



“They Kept Away”: Social Isolation of Cisgender Women Living with HIV in Hyderabad, India

Sameena Azhar¹ · Sabitha Gandham² · Jason Vaudrey¹ · Ganesh Oruganti² · Revina Suhasini Samuel²

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Abstract

Social isolation of cisgender women living with HIV has been recognized as a barrier to early detection of the virus, disclosure of HIV status to partners, and access to healthcare and social work services. The goal of this study is to explore how social isolation and depression affect cisgender women living with HIV in Hyderabad, India. Sixteen cisgender women living with HIV were asked to complete in-depth interviews regarding their experiences with HIV stigma and depression. All interviews were digitally audio-recorded in Hindi or Telugu, then translated, transcribed, and analyzed using thematic content analysis by two to three coders. Three main themes emerged from the qualitative interviews among these cisgender women living with HIV: (1) “They kept away”: Experiences with social isolation; (2) “I thought people would think badly about me”: Perceived experiences of discrimination; and (3) “I will live till I die”: Suicidality, resilience, and gaining hope. Our findings reinforce the need for emphasis on culturally appropriate interventions for depression for cisgender women living with HIV in India, including greater access to mental health resources, greater availability of trained counselors that share the same gender and are native speakers of Hindi or Telugu, and increased family and community support for socially isolated individuals.

Keywords HIV · Social isolation · Stigma · Depression · Hyderabad · India

Background

HIV remains a pressing public health concern in India with 2.1 million [95% CI 1.7–2.7 million] people living with HIV (PLWH) in the country (NACO 2017). The South Indian states of Telangana and Andhra Pradesh bear the highest adult HIV prevalence rate of the country (0.90%)—a rate three times that of the national average (NACO 2012b). There are about 500,000 (95% CI 424,000–596,000) people living with HIV in the states of Telangana and Andhra Pradesh, accounting for 20% of all HIV infections in the country (NACO 2012a). The HIV epidemic in India is also increasingly affecting cisgender women. UNAIDS (2017)

reports that there are about 750,000 cisgender women living with HIV in India (NACO 2017).

There are multiple social, contextual, and individual dynamics that contribute to health disparities for cisgender women living with HIV in India. Chief among these factors may be women’s position in a society that tends to be characterized by patriarchal gender roles and hierarchical social structures. Women’s sexuality in India is often heavily scrutinized, leading to women’s harsher experiences with HIV stigma (Malavé et al. 2014), which may prevent them from disclosing their HIV status to others and may serve as a barrier to receiving social support (Venable et al. 2006; Derlega et al. 2002). This reluctance may also translate to cisgender women’s lack of ease in disclosing HIV status to medical personnel, causing a decreased utilization of medical care as compared to their male partners (Raveis et al. 1998).

Despite the fact that most cisgender women have become infected with HIV via their husbands, they may nonetheless be blamed for being the source of HIV infection (Mohite et al. 2015). HIV stigma can cause women to be associated with drug use, sex work, homosexuality, or promiscuity (Bunting 1996), behaviors historically deemed to be

✉ Sameena Azhar
sazhar@fordham.edu

¹ Graduate School of Social Service, Fordham University, 113 W. 60th Street, New York, NY 10023, USA

² SHARE India, MediCiti Institute of Medical Sciences Campus, Ghanpur, RangaReddy District, Medchal, Telangana 501401, India

immoral (Ghose et al. 2008). The unequal treatment of cisgender men and women living with HIV in India may be a reflection of social values which assign different standards of sexuality by gender (Mitra and Sarkar 2011). This may also be related to gender roles in Indian culture, where the male head of the household is often held blameless of sexual wrongdoing.

Women are often socialized to take responsibility for sexual and reproductive health issues, such as infertility or male impotence (Gupta et al. 2008). Gendered mores in heterosexual relationships dictate that Indian women play a more submissive role, often remaining subordinate to their male partner's needs, even when in physically or emotionally abusive relationships (Hegde 1996). Patriarchal norms and the lack of women's leverage in intimate relationships can lead to domestic and sexual domination or violence (Mitra and Sarkar 2011). Women may subvert these restrictive gender roles through both active and passive means, such as obtaining independent employment, getting a divorce, having more equitable partnerships, or choosing to stay unwed.

Though there have been many advances in recent years in medical treatment, HIV continues to be a heavily stigmatized disease (Kempf et al. 2010). HIV stigma may be a driving force in creating and maintaining health disparities among women living with HIV in India (Fikree and Pasha 2004). Stigma has been recognized as a barrier to early detection of HIV, to disclosure of HIV status to partners, and to accessing healthcare services (Scrambler 2009; Steward et al. 2008). PLWH in India are at heightened risk for anxiety and depression (Nyamathi et al. 2011). Chronic depression, stressful events, and trauma can affect HIV disease progression by decreasing CD4 T cells, increasing viral load, and creating greater risk for clinical decline and mortality (Dasgupta et al. 2013; Leserman 2008). Women living with HIV who are diagnosed with major depression are more likely to have higher activated CD8 T lymphocyte counts and higher viral load levels (Evans et al. 2014)—both indicators of reduced immune functioning.

People living with HIV are often blamed for their illness, causing shame, guilt and social isolation (Mahendra et al. 2007). Stigma-related behaviors are often based on moral judgments and fears of HIV transmission. HIV stigma impacts retention in medical care (Sayles et al. 2009), adherence to antiretroviral medications (Rintamaki et al. 2006), and the likelihood of accessing prevention-of-mother-to-child services (Rahangdale et al. 2010). Extant research suggests that cisgender, heterosexual women experience heightened stigma and discrimination for their HIV status compared to their male partners, despite the fact that the majority of HIV positive women in India became infected by their husbands (Mohite et al. 2015; Praia 2003). In a study of 50 cisgender women living with HIV in Maharashtra, almost all women experienced perceived stigma and depression at

some point in their lives (Mohite et al. 2015). Many monogamous, married women were not diagnosed until their husbands became terminally ill with AIDS (Malavé et al. 2014), until they received required antenatal HIV testing at government hospitals, or until their child passed of AIDS-related complications (Sinha et al. 2009).

