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# 'I need time to start antiretroviral therapy': understanding reasons for delayed ART initiation among people diagnosed with HIV in Lusaka, Zambia'

Chanda Mwamba<sup>a</sup> , Laura K. Beres<sup>b</sup> , Stephanie M. Topp<sup>c</sup> , Njekwa Mukamba<sup>a</sup> , Sandra Simbeza<sup>a</sup> , Kombatende Sikombe<sup>a,d</sup> , Aaloke Mody<sup>e</sup> , Elvin Geng<sup>e</sup> , Charles B. Holmes<sup>f</sup> , Caitlin E. Kennedy<sup>b</sup> , Izukanji Sikazwe<sup>a</sup> , Julie A. Denison<sup>b</sup> and Carolyn Bolton Moore<sup>a</sup>

<sup>a</sup>Centre for Infectious Disease Research in Zambia, Lusaka, Zambia; <sup>b</sup>Department of International Health, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD, USA; <sup>c</sup>College of Public Health, Medical & Veterinary Sciences, James Cook University, Townsville, Australia; <sup>d</sup>Department of Public Health Environments and Society, Faculty of Public Health and Policy, London School of Hygiene and Tropical Medicine, London, United Kingdom; <sup>e</sup>Washington University School of Medicine in St. Louis, MO, USA; <sup>f</sup>Georgetown University, Washington, DC, USA

## ABSTRACT

**Introduction:** Rapid antiretroviral therapy (ART) initiation can improve patient outcomes such as viral suppression and prevent new infections. However, not everyone who can start ART does so immediately.

**Methods:** We conducted a qualitative study to inform interventions supporting rapid initiation in the 'Test and Start' era. We purposively sampled 20 adult patients living with HIV and a previous gap in care from ten health facilities in Lusaka, Zambia for interviews. We inductively analysed transcripts using a thematic, narrative approach. In their narratives, seven participants discussed delaying ART initiation.

**Results:** Drawing on messages gleaned from facility-based counselling and community information, many cited greater fear of rapid sickness or death due to imperfect adherence or treatment side effects than negative health consequences due to delayed initiation. Participants described needing time to 'prepare' their minds for a lifetime treatment commitment. Concerns about inadvertent HIV status disclosure during drug collection discouraged immediate initiation, as did feeling healthy, and worries about the impact of ART initiation on relationship dynamics.

**Conclusion:** Findings suggest that counselling messages should accurately communicate treatment risks, without perpetuating fear-based narratives about HIV. Identifying and managing patient-specific concerns and reasons for the 'need for time' may be important for supporting individuals to rapidly accept lifelong treatment.

## KEY MESSAGES

1. Fear-based adherence messaging in health facilities about the dangers of missing a treatment dose or changing the time when ART is taken contributes to Zambian patients' refusals of immediate ART initiation
2. Responsive health systems that balance a stated need for time to accept one's diagnosis and prepare to embark on a lifelong treatment plan with interventions to identify and manage patient-specific treatment related fears and concerns may support more rapid ART initiation
3. Perceived social stigma around HIV continues to be a significant challenge for treatment initiation.

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## KEY WORDS

ART initiation; delayed treatment; antiretroviral refusal; test and start; Zambia

## Introduction

Despite improved patient outcomes with rapid antiretroviral therapy (ART) initiation [1–4] and widespread adoption of the World Health Organization's 'test and start' guideline [5], many people living with HIV delay

ART initiation [6–11]. A clear understanding of the reasons and factors influencing delayed ART is needed to inform effective interventions for more rapid initiation [2,4]. Like many sub-Saharan African countries, Zambia

**CONTACT** Chanda Mwamba [Chandaruta84@gmail.com](mailto:Chandaruta84@gmail.com) Centre for Infectious Disease Research in Lusaka Zambia, Plot 34620, Lusaka, 10101 Zambia

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adopted the 'test and start' strategy in 2016 [12,13]. However, treatment initiation remains sub-optimal [11,14].

Multiple individual, psychosocial, structural, and health system-related factors are known to influence ART initiation [15–19]. A systematic literature review of studies prior to 'test and start' in sub-Saharan Africa, including two studies from Zambia, identified barriers to ART initiation including fear of stigma, disclosure, and side effects; competing livelihood commitments; structural barriers (e.g. distance and costs); and clinic-related barriers such as long queues and poor health care worker (HCW) attitudes [20–24]. Since 'test and start' began, four quantitative studies in Zambia [25–28] and qualitative studies from Swaziland and Mozambique identified barriers similar to the pre- 'test and start' era, with additions including difficulties accepting diagnosis [29–31]. Most of the extant literature on ART initiation in Zambia and the sub-Saharan African region is quantitative. Among published qualitative studies, only one, from Tanzania [32], utilises narrative methods. Narrative research allows for identification of meaning and sense-making from the perspective of the person relating the story [33–37]. This patient-centered [38] perspective is critical to understand and address drivers of delayed ART initiation. Our study sought to understand reasons for delayed ART start from the patient perspective and their interpretation of delayed ART experiences to inform interventions to optimise treatment outcomes in Zambia.

