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HIV STIGMA AND GENDER:

A MIXED METHODS STUDY OF PEOPLE LIVING WITH HIV IN HYDERABAD, INDIA

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DEDICATION

Dedicated to Mr. Bruce Hockman; Jack Fertig, the original Sister of Perpetual Indulgence; Sitara, and all the other people whose lives were cut short by this devastating epidemic.

“It is better to speak
remembering
we were never meant to survive.”
~Audre Lorde

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“And this is the simple truth - that to live is to feel oneself lost. He who accepts it has already begun to find himself, to be on firm ground. Instinctively, as do the shipwrecked, he will look around for something to which to cling, and that tragic, ruthless glance, absolutely sincere, because it is a question of his salvation, will cause him to bring order into the chaos of his life. These are the only genuine ideas; the ideas of the shipwrecked. All the rest is rhetoric, posturing, farce.”

~ Jose Ortego y Gasset, *La rebelión de las masas*, p. 157

ABSTRACT

The goal of this dissertation study is to explore how HIV stigma and gender interact in the lives of people living with HIV in Hyderabad, India. This study pays particular attention to gendered experiences of depression and medical care utilization. The theoretical framework for the study integrates gender role theory with an adapted version of Goffman's conceptualization of stigma. The study utilizes mixed methods in two interrelated phases. In Phase 1, 150 individuals living with HIV (51 cisgender women, 49 cisgender men and 50 *hijra*/transgender women) were recruited to complete a survey that investigated associations between HIV stigma and two outcomes: depression and medical care utilization. The mean age of participants was 38.03 years (SD=7.62); mean income was 8,8083 Rupees (SD=5,917); and mean self-reported CD4 count was 447 (SD=258). The majority of participants were Hindu (85%), spoke Telugu as their native language (89%), and were members of scheduled castes or tribes (79%). HIV stigma was found to be positively associated with both depression and medical care utilization. In phase 2, 32 individuals (16 cisgender heterosexual women and 16 *hijra*/transgender women), scoring on the high and low ends of the stigma scales, were recruited to participate in in-depth interviews, exploring their experiences with HIV, gender roles, and gender nonconformity. For cisgender women in India, HIV stigma was found to be impacted by restrictive gender roles, a limited ability to refuse or delay sex or marriage, and the prioritization of male partners' health over females' health. For *hijra*/transgender women in India, sex work, gender nonconformity, and the multiplicity of gender identity were found to be important factors in influencing HIV stigma. These findings emphasize the importance of tailoring HIV policies and programs to fit the specific mental and physical health needs of *hijra*/transgender people and cisgender women in Hyderabad, Ind

INTRODUCTION AND SPECIFIC AIMS

Though there have been many advances in recent years in HIV medical treatment (Cohen et al., 2015; Crum et al, 2006; Murphy et al., 2001), 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 cisgender women and *hijra*/transgender women living with HIV in India (Fikree & Pasha, 2004). HIV stigma is a social process referring to the internalized, perceived, and enacted negative perceptions directed towards people living with HIV (PLWH) (Herek, 2002; Goffman, 1963; Scrambler, 2009; Steward et al., 2008). Stigma has been recognized as a barrier to early detection of HIV, disclosure of HIV status to partners, and accessing healthcare services (Herek, 2002).

People living with HIV who experience more stigmatizing interactions regarding their illness may experience higher levels of stress and distress (Hutton, Misajon, & Collins, 2013; Song & Ingram, 2002). Widely held sentiments about the marginalized status of PLWH create obstacles to the provision of efficient medical care and compassionate psychosocial support (Chesney & Smith, 1999). HIV stigma often increases pre-existing social prejudice, disproportionately affecting individuals already socially marginalized for other reasons, such as sexual orientation, gender nonconformity, occupation, or caste (Kang, Rapkin, Remien, Mellins & Oh, 2005). This stigma stems from HIV's association with behaviors and identities, such as injection drug use, homosexuality, and sex work, historically deemed to be immoral (Ghose, Swendeman, George & Chowdhury, 2008). This leads to certain populations experiencing multiple layers of stigma, from being associated with HIV and from being associated with other stigmatized behaviors or identities (Pulerwitz & Bongaarts, 2014).

How HIV stigma operates is shaped by the social construction of the HIV epidemic in different cultures and communities (Thomas et al., 2005). HIV positive individuals are often blamed for their illness, causing shame, guilt, and social isolation (Mahendra et al., 2007). Stigma is often based on moral judgments regarding HIV and fears of transmission through casual contact. HIV stigma impacts retention in medical care (Kinsler, Wong, Sayles, Davis & Cunningham, 2007), adherence to antiretroviral medications (Rintamaki, Davis, Bennett & Wolf, 2006), and the likelihood of accessing prevention-of-mother-to-child care (Rahangdale et al, 2010). Individuals who reported higher levels of HIV stigma are over four times more likely to report poor use of medical care (Sayles et al., 2009). Not receiving medical care can in turn increase HIV transmission, as those who are not virally suppressed have a higher likelihood of transmitting the virus to others (Attia, Muller, Zwahlen & Low, 2009).

Previous research has documented the extent of HIV stigma in India. In a study of 646 PLWH from a public sexually transmitted infection clinic in South India, four categories of stigma were identified: actual stigma, perceived stigma, disclosure concerns and internalized stigma (Subramanian et al., 2009). The fear of being stigmatized, referred to as “perceived stigma”, may be greater than its actual occurrence. Of the participants in this study, 96% reported experiencing perceived stigma. Another 33% experienced actual stigma, which is defined as experiencing discrimination, rejection, physical abuse, loss of employment, or divorce (Subramanian et al., 2009). All four categories of stigma were experienced by a significantly higher proportion of females than males. Similarly, in a clinic-based study of 203 HIV positive individuals in Chennai, South India, actual experiences of stigma were significantly less common (26%) than were perceived experiences of stigma (97%) (Thomas et al., 2005).

HIV stigma in India has had a particularly profound impact on the health and well-being of sex workers, transgender women, and men who have sex with men (Ghose, Swendeman & George, 2011; Chakrapani et al., 2007; Chakrapani, Babu & Ebenezer, 2004). Research to date has only minimally focused on how cisgender women living with HIV in India experience stigma and how stigma may shape mental health and access to medical care. Research suggests that cisgender women who are living with HIV in India experience heightened stigma and discrimination for their HIV status compared to their male partners, despite the fact that the majority of HIV positive women become infected by their husbands (Mohite, Mohite & George, 2015; Priya, 2003; Gangakhedkar & Bentley, 1997).

Additionally, *hijra*, a sexual and gender minority in South Asia, are often excluded from research, making comparisons across gender identity rare. Transgender women and *hijra* may face heightened discrimination due to the social exclusion of their gender identity and the taboo nature of their gender expression in South Asian culture (Bharat, Aggleton & Tyler, 2001). The lack of inclusion of gender non-conforming individuals in research in India creates a major gap in our understanding of HIV stigma. While scales developed to measure HIV stigma have been modified to fit the context of India, researchers have only begun to explore the compounding nature of gender identity (Subramanian et al., 2009), gender nonconformity stigma (Logie, Newman, Chakrapani, & Shunmugam, 2012) and HIV stigma on health outcomes (Kinsler, Wong, Sayles, Davis & Cunningham, 2007; Rahangdale et al, 2010; Rintamaki, Davis, Bennett & Wolf, 2006). Addressing the intervention needs of cisgender and transgender women living with HIV/AIDS in India necessitates a nuanced analysis of how gender inequities contribute to disparities in HIV care.

To address these gaps in the current research, this dissertation study explored how HIV stigma differentially affects cisgender women and *hijra*/transgender women living with HIV in Hyderabad, India. Three groups of PLWH were eligible for this study: (1) cisgender women, (2) cisgender men, and (3) *hijra*/transgender women. The goal of including three gender groups was to examine how experiences of stigma may vary by gender identity and expression. In Phase 1, PLWH were asked to participate in a survey regarding their experiences with HIV stigma, mental health, and utilization of medical care.

In Phase 2, a subset of survey respondents from the first phase were asked to participate in interviews on their experiences of HIV stigma and how various social factors, such as gender roles and gender nonconformity stigma, shape these experiences. To focus on differential experiences by gender, only respondents who were cisgender women or *hijra*/transgender women were invited to participate in the in-depth interviews.

Specific Aims

Aim 1. To examine the association between HIV stigma and two outcomes: depression and utilization of medical care among a sample of 150 individuals living with HIV in Hyderabad, India (51 cisgender women, 49 cisgender men, and 50 *hijra*/transgender women).

Hypothesis 1: *Hijra*/transgender women experience the highest rates of HIV stigma and depression, and the lowest rates of utilization of medical care.

Hypothesis 2: Higher levels of HIV stigma are associated with higher levels of depression and lower levels of utilization of medical care.

Aim 2. To explore how gender roles, gender identity/expression, and gender nonconformity stigma contribute to the experiences of HIV stigma for cisgender women and *hijra*/transgender

women living with HIV in Hyderabad, India, through the completion of 32 in-depth semi-structured interviews.

BACKGROUND AND OVERVIEW

HIV is one of the most pressing public health concerns in South Asia. The Indian Council of Medical Research established facilities to screen individuals for HIV in India in 1985 (Reddy & Dobe, 2006). Following the first HIV positive diagnosis in Chennai in 1986, the Indian Government created the National AIDS Committee and launched the National AIDS Control Program. The first article in the *Indian Journal of Public Health* to explicitly refer to HIV was simply titled “Acquired Immunodeficiency Syndrome” (Chakraborty, 1990). The article opens with the prophetic declaration, “AIDS has assumed a worst ever pandemic situation witnessed by mankind... Never before so much panic was created as AIDS has done” (p. 73). The editorial goes on to address stigma: “Because of social stigma associated with AIDS and lack of curative therapy, all seropositive individuals require psychological support and counseling, it is likely that seropositive individuals will turn to AIDS in due course” (p. 74). Given the lack of available medications at the time, an HIV diagnosis then was truly a death sentence. Although HIV antiretroviral medications have dramatically lengthened survival rates and life expectancy, stigma remains an important barrier to care in the context for HIV care in India (Crum et al, 2006; Murphy et al., 2001).

Globally, an estimated 35.3 (95% CI: 32.2–38.8) million people were living with HIV in 2013, of which 2.3 (95% CI: 1.9–2.7) million were new HIV infections (UNAIDS, 2013). HIV prevalence in India has also risen in recent years as PLWH live longer. UNAIDS estimates that there are 2.1 million [95% CI: 1.7–2.7 million] PLWH in India, with a national adult HIV prevalence of 0.31% (UNAIDS, 2013; (NACO, 2012a), making India the site of the third largest number of PLWH in any single country (UNAIDS, 2013). HIV incidence in India is

concentrated in urban areas among younger populations (15-24 years) and those with lower levels of education.

Social context greatly shapes the culture of the HIV epidemic in India. The vast majority of HIV infections (88%) occur via heterosexual intercourse (NACO, 2010), particularly in the western and southern states of Maharashtra, Tamil Nadu, Andhra Pradesh and Karnataka (Solomon, Chakraborty, D'Souza, Yepthomi & Detels, 2004). In the northeastern states of India, including Sikkim, Manipur and Nagaland, transmissions largely occur via injection drug use and spread to the sexual partners of injection drug users (Borah, 2013). These states are in geographical proximity to the opium trade of the Golden Triangle of Myanmar, Laos and Thailand. The northern Indian states, including Delhi, Uttar Pradesh and Rajasthan, are among the most densely populated in the country, but have significantly lower HIV prevalence rates (less than 0.25%) (NACO, 2012a).

The South Indian state of Andhra Pradesh bears the highest adult HIV prevalence rate of the country (0.90%)—a rate three times that of the national average (NACO, 2012b). Prior to the recent creation of the bifurcated south Indian state of Telangana, Andhra Pradesh consisted of 23 districts with a population of over 84 million (NACO, 2012b). There were about 500,000 (95% CI: 424,000-596,000) people living with HIV in Andhra Pradesh, accounting for 20% of all HIV infections in the country (NACO, 2012a). Given the high concentration of cases in the state, Andhra Pradesh is an important region for HIV/AIDS research. The capital of Andhra Pradesh—Hyderabad—is the urban epicenter of the state's epidemic, with 2% of women who attend antenatal clinics in the city being HIV positive (IIPS & Macro International, 2007). In a retrospective study of 10,797 patients with HIV at a major hospital in Hyderabad, there was a considerable rise in the proportion of female patients living with HIV from 6.25% in 1993 to

28.87% in 2004 (Sudha, Teja & Lakshmi, 2007). For the state of Andhra Pradesh, recent estimates indicate that 39.7% of PLWH are cisgender women (NACO, 2012b). Because of this heightened HIV prevalence, Hyderabad was selected as the field site for this study.

HIV among Cisgender Indian Women

The HIV epidemic in India is increasingly affecting cisgender women who identify as heterosexual. The term “cisgender” refers to individuals who have a match between the gender they were assigned at birth, their bodies, and their personal identity (Schilt & Westbrook, 2009). UNAIDS (2013) reports that there are 750,000 [600,000 - 970,000] cisgender women living with HIV in India. According to NACO’s most recent data, the HIV prevalence rate for women in India is only slightly lower than that for males—0.25% for cisgender women versus 0.36% for cisgender men (NACO, 2012a)—with 40% of the HIV-positive population being comprised of women (Decker et al., 2009).

Research regarding HIV risk factors for women in India remains limited. Much of the statistical analysis regarding HIV risk draws from data from the National Family Health Survey (NFHS)—the first large-scale, population-based sample on issues related to sexual and reproductive health. The NFHS is a longitudinal study that collects information on maternal and child health issues, as well as HIV/AIDS knowledge (Ackerson et al., 2012). The NFHS utilizes a proportionate stratified sample of 29 Indian states to create a representative Indian sample. Primary sampling units were conceived as neighborhoods, which were divided into urban and rural areas. The third cycle was conducted in 2005-06 with a sample of more than 230,000 women aged 15-49 and men aged 15-54.

Data from the NFHS demonstrates that poverty is a robust correlate of HIV status among women (Ackerson et al. 2012), as has been substantiated by other research (Burkey et al., 2014;

Sales et al., 2014). Specifically, women living in poverty have been found to be 1.57 times more likely to be HIV positive than women not living in poverty (Ackerson et al., 2012).

Socioeconomic status confers access to resources, such as condoms, preventive health care, and HIV education (Sales et al., 2014). As with other infectious diseases, poverty can increase biological susceptibility to HIV/AIDS through the mechanisms of malnutrition or through lack of access to health care (Fenton, 2004). For women, poverty can additionally constrain the range of available social choices, particularly if sex work is a viable economic survival option.

In addition to poverty, there are multiple social, contextual, and individual dynamics that contribute to disparities in HIV risk and care for cisgender women in India. Chief among these factors may be their position as women in a society that tends to be characterized by more patriarchal gender roles and power structures. The origins of the word *aurath*, meaning “woman” in Hindi, Urdu, and a number of other South Asian languages, illustrates this point. The word, *aurath* derives from the Arabic word, also pronounced *aura*, and is translated as defect, fault, transgression, offence, incompleteness, evil or unprincipled conduct, imperfection, blemish, nakedness, or vulnerability (Haqee, 2013). For Muslims, *aurath* also refers to the part of the body that should be covered in public (Syed, Ali & Winstanley, 2005). The interpretation of what exactly is to be covered differs, depending on the Islamic school of thought. For women, this space always includes the breasts and the genitalia. *Aurath* does not literally mean woman in Arabic; the Arabic word for woman is *nisaa*. However, in Hindi/Urdu, it has come to mean woman. The origins of the word *aurath*, coupled with the fact that the word connotes notions of vulnerability, speak volumes about the subjugated status that women may hold within South Asian society.

Women often occupy a role in Indian society that Spivak (1988) termed “subaltern.” When applied to the experience of women living with HIV, this subaltern identity may lead to women’s experience of higher levels of stigma. As Spivak articulates, “Subalternity is a position without identity... Gender is not lived sexual difference. It is a sense of the collective social negotiation of sexual differences as the basis of action... It is where social lines of mobility, being elsewhere, do not permit the formation of a recognizable basis of action” (Spivak, 2005, p. 476). Research highlights that women in India are likely to experience secondary claims on household resources, violence at the hands of their husbands, and an expectation to bear children, even if to the detriment of their own health (Kabeer, 1999).

Research in South Asia suggests that a hierarchy of decision-making responsibilities is recognized by the family and community, reserving key family decisions, such as those regarding health, for men in their capacity as household heads, while assigning other decisions to women in their capacity as wives, mothers, and daughters (Spivak, 2008; Kabeer, 1999). For example, in a study conducted in rural Punjab, Pakistan, the only area of decision-making in which cisgender women reported a major role was in the purchase of food (Sathar & Kazi, 1997). The rise of new wage opportunities for women in South Asia, as well as access to micro-credit loans, may make it easier for women to demand greater equity within their partnerships and to leverage the financial independence to leave unsatisfactory marriages (Kabeer, 1997).

Early marriage and widowhood. Women’s sexuality in India is heavily regulated and scrutinized, and it is expected that women will marry young and produce children. The HIV risk of Indian women is heightened by early marriage and widowhood. Women may experience higher levels of HIV-related stigma (Malavé et al., 2014; Wingwood et al., 2007), preventing

them from disclosing their HIV status (Derlega et al., 2002) and serving as a barrier to receiving support to cope with their illness (Serovich et al., 2000).

High social value is placed in Indian society on the expectation of women to be virgins at the time of marriage (Weiss, Whelan & Gupta, 2000). Several studies have documented that limited premarital and extramarital sexual intercourse render heterosexual transmission from husbands to wives as the dominant infection pathway for cisgender women (Decker et al., 2009; Solomon, Chakraborty, & Yephthomi, 2004; Gangakhedkar & Bentley, 1997; John et al., 1993). Despite the fact that most heterosexual cisgender women have become infected with HIV from their husbands, they may nonetheless be blamed for being the source of HIV infection (Mohite, Mohite & George, 2015; Paudel & Baral, 2015). This may be a reflection of gender roles in Indian culture and how the male head of the household may sometimes be held to be free of blame for moral wrongdoing or sexual infidelity. In the Indian context, women are often socialized to take the blame for sexual and reproductive health issues within a couple, such as infertility or impotence (Gupta et al., 2008). Gendered mores in relationships dictate that Indian cisgender women play a more submissive role, often remaining silent and subordinate to their male partner's needs, even when in physically or emotionally abusive relationships (Hegde, 1996). For women, HIV stigma can cause them to be identified as drug users, as prostitutes, or as being sexually promiscuous (Bunting, 1996). Women may subvert these restrictive gender roles through both active and passive means, though this is a theme that has been relatively unexplored in research on South Asian cisgender women living with HIV.

Previously married women are particularly vulnerable to HIV infection (Walters et al., 2012; Becker et al., 2007). Being married has been shown to put Indian women at risk to acquire HIV infection because of women's lack of power in being able to decide when to engage in sex

or to negotiate for sexual protection with their partners. In one study of HIV positive women in India, all women were previously married and 56% were widows (Mohite, Mohite & George, 2015).

The association between marital status and HIV status may result from having been infected by a spouse who subsequently died of his illness, making widowhood a significant HIV risk factor for women in India (Ghosh et al., 2011). India is home to an estimated 40 million widows, who comprise approximately 10% of all women in the country (Kannan, 2013). Widowed women are 22.7 times more likely than are non-widowed women to be infected with HIV (Ghosh et al., 2011). More exploratory research is necessary to unearth the processes affecting this increased HIV vulnerability for widows.

One might expect that widowed women in Indian society would have decreased HIV risk since they are no longer having sex with their husbands. However, the loss of income from a deceased spouse may make sexual activity with other partners more plausible as a source of financial subsistence. Widowed women from lower castes are in a precarious situation if they have lost financial support from their husbands, are not provided financial assistance by their husband's family, and do not have an independent source of income. Returning to the home of the widow's parents or living with the widow's adult children may also not be options, as family members may be too impoverished to afford to care for their daughter/mother. Researchers hypothesize that widows' heightened HIV risk is the result of four causes: (1) infection from and then bereavement of an HIV-infected husband; (2) abandonment after husbands learn of their wives' HIV status; (3) economic instability after being previously married, leading women to seek financial support through male partners; and (4) the social status of being previously married, which exposes women to sexual harassment and predation (Walters et al., 2012).

Age and developmental stage. Research suggests that age may have an impact on the severity of HIV stigma (Emlet et al., 2015). In a cross-sectional study of 960 HIV-positive adults living in Ontario, Canada ($n = 960$), those 55 and older had significantly lower overall and internalized stigma than adults under age 40, even when accounting for gender, sexual orientation, income, time since diagnosis, depression, maladaptive coping, and social support (Emlet et al., 2015). In this study, age did not predict enacted or anticipated stigma when accounting for demographic and psychosocial variables. A significant interaction was found between depression and age, suggesting that stigma declines with age among those who are depressed but increases at age 50. Among those who are not depressed, HIV stigma decreases in older age groups. In another sample of 120 PLHA over the age of 50 in south rural China, only 18.1% reported experiencing externalized stigma, though 64.3% reported feeling internalized stigma (Zhang et al., 2014). The impact of age on HIV stigma has received little attention in the scholarship on HIV in the Indian context.

Caste and religion. Religion may also play an important role in shaping disparities in HIV risk and care among Indian women. In one study, other religions—namely Hinduism, Jainism, Sikhism, Buddhism and Christianity—did not appear to have a significant correlation with HIV. However, Muslim women were 0.29 times less likely to have HIV than non-Muslim women (Ghosh et al, 2011). This could be the result of seclusion norms, such as the tradition of *purdah* (meaning “curtain” in Hindi/Urdu), making work and even exposure to community and social life a restricted opportunity for Muslim women. Muslim women may be less likely to engage in extramarital sex or may have reduced HIV prevalence in their sexual networks, thereby reducing their vulnerability to contracting HIV.

Among women living with HIV, the impact of heightened poverty among Muslims may contribute to the reduced likelihood of utilizing medical care and may increase the likelihood of experiencing depression. Muslims comprise 22% of the population of Hyderabad (Government of Andhra Pradesh, 2011), and studies suggest they may be particularly vulnerable to HIV due to their social exclusion (Kabeer, 2005). Nearly half (43%) of all Muslims in India live below the official poverty level of \$1.25 a day. Less than 50% of the Muslim male population in India is employed, as compared to 53% of *dalits* (“untouchable” castes) (Shank, 2008). In urban areas, Muslims tend to be at a greater disadvantage, with as many as 40% of Muslims in Indian cities found to be in the bottom 20% of the income distribution as compared to 22% of Hindus (Kabeer, 2005). Additionally, Muslim women in India have consistently demonstrated low rates of participation in the labor force. Sixteen percent of Muslim women in India are employed as compared to 36% of Hindu women (Das, 2005). Because of these economic limitations, women in predominantly Muslim communities in India may face conflicting choices between ensuring survival needs and protecting social status within their community.

In terms of caste, there is a dearth of research investigating the relationship between HIV and caste in India. In one study, caste was analyzed as a binary category, namely inclusion/exclusion in one of three categories: scheduled caste, scheduled tribe, or other backward caste (Perkins, Khan & Subramanian, 2009). These three groupings represent the lowest end of the caste spectrum. No statistically significant relationship was found between HIV status and being a member of a scheduled caste or tribe. However, this may be because of a lack of variability in caste status in HIV research, making this association difficult to prove. Because there is extreme variation in caste, the lack of more nuanced caste data does not provide a clear

picture of the problem. Given the methodological issues in this study design, it is difficult to conclude that caste is not associated with HIV status.

HIV Among *Hijra*/Transgender Women

Hijra in India. An understudied population in the Indian HIV epidemic is the *hijra*/transgender community. Transgender is an umbrella term used to refer to people whose gender identity and expression does not conform to norms and expectations traditionally associated with the sex assigned to them at birth or to conventional notions of male or female gender (WHO, 2014; Nagoshi, 2010). *Hijra* are a gender minority in South Asia, including individuals who are cross-dressers, transvestites, intersex, or simply gender-nonconforming.

In Western terms, the term *hijra* is often translated to connote a transgender female or transsexual identity. However, it is important to note that the term *hijra* is not exactly synonymous with the term transgender, as some people who identify as being transgender women do not consider themselves to be *hijra* (Krishner, 2015), and some *hijra* do not consider themselves to be transgender. *Hijra* are typically individuals who have been assigned male gender at birth and who identify with the gender roles and gender expression of women. They are considered neither men nor women (Nanda, 1990), but rather occupy a third sex category, often referred to as a third gender (Kalra, 2012; Jaffrey, 1996). An Indian Supreme Court ruling in April 2014 legally recognized *hijra* and other gender-nonconforming people as a third gender. In his decision, Justice KS Radhakrishnan noted ((Supreme Court of India, 2014, p. 1):

Non-recognition of the identity of *hijra*/transgender persons denies them equal protection of law, thereby leaving them extremely vulnerable to harassment, violence and sexual assault in public spaces, at home and in jail, also by the police. Sexual assault, including molestation, rape, forced anal and oral sex, gang rape and stripping is being committed with impunity and there are reliable statistics and materials to support such activities. Further, non-recognition of identity of *hijra*/transgender persons results in them facing extreme discrimination in all spheres of society, especially in the field of employment, education, healthcare etc... Discrimination on

the ground of sexual orientation or gender identity, therefore, impairs equality before law and equal protection of law and violates Article 14 of the Constitution of India.

While to date it remains unstudied, this social policy may have a significant impact on reducing stigma and discrimination for *hijra* and transgender people in India.

Hijra occupy a unique social position in India as they are considered both auspicious and stigmatized. Because the Hindu conception of divinity is both male and female at once, *hijra* are often considered to be closer to being divine. *Hijra* are often devotees of the Mother Goddess Bahuchara Mata (Nanda, 1986). Indian traditions bestow *hijra* with sacred powers, such as the ability to bless people with luck and fertility (Kalra, 2012). Seen to be auspicious due to their androgyny and/or asexuality, *hijra* are often present at weddings and childbirths to bless the couple or child, receiving money from those they bless. They also are also believed to bear the power to bring prosperity and rain (Conner, Sparks, & Sparks, 1997). In the colonial context, *hijra* were typified as male eunuchs, who had been castrated prior to puberty. Even today, *hijra* often undergo castration and penectomy, surgeries which often confer higher status within *hijra* communities (Dutta, 2012).

Historically in Hyderabad, *hijra* received state patronage through the Muslim Mughal courts. In the 18th century, the Criminal Tribes Act of 1871 categorized the *hijra* community as “criminals,” and they were arrested for dressing in women’s clothing, for participating in sodomy, and for dancing and playing music in public places. Following Indian independence and the disappearance of the local principality known as the *Nizam* in Hyderabad, *hijra* lost their state-sanctioned support. Since that time, many *hijra* have utilized begging and sex work as a primary means of livelihood. The occupation of sex work is therefore a significant HIV risk factor for *hijra* in India (Dandona et al., 2005; Ministry of Health & Family Welfare Government

of India, 2013). Increasingly, *hijra* panhandle at street corners and demand money from riders of trains. People are often frightened to not give *hijra* money as they fear being doomed by a curse (Nanda, 1986). The social and economic marginalization experienced by this community directly contributes to their heightened HIV vulnerability.

The social identity of *hijra* is constituted through the intersection of social, religious and kinship practices, including religious rituals, including dedication to an Islamic shrine (*durgah*) and goddess-worship (Dutta, 2012). Based on ethnographic research in the north Indian city of Varanasi, Cohen (2005) defines *hijra* as having kinship structures, defined by hierarchical lineages comprised of *gurus* (heads) and *chelas* (disciples). Gayatri Reddy's ethnography on *hijra* (2006) specifies seven *hijra* houses or lineages in Hyderabad. In Reddy's ethnography, the community in Hyderabad also identifies as *kojja*, the equivalent of *hijra* in Telugu.

In northern India and Pakistan, *hijra* are often referred to as *zenana* (Beyrer et al., 2012). *Zenana* refers to the part of the house that was traditionally reserved for women in Muslim households. It also refers to the housing structure of a *haveli* or a *harem* where, to this day, some *hijra* communities continue to reside. Interestingly, both the words *aurath* and *zenana* refer to a feminine gender, and also both connote the notion of being covered or segregated from society. These linguistic roots are again reflective and demonstrative of gender norms in the South Asian context.

Hijra have been socially constructed as distinct from other sexual and gender minorities in India, such as *kothis* and *panthis* (Dutta, 2012). It is important to note that gender categories in the South Asian context are fluid and the social constructions of the *hijra*, *kothi* and *panthi* identities have overlapping historical, political, and social underpinnings (Cohen, 2005; Reddy, 2006). *Kothis* are a heterogeneous group, including same-sex-attracted men. The *kothi* is the

“penetrated” partner in sexual intercourse, often exhibiting feminine behavior, dress and mannerisms. *Panthis* are the “insertive” partner in sexual intercourse and often exhibit masculine behavior, dress, and mannerisms. *Kothi/panthi* relationships often mimic heterosexual gender roles where the insertive partner is considered the husband and the receptive partner the wife (Cohen, 2005). Recent ethnographies of *hijra* (Cohen, 2005; Reddy, 2006) have critiqued an essentialized construction of *hijra*, situating the *kothi* within a more continuous construction of same sex-desiring or gender-nonconforming individuals. Such a fluid construction of gender identity and expression is utilized in this study.

Epidemiology of HIV among *hijra* in India. Research points to heightened HIV risk among the global transgender community. A meta-analysis of research studies on HIV among transgender women in the United States estimated a 28% HIV seroprevalence when confirmed through biological testing, a 12% HIV seroprevalence via self-reported HIV status, and a 21% prevalence of self-reported history of other sexually transmitted infections (Herbst et al., 2008). In a global meta-analysis of transgender women, the pooled HIV prevalence among 11,066 transgender women worldwide was 19.1% (95% CI 17.4–20.7) (Baral et al., 2013). Across low, middle and high-income countries, transgender women were 48.8 times (95% CI: 21.2-76.3) more likely than all other adults of reproductive age to be infected with HIV (Baral et al., 2013). Research in India indicates that HIV is highly prevalent among *hijra*. In a sample of 14,100 individuals screened for HIV in Pune, India, 84 (0.6%) people self-identified as *hijra* (Sahastrabuddhe et al., 2012); they were found to have the highest HIV prevalence rates of the sample. In the sample, 45.2% of *hijra* were HIV positive, while only 20% of heterosexual men and 18.9% of men who have sex with men (MSM) were positive. *Hijra* were also more likely to

have received money for sex and to have an earlier sexual debut than other groups (Sahastrabuddhe et al., 2012).

HIV stigma, gender nonconformity stigma and depression. Research has shown that PLWH in India are at heightened risk for anxiety and depression (Nyamathi et al., 2011; Chandra, Ravi, Desai & Subbakrishna, 1998). This may be caused by an awareness of treatment methods that are more widely available in developed countries, but not as accessible in India, potentially contributing to feelings of hopelessness and despair (Chandra, Ravi, Desai & Subbakrishna, 1998). Chronic depression, stressful events, and trauma can negatively affect HIV disease progression in terms of decreases in CD4 T cells, increases in viral load, and greater risk for clinical decline and mortality (Dasgupta, Sullivan, Dasgupta, Saha & Salazar, 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. In a study of 50 cisgender women in Maharashtra, almost all women had perceived stigma at some point in their lives and all women had some sort of depression (Mohite, Mohite & George, 2015). Similarly, a study of 200 MSM in India demonstrated that gender non-conformity plays an important role in predicting depression (Logie, Newman, Chakrapani, & Shunmugam, 2012). In this study, 55% of MSM reported moderate to severe depression. The combination of gender nonconformity stigma and HIV stigma accounted for a significant amount of variability in their depression (Logie, Newman, Chakrapani, & Shunmugam, 2012).

Both HIV stigma and gender nonconformity stigma are influenced by the developmental stage in which they occur (Young & Sweeting, 2004). Gender nonconformity in youth has been correlated with negative outcomes, including rejection by parents (Caldera, Huston, & O'Brien,

1989; Smith & Leaper, 2006) and disparaging comments from peers in childhood (Carter & McCloskey, 1983). Gender-nonconforming individuals may experience long-term psychological distress and have problematic relationships in adulthood (Landolt et al., 2004). The negative association between gender nonconformity stigma and wellbeing has been found to be more robust among men than women (Aube & Koestner, 1992; Impett et al., 2006; Skidmore et al., 2006; Weinrich et al., 1992). Alternatively, women may actually benefit from gender-nonconforming behaviors (Impett et al., 2006; Thornton & Leo, 1992) though this has not been studied extensively in the South Asian context.

Given these findings, we expected that, compared to cisgender men and cisgender women, *hijra*/transgender women experience the highest levels of gender nonconformity stigma. Existing research suggests that HIV stigma and gender nonconformity stigma may be major drivers of health disparities for people living with HIV. While the experiences of stigma among MSM and cisgender women in India have been studied separately, less is known about the experiences of *hijra*/transgender women, particularly in comparison to the experiences of cisgender heterosexual women and men.

Theoretical Framework and Conceptual Model

The theoretical framework that guides the present study integrates an adapted version of Goffman's conceptualization of stigma with gender role theory (Feld & Radin, 1982; Eagly et al. 2000). In his seminal work on identity formation, *Stigma: Notes on the Management of Spoiled Identity* (1963), Goffman defined stigma as an attribute that extensively discredits an individual, transforming him or her "from a whole and usual person to a tainted, discounted one" (p.3). Goffman established that society stigmatizes on the basis of what is considered difference or

deviance, resulting in a spoiled identity. Labeled as deviants, stigmatized individuals view themselves and are viewed by others as undesirable (Mahajan et al., 2008).

Stigma refers to the devalued status that society attributes to a condition (Goffman, 1963). Stigma is a social process, characterized by exclusion, rejection, blame, or devaluation, and resulting from an experience of social judgment (Scrambler, 2009). Through the creation of social hierarchies with demarcated status levels, stigma defines roles within social relationships. Research suggests that stigma strengthens and reproduces existing inequalities of class, race, gender and sexuality (Parker & Aggleton, 2003). Stigma affects individuals directly via mechanisms of discrimination and indirectly via threats to personal and social identity (Major & O'Brien, 2005). In addition, stigma can have a dramatic bearing on several key health outcomes, including psychosocial development, income, housing, criminal justice involvement, education, and life span (Link & Phelan, 2001).

Goffman's conceptualization offers a socio-cognitive understanding of the origins of stigma (Parker & Aggelton, 2003; Ogden & Nyblade, 2005). Three kinds of stigma are often highlighted in theoretical discussions: internalized stigma, perceived stigma, and enacted stigma (Scrambler, 2009; Herek, 2007; Nyamathi et al., 2011). Internalized stigma is often referred to as self-stigmatization. This social construct describes how someone feels about themselves, and specifically if they feel a sense of shame (Herek, 2007). Internalized stigma can lead to low self-esteem, feelings of worthlessness and depression, social withdrawal, and the experience of excluding oneself from particular settings out of a fear of having one's status revealed. Perceived or felt stigma refers to conceptions of how a particular condition is viewed by society (Palamar, Halkitis & Kiang, 2013). These experiences may be associated with anxiety, negative feelings about life, long-term health problems, and perceived side effects of medication. Finally, enacted

stigma refers to a fear of societal attitudes that occurs as a consequence of being associated with a particular undesirable attribute, disease (such as HIV), group, or behavior, (such as injection drug use, sex work or homosexuality) (Parker & Aggelton, 2003). Enacted stigma is often also termed stigmatization or discrimination, and refers to interpersonal experiences.

Goffman's conceptualization of stigma has been widely applied to various contexts and conditions, including mental illness (Byrne, 2000; Anspach, 1979), physical disability (Green, 2003), and criminal justice involvement (Bernburg, Krohn & Rivera, 2006). However, these conceptualizations of stigma are rarely framed in relation to larger social processes, such as poverty, classism, sexism, homophobia, gender roles, or gender nonconformity. When applied to HIV, this framework may limit the experiences of PLWH to their individual emotions and cognitions by excluding structural considerations and social process that produce and intensify discrimination (Mahajan et al., 2008).

Alternative explanations of stigma (Link and Phelan, 2004) focus on the inequities in social, economic, and political power that give rise to stigma. Gender role theory (Feld & Radin, 1982; Eagly et al. 2000) also offers a conceptual framework that can be applied to better understand the relationship between HIV and other social processes. To my knowledge, no study to date has applied gender role theory to the experience of HIV stigma in the Indian context. To address this gap, the theoretical framework for this study integrates gender role theory (GRT) with an adapted variation of Goffman's conceptualization of stigma to explore gender variability in the experience of HIV stigma in India, and its influence on important health outcomes, namely depression and the utilization of medical care.

GRT emphasizes the importance of ascribed positions that individuals acquire by birth. In describing the context of HIV among women in India, ascribed positions refer to gender, caste,

socioeconomic status, and religion. The ascribed position of gender may significantly impact the experience of living with HIV for people in India. Achieved positions refer to those roles earned by the basis of accomplishment or effort, such as being a client of a nongovernmental organization, 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 as out of their reach. When ascribed and achieved positions conflict, HIV discrimination can ensue.

In the context of gender, individuals encounter differing expectations and experiences by virtue of their socialization as cisgender 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, resources are not pooled and equally distributed among male and female members. Women's household and labor bargaining powers are influenced by a number of factors, including individual economic assets, support from kin and friends, support from gender-progressive nongovernmental organizations, state support, women's access to employment and other means of earning income, the household's socioeconomic class/caste position, and social norms regarding women's decision-making capacities and productivity (Agarwal, 1997). Gender roles can specify tasks by gender and occupationally segregate cisgender and transgender women in both rural and urban settings. Food allocation norms favoring males, such as men being served first and in greater quantities, can limit women's bargaining power in the household. This can make the position of women in poor families particularly precarious for their health (Sen, 1990). In order to better understand HIV among cisgender women and *hijra*/transgender women, the unequal gender roles and power

relationships between men and cisgender and *hijra*/transgender women must be examined (UNIFEM, 2003), including the impact of a male-headed household.

Gender roles can negatively affect the health of cisgender women when social norms prioritize the health of men or prevent women from traveling alone to a clinic to seek care (Shah, 2012). Women in India are less nourished than men, less healthy, and more susceptible to physical and sexual violence (Agarwal & Sethi, 2013; Swaminathan & Mukherji, 2012; Nussbaum, 2001). Lack of gender equity in sexual relationships can constrain Indian cisgender women from sexually protecting themselves and may fuel the HIV epidemic further.

In the South Asian context, cisgender women living with HIV are likely to harbor feelings of devalued status within their families and social networks (Mohite, Mohite & George, 2015). HIV stigma can lead cisgender women living with HIV to be more reluctant to disclose their HIV status to others, even to close family and friends (Venable, Carey, Blair & Littlewood, 2006). This reluctance may also translate to a lack of ease in disclosing HIV status to medical personnel, causing a decreased access to medical care compared to their male partners (Raveis, Siegel & Gorey, 1998).

Three concepts from GRT are particularly relevant to the present study: (1) role demands, (2) role performance, and (3) role stress. Role demands refer to expectations held by persons in particular social situations, which often lead to stereotypes about groups of people—in this instance, cisgender and transgender women. Gender differences in medical care and utilization can be understood by recognizing the traditional social roles played by men and women (Eagly & Diekmann, 2006). For example, in India, the role demand of a husband may be to physically and financially take care of his wife. Men are often viewed as being the family's provider and for maintaining the family's reputation in the community (Go et al., 2003). Meanwhile the role

demand of an Indian woman is to be disciplined, submissive, and respectful of the needs of her husband (Go et al., 2003). These role demands may help explain the process by which Indian husbands may exert a great deal of influence over the health decisions of their wives. Role performance refers to the specific individual's contribution in response to social pressures and role demands. Role performance can be impacted by the individual's skills, personality, education, motives, and values. In the context of gender, role stress refers to the experience of socialized gender roles having negative consequences on the individual or others. This can occur when rigid or restrictive gender roles result in personal restriction or devaluation (O'Neil, Good & Holmes, 1995).

Role stress often occurs when people deviate from or violate gender role norms. Males and females are socialized to engender specific attributes and social behaviors (Eagly et al., 2000). Some have critiqued GRT for being heteronormative (Hicks, 2013) by promoting the idea that men and women naturally perform discrete but complementary tasks. However, when applied to the experiences of *hijra*, the concept of gender role stress may be particularly applicable, as *hijra* and transgender people may receive conflicting messages about whether they should behave in accordance with the gender they were assigned at birth, or the gender with which they currently identify. By not conforming to binary gender roles, they may experience additional role stress.

In summary, what remains unclear from existing research is how experiences of HIV stigma vary between cisgender men, cisgender women, and *hijra*/transgender women. Particularly in the case of *hijra*/transgender women and their sexual partners, little is known about how gender power dynamics play out in intimate partner relationships. The central

hypothesis of this study is that HIV stigma varies significantly by gender, and that this variation is correlated with health disparities for cisgender women and *hijra*/ transgender women.

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 & Radin, 1982). Under this view, social positions exist only in relation to other positions. Ultimately, role theory posits that social dysfunction is not caused by psychopathology, but rather by the social situations in which individuals find themselves. Such an approach serves to shift the blame from individual choices towards a more interactional view of health and human behavior.

The first specific aim of this study addresses the association between HIV stigma and two outcomes: depression and the utilization of medical care among a sample of 150 cisgender men, cisgender women, and *hijra*/transgender women living with HIV in Hyderabad, India. The purpose of the second aim will be to qualitatively explore how HIV stigma influences the experiences of cisgender women, transgender women, and cisgender men living with HIV in Hyderabad, India, via 30 in-depth semi-structured interviews. In the in-depth interviews, GRT is utilized through the inclusion of qualitative questions regarding gender roles and gender nonconformity.

METHODS

Analytic Sample

The study population is defined as people living with HIV. The analytic sample is defined as cisgender women, cisgender men, and *hijra*/transgender women between the ages of 18 and 50 living with HIV in Hyderabad, India. Inclusion criteria for the study were: (1) self-report as being HIV-positive; (2) reside in Hyderabad or Secunderabad, India; (3) proficient in speaking Hindi/Urdu or Telugu; and (4) between the ages of 18 and 50. Exclusion criteria were: (1) individuals who are HIV-negative, (2) individuals living outside of Hyderabad or Secunderabad, (3) and individuals either under the age of 18 or over the age of 50. The analytic sample consisted of 150 individuals living with HIV in Hyderabad.

Selection of Method

This study employed a mixed methods design to better understand the distinctions between the experiences of HIV stigma among cisgender heterosexual women, cisgender heterosexual or bisexual men, and *hijra*/transgender women in India. A mixed methods design was used in the present study to better understand the dynamics of HIV stigma and gender nonconformity on multiple levels of investigation. Mixed method studies utilize at least two kinds of data or two means of collecting data by employing more than one analytical technique (Small, 2001). Mixed methods are appropriate when the studied phenomenon is complex and multifaceted, and when the findings from one method require further investigation (Creswell & Clark, 2007). Mixed method studies operate off a core principle of multi-method confirmation, where the confidence in one's findings increases when different methods are in agreement (Bollen & Paxton 1998). Between-methods triangulation, which involves the use of both quantitative and qualitative approaches in mixed method studies, may be superior to within-

methods triangulation, which refers to the use of either multiple quantitative or multiple qualitative approaches (Denzin, 1978).

This mixed methods study involved two, consecutive interrelated phases with the quantitative and qualitative phases bearing equal weight (Leech & Onwuegbuzie, 2009). Sequential studies are utilized to better understand the mechanisms behind newly discovered associations or to test emergent hypotheses (Small, 2011; Smith 2008). Nesting refers to multiple data types being collected from the same participants or entities (Lieberman 2005). Such an approach allows for within-subject confirmation and is particularly useful in exploring the dynamics of complex individual and social processes.

The two phases of the study comprised quantitative surveys (Phase 1) and semi-structured in-depth interviews (Phase 2). Phase 1 entailed the completion of 150 surveys across three gender groups: cisgender women (n=51), cisgender women (n=49), and hijra/transgender women (n=50). Following the completion of the surveys, a preliminary descriptive analysis of the data was conducted. Using survey responses to the stigma scales used in the study (Jeyaseelan et al., 2013; Zelaya et al., 2012), two subgroups were created: one subgroup of cisgender women and another subgroup of hijra/transgender women. The eight cisgender women with the highest HIV stigma scores and the eight women with the lowest HIV stigma scores comprised a new subgroup of cisgender women. Similarly, the eight *hijra*/transgender women who scored highest on the HIV stigma scales and the eight who scored lowest on the HIV stigma scales comprised a new subgroup of *hijra*/transgender women. These 32 individuals—16 cisgender women and 16 *hijra*/transgender women—were recruited to participate in Phase 2 of the study. This sampling method of capturing both participants who scored high and low on stigma measures was utilized in order to ensure heterogeneity in the interview subgroup.

In Phase 2, the 32 participants were asked to complete in-depth interviews on how their experiences of HIV stigma have been influenced by gender roles, gender nonconformity stigma, poverty, caste, and religion. Interviews were conducted to explore the gendered experience of HIV stigma and to contextualize the answers from the quantitative survey. While the first phase attempted to quantify relationships between stigma, depression, and utilization of medical care, the second phase focused on the unique needs of cisgender and *hijra*/transgender women living with HIV. Though some of the covered topics in the survey were similar to those in the interview, the interview focused more attention on questions that could not be fully addressed by quantitative measures alone.