Theoretical Framework

The theoretical framework that guides the present study integrates an adapted version of Goffman's conceptualization of stigma (Steward et al. 2008) with gender role theory (Feld and Radin 1982; Eagly et al. 2000). Goffman (1963) explains that society stigmatizes on the basis of what is considered difference or deviance, resulting in a spoiled identity and devalued status. Labeled as deviants, stigmatized individuals view themselves and are viewed by others as undesirable (Mahajan et al. 2008).

Stigma is a social process, characterized by exclusion, rejection, blame or devaluation, and resulting from an experience of social judgment (Scrambler 2009). Research suggests that stigma strengthens and reproduces existing inequalities of class, race, gender and sexuality (Parker and Aggleton 2003) by directly affecting individuals via mechanisms of discrimination and indirectly via threats to personal and social identity (Major and O'Brien 2005). In addition, stigma can have a dramatic bearing on the distribution of life changes in terms of several health outcomes, including psychosocial development, income, housing, criminal justice involvement, education, and life span (Link and Phelan 2001).

Gender role theory (GRT) emphasizes the importance of ascribed positions that individuals acquire by birth. In describing the context of HIV among women in India, ascribed positions may refer to gender, caste, socioeconomic status, and religion. The ascribed position of gender significantly impacts the experience of living with HIV for people in India. Achieved positions refer to those roles earned on the basis of accomplishment or effort, such as being a client of a nongovernmental organization (NGO), a community organizer for public access to HIV treatment, or the spokesperson for a pharmaceutical company. Women in low-prestige ascribed positions may view the attainment of certain achieved positions, such as achieving quality health care, as out of their reach. When ascribed and achieved positions conflict, HIV discrimination can ensue.

Role theory postulates that the social behavior of individuals can be understood in terms of society's expectations for what is considered appropriate behavior for occupants of particular social positions in specific situations (Feld and Radin 1982). Ultimately, role theory posits that social dysfunction is not caused by psychopathology, but rather by social context. Such an approach serves to shift the blame

from individual choices and towards a more interactional view of health and human behavior.

In the context of gender, individuals encounter differing expectations and experiences by virtue of their socialization as men and women. Gender roles explain the division of labor within the household and the ascription of varying traits to men and women (Agarwal 1997). In the social construction of gender roles in India, economic resources are not typically equally distributed among male and female family members. Gender roles can negatively affect the health of cisgender women when social norms prioritize the health of men or prevent women from making independent health decisions, such as traveling alone to a clinic to seek medical care (Shah et al. 2007). Cisgender women in India are generally less nourished than men, less healthy, and more susceptible to physical and sexual violence (Agarwal and Sethi 2013; Nussbaum 2001). Lack of gender equity in sexual relationships can also constrain Indian women from protecting themselves during sexual intercourse and may fuel the HIV epidemic further. Existing research has not sufficiently addressed the social processes by which cisgender women in India uniquely experience HIV stigma, particularly in regard to gender roles, social isolation and depression. To address these gaps in the current research, the present study explores how HIV stigma affects experiences of social isolation for women living with HIV in Hyderabad, India.

Methods

Analytic Sample

The study population is defined as cisgender women living with HIV. The analytic sample was defined as cisgender women between the ages of 18 and 50 living with HIV in Hyderabad, India. Inclusion criteria for the study were: (1) identify as cisgender female; (2) self-report as being HIV-positive, (3) reside in Hyderabad or Secunderabad, India, (3) proficient in speaking Hindi/Urdu or Telugu, and (4) being between the ages of 18 and 50.

A mixed methods study was conducted, involving two interrelated phases that occurred consecutively, with the quantitative and qualitative phases bearing equal weight (Leech and Onwuegbuzie 2009). In Phase one of the study, 150 PLWH were asked to participate in a survey regarding their experiences with HIV stigma, depression, and access to medical care. One third of these respondents ($n=51$) were cisgender women. Following the completion of surveys, a preliminary descriptive analysis of these responses was conducted. Stratifying survey responses to the two HIV stigma scales used in the study (Jeyaseelan et al. 2013; Zelaya et al. 2008), a subgroup was created of cisgender women comprised of the eight cisgender women with the highest HIV

stigma scores and the eight women with the lowest HIV stigma scores. These 16 cisgender women were recruited to participate in Phase two of the study. This sampling method was utilized in order to ensure heterogeneity in the interview subgroup. In Phase two, participants were asked to complete in-depth interviews on how their experiences of HIV stigma have been influenced by gender roles. Interviews were intended to explore the gendered experience of HIV stigma and to contextualize the answers from the quantitative survey. Given that this manuscript focuses on experiences of social isolation, there is a larger cluster of individuals whose stories are included here that had scored “high” on the stigma scales.

Recruitment

Purposive and snowball sampling techniques were utilized to recruit study participants. For purposive sampling, participants were recruited through existing collaborations with five local NGOs serving individuals living with HIV in Hyderabad, as well as through additional snowball sampling of participants. Two of these organizations focused on offering services to people living with HIV in Hyderabad; another two organizations focused on services to third gender or queer communities; and the fifth organization focused on health services for rural communities.

