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Barriers and facilitators to linkage to HIV care after hospital discharge among adults living with advanced HIV disease in Uganda: a COM-B–guided qualitative study

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ABSTRACT

Background: Hospital discharge represents a high-risk transition period for people living with HIV, particularly those with advanced HIV disease. In low-resource settings, substantial gaps persist in linking these individuals to outpatient HIV care following hospitalisation. This study explored barriers and facilitators to post-discharge linkage to care from the perspectives of patients and healthcare workers (HCWs) in Eastern Uganda.

Methods: We conducted a descriptive qualitative study at Mbale Regional Referral Hospital between May and October 2025. Guided by the capability, opportunity, motivation, and behaviour (COM-B) model, we conducted 20 in-depth interviews with adults with advanced HIV disease who had recently been discharged from the medical ward (10 who successfully linked to care and 10 who did not), alongside 10 key informant interviews with HCWs involved in their care. Data were analysed using a thematic framework approach aligned with the COM-B constructs.

Results: Patient-reported barriers included physical weakness (physical capability), limited knowledge of the linkage process (psychological capability), high transport costs and long travel distances (physical opportunity), and stigma or non-disclosure of HIV status (social opportunity). HCWs identified the absence of standardised linkage protocols, post-discharge follow-up mechanisms, and incentive structures as key systemic barriers (physical opportunity). Facilitators reported by patients included initiation or resumption of antiretroviral therapy (ART) before discharge (physical opportunity), support from peer supporters and disclosure to caregivers (social opportunity), and fear of clinical deterioration (reflective motivation). HCWs identified the existing TB–HIV linkage system (reflective motivation) and the presence of ward-based linkage counsellors (physical opportunity) as enabling factors.

Conclusion: People living with advanced HIV disease face multiple, interrelated barriers to linkage with HIV care following hospital discharge, including physical debility, limited knowledge of the linkage process, financial and geographic constraints, and stigma. Conversely, pre-discharge ART initiation, peer support, and disclosure facilitate successful linkage. Strengthening post-discharge care will require standardised linkage protocols, structured follow-up mechanisms, and expanded use of peer supporters within health systems.

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KEYWORDS
Advanced HIV disease; linkage; hospitalisation; discharge; facilitators; barriers

Background

In 2024, an estimated 40.8 million people were living with HIV globally, with sub-Saharan Africa accounting for two-thirds of all HIV-related deaths [1]. In Uganda alone, 21,000 HIV-related deaths were recorded in the same year [2]. Among people living with HIV who require hospitalisation, many

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experience advanced HIV disease, multiple comorbidities, and a substantially elevated risk of mortality following discharge [3]. Evidence indicates that up to 50% of this population may die within six months of discharge [4,5], with delayed re-engagement with HIV care being a major contributing factor among those experiencing advanced HIV disease [3].

Globally, only 41.6% of people living with HIV who experience advanced HIV disease are successfully linked to HIV care within six months of hospital discharge [3]. Delayed re-engagement with HIV care following hospitalisation remains a critical barrier to achieving optimal HIV treatment outcomes for this population. Regional evidence reflects similar challenges: a study in Thailand reported that only 69.1% of people living with HIV were linked to care [6], while a study in northern Tanzania found that approximately 62.9% re-engaged with care within one month of discharge [4]. In Uganda, a 2011 study similarly reported that only 62.2% of people living with HIV accessed HIV care within one month following hospital discharge [7]. Although these regional figures exceed the global estimate reported by Ford et al. [2022], they nonetheless reflect persistently suboptimal rates of post-discharge linkage with care [3].

Several barriers have been reported to limit linkage to care after hospital discharge. These include denial of HIV status, perceived stigma, non-disclosure, lack of social and emotional support, and the burden of concomitant treatments for tuberculosis and other HIV-related comorbidities [8,9]. Behavioural health challenges such as depression and alcohol use further complicate engagement in care [8,9]. Additional health system-level barriers include lack of confidentiality during admission and poor communication between healthcare providers and across facilities during aftercare transitions following discharge [8,9]. Socioeconomic constraints, such as unemployment and insufficient funds for transportation and food, further hinder linkage to care [9]. In contrast, facilitators reported in prior studies include disclosure of HIV status, strong social support, financial stability, and reminder systems for follow-up appointments [8]. Collectively, these findings emphasise the need for implementation science strategies to improve linkage to HIV care after hospital discharge.

Although some studies have demonstrated successful interventions for timely linkage – defined as engaging people living with HIV in primary HIV care within 14 days of hospital discharge [10] – overall, post-discharge linkage rates remain suboptimal [3]. To design effective and contextually appropriate interventions, a comprehensive understanding of the barriers and facilitators influencing linkage is essential.

