Stigma Mechanisms in a Globalized Pandemic in India: A Theoretical Framework for Stigma

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Abstract Stigma has been documented to act as a significant barrier to healthcare access and healthcare-seeking behavior. Traditional frameworks of stigma and discrimination have been used in the past to explain the stigma associated with diseases such as tuberculosis, leprosy, and HIV. However, increasing globalization and unprecedented access to information via social media and the internet have altered infectious disease dynamics and have forced a rethink on mechanisms which propagate stigma. SARS, MERS, Ebola, and more recently COVID-19 have been

The members in the GRID COVID-19 Study Group are the co-authors of this chapter. Dr Anirban and Dr Balaji are representing the GRID COVID-19 Study Group in the author byline as the corresponding author.

Generating Research Insights for Development (GRID) COVID-19 Study Group has members located across institutions in 21 of 28 states and 3 of 8 union territories (UTs) in India. These include teaching faculty, residents in medical schools, and public health experts in academic research organizations. The members were identified based on their engagement in COVID-19 pandemic containment in various capacities (as program advisors, implementers, members of rapid response teams, treating physicians, and researchers) in respective states/UTs and at the national level. The group keeps track of developments in the COVID-19 in India.

The original version of this chapter has been revised. The text "The members in the GRID COVID-19 Study Group are the co-author of this chapter. Dr Anirban and Dr Balaji are representing the GRID COVID-19 Study Group in the author byline as the corresponding authors" has been included. The correction to this chapter can be available at https://doi.org/10.1007/978-981-99-1106-6_26

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associated with fear in communities across the globe due to the inherent uncertainties associated with emerging infectious diseases and a concurrent spread of misinformation—an infodemic. The authors present a theoretical framework to explain the evolution of COVID-19 associated stigma by exploring the complex interplay of various international and national mechanisms. It is anticipated that a conceptual framework which explains the evolution of stigma in fast-spreading global pandemics such as COVID-19 may also prove to be useful as a starting point for furthering the discussion on the progenitors, pathways, and manifestations of COVID-19-related stigma. This should be of practical use to researchers who are interested in exploring, validating, and identifying interventions for informing other frameworks for similar diseases.

Background

Stigma influences population health outcomes by worsening, undermining, and impeding social processes. It impacts social relationships, resource availability, and access (including care-seeking behavior), and triggers psychological and behavioral responses [1, 2]. The coronavirus disease 2019 (COVID-19) incited stigma as a prominent individual and societal reaction. Still, amidst the more tangible and observable dimensions of the pandemic (e.g., health and economic outcomes), the role stigma plays in influencing health outcomes is likely to remain under-assessed.

Stigma related to COVID-19 was maximally reported in India during the first wave of the pandemic (2020). Even though the fatality rate was 3–5%, people were afraid of adverse outcomes if they tested positive. Dead bodies were left unclaimed, pregnant women who had tested positive for SARS-CoV-2 found it difficult to get a hospital bed, patients' families refused to help them, and people were refused entry into their homes by family members and relatives even after they had recovered from COVID-19. Incidents were reported where family members of COVID-19 patients were discriminated against though they had tested negative. Cured persons and their families also suffered discrimination. Even healthcare workers faced stigma and discrimination.

Documented real-life experiences of patients admitted in COVID-19 wards underscored how internalized stigma, feelings of guilt of infecting near and dear ones, the shame of infecting others, and anger directed towards self, led to a vicious cycle of stigma and psychological distress among patients during and after their hospital stay [3].

It was also reported that stigma impeded care-seeking for COVID-19 which led to adverse outcomes. Many people avoided getting tested for SARS-CoV-2 even if they had symptoms of COVID-19. Incidents are reported of people quarantining inside a car instead of going home to their families. Stigma related to COVID-19, on occasion, resulted in arguments, conflicts, and feuds among individuals. Suicides were also reported due to COVID-related anxiety [3].

In the initial days of the pandemic in India, there seems to have been a lack of effective stigma mitigation and behavior change management strategy based on evidence that could translate into public education and community engagement and instill trust in the healthcare system and government initiatives.

