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The perceived stigma associated with COVID-19: Findings from a community survey in India

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Abstract

Objective: Stigma related to coronavirus disease 2019 (COVID-19) can be a potential barrier in the prevention of the disease. The current study aimed to measure COVID-19-related stigma among the people of India.

Materials and methods: A cross-sectional online survey was conducted using a semi-structured questionnaire regarding the socio-demographic background and perceived stigma towards COVID-19, using a convenient sampling technique.

Results: A total of 405 responses were received. The respondents' mean age was 25.6 ±8 years with an age range of 18-76 years, and 52.5% were male. Among the respondents: 60 believed that they would be judged negatively by other people if they disclose their COVID status; 59% believed that if the COVID-19 status of a person is reported to their employer, they are likely to lose their jobs;70% reported that they would feel uncomfortable with patients with COVID-19 infection; 67% thought that developing COVID-19 can make them isolated from society.

Conclusion: *Perceived stigma was found in the form of fear of being negatively judged and fear of losing their job after disclosing their COVID-19 status. The study warrants an urgent need for stigma reduction strategies which are focused on education and awareness concerning COVID-19.

INTRODUCTION

Stigma is associated with various medical conditions such as cancer, epilepsy, leprosy, tuberculosis, and HIV-AIDS (Sartorius, 2007).

It is commonly associated with severe illnesses, where the exact cause is unknown or mysterious, the course and prognosis are uncertain and a cure hasn't been discovered. Stigma alters attitudes towards disease and stands as a barrier in the pathway of care (Sartorius, 2007). Stigma is an important issue that stands as a hurdle before social integration. There have been reports of association of stigma with pandemics of influenza, AIDS/HIV, and Ebola infection (Barrett and Brown, 2008; Obilade, 2015; Williams and Gonzalez-Medina, 2011). Stigma is a more contagious phenomenon than any epidemic. Several factors (availability of resources, infrastructure, funding, political motivation, nature of the disease, seriousness of the disease, mode of spread, community support) stand as obstacles in pandemic control. Social stigma often stands as a challenge with controlling pandemics. Preparedness is required to combat the stigma associated with COVID-19 and for the successful control of the pandemic.

Over the past year, novel coronavirus infection (commonly known as COVID-19) has emerged as a global threat as it is highly contagious and results in high mortality. As per the latest World Health Organization (WHO) weekly COVID-19 update (01-03-2021) (WHO, 2021a), there are 114,753,130 confirmed cases and 2,544,452 deaths from 213 countries across the globe. Individuals who are unaware of COVID-19 are likely to have heard myths and be in distress (WHO, 2021b); hence WHO has been releasing daily advisories and accurate information related to COVID-19 (WHO, 2021b, 2020a). People's beliefs and attitudes are often clouded by stigma and misconceptions.

Since disease mechanisms are enigmatic and daunting to the general public, many facts are misinterpreted and incorrectly attributed. Many myths are prevailing among the general public related to COVID-19 (WHO, 2020b, 2020c), which attribute to the development of stigma. The commonly prevailing myths associated with COVID-19 are mostly related to the spread of COVID-19 and protection against it. The myths related to spread of COVID-19 are as follows (WHO, 2021b):

- COVID-19 can spread through mobile networks
- Cold weather favours the spread of COVID-19
- Mosquito bite can spread COVID-19
- COVID-19 affects older adults only
- Personal exposure to high temperatures may be protective against COVID-19
- Holindg your breath for more extended time rules out COVID 19 infection
- Alcohol consumption is beneficial in COVID-19
- Hot and humid climate is protective against COVID-19
- Hot bath protects from COVID-19 infection
- Hand dryers are protective against COVID-19
- Ultraviolet lamps can protect from COVID-19
- Saline and alcohol cleaning of nose and body protects against COVID-19
- Eating garlic protects against COVID-19
- Antibiotics are effective against COVID-19.

Patients infected with COVID-19 have been subjected to blame and scapegoating. To prevent victimisation and stigma, the WHO has issued an advisory message for the general public (CDC, 2020; UNICEF, 2020; WHO, 2020c). The individuals infected with COVID-19 need support and cooperation from society. People should avoid using traumatising and stigmatising phrases such as – "COVID-19 cases", "victim of COVID-19" etc., and should treat them equally as a part of this society. Stigma is not only associated with people infected with COVID-19, it also affects the family members of patients and healthcare professionals treating them, as well as those who have recovered from the infection (Chen et al., 2020; Rao, 2020; Sharma, 2020; WHO, 2020a; Yeung and Gupta, 2020). A recent study among India's educated masses revealed a moderate level of awareness among people related to COVID-19 (Roy et al., 2020).