Theoretical underpinning of the study

In public health practice, behavioural theories such as the capability, opportunity, motivation, and behaviour (COM-B) model provide a robust framework for understanding mechanisms underlying behaviour change and implementation. The COM-B model conceptualises behaviour as a function of capability, opportunity, and motivation [11]. In this study, the COM-B framework was applied to categorise and interpret qualitative findings on post-discharge linkage to HIV care, examining how physical and psychological capability, social and physical opportunity, and reflective and automatic motivation influence engagement in care. The model further facilitates mapping identified determinants to relevant intervention functions and policy actions through the behaviour change wheel (BCW), supporting the development of targeted strategies such as education to strengthen psychological capability or environmental restructuring to improve physical opportunity (Figure 1).

The COM-B model posits that behaviour is a function of three interacting components: capability, opportunity, and motivation [12]. According to this framework, behaviour change requires sufficient capability and opportunity, along with greater motivation to perform the target behaviour relative to competing alternatives. In this qualitative study, we applied the COM-B model to identify the barriers and facilitators influencing linkage to HIV care following hospital discharge, among people living with HIV who experience advanced HIV disease in Uganda.

Methods

Study design

People living with advanced HIV disease. This descriptive qualitative study used in-depth interviews (IDIs) and key informant interviews (KIIs) to explore barriers and facilitators to linkage to primary HIV care

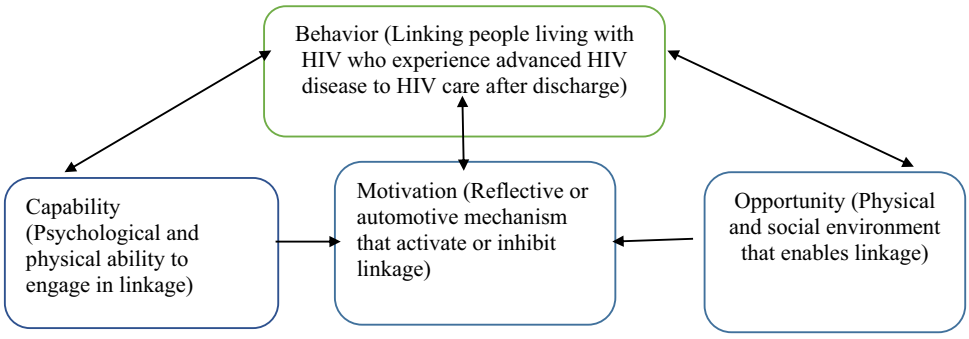


Figure 1. The capability, opportunity, motivation, and behavioural skills model. *Adopted from Michie et al. [12], Page 4.*

following hospital discharge among people living with HIV experiencing advanced HIV disease. IDIs captured the lived experiences of participants discharged from the medical ward, while KIIs elicited broader perspectives from healthcare workers (HCWs) involved in inpatient HIV care.

Study setting

Advanced HIV disease. The study was conducted at Mbale Regional Referral Hospital (MRRH), a 455-bed public tertiary hospital in Mbale City, Eastern Uganda, approximately 222 km from Kampala. MRRH is the main referral hospital for the Eastern region, serving a catchment population of approximately four million, and offers specialist services including medicine, surgery, psychiatry, paediatrics, obstetrics and gynaecologist, ENT, radiology, pathology, and ophthalmology. It is also a teaching site for the Busitema University Faculty of Health Sciences. Data collection took place on the 72-bed medical ward, which admits approximately 20 patients daily, including four to five adults living with HIV; about 70% of these have advanced HIV disease per WHO criteria. The ward is staffed by specialist physicians, medical officers, clinical officers, nursing officers, and HIV counselling staff.

Sample size

People living with advanced HIV disease. We purposively sampled 20 people living with HIV experiencing advanced HIV disease for IDIs prospectively after discharge, with equal numbers self-reporting timely and non-timely linkage to care. Additionally, KIIs were conducted with 10 HCWs (nurses, counsellors, and clinicians) on the medical ward. The patient sample size was informed by evidence that thematic saturation is typically achieved within 9–17 interviews [13].

Participants' selection

People living with advanced HIV disease. Study participants comprised people living with HIV experiencing advanced HIV disease who had been discharged from the medical ward, and HCWs involved in inpatient HIV services on the medical ward at MRRH. Advanced HIV disease was defined as age ≥18 years with CD4 count <200 cells/μL or WHO clinical stage 3 or 4 [14].

People living with HIV experiencing advanced HIV disease

Prospective participants were identified during hospital admission through file review and clinician consultation (with nurse-in-charge permission) and then contacted on the day of discharge. Eligibility criteria included: advanced HIV disease diagnosis with recent hospital discharge, age ≥18 years, consistent mobile phone access, and ability/willingness to provide informed consent (from the patient or a primary caregiver). Patients residing across the Kenya–Uganda border were excluded due to unreliable local network access.

Informed consent was obtained at discharge for follow-up contact 14 days later, consistent with Ugandan MOH guidelines recommending inter-facility linkage within this timeframe [15]; linkage status was determined by self-report during telephone contact. Recruitment continued until equal numbers of linked and non-linked participants were achieved, to capture a broad range of barriers and facilitators; participants unreachable after four attempts within two weeks were replaced. In total, 20 in-depth interviews were conducted with people living with HIV experiencing advanced HIV disease or their caregivers.

