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“Even an HIV infected person can live 100 years”: Perceptions of HIV among Hijras in Mysore, India

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Abstract

Hijras, a term referring to a “third gender” in India, engage in sex work with men for economic survival.¹ This has contributed to the high rates of HIV/ AIDS within this population.¹ The current study explores HIV/ AIDS knowledge and perceptions of HIV/ AIDS among Hijras residing in Mysore, India. A total of 14 Hijras participated in focus groups that asked questions probing for common beliefs about HIV acquisition and management, and basic knowledge about HIV/ AIDS acquisition and transmission. Most participants noted that they had received or were able to access HIV/ AIDS education programming. However, accurate HIV knowledge levels varied and HIV itself was not viewed as a significant health concern. Instead, distrust for healthcare workers was a greater concern for putting participants risk for HIV acquisition.

Key Words Hijra, HIV/ AIDS, India, health providers

INTRODUCTION

HIV prevalence among Indian sexual minorities (SM) is estimated to be over 20 times higher than the general population.^{1,2} Surveillance data shows that despite health education efforts these populations continue to be disproportionately affected by HIV.² This is because men who have sex with men (MSM) and other SM groups in India face unique sexual health prevention challenges and vulnerabilities.³⁻⁵ Further, the added stigmas around same sex behavior in Indian culture increases these populations’ risk for HIV and other health vulnerabilities, including other STI infections, intimate partner violence and negative interactions within health systems when social networks of peers or familial support systems are not perceived as stable, useful or in existence.⁴⁻⁶

Hijras, also known as the spiritual transgender community and institutionalized third gender in India⁷, are especially vulnerable to these risks due to their involvement in sex work.^{8,9} Research examining HIV/ AIDS in India have reported that a significant number of transgender individuals are HIV-positive.^{1,9} To address the ways in which this population gives meaning to this experience, the current study explores Hijras’ understandings of their health experiences, options and related stigmas as they relate to HIV/AIDS.

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Background

Hijras, a third gender recognized in several regions of India, are biologically male but live and dress as women, and may or may not be castrated.¹⁰ Western cultural frameworks have often used a range of descriptors to describe this population, ranging from transsexual to intersex.¹¹ However, many South Asian researchers assert that Hijras' identities move beyond just a gender or sexual orientation standpoint, and include a spiritual connection to beliefs related to birth, renewals, or new relationships.¹² For these reasons, Hijras have commonly held a special status in society; their dance and singing performances at births and certain festival celebrations are considered to be important sources of "good luck" in many traditional communities. Now however, most engage in sex work with men for economic survival.^{1, 10} This is one of the most common reasons for why rates of HIV/ AIDS remain so high among this population.^{3, 8, 13} Research has also noted that HIV prevalence is higher among men having sex with either Hijras (14%) or all 3 genders (e.g. with men, women and Hijras; 13%) than among those having sex with only men or women (8%)^{1, 3, 8, 13}

Unfortunately, empirical research examining the attitudes and beliefs about HIV/ AIDS risk among Hijras is limited. This lack of knowledge is problematic as such knowledge offers the potential of identifying key social and structural factors that created barriers to disclosure of virus status and to related sexual health concerns. Further, it can identify points for intervention to increase others' understandings of the health concerns this vulnerable population faces. To address this void in the literature, this qualitative study seeks to identify 1) young Hijras' knowledge and beliefs about HIV/ AIDS broadly, and 2) the perceptions they hold regarding their risk for acquisition or transmission of the virus.

METHODS

Participants. A total of 14 Hijras participated in one of two focus groups that were conducted. Participants were recruited via a local community organization in Mysore, India created to help Lesbians and Gays with HIV/AIDS prevention and awareness.

Procedures. Two data collection techniques were used: 1) semi-structured focus group interviews and 2) three researchers' notes taken by the main interviewer and two healthcare educators trained in qualitative research methods. Multiple sources of data were collected to confirm emergent themes and inconsistencies in the data.

After reading the Institutional Review Boards' approved letter of consent, participants completed a questionnaire to report various demographic information. Audio recording focus groups were then held, lasting 60 and 98 minutes. A questioning route provided a framework for developing and sequencing a series of semi-structured focus group questions that included: *What kinds of support do you receive from individuals in your life? What kinds of support would you like to receive or want to continue receiving?* Interviewers took notes during each audiotaped interview session.

Analysis. Content analysis techniques were utilized to develop coding categories and themes¹⁴ Codes were developed independently before comparison, discussion and reconciliation of differences. Through this iterative process, a single coding system was developed by the first and second authors, for phrases, sentences or paragraphs that allowed themes to emerge from the data. This approach provided insights into broad thematic trends that emerged from the data.

RESULTS

The 14 participants self-identified as being Hijra and their religion as Hinduism. The participants ranged in age from 26 to 55 (see Table 1); the average age was 34.28. All acknowledged engaging in sex work during the focus groups; however, only one reported this on the demographic survey. Instead, the primary occupation selected was collecting/ pleading for money from shops.

