



Published in final edited form as:

AIDS Care. 2023 April ; 35(4): 572–580. doi:10.1080/09540121.2022.2099511.

Intersectional stigma and gender non-affirmation hinder HIV care engagement among transgender women living with HIV in India

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Abstract

Among transgender women living with HIV (TGWLH) in India, little is understood about the mechanisms through which multiple intersecting stigmas impact HIV care engagement, or intervention strategies that might mitigate this impact. We conducted focus groups with TGWLH (N = 30) in three Indian cities and analysed data using theoretical frameworks related to HIV stigma, gender affirmation, and syndemics. Findings revealed that enacted and anticipated stigma due to transgender identity, HIV, or sex work status, and lack of gender affirmation (e.g., misgendering) in healthcare settings delayed ART initiation and promoted care disengagement. Having supportive physicians and counsellors within ART centres and peer outreach workers facilitated ART initiation, adherence, and retention. Findings also revealed that HIV stigma within TGW communities led to concealment of HIV status or syndemic conditions such as depression and alcohol use, thereby affecting care engagement. However, the TGW community itself was also described as a resilience resource, offering emotional, psychological and tangible support that decreased the impact of discrimination on care engagement. HIV care engagement efforts among Indian TGWLH could be strengthened by reducing intersecting stigmas in healthcare settings and within TGW communities, providing gender-affirming and culturally competent healthcare, addressing psychosocial syndemic conditions, and strengthening support within transgender communities.

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Disclosure statement

No potential conflict of interest was reported by the author(s).

Keywords

Intersectional stigma; syndemics; HIV care engagement; India; resilience; transgender women

Introduction

Globally, transgender women (TGW) experience a high burden of HIV (Poteat et al., 2016). In India, TGW have an estimated HIV prevalence of 3.1–7.5% (NACO, 2016, 2017a), with wide geographic variations (0.5–23%) (NACO, 2016). Since 2004, antiretroviral treatment (ART) has been available for free through India's National AIDS Control Programme and in 2017, India introduced a "test and treat" policy to immediately link all persons newly diagnosed with HIV to ART (NACO, 2017b). Evidence suggests that TGW living with HIV (TGWLH) experience suboptimal HIV care continuum outcomes (Jalil et al., 2017; Kalichman et al., 2017; Pina et al., 2018; Reisner et al., 2016). To effectively implement "test and treat" with TGWLH, it is critical to understand the unique challenges faced by this population in their engagement with India's ART programme.

The challenges faced by TGWLH in accessing HIV care may be understood through complementary theoretical frameworks: (1) the HIV stigma framework (Earnshaw et al., 2013; Reinius et al., 2018; Turan, Budhwani, et al., 2017), which illustrates how HIV-related stigma leads to poor HIV care-related outcomes; (2) syndemic theory (Operario & Nemoto, 2010; Singer & Clair, 2003), which posits that socio-structural forces, including multiple stigmas, lead to co-occurring synergistic epidemics or syndemics of psychosocial health problems affecting care engagement and (3) the gender affirmation framework (Sevelius et al., 2014, 2019), which posits that the lack of or need for gender affirmation influences healthcare-seeking behaviours, including HIV treatment. TGW in India experience rampant discrimination and violence from family, police, healthcare providers and society (Chakrapani et al., 2019; Shaw et al., 2012). Lack of educational and employment opportunities forces some TGW to engage in sex work for survival (Chakrapani et al., 2018; NACO, 2016). Thus, TGWLH face multiple intersecting stigmas based on their gender identity, HIV status, and sex work status, likely influencing care engagement. TGW in India have been shown to experience psychosocial syndemic conditions such as depression, problematic alcohol use and violence victimisation, which in turn increases their HIV risk (Chakrapani et al., 2017; Chakrapani et al., 2019). These syndemic conditions may similarly exist for TGWLH, affecting their engagement with HIV care (Kalichman et al., 2017; Poteat et al., 2016; Sandfort et al., 2019).