To recruit from these four NGOs, a local research assistant posted recruitment flyers in Hindi and Telugu at the field sites of the collaborating organizations. The research team visited each of the four organizations to recruit potential participants. To capture those men and women who were not currently connected to social service organizations, the team additionally utilized snowball sampling. Snowball sampling has been heavily utilized in disease prevention and public health intervention (Magnani et al. 2005). It is particularly well suited when the focus of study is a sensitive issue, and thus requires the knowledge of insiders (Coleman 1958; Biernacki and Waldorf 1981). By taking advantage of the social networks of identified respondents (Vogt 1999), greater variance may be assured in the sample. For the purposes of this study, individuals who were initially recruited from the five collaborating organizations were asked to share information about the study to eligible peers. To protect confidentiality, no additional contact information of these peers was elicited from recruiters. Interested peers had the option to directly contact the research team if interested in participating in the study.

Language of Surveys/Interviews

Surveys and interviews were conducted in both Hindi and Telugu. To ensure translation accuracy and internal consistency, all relevant documents, including flyers, consent forms

and surveys, were translated from English to both Hindi and Telugu, and then back-translated to English. A local translator conducted Hindi translations; a local research assistant conducted Telugu translations. Certificates of translation were produced for the University of Chicago Institutional Review Board (IRB) and the Internal Ethics committee at SHARE India. For respondents who were illiterate, the interviewer read questions aloud and recorded answers for the participant. These individuals consented to the study by utilizing a thumb print as their signature—a commonly accepted legal practice in India.

Incentives

All participants who completed either the survey or interview were compensated 200 Rupees (equivalent to \$3.14 USD at the time that this research was conducted). Individuals who participated in both phases of the study received a total of 400 Rupees (\$6.29 USD). This amount was determined after consulting with local staff members at community-based organizations, who indicated that this is a fair incentive for research participants in Hyderabad. If a participant assisted in recruiting other individuals through snowball sampling, the recruiter received an additional incentive of 100 Rupees per completed referral.

Interview Format

Interviews lasted about 90 min. The interview guide was organized around eight domains: (1) gender roles, (2) gender nonconformity stigma, (3) HIV diagnosis, (4) HIV disclosure, (5) HIV stigma, (6) caste, poverty and religion, (7) utilizing medical care, and (8) social isolation and depression. The first section of the interview asked questions related to gender roles and gender nonconformity. Gender roles were addressed by asking participants open-ended questions relating to their gender role demands and stress. This section also included questions regarding household dynamics, such as power to make decisions regarding money and health. Questions concerning HIV diagnosis and HIV disclosure followed next, followed by a section on HIV stigma, medical care, social isolation and depression. Some questions in this section were adapted from the HIV Stigma Index in India (GNP+, ICW & UNAIDS 2011).

Data Collection, Analysis and Ethics

All interviews were digitally audio recorded, then subsequently translated and transcribed directly into English. Transcripts of the interviews were imported into the data analysis program, NVivo 10 (QSR International 2014) for coding, using thematic content analysis (Krippendorff 2012). After reviewing the first ten transcripts, three

evaluators—the principal investigator, a U.S.-based research assistant, and an India-based research assistant—developed an initial codebook of themes. Relevant chunks from transcribed data were assigned codes (Charmaz 2006; Miles and Huberman 1994). Identified codes were placed in broad groupings. The codes under each heading were clubbed together and the content analyzed for common themes. Quotes or passages were selected to illustrate each of these themes (Smith et al. 2009).

After initial coding, the team met to discuss differences in how codes were applied. Code definitions were redefined, and codes were combined to reflect themes found in the data. Codes were then clustered together by specific themes to create a codebook. The refined codebook was subsequently used to code the remaining interviews with each interview being coded by at least two people. Whenever there was a discrepancy in a coding decision between two coders, the third coder would be asked to review the coding decisions and discuss any significant differences in coding decisions or patterns. After deliberation, consensus was reached on all coding decisions. Emergent themes included difficulties in disclosing HIV status to family members, gender role conflict, and lack of ease of accessing medical care. Only themes related to HIV stigma, social isolation, and depression are reported here. All names of participants have been changed to maintain the confidentiality of participants.

An IRB application was approved by the University of Chicago School of Social Service Administration/Chapin Hall in September 2015. In November 2015, IRB approval was also obtained through the internal ethics committee at SHARE India in Secunderabad, India. An additional IRB approval was approved by Fordham University in October 2018 for continued data analysis of the study findings. All participants' names and other identifying details were changed in this manuscript to protect their confidentiality.

Results

As indicated in Table 1, cisgender women in this sample had a mean age of 37.25 years ($SD = 7.67$) with a mean monthly income of 6777 Rupees ($SD = 4121.44$) and a self-reported CD4 count of 431.75 ($SD = 298.62$). All 16 women in the sample identified their gender as female and their sexual orientation as heterosexual. The majority of the sample was Hindu (77%). Most were members of a scheduled caste or tribe (75%), a designation of marginalized status conferred by the Government of India on particular sub-groups. The majority of these women (87%) spoke Telugu as their native language. Most women (84%) had a secondary level of education or less, approximately equivalent to the completion of the eighth grade in the United States.

