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## Barriers and facilitators to linkage to care and ART initiation in the setting of high ART coverage in Botswana

Poloko Kebaabetswe<sup>a</sup>, Kutlo Manyake<sup>a</sup>, Etienne Kadima<sup>a</sup>, Chloe Auletta-Young<sup>b</sup>, Unoda Chakalisa<sup>a</sup>, Tumulano Sekoto<sup>a</sup>, Oarabile Makgabana Dintwa<sup>a,1</sup>, Mompoti Mmalane<sup>a</sup>, Joseph Makhema<sup>a</sup>, Refeletswe Lebelonyane<sup>c</sup>, Pamela Bachanas<sup>d</sup>, Rebeca Plank<sup>b,e,2</sup>, Tendani Gaolathe<sup>a</sup>, Shahin Lockman<sup>a,b,e</sup>, Molly Pretorius Holme<sup>b</sup>

<sup>a</sup>Botswana Harvard AIDS Institute Partnership, Gaborone, Botswana;

<sup>b</sup>Harvard. T.H. Chan School of Public Health, Boston, MA, USA;

<sup>c</sup>Botswana Ministry of Health and Wellness, Gaborone, Botswana;

<sup>d</sup>Centers for Disease Control and Prevention, Atlanta, GA, USA;

<sup>e</sup>Brigham and Women's Hospital, Boston, MA, USA

### Abstract

We conducted a qualitative study using focus groups and in-depth interviews to explore barriers to and facilitators of linkage-to-care and antiretroviral treatment (ART) initiation in Botswana. Participants were selected from communities receiving interventions through the Ya Tsie Study. Fifteen healthcare providers and 49 HIV-positive individuals participated. HIV-positive participants identified barriers including stigma, discrimination and overcrowded clinics, and negative staff attitudes; personal factors, such as a lack of acceptance of HIV status, non-disclosure, and gender differences; lack of social/family support, and certain religious beliefs. Healthcare providers cited delayed test results, poverty, and transport difficulties as additional barriers. Major facilitators were support from healthcare providers, including home visits, social support, and knowing the benefits of ART. Participants were highly supportive of universal ART as a personal health measure. Our results highlighted a persistent structural health facility barrier: HIV-positive patients expressed strong discontent with HIV care/treatment being delivered differently than routine healthcare, feeling inconvenienced and stigmatized by separately designated locations and days of service. This barrier was particularly problematic for highly mobile persons. Addressing this structural barrier, which persists even in the context of high ART uptake, could bring gains in willingness to initiate ART and improved adherence in Botswana and elsewhere.

**Corresponding author:** Molly Pretorius Holme, Harvard T.H. Chan School of Public Health, FXB 406a, 651 Huntington Avenue, Boston, MA 02115; Phone: 617-432-4377; mpretori@hsph.harvard.edu.

<sup>1</sup>African Comprehensive HIV/AIDS Partnerships, Gaborone, Botswana;

<sup>2</sup>Merck Pharmaceuticals, Boston, MA, USA

Declaration of Interest Statement

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## Keywords

barriers; facilitators; linkage to HIV care; antiretroviral initiation; Botswana

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## Introduction

Rapidly scaling up universal antiretroviral therapy (ART) and increasing prevention strategies is projected to avert 21 million AIDS-related deaths and 28 million new infections by 2030 (UNAIDS, 2014). Swift ART initiation after a positive HIV test is central to reaping the benefits of universal ART for preventing transmission. Botswana is a southern African country with high HIV prevalence (23% of adults age 15–49; 27% in women, 18% in men (UNAIDS, 2017)). With a historically large HIV burden, Botswana became the first African country to provide free HIV treatment in 2002, and has since made remarkable progress identifying and treating HIV, with more than 70% of HIV-positive people on ART (Gaolathe et al., 2016; UNAIDS, 2017). In 2016 Botswana expanded ART eligibility to all HIV-positive individuals regardless of CD4 count/disease stage.