The limited data from India show that TGWLH experience barriers accessing ART in public healthcare settings, and face challenges in ART adherence and retention in care (Beattie et al., 2012; Chakrapani et al., 2011). Furthermore, TGW have been shown to have poor access to gender-affirming clinical services, with a lack of qualified healthcare providers (Singh et al., 2014; Srivastava et al., 2021). However, while multiple stigmas likely impact care engagement, limited information is available about how stigmas faced by TGWLH specifically influence HIV care engagement, and what role, if any, gender affirmation plays in HIV treatment engagement. While studies from other countries have shown that

limited access to supportive gender-affirming healthcare undermines TGWLH's engagement with HIV care (Kalichman et al., 2017; Reisner et al., 2017; Sevelius et al., 2014), such information is lacking in India.

We therefore conducted a qualitative study among TGWLH to explore potential pathways between multiple stigmas including discrimination experiences, gender affirmation, syndemic psychosocial health problems, and HIV care engagement.

Methods

Setting and participants

From September to November 2019, we conducted four focus group discussions (FGDs) among TGWLH (two FGDs in Delhi, one each in Mumbai and Hyderabad). Participants were recruited by peer outreach workers of HIV care and support centres, which offer treatment adherence/retention and support services and are managed by community-based organisations (CBOs). Many TGW in these cities have indigenous gender-diverse identities such as *hijra* and *Shiv-Shakti*, and often live together in *deras/gharanas* (clans) with hierarchical social structures – *guru* (master) and *chelas* (disciples) (Chakrapani et al., 2018). To capture diverse experiences, maximum variation sampling (e.g., diverse age groups, indigenous gender-diverse identities, engagement in sex work), a subtype of purposive sampling, was used (Patton, 2015).

Data collection

FGDs were conducted in local languages (Hindi, Marathi, and Telugu) by one or more of the authors, co-moderated by trained peer outreach workers. We developed an interview guide informed by three theoretical frameworks (HIV stigma framework (Earnshaw et al., 2013; Reinius et al., 2018; Turan, Budhwani, et al., 2017), syndemic theory (Operario & Nemoto, 2010; Singer & Clair, 2003), and gender affirmation framework (Sevelius et al., 2014, 2019)). It explored stigma and discrimination experiences related to HIV, gender identity, and sex work status; experience of psychosocial problems (e.g., depression, problematic alcohol use); and perceptions and experiences of how discrimination and psychosocial problems were connected, if at all, to HIV treatment initiation and retention. Each FGD ranged from 60 to 90 minutes. Participants received INR 200 (~2.5 USD) for their time. Interviews were audio-recorded and translated into English for data analysis. All participants provided written informed consent. Institutional Review Boards of India HIV/AIDS Alliance and Albert Einstein College of Medicine as well as India's Health Ministry Screening Committee approved the study.

Data analysis

A codebook was developed based on the aforementioned theoretical frameworks (a priori codes), and from the ideas and constructs identified during data analysis (emergent codes such as legal gender change and its impact on ART access). We used coding and categorising techniques adapted from both framework analysis (Ritchie & Spencer, 1994) and grounded theory approaches (Charmaz, 2014; Corbin & Strauss, 2015). Additionally, we used contiguity-based connecting strategies: a deterministic approach to understand the

cause and consequence(s) of an event or phenomenon by locating the relationships among them in the participants' narratives or among categories (Maxwell, 2012). Illustrative quotes are provided within the main text and in Table 1. The quotes in Table 1 are numbered (e.g., Q1, Q2) in the order in which they appear in the main text.

Results

Participant characteristics

Overall, 30 TGWLH participated in four FGDs. Most participants were either aged 25–30 years ($n = 15$; 50%) or 18–24 years ($n = 11$; 36%), 77% identified as hijras (the rest as “transgender woman”), and 37% ($n = 11$) engaged in sex work. Forty percent ($n = 12$) had completed higher secondary school or had a college degree.