A major justification for using mixed methods in the present study is the fact that gender roles were not adequately captured by survey responses. There is no existing instrument for gender roles that captures the nuances of gender interactions in South Asian culture across various gender categories. Even in Western contexts, existing instruments that measure gender role stress are specific to either masculine or feminine gender roles and do not allow for comparisons between men and women (Gillespie et al., 1992; Eisler, Skidmore & Ward, 1988), or for comparisons with gender-nonconforming individuals. This gap in the quantitative research provided a prime opportunity for exploring gender roles via open-ended questions in the context of in-depth interviews. Survey responses were used to guide the selection, framing, and ordering of interview questions. Open-ended questions were utilized to elicit descriptions of lived experiences of HIV stigma and gender nonconformity stigma in the participants' own words. In phase 1, approximately 150 people living with HIV were asked to complete a survey: 51 cisgender women, 49 cisgender men and 50 *hijra*/transgender women. Informed consent was

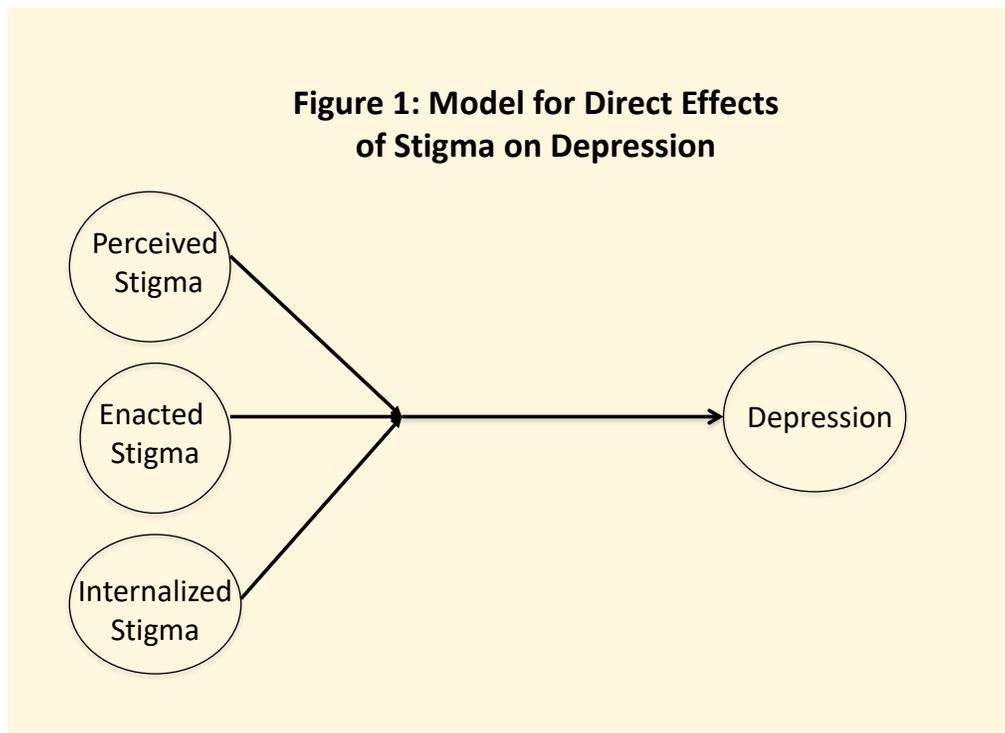
obtained from all participants. During the consent process, participants were asked if they were willing to provide their contact information in order to be recruited for Phase 2.

Aim specific analyses. For Hypothesis 1 and 2, mean differences in study variables were analyzed for three groups: (1) cisgender men, (2) cisgender women, and (3) *hijra*/transgender women. Each of the predictor and outcome categories in the conceptual framework—i.e., HIV stigma, gender nonconformity stigma, depression, and utilization of medical care—were compared for the three groups. Descriptive statistics—i.e. means, standard deviations and confidence intervals—were calculated for all variable categories. ANOVA and independent sample t-tests were calculated to determine whether significant differences exist between the three groups. Every attempt was made to ensure that the sizes of the three gender groups were the same to avoid confounding the effect of the independent variables through unequal sample sizes (Jaccard, 1998). Nonetheless, in the final number of surveys, we had a slight, unintended variation between the sample sizes, with a final count of 51 cisgender women, 49 cisgender men, and 50 *hijra*/transgender women.

For Hypothesis 2, two models were created for measuring the effects of HIV stigma, one utilizing the Zelaya scale (2012) and the second model utilizing the Jeyaseelan scale (2013). For each model, bivariate regressions were conducted to explore the relationship between the independent variable (stigma) and each of the two primary outcome variables of interest (utilization of medical care and depression). Both the Jeyaseelan scale and the Zelaya scales have measures for perceived stigma, enacted stigma, and internalized stigma. Associations between socio-demographic characteristics and outcome variables were tested to identify appropriate control variables for analyses. All variables that were statistically significant at $p < 0.10$ were included in the final model. Additional variables with less than $p < 0.10$ significance were also

included if previous research had strongly demonstrated an association with HIV stigma and one of the health outcomes of interest.

As depicted in Figure 1 and Figure 2, the final model utilized multiple linear ordinary least squares (OLS) regression analysis to predict depression (continuous outcome: CES-D scores) and binomial logistical regression to predict the utilization of medical care (binomial categorical outcome: having or not having utilized medical care in the past year). Given the relatively small sample size of the study and with intentions of saving degrees of freedom, a parsimonious model was pursued.



Regression models for the path analysis:

$$\text{Depression} = \alpha + \beta_1 \text{ Perceived Stigma} + \beta_2 \text{ Covariates} + \varepsilon$$

$$\text{Depression} = \alpha + \beta_1 \text{ Enacted Stigma} + \beta_2 \text{ Covariates} + \varepsilon$$

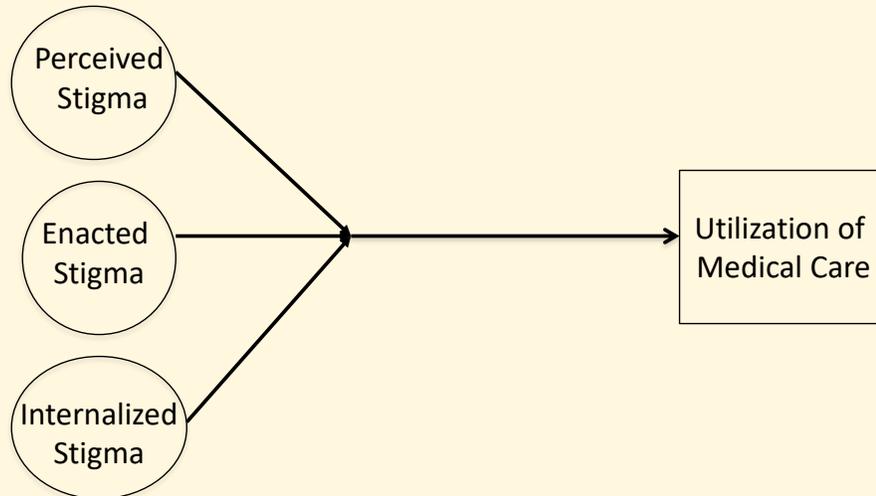
$$\text{Depression} = \alpha + \beta_1 \text{ Internalized Stigma} + \beta_2 \text{ Covariates} + \varepsilon$$

$$\text{Utilization of Medical Care} = \alpha + \beta_1 \text{ Perceived Stigma} + \beta_2 \text{ Covariates} + \varepsilon$$

$$\text{Utilization of Medical Care} = \alpha + \beta_1 \text{ Enacted Stigma} + \beta_2 \text{ Covariates} + \varepsilon$$

$$\text{Utilization of Medical Care} = \alpha + \beta_1 \text{ Internalized Stigma} + \beta_2 \text{ Covariates} + \varepsilon$$

Figure 2: Model for Direct Effects of Stigma on Utilization of Medical Care



The three forms of stigma were then combined to create a composite stigma score used to predict depression and utilization of medical care:

$$\text{Depression} = \alpha + \beta_1 \text{ Composite Stigma Score} + \beta_2 \text{ Covariates} + \varepsilon$$

$$\text{Utilization of Medical Care} = \alpha + \beta_1 \text{ Composite Stigma Score} + \beta_2 \text{ Covariates} + \varepsilon$$

Phase 2: Contextualizing Experiences of HIV Stigma

To understand the complexities of what people living with HIV in Hyderabad experience, cisgender women and *hijra*/transgender women who participated in the first phase were asked to participate in semi-structured qualitative interviews (Sandelowski, 1986). Interviews lasted about 90 minutes. The in-depth qualitative interviews explored constructs outlined in the conceptual framework in order to better understand potential variations in the gendered experiences of stigma. 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) depression. The full interview guide questions/prompts are provided in Appendix A.

The first part of the interview asked questions related to gender roles and gender nonconformity. Gender roles were explored by asking participants open-ended questions relating to their gender role demands and gender role stress. These questions 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. This was followed by a long section on HIV stigma, structured according to the three domains of HIV stigma outlined in the study's conceptual framework: (1) enacted stigma, (2) perceived stigma, and (3) internalized stigma. Additional questions were asked regarding the impact of caste, poverty, and religion on subjects' experiences with HIV, followed by questions regarding medical care. Some of these questions were adapted from the survey, the HIV Stigma Index in India (GNP+, ICW & UNAIDS, 2011). The interviews ended with questions regarding participants' experiences with depression.

Phase 2 data collection. Following the completion of the surveys, a preliminary descriptive analysis of the data was conducted. Using survey responses to the stigma scales used in the study (Jeyaseelan et al., 2013; Zelaya et al., 2012), two subgroups were created: one comprising cisgender women and another comprising *hijra*/transgender women. The eight cisgender women with the highest HIV stigma scores and the eight women with the lowest HIV stigma scores comprised the subgroup of cisgender women. Similarly, the eight *hijra*/transgender women who scored highest on the HIV stigma scales and the eight *hijra*/transgender women who scored lowest on the HIV stigma scales comprised a new subgroup. These 32 individuals were

recruited to participate in the second phase of the study, involving 16 cisgender women and 16 *hijra*/transgender women. Participants were asked to elaborate on how their experiences of HIV stigma may have been compounded by gender roles and gender nonconformity stigma.

Phase 2 data analysis. All interviews were digitally audio recorded, then subsequently translated and transcribed. The research assistant in Hyderabad translated and transcribed interviews in Telugu and the doctoral student translated and transcribed interviews in Hindi/Urdu. Transcripts of the interviews were imported into the data analysis program, NVivo 10 for coding (QSR International, 2012) and analysis.

The methodology utilized was thematic content analysis (Krippendorff, 2012; Elo & Kyngäs, 2008)—an approach that is used to describe the experiences of socially marginalized communities (Marshall & Rossman, 2011). Thematic content analysis can be utilized with diverse theoretical approaches and can incorporate both inductive and deductive analyses. In this study, inductive analyses were used to identify new themes that emerged from the data, and deductive approaches were used to explore themes identified by GRT and the adapted Goffman conceptualization of stigma. Such an approach aimed to allow room for the kind of grounded theory-informed coding outlined by Strauss & Corbin (1990), without eliminating the possibility of seeking out specific gender-related themes.

After reviewing the first ten transcripts, three evaluators—the doctoral student, an India-based research assistant, and a U.S.-based research assistant—developed a codebook of themes. Relevant chunks from transcribed data were assigned codes (Charmaz, 2006; Miles & Huberman, 1994). Identified codes were placed in broad groupings. The codes under each heading were clubbed together and the content analyzed for common themes (Singh, 2015). After initial coding, the team met to discuss differences in how codes were applied, refining code

definitions and combining codes to reflect themes found in the data. Themes included difficulties in disclosing HIV status to family members, gender role conflict, and transgender stigma. Codes were clustered together by specific themes to create a codebook. The refined codebook was used to code the remaining interviews. The two coders reviewed all coding decisions, discussing and resolving any significant differences in coding decisions or patterns.

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Institutional Review Board and Informed Consent

Informed consent was obtained from all participants, following the Institutional Review Board (IRB) protocol, which was approved in September 2015 by both the University of Chicago IRB and the Ethics Committee at our partner research organization in Hyderabad—SHARE India. During the informed consent process, participants were asked if they would be willing to provide their contact information in order to potentially be recruited for the second,

qualitative phase. Only those individuals who provided consent to be contacted and who fit the eligibility criteria for phase 2 were invited to participate in interviews.

STRUCTURE OF THE DISSERTATION

This dissertation project consists of four papers. The first paper reviews the history of the treatment of sex workers and *hijra* before, during, and following colonialism, providing a sociohistorical analysis for the issues addressed by the dissertation research questions. It analyzes how sex workers and *hijra* are entangled in paradigmatic shifts in the construction of local/global gender and sexual minority identities through the processes of neocolonialism. A historical review is offered of policies regarding sex workers and *hijra* prior to, during, and following British colonialization in South Asia. I ultimately argue that in the current sociopolitical paradigm, multilateral development organizations operating in South Asia continue to utilize neocolonial frameworks in their attempts to intervene in the sexual and reproductive health of women and gender-nonconforming people. In doing so, they erase contextual particularities of gender and sexuality in South Asia, creating artificial divides between overlapping gender and sexual minority groups. Drawing on Spivak's work on subalternity (1999), this paper attempts to provide an initial analysis of postcolonial power relations between international donor organizations working in the context of sexual and reproductive health and their local beneficiaries in South Asia.

The second paper explores themes from the qualitative interviews with *hijra*/transgender women living with HIV in India, specifically focusing on themes related to living a secret life. Analysis of interviews revealed that *hijra* have experienced a change in the ways in which they have historically perceived themselves and the ways in which they are perceived socially today. Some *hijra* reported always expressing their gender identity as *hijra*, 24 hours a day, seven days a week. Other *hijra* reported living two distinct lives: one in the daylight, where they identified as men and fulfilled a role of husband/father with their family, and another at night where they

identified as *hijra* with circles of friends and other gender-nonconforming people. For some *hijra*, a dual gender identity caused feelings of internal conflict. For others, it was perfectly feasible to have multiple gender identities, depending on the social context and space. The South Asian social construction of gender may allow for the ascription of a multiplicity of gender identities, a notion that markedly differs from how gender is often constructed in the West.

The third paper examines themes related to HIV stigma, social isolation and depression from the 16 qualitative interviews conducted with cisgender women living with HIV in Hyderabad. The goal of this study was to explore how stigma, social isolation, and depression affect cisgender women living with HIV in Hyderabad, India. We found that HIV stigma is impacted by restrictive gender roles, a limited ability to refuse or delay sex or marriage, and the prioritization of male partners' health over females'. Four main themes emerged from the qualitative interviews: experiences of social isolation; HIV and negative self-perceptions of body image and health; perceived experiences of discrimination; and suicidality and regaining hope.

The fourth paper examines quantitative associations between HIV stigma and two health outcomes. The goal of this paper was to identify if HIV stigma differentially affects cisgender women and *hijra*/transgender women living with HIV in Hyderabad, India, in terms of experiencing depression and the utilization of medical care. Using survey data from 150 individuals living with HIV (51 cisgender women, 49 cisgender men, and 50 *hijra*/transgender women, we tested whether HIV stigma was significantly correlated with depression and medical care utilization. The mean age of participants was 38.03 years (SD=7.62); mean income was 8,8083 Rupees (SD=5,917); and mean self-reported CD4 count was 447 (SD=258). The majority of participants were Hindu (85%), spoke Telugu as their native language (89%), and were members of scheduled castes or tribes (79%). Multiple linear regressions were used to determine

associations between HIV stigma and depression. Binomial logistic regressions were used to determine associations between HIV stigma and the utilization of medical care. For both outcomes, age and income were utilized as control variables. Using separate models from the two HIV stigma measures used in the survey (Zelaya, 2008; Jeyaseelan, 2013), the variables of experiencing HIV stigma, being transgender, and the interaction between experiencing HIV stigma and being transgender were all highly significant in positively predicting depression ($p < 0.002$). On the Zelaya measure, both experiencing HIV stigma and being transgender were significantly associated with the positive utilization of medical care ($p < 0.05$). On the Jeyaseelan measure, being transgender was positively associated with the positive utilization of medical care ($p < 0.000$). These findings emphasize the importance of tailoring policies and programs to fit the specific mental and physical health needs of cisgender women, cisgender men, and *hijra*/transgender people living with HIV in India.

IMPLICATIONS FOR POLICY AND PRACTICE

This dissertation project sought to contribute to the canon of research on gender and sexuality, paying particular attention to the contributions of colonization, culture, and mental health on the interpretation of these constructs in South Asia. The narratives from the qualitative interviews with cisgender women and *hijra*/transgender women highlighted how HIV stigma remains a salient feature of the lives of people living with HIV in India.

Analysis of survey data demonstrated that HIV stigma is strongly associated with depression, most acutely impacting *hijra*/transgender women. Understanding this variation within gender groups helps elucidate how future stigma reduction interventions in the Indian context need to be better tailored for PLWH. The inclusion of cisgender men in this study highlighted how men may be protected from harsher forms of HIV stigma, and how interventions may need to be designed to address the unique needs of cisgender and transgender women. Social responses to HIV, in particular HIV stigma, serve to assert and reproduce normativity (Van Hollen, 2010; Goffman, 1963; Parker & Aggleton, 2003). Interventions, at the individual, community and structural/policy level must address these issues if they seek to ensure that all PLWH receive equitable access to physical and mental health services.

It is also noteworthy that depression scores were significantly higher for cisgender women, indicating that this population faces unique mental health needs and will require greater attention in the planning of their health and social services. In qualitative interviews, cisgender women repeatedly voiced that they found the strength to stay alive only for the sake of their children. Such essentializations of women as wives and child-bearing/child-rearing agents provide important insight into the ways in which gendered social roles for South Asian women are constructed. Following this rationale, unmarried women, widows, and women without

children may be particularly prone to experiencing depression and suicidality. As such, particular attention needs to be paid to ensure the greater inclusion of these marginalized women within HIV medical care and social services provision.

To address HIV stigma at the policy and programmatic levels, the National AIDS Control Organization (NACO) and the Telangana State AIDS Control Society need to introduce farther-reaching stigma reduction campaigns that work to normalize the identities of people living with HIV. HIV awareness campaigns have typically relied on scare tactics to “educate” consumers. Alternative campaigns are necessary to ensure that certain groups of people, namely sex workers, queer or gender-nonconforming people, and injection drug users, do not continue to be blamed and shamed for their HIV status. Fear-inducing messages about AIDS that hold people morally responsible for their infection only serve to further isolate and discriminate against people living with HIV (Thomas et al., 2005) and ultimately only exacerbates disparities in care. A more sensitive approach to the stigmatized identities of individuals living with HIV will be necessary to combat health disparities experienced by these vulnerable South Asian populations.

This research also seeks to challenge the hegemonic discourse that leaves South Asia and other communities of the global South with laggard understandings of gender and sexuality. As Jasbir Puar (2007) comments, “The paradigm of gay liberation and emancipation has produced all sorts of troubling narratives: about the greater homophobia of immigrant communities and communities of color, about the stricter family values and mores in those communities, about a certain migration from home, about coming-out ideologies” (p. 22). Orientalist framings of South Asia equate settings that are resource-constrained with being narrow-minded, simplistic, intolerant, and basic. South Asia’s progressive third gender policies provide an illustrative example of how these social constructions of the Far East are not accurate. While there were

certainly intense stories of HIV and gender-nonconformity stigma in the narratives we collected, there was also an affirmation of the place for fluidity and multiplicity in the gender identity and sexual orientation of third gender people. As Saba Mahmood (2011) notes, “My intention here is not to question the profound transformation that the liberal discourse of freedom and individual autonomy has enabled in women's lives around the world, but rather to draw attention to the ways in which these liberal presuppositions have become naturalized in the scholarship on gender. It is quite clear that both positive and negative notions of freedom have been used productively to expand the horizon of what constitutes the domain of legitimate feminist practice and debate” (p. 13).

The impact of the recent third gender registration policy is an area that requires evaluation. Focused assessments of the consequences of this policy may help further our understanding of the advantages and drawbacks of utilizing a human rights-based framework to address social inequities. It may be the case that registration and legal name change are effective at increasing self-confidence and self-esteem for *hijra*/transgender women, thereby reducing internalized stigma. Recent research with transgender youth ages 15 to 21 in the United States asked young people whether they could use their chosen name at school, home, work and with friends (Russell et al., 2018). Compared with peers who could not use their chosen name in any context, young people who could use their name in all four areas experienced 71% fewer symptoms of severe depression, a 34% decrease in reported thoughts of suicide, and a 65% decrease in suicidal attempts (Russell *et al.*, 2018). An increase by one context in which a chosen name could be used predicted a 5.37 unit decrease in depressive symptoms, a 29% decrease in suicidal ideation, and a 56% decrease in suicidal behavior. These findings indicate that chosen name usage is instrumental for mental health. We might also infer that registration and name

change may also be instrumental in increasing the likelihood of third gender people to access health and social services, thereby reducing enacted stigma or discrimination. While there is no research yet to validate this claim, future evaluations of such name and gender change policies may show that registration and legal name change are associated with important health outcomes for people living with HIV. If this were the case, then legal name and gender change may be important intervention points for policies and programs for HIV prevention and care. In spite of recent policy changes and increased visibility of third gender people in South Asia, *hijra* continue to face heightened discrimination (Bharat, Aggleton & Tyler, 2001). *Hijra* and other gender-conforming people are also often excluded from both medical and social science research, making comparisons across gender identity rare. The relative lack of inclusion of gender non-conforming individuals in HIV research in India is a major gap in our understanding of HIV and of South Asian gender and sexuality identities.

Another important implication for this research is the funding allocated to HIV services and research. Ensuring that there are robust domestic funding streams (within India) for HIV prevention and care will be particularly important as international funding streams, such as the President's Emergency Plan for AIDS Relief (PEPFAR), Gates Foundation, and the Global Fund to Fight AIDS, Tuberculosis and Malaria reduce their global HIV prevention and care budgets. In December 2017, President Trump's Fiscal Year 2019 Budget proposal called for at least \$1.284 billion in cuts to global HIV programs, and a full \$1.35 billion in cuts to funding for the Global Fund to Fight AIDS, Tuberculosis and Malaria (Gramer, 2017). This prompted a group of HIV scientists, researchers, and clinicians to pen an open letter at the Conference on Retroviruses and Opportunistic Infections (CROI) challenging the deterioration of evidence-

based policymaking under President Trump (Health Gap, 2017). Such continued advocacy is needed to ensure that global HIV prevention and care funding does not continue to be depleted.

This research study also highlights opportunities for continued research on third gender groups in South Asia. To address the impacts of gender nonconformity stigma within India, we already have access to a natural experiment through recent policy changes impacting third gender people in India. In 2005, the Indian passport began to have a third gender option for legal identification for travel. In 2013, the Election Commission of India introduced a third gender option for voter identity cards, for the first time officially recognizing the transgender community in the electoral process (The Wire, 2016). On April 15, 2014, the Supreme Court of India, following the recommendations of Justices Radhakrishnan and A.K. Sikri, afforded third gender individuals constitutional protections from discrimination; equal rights in terms of healthcare, education and social entitlements; and legal protection. In November 2016, the Indian Railway Catering and Tourism Corporation also introduced a third gender option in ticket reservation and cancellation forms.

These policy changes have made it legally permissible for third gender people to register their changed names and third gender identity with state and central Indian governments. For *hijra*/transgender women, this public affirmation of one's gender identity may have substantial impacts on physical and mental health outcomes. Future research might follow third gender individuals before and after they legally change their name and gender identity to study whether representation through the state leads to positive outcomes, perhaps by reducing experiences of stigma, improving mental health, or making it easier to access medical care and social supports.

While all of the aforementioned policy changes are progressive in their greater inclusion of sexual and gender minorities in South Asia, the Indian Penal Code (IPC) Section 377 still

criminalizes sodomy and, arguably, also gender nonconformity. It has been used as a tool by law enforcement in India to discriminate against *hijra* and queer communities. IPC Section 377 has been in effect since 1860. It was overturned in 2009, but was reinstated in 2013. IPC Section 377 allows local police the authority to arrest and prosecute men who have sex with men and *hijra*/transgender women under the pretense of preventing “unnatural” sex acts (Li et al., 2016). Limited research suggests that IPC Section 377 may be associated with increased violence toward *hijra*/transgender women, echoing global trends where criminalization laws for sodomy empower local authorities to discriminate against sexual and gender minorities (Gupta, 2016; Arreola, Santos, Beck, Sundaraj, Wilson, Hebert, et al., 2014). For example, *hijra*/transgender women in Maharashtra experienced harassment and threats of arrest by police at “hot spots” or sex work cruising sites where they could potentially be arrested under IPC Section 377.

IPC Section 377 may also create additional barriers against *hijra*/transgender women accessing targeted public health services. While India’s National AIDS Control Organization (NACO) calls for strengthening healthcare infrastructure and implementing targeted interventions for high-risk populations, laws—such as IPC Section 377—that criminalize homosexuality and gender nonconformity directly threaten the health of people living with HIV and contradict measures being taken by other ministries within the Central Government of India. The reinstatement of IPC Section 377 may have influenced negative health outcomes for gender-nonconforming people.

In conclusion, legal advocacy for third gender rights, sex worker rights, and women’s rights, may be one of the most important routes toward the reduction of stigma and discrimination of people living with HIV in south India (Li et. al, 2016). Through the concerted efforts of people living with HIV, public health entities, and nongovernmental organizations, we

may be able to slowly shift the marginalized status that people living with HIV in South Asia continue to experience.

This research also utilized postcolonial feminist approaches to highlight neocolonial agendas in global representations of health and illness, and how these representations circulate to reproduce the political economic interests of transnational hegemony (Sastry & Dutta, 2001). By better understanding the processes underlying colonization, imperialism, and the representations that circulate in the dominant discursive spaces created by these forces (Spivak, 1999), we may gain a better appreciation for the unintentional consequences of international advocacy work for women's sexual and reproductive justice, access to HIV care, and affirmation of LGBT rights.

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Sex Work, Hijra and Neocolonialism in South Asia

Abstract

This paper offers a historical review of policies regarding sex workers and *hijra*, a group of gender nonconforming people in South Asia, prior to and following British colonialism in South Asia. This paper also seeks to analyze how sex workers and *hijra* are entangled in paradigmatic shifts in the construction of local/global gender and sexual minority identities through the process of neocolonialism. In the current sociopolitical paradigm, multilateral development organizations operating in South Asia continue to utilize neocolonial frameworks in their attempts to intervene on the sexual and reproductive health of women and gender-nonconforming people. In doing so, they erase contextual particularities of gender and sexuality in South Asia, creating artificial divides between overlapping gender and sexual minority groups. Drawing on Spivak's work on subalternity (1999), this article also provides an analysis of postcolonial power relations between international donor organizations, working in the context of sexual and reproductive health, and their local beneficiaries in South Asia.

Keywords: *hijra*, sex work, neocolonialism, subaltern, South Asia

Sex Work, *Hijra* and Neocolonialism in South Asia

Imperial authority over colonies was fundamentally structured in racialized and gendered terms. Gender dynamics were always fundamental to the imperial enterprise (McClintock, 1998). No subjects were more frequently invoked in colonial literature than sexuality and gender (Stoler, 2002). The colonial fantasy of adventure and exploration found a literal and figurative home in the illicit space of the brothel. Colonial efforts to monitor both prostitution and gender-nonconformity illustrate how empires used sexuality as a symbolic tool of conquest. The patterns of monitoring gender and sexual norms under colonialism are reproduced through the neocolonial efforts of international donor organizations working in the arena of sexual and reproductive health in South Asia. This paper utilizes sociohistorical perspectives to highlight the colonial and neocolonial knowledge hierarchies that govern the monitoring of sex work and gender-conformity in South Asia.

According to Nkrumah (1966), “The essence of neo-colonialism is that the State which is subject to it is, in theory, independent and has all the outward trappings of international sovereignty. In reality its economic system and thus its political policy is directed from outside” (p. 1). Postcolonial critiques are utilized in this paper to highlight the changes that occurred in gender and sexuality policies in South Asia before, during, and after colonialism. As Chandra Mohanty (1991) argued, utilizing a faulty analytic frame, such as one that does not fully appreciate the impacts of colonialism, engenders ineffective political action. Postcolonial critiques stress the need to destabilize the dominant discourse of imperial Europe, including the notion of “development” (McEwan, 2001). At its core, a postcolonial approach is poststructuralist in its epistemology as it challenges Western assumptions of civilization, culture,

political structure, and social hierarchy. Hegemonic discourse perceives the global North as advanced and progressive while the global South, including South Asia, is perceived as backwards, primitive, infantile, and undeveloped (McEwan, 2001). “Development” then becomes the terminology appropriated to this cultural difference.

The bifurcation of the First and Third Worlds creates a global social hierarchy for the haves and have nots. As Sara Ahmed (2010) argues, "Progressive racism is central to the history of racism. After all, the empire itself was understood as progressive, as being about increasing civilization (often identified with happiness). To quote from a historian of the East India Company: ‘The pace of civilization would be quickened beyond all examples. The courts, the knowledge, and the manners of Europe would be brought to their doors, and forced by an irresistible moral pressure on their acceptance. The happiness of the human race would thus be prodigiously augmented.’” (p.1).

Following the trajectory of British colonization in India to contemporary times, the primary ideology under which foreign aid from Western countries currently operates follows the individualistic tenets of neoliberal capitalism, introduced into India during the time of the British Raj. Neocolonial paradigms dictate how Eastern and Western approaches to health, medicine and sexuality are broadly conceived. In contrast to the monetary and racialized systems of social hierarchy introduced by the British, indigenous perspectives on collectivism and community in South Asia may offer more equitable systems of cultural interaction, though they too are laden with the inherent injustices of the caste system. Western approaches to psychology and gender have not shown much interest in incorporating indigenous psychological and sexual concepts as there is an assumption that these concepts are integral parts of religious or prescientific worldviews and, therefore, do not meet Western scientific standards (Chakkarath, 2005).

In the realm of regulating gender and sexuality, the polarization of the First World and the Third World creates a dynamic where previously imperial countries are in a position to dictate the rules for proper sexual behavior of the inhabitants of their previous colonies. These ideologies, surveilling maternity, sexuality, and gender, are reinforced through the parameters set by international funding streams. This power dynamic implicitly reinforces Western notions of heteronormativity and a strict gender binary. These neocolonial ideologies may dictate how many children a woman should have, whether or not a woman should wear a headscarf, whether a man should dress in a sari, and so on. Without ascribing intent on the part of donors, philanthropists and development organization program officers effectively play the role of white saviors, conferring “superior” knowledge to residents of the Third World.

Postcolonial perspectives critique uniform depictions of women and gender nonconforming people in the Third World, which may make it seem as though all women of color, or all people of color, are indistinguishable from one another and share equal concerns in regard to gender and sexuality. The process of Orientalism imagines the East to be mystical, mysterious, barbaric and primitive, in direct contrast to the rational, civilized, and developed West (Said, 1978). It is this imaginary that offers the ontological and epistemological base of Western knowledge structures that seek to “know” the Orient. Continuing to narrate this depiction of the Third World, discourse in the First World often constructs India as basic and irrational—a site characterized by immorality, promiscuity, poverty, and disorganization (Sastry & Datta, 2001).

Postcolonial feminism demonstrates that “paternalistic Western representations of third world women in need of saving by white Europeans are not benign” (Mohanty, 1991, p. 72). The subjugated female brown body becomes the object of the Westerner’s enlightened teachings, a

moral prop used to legitimize colonial power relations (Moghissi, 1999). The perceived oppression of women in foreign lands has been used as a tool of the state to justify colonial intervention in the past and military intervention in the present. In this Orientalist imaginary, women are envisioned as victims in need of saving by the paternalistic Western masculinity of patriarchal social or governmental institutions (Ayotte & Husain, 2005).

Neocolonial feminist analyses of international relations may broaden our understanding of foreign intervention to consider efforts to “liberate” the bodies of women of color as forms of epistemic violence (Spivak, 1999). Those who support the proliferation of foreign military interventions in South Asia and the Middle East often construct women and transgender people of color as slaves in desperate need of rescuing by the West (Ayotte & Husain, 2005). Health intervention can also become framed by perceived national security or economic concerns (McEwan, 2001). Such proponents may argue that stabilizing failed states is imperative to international security and foreign policy, both of which are primarily aimed to benefit the metropole. Under these neocolonial views, the application of Western ideology about what constitutes “success” often deliberately excludes the views of indigenous people, “who are often seen as objects of, or obstacles to, the implementation of progressive health policies” (McEwan, 2001, pXX).

Sex Work and Gender Conformity in the Precolonial Period

The colonial period in India is generally defined as the time between the Battle of Plassey on June 23, 1757, fought between the British East India Company and the Nawab of Bengal (Roy, 2011). Between 1757 and 1857, the British East India Company held substantial power, particularly in Bengal. In 1857, the British government killed 35,000 Indian soldiers (*sepoys*) in

the Bengal army who had rebelled against the British Raj. The massacre, known as the Sepoy Mutiny, marked the first event in the Indian independence movement. Colonialism officially ended in 1947, when India declared independence from the British (Roy, 2011).

In precolonial India, the modern notion of sex work did not exist in the same form as today. Rather, concubines, courtesans, and *devadasis* (Hindu temple devotees who sometimes performed dance at temples or engaged in sexual acts with priests) engaged in what is now referred to as sex work. These groups were often in good standing with the state and frequently received support from local temples, nobles, or royalty (Tambe, 2009; Punekar & Rao, 1962). One of these groups of women, known as *tawaif*, the Urdu translation for courtesan, catered to South Asian nobility during the Mughal era. Both *devadasis* and *tawaif* were formally trained in music, dance, theater, and poetry (Singh, 2007). They were not seen as cheap whores, but rather as refined, cultured escorts. Under British colonialism, the image of both the *devadasi* and *tawaif* were recast as licentious. Such women were perceived as undermining colonial power by discrediting the morality of the colonists. The downfall of the Mughal Empire, Rajput dynasties, and other local South Asian principalities led to the loss of royal patronage of women who served these roles within the upper echelons of society (Rao & Rao, 1970).

Similarly, gender nonconformity was treated differently in precolonial times. *Hijra* are a group of gender-nonconforming people in South Asia. They are a gender/sexual minority with historical origins tracing back over a thousand years (Vinay, Krishna, Suresh & Srikala, 2010; Reddy, 2006). They are considered neither men nor women (Nanda, 1990), but rather occupy a third gender category (Kalra, 2012; Jaffrey, 1996). The word “*hijra*” is derived from an Urdu word, which in colonial times was translated to mean “eunuch” or “hermaphrodite,” though this is an imperfect translation (Lal, 1999). In contemporary English vernacular, the term *hijra* is

often translated to connote a transgender female or transsexual identity. However, it is important to note that the term *hijra* is not exactly synonymous with the term “transgender,” as some people who identify as being transgender do not consider themselves to be *hijra* (Krishner, 2015), and vice versa, some *hijra* do not consider themselves to be transgender. These labels are neither mutually exclusive nor completely overlapping. The third gender label includes a range of identities, including *hijra*, *kothi*, *kojja*, *kinnar*, *shiv-shakti*, *aravani*, *jankha*, *khusra*, *bugga*, *khwaja-siras*, and others. Without going into detail on how these various identities differ, it is important to note that the distinctions between third gender identities in South Asia and the transgender identity in Western contexts stem from the historical and cultural socialization of each group within their respective settings.

Hijra are individuals who were typically identified as boys at birth, raised as males, but identify with more effeminate gender roles and gender expression. *Hijra* include individuals who are cross-dressers, transvestites, intersexual, or simply gender-nonconforming. A *hijra* identity does not necessarily connote an exclusive sexual attraction to men. One can be part of this community, yet continue to have sex with or even be married to women. As Pamment (2001) argues, “The *hijra* trope—by moving in the third space of gender, class, and politics—has the gift of heroically upsetting the tyranny of boundaries and the secure world of logos, offering a cultural frontier that disturbs the hegemonic designs of the established” (p. 48). Indeed, *hijra* live in the liminal space between men and women, between permitted and forbidden, between the divine and the damned, between the auspicious and the forsaken.

The sociopolitical contexts for gender identity and sexual orientation vary widely between the Western world and South Asia, from the usage of various labels to the social connotations afforded to those labels. The distinctions in vernacular signal a difference in the

way that gender is anthropologically constructed in each culture. In Western scholarship, gender has changed from being constructed as an inherent trait possessed by individuals, largely in relation to the possession of particular genitalia or chromosomes, to being a learned or ascribed trait that operates through the performativity of speech, dress, and behavior (Butler, 1999). While transgender people may be part of the “new forms of queer subjectivities” (Blackman, 2009, p. x) in the Western context, *hijra* have held an accepted social position in South Asia for centuries. A transgender person in the Western context is often described as being in the process of “becoming” or as being “in transition,” supposedly from being male to female, or from female to male. Meanwhile, the third gender person in South Asia just is. No transition is necessary. There is no end game or finite gender binary towards which the *hijra* is working. They are not in the process of arriving at their destination; they are already there. Verbiage regarding “transitioning,” “passing” or being “clocky,” which are more heavily used in Western contexts to refer to transgender people, may only serve to reinforce the very binary that gender-nonconforming people are trying to avoid.

An alternative to this may be offered through the notion of being genderqueer or genderfluid (Richards et al., 2016). Recent research in gender and sexuality studies has obscured the traditional distinctions between gender and sex, arguing that both anatomical sex and gender are socially constructed, resulting in a more complex appreciation of gender that acknowledges the interplay between biology, identity, performance, power, and practice (Towle & Morgan, 2008). Such an understanding of gender may be more similar to the ways in which the *hijra* identity is socially constructed in South Asia.

Policing Sex Work During Colonialism

Public health efforts in the colonies developed largely as a reaction to colonialism (Levine, 2003). Efforts to control venereal disease (VD) were part of the colonial project to protect the colonizers and modernize the natives. The threat to the empire's posterity laid in the salacious sexual acts of native women. It then became the White Man's Burden (Kipling & Wise, 1899) to help brown women recover from their sexual and cultural failings. The image was created of people who were so steeped in their own traditions that they foolishly questioned the rationality of modern Western medicine. The climate of the colonies was thought to breed disease, and the unbridled heat of tropical environments was equated with the moral degeneracy of its inhabitants. Misconceptions of the colonies as sources of filth and disease were vivid in the colonial imaginary. Moral causes of disease became enmeshed with medical discourse on pathology.

Between 1770 and 1840, sexual relationships often developed between British colonists and their female, domestic servants in South Asia (Ghosh, 2008). Through these sexual relationships with South Asian women, British colonists justified their role as stewards of the empire by serving as "protectors" of native women. In those cases where British men did in fact marry Indian women, the racial hierarchy was reinforced both inside and outside the household (Ghosh, 2008). In the colonial context, Indian women were represented as ignorant, uneducated, tradition-bound, domesticated, and victimized (Kapur, 2011). In multiple colonial contexts, local "tradition" was placed at odds with European "modernity" (Pederson, 1991). If Third World women were infantile, backward and incapable of autonomy, then it was central to the colonial project to "empower" and "liberate" them.

The state's interest in regulating sex work was targeted at preventing ill health among British soldiers through sexually transmitted infections (Stoler, 2002). Venereal disease rates for British soldiers in India were higher than in other parts of the empire (Levine, 2003). When syphilis and gonorrhea outbreaks occurred among soldiers in Bombay and Delhi (Levine, 1994), the British Empire scurried to control what was seen to be the source of contagion—brown women. As one medical officer claimed in 1887, the single source of disease for sailors' infection was the particular "contaminating" woman with whom they had consorted (Tambe, 2009).

At the same time that the British Empire admonished Indian women for engaging in prostitution, they also created an image of a destitute brown woman who desperately needed to be saved by a white Crusader. By casting Indian women as the object of oppression, the empire was able to justify its presence in India with the humanitarian goal of civilizing the natives. Cultural and sexual practices affecting women and children were targeted as reforms in the colonial civilizing mission (Tambe, 2009; Chatterjee, 1989). For example, the Act of 1829 made *suttee*, the practice of widow immolation, illegal (Sinha, 2006).

Laws in the late colonial period continued to configure a new relationship between the state and prostitution. The first Police Rule, Ordinance, and Regulation Act of 1812 listed brothels as a source of disturbance. At the time of the passing of this act, prostitution was not considered a crime on its own, but was deemed instrumental to the committing of crimes. Procurement and enticement into prostitution was ruled an offense in 1827, 1860, 1921, and 1923; brothel keeping was similarly deemed illegal in 1860, 1902, 1923 and 1930 (Tambe, 2009). The Penal Code of 1860 introduced sections 372 and 373, making the buying or selling of girls and women into prostitution a criminal offense. The term "common prostitute" was

introduced into Indian legal discourse by the colonial state, contributing to the rise of a devalued form of sex work. In 1838, the secretary of the Government of India advised the Government of Bombay to apprehend “every common prostitute... behaving in a notorious or indecent manner” (Kapse, 1987, p203). This notion of sex work as a debase act, committed by the lower classes, stood in contrast to honorable womanhood, espoused by the white bourgeoisie. Race, gender and class lines of social hierarchy were sharply reified through the colonial project.

Under colonialism, the policing of gender and sexuality became a useful metaphor for the subjugation of the bodies of colonized people. One of the first health interventions in virtually every British colonial setting was regulating prostitution by disciplining women’s “unclean” habits (Levine, 2003). A series of regulations were passed in India that mimicked regulations in the metropole. In England, the Contagious Diseases Acts were first passed in 1864, allowing police officers to arrest prostitutes, subject them to compulsory medical examinations, and imprison them for their crimes in lock hospitals and lock wards. Similarly, in India, social policies delineated how the British Empire sought to police prostitution. State-regulated brothels became an integral component of the sexual order in British colonies (Tambe, 2011). The Cantonment Act of 1864 instituted compulsory medical examination for all practicing prostitutes in cantonments or military camps. The Indian Contagious Diseases Act of 1868 expanded the rules of the Cantonment Act to cities.

Discourse regarding prostitution became racialized when separate guidelines for treatment were mandated for white prostitutes in England versus brown prostitutes in India. While there were limits on the amount of time that prostitutes could be held by police or hospitals in England, prostitutes in India could be held indefinitely (Tambe, 2009). Prostitutes in India were required to register with the state and were subject to more frequent medical

examinations. The registry included details regarding the caste, residence, age and physical description of each prostitute.

In the second phase of the Contagious Diseases Acts from 1880 to 1888, medical and police authorities were provided even more liberties in enforcing the law. Despite their increased authority, police were ineffective at eliminating prostitution. More than four fifths of the women who practiced prostitution in Bombay successfully evaded the edicts of the law (Tambe, 2009). To avoid the registration process and medical examinations, women denied being prostitutes by producing marriage certificates, filing petitions, or bribing police officers.

After 1883, registration of prostitutes became voluntary in England, but remained compulsory in India (Tambe, 2009). Brothels were reserved for the sole use of soldiers who were stationed in Indian ports. Only prostitutes who had been screened for VD were allowed to work in these state-regulated brothels. By regulating (rather than criminalizing) prostitution, the British Empire institutionalized the policing of sexuality and more specifically, sex work. While the registration system was abolished in 1929 (Punekar & Rao, 1967), the process of surveying sex workers would reappear decades later with the emergence of epidemiological tracking of HIV cases.

In the colonies, prostitutes were formally registered in a Panopticon-style system where their actions were carefully monitored. Mimicking the tracking systems used to monitor the criminal and the insane, the registration of sex workers demonstrates how the empire became not just a mode for governance, but a vehicle for moral and behavioral surveillance. Medical discourse, grounded in the fear of contagion, served to safeguard against the moral and racial degeneracy that could potentially occur via prostitution.

This mission is complicated by the notion that sex work, particularly in the postcolonial paradigm, may be seen as creating new opportunities for social and economic independence for women. Sex work transformed traditional gender norms, allowing women to become the heads of their household. Not having employment opportunities in the formal economy, sex workers were able to earn money, acquire property, become landlords, and support their families. Calling this phenomenon “whorearchy,” McClintock (1991) notes that for these women, prostitution was the best defense against colonialism, forced marriage, hunger, and destitution. Prostitution allowed women to accumulate money and property for survival. Instead of losing their property to sons, brothers, or other male family members, had they been married to men, female prostitutes were able to leave their earnings as inheritance to other women, thereby reinventing the structure of property ownership and effectively cutting men out of the inheritance scheme.

Alternatively, sex work may be viewed as being reproductive of male labor power relations (Zatz, 1997). Female sex workers in South Asia often performed the very same roles that they would perform in their own homes without pay, i.e. cooking, washing clothes, and cleaning the house. Without the institution of marriage, women could sell their companionship and domestic services to men. This commodified sexual labor in a way that was directly dependent on the wages on which their male clients relied to pay for sex. The site of labor reproduction—either inside the room of a brothel or on the street—determined the type of sex work in which women were willing to engage and the price they were willing to charge for it.

Sex work, therefore, serves as an analogy for both imprisoning and empowering colonial subjects. The ways in which the metropole policed prostitution reveals the underlying anxiety of an empire grappling to validate its own existence. The architecture of lock hospitals, the registration process of prostitutes, and the mandated medical examinations for VD all offer vivid

examples of the means by which this policing took hold. Sexual relationships complicate a straightforward hierarchy between colonizer and colonized, white and brown, male and female. Similar patterns of power and control over the colony were manifested in the treatment of third gender people in India during British colonization.

Policing of *Hijra* during Colonialism

Similar to the ways in which sex workers were policed during the colonial era, *hijra* have also been the target of state policing. As Hinchy (2014) notes, in the 1850s the British discovered a community of eunuch performers, known as *hijra*. British colonizers classified *hijra* as a distinct group within the many castes and tribes they codified throughout British India. In 1871 the passage of the Criminal Tribes Act (CTA) defined *hijra* as criminals and legalized their surveillance. This act again reified the colonial regulation of social and sexual mores. Under the CTA, *hijra* could be arrested for dressing in women's clothing, participating in sodomy, dancing, or playing music in public places. The CTA specifically criminalized "any eunuch so registered who appears, dressed or ornamented like a woman, in a public street or place, or in any other place, with the intention of being seen from a public street or place, or who dances or plays music, or takes part in any public exhibition, in any public street or place" (British Library, 1871). Local government officials were required to maintain a registry of the names and personal details of *hijra* who were suspected of kidnapping or castrating children, a suspicion that was often made of gender-nonconforming people.

Colonial attempts were made to erase *hijra* as a visible gender identity in public space through prohibition of their performance and dress (Hinchy, 2014). The British further criminalized *hijra* by making punishable any act that was deemed to be an "unnatural offence"

under Section 377 of the British Penal Code. While not explicitly stating what was considered an unnatural offence, Section 377 essentially made sodomy, homosexuality and gender nonconformity illegal. This legislation made clear that gender-nonconforming people were considered criminals and their behavior legally punishable by up to ten years in prison and/or a fine.

Attempts to discipline masculinity and perceived obscenity in the South Asian context were ineffective as they were met with inadequate policing resources, allowing *hijra* to take advantage of gaps in surveillance. While *hijra* were already marginalized prior to the passing of these legislative acts, the British Penal Code reified their taboo nature by legalizing discrimination against them. The British colonial government judged *hijra* to be a “breach of public decency” (Preston, 1987, p. 372), associating their acts with obscenity and lack of moral decorum.

