



# Slipping through the cracks: a qualitative study to explore pathways of HIV care and treatment amongst hospitalised patients with advanced HIV in Kenya and the Democratic Republic of the Congo

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## ABSTRACT

Advanced HIV causes substantial mortality in sub-Saharan Africa despite widespread antiretroviral therapy coverage. This paper explores pathways of care amongst hospitalised patients with advanced HIV in rural Kenya and urban Democratic Republic of the Congo, with a view to understanding their care-seeking trajectories and poor health outcomes. Thirty in-depth interviews were conducted with hospitalised patients with advanced HIV who had previously initiated first-line antiretroviral therapy, covering their experiences of living with HIV and care-seeking. Interviews were audio-recorded, transcribed and translated before being coded inductively and analysed thematically. In both settings, participants' health journeys were defined by recurrent, severe symptoms and complex pathways of care before hospitalisation. Patients were often hospitalised after multiple failed attempts to obtain adequate care at health centres. Most participants managed their ill-health with limited support networks, lived in fragile economic situations and often experienced stress and other mental health concerns. Treatment-taking was sometimes undermined by strict messaging around adherence that was delivered in health facilities. These findings reveal a group of patients who had "slipped through the cracks" of health systems and social support structures, indicating both missed opportunities for timely management of advanced HIV and the need for interventions beyond hospital and clinical settings.

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## Background

In 2018, there were nearly 770,000 AIDS-related deaths worldwide, with mortality rates remaining high in many settings despite the widespread provision of antiretroviral therapy (ART) (Osler et al., 2018; UNAIDS, 2019). In contrast to the early years of ART roll-out in sub-Saharan Africa, advanced HIV is now increasingly seen amongst patients on treatment, indicating treatment failure exacerbated by failings in the health system, limited social support structures, and challenges taking treatment over the long term (Chihana et al., 2019; Merten et al., 2010; Skovdal et al., 2017). In some settings, ART patients presenting at hospitals with advanced HIV disease arrive in such severely immunocompromised states that up to one-quarter die within 48 hours of hospital admission (Ousley et al., 2018).

A wealth of literature exists on the tensions between the lived realities of people living with HIV (PLHIV) and the features of HIV programmes. These tensions are driven by health system barriers (Wringe, Renju, et al., 2017), social and structural factors that underlie late HIV diagnoses (Musheke et al., 2013) or late treatment initiation following HIV diagnoses (Bukenya et al., 2017; Horter et al., 2017; Wringe, Moshabela, et al., 2017), and those that underpin challenges with adhering to ART over time (e.g. Burns et al., 2019; Heestermans et al., 2016; Nguyen et al., 2007). However, treatment-experienced PLHIV with advanced HIV may provide more extreme examples of these tensions that have contributed to life-threatening illnesses despite access to ART. Few studies have explored the experiences of patients with advanced HIV since ART was introduced (McCoy et al., 2009; Rao et al., 2013; Skovdal et al., 2019; Tarimo et al., 2009), and very few have explored the

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**Table 1.** Main characteristics of study sites.

	Homabay County Teaching and Referral Hospital	Centre hospitalier de Kabinda, Kinshasa
Setting	Rural	Urban
HIV prevalence	High (Kenya 4.9%, Homa Bay sub-county 26%)	Low (DRC 1.2%, Kinshasa 1.6%)
Hospital	MoH with MSF support since 2014 (patient fees)	MSF (free care since 2008)
% PLHIV admitted on ART >6 months	47%	56%
% PLHIV admitted with advanced HIV	84%	97%
In-hospital mortality among HIV patients	17%	30%

perspectives of hospitalised PLHIV in African settings. In studies conducted with hospitalised adolescents in Botswana and Kenya, adolescents' relationships to family, clinic and peers defined their engagement and retention in care (Enane et al., 2020) with reasons for delayed care-seeking including caregiver illness and death, and issues around disclosure of the adolescent's status linked to stigma (Enane et al., 2018). In a study by Venables et al. among hospitalised PLHIV, experiences of stigma, religious beliefs and limited economic resources were linked to patients' delayed access to care (Venables et al., 2019).