Unlike stigma associated with other health conditions (e.g., HIV/AIDS, tuberculosis, and mental health), the stigma associated with COVID-19 is unique in several aspects. Its evolution was speedy despite (and sometimes partially due to) the society having better access to information that was regulated, accultured, and more cohesive than before. This was the case because even though a hitherto unprecedented number of people could access and potentially consume information from a multitude of legitimate sources, there was a concurrent mushrooming of sources of misinformation on various platforms at a rate that rivaled the rate of the spread of COVID-19. This epidemic of misinformation, aptly named infodemic, was responsible for fostering stigma directed at those purported to be afflicted with COVID-19 and their caregivers [4]. Secondly, medical stigma is usually preceded by labelling followed by stereotyping. Another unique trait of COVID-19-related stigma is that although initially there were indications of the generation of stereotypes, the rapid progression and spread of the disease left little space for any enduring stereotype. Stigmatization seemed to be happening directly based on labelling [5–7]. Although unique, it seems that similar patterns of stigma can be theorized for earlier infectious disease pandemics in recent history [8, 9].

In this chapter, we review the existing definitions for stigma and the literature from India on stigma related to COVID-19 to propose a theoretical framework for the characterization of COVID-19-related stigma in India.

Existing Frameworks of Stigma

In the sociological context, stigma has been studied from as long back as the nineteenth century and is generally understood to be the process by which persons having a particular attribute are first labelled and then stereotyped. This stereotyping subsequently gives rise to stigma. Many theories have been proposed to define stigma and its operators in society (Table 1). Traditional stigma frameworks developed for medical conditions (HIV, obesity, or mental illnesses) have relied on the conventional progression from labelling to stereotyping and from stereotyping to stigmatizing. Unique socio-cultural backgrounds that foster stigma directed at various health conditions have necessitated the development of multiple stigma frameworks. Of late, there have been efforts to condense them into a broader more encompassing framework [2, 10]. For example, in the context of HIV/AIDS, stigma was seen to evolve through three phases. Firstly, those infected with HIV were labelled. This led to the evolution of group-based beliefs which were applied to all individuals with HIV. This was followed by their being stigmatized [11]. Such stigmatization usually followed the cycle of social stigma, internalized stigma, and anticipated stigma [11, 12]. Similarly, mental health stigma frameworks also envisage the process of labelling

followed by stereotyping which ultimately culminates into stigma which again cycles through social stigma, internalized stigma, and anticipated stigma [13–15]. Stigma frameworks have also been developed for obesity, tuberculosis, leprosy, and more recently, Ebola and severe acute respiratory syndrome (SARS) [9, 16–21].

Most stigma frameworks have focused on individualistic approaches to the development of stigma with either perspective from the victims or the perpetrators and the victims [9, 11, 15–18, 20, 22]. Very few stigma frameworks focus on the social

Table 1 Some of the popular theories of social stigma

Durkheim [23]	Rules of sociological methods	Explored the idea of stigma to be associated with crime or 'deviance'; postulated that such acts of 'deviance' shall be treated as criminal acts in society
Goffman [24]	Stigma: Notes on the management of spoiled identity	Described stigma to be arising from a behavior, attribute or reputation which leads to the labelling of people (or groups of people) displaying it as an undesirable stereotype
Farina and Hastorf [25]	Social stigma: The psychology of marked relationships	Described stigma as one where a deviant 'mark' links the identified person to undesirable characteristics that discredit him or her in the eyes of others
Stafford and Scott [26]	Stigma, deviance, and social control—in the dilemma of difference	It was proposed that social stigma 'is a characteristic of persons that is contrary to a norm of a social unit' where a 'norm' is defined as a "shared belief that a person ought to behave in a certain way at a certain time"
Mehta and Farina [22]	Associative stigma: Perceptions of the difficulties of college-aged children of stigmatized fathers	Speak of stigma by association. Define it as the process by which a person is stigmatized simply based on association with another person who is stigmatized
Link and Felan [27]	Conceptualizing stigma	Postulate that stigma is the co-occurrence of labelling, stereotyping, separation, status loss, and discrimination coupled with the exercise of power
Falk [28]	Stigma: How we treat outsiders	Elaborated that stigma is necessary to maintain group solidarity by separating 'insiders' from 'outsiders'; described stigma to be of two types: existential—wherein it is derived from a condition or conditions over which the stigmatized have little to no control, or achieved—wherein the stigmatized have either achieved stigma due to their actions or their contributions towards the evolution of the condition which eventually led to stigma
Deacon [29]	Towards a sustainable theory of health-related stigma: lessons from the HIV/AIDS literature	Defined stigma as a social process of 'othering, blaming, and shaming' that leads to status loss and discrimination

