

# Barriers and Facilitators to Antiretroviral Therapy in Northern Tanzania in the Era of Test and Treat

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## Research Article

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# Abstract

**Background** Tanzania adopted WHO's universal test and treat policy in 2016, recommending antiretroviral therapy (ART) for all people living with HIV (PLHIV). However, many individuals continue to confront challenges initiating or continuing ART. The study aims to understand how barriers and facilitators to ART have evolved since Test and Treat policy in Tanzania.

Between March and June 2018, 25 semi-structured in-depth interviews were conducted among PLHIV who were out of care, including PLHIV who never initiated ART and PLHIV who were formerly in care and discontinued ART. Participants were 18-years-old or older, identified from clinic databases at three health facilities and through home-based care providers. Data were coded and interpreted using content analysis and the socio-ecological framework.

**Results** Low HIV literacy, poor quality of health messaging and comprehension, stigma, structural factors, and poverty were identified as main barriers to care. HIV literacy appeared higher among those formerly in care and some misconceptions about ART differed whether or not participants had previously initiated treatment. Participants expressed desire for more information about their health and treatment, including more engagement with their healthcare providers.

**Conclusions** Our results are consistent with the barriers and facilitators to care reported prior to the implementation of the Test and Treat policy. Despite universal access to care, limited progress has been made in addressing the underlying challenges that PLHIV confront in initiating and continuing ART. Efforts such as increase in HIV literacy, improve health messaging, and strengthen healthcare provider-to-patient communication will facilitate access to care. The policy implication of these findings is that the landscape for barriers to ART has not changed drastically, efforts towards engagement to care need to be further refined and tailored to facilitate access to care.

## Introduction

Sub-Saharan Africa (SSA) is home to ~26 million people living with HIV (PLHIV) and accounts for almost two-thirds of new cases worldwide (UNAIDS 2019). Yet, access and adherence to antiretroviral therapy (ART) remains a challenge. Current estimates show only 67% of PLHIV in the East and South African regions are on ART (UNAIDS 2019). In 2013, the World Health Organization adopted "universal test and treat (UTT) or Test and Treat", recommending ART for all PLHIV regardless of their disease stage (UNAIDS, 2014). Test and Treat was adopted by the Tanzanian government in 2016 and represented a major shift in treatment recommendations (Bigna, Plottel & Koulla-Shiro 2016). Prior to this policy, PLHIV in Tanzania initiated ART based on specific clinical thresholds (i.e. CD4 count < 350 cells/mm<sup>3</sup>) - now considered below national and international guidelines (Lahuerta et al. 2013).

Previous studies have highlighted various barriers and facilitators to accessing ART among PLHIV in SSA, spanning several socio-ecological environments (Castro et al. 2015; MacPherson et al. 2014; Roura et al. 2009; Wachira et al. 2014). These barriers include demographic characteristics (male, youth and

adolescents), treatment-related concerns (fear of negative side effects), social environment (stigma, fear of disclosure), health systems (poor treatment from healthcare providers and clinic experiences), and poverty (Connelly 2011; Govindasamy et al. 2014; Wachira et al. 2014). Interventions targeting these barriers have used a variety of approaches to facilitate access and engagement in care such as home-based care provider (HBCs) engagement, mobile technologies, peer and family support, point-of-care testing, and the use of incentives (Franke et al. 2013; Govindasamy et al. 2014; Hayes et al. 2017; McCoy et al. 2015; Reddy et al. 2016). Yet, motivating PLHIV to initiate or continue ART remains a persistent challenge as evidenced by the high prevalence of HIV/AIDS in SSA, 9% (UNAIDS, 2019).

Despite robust literature pre-Test and Treat, there is limited understanding of how facilitators and barriers have evolved. Most studies on linkage to care after Test and Treat have focused on newly-diagnosed individuals (Kayabu, Ngocho & Mmbaga 2018; Kelly et al. 2019; Mwangome et al. 2017). However, identifying barriers and facilitators among key subgroups of PLHIV including those never in care and those previously in treatment but have since discontinued care (herein referred to as formerly in care), is critical to understanding challenges confronted when accessing treatment in today's environment. Thus, this study describes the barriers and facilitators to ART and factors that influence treatment decision-making among out of care PLHIV to inform current practices/interventions to increase ART access post-Test and Treat.

## **Methods**

### **Study Population and Recruitment**

Participants were identified through clinic databases of three health facilities (regional hospital, district hospital, and health center) and through HBC outreach activities in Northern Tanzania. Individuals 18 years or older, living with HIV infection, and designated as out of care between January 2016 and May 2018, were eligible to participate. Out of care was defined as PLHIV who never initiated ART or were formerly in care (defined as two weeks since a missed scheduled HIV clinic visit or 90 days since last scheduled clinic visit).

