

Investigating Stigma During the Early Stages of a Pandemic Through the Lens of COVID-19

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Abstract

Background: Individuals face stigma associated with numerous health conditions. Stigma can arise rapidly during the early spread of a new disease, adding to the burden felt by those affected. COVID-19 can be used as an example to study stigma during the early phases of a pandemic. This narrative review is a descriptive analysis that tracks the ways in which COVID-19 stigma was discussed in the scholarly literature during the first year of the pandemic to understand how stigma was viewed in the context of a rapidly spreading pandemic.

Methods: PubMed was used as a non-exhaustive sample of the literature. Searches for stigma and COVID-19 or SARS-CoV-2 were carried out in January 2021. To be included for review, articles had to be accessible in English, published on PubMed in 2019 or later, and focused on COVID-19/SARS-CoV-2, with at least a mention of stigma related to COVID-19. The included articles were then reviewed for chronological time, depth of emphasis on stigma, definition and interpretation of stigma, type of publication, and recommendations. Demographic features of the authors and studied populations were also tracked.

Results: This review identified 321 articles on PubMed discussing stigma and COVID-19. Of these, 180 articles met inclusion criteria and were reviewed. The earliest publication included in the review was from April 2020. Authors from India, the USA, and China published the most articles related to COVID-19 and stigma. The most frequent forms of publication were cross-sectional studies, commentaries, and letters to the editor. In nearly half of the publications, stigma was one of several factors studied. All of the included publications described the negative impact stigma has on the community. Five major types of recommendations were noted: need for further research, dissemination of accurate health information, expansion of resources, policy and pro-

ocol changes, and community engagement.

Conclusions: Stigma can have a profound impact on individuals affected by a disease, causing barriers to both treatment and attempts to stop disease spread. The stigma seen during the early days of COVID-19 provides useful information on pandemic-related stigma. The recommendations gleaned from this review can be helpful in the mitigation of disease-related stigma and used to slow the spread of stigma during the early stages of future pandemics.

Introduction

Stigma is commonly associated with numerous acute and chronic health conditions. Health-related stigma may come from conditions that are apparent, such as disabilities, or those concealed, such as mental illness or human immunodeficiency virus (HIV) infection. Stigma can be particularly pervasive in the context of a newly discovered disease, especially when it reaches pandemic-level proportions. During the early stages of a pandemic, when little is known about a novel disease, stigma can develop rapidly. This stigma spreads quickly through society just as the novel disease does.

The contemporary concept of stigma was developed by Goffman in 1963 as a relationship between an attribute and stereotype that causes the perception of an individual to be reduced from a “whole and usual person to a tainted, discounted one”.^[1] More recently, the World Health Organization (WHO) has defined stigma in the context of health as a “negative association between a person or group of people who share certain characteristics and a specific disease”.^[2] These definitions describe stigma as the effect of a certain attribute being aligned with a negative view in the eyes of others within a social or cultural context. In the context of a

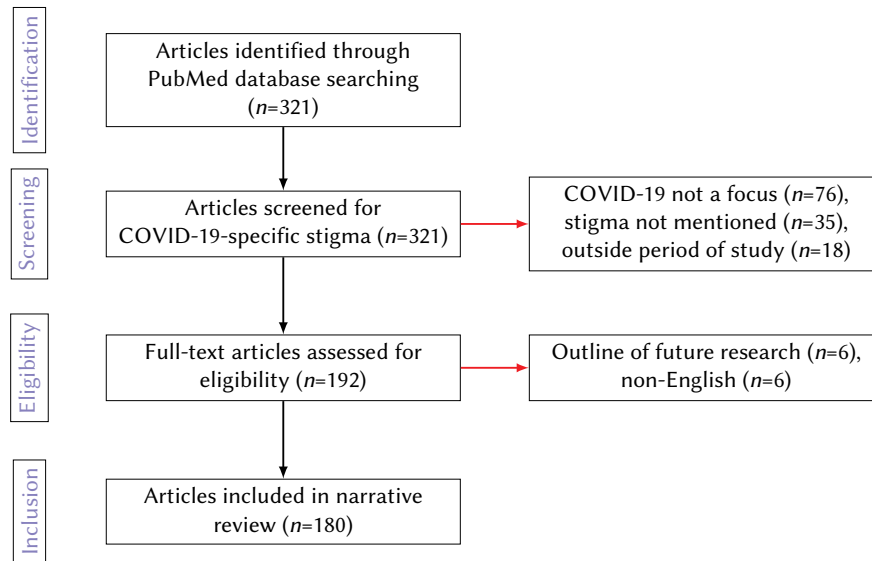


Figure 1. Inclusion process.

pandemic, stigma may cause individuals who contracted the disease to be viewed as dangerous or inferior, leading to an “othering” from the rest of society.

