Original Article

The perspectives of community members on COVID-19-related social stigma and mitigation strategies: A qualitative study in Madhya Pradesh, India

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Abstract

Aim: Stigma is a well-documented impediment to health-seeking behaviors and treatment adherence. An explicit societal understanding is essential to halt the stigmatization. Studies documented COVID-19-associated stigma among healthcare personnel. However, there is little evidence regarding community perceptions and experiences of the stigma associated with COVID-2019. We described how various communities perceive and experience the stigma associated with the COVID-19 pandemic. **Method:** We conducted a phenomenological study in three districts of Madhya Pradesh, with both urban and rural areas. We conducted 36 in-depth phone interviews. All the interviews were recorded, transcribed, and translated into English and analyzed using thematic analysis. **Results:** Two major themes were derived: 1) experiences of coronavirus disease 2019 recovered individuals and community members on discrimination and stigma, and 2) efforts to reduce coronavirus disease 2019-associated discrimination and stigma. Social support is critical in mitigating the adverse effects of stigma and thereby aiding in preventing disease spread. They express gratitude to the local government for moral support. Although activities involving information, education, and communication may be beneficial in reducing the stigma associated with COVID 2019, the mass media have a critical role. **Conclusions:** The multidisciplinary teams comprising medical, social, and behavioral scientists and communication and media experts should be formed to reduce the risk of ambiguous messages and misinformation related to COVID-19 at primary care at the community level. Furthermore, it is vital for anti-stigma orientation among community members via mass media.

Keywords: COVID-19, discrimination, pandemic, phenomenology, social stigma

Background

Health-related stigma includes the individual's experience of discrimination and the community members' attitudes toward the individual. Historically, epidemic outbreaks have been accompanied by stigma, discrimination, and prejudice, all of which have had negative consequences.[1,2] Stigma influences the help-seeking behavior of healthcare workers and harms their working attitude and environment.[3,4] Similarly, community members begin to hide their illnesses, avoid taking medication and testing until they are critically ill, and refuse to cooperate in efforts to identify contacts.[1,5] Stigma and discrimination can exacerbate mental health problems and impede individuals' access to timely care such as diagnosis, treatment, and rehabilitation, adversely affecting their recovery.[6-8] Moreover, social exclusion or isolation is linked to various mental illnesses such as depression and anxiety. The power of hidden beliefs and attitudes can underpin stigma-related behavior and an unconscious bias.[9,10]

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The majority of countries are still attempting to implement an effective risk communication strategy to prevent and mitigate the stigma associated with COVID-19.[3] The world cannot sustain a parallel pandemic of stigma, which will only accelerate the spread of infectious diseases and deteriorate people's health and social behaviors.[6] Psychosocial distresses experienced by COVID-19 patients and survivors, and healthcare workers must also be addressed by public health and healthcare professionals.[1,4,6] In the case of COVID-19, physical separation is necessary to reduce the pathogen's chances of transmission. However, this practice may foster stigma and discrimination, which can work against disease control.

The COVID-19 pandemic has increased healthcare inequalities and exposed inequities. Primary care supports health equity and can address many of these inequalities by providing timely access to coordinated and integrated mental health care. During the pandemic, primary care supported the health and wellness of communities worldwide.[11] Moreover, the stigma associated with any disease including SARS-CoV-2 infection hinders the health-seeking behavior of the affected persons and thereby refrains them to take primary care for the disease. Thus, it is of utmost importance to understand the stigma and its associated factors to ameliorate it and facilitate access to primary care for the ailment.

Stigma is a well-documented impediment to health-seeking behaviors, care engagement, and treatment adherence across a broad spectrum of health conditions globally. An explicit societal understanding must guide intervention development, research, and policy to halt the stigmatization process and mitigate the negative consequences of health-related stigma. Previous studies have documented the stigma associated with COVID-19 among healthcare personnel.[12-15] However, there is little evidence regarding community perceptions and experiences of stigma and discrimination associated with COVID-19. Therefore, we studied how different communities perceive and experience the stigma associated with the COVID-19 pandemic.

Methods

Study design and settings

We conducted a qualitative phenomenological study in three districts of Madhya Pradesh: Bhopal, Ujjain, and Sehore, with both urban and rural areas, purposefully chosen. We included COVID-19-recovered individuals and other community members; all participants were above 18 years. This study was a part of a national-level multicentric study on COVID-19 stigma.

Study participants

We contacted 56 people using the purposive sampling method, and 20 of them declined to participate. A total of 36 participants – 21 community members and 15 COVID-19 recovered individuals; 23 from urban areas and 13 from rural areas, with an equal number of male and female participants. The average age of community participants was 29.5 years (standard deviation [SD] 5.5), whereas COVID-19 recovered participants were 41.9 years (SD 14.6). Housewives, government and private sector employees, students, and self-employed people were among those who took part. Many participants had completed their tertiary education.

