministry of Health at both provincial, district, and clinic levels. Written informed consent was obtained from all participants as per the local Research Ethics Committee guidelines. All participants in interviews and focus group discussions provided written informed consent. Non-literate participants provided witnessed thumb-printed informed consent. Prior to conducting observations, all household members provided verbal consent and approval. Participants were interviewed in private venues of their choice. Data transcripts were anonymized by removing personal identifiable information such as home addresses and phone numbers. Additionally, the names of study communities and participants were anonymized.

Consent for publication

Participants gave written consent to participate in the study including giving consent to the following statement: "I agree that anonymized direct quotes from interviews, group discussions, and field notes in public reporting of findings from this study."

Competing interests

The authors declare no competing interests.

Author details

¹Maryland Global Initiatives Corporation Zambia, Lusaka, Zambia

²School of Public Health, Department of Behavioral and Community Health, University of Maryland, College Park, MD, USA

³Ciheb Zambia, Lusaka, Zambia

⁴School of Medicine, University of Zambia, Lusaka, Zambia

⁵Ministry of Health, Lusaka, Zambia

⁶Centre for International Health, Education, and Biosecurity, University of Maryland School of Medicine, Baltimore, MD, USA

⁷Institute of Human Virology, University of Maryland School of Medicine, Baltimore, MD, USA

⁸University of Zambia School of Public Health, Lusaka, Zambia

⁹University of Alabama at Birmingham, Birmingham, AL, USA

Received: 17 October 2024 / Accepted: 9 December 2024

Published online: 24 February 2025

References

1. Ministry of Health, Zambia. Zambia Population-based HIV Impact Assessment (ZAMPHIA) 2016; Ministry of Health. February 2019. ZAMPHIA.
2. UNAIDS. Zambia offering antiretroviral therapy regardless of CD4 count [Internet]. UNAIDS. 2018. https://www.unaids.org/en/resources/presscentre/featurestories/2017/august/20170818_zambia
3. CDC Zambia-Country-Profile-2023.
4. Haachambwa L, Kandiwo N, Zulu PM, Rutagwera D, Geng E, Holmes CB, et al. Care Continuum and Postdischarge outcomes among HIV-Infected adults admitted to the hospital in Zambia. *Open Forum Infect Dis*. 2019;6:ofz336.