Source Compiled by authors

and/or systemic and structural pathways engendering, emboldening, and perpetuating stigma [2]. Although most frameworks distinguish between the stigmatized and stigmatizer, frameworks such as the Health Stigma and Discrimination Framework proposed in 2019 do away with the differentiation between the victim and the perpetrator(s) of stigma, to discourage the process of 'othering', but also retain the baseline process of labelling, stereotyping, and stigmatization [2].

Literature Review

We conducted a scoping literature search to summarize published primary research on stigma and COVID-19 in India. Two searches of peer-reviewed manuscripts till August 2021 were conducted in July and in August 2021 using the PubMed and Scopus databases. Searches included terms related to [1] 'stigma' or other associated terms such as 'social stigma'; [2] 'COVID-19' and [3] 'India'. An initial title and abstract review were performed, followed by a full-text review of articles included during the first phase. For charting, data were extracted according to authors and year of publication, study design, sample size, objectives, and type of stigma measured (i.e., perceived, anticipated, internalized, experienced/enacted). The studies included in the chapter are listed below (Table 2).

Proposed Framework of COVID-19 Stigma

Our COVID-19 stigma framework is based on previously developed frameworks for other medical and health conditions. It is informed by prevalent theories of stigma and contemporary literature (Fig. 1) [9, 14, 16–29]. We observed that the stigma associated with COVID-19 had its inception in 'labelling' as soon as the person tested positive for SARS-CoV-2. Stereotyping was not universally obvious, though, at times, it was associated with health workers and other frontline personnel engaged in combating COVID-19.

There is considerable overlap between the various terminologies used in the context of stigma. As noted elsewhere, the term internalized stigma has been used to have the same contextual meaning as experienced stigma or perceived stigma. The terms internalized stigma and self-stigma have been used interchangeably. Anticipated stigma has been conflated with stigma concerns, stigma apprehension, and stigma consciousness. In the framework proposed by us, we have used the following definitions:

Table 2 Literature review summary

S. No	Authors	Title	Design	Population	Sample size	Objectives	**Stigma studied**
1	Gopichandran et al. [30]	A qualitative inquiry into stigma among patients with COVID-19 in Chennai, India	Cross-sectional and qualitative	People recovered from COVID-19	12	To inquire into the lived experiences of stigma among persons diagnosed with COVID-19 at various stages of their disease from the point of onset of illness, through diagnosis, care-seeking, hospitalization, isolation, recovery, and discharge to returning home after recovery	Social stigma
2	George et al. [31]	Challenges, experience and coping of health professionals in delivering healthcare in an urban slum in India during the first 40 days of COVID-19 crisis: A mixed-method study	Cross-sectional and mixed methods	Healthcare professionals	Qual-42 Quant-64	To describe the experience of running health services in one of the biggest slums of Bangalore during the first 40 days of the COVID-19 pandemic	Social stigma; Associated stigma

(continued)

Table 2 (continued)