Table 1 Descriptive statistics of cisgender women living with HIV in Hyderabad, India

	Cisgender women (<i>n</i> = 51)
Age	
Mean (SD)	37.25 (7.67)
Monthly income	
Mean (SD)	6776 (4121.44)
CD4 count	
Mean (SD)	431.75 (298.62)
Caste <i>n</i> (%)	
Brahmin	2 (4%)
Forward caste (e.g. Vaishya, Komati, Kamma, Kapu, Reddy)	10 (20%)
Scheduled caste	14 (27%)
Scheduled tribe/adivasi	0 (0%)
Backward class-A	1 (2%)
Backward class-B	13 (25%)
Backward class-C (Christian converts)	1 (2%)
Backward class-D	8 (16%)
Backward class-E	0 (0%)
Other	1 (2%)
Declined to state	1 (2%)
Any member of SC/ST	38 (75%)
Religion <i>n</i> (%)	
Hindu	39 (77%)
Muslim	8 (16%)
Christian	4 (8%)
Education <i>n</i> (%)	
No formal	17 (51%)
Primary	7 (14%)
Secondary	18 (35%)
Intermediate	7 (14%)
Vocational	0 (0%)
Graduation	1 (2%)
Post-graduation	1 (2%)
Native language <i>n</i> (%)	
Hindi	4 (8%)
Urdu	4 (8%)
Telugu	43 (87%)
Gender identity <i>n</i> (%)	
Female	51 (100%)
Sexual orientation <i>n</i> (%)	
Heterosexual	51 (100%)

All of the cisgender women in this sample reported becoming infected with HIV from their husbands, who they reported had been their only lifetime sexual partner. Many women reported being widowed after their husbands died of AIDS, leaving them alone to take care of multiple children. Receiving an HIV diagnosis often resulted in cisgender women experiencing long bouts of depression and suicidality, sometimes lasting multiple years. Many women reported

that the need to take care of their children was their major motivator to carry on with life. Three main themes emerged from the qualitative interviews: (1) “They kept away”: experiences of social isolation; (2) “I thought people would think badly about me”: perceived experiences of discrimination; and (3) “I will live till I die”: suicidality, resilience, and gaining hope.

“They Kept Away”: Experiences of Social Isolation

Upon disclosure of their HIV status, many women expressed being ostracized from their own biological families or from their in-laws. These interactions often centered on fears of contagion, from both health-related and moral avenues. One respondent, Sitara, recounted how her family had stayed away from her because of the negative associations ascribed to living with HIV. She also expressed that her family worried about becoming infected by her.

Sitara: I think, ‘What sin have I committed?’ I am facing all these difficulties. I am not happy, madam. I always think about my children. I have to give them a good life. When I became HIV-positive, I felt so much tension, madam, and my small daughter is also positive. People kept away from me, thinking that they will get the disease from me.

Interviewer: Who kept away from you?

Sitara: We lived together as a joint family. When they knew about this disease, they [my family] kept away. At that time, I felt very bad, thinking that everyone was healthy. Why has God given me this disease?... They kept away, madam, I felt very bad thinking about how I got this disease. I cried a lot... I felt like I was going to die tomorrow. My husband and I felt horrible and thought about committing suicide. Only because of our children did we not kill ourselves. In our family, nobody is aware of this disease. I have been living with HIV now for 14 years.

Sitara’s story highlights how HIV stigma from family members persists, even when they have been properly educated about transmission routes. Women often discussed how their HIV status led them to be seen as impure or unclean, even when others were aware that they could not be casually infected by socially interacting with them. In terms of sexual health, cisgender women were often accused of being the vectors of sexually transmitted infections, even though they reported that their only lifetime sexual partners were their husbands. These experiences speak to the lasting social impacts of HIV stigma and social isolation, and also highlight the gender imbalances between the experiences of cisgender women and their male partners.

Another participant, Layla, reported similar experiences of social isolation within her family. She recounted her

treatment in the hospital by her family and medical providers. When she was first diagnosed, she was blamed for having been infected with “HIV from [her] bad behavior.”

I was not tested when I was pregnant. Only about a half an hour before my delivery was I told of my HIV status. They called my husband and made him test also. He too was HIV positive. Then they tested my son, but they did not tell me anything. They were talking with each other, but no one was saying anything. Prior to this, they placed me in the general ward, but now they put me in a separate room. We have very little money and I wondered how we would be able to pay the bills for this big room. Before that day, doctors would come to check on me, but then no one would come to see me. They were only giving me medications and kept me in a separate room. No one bothered me... It was tense and we had little money. They had put me in an isolated room and after three days, I was discharged and taken directly to Gandhi Hospital. Everyone was talking, but no one was telling me anything. After going to Gandhi, I came to know [about my HIV status], but prior to then, I did not know anything. I was nervous, but they told me not to worry. My parents didn't say anything, and my in-laws thought I got HIV from my bad behavior. After my baby was delivered, I was taken to Gandhi Hospital and then they told me. We all cried a lot.

While experiences of discrimination within the health care system were undoubtedly traumatizing for PLWH, some of the most hurtful experiences of being shunned occur within participants' own families. Layla reported how her family treated her, following her diagnosis and how these experiences left her feeling rejected, socially isolated, and depressed. She reported that she had educated her family about the ways in which HIV could be transmitted, and they were aware that contact with saliva was not infectious. Nonetheless, Layla was treated differently by her family, following her diagnosis, and was told not to feed her niece with her own hands:

My mother treated me differently. When I was released from Gandhi Hospital, my parents took me back to their house. One day my mother gave me rice to eat, then my brother's daughter asked me to feed her. When I was feeding her [with my hands], my mother came and said, “Why are you feeding her your rice?” She said that she would feed my niece herself. I told my mother that I had not already eaten from the same plate, and that is why I was feeding her. Otherwise, I would not feed her... Sometimes I think that because of my HIV status and my husband's death, I have lots of problems and I often get fed up with my life.

But I have to be alive for my children. I feel sad that everyone is happy, but I am unable to be happy with them... My mother's sister also has the same feelings towards me. She told my family members to keep my plate, glass, soap—everything—separate. She would say, “Why are you always allowing her to be with you people?” I have suffered a lot this way.