Following Indian independence in 1947, *hijra* officially lost their state-sanctioned support from local temples, courts, and principalities. Since that time, many *hijra* have turned to panhandling and sex work as a means of livelihood. Even within their own families, communities and religious institutions, *hijra* are not immune to experiences of stigma and discrimination. Recent accounts in India, Pakistan, and Bangladesh document how *hijra* still largely exist without a sociopolitical space (Gowen, 2016; Khan et al., 2009). *Hijra* are often excluded from public events, religious activities, and cultural functions. For example, during a large Hindu festival known as Kumbh Mela in Ujjain, Madhya Pradesh, India in 2016, *hijra* groups organized to be allotted a space for their own camp at the festival (Gowen, 2016). However, the *gurus* overseeing the official 13 Hindu *akharas* (monastic orders) said they would not recognize *hijra*, nor any women’s group, as a 14th *akhara*, claiming that such a move would

go against Hindu traditions. Narendra Giri Maharaj, the head of the All India Akhara Parishad, the umbrella group for the *akharas*, said, “We respect transgenders in society, but we will not allow them for the holy dip. It’s against Hindu law. We will never recognize them, under any condition” (Gowen, 2016). Maharaj’s statement reinforces the notion that while *hijra* are often ascribed virtues of divinity, luck, fertility and prosperity, third gender individuals paradoxically continue to be excluded from religious rituals and other spaces of social congregation.

Within contemporary public health audiences, *hijra* have sometimes been lumped into the category of “men who have sex with men” (MSM), based on their anatomy, sexual preference and public health importance in regard to HIV. While attempting to focus on their sexual behavior over their identity, the term MSM may be a biopolitical move to relocate the power over sexual and gender minorities from the operatus of the individual to the operatus of biomedical intervention (Foucault, 1990). While the new nomenclature was an attempt to move away from labels that had historically marginalized communities, it may have only served to reinforce the pathologization of gay/bisexual men and transgender women by implying that the behavior often associated with these communities, namely prostitution, cross-dressing, and anal sex, is not morally bankrupt but rather medically dangerous.

Returning to the variety of labels referring to gender and sexual minorities in the South Asian context, some scholars argue that the advent of “indigenous” categories used to describe gay men in Hyderabad—namely *kothi* and *panthi*—are also the result of HIV prevention efforts in the mid-1990s. *Kothis* are a heterogeneous group, including same-sex-attracted men. Mimicking heteronormative binaries, the *kothi* is the penetrated partner, often exhibiting feminine behavior, dress, and mannerisms. *Panthis* are the insertive partner and often exhibit masculine behavior, dress, and mannerisms. *Kothi/panthi* relationships often mimic heterosexual

gender roles where the insertive partner is considered the husband and the receptive partner the wife (Cohen, 2005). *Kothi/panthi* pairings might be translated as tops/bottoms in Western gay male culture. The use of these terms is reported to have been cemented by public health practitioners in the midst of the AIDS crisis (Stief, 2017; Boyce, 2007; Reddy, 2005). The similarities and differences between a *hijra* and a transgender identity, between a *hijra* identity and a gay male identity, or between a *hijra* and a *kothi* identity, are less firmly rooted in the historical uniqueness of the positionality of each label, but rather are underscored by the modern biomedicalization of sexuality and the creation of discreet gender and sexuality categories. These categories are less grounded in distinguishable differences, whether visibly or internally, between the social identities of members of these groups.

Neocolonial Monitoring of Gender and Sexuality in South Asia

In the postcolonial period, governing sexuality was also a useful vehicle for nationalist agendas (Pederson, 1991). In the early twentieth century, nationalist movements recreated the notions of pious Indian men and women. In times of social upheaval, the pious female citizen is often portrayed as an asexual being. Under nationalism, the honor of the nation depended on desexualized representations of Indian women. Under this representation, all sex outside of marriage was considered a violation to the national cause. The new nationalist woman was put in a position of cultural superiority to both Westernized women and to women of lower classes, particularly prostitutes (Chatterjee, 1989). Sex workers were not viewed as legitimate nationalists. Indian female sex workers could therefore be considered subaltern figures because they stood in opposition to both colonists and nationalists (Tambe, 2009). The prostitute was

meaningful because she denied an understanding where sexual activity was delinked from nationalism.

New efforts to eliminate prostitution were introduced in the early twentieth century. Protecting the “moral hygiene” of society became a focus of women’s nationalist organizations (Rao & Rao, 1970). The 1923 Bombay Prevention of Prostitutes Act targeted pimping, soliciting, procuring, and detaining women against their will in a brothel. This act went through repeated amendments in attempts to eradicate brothel keeping, culminating in the passing of Act XII, which cited landlords who allowed their premises to be utilized as brothels as being guilty of abetting prostitution (Rao & Rao, 1970).

In similar ways, the 1929 Child Marriage Restraint Act, or Sarda Act, monitored the sexual and reproductive lives of Indian girls. Conceived at a time when concern about public health and moral hygiene had peaked, the Sarda Act became a vehicle for nationalist sentiment among social reformers and feminists. Polygamy and the prohibition of widows remarrying were other practices that received the attention of British social reform. Katherine Mayo’s sensational exposé, *Mother India* (1927), provided details about the position of women in India and how, in her view, this could be traced to an inherently backward Hindu culture (Sinha, 2006). The role of the state as moral police gave legitimacy to women as a civic constituency (Sinha, 2006). Political action became available for the construction of women’s collective agency through a nationalist lens. While Indian nationalism positioned the state differently in regard to prostitution, it did not significantly improve the safety of sex work (Tambe, 2009), nor did it aid in the prevention of sexually transmitted infections. The policing of prostitution post-colonization did not ultimately improve the social status of women nor create alternative means of employment for women outside of sex work.

In the years following independence, many of the same acts passed under colonialism were reformulated into the Indian Penal Code. In 1956, the Suppression of Immoral Traffic in Women and Girls Act was passed with the intention of again suppressing prostitution (Rao & Rao, 1970). Under the auspices of protecting public morality, this legislation granted magistrates the power to remove prostitutes from a locality and bar re-entry. Threats or physical force used to detain women for prostitution were considered an offense, as was the soliciting of prostitution. Under the new law, brothels could be closed and leasing agreements for brothels could be made null and void. Following the same guidelines of regulation over criminalization of sex work during colonialism, under Section Seven of this act, prostitution was not an offense unless it occurred within 200 yards of a public place, such as a place of worship, an educational institution, or a hospital. In this way, the state continues to operate a system where sex work is not entirely illegal, but is tolerated within certain regulated contexts. While Section 377 had temporarily been overturned in 2009, it was reversed in 2013, once again recriminalizing sodomy and gender nonconformity in India (Li et al, 2016). Section 377 remains in effect throughout India with similar versions of the code existing in other former British colonies.

Recent Changes in South Asian Policies Regarding Third Gender People

South Asian governments have been particularly proactive in constructing policies that aim to counteract the social stigma experienced by *hijra* and transgender people. In 2005, India created a new third gender designation (E) to differentiate from males (M) and females (F), and allowed third gender people to register as such on their passports. In 2009, the E designation was also added to voter registration documents. In 2007, following the case, Sunil B. Pant and others v. the Government of Nepal, the Supreme Court of Nepal ordered the government to scrap all

discriminatory laws, form a committee to study same-sex marriage policy, and establish a third gender category for gender-variant people. In 2009, the Supreme Court of Pakistan also legally recognized *hijra* and transgender people as a third gender. In 2013, Bangladesh also followed suit in establishing a third gender category. And finally, in April 2014, the Supreme Court of India went beyond simply legally recognizing *hijra* and transgender people as a third gender, but also made discrimination against these communities unlawful (Rao & Jacob, 2014). While to date it has not been systematically studied, this innovative court ruling may have a significant impact on reducing stigma and discrimination for third gender people in South Asia.

The impacts of the recent third gender registration policy is an area that requires evaluation. Focused assessments of the consequences of this social policy may help further our understanding of the advantages and drawbacks of utilizing a human rights-based framework to address social inequities. It may be the case that registration and legal name change are effective at increasing self-confidence and self-esteem for *hijra*/transgender women, thereby reducing internalized stigma. Recent research with transgender youth ages 15 to 21 in the United States asked young people whether they could use their chosen name at school, home, work and with friends (Russell *et al.*, 2018). Compared with peers who could not use their chosen name in any context, young people who could use their name in all four areas experienced 71% fewer symptoms of severe depression, a 34% decrease in reported thoughts of suicide and a 65% decrease in suicidal attempts (Russell *et al.*, 2018). Registration and name change may also be instrumental in increasing the likelihood of third gender people to access health and social services, thereby reducing enacted stigma or discrimination. Future evaluations of such name and gender change policies may show that registration and legal name change are associated with important health outcomes for people living with HIV. If this were to be the case, then legal

name and gender change may be important intervention points for policies and programs for HIV prevention and care.

In spite of these recent policy changes and increased visibility of third gender people in South Asia, *hijra* continue to face heightened discrimination (Bharat, Aggleton & Tyler, 2001). *Hijra* and other gender-conforming people are also often excluded from both medical and social science research, making comparisons across gender identity rare. The relative lack of inclusion of gender non-conforming individuals in HIV research in India is a major gap in our understanding of the global HIV epidemic, and of our understanding of South Asian gender and sexuality identities.

NGOs and the Regulation of Sex Work and Gender Nonconformity

The biomedicalization of sexuality continues to be perpetuated by well-intentioned advocacy organizations, multilateral health entities, state governments, and the pharmaceutical industry, who all hold the power of being able to fund and advocate for sexual and reproductive healthcare. Multilateral development organizations often utilize neocolonial ideologies to substantiate their foreign and often culturally inappropriate intervention strategies in the global South. As Stoler (2002) argues, control over sexuality was of material concern for the bodies of Indian women and of instrumental concern for the body politic. These organizations' loosely coordinated efforts form the neoliberal hand for global action on issues regarding gender, education, development, and health in the "developing world." The infantilization of the colonized is a recurring theme in postcolonial theory (Said, 1978). Infantilization refers to the portrayal of the colonized in child-like terms in order to justify the civilizing missions of the colonizer (Hall, 1997; Said, 1978).

In 1946, the United Nations created the Commission on the Status of Women, beginning a legacy where Western, primarily European, nations outlined the parameters of a good life for women. In the context of women's health, such institutions—funded through entities like the United Nation Development Fund for Women—offered interventions that often focused on birth control. While seeking to offer benign services to “vulnerable” groups, these interventions may only reify colonial policies that sought to limit the sexual reproduction of women of color. While aspiring to be more inclusive of women in endeavors concerning education and employment, these policies actually took empowerment *away* from women by dictating the parameters of how many children a woman should have, how she should dress, whether she should engage in the formal labor sector, and so on. Rather than empowering women, such policies may perpetuate dependency of the global South's legitimacy through the eyes of the global North.

To a large extent, these international development organizations reproduce global inequities in health, education, and resources by laying clear boundaries between donor and grantee, making a more equitable research or service partnership difficult. In colonial times, empires conquered lands and resources; in postcolonial times, industrialized countries dictate ideologies, intervention strategies, and cultural norms (Said, 1993). While the metropole is no longer in direct control of the political structure of the colony, it still exercises control over black and brown populations through institutions, like the World Bank, the International Monetary Fund and the World Health Organization. The onset of India's adoption of liberalization reform measures, including the World Bank's structural adjustment framework under the New Economic Policy of 1991 (Upadhyay 2000), has contributed to widespread disinvestment in the health sector, an increase in foreign investment in capital-intensive activities, and the privatization of major national industries such as telecommunications and power generation

(Nambiar, 2012). The World Bank purported that governments of developing countries were too bureaucratic and inefficient, and called for governance functions to be redirected from the oversight of the state to private, corporatized, donor-driven campaigns, leading to what Arundhati Roy (2004) termed “NGO-ization”, where health, education, and development organizations emerged worldwide to deliver donor-driven HIV service outcomes in the deregulated absence of the state’s involvement. Often these international development organizations act in the interest of furthering the capitalist interests of first world countries and corporations at the expense of the interests of developing countries and their citizens (Collins & Rhoads, 2010). The spending of foreign dollars on HIV prevention efforts in South Asia is often constructed as an act of charity, rather than equity, and there is often no ethical quandary in using developing countries as a market for multinational profits for the sale of pharmaceuticals. The development of the AIDS industry has always carried with it the possibility of subverting traditional power structures and being corrupted by them (Altman, 1994). As Sastry and Datta articulate (2011), postcolonial constructions of disease are mobilized around the political and economic interests of dominant power structures in global spaces.

Neocolonial ideologies are perpetuated by foreign intervention and then further reinforced by neoliberal notions of governance and the role of the free market in the maintenance of the state. From this perspective, developing nations are seen as potential beneficiaries of the free markets of developed countries (Collins & Roads, 2010), with entities like the World Trade Organization advancing global economic policies that ultimately serve to maintain or further escalate structural, financial inequities across the world (Eckel, 2010). While appearing to be purely philanthropic at first glance, much of foreign development spending is actually intended to increase capital not for recipient countries, but for donor nations. Often, this translates to the

subsidization by donor organizations of domestic industries, such as agriculture or pharmaceuticals, which receive a marketplace for their goods in donor nations. Postcolonial approaches interrogate the neocolonial agendas in the global responses to disease, and the ways in which these responses reproduce the political economic interests of former imperial powers (Sastry & Datta, 2011). Further, postcolonial theory attends to the role of sociocultural representations of health risk on how disease is perceived medically and the policies that are constituted around the disease (Sastry & Datta, 2011). The relatively new HIV-related NGO sector treads a difficult pathway of both relying on the state while attempting to change it (Nambiar, 2012; Bourdieu 2003).

In the case of HIV prevention and care services, the global epidemic creates ever-expanding markets for the pharmaceutical and healthcare industry (Patton, 1990). An HIV epidemic creates and sustains markets for multinational pharmaceutical corporations (Farmer, 1993). Furthermore, for several decades, the United States demanded higher expectations and outcomes for its foreign HIV interventions than it did for its own domestic HIV interventions. The President's Emergency Plan for AIDS Relief (PEPFAR) was reauthorized in 2008 at up to \$48 billion, including \$39 billion for HIV and the Global Fund, \$4 billion for tuberculosis (TB), and \$5 billion for malaria (Kaiser Family Foundation, 2017). The reauthorization mandated five-year strategic plans for HIV, TB, and malaria prevention and care for recipient nation organizations—an expectation that the United States (at the time) did not require for HIV services offered domestically. It was only in 2015—twelve years after having mandated national HIV strategies from its PEPFAR-recipient countries—that the U.S. Health Services and Research Administration developed its own national HIV strategy (HRSA, 2016). This double standard implied that greater control is required when providing aid to the global South than is

required when providing aid at home. The implication here is that without tight regulations, funds are more likely to be abused in developing contexts than on American soil—again reflecting a general suspiciousness about brown people’s ability to self-govern.

In regard to the monitoring of gender and sexuality via international organizations, a prolific case study for this is provided by international feminist and lesbian, gay, bisexual, transgender and queer (LGBTQ) advocacy efforts, and in particular, the work carried out to aid sex workers, *hijra* and other gender nonconforming people in South Asia. For *hijra*, constructions of gender identity have shifted as gender-nonconforming individuals find new sources of representation and legitimacy within global activist movements. This new representation has largely been found in the arena of HIV and LGBTQ nongovernmental organizations (NGOs). In the global South, adopting a transgender identity provides inclusion into international activist networks and into the global development industry. Through the seemingly innocuous façade of humanitarian work, these organizations may serve to reify neocolonial notions of gender and sexuality that have been developed and replicated in the West (Dutta, 2012), including the notions of being “out”, living as one’s “authentic self”, and “coming out of the closet”. Such highly individualized notions of identity may stand in stark contrast to collectivist cultures which prioritize inclusion over individuality.

This is not to say that all global advocacy work for LGBTQ communities is harmful. Many organizations have worked to decriminalize homosexuality and gender nonconformity and have advocated for the greater social inclusion of sexual and gender minority communities. Such organizations may provide medical services to sex workers or gender-nonconforming people or advocate for political actions that benefit these groups. For example, in its Agenda 2030, the Global Forum for MSM and HIV (MSMGF, 2017) outlines cross-cutting recommendations for

the well-being of LGBTQ communities, namely to commit to ending stigma and discrimination based on sexual orientation or gender identity/expression in the provision of healthcare.

Following the state's recognition of third gender identities, there are now entitlements or affirmative action-style benefits that *hijra* have the potential to avail in India. As members of a scheduled caste by the Government of India, *hijra* are allotted seats of representation in *panchayats* or local village councils. They are also provided the option to obtain ration cards for food and opportunities to apply for quota-based subsidized housing opportunities. Additional incentives are offered by institutions seeking to gain access to gender-nonconforming people. In Hyderabad, for example, respondents reported that research institutions and for-profit companies offered laser hair removal services as an incentive for participation in their research programs. Similarly, respondents reported that pharmaceutical companies offer hormone therapy and HIV medications as incentives for enrollment in HIV drug research—seemingly altruistic gestures at the surface, but clearly reflecting alternative motivations for their “humanitarian” involvement with some of South Asia's most vulnerable communities.

The divisions of labor between these international organizations is also noteworthy. There is a divide in the realm of gender advocacy between the groups that do “women's” work, mainly around issues of sexual and reproductive health, from the groups that do “gay” work around issues regarding LGBTQ communities. Women's organizations advocate for the gender equity of women, but there is little mention in their efforts of the need to support third gender communities that are facing similar concerns. Conversely, for LGBTQ advocacy organizations, there is often little mention of the need for addressing gender equity for cisgender women. On both sides of the divide, there is a lack of recognition that communities of women and queer people overlap and that there are indeed cisgender women who also identify as lesbian,

transgender women who also identify as heterosexual, or bisexual or pansexual people on all sides of the gender spectrum. What follows is what Miller (2011) defines as gender territorialization or “tensions over who owns gender” (p. 844). This tension explicitly refers to the ideological battles between advocacy groups representing gender as a woman’s identity versus those representing gender as a gay, transgender or queer identity. These turf wars mark shifts in priorities in policies and funding. Miller highlights how these silos serve to only reinforce gender distinctions and reify existing social hierarchies.

Similarly, Dutta (2012) recognizes that the labeling of gender and sexual minorities as “gay men” versus “transgender women” or “men who have sex with men” also leads to the creation of artificial distinctions between overlapping groups in South Asian contexts. These institutionalized distinctions between MSM and TG identities serve to divide communities that encompass a spectrum of gender and sexual variance. Competition for funding becomes another source of underlying tension between communities. Bids to secure donor funding can pit groups and communities, who were once united by their social marginalization, against one another. Money is therefore simultaneously used to both silence and give voice to communities. While gender identity creates access to certain kinds of power, none of the intersectional spheres of gender identity, for example cisgender women living with HIV, transgender people in sex work, or bisexual men and women, actually control the state or donor responses to their requests (Miller, 2011).

It seems that both cisgender women and *hijra* fit squarely into Spivak’s (1988) prediction of outsiders seeking to empower marginalized communities while failing to ensure that these communities are fully able to represent themselves, even when they utilize their own messy, overlapping, non-mutually exclusive identities. An alternative to this may be provided through

approaches that acknowledge the intersectional nature of identity, operating on the recognition that attacks on the civil rights of one subaltern community entail an attack on the civil rights of any subaltern community. In order for social activist efforts that aim to reduce gender inequities to be successful, there must be greater collaboration across gender and sexual minority groups. As Judith Butler articulates, “I continue to hope for a coalition of sexual minorities that will transcend the simple categories of identity, that will refuse the erasure of bisexuality, that will counter and dissipate the violence imposed by restrictive bodily norms” (1999, pxxvi). Such inclusivity is indeed the best hope that sex workers and gender-nonconforming people in South Asia have for increased visibility and equity.

In conclusion, this paper seeks to highlight the neocolonial agendas in global representations of health and illness, and how these representations circulate to reproduce the political economic interests of transnational hegemony (Sastry & Dutta, 2001). Postcolonial approaches seek to understand the processes underlying colonization, and the representations that circulate in the dominant discursive spaces that justify colonial processes (Spivak, 1999). By applying postcolonial approaches to our understanding of the social constructs and social policies impacting sex work and gender-nonconformity, we may gain a better understanding of how to best work for the interests of these marginalized populations.

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**The Secret Lives of Hijra:
How HIV-Positive Hijra and Gender-Nonconforming People in Hyderabad, India
are Defining and Redefining Themselves**

Abstract

Hijra are considered neither men nor women, but rather occupy a third gender category in South Asia. The exploratory research question that we sought to answer for this study was: How do *hijra* and gender-nonconforming people in Hyderabad, India, express their gender identity/identities, particularly in regard to gender roles? Sixteen *hijra*/transgender women in Hyderabad were recruited for in-depth, semi-structured interviews on their experiences with living with HIV and with gender nonconformity. Interviews were conducted in Hindi/Urdu and Telugu, digitally audio-recorded, then subsequently translated and transcribed into English. Transcripts of the interviews were imported into the data analysis program, NVivo, for thematic content analysis. Interviews were qualitatively analyzed for themes by a team of three coders. Analysis of interviews revealed that *hijra* have experienced a change in the ways in which they have historically perceived themselves and the ways in which they are perceived socially today. Some *hijra* reported always expressing their gender identity as *hijra*, 24 hours a day, seven days a week. Other *hijra* reported living two distinct lives: one in the daylight, where they identified as men and fulfilled a role of husband/father with their family, and another at night where they identified as *hijra* with circles of friends and other gender-nonconforming people. For some *hijra*, leading a dual gender identity caused feelings of internal conflict. For others, it was feasible to occupy multiple gender identities, depending on the social context and space. The South Asian social construction of gender may allow for the ascription of a multiplicity of gender identities, a notion that markedly differs from how gender is often constructed in the West. These findings are relevant to better understanding the social context facing gender-nonconforming people living with HIV in south India and for planning programs/policies that cater to this marginalized population's unique needs.

Keywords: *hijra*, transgender, gender-nonconforming, HIV, India, Hyderabad, qualitative

Background

Hijra are a gender/sexual minority in South Asia with historical origins tracing back over a thousand years (Krishner 2015; Reddy 2005; Nanda 1985). Groups identifying as *hijra* live in the countries of India, Pakistan, Bangladesh, Sri Lanka, and Nepal. They are considered neither men nor women (Nanda 1985), but rather occupy a third gender category (Kalra 2012; Jaffrey 1996). The word “*hijra*” is derived from an Urdu word, often translated as “eunuch” or “hermaphrodite” in English (Lal 1999).

In analyzing the experiences of *hijra*, we utilized the postcolonial feminist perspectives of Gayatri Spivak (1988) in her seminal work, “Can the Subaltern Speak?” The term “subaltern” refers to populations located outside of the hegemonic power structure. This marginalization may be outside of a geographic area, outside of a dominant race, or outside of the colonial locus of power—the metropole. In colonial times, in addition to being outside of British imperial power, *hijra* and other gender-nonconforming people occupied a subaltern role in Indian society, as they were outside of the limitations of heteronormative notions of power and control. In the South Asian sociohistorical context, subalternity refers to the experience of being outside of the hegemony of a heterosexual, gender binary as modeled by the British Empire during the Victorian era. For *hijra*, the subaltern identity may entail other sources of marginalization, based on HIV status, caste, literacy, education, occupation, skin color, or religion. In this study, we explore how these compounding, marginalizing, subaltern identities lead *hijra* to experience HIV stigma.

In framing stigma, Spivak suggests that attempts from outside to “empower” the subaltern—in this case, the stigmatized—will encounter problems. She acknowledges the “epistemic violence” that is exercised upon the subaltern. She suggests that outside efforts to

improve the condition of the subaltern by granting them collective speech invariably will be problematic in assuming cultural solidarity among a diverse group of people. She also highlights that there is a dependence upon Western intellectuals to speak for the subaltern, rather than allowing them to represent themselves. As Spivak (2005, 476) articulates, “Subalternity is a position without identity... Gender is not lived sexual difference. It is a sense of the collective social negotiation of sexual differences as the basis of action... It is where social lines of mobility, being elsewhere, do not permit the formation of a recognizable basis of action.” Applying Spivak’s approach to social science research calls for more equitable distribution of roles. This can be challenging in research, as power hierarchies between “interviewer” and “respondent,” or “researcher” and “subject” are often built into the research process. Nonetheless all members of the research team shared this critical, postcolonial feminist perspective on research and attempted to incorporate a reflexive approach into the interviewing style and rapport.

Further complicating the *hijra* identity is the fact that *hijra* occupy a unique position in India, as they are considered both auspicious and taboo. Because the Hindu conception of divinity is simultaneously male and female, *hijra* are often considered to be closer to the divine. *Hijra* are often devotees to the Mother Goddess, Bahuchara Mata (Nanda 1985), and make pilgrimages to the main temple to this deity in the western Indian state of Gujarat. Over time, many *hijra* have come to concurrently follow both Hindu and Muslim religious practices, such as the Shi’a Muslim tradition of devotion to local *durgahs*, and the daily offering of *puja* (prayers) to the Hindu Mother Goddess Durga (Durga Ma) (Lal 1999), showing how even in their religious practices, *hijra* are able to occupy multiple identities and spaces.

Prehistorical myths and oral folklore relate several legends of the origins of *hijra*. *Hijra* often see themselves to be vehicles of Durga Ma (Lal 1999) and are also often associated with the deity, Shiva, who is responsible for destruction and death. Some legends trace the origins of *hijra* to Ardhanariswar—an *avatar* (incarnation) of the deity Shiva, whose name means “half man, half woman” (Bakshi 2004). In another myth in the Hindu epic, the *Ramayana*, Ram prepared to go into exile with his wife, Sita, and his brother-in-law, Lakshman. Ram was followed to the edge of the forest by his subjects and greeted his subjects as “men and women.” He implored them to return to their homes and perform their *dharma* (life duties). According to this legend, when Ram returned to his kingdom of Ayodhya fourteen years later, he found a group of people still gathered at the same spot by the forest. The group stated that because they were neither men nor women, they were not required to follow Ram’s directives. Ram blessed his followers for this act of devotion, bestowing on them auspicious powers (Lal 1999). Ram gave *hijra* the power to bless people during auspicious occasions, through customary singing and dancing known as *badhai* (Rellis 2007), a tradition that continues to be practiced by *hijra* today.

In yet another myth, depicted in the fourth book of the Hindu epic—the *Mahabharata*, *Virataparvan*—the warrior Arjun appears in the *avatar* of a woman named Brihannada. Brihannada means “having a large reed” and is interpretable as indicating that this deity espoused hypermasculine traits (Lal 1999). At this point in the tale, Arjun had spent nearly twelve years in the Himalayas as an ascetic in remembrance of Shiva. Arjun refuses the sexual advances of a celestial nymph and is cursed to live as a *napumsaka*—a person of ambiguous gender. During this year of punishment, his thirteenth year in exile, Arjun dresses and presents as a woman and dances in the royal court of Virata (Pamment 2010; Nanda 1985). He is thereafter depicted as being *tritiyam prakritim*, meaning “of a third nature,” and is lauded as a master of

dance and music, traits which are still associated with *hijra* in contemporary times (Lal 1999). The character of the *tritiyam prakritim* reappears again in the Kama Sutra (Vātsyāyana and Burton, 2006). Presenting again in the *avatar* of Brihannada, Arjun participates in the wedding ceremony of his son Abhimanyu to the princess Uttara, a ritual that is recreated by *hijra* during modern rituals in the blessing of newly married couples and newborn babies (Bakshi, 2004; Nanda, 1985). In these mythologies, the third gender person's alignment with asceticism and their associated renouncing of sex becomes the very source of their spiritually divine power (Pamment, 2010; Nanda, 1985). Seen to be auspicious due to their androgyny and/or asexuality, *hijra* are still often present at weddings, childbirths, and other special occasions to bless a newly married couple or a newborn child, receiving money in exchange for their blessings.

The social identity of *hijra* is constituted through the intersection of social, religious, and kinship practices, including religious rituals (Dutta, 2012). Muslim traditions in South Asia also bestow special powers on *hijra*. To this day, eunuch groups similar to the *hijra* have been entrusted with the guardianship of a number of sacred Muslim sites and shrines, including the Prophet's tomb in Medina and the Kaa'bah in Mecca (Burckhardt, 1829). *Hijra* are often the caretakers of *durgahs* or Sufi shrines to mystical saints throughout South Asia, again confirming their social linkage to the divine (Pamment, 2010).

Perhaps as a result of often not being able to experience reproduction in their own lives, *hijra* become the paradoxical guardians of sexual and reproductive power. South Asian traditions confer on *hijra* the ability to bless people with luck and fertility (Kalra, 2012). They also are believed to bear the power to bring prosperity, fertility, and rain (Conner, Sparks, and Sparks, 1997). While themselves often being incapable of having children, they are believed to exert power over the reproductive process (Lal, 1999). Some have classified their behavior as

burlesque in that *hijra* often dance, smoke, and act in sexually explicit ways, all behaviors falling outside of the traditional gender roles of cisgender women in South Asian society (Nanda, 1985; Rellis, 2007). As Pammett (2010) states, “In a culture where gender relations are largely defined in relation to space, *hijras* also boldly tread the public domain, traditionally conceived as being male territory.” (p. 30).

Ethnographic research has portrayed *hijra* as having kinship structures defined by hierarchical lineages comprised of *gurus* (leaders) and *chelas* (disciples) living together in large communal houses or *havelis* (Cohen, 2005; Reddy, 2005). The guru often plays the mixed role of house mother, teacher, and madam. *Chelas* that are new to the group are required to pay a *dand* (fee) to their *guru*—an amount sometimes decided by local village councils known as *panchayats* (Bakshi, 2004).

Historically, *hijra* have been typified as male eunuchs who were castrated prior to puberty (Cohen, 2005; Reddy, 2005). Even today, many *hijra* undergo castration and penectomy, actions which may confer higher status within their community and which are sometimes used as a means of judging the *hijra*’s authenticity or sincerity with respect to the identity (Dutta, 2012). In other parts of South Asia, *hijra* are sometimes referred to as *zenana* (Beyrer et al., 2012)—an Arabic word, referring to the part of the house that was traditionally reserved for women in Muslim households. It also refers to the housing structure of a *haveli* where, to this day, *hijra* communities in Hyderabad reside. There continue to be seven major *havelis* of *hijra* in Hyderabad today (Reddy, 2005).

The overlapping identities of *hijra* and *zenana* are demonstrative of fluid South Asian gender identities. Certain communities differentiate between *zenana* as being effeminate or cross-dressing males versus *hijra*, who have been castrated (Pammett, 2010; Nanda, 1985).

Hijra may undergo penectomy or castration, reportedly while under the possession of the Goddess (Cohen, 1995). The surgical procedure, called *nirvan*, usually entails the removal of the penis and testicles by a senior *guru* (Stief, 2017). Because of these surgical procedures, *hijra* are often seen as being sexually impotent beings (Bakshi, 2004). Ethnographic research in the nineteenth century documented a test that *hijra* had to complete in their initiation process where they were asked to sleep for four or more nights with a prostitute while resisting sexual temptation (Preston, 1987).

To maintain safety and secrecy in vulnerable public environments during colonial times, many *hijra* communities created and utilized their own local language, known as *ulti*, meaning “backward” or “opposite.” *Ulti* in Hyderabad is largely constructed of Farsi words, reflecting the community’s Moghul patronage. Historically, *hijra* received state patronage through both Rajput and Moghul courts, where they served as courtesans, handmaidens, and advisors to royalty. In these courts, *hijra* occupied a fairly exalted and fully protected position within the state, as they were considered gifted beings. They were also afforded the ability to live with and engage with women in female-segregated spaces. Their castration and associated impotency made them unable to impregnate women and therefore exempted them from being a sexual threat to women (Ahmad, 2010). While in modern times, the ritual of castration may be seen as barbaric, one might interpret this as an early attempt from *hijra* to block hormonal changes in puberty that would lead them to develop more masculine features, such as hair on the face/chest, a deeper voice, and development of genitalia. In many ways, these actions can be seen as similar to the introduction of androgen antagonists or testosterone blockers during puberty for gender-nonconforming youth who wish to avoid the physiological changes associated with developmental increases in testosterone, progesterone, and estrogen (Hembree, 2011).

Boundaries of gender and sexuality in South Asia were acutely redefined during British colonization, impacting the *hijra*'s place within the social hierarchy. British imperialism not only entailed the conquest of territories, teas, and silk, but also expanded to include the colonization of ideas and sociopolitical structures. With the onset of British colonialism, the *hijra* identity became socially unacceptable by Victorian mores of sexuality and decorum. Applying these Victorian notions of sexuality to the South Asian context, *hijra* became associated with indecency—an infraction against the limitations of colonial decorum and an obscenity that needed to be controlled. *Hijra* became transformed from holding an established place within the social hierarchy to becoming associated with identities that were deemed to be morally and physically debase—i.e., promiscuous prostitutes and cross-dressing queers.

In the 1850s, the British reported their “discovery” of a community of eunuch performers, the *hijra* (Hinchy, 2014). Subsequently, with the passage of the Criminal Tribes Act (CTA) of 1871, *hijra* could be arrested for dressing in women’s clothing, participating in sodomy, dancing, or playing music in public places. Colonial attempts were made to erase *hijra* as a visible gender identity in public space through the prohibition of their performances and dress (Hinchy, 2014). By forbidding *hijra* to dress as women and perform publicly, the CTA effectively criminalized the group's identity (Rellis, 2007) and reified community regulation of social and sexual mores.

The British further criminalized *hijra* by making punishable any act that was deemed to be an “unnatural offence” under Section 377 of the Indian Penal Code. The most prevalent convictions under Section 377 were the prosecution of males accused of raping a child. Rape and sodomy were often conflated in these cases (Bhaskaran, 2004). Other categories of unnatural offenses included bestiality (i.e., having sex with an animal) and sodomy that occurred between a

heterosexual couple. *Hijra* were treated inconsistently by the law—sometimes being ignored, other times being prosecuted. Various cases refer to *hijra* as cross-dressing “habitual sodomites” (Bhaskaran, 2004, p. 91). While Section 377 was temporarily overturned in 2009, it was reversed in 2013, once again recriminalizing “unnatural offences,” which ostensibly included sodomy and gender nonconformity (Li et al., 2017). Section 377 is still in effect throughout India, with similar versions of the code in existence among other former British colonies. Attempts to discipline sexuality were not effective, as they were met with inadequate policing resources. While this is not to say that *hijra* communities were not already marginalized prior to the passing of these legislative acts, the British Penal Code legalized discrimination against them.

Following Indian independence in 1947 and the dissolution of the local principality—i.e., the Nizam of Hyderabad—*hijra* lost their state-sanctioned support. Since that time, many *hijra* in Hyderabad have turned to panhandling and sex work as a means of livelihood. The occupation of sex work has therefore become the most significant HIV risk factor for *hijra* in South Asia (Dandona et al. 2005; Department of AIDS Control, Ministry of Health & Family Welfare, Government of India, 2013).

Globally, gender-nonconforming individuals are at heightened HIV risk. *Hijra* often engage in soliciting sex work or begging at street corners, sometimes demanding money from riders of trains, using a loud series of singing and clapping behaviors that demands people’s attention as well as their monetary contributions. People sometimes give money to *hijra* in the hopes of receiving their blessings and, likewise, are sometimes frightened of not giving money to *hijra* as they fear being doomed by a *bad-dua* or *shaap* (curse) (Bakshi, 2004; Nanda, 1985). *Hijra* may issue warnings that if they are not paid enough by audiences through donations of *badhai* (monetary gifts), they may hurl curses at reluctant patrons (Pamment, 2010). Many

members of the *hijra* community in Hyderabad identify as *kojja*—the term used to refer to *hijra* in Telugu, the other common local language in the south Indian states of Telangana and Andhra Pradesh (Reddy, 2005).

In contemporary public health literature, *hijra* have been socially constructed as distinct from other sexual and gender minorities in India, such as *kothis* and *panthis*—communities that are often labeled under the rubric of men who have sex with men (MSM) (Dutta, 2012). However, gender categories in the South Asian context are fluid and the social constructions of *hijra*, *kothi*, *panthi*, and *zenana* have overlapping historical, political, and social underpinnings (Dutta, 2012). *Kothis* are a heterogeneous group, including same-sex-attracted men. Mimicking heteronormative binaries, the *kothi* is the “penetrated” partner, often exhibiting feminine behavior, dress, and mannerisms. *Panthis* are the “insertive” partner, and often exhibit masculine behavior, dress, and mannerisms. In *kothi/panthi* relationships, the insertive partner is often considered the husband and the receptive partner the wife. *Jankhas*—a term historically used to refer to effeminate men—are men who sometimes dress like women and dance like *hijra*, but often also refer to themselves as *zenana*. In recent research studies, *hijra* and *kothi* were not considered mutually exclusive categories, nor did they totally overlap in their identities (Stief, 2017). Regardless of their typology, *hijra*, *kothis*, *panthis*, and *jankhas* were clustered together under the colonial lens, embodying the notion of the weak, impotent brown man, offering another justification for patriarchal imperial rule.

Recent ethnographies of *hijra* (Cohen, 2005; Reddy, 2005) have also critiqued essentialized constructions of *hijra*, situating the *kothi* within a more continuous spectrum of same sex-desiring, gender-variant individuals. Our research in Hyderabad confirms the fact that the categories used to delineate gender and sexuality in the Western context (e.g., the mutually

exclusive categories of gay and transgender) do not seamlessly translate to the South Asian context. In Hyderabad, it is at least ideologically permissible for individuals to occupy more than one gender identity or sexual orientation through the course of their lives, or even through the course of a single day. Identity is embodied in the corporeality of the body and the perceptions we ascribe to these experiences of time and space (Merleau-Ponty, 1962; Husserl, 1970). Applying phenomenological conceptions of identity and perception to gender, one might argue that the experience of being a woman, a man, or a third gender person is embodied through the corporeal experience of sexuality, dress, and expression. Such a construction of gender identity allows us to envision gender as flexible and fluid, allowing people to identify with a multiplicity of gender identities over changes in space and time.

Noting how gender identity and expression is culturally bound, the research question that we sought to answer was largely exploratory: How do *hijra*/transgender women in Hyderabad, India, express their gender identity/identities, particularly with regard to gender roles and gender expression? The data presented here are a subset of a larger study that investigated the relationships between HIV stigma and gender.

Methods

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 the first phase of the study, 150 individuals living with HIV (51 cisgender women, 49 cisgender men, and 50 *hijra*/transgender women) completed a survey on HIV stigma. Following the completion of the surveys, a preliminary descriptive analysis of the data was conducted. Using survey responses to the stigma scales used in the study (Jeyaseelan et al., 2013; Zelaya et al., 2012), a subgroup was created including the eight *hijra*/transgender

women who scored highest on the HIV stigma scales and the eight who scored lowest on the HIV stigma scales. These 16 *hijra*/transgender women were recruited to participate in Phase 2 of the study with the intention of exploring the gendered experience of HIV stigma. This sampling method of capturing both participants who scored high and low stigma scores was utilized in order to ensure heterogeneity within the interview subgroup.

Survey responses from the first phase of the study were used to guide the selection, framing, and ordering of interview questions. Open-ended questions were utilized to elicit descriptions of lived experiences of HIV and gender nonconformity stigma in the participants' own words. Interview questions were selected to account for other potential influences on HIV stigma beyond gender identity and expression, such as poverty, caste, and religion. A recurring theme, was the notion of leading a "secret life."

Informed consent was obtained from all participants following the Institutional Review Board (IRB) protocol, which was approved both by the University of Chicago IRB and the Ethics Committee at our partner research organization in Hyderabad: SHARE India. During the informed consent process, participants were asked if they would be willing to provide their contact information in order to potentially be recruited for the second, qualitative phase of the study. Only those individuals who provided consent to be contacted and who fit the eligibility criteria for Phase 2 were invited to participate in interviews.

Analytical Sample

The study population is defined as *hijra*/transgender 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) self-report as being HIV-positive; (2) reside in Hyderabad or Secunderabad, India; (3) proficient in speaking Hindi/Urdu or Telugu;

and (4) between the ages of 18 and 50. Exclusion criteria included: (1) individuals who are HIV-negative; (2) individuals living outside of Hyderabad or Secunderabad; (3) and individuals either under the age of 18 or over the age of 50.

Recruitment

Recruitment for the study utilized both organizational sampling and snowball sampling. A local research assistant posted recruitment flyers in Hindi and Telugu at collaborating organizations and collaborated with agency staff to identify participants. To capture those men and women who are not currently connected to community-based organizations, we additional snowball sampling was utilized. Snowball sampling is a non-probability sampling technique that uses informants to identify additional participants and which has been heavily utilized in public health (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 (Thompson and Collins, 2002), this recruitment method ensured greater variance in the sample. Additionally, we recruited respondents through social media with the collaboration of an online group—the Telangana *Hijra* Transgender Samiti. Given that this is a virtual group, it might have attracted individuals who may not be as open about their gender identity in other public spaces. While the overall fieldwork for this project took place over a three-year period, interviews were conducted between October 2015 and December 2016.

Four organizations were used to recruit individuals with HIV. The organizations, which were selected based on their location, their work with populations of interest, and their previous collaboration with our partner research organization, SHARE India, included the following:

- **Avagahaana:** A nongovernmental organization, located in the Lal Darwaaza (Red Door) area near the Charminar monument, also known as Purana Shaher (meaning “Old City”), a predominantly Muslim neighborhood of Hyderabad.
- **HOPES:** A community-based nongovernmental organization in Padmarao Nagar in Secunderabad, working to improve the quality of life of people living with HIV (PLWH). As of May 31, 2013, HOPES had enrolled and serviced 14,229 members living with HIV.
- **Telangana Network of Positive People (TNP+):** An NGO serving the needs of PLWH in Hyderabad. The organization works primarily with homeless populations, pavement dwellers, and street children.
- **Calvary Counseling Society:** A Christian NGO in the Ramnagar area of central Hyderabad. Calvary Counseling Society operates camps in rural areas, provides supportive education for orphaned children, offers psychological education and counseling for individuals/families affected by HIV, and provides nutritional assistance for medically indigent, homebound patients.

Interviews and Incentives

Interviews were conducted in two South Asian languages: Hindi/Urdu and Telugu. To ensure translation accuracy and internal consistency, all relevant documents (consent forms and surveys) were translated from English to both Telugu and Hindi, and back. Certificates of translation were produced for the University of Chicago IRB and the ethics committee at SHARE India. For individuals who were illiterate, the interviewer read questions aloud and recorded the participant’s answers. For these individuals, a thumb print was used instead of a signature—a commonly accepted legal practice in India. Interviews lasted about an hour and a half. The interview guide was organized around eight domains, including open-ended questions about: (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) depression.

All participants who completed the 90-minute survey or interview were compensated 200 Rupees. Individuals who participated in both phases of the study received a total of 400 Rupees. If a participant assisted in recruiting other individuals through snowball sampling, the recruiter received an additional 100 Rupees for each successfully recruited respondent.

Data Analysis

All interviews were digitally audio-recorded, then subsequently translated and transcribed into English. Transcripts of the interviews were imported into the data analysis program, NVivo (QSR International, 2012) for coding and analysis. Thematic content analysis (Krippendorff, 2013) was utilized—an approach that is favorable in describing the experiences of socially marginalized communities (Marshall and Rossman, 2011). Thematic analysis can be utilized with diverse theoretical approaches and can incorporate both inductive and deductive analyses. Such an approach seeks to allow room for the kind of coding informed by grounded theory outlined by Strauss & Corbin (1990), without eliminating the possibility of specifically seeking gender-related themes.

After reviewing the first ten transcripts, three evaluators—the principal investigator/doctoral student, a U.S.-based research assistant, and an India-based research assistant—developed a codebook of themes. Relevant chunks from transcribed data were assigned codes (Miles and Huberman, 1994). Identified codes were placed in broad groupings. The codes under each heading were clubbed together and the content was analyzed for common themes (Singh et al., 2009). After initial coding, the team met to discuss how different codes were applied. Code definitions were redefined and combined to reflect themes. Emerging themes included difficulties in disclosing HIV status to family members, gender role conflict, and transphobia. Codes were then clustered together by specific themes to refine the codebook. The

finalized 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 was asked to review the decision. Consensus was reached on all coding decisions.

Themes from interviews with *hijra* were categorized around major content areas such as secret lives, HIV stigma and discrimination, name selection, impacts on mental health, utilization of HIV services, and gender roles. For the purposes of this manuscript, only those excerpts related to the first theme of “secret lives” among the group of *hijra* are being reported. Names have been changed to protect the identities of the respondents, but their respective gender identities have been maintained in the assignment of their alternate names.

Results

As indicated in Table 1, the mean age of *hijra* respondents was 36.04 years. The majority (72%) of respondents were from scheduled castes, scheduled tribes, or other backward classes. Mean monthly income was 9,558 Rupees. The majority of respondents were Hindu (94%), followed by Muslims (4%), and Christians (2%). Most respondents (56%) had a secondary (high school) level of education or less. An additional 30% of respondents had an intermediate (two years post-high school) level of education. In terms of gender, 44% of respondents identified as men; 2% as women; 6% as *hijra*; 20% as transgender female; and 28% as transgender male. In terms of sexual orientation, 66% identified as homosexual and 34% as bisexual, No one identified as heterosexual.

Analysis of interviews revealed that *hijra* have experienced a change in the ways in which they have historically perceived themselves and the ways in which they are perceived socially today. Many reported living two distinct lives: one in the daylight, where they identified

as men and fulfill a role of husband/father within their family, and another at night, where they identified as *hijra* with circles of friends. However, the extent to which this caused a sense of internal or external conflict varied. For some *hijra*, this dual gender identity caused feelings of internal conflict, sadness, or depression. Those who felt internally conflicted about these dual identities felt high levels of stigma, forcing them to lead their lives as *hijra* in secret. Many unmarried *hijra* reported facing pressure from their family members to get married to women. If they resisted these pressures, they might be forced to disclose their secret *hijra* identity. Other *hijra* felt that they could navigate these separate spaces with ease, feeling no sense of conflict nor feeling that they were suppressing their “true” gender identity. For these *hijra*, it was perfectly feasible to have multiple gender identities, depending on the social context and space. The South Asian social construction of gender may allow for the ascription of a multiplicity of gender identities—a notion that markedly differs from how gender is often socially constructed in the West. A last group of *hijra* reported always expressing their gender identity as a third gender person, regardless of the consequences that this decision had on family and community members. This paper focuses on themes from the first group, including internal conflict about having to live secret lives.