The government and several other agencies are working to sensitise people about this pandemic. Fake news is getting circulated through the media (particularly social media), which influences the beliefs and perceptions around COVID-19 and causes anxiety among people (Roy et al., 2020).

Worldwide a vast majority of people rely on and accept the advice of religious and spiritual leaders. Considering this fact, the WHO appealed to them to encourage people to adhere to the government initiatives and restrictions for the prevention of COVID-19 (WHO, 2020a). It was also emphasised addressing the issues of stigma, hate and violence (WHO, 2020d). During this COVID-19 pandemic in India, stigma significantly affected migrant workers, healthcare workers, people infected with COVID-19, and those dealing with the dead (Bhanot et al., 2020; Chatterjee et al., 2020; Menon et al., 2020). Suicides were also reported due to COVID-19-related stigma in India (Dsouza et al., 2020). An Indian study on COVID-19 survivors reported a significant amount of enacted and externalised stigma among these people (Dar et al., 2020).

India is a multicultural nation with various belief systems, intermediate literacy levels, geographical diversity, and a comprehensive coverage of various media types. This study attempted to determine the stigma associated with COVID-19 among the general population. The results would help in the formulation of practical targeted and behaviourally oriented measures.

METHODS

Data collection
This cross-sectional survey was conducted after the lockdown of India during the months of May and June 2020. Due to the COVID-19 pandemic and lockdown, we decided to collect the data through online platforms. An online semi-structured questionnaire was developed by using Google forms by the investigators referring to the previous literature (Barrett and Brown, 2008; Dar et al., 2020; Roy et al., 2020; Sartorius, 2007). We used convenience sampling techniques and approached contacts who were willing to participate in the survey. A link was shared on the investigators' social media profiles, which was again reshared by the participants. People of Indian nationality that were aged 18 years or above and who had access to smartphones and the internet were included as respondents. The participants, after clicking the link, first received information about the study and an online informed consent form. After accepting it, they automatically proceeded to the tools of the study. They were instructed to complete the questionnaire by clicking the link. People with an active COVID-19 infection and unable to understand the English questionnaires were excluded. The questionnaire link was sent to the investigators' contacts through emails, WhatsApp and other social media. Participants had to answer a yes-no question to confirm their willingness to participate

voluntarily. After confirmation, the participant was directed to complete the self-report questionnaire. The behavioural and attitudinal components of the questionnaire were in a multiple-choice format and/or on semantic scales. Clear instructions were given to respond to the items. Once the participants had responded to the items, they had to submit the survey by clicking the button, and the data was stored in the cloud. The calculated sample size for the survey was 385. We stopped the data collection at 405 responses. The data were extracted from the a Microsoft Excel spreadsheet and analysed further. Data was analysed using descriptive statistics and presented in terms of percentages, proportions and ratios.

Instruments

- Semi-structured socio-demographic proforma (age, gender, education, marital status, occupation, residence),
- Structured questionnaire to measure stigma associated with COVID-19 pandemic.

Tools

The tools of the study included two main parts, self-declaration about the current COVID-19 status, followed by a sociodemographic proforma that included details about the age, location, employment status and marital status. There was no available tool for assessing the stigma for COVID-19 so we did a rigorous review of literature of the tools that were used in other diseases like tuberculosis,

HIV and AIDS and leprosy (Heymans, 2008; Obilade, 2015; Williams and Gonzalez-Medina, 2011). After that this tool was designed and tried out. Initially after constructing the tool it was tried out on 50 participants and the **reliability** was calculated for internal consistency. The Reliability Chronbach's α of the whole tool was found to be **0.79**.

We decided not to modify the tool anymore and proceeded with the data collection.

Ethical aspects

The Ethics Committee (Letter No.249/ Ethics/2020; dated 13-05-2020) of King George's Medical University, Lucknow, India had approved (Ref. No: 101st ECM IB/P2) study protocol and procedures of informed consent before the formal survey.

RESULTS

We received a total of 405 responses. The respondents' mean age was 25.6 ±8 years with an age range of 18-76 years. More than half (n=213, 52.6%) of the participants were male, the majority of them were educated above the graduate level, and more than half were employed, (n=247) 61% were unmarried, and the majority of the participants lived in the urban areas from different parts of India (Table 1).