Stigma and discrimination experiences, and their impact on HIV care engagement

Discrimination in healthcare settings—Participants reported several incidents of discrimination from co-patients (Q1), doctors (Q2), nurses and counsellors (Q3). For example, when waiting for an HIV test result, a nurse told a participant, “[You] will be definitely HIV positive ... no need for HIV testing” – a comment highlighting the interconnection between HIV and transgender identity stigmas. Although some participants have had positive experiences with counsellors in ART centres, negative experiences were reported by many, which included a lack of knowledge about TGW and being asked irrelevant questions related to sexual life. For instance, a counsellor at the ART centre asked a participant: “What enjoyment do you get by being a receptive partner?”

Participants reported that very few doctors were both TGW-friendly and culturally and clinically competent (e.g., knowledge about potential interactions between ART and gender-affirming hormones). Most doctors at ART centres, were perceived to be discriminatory – but not necessarily overtly. For example, participants reported that some doctors tried to “keep a distance” (Q2), avoided touching or examining them, and had only brief interactions.

Discrimination within hijra/TGW communities and from birth families—TGWLH reported facing discrimination within their communities due to their HIV status. Participants reported that a person's HIV status could spread as fast as a “wildfire” within *hijra* communities, their key support system. In the study cities, *deras* (place of residence/ house of a group of hijras) or *gharanas* (clans) are generally organised based on the type of work; for example – sex work, *doli-badhai* (performing in ceremonies by singing, dancing and playing drums) and *mangti* (asking money for providing blessings). An HIV-positive hijra belonging to *doli-badhai* or *mangti dera*, could potentially be expelled to protect *dera's* reputation of being “pure” or “divine”, under the assumption that she engages in sex work (Q4). Thus, many TGWLH reported not disclosing their HIV status to even their co-*chelas* (co-disciples). TGWLH engaging in sex work also reported that sometimes other TGW engaged in sex work would out their HIV status to potential male clients (as other TGW perceive they might contract HIV from clients of TGWLH) – affecting their livelihood.

Consequently, these efforts to avoid HIV status disclosure may delay the initiation of and adherence to ART.

Given the high prevalence of both HIV-related enacted and anticipated stigmas, TGW often sought to avoid creating suspicions about their HIV status among peers by skipping medications when visiting peers' homes or when travelling to other cities to attend trans-community events (Q5, Q6). For TGW diagnosed recently, coming to terms with their HIV diagnosis and dealing with associated depression delayed ART initiation (Q7). Participants also described consuming alcohol to cope with depression resulting from a lack of support from their birth families and societal discrimination (Q8). Thus, discrimination experiences contributed to psychosocial syndemic conditions (e.g., depression and alcohol use) and subsequently ART initiation and non-adherence.

Unmet gender affirmation needs and HIV care engagement

In ART centres, participants recounted incidents of misgendering by healthcare providers and insensitive comments about their gender by cisgender patients. Within the ART centres, names and gender are recorded on medical forms based on their legal identity card. Thus, some TGW were called by their birth-assigned male names (i.e., deadnaming), which hurt and embarrassed them. Participants also reported that some TGWLH who initially registered in the ART centres using birth-assigned names and who subsequently changed their legal name faced interruptions in obtaining medications due to bureaucracy or delay in changing their names in ART centres. Thus, the unmet need for social and legal gender affirmation (Q10) may likely contribute to care disruptions and disengagement.

TGWLH also reported that they usually do not inform physicians in ART centres that they were on feminising hormones (often prescribed by private medical practitioners), as they did not see relevance in sharing that information with ART physicians who were presumed to have inadequate knowledge about hormone therapy and its interactions with ART. It is possible that concerns about interactions between ART and hormones may impact ART adherence, but none of the participants reported such concerns as they might have received information about the lack of interactions from their peers or non-governmental agencies that link them to ART centres.

