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“Ashamed of being seen in an HIV clinic”: a qualitative analysis of barriers to engaging in HIV care from the perspectives of patients and healthcare workers in the *Daraja* clinical trial

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Abstract

Background There is high post-hospital discharge mortality among persons with HIV who are hospitalized, and post-hospital survival is strongly associated with early HIV clinic linkage, clinic attendance, and antiretroviral therapy adherence. The *Daraja* intervention, a context-tailored case management strategy implemented and tested through a randomized trial in Tanzania, was associated with improved HIV clinic linkage, retention, and ART initiation and adherence.

Methods We conducted in-depth interviews (IDIs) in a sub-sample of 40 study participants (20 control and 20 intervention) 12 months after enrollment into the trial to gain an in-depth understanding of the barriers to HIV care engagement and the perceived mechanisms through which the *Daraja* intervention impacted these barriers. We also conducted IDIs with 20 health care providers. We used a thematic analysis approach to generate themes following the Gelberg-Andersen behavioral model for vulnerable population domains.

Results Perceived stigma, coupled with the mistrust of healthcare providers, underemployment or lack of reliable income, unreliable transport, and a lack of social support, were identified as key barriers to HIV clinic attendance and ART adherence. Perceived stigma complicated not only linking to and attending an HIV clinic but also decision-making regarding the choice of the clinic’s location. The *Daraja* intervention was reported to help normalise HIV diagnosis, plug the social support gap, increase patients’ self-efficacy and their capacity of participants to navigate the HIV clinic during HIV clinic linkage.

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Conclusion These qualitative research results identified several important barriers to engaging in HIV care and provide insights into the mechanisms through which the *Daraja* intervention operated to affect the perceived stigma, social support, self-efficacy, and increased capacity of participants to navigate the HIV clinic during HIV clinic linkage.

Daraja trial registration ClinicalTrials.gov, NCT03858998. Registered on 01 March 2019.

Keywords Barriers, Clinic attendance, ART adherence, Perceived stigma, Tanzania

Introduction

People living with HIV (PLWH) constitute a high number of inpatient admissions in countries with a high HIV burden, and it is an important population due to the high risk of death after hospital discharge [1–3]. A recent systematic review shows that the highest risk of mortality among PLWH has been observed in studies from Africa [2]. In a Tanzanian study, 50% of hospitalized PLWH died within 12 months after hospital discharge [4]. Studies examining factors that influence the post-discharge outcome for the PLWH population have shown a strong association between post-discharge survival among PLWH and early HIV clinic linkage, regular clinic attendance, and adherence to ART [5–8]. Tanzania is among the countries that have made significant strides towards the UNAID 95-95-95 targets. However, there are significant variations by region, gender, and age group. Due to these variations, there is still a significant proportion of people living with HIV in the country who are still unaware of their status and/or people living with HIV have not achieved viral load suppression [9].

The complex web of factors influencing HIV care-seeking behavior requires a theory-based approach to understand the factors and adapt the intervention to those most critical to HIV care service utilization [10]. The Gelberg and Andersen Behavioural Model of Health Care Utilization for Vulnerable Populations has illustrated how the three domains—predisposing characteristics, enabling resources, and need factors operate together to predict service utilization [11]. The model is based on the premise that no single factor can explain health-seeking behavior and has proven to be useful in identifying surmountable barriers to service utilization to develop interventions to improve outcomes [11–14]. The model has also been used to understand the challenges that PLWH face post-admission, both in Africa and in the US [15, 16].

A multi-site randomized controlled trial (the *Daraja* intervention trial) aimed at evaluating the effectiveness of a *social worker*-based intervention in reducing mortality among hospitalized HIV-infected patients after discharge from the hospital has recently been completed [15, 17]. The trial recruited 500 hospitalized HIV-infected adults who were either ART naïve or had stopped taking ART for >7 days and randomized them to either the standard of care HIV linkage (*control group*) or the *Daraja*

intervention (*intervention group*). The intervention strategy was adapted from the Anti-Retroviral Treatment and Access to Services (ARTAS) intervention and contextualized to address the barriers to HIV care linkage that had been identified in hospitalized HIV patients [18]. It involved an individual-level, time-limited, five-session case management intervention to link hospitalized HIV-infected patients to outpatient HIV care upon discharge [15]. Although the intervention did not have a significant effect on post-hospital discharge mortality at the a priori designed end-point of 12 months post-hospital discharge, it significantly reduced time to HIV clinic linkage and antiretroviral therapy initiation. Similarly, intervention participants achieved higher rates of HIV clinic retention, antiretroviral therapy adherence, and HIV viral load suppression at 12 months [16]. This qualitative paper aims to describe and analyze the barriers to HIV clinic and ART adherence from the perspective of the *Daraja* trial participants and healthcare providers.

Methods

Study sites and setting

The *Daraja* intervention enrolled participants from 20 hospitals offering HIV inpatient care in six districts in the Mwanza region. The region is the second most populous, located on the southern shores of Lake Victoria in northwest Tanzania. The qualitative study was conducted in a subsample of sites and participants enrolled in the *Daraja* trial.

Participants

Qualitative interviews were conducted with a subset of 20 participants in the intervention arm, 20 participants in the routine care control arm 12 months after enrolment. In addition, 20 healthcare workers (9 nurses and 11 clinicians) were also interviewed. Trial participants were purposively selected from the list of participants who had completed 12 months since enrollment. To capture views and insights from participants with varied characteristics and experiences, the sample was selected from men and women across varying age groups. A total of 58 patients were invited to participate in the qualitative interviews. Eighteen of these (12 females and 6 males; 11 from urban and 7 from rural health facilities) declined/were unavailable to participate in the qualitative interviews. The main reasons for declining to take part in the interview were:

being outside Mwanza region at the time of the qualitative interview (10), not being reached by the study team (4), fear that participation in the interview could result in disclosure of their HIV status (2), being busy (1), and 1 participant did not give a reason for refusal. A total of 26 healthcare workers (two healthcare workers per site) were invited to take part in the qualitative study. Six healthcare workers declined/unavailable to be interviewed. Four declined due to busy clinical schedules, while two were outside Mwanza region at the time of the interview. The healthcare workers included nurses and clinicians attending to patients at the time of enrollment for *Daraja* study participants. To ensure representation of health workers voices from different settings and health facilities, we purposively selected from both rural and urban facilities.

