

Exploring the barriers for eye care among transgenders and commercial sex workers in Pune, Maharashtra

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Purpose: To explore all possible barriers faced by transgenders (TG) and commercial sex workers (CSW) in accessing eye care in Pune city in western India. **Methods:** This qualitative study was conducted at a tertiary eye care center in Pune. Interview topic guides for face-to-face interviews and focused group discussions were developed. Comprehensive eye check-up was organized in the residential localities of TG and CSW communities in Pune. Those with severe visual impairment or blindness were identified. A sample of TGs and CSWs from this group was purposively selected and invited to participate in this study. Face-to-face interviews were conducted with each TG and CSW. A group of health care providers and NGO workers serving these communities were invited to participate in focused group discussions. All interviews/discussions were audio recorded, transcribed, and translated into English. A qualitative software (N vivo 12, QRS International, Australia) was used to identify various themes and subthemes under each domain of barriers. **Results:** A total of 24 people (6 each from TGs, CSWs, health care provider, and NGO worker groups) participated in this study. The most common barriers reported were social stigma, discrimination, poverty, financial exclusion, and mental health factors. Non availability of gender-neutral facilities in clinics was a unique barrier reported by TGs. **Conclusion:** Marginalized communities of TGs and CSWs in Pune face several previously unexplored and unique barriers for access to eye care despite the availability of services in the vicinity.

Key words: Barriers, commercial sex workers, eye care, transgenders

Good health and well-being is one of the sustainable development goals (SDGs) identified by United Nations Development Programme (UNDP) in 2015.^[1] In 2014, World Health Organization (WHO) adopted a “global eye health action plan 2014–2019” to ensure universal eye health coverage globally.^[2] Barriers faced by certain sections of society are an important reason why wide coverage of universal eye care is difficult to achieve in India.^[3–5] Apart from financial barrier which is perhaps the most common, other personal factors such as gender, family size, and rural/urban residence and service related factors such as cost, waiting list, and distance have been found to influence the utilization of eye services in India and some other low- and middle-income countries.^[5–9]

Marginalized communities often face manifold barriers compared to the general population when it comes to accessing health care.^[7,8,10] Transgenders (TGs) and commercial sex workers (CSWs) comprise stigmatized groups in India. There have been studies from different regions of the world reporting unique problems faced by TGs and CSWs in accessing health care.^[11–17] However, there have been very few studies from India focusing on CSWs^[18] and none so far on TGs. Despite efforts to reduce the prevalence of blindness, barriers to access for eye care among TGs and CSWs may have remained unique and unchanged. This

study to identify barriers faced by TGs and CSWs in accessing eye care was carried out in Pune, Maharashtra. Pune city is an educational/industrial hub and has a significant proportion of migrant population. There are several local and international NGOs working to improve living and health conditions of TGs and CSWs. To the best of the authors’ knowledge, this is first such study undertaken for this group in India.

Methods

This qualitative study was undertaken between December 2017 and December 2018 and adhered to the tenets of the Helsinki protocol. Institutional ethics committee approved this study.

An interview topic guide (ITG) was developed for in-depth interviews and a semi-structured questionnaire for focus group discussions (FGD). These were made and pretested by a group of ophthalmologists and public health specialists using both deductive and inductive approaches,^[19] where some pre-identified domains (social, mental health, attitude and beliefs, finances, etc.) were included in the questionnaire and a scope to identify previously unexplored domains was kept open.

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Sample selection

Purposive sample of TGs and CSWs with severe visual loss/blindness was identified through comprehensive eye check-up camps organized for them in their residential areas. Health care professionals (HCPs) and Non-governmental organization (NGO) workers serving these communities were identified with the help of local community leaders [Fig. 1]. After explaining the purpose of this research, potential candidates were invited to participate and written informed consent was obtained before face-to-face interviews for TGs/CSWs and for FGDs for HCPs and NGO workers. Face-to-face interviews/FGDs were conducted in local language (Marathi/Hindi) ensuring the privacy of the participant/s. For the participants not knowing any of the local languages, an experienced NGO volunteer worked as a translator. An experienced medical social worker attended interviews and took field notes/offered support if needed.

Interviews/discussions were recorded in a digital audio recorder ensuring complete confidentiality of the participants' personal data. Recorded interviews were then transcribed into the local language before being translated into English. Two investigators translated interviews separately to ensure validity. A qualitative data management software (NVivo12, QSR International, Microsoft, USA) was used for data management.

All the TGs/CSWs with severe visual impairment (SVI)/blindness were offered free treatment/rehabilitation irrespective of their participation in the study.