## Methods

### **Study background and population**

Participants were sampled from a larger study that identified vital status and care outcomes among a probability sample of adult patients considered lost to follow-up from HIV care in Zambia [39,40]. Qualitative interviews were conducted between January and June 2019 with a subset of participants from Lusaka Province who self-identified as disengaged from care, but subsequently re-engaged [41]. Out of 65 eligible participants with telephone contact details in their medical files, 51 had working telephone numbers. After  $\geq 3$  call attempts to all 51, we successfully contacted 27, of whom 4 had died, 3 declined, and 20 consented to participate. Among the 20 participants, seven narrated experiences of delaying ART during the broader narrative of their HIV care journey. Since it was not asked about directly, understanding delayed ART among the subset of participants who raised it as

a noteworthy component of their HIV care narrative offers unique and important insight into the behaviour that can guide intervention development. This paper presents the results of a secondary data analysis of the sub-group of participants who discussed delaying ART initiation in their interviews.

### **Procedures**

Participants were recruited and interviewed in person by the lead author (CM) following written informed consent. Interviews were conducted in English, Nyanja or Bemba, per patient preference and lasted 1–2 h. Using an individualised guide designed to elicit a patient's narrative of care engagement, participants narrated their experience of their HIV care and treatment journey since their HIV diagnosis. Participants were not directly questioned about reasons for delayed ART initiation. The narrative approach allowed for patient-led sharing of events and contexts associated with delayed ART start, and the meaning attached to these experiences [33–37].

### **Analysis**

Interview audio recordings were simultaneously translated into English and transcribed verbatim. After each interview, an analysis memo was created within 24 h and LB and CM discussed the memos and their meanings. Based on the interview scripts, memos and dialogue, we created chronological narratives of each patient's care journey describing contexts and events that influenced their disengagement, re-engagement and any subsequent delays with ART initiation. Each patient summary and transcript was iteratively read in detail, inductively coded using narrative thematic analysis and categorised into themes [33–37]. Analysis and interpretation of ART-delay related themes was restricted to narratives mentioning delayed ART initiation. Analysis was conducted by LB and CM, including dialogue throughout the stages of the analysis process.

### **Results**

Seven participants from seven health facilities, aged 21–50 years, and all-female but one, described delayed ART initiation. They were recommended to start ART and initiated between 2013 and 2017. While the exact length of treatment delay was not captured, narratives suggested delays of 3–12 months. Other elements of patient journeys, including entry into care, time from

**Table 1.** Themes and quotes.

Theme	Quote
'If you skip treatment you will die': Misconceptions and misinformation	At the clinic where we were collecting drugs, they were saying that you don't need to miss taking drugs and don't exceed the allocated time for taking drugs, like if you are taking drugs at twenty-one hours then you take at twenty-three hours, this means that you are creating your own problems, because of that I was getting scared knowing that sometimes one may forget or one may be busy at the time they take medicine such that by the time you take the drugs maybe some minutes would have passed, so I was worried that this will be our death now. [Female, 35–44] (Friends) said that when you skip the treatment you will die, while others said when you forget to take them you will die (...), so those who have not yet started, they tend to be scared [Female, 55+] Okay, what happens when you start then you stop, (...) it's like you're giving chance to that virus to come with full force (...) And when it comes with full force a lot of illnesses keep coming in. So that's what I didn't want because with me I felt it's better for me like this without such complications, it will be better than starting something which I won't manage to finish by the end of the day. [Male, 25–34] I said I need to think about it because you know, it's not something easy whereby you just wake up and say let me start this. That's why sometimes you find that people start then they fail to continue or stop. [Female 34–44]
'I need to think': Preparing for a life-long commitment	At first, because I was scared, thinking ... how will I start ... at which facility will I start from, so you think of all that, that's why I was holding back to say I will start taking drugs but needed them (HCWs) to wait for me first. (Female 18–24)
'I don't want people to know my status': Concerns about HIV disclosure	that issue of screaming [calling out names of people waiting for ART at the clinic] affects me because I don't want people to know my status, I don't want them to know, for me I don't! maybe I might get depressed and stop my medicine and that is something I don't want to do. [Female, 18–24] I could get embarrassed because if you meet someone you know at the clinic then they could tell someone they know, they could be talking in the community that we have found such a person collecting drugs at the clinic, so that is what I was scared of [Female, 35–44]
'I was feeling well with my health': Difficulty accepting HIV Diagnosis	'So, when I went there (VCT), I was told, you are HIV positive, then I said hmm how come? I could not believe it because I was feeling well with my health. Then from there, I went to another clinic to test again' [Female 45+] R: I didn't feel good [about diagnosis], and the reason I didn't feel good is that I looked at my life and what I went through, how I looked after myself... I had not had multiple partners [Female, 25–34] You know the way we look at HIV ... [made accepting my HIV status] quite challenging, it was something scary because now I was thinking so I will die soon! Then even when you know the fact that you can't die if you take your medication and accept your status and you can live long, there is just always that fear, it will just pop into your mind. [Female, 25–34 years]
'How am I going to manage': Concerns about ART consumption	By then, people would talk that the drugs, the tablets are big and then I thought about it, because already I have a problem taking drugs like Panadol, I usually break it, how about ARVs how am I going to manage them? [Female, 35–44] because I've seen some side effects from some other people I don't know, you find that others start developing a big tummy or maybe the chest is too big (...). You can even tell just from the way they look that they are on treatment. Yes so I was scared of such side effects so to me it was like a gamble because I didn't know if I'll have the same side effects or not. [Female, 25–34]

