

# The Convergence of Disclosure Concerns and Poverty Contributes to Loss to HIV Care in India: A Qualitative Study

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## Abstract

In India, there is little evidence on reasons for high rates of loss to HIV care. We conducted a clinic-based qualitative study at the YR Gaitonde Centre for AIDS Research and Education to explore factors that influence loss to care. In all, 17 men and 14 women were interviewed; median age was 42 (interquartile range [IQR], 36-48) and median CD4 count was 448 (IQR, 163-609). A majority reported avoiding treatment freely available at nearby government facilities because of disclosure concerns and perceptions of poor quality. As a result, participants sought care in the private sector where they were subjected to medication and transport costs. Life circumstances causing lost wages or unexpected expenditures therefore prevented participants from attending clinic, resulting in loss to care. Improving perceptions of quality of care in the public sector, addressing disclosure concerns, and reducing economic hardships among people living with HIV may be important in reducing loss to HIV care in India.

## Keywords

loss to care, disclosure, poverty, India

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## Introduction

India has one of the world’s largest HIV epidemics, with over 2 million people living with HIV (PLHIV).<sup>1</sup> Coordinated private and public sector efforts have led to falling infection rates, with new infections having decreased by 46% and AIDS-related deaths having fallen by 22% since 2010.<sup>2</sup> As in other low- and middle-income countries (LMICs), recent evidence in support of antiretroviral therapy (ART) for prevention of HIV transmission has raised hopes that ART expansion might lead to the end of the HIV epidemic in India.<sup>3</sup>

Despite this progress, India’s goal of becoming AIDS-free in a generation is threatened by high rates of loss to HIV care. Loss to care is usually operationalized as the unplanned passage of more than 180 days since the last clinic visit.<sup>4</sup> In a systemic review and meta-analysis of studies from 2008 to 2013, the average retention rate at 36 months among PLHIV in Indian cohorts was 67%.<sup>5</sup> According to the Joint United Nations Programme on HIV/AIDS,<sup>6</sup> only 49% of all Indian PLHIV, and only 63% of Indian PLHIV who are aware of their

serostatus, are estimated to be on ART. Rates of loss to care in India may be especially high among key populations. In a nationwide cohort of men who have sex with men (MSM) and

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### What Do We Already Know about This Topic?

High rates of loss to HIV care threaten India's goal of becoming AIDS-free generation. Unfortunately, relatively little is known about reasons for high rates of loss to HIV care in India.

### How Does Your Research Contribute to the Field?

In this qualitative study of people living with HIV (PLHIV) in southern India, we found that the decision to access the private sector for HIV care and in many cases to travel long distances to manage disclosure concerns and to obtain better care leaves Indian PLHIV vulnerable to changes in economic status.

### What Are Your Research's Implications toward Theory, Practice, or Policy?

Our findings suggest that improving perceptions of quality of care in the public sector, addressing disclosure concerns, and reducing economic hardship among PLHIV may be important in reducing loss to HIV care in India.

people who inject drugs (PID), only 10% of those who were found to be HIV seropositive were on ART and virologically suppressed.<sup>7</sup> One modeling study estimated that high rates of loss to care in India could account for approximately 533 000 new HIV infections and 472 000 excess HIV-related deaths over 20 years.<sup>8</sup> As a result, one of the objectives of the Indian National Strategic Plan for HIV/AIDS and STI 2017-2024 is ART initiation and retention in care of 90% of PLHIV by 2024.<sup>9</sup>

A relatively robust evidence base on reasons for loss to care has been built in sub-Saharan Africa, where psychosocial factors such as depression and HIV-related stigma, structural factors such as poverty and excessive distance to clinic, and adverse clinic/health system characteristics such as lack of respect from clinicians have been associated with loss to HIV care.<sup>10</sup> However, it is unclear how applicable these studies are to India, which features a markedly different sociocultural environment and an epidemic that is highly concentrated among female sex workers, MSM, and PID.<sup>11</sup> Unfortunately, there have been few studies investigating the causes of loss to care in India, and these studies are relatively old, predating the national policy of "Test and Treat" instituted in 2017 making all PLHIV eligible for ART regardless of CD4 count. For example, in one retrospective cross-sectional study in Uttar Pradesh, PLHIV who enrolled in HIV care in 2009 but had been lost to care prior to initiating ART cited inconvenient clinic timings, perceived improved health, transportation and financial difficulties, and lack of social support as reasons for

loss to care.<sup>12</sup> In a cohort of PLHIV attending a public ART center in Karnataka between 2010 and 2012, factors associated with loss to care at 12 months included age greater than 45 years, low educational level, being unmarried, rural residence, and advanced World Health Organization stage disease.<sup>13</sup>

Improving our understanding of the factors that contribute to loss to HIV care in the current era of "Test and Treat" in India would help identify PLHIV at risk for loss to care and who would potentially benefit from interventions to keep them in care and virologically suppressed. To help fill this knowledge gap, we conducted a qualitative study at a large, private ART care center in southern India to identify the factors contributing to loss to HIV care in India.