Results

Overall 326 people were screened and 19 (9 TGs and 10 CSWs) were found to have SVI/blindness. Similarly, a group of 21 HCPs and NGO members who were working for these groups in the locality were identified. A total of 24 participants could be enrolled for interviews/FGDs. Table 1 shows characteristics of the selected sample. None of the TGs and CSWs were educated beyond primary school; one-third (4/12, 33.3%) were illiterate.

Both, TGs and CSWs, reported several (including few previously unidentified) barriers despite the availability of eye care centers in the vicinity. This was confirmed through FGDs among HCPs and NGO workers. The barriers are reported below.

Attitude/beliefs

Social stigma

Most TGs expressed apprehension of visiting crowded public health facilities due to the fear of facing discrimination at the hands of HCPs. Nearly all said they were forced to go to private doctors and had to pay out of pocket for eye care.

"We don't get proper respect in government hospital. They don't care. They don't listen to our complaints. Hence, we go to private clinics." (11.4.1.2) (60-year-old TG)

Most CSWs said they had to hide their identity from doctors to save themselves from discrimination.

"My doctor said I may have a diabetes-related eye problem. I am scared of visiting an eye hospital. What if they come to know what I do for a living?" (2.3.1.3) (55-year-old CSW)

All the HCPs and NGO workers felt that social stigma is one big barrier preventing them from going to eye care centers.

"The way society looks at them simply prevents them from going to a doctor. They often face insulting behavior." (24.8.1.1) (53-year-old HCP)

"Yes. Bias is not only prevalent in society, but also among some doctors. So they do think hundred times before seeking care." (15.9.1.1) (35-year-old NGO)

Community attitude

When asked about interaction with the community, nearly half of the CSWs said that they were ill-treated by people in the neighborhood.

"They treat me very badly, keep cursing me. They give me bad names, when I step out of the house because I was a prostitute." (6.11.1.1) (65-year-old CSW)

Many NGO workers felt that the situation of CSWs and TGs in villages was far worse.

"In rural areas, there are neither NGOs nor good hospitals. To add to that, social stigma is worse. The female sex workers there are usually hidden sex workers. Such women often hide their health issues. They either go for self-medication or to a quack." (22.13.1.1) (37-year-old NGO worker)

Several NGO volunteers expressed concern about disrespectful behavior of HCPs towards CSWs and TGs. Some reported higher fees were charged and that sexually harassment by HCPs had been reported.

"There have been few incidents when doctors have abused them, after knowing that they are sex workers." (21.4.1.2) (41-year-old NGO worker)

Superstitions

One NGO volunteer mentioned the myths and superstitions that are prevalent in rural areas.

"In rural areas, these CSWs and especially TGs have so many myths. If someone falls ill, they think it is a black magic and worship Gods and Godmen (instead of visiting a doctor)." (21.18.1.1) (41-year-old NGO worker)

Table 1: Characteristics of study participants

Type of participant	n	Gender			Age (range in years)	Work experience (Range in years)
		M	F	Other		
Commercial sex workers	6	0	6	0	47-65	NA
Trans genders	6	0	0	6	39-60	NA
Health care professionals	6	4	2	0	32-65	7-35
NGO workers	6	1	5	0	34-59	2-21
Total						

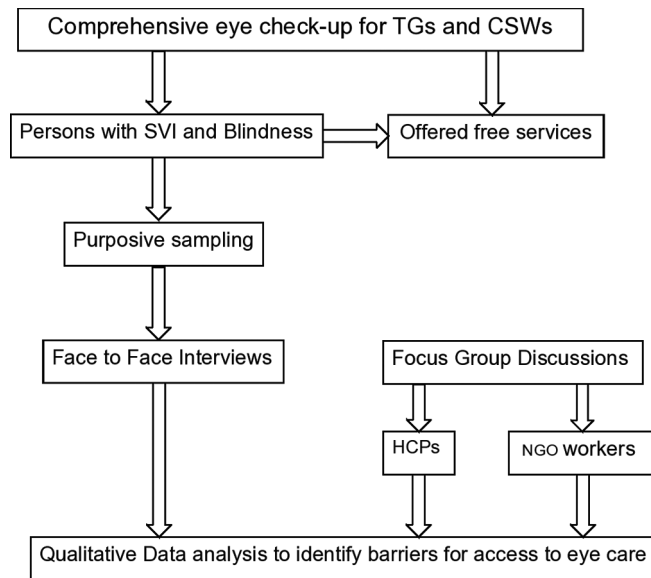


Figure 1: Methodology of the study

Financial factors

Poverty

All TGs and CSWs reported living in poverty and facing huge financial challenges.

None of the TGs had a job or a fixed source of income. Almost all of them had to either beg or engage in sex work in order to earn a livelihood. Seeking eye care was a secondary concern for some.

"I have no time (to go to eye doctor). We have to roam here and there begging for money." (12.13.1.1) (40-year-old TG).