The COVID-19 stigma scale consisted of three main sections mentioned as disclosure concerns, anticipated

Table 1: Socio-demographic profile of the participants (N=405)

Serial Number	Variable	Value		
1	Age	Mean age		25.6 ±8 years
		Attribute	Frequency	Percentage
		Male	213	52.6%
2	Gender	Female	191	47.2%
		Other	1	0.2%
		High-school	10	2.5%
		Graduate	176	43.5%
3	Education	Postgraduate	123	30.4%
		Professional	83	20.5%
		Others	13	3.2%
		Employed	215	53.1%
		Unemployed	26	6.4%
4	Employment status	Student	153	37.8
		House-wife	5	1.2%
		Others	6	1.5%
		Married	154	38%
5	Marital Status	Unmarried	247	61%
		Others	4	1%

<p align="center">Table 2: Perceived stigma regarding the COVID-19 pandemic (N=405)</p>

Sl.	Domain	Item	Yes	No	Maybe	Relative Importance Index (RII)
1	Disclosure concerns	Are you worried to disclose your COVID-19 status with anyone, if you develop the infection in the future?	68 (16.8%)	292 (72%)	45 (11.1%)	0.482305
		Are you worried to disclose your COVID-19 status with anyone if you develop the infection in future and recovered subsequently?	64 (15.8%)	298 (73.6%)	43 (10.6%)	0.474074
		Are you worried to disclose the COVID-19 status of a family member if they developed the infection in the future?	80 (19.7%)	284 (70.1%)	41 (10.1%)	0.498765
		Do you believe telling someone that you have COVID-19 is risky?	185 (45.7%)	181 (44.7%)	39 (9.6%)	0.669959
		Do you worry that people may judge you when they hear you have COVID-19?	167 (41.2%)	161 (39.7%)	77 (19%)	0.671605
2	Anticipated stigma	Do people affected by COVID-19 lose their jobs when their employers find out?	103 (25.4%)	166 (41%)	136 (33.5%)	0.614815
		Are people affected by COVID-19 treated like they are a public nuisance?	114 (28.1%)	203 (50.1%)	88 (21.7%)	0.593416
		Do people feel uncomfortable around someone affected by COVID-19?	277 (68.4%)	69 (17%)	59 (14.5%)	0.83786
		Do people think that a person affected by COVID-19 is disgusting?	74 (18.3%)	259 (66.4%)	72 (17.7%)	0.514403
3	Internalised Stigma	Will you feel guilty if you have COVID-19?	81 (20%)	264 (64.2%)	60 (14.8%)	0.516049
		Will you feel you are not as good as others if you had COVID-19?	91 (22.5%)	249 (61.5%)	65 (16%)	0.536626
		Will you feel embarrassed if you develop COVID-19?	86 (21.2%)	268 (63.7%)	51 (12.5%)	0.516872
		Will having a COVID-19 infection make you feel unclean?	92 (22.7%)	241 (60%)	72 (17.7%)	0.544033
		Will you feel set apart and isolated from the community if you have COVID-19?	272 (67.1%)	81 (20%)	52 (12.8%)	0.823868
		Will having COVID-19 make you feel that you are a bad person?	28 (7%)	352 (87%)	25 (6%)	0.4

stigma, and internalised stigma. They were scored separately on the scale (Table 2).

Disclosure concerns

This subscale has five items. Regarding the first item's response, 72% (292) of respondents believed that disclosing their COVID-19 status would not instil worry among them. Almost two-thirds of the participants reported that they would not be worried about disclosing their COVID-19 status after their infection and subsequent recovery. Almost 70% (n=298) of the participants reported that they would not be worried if some of their family members got infected and subsequently recovered. More than half of the people believed that disclosing their COVID-19 status would be risky; 60% (n=224) of the respondents also believed that they would be judged negatively by others if they disclosed their COVID-19 status.

Anticipated stigma

The anticipation about the stigma subscale reported about four items. A total of 59% (n=239) of the respondents believed that if the COVID-19 status of a person is reported to their employer, they are likely to lose their job. And 50% (n=202) of the respondents believed that COVID-19 patients were not public nuisances and 66.4% (n=259) of people thought that being affected by COVID-19 was not disgusting. Moreover, 68% (n=277) of people reported that they would feel uncomfortable around COVID-19 patients.

Internalised stigma

The internalised stigma was evaluated using six items. Almost 65% (n=264) of the participants thought that they would not feel guilty about having the COVID-19 illness, 61% (n=249) would feel not as good as others if they had COVID-19 status, (n=268), 63% did not think that they would be embarrassed to develop the infection, 60% (n=241) did not think that developing the disease would render them unclean, 67% (n=272) thought that developing COVID-19 could make them isolated from society.

The relative importance index was calculated for the perceived stigma domains. Among the least important domains of perceived stigma is self-labelling as a bad person, followed by stigma related to self-disclosure of COVID-19 status. The most critical perceived stigma domain is feeling discomfort around someone who is infected with COVID-19, and followed by a fear of getting isolated from mainstream society if infected with COVID-19.