Gender affirmation outside healthcare settings from family members (Q11, Q12) and partners also appeared to be important to supporting adherence. For instance, a participant reported that after her husband (also living with HIV) left her for a cisgender woman, she became depressed as she believed that her ex-husband did not accept her as a real woman. Thus, the lack of gender affirmation by partners and family led to depression, potentially interrupting ART adherence.

The role of resilience and support in buffering the effects of stigma on HIV care outcomes

Participants' experiences revealed the presence of resilience at the individual and TGW community levels. At the individual level, resilience was illustrated by several strategies used by TGWLH to adhere to ART: taking medications at night (after household members have gone to sleep), storing ART in unlabelled containers, and telling their *guru* and co-

chelas that the ART were hormone pills. These strategies could also be seen as approaches to protect from HIV status disclosure.

Participants described the TGW community as a resource for resilience, despite also reporting discrimination faced by TGWLH within *hijra* communities. Participants reported that even if a trans-woman disclosed her HIV status to some of the trusted co-*chelas*, these co-disciples often do not out her HIV status to other *chelas* or *guru*. Some TGWLH were also able to form informal support groups within *hijra* communities and supported each other in varied ways: exchanging information about HIV care, accompanying other TGWLH to ART centres, supporting one another for adherence (e.g., using code words to remind taking ART when speaking on phone), and offering emotional and material support for HIV care (Q13). A participant from Delhi stated that some *hijra gurus* supported TGWLH, but most often in secret: “My guru is very supportive. She helps her *chela* in initiating ART. But she asked me not to disclose my HIV status.” Here, the *guru* apparently did not want the prestige or reputation of their *dera* to be affected, especially when *dera* members are not supposed to engage in sex work – another example of intersecting stigma due to both HIV and sex work status. This occurrence also exemplifies how provision of support can co-occur with stigmatisation.

Finally, participants reported receiving support from peer outreach workers (ORWs) employed in transgender-specific community centres (often supported by the Global Fund) or in HIV outreach interventions supported by India’s National AIDS Control Organisation. Peer ORWs helped TGWLH navigate ART centres and provided adherence counselling. For example, when an ART centre staff demanded an identity card to register a participant, an ORW helped her obtain an identity card expeditiously (Q14) and avoided delays in initiating ART.

Discussion

This qualitative study extends the limited literature on how multiple intersecting stigmas, gender affirmation needs, and syndemic conditions influence HIV care engagement among transgender women living with HIV globally and in India. Findings illustrate the processes by which enacted or anticipated stigma experiences related to gender identity, HIV, sex work, and unmet gender affirmation needs (e.g., misgendering, lack of transgender health competency) in healthcare settings pose challenges to HIV care engagement (Figure 1). Results also showed that discrimination experiences or lack of gender affirmation contributed to the production of inter-connected psychosocial syndemic conditions such as depression and alcohol use, which in turn potentially affects ART adherence and retention in care. Our findings also demonstrate the utility of a novel combination of theoretical frameworks (a modified Earnshaw’s HIV stigma framework, gender affirmation framework, and syndemic theory) in explaining HIV care disengagement among TGWLH in India (Figure 1).

Intersectional stigma, syndemics production, and HIV care engagement

This study found the presence of multiple intersecting stigmas among TGWLH – transgender identity stigma, HIV-related stigma, and sex work stigma – similar to the

intersectional stigma reported in studies among TGW from other countries (Lacombe-Duncan, 2016; Logie et al., 2019). Our findings showed that within TGW communities, TGWLH experienced discrimination. Consequently, fear of discrimination from the TGW community, sometimes their only source of support, also prevents TGWLH from disclosing their HIV status and contributes to delayed ART initiation or non-adherence. We also found that the support offered to TGWLH by the closely-knit, although hierarchical, hijra communities could potentially counter the effects of transgender identity and sex work stigmas – thus, serving as a resilience resource (Woodward et al., 2017).