Despite successful ART rollout, many countries have not yet achieved similarly high coverage, and there is uncertainty even in high-coverage programs whether the remaining untreated persons living with HIV will accept ART under a universal treatment paradigm. Several barriers to linkage-to-care and subsequent ART initiation have been described in sub-Saharan Africa (Govindasamy, Ford, & Kranzer, 2012), commonly related to logistical obstacles, stigma, fear of disclosure, or drug side-effects.

Offering fast-track initiation of universal ART will eliminate many structural problems associated with attrition while awaiting ART eligibility assessment. A critical next step is to understand and address persistent barriers in the context of expanded ART availability, and to identify any unique barriers that may disproportionately affect subpopulations with lower ART initiation rates, such as young adults and men (Bachanas, 2018; Muula et al., 2007; Novitsky et al., 2018). Understanding the remaining barriers to and facilitators of ART initiation in the context of existing high ART coverage in Botswana will inform improvements to evolving programs elsewhere. We therefore conducted a qualitative study to explore locally relevant barriers and facilitators for linkage-to-care and ART initiation from both HIV-positive patients' and healthcare providers' perspectives.

## Methods

From June–December 2016, HIV-positive participants in “Ya Tsie” (also known as the Botswana Combination Prevention Project) and associated healthcare providers were invited to participate in an in-depth qualitative study of barriers to and facilitators of linkage-to-care and ART initiation. Ya Tsie is a 30-community randomized trial evaluating the impact of interventions including household-based and mobile HIV testing/counseling, linkage-to-care services, and expanded ART on HIV incidence (NCT01965470) (Gaolathe, et al., 2016; Perriat et al., 2018). We used individual in-depth interviews (IDIs) and focus group discussions (FGDs) and the phenomenological paradigm to identify factors that facilitate or hinder linkage-to-care and ART initiation.

## Participant recruitment

Ya Tsie household-survey enrollees were eligible for interview or a focus group if they were: resident of a study community randomized to the intervention; age 18–64; HIV-positive; Botswana citizen; eligible for ART but not yet treated at the time of enrollment to the Ya Tsie cohort; providing informed consent.

Inclusion criteria for staff participants were being a Ya Tsie staff member/nurse prescriber in an intervention-community clinic; age 18 years; and providing informed consent.

A purposeful sampling method was used to select eligible participants from the Southern and Central regions of Botswana. HIV-positive participants were recruited at or after an annual revisit to their household, to assess if those referred to care at enrollment had actually linked or started ART approximately 1 year later. We included as many not-linked/not-initiated participants as were eligible to obtain information from this subgroup of interest. We recruited linked/initiated participants until we had sufficient numbers for the focus groups, regardless of sex or age.

## Data collection and analysis

An investigator with behavioral research expertise (PK) trained research assistants to conduct IDIs and FGDs.

IDIs lasted ~45 minutes; FGDs on-average lasted an hour. Data collection was done in Setswana using structured guides, and audio-recorded. Discussion topics included factors influencing ART-start and optimal timing, social norms, disclosure, self-efficacy, health attitudes, Ya Tsie's impact, and ideas about reaching men and youth. Data collection continued until thematic saturation.

Two independent investigators cleaned, transcribed and analyzed the data. Transcripts were verified for accuracy prior to analyses. Data were coded using Atlas.TI version 7 software (Cleverbridge, Inc. Chicago IL) to identify and categorize common themes with an inductive approach.

## Ethical considerations

All participants provided written informed consent. FGD participants signed a confidentiality agreement. IRBs at the U.S. Centers for Disease Control and Prevention and the Botswana Ministry of Health approved the study.

## Results

Forty participants were invited to participate in an IDI. Thirty-four, (85%) agreed, 28 who reported initiating ART and 6 who had not linked-to-care approximately one year after referral (Table 1). The main reasons for declining were lack of time or interest.

Four FGDs were conducted, two for participants who had initiated ART, and two for healthcare providers, each involving 7–8 participants. The number of not-linked participants was insufficient for a FGD.

### Barriers identified by HIV-positive participants

HIV-positive participants identified several factors impacting whether they seek care and initiate treatment. These factors comprised three main categories including clinic-related, personal, and social/community-level barriers.