## Methods

### Study Design and Overview

We conducted this patient-focused qualitative study informed by grounded theory and content analysis as part of a larger US National Institutes of Health K23-funded project (K23MH110338) focused on understanding and addressing syndemic psychosocial and structural factors affecting loss from the HIV care continuum in India. The qualitative interviews were conducted for the sole purpose of the study at hand, although there was a concurrent questionnaire-based study in which some of the participants also enrolled. A separate study team administered this quantitative study, and there was minimal contact between the research assistants (RAs) for the 2 studies. Our aim was to use qualitative research to understand from the patient perspective the factors that influence loss to care and the mechanisms by which these factors increase the likelihood of loss to care. By doing so, we hoped to develop a conceptual model of factors contributing to loss to care among Indian PLHIV.

### Study Site

The study was based at the YR Gaitonde Centre for AIDS Research and Education (YRG CARE) in Chennai, the capital of Tamil Nadu in southern India. As one of the largest private HIV providers in India, having provided care to over 20 000 PLHIV, YRG CARE hosts a range of services including voluntary counseling and testing, comprehensive treatment, medication disbursement with its in-house pharmacy, community-based training for health care professionals, and specialized care for expectant mothers living with HIV. Although there are no publicly available data on the number of PLHIV in care in the private sector, there are over 3500 private HIV testing and counseling centers across India and the Indian National Strategic Plan for HIV/AIDS and STI 2017-2024 recognizes the private sector as a cornerstone of its END-AIDS strategy.<sup>9</sup> YRG CARE serves patients who are newly diagnosed with HIV as well as patients referred from other HIV providers (including the public sector), within a catchment area primarily consisting of Tamil Nadu and Andhra Pradesh states.

Unlike the public sector, however, YRG CARE charges modest fees for treatment and care. At the time of the study, typical first-line treatment (efavirenz-based ART) was the same as in the public sector. Patients newly diagnosed with HIV are encouraged to visit YRG CARE at least every 3 months for the first year while more stable patients may visit as infrequently as once yearly. Prior to meeting with a physician, each patient is seen by an HIV counselor, providing an integrated social and biomedical treatment approach. Most patients at YRG CARE self-identify as heterosexual, as there are other organizations in Tamil Nadu specializing in HIV care for sexual and gender minorities.

### *Sampling and Recruitment*

All participants in this study were PLHIV who had previously established care at YRG CARE and were presenting for a follow-up visit between June and August 2017. We used maximum variation sampling to identify participants based on lost-to-care status (previously lost to care versus never lost to care), gender, and urban versus rural residence. We defined previously lost to care as having been unexpectedly absent from care for at least 180 days. For example, a patient who had missed her 6-month appointment, had not been heard from more than 3 months afterward, but who was subsequently returning to seek care for any reason was considered eligible for the study as a previously lost-to-care patient. We also attempted to obtain reasonable diversity in caste representation, primary language (Telugu versus Tamil), and marital status. Participants were offered 250 Indian rupees (approximately 3.50 USD) and a lunch token at the clinic's cafeteria (worth approximately 30 rupees or 0.50 USD) for their participation in the study.

### *Informed Consent*

Research assistants read aloud informed consent forms in Tamil or Telugu to participants and obtained signed informed consent documents. In lieu of signatures, RAs obtained thumbprint in cases of illiteracy. We obtained ethical approval for study procedures from the institutional review boards of Partners Healthcare, Boston, Massachusetts, USA and YRG CARE as well as the Health Ministry Screening Committee of the Government of India. In addition, the YRG CARE Community Advisory Board reviewed and approved all study procedures.

### *Data Collection and Preparation*

Indian and US research staff developed the interview guides together to explore a variety of clinic-based, psychosocial, and structural factors that could potentially impact loss to HIV care. We pilot tested this guide on YRG CARE staff members and a small group of YRG CARE patients to ensure accuracy of meaning, understandability, and cultural sensitivity. The first half of the interview consisted of open-ended questions about the participant's current care status and insights into their HIV care in general (eg, "What are the challenges or barriers that

you personally encounter which make it more difficult to take your HIV medications or come to appointments regularly?"). The interviewer then asked questions about specific clinic-based, psychosocial and structural factors that influenced the participant's ability and desire to seek continued HIV care from the clinic. Throughout, RAs were expected to ask appropriate follow-up and probing questions. The Indian RAs had experience in qualitative research from previous studies conducted at YRG CARE and all RAs were given further qualitative research training via several in-person sessions with the study's principal investigator, who is an experienced mixed-methods researcher. These sessions included skill training related to effective questioning and listening methods, practice scenarios, and intense cultural sensitivity training. RAs conducted interviews in Tamil or Telugu, with one of 2 English-speaking research staff present for most interviews. Interviews were conducted in a private room, digitally recorded with the participant's permission, and then transcribed and translated into English.

