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HEALTHCARE NEEDS AND PERCEPTION OF HEALTH SYSTEM RESPONSIVENESS IN LGBTQIA+ COMMUNITY IN INDIA: A SURVEY BASED CROSS SECTIONAL STUDY

Public Health

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ABSTRACT

Background: Lesbian Gay Bisexual Transgender Queer Intersex Asexual+ (LGBTQIA+) community faces health disparities because of social stigma, discrimination, denial of civil and human rights. On the basis of their sexual orientation and/or gender identity, they face barriers to healthcare access. Healthcare professionals who have little knowledge about the LGBT community can lead to poor health care of the community. The discrimination faced by them increases the risk of poor mental and physical health. Thus, a 'queer-friendly healthcare for all' is the need of the hour. **Objectives:** The objective of this study was to evaluate distinct healthcare needs and barriers to healthcare among LGBTQIA+ community and analyse the perceived health system responsiveness in the LGBTQIA+ community. **Materials and methods:** Using social media, cross-sectional survey was conducted. Respondents were directed to an online questionnaire-based Google form. Respondents 18 years of age or older who self-identified to belong to LGBTQIA+ community participated in this study. **Results:** A total of 253 participants were involved in the study. We found out barriers to come out, and unique healthcare problems affecting mental health, sexual health and physical health among LGBTQIA+ community. We also found that there were barriers to access healthcare and according to them, health system is unresponsive towards the LGBTQIA+ community and there face significant health disparities. **Conclusion:** There is a need for sensitization of the healthcare providers towards the needs of LGBT community. The study also identifies the first step (identification) on the long path to acceptance of the diversity and variegated hues that nature has created. Progressive and inclusive realization of social rights and right to privacy embracing all and to start a dialogue is necessary for ensuring equal rights and opportunities for "less than equal" sections of the society.

KEYWORDS

Healthcare responsiveness, barriers to access healthcare, mental health, health disparities

1. INTRODUCTION:

LGBTQIA+ is an acronym for lesbian, gay, bisexual, transgender, queer, intersex, asexual/aromantic/agender. The acronym, which is often used as a blanket term to refer to the queer community as a whole also includes many other identities such as bigender, crossdresser, drag queen, drag king, demisexual, genderfluid, gender non-confirming, gender queer, non-binary, pangender, pansexual, transsexual, etc. It refers to a broad coalition of people belonging to different genders, sexual orientation, race/ethnicity and socioeconomic status. It first became popular in 1980s when it replaced the term gay to refer all those who do not identify as heterosexual. Since then it has grown to LGBTQIA+, to encompass various other sexual and gender identities. Studies from various nations, conducted at different time periods shows the statistics ranging as 1.2 to 6.8 percent of the adult population identifying as LGBT. [1,2]

In India, there is no demographic evidence regarding the statistics of LGBTQIA+ community. However, the Supreme Court of India recognised that there are 4.8 million transgenders an estimation of 2.5 million gay population.[3]

Research shows that these individuals face health disparities because of social stigma, discrimination, denial of civil and human rights. On the basis of their sexual orientation and/or gender identity they face barriers to healthcare access.[4,5] The explanations of barriers between healthcare professionals and LGB patients are homophobia, assumptions of being heterosexual, lack of information, mis understandings, over-cautiousness; barriers of instituions, inappropriate referrals, lack of patient confidentiality, discontinuity of care,lack of LGBT-specific healthcare, absence of relevant psycho-sexual training.[6,7] Because of these reasons they may avoid or delay visiting health care professionals or may receive improper or inferior care.[8.]

There is a perceived deficiency in healthcare among LGBT people, due to neglected LGBT health training in medical schools.[9] Healthcare professionals who have little knowledge about the LGBT community can lead to poor health care received by the community. This leads to an overall negative experience.

All this leads to minority stress which means they have low self-esteem, fear of discrimination, internal stigma which further adds to health disparities.[10] The discrimination faced by them, stigma, prejudice creates a hostile climate which increases the risk of poor mental and physical health, even for those who are not directly exposed to the discrimination. Thus, most of them approach queer friendly initiatives. Hence a 'queer friendly healthcare for all' is the need of hour.