S. No	Authors	Title	Design	Population	Sample size	Objectives	**Stigma studied**
3	Sumesh et al. [32]	Collecting the 'thick descriptions': A pandemic ethnography of the lived experiences of COVID-19-induced stigma and social discrimination in India	Cross-sectional and quantitative	General population		To investigate the lived experiences of stigma and social discriminations in the context of the COVID-19 pandemic in India	Social stigma
4	Moideen et al. [33]	COVID-19-related stigma among inpatients with COVID-19 infection: A cross-sectional study from India	Cross-sectional and quantitative	COVID-19 patients in the hospital	56	To explore stigma among COVID-19 patients	Anticipated stigma
5	Uvais et al. [34]	COVID-19-related stigma and perceived stress among dialysis staff	Cross-sectional and quantitative	Dialysis staff	335	To measure the perceived stigma of dialysis staff regarding COVID-19	Anticipated stigma
6	Sahoo et al. [35]	Lived experiences of the Corona survivors (patients admitted in COVID wards): A narrative real-life documented summaries of internalized guilt, shame, stigma, anger	Case Narrative	Persons diagnosed with COVID-19 infection and admitted to the COVID ward	3	To document the experience of 3 persons diagnosed with COVID-19 infection and admitted to the COVID ward	Self-stigma and anticipated stigma

(continued)

Table 2 (continued)

S. No	Authors	Title	Design	Population	Sample size	Objectives	**Stigma studied**
7	Singh et al. [36]	Patients' experiences and perceptions of chronic disease care during the COVID-19 pandemic in India: A qualitative study	Cross-sectional and qualitative	Participants with chronic conditions (hypertension, diabetes, stroke, and cardiovascular diseases)	42	To describe patients' lived experiences, challenges faced by people with chronic conditions, their coping strategies, and the social and economic impacts of the COVID-19 pandemic	Social stigma
8	Uvais [34]	Perceived stress and stigma among doctors working in COVID-19-designated hospitals in India	Cross-sectional and quantitative	Physicians	58	To measure the perceived stigma of doctors regarding COVID-19	Anticipated stigma
9	Sahoo et al. [37]	Psychological experience of patients admitted with SARS-CoV-2 infection	Cross-sectional and quantitative	Persons diagnosed with COVID-19 infection and admitted to the COVID ward	50	To evaluate the experiences of patients with COVID-19 infection during their inpatient stay in COVID isolation wards and intensive care units (ICUs)	Anticipated stigma

(continued)

Table 2 (continued)

S. No	Authors	Title	Design	Population	Sample size	Objectives	**Stigma studied**
10	Banerjee et al. [38]	Psychosocial framework of resilience: Navigating needs and adversities during the pandemic, a qualitative exploration in Indian frontline physicians	Cross-sectional and qualitative	Physicians	172	To explore the 'lived experiences' of frontline physicians in terms of their challenges, unmet needs, and psychological resilience during the crisis	Social stigma
11	Dar et al. [39]	Stigma in coronavirus disease-19 survivors in Kashmir, India: A cross-sectional exploratory study	Cross-sectional and quantitative	COVID-19 survivors	91	To measure stigma among COVID-19 survivors	Social stigma and self-stigma
12	Radhakrishnan et al. [40]	The perceived social stigma, self-esteem and its determinants among the health care professionals working in India during COVID-19 pandemic	Cross-sectional and quantitative	The frontline health workers	600	To understand health workers perceived stigmatizing experiences and self-esteem during the COVID-19 pandemic	Social stigma
13	Kumar et al. [41]	The experiential impact of isolation and quarantine on patients during the initial phase of the COVID-19 pandemic in India	Cross-sectional and qualitative	Patients in isolation and quarantine due to COVID-19	10	To assess the experiences of patients in isolation and quarantine in the initial stage of the COVID-19 pandemic	Social stigma and self-stigma: Associated stigma