### *Data Analysis*

We used a multi-step approach to data analysis informed by grounded theory<sup>14</sup> and content analysis.<sup>15,16</sup> First, we conducted open coding to inductively draw out key themes and categories. We then created a codebook, listing each theme accompanied by a detailed description, inclusion/exclusion criteria, and examples. Two authors independently coded a subsample of transcripts, and intercoder reliability was assessed using Cohen  $\kappa$ . After several refinements of the codebook, we finalized and applied the codebook to the entire sample, using axial coding to examine relationships within and among categories. We regularly discussed issues of reflexivity and the possible influence of personal opinions, experiences, and expectations on the conclusions being drawn, as recommended in Maxwell.<sup>17</sup> We paid special attention toward gender-based differences and any data that contradicted the main conclusions. We agreed upon illustrative quotations that best described factors that affect loss to HIV care. Finally, we integrated the key conclusions into a conceptual model of psychosocial, structural, and clinic-based factors affecting loss to care. Throughout, we used Dedoose software to assist in data management and analysis.

## **Results**

### *Study Participants*

We approached 33 individuals to enter into the study. Two participants who qualified for the study declined to participate. The study included 31 interviews, with 14 female and 17 male participants (Table 1). The average age of participants was 42, and just over two-thirds of participants lived in rural settings. Seventeen participants had remained consistently in care, and the remaining 14 participants were previously lost to care until the day of the interview. The Cohen's Kappa for intercoder reliability was 90%.

**Table 1.** Characteristics of Study Participants.

Characteristic	n = 31
Female	14 (45%)
Age, median (IQR), years	42 (36-48)
Rural (versus urban) residence	21 (68%)
CD4 count, median (IQR), cells/mm <sup>3</sup>	448 (163-609)
Lost-to-care status	
Previously lost to care	14 (45%)
Regular care	17 (55%)

Abbreviation: IQR, interquartile range.

### Desire to Seek Treatment

Almost every participant expressed a strong desire to seek treatment, noting that regular clinic visits would be beneficial for their health. If healthy, participants thought that they could live a normal life and complete all of their daily work.

If I take tablets, I don't have aches. I can go here and there. Then I feel good. If I stop tablets, I feel body aches. (39-year-old man, rural resident)

It is for the medicines, it's for better health. I want to stay a little longer for my children, because of that I desire the medication . . . I have some responsibilities. With these medicines, they'll let me prolong [my life]. (44-year-old woman, rural resident)

Despite this professed desire to benefit from regular ART and HIV care, participants identified a range of factors that affected their ability to stay in care, as discussed subsequently.

### Fears of Disclosure

One of the strongest and most commonly cited impediments to remaining in HIV care was fear of serostatus disclosure. Participants perceived the consequences of serostatus disclosure to be grave, in particular social exclusion and loss of social standing. This was especially reported among participants in rural areas, where tightly knit family and community groups can facilitate the rapid spread of sensitive information.

*Interviewer:* What kind of challenges do you face coming here and getting the medicine?

*Participant:* I have to hide from my mother and father, from my children, from my neighbors.

*Interviewer:* So this feeling that you have to hide from everyone.

*Participant:* Yes, that feeling that others can't know that I am taking this medicine.

*Interviewer:* So to hide that you are taking medications, it's difficult.

*Participant:* Yes, we can have the medicines only after the children have eaten at night. In the morning, we can only take the medicine after the children have gone to school. Like that. (40-year-old woman, rural resident)

See, if I tell people that I take tablets because of the illness, even the friends that I have right now will distance themselves from me. (43-year-old man, rural resident)

Participants often expressed more concern over the impact of social exclusion on family members rather than on themselves, particularly in regards to marriage prospects. Given the association of HIV with deviance and moral turpitude, some participants worried that serostatus disclosure would reflect poorly on family members by association.

The eldest knows our condition, as he is part of our family. But the second one does not know. We don't take [ART] when he is around. We are concerned that my daughter will suffer if he comes to know. (47-year-old man, rural resident)

If I discuss this [my serostatus] in Chennai city, people may not say anything. My place is rural. If I say this to anyone, they will say something about me and I will get bad names. They will think bad about me. It will affect my children's life. (44-year-old man, rural resident).

*Interviewer:* What will happen if others get to know [your status]?

*Participant:* It doesn't bother me, but of course my children will be affected. My son maybe, my daughter will have more of an impact. The place where she goes to get married, they will say, "Oh, your father was like that, so maybe you're like that too." For the safety of my children, I do not want to reveal this to anybody as far as this is concerned. Besides my own family, I have not informed others. If I do it will not be desirable and it will infringe upon their social status and respect . . . If I am inconvenienced, it does not matter, but my family will be put through so many social inconveniences. For example, if my son got into a fight with someone else, the other person would insult him by saying "Like father, like son." . . . When our daughter goes out, for some socialization, they might talk. People will assume that she is engaging in sexual activity. That is the stigma of HIV. (65-year-old man, urban resident).

Some participants mentioned the need to conceal ART in secret hiding places and remove the medication's packaging. Participants also reported that uncomfortable questioning from others made it difficult to come freely and regularly for HIV care.