Healthcare workers

Ten HCWs (including nursing officers, medical officers, counsellors, physicians, and clinical Officers) on the medical ward of MRRH were approached by the study investigators (RK and INM), who explained their roles and the reasons for conducting the study and asked the HCWs to participate. All of them agreed to participate in the study.

Data collection procedures and methods

Data were collected between May and October 2025 by a team comprising the principal investigator (R.K., a male PhD student), a Public Health Specialist with Master's-level qualitative research training (N.R., female), and a graduate nurse (I.N.M., female). N.R. conducted the initial interviews while R.K. and I.N.M. observed, took notes, and received on-the-job training; thereafter, R.K. and I.N.M. conducted the remaining interviews. All team members were oriented to the study objectives, trained on the study tools, and piloted the interview guides to assess question flow and interpretation.

In-depth interviews (IDIs) with people living with HIV who experience advanced HIV disease

Researchers introduced themselves and explained the study's purpose at the start of each interview. Interviews were conducted by telephone via speakerphone in the participant's preferred local language (Lumasaaba or Luganda, determined during discharge consent) or English, audio-recorded with consent, and later transcribed verbatim. Caregivers were interviewed when patients were unable to respond, and relatives of deceased patients were interviewed to obtain available information. Field notes captured key points during each interview, which lasted 45–60 minutes.

The interview guide, informed by the COM-B model, comprised nine open-ended questions exploring barriers and facilitators to linkage to HIV care after hospital discharge (Supplementary 1). It was developed in English, refined through pilot testing at a non-study primary health facility, and translated into Luganda and Lumasaaba to support participant understanding.

Key informant interviews (KIIs) with HCWs

People living with HIV. KIIs were conducted in English, audio-recorded, and transcribed verbatim; field notes were also taken. Participants unwilling to be recorded were excluded. Interviews lasted 40–60 minutes. As with the IDIs, the KII guide was developed using the COM-B model and comprised eleven open-ended questions exploring barriers and facilitators to linkage to HIV care after hospital discharge (Supplementary 2). The guide was drafted in English and piloted at a non-study primary health facility.

Data analysis

At the end of each interview, audio recordings were independently transcribed and translated into English by two bilingual research assistants, cross-checked for consistency, and discrepancies adjudicated by a third bilingual researcher experienced in qualitative methods; the study nurse transcribed HCW interviews. Before analysis, the lead investigator (RK) verified all transcripts for accuracy by concurrently reading and listening to recordings.

Data were analysed using a thematic framework approach, appropriate for exploring participants' perspectives and identifying similarities, differences, and unexpected insights [16]. Analysis followed Braun and Clarke's six-step approach: familiarisation, coding, theme generation, review, definition, and write-up. A hybrid deductive-inductive approach was used [17]: deductive coding was guided by the COM-B model, while inductive coding captured barriers and facilitators emerging directly from participants' narratives. Transcripts were coded manually in MS Word by RK and independently by a qualitative researcher not involved in the study, for quality control; discrepancies were resolved by consensus.

IDI and KII transcripts were organised separately, with columns representing barrier and facilitator themes. Analysis proceeded through repeated listening to achieve familiarisation, transcription and translation to identify recurring meanings, data collation into codes and categories, and theme generation guided by the COM-B model's individual, community, and health-system levels. Emergent themes were classified as facilitators or barriers to linkage to HIV care after hospital discharge (Table 2), with illustrative participant quotes identified by ID number. Reporting adhered to the consolidated criteria for reporting qualitative research (COREQ) guidelines [18] people living with HIV experiencing advanced HIV disease.

Rigour

Trustworthiness was ensured using Lincoln and Guba's criteria [19]. Credibility was strengthened through regular pre-interview team discussions and attention to researcher positionality. Dependability was enhanced by conducting interviews in safe, non-judgmental settings, with telephone participants consulted in advance on preferred time and location; open-ended questions and probing minimised premature interpretive closure, and interviews were framed as reciprocal dialogues to reduce power asymmetries. Confirmability was achieved through triangulation of perspectives from healthcare workers and people living with advanced HIV disease, ensuring consistent and comprehensive interpretation across groups. Together, these measures strengthened trustworthiness and transferability to similar settings.

Reflexivity

The study was led by RK, a physician-PhD researcher practicing on the study ward, supported by nurses, public health specialists, and supervisors with extensive HIV research experience in Uganda, including a social scientist with qualitative research expertise in HIV care across sub-Saharan Africa. The team maintained an explicit reflexive stance throughout, critically examining how their disciplinary backgrounds, social positions, and clinical experience shaped data collection, analysis, and interpretation. Given the study's sensitive nature, particular attention was paid to power asymmetries in the researcher-participant relationship and the broader social context of HIV care, with consistent efforts to foster a respectful, open environment for authentic, contextually sensitive representation of participants' voices.