Commercial sex workers had similar experiences to share.

"I don't have enough money to eat or pay the rent of my house (let alone pay for my eye problem)." (2.6.1.3) (55-year-old CSW)

"Money is the only problem which is preventing me from getting operated." (3.6.1.4) (47-year-old CSW)

Some CSWs reported having financial burden of supporting their poor families in other states, while hiding their livelihood means.

"I send money to my brother and his family living in our village in Karnataka. They don't know about my work." (3.6.1.5) (47-year-old CSW)

Financial exclusion

Every NGO worker felt that poverty and financial exclusion is the most important reason why TGs and CSWs do not access eye care.

"They don't have bank accounts; they are excluded from the banking system. After demonetization, they couldn't safeguard their money. All their savings were in cash." (19.7.1.6) (40-year-old NGO worker)

Environmental factors

Language barrier

Some CSWs were trafficked from outside the state/country at a very young age and did not know the local language. One CSW

reported that she was brought from Assam (northeastern state) at the age of 17 and did not go to eye doctor for her problem because she could not communicate with him.

"I did not go because I don't know anyone here. I don't know their language and they don't understand mine." (4.9.1.1) (64-year-old CSW)

One health care professional also identified this as another important barrier.

"Most of them are from east/south India and have never been allowed to learn Marathi/Hindi. This prevents them from visiting a doctor." (14.12.1.1) (49-year-old HCP)

Lack of legal status

Many HCPs and NGO workers reported that often CSWs and TGs involved in sex work were not allowed to go out by brothel owners and the fact that commercial sex work is illegal in India means this group is disempowered when it comes to daily life decisions.

"Many times, seeking treatment is not in their hands. Unless the (brothel) owner gives permission and money, they cannot meet any doctor." (15.6.1.1) (52-year-old HCP)

Mental health factors

Depression

When asked about any anxiety/worries, all the CSWs admitted to being in deep distress/depression. Most TGs and CSWs reported being "disowned" by their families and lack of emotional/financial support from them.

"When I think about my life, I feel like running away or consuming poison (starts sobbing). My life is meaningless. (Weeps uncontrollably)" (2.10.1.1) (55-year-old CSW)

"I feel miserable looking at my past. But cannot change anything. I feel depressed at the way people treat me." (6.10.1.1) (65-year-old CSW)

More than half of the TGs reported suffering from depression and felt that emotional conflicts were far too overpowering for them to access eye care services.

"Yes, it (depression and diabetes) does affect me and I don't feel like going to a doctor. People say nasty things to me. I get disheartened. Sometimes I feel like committing suicide." (8.16.1.1) (60-year-old TG)

All the NGO volunteers felt that most CSWs and few TGs face psychological issues and need care.

"Yes. Many of the CSWs have tried committing suicide. They suffer from depression and have negative thoughts about life." (23.9.1.1) (59-year-old NGO member)

Addictions

Few NGO workers reported that substance abuse makes CSWs and TGs vulnerable to indulging in risky behavior and not seeking eye care on time.

"Most of them have addictions. Alcohol, smoking, and tobacco chewing are very common among them. They develop diabetes/liver issues/HIV very commonly." (21.1.1.1) (41-year-old NGO worker)

"These people spend a lot on their vices such as alcohol, smoking, etc., due to which their finances are always tight." (20.17.1.1) (53-year-old NGO member)

Systemic challenges

Gender specific challenges

This barrier was unique to TGs. Some reported that they find it hard to even register for health care due to option of only two (male/female) genders in some hospital systems. There is no third option in some hospitals/clinics.

One TG reported not being able to get operated for cataract due to lack of a separate stay facility.

“There are only male or female wards in the hospital. Where do people like me stay? Other patients would abuse me. Therefore, I am avoiding cataract surgery.” (8.16.1.1) (60-year-old TG)

Awareness

All the TGs/CSWs were aware of their eye diseases and availability of treatment. However, few NGO workers reported that in rural areas, awareness about eye health was very poor among TGs/CSWs.

Discussion

Barriers to eye care such as poor awareness, cost, fear, distance, etc., have been reported from India and other countries in the past.^[5-9] Most often, the barriers are reported for specific population groups such as poor/remote rural communities, children, etc., There are several vulnerable groups in the urban areas who may find accessing care difficult despite availability of services. Population subgroups such as rural residents, low-income group, women, persons with disabilities, ethnic minorities, and refugees are reported to be facing difficulties in accessing eye care.^[20] However, barriers faced by relatively smaller and marginalized communities such as TGs and CSWs have not been explored before. These are likely to be unique and sometimes insurmountable. The complex and intermingled nature of the barriers may make them difficult to elicit in a quantitative manner. Hence, a qualitative approach was adapted.