Given the high mortality rates amongst patients with advanced HIV, there is a pressing need for more research to understand "what went wrong" in patients' interactions with treatment and care services. Adherence and care engagement have often been described as cyclical (Merten et al., 2010; Skovdal et al., 2017), with an estimated 25% of PLHIV on ART interrupting their treatment at some stage (Kranzer & Ford, 2011). Many researchers have argued for the need to move beyond conceptualisations of patient engagement that focus on their responsibility for appointment attendance, treatment adherence, gratitude for care and allegiance to biomedical interventions (Paparini & Rhodes, 2016; Russell et al., 2016). Examining pathways of care amongst PLHIV may illuminate layers of exclusion and inequity that make some of these individuals particularly vulnerable to mortality and morbidity risks in the context of fragile health systems in sub-Saharan African settings. To inform interventions to reduce mortality among patients with advanced HIV, this study explored their pathways of care in rural Kenya and urban Democratic Republic of the Congo (DRC).

## Methods

### Study context

We draw on qualitative data that were collected as part of a mixed-methods study that investigated drug resistance to first-line ART and associated factors amongst hospitalized patients with advanced HIV disease in two hospitals supported by *Médecins sans Frontières*

(MSF) in Homa Bay, Kenya and Kinshasa, DRC (Table 1). Advanced HIV was defined as  $CD4 \leq 350$  cells/ $\mu$ L. The quantitative component of this study measured the proportion of treatment failure (virological failure and major drug resistance mutations) among these patients using a cross-sectional design.

Despite the differences between the settings, both hospitals faced high rates of advanced HIV among patients who were admitted with an HIV diagnosis. In both sites, around half of all patients admitted to hospital with HIV had been on ART for at least 6 months, and the majority were admitted with advanced HIV. Mortality among HIV patients following hospitalisation was high in both settings: 30% died in hospital in Kinshasa and 17% in Homa Bay with an additional 30% dying post-discharge after a median observation time of 9 months in Homa Bay (Ousley et al., 2018). The main causes of death amongst these patients were tuberculosis and neurological infectious diseases, including cryptococcal meningitis. 70% and 48% of participants in the cross-sectional study had self-presented to the hospital in Homa Bay and Kinshasa respectively, and 25% and 23% had been hospitalised in the last 3 months indicating that patients cycle in and out of hospital and may not access timely referral when their health deteriorates (Bossard et al., 2021). Prior to hospitalisation, patients in Homa Bay had generally been receiving HIV care at a government health centre (49%) or hospital (30%), and in Kinshasa

**Table 2.** Participant characteristics.

Participant characteristics	Homa Bay (n)	Kinshasa (n)
Sex	M	7
	F	8
Viral load (copies/ml)	$\geq 1000$	6
	$< 1000$	9
Time on ART (years)	$\leq 4$	8
	$> 4$	7
CD4 (cells/ $\mu$ L)	$< 200$	9
	$\geq 200$	6
ART adherence (self-reported as % of treatment taken in the last month)	90% or 100%	7
	$\leq 80\%$	8
Age group (years)	18–30	4
	31–50	7
	51–70	4
Total	15	15

at the MSF-supported hospital OPD (38%) or a faith-based facility (23%).

### Sampling strategy

Fifteen patients from each site participated in the qualitative component of the study (Table 2). Participants had a median age of 40 years in Homa Bay and 39 years in Kinshasa and at the time of their interview a median time of 4 years on ART in Homa Bay and 6 years in Kinshasa. Participants were sampled from the cross-sectional component of the study for which eligibility criteria included having initiated first-line ART at least 6 months ago, with  $CD4 \leq 350$  cells/ $\mu$ L on presentation to the hospital. A purposive sampling strategy was used to ensure diversity in terms of sex, age, time of treatment and self-reported ART adherence (Table 2). Patients were only eligible for the study if their clinician considered them well enough to participate. Patients were invited to participate by a Research Assistant who also conducted the interview following written informed consent.