2. OBJECTIVES:

The objective of this study was to evaluate distinct healthcare needs and barriers to healthcare among LGBTQIA+ community and analyse the perceived health system responsiveness in the LGBTQIA+ community.

3. MATERIAL AND METHODS:

Using social media, a descriptive, cross-sectional survey design was conducted to obtain data on healthcare needs and perception of health system responsiveness in LGBTQIA+ community in India. Respondents were directed to an online survey via an online questionnaire based google form. The questionnaire was formulated based on World Health Organization (WHO) Health System Responsiveness estimation guidelines accessed from the official website.[11] The survey was administered in English. The survey included items on demographic information, health related problems, perceived barriers to health care, and health system responsiveness. Study duration was for 4 weeks.

4. DATA ANALYSIS:

Descriptive analysis was used to summarize participants' demographic data, health related problems, perceived barriers to come out, perceived barriers to healthcare and other responses to the survey questions. Categorical data are presented as number and percentages

5. RESULTS:

A total of 253 respondents 18 years of age or older who self-identified to belong to LGBTQIA+ community participated in this study.

Baseline Characteristics:

The baseline characteristics of study population are shown in table 1.

Table 1: Baseline characteristics of the study population

	N	%age
AGE:		
18-24	200	79%
25-34	46	18.3%
35-44	5	2%
45-54	1	0.40%
GENDER:		
Ciswoman	87	34.5%
Cisman	76	30.2%
Transgender	22	8.7%
Non-Binary	18	7.1%
Prefer not to say	18	7.1%
Gender fluid	16	6.3%
Gender queer	15	6%
WHO DO YOU LIVE WITH:		
Parents	199	79%
Alone	42	16.7%
Relatives	4	1.5%
Partner	7	2.8%
RELATIONSHIP STATUS:		
Single	190	75.7%
Partnered living separately	53	21.1%
Partnered living together	8	3.2%
SEXUAL ORIENTATION:		
Gay	65	25.8%
Lesbian	32	12.7%
Bisexual	63	25%
Straight	19	7.5%
Pansexual	19	7.5%
Queer	27	10.7%
Questioning	10	4%
Genderqueer	3	1.2%
Asexual	7	2.8%
Prefer not to say	7	2.8%
INDIVIDUAL MONTHLY INCOME:		
Student	173	68.7%
Less than 24,999 Rs	45	17.9%
25,000-49,999 Rs	23	9.1%
More than 50,000 Rs	11	4.4%

The largest number of participants were from the age group 18-24 years 200 (79%). Largest gender group in this study sample comprised of ciswoman 87 (34.50%).Sixty five (25.80%) Gay men comprised the largest group of sexual orientation. Most respondents indicated that they were single 190 (75.70%) and those who are in a relationship are living separately 53 (21.10%). Largest number of participants were students 173 (68.70%) and others who were working consisted of those earning less than 24,999 Rs 45 (17.90%), 25,000 -49,999 Rs 23 (9.10%) and more than 50,000 Rs 11 (4.40%). Most of them are residing with their parents 199 (79.00%). (Table 1)

Perceived Barriers To Come Out:

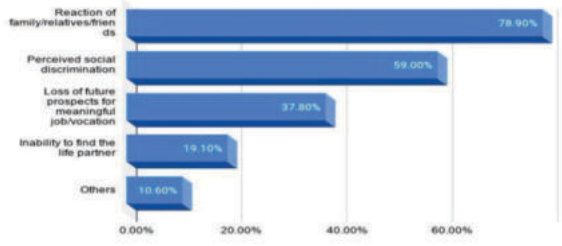

Figure 1: Perceived barriers to come out

Major perceived barriers to come out were reaction of family/relatives/friends (78.9%), perceived social discrimination (59%), loss of future prospects for meaningful job/vocation (37.80%) and inability to find the life partner (19.10%) (Figure 1). Other reported barriers were financial instability in students, laws against LGBTQ community, fear of honor killing, homelessness and abandonment. Few of them 14 (5.5%) also reported that there were no barriers to come out and they were out and proud. (Figure 1)