Pune is one of the largest metropolitan regions in western India with the presence of around 600 ophthalmologists (80% private sector, 15% NGO sector, 5% public sector) (Personal communication). There is a red-light area in the city where a large population of TGs and CSWs resides.

One of the most common reasons for not accessing eye care, cited by several study subjects, was negative attitude of not only the community but also of some HCPs towards them. Commercial sex workers have no legal status in India. Similarly, the movement for the rights of lesbian, gay, bisexual, transgender, queer (LGBTQ) community has only recently acquired momentum after article 377 was nullified by the supreme court of India in 2018.^[21] Social stigma and discrimination came to the fore as important barriers to access eye health services for both TGs and CSWs. Discrimination and abuse have been reported by TG and CSW community from various countries including from high-income countries.^[12-16,18,22] Such experiences and compounding challenges may make their life difficult in navigating daily life situations including their access to health. A study from India^[18] to assess effectiveness of community-based caregivers to address mental health problems of the CSWs reported that about half of them had depression and poor health-seeking behavior. In the present study too, several participants confessed about having mental health issues which

made their life miserable and perhaps affected health-seeking behavior. Other experiences reported in the present study were higher fees for services and even sexual harassment at health care facilities. These findings were validated by NGO workers too. Illegal status and social stigma make TGs/CSWs vulnerable and unable to take a stand. A prolonged behavior change campaign is necessary to transform prevalent attitudes in order to achieve free access to eye care services for this group. Role of NGOs and support groups to raise awareness about basic human rights of this group is crucial for removing this attitudinal bias. Superstitions among TGs were reported by few NGO workers. Better education/work opportunities and integration into society can abolish superstitions among them and prevent them from going to quacks.

Extreme poverty and worry about day-to-day survival was another significant barrier and it dominated decision making when it came to accessing eye care services in this group. “Cost of services” as a barrier has been reported in general population in several previous studies.^[5,9] Several participants in the present study too had to remain visually impaired for fear of losing income or due to lack of money. Exclusion from the banking system was a unique factor perhaps reported for the first time for TGs/CSWs. This was less likely to be a systematic exclusion. Factors such as low education, lack of legal documents, discrimination, and general disempowerment might be responsible for this. Being dependent only on cash transactions makes them vulnerable to financial losses. There needs to be an active effort to ensure financing for eye care services and financial inclusion for this group. Recently launched universal health scheme^[23] by the government of India and National program for control of blindness (NPCB)^[24] do have financing for various eye care services. Social organizations can help increase awareness about this and help them access this financing.

Language barrier, illegal status, and several mental health factors were also reported in this study. Coordination between NGOs and “law and order agencies” is essential to help CSWs and TGs overcome these barriers and access eye care freely. Depression and addiction were also reported very common among CSWs and TGs. Larger underlying issues such as human trafficking, exploitation by handlers, social/emotional isolation, lack of family/systemic support, etc., are likely to be at the root of this. Support groups, NGO workers, and community leaders can help establish linkages with interpreter, psychologists, psychiatrists, and legal services to minimize barriers and improve utilization of health care services.

One unique barrier reported by TGs was the unavailability of gender-neutral facilities in hospitals. Expensive private room services are difficult to access for most TGs. This brings out an important fact that gender-nonconforming communities find it difficult to use public facilities. Creation of awareness about this unique need and development of inclusive and equitable infrastructure in hospitals is necessary for better access to eye care.

There is a strong correlation between education level and health-seeking behavior.^[25] Lack of awareness about eye health which was reported by some NGO workers can be explained by low educational status among participants.

Although this study focused on eliciting barriers for access to eye care, the findings of this study are likely to be

applicable to wider issues of access to health, education, and basic human rights of CSWs and TGs. For them, the barriers to access any of the above could be similar to those elicited in the present study. A long drawn campaign to bring about much needed social reforms where there is no discrimination based on a person's social/professional/gender identity is what is needed. Public-private partnership can indeed bring about changes gradually through several interventions such as awareness activities, behavior change campaign, inclusion of and discussion on these issues in school education programs, legislative approach to curb discriminatory practices, provision of social/legal services to CSWs/TGs, referral linkages for health issues, etc., Although such social reforms might take several decades to show impact, this study is a good start to planning such interventions.

Small sample size and lack of representation of TGs/CSWs from rural area are some of the limitations of this study due to which some barriers might have remained unexplored. A sustained behavior change campaign and providing health insurance are needed to mainstream TGs/CSWs, improving their access to eye care.

Conclusion

In conclusion, our study expounded many intermingled barriers such as social stigma, exploitation, poverty, mental health factors, language, lack of family support, and financial exclusion which were specific to TGs/CSWs.

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Conflicts of interest

There are no conflicts of interest.

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