### **Study design**

This qualitative assessment was nested within a larger quantitative study (n = 75) that investigated the effectiveness of HBCs in identifying out of care PLHIV and successful linkage to ART. Included as part of the initial quantitative study was an assessment of participant's HIV health literacy, knowledge of HIV transmission, and how to stay healthy. After the quantitative survey was completed, HBCs counseled participants to return to care and then invited a subset (n = 30) to participate in in-depth interviews. These interviews were scheduled one month after the quantitative survey to allow time for participants to seek care, if they so desired.

### **Theoretical Framework**

Grounded in the socio-ecological framework (Wachira et al. 2014), we assessed barriers and facilitators to care via key domains including individual (e.g., care-seeking behaviors), intrapersonal (e.g., knowledge, attitudes), interpersonal (e.g., social networks, support), and institutional or government policies (e.g., health facility guidelines, national policies) (Baral et al. 2013; Kaufman et al. 2014).

## Data Collection

A semi-structured interview guide, designed in alignment with the research question and socioecological framework domains, contained open-ended prompts to probe for detailed feedback while allowing the interviewer flexibility. Two local team members (AM, KH), trained in qualitative data collection, completed the interviews; it took ~ 1.5 hours. The audio-recorded interviews were transcribed and translated from Swahili into English. Five thousand Tanzanian shillings (~\$2) was provided to participants as compensation for their time.

## Data Analysis

The codebook was created *a priori* based on the socio-ecological domains. Content analysis was conducted for each transcript and a list of codes was finalized by two researchers (OM and PN). Transcripts were then coded using NVIVO 12®, qualitative analytical software. Two researchers analyzed the transcripts (OM and RH); one coded all the transcripts while a second coder randomly selected transcripts (50%) to ensure inter-rater reliability (Kappa coefficient = 98%). Similarities and discrepancies observed during the coding process were discussed and additional codes were added as needed. The US and Tanzania research teams discussed main themes and sub-themes identified during the coding process for additional context and validation of findings. Where possible, we explored whether the barriers and facilitators differed by PLHIV subgroups such as those never in care versus those formerly in care (hereafter “PLHIV groups”).

The study was approved by the National Health Research Ethics Sub-Committee, National Institute for Medical Research (NIMR), Tanzania and the Committee for Protection of Human Subjects (CPHS) at University of California, Berkeley.

## Results

Of the 30 invited from the larger quantitative study, 83% consented and completed interviews (60% - never in care and 40% - formerly in care). Fifty-two percent of respondents were female, 48% were male, with a median age of 34 years. All study participants completed primary education. Only 25% had re-engaged in care by the time of the interview. See Table 1 below

Table 1  
Demographic characteristics

<b>TOTAL</b>	<b>25 (100%)</b>
<b>PLHIV GROUP AT ENROLLMENT</b>	
<b>NEVER IN CARE</b>	<b>15 (60%)</b>
<b>FORMERLY IN CARE</b>	<b>10 (40%)</b>
<b>SEX</b>	
<b>MALE</b>	<b>12 (48%)</b>
<b>FEMALE</b>	<b>13 (52%)</b>
<b>AGE</b>	
<b>MEDIAN AGE (YEARS)</b>	<b>34</b>
<b>COMPLETED PRIMARY SCHOOL</b>	<b>25 (100%)</b>

We identified several barriers and facilitators to care post-Test and Treat: 1) low HIV literacy, 2) limited comprehension and quality of health messaging, 3) stigma, 4) awareness of Test and Treat, and 5) structural barriers.

## Individual factors: Low HIV Literacy

### Participant’s knowledge of HIV diagnosis and ART medication regimen

When participants were asked to discuss their HIV diagnosis or past treatment, their responses reflected low levels of HIV literacy. Comments and discussion about their diagnosis was limited; for example, most were unaware of the effects of the virus on their bodies or the importance of initiating or remaining in care. Participants who were formerly in care discussed how clinic health seminars, typically comprised of a 3-day mandatory counselling session conducted prior to ART initiation or re-initiation, were a useful source of information on their HIV health. However, knowledge was generally limited to medication pick-up and reasons for ART use (e.g., to slow down the virus). Others shared dated or misinformed messages quoted from health seminars.

To provide additional context on HIV health literacy among this group of participants, we triangulated the qualitative interviews to their responses to literacy questions conducted as part of the quantitative assessment - when asked about HIV progression, CD4 count and viral load; less than 30% of qualitative study participants reported being familiar with these terms. Furthermore, when asked about HIV

transmission via public toilets, needle sharing, kissing, etc., the majority of participants (~ 60%) could not accurately identify how HIV could be transmitted, independent of PLHIV group.

Among those never in care, a prevailing misconception was – it is better not to initiate ART than to initiate and then discontinue use. This was a slight distinction in health literacy between those never in care and those formerly in care. Those never in care, some expressed lack of readiness to seek care based on health seminar messaging, where they learned the importance of remaining in care and not starting and subsequently stopping ART. Furthermore, some mentioned not initiating treatment because of their “good” current state of health, failing to understand medication is needed in spite of “good health.”