Because stigma grows so quickly in the early days of a pandemic, it is important to look at this stage to understand how stigma spreads and to determine ways to mitigate its impacts. Coronavirus Disease 2019 (COVID-19), which has caused the most consequential pandemic in contemporary times, can illuminate the ways that stigma develops as disease spreads. Given its rate of transmission and impact on society, COVID-19 serves as a good example through which to study stigma. Now several years into the COVID-19 pandemic, a reflection on how stigma was discussed early in the pandemic can provide insight into how stigma could have been minimized. COVID-19 also provides interesting insight on stigma as the rapidly changing landscape of the COVID-19 pandemic led to dramatic societal and political debate.

Stigma has played out across the globe throughout the COVID-19 pandemic. Individuals with or who have recovered from COVID-19, including healthcare workers, have faced violence and discrimination because of this stigma. These effects were felt most acutely in the early months of the pandemic. Healthcare workers in Mexico and Malawi were barred from using public transportation.[3] In India, healthcare workers were forced out of rented homes and even attacked.[3] A COVID-19 survivor in Zimbabwe was socially ostracized when many refused to use the road outside his home.[3] Stigma surrounding COVID-19 became so pervasive that 13 healthcare organizations, including the International Committee of the Red Cross, issued a statement condemning the over 200 documented COVID-19 re-

lated attacks.[4] These instances of violence and discrimination demonstrate the ways that stigma added to the physical impact of COVID-19 in the early phases of the pandemic.

The aim of this review is to understand how COVID-19 stigma was perceived during the early stages of the pandemic, allowing for insight into stigma during pandemics more broadly. Although the physical cost of a pandemic is felt by the thousands who are affected, one of the less obvious costs is the struggle of individuals against stigma. A focus on how stigma is viewed early in a pandemic can help to understand its inception and ways to mitigate its spread. The lessons learned from this investigation will help to illuminate ways to combat stigma associated with present and future diseases.

Methods

To assess the overall themes surrounding stigma and COVID-19, a narrative review format was chosen as a form of exploratory literature review that seeks to formulate a general discussion around a topic, often with no stated hypothesis. Although this review utilizes elements of a systematic review, including synthesis of large pools of research and adherence to guidelines for inclusion, we did not aim for an exhaustive survey of the literature. Instead, the narrative review was chosen as it allows for a much wider range of issues to be investigated than in a systematic review. A broad range of included literature also helps to show what is missing from the literature, including marginalized voices and viewpoints. A narrative review also allows for a more nuanced understanding of the literature included as it seeks to identify patterns

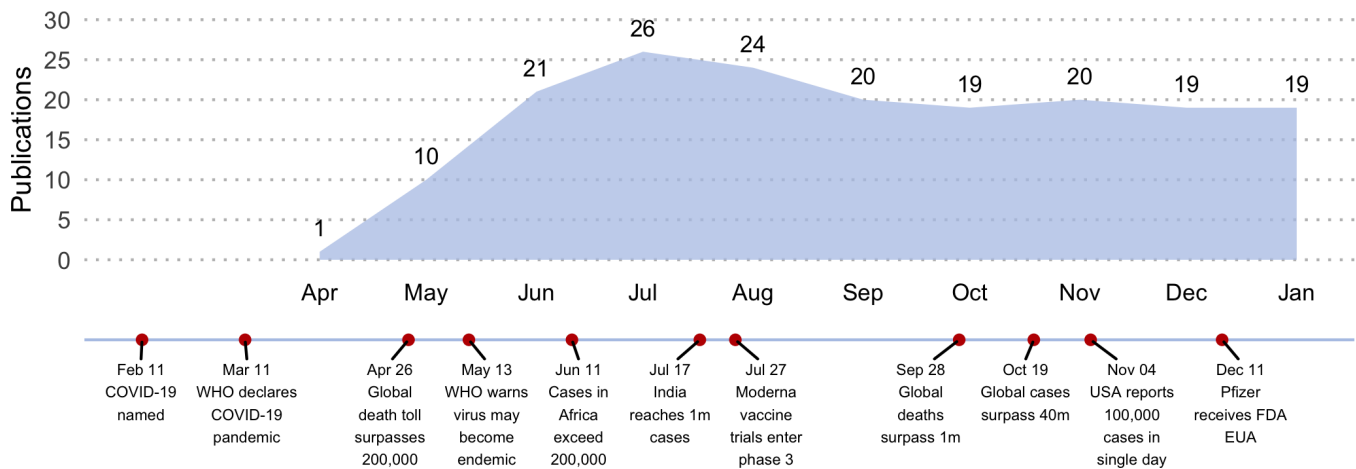


Figure 2. Timeline of COVID-19 and publications. **Abbreviations:** EUA, emergency use authorization; FDA, U.S. Food & Drug Administration; WHO, World Health Organization.