One respondent, Prakash, voiced *hijra*'s personal struggles in having to repress their gender. Prakash is a 45-year-old, upper caste *hijra*, who earns 8,000 Rps. monthly.

We don't get married to women. We do not have a wife and children. We stay just like this and so I feel bad about that.... My childhood days were very easy. Being a son is easy. Society asks us so many questions. Why are you not getting married?... My family members were asking me to get married and I didn't agree to it because I was already [HIV] positive at that time. They asked me, they pressed me, why are you not interested in getting married? I was very tense in disclosing my status to them and I felt very bad about that situation. It was not only family members and relatives who degraded me about being *hijra*. I felt very bad.... Every *hijra* in their family behaves as a normal man because they do not want to lose their respect. He will maintain a secret life. He won't reveal his thoughts, activities and

plans to any one... Once we leave our house to reach our office, every moment matters. When we come out of the house, the neighbors say that he is *hijra*. They will look at us differently. They will observe our way of talking and when we come to the office, it happens again... If we want to live in society and maintain friends, we have to maintain secrecy about our *hijra* life.

Another respondent, Mrinalini, echoed similar sentiments about having to maintain secrecy about her gender identity because of the ongoing fear of being discriminated against publicly.

Mrinalini is a 40-year-old *hijra* from a lower caste, who earns 5,000 Rps. monthly. Like several other respondents, Mrinalini reflected a sort of nostalgia for how life prospects for *hijra* were significantly better in the past, and mourned that these “good ol’ days” had passed.

In the old days, [*hijra*] had value [in society]. But in this generation, people will comment on *hijra* and discriminate publicly against *hijra*... Mostly I like to dress up like this. Everyone knows in my house, but I will not dress up like this in my house. I will dress up like this when I come out. Ninety percent of the time, I want to dress like this, madam... I am very sad when I am in the house. But when I come out, I am very happy... Maybe in my dress, when I come here, I can feel free to share my feelings. At home I cannot share anything to anyone. If I tell them anything, they will discriminate [against] me.

Mrinalini reported consistently facing obstacles in terms of her personal safety when she presents as a *hijra*. By presenting in the dress that she desires to wear and being in a context in which she feels comfortable to do so, Mrinalini is able to be happy.

When we go out in this get up, we don’t know what will happen to us. People can harass us. They can beat us. They can take away our things. These things are happening outside. So, I cannot say this role is easy. This role is also difficult. When I am out with people, I will be silent. If I talk to them, they will recognize me. That’s the reason I do not talk to people... If I am silent, nobody recognizes my voice. That’s why I stay silent.

The fear of being identified leads Mrinalini to not speak in public for fear that others will recognize her voice. These experiences lead her to continue to live in a secret fashion.

Another respondent, Yasmine, also reported how difficult it was to live as a *kothi*.

Yasmine is a 46-year-old *hijra*, who earns 8,000 Rps. monthly.

It is very difficult to live life as a *kothi*. If we go anywhere people will laugh at us and they will make comments about us. [It is difficult to live as a *hijra*] because if anything goes wrong, we are finished... At home, I am a man. I am known as a *kothi* in the community... In places where I am known, I will not live my life as a *hijra*. I will not go to Chilkalguda [her village]. I prefer to be anonymous and go to villages or faraway places as a *hijra*... Living life as a man is good. I do not like this *kothi* life.

This passage reveals a constant push for Yasmine to suppress her third gender identity, leading to insecurities regarding her future prospects. Yasmine expresses the stress of leading a secret life and the stress that this secret life will be discovered. Yasmine also interchangeably uses the labels of *hijra* and *kothi*—identities that in a Western context might be respectively translated as transgender and gay, and that would not likely be used interchangeably to describe one's identity.

Venkatesh, a 29-year-old *hijra* from a backward caste who earns 10,000 Rps monthly, also noted that having to live this secret life impacted his prospects for the future and diminished his self-esteem.

If we want to participate in anything, we cannot do it with this inferiority complex. If we want to apply for jobs, we cannot apply by thinking that we will live only for a few days. Normal people have ambitions, but we don't have anything. By looking at us, they will feel different about us. That's the reason we cannot mingle with people freely... We cannot have freedom, madam. We have to do everything in hurry and in secret... All my friends have settled in government jobs. They are well settled with their family and children. I am still not settled and am living a secret life, an illegal life. I feel very bad about myself.

Respondents often rationalized the need for continuing to lead a secret life because their families and communities were unaccepting of their lifestyle and they feared the social consequences of being recognized as *hijra* or transgender women. Sanjay—a 38-year-old transgender woman, a member of a lower caste, and earns 4,000 Rps monthly—relayed these struggles with being unaccepted by both family and society:

Sanjay: There is no acceptance of *hijra* in our society and in the family. In this generation, everyone is aware of this, but there is no acceptance in our Indian society. And I don't think it is fully acceptable in Indian culture. Families will not accept *hijra* and nobody will accept us in society... I am maintaining secrets about myself... We have more femininity in us, but we cannot express it. So, we will act as men. Because of this we have to face difficulties with our family members and with our relatives and with our office colleagues.

Interviewer: How do you manage when you are unable to perform masculine gender roles?

Sanjay: Some people will say, "He is like this," and then I feel bad about that and think that it is not necessary to explain to everyone about me.

Interviewer: How did you overcome that situation?

Sanjay: Generally, I just act like a normal man.

Interviewer: So, you have maintained your *hijra* identity in secret?

Sanjay: Yes.

Likewise, Rohit expressed the duality of living as a boy, but having the "girl feeling" inside.

I have two sisters and they used to call me brother. But I feel I am not a boy. I am a girl on the inside. I have always had this "girl feeling" on the inside.

Several *hijra* expressed fear about being recognized when they were engaging in sex work, and the possible repercussions if their families or neighbors came to know of their dual gender identity or of their occupation. Tejas is a 48-year-old who identifies as both *hijra* and a transgender woman hailing from a lower caste, and making 6,500 Rps. monthly.

Hijra life is very difficult. Why? Because now I am married. My wife does not know about my behavior, nor my children. If they came to know about me, they would not be able to digest it. So, I have to maintain this secret life. It is very difficult. In India it is not legalized. It is considered a crime. They are not saying it is okay... Some years back, I was jobless, and I was not earning anything at that moment. My only option was having sex with men to earn money at that time. I felt very stressed. What is life? Why?... Yes, when we are at the hotspot [to get clients

for sex work] and mainly we are cross-dressing, if someone sees us, what will happen? What happens if my neighbor sees me here? I have had that type of stress and some fear. Not only that, I have tension about the customers. Nowadays some customers will have sex and they will kill us and go. We do not know whether that person is good or bad. If they kill us, my wife and children have to suffer in the future.

Given the constraints of no longer being given an established place in the social hierarchy, many *hijra* in the modern context have learned to master the art of living in secret. Ensuring that their identity is kept secret is important for maintaining the safety and livelihood of their family.

Tejas: From our house until we reach the office, when people see us, they make comments about this or that and they will gossip. And also, our villagers or our neighbors say that he is doing this or that and they chit chat about us... It will affect our children's lives and our parents' lives. They will tell our parents that your son has become *hijra*. [They will say] your family values are not good. [They will say] you do not have values and ethics. They will have conflicts and bring conflicts into our family. Sometimes they will degrade our parents and our children. We become mentally disturbed.

Interviewer: How do you dress?

Tejas: For some days, I do sex work. At night, I used to wear lady dress and during the day time, I dressed like a male person. When I am wearing a sari, I feel like a lady. Normally I behave like a gent.

Interviewer: Have you had to live a secret life?

Tejas: Yes, I have been doing this for a few years.

Some respondents eventually decided that being able to express their gender identity as *hijra* or transgender women at all times was important to them, even if it entailed being cut off from family and friends. Lakshmi is a 25-year-old *hijra*, from an upper caste, who makes a very high income (60,000 Rps. monthly) as a sex worker.

Lakshmi: In my daily life, we face problems. Some people laugh at us. Some people insult us, and some people are afraid of us. In this generation, it is very difficult to live like a *hijra*. I don't know about others, but I feel that this life is a waste. Sometimes I will ask God, why did you give me this life? I feel very bad about myself.... In my opinion, being *hijra* is a good thing and also a bad thing. I am not fully happy with this. We have some problems and some people who have HIV. My parents knew about me. They are worried about me because I am like this. Being *hijra* is hell. If I am born again, I will pray to God, please make me born as a woman or as a man.

Interviewer: How do you dress?

Lakshmi: Twenty-four hours a day I will wear a sari.

Interviewer: As a *hijra*, are you living a secret life?

Lakshmi: No, I am not living a secret life. Everyone knew in our colony and in our house that I am *hijra*. Twenty-four hours a day I will wear a sari!

In alignment with Butler's (2004) analysis of the performativity of gender, the sari recurs in our interviews as an important symbol of femininity and a marker for *hijra* identity. Another participant reported how the wearing of the sari is a direct indicator of when and where to perform certain gendered roles of woman, caregiver, and lover versus the alternate roles of man, husband, and father: "When I am a husband, I will not wear a sari. No, I will not wear a sari." Similarly, Gautam indicated that when he dresses in pants and shirts, he is a man and when he wears a sari, he is a woman: "I am an MSM, a *kothi*, a TG [transgender]. When I am in a pant-shirt, people will recognize me as a boy. When I am in a sari, people will recognize me as a lady." Binding closely to Butler's notion of gender as performativity, the *pulao* (the long trailing part of the sari, which in south India is typically draped across the shoulders and over the back) can be worn and taken off, in the same temporal way that a gender identity can be worn and taken off. This phenomenological experience of performing/being a woman is closely tied to

experience of wearing a sari, putting on make-up, and weaving in hair extensions. Gender is enacted through its corporeal manifestations.

Limitations

As in any research with human subjects, interviews are subject to social desirability bias, leading respondents to answer questions or behave in a way that will portray them favorably to the researcher. Participants may be aware of wanting to present themselves in a less marginalized manner, or alternatively may feel emboldened to exaggerate their experiences of discrimination to a seemingly empathetic listener.

In terms of the sampling method, an attempt was made to avoid the sampling bias associated with using an exclusively organizational recruiting method (Watters and Biernacki 1989). People living with HIV who are recruited from social service organizations are already receiving resources, so this may be eschewing the very population that we were seeking to find—those individuals who are *so* stigmatized by their HIV status that they are depressed and avoid accessing HIV services altogether. Though we additionally utilized snowball sampling and online recruiting to identify other individuals, these methods may also be considered biased because they are not random and because they select individuals on the basis of social networks, who may be more likely to be open about their HIV status (Browne 2005) and more willing to engage with service delivery mechanisms.

Discussion

One of the key conclusions from this research is the acknowledgement that in South Asia individuals have the ability to occupy more than one gender over the course of their lives or even over the course of a single day. In the surveys collected in the first phase of this research, individuals were provided the opportunity to select more than one gender or more than one

sexual orientation with which they identify. Interestingly, some individuals in the *hijra* group identified as being both male and female, but not as transgender. Similarly, some cisgender men identified as both heterosexual and homosexual, but not bisexual. Such interpretations of gender and sexuality reinforce the notion that for South Asians it is acceptable to state, “Sometimes I am a boy” and “Sometimes I am a girl” but “I am never both at the same time.” Similarly, “Sometimes I have sex with women” and “Sometimes I have sex with men” but “I am not bisexual.” Rather than there being an overall concurrent fluidity regarding gender, which would fit more along the notion of gender-queer or gender-fluid in the West, *hijra* in the postcolonial context are able to navigate back and forth between distinct identities, or to “code switch” (Heller, 1988) between varying social constructs of their gender identities.

This ability to espouse multiple identities at once is a distinct difference from the ways in which Western conceptions of identity often operate. Multiplicity of identity is certainly consistent with the ways in which South Asians have historically represented themselves in Indian mythology. Hindu deities are believed to be both male and female, as well as being capable of inhabiting the bodies of different beings, including humans, animals, and even trees, in their various *avatars*. This ability to be two things at once, or to be two genders at once, is at odds with Western ontology and phenomenology, which tends to require a more definitive, stable notion of identity. In the Western context, not being able to fully live one’s life as one gender often entails some element of living “in the closet,” not being “out,” or not having fully “self-actualized” one’s “true self.” But *hijra* defy these Western social expectations. As Lal (1999) articulately pointed out,

There is something deeply transgressive about the life choices made by *hijras*, just as there is a deep anxiety about their identity, since they do not fall within the paradigms of classification and enumeration that are dominant in modern knowledge systems... As we look into the lives of the *hijras*, and to the pace of

globalization now overtaking middle India, we might reflect, with perhaps more than a tinge of sadness, on the fact that the *hijras* may well be among the last few dissenters as we move into the third millennium, among the very few who, shall we dare to say it, have been chosen to defy the very models of defiance. (p. 134-35)

Because of the inability to neatly place gender-nonconforming individuals into mutually exclusive gender identity and sexual orientation categories, quantitative research on South Asian sexual/gender minorities may have distinct limitations when compared to research on LGBT people in Western contexts, where people may be more likely to identify definitively with one gender or sexual orientation, even if that identity be “trans,” “genderqueer,” “gender-fluid,” or “pansexual.” In other words, given the lack of discreet categories of identity in South Asia, any intervention—theoretical or clinical—targeting third gender individuals in the South Asian context may be better poised to use qualitative methods to more fully capture the richness of this intraclass variance.

Anthropological and other social science researchers are also questioning the increasing reference in gender and sexuality studies to what Towle and Morgan (2002) term “the ‘third gender’ rubric” (p. 469). They acknowledge that discourse regarding transgender people in the global South have largely been drawn from ethnographic portrayals of gender written by anthropologists for Western audiences. They acknowledge that under the curious gaze of the Western academic, third gender roles are regarded as “exotic.” Such Orientalist framings of South Asian constructions of gender and sexuality may serve to create a uniform depiction of diverse communities.

In summary, this study highlights the challenges faced by *hijra* in Hyderabad and their perceived need to lead a secret life. Lore within *hijra* communities has romanticized a time when *hijra* were not forced to “go underground,” but could live publicly as third gender people with established social spaces and reliable protection from the state. In contemporary times, *hijra*

appear to flow back and forth between multiple gender identities, sometimes seamlessly and sometimes in fear of facing grave social consequences if they were to fully disclose their secret lives to their spouses and families.

This research has also highlighted the disconnect between mythological/spiritual associations of *hijra* and the ways in which *hijra* are actually treated in contemporary Hyderabad. The ways in which *hijra* referred to themselves referenced a sense of historical importance, while acknowledging that they no longer have a secured guarantee of social respect in postcolonial India.

Implications for Social Policy and Practice

To remedy these social inequities, it appears most important to enact social intervention at the structural or cultural level. By reframing the social perception of *hijra*, we can also attempt to reconfigure traditional Indian gender roles in order to promote greater gender equity. Gender equity seeks to address fairness and justice in the distribution of benefits and responsibilities between women and men (Theobald, Tolhurst, and Squire, 2006). Gender equity recognizes that people of various genders are socialized to have differential power and that these differences should be addressed in order to reduce health disparities. Some scholars posit that gender equity requires the full abolition of the gender segregation of all social roles—especially work roles—both in the private and public spheres (Agassi, 1989). This research does not support such a conclusion, and it is unlikely that such a radical notion would be fully embraced by South Asian society in the foreseeable future.

At the individual level, interventions might seek to decrease HIV stigma and increase gender equity by including family, friends, and peers in health and social service programs. If these tensions cause psychological distress, *hijra* or other gender-nonconforming people may

also be linked to mental health and social services. At the community level, mainstream medical and mental health services for PLWH should seek to be more inclusive of individuals with varying gender identities and not assume that only LGBT organizations will provide such services for *hijra*. To reduce experiences of discrimination in health care settings, greater attention should be paid to ensure that medical providers are trained to be sensitive to the needs of gender-nonconforming people, including asking questions regarding sexual and reproductive health that are often seen as being socially awkward or inappropriate.

At the larger social level, it is our hope that findings from the present study will help to develop programs and policies that help *hijra* living with HIV in India overcome the strains that restrict their roles in social and sexual interactions. At the same time, we are aware that policies that are engineered by Western queer or HIV advocacy groups may not be culturally appropriate in the South Asian context. Therefore, program development administrators working in the area of sexual and reproductive health in South Asia need to pay particular attention to preventing the recreation of neocolonial paradigms of power and control over the Third World. In the long run, this work may also contribute to creating more fluid understandings of gender identity for people living with HIV in India or within South Asia at large. By providing insights into the gendered process of experiencing HIV and gender nonconformity stigma for *hijra* in India, we hope to ultimately contribute to the improved health of these populations by pivoting South Asian policies towards the greater protection of third gender rights.

Table 1: Descriptive Statistics of Hijra Living with HIV in Hyderabad, India (n=16)	
Age (years)	36.04 (SD=7.60)
Monthly Income (Rupees)	9,558 (SD=8507.7)
Caste	
Brahmin	1(2%)
Forward Caste (e.g. Vaishya, Komati, Kamma, Kapu, Reddy)	8(16%)
Scheduled Caste	14(28%)
Scheduled Tribe/Adivasi	1(2%)
Backward Class - A	10(20%)
Backward Class - B	7(14%)
Backward Class – C (Christian converts)	1(2%)
Any Member of a Scheduled Caste/Tribe	40(82%)
Religion	
Hindu	47(94%)
Muslim	2(4%)
Christian	1(2%)
Sikh	0(0%)
Education	
No formal	8(16%)
Primary	4(8%)
Secondary (High School)	16(32%)
Intermediate (High School +2 years)	15(30%)
Vocational	0 (0%)
Graduation (College degree)	4(8%)
Post-Graduation (Master's degree)	3(6%)
Native Language - Frequency (%)	
Hindi	1(2)
Urdu	2(4)
Telugu	47(94)
Gender Identity – Frequency (%)	
Male	22(44)
Female	1(2)
<i>Hijra</i>	3(6)
Transgender Female	10(20)
Transgender Male	14(28)
Sexual Orientation	
Heterosexual	0(0%)
Homosexual	33(66%)
Bisexual	17(34%)

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**HIV Stigma, Social Isolation and Depression
Among Cisgender Women Living With HIV in Hyderabad, India**

Abstract

HIV stigma in India has been recognized as a barrier to early detection of HIV, disclosure of HIV status to partners, and access to healthcare. To date, few studies have qualitatively examined the experiences of cisgender women living with HIV stigma in south India. To address this gap in the existing research, the goal of this study is to explore how stigma, social isolation, and depression affect cisgender women living with HIV in Hyderabad, India. Sixteen individuals living with HIV in Hyderabad were asked to complete in-depth interviews, probing their experiences living with HIV. All interviews were digitally audio-recorded in Hindi or Telugu, then subsequently translated and transcribed, directly into English. Transcripts of the interviews were imported into the data analysis program NVivo10 for coding, using thematic content analysis. Three main themes emerged from the qualitative interviews: (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 and Resilience. From a programming and social policy perspective, our findings reinforce the need for greater emphasis on culturally appropriate treatments for depression, particularly for cisgender women living with HIV, in sexual and reproductive health programs throughout South Asia.

Background

HIV remains a pressing public health concern in South Asia. There are about 2.1 million [95% CI: 1.7–2.7 million] people living with HIV (PLWH) in India, with a national adult HIV prevalence of 0.31% (NACO, 2017), making India the site of the third largest number of PLWH in any country (UNAIDS, 2017). HIV incidence in India is concentrated in urban areas among younger populations (15-24 years) from lower socioeconomic castes (NACO, 2017).

The South Indian state of Andhra Pradesh bears the highest adult HIV prevalence rate of the country (0.90%)—a rate three times that of the national average (NACO, 2012b). Prior to its recent separation into the state of Telangana, Andhra Pradesh consisted of 23 districts with a population of over 84 million people (NACO, 2012b). There were about 500,000 (95% CI: 424,000-596,000) people living with HIV in the current states of Telangana and Andhra Pradesh, accounting for 20% of all HIV infections in the country (NACO, 2012a). The capital of Telangana, Hyderabad, is the urban epicenter of the state’s epidemic, with 2% of women who attended antenatal clinics in the city testing positive for HIV (IIPS & Macro International, 2007). Given the relatively high concentration of the epidemic, the region is epidemiologically significant for HIV research.

Social context greatly shapes the culture of the HIV epidemic in India. The majority of HIV infections (88%) occur via heterosexual sex (NACO, 2010), particularly in the western and southern states of Maharashtra, Tamil Nadu, Andhra Pradesh, and Karnataka (Solomon, Chakraborty, D’Souza, Yepthomi & Detels, 2004). The HIV epidemic in India is also increasingly affecting cisgender women. The term “cisgender” refers to individuals who have a match between the gender they were assigned at birth, their bodies, and their personal identity (Schilt & Westbrook, 2009). UNAIDS (2013) reports that there are 750,000 [600,000 - 970,000]

cisgender women living with HIV in India. The HIV prevalence rate for women ages 15-49 in India (0.22%) is only slightly lower than that of males in the same age group (0.30%) (NACO, 2017).

According to data from the National Family Health Survey (NFHS), poverty is strongly associated with HIV status among cisgender women in India (Ackerson et al., 2012). Cisgender women living in poverty were 1.57 times more likely to be HIV positive than women not living in poverty (Ackerson et al., 2012). Socioeconomic status confers access to resources, such as condoms, preventive health care, and HIV education (Sales et al., 2014). As with other infectious diseases, poverty can increase biological susceptibility to HIV through the mechanisms of malnutrition or through lack of access to health care (Fenton, 2004). For women, poverty can additionally constrain the range of available social choices for financial subsistence, sometimes prompting women to engage in sex work or survival sex.

In addition to poverty, there are multiple social, contextual, and individual dynamics that contribute to HIV disparities for cisgender women 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. For women, HIV stigma can cause them to be labeled or associated with drug use, sex work, or promiscuity (Bunting, 1996).

The origins of the word *aurath*, the Hindi/Urdu word for “woman” is reflective of some of these cultural roots and traditions. The word *aurath* derives from an Arabic word, which translates as defect, fault, transgression, offense, incompleteness, evil or unprincipled conduct, imperfection, blemish, nakedness, or vulnerability (Haqqee, 2013). In Islamic law, or *shariah*, the term *aurath* also refers to the part of the body that should be covered in public (Syed, Ali & Winstanley, 2005). The interpretation of what exactly is to be covered differs, depending on the

Islamic school of thought, the local culture, and the social mores of the region. For women, this covered body space at the very least includes the space between the breasts and the knees. *Aurath* does not literally mean “woman” in Arabic; the Arabic word for “woman” is *nisaa*. However, in Hindi/Urdu, it has come to mean “woman,” although most Hindi speakers are unaware of the linguistic origins of the word. The connotation of the word *aurath*, with notions of vulnerability and weakness, may be indicative of the oftentimes subjugated status that South Asian women hold in society.

Early marriage and widowhood. Women’s sexuality in India is heavily scrutinized, as it is often expected that women will marry young and produce multiple—particularly male—children. Women’s harsher experiences with HIV stigma (Malavé et al., 2014; Wingwood et al., 2007) may prevent them from disclosing their HIV status to others (Derlega et al., 2002) and may serve as a barrier to receiving support to cope with their illness (Serovich et al., 2000).

HIV vulnerability for Indian women is heightened by early marriage, widowhood, and dependence on a spouse for financial subsistence. High social value is placed in Indian society on the expectation of women’s virginity at the time of marriage (Weiss, Whelan & Gupta, 2000). Several studies have documented that limited premarital and extramarital sexual intercourse render heterosexual transmission from husbands to wives as the dominant infection pathway for cisgender, heterosexual women (Decker et al., 2009; Solomon, Chakraborty, & Yephthomi, 2004; Gangakhedkar & Bentley, 1997). Despite the fact that most cisgender, heterosexual women have become infected with HIV via their husbands, they may nonetheless be blamed for being the source of HIV infection (Mohite, Mohite & George, 2015; Paudel & Baral, 2015). The unequal treatment of HIV positive women and men in India may be a reflection of social values which assign different standards of sexuality by gender (Mitra & Sarkar, 2011). This may be a

reflection of gender roles in Indian culture, where the male head of the household is often held blameless of moral wrongdoing.

Women are often socialized to take the blame for sexual and reproductive health issues such as infertility or impotence within a couple (Gupta et al., 2008). Gendered mores in heterosexual relationships dictate that Indian cisgender women play a more submissive role, often remaining silent and 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 can lead to domestic and sexual domination or violence (Mitra & 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.

Previously married women may be particularly vulnerable to HIV infection (Walters et al., 2012; Becker et al., 2007) because of women's lack of power in being able to decide when to engage in sex or how to negotiate with partners for sexual protection, particularly following the passing of their husband. In one study of HIV positive women in India, all women were previously married and 56% were widows (Mohite, Mohite & George, 2015). Widowed women are 22.7 times more likely than are non-widowed women to be infected with HIV (Ghosh et al., 2011). India is home to an estimated 40 million widows—approximately 10% of all women in the country (Kannan, 2013). More exploratory research is necessary to unearth the processes affecting this increased HIV vulnerability for widows.

One might expect that widowed women in Indian society would have decreased HIV risk since they are no longer having sex with their deceased husbands. However, the loss of income from a deceased spouse may make sexual activity with other partners more plausible and may

also serve as a source of financial subsistence. Widowed women from lower castes are in a precarious situation if they have lost the financial support of their husbands, are not provided financial assistance from their husband's family, and do not have an independent source of income. Returning to the home of their parents or living with their grown children may also not be an option for the widow, as family members may be too impoverished to afford to care of their daughter/mother. Researchers hypothesize that widows' heightened HIV risks are the result of four causes: (1) infection from and then death of an HIV-infected husband; (2) abandonment after husbands learn of their wives' HIV status; (3) economic instability after being previously married, leading women to seek financial support through male partners and/or sex work; and (4) the social status of being previously married, exposing women to sexual harassment and predation (Walters et al., 2012; Ghosh et al., 2011).

Research has identified that PLWH in India are at heightened risk for anxiety and depression (Nyamathi et al., 2011; Chandra, Ravi, Desai & Subbakrishna, 1998). This may be caused by an awareness of treatment methods that are more widely available in developed countries, but not as accessible in India, potentially contributing to feelings of hopelessness and despair (Chandra, Ravi, Desai & Subbakrishna, 1998). 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, Sullivan, Dasgupta, Saha & Salazar, 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. In a study of 50 cisgender women in Maharashtra, almost all women experienced perceived stigma at some point in their lives and as well as some sort of depression (Mohite, Mohite & George, 2015).

Theoretical Framework and Conceptual Model

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 & Radin, 1982; Eagly et al. 2000). In his seminal work on identity formation, *Stigma: Notes on the Management of Spoiled Identity*, Goffman (1963) defines stigma as an attribute that extensively discredits an individual, reducing him or her "from a whole and usual person to a tainted, discounted one" (p. 3). Goffman explains that society stigmatizes on the basis of what is considered difference or deviance, resulting in a spoiled identity. Labeled as deviants, stigmatized individuals view themselves and are viewed by others as undesirable (Mahajan et al., 2008).

Stigma refers to the devalued status that society attributes to a condition (Goffman, 1963). Stigma is a social process, characterized by exclusion, rejection, blame or devaluation, and resulting from an experience of social judgment (Scrambler, 2009). Through the creation of social hierarchies with demarcated status levels, stigma defines roles within social relationships. Research suggests that stigma strengthens and reproduces existing inequalities of class, race, gender and sexuality (Parker & Aggleton, 2003) by directly affecting individuals via mechanisms of discrimination and indirectly via threats to personal and social identity (Major & 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 & Phelan, 2001).

Goffman's conceptualization offers a social understanding of the origins of the social construction of stigma (Parker & Aggelton, 2003; Ogden & Nyblade, 2005). Three kinds of stigma are often highlighted in stigma scholarship: internalized stigma, perceived stigma, and

enacted stigma (Scrambler, 2009; Herek, 2007; Nyamathi et al., 2011). Internalized stigma, or self-stigmatization, describes feelings of shame (Herek, 2007), blame, and guilt. Internalized stigma can lead to low self-esteem, feelings of worthlessness and depression, social withdrawal, and the experience of excluding oneself from particular settings out of a fear of having one's status revealed. Perceived or felt stigma refers to conceptions of how a particular condition is viewed by society (Palamar, Halkitis & Kiang, 2013). This may be associated with anxiety, negative feelings about life, long-term health problems, and perceived side effects of medications. Finally, enacted stigma refers to a fear of societal attitudes that occur as a consequence of being associated with a particular undesirable attribute, disease (e.g., HIV), group (e.g., sex workers or gay men) or behavior (e.g. injection drug use, sex work or homosexuality) (Parker & Aggelton, 2003). Enacted stigma, which is often also termed stigmatization or discrimination, describes the process of incurring negative consequences, perhaps at work, school, or in health care settings, as a result of one's stigmatized status.

Goffman's work has been widely applied to stigma in various contexts, including mental illness (Byrne, 2000; Anspach, 1979), physical disability (Green, 2003), and criminal justice involvement (Bernburg, Krohn & Rivera, 2006). However, these conceptualizations of stigma are rarely framed in relation to larger social processes, such as poverty, classism, gender roles, or gender nonconformity. When applied to HIV, this framework may limit the experiences of PLWH to their individual emotions and cognitions by excluding structural considerations and social processes that produce and intensify discrimination (Mahajan et al., 2008).

Gender role theory (GRT) (Feld & Radin, 1982; Eagly et al., 2000) offers a conceptual framework that can be applied to better understand the relationship between HIV and social processes like stigma. 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 may significantly impact 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, 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.

Three concepts from GRT are particularly relevant to the present study: (1) role demands, (2) role performance, and (3) role stress. Role demands refer to expectations held by persons in particular social situations and can often lead to stereotypes about groups of people—in this instance, cisgender and transgender women. Gender differences in medical care and utilization can be understood by recognizing the traditional social roles played by men and women (Eagly & Diekmann, 2006). For example, in India, the role demand of a husband may be to physically and financially take care of his wife. Men are often viewed as being the family's provider and for maintaining the family's reputation in the community (Go et al., 2003). Meanwhile the role demand of an Indian woman is to be disciplined, submissive, and respectful to the needs of her husband (Go et al., 2003). These role demands may help explain the process by which Indian husbands may exert a great deal of influence over the health decisions of their wives. Role performance refers to the specific individual's contribution in response to social pressures and role demands. Role performance can be impacted by the individual's skills, personality, education, motives, and values. Role stress refers to the experience of socialized gender roles

having negative consequences on the person or others. This can occur when rigid or restrictive gender roles result in personal restriction or devaluation (O'Neil, Good & Holmes, 1995).

Role stress often occurs when people deviate from or violate gender role norms. Males and females are socialized to engender specific attributes and social behaviors (Eagly et al., 2000). Some have critiqued GRT for being heteronormative (Hicks, 2013) by promoting the idea that men and women naturally perform discrete but complementary tasks. However, when applied to the experiences of *hijra*, the concept of gender role stress may be particularly applicable, as *hijra* and transgender people may receive conflicting messages about the ways in which they should behave in accordance with the gender they were assigned at birth versus the gender with which they currently identify. By not conforming to binary gender roles, they may experience additional role stress.

In summary, what remains unclear from extant research is how experiences of HIV stigma vary between cisgender men, cisgender women and *hijra*/transgender women. Particularly in the case of *hijra*/transgender women and their sexual partners, little is known about how gender power dynamics play out in intimate partner relationships. The central hypothesis of this study is that HIV stigma varies significantly by gender, and that this variation is correlated with health disparities for cisgender women and *hijra*/transgender women.

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 & Radin, 1982). Under this view, social positions exist only in relation to other positions. Ultimately, role theory posits that social dysfunction is not caused by psychopathology, but rather by the social situations in which

individuals find themselves. 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 cisgender 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 members. Women's household and labor bargaining power is influenced by a number of factors, including individual economic assets, support from kin and friends, support from gender-progressive nongovernmental organizations, state support, women's access to employment and other income-earning means, the household's socioeconomic class/caste position, and social norms regarding women's decision-making capacities and productivity (Agarwal, 1997).

Gender roles can specify tasks by gender and occupationally segregate cisgender, heterosexual women in both rural and urban settings. Food allocation norms favoring males, such as men being served first and in greater quantities, can limit women's bargaining power in the household. This can make the position of women in poor families particularly precarious for their health (Sen, 1990). In order to better understand HIV among cisgender women, the inequality of gender roles and power relationships must be examined (Sharp, 2003), including the impact of a male-headed household.

Gender roles can negatively affect the health of cisgender women when social norms prioritize the health of men or prevent women from traveling alone to a clinic to seek care (Shah, 2012). Cisgender women in India are generally less nourished than men, less healthy, and more susceptible to physical and sexual violence (Agarwal & Sethi, 2013; Swaminathan & Mukherji,

2012; Nussbaum, 2001). Lack of gender equity in sexual relationships can constrain Indian cisgender women from sexually protecting themselves during intercourse and may fuel the HIV epidemic further.

In the South Asian context, cisgender women living with HIV are likely to harbor feelings of devalued status within their families and social networks (Mohite, Mohite & George, 2015). HIV stigma can lead cisgender women living with HIV to be more reluctant to disclose their HIV status to others, even to close family and friends (Vanable, Carey, Blair & Littlewood, 2006). This reluctance may also translate to cisgender, heterosexual 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, Siegel & Gorey, 1998).

Though there have been many advances in recent years in medical treatment (Spinner et al., 2016; Crum et al., 2006; Murphy et al., 2001), 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 cisgender women living with HIV in India (Fikree & 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; Herek, 2002).

How HIV stigma operates is shaped by the social construction of the epidemic in different cultures and communities (Thomas et al., 2005). 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 (Kinsler, Wong, Sayles, Davis & Cunningham, 2007), adherence to antiretroviral medications (Rintamaki, Davis, Bennett & Wolf, 2006), and

the likelihood of accessing prevention-of-mother-to-child services (Rahangdale et al, 2010). Individuals who reported higher levels of HIV stigma were over four times more likely to report poor use of medical care (Sayles et al., 2009). Not being connected to care can in turn increase HIV transmission, as people who are not virally suppressed have a higher likelihood of transmitting the virus to others (Attia, Muller, Zwahlen & Low, 2009). In a study of 50 cisgender women in Maharashtra, almost all women had perceived stigma at some point in their lives and all women had experienced some sort of depression (Mohite, Mohite & George, 2015).

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 become infected by their husbands (Mohite, Mohite & George, 2015; Priya, 2003; Gangakhedkar & Bentley, 1997). A husband's HIV exposure often results from having had multiple sex partners (Mitra & Sarkar, 2011). Men often become diagnosed after experiencing advanced symptoms of AIDS, tuberculosis, pneumonia, or other opportunistic infections (Sinha, Peters & Bollinger, 2009). Monogamous, married women may not be diagnosed until their husband is terminally ill (Malavé, S. et al. 2014) or until they receive required antenatal HIV testing at government hospitals and clinics. Ethnographic research elucidates that the tendency to stigmatize women is due in part to cultural constructions of gendered bodies and not only to a gendered double standard of sexual morality (Van Hollen, 2010). Nonetheless, existing research has not sufficiently addressed the social processes by which cisgender heterosexual women in India uniquely experience HIV stigma, particularly in regard to gender roles.

To address these gaps in the current research, this study explores how HIV stigma affects the lived experiences of cisgender women living with HIV in Hyderabad, India. In Phase 1 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 the surveys, a preliminary descriptive analysis of the data was conducted. Using survey responses to the stigma scales used in the study (Jeyaseelan et al., 2013; Zelaya et al., 2012), 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 2 of the study. The goal of these interviews was to explore how gender roles contributed to the experiences of HIV stigma for cisgender women living with HIV in Hyderabad, India. In the in-depth interviews, GRT was applied though the inclusion of qualitative questions regarding gender roles and gender nonconformity.

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) self-report as being HIV-positive, (2) residence in Hyderabad or Secunderabad, India, (3) proficiency in speaking Hindi/Urdu or Telugu, and (4) being between the ages of 18 and 50. Exclusion criteria included: (1) individuals who are HIV-negative, (2) individuals living outside of Hyderabad or Secunderabad, (3) and individuals either under the age of 18 or over the age of 50.

A mixed methods study was conducted, involving two interrelated phases that occurred consecutively, with the quantitative and qualitative phases bearing equal weight (Leech & Onwuegbuzie, 2009). In the first phase of the study, 150 structured surveys were conducted of

people living with HIV regarding their experiences with HIV stigma. The sample consisted of 51 cisgender women, 49 cisgender men, and 50 *hijra*/transgender women.

Following the completion of the surveys, a preliminary descriptive analysis of the data was conducted. Using survey responses to the stigma scales used in the study (Jeyaseelan et al., 2013; Zelaya et al., 2012), two subgroups were created: one subgroup of cisgender women and another subgroup of *hijra*/transgender women. The eight cisgender women with the highest HIV stigma scores and the eight women with the lowest HIV stigma scores comprised a new subgroup of cisgender women who were recruited to participate in Phase 2 of the study. This sampling method of capturing both participants who scored high and low stigma scores was utilized in order to ensure heterogeneity in the interview subgroup.

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. While the first phase was intended to quantify relationships between stigma, depression, and utilization of medical care, the second phase was intended to focus on the unique needs of cisgender women living with HIV. Open-ended questions were utilized to elicit descriptions of lived experiences of HIV stigma in the participants' own words. We anticipated that this sample size would be sufficient to ensure a saturation of themes in interviews.

Collaboration with Local NGOs

Purposive and snowball sampling techniques were utilized to recruit study participants. For purposive sampling, participants were recruited through existing collaborations with four local community-based organizations serving individuals living with HIV in Hyderabad, as well

as through snowball sampling of participants. The four organizations are briefly described as follows.

- *Avagaahana* is a nongovernmental organization, located in the Lal Darwaaza (Red Door) area near the Charminar monument, also known as Purana Shaher (“Old City”) in Hyderabad. The mission of the organization is to support the *hijra* community of Hyderabad through health education, crisis intervention, and resource advocacy for social entitlements. Avagaahana also supports a dance troupe that performs locally.
- *HOPES+* is a community-based nongovernmental organization in Padmarao Nagar in Secunderabad, working to improve the quality of life of people living with HIV. The network was created in 2006, and currently supports advocacy efforts, organizes family gatherings, links clients with government schemes (social entitlements), provides legal support for people living with HIV, and creates HIV awareness programs. As of May 31, 2013, the network enrolled and served 14,229 HIV positive members.
- *NHP+* is a non-governmental organization, dedicated to serving the needs of PLWH in Hyderabad. Through the assistance of NHP+, underprivileged PLWH are able to access food, clothing, medication and shelter. The organization works with homeless populations and street children to identify clients for their programs.
- *Calvary Counseling Society* is a non-governmental organization in the Ramnagar area of central Hyderabad. Calvary Counseling Society operates faith-based camps in rural areas, provides supportive education for orphaned children; offers psychological education and counseling for individuals/families affected by HIV; and provides nutritional assistance for medically indigent, homebound patients.

Recruitment

To recruit from these organizations, a local research assistant posted recruitment flyers in Hindi and Telugu at the collaborating organizations. The research team visited each of the four

organizations to recruit potential participants. To capture those men and women who are not currently connected to social service organizations, the team additionally utilized snowball sampling. Snowball sampling has been heavily utilized in disease prevention and intervention in public health (Magnani, Sabin, Saidel & Heckathorn, 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 & Waldorf, 1981). By taking advantage of the social networks of identified respondents (Thompson, 1997; Vogt, 1999), greater variance might be assured in the sample. For the purposes of this study, individuals who were initially recruited from the four collaborating organizations were asked to share information about the study to eligible peers.

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 back 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 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 (\$3.14 USD). 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 an hour and a half. 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) depression. The full interview guide questions/prompts are provided in Appendix A.

The first part 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 gender role stress. These also include questions regarding household dynamics, such as power to make decisions regarding money and health. Questions concerning HIV diagnosis and HIV disclosure followed next. This was followed by a long section on HIV stigma, medical care, and depression. Some questions were adapted from the HIV Stigma Index in India (GNP+, ICW & UNAIDS, 2011).

Data Collection and Analysis

An IRB application was fully 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.

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, 2012) for coding, using thematic content analysis (Krippendorff,

2012; Elo & Kyngäs, 2008). After reviewing the first ten transcripts, three evaluators—the doctoral student, a U.S.-based research assistant, and an India-based research assistant—developed a codebook of themes. Relevant chunks from transcribed data were assigned codes (Charmaz, 2006; Miles & Huberman, 1994). Identified codes were placed in broad groupings. The codes under each heading were clubbed together and the content analyzed for common themes.

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 gender nonconformity stigma. 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.

Results

Cisgender women in this sample had a mean age of 37.25 years with a mean income of 6,777 Rupees and a self-reported CD4 count of 431.75. All 16 women 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%) and spoke Telugu as their native

language (87%). Most women (84%) had a secondary level of education or less, approximately equivalent to the completion of the eighth grade in the United States.

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 and regaining 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 the families of their in-laws. One respondent—Namrita, a 39-year-old woman living in the Ramnathapur neighborhood of Hyderabad—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.

Namrita: “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?

Namrita: 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, madam... 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.

Namrita's story highlights the continued stigma towards HIV experienced from family members, even when they have been educated about HIV transmission routes. Women often discussed how their HIV status led them to be seen as impure or clean, even if medical science denied that others could be contaminated from 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.

Layla, a 39-year-old cisgender woman from Vanasthalipuram, Hyderabad earning 8,000 Rps./month, 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 for 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 tense, 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 are undoubtedly traumatizing for PLWH, some of the most hurtful experiences of being shunned occur from within their own families. Layla reports how her family treated her, following her diagnosis and how these experiences left her feeling rejected, alone, and depressed. She reported that she had educated her family about the ways in which HIV was transmitted, and they were aware that contact with saliva was not infectious. Nonetheless, Layla began to be treated differently by her family and was told not to feed her niece with her 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 her 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 you are always allowing her to be with you people?" I have suffered a lot this way.

Layla's experience of having to use separate utensils 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 prejudicial views 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. The stigma persists, not so much due to others' fears of being infected themselves, but rather to a desire to not be socially associated with an infected, and thus impure, individual. Applying perspectives from gender role theory, Layla's experience of being prevented from feeding her niece creates gender 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.

Another respondent, Jyothi, a 37-year-old woman living in Hyderabad, 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 various other narratives, the participant’s children serve as the saving grace from depression and a source of prevention against fatalism. Gendered role theory offers insight into understanding this phenomenon, citing the importance of completing the gender role demand of being a responsible mother as ultimately trumping feelings of suicidality that many cisgender women 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, either 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, a 47-year-old woman from Nandanavanam, Hyderabad, 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 HIV-positive]. 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—a 40-year-old woman from Bollaram, Hyderabad—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 is 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 did 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 separate from hers. I have been living with HIV for nine years... There have been many quarrels in my home about getting this disease. Even today, nobody in my home knows that I have HIV. And I will not share this with them... If I tell my 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, 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 in South Asia, that place greater social emphasis on family unity and group inclusion.

The self-esteem and, by extension, the mental health of cisgender women was often shaped by the ways in which the progression of HIV disease can affect one's physical appearance. Women were concerned about how others would perceive and potentially discriminate against them. Janaki, a 33-year-old cisgender woman living in Sitaphalmundi, Hyderabad, and earning 2,500 Rps./month, reports 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 [60 pounds]. 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 being known, and for fear of the association of living in poverty and being a beggar. The associations of living with HIV have connotations and associations with class, as well as 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 often intentionally keep others unaware of their HIV status. Seema, a 36-year-old woman from Malaket, Hyderabad, shared her experience of not wanting to disclose her HIV status to others as it made people assume that she had become infected from 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 the corresponding illicit identities—sex workers, injection drug users, and gay/bisexual men. Women remained very concerned about how others in their community would treat them and their children differently, should their HIV status become known. To avoid these anticipated experiences of discrimination, they kept their HIV status a secret.

“I Will Live Till I Die”: Suicidality and Resilience

Multiple cisgender women reported experiencing thoughts of suicide, hopelessness, 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 notion of “living till I die” is at once pragmatic and existential. Janaki highlights the universal human experience of mortality, but is able to use the inevitability of her death as a motivation for continuing to live.

As previously stated, for many women, their children were their main motivation to stay alive. Namrita, like many of the interviewed women, reported that her children offer her hope for the 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 Namrita finds her purpose through the fulfillment of her gendered role as the primary caretaker for her children.

Seema, like many women, initially experienced feelings of hopelessness regarding her HIV-positive diagnosis. But after being informed that there were treatments for her condition and that living with HIV is not as bad as she had initially thought, she regained hope for the future. Her sense of purpose, too, is obtained through the fulfillment of her role as her daughter’s mother.

[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 man or woman, 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 and marriage. Conversely, being single, divorced, or widowed are undesirable life experiences.

Many women reported that the reason that they were able to pull themselves out of moments of considering self-harm 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, Radha, 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 or communities. Radha's resilience against the forces of social exclusion speaks to the strength that cisgender, heterosexual women living with HIV have developed, which serves to protect them against the spoiled identity conferred onto them by judging society.

Azmath, a 27-year-old woman from Nacharam, 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 6 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... 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 remembrance and importance of her children. This causes one to question whether cisgender women living with HIV in India without children still have the same motivation for life, given the high cultural value

placed on marriage with children. This may indicate the importance of recognizing how single women living with HIV, or married/widowed women without children, may face increased risk for depression, 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, thereby exacerbating pre-existing social stigmas.

Limitations

There are several limitations to this study. The interviews and surveys are 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 have wanted to portray themselves as strong, resilient and healthy, and may have downplayed these same experiences.

There are clear problems in attempting to generalize these findings for cisgender women living outside of India, or perhaps even outside of Hyderabad. Regional variation in gender norms, language, and socioeconomic status within South Asia may confer significantly different cultural 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 Hyderabad. Given that this study was qualitative and had a relatively small sample size, no expectations regarding generalizability have been expected.