It remains unclear how some of this messaging is delivered at the health seminars or received the communities from other PLHIV. These types of misinformation may serve as a barrier to whether or not PLHIV initiate ART or how quickly treatment is sought. Notwithstanding limited knowledge, participants expressed wanting to learn more about HIV, particularly about their care, side effects, and treatment management.

## **Interpersonal factors: Limited comprehension and quality of health messaging**

### **Communication between healthcare providers and patients and health messaging**

When asked about interactions with healthcare providers, those formerly in care or had initiated care expressed that there was limited discourse with their providers. The majority of participants reported that they generally did not share HIV-related questions with their providers; nonetheless, participants asked several HIV-related questions to the interviewers, suggesting that they sought information not previously received or unsatisfied with the information provided during their health visits.

When communication with healthcare providers occurred, miscommunication or misinformation were reported. Some participants believed that food was required to take their medication. Therefore, in cases of food insecurity, participants opted not to take their medication as they believed the absence of food was contraindicated for medications. Responses suggested that these misconceptions were often learned through community members and were not discussed with their healthcare providers.

## **Perceived Stigma**

When discussing ART initiation or re-initiation in care, those formerly in care reported feeling shame when they visited the clinic or when HBCs visited their homes. Thus, to avoid seeing people they knew, a few participants mentioned making concerted efforts to visit the clinic at odd hours or travelled to clinics farther away when they were in care.

## **(socio-)Structural Factors**

# Awareness of National Test & Treat policy

When asked about the national Test and Treat policy, most participants expressed not knowing the government initiative by name but some reported knowing about their eligibility to initiate ART. Participants also reported hearing about the change in treatment guidelines through radio messaging, healthcare providers, health seminars, family, friends, or through outreach activities by other NGOs, suggesting that the core messaging of the initiative was reaching PLHIV.

In some cases, participants who knew of Test and Treat before getting diagnosed were motivated to get tested and sometimes initiated treatment, suggesting that Test and Treat messaging may facilitate initiation of care for some, despite being out of care at the time of the interview.

## Health facility concerns

Those formerly in care discussed how health facility-related barriers such as long distances to the clinic, long wait times, overcrowding at the clinic, and occasional ART stock-outs influenced their decision to discontinue care. Most emphasized that clinic visits often required spending all day at the clinic and noted they prioritized work or other responsibilities over treatment.

## Socioeconomic barriers to care

Most participants discussed limited financial means and resources as a barrier to ART engagement. Despite ART being free of charge for all under Test and Treat, participants reported needing money for other key necessities such as food, transportation, and other basic needs, which impeded their ability to access care. Others expressed forgoing clinic visits in search of paid work.

## Discussion

Despite WHO's UTT, uptake and awareness of treatment guidelines across the various regions of Tanzania has been differential. This qualitative study revealed key barriers and facilitators to HIV care post-UTT in Northern Tanzania - individual factors including low health literacy, misinterpretation of health messages; interpersonal factors including perceived stigma and poor communication with healthcare providers, as well as structural factors such as poverty, facility-related barriers, and unawareness of the government-led UTT policy.

Despite one-on-one HBC counseling, plus mandatory health seminars for new ART initiates and individuals re-engaging in care, there were still major gaps in knowledge. Besides knowing their HIV status and the need for treatment, participants had limited ability to describe either diagnosis or treatment. Studies have shown that higher health literacy is associated with higher retention in care and viral suppression (Kalichman & Rompa 2000; Wawrzyniak et al. 2013). Health literacy seemed to vary by whether participants were never in care or formerly in care. It is plausible that those who previously come in contact with the healthcare system are more knowledgeable about their health than those with limited contact; however, how health literacy in this study participants compare to other PLHIV currently in care was not

explored. Nevertheless, all participants consistently reported wanting more information about their health/treatment to increase their HIV health literacy.

Furthermore, misinformation about HIV diagnosis and treatment was prevalent; mostly received through various sources including, friends, family, HBCs, and pre-ART health seminar classes. For example, those never in care expressed it was better not to initiate treatment than to initiate and then discontinue care – a message received from the mandatory health seminar. This may be due to misunderstanding health messages or an unintended consequence of strict adherence messaging. Although some described health seminars as a valuable health source, it remains unclear if participants misunderstood the information or if misinformation occurred due to health staff's low literacy. Similar findings were reported in a study conducted in Iringa, southern Tanzania, which assessed community HIV/AIDS knowledge and health communication. Understanding HIV/AIDS messaging varied significantly among participants with different levels of education and marital status (Rumisha et al. 2005). Even among those with high comprehension, poor application of HIV/AIDS messages, which could be attributed to culture, illiteracy, and/or poverty, was observed.