5. Wajanga BM, Webster LE, Peck RN, Downs JA, Mate K, Smart LR, et al. Inpatient mortality of HIV-infected adults in sub-Saharan Africa and possible interventions: a mixed methods review. *BMC Health Serv Res*. 2014;14:627.
6. Ford N, Patten G, Rangaraj A, Davies M-A, Meintjes G, Ellman T. Outcomes of people living with HIV after hospital discharge: a systematic review and meta-analysis. *Lancet HIV*. 2022;9:e150–9.
7. Matoga MM, Rosenberg NE, Stanley CC, LaCourse S, Munthali CK, Nsona DP et al. Inpatient mortality rates during an era of increased access to HIV testing and ART: A prospective observational study in Lilongwe, Malawi. Pett SL, editor. *PLOS ONE*. 2018;13:e0191944.
8. Peck RN, Wang RJ, Mtui G, Smart L, Yango M, Elchaki R, et al. Linkage to Primary Care and Survival after Hospital Discharge for HIV-Infected adults in Tanzania: a prospective cohort study. *JAIDS J Acquir Immune Defic Syndr*. 2016;73:522–30.
9. Lamprecht DJ, Martinson N, Variava E. Effect of HIV on mortality among hospitalised patients in South Africa. *South Afr J HIV Med* [Internet]. 2023 [cited 2024 Aug 31];24. <https://sajhivmed.org.za/index.php/hivmed/article/view/1477>
10. Sikazwe I, Eshun-Wilson I, Sikombe K, Czaicki N, Somwe P, Mody A et al. Retention and viral suppression in a cohort of HIV patients on antiretroviral therapy in Zambia: Regionally representative estimates using a multistage-sampling-based approach. Newell M-L, editor. *PLOS Med*. 2019;16:e1002811.
11. Mody A, Sikombe K, Beres LK, Simbeza S, Mukamba N, Eshun-Wilson I, et al. Profiles of HIV Care disruptions among adult patients lost to follow-up in Zambia: a latent class analysis. *JAIDS J Acquir Immune Defic Syndr*. 2021;86:62–72.
12. Beres LK, Mwamba C, Bolton-Moore C, Kennedy CE, Simbeza S, Topp SM, et al. Trajectories of re-engagement: factors and mechanisms enabling patient return to HIV care in Zambia. *J Int AIDS Soc*. 2023;26:e26067.
13. Ehrenkranz P, Rosen S, Boule A, Eaton JW, Ford N, Fox MP, et al. The revolving door of HIV care: revisiting the service delivery cascade to achieve the UNAIDS 95–95–95 goals. *PLOS Med*. 2021;18:e1003651.
14. Bond V, Nomsenge S, Mwamba M, Ziba D, Birch A, Mubekapi-Musadaidzwa C, et al. Being seen at the clinic: Zambian and South African health worker reflections on the relationship between health facility spatial organisation and items and HIV stigma in 21 health facilities, the HPTN 071 (PopART) study. *Health Place*. 2019;55:87–99.
15. Mwamba C, Sharma A, Mukamba N, Beres L, Geng E, Holmes CB, et al. They care rudely! resourcing and relational health system factors that influence retention in care for people living with HIV in Zambia. *BMJ Glob Health*. 2018;3:e001007.
16. Topp SM, Mwamba C, Sharma A, Mukamba N, Beres LK, Geng E et al. Rethinking retention: Mapping interactions between multiple factors that influence long-term engagement in HIV care. Isaakidis P, editor. *PLOS ONE*. 2018;13:e0193641.
17. Ankamah A, Ganle JK, Lartey MY, Kwara A, Nortey PA, Okyerefo MPK, et al. ART access-related barriers faced by HIV-positive persons linked to care in southern Ghana: a mixed method study. *BMC Infect Dis*. 2016;16:738.
18. Fonner VA, Geurkink D, Chiwanga F, Amiri I, Likindikoki S. Long-Distance Travel for HIV-Related Care—Burden or Choice? A mixed methods study in Tanzania. *AIDS Behav*. 2021;25:2071–83.
19. Hlongwa M, Jama NA, Mehlomakulu V, Pass D, Basera W, Nicol E. Barriers and facilitating factors to HIV Treatment among men in a High-HIV-Burdened District in KwaZulu-Natal, South Africa: a qualitative study. *Am J Mens Health*. 2022;16:155798832211209.
20. Truong M, Rane MS, Govere S, Galagan SR, Moosa M-Y, Stoep AV, et al. Depression and anxiety as barriers to art initiation, retention in care, and treatment outcomes in KwaZulu-Natal, South Africa. *EClinicalMedicine*. 2021;31:100621.
21. Bond V, Chiti B, Hodinott G, Reynolds L, Schaap A, Simuyaba M, et al. The difference that makes a difference: highlighting the role of variable contexts within an HIV Prevention Community Randomised Trial (HPTN 071/PopART) in 21 study communities in Zambia and South Africa. *AIDS Care*. 2016;28:99–107.
22. Bronfenbrenner U. Toward an experimental ecology of human development. *Am Psychol*. 1977;32:513–31.
23. Pope C. Qualitative research in health care: analysing qualitative data. *BMJ*. 2000;320:114–6.
24. Knight L, Schatz E. Social Support for Improved ART Adherence and Retention in Care among older people living with HIV in Urban South Africa: a Complex Balance between Disclosure and Stigma. *Int J Environ Res Public Health*. 2022;19:11473.
25. Kimeu M, Burmen B, Audi B, Adega A, Owuor K, Arodi S, et al. The relationship between adherence to clinic appointments and year-one mortality for newly enrolled HIV infected patients at a regional referral hospital in Western Kenya, January 2011–December 2012. *AIDS Care*. 2016;28:409–15.
26. Villiera JB, Katsabola H, Bvumbwe M, Mhango J, Khosa J, Silverstein A, et al. Factors associated with antiretroviral therapy adherence among adolescents living with HIV in the era of isoniazid preventive therapy as part of HIV care. Kerkhoff AD, editor. *PLOS Glob Public Health*. 2022;2:e0000418.
