

Stigma and stigmatization related to COVID-19: integrative review protocol

Estigma e estigmatização relacionados a COVID-19: protocolo de revisão integrativa

Estigma y estigmatización relacionados con la COVID-19: protocolo de revisión integradora

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REVISA

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RESUMO

Objetivo: Apresentar protocolo de revisão integrativa que pretende evidenciar como ocorrem o estigma e a estigmatização das pessoas que adoeceram por COVID-19. Metodologia: Protocolo de revisão integrativa elaborado com base no Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2020. Critérios de inclusão: estudos primários com abordagem qualitativa ou quantitativa; publicadas entre 2020 e 2023. Critérios de exclusão: estudos de revisão, ensaios, cartas e comentários. Serão utilizados os descritores: Estigma social, Estereotipagem, COVID-19, Infecção por Coronavírus, Pandemia e seus respectivos sinônimos, nos idiomas inglês e espanhol. A busca e a avaliação dos estudos serão realizadas por dois pesquisadores independentes, nas bases de dados Pubmed, Literatura Latino-Americana e do Caribe em Ciências da Saúde (LILACS), Medical Literature Analysis and Retrieval System Online (Medline), Scientific Electronic Library Online (SciELO), Web Of Science, Excerpta Medica Database (Embase) e SCOPUS. Os resultados serão organizados e apresentados através da sua síntese.

Descritores: Estigma Social; Estereotipagem; COVID-19; Infecções por Coronavírus; Pandemias.

ABSTRACT

Objective: To present an integrative review protocol to demonstrate how the stigma and stigmatization of people suffering from COVID-19 occur. Methodology: Integrative review protocol prepared based on Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2020. Inclusion criteria: primary studies with a qualitative or quantitative approach published between 2020 and 2023. Exclusion criteria: review studies, essays, letters, and comments. The scripts will be used: Social stigma, Stereotyping, COVID-19, Coronavirus Infection, Pandemic, and their respective synonyms in English and Spanish. The search and evaluation of two studies were conducted by two independent researchers in the databases PubMed, Latin American and Caribbean Literature in Health Sciences (LILACS), Medical Literature Analysis and Retrieval System Online (Medline), Scientific Electronic Library Online (SciELO), Web of Science, Excerpta Medica Database (Embase), and SCOPUS. The results will be organized and presented in a summary.

Descriptors: Social Stigma; Stereotyping; COVID-19; Coronavirus Infections; Pandemics.

RESUMEN

Objetivo: Presentar un protocolo de revisión integrativa para demostrar cómo se producen el estigma y la estigmatización de las personas que padecen COVID-19. Metodología: Protocolo de revisión integrativa elaborado con base en los Elementos de Informe Preferidos para Revisiones Sistemáticas y Metaanálisis (PRISMA) 2020. Criterios de inclusión: estudios primarios con un enfoque cualitativo o cuantitativo publicados entre 2020 y 2023. Criterios de exclusión: estudios de revisión, ensayos, cartas y comentarios. Se utilizarán los siguientes guiones: Estigma social, Estereotipos, COVID-19, Infección por Coronavirus, Pandemia y sus respectivos sinónimos en inglés y español. La búsqueda y evaluación de dos estudios fue realizada por dos investigadores independientes en las bases de datos PubMed, Literatura Latinoamericana y del Caribe en Ciencias de la Salud (LILACS), Medical Literature Analysis and Retrieval System Online (Medline), Scientific Electronic Library Online (SciELO), Web of Science, Excerpta Medica Database (Embase) y SCOPUS. Los resultados se organizarán y presentarán en un resumen.

Descritores: Estigma social; Estereotipos; COVID-19; Infecciones por coronavirus; Pandemias.

Introduction

Since 2019, when a new type of coronavirus and COVID-19, a viral infectious disease, were first detected and spread across the world, a pandemic was triggered—one responsible for the illness and death of countless people¹. Estimates indicated that by April 2023, more than 750 million cases of the disease had been reported globally, with approximately 7 (seven) million deaths resulting from the illness².

Most people who become ill with COVID-19 tend to develop mild to moderate symptoms, typically characterized by flu-like symptoms such as fever, fatigue, and cough, and are able to recover without the need for hospitalization. However, others may experience more severe symptoms, with greater respiratory compromise and the development of severe acute respiratory syndrome, requiring more complex care^{2,3}.