### Data generation

In-depth interviews took place between October and November 2017 in Kinshasa, and between February and April 2018 in Homa Bay. In Kinshasa, interviews were conducted by a trained, non-clinical male research assistant in Lingala or French in a quiet, private room inside the ward. In Homa Bay, interviews were conducted in Dholou (often with segments of English and Swahili) by a non-clinical, female, Kenyan social scientist in a private outdoors location on the hospital grounds. Interviews lasted for between 20 and 120 minutes, and covered participants' lived experiences of illness since their HIV diagnosis, their health journeys, experiences with treatment and pathways of care. Regular pauses were proposed during the interview to enable the participant to rest.

### Data management and analysis

Interviews were audio-recorded with consent, transcribed and translated into either French (Kinshasa) or English (Homa Bay) by a trained staff member. Transcripts were reviewed for quality, and any discrepancies in translation were verified and corrected with the assistance of the research assistants. Data from transcripts were coded manually in Kinshasa and with the aid of NVivo 11 software in Homa Bay. A thematic analysis was undertaken by the research lead in each site, drawing on the principles of grounded theory,

whereby codes were raised to a conceptual level considering their underlying meaning and their interrelationship (Charmaz, 2014; Green & Thorogood, 2004). Detailed analytical summaries of the emerging themes and sub-themes were shared regularly between the research leads in each site. Further refinement of the analysis was undertaken by the lead author, with three main themes emerging in relation to the study objective.

### Ethics

Ethics approval was granted from the MSF Ethics Review Board (Protocol ID: 1743), the KEMRI Scientific and Ethics Review Committee in Kenya and the *Comité D'Ethique à la Recherche Scientifique* in DRC.

### Results

In both sites, participants usually self-presented at hospital after their health had severely deteriorated. Three main themes emerged from the analysis that characterised their pathways to hospitalisation: (i) social and economic stresses; (ii) multiple and complex care journeys and (iii) the burden of daily pill-taking and the messaging around treatment and illness.

#### **"I have a heavy heart": social and economic stress**

Interviewees listed multiple and often severe symptoms that resulted in their admission to hospital. Illness was often prolonged, exemplified by issues like major weight loss over time as one man from Kinshasa explained:

*I weighed 75 kilos: because of the disease I lost weight down to 42 kilos and then I weighed in here [at hospital] at 39. [Man with advanced HIV, aged 30–40, Kinshasa]*

Illness had compromised many participants' livelihoods, often with gendered consequences. Several men reported stress at being unable to provide for their families, while women's major concerns tended to revolve around caretaking for children, including managing school fees. These patients had often used their limited resources without recovering from prior illnesses, leaving some to worry about how they would even be able to cover the costs of the hospital treatment that was keeping them alive:

*My treatment is going well, and I am getting better, but when they will ask me to pay the bill, I will be stranded. [Man with advanced HIV, aged 40–50 years, Homa Bay]*

Some participants attributed various physical symptoms including stomach disorders, headaches and pain to manifestations of stress. In both sites, participants'

accounts revealed their mental health was linked to their severe symptoms and dependence on others. Many felt isolated and alone, and were concerned about who would care for them when discharged, including cooking and covering transport costs to return to hospital, making service use, treatment taking and self-care onerous. There was limited social support for those who had not disclosed their HIV status to household members or family. In some of the most extreme cases, participants felt so desperate that they wanted to stop their drugs to end their life:

*No one has come to pay me a hospital visit, they don't care to know how my health is. I have also had challenges at home. When they leave and go to the lake [for fishing] no one remains at home. There is no one who can give you even water to drink when you are down. ... I have a heavy heart ... I have thought of committing suicide. (Man with advanced HIV, aged 20-30, Homa Bay).*

Men's social stress at times centred on their role as a husband, as defined by masculinity norms, including their inability to maintain sexual relations with their wives due to ill-health:

*It is really disturbing me ... as a man if I cannot have sex with my wives ... I don't have peace... I have two wives, but when it reaches the time when you want to engage in such a thing ... My libido just went down ... how can that be helped? (Man with advanced HIV, aged 40-50, Homa Bay)*