Layla's experience of having to use separate dishes within her own home and being advised to not feed her niece are examples that showcase how HIV stigma is based not on lack of HIV knowledge, but rather on social stigma and prejudice about the cleanliness/purity of the infected individual. Often these fears and prejudices persist even when people have been educated about HIV transmission routes, as this family had been. The stigma continues, not solely out of the family members' fear of being infected themselves, but also out of a desire to not be socially associated with an infected, and thus morally impure, individual.

Another respondent, Jyothi, reported how she finds it difficult to move freely in the world, as the tethers of HIV stigma limit her everyday experiences.

Yes, madam, every day I am very sad about myself. Because we cannot move freely with everyone, like regular people... At that time [when I was first diagnosed], I felt very bad about myself. I thought, ‘Why should I live this life?’ If I die, who will take care of my children? If I didn't have children, I would have died... I have thought about suicide, but because I have children, I have not attempted suicide. [At the government hospital] we are treated differently, compared with normal people. We are kept away. And when they prescribe us medicine, they do so without touching us.

As has been shown in other narratives, the participant's children serve as their saving grace from depression and act as a source of prevention against fatalism. Gender role theory offers insight into understanding this phenomenon as the demand of being a responsible mother is of critical social importance to an Indian woman. This sense of *dharma* or the completion of one's familial duties and obligations, ultimately trumped feelings of depression and suicidality that many women living with HIV in India experience.

“I Thought People Would Think Badly About Me”: Perceived Experiences of Discrimination

In this section, we discuss ways in which people fear how the body will be negatively perceived by others as a result of being associated with sickness or ugliness. Several women reported their fears of incurring judgment from others if their HIV status became publicly known. Most women who worked in the formal labor sector reported being

worried about losing their employment if their employer came to know about their HIV status. Sujatha recounts this experience:

I have not told anyone at work that I'm HIV positive for fear I might lose my job. Because I am afraid that if I tell them that I have HIV, they will remove me from my job. That's why I did not tell anyone... People would not touch me [if they knew I was living with HIV]. And they would not even talk in close proximity to an HIV-positive person... They were afraid that if they touch me, they would also get the disease.

Similarly, Lakshmi reports how she refrains from sharing her status with others because they will assume that she had been infected through immoral actions and that her illness was a deserved consequence of these actions.

I thought people would think badly about me, they would say she doesn't have a husband. She must have done wrong things. That's the reason she got this. And I thought they would hate me. Because of this fear, I do not tell them. People in the community think that people who are HIV positive made bad choices and that is the reason they are HIV positive. When we go to the hospital they will hate us and harass us... I have been treated differently by my sister. She did not say anything directly, but her behavior changed. She stores our clothes separately from her own. I have been living with HIV for nine years... There have been many quarrels in my home about getting this disease. Even today, none of my in-laws in my home know that I have HIV. And I will not share this with them... If I tell my [sisters'] in-laws, they will quarrel with my sisters. They will say your sister got this, ask them where I went, and how did I get this. They will pick on my sisters and say, "You are well. Why did your sister get this disease and not you?" They will fight with my sisters, so I don't want to tell them.

Keeping one's HIV status a secret serves to protect not only the women themselves from stigma, but also their family members. Such group associations, when the action of one member of the family is reflective on the entire family, are more typical of collectivist cultures, like that of South Asia, that place greater social emphasis on family unity, honor and group inclusion over individual freedom and autonomy.

The self-esteem and the mental health of women living with HIV were often shaped by the ways in which the progression of their disease affected their physical appearance. Women were concerned about how others would perceive them and then potentially discriminate against them, based on their looks. Janaki reported how she felt ashamed when she started to lose weight and began to look visibly ill.

I felt people didn't want to talk to me because I had this disease. I felt embarrassed when I was walking on the street because I used to look so ugly. I was 27 and my weight was 27 kg [approximately 60 lb]. My hair color was black, but I had lost all my hair and looked like a beggar. I felt that people would be afraid of me when they saw me. It was difficult for me to leave the house. I used to leave the house only once a month, to pick up my medication. It was like this for two years... I did not tell my relatives and neighbors [about my HIV status]. I did not tell my friends. When my friends asked me, "Why did you become like this?" I told them I became depressed when my husband died. I was fearful that if I told them, they would stop talking to me. And then they would tell my parents and my parents would send me out. When I became part of the HIV network, I heard of parents kicking their children out of the house after finding out about their HIV status. That is the reason I did not tell anyone.

Most women do not share their HIV status for fear of the negative consequences of having their condition be known, and for fear of the association of living in poverty or becoming a beggar. The associations of living with HIV have connotations with socioeconomic status, as well as with illness.

Throughout the interviews, we found that HIV disclosure outside of one's immediate family was a rare occurrence for most cisgender women. Because of fears of perceived discrimination, women chose to not disclose their HIV status, often even to people within their own family. Another research participant, Seema, shared her experience of not wanting to disclose her HIV status to others as it made people assume that she had become infected through engagement in sex work:

I have only told my sister and my brother-in-law. Some people have [HIV] awareness and some people do not. If I tell people that I am HIV positive, people will look at us like we are cheap, and they will think I am a street lady [sex worker]. Because of this reason, I do not tell everyone.

The source of HIV's heightened stigma appears to be caused by its recurring association with illicit behaviors—sex work, injection drug use, sex between men—or their corresponding illicit identities—sex workers, injection drug users, and gay/bisexual men. Women remained acutely concerned about how others in their community would treat them and their children differently, should their HIV status become publicly known. To avoid these anticipated experiences of discrimination, they kept their HIV status a secret.