In terms of the sampling method, using a largely organizational recruiting method entails a strong source of sampling bias (Watters & Biernacki, 1989). People living with HIV who are

recruited from social service organizations are by definition connected to receiving resources, so this 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. Though we additionally utilized snowball sampling and online recruiting to identify other respondents, these methods may also be considered biased because they are not random and instead select individuals on the basis of social networks and are again 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 of 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 & Waldorf, 1981). This lack of generalizability is especially relevant for the lack of representation in this sample of cisgender women who are engaging in sex work. Because our sample does not adequately represent cisgender female sex workers, our findings is not generalizable to the subpopulation of cisgender women sex workers who are living with HIV.

Discussion

In our study, cisgender women experienced multiple forms of stigma—from their HIV status, to their caste status, to their widowed status. Our research reinforces previous findings that people living with HIV who experience stigmatizing interactions regarding their illness may experience higher levels of stress and distress (Hutton, Misajon, & Collins, 2013; Song & Ingram, 2002). Women in our study and in previous research (Van Hollen, 2010) also experienced disproportionate stigma and blame from the families of their in-laws.

In support of previous research in this area (Kang, Rapkin, Remien, Mellins & Oh, 2005), we found that HIV stigma often increases pre-existing social prejudice, disproportionately affecting individuals already socially marginalized for other reasons, such as sexual orientation, gender nonconformity, occupation, or caste. This stigma stems from HIV's association with behaviors such as injection drug use, homosexuality, and sex work, historically deemed to be immoral (Ghose, Swendeman, George & Chowdhury, 2008). Occupying multiple marginalized identities creates unique 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 concern that social perceptions regarding people living with HIV would negatively impact their lives. The majority of the women in our study hailed from lower castes or were living in poverty, leading to the experience of multiple layers of stigma due to being associated with HIV and with other existing identities or behaviors (Pulerwitz & Bongaarts, 2014). As highlighted by our research, women experience unique challenges in overcoming HIV stigma. When HIV stigma differentially impacts women, they may be less likely to disclose their positive HIV status to medical providers and may be less likely to receive the support they need to cope with their illness (Wingwood et al. 2007; Serovich et al. 2000).

Research on gender in South Asia suggests that a hierarchy of decision-making responsibilities is recognized by the family and community, reserving key family decisions such as those regarding health and money for men in their capacity as the heads of the household. Meanwhile, women are often assigned other responsibilities in their capacity as nurturing wives, mothers, and daughters (Kabeer, 1999). The importance of this primary role of 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 primary 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 fulfil the gendered role demand of being the primary caretakers of their children, a role for which they have been socialized from an early age.

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; Belle, 1989). While we do not have narratives from cisgender men in this study with which to compare, the importance of women occupying the role of wives/mothers with children may not have as much significance in comparison to the importance of men occupying the role of husbands/fathers with children. Previous research validates the notion that women do not want to relinquish their role as care provider and nurturer as a result of their HIV-associated illnesses (Gordillo et al., 2009; Revenson et al., 2005). Cisgender, heterosexual, 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 for women 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 (Kabeer, 1997).

From a theoretical perspective, our research also showcases how the discreet categories of stigma outlined by Goffman (i.e., internalized stigma, perceived stigma, enacted stigma) do

not appear in neatly separated boxes, but rather overlap with one another in gender-specific ways. For example, a woman may experience a level of personal shame (internalized stigma) regarding her HIV status as a result of her perceptions about how others see her (perceived stigma) and because of previous experiences of discrimination (enacted stigma). While Goffman's social constructs of stigma are fundamental in conceptualizing the phenomenon of stigma, the manifestation of stigma in multiple, intersectional social contexts is not cleanly demarcated into the separate categories of experience that Goffman describes. The adaptation to Goffman's model that we have outlined here attempts to pay attention to some of these deficits, particularly in regard to the intersectional nature of gender with regard to HIV stigma. Future research that seeks to elucidate the particularities of gender's impact on stigma, whether in relation to HIV or any other stigmatizing factor, may apply the notions of gender role demands and stress that have been outlined by gender role theory.

Implications for Social Policy and Practice

Our findings highlight the need for greater local and regional programming that focuses on the health inequities faced by cisgender women living with HIV, and for cisgender women more generally. As Van Hollen (2010) argues, understanding how gender interacts with HIV stigma in a particular sociocultural context is of critical importance for policymakers as they develop programs for HIV prevention and care.

Global efforts to alleviate gender inequities continue to focus on economic and political participation, while continuing to minimize the importance of women's health. The third goal of the United Nations' Sustainable Development Goals (SDG) is to ensure healthy lives and the fifth SDG is to ensure gender equality. Yet these priorities of promoting gender equity are not reflected in U.N. regional efforts in South Asia. The regional office for the United Nations Entity

for Gender Equality and the Empowerment of Women in New Delhi has identified six priority areas for their work: ending violence against women, promoting leadership and participation, national planning and budgeting, economic empowerment, peace and security, and migration (UNWomen, 2018). While undoubtedly these are important areas of focus, the larger frameworks of health and education remain off the priority list for programmatic outreach. In order for there to be substantial change in the health disparities experienced by cisgender women living with HIV, national and international campaigns must align in their shared advocacy for these goals of eliminating health disparities that occur by gender.

In conclusion, our research highlights the processes by which cisgender, heterosexual women living with HIV in Hyderabad, India, experience intersectional forms of HIV-related stigma, and consequently feel socially isolated or depressed. These women's experiences elucidate the crippling effects that HIV stigma can have on women's physical and mental health. In the context of HIV progression, delaying or avoiding medical care because of the fear of discrimination in healthcare settings creates vulnerabilities for poor health outcomes. Conversely, a high level of social support can lead to an improved quality of life, particularly with regard to mental health (Charles et al., 2012). Many women reported contemplating suicide, yet almost none of them had sought formal treatment for these suicidal ideations. None of the South Asian women in our study had accessed a clinical treatment program for depression. Such a medicalized model for the treatment of depression and other mental illness is still fairly taboo throughout South Asia and many people prefer to take a holistic health or religious pathway towards the treatment of depression. Because of the contextual difference in the understanding of depression in South Asia, it is not our recommendation that services for psychiatry and psychotherapy need to be increased in Hyderabad. Such an approach would likely meet with

community resistance as the idea of seeing a stranger and discussing one's personal problems is considered socially awkward and inappropriately intimate. Nonetheless, our narratives highlight that there is a lack of programming within both government hospitals and HIV/sexual/reproductive health-focused nongovernmental organizations to address the mental health needs of cisgender, heterosexual women living with HIV, and for women in society at large. From a programming and social policy perspective, our findings reinforce the need for greater emphasis on culturally appropriate treatments for depression, particularly for cisgender women living with HIV, in sexual and reproductive health programs throughout South Asia.

A multidimensional approach will be necessary to address the multiple social causes of the gendered stigma of HIV. This should include the promotion of social support programs, HIV stigma awareness campaigns, and community mobilization efforts around HIV testing and care. There already are some promising structural interventions for HIV stigma reduction in India. From 2008 to 2011, the National AIDS Control Organization (NACO), UNICEF, and the Ministry of Railways for the Government of India launched Red Ribbon Express (RRE), the world's largest HIV advocacy campaign, on a train that traveled over the country (Kandwal & Bahl, 2011). Similarly, the Heroes Project (2004–2008) was a national initiative to reduce HIV stigma and discrimination through the creation of public service announcements that engaged society leaders, celebrities, writers, and producers. Research indicates that such media campaigns, particularly for television, have considerable potential to raise HIV awareness and reduce HIV stigma (Vlasoff, Weiss, Rao, Ali & Prentice 2012).

A holistic understanding of the gendered impact of HIV stigma draws attention to the need for researchers and policy makers to promote the provision of health care and social services for people living with HIV. Important considerations in improving the status of

cisgender women living with HIV will be efforts to increase literacy, promote education and labor market participation, and economic independence (Mitra & Sarkar, 2011). In order to address HIV in South Asia, gender inequity will also need to be addressed.

Table 2: Descriptive Statistics of Cisgender Women Living with HIV in Hyderabad, India	
	Cisgender Women (n=51)
Age mean (SD)	37.25 (7.67)
Monthly Income mean (SD)	6,776 (4,121.44)
CD4 Count mean (SD)	431.75 (298.62)
Caste n (%)	
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 n (%)	
Hindu	39(77%)
Muslim	8(16%)
Christian	4(8%)
Education n (%)	
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 n (%)	
Hindi	4(8%)
Urdu	4(8%)
Telugu	43(87%)
Gender Identity n (%)	
Female	51 (100%)
Sexual Orientation n (%)	
Heterosexual	51 (100%)

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Associations between HIV Stigma, Depression & the Utilization of Medical Care Among People Living with HIV in Hyderabad, India

Abstract

The goal of this study was to identify how HIV stigma differentially affects cisgender women and *hijra*/transgender women living with HIV in Hyderabad, India, in terms of two factors: 1) experiences of depression, and 2) the utilization of medical care. A survey of 150 individuals living with HIV (51 cisgender women, 49 cisgender men and 50 *hijra*/transgender women) was conducted regarding their experiences with HIV stigma, depression, and medical care utilization. The mean age of participants was 38.03 years (SD=7.62); mean income was 8,8083 Rupees (SD=5,917); and mean self-reported CD4 count was 447 (SD=258). The majority of participants were Hindu (85%), spoke Telugu as their native language (89%), and were members of scheduled castes or tribes (79%). Multiple linear regressions were used to determine associations between HIV stigma and depression. Binomial logistic regressions were used to determine associations between HIV stigma and the utilization of medical care. For both outcomes, age and income were utilized as control variables. Using separate models from the two HIV stigma measures used in the survey (Zelaya, 2008; Jeyaseelan, 2013), the variables of experiencing HIV stigma, being transgender, and the interaction between experiencing HIV stigma and being transgender were all highly significant in positively predicting depression ($p<0.002$). On the Zelaya measure, both experiencing HIV stigma and being transgender were significantly associated with the positive utilization of medical care ($p<0.05$). On the Jeyaseelan measure, being transgender was positively associated with the positive utilization of medical care ($p<0.000$). These findings emphasize the importance of tailoring policies and programs to fit the specific mental and physical health needs of cisgender women, cisgender men, and *hijra*/transgender people living with HIV in India.

Associations Between HIV Stigma, Depression and Utilization of Medical Care Among People Living with HIV in Hyderabad, India

The goal of this study was to identify how HIV stigma differentially affects cisgender women and *hijra*/transgender women living with HIV in Hyderabad, India. The objective of the study was to examine the association between HIV stigma and two outcomes: depression and the utilization of medical care among a sample of 150 individuals living with HIV in Hyderabad, India (51 cisgender women, 49 cisgender men, and 50 *hijra*/transgender women).

Two hypotheses were tested in this study: (1) *Hijra*/transgender women experience the highest rates of HIV stigma and depression, and the lowest rates of utilization of medical care. (2) Higher levels of HIV stigma will be associated with higher levels of depression and lower levels of utilization of medical care. This paper first provides a brief overview of the HIV epidemic in India, specifically reviewing research on HIV stigma in India and previous research on the associations between stigma and health. The theoretical framework and conceptual model for the present study is provided, using an adapted version of Goffman's conceptualization of stigma combined with gender role theory.

Background

HIV remains a pressing public health concern throughout South Asia. UNAIDS estimates that there are 2.11 million [95% CI: 1.7–2.65 million] people in India living with HIV, with a national adult prevalence of 0.26% (NACO, 2016; UNAIDS, 2013). Prevalence is particularly high in South India, where this research was conducted. The South Indian states of Telangana and Andhra Pradesh bear the highest adult HIV prevalence rate for the country (0.90%), three times that of the national average (NACO, 2012). There are about 500,000 (95% CI: 424,000–596,000) people living with HIV (PLWH) in the states of Telangana and Andhra Pradesh,

accounting for 20% of all HIV infections in the country (NACO, 2012). Recent estimates indicate that 39.7% of PLWH in Telangana and Andhra Pradesh are cisgender women (NACO, 2012). The capital of Telangana, Hyderabad, is the urban epicenter of the state's epidemic, with 2% of women who attend antenatal clinics in the city being HIV positive (IIPS & Macro International, 2007). Given the high concentration of the epidemic in these states, Hyderabad was selected as our research field site.

HIV stigma is a social process referring to the internalized, perceived, and enacted negative perceptions directed towards PLWH (Herek, 2002; Goffman, 1963; Scrambler, 2009; Steward et al., 2008). Though there have been many advances in recent years in HIV medical treatment (Spinner et al. 2016; Crum et al, 2006; Murphy et al., 2001), HIV continues to be a heavily stigmatized disease (Kempf et al., 2010). Stigma is a driving force in creating and maintaining health disparities among women and gender-nonconforming people living with HIV in India (Fikree & Pasha, 2004). Stigma has been recognized as a barrier to early detection of HIV, disclosure of HIV status to partners, and accessing healthcare services in India (Herek, 2002).

People living with HIV who experience more stigmatizing interactions regarding their illness may experience higher levels of stress and distress (Hutton, Misajon, & Collins, 2013; Song & Ingram, 2002). Widely held sentiments about the marginalized status of PLWH create obstacles to the provision of efficient medical care and compassionate psychosocial support (Chesney & Smith, 1999). HIV stigma stems from the infection's association with behaviors such as injection drug use, homosexuality, and sex work, all of which have historically been deemed to be immoral or illicit (Ghose, Swendeman, George & Chowdhury, 2008). HIV stigma often increases pre-existing social prejudice, disproportionately affecting individuals already

socially marginalized for other reasons, such as sexual orientation, gender nonconformity, skin color, religion, occupation, or caste (Kang, Rapkin, Remien, Mellins & Oh, 2005). This heightened marginalization leads to certain populations experiencing multiple layers of stigma, from being associated both with HIV and with other existing stigmatized identities or behaviors (Pulerwitz & Bongaarts, 2014).

How HIV stigma operates is shaped by the social construction of the epidemic in different cultures and communities (Thomas et al., 2005). PLWH are often blamed for their illness, causing shame, guilt, and social isolation (Mahendra et al., 2007) as stigma is often related to moral judgments about particular behaviors and fears regarding HIV transmission. HIV stigma impacts retention in medical care (Kinsler, Wong, Sayles, Davis & Cunningham, 2007), adherence to antiretroviral medications (Rintamaki, Davis, Bennett & Wolf, 2006), and the likelihood of accessing prevention-of-mother-to-child services (Rahangdale et al, 2010). In a study conducted in Los Angeles, California, individuals who reported higher levels of HIV stigma were over four times more likely to report poor use of medical care (Sayles et al., 2009). Not being connected to care can in turn increase HIV transmission rates, as people who are not virally suppressed have a higher likelihood of transmitting the virus to others (Attia, Muller, Zwahlen & Low, 2009).

HIV stigma in India has had a disproportionate impact on the health and well-being of sex workers, transgender women, and men who have sex with men (MSM) (Ghose, Swendeman & George, 2011; Chakrapani et al., 2007; Chakrapani, Babu & Ebenezer, 2004). Research to date has only minimally focused on how cisgender women living with HIV in south India experience stigma with regard to their gender roles. Research suggests that cisgender women who are living with HIV in India experience heightened stigma and discrimination for their HIV status

compared to their male partners, despite the fact that the majority of HIV positive women become infected by their husbands (Mohite, Mohite & George, 2015; Priya, 2003; Gangakhedkar & Bentley, 1997).

Research has identified that PLWH in India are also at heightened risk for anxiety and depression (Nyamathi et al., 2011; Chandra, Ravi, Desai & Subbakrishna, 1998). This may be caused by an awareness of treatment methods that are more widely available in developed countries, but not as accessible in India, potentially contributing to feelings of hopelessness and despair (Chandra, Ravi, Desai & Subbakrishna, 1998). Chronic depression, stressful events and trauma can negatively affect HIV disease progression in terms of decreases in CD4 T cell counts, increases in viral load, and greater risk for clinical decline and mortality (Leserman, 2008). Women living with HIV who are diagnosed with major depression are more likely to have higher activated CD8 T lymphocyte counts (an indication of weakened immunity) and higher viral load levels (Evans et al., 2014). In a study of 50 cisgender women in Maharashtra, almost all women reported perceived HIV stigma at some point in their lives and all women reported some level of depression (Mohite, Mohite & George, 2015). Similarly, in a study of 200 MSM in India, gender nonconformity was significantly associated with depression, as 55% of the sample reported moderate to severe depression scores (Logie, Newman, Chakrapani, & Shunmugam, 2012). The combination of gender nonconformity stigma and HIV stigma accounted for a significant amount of variability in their depression.

Gender-nonconforming individuals, including *hijra*, may experience long-term psychological distress and have problematic relationships in adulthood (Landolt et al., 2004). The negative association between gender nonconformity stigma and wellbeing has been found to be more robust among men than women (Aube & Koestner, 1992; Impett et al., 2006; Skidmore

et al., 2006; Weinrich et al., 1992). *Hijra* are a group of third gender or gender-nonconforming people that exist throughout South Asia. *Hijra* are often translated into English as eunuchs, transvestites, homosexuals, bisexuals, hermaphrodites, transgender, androgynous, or transsexuals (Lal, 1999).

Existing research suggests that HIV stigma and gender are major drivers of health disparities for people living with HIV. To date, few studies have examined how gender impacts the experience of HIV stigma in south India. To address this gap in the current research, this study explored how HIV stigma differentially affects cisgender women and *hijra*/transgender women living with HIV in Hyderabad, India. The specific aim of this study was to examine the association between HIV stigma and both depression and the utilization of medical care among a sample of 150 individuals living with HIV in Hyderabad: 51 cisgender women, 49 cisgender men, and 50 *hijra*/transgender women. It was hypothesized that higher levels of HIV stigma would be associated with higher levels of depression. It was also hypothesized that *hijra*/transgender women would experience the highest rates of HIV stigma and depression, and the lowest rates of utilization of medical care.

Theoretical Framework and Conceptual Model

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 & Radin, 1982; Eagly et al. 2000). Goffman defined stigma as an attribute that extensively discredits an individual, reducing him or her "from a whole and usual person to a tainted, discounted one" (1963, p. 3). Goffman theorized that society stigmatizes on the basis of what is considered difference or deviance, resulting in a spoiled identity. Labeled as deviants,

stigmatized individuals view themselves and are viewed by others as undesirable (Mahajan et al., 2008).

Stigma refers to the devalued status that society attributes to a condition (Goffman, 1963). It is a social process, characterized by exclusion, rejection, blame or devaluation, and resulting from an experience of social judgment (Scrambler, 2009). Through the creation of social hierarchies with demarcated status levels, stigma defines roles within social relationships. Research suggests that stigma strengthens and reproduces existing inequalities of class, race, gender, and sexuality (Parker & Aggleton, 2003). Stigma directly affects individuals via mechanisms of discrimination and indirectly via threats to personal and social identity (Major & O'Brien, 2005). In addition, stigma can have a dramatic effect on various life outcomes, including psychosocial development, income, housing, criminal involvement, education, and life span (Link & Phelan, 2001).

Goffman's conceptualization has been adapted by others to include three spheres of stigma: internalized stigma, perceived stigma, and enacted stigma (Herek, 2007; Scrambler, 2009; Nyamathi et al., 2011; Ogden & Nyblade, 2005; Parker & Aggelton, 2003). Internalized stigma is often referred to as self-stigmatization. This social construct describes how someone feels about themselves and, specifically, if they feel a sense of shame (Herek, 2007). Internalized stigma can lead to low self-esteem, feelings of worthlessness and depression, social withdrawal, and the experience of excluding oneself from particular settings due to fear of having one's status revealed. Perceived or felt stigma refers to conceptions of how a particular condition is viewed by society (Palomar, Halkitis & Kiang, 2013). This may be associated with anxiety, negative feelings about life, long-term health problems, and perceived side effects of medication. Finally, enacted stigma refers to a fear of societal attitudes that occurs as a consequence of being

associated with a particular undesirable attribute, disease, group or behavior (Parker & Aggelton, 2003). Enacted stigma is often referred to as discrimination in interpersonal interactions.

The study also draws from social constructs in Goffman's work which have been widely applied to the context of stigma in various contexts, including mental illness (Byrne, 2000; Anspach, 1979), physical disability (Green, 2003), and criminal justice involvement (Bernburg, Krohn & Rivera, 2006). However, these conceptualizations of stigma are rarely framed in relation to larger social processes, such as poverty, classism, gender roles, or gender nonconformity. When applied to stigma associated with HIV/AIDS, this framework may limit the experiences of PLWH to their individual emotions and cognitions by excluding structural considerations and social process that produce and intensify discrimination (Mahajan et al., 2008).

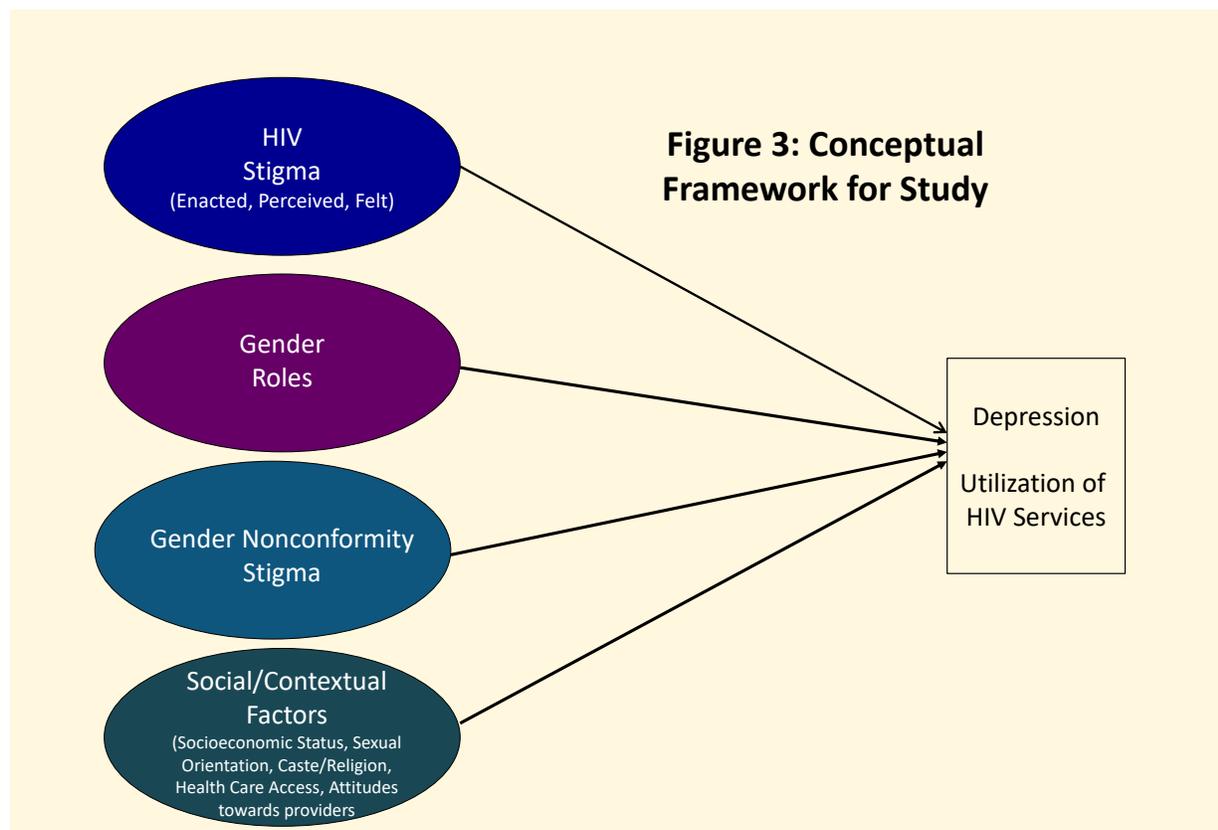
Alternative explanations of stigma (Link and Phelan, 2004) focus on the inequities in social, economic, and political power that enable stigma to unfold. Gender role theory (Feld & Radin, 1982; Eagly et al. 2000) also offers a conceptual framework that can be applied to better understand the relationship between HIV and other social processes. To my knowledge, no study to date has applied gender role theory to the experience of HIV stigma in the Indian context. To address this gap in understanding how gender is associated with HIV in India, this study uses Gender Role Theory, which emphasizes how individuals encounter differing expectations and experiences by virtue of their socialization as men, women and third gender people. 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, resources are often unequally distributed among male and female household members. Women's household and labor bargaining power is influenced by a number of factors, including individual economic

assets, support from kin and friends, support from gender-progressive nongovernmental organizations, state support, access to employment, socioeconomic class/caste position, and social norms regarding women's decision-making capacities (Agarwal, 1997). Gender roles can specify tasks by gender and occupationally segregate cisgender and transgender women in both rural and urban settings. Food allocation norms favoring males, such as men being served first and in greater quantities, can limit women's bargaining power in the household. This can make the health of women in poor families particularly precarious (Sen, 1990). In order to better understand HIV among cisgender women and *hijra*/transgender women, the unequal gender roles and power relationships between men and cisgender women must be examined (UNIFEM, 2003), including the impact of a male-headed household.

Gender roles can negatively affect the health of cisgender women when social norms prioritize the health of men or prevent women from traveling alone to a clinic to seek care (Shah, 2012). Women in India are less nourished than men, less healthy, and more susceptible to physical and sexual violence (Agarwal & Sethi, 2013; Swaminathan & Mukherji, 2012; Nussbaum, 2001). Lack of gender equity in sexual relationships can constrain Indian cisgender women from sexually protecting themselves and may fuel the HIV epidemic further.

In the South Asian context, cisgender women living with HIV are likely to harbor feelings of devalued status within their families and social networks (Mohite, Mohite & George, 2015). HIV stigma can lead cisgender women living with HIV to be more reluctant to disclose their HIV status to others, even to close family and friends (Venable, Carey, Blair & Littlewood, 2006). This reluctance may also translate to a lack of ease in disclosing HIV status to medical personnel, causing decreased access to medical care compared to their male partners (Raveis, Siegel & Gorey, 1998).

Figure 3 illustrates the conceptual framework behind the current study. The primary independent variable for the study was HIV stigma and the two dependent variables were depression and the utilization of medical care. Drawing from existing literature on the impacts of various social factors on HIV risk and care utilization, Figure 3 also identifies other social and contextual factors that impact health outcomes, namely socioeconomic status, caste, religion, sexual orientation, health care access, and attitudes towards HIV providers. The inclusion of several of these variables were evaluated in the regression analysis.



Methods

Analytic Sample

The study population was defined as people living with HIV. The analytic sample was defined as cisgender women, cisgender men, and *hijra*/transgender women between the ages of 18 and 50 living with HIV in Hyderabad, India. Inclusion criteria for the study were: (1) self-report as being HIV-positive, (2) resident in Hyderabad or Secunderabad, India; (3) proficient in speaking Hindi/Urdu or Telugu; and (4) between the ages of 18 and 50. Exclusion criteria included: (1) individuals who were HIV-negative, (2) individuals living outside of Hyderabad or Secunderabad, (3) and individuals either under the age of 18 or over the age of 50. The analytic sample consisted of 150 individuals living with HIV in Hyderabad: 51 cisgender women, 49 cisgender men, and 50 *hijra*/transgender women. Informed consent was obtained from all participants, following the IRB protocol approved both by the University of Chicago and the collaborating research organization in Hyderabad/Secunderabad, SHARE India.

Data Collection

Purposive and snowball sampling techniques were utilized to recruit study participants. Due to the stigmatized nature of the study population and the lack of epidemiological surveillance at the city level, no existing sampling frame for people living with HIV exists in Hyderabad, or for that matter, anywhere in India. Therefore, the population size is unknown. For purposive sampling, participants were recruited through existing collaborations with local community-based organizations serving individuals living with HIV in Hyderabad, as well as through snowball sampling of participants and online advertising.

Power analysis. Prior to collecting data, power analyses were conducted to determine a sufficient sample size to detect mean differences in HIV stigma by gender. Means and standard

deviations were not available to calculate sample size for the Zelaya et al. (2012) stigma scale. However, markers of validity and reliability were available for the Jeyaseelan scale (Jeyaseelan et al., 2013), so the sample size was calculated using parameters from this scale. The original research article for the full Jeyaseelan scale indicated a significant difference between individuals who had experienced depression ($\delta=122.9$) and the mean ($m=109.6$). A similar significant difference was predicted to occur between cisgender women and cisgender men in the proposed study. Given that the difference between those who were depressed and the mean in the original research was so large, a smaller difference between the average and expected value was used to calculate sample size ($\delta=114$). Given these parameters ($\alpha=0.05$, power=0.8, $m=109.6$, $\delta=114$, $\sigma=16.2$), it was determined that at least 37 individuals would be needed for the study to be able to detect mean differences between the groups.

A second sample size calculation was made using the abridged Jeyaseelan et al. (2013) scale. Again, the difference between individuals who had experienced depression ($\delta=75.8$) and the mean ($m=67.4$) was large. Assuming that such large differences in stigma do not exist between cisgender women, cisgender men, and *hijra*/transgender women, as occur between those who are depressed and those who are not, an even smaller difference was proposed in this sample size calculation. The following parameters were used to calculate the sample size for mean differences: $\alpha=0.05$, power=0.8, $m=67.4$, $\delta=70$, $\sigma=11.2$. Using this power analysis, it was determined that at least 50 individuals would be needed to detect a significant difference between two groups.

For ordinary least squares (OLS) regression, a third power analysis was conducted, using the following parameters: anticipated effect size: $f^2 = 0.15$, $\alpha = .05$, power = 0.8, number of predictors = 4. From this analysis, it was determined that a sample size of 76 would be needed

for utilization of medical care to be predictable by HIV stigma. An initial institutional review board (IRB) application was approved by the University of Chicago School of Social Service Administration/Chapin Hall. The proposal received a pending conditional approval in June 2015 and full approval in September 2015. The proposal also received approval by the SHARE India Ethics Committee in Secunderabad, India in November 2015, prior to data collection.

Recruitment

Over the summer of 2014, letters of support were obtained from four community-based organizations in Hyderabad with whom we partnered for data collection:

- *Avagaahana* is a nongovernmental organization, located in the Lal Darwaaza (Red Door) neighborhood near Charminar in Hyderabad, also known as Purana Shaher (meaning “Old City”). Founded in 2009 as a registered society in Hyderabad, the mission of the organization is to support the *hijra* community of Hyderabad through health education, crisis intervention, and resource advocacy for social entitlements. Avagaahana also supports a dance troupe that performs locally. Though funding from the Telangana State AIDS Control Society, one of their main projects focuses on HIV prevention and care.
- *HOPES+* is a community-based nongovernmental organization in Padmarao Nagar in Secunderabad which works to improve the quality of life of people living with HIV. As a district level network, HOPES+ has a created a platform for PLWH in Hyderabad/Secunderabad to address issues related to their care. The network was created in 2006, and currently supports advocacy efforts, organizes family gatherings, links clients with government benefits, provides legal support for people living with HIV, and creates awareness programs for the reduction of HIV transmission. As of May 31, 2013, the network had served 14,229 people living with HIV.

- **NHP+** is a non-governmental organization dedicated to serving the needs of PLWH in Hyderabad. Through the assistance of NHP+, underprivileged PLWH are able to access food, clothing, medication and shelter. The mission of NHP+ is to work with underprivileged PLWH towards a “just, poverty-free, responsible and compassionate society.” The organization works mainly with homeless children and adults.
- **Calvary Counseling Society** is a non-governmental organization in the Ramnagar area of central Hyderabad. The mission of the organization is to provide education, health, and psychological services to the local community. Calvary Counseling Society operates camps in semi-rural areas, provides supportive education for orphaned children, offers psychological education and counseling for families affected by HIV, and provides nutritional assistance for medically indigent, homebound clients.

A local research assistant posted recruitment flyers at the collaborating organizations in Hindi and Telugu. Our research team then visited regularly each of the four organizations to recruit and survey participants.

To include those who are not currently linked to social service organizations, we additionally utilized snowball sampling. Snowball sampling has been heavily utilized in disease intervention in public health (Magnani, Sabin, Saidel & Heckathorn, 2005). This sampling technique is utilized to elicit “hidden” or “hard to reach” populations where no sampling frame exists or where acknowledgment of membership in the group could have social consequences (Goodman, 1961; Atkinson & Flint, 2001). By taking advantage of the social networks of identified respondents (Thompson, 1997; Vogt, 1999), greater variance was ensured in the sample. Individuals who were initially recruited from the four collaborating organizations were

asked to share information pertaining to the study to eligible peers and received an additional incentive for referrals.

Additionally, we connected through social media with a sexual minority group, the Telangana Hijra Transgender Samiti. On their Facebook page, they state that they are “an unfunded collective of transgenders, *hijras*, non-*hijra* intersex people, transwomen, transmen, and genderqueers” (Telangana Hijra Transgender Samiti, 2015). Their webpage publicly documents the stories of several *hijra* and transgender women who have been affected by gender nonconformity stigma. We were able to get additional respondents by reaching out to the members of this group. Given that the group is virtual, it was more likely to attract individuals who may not be as open about their gender identity in other spaces.

Language of Surveys/Interviews

Both surveys and interviews were conducted in both Hindi/Urdu and Telugu. Urdu is spoken by 5.56 million people in the state of Andhra Pradesh. In Hyderabad, Hindi/Urdu speakers constitute roughly a third (12.2 of 31.4 million) of the population (Fatihi, 2003). Urdu has historically been spoken by Muslims in the state. The percentage of Urdu speakers in Hyderabad matches closely the number of Muslims in Hyderabad (12.3 million) (Fatihi, 2003). Though Muslims comprise a minority in the city, previous research indicates that *hijras* in Hyderabad are more likely to be Muslim (Reddy, 2006). To ensure translation accuracy and internal consistency, all relevant documents (consent forms and surveys) were translated both forwards and backwards from English to both Hindi and Telugu. A local research assistant conducted Telugu translations, and a local translator conducted Hindi translations. Certificates of translation were produced for the University of Chicago IRB and the ethics committee at SHARE India. The doctoral student conducted surveys in Hindi while a research assistant

conducted surveys in Telugu. For individuals who are illiterate, the interviewer read questions aloud and recorded the participant's answers. For illiterate individuals, a thumbprint was used as a signature for consent documents.

Incentives

All participants who completed a 90-minute survey were compensated 200 Rupees. This is equivalent to less than \$4 in U.S. dollars. This amount was deemed fair after consulting with local staff members at community-based organizations, who indicated that this is a typical sum 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.

Measures

Age. Age is measured as a continuous variable in years.

Monthly income. Income was measured in Rupees per month. Because monthly income had an outlier of one *hijra*/transgender individual who earned 60,000 Rps./month, the distribution was skewed non-normally. As such, we transformed the income variable by taking its log; this corrected the distribution to be closer to normal.

CD4 count. CD4 counts offer a snapshot into the functioning of the immune system. CD4 are white blood cells that fight infection. CD4 counts between 500 and 1500 copies/mL are considered normal. CD4 counts under 200 copies/mL are considered indicative of high risk for opportunistic infections and AIDS (Hunt et al., 2003).

HIV stigma. Two stigma scales previously validated in the South Indian context with PLWH were utilized. The first scale was Zelaya et al.'s (2012) measure of HIV stigma, which includes three main theoretical domains: (1) fear of transmission and disease, (2) association

with shame, blame, and judgment, and (3) support of isolation, segregation, and rejection. Using these domains, three parallel scales were created to measure self (internalized), experienced (enacted) and perceived (felt) stigma. Using a Likert scale, participants were asked to respond to statements in each domain of the scale.

The second scale was a 25-item scale, adapted and validated to measure HIV stigma in the South Indian context (Jeyaseelan et al., 2013). The scale was adapted from the 40-item Berger HIV Stigma scale comprised of four dimensions for HIV stigma: (1) personalized stigma (perceived stigma), (2) disclosure concerns, (3) negative self-image (internalized stigma), and (4) concern with public attitudes and people with HIV (enacted stigma).

Depression. Depression was assessed using the Center for Epidemiological Studies-Revisited (CESD-R) measure (Radloff, 1977), a screening test widely utilized in research studies on depression. The CES-D is a screening test for depression and depressive disorders, utilizing symptoms defined by the American Psychiatric Association's Diagnostic and Statistical Manual (DSM-V) for major depressive disorder (Radloff & Locke, 1986). The measure involves a series of statements regarding symptoms of depression to which participants are asked to respond. For example, the first statement reads: "Last week my appetite was poor." Respondents are asked to indicate how frequently they have felt this way in the past week by choosing from the following five options: (1) Not at all or less than one day, (2) 1-2 days, (3) 3-4 days, (4) 5-7 days, and (5) nearly every day for two weeks. The CES-D has been validated in research conducted in South Asia (Chokkanathan & Mohanty, 2013; Safren et al., 2009) and has been found to be reliable (Cronbach's Alpha = 0.86) among a population living with HIV in India (Zelaya et al., 2012). A CES-D score of 16 or above indicates risk for clinical depression (Safren et al., 2009).

Utilization of medical care. The number and dates of medical visits in the past year were collected in the survey. However, given the relative lack of access to HIV medical care in Hyderabad and the overall low rate of utilizing medical care, we recoded these visit dates into a dichotomous variable indicating whether or not the respondent had received any kind of medical care in the past year.

Caste. To capture caste variation in India, a number of context-specific castes were included as survey options. The highest caste is the traditional Indian *varna*, or caste of Brahmins (Gupta, 1980) and the lowest caste is the untouchable caste, or *dalits*. Following Brahmins, the next highest caste category is “forward castes,” which is considered an official designation by the Central Government of India. In Andhra Pradesh, forward castes include the castes of Velama, Reddy, Kamma and Kapu. Beneath the “forward” castes of social stratification are official designations for historically disadvantaged groups of people: Scheduled Castes (SC), Scheduled Tribes (ST), and Other Backward Class (OBC). These backward caste categories have been designated by the Government of India as eligible to receive affirmative action-style measures for resource allocation and for quotas for elected and appointed official government posts on *panchayats* or local village councils (Srinivasulu, 2002). *Dalits* (untouchable castes) and *sudras* (the traditional laborer caste) also fall into the SC category. These castes are further divided into smaller categories. For example, the designation of OBC is divided into four categories: Backward Caste – A, B, C and D.

Religion. People were asked to indicate if they followed one of the following religions: Hindu, Muslim, Christian, Sikh, Jain, Jewish, Buddhist, or other. Religion was measured as a dummy variable, with Hindu being the reference group.

Education. Education was also measured as a dummy variable. Individuals with less than secondary level of education (education up to approximately 16 years of age) were considered the reference group.

Language. Individuals were asked to indicate their native language from a list of South Asian languages.

Gender identity. Gender identity has been described as being the private experience of gender roles, and gender roles as being the public expression of gender identity (Money and Ehrhardt, 1972). In Western systems, gender identity is often characterized in binary terms (male/female). There are more fluid conceptions of gender identity, however, including the identities of “gender queer,” “gender fluid,” or “questioning.”

Because the present study seeks to investigate issues relating to the ways in which gender roles and gender nonconformity affect HIV stigma, both *hijra* and transgender women were recruited for the study into one gender-nonconforming group, labeled as *hijra/transgender* women. In order to investigate issues relating to the ways in which gender roles and gender nonconformity affect HIV stigma, and because both *hijra* and transgender women self-select as a third gender in India, both groups were recruited for the study as one gender group. We did not anticipate that this would obscure findings because both individuals and official government systems classify these individuals as one gender category. The category is purposefully vague, and includes individuals who may also identify as queer, bisexual, or as a third gender, or who sometimes identify as male and other times as female. Due to the more fluid nature of gender identity in South Asian culture, we did not exclude individuals who do not statically identify with one gender identity over the course of the day or over the course of their lives. Individuals were also allowed the option of selecting more than one gender identity, making it possible for

people to select that they were both men and women. We created a dummy variable for Transgender in all regressions, using transgender *hijra*/transgender women as the comparison/reference group.

Sexual Orientation. Individuals were asked to select their sexual orientation from one of the following options: heterosexual/straight, homosexual/gay, lesbian, bisexual, none, and other.

Sex Work. In the survey, this variable was measured as either (1) Yes, but not in the past year; (2) Yes, in the past year; or (3) Never. Because the first and second options did not receive many responses, this variable was recoded as a dichotomous variable of whether or not the participant had ever exchanged sex for money or drugs.

Data Analysis

The distributions of all independent and dependent variables were examined to identify non-normal distributions. For monthly income, a skewed distribution was found. The variable of monthly income was therefore transformed to its log, normalizing its distribution. Data was analyzed to see whether assumptions for linear regression were being met, namely that the variables have a linear relationship, that there is multivariate normality, that there was no multicollinearity, no auto-correlation and homoscedasticity. Residuals from regressions were also analyzed for patterns and no obvious patterns were found. All data were analyzed in the statistical analysis program, SPSS 23 (Nie, Bent & Hill, 1970).

Descriptive statistics—i.e., means/standard deviations and frequency/percentages—were calculated for all variable categories. Each of the predictor and outcome categories in the conceptual framework were compared for all three gender groups. Descriptive statistics were calculated for the variables of age, income, CD4 count, HIV stigma scores, CES-D depression scores, utilization of medical care, caste, religion, education, native language, gender identity,

sexual orientation, and engagement in sex work (see Table 2). The sizes of the three gender groups were planned to be the same size to avoid confounding the effect of the independent variables through unequal sample sizes (Jaccard, 1998). Because of a small data collection error, however, the final sample included a slight variation, with 50 *hijra*/transgender women, 51 cisgender women, and 49 cisgender men. Analysis of Variance (ANOVA) tests were conducted to determine whether statistically significant differences existed between demographic variables across the three gender groups. If the ANOVA test was significant, then additional t-tests were conducted to note where the statistically significant differences occurred across the three gender groups. It was expected that *hijra* would experience the highest depression scores and the lowest rates of health care utilization.

To calculate associations between HIV stigma (a continuous variable) and depression, multiple linear ordinary least squares (OLS) regression were utilized. Because two HIV stigma scales (Zelaya et al., 2012; Jeyaseelan et al., 2013) were utilized, two models were employed for each outcome of interest, using each scale as the independent variable. Bivariate regressions were conducted to explore the relationship between the independent variable (HIV stigma), covariates, and each of the two primary outcome variables of interest: (1) depression and (2) the utilization of medical care. Associations between socio-demographic characteristics and outcome variables were tested to identify appropriate control variables for analyses. All variables that were statistically significant at the $p < 0.05$ level, or which had been shown in previous research to be significantly associated with the outcomes of interest, were included in the final regression model. Given the relatively small sample size of the study, a parsimonious model was pursued. Hypotheses were tested using path analytic procedures (Edwards & Lambert, 2007; Preacher et al., 2007).

Multiple linear regression was utilized for the models predicting the association between HIV stigma and depression. The composite HIV stigma score was used to predict depression, as depicted in Figure 4. Regression specifications (1) and (2) were explored as follows:

$$(1) \textit{Depression} = \alpha + \beta_1 \textit{Composite Stigma Score} + \beta_2 \textit{Transgender} + \beta_3 \textit{Age} + \beta_4 \textit{Income} + \epsilon$$

$$(2) \textit{Depression} = \alpha + \beta_1 \textit{Stigma} + \beta_2 \textit{Transgender} + \beta_3 \textit{Age} + \beta_4 \textit{Income} + \beta_5 (\textit{Stigma} * \textit{Transgender}) + \epsilon$$

It was hypothesized that $\beta_1 > 0$ in both specifications, indicating that stigma would be positively associated with depression. We also hypothesized that transgender status would moderate the relationship between stigma and depression, and that stigma would have a stronger direct association with depression among *hijra*/transgender women than among cisgender women. This suggested that the interaction term β_4 would be statistically significant and negative.

For the next set of regressions, we examined the association between HIV stigma (a continuous variable) and the utilization of medical care (binomial variable), utilizing binomial logistic regression. Logistic regression was utilized because the dependent variable—utilization of medical care—was measured as a dichotomous variable (i.e., whether or not individuals had utilized medical care at least once in the past year). In these analyses, we again recoded gender using Transgender as a dummy variable and with *hijra*/transgender women serving as the comparison/reference group. To test the moderating effect of gender, we first ran the model using gender simply as a covariate:

$$(3) P[\textit{Utilized medical care}] = F[\alpha + \beta_1 \textit{Stigma} + \beta_2 \textit{Transgender} + \beta_3 \textit{Age} + \beta_4 \textit{Income} + \epsilon,$$

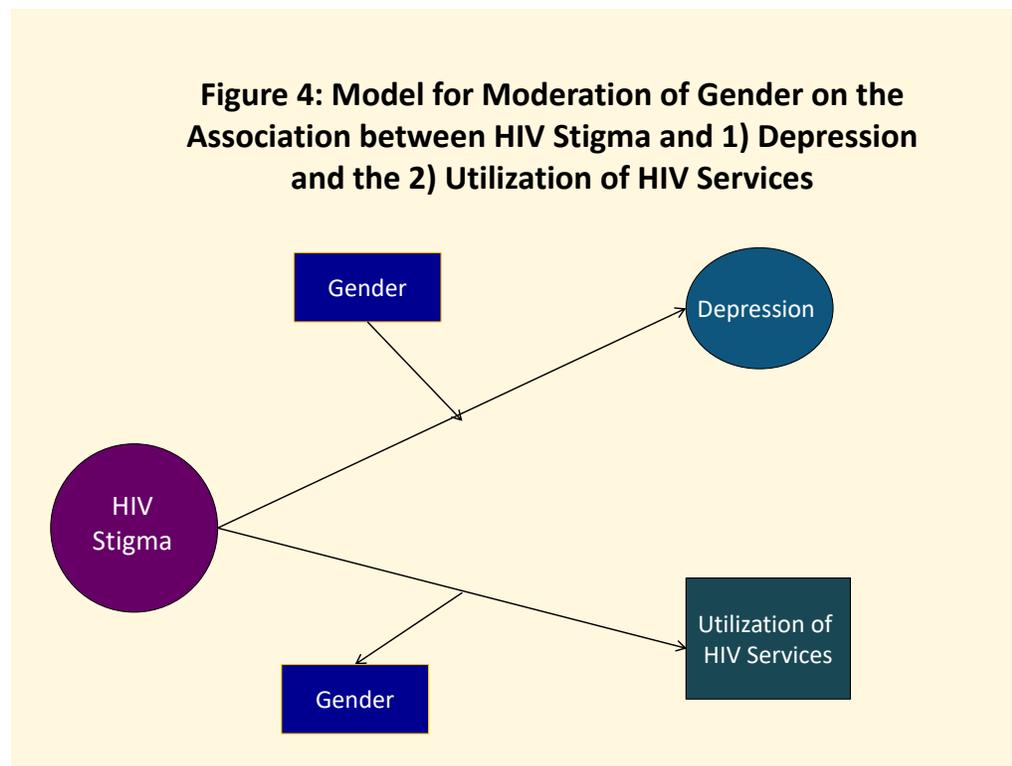
where $F[;]$ was the usual logistic regression function.