Some women who disclosed their HIV status to their partners reported being unsupported, while most women in the Homa Bay site reported violence perpetrated by their partner, often including sexual violence. This further undermined their resilience to living with HIV, to self-care or effectively seek help for their condition:

*... every time I went to the clinic I would be told that my viral load is high ... I would tell him that maybe it is because we are having sex without a condom ... He is very quarrelsome ... I know that he (my partner) can burn me in that house until I turn to ashes, I don't I know if I will wake up and find my cattle turned into meat. This has really disturbed me. (Woman with advanced HIV, aged 30-40, Homa Bay)*

### **“I did not get healed”: complex pathways of care**

Most participants reported multiple attempts to seek help for their condition either at facilities where they normally received HIV services, or at other sites such as government clinics, primary health facilities, dispensaries, and in some cases from pharmacies. Most participants eventually self-presented at a hospital, revealing a pattern of inadequate referral as their health deteriorated:

*I had taken ARVs for about a year then a wound appeared on my head. I went to Nyatoto but I did not get healed ... ‘Go to Nakuru there are dermatologists there’ ... they gave me ointments and oral drugs ... go to a hospital ... a (sample) was to be taken to India for testing ... I was being told to go to Eldoret ... I went to Alupe and they gave oral medication and ointment. I did not get healed ... why was I wasting money? I just bought the drug from the chemist ... the pain was too much, I felt I was dying. (Woman with advanced HIV, aged 50-60, Homa Bay)*

Repeated hospitalisation was also common, with some participants too sick to collect their treatment, thus deteriorating further, without adequate post-discharge care or support. Decentralisation of HIV services to community sites in Kinshasa meant that out-patients sometimes waited until their next scheduled appointment to seek medical advice if they were sick:

*I was late [attending the hospital] because of the appointment. I knew that I had an appointment on the 27th, but before that I started to get some symptoms, so I told myself that I would explain everything to the doctor when I had my appointment. (Man with advanced HIV, aged 30-40, Kinshasa)*

Some participants reported negative or critical responses from health workers over poor adherence or missed appointments, and some felt intimidated to return to care if they had previously disengaged from a service:

*I made them angry since I could miss my appointed dates ... sometimes they even closed my file. When they got angry, it was my mum who used to talk to them, then they allowed me into the system again. (Man with advanced HIV, aged 18-30, Homa Bay)*

For other participants HIV was accepted as a lifelong, chronic disease, and they perceived less urgency to seek regular care unless their symptoms were severely affecting their daily life. Community Health Workers and peer-educators living with HIV often played a key role in triaging patients with serious symptoms from among those with minor health complaints, and in urging the former to present at hospital, especially in Homa Bay. Family support was also essential, with most participants able to travel to a hospital due to physical or financial support from caretakers.

### **“We were told that we should not take ARVs after midday”: treatment-taking and making sense of illness**

Whilst adherence was impacted by social and economic stress, many participants recited strategies for treatment adherence such as setting an alarm, keeping a reserve for travel or having “treatment buddies”

to help them. Despite these approaches, many participants faced challenges integrating pill-taking into their daily lives, including managing timing of doses which clashed with activities such as travel for work. Some described treatment fatigue or stopped taking pills during periods of good health, or questioned their original diagnosis:

*I got angry and I told them that I wouldn't take my treatment anymore because I don't think it's right... how come I have AIDS and not my children? (Woman with advanced HIV, aged 30–40, Kinshasa)*

Treatment adherence and condom use were often couched in moralized language or imbued with shame, with some participants apologising for behaviours that they believed had led to their illness or treatment failure. Overly strict treatment messages were reportedly imparted by providers and discouraged some participants from adhering if they could not meet health workers' expectations:

*We were told that we should not take ARVs after mid-day, that if you took them past that time then it will be of no effect. (Man with advanced HIV, aged 40–50, Kinshasa)*

