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## **HIV stigma, HIV status disclosure, and ART adherence in the context of an integrated opioid use disorder and HIV treatment setting in Dar es Salaam, Tanzania**

**Haneefa T. Saleem,**

Department of International Health, Bloomberg School of Public Health, Johns Hopkins University, Baltimore, Maryland, United States of America, 615 North Wolfe Street, Room E5033, Baltimore, Maryland 21205

**Deja Knight,**

Department of International Health, Bloomberg School of Public Health, Johns Hopkins University, Baltimore, Maryland, United States of America, 615 North Wolfe Street, Room E5033, Baltimore, Maryland 21205

**Cui Yang,**

Department of Health, Behavior, and Society, Bloomberg School of Public Health, Johns Hopkins University, Baltimore, Maryland, United States of America, 2213 McElderry Street, 2<sup>nd</sup> Floor, Baltimore, Maryland USA 21205

**Michael Kidorf,**

Department of Psychiatry and Behavioral Sciences, School of Medicine, Johns Hopkins University, Baltimore, Maryland, United States of America, Johns Hopkins Bayview Medical Campus, 5510 Nathan Shock Drive, Baltimore, MD USA 21224

**Carl Latkin,**

Department of Health, Behavior, and Society, Bloomberg School of Public Health, Johns Hopkins University, Baltimore, Maryland, United States of America, 624 North Broadway Avenue, Hampton House Room 737, Baltimore, Maryland USA 21205

**Iddi Haruna Nkya**

Department of Psychiatry and Mental Health, School of Medicine. Muhimbili University of Health and Allied Sciences, Dar es Salaam, Tanzania, P.O. Box 65001, Dar es Salaam, Tanzania

### **Abstract**

Little is known about social factors, including stigma, that affect antiretroviral therapy (ART) adherence among people enrolled in opioid use disorder treatment (OUDT) in the context of integrated OUDT and HIV treatment models. We qualitatively examined the relationship between HIV stigma, HIV status disclosure, and ART adherence among clients living with HIV at an OUDT clinic with integrated HIV services in Tanzania. We conducted in-depth interviews with 25 clients receiving HIV care at an OUDT clinic in Dar es Salaam, Tanzania between January and April 2020. HIV stigma, particularly anticipated stigma, and HIV status disclosure were key

factors that affected ART adherence. Participants feared non-voluntary HIV status disclosure to and HIV stigma from their peers enrolled in OUDT. Most participants reported concealing their HIV status from peers at the OUDT clinic and not associating with other clients living with HIV at the clinic. Reducing HIV stigma and enhancing clinic structures and procedures to maintain privacy and confidentiality are essential to mitigating the effects of stigma on ART adherence.

## Keywords

ART adherence; social networks; HIV status disclosure; HIV stigma; opioid use disorder treatment

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## Introduction

Opioid use disorder (OUD) treatment, including medications for OUD (MOUD) such as methadone maintenance therapy, has been shown to improve antiretroviral therapy (ART) adherence, for people who use drugs (Low et al., 2016). OUDT increases access to HIV care (Guise et al., 2017), and integrated OUD and HIV services in OUDT settings can be effective in improving HIV treatment outcomes (Oldfield et al., 2019). Much of the literature on the effect of OUDT on HIV outcomes focuses on the service components of adequate dosage and integrated OUD and HIV care models (Mohd Salleh, Voon, Karamouzian, Milloy, & Richardson, 2021). Less is known about social factors, including stigma, that affect ART adherence among people receiving medications for OUD, particularly in the context of integrated OUD and HIV care in low- and middle-income countries. HIV and substance use stigmas have been documented as negatively affecting HIV treatment among people living with HIV who use drugs (Shrestha, Altice, & Copenhaver, 2019; Stringer et al., 2019) in high-income countries. Internalized stigma, when one holds a stigmatizing concept of oneself, and anticipated stigma, the belief that one will be discriminated against because of one's condition, can lead to withdrawal from social support, social isolation, and avoidance of or withdrawal from treatment (Katz et al., 2013; Turan et al., 2016). This paper examines the relationship between HIV stigma, HIV status disclosure, and ART adherence among clients living with HIV at an OUDT clinic with integrated HIV services in Tanzania.