Interviews were conducted in Swahili by three Tanzanian social scientists (2 females and 1 male) who were not part of the intervention team. The team received three days of training, which involved reviewing the *Daraja* intervention protocol, revisited the basic principles of qualitative inquiry, reviewed the interview guides, and were trained on the basic principles of human research ethics, including the consenting process. Interviews were based on guides and explored participants' experiences with linking to HIV clinics, possible barriers to linking, and challenges met in the course of HIV care. Identical guides were used for intervention and control group participants. Key questions included: *What has been your experience in trying to link to HIV clinic care? What challenges or barriers have you experienced in linking to HIV clinic care? What challenges or barriers have you experienced in taking antiretroviral therapy?* The interview guide for healthcare workers focused on exploring perceived barriers to HIV care service utilization among people recently diagnosed with HIV. The interview guides were developed in English, translated into Swahili, and pilot-tested during the three days of training using role plays. Full interview guides have been included as supplementary material (Table [s1](#)). The research team reconvened after the first day of conducting interviews to further assess the appropriateness and clarity of the questions in the guide. All interviews were conducted at a time and place chosen by the respondents, which was comfortable, safe and ensured the necessary confidentiality. Whereas all health worker interviews were conducted at health facilities, 27 of patients' interviews were conducted at the HIV clinic, 8 at home, and 5 at other places outside home/health facilities selected by the participants. Interviews took approximately one hour and were audio-recorded with the participants' consent. Data collection occurred between June and December 2022.

Analysis

The recordings of the interviews were transcribed verbatim into Word documents and analyzed using the NVIVO 12 data analysis software [19]. Two team members independently read the transcripts to familiarize themselves with the data and to construct preliminary codes. The preliminary codes informed the development of a structured codebook. The code book combined both codes grounded in data and pre-determined codes based on the Gelberg-Anderson model [10]. The transcripts were uploaded to NVIVO 12, and a systematic analysis was performed by re-reading each transcript and applying codes to thematically identify similar passages of text using the final codebook. After coding, codes were used to retrieve segments of data, and analytic memos were written to synthesize the content and make comparisons across participant groups. These memos followed an established template of Gelberg model domains to extract and synthesize the core meaning from text related to each theme and to identify representative quotes. At each step, the analysis team returned to the original data to ensure that participants' narratives and perspectives were retained. The analysis of healthcare workers' interview data focused on understanding their perceptions about barriers to HIV clinic attendance and medication adherence as experienced by or observed among *Daraja* trial participants. For this study, the predisposing characteristics were defined as those that influence decision-making and one's ability to attend the HIV clinic and adhere to medication, including having a reliable source of income and health beliefs related to HIV. Enabling factors were those relating to an individual having appropriate community and individual-level resources necessary for accessing HIV care. The needs domain was defined as how individuals view their own need for HIV services and their actual physical ability to attend a clinic.

Ethical considerations

This study received approvals from the Medical Research Coordinating Committee (MRCC) in Tanzania (NIMR/HQ/R.8a/Vol. IX/2811), the Ethics Committees of Weill Cornell Medicine (1804019134), and the London School of Hygiene and Tropical Medicine (LSHTM Ethics Ref 16173). All participants provided written informed consent to participate and to be audio recorded after an explanation of the rationale and procedures for the qualitative interviews was provided. A copy of the signed consent form was given to them for their records. All participants were assigned a de-identified study ID number to maximize confidentiality.

Table 1 Participants' and health workers' characteristics

Participants characteristics	Intervention group participants (N = 20)	Control group participants (N = 20)	Health Workers (N = 20)
Age, mean (age range)	37 (20–73)	37 (18–68)	41 (30–57)
Gender			
Male	5	8	9
Female	15	12	11
Education			
No formal Education	6	4	-
Primary education	9	16	-
Secondary education and above	5	0	20
Occupation			
Employed	2	5	20
Self-employed	16	12	-
Unemployed	2	3	-
Health workers' professional background			
Medical Doctor (Bachelor)	-	-	6
Assistant Medical Officer (Diploma)	-	-	5
Nursing Officer (Bachelor)	-	-	4
Registered Nurse (Diploma)	-	-	3
Assistant Nursing Officer (Certificate)	-	-	2

Table 2 Summary of specific barrier identified by trial participants and Healthcare workers

Domain	Specific barriers	Source
Barriers fitting within the Gelberg-Andersen Behavioral Model		
Predisposing Factors (Demographics)	Unemployment/lack of reliable source of income	IPs*, CPs**, HWs***
Predisposing factors (Health beliefs)	Beliefs about HIV and ART	IPs, CPs
Personal/Family related barriers	Perceived stigma	IPs, CPs, HWs
	Lack of reliable transport	IPs, CPs, HWs
	Low self-efficacy	CPs
	Lack of social support	IPs, CPs, HWs
Low perceived needs for service	Absence of symptoms	Ips
Other barriers identified in the study		
Predisposing Factors (Demographics)	Inadequate housing situation	IPs, CPs
Community related barriers	Mistrust of healthcare providers,	IPs, CPs, HWs
	Barriers related to one's work situation/competing priorities	IPs, CPs

*Intervention participants, **Control participants, ***Healthcare workers

Results

Participants characteristics

The socio-demographic characteristics of the participants are shown in Table 1. The median age was 37 years, ranging from 20 to 73 years in the intervention group and from 18 to 68 years in the control group. Overall, 37% of participants were men, and up to 50% were people aged 35 years and older. Most participants in the intervention

and control groups reported that they had at least primary education, and the majority were self-employed in petty trades and small businesses. Healthcare workers had a median age of 41 years, ranging from 30 to 57 years, and all had secondary school education or higher.