entry to recommended initiation, and disengagement were varied across the seven participants [42]. Key themes are described below. Supporting quotes are summarised in Table 1.

### ***'If you skip treatment you will die': Misconceptions and misinformation***

Participants reported receiving counselling messages that emphasised the importance of perfect adherence, rather than the overall benefits of treatment. These post-test messages from HCWs were reinforced through information heard in participants' communities. Participants described understanding that delaying treatment was better than starting if they could not guarantee that they would take ART at the same time, daily, for a lifetime. They feared that skipping a dose or stopping for any reason would 'bring a lot of

illnesses with full force', likely causing death more quickly than if they had not initiated.

### ***'I need to think': Preparing for a life-long commitment***

When a HCW recommended ART, some participants explicitly asked to delay immediate start and return after they had time to 'prepare' themselves to commit to a lifetime of treatment. Preparation was considered necessary to avoid defaulting. One female participant 'negotiated' with the HCW for 3 months before starting ART, stating she needed the time to think about a 'lot of things' as starting ART is 'not something easy whereby you just wake up and say let me start this.' Preparation time also involved planning treatment access, and reflection on dealing with potential unintentional status disclosure.

### ***'I don't want people to know my status': Concerns about HIV disclosure***

Worries about inadvertent status disclosure and social consequences of disclosure also discouraged initiation. Participants cited crowded health facilities and the ongoing practice of 'screaming' out ART patient names when it was their turn to see a clinician as threatening disclosure, leading to 'being gossiped about', 'embarrassment', 'shame', and 'depression'. Social relationship dynamics modulated disclosure fears, with emphasis on how family and friends would think of them henceforth. One married participant's fear of being blamed for infecting her husband with HIV led her to seek re-testing as a couple before initiation.

### ***'I was feeling well with my health': Difficulty accepting HIV diagnosis***

Many participants described initial difficulty accepting their HIV diagnosis, and associated fear of HIV and its consequences, delaying ART start. Participants said they tested repeatedly at different clinics to verify results and felt 'lazy' to start treatment if they considered themselves 'healthy'. Having been faithful to a sexual partner compounded difficulties with status acceptance

### ***'How am I going to manage': Concerns about ART consumption***

Concerns about ART, particularly fears of possible side effects and difficulties swallowing large pills delayed initiation. Participant fears were heightened by community narratives about 'big tablets', hallucinations, bad dreams, tumours, and body changes. Contrary to fears before starting ART, multiple participants narrated personal experiences of minimal side effects post-initiation.

## **Discussion**

We identified factors influencing delayed ART initiation among adult, Zambian patients with a history of a gap in HIV care. While adherence remains a key part of the clinical narrative, we found that fear-based messaging from HCWs emphasising the consequences of non-adherence are an important factor in delayed initiation. Our finding highlights the need for clear, positive, and nuanced facility-based communications around ART to assist patients in overcoming feelings

of fear and assist them in taking decisive steps to initiate life-long treatment.