DISCUSSION

This is the first study in India of its kind that attempted to measure stigma among the general population related to COVID-19. We assessed the perceived stigma regarding COVID-19 in India in three domains: disclosure concerns, anticipated stigma, and internalised stigma. We found that stigma is a part of a belief system and can greatly impact a person's behaviour and perception about the healthcare needs, the gravity of the situation, and the importance laid on the healthcare advisories. In the stigmatisation phenomenon, there is a linkage between the development of cognitive categorisations. Those cognitive categorisations later get linked with stereotyped belief systems that give rise to behaviours leading to more significant issues. Stigma develops and creates further discrimination, lack of opportunities, access to health facilities, and various significant aspects of life. We tried to assess the general population's perceived stigma; our population was mostly educated, employed, and unmarried. We found that the majority (more than 50%) of people were worried about disclosing their status of a positive COVID-19 infection, which helps us understand that people have a negative attitude towards COVID-19 infection (highly contagious, increasing mortality, non-availability of treatment and vaccination). Another study also reported the possibility of developing inequality of healthcare access due to stigma (Hatzenbuehler et al., 2013). This can impact the health of the population negatively. In our study, we also find that people are unwilling to disclose their status about COVID-19, and they have a fear of judgment; this can create an un-dissolvable barrier towards seeking help. There is an apprehension among the public that they would be judged negatively if they get infected and disclose their infection status. Due to this belief, many people do not disclose their travel history or symptoms of COVID-19 as reported in electronic and print media (Chetterje, 2020; Press Trust of India, 2020). Similarly, people also attempted to escape from hospital quarantine (Chetterje, 2020). All the above activities facilitate the transmission of COVID-19 in the community.

During past epidemics and pandemics, it has been seen that stigma associated with illness influences the community's treatment-seeking behaviour (Obilade, 2015). Stigma also prevents the control of the spread of infection and during the Ebola epidemic, it was seen that fear was the most common cause of stigma, and rooted among the public as there was no cure for the Ebola virus infection (Obilade, 2015). A study on HIV-related stigma reported that there was a perceived stigma of the illness because of its unpredictable nature and lack of a cure; it was reported that there was an increased stigma in HIV as there was no systematic approach to handle the stigma. This study also reported a great need for religious organisations to participate actively in the de-stigmatisation process to reduce the associated stigma with such contagious illnesses (Heymans, 2008). The same thing applies to COVID-19 infection, too, as it has rapidly spread.

In our study, people anticipated stigma due to COVID-19 and feared losing their job if they developed the infection. There is also a fear of social casting out. These beliefs among the public get deep-rooted. The media reported that healthcare workers working with COVID-19 patients were denied access to their homes by their relatives (Ellis-Petersen, 2020; Kalra and Ghoshal, 2020; Yeung and Gupta, 2020).

In our study, nearly one-third of the population had internalised stigma. These people reported feeling guilty, bad about themselves, isolated, embarrassed, and inadequate if they developed the COVID-19 infection. Another study from the US about the stigma of various contagious diseases was conducted, which also measured the perceived stigma on H1N1 influenza. They used a feeling thermometer and similar Likert scales to assess prejudice and stigma about H1N1 flu. They conducted a study of university students; their study reported that physical distancing was the most critical factor to be identified for contagious Influenza (Earnshaw and Quinn, 2013).

Stigma stands as a barrier between the patients infected with a particular disease and the healthy society (Williams and Gonzalez-Medina, 2011). It may result in poor help-seeking behaviour and the possible spread of the infection in the community, which may further worsen the stigma. There is a need to break the vicious cycle of stigma for the effective control of pandemics like COVID-19. There is a need to work collaboratively to combat the stigma associated with COVID-19.

Strengths and limitations

This is the first study on stigma among community populations due to COVID-19 pandemic. This study only included the English-speaking population of India (educated population). However, it is expected that the stigma may be more intense among people with inadequate awareness about COVID-19. The current study is an online self-report-based questionnaire that has the possibility of incurring self-report bias. Purposive sampling techniques that were used may be responsible for biases in selection. The socio-economic status has not been assessed in the current study so the economic and social status cannot be commented upon. We also used the snowball sampling method, and so the study is not nationally representative.

CONCLUSION

Despite intense sensitisation programmes related to COVID-19 worldwide, stigma is closely associated with it. Even the educated population experienced internalised stigma, anticipated stigma, and self-disclosure-related stigma due to the COVID-19 pandemic. India's community resources have been a leading source of strength of the nation, and when a phenomenon such as a stigma happens, education and circulating information plays a vital role in the de-stigmatisation process. The involvement of community resources like educational institutions, influential leaders in media, social media, and religious bodies can support the propagation of de-stigmatisation by spreading accurate information and government bodies using their platforms and media to rapidly spread accurate information. Centers and toll-free numbers providing information regarding the COVID-19 stigma can be established to reduce the impact and harassment of patients affected by COVID-19. Future studies should target a larger population and special population groups (marginalised populations) to understand stigma and plan specific interventions.

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