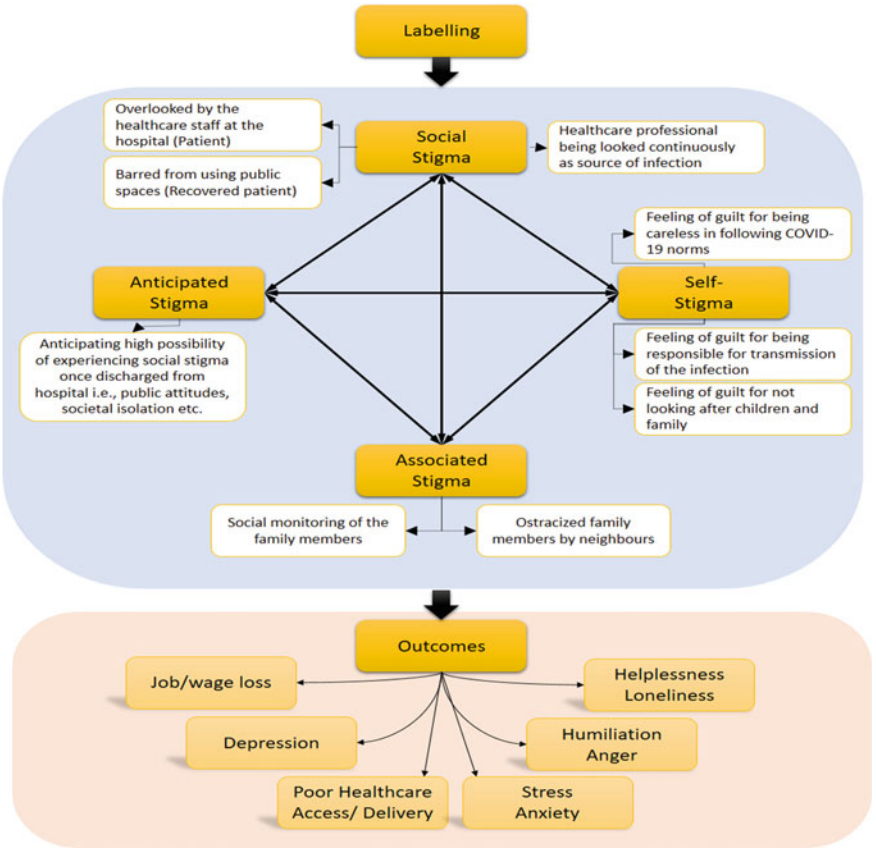

Fig. 1 Conceptual framework of engenderment of the stigma associated with COVID-19. *Source* Compiled by authors

Social Stigma

The term social stigma is used to define people's reaction to someone who is assumed/confirmed to be having the stigmatized condition. It was first described by Goffman and later by Farina et al. [24, 25, 29]. Recent insights into stigma acknowledge the role that structural factors play in the persistence of stigma in the community, provisionally defined as "societal-level conditions, cultural norms, and institutional policies that constrain the opportunities, resources, and wellbeing of the stigmatized" [27, 42]. Structural factors range from governmental and systemic policies which discriminate against the stigmatized (such as against 'undocumented' immigrants and gender and sexual minorities) to prevalent cultural norms which stigmatize certain identities and conditions (such as mental illness or sexual identities) [43–46]. In addition, it is postulated that power differentials may play a formative role in the production

of stigma. For example, studies on schizophrenia patients report that greater social power was associated with less internalized stigma and negative symptoms as well as more stigma resistance. Studies define social power as "the perception of one's ability to influence another person or other people" [12, 47].

Policies based on the premise of social stigma in existing literature define social stigma "as the process by which the victim is labelled and subsequently discriminated against by society based on the suspicion/confirmation of harboring SARS-CoV-2". Early evidence from India showed that patients who recovered from COVID-19 experienced social stigma and prohibition from essential services due to social stigma [30, 36, 39]. They were restricted from dining in public spaces, using public bathrooms in hostels, grocery shopping, and procuring water from public tap facilities. One study reported stigmatization at the health facilities; patients reported that they were almost abandoned and overlooked by health providers in the hospitals. Few patients reported that after being admitted to the hospital, the doctors asked them to measure their blood pressure and oxygen saturation level [30]. Health professionals, who are on the frontline in the COVID-19 pandemic also experienced social stigma. Health professionals reported that the people in their locality considered them to be carriers of infection and avoided them [31, 38, 40]. We hypothesize that this stigma is fueled by the fear of contracting COVID-19 from the victim.