Data collection procedure

We conducted 36 in-depth telephonic interviews using an interview guide. VD, MS, and research staff conducted all interviews; they were natives of the study settings, had long-standing relationships with community members, spoke the local language, and were trained in qualitative research. All authors come from various educational and professional backgrounds, but they all have a social science and medicine perspective. We conducted all interviews between September and November 2020, following the first phase of the national lockdown (March to June 2020). Everyone who took part did so voluntarily. We scheduled the interviews at times that were convenient for the participants. There was no one else present during the interview except the participant and the interviewer. We did not conduct any repeat interviews.

Data management and analysis

We recorded all the interviews. The interviews ranged in length from 18 to 30 min, with an average of 23 min. We conducted the interviews until the data were saturated. We transcribed audio files verbatim first, and then the Hindi transcripts were translated into English.

We used thematic analysis.[16] We identified the meaning units from the transcript and open-coded them with the MAXQDA software (MAXQDA Analytics Pro 2020, VERBI GmbH Berlin). We read the transcripts several times to understand the exact meaning. Authors VD, KCS, and SN coded the data. We performed data processing and analysis simultaneously. The team discussed summarized data, and we identified themes and categories. We followed the source and investigator triangulation to enhance the credibility of the findings. We debriefed the results with seven participants for member checks. We used the consolidated criteria for reporting on qualitative research guidelines[17] to report the study.

Ethical consideration

The Institutional Ethics Committee of ICMR-NIREH (NIREH/BPL/IEC/2020-21/196 dated June 22, 2020) approved this study. We provided information to the participants in the local language about the purpose of the research and informed them about confidentiality and the voluntary nature of participation. We obtained informed consent from all the study participants to participate in the study and audio-recording the interviews.

Findings

Two major themes were derived: 1) experiences of COVID-19-recovered individuals and community members on discrimination and stigma, and 2) efforts to reduce

COVID-19-associated discrimination and stigma. The participants' quotations are presented under each category to illustrate the findings. The detailed coding tree is provided in Table 1.

Experiences of COVID-19 recovered individuals and community members on discrimination and stigma

COVID-19 recovered individuals experience before and after COVID-19 test outcome

Participants who recovered from COVID-19 described their initial reactions after being diagnosed COVID-19 positive. The majority of participants mistook the initial symptoms for the common flu and tried to self-treat. When they did not get any relief, they went to the doctor and tested for COVID-19. Fear, devastation, shock, worry, and panic gripped the majority of them. According to the respondents, COVID-19-positive cases were initially denied home quarantine under the protocol. Instead, admission to a medical facility was required. As a result, those who tested positive were admitted to a medical facility right away. When asked about their hospitalization experiences, participants described them as stressful and difficult.

> *"But that night, I could not sleep because patients were coming continuously – whole night people were coming and going. Fear was also there – unknown place, nighttime, and I am alone."* (COVID-19 recovered urban female)

Discrimination, avoidance, and eventual acceptance of community members

The COVID-19 recovered participants discussed their experiences with prejudice after receiving a COVID-19 positive test report and during their isolation and hospital admission. After receiving a positive report, they experienced discrimination and avoidance from their neighbors. The most frequently reported behaviors were untouchability and avoidance by the community members. Even though the other family members were COVID-19-negative, a few participants said their neighbors discriminated against their children. One urban participant revealed that due to his COVID-positive status, he lost his job, and his son was terminated from his job, leaving both of them unemployed. A few rural participants reported that although they initially felt uneasy and untouchable due to testing positive, their lives returned to normal after a few days, and they resumed working.

> "*Neighbors treated us as like a criminal. Even they saw my children, and they do not talk anything. They closed the house. They sealed our home. My girls were crying, but nobody cared about them."* (COVID-19 recovered urban female)

Many COVID-19 recovered participants had a positive experience with their neighbors and friends. They received much-needed assistance in meeting their basic daily needs. One of the participants mentioned how the arrival of his daughter and nephew provided him with great support and solace during difficult times. Many respondents from rural areas, however, stated that they had encountered hardly any discrimination and stigma during COVID-19. Instead, society supported them by applauding and congratulating them on their victory over COVID-19.