[My] sons-in-law don't know [my serostatus]. When they're at my place, I cannot come to the hospital. They'll ask, where am I going? They'll start questioning. So then I cannot come. (44-year-old woman, rural resident)

There were a few exceptions of participants who reported no significant disclosure concerns. One rural resident reported that his serostatus was known to the entire village. Notably, this was an individual who had not been lost to care.

*Interviewer:* Do you think you should let everybody know, or just a small percentage?

*Participant:* Everybody knows, all in my family.

*Interviewer:* Is it good everyone knows?

*Participant:* Yes, it is good everyone knows. I live in a village, only 50 houses in a village, all 50 houses know . . .

*Interviewer:* There is no problem that everyone knows?

*Participant:* No. Wherever I go, nobody asks me to sit in the back because of this illness. (49-year-old man, rural resident)

### **Avoiding Government ART Facilities and Choosing Care at a Private ART Center**

Concerns over serostatus disclosure affected some rural participants' decisions to avoid government ART centers and opt for care at a private facility. As part of India's HIV eradication strategy, free ART and HIV care are available at government-run health clinics. However, participants reported a desire to avoid government ART centers because of concerns over serostatus disclosure.

I did consider [going to the government], but I don't want anyone to find out. You see, there shouldn't be any negative effects on the lives of my children. See, I have older boys. The older one has a girl he wants to marry. My other boy is going to college now. I don't want the other people to laugh at him because they know his parents have this disease. That's the most important. (40-year-old woman, rural resident)

Except for my family members . . . no one knows about my status, otherwise I would go to the government. If I go to the government hospital, people would come to know I have HIV. (44-year-old man, rural resident)

However, concerns over serostatus disclosure were not the only impediment to seeking care in the public sector. Participants frequently related impressions that care at government clinics was inferior to care at private facilities.

Half the time, the doctors aren't even there. They ask you to wait, wait, and wait and they'll give you a card. Sometimes the nurse will dispense the meds without the doctor. (40-year-old man, urban resident)

*Interviewer:* Why did you not seek assistance from the government? Why would you come all the way here and spend your own money. Why?

*Participant:* See, government talks about things like this but it's not easy. I see people going to the government for medicines; some days they get it, some days they don't. See, I'm coming

here because this is consistent. (44-year-old woman, rural resident)

In addition to long waits and substandard care from clinicians, some participants did not trust the ART given out at government clinics, instead expressing the desire to get medication from a private facility despite the extra costs.

*Participant:* I used to take meds at government hospital before, but they didn't work.

*Interviewer:* Why?

*Participant:* Well, I tried, but after I took it I felt very fatigued, I couldn't walk, and I was bedridden. At that time I knew a person, he told me to go to YRG CARE and he brought me here . . .

*Interviewer:* Why don't you get [the ART] locally?

*Participant:* It doesn't work for me. (49-year-old man, rural resident)

It is nice to buy ART from here. I am satisfied. It does not feel good to buy from the government. I am not satisfied. Some others died under government follow up and ART. When I am taking medication from YRG CARE, I am feeling good and not finding any health issues, so even though I have to pay for ART from YRG CARE, I prefer to come here to get medicine. (44-year-old man, rural resident)

One participant also reported an intolerable lack of respect shown by caregivers in the public sector.

You know why I'm not going to government hospital? They don't treat you with respect. They look down, they don't treat you well in government hospitals. It's not good there at all. (40-year-old man, rural resident)

Because of perceptions of stigma at home and in their communities, where livelihoods and family reputations could be harmed, as well as perceptions of poor quality, inferior ART, and lack of respect shown in the public sector, participants opted to spend money on travel and treatment at YRG CARE, a private ART center.

Other people, some of them behave differently and don't treat us the same because we have HIV; here [at YRG CARE] everyone is respectful so we don't have any problems like that. My husband was admitted here at the hospital and everyone gave him treatment very nicely . . . when my husband got very sick, they admitted him at [the government hospital]; they didn't tell us anything, and we didn't know what doctors are good and what doctors are not good. He said that my husband is very sick and did not tell us anything else. Also, the nurses over there—they were behaving like they could not touch him, and we didn't even know there were problems like this. They were not telling me anything. (45-year-old woman, urban resident)

If my mother came to know I have HIV, her heart would be broken. So for that I do not want to make my mom feel bad, so I am telling some lie when I come here [YRG CARE] to get medications . . . For example, I say I have vision complaints or a cold so I am going to show the doctor. (44-year-old man, rural resident)

### *Burden of Routine Expenses*

The choice to access care in the private sector imposed on participants a burden of routine expenses related to regular HIV care and ART. For rural dwellers, it was common to leave home during the evening of the day preceding their appointment, traveling overnight on trains or buses to arrive in Chennai during the morning. As most appointments took place during morning hours, participants would return home the same night. Participants often said that their health took priority over the inconvenience caused by long journeys. Nevertheless, for many, transportation costs were problematic, particularly because many of these participants were employed in low-paying, manual labor. Moreover, participants cited the opportunity cost of lost wages incurred as a result of traveling long distances and taking at least a day to attend clinic as an important burden.