## Methods

We conducted in-depth interviews with 25 clients living with HIV enrolled in an OUDT clinic at a referral hospital in Dar es Salaam, Tanzania, between January and April 2020. The clinic offers integrated HIV testing and treatment, including options for monthly or daily, directly observed ART dispensing on site. Some clients are recommended for directly observed ART by providers to improve ART adherence, while others opt to take their ART at the clinic because they do not have stable housing and support to store ART medications. Clients who enroll in HIV care at the OUDT clinic have the option to continue to receive their HIV care at the clinic even when they are no longer receiving MOUD. Participants were purposively sampled based on gender and OUDT status. They provided informed consent before the interview. Interviews included questions on barriers and facilitators to ART adherence and lasted about one hour. Interviews were audio-recorded, transcribed, and then translated to English. Two study team members coded transcripts using a codebook

with deductive and inductive codes. Discrepancies in coding were either resolved through team consensus or used to inform the analysis by identifying diverse interpretations. We identified themes by comparing codes across participants, including by gender, and examining relationships between codes.

The study received ethical approval from Muhimbili University of Health and Allied Sciences, the Johns Hopkins Bloomberg School of Public Health institutional review boards, and the Tanzania National Institute for Medical Research.

## Results

Among the 25 clients living with HIV interviewed for the study, 13 were women and 12 men. The mean age of participants was 38 years old, ranging from 21 to 49 years old. Eighteen out of 25 participants were receiving MOUD at the time of the interview. The median time on ART was 5 years and ranged from less than 6 months to 20 years. However, nearly a third of participants could not remember when they first initiated ART.

### HIV Stigma from Peers Enrolled in OUDT

More than half of the participants, mostly women, reported fear of being stigmatized because of one's HIV status as negatively affecting their adherence to ART. Collecting ART or taking directly observed ART doses at the OUDT clinic posed a challenge for some participants, as they did not want to be seen taking ART at the clinic by their peers (Table 1, Quote #1). Clients formerly enrolled in OUDT but who continued to receive HIV care at the OUDT clinic believed attending HIV care appointments exposed them to involuntary HIV status disclosure and HIV stigma (Table 1, Quote #2). Internalized HIV stigma, particularly shame, led some clients to lose hope and discontinue ART altogether (Table 1, Quote #3).

### HIV Status (Non-)Disclosure

Fear of stigma appeared to determine to whom participants disclosed their HIV status. Most participants, regardless of gender, reported concealing their HIV status from peers at the OUDT clinic and not wanting to associate with other clients living with HIV for fear of being discovered as having HIV (Table 1, Quote #4).

Though HIV status disclosure to peers at the OUDT clinic was limited, nearly all participants reported having disclosed their HIV status to at least one close family member or an intimate partner. For a few participants, enrollment in OUDT served as a catalyst for restoring familial ties, rebuilding trust that had been lost during periods of active heroin use. HIV status disclosure coupled with renewed social ties to family appeared to influence participants' access to social support and other resources that supported ART adherence. Participants reported receiving emotional, instrumental, and informational support from family and intimate partners who were aware of their HIV status. Female clients were more likely than male clients to report HIV status disclosure to an intimate partner. Emotional support manifested in encouraging them to take ART, normalizing HIV, and giving hope. Some participants described receiving instrumental support from family and intimate partners who were aware of their HIV status, such as reminders to take ART

medications, being accompanied to the clinic, and fetching ART medications (Table 1, Quote #5)

Having a close person, like an intimate partner, who also had HIV and was adherent to ART also served as a positive influence on treatment adherence, facilitating positive behavioral modeling (Table 1, Quote #6).

## Discussion

We qualitatively examined the relationship between HIV stigma, HIV status disclosure, and ART adherence among clients living with HIV at an OUDT clinic in Dar es Salaam, Tanzania. HIV stigma, including anticipated stigma and internalized stigma, and HIV status disclosure were key factors that affected ART adherence.

Anticipated stigma from peers was a barrier to ART adherence among participants. Disruptions of social ties, especially familial ties, during periods of drug use and broader stigma and discrimination against people who use drugs may heighten the importance of peer relationships for social support in the lives of clients enrolled in OUDT. HIV status disclosure to peers enrolled in OUDT who hold stigmatizing attitudes toward people living with HIV may result in withdrawal of needed support without intervening to address the sources of stigma. Though the co-location of OUD and HIV care services at the OUDT clinic makes accessing ART convenient (Cooke et al., 2017) and has contributed to high rates of ART initiation (Hassan et al., 2019), anticipated HIV stigma from peers at the clinic exists, especially among clients receiving HIV care at the clinic but who are no longer enrolled in OUDT, and should be addressed through stigma reduction interventions (Andersson et al., 2020; Katz et al., 2013; Yigit et al., 2020). In addition to reducing HIV stigma, enhancing clinic structures and procedures to maintain privacy are essential to protecting patient confidentiality and supporting ART adherence.