Participants noted stigma and discrimination, overcrowding at clinics, and negative staff attitudes as clinic-based barriers. For example, participants raised concerns that the current HIV care structure fuels stigma and perceived discrimination. HIV-positive patients often receive care and prescriptions at separate infectious disease care centers (IDCCs), or at different locations and/or specific times, within regular clinics. Linked FGD participants pointed out:

“... People would not want to go to where it is written ‘IDCC’ because once people see you going there, people would know that you are living with HIV and that may make other people decide to stay at home.”

“When medications are not obtained from a central place... Most people feel they are discriminated from the clinic as we are separated....”

All participants mentioned problems with lack of flexibility for medication refills, specifically that they should refill at the location of initial registration, and only on certain days/times. They complained that collecting medication only at their original clinic was expensive and inconvenient. They suggested that ARV’s like other medications should be collected at any health facility any time.

“For example if I took them in Francistown where I registered, I should be able to take the next supply anywhere I have moved to rather than being forced to travel to Francistown. It is expensive and employers get to know we are on treatment by seeking permission to go back where one started.”

Linked FGD participant

“I travel around, that’s what prevents me to start... I could get services if I stayed in Lerala.”

Not initiated IDI participant

“Patients should go every day to access services, not a case whereby you only have to come on Wednesdays or Mondays.”

Not initiated IDI participant

Participants were also concerned about unwelcoming behavior in clinics, adding that overcrowding worsened matters.

“Deal with nurses’ attitudes towards clients. They are rude. In Gaborone they refused to give tablets as I was initiated in Lentsweletau - I had taken my last pill and I reached Lentsweletau clinic around 2pm - the nurses were angry with me and I refused to go back, eventually they gave me and told me I should never come in the afternoon.”

Linked FGD participant

“There is always overcrowding in the clinic because there are different days for refill and a different day for doctors.”

Linked FGD participant

HIV-positive participants identified personal factors, such as lack of acceptance of HIV status, relationship problems, and non-disclosure as potential barriers to linkage and treatment-initiation. They also mentioned that women had more problems accepting their HIV status than men.

“Non-acceptance, people need a lot of counseling to accept status, to disclose and go to clinics. Failure to disclose one’s status was a problem because one would hide or throw away the medicine for fear of being seen by a partner and this could be worse if partner’s results are different.”

Linked FGD participant

“If the woman tests positive while their husband is negative this may make women fear to take ARVs.”

Linked FGD participant

Although participants acknowledged that men are reluctant to use health services generally, women tended to fear stigma more, preferring to attend clinics outside their communities.

“I think it is more women than men who have not accepted their status; women prefer not to take treatment from their local clinics.”

Linked FGD participant

“I will want to take them [ARVs] from a different clinic and not the one that is near me. I will be afraid of going to the clinic because I will know that a lot of people may know me and they are going to see me there.”

Not initiated female IDI participant

In contrast, linked male IDI participants expressed a strong preference for using local clinics for convenience, and were not concerned about stigma.

“The reason I choose the one in my village is because I stay in that village... I can get services faster here, rather than having to go a long distance.”

“I’ve made a decision to take ARVs whether someone sees me or not, I don’t hide. I just go and get what I’m supposed to take.”

Participants highlighted that lack of social/family support, or religious beliefs could pose significant barriers. All agreed that HIV-positive patients lacking social support may be reluctant to start ART.

Linked FGD participants worried that certain churches discourage ART.

“... We are deceived by different religious beliefs like some churches do not allow people to go to hospital”.

### Barriers as perceived by healthcare providers

Healthcare providers identified similar factors influencing ART-start, including: lack of acceptance of HIV-status, delayed laboratory results, fear of discrimination, certain religious beliefs, and poverty. Healthcare providers also noted that patients complained of transport difficulties, shortage of physicians, and overcrowding related to staffing shortages. Importantly, providers noted that some patients object to collecting HIV tablets separately from other medications, or receiving HIV care in a separate location/time from routine care due to fear of stigma.

The Botswana HIV program strongly encourages patients to involve a *Mopati* (adherence partner) in their care, including ART initiation. Some providers felt a *Mopati* was necessary and ideally a sexual partner, while the majority felt requiring an adherence partner was unnecessary, for example observing:

“Adherence partner can be a drawback as it increases dependency.”