We leave at 5 o'clock [PM], and we arrive here in the morning. What time in the morning? 7-7:30 am; by the time I get to the hospital, it's 8:30 am. (36-year-old woman, rural resident)

To come and go, it is definitely expensive. It will definitely come to 2000 rupees. So you see, today the business is gone. If we had been there today, we would definitely have made 500 rupees. See if we had sold one flower garland and some other things, we would have made 500 rupees. But we didn't make that. Today, we closed the shop and came. (40-year-old woman, rural resident)

In addition to transportation and opportunity costs, many participants felt that medication costs were a significant burden. YRG CARE subsidizes ART for patients who opt to receive medication from the clinic's private pharmacy, but treatment can still cost several thousand rupees (tens of USD) per month after this subsidy. Some patients opt to attend YRG CARE for clinical consultations but obtain ART free from the government. As discussed above, however, some participants insisted on paying for medications at YRG CARE because of the perception that this ART was superior to ART available in the public sector. For several participants who earned 200 rupees (approximately 3 USD) or less per day, this monthly medication bill quickly added up. Several participants who were lost to care cited the routine expense of buying medications as the primary reason they stopped coming to the clinic. If they could not afford to buy the medicine, what use was it to come to the clinic and see the doctor?

I just come here because the meds are good... if I had money, I would come regularly. (27-year-old man, urban resident).

See, I've been telling you since I started: if the meds are dispensed for free, I will take regularly. Why else would I stop? I would take regularly, but I'm not able to purchase meds. Every time I come here it costs 5,000 rupees. 5,000 for me, 5,000 for [my husband]. Our monthly income is 10,000 rupees, how do you expect us to buy meds? (40-year-old woman, rural resident)

### *Life Shocks Causing Loss to Care*

The everyday burden of expenditures related to HIV care—including the cost of medications at YRG CARE, lost wages, and for rural dwellers, transportation cost—stretched many already financially insecure participants to the breaking point. This left them vulnerable to sudden, adverse life events that required attention and resources, disrupting their ability to stay in HIV care. For example, several participants mentioned that family members had sudden medical emergencies or unforeseen illnesses of their own. These events diverted thinly spread financial resources away from the participant's HIV treatment and toward the affected family member's treatment.

Because of my family situation, I missed. I don't have money. I had to spend for my son's medical treatment so I was unable to come. I tried to come and get medicine, but I had lots of expenses. For my son's hospitalization, room rent was 2300 [rupees] per day. I am not a well off person. I am a flower seller, so I found it difficult to arrange medicine for his treatment. Through my flower selling business, I can't pay for the children's studies and treatment. Before, I was never finding it difficult because my children are small and there were no higher study fees. But now, my children are grown up and I have to pay for higher study fees. I built a new home and have to pay EMI [mortgage] and I have family expenses. After I built my new home, within six months, [my son] had an accident so I was unable to come for treatment. Everything came together so I was unable to make it. (44-year-old man, rural resident)

### *Social Support*

Many participants reported financial concerns; yet, some were able to stay in care whereas others made difficult choices to deprioritize their HIV care. Participants who remained in care despite financial difficulties frequently said that they could rely on friends or family members to help them out when money became tight. Beyond instrumental support, these family members and friends also provided needed encouragement during difficult times. Female participants tended to frame social support in terms of instrumental support whereas male participants tended to describe social support in more abstract terms (eg, emotional support and medical recommendations).

Madam, I have a brother. And he has small children. The time when the doctor asks me to come, there could be things that are going up at home, they could be sick, other things. My brother is working for my help, all of the things he takes as projects, he is trying to help me. He is putting aside his own children to take care of me. He is very helpful. He is even giving up some of his own projects to take care of me. He is trying to get this taken care of. He says, this project has to be successful; this is her health. (36-year-old woman, rural resident)

When I was having fever a long time back, the doctor asked me to take HIV test. They found I was positive. I told my brother I have HIV. My brother told my uncle. My uncle's friend knows this hospital. He used to come and get medicines here. Through the

uncle's friend who knows this hospital I was taken here for treatment and to consult the doctor. The uncle's friend consoled me and said, 'Don't worry, I will take you to a hospital—they will treat you nicely . . .' So after eight years, I am not having any problems. (44-year-old man, rural resident)

On the other hand, disclosure concerns meant that some participants could not rely on family members or friends for instrumental support. Lack of a robust social safety net from the government meant that such participants would be largely left to fend for themselves.

So if I were to tell all my relatives, they would hate me, so how could I go to them and ask for money? (40-year-old woman, rural resident)

Nobody is there to help in the society. We have to take care of ourselves. You get very little help from the outside. Either we earn or we suffer; we have to get through. (40-year-old woman, rural resident)

There was no evidence of support that was unwanted or unhelpful, so-called "negative" support. Participants were often very selective about serostatus disclosure and may have avoided disclosing to those who would not provide positive support.