As a result, some participants skipped doses rather than taking their drugs later than the recommended time. Similarly, condom use was emphasised by health workers as a primary way that participants could avoid treatment failure through preventing “re-infection” with HIV. This was a common explanation proposed by participants as to why their ART had “stopped working” or why their health had deteriorated:

*I think [I am sick] because of the regular sex we were having. Having sex daily multiplies the virus in you. I learned this when we went for counselling, that is where we were taught that if have HIV, we have to use a condom while having sex. (Woman with advanced HIV, aged 40–50, Homa Bay)*

## Discussion

This study explored pathways of care amongst hospitalised patients with advanced HIV in DRC and Kenya to understand their circumstances prior to hospital presentation. Although people with advanced HIV infection have a high mortality risk, few studies have explored patients' accounts of “what went wrong” which is an essential precursor for ensuring that services provide tailored and patient-centred care. Our findings challenge assumptions that advanced HIV is primarily an issue of patient dis-engagement or “late” presentation to care, notions which cast patients as personally responsible for their ART adherence, without

acknowledging the social constraints and circumstances that shape their engagement with care within global HIV programming (Nguyen et al., 2007; Papparini & Rhodes, 2016; Whyte et al., 2013). Many of our participants in both settings sought care multiple times as their health declined without adequate service provision. Despite its obvious benefits, decentralisation of HIV care into primary health centres in African contexts may create challenges in terms of delayed referral or inadequate management of some patients, as our findings suggested. Reducing the burden of advanced HIV will require strengthening decentralised health services to enable staff to identify the danger signs in patients at risk of advanced HIV, provide timely case management, ensure referral and provide post-discharge support to those with ongoing clinical needs (Ndlovu et al., 2020).

Our findings also indicate the need for patient support beyond clinical HIV interventions at a hospital level, given that treatment and care success was often influenced by mental health and experiences of violence and economic hardship, factors which were often gendered. The “triple epidemic” of HIV, gender-based violence and mental health has been explored elsewhere (Gilbert et al., 2015; Mitchell et al., 2016), and there is increasing recognition that HIV programming could be strengthened by addressing these health concerns concurrently, for example through greater service integration (Christofides & Jewkes, 2010; Chuah et al., 2017). Furthermore, national HIV programmes in many African settings are limited to counselling in the context of HIV testing or ART adherence (Bird et al., 2011; Mall et al., 2012), these existing services could be reinforced to acknowledge the wider range of mental health and social challenges faced by some patients. Economic support or a reduction in patient fees at the hospital level may also help some patients cope with livelihood disruptions during illness as well as reducing stress and anxiety which further undermine positive health outcomes.

Our participants' accounts of the challenges in integrating treatment taking with their daily lives accord with research undertaken elsewhere (Burns et al., 2019; Heestermans et al., 2016; Merten et al., 2010). Our findings also show the impact of social and economic stress on treatment taking. Overly strict messages on pill-taking and moralised views on treatment failure that were imparted by providers often discouraged pill-taking or led to misunderstandings on how advanced HIV could be prevented. In addition patients' own perceptions of their health may not align with clinical assessments of the severity of their symptoms, as documented elsewhere (Venables et al., 2019).

Our findings should be considered in light of various limitations. Firstly, very few patients were well enough to participate in an interview, limiting our ability to capture the experiences of those with severe illness. Furthermore, participants from both sites were interviewed in a hospital setting, which may have generated reluctance to give negative feedback on the health services received. Where possible, this was mitigated by conducting the interviews outside of the wards, by non-clinical interviewers who were not involved in their care.

In conclusion, we found that hospitalised patients with advanced HIV in both settings had remarkably similar experiences that had led to extreme deteriorations in their health. Their pathways to hospitalisation were marked by social and economic stresses, complex care journeys as they engaged with multiple services over time, and common experiences around the burden of daily pill-taking alongside overly strict messaging around treatment and illness. This analysis aids efforts to understand the continued challenge of advanced HIV in settings with widespread ART coverage. It highlights the need to address concurrent health and social problems in tandem, rather than as separate threats, considering that patients who develop advanced HIV may be a sub-group of PLHIV who have “slipped through the cracks” of health and social support structures.

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