In line with Stall et al.'s syndemics production model among gay men (Stall et al., 2008), we found that psychosocial syndemic conditions such as depression and problematic alcohol use can result from cumulative experiences of discrimination in healthcare settings and from TGW communities (Figure 1); future research is needed to explore these pathways in detail. Other studies too have reported associations between discrimination experiences, depression, and problematic alcohol use among TGW (Lacombe-Duncan et al., 2019; Nemoto et al., 2011). Similarly, the present study's finding that syndemic conditions (e.g., depression and problematic alcohol use) can lead to ART non-adherence or HIV care disengagement is consistent with the results from diverse settings (Glynn et al., 2019; Kalichman et al., 2017; Lacombe-Duncan et al., 2019). Although not explicitly reported by the present study's participants, constant vigilance in keeping one's HIV status a secret, including hiding antiretrovirals, is likely to be highly stressful – affecting one's mental health (Turan, Hatcher, et al., 2017), and likely influencing treatment engagement.

Gender affirmation and HIV care engagement

We found that lack of social gender affirmation from healthcare providers (e.g., misgendering), unmet need for medical gender-affirmation procedures (e.g., feminising hormone therapy) in public hospitals (Singh et al., 2014), and problems related to legal gender affirmation (e.g., need for legal identity documents for ART registration) were related to delayed ART initiation (Beattie et al., 2012; Chakrapani et al., 2011) or care interruptions (Figure 1). Studies from high-income countries too have identified similar connections between different types of gender affirmation (social, medical, and legal gender affirmation) and HIV care disengagement (Cicero et al., 2019; Sevelius et al., 2019), underscoring the need to offer gender-affirming care to improve HIV care engagement. Furthermore, we found that the lack of social gender affirmation by partners was linked to depression and this may influence HIV care engagement, an area that warrants further exploration.

Role of resilience

Resilience, the process of overcoming the negative effects of adversity and avoiding the negative trajectories, is not necessarily an individual trait, but also operates at interpersonal and community levels (Fergus & Zimmerman, 2005). Our findings showed that, despite its hierarchical nature and associated power dynamics, hijra communities serve as an important source of resilience for TGWLH, especially as most TGW do not have support from their birth families (Chakrapani et al., 2018). The present study's findings showed that *gurus* and *co-chelas* provide financial support and other tangible support like reminders to

take antiretrovirals, and affirm the gender identity of TGW community members. These interpersonal and community-level resilience resources thus seem to partly mitigate the effects of multiple stigmas (from sources outside TGW communities) on ART initiation and retention in care. Our findings are in line with studies from other countries showing that support from TGW communities is an important resilience resource in contributing to better mental health (Puckett et al., 2019) and to access health services (Perez-Brumer et al., 2017). Thus, interventions to enhance support provision from within TGW communities to improve HIV treatment outcomes and the overall wellness of TGW are likely to be effective and efficient, and merit further evaluation.

Limitations

This study has several limitations. We used a purposive sample of TGWLH recruited from urban CBOs that provide HIV-related services. TGWLH not associated with CBOs and those in rural areas may experience a different set of barriers to HIV care than did those in our sample. Future studies would also benefit from conducting in-depth or key informant interviews with healthcare providers and trans-community leaders, providing source and methods triangulation (Denzin & Lincoln, 2018). Future studies on HIV care engagement among TGW also need to consider including additional subgroups of TGWLH (e.g., those not in HIV care, those in rural areas) using longitudinal mixed methods approaches to better understand potential causal pathways we found between multiple stigmas, gender affirmation needs, psychosocial syndemic conditions, and ART initiation and retention in care.

