

Multi-level barriers to ART adherence among hijra-/thirunangai-identified trans women in India: a qualitative investigation



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+ BACKGROUND



- Free ART program since 2004
- Decline in the number of annual AIDS related deaths
- Trans women are emerging as a high risk group with high levels of HIV
 - ~62,000 trans women in 17 states (Subramaniam et al., 2014)
 - Average national HIV prevalence among trans women: 8.8% (National HIV sero-surveillance, 2011)
- Limited knowledge of ART adherence among transgender community
- Heavy stigma associated with transgender community
 - Barriers to ART adherence

+ OBJECTIVES

Understand attitudes and beliefs regarding difficulties and experiences with ART adherence among HIV-positive transgender women

Conduct in-depth interviews with

- Trans women in Chennai and New Delhi
- Key informants
 - Community based organization leaders
 - HIV healthcare workers
 - Government officials





STUDY DESIGN – Qualitative methodology

- In-depth interview (n = 22)
 - 45 minutes - 1 hour
 - Open-ended questions
 - Tamil, Hindi, and English
- Purposive sampling
 - Peer recruiters
 - CBO partners:
 - MITR Trust in New Delhi
 - Sahodaran/Thozhi in Chennai
- Eligibility criteria:

Trans women	Key informants
<ul style="list-style-type: none">• Known HIV positive status• ART for at least 6 months• 18 years of age or older• Capable of giving informed consent	<ul style="list-style-type: none">• Worked with or provided HIV services to trans women• 18 years or older• Capable of giving informed consent



+ ANALYSIS

- Interviews were audio taped, transcribed in the native language, and subsequently translated into English
- Framework analysis approach (Ritchie & Spencer, 1994):
 - Established a-priori categories
 - Emergent codes from the data
 - Constant comparison method
 - Identify similarities and differences
 - Comparison of narratives/perspectives of trans women and key informants



+ SAMPLE



TRANSWOMEN			KEY INFORMANT		
	NEW DELHI	CHENNAI		NEW DELHI	CHENNAI
SAMPLE SIZE	n = 8	n = 8	SAMPLE SIZE	n = 3	n = 3
MEAN AGE	31	34	MEAN AGE	39	36
OCCUPATION :			OCCUPATION:		
Sex Work	62.5% (n = 5)	25% (n = 2)	Service provider	66.6% (n = 2)	66.6% (n = 2)
Begging	25% (n = 2)	25% (n = 2)	Community Leader	33.3% (n = 1)	33.3% (n = 1)
CBO peer educator	12.5% (n = 1)	37.5% (n = 3)			
Folk Dancer	0% (n = 0)	12.5% (n = 1)			

+ RESULTS



SOCIAL –
STRUCTURAL



HEALTHCARE



INDIVIDUAL

+ RESULTS





RESULTS: *Social-structural*



- Trans women value relationships with peers and gurus
 - Revealing HIV status threatens community support
 - Vigilant of clues that might reveal HIV status
 - Example: transferring ART pills to vitamin pill containers
 - Steps to hide HIV status interferes with taking medication on time
- Gurus can serve either as barriers or facilitators to ART adherence
 - HIV-positive trans women threaten the community image in communities where sex work is condoned
 - HIV care can be managed within community networks because of the level of support and acceptance from gurus or peers
- Lack of confidentiality within the trans community

+ RESULTS: *Social-structural*

“People like me who stay with several people in one house have to be careful. If they catch me going to an ART center or see me taking my medication, they will know my HIV status and send me out of the house...they will talk bad about me and tell everyone I have HIV.”

~ trans participant

“I fear that my community people might see me. If one person sees, they inform 10 people, those ten will become 100. So, fearing that I have not collected medicines”

~ trans participant



+ RESULTS

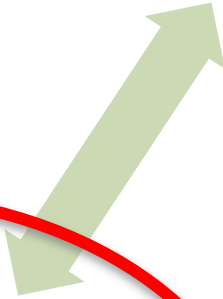


SOCIAL –
STRUCTURAL



HEALTHCARE

INDIVIDUAL





Results: *Healthcare*



- Negative experiences with healthcare providers
 - Covert discrimination
 - Inadequate ART counseling time
 - Non-disclosure of adherence patterns to doctors
- Infrastructure
 - Frequent ART stock-outs
 - Procedures to receive medication in ART center is long and arduous (5-6 hours)
 - Fear of losing job and income for the day
 - Increases chances of running into other trans women
 - Postpone or avoid visiting ART centers



Results: *Healthcare*

“Sometimes I miss my medications because the ART center will not have it. How can that be? How can they have the medicine out of stock so many times? I had to wait 15 days once.”

~ trans participant

“The counsellor will start with a very negative statement – from where did you get this HIV? The question is a nice question but the tone of the question is bad because they will immediately assume they are in sex work. The counsellor assumes everything. He or she will cut you down. If it was a woman, they will spend 45 minutes with them. But for a trans person, they will only spend 5 to 7 minutes. It is unethical. A person should have 45 minutes of counselling because only then will they be motivated and adhere to their medications.”

~ key informant



+ RESULTS



SOCIAL –
STRUCTURAL



HEALTHCARE



INDIVIDUAL





Results: *Individual*



- Misleading or lack of information on ART
- Fear of harmful interactions between alcohol and ART
 - High levels of alcohol and drug use among trans women
- Fear of harmful interactions between female hormonal treatment and ART
 - Reported by participants in sex work
- Fear of visible side-effects
 - Characteristic fat depositions from long-term use of ART

+ Results: *Individual*

“People are so deeply engrossed that they are trapped in the wrong body so this gender transition is very important to them. For example, many take Mala-D pills to get breasts but if you take that with HIV, you have severe effects. The problem is that they will not disclose this to the ART doctor or the hormonal treatment doctor. I will never tell my hormonal treatment doctor that I have HIV because they will discriminate against me. I will never disclose to my ART doctor that I am taking hormonal pills because I think that it is not important to tell them. The doctor will never ask me, ‘Are you taking other medications?’”

~ (key informant)



+ PRACTICE & POLICY IMPLICATIONS



SOCIAL-STRUCTURAL

- Promoting acceptance of HIV-positive trans women among trans communities

HEALTHCARE

- Improving sensitivity and competency among providers and train them on prescribing ART among trans women on hormones
- Increasing access to mental health support services
- Providing a comprehensive ART education

INDIVIDUAL

- Assisting TG in adopting tailored adherence strategies

+ LIMITATIONS

- Diversity in relation to participants from urban vs. rural areas and age groups
- Presence of co-infections (Hep. B/Hep. C/TB)
- Trans participants recruited from CBO networks



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IMAGES

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