### Psychosocial Factors

With few exceptions, persistent depressive symptoms, alcohol use, and illicit substance use were not reported as reasons for loss to care. Although some participants reported some mental distress upon learning their HIV diagnosis, feelings of despondence or self-blame were generally not sustained. One participant reported "mental pressure" but only related to financial woes. One 43-year-old man reported being treated with antidepressants and antipsychotics for concomitant mental illness; however, this participant had been regular in HIV care. He reported that one motivation for staying in HIV care was to prevent transmission to his HIV-negative wife. Another participant, a 36-year-old woman, reported having been molested as a child and bearing shame over her HIV diagnosis. However, she too had been regular in HIV care, having benefited from financial and other support from her brother.

### Conceptual Model of Loss to Care in Southern India

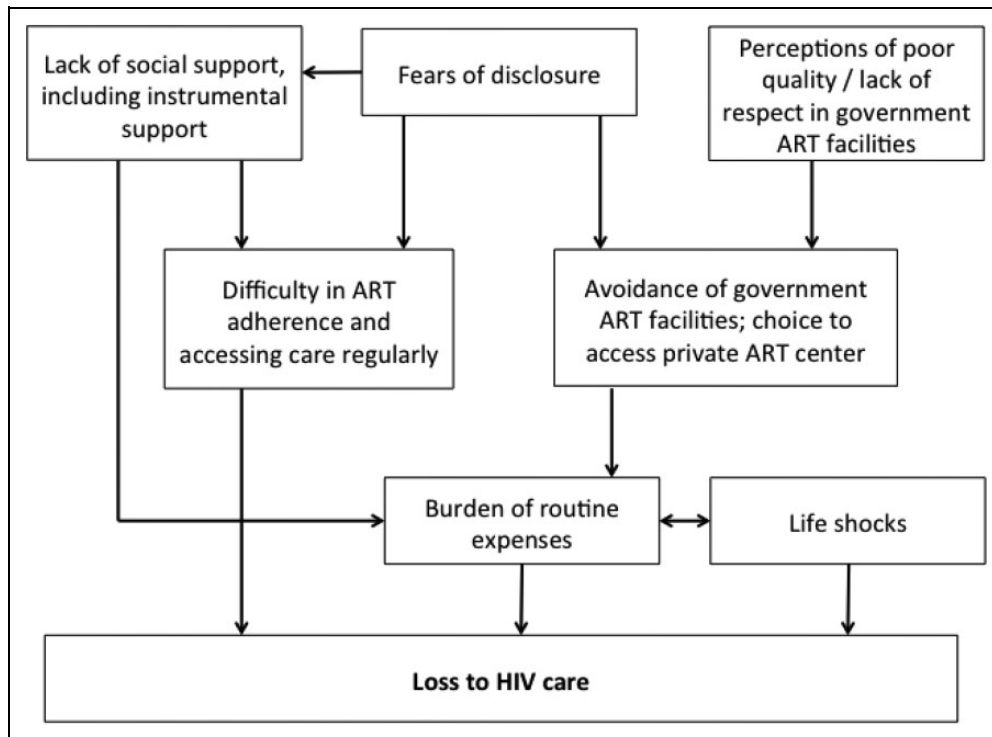
We integrated our findings into a conceptual model of loss to HIV care in southern India (Figure 1). Selected key themes by lost-to-care status and rural versus urban residence are presented in Table 2. Fears of serostatus disclosure were a pervasive influence on the lives of most participants in our sample. These fears appeared to be based on the *anticipation of stigma* in the event of serostatus disclosure, including loss of status and social distancing. Avoiding these perceived consequences of serostatus disclosure made adherence to medication and regular clinic visits more difficult. The desire to avoid unwanted serostatus disclosure, as well as perceptions of poor quality of

care, inferior ART, and lack of respect shown by health care workers, led participants to avoid HIV care freely available in the public sector and to seek care at a private, relatively distant private facility. While participants valued the care given at YRG CARE, routine expenses related to care at a private facility, especially transportation costs, medication costs, and costs related to lost wages, posed a burden. Hence, participants were left vulnerable to life shocks that diverted attention and scarce financial resources from what was needed to maintain regular HIV care. Participants who were able to leverage social support, particularly instrumental support, in times of financial stress were generally able to stay in care. However, those participants with less social support (including those who could not call upon family and friends to whom they had not disclosed their serostatus) were generally forced to default from care.

### Discussion

While progress is being made in India's fight for an AIDS-free generation, PLHIV continue to be lost from the HIV care continuum at a high rate. We conducted this study to gain a better understanding of the factors that result in loss to HIV care in India. The insights provided by participants allowed us to construct a conceptual model of loss to HIV care centered around fears of disclosure/anticipated stigma and economic vulnerability. Disclosure concerns not only encumbered access to regular HIV care and the recruitment of social support from family and friends but also in combination with distrust of HIV care freely available at nearby public facilities drove PLHIV to seek care at a private ART center. The decision to access the private sector (in many cases a long distance away from their primary residence) incurred a burden of regular expenses and opportunity costs, leaving PLHIV, especially those without adequate social support, vulnerable to unforeseen changes in economic status, and other life shocks that forced them to default from HIV care.