Conclusion

We found that stigmas related to gender identity, sex work, and HIV status either alone or in combination directly or indirectly (through the production of one or more psychosocial syndemic conditions) contribute to delayed ART initiation and care disengagement among TGWLH. Unmet social, medical and legal gender affirmation needs also negatively influence retention in HIV care. Improving HIV care engagement efforts among TGWLH could be efficiently strengthened with interventions to reduce multiple and intersecting stigma at healthcare and transgender community levels by: incorporating screening for and addressing psychosocial syndemic conditions in existing individual-level HIV care interventions; providing gender-affirming and non-discriminatory culturally and structurally competent care in healthcare settings (Metzl & Hansen, 2014); and fostering resilience by increasing support from and solidarity within transgender communities in India.

Acknowledgements

The authors wish to thank the transgender women site leaders and peer outreach workers in Delhi, Mumbai, and Hyderabad; India HIV/AIDS Alliance's Gender and Sexuality team; and Vihaan Care and Support program teams for their support.

Funding

This work was supported by the United States National Institutes of Health (NIH) grants R21MH118102 and P30AI124414, National Institute of Allergy and Infectious Diseases, National Institute of Mental Health.

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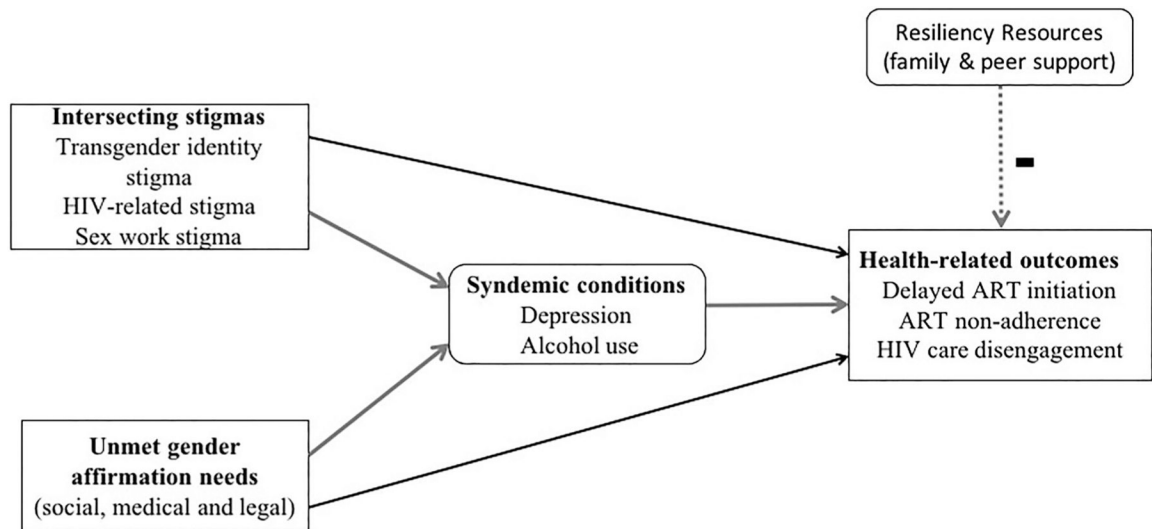


Figure 1. Pathways between multiple and intersecting stigmas, unmet gender affirmation needs, and HIV care engagement among transgender women living with HIV in India: A conceptual model. (Note. Resilience decreases the chances of negative health outcomes).

Additional illustrative quotes highlighting discrimination experiences, gender non-affirmation, and resilience among transgender women living with HIV (TGWLH) in India.