Healthcare providers also observed that female youth tended to use clinics outside their communities more than males, not wanting to be seen by relatives.

Traditional beliefs were mentioned as barriers, with patients consulting traditional healers who advised them against ART:

“Other people believe in traditional doctors, they give them enemas. This delays some people to seek medical care and they will eventually be taken when they have no choice, not willingly but being taken because they are severely ill.”

### Facilitators of ART initiation

Major facilitators of ART initiation were support from healthcare providers, including home visits, social support, and knowing the benefits of ART.

Linked participants endorsed a good staff-client relationship as an important motivator to take ART.

“Manyana clinic, you won’t take close to an hour while queuing for the doctor or for pills, they treat you respectfully and give you a smile, even when they have challenges they will tell you and politely ask you to wait.”

Linked FGD participant

Linked participants indicated that they were supported by family and friends and were thus motivated to take ART.

Participants mentioned several benefits of ART (such as viral suppression, increasing CD4-count, protecting an unborn baby, better health and quality of life) as important ART facilitators.

“I have experienced the benefits first hand - I looked like a puff adder, I even feared going in public as I had some swelling, today, I am confident and healthy when I am seated next to someone HIV negative...”

Linked FGD participant

Participants also highlighted that home visits provided by Ya Tsie counselors, which occurred for cohort follow-up, and for linkage-to-care efforts, motivated people to start ART—men, in particular.

“I find it important to have these people check on me.” Linked male IDI participant

Participants repeatedly suggested that men might be more widely reached for HIV services if these could be delivered in their occupational or social gathering places, such as cattle posts or football grounds.

### **Attitudes toward optimal timing of ART initiation, and universal ART**

Both HIV-positive individuals and healthcare providers felt that ART should be started early, when a person was still well and had accepted their status after counseling. Healthcare workers differed in opinion on universal ART. Some foresaw benefits of reducing opportunistic infections, normalizing ART, and reducing stigma. Others were concerned about drug resistance, or overburdening facilities.

“Resources are low; there are few staff to meet the high demand. The Government should strengthen health facilities first before roll-out because shortage of staff can affect quality.”

However linked participants supported early ART initiation.

“When someone is found to be HIV positive, whether healthy or not healthy, they should start immediately. “

Linked FGD participant

Even those who were unaware of the availability of universal ART felt that waiting for CD4-decline and becoming weak, or appearing ill to others, should be avoided by starting ART early.

“When you take your cattle for grazing, you take them before they lose the flesh because if you take them already weak, when they get there they eat the grass and drink water and they don’t make it. So even for a human being, when she/he is very weak, even if you try to revive them it will not help”

Linked IDI participant

## **Discussion**

Our study was conducted in a setting that likely foreshadows future conditions in other sub-Saharan African countries: Botswana has high HIV prevalence and a mature treatment program with very high existing ART coverage, and moved to offering universal ART in 2016. Participants in this context identified many of the same barriers to linkage-to-care and ART initiation that have been described in prior studies in sub-Saharan Africa and some of the same facilitators of engaging in care. In addition, participants were very supportive of starting ART shortly after HIV diagnosis, rather than waiting for CD4-decline.

The most prominent barriers to linkage and ART expressed by our participants were stigma and inconvenience associated with the current (generally segregated) clinic model of HIV



care, as well as time and cost associated with clinic visits. Other studies have reported conflict between the reality of patients' daily lives and the mechanisms in which they receive HIV services (Alamo et al., 2012; Topp et al., 2018). Prior studies have also revealed transport costs, travel distance, stigma and fear of disclosure, clinical staff shortages, long waits, and lost work as barriers to HIV care (Govindasamy, et al., 2012; Tso et al., 2016). In our study, participants suggested that daily ARV dispensing, allowing refills at different locations, and providing larger antiretroviral supplies (3–6 months) would reduce their number of clinic visits, improve adherence, and alleviate overcrowding and queues. In a separate analysis, we found mobile individuals more likely to be viremic (Mmalane et al., 2018), further suggesting that flexibility in location of care and medication refills along with education about transferring care when needed may be an important unmet need in places where mobility is common for economic and agricultural reasons. Complaints about staff attitudes were often related to overburdened clinics. Integrating HIV care with routine care was recommended to mitigate stigma and encourage patients, especially women and youth, to use facilities in their own communities.