Self-stigma

The term self-stigma has been used to describe the process by which victims internalize the labels applied to them and eventually end up believing those ascribed labels to be true [48]. Furthermore, self-stigma may be enacted alongside anticipated stigma, especially in cases where the stigmatized identity is not visible. The fear of being discovered, along with the negative connotations of the stigmatizing label, collectively act as a source of psychological distress [49].

We base our definition of self-stigma on previous definitions provided in the Encyclopedia of Critical Psychology by Corrigan, Pattyn et al., and Mak and Cheung [50–53]. We define self-stigma "as the process by which victims become aware of social stigma, agree with and internalize the label applied to them". Similar evidence emerged from a study conducted on lived experiences of individuals. In addition to the anticipated stigma, because of being traced as the source of infection within the household and community, individuals started blaming themselves for their carelessness and felt ashamed and guilty [35]. Self or internalized stigma was reported to be high in a study conducted on COVID-19 survivors in Kashmir, India [39].

Anticipated Stigma

Anticipated stigma is an essential component of our framework because, in the case of COVID-19, the stigmatized label may not be visible. We hypothesize that anticipated stigma would influence the healthcare-seeking behavior of the victims as they would try and avoid enactment of the anticipated stigma into social stigma [46]. We base our definition of anticipated stigma on definitions provided by Scambler and Hopkins, Quinn and Chaudoir, and Earnshaw and define anticipated stigma "as the degree to which individuals expect that others will stigmatize them if they know about their concealed stigmatized identity" [54–56]. In one study participants on being discharged from the isolation ward, were concerned about the likelihood of facing stigma from the community and the neighborhood after going back home [30]. Similar findings were reported by another study, wherein on being discharged from the hospital, the participants reported a high level of anticipated societal stigma as compared to self-stigma and apprehension of being stigmatized by their family members [37]. Additionally, patients who were still in the hospital and undergoing treatment for COVID-19 reported their concerns about being stigmatized on their return to the community. Another study on stigma in COVID-19 inpatients reported that 7.1% of the respondents had significantly higher stigma scores, especially in the domain of concern about public attitudes [33]. In a study from Kerala, a southern state of India, the investigators discovered high anticipated stigma scores among doctors on COVID duty [34].

Associated Stigma

It is observed that in the case of medical stigma, conditions as disparate as mental illness, leprosy, and HIV have the potential to affect, not only the patients, but also the family, friends, and caretakers by association [57–59]. Such stigma has been called 'courtesy' stigma by Goffman and was first described by Mehta and Farina as a stigma by association [22, 24]. Further work on stigma by association or associative stigma has been done by Lefley, Phelan et al., and Byrne, Struening and Kjellin [60–64]. There is also evidence of associative stigma affecting medical professionals associated with caring for the stigmatized such as among mental health professionals [65, 66]. We define associative stigma as "stigma felt by family members and caregivers of the stigmatized victim who is, in this case, a person suspected/confirmed of harboring SARS-CoV-2, simply due to their association with the stigmatized". We hypothesize that in the case of COVID-19, associative stigma may arise due to suspicion of the care-giver(s) acting as 'vectors' of the disease. Other studies report that there is ostracized behavioral and social monitoring of the infected and their family members by the neighborhood [31, 41].

Currently, evidence related to stigma and its manifestation has been reported widely, however, limited studies have also reported the intervention to deal with the

stigma and its outcome. Video-based interventions reported reductions in COVID-19-related fear and stigma [67].

Conclusion

It must be understood that the realization and perception of stigmas are contextual and are influenced by the victims' understanding and perspective of how they conceptualize and realize the stigma directed towards them. This is more so for stigma directed towards identities not visible in the victim. Therefore, while constructing the stigma framework for COVID-19, we recognize that stigma would have differential impacts depending, not only on how victims are stigmatized, but also on how they perceive they are being stigmatized. Stigma related to COVID-19 has a temporal trend and is subject to individual awareness, population behavior change management interventions, and public information. The framework proposed by us is generic. We suggest that by using available evidence, the conceptual framework that we have proposed be used as an initial model for future improvisation and validation— a starting point to study and develop interventions to address stigma during similar pandemics in future.

Appendix I

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