27. Mandlate FM, Greene MC, Pereira LF, Gouveia ML, Mari JJ, Cournos F, et al. Association between mental disorders and adherence to antiretroviral treatment in health facilities in two Mozambican provinces in 2018: a cross-sectional study. *BMC Psychiatry*. 2023;23:274.
28. Nguyen MX, McNaughton Reyes HL, Pence BW, Muessig K, Hutton HE, Latkin CA, et al. The longitudinal association between depression, anxiety symptoms and HIV outcomes, and the modifying effect of alcohol dependence among ART clients with hazardous alcohol use in Vietnam. *J Int AIDS Soc*. 2021;24:e25746.
29. Zeleke TA, Alemu K, Ayele TA, Denu ZA, Mwanri L, Azale T. Systematic review and meta-analysis on the effect of depression on ART adherence among women living with HIV. Buh A, editor. *PLOS ONE*. 2024;19:e0300106.
30. Kwarisiima D, Atukunda M, Owaraganise A, Chamie G, Clark T, Kabami J, et al. Hypertension control in integrated HIV and chronic disease clinics in Uganda in the SEARCH study. *BMC Public Health*. 2019;19:511.
31. Sando D, Kintu A, Okello S, Kawungezi PC, Guwatudde D, Mutungi G, et al. Cost-effectiveness analysis of integrating screening and treatment of selected non-communicable diseases into HIV/AIDS treatment in Uganda. *J Int AIDS Soc*. 2020;23:e25507.
32. Deeks SG, Lewin SR, Havlir DV. The end of AIDS: HIV infection as a chronic disease. *Lancet*. 2013;382:1525–33.
33. Moyo-Chilufya M, Maluleke K, Kgarosi K, Muyoyeta M, Hongoro C, Musekiwa A. The burden of non-communicable diseases among people living with HIV in Sub-Saharan Africa: a systematic review and meta-analysis. *eClinicalMedicine*. 2023;65:102255.
34. Ingersoll KS, Cohen J. The impact of medication regimen factors on adherence to chronic treatment: a review of literature. *J Behav Med*. 2008;31:213–24.
35. Gebremariam MK, Bjune GA, Frich JC. Barriers and facilitators of adherence to TB treatment in patients on concomitant TB and HIV treatment: a qualitative study. *BMC Public Health*. 2010;10:651.
36. Hurley EA, Harvey SA, Keita M, Kennedy CE, Roter D, Dao S, et al. Patient-provider communication styles in HIV treatment programs in Bamako, Mali: a mixed-methods study to define dimensions and measure patient preferences. *SSM - Popul Health*. 2017;3:539–48.
37. Henly SJ. Health Communication Research for Nursing Science and Practice. *Nurs Res*. 2016;65:257–8.
38. Flickinger TE, Saha S, Moore RD, Beach MC. Higher Quality Communication and relationships are Associated with Improved Patient Engagement in HIV Care. *JAIDS J Acquir Immune Defic Syndr*. 2013;63:362–6.
39. Beach MC, Keruly J, Moore RD. Is the quality of the patient-provider relationship associated with better adherence and health outcomes for patients with HIV? *J Gen Intern Med*. 2006;21:661–5.
40. Lazarus JV, Cascio M, Anderson J, Pasanen S, Harding R. A person-centred approach to enhance the long-term health and wellbeing of people living with HIV in Europe. *J Int AIDS Soc*. 2023;26:e26117.
41. Dapaah JM. Attitudes and Behaviours of Health Workers and the Use of HIV/AIDS Health Care services. *Nurs Res Pract*. 2016;2016:1–9.
42. Eriksen AA, Fegran L, Fredwall TE, Larsen IB. Patients' negative experiences with health care settings brought to light by formal complaints: a qualitative metasynthesis. *J Clin Nurs*. 2023;32:5816–35.
43. Kolié D, Guillard E, Sow A, Manet H, Camara BS, Bigirimana T, et al. Exploring experiences of HIV care to optimize patient-centred care in Conakry, Guinea: a qualitative study. *Front Reprod Health*. 2024;6:1134404.
44. Integrating the prevention, and control of noncommunicable diseases in HIV/AIDS, tuberculosis, and sexual and reproductive health programmes.
45. Knettel BA, Fernandez KM, Wanda L, Amiri I, Cassiello-Robbins C, Watt MH, et al. The Role of Community Health Workers in HIV Care Engagement: a qualitative study of stakeholder perspectives in Tanzania. *J Assoc Nurses AIDS Care*. 2021;32:682–92.
46. Hartzler AL, Tuzzio L, Hsu C, Wagner EH. Roles and Functions of Community Health Workers in Primary Care. *Ann Fam Med*. 2018;16:240–5.
47. Viljoen L, Mainga T, Casper R, Mubekapi-Musadaidzwa C, Wademan DT, Bond VA, et al. Community-based health workers implementing universal access to

- HIV testing and treatment: lessons from South Africa and Zambia—HPTN 071 (PopART). *Health Policy Plan.* 2021;36:881–90.
48. Mwai GW, Mburu G, Torpey K, Frost P, Ford N, Seeley J. Role and outcomes of community health workers in HIV care in sub-saharan Africa: a systematic review. *J Int AIDS Soc.* 2013;16:18586.
49. Chiti Bwalya, Hachaambwa L, Muchanga G, Taonga Musonda M, Mwale T, Daka et al. Inpatient Navigation Model to Improve Delivery of Advanced HIV Disease Package For Hospitalized Adults With HIV in Zambia: A Randomized Pilot Trial. 2023 [cited 2024 Sep 10]; <https://rgdoi.net/https://doi.org/10.13140/RG.2.2.35950.38724>
50. Stangl AL, Jennifer K, Lloyd LM, Brady CE, Holland, Baral S. A systematic review of interventions to reduce HIV-related stigma and discrimination from 2002 to 2013: how far have we come? *J Int AIDS Soc.* 2013;16:18734.

Publisher's note

Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.