Participants expressed concern that some popular religious leaders discouraged treatment. Studies from Namibia and Cameroon have described interference with ART by some Pentecostal churches (Pefura-Yone, Soh, Kengne, Balkissou, & Kuaban, 2013; Seeling, Mavhunga, Thomas, Adelberger, & Ulrichs, 2014). These concerns seem to pertain to specific churches or church-leaders, however (rather than with religion overall). In a separate analysis in the Ya Tsie household cohort, we found having any religious affiliation was associated with increased uptake of HIV testing, treatment and viral suppression (Mmalane et al., 2017).

Participants identified disclosure of HIV status to family and friends for social and practical support as an important facilitator, and generally appreciated the home-based testing offered by Ya Tsie. Other studies conducted in the region have identified many of these facilitators (Govindasamy, et al., 2012) including disclosure (Govindasamy et al., 2011; Medley et al., 2013), knowing a friend/family member receives HIV care (Medley, et al., 2013), social support (Kelly, et al., 2014; MacPherson et al., 2012), and home-based counseling/testing (Knight, Van Rooyen, Humphries, Barnabas, & Celum, 2015). Our participants also suggested that community-based outreach could be particularly effective among men. Indeed various approaches to community-based HIV testing interventions have successfully increased linkage-to-care among men (Sharma, Barnabas, & Celum, 2017), and may improve coverage in Botswana and similar settings.

A unique aspect of our study was the ability to assess attitudes toward universal ART, as it was being rolled out in Botswana. It was uncertain whether HIV-positive people with higher CD4 counts and feeling well would start ART at the same rates as those with low CD4 counts/illness. While few knew about universal ART for transmission-prevention, it was highly supported by HIV-positive participants in our study for health reasons, similar to findings from another study in South Africa (Bond et al., 2016). However, both patients and providers expressed some concern about burdening clinics and drug supply. Educating the public about Botswana's pre-existing high coverage and the small proportional increase in ART-use prompted by universal ART may provide reassurance.



A limitation of our study was that we interviewed few people who had not initiated ART (due to high ART uptake), making it difficult to identify barriers unique to this group. While we recorded observations and experiences of barriers faced by some men and youth, small numbers prevented subgroup analyses to directly evaluate contributors to their disproportionate ART coverage levels. Universal ART launched simultaneously with this study, so we could not examine implementation or the fast-track component. In addition, results from a small qualitative study may not be generalizable to other populations.

Our results highlight the need to address structural barriers at health facilities. HIV-positive patients (whether on ART or not) repeatedly expressed strong discontent with receiving HIV care and treatment outside of routine healthcare, feeling inconvenienced and stigmatized by the separately designated locations and days of service for HIV. Addressing this barrier could bring gains in willingness to initiate ART and improved adherence. Our study also suggested that the main barriers to ART initiation are the same, whether treatment is offered in a universal or CD4-driven manner—namely health systems or stigma/confidentiality concerns. We learned that these remain the primary concerns, even in this setting with excellent ART indicators. The challenges voiced by our study participants, most of whom were successfully linked to care and on ART, support the need for more patient-centered approaches to HIV service delivery to reach the untreated, especially as universal ART is taken to scale.

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**Table 1.**

Summary of study participants

Method	Participant Group	Gender	Age range (years)	Knowledge of HIV Status at Enrollment
<b>In-depth interviews N=34</b>	Not linked to care/not on ART, N=6	2 Men	27–56	1 Known Positive
		4 Women		5 Newly Diagnosed
	Linked and initiated ART, N=28	5 Men	22–59	9 Known Positive
		23 Women		19 Newly Diagnosed
<b>Focus group discussion participants N=30</b>	2 FGDs among patients who linked and initiated ART, N=15	7 Men	31–59	7 Known Positive
		8 Women		8 Newly Diagnosed
	2 FGDs among healthcare providers N=15	4 Men	Not available	N/A
		11 Women		

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