Participants managed HIV stigma through selective HIV status disclosure and concealment. Non-disclosure of HIV status limited social support and access to resources that could support ART adherence. Future studies should examine relationship dynamics and context of social ties, such as HIV status disclosure, trust, and stigma to illuminate further processes through which social relationships positively and negatively affect HIV status disclosure and ART adherence. Relatedly, internalized HIV stigma can prevent some people from connecting with others living with HIV, which we found in our study, and limit a sense of belonging to a community of people living with HIV who can provide mutual emotional support, model positive adherence behaviors, and correct misinformation. Though providers might counsel clients to maintain privacy around their medical and psychiatric conditions, non-disclosure due to internalized stigma and/or fear of anticipated stigma can result in a loss of solidarity and support, particularly with others living with HIV. Low social connectedness among people living with HIV has been associated with poor HIV outcomes (Chen et al., 2021). Interventions that mitigate internalized stigma and strengthen social connections to those living with HIV or others who might serve as sources of social support may increase ART adherence in this population (Brown et al., 2020).

There are limitations of the study worth noting. Due to the in-depth nature of qualitative research, the sample size was small; hence, findings may not generalize to the population of clients living with HIV at the clinic. We relied on self-report of time since ART initiation. Many participants were unable to recall when they had initiated ART. Those who had been on ART longer may have different experiences than those more recently initiated on ART. Despite these limitations, this study highlights the importance of interpersonal and structural stigma reduction interventions to improve ART adherence, and ultimately HIV outcomes, in the context of integrated OUD and HIV treatment programs.

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Illustrative direct quotes from study participants related to key themes of HIV stigma, particularly from peers enrolled in OUDT, and HIV status (non-)disclosure.

**Table 1.**

<p><b>HIV stigma from peers enrolled in OUDT as a barrier to ART adherence</b></p>	<p>Quote #1</p>	<p><i>I did not have [any more ART pills]. When you come here to take the medicine, they tell you 'Yesterday you didn't come to take [your ART], you don't have [ART pills] to take?' If I say I don't have them here, they will tell me to swallow them right there and inside there are many people who go to swallow [their ART pills], you pass by each other and so forth. So, if you pass by someone who knows you are going to take that medicine [ART], then you are irritated. So, even if I don't have [any more ART pills], I will lie and say that I have about five or six to last me for some days... So, on those days I would just stay without taking [ART], since I don't have the medicine. I lie to them because I don't want to go inside to take my medicine.</i>                   (Female client, 41 years old, formerly enrolled in OUDT)</p>
	<p>Quote #2</p>	<p><i>There is a challenge [with taking ART] ... First, people are aware that you are going to take your medicine, so they point fingers at you, 'She is going to take ART.' How do they know? There are no secrets at the methadone clinic... I no longer drink methadone. So, they say, 'What has she come here for?' She is going to take ART. She is infected [with HIV]. Look at her body.'</i>                   (Female client, 42 years old, formerly enrolled in OUDT in a relationship with a current MAT client)</p>
	<p>Quote #3</p>	<p><i>Most of us feel ashamed to take ART at the clinic... There are many who have stopped taking their ART and they always look very weak when they come back to treatment.</i>                   (Male client, 40 years old, currently enrolled in OUDT)</p>
<p><b>HIV status non-disclosure as a barrier to ART adherence</b></p>	<p>Quote #4</p>	<p><i>There is a lot of movement inside the [OUDT] clinic. There are patients with TB and patients who take ART pills... There are people who take the same medication that I am taking [ART] and I do not want to mix myself with them. It is unnecessary for everyone to know that so and so is also taking [ART], no. You see, that is a secret.</i>                   (Female client, 43 years old, currently enrolled in OUDT)</p>
<p><b>Selective HIV status disclosure as an indirect facilitator of ART adherence through social support</b></p>	<p>Quote #5</p>	<p><i>I skipped [my daily ART doses] like four times, different days because of forgetting. But when I started taking my ART dose at night, there was not a single day that I forgot because my wife is sharp in reminding me to take my medication.</i>                   (Male client, 49 years old, currently enrolled in OUDT)</p>
	<p>Quote #6</p>	<p><i>[My husband] is also taking [ART]. We remind each other, 'Take your medication.'</i>                   (Female client, 30 years old currently enrolled in OUDT married to former MAT client)</p>