Health Problems :

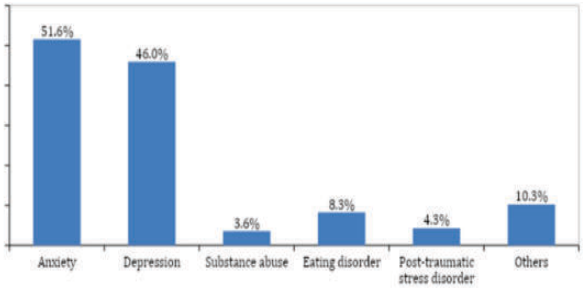

Figure 2: Mental health

Major reported mental health issues in the LGBTQIA+ community were anxiety (51.6%), depression (46%), substance abuse (3.6%), eating disorders (8.3%) and post-traumatic stress disorder (PTSD) (4.3%). Anxiety being the leading mental health issue. Other issues (10.27%) were bipolar disorder, borderline personality disorder, obsessive compulsive disorder, autism, schizophrenia and panic attacks. (Figure 2)

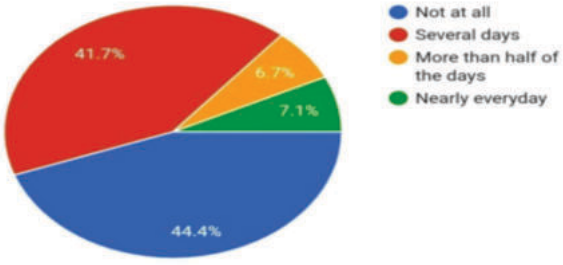

Figure 3: Suicide ideation

More than half of the respondents (n=140, 55.3%) have had thoughts that they would be better off dead or hurting themselves in some way. (Figure 3)

Two respondents (0.8%) suffered from human immunodeficiency virus (HIV) and one respondent (0.4%) reported to have sexually transmitted diseases (STD) (gonorrhea/chlamydia/syphilis).

Twenty one respondents (8.3%) reported to have polycystic ovarian disease and 19 respondents (7.5%) reported to have obesity. Other reported diseases were skin conditions, epilepsy, diabetes, thyroid cancer, hypothyroidism, multiple sclerosis, asthma, vitamin A deficiency, vertigo, spondylitis, endometriosis, migraine, etc. One hundred ninety eight (78.2%) reported that they did not suffer from any disease or physical health relation condition.

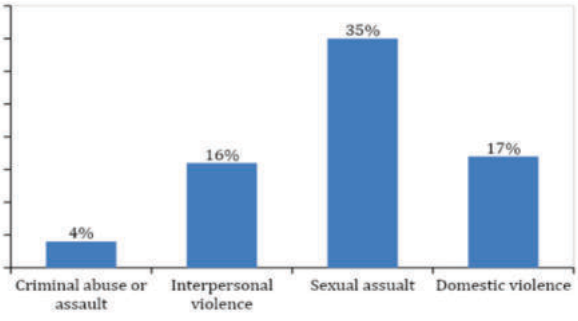

Figure 4: Criminal/Sexual assault, Interpersonal/Domestic violence

Respondents reported to have suffered from criminal abuse or assault 10 (4%), interpersonal violence 41(16%), sexual assault 89 (35%), domestic violence 43 (17%) (Figure 4).

Barriers To Access Healthcare :

Respondents reported numerous barriers to seeking health care, which included lack of personal financial resources, fear of being treated differently if the healthcare personnel finds out that they are an LGBT individual, lack of adequately trained health professionals to deliver healthcare to LGBT people, lack of transportation to get to the services needed, lack of Queer friendly healthcare, lack of psychological

support groups for LGBT community, lack of mental health counsellors (psychologists/psychiatrists/social workers) who can help LGBT community with their mental health issues, etc.