Among the participants in our study, fear of serostatus disclosure was one of the strongest and most commonly cited impediments to staying in HIV care. We have previously reported high rates of disclosure concerns among PLHIV at YRG CARE<sup>18</sup> that stem from the belief—based on a subjective awareness of prevalent stigmatizing attitudes in the community—that people found to be HIV positive will be devalued and subjected to discrimination. There is evidence from India that PLHIV fear the consequences of serostatus disclosure due to a high degree of "vicarious stigma" in the form of stories and gossip about stigma enactments.<sup>19</sup> In this study, the consequences of serostatus disclosure, particularly social exclusion and loss of social standing, were perceived to be grave not only for the participant but perhaps more importantly for his or her family members. Taking pains to avoid serostatus disclosure made it more difficult to regularly adhere to ART and attend clinic. Participants also noted that disclosure concerns made them reluctant to ask friends or family for instrumental support that would have helped them stay in HIV care. Our results are



**Figure 1.** Conceptual model of loss to care in southern India.

in keeping with findings from India, in which disclosure avoidance has been associated with delays in seeking HIV care,<sup>20</sup> and with findings in other LMICs, in which nondisclosure of serostatus has been associated with negative outcomes including poor mental health and reduced quality of life,<sup>21,22</sup> loss to care,<sup>23</sup> and virological failure.<sup>24</sup>

In this study, disclosure concerns, together with perceptions of poor quality of care and lack of respect, also had discouraged participants from seeking care in the public sector. Antiretroviral therapy and HIV care have been freely available in government facilities in India since 2004.<sup>25</sup> Unfortunately, participants in our study, particularly those who reside in rural settings, reported a reluctance to attend government ART centers for fear of being revealed as HIV positive to people in their community. Moreover, participants perceived poor quality of care, inferior and sometimes unavailable ART, and lack of respect shown by clinicians in the public sector. As concerns about poor quality of care and low clinician effort have plagued the Indian public health sector generally,<sup>26</sup> it is unsurprising that these perceptions exist in the realm of HIV care.

The combination of disclosure concerns and distrust of the public sector encouraged participants to seek care at a private ART center, including participants who were not financially secure and who lived far away. Participants highly valued the perceived high quality of care and ART at YRG CARE, the respect shown by caregivers, and the lower risk of unwanted serostatus disclosure. For participants in the study, making this choice benefited their personal health as well as their own individual and family's social standing. However, this choice came with a burden of routine economic hardships related to

medication and transportation costs and lost wages. For some participants in precarious financial situations, this routine burden was enough to make it impossible to stay in regular HIV care. In other cases, life shocks such as family illness forced participants to shift financial resources and attention away from routine HIV care, causing them to default from care.

Participants with strong social support, especially those who could rely on friends and families for instrumental support, could better weather the burden of routine expenses and life shocks. On the other hand, participants with poor social support—often those who were reluctant to disclose their serostatus to friends and family—were less able to withstand these financial burdens. This is in keeping with findings from sub-Saharan Africa in which instrumental support helps to keep PLHIV in care and on ART and, in turn, creates an expectation on the part of PLHIV to adhere faithfully to ART to fulfill social responsibilities and preserve social capital.<sup>27</sup> In settings such as India or most countries in sub-Saharan Africa where the social safety net is relatively weak, instrumental support from family and friends may be critical for everyday survival, let alone maintenance of regular HIV care. Female PLHIV more frequently cited the importance of instrumental support, perhaps reflecting the socioeconomic vulnerabilities faced by women in Indian society.

Of note, we found that mental health factors such as substance use, depression, and history of violence were less frequently cited as factors causing loss to HIV care. This was surprising, given our previous findings of high rates of these conditions among PLHIV at YRG CARE<sup>28</sup> and evidence of an association of these conditions with loss from the HIV care