Results

Characteristics of study participants

Thirty interviews were conducted, including 20 IDIs with people living with HIV who experience advanced HIV disease and 10 KIIs with HCWs. The patient interviews included individuals both linked to HIV care and not linked, in equal numbers (Table 1). Participants' age ranged from 18 to 60 years, and the majority (70%) of people living with HIV who experienced advanced HIV disease were on ART at the time of discharge. The HCWs consisted of two nursing officers, two medical officers, two counsellors, two physicians, one Clinical Officer, and one ward nurse in charge.

Barriers and facilitators to timely linkage to HIV care after hospital discharge

People living with advanced HIV disease. Findings are organised per the COM-B model into two main themes: barriers to and facilitators of linkage to HIV care after hospital discharge. Barriers were explored among participants not linked to care, and facilitators among those linked. As these factors are largely

Table 1. Demographic characteristics of in-depth interview participants.

Characteristic	Number (%)
Sex	
Female	15 (75%)
Male	5 (25%)
Age (years)	
21–40	9 (45%)
41–60	8 (40%)
>60	3 (15%)
Patients receiving ART	
Yes	14 (70%)
No	6 (30%)
Linkage status after hospital discharge	
Yes	10 (50%)
No	10 (50%)

Table 2. Barriers and facilitators to linkage to HIV care after hospital discharge related to the COM-B domains.

	Sub-themes					
	Capability		Opportunity		Motivation	
Themes	Physical	Psychological	Physical	Social	Automotive	Reflective
1. Barriers	Physical weakness of patients after discharge	1.1. HCWs lack clarity on when patients should report for post-discharge HIV care. 1.2. Patients are unaware that they need to go for HIV care shortly after discharge.	1.3. Transportation costs hinder patients' ability to attend follow-up visits. 1.4. No standardised protocols for post-hospital linkage on the ward. 1.5. No follow-up tracking mechanism, as the hospital cannot verify whether referred patients reached their follow-up facility for HIV care. 1.6. Long distance to facilities with HIV care services	1.7. Fear of stigma discourages patients from seeking HIV care services after discharge. 1.8. Lack of disclosure limits caregiver support for linkage		
2. Facilitators			2.1. Starting ART before discharge facilitates linkage. 2.2. Testing counsellors facilitate referral and linkage	2.3. Peer supporters encourage clinic attendance. 2.4. Disclosure to caregivers	2.5. Perceived patient improvement	2.6. The existing TB linkage support system supports linkage. 2.7. Fear of the illness worsening

cross-cutting, they are presented together, with similarities or differences highlighted where relevant. Findings for each theme are summarised in Table 2 and detailed in the following subsections, illustrated with participant quotes.

a) **Barriers to linkage of people living with HIV who experience advanced HIV disease to HIV care after hospital discharge**

The main barriers to HIV care linkage among people living with HIV who experience advanced HIV disease included: lack of awareness about when to return for follow-up, insufficient information on why follow-up was necessary, post-discharge physical weakness, high transportation costs, long distances to HIV care clinics, absence of a mechanism to track linkage status, lack of ward-based linkage discharge guidelines, and no dedicated incentive to specifically target people living with HIV for post-discharge linkage, as detailed below.

Psychological capability: this refers to having the knowledge, understanding, and skills needed to access HIV care. Barriers here included lack of awareness of the need for post-discharge linkage and unclear timing for follow-up.

Most HCWs reported limited awareness among patients regarding when to attend HIV care follow-up after discharge. This knowledge gap was believed to hinder appropriate care-seeking behaviour, contributing to

serious outcomes including readmissions, viral load monitoring issues, and higher mortality among people living with HIV who experience advanced HIV disease.

> *"At home I stay alone with just the patient we stay only two in the house and that time when they were giving us that discharge form, they didn't tell me anything, and after discharge there's nothing the patient told me, she had that form and again we came back with it when we were coming for this other second admission." (Care taker of Patient 010 Not linked).*

Some patients and caregivers reported lacking information on why they should return to HIV care for follow-up after discharge. A few participants who had prior admissions instead simply waited for their scheduled appointment dates before reporting to their HIV care clinics for routine check-ups. '*Going back to TASO (HIV ART care facility) immediately after discharge? I haven't understood that. I believe those services aren't offered at TASO because in 2012 I fell sick, but I never returned, and since then, whenever I get sick, I wait until my appointment day.' (Patient 004 Not Linked).*

This lack of awareness hindered health workers' ability to provide accurate guidance on when patients should attend peripheral HIV care clinics post-discharge, leaving providers unsure about the specific instructions to give at discharge. '*We don't have any specific guidelines based on WHO or MOH recommendations regarding when these patients should be advised to return for routine HIV care, especially those previously in care. We rely on our medical judgment that patients should come for reviews after discharge, but we lack specific guidelines for* people living with HIV who experience advanced HIV disease*.' (Medical Officer on the ward).*

Physical capability: this refers to the strength, stamina, and physical limitations affecting an individual's ability to perform a behaviour – here, linkage to HIV care after discharge. Barriers included post-discharge physical weakness, high transportation costs (particularly when caregiver accompaniment was needed), and long distances to HIV care clinics.