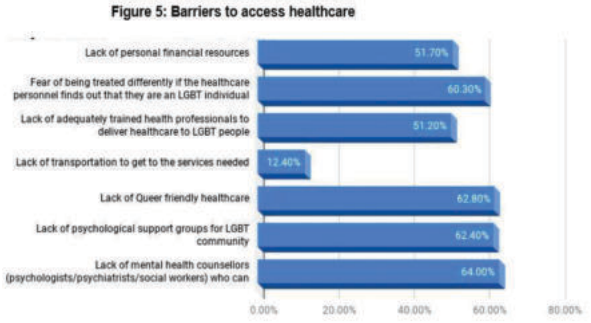

Figure 5: Barriers to access healthcare

More than half of the respondents reported that lack of personal financial resources 125 (51.7%), Fear of being treated differently if the healthcare personnel finds out that they are an LGBT individual 46 (60.3%), Lack of adequately trained health professionals to deliver healthcare to LGBT people 124 (51.2%), Lack of Queer friendly healthcare 152 (62.8%), Lack of psychological support groups for LGBT community 151 (62.4%), Lack of mental health counsellors (psychologists/psychiatrists/social workers) who can help LGBT community with their mental health issues 155 (64%) were the major barriers to access the health care. (Figure 5)

Health System Responsiveness:

Table 2: Health system responsiveness

No.	Question	Yes	No	NA
1.	In the last 12 months did you make an appointment for which you received care right away?	165 (65.2%)	88 (34.8%)	-
2.	Did the health care provider there wish to consult your family about the tests or treatment?	104 (41.1%)	149 (58.9%)	-
3.	At healthcare facilities, is there more than one doctor, nurse or other health care provider you can choose from?	89 (35.1%)	107 (42.3%)	57 (22.6%)
4.	Have you ever avoided/delayed getting admitted to a hospital because of fear of being treated differently/past Experience of the same/misjudgements by fellow patients/ healthcare workers?	57 (22.6%)	128 (50.6%)	68 (26.8%)
5.	Is it a problem to get to use another healthcare service other than the one you usually go to?	111 (43.8%)	73 (28.9%)	69 (27.3%)
6.	Have you ever avoided going to a healthcare facility because of fear of being treated differently or because of past experience of the same?	123 (48.6%)	76 (30%)	54 (21.4%)
7.	If you have come out to your healthcare provider, has the provider treated you differently?	37 (14.6%)	77 (30.4%)	139 (55%)

It was reported that 88 (34.9%) did not receive care right away on making an appointment. 107 (42.3%) reported that at healthcare facilities, they could not choose from more than one doctor, nurse or other health care provider. A total of 57 (22.6%) have avoided/delayed getting admitted to a hospital because of fear of being treated differently/past experience of the same/misjudgements by fellow patients/ healthcare workers.

A total of 111 (43.8%) reported that it is a problem to get to use another healthcare service other than the one they usually go to. One hundred and twenty three (48.6%) reported avoiding going to a healthcare facility because of fear of being treated differently or because of past experience of the same. (Table 2)