Barriers to HIV clinic attendance and adherence to ART

We identified ten barriers for participants to link to an HIV clinic and to remain in care after being linked to the clinic (Table 2). The identified barriers included perceived stigma, inadequate housing, mistrust of healthcare workers, lack of reliable transport, unemployment or lack of reliable income, lack of social support, beliefs about HIV and ART, low self-efficacy, absence of symptoms, barriers related to one's work situation or competing priorities. All the barriers except beliefs about HIV/ART and physical weakness were identified by both the participants and healthcare workers. Seven of these barriers were similar to barriers in the Gelberg-Andersen behavioral model, while three were specific to our study.

Perceived stigma

The most common and strongest barrier to HIV clinic linkage, clinic attendance, and adherence to ART for both intervention and control groups was perceived stigma. The fear of being recognized by people and the shame of being identified as an "HIV victim" were the recurring themes especially among participants in the control group. Most participants reported feeling a sense of shame about having received an HIV diagnosis. One woman explained that she was worried and nervous because she did not want people to know she was suffering from the 'shameful disease.'

“The main challenge at the time when they linked me to the HIV clinic was going to the clinic to collect medicine. To tell you the truth, at the beginning, I was afraid that I would meet people who knew me. I fear the shame of being recognized. I worried that people would see me and say, ‘So this woman is an HIV victim...’” [34-year-old woman, intervention group].

“I was always afraid of going to the HIV clinic. I was always worried that someone would see me collecting ARV drugs and know that I was infected with HIV. I did not want people to see me collecting drugs.” [43-year-old woman, control group].

The reported hesitance due to fear of being recognized was supported by quotes from the health workers.

“Others worry that if they went to the HIV clinic and joined the queue, there was a likelihood of meeting or being recognized by a relative or friend. They don’t want people to know that they are sick, but we just continue encouraging them.” [35-year-old female healthcare worker].

Inadequate housing situation

Coupled with the perceived stigma, made medication adherence to ART particularly difficult. Most participants across the intervention and control groups had very poor and crowded housing conditions that compromised participants’ privacy and made it difficult to take ART without being seen by other members of the household. Some participants changed medication times to avoid inadvertent disclosure to other members of the household. One participant reported changing times for taking medication because of sharing accommodation with someone to whom the participant had not and did not intend to disclose their HIV status.

“...I used to share a room with the daughter of my host. To avoid raising suspicion about me taking drugs every day, I changed the time and started taking them in the morning before starting my daily activities, so I am not sure if that caused a problem (with my HIV).” [38-year-old woman, control group].

Perceived stigma was further expressed by how the participants chose their preferred location of HIV clinics. Although most participants acknowledged the existence of health facilities with HIV clinic services within reasonable distances in their communities, they preferred using health facilities located far away from their communities to reduce the risk of inadvertent disclosure of HIV status. Many participants noted that nearby HIV clinics are located in open areas where passersby could see and hear the conversation between patients and service providers.

“I was worried that if some of these people knew, they might decide to tell everyone about my HIV status. When the doctor asked me to choose an HIV clinic, I chose this one (meaning:’ more distant from her home) because, in the other health facility, they can easily test you for HIV

and reveal your secret.” [34-year-old woman, intervention group].

Mistrust of healthcare workers

Linked to stigma were concerns about the lack of trust in service providers in the HIV clinic within the communities. Participants did not trust that the HIV clinic providers in their community were capable of keeping patients’ HIV status confidential.

“There is just this one service provider that, if you do not go for a refill and you meet her in a public place, she will just ask, ‘Why didn’t you come for a refill?’. When you sit with other people, you hear the same complaints that this health worker can embarrass you in front of people. I did not want this to happen to me, so I decided to use a different HIV clinic.” [34-year-old woman, intervention group].

Equally, the healthcare workers’ data pointed to the lack of a trusting relationship between the service providers and patients. Some healthcare workers argued that the lack of a trusting relationship made patients feel unwelcome or uncared for, which may have increased the perceived stigma associated with accessing HIV service and had an impact on clinic attendance and ART adherence.

“There are generally three parts to these barriers: the first part is related to the service providers; the second part relates to the patients themselves; and the third part is the family or community where the patient comes from. When patients receive an HIV diagnosis, they experience psychological problems and self-stigma, which affects how they respond to service providers. They are often rude, stubborn, and difficult to convince. Service providers may also be a barrier in that the language some use is either outright discouraging or not convincing enough to encourage patients to attend a clinic or use the medication as prescribed. The third part is the lack of support from family or community, either because of a limited understanding of HIV or simply because the extended family or community where the patient comes from is naturally not supportive.” [55-year-old female healthcare worker].

This was supported by the experience of participants in the control group who stopped attending clinics or avoided certain HIV clinics after a negative experience with service providers.

“I tested positive for HIV about 10 years ago. Although I did not start ART then, I attended an HIV clinic for my child. But I stopped attending because a health worker was very rude to me. She used very harsh words because I was late one day, saying, ‘You are the one who is sick, and you expect to show up whatever time you choose, and we should wait for you?’ Since then, I stopped visiting the clinic. That is the reason I did not choose the same clinic when I started ART last year.” [30-year-old woman, control group].

Health workers largely attributed the mistrust to failed communication between patients and health workers due to patients' emotional state after receiving HIV diagnosis. However, they also acknowledged the contribution of individual health worker characteristics such as rudeness and a lack of skills to communicate the importance of regular clinic visits and medication adherence.

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Unemployment/lack of reliable income

As shown in Table 1, only a few participants in both the intervention and control groups were formally employed and had reliable sources of income. Most participants relied on income from petty trading, such as selling vegetables, firewood, silverfish, or second-hand clothing. A few were farmers, and others relied solely on relatives for support.