Some patients and caregivers reported that profound physical weakness after discharge limited patients' ability to attend follow-up appointments independently, often requiring caregiver accompaniment – which increased transportation costs, as two individuals needed to travel to the clinic – further compounded by long distances from home to the health facility.

> *"The problem I faced is that I found it hard to carry the patient, because she was still weak and not able to walk, which means I have to carry her, and yet I am alone, that's the problem I faced. But if I am alone, I can easily move and come to the hospital and pick up medicine, but when they tell me to come with her, I find it hard because I have to hire a motorcycle to bring her to the hospital. And you know hiring a motorcycle comes with money, and it's also hard to get it." (Caretaker for Patient 003, not linked).*

Social opportunity: this refers to the external social environment – cultural norms, social cues, and interpersonal influences – that enables a behaviour such as linkage to HIV care after discharge. Barriers here included stigma and non-disclosure to relatives. People living with HIV experiencing advanced HIV disease.

> *"… I have not told even my people at home that I have HIV because I get ashamed, although some may know. Therefore, they may not come to help even if I need their help to take me to the health facility." (Patient 012 not linked)*

Physical opportunity: this refers to external factors like time, resources, and cues enabling behaviour. Barriers here included the lack of a mechanism to track linkage status and the absence of ward-based discharge guidelines. Most key informants reported no effective system to confirm whether people living with HIV reached HIV care, which reduced their motivation, as they could not verify outcomes even after completing linkage forms.

> *"Ideally, that is what I initially hinted at: like any other referral system, before you refer, you need to have a contact on the other side to communicate with a colleague that you are referring a patient and their history. When the patient arrives, you follow up, or when the colleague manages the case, they are responsible for writing a line or two back to you." (Medical Officer on the ward)*

In contrast, a few key informants noted that MOH comprehensive HIV guidelines include a section on inter-facility linkage, but high patient loads on the wards made it difficult to prioritise HIV patients specifically. '*..Even though MOH provides guidelines on linkage after hospital discharge, we rarely tell*

patients about it because I have to write discharge forms for over 20 patients on a single day' (Medical Officer on the ward)

Many key informants expressed uncertainty about when and how patients should be linked to HIV care post-discharge. The absence of standardised linkage guidelines – particularly for previously disengaged patients – and clearly defined timelines led to inconsistent practices across providers.

> *"There is no specific guidance on the ward…most of the guidelines we use are for patients who are newly diagnosed, but not those who had been in care but disengaged, so it depends on how much the patient has improved. If there were specific guidelines about linkage on the ward patients, then that would be better to implement." (Nursing Officer, Medical Ward)*

Automatic motivation: this refers to unconscious, emotional processes driving behaviour, such as impulses, desires, inhibitions, and habits. The key barrier identified was the lack of dedicated incentives to specifically target HIV patients for post-discharge linkage. Key informants noted that all patients with chronic conditions require post-discharge follow-up, so focusing exclusively on people living with HIV who experience advanced HIV disease would demand additional resources, including personnel – given already-stretched staffing – and funding.

> *"There are no incentives for us to work on linkage as a whole. They are no longer available; I believe it ended with STAR E (a USAID-funded project). They used to be there, which involved the more HIV clients you get and linked to care, the more money, and this would motivate us, the healthcare workers." (Medical Officer on the ward)*

b) Facilitators to linkage of people living with HIV who experience advanced HIV disease to HIV care clinic after hospital discharge.

Five main facilitators emerged, and these include: friendly health care workers at the HIV care clinics, initiation and re-initiation of ART while still admitted, and counselling on the ward, presence of peer and family support, and a good linkage system for people living with HIV diagnosed with Tuberculosis/ Cryptococcal meningitis (TB/CCM), and Fear of the illness worsening.

Physical capability: facilitators under this category included friendly HCWs at HIV care clinics; patients already in care reported that friendly staff motivated them to disclose their status and continue treatment.

> *"The HCWs at my HIV care clinic make me feel comfortable, they comfort me, and they counsel me, and they give me good advice on how to take my medication." (Patient 009 Linked)*

Physical opportunity: facilitators under this domain included ART initiation or re-initiation and counselling during admission. For treatment-naïve patients, ward-based counselling alongside ART initiation was a significant facilitator: understanding the life-saving benefits of medication motivated patients to prioritise follow-up, often leading to earlier-than-expected linkage to their designated HIV care clinics.