> *"When I came from the hospital, everyone was standing outside, and they welcomed me. They clapped and said that I fought with Corona and came back. We should not despise corona survivors; we should provide moral and social support to them"* (COVID-19 recovered rural male)

Efforts to reduce COVID-19-associated discrimination and stigma

Community effort to reduce stigma

According to many community members, stigma and fear go hand in hand. Some participants believed that COVID-19 patients and

Table 1: Detail of coding tree

Themes	Experiences of COVID-19-recovered individuals on discrimination and stigma		Efforts to reduce COVID-19-associated discrimination and stigma		
Categories	Experience before and after COVID-19 test outcome	Discrimination, avoidance, and eventual acceptance	Community efforts to reduce stigma	Community appreciation of government awareness to reduce COVID-19 stigma	Role of media to reduce social stigma during COVID-19
Codes	Hospitalization-stressful and difficult experience. Initial reaction-fear, worry, shock, devastation, and panic. Mandatory admission to the health facility. Mistook initial symptoms for common flu. Tried self-treatment.	Assistance in meeting their basic daily needs Discrimination and avoidance from their neighbors. Family and relatives: the pillar of support and solace. Loss of employment. No discrimination was experienced by rural participants. Societal support-applauding and congratulating post-COVID recovery. Untouchability.	Fear of COVID-19 infection. Mixed feelings about COVID-19-infected or recovered people. Non-social behavior. Societal and public support-pillar of help in reducing stigma. Stigma and fear go hand in hand. Treated COVID-positive patients as "criminals."	Credible sources of information on social media Moral support- Municipality and panchayats Multi-sectoral team approach. Self-less service by healthcare providers, sanitation workers, and police officers struggled to meet basic needs.	Information, education, and communication – beneficial in reducing stigma. Media – an instrument of community integration and health promotion. Media useful in disseminating safety precautions. Report the true picture of the disease.

their families were not subjected to discrimination. However, they justified the non-social behavior in the community by claiming that fear of COVID-19 infection caused it. Many participants had mixed feelings about COVID-19-infected or recovered people in society. A few rural participants believed that the COVID-positive person should be removed from the village or isolated because other people could become infected or die. However, other participants thought it was unfair that society treated COVID-positive patients as if they were criminals. Participants agreed that societal and public support could serve as pillars of help in reducing the stigma associated with COVID-19. Participants stressed that the general public should not discriminate against COVID-19 patients but rather welcome, encourage, and support them.

> *"The public remains fearful of contracting the disease. People are behaving criminally around infected individuals – as if they committed a crime by becoming ill. This is unfair. There is a need to educate people that this is a common disease, that they should not discriminate against anyone, and that anyone can contract it."* (Urban community member, male)

Community appreciation of government awareness to reduce COVID-19 stigma

Many members of the community praised the government's efforts to minimize COVID-19-related stigma. Some of them stated that they had heard on the news that the government had stated that "despite all precautions, if someone gets affected by COVID-19, it is not their fault, maintain physical distance from them, but help them and provide moral support." Furthermore, during COVID-19, healthcare providers, sanitation workers, and police officers performed selfless service; please cooperate, thank, and respect them. To prevent spreading fear and panic, just a few of them were motivated to post only credible sources of information on social media. According to the respondents, a multi-sectoral team comprising Panchayats, non-governmental organizations, Anganwadi workers, and health departments collaborate to reduce stigma. Additionally, the participants discussed the economic challenges associated with the COVID-19 pandemic. Families of COVID-positive patients often struggled to meet basic needs. Simultaneously, so many participants expressed gratitude to the local government—municipality and panchayat—for moral support.

> *"To reduce stigma, panchayats, non-governmental organizations, government agencies, and the health department collaborate in campaigns, using an inter-sectoral approach."* (Rural community member, female)

Role of media to reduce social stigma during COVID-19

Participants felt that media could be instrumental in community integration and in promoting healthcare. At the same time, the false media information can also be destructive in the fight against COVID-19. Hence, the media should create awareness while reporting the true picture of the disease. One respondent narrated the influence of media on his neighbors. They can be used to disseminate information about COVID-19 safety precautions and a positive attitude toward COVID-19-recovered people. Respondents noted that people overreacted and misbehaved with COVID-19-positive/rescued persons because of a lack of knowledge. They realized that anyone could become infected with COVID-19, including their family. As a result, activities involving information, education, and communication may be beneficial in reducing the stigma associated with COVID-19.

> *"At times, the media has created a fearful environment. To avoid stigma and discrimination, the media should raise awareness without hiding the truth. The media must launch an anti-stigma campaign."* (Urban community member, male)

Discussion

After testing positive for COVID-19, patients and family members faced discrimination and stigma. However, many participants reported having positive interactions with their neighbors and friends. Support from society and the public could act as pillars in reducing the stigma associated with COVID-19. Social support is critical in mitigating the adverse effects of stigma and thereby aiding in preventing disease spread. Thus, many community members emphasized the importance of not discriminating against COVID-19 patients but rather welcoming, encouraging, and supporting them. Although activities involving information, education, and communication may be beneficial in reducing the stigma associated with COVID-19, the mass media played a critical role in reducing the community stigma associated with pandemics. They express gratitude to the local government for moral support—municipality and panchayat.