"I sell second-hand clothes. Currently, that is the only thing I do. Sometimes it takes a day or two to finish the stock; other times, when business is not good, a stock can take up to 2 weeks before I can buy a new stock." [35-year-old woman, intervention group].

"I have not been able to work for the last 15 or 16 months. My living expenses have been in other people's hands. I have not been employed or had anything generating income." [42-year-old male, control group].

There were also indications in the participants' narratives that income-generating activities were severely affected by hospital admissions. Some participants reported using their financial savings for treatment and other needs after falling ill, and others reported losing their job due to a long illness.

"When I fell ill, I lost my job. Now this family is looking at me. I am both the father and the mother. My partner is just drinking alcohol. So, since I stopped working, it has been a real challenge. I am at home, and I am breastfeeding. Even finding food is a real challenge." [29-year-old woman, intervention group].

Lack of stable income made it difficult to buy food, pay rent, and transport costs for hospital visits for ART refills or treatment for other illnesses.

"Money has been scarce because it has been difficult to get employment. Before I fell ill, I was employed, but I met some challenges when I fell ill and lost my job. Currently, I am relying on support from relatives and small businesses that I have started. That is how I live now." [36-year-old woman, control group].

Lack of reliable transport

Lack of reliable transport to HIV clinics was reported by participants across all groups as a barrier to HIV care service utilization. This barrier was magnified by the common unwillingness of participants to attend an HIV clinic within their communities due to perceived stigma and discrimination. As a result, most participants in both the intervention and control groups had to travel long distances to obtain HIV care, which required a substantial transportation cost. This was despite the fact that all participants in both intervention and control groups acknowledged the existence of HIV clinics located near their homes. For example, some participants chose to attend an HIV clinic that required them to pay transport of between TZS 5000 and 10,000 (about \$ 2–4) per visit instead of using facilities within their communities that would cost them <TZS 2000 (<\$1) per visit. They noted that facilities that were located far away from their communities reduced the risk of inadvertent disclosure of HIV status.

"When children fall sick, they are usually treated at B health facility. The health facility is about 15 minutes by public transport and costs TZS 1000 (about \$ 0.41) for a return journey. But for HIV service, I go to PA health facility, which is about an hour away, and a return journey takes about 2 hours and involves taking two buses to get to the facility. Their services are good, and there are no worries about meeting people who know you." [38-year-old woman, control group].

"There is a health facility within the community called NY, a few kilometers from my home. One needs TZS 2000 (about 0.80 USD) for a return journey using a motorcycle. But I don't use it for any services because if you go there complaining of fever or suspecting malaria, they will ask you to test for HIV, and then everybody in the village will know your results. I don't usually go there. I buy drugs from the pharmacy. I attend NG hospital for HIV and ART refills, where I need (about 4.00 USD) for transport every time I need to go for HIV care." [41-year-old woman, intervention group].

Lack of social support

Participants from both groups and health care workers mentioned lack of social support as a barrier to clinic attendance. Some participants reported being abandoned or discriminated against by their spouses or family members after their HIV diagnosis.

"I was tested together with the father of my child, but after testing, he left. He went to an island in the lake, but he never returned, so I had no support. I never attended clinics. But when I fell very ill, a nurse who knew my story said to me, 'The man you had a child with has abandoned you. If you die, who will look after your child? Go

and collect medicine.' She encouraged me to start ART" [35-year-old woman, intervention group].

"I cannot really say I have a person or people that love and support me... No, because when I was last admitted last year, my relatives abandoned me in the hospital, with some saying, 'But he is always having problems, always asking for help; we have our own issues to deal with.' Would you say such people love you? Would you pick up the phone to call them when they look at you as a problem?" [48-year-old man, control group].

In addition to the rich narrative from patients both in the control and intervention groups on how stigma and lack of social support impacted clinic attendance and adherence to ART, data from service providers equally reflected how perceived stigma and lack of support hindered clinic attendance and ART adherence, often leading to negative health outcomes, including death.

"We had a very sick patient brought in by the stepmother, but when she received the diagnosis, she asked us not to tell her stepmother, claiming that she would be discriminated against and would easily be thrown out of the house. We started a patient on ART, but due to a lack of support, she stopped taking medicine, and unfortunately, she died. I felt very sad that she died due to perceived stigma and fear discrimination from the stepmother." [35-year-old male healthcare worker].

Healthcare workers also linked the lack of social support to a limited community understanding of HIV, which led to discrimination.

"Some of the patients are abandoned by their immediate, extended families or even the larger community because of a lack of sufficient knowledge about HIV, which leads to discrimination. In such cases where a patient does not have anyone to support them, it is difficult for them to regularly attend a clinic." [55-year-old female healthcare worker].

Absence of symptoms

Participants who had tested positive prior to admission and enrollment in the *Daraja* intervention reported that having no obvious HIV symptoms was a reason for not initiating ART or adhering to ART.

"I was tested during the antenatal clinic. I was linked to an HIV clinic and initiated on ART to protect the baby from contracting HIV. I used the drugs during that period, but when my baby was one year old, I stopped breast feeding and stopped taking medicine. I was not sick; I was only using medicine to make sure the child did not get infected." [38-year-old woman, control group].

Another participant described how she had tested for HIV during a regular antenatal clinic. However, she and her partner, who was also HIV positive, agreed to defer initiating ART because they were both without any symptoms.

"I was tested and found positive some years ago; my partner was also HIV positive, but we were not sick then, so we agreed not to use ART. He secretly started taking ART, but he died in 2021. I was stressed; I started falling sick as well, and I was admitted, so I started using ART." [39-year-old female, intervention group].

On the other hand, the severity of symptoms and hospital admission at enrolment pushed participants to accept HIV testing and initiate treatment. A few noted that the observed benefits of ART after enrollment and initiation provided motivation for ART adherence.

"I was very sick when I was admitted; I was, at the very end, about to die. If I had not started ART, then I would be dead by now. I was linked to the HIV clinic, received counseling, and started using ART. A few months after I was discharged from the hospital, I was feeling better, and since I started using ART, I have not missed." [35-year-old woman, intervention group].