> *"When I fell sick, I did not know it was HIV, and when they tested and found that I had HIV, I was advised to start ARVs. I was informed that I will take these drugs for life. The counsellor told me I will be referred to Busolwe health centre, which is close to my home, and continue getting my ARV medicine from there. I was told to go there as soon as I am discharged from the hospital so that they can register me to make orders for my drugs. That is why, immediately after my discharge, I went to Busolwe." (Patient 024 Linked).*

> For patients with prior treatment interruption, ART re-initiation during hospitalisation served as a critical motivator for post-discharge linkage. A strong desire to avoid recurrent clinical deterioration prompted renewed commitment to adherence and timely follow-up at their HIV care clinics. *'I was given ARVs when I tested positive in 2023 and took them for a year, but when I went to work in Kenya, I stopped taking them and did not return to Nakaloke Health Center in Uganda to get more.. I fell ill and was kept down for nearly six months until I was admitted to Mbale Hospital, where they advised me to start taking ARVs again and told me never to stop. They provided me with ARVs for only two weeks and instructed me to go to a nearby hospital to continue receiving them. They also checked my CD4 count and the amount of virus in my blood. Once I improved and was discharged, I had to go to the ART Clinic in Mbale to register and continue my medication because I do not want to revert to the previous state I was in when I was admitted.' (Patients 019 Linked).*

Social opportunity: peer and family support was the major theme under social opportunity; people living with HIV on ART who received peer support were more often reminded by peers to attend the health facility for continued care.

"...ah, I would always be reminded to go back for review at the HIV care clinic by my friends...and they would also escort me there to help me navigate the line because I was very weak after I got discharged from here." (Patient 015 linked).

Reflective motivation: under this domain, key informants reported that people living with HIV co-diagnosed with TB/CCM are followed up post-discharge to ensure linkage to HIV care, facilitated by hospital TB focal persons who monitor patients to ensure continued medication at the nearest facility.

"With hospital linkages after discharge, we refer individuals on ART and diagnosed with TB or CCM to nearby facilities to obtain medicines close to their homes, as these two diseases cause many deaths among people living with HIV. For TB, it is easy to contact the ward focal person, who manages all follow-up." (MO on the ward).

Another key motivator for timely linkage was fear of clinical deterioration if specialised HIV monitoring was interrupted. Participants preferred providers at their regular HIV clinics, viewing them as more knowledgeable in HIV management than general hospital staff, and thus prioritised returning to their primary care sites for continued assessment after discharge.

"I also know that if I don't follow the instructions of the healthcare workers who discharged me from the hospital, my condition might worsen, and I could be readmitted. Additionally, I have been attending my ART clinic for six years now, and my doctors at the Muyembe Clinic understand my condition better than those at this hospital because they only treat HIV patients. That's why I had to go there early for assessment after being discharged from the hospital." (Patient 008 Linked).

Although some people living with HIV who experienced advanced HIV disease were linked to HIV care after discharge, others did not fully understand the concept of post-discharge linkage, as they had not been informed about it during discharge.

"*…I went to my HIV clinic after I had been discharged by myself without getting clear guidance from the HCWs at Mbale Hospital. At the hospital, they gave a discharge form and was told to go for review after two weeks but no more information was provided and whether it was really Urgent or not.."(Patient 006 Linked).*

Conceptualising determinants of linkage to HIV care after hospital discharge

Our study aimed to identify barriers and facilitators to post-hospital discharge linkage to inform an intervention to improve it. Thematic analysis revealed barriers spanning individual, social, environmental, and health system levels (Figure 2). Failure to link was multifactorial, with negative factors often interacting across levels to compound the risk of non-linkage. At the health system level, absent standardised protocols and tracking mechanisms led HCWs to omit linkage information, contributing to patient unawareness and non-linkage; structural barriers such as distance and transportation costs further forced difficult choices that undermined linkage. At the individual level, long distances, limited awareness, and stigma-related fear contributed to linkage failure. At the social level, fear of stigma directly prevented disclosure to caregivers, eliminating caregiver support and isolating patients, further impeding linkage.

Conversely, at the health system level, pre-discharge ART initiation can bypass this systemic barrier by providing linkage information and increasing patients' awareness of its benefits through adherence counselling, while peer supporters directly raise awareness to counter stigma.

Discussion

This study examined barriers and facilitators to post-discharge HIV care linkage among adults with advanced HIV disease at a regional referral hospital in Eastern Uganda, aiming to inform targeted intervention design. Using the COM-B framework, barriers spanned all three components: patient-level barriers included physical weakness, limited knowledge, high transport costs, long clinic distances, stigma-related fear, and non-disclosure to caregivers, while health system-level barriers included the absence of standardised linkage protocols, lack of structured follow-up, and limited incentives. Facilitators included pre-discharge ART initiation or re-initiation, peer supporter involvement, caregiver disclosure, and