HIV/ AIDS Knowledge. Incorrect modes of transmission were reported by three of the participants. These participants stated that HIV could be spread by mosquitoes and by sharing food. A fourth argued that it could only be spread via sexual intercourse.

While sleeping together... by mosquito bites also it spreads.

By having sex only- [that is how] it spreads.

However, these participants were quickly corrected by others during the focus group. Most participants noted that they had received or were able to access HIV/ AIDS education programming (n= 12); all agreed that these programs provided accurate information about the virus, how it is transmitted and modes of prevention. Most participants gave a biomedical explanation about the virus, modes of transmission, and potential impact on health outcomes (n= 11).

[The HIV virus is transmitted] through intercourse, blood, and syringe. We should be aware about these things and lead the life.

While we come to this profession they give us classes, villages advice you are going to that place, don't have sex without condoms, which will protect from HIV VIRUS, blood spill, interaction with them and fourth one syringe is not used that much.

We can prevent it, while getting injection from doctor we should inform not to use the same to another person. Use new needles.

While having sex we use condoms. And we are careful during intercourse. When we go to doctor for check-up for illness, while taking injections we ask the doctor use the new [needle]. We are taking precautionary action and educating the community.

HIV/AIDS Concerns and Perceptions of Risk. Overall, HIV transmission and acquisition risk was not viewed as a significant health concern by the Hijras in this study (n= 10) This was not only because they felt knowledgeable about HIV/ AIDS, but also perceived themselves as engaging in safer sex practices (n= 8). They noted their requirement for using a condom when engaging in sex work; nine of the participants reported this was something they always tried to use. However, several acknowledge that offers for additional money from customers was an incentive for them to not use condoms.

Our 'mother' or head of our group, they advise us to go in a right path, asked us not to go out without condoms and they also tell us not to be greedy over money.

We have to carry condoms without fail, whoever goes to that place then they should carry.

The customers tell us they pay extra money if we do without condoms. For money sake we do without condoms.

However, when discussing their safe sex practices outside of sex work, three participants reported it was fine to engage in unprotected sex with their long-term partners. This is because they viewed their partners' level of risk and familiarity differently than that of customers'.

Everyone uses condoms while having sex [for money]. We adjust with our family members, and partners who will be with us for a life time. I have seen [her partner's] body condition, he has seen mine. And we know each other's blood group. And we both know the report says we both have nothing, no infection. So without condoms we have sex. But when we do [have sex] for money, we use condom.

Interestingly, two participants expressed little concern about becoming HIV positive. The virus was viewed by these participants as a type of chronic disease that could be managed with medicines and following prescribed health regimens. Further, six participants used cancer as a reference point of comparison when assessing HIV risk. They noted that cancer was a more “dangerous” disease that could not be treated as easily as HIV.

Even an HIV infected person can live 100 years. Because it has its own quotation, taking the medicine, and by following the rules and regulations, having clean and hygienic food, be good we can face the risk. We can show I can face the worst and live 100 years. Should not worry, it should be treated like cough, [diabetes]... HIV is common... and [you can] live happily.

One of the incurable diseases, if we think... cancer is the most dangerous disease- which doesn't have any medicine. But there are medicines for HIV.

In [local hospital] only 1% of the patients are cured of cancer. [The hospital] is one of the best hospitals for cancer, isn't it? But HIV patients almost all can lead a normal life, if they follow the doctor's instructions.

Of note was the fact that five perceived “unscrupulous” healthcare providers as risk factors in the spread of HIV among Hijras. They were characterized as engaging in behaviors that purposefully increased Hijras and other patients' risks for HIV acquisition. These study participants believed that some health workers intentionally infected Hijras and other SMs for financial gain, due to homophobic attitudes, or to increase their prestige within the Indian health or political systems.

They may organize a health check-up or something, if a healthy person go whether transgender or gay, by giving false information they say, 'you are HIV positive' we will avail you these facilities and gives unwanted injection, adds that person to HIV group, and increase their income from other sources but not providing the health services correctly. The doctors also are cunning there.

I am telling you. Today they put bolts, tomorrow publicizing. They cheat people. Today many are registered under government schemes identified as HIV are not treated well, if said in public they get punishment. Study not done regarding it. Those who died were strong, never shown out. Finding them publishing their photos, keeping out of community, casting them aside, untouchable – by this ill treatment many died out of grief, nowadays it has decreased.