"I started falling sick frequently. When I was tested during the last admission, they found I had the virus. They advised me to start medication, and I accepted and started using drugs. I did it because I wanted my health to improve. I did not want to always be sick and weak." [44 years, female, intervention group].

Beliefs about HIV and ART

Health beliefs about HIV and ART did not emerge prominently as barriers to clinic attendance and ART adherence. Only a few participants indicated that their own beliefs or the beliefs of their family, friends, or other community members were among the barriers to linking to the HIV clinic or starting ART. One participant, reported how advice against ART from a friend led to delayed ART initiation.

"I was advised not to start ART early. I was told if you start drugs early, you will get tired, and people will know your HIV status. Although during ANC I was encouraged to take ART during pregnancy to protect the baby, I stopped after the birth of the baby" [38-year-old woman, control group].

Another participant who had known her HIV status before but joined the intervention reported how a rumor she heard on the street made her hesitate to link to the HIV clinic and start ART.

"I heard people who were seated in a group talking about HIV drugs and that if you start the HIV drugs, you do not stop because if you stop even for one day, you will die. So, I took it that if you start and stop, your health will suddenly deteriorate, making people curious about your health." [34-year-old woman, intervention group].

Low self-efficacy

Several participants in the control group did not trust their ability to take ART daily for life. They reported

anxiety related to taking ART for life as the main reason for their initial hesitance to link to an HIV clinic.

"The first thing is that I am not used to taking drugs. I fear taking drugs. I may take them today but not the next day, asking myself, 'Am I going to be able to take these drugs?' I don't think I can. I didn't think I could start taking these drugs." [26-year-old woman, control group].

The perceived lack of self-efficacy among the patients was also evident in the service providers' narratives. Young women in particular struggled to link and use ART without permission from significant others. Some indicated to the service providers that they would not be able to link to the HIV clinic and start on ART until they had obtained permission from or consulted a spouse or another family member with decision-making power in the household.

"One patient informed me that her husband was away, so she had to wait for him to return, and she would seek permission to link and start ART. Another one said she needed to consult her elder sister before she could link to the HIV clinic. Some patients were unable to make decisions, and someone had to make decisions about the use of HIV services for them." [37-year-old female healthcare worker].

Other barriers

Barriers related to participants' work situation and competing priorities

A few participants employed in sectors that demanded presence at work, such as security service providers, mentioned the nature of their employment as a barrier to clinic attendance and ART adherence. Two participants highlighted difficulties in getting permission or time from employers to attend the HIV clinic and collect medication or take medication.

"As I indicated at the beginning, I had trouble getting permission from my employer to attend clinics. I was working as a security guard, and that kind of job has no weekend or Christmas. You are working throughout, and if you want to go somewhere, you have to seek permission, but you can ask for permission today and get permission next week. My workplace is also very far from the clinic, so you can't even say, let me run to the clinic early, then I go to work." [29-year-old woman, intervention group].

"...sometimes for some of us who do manual jobs, you are at work, and maybe it is close to the time of taking the drugs, but the boss calls you and gives you an assignment that takes you away from where you keep your drugs, and the assignment goes beyond your time for taking drugs..." [48-year-old man, control group].

Several participants failed to combine working to earn income with sustaining HIV care, especially ART adherence. This was especially reported by participants who viewed HIV treatment and livelihood activities as

competing priorities. Hence, busy livelihood activities related to employment and/or domestic chores were, for many, a barrier to adherence to clinic appointments and ARV drugs.

"...My sister sells fish, and sometimes when she travels, like going for a burial, I am left with a lot of responsibilities, like selling and sorting out funds for financial self-support groups (such as savings and credit cooperative societies). I find myself getting home after 11 p.m., and I have not taken my drugs. For the whole of this month, for example, I have not been able to take drugs on time." [28-year-old woman, control group].

"...Because of many things that one has to attend to, one can forget; for example, in one of my clinic appointments, I forgot and went to the market... I came to realize that when I received a phone call from the HIV clinic at 3 p.m., that is when I remembered that I was supposed to attend the clinic but was very far away." [26-year-old woman, intervention group].

Participants' views of the Daraja intervention

Help with navigating the HIV clinic to address low self-efficacy

One of the key aspects of the *Daraja* intervention mentioned by all intervention group participants was the role of the *Daraja* trial staff, especially the social workers, in helping participants navigate HIV clinic procedures.

"I was helped to link to the HIV clinic by one of the Daraja ladies; she convinced me. She was the kind of person who would come and hold my hand and say, 'Let us go.' She supported me like my own sister. She took me and literally handed me to the nurses at the HIV clinic and explained to them that I had started ART but got discouraged and stopped..." [26-year-old woman, intervention group].

Addressing perceived stigma

Intervention group participants noted that the sessions delivered by social workers made it easier for them to accept their HIV status and recognize that they were able to manage their HIV and live a normal life. Most participants who had not disclosed their HIV status to a family member or friend for perceived stigma and other social consequences were particularly appreciative of the *Daraja* social workers. Such participants were glad to have someone to speak to about their HIV and ART-related worries without fear of discrimination or stigma.

"I had lost hope, and I had very bad thoughts. That day, I escaped, but I failed to find a way out, so they found me. I had said, let me die. I could not stand the shame of having HIV. I did not know how my children would react to my having HIV. I wanted to die. But they counseled me, encouraged me, and told me stories of other people living with HIV." [44-year-old woman, intervention group].

Most healthcare workers acknowledged the contribution the *Daraja* intervention made in addressing fear of stigma among the intervention participants. Some pointed out specific aspects of the intervention, such as home visits and extended engagement with participants.

“Some participants had lost hope and did not see the value of taking medicine or continuing to live. The intervention team had time to build trusting relationships with the participants, which, as regular health workers, we are sometimes unable to do because of a lack of time or a high workload. Taking time to counsel made the participants feel valued as human beings... I would also say that some participants lived in difficult circumstances that made taking ART difficult; for example, some lived with friends or distant relatives. The home visits gave the team a picture of the context in which the patients lived, allowing the team to provide relevant advice and support.” [37-year-old female healthcare worker].