Table 3: Health system responsiveness

No	Question	Never	Sometimes	Usually	Always
8.	In the last 12 months, when you went to a healthcare facility, how often did doctors, nurses or other health care providers treat you with respect?	10 (4%)	39 (15.5%)	95 (37.5%)	109 (43%)
9.	In the last 12 months, how often did the office staff, such as receptionists or clerks there, treat you with respect?	13 (5.2%)	45 (17.8%)	88 (34.7%)	107 (42.3%)
10.	In the last 12 months, how often were your physical examinations and treatments there done so the privacy of your body was respected?	27 (10.7 %)	28 (11.1%)	55 (21.7%)	143 (56.5%)
11.	In the last 12 months, how often did doctors, nurses or other health care providers at healthcare facilities listen carefully to you?	11 (4.3%)	46 (18.2%)	86 (34%)	110 (43.5%)
12.	In the last 12 months, how often did doctors, nurses or other health care providers there explain things in a way you could understand?	16 (6.3%)	147 (8.7%)	90 (35.5%)	100 (39.5%)
13.	In the last 12 months, how often did doctors, nurses, or other health providers there give you time to ask questions about your health problem or treatment?	24 (9.5%)	53 (20.9%)	83 (32.8%)	93 (36.8%)
14.	In the last 12 months, how often did doctors, nurses or other health care providers there involve you as much as you wanted to be in deciding about treatment or tests?	23 (9.1%)	58 (22.9%)	79 (31.2%)	93 (36.8%)
15.	In the last 12 months how often did doctors, nurses or other health providers there ask your permission before starting tests or treatment?	29 (11.5 %)	29 (11.5%)	59 (23.4%)	136 (53.6%)
16.	In the last 12 months when you went to a healthcare facility how often did your doctor, nurse or other health care provider keep your personal information confidential (that means that anyone whom you did not want informed could not find out about your medical conditions)?	27 (10.7 %)	31 (12.3%)	59 (23.4%)	136 (53.6%)

In the last 12 months, a total of 144 (57%) reported some deficiency by doctors, nurses or other health care providers in treating them with respect whereas 146 (57.7%) participants reported some deficiency of office staff, such as receptionists or clerks in treating them with respect. According to 110 (43.5%) reported privacy of their bodies was

not fully respected during physical examinations and treatments and 143 (56.5%) reported deficiency in listening to their problems by health care providers. According to 153 (60.5%) there was a deficiency in explaining things in a way they could understand and 160 (63.2%) reported not getting enough time to ask questions about their health problem or treatment and be involved as much as they wanted in deciding about treatment or tests. A total of 117 (46.4%) mentioned that healthcare providers did not always ask for their permission before starting tests or treatment and when they went to a healthcare facility doctor, nurse or other health care provider did not always keep their personal information confidential. (Table 3)

6. DISCUSSION:

There is an emerging awareness about gender identity and it does not merely encompass sexual preferences but also includes development of Human person as a whole. As an indivisible element of the society, the rights of the individuals identifying with LGBTQ community need to be guarded and ensured. This will ensure the exercising of the right to privacy as granted by Indian constitution. To do this we need to first identify the prejudices which we try to do in the sphere of healthcare responsiveness in the present study.

Our study majorly consisted of age group 18-24 years. It seems that acceptance in the Indian community is increasing and is the reason why many young people are identifying themselves as a part of the LGBTQIA+ community and coming out to their parents and friends. Also, social activists and social role models are making it easy for them to accept their identity. Rest of the demographic characteristics point towards the study population being young which comprises the majority of students living with their parents and some are living alone. Largest group in our study sample consisted of a cismen. Out of them 61.8% identified as gay and 18.4% identified as bisexuals. Whereas ciswoman was the second largest group out of which 40.2% identified as bisexual and 23% identified as lesbians.

Most of the participants in our study were single which indicates that they probably have a fear of getting rejected by society because their sexual preferences lead to loneliness.

As per a previous study,[12] lack of familial acceptance and rejection is crucial for health and well-being. In our study we found that there is a lack of parental support, fear of getting rejected by family/ relatives/ friends, fear of losing job opportunities, etc all this affects mental health of these individuals. A review has shown that there is increased prevalence of mental health concerns in the LGBTQIA+ community. [13]

Our study also shows similar findings reporting an increased prevalence of psychiatric conditions like anxiety, depression, substance abuse, eating disorders, Post traumatic stress disorder, etc. These people are at a greater risk of suicidal ideation. Thus, mental health is found to be a major concern in the LGBT population. If not addressed or treated on time, it may lead to worsening of mental health, deteriorating immune system in anxiety patients, loss of appetite, isolation, low self- esteem, suicidal ideation, etc. All these mental health issues are contributed by discrimination, non-acceptance, lack of queer friendly healthcare facilities, etc. In order to improve the health conditions of the LGBT community it is necessary that the discrimination is tackled.