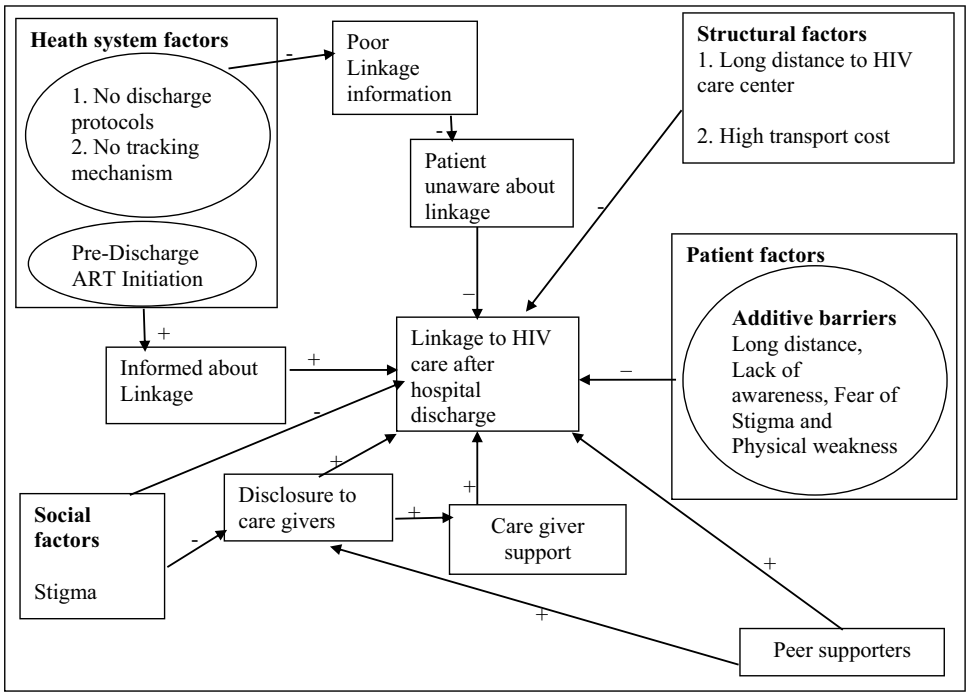


Figure 2. Shows the connectivity of the different sub-thematic areas and how they explain linkage to HIV care after hospital discharge.

patients' motivation to avoid clinical deterioration, alongside health system facilitators such as existing TB linkage infrastructure and dedicated ward-based linkage counsellors.

While stigma, non-disclosure, and high transport costs align with existing literature on post-discharge linkage [8,9], this study identified additional structural challenges. HCWs highlighted the absence of standardised guidelines for re-engaging hospitalised people with advanced HIV disease after discharge. Current national guidelines focus on newly diagnosed individuals, emphasising community-to-facility or inter-facility transfer [15], yet the inpatient population is heterogeneous – comprising newly diagnosed individuals, those previously disengaged from care, and patients on community-based differentiated service delivery (DSD) models [20]. Given Uganda's guidelines recommend facility-based care with monthly review for this population [15], HCWs require clear, context-specific guidance on structured re-engagement and timely viral load monitoring to support adherence and continuity of care. Post-discharge frailty and impaired functional status were also key barriers: patients often experience substantial functional decline at admission [20], reflected in low Karnofsky scores, and may not have fully recovered by discharge. This limits self-management and independent travel, often necessitating caregiver support, while long distances [8] further increase transportation costs for economically disadvantaged patients [9], undermining timely follow-up.

Limited patient and caregiver awareness also emerged as a significant barrier. Although many hospitalised adults with HIV were already engaged in care before admission [20], some resume prior routine appointment schedules after discharge without recognising that hospitalisation necessitates transition to a more intensive, facility-based care model – impeding timely follow-up, including viral load monitoring and resistance testing.

HCWs also identified the absence of incentives for linkage activities as a motivational barrier. While previous donor-funded initiatives deployed dedicated ward-based counsellors for newly diagnosed individuals, government-employed HCWs reported reduced motivation absent comparable incentives, and suggested expanding counsellor roles to support post-discharge linkage for all people with HIV.

Both patients and HCWs reported fear of stigma as a barrier, which could also deter disclosure to caregivers. Most hospitalised patients had previously been in care but disengaged, with stigma a commonly

cited reason [21]; HIV-related stigma negatively affects all stages of the care cascade [22], including post-discharge linkage.

Despite these barriers, several facilitators were identified. Common facilitators for both HCWs and patients included disclosure to relatives/caregivers, peer supporter involvement, good ART adherence, and co-diagnosis with TB and/or cryptococcal meningitis (CCM). Patients' desire for better health outcomes was a strong internal motivator. HCW-specific facilitators included knowledge of linkage procedures and ART initiation or re-initiation before discharge, while dedicated project-funded counsellors helped establish initial linkage. Patients also highlighted trust in HCWs as a crucial relational factor supporting ongoing engagement.

ART initiation or re-initiation during hospitalisation was identified as a particularly significant facilitator, likely reflecting the structured counselling and adherence preparation it involves [15]. Co-diagnosis with TB and CCM also served as strong enablers: established TB programme infrastructure, including focal persons and follow-up mechanisms, naturally reinforces linkage, while CCM's high morbidity and mortality heighten vigilance among patients, caregivers, and HCWs; national protocols requiring post-treatment fluconazole prophylaxis further necessitate return visits [15]. Consistent with prior literature, disclosure to caregivers or family was a key facilitator of linkage and retention [23–25], with caregivers providing emotional, instrumental, informational, and appraisal support [26] that enhanced patients' motivation and ability to attend clinics. Peer support – assistance and encouragement from equals [27] – was similarly identified as a key facilitator, shown to improve linkage, adherence, and retention [28,29] by strengthening HIV-related knowledge, emotional support, trust in health services, and confidence [29,30], suggesting peer supporters could be an effective intervention to enhance post-discharge linkage.