“I Will Live Till I Die”: Suicidality, Resilience and Gaining Hope

Multiple cisgender women in this study reported experiencing thoughts of suicide, hopelessness, social isolation, and severe depression. Janaki reported how difficult it was to maintain the desire to be alive.

Having HIV is like hell... For two years, I saw hell on earth. Besides, I also get side effects. I thought, “Why do all these things happen to me?” Sometimes I think it is better to die... After that, I gave myself courage. I don’t have any problem with this. And I realized, “Why should I die for this reason?” I will live till I die. Then I will stop thinking about death.

The statement of “living till I die” is at once pragmatic and existential. Janaki highlights the universal human experience of mortality, and the accompanying fear of death that chronic illness may instill. However, she is nonetheless able to use the inevitability of her death as a motivation for continuing to live.

For many women, their children were their main motivations to stay alive. Sitara, like many of the interviewed women in this study, reported that her children offered her the sole hope for her future.

At first, I cried a lot and did not understand why I had this disease. My mother did not know what this disease was. Today I feel that every person will die someday. We will die a little early. I have no fear because I am living a happy life with my children.

Applying the constructs of gender role theory, we see that Sitara finds her purpose through the fulfillment of her gendered role as the primary caretaker for her children.

Seema, like many women in the study, initially experienced feelings of hopelessness regarding her HIV diagnosis. But after being informed that there were treatments for her condition and that living with HIV would not necessarily lead to an early death, she regained hope for the future. It is noteworthy that her sense of purpose is also obtained through the fulfillment of her role as the mother of her daughter.

[My husband] was sick, madam. He got piles [hemorrhoids] and jaundice. He was becoming very sick. We took him to the hospital. When the doctor did an HIV test for him, we came to know that he is positive. Then the doctor immediately did the same test on me, and we found out that I also have HIV. I was very depressed, and I cried a lot. I thought my life was a waste because I have only one daughter. I thought, we all have HIV. My daughter might also have this. We thought to die. But I gave my husband courage. Why

should we die? We have medicine. We will take medicine. When we came to know, at first I cried a lot. I did not eat rice for two days and thought, “Why has our life become like this?” After that, we got used to it... My husband also cried a lot. He might have done a wrong thing, knowingly or unknowingly, and he said, “Sorry” to me. As a wife and husband, we cannot quarrel and separate. If I am healthy and separated, that would be different. He has HIV and I have HIV... We thought to die. But for our daughter’s sake, we stayed alive.

Once again, the recurring theme of remaining alive for the sake of one’s children is evident in this passage. Seema also highlights traditional views regarding the lasting nature of marriage, and how quarrels between husband and wife need to be worked out, regardless of infidelity or sickness. She hints at his infidelity as she mentions her husband “hav[ing] done a wrong thing, knowingly or unknowingly.” Perhaps this “wrong thing” was injection drug use, having sex with another male or female person, or having solicited a sex worker. Seema’s strong commitment to maintaining a marriage at all costs is again reflective of the importance placed in South Asian culture on family unity. Conversely, being single, divorced, or widowed in South Asian culture are considered undesirably tragic life experiences.

Many women reported that the reason that they were able to pull themselves out of moments of considering self-harm or suicide was because of the responsibility they felt for the well-being of their children. Seeking purpose only through one’s children is a recurring theme, reinforcing the notion of women’s primary and essentialized role as mothers and caretakers. One participant, Rubaina, reported:

My husband would cry a lot. We have a big family. My husband has six brothers in his family and we used to think that we should die, without suffering and without giving trouble. We used to cry often thinking about our children. We would wonder that if we were to die, who would take care of our children? My husband was taking homeopathic medications, but he was becoming sicker by the day. After seeing him become more ill for two months, I stopped taking homeopathic medications. At the time of his death, I was very afraid, but I thought I should live for my children. If I died, I knew anyone would be able to take care of my elder daughter, but nobody would take care of my younger daughter because she is HIV positive. It was then that I regained the courage to live. We used to go to Freedom Foundation for a checkup every month. People there were so friendly and would take us to lunch. My daughter would come with me. People said that even though my husband died, I should live for my children and give them a good future. I got a lot of courage from Freedom Foundation.

This example illustrates how community-based organizations play an important role in linking people living with HIV with health care and social services. These settings serve as spaces where women can receive the type of social support that is often unavailable to them from their own families, communities, or the government health care system. Radha's resilience against the forces of social exclusion speaks to the strength that cisgender, heterosexual women living with HIV have developed in the Hyderabad context. These traits serve to protect them against the spoiled identity conferred onto them by the judgments of society. Another participant, Azmath, reported her feelings upon being diagnosed with HIV.

After I found out I had HIV, there was not one day I did not cry. First, I cried about my husband and when I found out I had HIV, I continued to cry. In the beginning, I was not aware of this disease. My doctors told me I had AIDS and I would not live for more than six months to a year. They told me to not give my milk to my son nor kiss him. They told me to go to Hyderabad where there are many hospitals. Otherwise, go to Kurnool [her village], and you can get medicine for this. I thought if I take medicine, the disease will go away. When I saw my husband, I feared I would become like him and die. When the doctors said to me to keep away from my son and not to kiss him, I became very depressed, not about my disease. I was depressed about the doctors' words [about keeping away from my son]... When I felt suicidal and attempted suicide, my relatives told me to get married again, that my husband did not make me happy, and that I would not get any property from my in-laws. "Give your children to your mother and get married," they would say. Wherever I would go, I heard this sort of talk and I was fed up with this talk and I decided I wanted to commit suicide... I took a few pills, but I thought of my children and that God had taken their father. If I were to commit suicide, who will take care of them? Immediately, I went to my mother and told her I took these pills, and she took me to the hospital and I was given treatment.