We found that the quality of participant-to-healthcare provider interactions were limited and participants expressed a desire to this strengthen communication. Most felt unable or prepared to seek additional information about their health or treatment regimen. Further efforts should assess how to improve healthcare provider engagement with patients to ensure dissemination of clear and accurate health information. Our findings highlight the potential for HBCs to serve a key role in bridging the communication gap between PLHIV and health facility providers. In SSA and other resource-limited settings, there has been limited research conducted on health dissemination messaging and strategies; some publications have targeted the role of internet in health dissemination and access (Edejer 2000; Shiekh 2014), or health information systems (Mutale et al. 2013), with few focused on patient comprehension. A recent systematic review by Schipper and colleagues (2015) assessed dissemination strategies to educate patients about their health and found that consistent patient involvement was critical, including a plan that involved healthcare providers early in the process. Although not comprised of studies in SSA, they showed that early patient engagement was important and systemic dissemination plans involving patients and healthcare providers were instrumental in effective communication.

In this study, we observed that despite government's efforts, PLHIV had limited awareness of the Test and Treat policy in name. There have been widespread efforts to provide ART to all PLHIV in Tanzania; however, gaps in disseminating this national program remains, particularly for individuals in the rural areas who often have limited access to information and experience high levels of poverty. Those with access to information reported that health information campaigns, HBCs, and radio announcements were helpful in delivering information on the current recommendations for treatment. These modes of communication are common across SSA (Rumisha et al. 2005) and these findings suggest their potential to provide targeted health messaging and outreach to PLHIV who may not be in care or at risk for discontinuing care. This study highlights the need to adapt modes of communication to reach targeted populations that may not have access to health messages delivered through popular channels.

It is important to note that these barriers revealed in this study have long been reported among PLHIV in SSA and in spite of Test and Treat. We observed that socio-structural factors such as poverty – limited access to money for food, transportation, and other basic needs further contribute to individuals not initiating or continuing in care despite universal access to ART. Distance to the clinic and long wait times at the clinics were also reported as barriers to care. These socioeconomic and structural barriers to ART observed in this study suggest that access for the most vulnerable PLHIV hinges on addressing socioeconomic barriers to care. These findings are supported by the extensive body of research in SSA on barriers to care (Connelly 2011; Geng et al. 2010; Ma et al. 2016; Roura et al. 2009) and emerging studies on the use of incentives which have showed some success in encouraging PLHIV to engage in ART (Bassett et al. 2015; McCoy et al. 2017). For example, a study by McCoy (2015) in the same region of Tanzania as the current study, found that short term cash and food assistance improved ART possession, appointment attendance, and reduced loss to follow up.

This study is one of the few studies that explored barriers and facilitators to care in Northern Tanzania post-Test and Treat implementation. The ability to triangulate qualitative results on health literacy with the quantitative assessment allowed for a more robust assessment. Notably, this study elicited perspectives from two key groups of PLHIV – PLHIV never in care and those formerly in care. However, exploring some of these questions among individuals that were in care may have allowed for key comparisons and added to the understanding of how this group differs from those who are in care. Additionally, although our assessment covered all constructs within the socio-ecological framework, we focused on resounding themes within each constructs as emphasized by the participants instead of highlighting all the barriers within each categories, as previously done in other studies.

## Conclusion

Our study suggests that barriers and facilitators to care have remained relatively unchanged since the implementation of Test and Treat in Tanzania. Our results underscore the importance of health literacy and messaging for PLHIV, specifically the need to focus efforts on improving patient understanding of diagnosis and treatment to subsequently influence ART initiation and retention. Our findings also highlight the need to strengthen healthcare provider-patient communication to improve engagement in care.

## Declarations

**Ethics approval:** The study was approved by the National Health Research Ethics Sub-Committee, National Institute for Medical Research (NIMR), Tanzania and the Committee for Protection of Human Subjects (CPHS) at University of California, Berkeley.

**Consent to participate:** Informed consent was obtained from all subjects. All research methods were carried out in accordance with the National Health Research Ethics Sub-Committee, National Institute for Medical Research (NIMR), Tanzania and the Committee for Protection of Human Subjects (CPHS) at University of California, Berkeley.

**Consent for publication:** Not applicable

## **Availability of data and materials**

The datasets analyzed in this study are available from the corresponding author on reasonable request.

**Competing interests:** All authors declared that they have no competing interest

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## **Authors' Contributions**

Contributions to conception and design – OM, SM, PN

Acquisition of data, or analysis – OM, RH, AM, KH, PN

Interpretation of data - OM, RH, AM, KH, PN, SM

Drafting the paper or revising it critically for important intellectual content: OM, RH, AM, KH, PN, SM

Final approval of the version to be published: OM, RH, AM, KH, PN, SM

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