**Table 2.** Selected Key Themes by Lost-to-Care Status and CD4 Count.

Lost-to-care status	Key themes
Not lost to care	
Overall	Participants reported trust in benefits of ART and sought care despite fears of serostatus disclosure. “Of course, that’s why I’m taking [ART], it makes me healthy . . . Yes [I believe in it], why else would I come?” “Yes [I am ashamed]. I’m not comfortable with this. You know, they’re putting ads on radio and places. They say it’s all right to travel, sit, use the same toilet seat as someone with HIV. But people still don’t understand.”
Rural residents	Despite high rates of poverty, participants prioritized maintaining health, particularly to fulfill responsibilities for others. “Yes it’s difficult, but I have to take [ART] or it won’t work. I cannot live without the medicines. Even for a short period of time I have to live for my children. I have to bring up my children so I have to take medicines. I have to keep my health. Yes it’s difficult but I have to come.” “It’s some financial [problems] as well . . . My son he wants to study well but I can’t send him to college after school . . . I will never not take meds. But sometimes I will not eat.”
Urban residents	No distinct key themes
Lost to care	
Overall	Both urban and rural participants cited the desire to take ART and maintain their health. However, intense disclosure concerns related to perceptions of stigma in the community created barriers to regular care. “I keep it in my mind that I have HIV, and I have to be constantly aware what I say to people. Every word I speak, I am conscious.” “If I say this [the HIV diagnosis] to anyone they will say something about me and I will get bad names. They will think bad about me. It will affect my children’s life.” “I don’t tell anybody about my trips here.”
Rural residents	Participants placed importance on maintaining health, but long commutes to the clinic and the cost of medication became barriers to regular care. “These tablets only cost 3 k rupees, but coming and going costs me at least 2 k rupees . . . I skip for that reason.” “I’m not able to purchase meds, every time I come here it costs 5 k rupees. 5 k for me, 5 k for him. Our monthly income is 10 k rupees, how do you expect us to buy meds?” Unexpected adverse life events and competing needs exacerbated participants’ difficulties in traveling to the clinic. “My son had an accident, and we spent money on him. We felt like we should come to the hospital, but we weren’t able to take care of our health because of our son. Money can go and come but we need a son.”
Urban residents	Urban participants more often reported an elevated sense of self-efficacy. “I don’t depend on anybody.” “Just like blood pressure and sugar [issues], I have HIV. So it’s easy to handle.”

Abbreviation: ART, antiretroviral therapy.

continuum in other LMICs.<sup>29</sup> Mental distress among participants often resulted from learning their HIV diagnosis and was generally transient. We caution that our finding in this regard may be influenced by our strategy of sampling participants who had the wherewithal to remain in or return to HIV care, which may have missed PLHIV with debilitating mental health or substance use conditions. Furthermore, social desirability bias may have caused participants to underreport histories of substance use, violence, or mental health disorders that are perceived to be shameful.

Our finding that disclosure concerns and economic vulnerability are important contributors to loss to HIV care in India is important for policy-makers, as it suggests several targets for possible interventions. Disclosure concerns could be addressed on several levels. Interventions to reduce stigmatizing attitudes in the general population, such as educational campaigns<sup>30</sup> and contact interventions,<sup>31</sup> could reduce the perceived risks of serostatus disclosure among PLHIV. Interventions to help PLHIV safely disclose their serostatus to friends and family could allow them to build stronger social support networks and to feel more comfortable seeking care at nearby government

ART centers. Enhancing perceptions of quality of care in the public sector by reducing medication stock-outs and ensuring adequate staffing could encourage PLHIV to seek care in government facilities rather than distant, private ART centers. As stigmatizing attitudes toward PLHIV have been shown to be common among all types of health care workers in India,<sup>32</sup> innovative and interactive interventions including mHealth-based interventions<sup>33</sup> to train health care workers to engage with PLHIV respectfully could be particularly helpful. Finally, policy-makers should consider scaling-up interventions to alleviate economic hardship such as transportation incentives, food support, and microenterprise interventions. Such interventions have already been successfully implemented in several Indian states including Gujarat, Rajasthan, Tamil Nadu, and Orissa.<sup>34</sup>

There are several limitations to our study. First, as noted above, we used a clinic-based sample of participants who were currently in care or who were returning to care after previously defaulting. As a result, our data may not reflect the factors associated with loss to HIV care among PLHIV who were unwilling or unable to return to the clinic. Second, although YRG CARE is one of the largest providers of HIV care in India,

our data may not reflect reasons for unsuccessful ART initiation elsewhere within India, including government ART centers and centers that serve greater numbers of sexual and gender minorities. Sampling participants only at a private clinic likely influenced our findings on perceptions of quality of care in the public sector. Nevertheless, we believe that the fact that so many PLHIV continue to seek care at YRG CARE is a meaningful finding in and of itself. The choice of PLHIV to seek care at a private clinic, even at risk of later becoming lost to care due to other significant life challenges, demonstrates the need to improve perceptions of quality of care in the public sector, if not the quality of care itself. Further research on loss to HIV care should be conducted in a variety of settings throughout India, including government ART centers.

## Conclusions

In conclusion, in this qualitative study of factors associated with loss to HIV care in India, we found that disclosure concerns and distrust of HIV care freely available in the public sector pushed Indian PLHIV to seek care at a private ART center. This, in turn, created a burden of expenses related to HIV treatment and a vulnerability to life circumstances causing lost wages or unexpected expenditures that forced PLHIV to default from HIV care. Our findings should encourage further research into the factors that create the conditions for loss to HIV care in India as well as spur investment into interventions to improve perceptions of quality of care in the public sector, reduce stigmatizing attitudes in the general population, and provide instrumental support for vulnerable PLHIV.

## Authors' Note

Jared Perlo and Isabella Colocci contributed equally to this study. A preliminary version of this analysis was presented at the XXII International AIDS Conference; July 25, 2018; Amsterdam, Netherlands.

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## Supplemental Material

Supplemental material for this article is available online.

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