Policy implications for future research

While most national HIV programmes and WHO linkage protocols primarily target newly diagnosed or first-time care-engaging individuals, hospitalisation presents a crucial, often overlooked opportunity for engaging or re-engaging people living with HIV in care. Patients with advanced HIV disease frequently experience poor post-discharge outcomes, including high mortality and readmission rates [3,5].

WHO guidelines recommend post-discharge linkage as a key intervention to reduce mortality in this population [31], but do not specify a timeframe for initiating tracing when patients miss scheduled appointments. Our findings indicate that patients diagnosed with TB during admission are linked to care more promptly after discharge, suggesting national HIV programmes could leverage the National TB programme's linkage methodology. WHO and National TB programme guidelines recommend hospital-based TB focal persons and contact tracing registers to track post-discharge linkage [32], alongside community health workers who ensure continued treatment at patients' preferred facilities. This approach is supported by our systematic review of post-discharge linkage strategies, which found that successful interventions begin engagement during admission and continue through community-based follow-up after discharge [10]. Similarly, systematic reviews of discharge interventions for other chronic diseases – heart failure [33] and COPD [34] – have shown reduced readmissions and, in some cases, improved mortality, offering indirect evidence that structured post-discharge approaches could similarly benefit people with advanced HIV disease.

By systematically identifying health system and individual-level barriers, this study provides a foundation for developing evidence-based interventions to improve linkage in this high-risk population. These findings can guide tailored strategies that address identified barriers and leverage existing facilitators to strengthen post-discharge linkage to HIV care.

Limitations and strengths

This study had several limitations. First, identification of barriers and facilitators relied on self-reported data, with patient information elicited retrospectively via telephone, introducing potential recall and social desirability bias; this was mitigated through triangulation across patients, HCWs, and HIV programme staff, and use of multiple data collection methods (KIIs and in-depth interviews).

Second, barriers and facilitators were elicited only from patients successfully contacted two weeks post-discharge, introducing possible selection bias and excluding those who died during this critical period –

who likely faced more significant, undocumented barriers. Future research should explore interviewing family members or close contacts of deceased patients to retrospectively capture insights into factors contributing to poor outcomes and failed linkage.

Third, participants did not recheck transcripts or findings, which could have introduced investigator bias; this was minimised through data triangulation and multiple coders. Additionally, the study did not include patients admitted to non-medical wards for non-HIV-related conditions, who may face additional barriers; future studies should include such patients to document their specific experiences.

Finally, this single-site study at an up-country regional referral hospital may limit generalisability, though many such hospitals – which admit most people living with HIV in Uganda and other sub-Saharan African countries – face similar challenges. Purposive sampling, while well-suited to qualitative inquiry, further limits generalisability beyond the study population.

Despite these limitations, the study has notable strengths. First, purposive engagement of diverse stakeholders – HCWs and people living with HIV – ensured comprehensive understanding of contextual factors influencing post-discharge linkage, consistent with implementation science evidence that stakeholder involvement in early intervention development enhances buy-in, ownership, and sustainable implementation. Second, application of the COM-B model provided a theoretically grounded, systematic behavioural diagnosis of identified barriers and facilitators, establishing a robust evidence base for subsequent design of contextually appropriate interventions using the behaviour change wheel (BCW) framework, thereby strengthening the study's translational value.

Conclusion

This study identifies key barriers to post-discharge linkage to HIV care among people with advanced HIV disease, including physical weakness, limited knowledge, high transportation costs, stigma, and non-disclosure to family. Facilitators include HIV disclosure, in-hospital ART initiation, peer support, and patients' motivation to improve. Enhancing post-discharge linkage requires integrated interventions, including structured hospital-based linkage protocols and peer supporter engagement.

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Author contributions

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Data availability statement

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Ethical considerations

The study received ethical approvals from Makerere University School of Medicine Research and Ethics Committee (MAK-SOMREC-2023-663) and the Uganda National Council of Science and Technology (HS5890ES). Before each interview, participants provided written informed consent, including consent to audio-record the interviews. We also obtained administrative approval from the MRRH. All research methods were conducted in accordance with good clinical practice and other relevant guidelines and regulations.

Abbreviations

ART	Antiretroviral Therapy
BCW	Behavioural Change Wheel
COM–B	Capability Opportunity and Motivation for Behaviour
DSD	Differentiated Service Delivery Models
HIV	Human Immunodeficiency Virus
LMI	Low-middle Income Countries
MOH	Ministry of Health
SSA	Sub-Saharan Africa
WHO	World Health Organisation

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