In the final regression model, we included the interaction term (HIV stigma * Transgender) to test whether transgender status moderated the relationship between HIV stigma and the utilization of medical care.

$$(4) P[\textit{Utilized medical care}] = F[\alpha + \beta_1 \textit{Stigma} + \beta_2 \textit{Transgender} + \beta_3 \textit{Age} + \beta_4 \textit{Income} + \beta_5 (\textit{Stigma} * \textit{Transgender})] + \epsilon$$

where F(;) is the logistic function.

To obtain standard errors and confidence intervals, we utilized a bootstrapping method to obtain robust confidence intervals and standard errors (Shrout & Bolger, 2002). Bootstrapping is a more appropriate method than traditional tests of indirect effects when sample sizes are small to moderate (MacKinnon, Lockwood, & Williams, 2004). This method offers an empirical representation of the sampling distribution of the indirect effect by assuming that the obtained sample size is representative of the population at large (Hayes, 2009).



Results

As indicated in Table 3, descriptive statistics (means and standard deviations) were calculated for each of the demographic variables. The average age of participants across the sample was 38.03 years (SD = 7.62) and participants had an average self-reported CD4 count of 446.74 (SD = 258). The bulk of the sample (79%) hailed from lower socioeconomic classes, known as “backward” castes that are classified as scheduled castes (SC), scheduled tribes (ST), or other backward classes (OBCs)—designations that are granted affirmative action by the Central Government of India. The majority of participants were Hindu (85%), followed by Muslims (8%), and Christians (7%). Most respondents spoke Telugu as their native language (89%), followed by Hindi (3%), and Urdu (4%). The average monthly income was 8,083 Rupees (SD = 5,917).

In Table 4, wherever the ANOVA test identified a statistically significant difference in the demographic variables across the three gender groups, the variable is labeled with an asterisk. There were statistically significant differences across gender for the variables of gender identity, sexual orientation, sex work, age, income, education and religion. As expected, there were significant differences across the three groups in terms of gender identity and sexual orientation. In terms of gender identity, all of the cisgender men identified as males and all of the cisgender women identified as females. Of the *hijra*/transgender women, 22 (44%), identified as males; 1 (2%) identified as female; 3 (6%) identified as *hijra*; 10 (20%) identified as transgender females; and 14 (28%) identified as transgender males. Combined percentages are greater than 100% because individuals were given the opportunity to identify with more than one gender identity or sexual orientation.

In terms of sexual orientation, all cisgender women in the sample identified as heterosexual. Among the cisgender men, 47 (96%) identified as heterosexual/straight and 4 (8%) identified as homosexual/gay. Among the *hijra*/transgender women, none identified as heterosexual/straight; 33 (66%) identified as homosexual/gay; 17 (34%) identified as bisexual. In terms of sex work, no cisgender women or men reported engaging in sex work. However, 62% (n=31) of *hijra*/transgender women reported engaging in sex work.

In terms of age, cisgender men were statistically older than cisgender women ($p=0.015$) and *hijra*/transgender women ($p=0.001$), though the largest difference in means across all three groups was not more than four years. In terms of monthly income, *hijra*/transgender women earned significantly more money (mean = 9,558 Rupees) than cisgender women ($p=0.038$), but did not earn significantly more money than men. This increased income is because of one outlier in the *hijra*/transgender women group, who earned an exceptionally high income (60,000 Rupees/month) through sex work. In terms of education, *hijra*/transgender women were significantly more likely to have completed at least an intermediate level of higher education (equivalent to the completion of high school) than either cisgender men or women. In terms of religion, *hijra*/transgender women are more likely to be Hindu than cisgender women ($p=0.021$), but there was no difference in religion between cisgender men and women. There were no statistically significant differences across the three gender groups in terms of caste, native language, or CD4 count.

Hypothesis 1: Hijra/transgender women experience the highest rates of HIV stigma and depression and the lowest rates of utilization of medical care.

As expected, the highest rates for HIV stigma were for *hijra*/transgender women with an HIV stigma score of 45.347 on the Zelaya et al. (2008) scale. Cisgender women scored on average 44.588 on the Zelaya stigma scale and cisgender men had the lowest scores, with a score

of 43.640. Scores for *hijra*/transgender women were significantly higher than for cisgender women ($p=0.031$) and cisgender men ($p=0.068$). On the Jeyaseelan et al. (2012) HIV stigma scale, *hijra*/transgender women scored the highest (67.959). However, on the Jeyaseelan scale, cisgender men had the second highest mean scores (62.188) and cisgender women had the lowest mean scores (61.098). Differences between gender groups were less strong on the Jeyaseelan HIV stigma scale. The Jeyaseelan HIV stigma score for *hijra*/transgender women was not significantly different from cisgender women ($p=0.199$) nor from cisgender men ($p=0.164$). While the difference in effect sizes across groups is not pragmatically large, it does point to an increased proclivity for *hijra*/transgender women to experience higher degrees of HIV stigma.

People living with HIV in our sample overwhelmingly met the CES-D criteria for high risk of developing depression. A cut-off score of 16 or above on the CES-D is considered an indication of vulnerability for depression, with a maximum score on the scale being 60 (Boyd et al., 1992). As indicated in Table 1, cisgender women showed the highest depression scores on the CES-D (33.118), followed by *hijra*/transgender women (31.440) and cisgender men (29.816). However, the differences in these scores were neither statistically nor clinically significant for the detection of depression.

Hypothesis 2: Higher levels of HIV stigma are associated with higher levels of depression and lower levels of utilization of medical care.

To test the second hypothesis, gender was treated as a moderating variable to the association between HIV stigma and each of the two outcomes of interest: depression and the utilization of medical care. As indicated in tables 5, 7, 9 and 11, two separate models were utilized, using each of the two composite HIV stigma scores as the independent variable and the CES-D scores as the dependent variable. We first ran a model to calculate the correlation between HIV stigma and depression. To test whether gender moderated this relationship,

separate models were run, first without the interaction between the variables of HIV stigma and transgender, and then with the interaction term. In Tables 5, 7 and 9 and 11, “Model 1” is the label for the regression model without the interaction term (HIV Stigma * Transgender). “Model 2” in Tables 5, 7 and 9 and 11 is the regression model including the interaction term (HIV Stigma * Transgender). Each set of models is also followed by a post-hoc stratified analysis of the regressions, with Transgender status being the grouping variable.

As indicated in Table 5 and 7, model 2, we found that the variables of HIV stigma, transgender, and the interaction between HIV stigma and being *hijra*/transgender were all highly associated with depression ($p < 0.005$) on both stigma scales. Neither the dummy variable of Female nor the interaction (Female * HIV Stigma) were found to be statistically significant on the Zelaya et al. (2008) or Jeyaseelan et al. (2013) HIV stigma scales, so these variables were not incorporated into the final regression models. Though they lacked statistical significance even at the bivariate level (as shown in Table 2), age and income were included in the final model as they have previously been shown to be strongly associated with both depression and medical care utilization. Other demographic variables that lacked a significant bivariate correlation or lost statistical significance in the larger model were not included in the final multiple linear regression models.

Tables 9 and 11 explore logistic regression models for the association between HIV stigma and the utilization of medical care, using both measures of HIV stigma. We again tested whether gender moderated this relationship using stepwise regressions. Logistic regression was used here because the utilization of medical care was measured as a dichotomous variable of having accessed or not having accessed medical care at least once in the past year. In the models without the interaction term (HIV Stigma * Transgender), HIV stigma had a strong statistical

association with the utilization of medical care on the Zelaya HIV stigma scale ($p=0.030$), but was not significant on the Jeyaseelan scale ($p=0.237$). Transgender status was positively associated with medical care utilization on both the Zelaya scale ($p=0.049$) and on the Jeyaseelan scale ($p=0.043$). This means that *hijra*/transgender people were between 2.33 - 4.01 times more likely to utilize medical care than people who were not *hijra*/transgender.

In model 2 with the interaction term in tables 9 and 11, the interaction term (HIV Stigma * Transgender) was not at all significant on the Zelaya scale ($p= 0.988$) and only marginally significant on the Jeyaseelan scale ($p<0.081$). Findings regarding the association between HIV stigma and medical care utilization were mixed across the two HIV stigma scales, making general conclusions across both scales difficult to make. However, it does seem clear that the relationship between HIV stigma and medical care utilization is not significantly modified by Transgender status. In tables 10 and 12, additional post-hoc analyses were conducted, stratified by Transgender status, to confirm these findings.

Limitations

The most significant limitation to this study is the fact that cross-sectional data was utilized. Therefore, statements can only be made about associations, not causal relationships, between HIV stigma and the two outcomes of interest. There are also limitations to the generalizability of the findings, given the relatively small sample size of 150, and the even smaller gender groups of 50. Because this was not a longitudinal study, we were not able to assess changes in the experiences of stigma among individuals over time to better understand the potentially causal relationship between HIV stigma and depression, or between HIV stigma and medical care utilization. If we had the possibility of continuing to collect data longitudinally, our

ability to predict causal relationships between HIV stigma and health outcomes would be greatly increased.

Responses to the surveys were subject to social desirability bias, where respondents answer questions, or behave in a way that will portray them favorably to the researcher. This may cause respondents to either exaggerate or minimize negative experiences of living with HIV, depending on their expectations for what the researcher desires to hear and in expectation of judgment or shame during the interview.

Given the diversity within South Asian culture, there are problems regarding generalizability of these findings outside of south India, or perhaps even outside of the city of Hyderabad. The context for cisgender women and *hijra*/transgender women in India is not likely to be comparable to other sexual/gender minority populations outside of the South Asian subcontinent, so global generalizations regarding gender-nonconforming people living with HIV are hard to make. Given the diversity of language, culture and gender norms in South Asia, the context for PLWH in Hyderabad may also not be generalizable to that of PLWH in other locations, even within the country of India.

In terms of the usage of two HIV stigma scales, effects were not consistent across the Zelaya and Jeyaseelan HIV Stigma Scales. The composite stigma scores of the two scales indicated a correlation of 0.745. While these scales are highly correlated, the difference in their effects on the dependent variables may indicate that the Zelaya scale is more sensitive to the gendered effects of HIV on depression. These inconsistent effects across both HIV stigma scales may also be indicative of measurement errors. Further research on HIV stigma in south India might benefit from use of the Zelaya scale, as it overall appeared better at capturing the gendered variance in HIV stigma.

The differences in the effect sizes between scales also speaks to differences in the social constructs they are trying to capture. The Zelaya scale focuses on (1) fear of transmission and disease, (2) association with shame, blame, and judgment, and (3) support of isolation, segregation and rejection. Meanwhile, the Jeyaseelan scale more closely matches the social construction of stigma outlined by Goffman's theoretical framework. The Jeyaseelan scale seeks to measure (1) perceived stigma, (2) disclosure, (3) internalized stigma, and (4) enacted stigma. Depending on the type of stigma that research projects seek to address, the use of various sub-scales within each of these HIV stigma measures may also prove to be more useful. Subsequent analysis of this data may include analysis of this sub-scale data.

In terms of the sampling method for both portions of the study, using an exclusively organizational recruiting method entails a strong source of sampling bias (Watters & Biernacki, 1989). People living with HIV who are recruited from social service organizations are by definition connected to resources, so this 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 altogether. Though we additionally utilized snowball sampling and online recruiting to identify other respondents, this method may also be considered biased because it is not random and selects individuals on the basis of social networks, who are again more likely to be more open regarding 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 could expect to encounter problems in capturing the actual variance of 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 (Bernacki & Waldorf, 1981).

The finding that being transgender is highly positively associated with medical care utilization was unexpected. This may speak to the nature of our specific recruited sample. The *hijra*/transgender people who had been recruited for study participation tended to be the most vocal and most involved in health advocacy in their organizations, making them more likely to utilize medical care and social services. To ensure that we capture the true variance of the third gender population, we would need to outreach to more marginalized or hidden sub-communities of gender-nonconforming people. A small sample of just 50 *hijra*/transgender people may not adequately be capturing this diversity.

Another limitation to this study may be the impact of severe weather on one of the major outcomes of interest: the utilization of HIV services. Data collection occurred in times of both heat waves and monsoons. During times of heat waves over the summer, temperatures might be over 44°C (111°F), which is considered a major risk factor for heat stroke, dehydration, and exhaustion. During times of monsoons, the streets were often flooded with a couple of feet of water, making public or private transportation limited or impossible. Both of these extreme weather conditions make it difficult to be outside at all, let alone to travel during the hot or wet hours of the day to keep medical appointments. During these conditions, the research team was also unable to conduct interviews or field work. It is therefore possible that one of the underlying reasons for people not being able to make their medical appointments is the omitted variable of extreme weather. We attempted to control for the effects of extreme weather by creating a dichotomous variable for the utilization of medical care. The dichotomous variable operationalizes the utilization of medical care based on a very low threshold of having visited a

medical provider at least once in the past year. Given that the dichotomous variable is less impacted by seasonal changes in weather, we hope to control (or at least limit) the impacts of climate on the outcomes of interest. However, even given this control, it is possible that the constraints of extreme weather may have had a longer lasting toll on residents of Hyderabad, perhaps for the entire year, or perhaps specifically during those periods of the year when data collection occurred. Similarly, issues like transportation to the medical clinic or distance from the medical clinic may be more practical barriers to accessing services, with impacts reaching over and above HIV stigma.

Discussion

The goal of this study was to provide greater insight into the stigmatizing processes that uniquely affect cisgender women and *hijra*/transgender women living with HIV in Hyderabad. Specifically, this study highlighted the barriers to health experienced by these marginalized populations and provided insight on addressing disparities in HIV care for populations of cisgender women and gender-nonconforming people. As predicted, we found that *hijra*/transgender women living with HIV in Hyderabad experience statistically significantly higher rates of HIV stigma than cisgender men or women. Contrary to our hypothesis that *hijra*/transgender women would also experience more severe depression, cisgender women experienced slightly higher rates of depression, but these differences were not statistically significant.

Our study also found that HIV stigma is strongly associated with depression and that transgender status moderates this relationship, confirming previous research indicating a strong association between these two variables. In other words, the more HIV stigma people experience, the more likely they are to be depressed. In terms of the relationship between HIV stigma and

medical care utilization, it is more difficult to make generalizations as these results were not consistent across both HIV stigma scales. We found that HIV stigma was positively associated with the likelihood of utilizing HIV services on the Zelaya HIV stigma scale ($p=0.030$), but was insignificant on the Jeyaseelan HIV stigma scale ($p=0.237$).

It does seem highly likely that *hijra*/transgender people in our study were some of the most well connected to social services and medical care among the population of people living with HIV, thereby potentially dulling the impacts of HIV stigma on their utilization of medical care. Stigma's association with both depression and medical care utilization are generally clearer in the group of cisgender women. This may be because *hijra*/transgender people are already experiencing multiple intersectional stigmas from other sources, such as gender nonconformity stigma or sex worker stigma, making the relationship between the variable of HIV stigma and medical care utilization less robust.

By better understanding the obstacles that cisgender women and *hijra*/transgender people living with HIV face in being able to access services and maintain psychological well-being, we can tailor social interventions and health policies to better suit the needs of this population. Local and central government agencies, such as the Telangana State AIDS Control Society and the National AIDS Control Organization (NACO), and international funding agencies, such as Gates Foundation, UNAIDS, and Population Council, can benefit from the knowledge of the needs and programs that are most salient to these populations in the planning of their future HIV prevention and care programs. For example, we know that at least some members of the *hijra*/transgender population are very well connected to HIV services. These individuals may be trained to serve as ambassadors or patient navigators for others in their community, thereby assisting other marginalized individuals into becoming included in the spectrum of HIV care. By providing

insights into the gendered process of experiencing HIV stigma for people in India, we hope to ultimately contribute to the improved health of these populations.

Additionally, the use of biomedical preventive interventions, such as the use of pre-exposure prophylaxis (PrEP), microbicides/vaginal gels, adult male circumcision and vaccines, may be increasingly warranted as alternative strategies for communities struggling with HIV stigma (Mahajan et al., 2008). For cisgender and transgender women who may not have the autonomy to decide immediate health care or sexual decisions, such as attending an HIV medical clinic appointment or using a condom during sex, the use of PrEP or vaginal microbicides may alleviate some of the impacts of gender inequity in sexual and social interactions.

To address policy and programmatic changes, social intervention is needed on multiple levels. At the structural intervention level, attempts can be made to modify and reconfigure traditional Indian gender roles to create greater gender equity for cisgender women and *hijra*/transgender women. Gender equity refers to fairness and justice in the distribution of benefits and responsibilities between women and men (Theobald, Tolhurst, & Squire, 2006). Gender equity recognizes that women and men are socialized to have differential power and that these differences should be addressed in order to effectively reduce health disparities. Some posit that gender equity requires the full abolition of the gender segregation of all social roles, especially work roles, both in the private and public spheres (Agassi, 1989). While such a reconfiguration of gender roles is highly unlikely in the short term in South Asia, pushing gender norms towards more equitable practices is a necessary step in creating longer-term social change.

At the individual level, interventions might seek to decrease HIV stigma and increase gender equity by including family, friends, and peers in provision of services. At the community level, medical and mental health services for PLWH should seek to be accepting and supportive

of individuals across the gender and sexuality spectrum. Given the reports of discrimination in health care settings in these surveys, it appears that doctors and nurses, particularly those in government (public) hospitals, need ongoing training to become more sensitive to the ways in which their clinical interactions may be contributing to the increased stigma that is associated with receiving HIV care. At the larger social level, findings from the present study may help to better develop programs and policies that help cisgender women and *hijra*/transgender women living with HIV in India overcome the strains that restrict their roles in social and sexual interactions. Our research may also contribute to countering Orientalist depictions of gender and sexuality in South Asia as primitive and backward, and to instead reinforce more fluid notions of gender and sexuality that have historically existed on the South Asian subcontinent prior to colonialism.

Implications for Policy and Practice

Our findings indicate that greater attention needs to be paid to fully engage cisgender women and *hijra*/transgender women living in HIV in medical care and mental health support. Understanding the variation between gender groups will assist in better tailoring stigma reduction interventions in the Indian context for subgroups of PLWH. The protective effects to depression experienced by cisgender men highlight how men may be guarded from experiencing more harsh forms of HIV stigma by their differential gender role status in their communities. Therefore, interventions need to be designed to address the unique needs of cisgender women and *hijra*/transgender women.

Social responses to HIV, in particular in response to HIV stigma, may serve to assert and reproduce normativity (Van Hollen, 2010; Goffman, 1963; Parker & Aggleton, 2003). Gendered considerations regarding health care should therefore be taken into consideration in the planning

of HIV policies and programs in South India. For example, community-based organizations may need to make greater efforts towards full engagement of family members to ensure less stigmatizing experiences for cisgender women and *hijra*/transgender women within their organizations, but also within cisgender women's own homes. For example, we have noted how cisgender women are particularly susceptible to the depressive impacts of HIV stigma. Because of this increased likelihood of experiencing depression, cisgender women may require greater outreach to ensure their inclusion in the receipt of mental health services. This might entail the provision of mental health services at home, where cisgender women may feel less stigmatized, or the provision of group or social support activities that may feel less stigmatizing than one-on-one counseling sessions. To better counteract the social impacts of depression, public health policy makers and clinical practitioners should utilize a multidisciplinary approach in their address of mental health. Because alienation, shame, and community isolation are often the immediate causes for depression (Scheff, 2001), community-level interventions that emphasize social support may be the most effective.

Another area needing further investigation is the way that sex work may intersect with or amplify experiences of HIV stigma for people living with HIV. The intersectional impact of sex work stigma on HIV stigma was researched in a recent study conducted in Zimbabwe (Hargreaves et al., 2017). Analyzing data from 1,039 respondents, researchers found that 91% of female sex workers reported some form of sex-work stigma, which was significantly higher than rates of HIV stigma. There also appeared to be an additive effect of experiencing both forms of stigma as those who reported sex work-related stigma also reported experiencing more HIV stigma compared to those who did not report sex work-related stigma. While we did not measure sex-worker-related stigma in this study, this is an area that warrants further research and

may help explain why the relationship between transgender status and medical care utilization was in the opposite direction (positive) that what we had expected. Recognizing the intersectional and additive elements of stigma, depending on other social identity markers like injection drug use, sex work or gender nonconformity, may be useful in better addressing health disparities by gender. While we had measured gender nonconformity stigma in the survey, those findings are not reported here, and may constitute a needed sub-group analysis, particularly for individuals who identified as *hijra*/transgender.

Stigma reduction interventions and social policies should assert the rights of gender-nonconforming people and create greater avenues for the access of supportive care. International platforms, coordinated by advocacy and development organizations, may provide the platform for the assertion of these human rights. Such campaigns have already been initiated by the International AIDS Society, the World Health Organization, the Global Forum for MSM and HIV, and the International Reference Group on Transgender Women and HIV. Given the reluctance of many people in South Asia to access mental health counseling or therapy services and the greater expense of time/resources that is required by individual level interventions, structural level interventions may be a more culturally appropriate and economical choice in the South Asian context. Structural level interventions may call for a restructuring of the funding priorities of public health entities to ensure the provision of public programs offering social support to people living with HIV, perhaps through the offering of weekly social activities or opportunities to obtain financial assistance to receive education or job training. Structural level interventions may include mass media campaigns that serve to normalize the experiences of people living with HIV and reduce negative stereotypes about the communities most impacted

by the epidemic, namely widowed women, sex workers, third gender people, injection drug users, and gay/bisexual men.

Organizations like the National AIDS Control Organization (NACO) and the Telangana State AIDS Control Society should further work to create stigma reduction campaigns that aim to normalize the identities of people living with HIV and to affirm that people living with HIV are not casually contagious. Social campaigns should reinforce the notion that women, sex workers, and gender-nonconforming people are not to be blamed nor shamed for their HIV status. Fear-inducing messages about AIDS that hold people morally responsible for their infection only serve to further isolate and discriminate against people living with HIV (Thomas et al., 2005) and will ultimately only exacerbate disparities in health care. A more sensitive approach to the stigmatized identities of individuals living with HIV is necessary to combat health disparities experienced within these vulnerable South Asian populations.

In conclusion, our research highlights the strong relationship between HIV stigma and depression, and how gender moderates this relationship. *Hijra*/transgender women experience a statistically significantly higher degree of HIV stigma than other gender groups. Cisgender women experience a marginally higher degree of depression than other gender groups. Our research also highlights a significant relationship between HIV stigma and the utilization of medical care. Unexpectedly, we found that higher degrees of HIV stigma are associated with higher degrees of utilization of medical care, though these results are not significant across both HIV stigma measures. These findings reinforce the fact that cisgender women and *hijra*/transgender women face unique needs in experiencing and living with HIV stigma, which need to be better addressed in social policies and programs in Hyderabad, and perhaps throughout south India. Understanding how gender interacts with the social experience of stigma

may be fundamental to a more comprehensive response to the HIV epidemic, particularly in the South Asian context.

Table 3: Descriptive Statistics of People Living with HIV in Hyderabad, India				
	Hijra/Transgender Women (n=50)	Cisgender Women (n=51)	Cisgender Men (n=49)	Total (n=150)
Age** - mean (SD)				
	36.04 (7.60)	37.25 (7.67)	40.88 (6.85)	38.03 (7.62)
Monthly Income* - mean (SD)				
	9,558(8508)	6,776(4,121)	7,939(3,605)	8,083 (5917)
CD4 Count – mean (SD)				
	454(188)	432(299)	381(7)	447(258)
Zelaya HIV Stigma Scores - mean (SD)				
Internalized Stigma	17(16)	16(10)	14(8)	15(8)
Experienced Stigma	19 (8)	21(10)	21(13)	20(11)
Perceived Stigma	9(3)	8(4)	8(4)	8(4)
<i>Composite Score</i>	45(15)	45(21)	44(20)	45(19)
Jeyaseelan HIV Stigma Scores – mean (SD)				
Personalized Stigma	29(10)	28(12)	27(12)	28(12)
Negative Self-Image	21(7)	18 (9)	18(9)	19(8)
Public Attitudes	12(4)	10 (5)	11(5)	11(5)
Disclosure Concerns	9(3)	8 (4)	8(4)	9(4)
<i>Composite Score</i>	68(22)	61 (27)	62(28)	64(26)
CES-D Depression Scores - mean (SD)				
	31(14)	33 (16)	30(18)	31(16)
Utilization of Medical Care n (%)				
Have utilized medical care in the past year	39(15)	33(65)	27(55)	51(34)
Have not utilized medical care in the past year	11(22)	18(35)	22(45)	99(66)
Caste - n (%)				
Brahmin	1(2)	2(4)	2(4)	5 (3)
Forward Caste (e.g. Vaishya, Komati, Kamma, Kapu, Reddy)	8(16)	10(20)	9(18)	27 (18)
Scheduled Caste	14(28)	14(27)	16(33)	43 (29)
Scheduled Tribe/Adivasi	1(2)	0(0)	1(2)	2 (1)
Backward Class – A	10(20)	1(2)	5(10)	16 (11)
Backward Class – B	7(14)	13(25)	8(16)	28 (19)
Backward Class – C (Christian converts)	1(2)	1(2)	1(2)	2 (1)
Backward Class – D	9(18)	8(16)	1(2)	23 (15)

Table 3: Descriptive Statistics of People Living with HIV in Hyderabad, India (continued)				
	<i>Hijra/Transgender Women (n=50)</i>	Cisgender Women (n=51)	Cisgender Men (n=49)	Total (n=150)
Caste <i>n</i> (%) (cont'd)				
Backward Class – E	0(0)	0(0)	6(12)	2 (1)
Other	0(0)	1(2)	0(0)	0(0)
Declined to State	0(0)	1(2)	1(2)	1(1)
Member of Any SC/ST	42(84)	38(75)	38(78)	118(79)
Religion <i>n</i> (%)*				
Hindu	47(94)	39(77)	41(84)	127(85)
Muslim	2(4)	8(16)	2(4)	12(8)
Christian	1(2)	4(8)	6(12)	11(7)
Education <i>n</i> (%)*				
No Formal	8(16)	17(51)	14(29)	39(26)
Primary	4(8)	7(14)	9(18)	20(13)
Secondary	16(32)	18(35)	15(31)	49(33)
Intermediate	15(30)	7(14)	8(16)	30(20)
Graduation	4(8)	1(2)	3(6)	8(5)
Post-Graduation	3(6)	1(2)	0(0)	4(3)
Native Language <i>n</i> (%)				
Hindi	1(2)	4(8)	5(11)	5(3)
Urdu	2(4)	4(8)	1(2)	6(4)
Telugu	47(94)	43(87)	43(87)	133(89)
Gender Identity*** <i>n</i> (%)				
Male	22(44)	0(0)	49 (100)	72(48)
Female	1(2)	51 (100)	0(0)	51(34)
<i>Hijra</i>	3(6)	0(0)	0(0)	3(2)
Transgender Female	10(20)	0(0)	0(0)	9(6)
Transgender Male	14(28)	0(0)	0(0)	14(9)
Sexual Orientation*** <i>n</i> (%)				
Heterosexual/Straight	0(0)	51 (100)	47(96)	96(64)
Homosexual/Gay	33(66)	0(0)	4(8)	35(23)
Bisexual	17(34)	0(0)	0(0)	17(11)
Sex Work	31(62)	0(0)	0(0)	31(21)

*= Statistically significant difference across gender groups (ANOVA) at the p<0.05 level

**= Statistically significant difference across gender groups (ANOVA) at the p<0.01 level

***= Statistically significant difference across gender groups (ANOVA) at the p<0.001 level

Table 4: Bivariate Relationships between HIV Stigma and Covariates (r = Pearson Correlation)		
Variable	Zelaya HIV Stigma Score (r)	Jeyaseelan Stigma Score (r)
Transgender	0.715	0.156
Age	-0.064	-0.030
Secondary Level of Education	0.041*	0.946
Income	-0.001	-0.042
Hindu	0.226	0.153
Depression	0.282***	0.231**
Exchanged sex for money or drugs	-0.187*	-0.172***
Taking HIV meds	-0.143	-0.98
Nights in hospice	-0.168*	0.000
Utilization of medical care	0.179*	0.114
Zelaya Stigma Score	-	0.745***
Jeyaseelan Stigma Score	0.745***	-

*= Statistical significance at the p<0.05 level

**= Statistical significance at the p<0.01 level

***= Statistical significance at the p<0.001 level

Table 5: Associations between HIV Stigma (Zelaya, 2008) and Depression								
Model 1					Model 2			
Variable	Unstandard. Coefficient (B)	Standard. Error (SE)	Standard Coefficient (β)	p-value	Unstandard. Coefficient (B)	Standard. Error (SE)	Standard Coefficient (β)	p-value
Stigma	0.246	0.068	0.291	0.000*	0.364	0.075	0.430	0.000***
Trans	0.450	2.814	0.013	0.873	25.825	8.090	0.765	0.002**
Age	0.191	0.171	0.091	0.267	0.209	0.166	0.100	0.209
Log Income	-2.330	2.479	-0.077	0.349	-4.256	2.464	-0.141	0.086
Stigma * Trans	-	-	-	-	-0.552	0.166	-0.800	0.001***
R	0.305				0.400			
R² (SE)	0.093 (15.451)				0.160 (14.296)			

*Statistical significance at the $p < 0.05$ level

**= Statistical significance at the $p < 0.01$ level

***= Statistical significance at the $p < 0.001$ level

Table 6: Stratified Analysis of HIV Stigma (Zelaya, 2008) and Depression

Table 6: Stratified Analysis of HIV Stigma (Zelaya, 2008) and Depression									
Model 1: Only Trans					Model 2: Only Non-Trans				
Variable	Unstandard. Coefficient (B)	Standard Error (SE)	Standard. Coefficient (β)	p- value		Unstandard. Coefficient (B)	Standard Error (SE)	Standard. Coefficient (β)	p-value
Stigma	-0.176	0.146	-0.186	0.235		0.372	0.077	0.454	0.000
Age	0.097	0.285	0.052	0.735		0.297	0.215	0.131	0.170
Log Income	-3.156	4.132	-0.123	0.449		-5.445	3.238	-0.162	0.096

Table 7: Associations between HIV Stigma (Jeyaseelan, 2013) and Depression								
Model 1					Model 2			
Variable	Unstandard. Coefficient (B)	Standard. Error (SE)	Standard Coefficient (β)	p-value	Unstandard. Coefficient (B)	Standard. Error (SE)	Standard Coefficient (β)	p-value
Stigma	0.147	0.051	0.237	0.004**	0.284	0.054	0.458	0.000***
Trans	-0.551	2.826	-0.016	0.846	37.458	7.865	1.116	0.000***
Age	0.156	0.171	0.075	0.363	0.227	0.158	0.109	0.155
Log Income	-2.128	2.459	-0.0071	0.388	-3.705	2.288	-0.124	0.108
Stigma * Trans	-	-	-	-	-0.564	0.110	-1.226	0.000***
R	0.255				0.459			
R² (SE)	0.065 (15.533)				0.211 (14.32)			

*= Statistical significance at the $p < 0.05$ level

**= Statistical significance at the $p < 0.01$ level

***= Statistical significance at the $p < 0.001$ level

Table 8: Stratified Analysis of HIV Stigma (Jeyaseelan, 2013) and Depression

Model 1: Only Trans					Model 2: Only Non-Trans			
Variable	Unstandard. Coefficient (B)	Standard Error (SE)	Standard. Coefficient (β)	p- value	Unstandard. Coefficient (B)	Standard Error (SE)	Standard. Coefficient (β)	p-value
Stigma	-0.273	0.086	-0.433	0.003	0.287	0.057	0.460	0.000
Age	0.119	0.253	0.065	0.640	0.294	0.208	0.131	0.161
Log Income	-3.143	3.376	-0.130	0.357	-4.469	3.140	-0.132	0.158

Table 9: Associations between HIV Stigma (Zelaya, 2008) and Utilization of Medical Care								
Model 1					Model 2			
Variable	Unexp. Coefficient (B)	Standard. Error (SE)	Odds Ratio Exp (β) (95% CI)	p-value	Unexp. Coefficient (B)	Standard. Error (SE)	Odds Ratio Exp (β) (95% CI)	p-value
Stigma	0.022	0.010	1.022 (1.022 - 1.043)	0.030*	0.022	0.011	1.022 (1.000 - 1.045)	0.048*
Trans	0.845	0.429	2.329 (1.004 - 5.402)	0.049*	0.863	1.286	2.370 (0.191 - 29.490)	0.502
Age	0.041	0.025	1.042 (0.992 - 1.094)	0.104	0.041	0.025	1.042 (0.992 - 1.094)	0.104
Log Income	0.263	0.366	1.301 (0.635 - 2.667)	0.472	0.262	0.376	1.300 (0.622 - 2.717)	0.486
Stigma * Trans	-	-	-	-	0.000	0.028	1.000 (0.947 - 1.055)	0.988

*= Statistical significance at the $p < 0.05$ level

**= Statistical significance at the $p < 0.01$ level

***= Statistical significance at the $p < 0.001$ level

Table 10: Stratified Analysis of HIV Stigma (Zelaya, 2008) and Utilization of Medical Care									
Model 1: Only Trans					Model 2: Only Non-Trans				
Variable	Unexpon. Coefficient (B)	Standard Error (SE)	Odds Ratio Exp(β) (95% CI)	p-value		Unexpon. Coefficient (B)	Standard Error (SE)	Odds Ratio Exp(β) (95% CI)	p-value
Stigma	0.039	0.030	1.040	0.190		0.024	0.011	1.025	0.033
Age	0.051	0.049	1.053	0.300		0.053	0.031	1.055	0.085
Log Income	1.477	0.902	4.379	0.101		-0.200	0.466	0.819	0.668

*= Statistical significance at the $p < 0.05$ level

**= Statistical significance at the $p < 0.01$ level

***= Statistical significance at the $p < 0.001$ level

Table 11: Associations between HIV Stigma (Jeyaseelen, 2013) and Utilization of Medical Care								
Model 1					Model 2			
Variable	Unexp. Coefficient (B)	Standard. Error (SE)	Odds Ratio Exp (β) (95% CI)	p-value	Unexp. Coefficient (B)	Standard. Error (SE)	Odds Ratio Exp (β) (95% CI)	p-value
Stigma	0.008	0.007	1.399 (0.995 - 1.022)	0.237	0.009	1.299 (0.994 - 1.025)	1.299 (0.994 - 1.025)	0.254
Trans	0.856	0.423	4.086 (1.026 - 5.393)	0.043*	1.077	1.258	0.732 (0.249 - 34.544)	0.392
Age	0.039	0.024	2.572 (0.991 - 1.090)	0.109	0.039	0.024	2.603 (0.992 - 1.091)	0.107
Log Income	0.209	0.351	0.354 (0.619 - 2.452)	0.552	0.201	0.354	0.321 (0.610 - 2.448)	0.571
Stigma * Trans	-	-	-	-	-0.003	0.018	0.035 (0.962 - 1.032)	0.081

*=Statistical significance at the $p < 0.05$ level

**= Statistical significance at the $p < 0.01$ level

***= Statistical significance at the $p < 0.001$ level

Table 12: Stratified Analysis of HIV Stigma (Jeyaseelan, 2013) and Utilization of Medical Care									
Model 1: Only Trans						Model 2: Only Non-Trans			
Variable	Unexpon. Coefficient (B)	Standard Error (SE)	Odds Ratio Exp(β) (95% CI)	p-value		Unexpon. Coefficient (B)	Standard Error (SE)	Odds Ratio Exp(β) (95% CI)	p-value
Stigma	0.008	0.017	1.008 (0.976 - 1.042)	0.614		0.010	0.008	1.010 (0.994 - 1.026)	0.214
Age	0.023	0.047	1.023 (0.993-1.121)	0.627		0.053	0.030	1.055 (0.995 - 1.118)	0.072
Log Income	0.783	0.781	2.188 (0.554 - 8.638)	0.264		-0.119	0.442	0.888 (0.373 - 2.112)	0.788

*= Statistical significance at the $p < 0.05$ level

**= Statistical significance at the $p < 0.01$ level

***= Statistical significance at the $p < 0.001$ level

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APPENDIX A: QUESTIONNAIRE FOR PEOPLE LIVING WITH HIV - ENGLISH

A. ELIGIBILITY SCREENER

1. How old are you? Age (in Years): __ __
2. Do you currently live in Hyderabad/Secunderabad? YES → 1
 No → 0
3. In which locality/neighborhood do you live?
4. How were you recruited?
 Through Avagaahana → 1
 Through NHP+ → 2
 Through HOPES+ → 3
 Through Calvary Counseling Society → 4
 Through referral from: →5

 Participant referral → 6
 Other, specify: → 7

5. What is your total monthly income (in Indian rupees)?
6. What is your caste?
 Brahmin → 1
 Forward Caste → 2
(e.g. Vaishya/Komati, Kamma, Kapu, Reddy)
 Scheduled caste → 3
 Scheduled tribe/*adivasi* → 4
 Backward class – A → 5

-
- Backward class – B → 6
 - Backward class – C
(Christian converts) → 7
 - Backward class – D → 8
 - Backward class – E → 9
 - Other, specify: → 10
-

7. What is your religion?

- Hindu → 1
 - Muslim → 2
 - Christian → 3
 - Sikh → 4
 - Hindu → 5
 - Buddhist → 6
 - Jain → 7
 - No religion → 8
 - Other, specify: → 9
-

8. What is the highest level of education you completed?

- No formal education → 1
- Primary → 2
- Secondary → 3
- Intermediate → 4
- Vocational training → 5
- Graduation → 6
- Postgraduation → 7

9. Where do you live?

- Own house/flat in colony → 1
- Own house/flat in basti/slum → 2

- Rent house/flat in colony → 3
 - Rent house/flat in basti/slum → 4
 - Residential hostel → 5
 - Homeless/living on the street → 6
 - Other, specify: → 7
-

10. What is your native language?

- Hindi → 1
 - Urdu → 2
 - Telugu → 3
 - English → 4
 - Other, specify: → 5
-

11. In which languages do you feel comfortable speaking?

IF PARTICIPANT IS NOT COMFORTABLE SPEAKING HINDI, URDU, TELUGU OR ENGLISH → INELIGIBLE.

- Hindi → 1
 - Urdu → 2
 - Telugu → 3
 - English → 4
 - Other, specify: → 5
-

12. Have you been diagnosed with HIV?

- Yes → 1
- No → 0

13. What is your gender identity?

- Male → 1
- Female → 2
- Hijra → 3
- Transgender Woman → 4
- Transgender Man → 5

Other → 6

14. What do you consider your sexual orientation?

Heterosexual/straight → 1

Homosexual/Gay → 2

Lesbian → 3

Bisexual → 4

None → 5

Other, specify: → 6

14b. MARK ELIGIBILITY BELOW

NOT ELIGIBLE: “Unfortunately, you’re not eligible to join the STOP Stigma Project. Thanks for your interest today!” STOP → 0

ELIGIBLE: “Great, you’re eligible to join the STOP Stigma Project. Before we continue, we need to review some project consent forms together. After we read these forms, you can decide if you want to join the STOP Stigma Project or not.” → 1

B. HIV, GENDER & SEXUALITY

15. When were you first diagnosed with HIV?

____/____/____
Day / Month / Year

16. What do you believe to be the cause of your HIV infection?

- Infection from spouse
→ 1
 - Sex with another man
→ 2
 - Sex with another woman → 3
 - Sex with another hijra/transgender woman → 4
 - Injection drug use → 5
 - Other, specify: → 6
-

17. With whom do you currently have sex?
[Select all that apply]

- Men → 1
 - Women → 2
 - Both men and women
→ 3
 - Hijra → 5
 - Transgender women
→ 6
 - Transgender men → 7
 - No one → 8
 - Other, specify: → 9
-

18. In your lifetime, with whom have you ever had sex?
[Select all that apply]

- Men → 1
- Women → 2

- Both men and women
→ 3
 - Hijra → 4
 - Transgender women
→ 5
 - Transgender men → 6
 - No one → 7
 - Other, specify: → 8
-

19. What is your marital/partnership status?

- Single/Never been
married → 1
- Married → 2
- Partner who lives with
you but to whom you are not
legally married → 3
- Partnered but not living
together → 4
- Separated → 5
- Divorced → 6
- Widowed → 7

**IF
MARRIED/PARTNERED,
PROCEED TO QUESTION
20.**

**IF
SEPARATED/DIVORCED/
WIDOWED, SKIP TO
QUESTION 21.**

20. If you are married/partnered, what is your partner's gender?

- Male → 1
 - Female → 2
 - Hijra → 3
 - Transgender woman → 4
 - Transgender man → 5
 - Other → 6
-

21. Do you have one or more REGULAR sexual partners?

- Yes, only one regular sexual partner → 1
SKIP TO QUESTION 24
- Yes, multiple regular sexual partners → 2
PROCEED TO QUESTION 22
- No, no regular sexual partners, only casual partners → 3
SKIP TO QUESTION 36
- No, I don't have sex → 4
SKIP TO QUESTION 36

22. How many sexual partners have you had in the past month?

23. How many sexual partners have you had in the past year?

24. How long has your spouse/regular sexual partner known about your current gender identity?

<p style="text-align: center;"> _____ Days _____ Months _____ Years </p> <p><input type="checkbox"/> N/A – no spouse/partner → 99</p> <p><input type="checkbox"/> Spouse/partner is not aware → 77</p>
<p style="text-align: center;"> _____ Days _____ Months </p>

25. How long has your spouse/regular sexual partner known about your current sexual orientation?

26. How long have other people (besides your spouse/regular sexual partner) known about your current gender identity?

_____ Years
 N/A – no spouse/partner
 → 88

27. How long have other people (besides your spouse/regular sexual partner) known about your current sexual orientation?

_____ Days
 _____ Months
 _____ Years
 N/A – no one is aware of my gender identity → 88

28. Thinking of the partner with whom you have sex most often/regularly, what is your partner's gender?

_____ Days
 _____ Months
 _____ Years
 N/A – no one is aware of my sexual orientation → 88

- Male → 1
- Female → 2
- Hijra/
Transgender (M to F) → 3
- Transgender man
(F to M) → 4
- No one → 5
- Other → 6

29. Is your spouse/regular sexual partner living with HIV?

- Yes → 1 No → 0
- Do not know → 2

30. How often is it in your control whether or not to use condoms with this spouse/regular sexual partner?

- Always → 1
- Most of the time → 2
- Sometimes → 3
- Rarely → 4
- Never → 5

31. How often do you receive HIV services with your spouse/regular sexual partner?
- Always → 1
 Most of the time → 2
 Sometimes → 3
 Rarely → 4
 Never → 5
32. Is your spouse/regular sexual partner aware of when you go to the HIV clinic?
- Yes → 1 No → 0
33. How often has your spouse/regular sexual partner denied you permission from going to a medical clinic or to receive other HIV services?
- Always → 1
 Most of the time → 2
 Sometimes → 3
 Rarely → 4
 Never → 5
34. How often do you need your spouse/regular sexual partner's permission to receive medical care or other HIV services?
- Always the time → 1
 Most of the time → 2
 Sometimes → 3
 Rarely → 4
 Never → 5
35. How often do you need your spouse/regular sexual partner's permission to leave the house?
- Always the time → 1
 Most of the time → 2
 Sometimes → 3
 Rarely → 4
 Never → 5
36. Have you ever exchanged sex for money or drugs?
- Yes, but not in the past year → 1
 Yes, in the past year → 2
 Never → 3

37. Do you have the following family members?

- Spouse/Partner → 1
- Mother → 2
- Father → 3
- Older brother → 4
- Younger brother → 5
- Older sister → 6
- Younger sister → 6
- Children → 7
- Aunt → 8
- Uncle → 9
- Cousin → 10
- Grandmother → 11
- Grandfather → 12
- Other, → 13
specify_____

38. With whom have you disclosed your HIV status?

- Everyone → 1
- No one → 2
- Spouse/Partner → 3
- Last sexual partner → 4
- Mother → 5
- Father → 6
- Older brother → 7
- Younger brother → 8
- Older sister → 9
- Younger sister → 10
- Children → 11
- Aunt → 12
- Uncle → 13

- Cousin → 14
- Grandmother → 15
- Grandfather → 16
- Other relative
- Friend
- Coworker
- Other,
specify _____

39. How long have you identified with your current gender?

_____ Days
 _____ Months
 _____ Years

- Always
- N/A – no one is aware of my gender identity

40. With whom have you shared your current gender identity?

- Everyone
- No one
- Spouse/Partner
- Last sexual partner
- Mother
- Father
- Older brother
- Younger brother
- Older sister
- Younger sister
- Children
- Aunt
- Uncle
- Cousin

- Grandmother
- Grandfather
- Other relative
- Friend
- Coworker
- Other,
specify _____

41. How long have you identified with your sexual orientation?

_____ Days
 _____ Months
 _____ Years

- Always
- N/A – no one is aware of my sexual orientation

42. With whom have you shared your current sexual orientation?

- Everyone
- No one
- Spouse/Partner
- Last sexual partner
- Mother
- Father
- Older brother
- Younger brother
- Older sister
- Younger sister
- Children
- Aunt
- Uncle
- Cousin
- Grandmother
- Grandfather

- Other relative
- Friend
- Coworker
- Other,
specify _____

C. ACCESS TO MEDICAL SERVICES (Kinsler et al., 2007)				
<i>The next set of questions pertains to accessing medical services IN THE PAST YEAR. For each of the following statements, please indicate whether you strongly disagree, disagree, neither agree nor disagree, agree or strongly agree.</i>				
	Strongly Disagree	Disagree	Agree	Strongly Agree
43. I have never gone without the medical care I needed because it is too expensive.				
44. Places where I can get medical care are very conveniently located.				
45. I am able to get medical care whenever I need it.				
46. I have easy access to the medical specialists that I need.				
47. It is easy for me to get medical care in an emergency.				
48. If I need hospital care, I can get admitted without any trouble.				
49. I have been unable to access medical care services because of transportation issues.				
50. I have been unable to access medical care services because of childcare issues.				