Once again, the saving grace in this instance was the woman's recognition of the importance of her children. Given the high cultural value placed on marriage with children, this causes clinicians to question whether cisgender women living with HIV in India who are unmarried or without children, like Lasksmi, still have the same motivations for life. Clinicians working with single, divorced or widowed women living with HIV should take utmost care to ensure the prevention of extreme depression in their clients as these women are at increased risk for social isolation and suicidality. Azmath's report that her doctor told her not to kiss her son is reflective of misinformation about

HIV transmission that is being disseminated by medical staff to their patients in India, thereby exacerbating pre-existing social stigmas.

Limitations

Both the interviews and surveys were subject to social desirability bias, where respondents answer questions or behave in a way that will portray them favorably to the researcher. Participants may have consciously wanted to present themselves in a way that emphasizes the challenges they have experienced as a result of living with HIV. Alternatively, they may also have wanted to portray themselves as strong, resilient and healthy, and may have downplayed these same experiences.

These results were not intended to be generalized for cisgender women living with HIV outside of India, or perhaps even outside of the city of Hyderabad. Regional variation in cultural norms, religion, language, and socioeconomic status within South Asia confer significantly different contexts for the interpretation of gender roles and social interactions. The context for cisgender, heterosexual women may not be readily comparable to populations outside of south India, making it difficult to make generalizations regarding PLWH in locations outside of the cities of Hyderabad and Secunderabad. Given that this study was qualitative and had a small sample size, no expectations regarding generalizability have been made.

In terms of the sampling method, using a largely organizational recruiting method entails a strong source of sampling bias (Watters and Biernacki 1989). People living with HIV who are recruited from social service organizations are by definition connected to receiving resources, so we may be eschewing the very population that we are seeking to find—those individuals who are *so* stigmatized by their HIV status that they are avoiding medical treatment or HIV-related social services altogether. Although we additionally utilized snowball sampling and online recruiting to identify respondents, these methods may also be considered biased because they are not random and instead select individuals on the basis of social networks, who again, are more likely to disclose their HIV status (Browne 2005). Another issue with snowball sampling is whether the phenomenon being studied actually results in the formation of social networks. If the phenomenon is private, as is HIV stigma, and snowball sampling is network dependent, we can expect to encounter problems in capturing the actual variance within the population. Additionally, the verification of eligibility and the accounts of respondents may be compromised as the sources used to initiate referral chains become more distant (Biernacki and Waldorf 1981).

Discussion

In our study, cisgender women experienced multiple forms of intersectional stigma—from their HIV status, to their caste position, to their widowhood. Our research adds to a body of evidence that demonstrates how intersecting systems of oppression intimately affect the lives of women in developing contexts. Our findings validate previous research that highlights how people living with HIV who experience stigmatizing interactions experience higher levels of stress and distress (Hutton et al. 2013; Van Hollen 2010). Women in our study experienced disproportionate stigma and blame from their husbands and the families of their in-laws, causing them to have painful experiences of social isolation. Confirming previous research (Kang et al. 2005), we found that HIV stigma increases pre-existing social prejudice, disproportionately affecting individuals already socially marginalized for other reasons, such as sexual orientation, gender nonconformity, occupation, or caste. Occupying multiple marginalized identities creates intersectional vulnerabilities for cisgender women living with HIV, making it more difficult to obtain quality medical care and compassionate psychosocial support.

Many participants expressed their fears regarding HIV disclosure and were concerned that social perceptions regarding people living with HIV would negatively impact their lives. The majority of the women in our study hailed from scheduled castes or were living in poverty, leading to the experience of multiple layers of stigma (Pulerwitz and Bongaarts 2014). As highlighted by our research, cisgender women experience unique challenges in overcoming HIV stigma. Because of the ways in which HIV stigma differentially impacts women, women are less likely to disclose their positive HIV status to medical providers and are less likely to receive the support they need to cope with their illness (Wingwood et al. 2007).

Our research has important implications for social work research and policy. Research on gender and sexuality in South Asia suggests that a patriarchal hierarchy for decision-making is recognized by both families and communities. Key family decisions, such as those regarding health and money, are reserved for men in their capacity as heads of the household. Women are often assigned other responsibilities in their capacity as nurturing wives, mothers, and daughters (Kabeer 1999). The importance of this primary role as mother and wife is repeated throughout the narratives of the cisgender women in our study. The primary gender role of mother is reflected in women's explanation that their children are their main justification for remaining alive. According to gender role theory, from the time of childhood, men and women are socialized to engender specific attributes and social behaviors (Eagly et al. 2000).

In the South Asian context, it becomes increasingly important for women to fulfill the gender role demand of being mothers and being the primary caretakers of their children. For example, Layla's experience of being prevented from feeding her niece creates role stress, as she is unable to complete her role as a mother, caretaker, and nurturer within the home. The inability to perform this role leads Layla to "[suffer] a lot this way," an experience which we might translate as gender role stress.

The existing literature examining gender roles and differences in social support and well-being suggests that men and women differ not only in their social behaviors, but also in the sources from which they draw support (Eagly et al. 2000). Previous research indicates that women do not want to relinquish their role as care providers and nurturers as a result of their HIV-associated illnesses (Gordillo et al. 2009). Married women in India are also likely to experience secondary claims on household resources, violence at the hands of their husbands, and a willingness to bear and support children to the detriment of their own health (Kabeer 1997). The rise of new waged opportunities and changes in gender roles in South Asia may make it easier for women to demand greater equity within their sexual and marital partnerships or to gain the financial ability to leave unsatisfactory marriages without fear of living in poverty. There may be important implications of these nuances in gender interactions in the south Indian context for social and public health policies impacting women living with HIV.