over time. The review helps to capture the broader themes relating to COVID-19 stigma.

Search Strategy

A review of the literature was performed with a focus on papers between December 2019 and January 2021. PubMed was used as a non-exhaustive sample of the literature, allowing for a large sample of publications, though not comprehensive. Searches on PubMed were carried out in January 2021. The following search terms were used: ‘stigma’, ‘COVID-19’, and ‘SARS-CoV-2’.

Selection Criteria

To be included for review, articles had to be accessible in English and published on PubMed between December 1, 2019, and January 31, 2021. This represents the pre-vaccine era of COVID-19. Articles also had to focus on COVID-19/SARS-CoV-2 with at least a mention of stigma related to COVID-19. As an inclusion criterion, the relationship between stigma and COVID-19 must have been explicitly described and defined as stigma in relation to COVID-19, not stigma related to other possible comorbidities. For example, a publication about people who inject drugs and stigma during the COVID-19 pandemic would not be included. To capture the breadth of early COVID-19 stigma discussions in the literature, a wide variety of publication types were included. The only publication type excluded from review was outlines for future research.

One reviewer examined the abstracts and titles of the identified publications for mention of COVID-19 and stigma for a preliminary collection of papers ($n=192$). The remaining articles were then screened for eligibility, and ineligible articles

were removed ($n=12$). The screening process is included in **Figure 1**. The inclusion criteria and any papers that required further consideration were discussed with all three reviewers.

Data Extraction

The included articles were reviewed to identify the period of study, depth of stigma studied, definition and interpretation of stigma, type of publication, and recommendations. Depth of stigma was operationalized as ‘focus of study’ if stigma was the only variable investigated, ‘one of several factors’ if other variables were described, and ‘only mentioned’ if stigma was not a variable described but was discussed in the publication. All recommendations from included papers were recorded and placed into a categorical group. The most common types of recommendations are described in this review. Demographic features of the authors and study populations were also tracked.

Results

This review identified 321 articles published on PubMed discussing stigma and COVID-19. Of these, 180 articles met inclusion criteria and were reviewed (**Figure 1**). The earliest publication identified in this review was a letter to the editor published in April 2020 and was the single publication that month.^[5] The number of publications gradually increased over the following months to a peak in July 2020 (26 publications). The number of publications remained fairly constant through the rest of 2020, with around 20 papers per month (**Figure 2**).

Author Demographics

Authors from India, the USA, and China published the majority of articles related to COVID-19 stigma. Regionally, Asian authors produced the largest percentage of publications (48.3%; **Table 1**). North American authors were second with 14.4% of publications, followed by European with 13.3%, African 9.4%, South American 2.2%, and Australian/Oceania 2.2%. A total of 10% of publications were produced as a collaboration between authors from several regions. An overwhelming majority (97.8%) of publications were produced by authors in urban areas, with only two articles (1.1%) from authors in rural areas. Of the 176 publications from urban areas, 160 were from authors in academic settings, 12 in non-academic settings (including NGOs), and four in governmental agencies.

Table 1. Characteristics of included publications.

Characteristic	<i>n</i> (%)
Region	
North America	26 (14.44)
South America	4 (2.22)
Asia	87 (48.33)
Europe	24 (13.33)
Australia/Oceania	4 (2.22)
Africa	17 (9.44)
International	18 (10)
Author demographics	
Urban	176 (97.78)
Academic	160
Non-academic	12
Governmental	4
Rural	2 (1.11)
Not stated	2 (1.11)
Type of publication	
Cross-sectional	60 (33.33)
Commentary	28 (15.56)
Letter to editor	24 (13.33)
Review	21 (11.67)
Editorial	12 (6.67)
Proposal	10 (5.56)
Case report	7 (3.89)
Other	18 (10)
Level of stigma	
Focus of study	51 (28.33)
One of several factors	88 (48.89)
Only mentioned	41 (22.78)

Publication Characteristics

The most frequent types of publication in the review were cross-sectional studies (33.3%), commentaries (15.6%), and letters to the editor (13.3%). Other publication types included reviews, editorials, proposals (including policy and procedural change proposals), and case reports. In nearly half of the publications, authors discussed stigma as one of several variables measured in investigations on the social, physical, or psychological impacts during COVID-19. In 28.3% of articles, COVID-19 stigma was the focus of the publication. In 22.8% of articles, COVID-19-related stigma was mentioned, meaning that the authors addressed stigma in relation with COVID-19, but it was not the focus of the paper.