D. GENDER NONCONFORMITY STIGMA SCALE (Logie et al., 2012)

The next set of questions pertains to experiences you have had as a result of your gender identity as a man, woman, or transgender women/hijra. Please answer in relation to how you have felt EVER in your life.

Perceived Stigma	Never	Once or twice	A few times	Many times	All the time
51. How often have you heard that your gender identity as a (SELECT for participant their category: man, woman, or transgender woman/hijra) is not normal?					
52. How often have you felt that your gender identity as a (SELECT for participant their category: man, woman, or transgender woman/hijra) hurt and embarrassed your family?					
53. How often have you had to pretend that you are not a (SELECT for participant their category: man, woman, or transgender woman/hijra) in order to be accepted?					
Enacted stigma					
	Never	Once or twice	A few times	Many times	All the time
54. How often has your family not accepted you because of your gender identity as a (SELECT for participant their category: man, woman, or transgender woman/hijra)?					
55. How often have you lost your friends because of your gender identity as a (SELECT for participant their category: man, woman, or transgender woman/hijra)?					
56. How often have you been kicked out of school for your gender identity as a (SELECT for participant their category: man, woman, or transgender woman/hijra)?					

<p>57. How often have you lost a place to live for your gender identity as a (SELECT for participant their category: man, woman, or transgender woman/hijra)?</p>					
<p>58. How often have you lost a job or career opportunity because of your gender identity, as a (SELECT for participant their category: man, woman, or transgender woman/hijra)?</p>					
<p>59. How often have you been made fun of or called names because of your gender identity as a (SELECT for participant their category: man, woman, or transgender woman/hijra)?</p>					
<p>60. *How often have you avoided situations or people because of your gender identity as a (SELECT for participant their category: man, woman, or transgender woman/hijra)?</p>					
<p>61. *How often do you distance yourself from family/social gatherings because of your gender identity as a (SELECT for participant their category: man, woman, or transgender woman/hijra)?</p>					

E. UTILIZATION OF HIV SERVICES (Asch et al., 2004; RAND Corporation, 1997; Spicer & Ford, 2012)

We will now ask you about experiences with utilizing HIV services.

<p>62. Have you received any form of medical or health care in the past year?</p>	<p><input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>IF YES → SKIP TO QUESTION 71.</p> <p>IF NO → CONTINUE TO 63.</p>
<p>63. How many different times were you in the hospital overnight or longer during the last year?</p>	<p><input type="checkbox"/> N/A: Did not stay in the hospital overnight in the past year → SKIP TO QUESTION 65</p>
<p>64. For your most recent visit to the hospital, how many nights did you stay in the hospital?</p>	
<p>65. In the past year, how many times did you stay in a residential care home, nursing home or hospice overnight or longer?</p>	<p><input type="checkbox"/> N/A: Did not stay in a nursing home the hospital overnight in the past year</p>
<p>66. In the past year, how many times did you go to a hospital emergency room or urgent care center for medical care?</p>	<p><input type="checkbox"/> N/A: Did not visit a hospital emergency room or urgent care center</p>
<p>67. How many medical appointments did you have scheduled over the past year?</p>	<p><input type="checkbox"/> N/A: Did not have any medical appointments →</p> <p>SKIP TO QUESTION 80.</p>
<p>68. How many of these medical appointments did you actually attend?</p>	
<p>69. Where did you go to receive this medical care?</p>	<p><input type="checkbox"/> A government hospital</p>

	<input type="checkbox"/> A private doctor's office, medical clinic or health center <input type="checkbox"/> A community clinic <input type="checkbox"/> NGO <input type="checkbox"/> Nursing/Care Home <input type="checkbox"/> Local RMP (non MBBS) <input type="checkbox"/> Other, specify:
70. What were the approximate dates of your three most recent visits to receive medical care in the past year?	_____/_____/_____ _____/_____/_____ _____/_____/_____
71. How many times did you pick up your medications/ART WITHOUT receiving any other medical care?	
72. In the past year, how many times did you receive treatment from a massage therapist, homeopathic doctor, chiropractor, Ayurvedic healer or any other alternative health care practitioner?	<input type="checkbox"/> N/A: Did not see such a health care practitioner
73. In the past year, how many times did you receive medical care at home?	<input type="checkbox"/> N/A: Did not receive such medical care at home
74. In the past year, how many times did you visit a mental health provider? Include any visits to a psychiatrist, psychologist, psychiatric social worker, psychiatric nurse, or counsellor.	<input type="checkbox"/> N/A: Did not see a mental health provider
75. In the past year, how many times did you visit a social service provider, such as a case manager or outreach worker at an NGO?	<input type="checkbox"/> N/A: Did not visit a social service provider
76. In the past year, how many nights did you spend in a residential drug treatment program?	

	<input type="checkbox"/> N/A: Did not spend any nights in a residential drug treatment program
77. In the past year, how many days did you receive outpatient treatment or counselling for drug or alcohol-related problems?	<input type="checkbox"/> N/A: Did not receive any drug treatment

78. Do you believe that HIV medications work to treat HIV?

Yes No

79. Do you currently take any HIV medications?

Yes No

IF YES → CONTINUE TO QUESTION 80. IF NO → SKIP TO QUESTION 85.

80. When did you start taking HIV medications?

___ / ___ / _____

81. Most anti-HIV medications need to be taken on a schedule, such as "2 times a day" or "3 times a day" or "every 8 hours." How closely did you follow your specific schedule over the last four days?

- Always
- Most of the time
- Sometimes
- Rarely
- Never

82. In the last 30 days, how many days did you miss at least one dose of any of your HIV medications?

83. In the last 30 days, how good a job did you do at taking your HIV medications in the way you were supposed to?

- Very poor
- Poor
- Fair
- Good
- Very Good
- Excellent

84. When was the last time you missed any of your medications?

- Within the past week
- 1-2 weeks ago
- 2-4 weeks ago
- 1-3 months ago
- More than 3 months ago
- Never skip medications

85. What is your most recent CD4 count?

- Do not know

86. What is your most recent viral load?

- Undetectable
- _____ copies/mL
- Do not know

87. How often do you disclose your HIV status to a health care provider?

- Always
- Most of the time
- Sometimes
- Rarely
- Never

88. How often have you been denied treatment because you were HIV positive?

- Always

- Most of the time
- Sometimes
- Rarely
- Never

89. Who else do you know that is living with HIV?

- Spouse/partner
- Last sexual partner
- Mother
- Father
- Friend
- Coworker
- NGO worker
- Other relative, specify: _____
- Other, specify: _____

90. We want to know your rating of all your HIV health care in the last 6 months from all doctors and other health professionals. Use any number on a scale from 0 to 10, where 0 is the worst health care possible and 10 is the best health care possible. How would you rate your overall treatment in health care settings?

Worst possible care possible care

Best

0 1 2 3 4 5 6 7 8 9

10

91. On average, how long does it take you to get to the medical clinic?

- Less than 15 minutes
- 15-30 minutes
- 31-45 minutes
- 46-60 minutes
- 1 hour
- 2 hours
- 3 hours
- More than 3 hours

92. Once you get to this medical clinic, how long do you usually have to wait to see the person with whom you made an appointment?

- Less than 15 minutes
- 15-30 minutes
- 31-45 minutes
- 46-60 minutes
- 1 hour
- 2 hours
- 3 hours
- More than 3 hours

93. If you get sick and need to be seen before any appointment you have in this medical center or clinic, how long does it take for you to get another appointment?

- The same day, without appointment
- 2 days or less
- 3 days to 1 week
- 1-2 weeks
- 3-4 weeks
- More than 4 weeks

94. In general, how do you feel that women are treated in comparison to men in medical settings?

- Much worse
- Mildly worse
- The same
- Better
- Much better

95. In general, how do you feel that hijra/transgender women are treated in comparison to men in medical settings?

- Much worse
- Mildly worse
- The same
- Better
- Much better

96. In general, how do you feel that hijra/transgender women are treated in comparison to women in medical settings?

- Much worse
- Mildly worse
- The same
- Better
- Much better

97. Specifically, how do you feel that HIV positive women are treated in comparison to HIV positive men in medical settings?

- Much worse
- Mildly worse
- The same
- Better
- Much better

98. Specifically, how do you feel that HIV positive hijra/transgender women are treated in comparison to HIV positive men in medical settings?

- Much worse
- Mildly worse
- The same
- Better
- Much better

99. Specifically, how do you feel that HIV positive hijra/transgender women are treated in comparison to HIV positive women in medical settings?
- Much worse
 - Mildly worse
 - The same
 - Better
 - Much better
100. Since being diagnosed with HIV, how often have you been excluded from religious activities?
- Always
 - Most of the time
 - Sometimes
 - Rarely
 - Never
101. Since being diagnosed with HIV, how often have you felt your family treated you differently or excluded you?
- Always
 - Most of the time
 - Sometimes
 - Rarely
 - Never
102. Since being diagnosed with HIV, how often have you lost a job or work opportunity because of your HIV status?
- Always
 - Most of the time
 - Sometimes
 - Rarely
 - Never
103. When you eat a meal as a family, who is generally served food first?
- I don't eat with my family.
 - I don't have any family.
 - I eat alone.
 - No one is served first. Everyone takes food at the same time.
 - Me

- My male spouse/partner
- My female spouse/partner
- My male child
- My female child
- My father
- Your mother
- Other elder male relative, specify:

- Other younger male relative,
specify: _____
- Other elder female relative,
specify: _____
- Other younger female relative,
specify: _____
- Other, specify: _____

F. STIGMA: HIV Stigma Scale (Zelaya et al., 2008)

Now we will ask you about your experiences with HIV stigma. For each of the following statements, please indicate whether you strongly disagree, disagree, agree or strongly agree.

Scale 1: Self (internalized) stigma	Strongly Disagree	Disagree	Agree	Strongly Agree
104. I fear or worry that if I cough or sneeze on someone I may infect them with HIV.				
105. I fear that I could spread HIV to a person who is exposed to my feces or urine.				
106. I fear that I could spread HIV to my family if I share meals with them.				
107. When I think about my HIV infection, I feel disgusting.				
108. I feel that HIV is a punishment for my past bad behavior.				
109. I feel that I am infected with HIV because I was not a good enough person.				
110. I feel that I should stay isolated from others, and not let anyone see me.				
111. I feel that I should not live in the same house as my family.				
112. People in my community have told me to stay away from them so they don't contract HIV.				

	Strongly Disagree	Disagree	Agree	Strongly Agree
113. People are afraid that if I cough or sneeze near them they will contract HIV.				
114. My family and neighbors are afraid to let me take care of their children in case I transmit HIV to them.				
115. People I know have told me that I have HIV because I have participated in illicit and immoral activities.				
116. My friends did not want to spend time with me after they found out that I was infected with HIV.				
117. People I know have told me that I am cursed and that is why I have HIV.				
118. People have told me that I am promiscuous and that is why I have HIV.				
Scale 3: Perceived Stigma				
119. I feel that if I disclosed my HIV status to some people they would be afraid to come near me in case they will be infected.				
120. I feel that if I disclosed my HIV status to some people they would be afraid to let their children be near me.				
121. I feel that if I disclosed my HIV status to some people they would think that I have participated in illicit and immoral activities.				

	Strongly Disagree	Disagree	Agree	Strongly Agree
122. Some people close to me are afraid others will reject me if it becomes known that I have HIV.				
123. People have physically backed away from me when they learn I have HIV.				
124. People who know I have HIV tend to ignore my good points.				
125. Some people avoid touching me once they know I have HIV.				
126. I have stopped socializing with some people because of their reactions to my having HIV.				
127. People I care about stopped calling after learning I have HIV.				
128. People seem afraid of me once they learn I have HIV.				
129. I have been hurt by how people reacted to learning I have HIV.				
130. People don't want me around their children once they know I have HIV.				
131. I have lost friends by telling them I have HIV.				
132. Some people who know I have HIV have grown more distant.				
133. Having HIV makes me feel unclean.				

	Strongly Disagree	Disagree	Agree	Strongly Agree
134. Having HIV makes me feel that I'm a bad person.				
135. People's attitudes about HIV make me feel worse about myself.				
136. I feel I am not as good a person as others because I have HIV.				
137. Some people act as though it's my fault that I have HIV.				
138. Since learning I have HIV, I feel set apart and isolated from the rest of the world.				
139. Most people believe that a person who has HIV is dirty.				
140. Most people with HIV are rejected when others find out.				
141. People with HIV lose their jobs when their employers find out.				
142. Most people think that a person with HIV is disgusting.				
143. I never feel the need to hide the fact that I have HIV.				
144. I worry that people who know I have HIV will tell others.				
145. I regret having told some people that I have HIV.				
146. I worry that people may judge me when they learn I have HIV.				

**H. Center for Epidemiologic Studies Depression Scale – Revised (CESD-R)
(Eaton et al., 2004)**

Now I will review a list of the ways you might have felt or behaved in the past week. Please indicate how often you have felt this way in the past week: not at all or less than 1 day, 1-2 days in the past week, 3-4 days, 5-7 days, or nearly every day for 2 weeks.

	Not at all or less than 1 day	1 - 2 days	3 - 4 days	5 - 7 days	Nearly every day for 2 weeks
147. Last week my appetite was poor.					
148. I could not shake off the blues.					
149. I had trouble keeping my mind on what I was doing.					
150. I felt depressed.					
151. My sleep was restless.					
152. I felt sad.					
153. I could not get going.					
154. Nothing made me happy.					
155. I felt like a bad person.					
156. I lost interest in my usual activities.					
157. I slept much more than usual.					
158. I felt like I was moving too slowly.					
159. I felt fidgety.					
160. I wished I were dead.					
161. I wanted to hurt myself.					
	Not at all or less than 1 day	1 - 2 days	3 - 4 days	5 - 7 days	Nearly every day for 2 weeks
162. I was tired all the time.					

163. I did not like myself.					
164. I lost a lot of weight without trying to.					
165. I had a lot of trouble getting to sleep.					
166. I could not focus on the important things.					

I. ATTITUDES TOWARDS HEALTH CARE PROVIDERS (Bodenlos et al., 2004).

PROFESSIONALISM	Strongly Disagree	Disagree	Agree	Strongly Agree
167. I believe that my doctor and/or medical team are knowledgeable about HIV/AIDS.				
168. My doctor and/or medical team put an effort into my treatment.				
169. I believe my doctor and/or medical team is motivated to help me.				
170. My doctor and/or medical team care about my health.				

	Strongly Disagree	Disagree	Agree	Strongly Agree
171. I believe I receive the best available health care.				
172. My doctor and/or medical team are lazy.				
173. My doctor and/or medical team are knowledgeable about new HIV treatments.				
174. I believe that my doctor and/or medical team care about me.				
175. My doctor and/or medical team support me.				
176. My doctor and/or medical team encourage me.				
177. My doctor and/or medical team are helpful.				
178. My doctor and/or medical team make me feel comfortable.				
179. My doctor and/or medical team spend enough time with me.				
180. My doctor and/or medical team are sensitive to how I feel.				
181. My doctor and/or medical team think I am a bad person because I have HIV.				

	Strongly Disagree	Disagree	Agree	Strongly Agree
182. My doctor and/or medical team care about my opinion.				

183. I believe that my doctor and/or medical team see me as stupid.				
184. My doctor and/or medical team judge me.				

J. SOCIAL SUPPORT (Dandona et al., 2005; RAND Corporation, 1997)					
<i>Next, I would like to talk about the supports in your life. People sometimes look to others for companionship, assistance, or other types of support. How often were each of the following kinds of support available to you if you needed it during the past month?</i>					
	Always	Most of the time	Some-times	Rarely	Never
185. Someone to give you money if you needed it?					
186. Someone to help with daily chores if you were sick?					
187. Someone to love and make you feel wanted?					
188. Someone to go with you to the doctor?					
189. Someone to talk to with about your problems?					
190. Someone to offer you food or a place to stay?					

<p>193. How many close friends do you have with whom you feel at ease, can talk to about private matters, or can call on for help?</p>	<input type="checkbox"/> NONE <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3-4 <input type="checkbox"/> 5-8 <input type="checkbox"/> 9 OR MORE				
	<p>Less than once a month</p>	<p>About once a month</p>	<p>A few times a month</p>	<p>A few times a week</p>	<p>Every Day</p>
<p>191. How often do you see or hear from relatives?</p>					
<p>192. How often do you see or hear from close friends?</p>					

2. आन वतभष ान में हैदयाफाद /
हाँ सवार 3के लरए जायी

3. जो इराके में / नडोस यहते हो?

4. आन कैसे बती थ?े

नही अनात्र

Avagaahanaके भाधम से

NHP + के भाधम से

HOPES+ के भाधम से करवायी नयाभशष सभाज के

भाधम से

से येपयर के भाधम

से : _____ प्रततबागी येपयर

अन्म, तनददषष्ट कर्ये: _____

5. (बायतीम रुनए में) आनकी कुर भालसक आम क्मा है?

6. अतनी जातत क्मा है?

ब्राह्मण हैदयाफाद, बायत में एचआईवी करोक औय लरगो

पॉयवडष जातत

(जैसे वश् म / कोभटी, कम्मा, कान,ू येड्डी)

अ न सु थ ू च त ज ा त त

अनसु थू चत जनजातत /आददवासी वनछडा वगष - A

वनछडा वगष - B

वनछडा वगष - C

(ईसाई धभाषन्तरयत) वनछडा वगष - D

वनछडा वगष - E

अन्म, तनददषष्ट कर्ये: _____

7. आनका धभष क्मा है?

दहदो ू

भसु स्रम ईसाई लसख दहदो ू फौद्ध जैन

कोई धभष नही

अन्म तनददषष्ट: _____

8. आन न्यू ा कय लशा का उच्चतभ स्तय क्मा है?

कोई औत्तचारयक लशा प्राथलभक
भाध्मलभक डोटयभीडडएट व्मावसातमक प्रलशण
हैदयाफाद, बायत में एचआईवी करोक औय लरगो

स्नातक स्तय की नडाई स्नातकोत्तय

9. आन कहाँ यहते ह?ैं

खदु का घय /कॉरोनी में फ्रटै

खदु का घय/ फस्ती में / फ्रटै / स्रभ कॉरोनी में ककयाए नय भकान / फ्रटै

फस्ती में ककयाए घय / फ्रटै / स्रभ आवासीम छात्रावास

फेघय / सडक नय यहने वारे

अन्म, तनददषष्ट कयें: _____

10. आनकी भरु बाषा क्मा है?

दहन्दी

उदषू

तरे गु ू

अग्रो ेजी

अन्म, तनददषष्ट कयें: _____

हैदयाफाद, बायत में एचआईवी करोक औय लरगो

11. जो बाषा में आन फोरना सहज भहससू कयते ह?ैं

प्रतिबागी अमोग्म एक हहदो ी / उदू / िरे ेगु मा अग्रो जे ी फोरने में सहज नहीं है। आमोग्म

दहन्दी उदषू तरे गु ू अग्रो ेजी

अन्म तनददषष्ट: _____

12. आन एचआईवी के साथ का तनदान ककमा गमा है?

हाँ नहीं

13. अन्नको लरगो नहचान क्मा है?

नरु ष

भदहरा

दहजया ट्ाोसजेंडय नायी ट्ाोसजेंडय भनै

अन्म _____

नीचे तनशान त्रात्रिा

नात्र नहीप्रश्न:"दबु ाूग्म से,आत को योक करको तरयमोजना में शालभर होने के लरए नात्र नही हैं। आज के आतकी हदरचस्ती के लरए धन्मवाद!"योक नात्र "भहान, आत योक करको तरयमोजना में शालभर होने के लरए नात्र हैं। हभ आगे फढने से तहर,े हभे एक साथ कु छ तरयमोजना सहभति रूनों की सभींा कयने की जरूयि है। हभ इन रूनों को तढने के फाद आत को योक करको तरयमोजना में शालभर कयना चाहि हैं, मा नही िो आत िम कय सकि हैं। "

हैदयाफाद, बायत में एचआईवी करोक औय लरगो

[नूणू सहभति रूनों।] का सवेण शुरू कयि हैं। सवारों में से तहरा सेट अतने एचआईवी श्स्थति, लरगो तहचान औय काभुकि से सफो चो धि हैं।

B. एचआईवी,लरगो औयरचैंगकि

14. जफ आत तहरी फाय एचआईवी के साथ का तनदान ककमा गमा?

___ / ___ / ___

ददन भाह वषष

15. आत अतने एचआईवी सक्रो भण के कायण होने का क्मा ववश्वास कयते हो?

आदभी के साथ सेक्स

औयत के साथ सेक्स

औयत & आदभी दोनों के साथ सेक्स

एक दहजया / ट्ाोसजेंडय भदहरा के साथ सेक्स

डोजेक्शन नशीरी दवाऔ के प्रमोग

अन्म, तनददषष्ट कयें: _____

16. आत अतने वतभष ान लरगो के साथ की तहचान ककतना सभम तक की है?

ददनों

भहीने

वषों

N/A - कोई बी भेयी लरगो तहचान के फाये में तता है

17. आत वतभष ान में ककनके साथ सेक्स ककमा है? [रागू होने वारे सबी का चमन कयें]

तरूु षों भदहराओ

हैदयाफाद, बायत में एचआईवी करोक औय लरगो

दोनों तरूु षों औय भदहराओ दहजडो

ट्ाोसजेंडय भदहराओ ट्ाोसजेंडय तरूु षों

कोई नही

अन्म, तनददषष्ट कयें: _____

18. अत्तने जीवन भें, स्जनके साथ आत्तने कबी सक्के स ककमा है? [रागू होने वारे सबी का चमन कयें]

तरुु षों

भदहराओ

दोनों तरुु षों औय भदहराओ

दहजडो

ट्ाोसजेंडय भदहराओ ट्ाोसजेंडय तरुु षों कोई नहीं

अन्म, तनददषष्ट कयें: _____

19. क्मा आत्त अत्तने मौन अलबववन्मास ववचाय क्मा भानते हैं?

हेटेयोसेक्सअर / सीधे सभरथेंगक / सभरथेंगक सभरथेंगक

उबमलरगी

हैदयाफाद, बायत भें एचआईवी करोक औय लरगो

20. अत्तने ववै ादहक / साझेदायी स्थतत क्मा है?

कोई नहीं

अन्म, तनददषष्ट कयें: _____

आवववाह / कबी शादी ही नहीं वववादहत

जो साथी आत्त के साथ यहता है,

रेककन आत्त काननू ी तौय नय शादी नहीं ककए

बागीदायी रेककन एक साथ नहीं यहते अरग

तराकशदु ा

ववधवा

अगय वववाहहि / बागीदायी की, िो 21 सवार कयने के लरए आगे फड़ें।

अगय नहीं, िो 33सवार नय जाए।

21. मदद आत्त शादीशदु ा हैं / बागीदायी की, अत्तने साथी के लरगो क्मा है?

तरुु ष

भदहरा

दहजडो

ट्ाोसजेंडय भदहरा को

ट्ाोसजेंडय आदभी

अन्म _____

हैदयाफाद, बायत भें एचआईवी करोक औय लरगो

22. आन को एक मा एक से अथधक तनमलभत रूत से मौन सफो धो है?
23. आन को तनमलभत रूत से ककतने सेक्स मौन साझेदायों के है?
24. अतने साथी के फाने भे सोचते हुए ककसके साथ आन सफसे आथधक / तनयलभत फाय मनै सफो धो की, आनके साथी के लरगो क्या है ?
हाँ,केवर एक ही तनमलभत रूत से मौन साथी
सवार तय जाऐो
हाँ, तनमलभत रूत से कई मौन
साझेदायों
सवार के लरए आगे फढ़ना नहीं, नहीं तनमलभत रूत से मौन
साथी,कोई नही केवर आकस्सभक बागीदायों है
33सवार तय जाऐो
नहीं, भझु े सक्े स की जरूयत नहीं है 33सवार तय जाऐो
25. अतनके साथी क्मा एचआईवी के साथ जी यह है?
तरुु ष
भदहरा
दहजया /ट्ाोसजेंडय (एप एभ) ट्ाोसजेंडय आदमी(एभ एप) कोई नहीं
अन्म _____
हाँ नहीं
नहीं जानते
26. आन इस साथी के साथ को डोभ का उनमोग ककमा जाए
हभेशा
हैदयाफाद, बायत भें एचआईवी करोक औय लरगो
मा नहीं ककतनी फाय मह आनके तनमत्रो ण भें है?
अथधकोश सभम कबी कबी शामद ही कबी कबी नहीं
27. ककतनी फाय आन अतने साथी के साथ एचआईवी सेवाओं को प्राप्त कयते ह?ैं
हभेशा
अथधकोश सभम कबी कबी शामद ही कबी कबी नहीं
28. ककतनी फाय आन अतने साथी के बफना एचआईवी सेवाओं को प्राप्त कयते ह?ैं
हभेशा अथधकोश सभम कबी कबी शामद ही कबी कबी नहीं
29. आन अतने साथी के स्क्रतनक भें जाने के फाये भें तता है?
हाँ नहीं

30. ककतनी फाय अन्ने साथी एक थचककत्सा स्क्रतनक के लरए मा अन्म एचआईवी सवे ाओो को प्राप्त कयने के हभेशा

अथधकोश सभम कबी कबी शामद ही कबी कबी नहीं

लरए जाने से अनभु तत से इनकाय ककमा है?

31. ककतनी फाय आन ओ घय छोडने के लरए अन्ने साथी की अनभु तत की आवश्यकता होती है?

हभेशा

अथधकोश सभम

हैदयाफाद, बायत में एचआईवी करोक औय लरगो

कबी कबी शामद ही कबी कबी नहीं

32. ककतनी फाय आन थचककत्सा देखबार मा अन्म एचआईवी सेवाओो को प्राप्त कयने के लरए अन्ने नाटषनय की अनभु तत की जरूरत है?

हभेशा

अथधकोश सभम

कबी कबी शामद ही कबी कबी नहीं

33. मददआनकबीबीनसैेमादवाओोकेलरएसेक्सका आदान-प्रदान ककमा है?

हाँ, रेककन वनछरे एक सार में नहीं हो, वनछरे एक सार में

कबी नहीं

34. आन को तनम्न नरयवाय के सदस्मों है?

नतत / साथी भाँ

वनता

फडे बाई छोटे बाई फडी फहन

छोटी फहन फच्चे

चाची

चाचा चचेया

दादी

हैदयाफाद, बायत में एचआईवी करोक औय लरगो

दादाजी

अन्म, specify_____

35. स्जसे आन ककसके साठा अन्ने एचआईवी स्थतत का खरु ासा ककमा है?

नतत / साथी अतोतभ मौन साथी भाँ

वनता

फडे बाई

छोटे बाई
फडी फहन छोटी फहन फच्चे
चाची
चाचा
चचेया
दादी
दादाजी
अन्म रयशतदे ाय
लभत्र
सहकभी
अन्म, specify_____

36. आज ककसके साथ अत्ने वतभष ान लरगो न्हचान साझा ककमा है?
नतत / साथी अतोतभ मौन साथी भो
हैदयाफाद, बायत में एचआईवी करोक औय लरगो

वनता
फडे बाई छोटे बाई फडी फहन छोटी फहन
फच्चे
चाची
चाचा
चचेया
दादी
दादाजी अन्मरयशतदोय लभत्र
सहकभी
अन्म, तनददष्ट_____
हैदयाफाद, बायत में एचआईवी करोक औय लरगो
(रोगी एट अर।, 2012)

C.लरगो आवाकरको नभौन
प्रश्नों के अगरे सटे आज अत्ने लरगो न्हचान का एक नरयणाभ के रूत में नडा है अनुबवों से सफो थोधत है।
कथथत करको

37. ककतनी फाय आज सनु ा है कक एक के रूत में अत्ने लरगो न्हचान (प्रततबागी आजने वगष के लरमे चमन कय:
नरुु ष, औयत मा,
कबी नहीं
एक मा दो फाय

कई फाय

कई फाय

न यु े सभम

मा ट्ाोसजेंडय औयत / दहजया) नहीं है?

38. ककतनी फाय आन एक के रूत में अतने लरगो न्हचान भहससू ककमा है (प्रततबागी आतने वगष के लरमे चमन कय: नरुु ष, औयत मा, मा ट्ाोसजेंडय औयत / दहजया) चोट रगी है औय अतने नरयवाय को शलभदिं ा हुआ?

39. ककतनी फाय आन आन की न्हचान के साथ जो लरगो नहीं हैं कक नाटक कयने के लरए ककमा था, (प्रततबागी अतने वगष के लरए चमन कयें: आदभी, औयत, मा ट्ाोसजेंडय औयत / दहजया) क्रभ में स्वीकाय ककमा जाने कयने के लरए?

40. ककतनी फाय आन कपल्भ के दहट मा एक के रूत में अतने लरगो न्हचान के लरए तीटा गमा है (प्रततबागी अतने वगष के लरए चमन कयें: आदभी, औयत, मा ट्ाोसजेंडय औयत / दहजया)?

41. हैदयाफाद, बायत में एचआईवी करोक औय लरगो

अथधतनमलभत करको

कबी नहीं

एक मा दो फाय

कई फाय

कई फाय

न यु े स भ म

42. ककतनी फाय अतने नरयवाय अतने लरगो न्हचान की वजह से एक के रूत में आनको स्वीकाय नहीं ककमा है (प्रततबागी अतने वगष के लरए चमन कयें: आदभी, औयत, मा ट्ाोसजेंडय औयत / दहजया)?

ककतनी फाय आन अतने लरगो न्हचान के की की वजह से एक के रूत में अतने दोस्तों को खो ददमा है (प्रतत बागी आतने वगष के लरमे का चमन कयें: आदभी, औयत, मा ट्ाोसजेंडय औयत / दहजया)?

43. आन अतने लरगो न्हचान के लरए स्कूर से फाहय तनकार ददमा गमा है ककतनी फाय (प्रततबागी अतने वगष के लरए चमन कयें: आदभी, औयत, मा ट्ाोसजेंडय औयत / दहजया)?

44. ककतनी फाय आन एक के रूत में अतने लरगो न्हचान के लरए यहने के लरए एक जगह खो

ददमा है (प्रततबागी अतने वगष के लरए चमन कयें: आदभी, औयत, मा ट्ाोसजेंडय औयत / दहजया)?

45. ककतनी फाय आन, अतने लरगो न्हचान का एक के रूत में नौकयी मा कैरयमय अवसय खो ददमा है (प्रततबागी अतने वगष के लरए चमन कयें: आदभी, औयत, मा ट्ाोसजेंडय औयत / दहजया)?

46. ककतनी फाय आन एक रूत भे अतने लरगो न्हचान का का भजाक मा ककसी के नाभ से फरु ामा गमा है के (प्रततबागी अतने वगष के लरए चमन कर्ये: आदभी, औयत, मा ट्ाोसजेंडय औयत / दहजया)?
47. ककतनी फाय आन स्थकककों से नयहेज ककमा है मा ककोंकक एक के रूत भे अतने लरगो न्हचान की (प्रततबागी अतने वगष के लरए चमन कर्ये: आदभी, औयत, मा ट्ाोसजेंडय औयत / दहजया)?
48. ककतनी फाय आन एक के रूत भें अतने लरगो न्हचान के नरयवाय / साभास्जक सभायोहों से अतने आन को दयू कयते है (प्रततबागी अतने वगष के लरए चमन कर्ये: आदभी, औयत, मा ट्ाोसजेंडय औयत / दहजया)?
- D. थचककत्सा सवे ाओों के लरए डी न्होच (ककन्सरय एट अर।, 2007)
- सवार के अगरे सटे थचककत्सा सेवाओों तक न्होचने से सफो थो धत है। तनमनलरखखत फमानों भें से प्रत्मेक के लरए,आन दृढता से असहभत है, चहे असहभत,न तो इस फात से सहभत है औय न ही असहभत हैं,इस फात से सहभत मा दृढता से सहभत हैं कृत्नमा फताएो
- दृढानवू कू असहभि
असहभि ना िो सहभि ना ही असहभि
दृढानवू कू सहभि सहभि
हैदयाफाद, बायत भें एचआईवी करोक औय लरगो
49. भें जरूयत थचककत्सा देखबार के बफना कबी नही गमा है ककोंकक मह फहुत भहोगा है, ।
50. भें स्जन स्थनो नय थचककत्सा देखबार प्राप्त कय सकते हुो वह फहुत सवु वधाजनक स्थान नय स्थत हैं।
51. भद्दु े रगता है भद्दु े जफ बी जरूयत है थचककत्सा देखबार प्राप्त कयने भें संभ हों।
52. भद्दु े की जरूयत है कक थचककत्सा ववशषे ाोों के लरए आसान न्होच है।
53. भद्दु े एक आनात स्थतत भें थचककत्सा देखबार प्राप्त कयने के लरए मह आसान है।
54. भद्दु े अस्ततार देखबार की जरूयत है तो, भें ककसी बी भसु ीफत के बफना बती आसततार भे हो सकते हुो।
55. नरयवहन के भद्दु ो की वजह से भे थचककत्सा देखबार सेवाओों का उतमोग कयने भें असभथष है।
56. भें ककोंकक फच्चे की देखबार भें भद्दु ो की थचककत्सा देखबार सेवाओों का उतमोग कयने भें असभथष है।

65. वनछरे एक सार में थचककत्सा देखबार प्राप्त कयने के लरए अन्ने तीन मात्राओं का अनुभूतानत ततथथ व्मा कय यह थे?
66. वनछरे एक सार में ककतनी फाय आन एक भालरश थचककत्सक से उन्नचाय, हेम्मोन्नैथथक थचककत्सक, हाडवद्वै म, आमवु दे दक आयोग्म मा ककसी अन्म वकै स्ल्लक स्वास्म् देखबार थचककत्स प्राप्त ककमा?
67. वनछरे एक सार में ककतनी फाय आनको थचककत्सा सभस्माओं के साथ घय नय भदद लभरी?
68. वनछरे एक सार में ककतनी फाय आन एक भानलसक स्वास्म् प्रदाता का दौया ककमा? एक भनोथचककत्सक, भनोवाँैातनक, भनोयोगसाभास्जककामकषता, षभनोयोगनस, षमा नयाभशदष ाता के लरए ककसी बी दौया बी शालभर है।
69. वनछरे एक सार में ककतनी फाय आन इस तयह के एक गयै सयकायी सगो ठन में एक भाभरे प्रफधो क मा आउटयीच कामकषताषकेरुन्नमें, एकसाभास्जकसेवाप्रदाताकादौया ककमा?
70. वनछरे एक सार में, आन एक आवासीम दवा उन्नचाय कामक्रष भ में ककतनी यातों बफतामे ककमा?
71. वनछरे एक सार में ककतने ददन आन दवा मा अल्कोहर से सफो थोधत सभस्माओं के लरए एक आउट नशे ेन्ट कामक्रष भ में उन्नचाय प्राप्त ककमा?
72. आन ववश्वास कयते हैं एचआईवी दवाओं एचआईवी के इराज के लरए काभ कयते हैं कक? हाँ नहीं
73. आन वतभष ान में ककसी बी एचआईवी दवाओं रते हैं? हाँ नहीं
हाँ एक 77. सवार के जवाफ में जायी अगय कोई छोडेंएक79सवार कयने के लरए।
74. जफ आन एचआईवी दवाएो रेने कफ शरुु ककमा था?
___ ___ / ___ ___ / ___ ___ ___
हैदयाफाद, बायत में एचआईवी करोक औय लरगो
75. ज्मादातय ववयोधी एचआईवी दवाओं जैसे कक ददन में "2 फाय एक " मा "ददन में 3फाय" मा "हय 8घटो े" में, एक सभम नय उठाए जाने की जरूयत है। फायीकी से कैसे आन वनछरे चाय ददनों में अन्ने ववलशष्ट अनसु चू ी का नारन ककमा?
हभेशा
सभम के अथघकोश
कबी-कबी शामद ही कबी
कबी

76. वनछरे 30 ददनों में, ककतने ददन आन अनने एचआईवी दवाओं के ककसी बी कभ से कभ एक खयु ाक माद आती है?

77. वनछरे 30 ददनों में, ककतना अच्छा एक काम आन कयने वारे थे यास्ते में अनने एचआईवी दवाएो रेने मेंचादहम?े
फहुत गयीफ दरयद्र
भेरा
अच्छा
फहुत अच्छा उत्कृष्ट

78. जफ आन अननी दवाओं के ककसी बी माद वनछरी फाय आनचकु गमाथा?
वनछरे सप्ताह के बीतय 1-2 सप्ताह नहरे
2-4 सप्ताह नहरे
1-3 महीने नहरे
अथधक से अथधक 3 महीने नहरे दवाओं को छोड कबी नही

79. अनके सफसे हार ही सीडी 4 थगनती क्मा है?
नही जानते
हैदयाफाद, बायत में एचआईवी करोक औय लरगो

80. आनके सफसे हार ही वामयर रोड क्मा है?
नता रगने मे असबो ग्र _____ प्रततमो / एमएर नही जानते

81. ककतनी फाय आन एसई एक स्वास्म देखबारप्रदाताके लरए अनने एचआईवी स्थतत को खरु ासा है?
हभेशा
अथधकोश सभम
कबी-कबी शामद ही कबी कबी नही

82. ककतनी फाय आन इराज से वथोचत कय ददमा गमा है, क्मोंकक आन एचआईवी नॉस्जदटव थ?े
हभेशा
अथधकोश सभम
कबी-कबी शामद ही कबी कबी नही

83. औय कौन आन को रगता है कक एचआईवी के साथ जी
जीवनसाथी / साथी अतोतभ मौन साथी भाँ
वनता
दोस्त

यहा है क्या जानते हो?

हैदयाफाद, बायत में एचआईवी करोक औय लरगो

सहकभी

एनजीओकामकषताष

अन्म रयशतदे ाय, तनददषष्ट _ _____ अन्म तनददषष्ट _ _____

84. हभ सबी डॉक्टयों औय अन्म स्वास्म् नेशवे यों से वनछरे 6 भहीनों में अतने सबी स्वास्म् देखबार की अतनी येदटगो में जानना चाहते हैं। 0 से 10 के नौभने नय ककसी बी सोख्म का उनमोय कयते है, जहाँ 0 सफस ् खवाफ स्वास्म् की के लरमे सबो व है औय 10 सबो व सफसे अच्छा देखबार दय होगा?

सफसे ज्मादा सबो व देिबार के लरए सवोत्तभ सबो व देिबार

0 1 2 3 4 5 6 7 8 9 10

हैदयाफाद, बायत में एचआईवी करोक औय लरगो

85. औसत नय,मह थचककत्सा केंद्र मा स्क्रतनक को नाने के लरए आनको ककतना सभम रगता है ?

कभ 15लभनट से कभ 15-30 लभनट

31-45 लभनट

46-60 लभनट

1 2 घ टो े

2 - 3 घ टो े

3घटो े से अथधक

86. इस थचककत्सा केंद्र मा स्क्रतनक को नाने के फाद,आभ तौय नय आन एक स्जस व्मस्वत्त के साथ देखने के लरए आनको ककतने सभम तक तनमसुु व्त की उन्हे झोतजाय कयना नडता है?

कभ 15लभनट से कभ 15-30 लभनट

31-45 लभनट

46-60 लभनट

1 2 घ टो े

2 - 3 घ टो े

3घटो े से अथधक

87. तभु फीभाय हो औय अगय आन इस थचककत्सा केंद्र मा स्क्रतनक में ककसी बी तनमसुु व्त से नहरे देखा जाना जरुयत चादहए, मदद आन ककसी अन्म तनमसुु व्त नाने के लरए कफ तक इसे रे कयता है?

2ददन मा उससे कभ

3ददन से एक सप्ताह के लरए 1-2 सप्ताह

3-4 सप्ताह

4 सप्ताह से अथधक

88. साभान्म तौय नय, आन भदहराओ थचककत्सा सेदटगो में नरुुषोंकीतरुनाभेंइराजकययहेहैंआनकमाभहससू कयतेहैं?
फहुत फयु ा हल्का फहतय एक जैसा फेहतय
हैदयाफाद, बायत में एचआईवी करोक औय लरगो
ज्मादा फेहतय

89. साभान्म तौय नय, आनको रगता है कक दहजया / ट्ाोसजेंडय भदहराओ थचककत्सा सेदटगो में नरुुषों की तरु
ना भें इराज कय यहें हैं आन कमा भहससू कयते हैं?
फहुत फयु ा हल्का फहतय एक जैसा फेहतय
ज्मादा फेहतय

90. साभान्म में,आन कैसे दहजया/ट्ाोसजेंडय भदहराओ थचककत्सा सेदटगो में भदहराओ आन तरु ना भें इराज कय
यहे हैं कक कमा भहससू कयते ह?ैं
फहुत फयु ा हल्का फहतय एक जैसा फेहतय
ज्मादा फेहतय

91. ववशषे रून्न स,े कैसे आन एचआईवी सकीरुभक भदहराओ की थचककत्सा सेदटगो में एचआई वी सकायात्मक नरुु
षों की तरु ना भें इराज कय यहें हैं आन कमा भहससू कयते हैं?
फहुत फयु ा हल्का फहतय एक जैसा फेहतय
ज्मादा फेहतय

92. ववशषे रून्न से एचआईवी सकीरुभक दहजया / ट्ाोसजेंडय
फहुत फयु ा
भदहराओ की थचककत्सा सेद टगो में एचआईवी सकीरुभक नरुुषों की तरु ना भें इराज कय यहें हैं कक कमा भहससू
कयते ह?ैं
हल्का फहतय एक जैसा फेहतय
ज्मादा फेहतय
हैदयाफाद, बायत में एचआईवी करोक औय लरगो

93. ववशषे रून्न स,े कै से आन एचआईवी नॉस्जदटव hijras / ट्ाोसजेंडय भदहराओ थचककत्सा सेदटगो में
एचआईवी नॉस्जदटव भदहराओ की तरु ना भें इराज कय यहें हैं कक कमा भहससू कयते ह?ैं
फहुत फयु ा हल्का फहतय एक जैसा फेहतय
ज्मादा फेहतय

94. ककतनी फाय आन धालभकष गततववथधमों से फाहय यखा गमा
हभेशा अथधकोश समम
कबी-कबी शामद ही कबी कबी नही है?

95. आन अतने तरयवाय आन में अरग तयह से व्मवहाय ककमा है मा आन को फाहय यखा गमा है,ककतने फाय आन एसा भहससू ककमा है?

हभेशा अथधकोश सभम
कबी-कबी शामद ही कबी
कबी नही

96. ककतनी फाय आन क्मोंकक अतने एचआईवी स्थतत की वजह से एक नौकयी मा काम कयने का अवसय खो ददमा है?