In many cases sexual violence cases may go unreported. We found that in our study sample in the LGBT community alone sexual assaults, interpersonal violence and domestic violence rates were high in our study sample which were consistent with previous studies stating the same.[14]All these factors take a toll on their mental health and are indicators of depression, PTSD, etc.

Studies have shown that these individuals face many barriers to access healthcare which creates a void between healthcare and the community.[15 16 17]A study also highlighted the need of psychiatrist's role in recognizing the individual and the specific needs of this community in order to close the health gap.[18]People from the community face unique health care needs and hence it becomes necessary to dissolve these barriers.[19]

We found that major barrier to access healthcare was lack of mental health counsellors (psychologists/psychiatrists/social workers) who can help LGBT community with their mental health issues followed by lack of Queer friendly healthcare and lack of psychological support groups for LGBT community, fear of being treated differently if the healthcare personnel finds out that they are an LGBT individual, lack of adequately trained health professionals to deliver healthcare to LGBT people. Thus our study findings are consistent with previous research done. This suggests that it makes it difficult for the LGBTQIA+ community to approach and access healthcare. Hence there is an emerging need to bridge the gap between healthcare and the community and make it more accessible to them so that their healthcare needs are met and they feel more comfortable and leave behind their negative experiences about healthcare. This can be achieved by creating a welcoming environment at healthcare facilities for which clear guidelines can be set by involving people from this community and creating awareness amongst doctors and also the staff at the hospital. Displaying brochures, gender inclusive washrooms, wards, having a consent form, etc are necessary to make a healthcare facility queer friendly so that people from community feel included and comfortable. Another barrier found was lack of personal financial resources, thus there should be regulation of insurance policies for this community.

According to us, there is limited literature from India addressing the health system responsiveness towards the LGBTQIA+ community. Previous research has shown significant healthcare disparities in these people. [20]Also, LGBTQIA+ community is one of the least represented communities in health equity research in India. [21]In our study we found that the healthcare system was unresponsive towards the LGBTQIA+ community. People from the community should receive care right away like any other patient and not be discriminated against on the basis of gender, sexual orientation. There should be more than one doctor, nurse or other health care provider to choose based on their comfort level.

Our study sample reported that they have avoided going to a healthcare facility and avoided/delayed getting admitted to a hospital because of fear of being treated differently/past experience of the same/misjudgements by fellow patients/ healthcare workers. This will lead to worsening of health care problems amongst the community. When it comes to visiting another healthcare service they face a difficulty to get accustomed to it. Even if they have come out or they haven't come out to the healthcare provider, it is important to understand that they shouldn't be treated differently based on the fact that they belong to the LGBT community.

Just like any other patient that walks into the healthcare facility they should be treated with the same respect as anyone else and should not be discriminated against based on gender and sexuality.[22]They should be asked for their consent before physical examinations and treatments and privacy of their bodies should be respected. It is important for a healthcare provider to listen carefully to all the complaints and grievances of these patients and address the same. They should be given time to ask questions about their problems and treatments. They should be given treatment options and should be as much involved as well. They should explain things in a way and language they can understand. Respect comes first and it should be seen that all the fellow patients and members like clerks, receptionists and other healthcare providers treat them with the same respect and create a healthy environment for them. Confidentiality about personal information and medical conditions should be maintained. Research has shown that training and education is necessary to have a positive influence in providing LGBTQIA+ care. This training should be incorporated in medical, nursing, dental students as well as providers.[23]

The limitation of our study was that we could enrol a predominantly young population, people who use smartphones, social media like instagram and are able to read English. This represents the educated population belonging to the community and thus generalizability of the findings is weak. There was thus, an inability to reach the most challenging people from the community.

7. CONCLUSION:

The present study shows the necessity of the sensitization of the healthcare providers towards the needs of LGBT community. The study also identifies the first step (identification) on the long path to acceptance of the diversity and variegated hues that nature has created which must be taken now by undoing the wrongs done so as to make way for a progressive and inclusive realisation of social rights and right to privacy embracing all and to start a dialogue for ensuring equal rights and opportunities for “less than equal” sections of the society.

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