| Domain | Illustrative quotes |
|--|--|
| Discrimination in healthcare settings | <p>Q1: A woman standing in the queue in the ART centre asked me. “You are neither a man nor woman ... how did you get the disease?” I told her that when I was getting operated I got it through blood transfusion. I could not tell her the fact [engagement in sex work]. (TGWLH, Hyderabad)</p> <p>Q2: Even doctors in the hospital keep a distance from us while talking with us. People start staring at us while we are standing in the queue and ask a lot of questions regarding our gender identity and HIV status (TGWLH, Delhi)</p> <p>Q3: A main reason for discontinuing ART is the behaviour of counsellors and the nurses there. They don't have knowledge of transgender people ... and they ask weird questions to us. Even LT (lab technician) ask us about the number of partners. Others [co-patients] start staring and used to give bad look at me. (TGWLH, Delhi)</p> |
| Discrimination within hijra/transgender communities | <p>Q4: When I was diagnosed with HIV, I went into depression because of the fear of discrimination. But after some time, I started ART without informing anyone in the <i>dera</i>. One day, a community member saw the medicine in my bag, and she informed <i>guru</i>. Thus, I had to leave that <i>dera</i> ... my only source of support. (TGWLH, Delhi)</p> |
| Fear of discrimination and non-adherence | <p>Q5: Once there was a function called [X] in my <i>dera</i>, so we have to go out for about 5 to 10 days to attend it. So, we have to quit medicines at that time because if we take any kind of medicine then everyone starts asking us a lot of questions. (TGWLH, Delhi)</p> <p>Q6: If someone is in <i>dera</i>, then they face a lot of problems in continuing their ART because [those living with HIV] are not allowed in <i>deras</i>. There is a function called “roti” in our <i>dera</i>, so we have to go out for about 5 to 10 days to attend it. At that time we have to quit our medicines because if we take any kind of medicine then everyone starts asking us a lot of questions. (TGWLH, Delhi)</p> |
| Depression and delay in ART initiation | <p>Q7: First, they did the test and the doctor said that the report would be given the following day. I didn't go the next day. But my friends called me and told me that I was HIV positive. But out of fear I didn't go. I didn't show have interest to visit the doctor. I was in a feeling that I wanted to die. After some days other people of my community encouraged me. That helped me in overcoming that feeling of depression. Later, in the [community agency] office counsellor madam counselled me ... Then I started using tablets. (TGWLH, Hyderabad)</p> |
| Discrimination contributing to depression and alcohol use | <p>Q8: We drink alcohol because of the problems faced from the clients at the [sex work] site. Some of us think that if they drink then they can face the persons who misbehave with them at the [sex work] site ... To get rid of depression and stress, we take alcohol. (TGLWH, Mumbai)</p> <p>Q9: Once I was in the ART center ... Even doctor did not do the check-up properly. Then I was totally depressed and had negative thoughts in my mind (TGWLH, Delhi)</p> |
| Unmet gender affirmation needs: Family and societal non-acceptance or acceptance | <p>Q10: To file the [police] case, they have to write our name, my name is [xxx] but they ask what is your “alias” name, what was my previous name, in my aadhar card my name is [chosen name], my gender is transgender, my profession is clapping hands and begging, even then they will ask like that ... we face discrimination every second. (TGWLH, Hyderabad)</p> |

Domain

Illustrative quotes

Q11: Family is not accepting us at all because of the society. They start questioning to us like what the society and relatives would say, how will you get married? My friend's family know about my identity as hijra [but not her family], but they pressured me to change myself. I don't want to leave my family, so I have to hide my identities - both gender identity and HIV status - from others because of our family.

(TGWLH, Mumbai)

Q12: My family support me a lot. Because they love me a lot. And supported me at every stage of my life. They understand my feeling. They also know about my gender identity and HIV status. Even then, they helped me a lot.

(TGWLH, Mumbai)

Q13: When someone in our community is sick, she might be HIV positive or negative, we will all collect money and give them that money. We started this in the [name of the area] and we helped at least 2 or 3 people. Once [name of the person] was not provided proper care in government hospital. So, she went to the private hospital and we supported her (financially). We didn't ask for support from others, we all contributed.

(TGWLH, Hyderabad)

Resilience and peer support

Q14: That outreach worker [a transgender woman] used to have good connections with many officials. An hijra was asked to provide her [identity] card for registration in ART center. We did not know how she [outreach worker] did it but she could get a card next day itself.

(TGWLH, Delhi)