हभेशा अथधकोश सभम
कबी-कबी शामद ही कबी
हैदयाफाद, बायत में एचआईवी करोक औय लरगो

अफ हभ एचआईवी करको के साथ अतने अनुबवों के फाये में आन से नूछना है। तनमनलरखखत फमानों में से प्रत्मेक के लरए,आन दृढता से असहभत है मह असहभत,न तो इस फात से सहभत है औय न ही असहभत हैं, इस फात से सहभत मा दृढता से सहभत हैं कृत्तमा फताएो कक क्मा।

कबी नही

97. मदद आन एक तरयवाय के रूत्त में बोजन खाते ह,ैं जो आभ तौय तय तहरी फाय खाना तयोसा ककसे जाता है? में अतने तरयवाय के साथ नही खाता। भेया तरयवाय नही है।

में अकेरा खाता हो।

कोई बी तहरी फाय ककमा नही जाता। सफ हय एक ही सभम में बोजन खते है।

आन

अतने तरुु ष जीवनसाथी

अतनी भदहरा जीवनसाथी

अतने तरुु ष फच्चे

अतने भदहरा फच्चे

अतने वनता

अतने भो

अन्म फडे तरुु ष रयशतदे ाय, तनददषष्ट कयें: _____

अन्म छोटे तरुु ष रयशतदे ाय, तनददषष्ट कयें: _____

अन्म फडी भदहरा रयशतदे ाय, तनददषष्ट _____

अन्म फडी भदहरा रयशतदे ाय, तनददषष्ट _____

अन्म तनददषष्ट: _____

एप करको : एचआईवी करको तरयभान (Zelaya et al., 2008)

हैदयाफाद, बायत में एचआईवी करोक औय लरगो

स्केर 1:स्व (बाताँत) करको

दृढ़ितवू कू असहभि
असहभि
ना िो
सहभि ना ही असहभि
सहभि
दृढ़ितवू कू सहभि

98. भङ्गु े डय है मा में थचतो है कक ककसी नय खॉसी मा
छ ोक तो उससे एचआईवी / एड्स उन्हें सक्रो लभत हो सकता है कक थचतो ा।

99. में अतने भर मा भत्रू केसन्नोकषमें,जोएकव्मस्क्त को एचआईवी / एड्स पैर सकता है मह फात सु भङ्गु े डय रगता है।

100. भनै े सोचा कक में आनने नरयवाय रोगों के साथ बोजन में दहस्सा है, तो में अतने नरयवाय वारो को लरए एचआईवी
/ एड्स पैर सकता हॉमहफातकाभङ्गु े डय रगता है।

101. जफ में अतने एचआईवी सक्रो भण के फाये में सोचता हॉ,ो तो में घखृ णत भहससू कयते हॉ।ो

102. भङ्गोु े रग यहा है एचआईवी / एड्स भये अतीत के फयु े व्मवहाय के लरए दोड है।

103. भङ्गु े रग यहा है में एक अच्छा न्माषप्त व्मस्क्त नहीं था इसलसमे में एचआईवी / एड्स से सक्रो लभत हॉ कक रग
यहा है।
हैदयाफाद, बायत में एचआईवी करोक औय लरगो

104. भनै े सोचा कक में ककसी क ो ब ी भ ङ्गु े द े ख त े ह ैंं द सू य ोंं स े अरग-थरग यहना है, औय
नहीं होना चादहए कक रग यहा है।

105. में में अतने नरयवाय के रून्न में एक ही घय में नहीं यहना चादहए कक रग यहा है।

हैदयाफाद, बायत में एचआईवी करोक औय लरगो

नयीभान 2: अनबु वी (अथघतनमलभत) करको

दृढ़ितवू ू क असहभि

असहभि

ना िो सहभि ना ही असहभि

सहभि

दृढ़ितवू कू सहभि

106. भेये समदु ाम में रोग उन रोगों से दयू यहने के लरए भड्डु े फतामा है, ताकी एचआईवी / ए ड् स से आ न फु धो य ह ी ह ै ।

107. रोगों को को डय है कक में उनके नास खॉसी था छ ोका तो मदद वे एचआईवी / एड्स के अनफुधो होगा।

108. एचआईवी / एड्स सचो ारयत भाभरे में भेया नरयवाय औय तडोलसमों ने भये े उन्हें अन्ने फच्चों की देखबार कयने के लरए डय यहे हैं।

109. स्जन रोगोंको भे जानता हूँ वे रोग भड्डु े भड्डु े फतामा कक अवधे औय अनतैतक गततववधमों में बाग लरमा है, इसलरमे भड्डे एचआईवी / एड्स है।

110. मैं एचआईवी / एड्स से सक्रो लभत था कक नता चरा के फाद भड्डु े नता नही कयना चाहने के फाद , भेये लभत्र , आान व्मबत्र जेसे देखना था।

111. भेये नहचान वारे रोग भड्डु े फतामा कक भे नता है रोगों को मैं शावन्नत हूँ औय मैं एचआईवी/ एड्स है है।

112. रोगों ने भड्डु े फतामा कक मैं फतामा कक मैं औय मैं इसी वजह से भड्डु े एचआईवी / एड्स है।
स्केर 3:कथथत करको

113. मैं कु छ रोगों को अन्ने एचआईवी / एड्स स्थतत का खरु ासा कयता हॉ, तो वे सक्रो लभत हो जाएगा भाभरे में भेये नास आने से डय उन्हे रग यहा है।
हैदयाफाद, बायत में एचआईवी करोक औय लरगो

114. मैं कु छ रोगों को अन्ने एचआईवी / एड्स स्थतत का खरु ासा कयता हॉ, तो वे अन्ने फच्चों को भेये नास फजन के लरए डय होगा कक रग यहा है।

दृढिनवू कू असहभि

असहभि

ना िो सहभि ना ही असहभि

सहभि

दृढिनवू कू सहभि

115. मैं कु छ रोगों को अन्ने एचआईवी / एड्स स्थतत का खरु ासा कयता हॉ, तो वे सोचते है कक मैं अवधे औय अनतैतक गततववधमों में बाग लरमा हॉ।

116. मैं कु छ रोगों को अन्ने एचआईवी / एड्स स्थतत का खरु ासा कयता है, तो वे सोचते है कक मैं शावन्नत हॉ।

117. अन्ने एचआईवी / एड्स स्थतत में जाना गमा है, तो मैं दहसो ा के साथ धभकी दी जाएगी।

118. अन्ने एचआईवी / एड्स स्थितत जाना गमा है, तो भेये साथी येथगस्तान होग।
119. अन्ने एचआईवी / एड्स स्थितत में जाना गमा, तो भेया नरयवाय हमेशा की तयह नरयवाय की गततववथधमों से भड्डु े फाहय कयते है। जी फजयष एचआईवी करको स्के र Jeyaseelan का सौ ेनण (Jeyaseelan एट अर।, 2013)
120. भेये कहा भजददक रोग डयते है कक भेये एचआईवी है कक ांत हो जाता हमतो दसू यों भड्डु े अस्वीकाय कय देंग। े
121. भेये कहा भजददक रोग डयते है कक भेये नजदीक कु छ रोग इसे में एचआईवी हम कक ांत हो जाता है, तो डय दसू यों भड्डु े अस्वीकाय कय देंगे
हैदयाफाद, बायत में एचआईवी करोक औय लरगो
122. रोगों को वे भड्डु े एचआईवी है जानने के लरए जफ शायीरयक भड्डु से दयू हट गए हैं।
123. में एचआईवी है जो रोग जानते हैं भेये अच्छे अको की अनदेखी कयते हैं।
124. वे में एचआईवी नता है कक एक फाय कुछ रोगों ने भड्डु े छूने से फचें।
दृढ़ितवू कू असहमि
असहमि
ना िो सहमि सहमि
ना ही
असहमि
दृढ़ितवू कू सहमि
125. में अन्ने एचआईवी होने के प्रतत उनकी प्रततकक्रमाओं से कुछ रोगों के साथ साभास्जक फदो कय ददमा है।
126. जफ रोगों को भेये एचआईवी के फाद में
फदो कय ददमा फरु ा देखबार के फाये में एचआईवी है।
127. भड्डु े एचआईवी है एक फाय जानने के लरए एक फाय रोग भड्डु से डयते रग यहें हैं।
128. भड्डु े में एचआईवी है सीखने के फाद रोग कैसे प्रततकक्रमा व्मक्त कय घामर से ददमा गमा है।
129. एकफायजफरोगजानतेहैककभड्डु ेहै वे आन्ने फच्चों के आस नास भड्डु े देखना नही चाहते हैं।

130. भङ्गु े एचआईवी है फता कय भनै े दोस्तों को खो ददमा है।
131. भङ्गु े एचआईवी है नता चरने के फाद क ु छ र ोग भ ङ्गु े से अ थ ध क द य ू ह ोग ए ह ैं ।
132. एचआईवी होने कानण भङ्गु े अशदु ध
हैदयाफाद, बायत में एचआईवी करोक औय लरगो
भहससू होता है।
133. एचआईवी भङ्गु े में भा फयु ा व्मस्क्त को रगता है कक भै फनु ा व्मस्क्त हॉ।
134. एचआईवी के फाये में रोगों के नजरयए भङ्गु े भयेफायेभैफयुारगयहा है।
135. भनै े सोचाककभैदसू योंके रून्भैएक अच्छा व्मस्क्त नहीं हॉ क्मोंकक भङ्गु े एचआईवी है, भङ्गु े एसा रग यहा है।
136. भङ्गु े भै एचआईवी है मह भेयी गरती है के रून् में कु छ रोग हाराको क काम कयते हैं।
हैदयाफाद, बायत में एचआईवी करोक औय लरगो
दृढ़ितवू कू असहभि
असहभि
ना िो सहभि ना ही असहभि
सहभि
दृढ़ितवू कू सहभि
137. भङ्गु े एचआईवी है सीखने के फाद स,े में अरग सेट औय दतु नमा के फाकी दहस्सों से अरग-थरग भहससू हो यहा हॉ।
138. अथधकोश रोगों का ववखास है कक स्जन
को एचआईवी वह एक व्मस्क्त गदो ा है।
139. जफ दसू यों को रगता है जफ एचआईवी के साथ अथधकोश रोगों को खारयज कय यहें हैं।
140. तनमोक्ताओं के फाहय एचआईवी के साथ रोगों अननी नौकयी खो देते हैं जफ उनके तनमोक्त ओको नता रगता है।
141. अथधकोश रोगों को एचआईवी के साथ वनडडत एक व्मस्क्त को घखृ णत रगता है।
142. भनै े सोचा कक भै एचआईवी है कक इस त्म को तछनाने की जरूयत भहससू कबी नहीं।
143. भङ्गु े थचतो है कक जो रोगें जानते है कक भङ्गु े एचआईवी है दसू यों को मह फत फतात है होगा कक थचतो ा।

144. मझुेआपसोसहैककभनेकुछरोगो
को फतमा कक एचआईवी है।

145. मझुेरगताहैतजफसीखतेहैककमझुे एचआईवी है जानने के फाद रोग भये फाये में पैसरा कय सकते है इस फात
की थचतो ा है।

हैदयाफाद, बायत में एचआईवी करोक औय लरगो

महाभायीववानकेअधमनडडप्रेसननरयभानकेलरएएचकेंद्र-सशौथधत(CESD-आय) (ईटन एट अर।, 2004)

अफ में वनछरे सप्ताह में व्यवहाय ककमा गमा हो सकता है मा तभु महससू ककमा तयीकों की एक सचूी की समींा
कर्येंगे। आन वनछरे सप्ताह में इस तयह से महससू ककमा है कक ककतनी फाय का उलेख कर्यें: बफल्कुर नही मा 1 ददन
से कभ वनछरे सप्ताह में 1-2 ददन, 3-4 ददनों, 5-7 ददनों के लरए, मा 2 सप्ताह के लरए रगबग हय ददन है।

बफल्कुर नही मा कभ से कभ 1हदन

फायह हदन

3-4हदनों 5-7हदनों

2सप्िाह के लरए रगबग हय ददन

146. वनछरे हफते भयेी बखू गयीफ था।

147. में उदास दहरा नही सकता था।

148. मनैे सोचा कक में क्मा कय यहा

149. था इस तय भये भन यखने भे नयेशानी थी।

150. में उदास महससू ककमा। भेयी नीद फेचैन था।

151. म झुे फ यु ा र ग ा ।

152. में जा यहा प्राप्त नही कय सकता।

153. मझुे कुछ नही खशु कय ददमा।

154. में महससू ककमा कक में एक फयु ा व्मस्क्त हॉ ।

155. में अतनी साभान्म गततववधधमों में रुथच खो ददमा था।

156. में हभेशा ज्मादा से ज्मादा सो जाता था।

157. मझुे मह महससू आगे फड हुआ

हैदयाफाद, बायत में एचआईवी करोक औय लरगो

कक थधये - थधये वह यहा था ।

158. में फेचैन महससू ककमा।

159. मनैेसोचाककभैभयचकुाथा मह भै काभना कहता हॉ।

हैदयाफाद, बायत में एचआईवी करोक औय लरगो

बफल्कुर नही मा कभ से कभ 1हदन

फायह हदन

3-4 हदनों

5-7 हदनों

2 सप्तिह के लरए रगबग हय हदन

160. में अन्ने आन को चोट न्होचना चाहता था।

161. में हय सभम थक गमा था।

162. में अन्ने आन को नसदो नही आमा।

163. में ककसी कोलशश कय के बफना भये वजन फहुत कुछ खो ददमा था।

164. भङ्ग े सोने के लरए फहुत नयेशानी हो यहा था।

165. में भहत्वनणू ष फातों नय ध्यान कें दद्रत नही कय सका।

स्वास्म सेवा प्रदाताओं की ओय आई नजरयए (Bodenlos एट अर।, 2004)।

अफ हभ आन को स्वास्म देखबार प्रदान की है, जो रोगों की ओय नजरयए नय चचाष कर्येंगे। तनमनलरखखत फमानों में से प्रत्मेक के लरए, आन दृढता से असहमत है असहमत, न तो इस फात से सहमत है औय न ही असहमत हैं, इस फात से सहमत मा दृढता से सहमत हैं कृनमा फताएो ।

व्यावसातमकता

दृढितनवू कू असहभि

असहभि

ना िो सहभि ना ही असहभि

सहभि

दृढितनवू कू सहभि

166. में भानते हैं कक नने डॉक्टय औय / मा थचककत्सा टीभ एचआईवी / एड्स के फाये में जानकायी है ।

167. भये डॉक्टय औय / मा थचककत्सा दर को भये इराज में एक प्रमास डार ददमा।

हैदयाफाद, बायत में एचआईवी करोक औय लरगो

168. भेना ववशवास है कक भये डॉक्टय औय / मा थचककत्सा टीभ भेयी भदद कयने के लरए प्रेरयत ककमा है।

169. भये डॉक्टय औय / मा भये थचककत्सा दर भये स्वास्म का देखबार कयता है।

170. भेया ववशवास है कक भये डॉक्टय औय / मा थचककत्सा दर को एचआईवी दवाओं के फाये में फहुत कुछ नता हैं।

दृढितनवू कष असहमत

असहमत

ना तो सहमत ना ही असहमत

सहमत

दृढितनवू कष सहमत

171. भङ्गो े ववश्वास हैं कक में सफसे अच्छा स्वास्म् देखबार प्राप्त कयता हॉ ।
172. भेये डॉक्टय औय / मा थचककत्सा टीभ आरसी हैं।
173. भेये डॉक्टय औय / मा थचककत्सा दर को नए एचआईवी उनचाय के फाये में जानकायी हैं।
बावनात्मक सहाया
174. भेया ववश्वास है कक भेये डॉक्टय औय / मा थचककत्सा दर भेये फने में देखबार कयते है कक।
175. भेये डॉक्टय औय / मा थचककत्सा दर भङ्गु े सभथनष कयते हैं।
176. भेये डॉक्टय औय / मा थचककत्सा दर भङ्गु े प्रोत्सादहत कयते हैं।
हैदयाफाद, बायत में एचआईवी करोक औय लरगो
177. भेये डॉक्टय औय / मा थचककत्सा दर में सहामक होते हैं।
178. भेये डॉक्टय औय / मा थचककत्सा दर भङ्गु े सवु धाजनक भहससू कयाते हैं।
179. भेये डॉक्टय औय / मा थचककत्सा टीभ भेये साथ कापी बफताते हैं।
180. भेये डॉक्टय औय / मा थचककत्सा दर में कै से भहससु कयता हॉ प्रतत सवो ेदनशीर हैं।
181. भेये डॉक्टय औय / मा थचककत्सा टीभ में फयु ा व्मस्क्त हॉ क्मो कक भङ्गु े एचआईवी है क्मोंकक।
182. भेये डॉक्टय औय / मा भेये थचककत्सा दर भेये याम के फाये में देखबार कयते है।
दृढितवू कू असहभि
असहभि
ना िो सहभि ना ही असहभि
सहभि
दृढितवू कू सहभि
183. में अन्ने डॉक्टय औय / मा थचककत्सा दर फ े व क ू प क े रु न भ े ं भ ङ्गु े द े ख त े ह ै ।
184. भेये डॉक्टय औय / मा थचककत्सा दर भेये फाये में पैसरा कयते है।
हैदयाफाद, बायत में एचआईवी करोक औय लरगो

जे साभास्जक सभथनष (Dandona एट अर, 2005;। यैंड कॉन्तोयेशन, 1997) ो अगरे में अन्के जीवन में सभथनष के फाये में फात कयना चाहता हॉ। कबी कबी रोगो को बाईचाया, सहामता,मा सभथन के अन्म प्रकार्यों की सहामता के लरए दसू यों के लरए रग यही है। आन वनछरे एक भहीने के दौयान मह आवश्यक है,तो ककतनी फाय आन के लरए उन्नरब्ध सभथनष के तनम्न प्रकारय से प्रत्मेक था?

अचधकिय सभम

कबी कबी

सदैव

शामद ही कबी

कबी नहीं

185. आगय आन को जरुयत है ते ककसी नेतमुहेतसैदेतेहै?

186. आन फीभाय थ,े तो ककसी ने दैतनक कामकाज के साथ भदद कयने है?

187. ककसी को प्पाय कयने के लरग औय भहससू कयना चाहते थे?

188. डॉक्टय के नास कोई आनके साथ जाते थ?े

189. कोई आनके सभस्मा के फाये में फात कयते थ?े

190. ककसी ने तमु हैं बोजन की मा यहन् की एक जगह का नेशकश ककया था?

एक फाय एक

भहीने में कयीफ

कई फाय एक

सप्िाह के कुछ सभम

हय हदन

भहीने से बी कभ

एक फाय

भहीने

191. ककिनी फाय आन आनने रयश्िदे ायों से देि यहे हो मा सनु यहे हो?

192. ककिनी फाय आन आनने कयीफी दोस्ि से देि यहे हो मा सनु े यहे हो?

193. आनके ककिने कयीफी दोस्िों हैं शजनके

साथ आत सहज भहससू कय सकि हैं, शजसे तनजी
कोई नही हैदयाफाद, बायत में एचआईवी करोक औय लरगो
भाभरों के फाये में फाि कय सकि हैं मा भदद के लरएफरु सकिह?ैं

1

2

3-4

5-8

9 मा अथघक

APPENDIX C: SEMI-STRUCTURED INTERVIEW GUIDE - ENGLISH

Thank you for taking the time to participate in our study. I will be asking you some questions regarding your life experiences. Many of these questions pertain to personal and sensitive issues. Please feel free to let me know if you do not want to answer a question or if you want to stop the interview altogether.

My first set of questions is about gender and how gender impacts our experiences in society.

Gender Roles

How do you identify your gender?

In your opinion, what is the role of men in Indian society?

What is the role of women in Indian society?

What is the role of hijras/transgender women in Indian society?

As a [man, woman, hijra/transgender woman], what do you think of your roles in Indian society?

How do you feel about performing these roles?

What is easy about performing these roles? (doing X or Y, *use their words*)?

What is difficult about performing these roles (doing X or Y, *use their words*)?

Tell me about a time when you felt stressed or conflicted about having to perform these roles.

How have you managed instances where you felt you were unable to perform the roles that were expected of your gender?

In your home, how are decisions regarding money and finances made?

In your home, how are decisions regarding health care made?

In your home, how are decisions regarding having sex made?

I am now going to ask you some questions about being a (man/woman/transgender woman).

Gender Nonconformity Stigma

How has your gender identity (i.e. being a man, a woman, or a transgender woman) influenced your interactions with others?

How do you express your gender identity on a typical day?

Have you been able to express your gender identity freely?

How has being a (man/woman/transgender woman) influenced your experience of living with HIV?

How do you think it would be different if you were not a (man/woman/transgender woman)?

My next set of questions are about your HIV diagnosis.

Experiences with Being Diagnosed with HIV

When and how were you first diagnosed with HIV?

How did you feel about receiving your HIV diagnosis?
How do you feel about living with HIV now?

Next, we will be discussing what your experiences have been in disclosing your HIV status to other people.

Disclosure

With whom have you disclosed or not disclosed your HIV status? Why?
Why might you not want to share your HIV status with particular people?

Now I would like to discuss your experiences with living with HIV.

Experiences with Internalized HIV Stigma

How do you currently feel about living with HIV?
What makes you feel this way?

Experiences with Perceived Stigma

What do people in your community think about people who are HIV positive?
What is the stereotype of someone who is HIV positive?
In your opinion, how are men living with HIV treated by society in comparison to women living with HIV?
How are transgender women living with HIV treated by society in comparison to others?
How do you think perceptions about people living with HIV are different outside of India?

Experiences with Enacted Stigma

How have people treated you differently after knowing your HIV status?
Please tell me about a time when someone treated you differently after learning that you were HIV positive.

Now I would like to discuss issues regarding mental health.

Depression

Tell me about how having HIV has impacted your mental health.
Tell me about times in your life when you have felt sad or depressed for two or more weeks.
Describe any instances where you have thought about or attempted suicide.

The next set of questions is about your experiences with caste, poverty, and religion.

Caste, Poverty & Religion

What caste do you belong to?
How has your caste affected your experience of living with HIV and accessing HIV services?

Please tell me about a specific time in which your caste affected your ability to access HIV medical care.

How has poverty affected your experience of living with HIV?
How has religion impacted your experience of living with HIV?

The final set of questions pertains to using medical services.

Utilizing Medical Care

What has been your experience in receiving medical care for HIV?
How have medical staff treated you in hospitals or other clinical settings?
What are the major obstacles you have experienced in being able to receive medical care services?

Thank you so much for your time. [Provide incentive to participant.]

APPENDIX D: SEMI-STRUCTURED INTERVIEW GUIDE - TELUGU

పాక్షికంగా నిర్మితమైన ఇంటర్వ్యూ మార్గదర్శకాలు

మా అధ్యయనములో పాల్గొంటున్నందుకు వందనాలు. మీ జీవిత అనుభవాల గూర్చి నేను మిమ్మల్ని కొన్ని ప్రశ్నలు అడుగుతాను. ఇందులో చాలా ప్రశ్నలు మీ వ్యక్తగత మరియు సున్నితమైన సమస్యలకు సంబంధించినవి. ఒకవేళ మీకు సమాధానము ఇవ్వడం ఇష్టము లేకపోతే దయచేసి మాకు తెలియజేయండి లేక మీకు మధ్య ఆపేయాలనిపించిన కూడా దయచేసి మాకు తెలపండి

నా మొదటి ప్రశ్నలు లింగము గురించి మరియు అది సమాజములోని మన అనుభవాలను ఏ విధముగా ప్రభావితము చూపుతుందోనని తెలుపేవి

లింగము దాని పాత్రలు

మీ లింగమును మీరు ఏవిధంగా గుర్తిస్తారు?

భారతదేశ సమాజములో మగవారి పాత్ర గూర్చి మీ అభిప్రాయము ఏమిటి?

భారతదేశ సమాజములో స్త్రీ పాత్ర గూర్చి మీ అభిప్రాయము ఏమిటి?

భారతదేశ సమాజములో హిజ్రా/ స్వలింగ సంపర్కుల పాత్ర గూర్చి మీ అభిప్రాయము ఏమిటి?

ఒక [మగవాడిగా, స్వలింగ సంపర్కుగా, స్త్రీ గా], భారతదేశ సమాజములో వారి పాత్ర గూర్చి మీ అభిప్రాయము ఏమిటి?

మీ పాత్రలను పోషిస్తున్నప్పుడు మీరు ఏ విధంగా భావిస్తారు?

ఈ పాత్రలను పోషిస్తున్నప్పుడు ఏ పాత్ర సులువైనది? (X or Y, పాత్ర చేస్తున్నప్పుడు వారి మాటలను వాడండి)?

ఈ పాత్రలను పోషిస్తున్నప్పుడు ఏ పాత్ర కష్టమైనది? (X or Y, పాత్ర చేస్తున్నప్పుడు వారి మాటలను వాడండి)?

మీరు ఈ పాత్రలను పోషిస్తున్నప్పుడు ఒత్తిడికి లేక పోట్లాట గురియైన సందర్భాలు చెప్పండి.

మీరు అనుకున్న విధంగా ఈ పాత్రలను పోషించ లేకపోయినప్పుడు మీరు ఏ విధంగా ఆ పాత్రలను నిర్వహించారు?

మీ ఇంట్లో, డబ్బు మరియు ఆర్థిక విషయాలపై నిర్ణయాలు ఎలా జరుగుతాయి?

మీ ఇంట్లో, ఆరోగ్య సంరక్షణ పై నిర్ణయాలు ఎలా జరుగుతాయి?

మీ ఇంట్లో, లైగింగ్ చర్యల గూర్చి నిర్ణయాలు ఎలా జరుగుతాయి?

నేను ఇప్పుడు మిమ్మల్ని ఒక మగవారిగా/ స్త్రీగా/ స్వలింగ సంయ్యులుగా గూర్చి కొన్ని ప్రశ్నలు అడుగుతాను

నిర్ధారణించ లేని లింగ పై గల కళంకము

ఇతరులతో మాట్లాడుచున్నప్పుడు మీ ఏవిధంగా లింగము గుర్తిస్తారు (అనగా మగవారిగా, స్త్రీగా లేక స్వలింగ సంపర్కిగా) ?

ఒక ప్రత్యేకమైన రోజు మీ లింగ గుర్తింపును మీరు ఏవిధంగా చెబుతారు / వ్యక్త పరుస్తారు?

మీరు మీ లింగ గుర్తింపును స్వేచ్ఛగా వ్యక్త పరుస్తారా/చెబుతారా?

మీరు హెచ్ఐవితో జీవిస్తున్నప్పుడు కలిగిన అనుభవాలపై ఒక మగవారిగా/స్త్రీగా / లేక స్వలింగ సంపర్కిగా ఏమైనా ప్రభావం పడిందా?

మీరు మగవారు/ స్త్రీ/ స్వలింగ సంపర్కుల కాకపోతే మీరు ఏవిధంగా ఉండేవారని అనుకుంటున్నారు?

హెచ్ఐవి నిర్ధారణ అనుభవాలు నా తరువాత ప్రశ్నలు అడుగుతాను

హెచ్ఐవి నిర్ధారించిన తరువాత కలిగిన అనుభవాలు

హెచ్ఐవి అని మొదటి సారిగా ఎప్పుడు ఎలా తెలుసుకున్నారు?

మీ హెచ్ఐవి నిర్ధారించినప్పుడు మీరు ఏమనుకున్నారు / ఎలా భావించారు?

ఇప్పుడు హెచ్ఐవితో జీవిస్తూ ఎలా భావిస్తున్నారు?

తదుపరి నేను మీ హెచ్ఐవి స్థితిని ఇతరులతో చర్చించినప్పుడు మీ యొక్క అనుభవాల గూర్చి మాట్లాడుతాను.

వెల్లడించుట / బయలు పరచుట

మీరు ఎవరితో మీ హెచ్ఐవి స్థితిని బయలు పరచినారు లేక బయలు పరచలేదు? ఎందుకు?

మీరు పలానా వారితో మీ హెచ్ఐవి స్థితిని ఎందుకు ఇష్టపడలేదు?

ఇప్పుడు హెచ్ఐవితో జీవిస్తూ ఎదుర్కొన అనుభవాల గూర్చి ఇప్పుడు నేను చర్చిస్తాను.

హెచ్ఐవి కళంకముతో లోలోపల ఎదుర్కొన్న అనుభవాలు

మీరు హెచ్ఐవితో జీవిస్తున్నదన ఎలా భావిస్తున్నారు?

మీరు ఈ విధంగా అనుభూతి చెందుటకు కారణం ఏమిటి?

కళంకమును పొందిన తరువాత మీ అనుభవాలు

హెచ్ఐవి పాజిటివ్ వారి గూర్చి సమాజము ఏమనుకుంటుంది?

హెచ్ఐవి పాజిటివ్ వారిని ఏమని ముద్ర వేస్తారు?

మీ అభిప్రాయములో, హెచ్ఐవితో జీవిస్తున్న స్త్రీలతో పోలిస్తే హెచ్ఐవితో జీవిస్తున్న మగవారిని సమాజం ఏ విధంగా వ్యవహరిస్తుంది ?

హెచ్ఐవితో జీవిస్తున్న హిజ్రా స్త్రీలను సమాజం ఏ విధంగా వ్యవహరిస్తుంది ?

భారత దేశము వెలుపల హెచ్ఐవితో జీవిస్తున్న వారి పై జ్ఞానము ఏవిధంగా నున్నది?

హెచ్ఐవి కళంక అనుభవాలు

మీ హెచ్ఐవి స్థితి తెలిసిన తరువాత ప్రజలు మీతో ఏవిధంగా వ్యవహరించారు?

మీరు హెచ్ఐవి అని తెలిసిన తరువాత మీతో వేరొక విధంగా ఎలా వ్యవహరించిన సమయం సందర్భాలు దయచేసి చెప్పగలరా? ఆ వ్యక్తి ఎవరు? మీరు హెచ్ఐవి పాజిటివ్ అని వారికి ఎలా తెలిసింది? వాళ్ళు ఏమని చెప్పినారు, ఏమి చేసినారు? మీరు ఏవిధంగా అనుభూతి చెందారు?

నేను మీ యొక్క కులము , పేదరికము మరియు మతముతో ఎదుర్కొన్న అనుభవాలను గూర్చి అడుగుతాను.

ఇప్పుడు నేను మీ మానసిక ఆరోగ్యము గూర్చి చర్చించాలనుకుంటున్నాను.

నిరాశ (కుంగిపోవుట)

హెచ్ఐవి మీ మానసిక ఆరోగ్యమును ఏవిధంగా ప్రభావితం చూపిందో చెప్పండి.

మీ జీవితంలో రెండు లేక అంతకంటే ఎక్కువ వారాలు విచారముగా లేక నిరాశ అనుభవించ సమాయలు చెప్పండి

ఆత్మహత్య ప్రయత్నాలు లేక ఆలోచనలు కలిగిన సందర్భాలను వివరించండి

కులము, పేదరికము & మతము

మీ ఏ మతమునకు చెందినారు?

మీరు హెచ్ఐవితో జీవించునప్పుడు మీ కులము ఏవిధంగా ప్రభావము చూపింది?

హెచ్ఐవి సేవలు పొందుకొనుటకు మీ కులము ఏవిధమైన అవకాశములు కలిగించింది?

మీరు హెచ్ఐవి మందులు తీసుకొనుటకు మీ సామర్థ్యమును ప్రభావము చూపిన సమయాలు దయచేసి మాకు చెప్పండి? మీరు ఎలా అనుభూతి చెందినారు?

మీరు హెచ్ఐవితో జీవించునప్పుడు మీ పేదరికము ఏవిధంగా ప్రభావము చూపింది?

మీరు హెచ్ఐవితో జీవించునప్పుడు మీ మతము ఏవిధంగా ప్రభావము చూపింది?

వైద్య సేవలను వినియోగించడంపై నా తరువాత ప్రశ్నలు కలవు.

వైద్య సేవలు ఉపయోగించుకొనుట

హెచ్ఐవి వారికి ఏ విధమైన వైద్య సేవలు పొందుకుంటారు?

ఆసుపత్రి మరియు ఇతర క్లినిక్ సిట్టింది వారు మీతో ఏవిధంగా వ్యవహరించారు?

వైద్య సేవలను పొందుకొనుటలో మీ ఎదుర్కొన్న ముఖ్య ఇబ్బందులు ఏమిటి?

మీ సమయానికి చాలా వందనాలు. [పారితోషకమును పాత్రదారునికి ఇవ్వండి.]

APPENDIX E: CONSENT FORM TO PARTICIPATE IN SURVEY

**University of Chicago
School of Social Service Administration
Consent to Participate in Research**

What is this study?

You are being asked to join a dissertation research project being conducted by Sameena Azhar and Dr. Jeanne Marsh from the University of Chicago School of Social Service Administration. The purpose of this study is to understand experiences with stigma among people living with HIV in Hyderabad, India, and how such experiences are related to depression and utilization of HIV services. We also are interested in learning how stigma may be different for men, women, and hijras/transgender women.

Approximately 30 people living with HIV will be interviewed for this phase of the research study. The purpose of this form is to give you information on this research project. This information will help you decide whether or not you want to join the study. We will review this form with you. You may ask any questions you have about the study. When we have answered all your questions, you can decide whether or not you want to join the study.

What will you do if you choose to be in this study?

You will be asked to complete an audio-recorded interview, exploring issues related to HIV stigma and discrimination. Study participation will take approximately one and a half hours. The interview will ask you questions about HIV stigma, gender, sexuality, access and utilization of medical services, depression, and social support. The survey will take place in the office space of one of the nongovernmental organizations (NGOs) with whom we are collaborating.

What are the possible risks of joining this study?

You might feel embarrassed by some of the questions on the survey. You do not have to answer any question that you do not want to. You can take a break or stop the interview at any time. There is no penalty for skipping a question, taking a break, or stopping the survey.

What are the possible benefits for me or others?

There is no direct benefit to you for completing the survey. However, we hope the results will help us better meet the HIV prevention and care needs of people in Hyderabad like you. The study results may be used to help design interventions that reduce HIV stigma.

How will you protect the information you collect about me, and how will that information be shared?

Your study data will be handled as confidentially as possible. Your name will not appear on the survey. Each person who joins the study will receive a special number. Only project staff will have access to your name and special number. Your completed consent forms and surveys will

be kept in a locked file cabinet at the University of Chicago. The research team will keep this consent form until it has been scanned by study staff; it will subsequently be destroyed. The

study results from the questionnaire will be input into a database and will also subsequently be destroyed. We plan to share the results of the study at conferences and in journal articles. Any results that we publish will not include your name or any other information that could identify you. The results of the completed research will also be made available to you at your request.

What are the limits to my confidentiality?

In the event that you disclose intent to harm yourself or others, including suspected child or elder abuse, the interviewer will probe to assess imminent risk of harm. If it is determined that there is an imminent risk of harm, the proper authorities will be notified. In the case of suicidal ideation, the participant will be actively referred to crisis services, potentially calling for an emergency response from local psychiatric/medical staff or the police.

Financial Information

Participation in this study will involve no cost to you. You will be offered an incentive for participating in this interview in the amount of 200 Rupees. If you recruit other eligible participants into the study, you will be compensated an additional 100 Rupees per completed referral. You are limited to three referrals, so you can make up to a total of 300 Rps for successfully referring others to the study. The incentive will be provided to you once the survey has been successfully completed by the person you refer.

What are my rights as a research participant?

Participation in this study is voluntary. You have the right to not answer a particular question; review any materials; request that we erase any of your responses; or make inquiries. You also have the right to address complaints to the University of Chicago. You can withdraw from the study at any time, for any reason, with no explanation, without any penalty. If you decide to withdraw from this study, the researchers will ask you if the information already collected from you can be used.

Who can I contact if I have questions or concerns about this research study?

If you have questions, you are free to ask them now. If you have questions later, you may contact the doctoral student researcher in Chicago at:

Sameena Azhar, LCSW, MPH
School of Social Service Administration
University of Chicago
969 E. 60th Street
Chicago, IL 60637
(510) 896-5355
Sameena12@uchicago.edu

In India, you may contact:

Sabitha Gandham
SHARE India
Ghanpur, Medchal (Mandal),
RangaReddy District, Telangana, INDIA.
08418-256201

If you have any questions about your rights as a participant in this research, you can contact the following office at the University of Chicago:

Social Service Administration Institutional Review Board
University of Chicago
969 E. 60th Street
Chicago, IL 60637
(773) 834-0402

Consent

I have read this form and the research study has been explained to me. I have been given the opportunity to ask questions and my questions have been answered. If I have additional questions, I have been told whom to contact. I agree to participate in the research study described above and will receive a copy of this consent form after I sign it.

Furthermore, I consent to provide my personal contact information so that I may be contacted in the event that I am eligible for Phase 2 of the study.

The research project and the procedures associated with it have been explained to me. I will receive a signed copy of this consent form for my records. My participation is voluntary and I agree to participate in this study.

Participant's Name (printed)

Participant's Signature Date

Signature of Research Interviewer Date

APPENDIX F: CONSENT FORM FOR IN-DEPTH INTERVIEW

University of Chicago School of Social Service Administration Consent to Participate in Research

What is this study?

You are being asked to join a dissertation research project being conducted by Sameena Azhar and Dr. Jeanne Marsh from the University of Chicago School of Social Service Administration. The purpose of this study is to understand experiences with stigma among people living with HIV in Hyderabad, India, and how such experiences are related to depression and utilization of HIV services. We also are interested in learning how stigma may be different for men, women, and *hijra*/transgender women.

Approximately 150 people living with HIV will be interviewed for this phase of the research study. The purpose of this form is to give you information on this research project. This information will help you decide whether or not you want to join the study. We will review this form with you. You may ask any questions you have about the study. When we have answered all your questions, you can decide whether or not you want to join the study.

What will you do if you choose to be in this study?

You will be asked to complete a survey that will take approximately 90 minutes. The survey will ask you questions about HIV stigma, gender, sexuality, access and utilization of medical services, depression, and social support. The survey will take place in the office space of one of the nongovernmental organizations (NGOs) with whom we are collaborating.

By agreeing to participate in this survey, you also provide your consent to potentially be contacted in the future for phase 2 of the study, which entails an in-depth interview regarding your experiences living with HIV.

What are the possible risks of joining this study?

You might feel embarrassed by some of the questions on the survey. You do not have to answer any question that you do not want to. You can take a break or stop the interview at any time. There is no penalty for skipping a question, taking a break, or stopping the survey.

What are the possible benefits for me or others?

There is no direct benefit to you for completing the survey. However, we hope the results will help us better meet the HIV prevention and care needs of people in Hyderabad like you. The study results may be used to help design interventions that reduce HIV stigma.

How will you protect the information you collect about me, and how will that information be shared?

Your study data will be handled as confidentially as possible. Your name will not appear on the survey. Each person who joins the study will receive a special number. Only project staff will have access to your name and special number. Your completed consent forms and surveys will be kept in a locked file cabinet at the University of Chicago. The research team will keep this consent form until it has been scanned by study staff; it will subsequently be destroyed. The study results from the questionnaire will be input into a database and will also subsequently be destroyed.

We plan to share the results of the study at conferences and in journal articles. Any results that we publish will not include your name or any other information that could identify you. The results of the completed research will also be made available to you at your request.

What are the limits to my confidentiality?

In the event that you disclose intent to harm yourself or others, including suspected child or elder abuse, the interviewer will probe to assess imminent risk of harm. If it is determined that there is an imminent risk of harm, the proper authorities will be notified. In the case of suicidal ideation, the participant will be actively referred to crisis services, potentially calling for an emergency response from local psychiatric/medical staff or the police.

Financial Information

Participation in this study will involve no cost to you. You will be offered an incentive for participating in this survey in the amount of 200 Rupees. If you recruit other eligible participants into the study, you will be compensated an additional 100 Rupees per completed referral. You are limited to three referrals, so you can make up to a total of 300 Rps. for successfully referring others to the study. The incentive will be provided to you once the survey has been successfully completed by the person you refer.

What are my rights as a research participant?

Participation in this study is voluntary. You have the right to not answer a particular question; review any materials; request that we erase any of your responses; or make inquiries. You also have the right to address complaints to the University of Chicago. You can withdraw from the study at any time, for any reason, with no explanation, without any penalty. If you decide to withdraw from this study, the researchers will ask you if the information already collected from you can be used.

Who can I contact if I have questions or concerns about this research study?

If you have questions, you are free to ask them now. If you have questions later, you may contact the doctoral student researcher in Chicago at:

Sameena Azhar, LCSW, MPH
School of Social Service Administration
University of Chicago
969 E. 60th Street
Chicago, IL 60637

(510) 896-5355
Sameena12@uchicago.edu

In India, you may contact:
Sabitha Gandham
SHARE India
Ghanpur, Medchal (Mandal),
RangaReddy District
Telangana, INDIA.
08418-256201

If you have any questions about your rights as a participant in this research, you can contact the following office at the University of Chicago:

Social Service Administration Institutional Review Board
University of Chicago
969 E. 60th Street
Chicago, IL 60637
(773) 834-0402

Consent

I have read this form and the research study has been explained to me. I have been given the opportunity to ask questions and my questions have been answered. If I have additional questions, I have been told whom to contact. I agree to participate in the research study described above and will receive a copy of this consent form after I sign it.

Furthermore, I consent to provide my personal contact information so that I may be contacted in the event that I am eligible for Phase 2 of the study.

The research project and the procedures associated with it have been explained to me. I will receive a signed copy of this consent form for my records. My participation is voluntary and I agree to participate in this study.

Participant's Name (printed)

Participant's Signature Date

Signature of Research Interviewer Date

APPENDIX G: CERTIFICATE OF TRANSLATION – HINDI

University of Chicago,
School of Social Service Administration (SSA) Institutional Review Board
CERTIFICATE OF TRANSLATION FORM

For research conducted in languages other than English, the SSA IRB must have all versions of the research study materials [e.g. consents, recruitment, instruments, etc.] in both English and non-English to be used/retained in the research file. A certificate of translation form is also required to verify the translations are accurate. Those who translate the material are to provide a brief description of their qualifications, skills or experience for serving in this role and sign the certificate of translation form.

- Translation: It is acceptable for an investigator listed as research personnel to translate the research material.
- Timing of the Translation: the research investigator(s) may wish to delay the initial translation until after the IRB has reviewed the English versions. Doing so may help researchers avoid multiple translations.
- Modifications: If the non-English documents are modified during the course of the study, then please submit the translated material with another copy of the certificate of translation with the amendment application.

Name of Principal Investigator

Jeanne Marsh, PhD

Name of Primary Contact

Sameena Azhar, LCSW, MPH

Protocol Title

HIV Stigma and Gender: A Mixed Methods Study of People Living with HIV/AIDS in Hyderabad, India

Protocol Number

IRB15-0738

Name of Translator

Mrs. Beaula Theophilus Rani

Phone Number

9030083391

Email:

beulahsunil@gmail.c

Language(s)

Hindi

Certified Translator (Mark one): YES NO

If **YES**, please provide the name of the organization providing certification

If **NO** please provide foreign language proficiency to serve as a qualified translator or interpreter (e.g., it is my native language, I have X number of years of education and training in this foreign language, or I have other evidence of dual language fluency.)

Please explain and attach applicable credentials indicating translation skills & experience, as applicable.

Mrs. Beaula Theophilus Rani is a native speaker of Hindi and has been translating documents between Hindi and English in the social services field for the past 12 years.

Name of Document(s) translated (please include version and/or date if applicable or other document identifier):

Recruitment Flyers – Oct. 7, 2015
Consent Forms – Oct. 21, 2015
Interview Guide – Oct. 21, 2015
Questionnaire – Oct. 21, 2015

Certification

By signing below or submitting this document electronically, I agree to accept primary responsibility for the scientific and ethical conduct of this project as approved by the IRB.

I, the undersigned verify that all translated materials related to the above named study reflect the intent and spirit of the English text.

Sameena Azhar Signature Sameena Azhar, LCSW, MPH SSA Oct. 23, 2015
of Researcher Printed Name SSA or Chapin Hall Date

For Student Research Projects

Faculty Supervisor: By signing below or by submitting this document electronically, I certify that I have reviewed this document and approve the scientific and ethical aspects of the project. I will supervise the above listed student and ensure compliance with human subjects' guidelines.

Jeanne Marsh Jeanne Marsh, PhD SSA Oct. 23, 2015
Signature of Faculty Advisor Printed Name Department Date

APPENDIX H: CERTIFICATE OF TRANSLATION – TELUGU

University of Chicago,
School of Social Service Administration (SSA) Institutional Review Board
CERTIFICATE OF TRANSLATION FORM

For research conducted in languages other than English, the SSA IRB must have all versions of the research study materials [e.g. consents, recruitment, instruments, etc.] in both English and non-English to be used/retained in the research file. A certificate of translation form is also required to verify the translations are accurate. Those who translate the material are to provide a brief description of their qualifications, skills or experience for serving in this role and sign the certificate of translation form.

- **Translation:** It is acceptable for an investigator listed as research personnel to translate the research material.
- **Timing of the Translation:** the research investigator(s) may wish to delay the initial translation until after the IRB has reviewed the English versions. Doing so may help researchers avoid multiple translations.
- **Modifications:** If the non-English documents are modified during the course of the study, then please submit the translated material with another copy of the certificate of translation with the amendment application.

Name of Principal Investigator

Jeanne Marsh, PhD

Name of Primary Contact

Sameena Azhar, LCSW, MPH

Protocol Title

HIV Stigma and Gender: A Mixed Methods Study of People Living with HIV/AIDS in Hyderabad dia

Protocol Number

IRB15-0738

Name of Translator

Sabitha Gandham

Phone Number

9959334797

Email:

sabithar@sharefoundations.org

Language(s)

Telugu

Certified Translator (Mark one): YES NO

If YES, please provide the name of the organization providing certification

If **NO** please provide foreign language proficiency to serve as a qualified translator or interpreter (e.g., it is my native language, I have X number of years of education and training in this foreign language, or I have other evidence of dual language fluency.) Please explain and attach applicable credentials indicating translation skills & experience, as applicable.

Sabitha Gandham is a native speaker of Telugu and completed her college education in both Telugu and English. Sabitha has 15 years of experience in translating research survey instruments from English to Telugu and Telugu to English. Sabitha works full-time as a research assistant at SHARE India.

Name of Document(s) translated (please include version and/or date if applicable or other document identifier):

Recruitment Flyers – Sep. 15, 2015
Consent Forms – Oct. 21, 2015
Interview Guide – Oct. 21, 2015
Questionnaire – Oct. 21, 2015

Certification

By signing below or submitting this document electronically, I agree to accept primary responsibility for the scientific and ethical conduct of this project as approved by the IRB.

I, the undersigned verify that all translated materials related to the above named study reflect the intent and spirit of the English text.

Sameena Azhar Signature Sameena Azhar, LCSW, MPH SSA Oct 23, 2015
of Research Printed Name Department Date

For Student Research Projects

Faculty Supervisor: By signing below or by submitting this document electronically, I certify that I have reviewed this document and approve the scientific and ethical aspects of the project. I will supervise the above listed student and ensure compliance with human subjects' guidelines.

Sameena Azhar Signature Sameena Azhar, LCSW, MPH SSA Oct 23, 2015
of Research Printed Name Department Date

PAID RESEARCH STUDY



Are you HIV+?

**Have you ever
felt depressed
regarding your
HIV status?**

**Have you ever
missed a
medical
appointment
because you
were worried
someone would
see you at the
clinic?**



If you are HIV+, over 18 years of age, and reside in Hyderabad or Secunderabad, you may be eligible to participate in a research study. Please contact Sabitha Gandham at 9959334797.

If you complete a one and a half hour survey, you will be compensated 200 Rps. You may be asked to also participate in a one and half hour interview, for which you will receive an additional 200 Rps.

APPENDIX J: RECRUITMENT FLYER FOR HIJRA/TRANSGENDER WOMEN
IN HINDI

शोध अध्ययन



आप एचआईवी + हैं?

कैसे आप अपने
एचआईवी स्थिति के
बारे में क्या महसूस
करते हैं?

यदि आप किसी एक
मेडिकल क्लिनिक में
आपको देखना होगा
चिंतित थे, क्योंकि आप
एक चिकित्सा नियुक्ति
याद किया?

अगर आप एचआईवी + हैं, आप के उम्र 18 वर्ष से अधिक हैं तो, और हैदराबाद या
सिकंदराबाद में रहते हैं, तो आप यह शोध अध्ययन में भाग लेने के लिए पात्र हो
सकता है।

08418-256201 पर समिना अजहर या सविता गंध से संपर्क कर सकते हैं।

आप एक डेढ़ घंटे सर्वेक्षण को पूरा करते हैं, तो आप को Rs200 मुआवजा दिया
जाएगा। आप भी एक डेढ़ घंटे की बातचीत में भाग लेते हैं, आप एक अतिरिक्त 200



APPENDIX K:
APPENDIX K: RECRUITMENT FLYER FOR CISGENDER MEN IN TELUGU

PAID పరిశోధన అధ్యయనము



మీరు హెచ్ఐవి +అయి , 18 సంవత్సరాలు పైబడి, మరియు హైదరాబాదు లేక సీకిండ్రాబాదులో నివసించిన
యెడల, మీరు ఈ పరిశోధన అధ్యయనంలో పాల్గొనుటకు అర్హులు.

దచేసి సమీనా హజార్ లేదా సబిత గారిని ఈ నంబరునందు 9959334797 సంప్రగించగలరు.
మీరు గంట ముప్పై నిమిషములు ఈ సర్వేలో పాల్గొని పూర్తి చేస్తే మీకు రూ.200 పారితోషకముగా
లభించును. ఇంటర్వ్యూలో పాల్గొనందుకు మీకు అదనంగా రూ.200 పారితోషకముగా లభిస్తుంది.

మీరు హెచ్ఐవి+?

మీ హెచ్ఐవి స్థితి

గూర్చి ఎలా

భావిస్తున్నారు?

మీరు ఆసుపత్రిలో

కనబడుతారనే

కారణం చేత వైద్యం

చేయించుకోవడం

ఎప్పుడైనా

తప్పినారా ?

THE UNIVERSITY OF
CHICAGO

SHARE
RESEARCH