Given patients' need for preparation, targeted improved counselling efforts are likely required to serve the health system goal of rapid initiation. Better counselling may include supporting patients to adjust to initiation of ART then subsequent, follow-ups to support the readiness needed for sustaining ART long-term; options-based messaging such as contingency planning for what to do if a dose is missed (e.g. take immediately, skip until next dose, etc); and/or addressing human resource constraints that limit time and quality of counselling interactions. Improved approaches may also help address how patients' experiences of good health can motivate ART initiation [15,16,31]. Further, community intervention is needed to clarify ART requirements and benefits for patients and their partners [43–45]. Our findings align with other qualitative studies in the region since the 'test and start' era, which identifies the need by some patients for time to emotionally process the diagnosis, come to terms with the new realities of illness and treatment, and weigh the potential social and individual consequences of being on ART [16,28,46–48]. Given extant literature demonstrating an increased risk of loss-to-follow-up after same-day ART initiation (2.5 times the likelihood in one Ugandan study) [49], the identified factors warrant an intentional response to improve rapid initiation [50–53]. Such approaches may include patient-centred approaches [54,55] that offer appropriate follow-up support to retain patients after ART initiation. Outreach and kindness can facilitate patient engagement [56]. Our study reinforces the literature that the social complications associated with disclosure affect myriad HIV-related concerns, including, as shown in our data, delayed initiation of ART [30]. While there have been consistent efforts targeted at couples such as HIV couple counselling and testing [57], there is a need to recognise that HIV initiation is a socially constructed decision [58] with individuals weighing their social situations in decisions to initiate on ART. ART programs can address patients' social circumstances when initiating ART by using patient-centered communication strategies and tools such as differentiated service delivery (DSD) and community-engagement to facilitate more rapid initiation [54,59,60].

## **Study limitations**

This study inductively identified themes from seven patient narratives of HIV care and treatment among previously disengaged patients. While a small sample

size, the use of a narrative approach provided rich, unprompted, information, which reflects participants' lived experiences. However, the study sample had only one male, and the study was limited to the capital city, which is more urban and wealthier than other areas. Therefore, the study may not have identified the full breadth of reasons for the delay for these other categories. Our sample included all willing participants among patients from the probability-based sample of the parent study who returned to HIV care in Lusaka. The proportion recounting delay was consistent with regional estimates of treatment refusal [17,41].

## Conclusion

Health providers in the 'test and start' era must be aware of misperceptions and a "fear narrative" about HIV, its treatment demands, and side effects. It is important then that the facility messaging addresses these fears to reassure patients while giving them comprehensive and accurate information about the benefits and realities of ART. Consistency in reasons for delayed ART initiation across settings warrants a dedicated response to reduce time to initiation. Interventions to appropriately support patients' need for time while building individual judgement and agency of HIV care, social and health system resilience may shorten their time to initiation.

## Ethical approval and consent to participate

This study was approved by the University of Zambia Research Ethics Committee, the Zambian Ministry of Health, and the University of Alabama at Birmingham Institutional Review Board (UAB IRB). The Johns Hopkins University and the University of California at San Francisco had reliance agreements with the UAB IRB. Written informed consent for participating in the study was sought and granted by all the interviewees who agreed to participate in the study. Permission to record interviews was sought from all the study participants

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## Disclosure statement

No potential conflict of interest was reported by the author(s).

## Author contributions

LKB, SMT, EG, CK, IS, JAD supported conceptualisation; LKB, CM, CBM, SS, NM supported data collection; LKB, CM conducted formal analysis; LKB, CM, CBM, SMT, SS, KS, NM, AM, CBH, CK, IS, JAD contributed to data interpretation; LKB, JD, IS, CBH, EG, CBM acquired study funding; LKB, CBM, SMT, KS, AM, EG, CBH, IS were study investigators; LKB, CM, SMT, CK, JAD designed the methodology; SS, KS conducted project administration; LKB wrote the original manuscript draft; All co-authors reviewed and edited the final draft.

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## ORCID

Chanda Mwamba  <http://orcid.org/0000-0002-7626-6273>  
 Laura K. Beres  <http://orcid.org/0000-0002-4731-7828>  
 Stephanie M. Topp  <http://orcid.org/0000-0002-3448-7983>  
 Njekwa Mukamba  <http://orcid.org/0000-0002-5757-6858>  
 Sandra Simbeza  <http://orcid.org/0000-0002-0150-3369>  
 Kombatende Sikombe  <http://orcid.org/0000-0002-8187-8661>  
 Aaloke Mody  <http://orcid.org/0000-0003-3787-365X>  
 Elvin Geng  <http://orcid.org/0000-0002-0825-1424>  
 Charles B. Holmes  <http://orcid.org/0000-0002-7924-6761>  
 Caitlin E. Kennedy  <http://orcid.org/0000-0001-6820-063X>  
 Izukanji Sikazwe  <http://orcid.org/0000-0002-3898-2607>  
 Julie A. Denison  <http://orcid.org/0000-0002-4670-093X>  
 Carolyn Bolton Moore  <http://orcid.org/0000-0001-9103-7746>

## Data availability statement

'Human subjects' protection approval for this study was given on condition that the confidentiality of all respondents would be upheld. Therefore, sharing direct interview transcripts which include locations and personal information may identify respondents which would be inappropriate.

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