During illness, some individuals affected by COVID-19 may develop long-term effects, with the persistence or emergence of new symptoms three months after the initial infection—a condition known as long COVID or post-COVID condition. This condition may last from weeks to years and can affect anyone exposed to the virus, regardless of age or the severity of symptoms during the acute phase. Some of the symptoms may include shortness of breath, fatigue, and cognitive dysfunctions. Additionally, a wide range of other symptoms have been reported, potentially causing significant disruption to the daily lives of those affected^{4,5}.

Within the pandemic context, the emergence of COVID-19—initially associated with fear surrounding an unfamiliar disease—precipitated the phenomenon of stigma directed at people experiencing infection and illness⁶. The fear surrounding the disease, fueled early on by uncertainty, gave rise to prevailing stigma. Moreover, recommended public health practices for controlling transmission—such as the isolation of infected individuals—further amplified this phenomenon, which extended not only to those infected but also, to some extent, to those who had recovered, the families of those who were ill, and even healthcare professionals⁷.

It became evident that a negative perception emerged around people who had fallen ill with COVID-19, marked by the blaming of individuals for their own contagion, labeling, and the adoption of stereotypes—resulting in discriminatory treatment in various social interactions, all of which are key aspects of stigmatization⁸.

The stigmatization of individuals due to COVID-19 involves multiple determining and conditioning factors, including beliefs and self-blame or the blaming of others for contracting the disease. Feelings of guilt and shame may be exacerbated by factors such as the infodemic (the excessive circulation of misinformation), leading to reduced access to healthcare, hesitancy in testing, delays, and poor adherence to treatment measures, among other consequences⁹.

In situations like a pandemic, where health authorities must recommend and adopt mitigation, control, and prevention measures to contain disease transmission, stigma can act as an obstacle by discouraging stigmatized individuals from adhering to those measures¹⁰. Therefore, stigma and stigmatization are phenomena present in the context of infectious disease and illness that not only affect the quality of life of those impacted, but also

compromise, in broader terms, preventive practices, research investment, service provision, and public policy development¹¹.

Theoretically, the concept of stigma is derived from Goffman, who defines it as a characteristic attributed to an individual that carries a negative connotation, thereby distinguishing the individual in various social interactions¹². Stigma operates through the interrelated presence of human difference identification and labeling, social separation, associated loss of status, and discrimination—phenomena that intensify under conditions of inequality¹³.

Furthermore, the social context is emphasized as the space in which stigma emerges and operates. Stigma reflects the values of a specific culture and historical moment. Therefore, cultural meanings of stigma and the surrounding context are essential to its structure, as both its nature and the responses of stigmatized individuals reveal socially constructed and shared values and beliefs¹⁴.

Given this, considering the emergence and persistence of COVID-19 on the global stage during the pandemic, expanding knowledge about the different aspects of the illness experience—and how these impact health care on both individual and collective levels—becomes essential. In particular, the consequences of stigma and stigmatization among those affected by the disease may intensify health inequities in terms of access, assistance, and care.

Moreover, this integrative review will enable a broader understanding of the phenomenon, contributing significantly to decision-making and, above all, supporting healthcare professionals in developing practices aimed at preventing, mitigating, and reducing stigma and stigmatization of people affected by COVID-19.

To this end, this review protocol adopts the following research question: “How do stigma and stigmatization occur among people who became ill due to COVID-19?” and aims to highlight how stigma and stigmatization affect people who became ill with COVID-19.

Methodology

This is an integrative review protocol—a public record that outlines the approach to be developed in the integrative review, including the description of the problem of interest, inclusion criteria, search strategies, information sources, and procedures for data analysis and presentation¹⁵. Furthermore, this protocol is registered with the International Prospective Register of Systematic Reviews (PROSPERO), under the number CRD42023444194. To structure it, various recommendations were consulted, such as those from the Gerstein Science Information Centre of the University of Toronto (UofT)¹⁶, the Joanna Briggs Institute (JBI)¹⁷, and The Cochrane Collaboration¹⁸.

The integrative review is a broad review modality that combines different types of data from both theoretical and empirical literature, including experimental and non-experimental studies. It may serve a variety of purposes such as concept definition, theory review, evidence identification, and analysis of methodological aspects. This approach enables a deeper understanding of the phenomenon of interest¹⁹.