Clinical Implications for Social Work Practice

Our findings highlight the need for greater local and regional public health programming that focuses on the health disparities faced by cisgender women living with HIV. Understanding how gender interacts with HIV stigma is of critical importance for policymakers as they develop programs for HIV prevention and care (van Hollen 2010). In the context of HIV progression to AIDS, delaying or avoiding medical care because of the fear of discrimination in healthcare settings ultimately leads to poor health outcomes. Conversely, a high level of social support can lead to an improved quality of life, particularly in regard to mental health. Strong social support has been shown to be protective against the negative impacts of depression and social isolation (Charles et al. 2012).

In our study, many women reported contemplating suicide, yet almost none of them had sought formal treatment for these suicidal ideations or attempts. These narratives also highlight that there is a lack of publicly available programming within government hospitals and NGOs to address the mental health needs of cisgender women. From a cultural perspective, it also reiterates how many Indian women see

their mental health to be a private problem and would feel uncomfortable sharing these experiences with a counselor who they perceive to be a stranger. Mental health professionals may be viewed as outsiders to the family and bringing up such issues to them may be viewed as causing shame or dishonor to the family.

From a clinical social work perspective, our findings reinforce the need for greater emphasis on culturally appropriate treatments for depression, particularly for cisgender women living with HIV. Such programs need to be made available within the context of sexual and reproductive health care as Indian women are more likely to seek out obstetric/gynecological care over mental health care. A more holistic approach to the wellness of women living with HIV will need to pay attention to not only immunological functioning, but mental health as well. Individual counseling and the taking of psychotropic medications for anxiety and depression are still not widely accepted practices in the Indian context. Therefore, both psychoeducation and the tailoring of social interventions for the cultural context of South India are needed to ensure the success of clinical outcomes. Family and community-level interventions are also sorely needed to ensure that misinformation about disease transmission does not cause people living with HIV to continue to be socially isolated from their family or community members. Additionally, education, vocational training and employment opportunities for cisgender women living with HIV are needed to help foster women's financial independence; this may be especially relevant for women who have lost their partners to AIDS.

Given the greater emphasis on groups and collectivism in the South Asian context, the practice of group therapy or social support groups may be a more appropriate intervention for women experiencing depression. In a clinical pilot intervention in San Francisco, an HIV stigma-reducing group intervention was held in a community mental health setting to gay and bisexual men living with HIV who were currently connected with care, but reported ongoing difficulties due to HIV stigma. Based on acceptance and commitment therapy, this intervention was effective in reducing stigma among persons with substance abuse histories and in reducing internalized homophobia. The intervention incorporated exercises from compassion-focused therapy to increase compassion while decreasing shame (Skinta et al. 2015). Such an intervention might be adapted for the context of cisgender women living with HIV in India.

In another group-based behavioral intervention for adolescents and young adults newly diagnosed with HIV, four dimensions of HIV-related stigma were addressed: personalized stigma, disclosure concerns, negative self-image, and concern with public attitudes about people with HIV (Harper et al. 2014). While results were effective at reducing stigma for males across all four dimensions, females

only experienced a decrease in personalized stigma and this effect was not maintained at a 3-month follow-up. All other types of stigma actually increased for women at post-intervention and 3-month follow-up. These findings lead us to conclude that researchers have failed to identify effective means of decreasing HIV stigma for women, reiterating the need for further research on gender-specific health interventions.

Previous research has demonstrated that women with a heightened sense of fear around health-decline and death may use avoidant coping behaviors to manage their anxiety, resulting in poor self-care behaviors, such as lack of adherence to HIV medications (Willie et al. 2016). Psychosocial factors are important predictors of quality of life for women living with HIV. In a study of 600 women living with HIV in India, an intervention led by nurses who worked as "social health activists" was found to be effective at increasing women's access to social resources and social support (Garfin et al. 2019). This case management approach, well known to clinical social workers, may be especially useful in not only helping link women living with HIV with needed resources, but also ensuring that they are connected to circles of social support. In another intervention, a support group used narrative therapy to help PLWH process experiences of suffering, and share insights, connections and comfort to each other (Dean 1995). Social workers working with PLWH should incorporate the association between stigma and depression into their programs (Li et al. 2009) and should address social support as a protective factor for mental health. Given the intersectional nature of HIV stigma in India, it is especially important for women living in poverty to overcome social isolation in order to lead healthy and connected lives.

Similarly, for social workers who serve women living with HIV, certain clinical insights may be important to consider. For clinicians who have been doing HIV work for a long time, there must be an awareness of the vicarious trauma and compassion fatigue that can result from having witnessed the illness and death of many clients over time (Gabriel 1991). In such cases of having "survived" one's patients', it is the clinician who becomes the bereaved, causing experiences of grief, mourning, and loss. Being carefully attuned to countertransference and the impacts that this work can have on clinicians may help prevent burnout and sustain a clinical social worker's career longevity in the field of HIV care. Clinicians working with PLWH may be further aided by receiving clinical supervision, being in psychotherapy themselves, and taking meaningful breaks away from the work (Smith 2007). Addressing social isolation in vulnerable communities, like women living with HIV in India, who are experiencing multiple forms of marginalization requires clinical tenacity, resilience and compassion.

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Sameena Azhar has 15 years of clinical and research experience in the fields of mental health, substance abuse and HIV. She is currently an Assistant Professor in Social Work at Fordham University and a fellow with the HIV and Drug Abuse Prevention Research Ethics Training Institute (RETI).