DISCUSSION

To our knowledge, this is the first study to systematically investigate Hijras' perceptions and knowledge of HIV/AIDS. Our findings indicate that Hijras in Mysore hold both biomedical knowledge about the transmission of HIV/AIDS, but also hold beliefs about non-biological modes of transmission. This indicates that education efforts that focusing on transmission risks and appropriate methods for prevention have been successful in improving knowledge in these areas.^{15, 16, 6} However, some held the belief that engaging in unprotected sex with long-term partners was safe, despite their engagement in sex work. This reinforces the need for education efforts that address intimate relationship ideals and negotiation skills within the context of HIV risk, both from their partners or engagement in sex work.

This group of Hijras did not view HIV as being a major health concern. This lack of concern about HIV acquisition and transmission could be due to their prioritization of other numerous risk they face, such as harassment, sexual abuse, and violence.^{1, 3, 7} Furthermore, the fact that HIV risk transmission rates in South India are dropping could be contributing to this decrease in fear of transmission.¹⁵ However, the continually high incidences of HIV in SM populations points to the need for continued HIV/AIDS educational programs for Hijras.⁶

However, it is important that the health community focus on building a positive and trusting relationship with this population. There was a clear lack of distrust and perception that health workers were not honest and respectful towards them. Specifically, participants' belief that healthcare workers were purposefully infecting Hijras or not providing them with quality health for personal gain was of great concern. Although some may perceive these assertions as conspiracy theories, research has shown that healthcare fraud among physicians, drug companies and health regulators is common in India—unfortunately, often to the detriment of patients' well-being.¹⁷⁻¹⁹ Further, discrimination against SMs in India was found to decrease their willingness to seek out and continue using HIV/AIDS and other general health care services.^{3, 5, 9}

PRACTICAL IMPLICATIONS

Findings point to the need for intervention programs that center and are led by members of SM communities. It is pivotal that these intervention programs directly engage this population through its development of leadership to ensure that trust is built between the community and the healthcare workers. Through this collaborative approach, global health researchers will be able to better identify the culturally specific long-term HIV educational needs of Hijras. As noted by prior research, this should include a focus on the provision of accurate and relevant information about modes of transmission.^{1,10} Further, the inclusion of content that discusses its real and significant impacts on daily functioning must be balanced with messages that do not stigmatize HIV positive individuals.

Further, it is important to address the lack of trust and associated stigmas' these participants perceived as occurring within some healthcare settings. The lack of trust and negative stigmatization have implications for both proactive and reactive efforts, as prior research has noted that SMs and People Living with HIV (PLHIV) often avoid or delay. Stigma and bias training must be an integral part of healthcare training as targeted HIV stigma reduction interventions can rapidly improve health provider attitudes and increase service satisfaction among marginalized populations.^{20,21}

CONCLUSION

Although this study provides foundational information about Hijras perceptions of HIV/ AIDS and sexual health experiences, there are methodological limitations that must be considered. First, it is important to note that this study required participants to report knowledge and beliefs related to sexual health and STIs. Social desirability bias in this group setting could have influenced participants' willingness to share openly their feelings, or to provide what they viewed as appropriate responses²². Further, this small sample of Hijras came from a specific community within the southeastern region of India; this means that these participants' beliefs and understandings will be informed by regionally specific health services, and community level attitudes about their identities. Further, although appropriate for qualitative methods, the sample size does limit our ability to make broader generalizations to other Hijra communities across India²². The services, cultural values, and health policies differ across regions, so Hijras in a community just a couple of hours away may have distinctly different experiences. Future research targeting SM populations would benefit from increasing the number of participants recruited, and conducting one-on-one interviews to assess how knowledge of HIV/AIDS contributes to increased engagement in behaviors that put them at risk of contracting HIV.

Despite these limitations, the results from this study reinforces the need for continued culturally specific HIV/ AIDS information that integrates their experiences and values in the context of their broader healthcare needs.^{1,10} Future research must address the changes in perceptions of HIV as a chronic

condition and the ways this shapes perception of risk. Additionally, researchers must develop culturally appropriate tools of assessment of risk and prevention to better understand the varying ongoing and dynamic behaviors of this unique population. This includes integrating factors that better validate and embrace the experiences of this unique population.

COMPLIANCE WITH ETHICAL STANDARDS

Compliance with Ethical Standards: The authors declare that they have no conflict of interest. No funding was received to conduct this study.

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APPENDIX: TABLES & FIGURES

TABLE I. PARTICIPANT DEMOGRAPHICS

Demographics	Total (N = 14)	%	Range	Mean
	n			
Religion		100.0		
Hindu	14	100.0		
Age	14	100.0	26–55 years	34.28.
Education	14	100.0		
No formal education	5	35.71%		
6 th Form	1	7.14%		
7 th Form	0	0		
8 th Form	2	14.28%		
9 th Form	1	7.14%		
10 th Form	3	21.42%		
11 th Form	0	0		
12 th Form	2	14.28%		
Reported Sources of Income	14	100.0		
Collecting/ pleading for money from shops	14	100%		
Dramatic & Dance Arts	2	14.28%		
Sex Work	1	7.14%		

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