Impacts of Stigma

During the review date range, the literature consistently described the negative impact stigma had on the community. Every article included in this review acknowledged the negative role that stigma played during the COVID-19 pandemic. Although the negative role was not always clearly defined, it was a consistent presence across the literature, as stigma adds another layer of difficulty for individuals with COVID-19 disease. Several articles included discussions of ways to combat stigma and create positive outcomes. These included campaigns to create a more supportive social environment for patients with COVID-19 and battle against healthcare workers' COVID-19-related stigma, such as through provision of care packages and public praise for health care workers.[3, 6–8]

Definitions of Stigma

A wide variety of stigma definitions in the literature were noted during this review. However, out of the 180 publications reviewed, 97 (53.9%) did not include a clear definition of stigma. Within this group, the discussion of stigma often included ties to discrimination, isolation, and fear. When stigma was defined in the publication, it most often included the negative process of labeling an individual as a social outcast based on a certain characteristic. Common themes within these definitions included an undesirable characteristic leading to isolation, fear of a certain group, blaming and rejection leading to discrimination, and loss of identity to a disease.

Twelve of the publications cited Erving Goffman.[1] Four of the articles cited Link and Phelan, who defined stigma in 2001 as a “co-occurrence of its components,” which include labeling, stereotyping, separation, status loss, and discrimination.[9] Although the aforementioned themes carried throughout much of the included literature, there was no clear, unifying definition of stigma.

An interesting tool that was used in 19 publications—mostly cross-sectional studies—for the definition of stigma was a stigma scale. A stigma scale is a tool, usually a survey, designed to measure the stigma an individual experiences in the context of a certain disease. Eight publications used a modified Berger-HIV stigma scale, three used a modified MERS stigma scale, and a few publications used a modified Internalized Stigma of Mental Illness (ISMI) scale, a self-stigma scale, a tuberculosis (TB) stigma scale, a healthcare worker stigma scale, or a Chinese Courtesy Stigma scale. Three publications included novel stigma scales created to measure COVID-19 stigma.[10–12]

Recommendations

The majority of publications recommended ways in which stigma could be mitigated in the context of COVID-19. Although these recommendations were often within the context of specific study populations, several categories of recommendations were common across the reviewed publications. Five major types of recommendations were noted:

(1) Need for further research: recommendation to investigate the social impact of COVID-19 further. Publications that included this recommendation often called for research into certain affected populations or in specific social settings. Recommended avenues of future research include studying stigma against health care workers [13–15], stigma propagated through social media [16], and differences in stigma faced based on gender or age.[5]

(2) Dissemination of accurate health information: recommendation to combat misinformation and provide evidence-based information from the scientific community to properly educate the general public. Several explicit recommendations for dissemination of accurate health information included public health education campaigns through social media [17], providing resources with facts on transmission [18], and direct distribution of information by government.[19, 20] One specific resource that was proposed was a comprehensive “Antistigma Psychoeducation Guide” created by Adiuoku *et al.*, which outlines specific ways of combating misinformation.[21]

(3) Expansion of resources: recommendation to provide aid to communities impacted by COVID-19 stigma, with a great emphasis on mental health resources. Several publications recommended targeting health care workers with psychological interventions.[11, 22–24] Mental health resources for other affected populations were also recommended. Other forms of resources mentioned focused on strengthening family and community support [25] and economic empowerment of those affected by COVID-19.[10]

(4) Policy and protocol changes: recommendation to in-

roduce institutional or governmental changes. This recommendation included addressing stigma through medical education [26], incorporating anti-stigma practices in the treatment of COVID-19 [27], and government/institutional policies that directly condemn COVID-19 stigma.[24, 28–31] This includes the careful use of non-stigmatizing language when discussing COVID-19, such as the use of “people who may have COVID-19” instead of “COVID suspect”.[32]

(5) Community engagement: recommendation to engage community leaders and media to disseminate anti-stigma messaging to the public through trusted outlets. Other avenues of community engagement, beyond direct collaborations with the media, included the use of COVID-19 survivors to disseminate anti-stigma messaging [33–35] and outreach to social and religious leaders.[35–38]

Discussion

This review describes the ways in which COVID-19-related stigma was discussed in the medical literature during the first year of the pandemic. Using COVID-19 as a lens through which to view other pandemics, this review allows for a better understanding of how discussions of stigma evolve during the early phases of a pandemic.