Bridging the social support gap

For most participants in the intervention group, the *Daraja* social worker became a crucial part of their social support system in the post-hospital period. Through the intervention, participants received consistent encouragement to take medicine, which helped with ARV adherence, especially at the beginning when many participants experienced some ART-related side effects. Sessions and the phone calls made by the *Daraja* social workers were described as “lifesaving,” especially to those who had lost hope of living after receiving a diagnosis of HIV. They noted that the sessions and phone conversations during follow-up revived their hope of living again. For participants with strong religious beliefs, meeting with the *Daraja* intervention team was God’s way of answering their prayers in times of crisis.

“Before I met the Daraja team, I had lost hope... You know this disease needs courage, especially if you do not have money and are unsure where you will get it from, even just for food... But when I met them, they provided information about HIV and ART and changed my way of thinking. D and N (Daraja staff members) encouraged me to be strong and to continue taking drugs.” [35-year-old woman intervention group].

“They (the Daraja team) encouraged me. There were times I had lost all hope, but when I met them, they strengthened me. They told me, ‘You are not the first one to get HIV; many people are living with this disease. All you need to do is follow the doctor’s instructions. Eat well, and life will go on.’” [29-year-old woman, intervention group].

Addressing underemployment

The *Daraja* social workers worked with participants who had lost income due to illness to encourage them to find alternative income-generating activities. At the time of

the interviews, several participants reported involvement in small income-generating activities after their health improved.

“Last year was the toughest year. I did not have anything, but with improvement in my health and the encouragement from the Daraja team, life is much better now. I have a small business selling firewood, which gives me some income when the business is good. I am also able to do work for people, like washing clothes, and I get money to buy school materials for my children.” [35-year-old female, intervention group].

As part of the intervention, the participants were provided with TZs 5000 (an equivalent of US \$2) at some intervention visits to help with HIV clinic transport costs. In addition, some social workers made small charitable donations to participants in dire financial situations during their visits. Several participants noted that the small amount provided helped the participants offset some of their household costs, such as buying food, covering health care costs, or purchasing school supplies for children.

“When one of the (Daraja) social workers came, for two days I did not have food, soap, or cooking oil. As you know, I have a four-year-old. So, when I wake up, he needs porridge (participant cries). At the time, I was very unstable, but lucky enough, the Daraja social worker came and gave me TZS 10,000 (the equivalent of US \$4). I went to a milling machine to get flour, bought soap, and some lotion for myself...” [34 years, female, intervention group].

Addressing lack of reliable transport

In addition to offsetting the household budget, the money provided by the intervention covered the cost of transport to the HIV clinic. For most participants, such support was considered a subsidy to the family budget, allowing the family to spend money on other family needs.

“The Daraja team helped me very much. They would come and check on me, encourage me, and leave me with some money. I usually used to go to the clinic to collect drugs, which helped me to continue taking drugs. They also supported me at the point when I was sick but did not have money to go for treatment.” [26-year-old woman, intervention group].

Discussion

We conducted a qualitative study to gain an in-depth understanding of barriers to HIV clinic attendance and ART adherence and how the *Daraja* intervention may have impacted these barriers in a sub-population of recently discharged HIV-positive adults participating in the *Daraja* trial in the Mwanza region, NW Tanzania. We also examined any residual barriers that might exist after the intervention, which could be a future target for

intervention in this population. We used the Gelberg Model [10], a theory-based behavioral model of service utilization, to examine the barriers to HIV clinic attendance and ART adherence. We found the perceived stigma, unemployment/lack of reliable income, unreliable transport, lack of social support, beliefs about HIV and ART, and low self-efficacy to be the key barriers to HIV care seeking. The *Daraja* intervention was reported to have impacted perceived stigma, social support, and self-efficacy and increased the capacity of participants to navigate the HIV clinic during HIV clinic linkage. Although only few studies assessed barriers to clinic attendance and ART adherence among patients discharged from hospital in sub-Saharan Africa, studies of general PLWH populations have reported similar barriers [7, 8, 20–24].

A key finding from the current study was the heightened levels of perceived stigma reported by recently hospitalized PLWH. The perceived stigma reported by this population has many implications, both financial and those that are directly related to ART adherence. The stigma was likely a reason for both their hospitalization and poor post-hospital outcomes. Equally, the perceived stigma made it difficult for this population to benefit from community-based or primary care-based HIV services intended to reduce health system-related barriers to ART adherence [25, 26]. Our findings show that participants with a high level of perceived stigma refused to attend nearby community-based HIV clinics. Choosing HIV clinics that were further away to avoid stigma resulted in not only additional transportation costs but also made it very difficult to attend care, especially in a physically weakened state, as often occurs after hospitalization. The interviews in this study, which were conducted with a purposively selected sample of participants who completed the 12-month follow-up visit of the *Daraja* trial, probably represent the best-case scenarios for recently hospitalized PLWH. Those who died before or were lost to follow-up might have experienced even greater barriers to HIV care. To be effective, any intervention aiming to facilitate linkage to an HIV clinic and improve ART adherence should address the problem of stigma, whether experienced or perceived. The *Daraja* intervention attempted to integrate stigma reduction efforts into the sessions, and from the participants' point of view, the intervention helped to reduce the perceived stigmatization.

The narrative about how the perceived stigma impacted health seeking behaviour for the *Daraja* trial participants is supported by the intervention implementation data, which shows that perceived stigma ranked highest on the reported barriers to HIV service utilization. Almost 50% of the intervention participants indicated perceived stigma as the main barrier to linking and initiating ART during the first session of the intervention

(Supplementary material Table s2). In the qualitative data, perceived stigma was evident in both the intervention and control groups. However, the perceived stigma was a stronger barrier to linking to and attending an HIV clinic in the control group. The participants in this group reported making several failed attempts to link to the HIV clinic due to fear and shame of being recognized as having HIV. This finding contributes to our understanding of some of the key barriers to engaging in HIV care that, when addressed, may help accelerate the progress in achieving the UNAIDS 95-95-95 targets, especially for the regions and the population sub-groups that are lagging behind.