Community perceptions and experiences regarding COVID-19 stigma and discrimination are critical for mitigating future pandemic-related consequences. Previous research has established that COVID-recovered patients and their families face stigma. In the United States, a study discovered that 22% of participants and their families had encountered stigma.[18] Similarly, approximately 40% of participants in a Sri Lankan study reported feeling stigmatized following a diagnosis of COVID-19. Both the community and healthcare workers reported stigma in labeling, insulting, defamation, job loss, difficulty accessing basic needs, and communication barriers with healthcare workers, consistent with our findings.[19,20] Stigma and discrimination frequently result in patients concealing their accurate diagnoses, preventing them from seeking prompt treatment and compelling them to self-treat, which can affect disease prognosis and jeopardize the health of others. Many COVID-19 patients preferred not to disclose their positive report status for fear of being treated differently or discriminated against by society. However, a few studies found that a few participants received social support from their families, friends, neighbors, and their employers, which is consistent with our findings.[18,21] Effective communication about disease progression and prevention can effectively alleviate community fear and reduce stigma and discrimination.[21]

National and local governments play a critical role in reducing stigma through integrated action and the formation of multidisciplinary teams. The stigma attached to COVID-19 may jeopardize efforts by healthcare providers to control and prevent disease transmission.[22] As a result, the government can implement various strategies to combat social stigma in collaboration with stakeholders from diverse disciplines. First, efforts to promote the spread of scientific and accurate information via social and mass media must be bolstered.[23] The scientific community can significantly reduce social stigma by immediately condemning stigma-related social media news. Additionally, in addition to preventing the spread of infection, healthcare workers should discuss the existing stigma with patients and family members when dealing with a specific case.[24] Additionally, because the panchayat wields significant influence over the rural populace, their services could alleviate stigma and increase awareness.[12]

The mass media's role in avoiding fake messages and promoting stigma prevention is critical. Rumors, stigma, and discrimination have long been documented during public health crises, affecting both the sick individual and the health system. The primary reason for the spread of rumors and stigma is that society is misinformed about the disease.[19] The media is critical in disseminating public health information during an epidemic. Despite being the most effective tool for communicating information, one of the platform's potential drawbacks is the rapid spread of falsehoods. According to a Sri Lankan study, the primary causes of social stigma during COVID-19 were irresponsible media reporting, which resulted in violations of patients' privacy, as well as defamation and false accusations. Similarly, a global social media study found that 82% of 2,276 media reports were false, 8% were misleading, and 1% were unproven facts.[25] Social stigma can have various negative consequences for COVID-infected or recovered individuals, including anxiety, depression, social rejection, and self-devaluation. Thus, when developing public health policies, the government must consider the role of social media portals to ensure that the population receives an accurate and true picture of information. Additionally, media content must be rigorously reviewed and monitored to prevent the spread of stigma or rumors.

Fear of social stigma frequently outweighs the disease's risk. As a result, many individuals hide their symptoms, which delays the diagnosis and treatment. Knowledge about pandemic prevention and transmission among the general public is critical for fostering a secure and supportive environment. Policies are required to safeguard infected individuals' confidentiality to alleviate fear and social stigma associated with COVID-19. As a result, it is possible to facilitate the screening, testing, quarantine, isolation, and treatment of infected individuals. Additionally, portraying healthcare workers (HCWs) positively in the media and compensating them appropriately for their services may reduce stigma. To meet ongoing population health needs and mitigate the negative impacts of the COVID-19 outbreak, nationally agreed primary care programs must ensure capacity for preventing morbidity and mortality through the community-based delivery of essential services.[11]

Conclusions

Multidisciplinary teams comprising medical, social, and behavioral scientists and communication and media experts should be formed to take on this critical task and reduce the risk of ambiguous messages and misinformation. Furthermore, it is vital for anti-stigma orientation among community members via mass media to be aware of certain beliefs and behaviors' subtle and unintended consequences.

List of abbreviations

COVID-19 = Coronavirus disease 2019.

Ethical approval and consent to participate

The Institutional Ethics Committee of ICMR-NIREH (NIREH/BPL/IEC/2020-21/196 dated June 22, 2020) approved this study. We provided information to the participants in the local language about the purpose of the research and informed them about confidentiality and the voluntary nature of participation. We obtained informed consent from all the study participants to participate in the study and audio-recording the interviews.

Author's contributions

VD: conceptualization, methodology, data collection, supervision, implementation, data analysis, and first draft preparation. MS: conceptualization, methodology, implementation, and review of first draft RRT: conceptualization, methodology supervision, data analysis. and review of the first draft MR: methodology, data analysis, and review of the first draft. SKC: methodology, data analysis, and first draft preparation, and NS: data analysis, first draft preparation. All authors have approved the final version.

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Conflicts of interest

There are no conflicts of interest.

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