As seen in the early months of the COVID-19 outbreak, stigma can spread rapidly and disproportionately affect certain populations, necessitating an early stigma mitigation strategy. The recommendations outlined in this review can be used to create such a strategy. Five recommendations were gathered: the need for further stigma research, dissemination of accurate health information, expansion of resources, policy and protocol changes, and community engagement. These recommendations can be extrapolated to other diseases to aid in stigma reduction, including during the early stages of future pandemics.

Those involved in public health preparedness should be cognizant of stigma when a new disease outbreak occurs and investigate this stigma in the early days of an outbreak. Accurate and reliable information about the disease should be spread throughout the community, which can be achieved through collaboration with community leaders. This community engagement can also be used to directly combat stigma, such as by broadcasting the experiences of survivors. Resources should be allocated not only to the direct eradication of a disease but also to programs that will help stigmatized individuals, such as psychosocial support. Anti-stigma messaging should also be directly incorporated into the treatment of the disease through strategies such as the use of non-stigmatizing language and the direct condemnation of disease-related stigma. By focusing on stigma early in a pandemic, the lasting effects of stigma felt by affected individuals

can be lessened.

The need for early stigma reduction during pandemics can be seen in the more recent Mpox outbreak. As the Mpox virus overwhelmingly has affected the population of men who have sex with men (MSM), this population faces stigma and discrimination. The recommendations gathered in this review can be used to combat stigma in this early phase of the outbreak. For example, the dissemination of accurate health information, a recommendation seen often in the reviewed literature, can be utilized to spread accurate information about how Mpox is contracted.

This review also shows disparities in the literature on pandemic-related stigma. The largest disparity recorded was the description of patients in rural versus urban settings, with only 2 publications written by authors located in rural areas. This disparity demonstrates a major gap in COVID-19 stigma research as these authors provide an important perspective on rural patient populations. This gap in understanding the rural experience of COVID-19 stigma demonstrates a need for further research about stigma in these areas. Understanding how rural populations face stigma compared to their urban counterparts is an important step in mitigating the effects of stigma, especially as these rural populations often face large shortages in resources. This may be compounded early in a pandemic when health resources can become quickly depleted.

Another interesting disparity seen in this review was the majority of articles coming from three countries: India, the USA, and China. The reason for this predominance is unclear, but there may be several causes. These countries may, at baseline, produce more literature. It may also be true that stigma is more commonly discussed in these cultures. Further, it is unclear whether certain countries do not produce stigma research because they do not observe as much stigma in their societies or because it is not readily discussed. However, six articles were excluded for being in non-English languages, which may have slightly skewed these data. This provides an avenue for further health stigma research in countries that have not published a large amount of research on the subject.

The reviewed literature did not use a standardized definition of stigma. The majority of publications included no explicit definition of stigma, relying on concepts such as discrimination, isolation, and fear to define stigma. Although the term “stigma” may be ubiquitously understood, the lack of a clear definition may lead to confusion as to the role of health-related stigma and a possible misunderstanding of the severity of stigma’s impact. For this reason, stigma should be directly defined when it is being discussed in medical literature.

A major limitation of this review was the use of PubMed as a non-exhaustive sample of the literature. Because of this

limitation, other relevant publications may have been omitted from this review. However, this search met the goal of this narrative review as descriptive analysis by capturing a broad view of the existing literature. Although this review only used one database to identify potential articles, it provides a baseline for further research on stigma early in a pandemic.

Stigma characterizes how patients grapple with their own health and self-image. Stigmatized populations experience discrimination, which can directly cause adverse health outcomes due to limited access to health care resources, safe housing, or proper nutrition. Stigma magnifies and adds to the burden of a disease, especially in populations who already face discrimination due to race, ethnicity, class, or sexuality.[37] Mitigating the impact of stigma can therefore alter the course of a disease, physically and mentally. The recommendations gleaned from this review can be helpful in the mitigation of stigma seen in the early phases of future pandemics.

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