Our findings from this qualitative study provide insight into how different factors operate to hinder HIV clinic attendance and ART adherence. It also elucidated how the various components of a context-tailored theory-based intervention may work to address the barriers to HIV care, including shortening the time to linkage and improving clinic attendance and ART adherence. The qualitative results showed that the presence of an HIV clinic navigator—a social worker—who supported the participants through the HIV clinic's initial procedures and encouragement had a positive impact on linkage to care, HIV attendance, and ART adherence. Access to consistent encouragement to take medicine helped with ARV adherence, especially at the beginning when most experienced some side effects, which was critical. For example, the presence of a social worker to bridge the social support gap, regular follow-up to check on patients, and continued encouragement and sharing of information on how to manage medication side effects were imperative in addressing the lack of social support and low self-efficacy. The *Daraja* intervention was not designed to address the perceived stigma, which was a key barrier to linkage and adherence. However, the provision of information about HIV and ART and the normalization of HIV discussion made it easier for participants to accept their HIV-positive status and recognize that they were able to manage their HIV infection and live a normal life. Participants were glad to have someone to speak to about their HIV infection and medication-related worries without fear of discrimination and stigma. Equally, the training on individual problem-solving skills coupled with limited financial support was crucial in addressing clinic attendance and ART adherence in this population. A systematic review of HIV stigma reduction interventions in low-middle-income countries showed that an intervention to empower PLWHs socially and counseling to help individuals recognize negative or unhelpful thought and behavior patterns had the most consistent effect in reducing self-stigma [27].

The integrated minimum financial support to facilitate participants to attend session meetings coupled with

encouraging participants to identify income generating activities within their reach was reported to impact participants ability to attend clinic. Interventions attempting to address barriers to HIV clinic attendance should also include components to improve patients' access to income [16]. Evidence shows that context-specific evidence-based interventions generally deliver better results [10, 28].

Strengths and limitations of the study

We aimed to describe and analyze barriers to clinic attendance and ART adherence among HIV-positive adults enrolled in the *Daraja* intervention. The qualitative design enabled us to identify individual barriers to HIV clinic attendance and ART adherence that may otherwise be missed by other methodological approaches. However, our participants were asked to recall their experiences with the barriers to attending and adhering to therapy, which may have resulted in recall bias. Our sample was small, thus limiting the generalizability of our results. However, the use of purposive sampling while paying attention to important variations within the study population, such as gender and age, made it possible to attribute the findings to the *Daraja* trial population.

Conclusion

Perceived stigma and fear of discrimination, underemployment and lack of reliable income, lack of reliable transport, lack of social support, low self-efficacy, erroneous beliefs about HIV infection, and lack of permission from the employer were key barriers to HIV clinic attendance and adherence to antiretroviral therapy among the recently discharged HIV-positive population. A context-tailored social worker intervention showed promising results in addressing these barriers.

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12889-024-21231-z>.

Supplementary Material 1

Supplementary Material 2

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Author contributions

ESO, RP, LRM, SK, HG, SK, designed the qualitative research and the interview guides. MC collected and transcribed the data. BI, KA, GK supervised the qualitative data collection. DM & ESO analyzed the data, ESO drafted the manuscript and made revisions based on feedback from the other authors. SK, RP, HG, LRM, DF, TR, ML, SK, PA, BI, KA, GK provided critical review of the manuscript for important intellectual content. All authors read and approved the final version.

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Data availability

The dataset analysed for this manuscript can be made available from the corresponding author on request.

Declarations

Ethics approval and consent to participate

This study received approvals from the Medical Research Coordinating Committee (MRCC) in Tanzania (NIMR/HQ/R.8a/Vol. IX/2811), the Ethics Committees of Weill Cornell Medicine (1804019134), and the London School of Hygiene and Tropical Medicine (LSHTM Ethics Ref 16173). All participants provided written informed consent to participate and to be audio recorded after an explanation of the rationale and procedures for the qualitative interviews was provided. A copy of the signed consent form was given to them for their records. All participants were assigned a de-identified study ID number to maximize confidentiality. All interviews were conducted in participants homes or other private settings identified in consultation with the participants.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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References

1. Burke RM, Twabi HH, Johnston C, Nliwasa M, Gupta-Wright A, Fielding K, et al. Interventions to reduce deaths in people living with HIV admitted to hospital in low- and middle-income countries: a systematic review. *PLOS Global Public Health*. 2023;3(2):e0001557.
2. Ford N, Patten G, Rangaraj A, Davies MA, Meintjes G, Ellman T. Outcomes of people living with HIV after hospital discharge: a systematic review and meta-analysis. *Lancet HIV*. 2022;9(3):e150–9.
3. Ford N, Shubber Z, Meintjes G, Grinsztejn B, Eholie S, Mills EJ, et al. Causes of hospital admission among people living with HIV worldwide: a systematic review and meta-analysis. *Lancet HIV*. 2015;2(10):e438–44.
4. Peck RN, Wajanga B, Downs JA, Mteta K, Fitzgerald DW. Linkage to Primary Care and Survival after Hospital Discharge for HIV-Infected adults in Tanzania: a prospective cohort study. *J Acquir Immune Defic Syndr*. 2016;73(5):522–5305.
5. Bukenya D, Mayanja BN, Nakamanya S, Muhumuza R, Seeley J. What causes non-adherence among some individuals on long term antiretroviral therapy?

- Experiences of individuals with poor viral suppression in Uganda. *AIDS Res Ther.* 2019;16(1):2.
6. Dear N, Esber A, Irezindu M, Bahemana E, Kibuuka H, Maswai J, et al. Routine HIV clinic visit adherence in the African cohort study. *AIDS Res Therapy.* 2022;19(1):1.
 7. Hlophe LD, Tamuzi JL, Shumba CS, Nyasulu PS. Barriers and facilitators to anti-retroviral therapy adherence among adolescents aged 10 to 19 years living with HIV in sub-saharan Africa: a mixed-methods systematic review and meta-analysis. *PLoS ONE.* 2023;18(5):e0276411.
 8. Stecher C, Palimaru AI, Odiit M, Lunkuse L, Walukaga S, Linnemayr S. Barriers and facilitators of antiretroviral therapy (ART) adherence habit formation in Sub-saharan Africa: evidence from a qualitative study in Kampala, Uganda. *Volume 317. Social Science & Medicine;* 2023. p. 115567.
 9. National Bureau of Statistics. The Tanzania HIV Impact Survey 2022–2023 (THIS 2022–2023), NBS. 2023, Government of Tanzania: https://www.nbs.go.tz/nbs/takwimu/THIS2022-2023/THIS2022-2023_Summary_Sheet
 10. Michie S, Johnston M, Francis J, Hardeman W, Eccles M. From theory to intervention: Mapping theoretically derived behavioural determinants to Behaviour Change techniques. *Appl Psychol.* 2008;57(4):660–80.
 11. Gelberg L, Andersen RM, Leake BD. The behavioral model for vulnerable populations: application to medical care use and outcomes for homeless people. *Health Serv Res.* 2000;34(6):1273–302.
 12. Babitsch B, Gohl D, von Lengerke T. Re-visiting Andersen's behavioral model of Health services Use: a systematic review of studies from 1998–2011. *Psychosoc Med.* 2012;9:Doc11.
 13. Bazzi AR, Drainoni ML, Biancarelli DL, Hartman JJ, Mimiaga MJ, et al. A systematic review of HIV treatment adherence research among people who inject drugs in the United States and Canada: evidence to inform pre-exposure prophylaxis (PrEP) adherence interventions. *BMC Public Health.* 2019;19:1–0.
 14. Hajek A, Kretzler B, König HH. Determinants of healthcare use based on the Andersen model: A systematic review of longitudinal studies. *InHealthcare* 2021 Oct 12 (Vol. 9, No. 10, p. 1354). MDPI.
 15. Kisigo GA, Issarow B, Abel K, Hashim R, Okello ES, Ayieko P, et al. A social worker intervention to reduce post-hospital mortality in HIV-infected adults in Tanzania (Daraja): study protocol for a randomized controlled trial. *Contemp Clin Trials.* 2022;113:106680.
 16. Metsch LR, Feaster DJ, Gooden L, Matheson T, Stitzer M, Das M, et al. Effect of patient navigation with or without financial incentives on viral suppression among hospitalized patients with HIV infection and substance use: a randomized clinical trial. *JAMA.* 2016;316(2):156–70.
 17. Peck RN, Issarow B, Kisigo GA, Kabakama S, Okello E, Rutachunzibwa T. et al., Linkage Case Management and Posthospitalization Outcomes in People With HIV: The Daraja Randomized Clinical Trial. *JAMA.* 2024 Mar 6.17.
 18. Gardner LI, Metsch LR, Anderson-Mahoney P, Loughlin AM, Del Rio C, Strathdee S, et al. Efficacy of a brief case management intervention to link recently diagnosed HIV-infected persons to care. *Aids.* 2005;19(4):423–31.
 19. QSRIP Ltd. NVivo (released in March 2020). <https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home>; 2020.
 20. Ammon N, Mason S, Corkery JM. Factors impacting antiretroviral therapy adherence among human immunodeficiency virus-positive adolescents in Sub-saharan Africa: a systematic review. *Public Health.* 2018;157:20–31.
 21. Ayieko J, Brown L, Anthierens S, Van Rie A, Getahun M, Charlebois ED, et al. Hurdles on the path to 90-90-90 and beyond: qualitative analysis of barriers to engagement in HIV care among individuals in rural East Africa in the context of test-and-treat. *PLoS ONE.* 2018;13(8):e0202990.
 22. Azia IN, Mukumbang FC, Van Wyk B. Barriers to adherence to antiretroviral treatment in a regional hospital in Vredenburg, Western Cape, South Africa. *South Afr J HIV Med.* 2016;17(1):1–8.
 23. Kanguya T, Koyuncu A, Sharma A, Kusanathan T, Mubanga M, Chi BH, et al. Identifying barriers to ART initiation and adherence: an exploratory qualitative study on PMTCT in Zambia. *PLoS ONE.* 2022;17(1):e0262392.
 24. Lyimo RA, de Bruin M, van den Boogaard J, Hospers HJ, van der Ven A, Mushi D. Determinants of antiretroviral therapy adherence in northern Tanzania: a comprehensive picture from the patient perspective. *BMC Public Health.* 2012;12:1–8.
 25. Barnes E, Zhao J, Giumenta A, Johnson M. The effect of an integrated health system specialty pharmacy on HIV antiretroviral therapy adherence, viral suppression, and CD4 count in an outpatient infectious disease clinic. *J Managed Care Specialty Pharm.* 2020;26(2):95–102.
 26. Decroo T, Rasschaert F, Telfer B, Remartinez D, Laga M, Ford N. Community-based antiretroviral therapy programs can overcome barriers to retention of patients and decongest health services in sub-saharan Africa: a systematic review. *Int Health.* 2013;5(3):169–79.
 27. Mbuagbaw L, Hajizadeh A, Wang A, Mertz D, Lawson DO, Smieja M, et al. Overview of systematic reviews on strategies to improve treatment initiation, adherence to antiretroviral therapy and retention in care for people living with HIV: part 1. *BMJ open.* 2020;10(9):e034793.
 28. Amico KR, Mugavero M, Krousel-Wood MA, Bosworth HB, Merlin JS. Advantages to using social-behavioral models of medication adherence in research and practice. *J Gen Intern Med.* 2018;33:207–15.

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