Integrative reviews allow for the synthesis of knowledge from primary studies and can contribute to an accurate representation of the state of scientific

production on a given topic. Additionally, they make it possible to assess the strength of evidence, identify gaps and the need for future research, build bridges between related areas, map key issues within a specific field, identify a theory or conceptual framework, and explore successful research methods²⁰.

The structure of this review will be developed through the following steps: (i) identification of the problem, (ii) literature search, (iii) data evaluation, (iv) data analysis, and (v) presentation¹⁹.

Question Framework

The research question guiding this review was structured using the PICO mnemonic (Population; Interest phenomenon; Context)^{17,21}, considering that the research problem lies at the intersection of individuals' social relations and interactions—in this case, the experience of stigmatization among people who became ill with COVID-19, as shown in Table 1.

Chart 1 - Structure of the question. Best Time to See Salvador, BA, Brazil 2024

PICO	
Population	People who have fallen ill
Phenomenon of Interest	Stigma and stigmatization
Context	COVID-19
Question: How does stigma and stigmatization occur for people who are sick because of COVID-19?	

Inclusion and Exclusion Criteria

The inclusion criteria for studies in this review will consider: (i) those involving participants who became ill with COVID-19, and (ii) those addressing the stigma and stigmatization of these individuals.

Studies available in English, Spanish, and Portuguese will be included. The time frame adopted will correspond to the duration of the COVID-19 pandemic, from 2020 to 2023. As this is an integrative review, both quantitative and qualitative studies (or those combining both approaches) will be considered.

Exclusion criteria will include: (a) review studies, essays, letters, or commentaries; (b) studies exclusively involving children, adolescents, and/or elderly individuals; and (c) studies in which the population consisted of healthcare professionals.

Search Strategies

The following portals and databases will be used to search for studies: PubMed, Literatura Latino-Americana e do Caribe em Ciências da Saúde (LILACS), Medical Literature Analysis and Retrieval System Online (Medline), Excerpta Medica Database (EMBASE), Web of Science, SCOPUS, and Scientific Electronic Library Online (SciELO).

The search strategy will follow a three-step process, as recommended by JBI²⁷: the first step involves identifying keywords and building a logical

framework based on field knowledge, which initially guides the search, with tailored strategies for each database. The second step involves the actual search in each of the specified databases, as outlined in the protocol. The third step includes reviewing the reference lists of all retrieved studies for further evaluation and potential inclusion of additional studies.

The respective search strategies applied to each database or portal were developed with guidance from a librarian and a university professor, through the identification and combination of Health Sciences Descriptors (DeCS) or Medical Subject Headings (MeSH), and the use of Boolean operators “AND” and “OR,” as shown in Table 2.

Chart 2 - Search strategies in databases and portals. Best Time to See Salvador, BA, Brazil 2024.

Database/Portal	Search Strategies	Articles found
<i>Pubmed</i>	("Patients"[MeSH Terms] OR ("client s"[All Fields] OR "Patients"[MeSH Terms] OR "Patients"[All Fields] OR "client"[All Fields] OR "clients"[All Fields]) OR ("client s"[All Fields] OR "Patients"[MeSH Terms] OR "Patients"[All Fields] OR "client"[All Fields] OR "clients"[All Fields])) AND 2020/01/01:2024/12/31[Date - Publication] AND (("Social Stigma"[MeSH Terms] OR "Social Stigmas"[All Fields] OR "stigmas social"[All Fields] OR "stigma social"[All Fields] OR "stereotyping"[MeSH Terms] OR ("stereotyping"[MeSH Terms] OR "stereotyping"[All Fields] OR "stigmatization"[All Fields] OR "stigmatizations"[All Fields] OR "stigmatize"[All Fields] OR "stigmatized"[All Fields] OR "stigmatizers"[All Fields] OR "stigmatizes"[All Fields] OR "stigmatizing"[All Fields])) AND 2020/01/01:2023/12/31[Date - Publication]) AND (("COVID-19"[MeSH Terms] OR "covid 19 pandemic"[All Fields] OR "covid 19 pandemic"[All Fields] OR "pandemic covid 19"[All Fields] OR "COVID-19 Pandemics"[All Fields]) AND 2020/01/01:2023/12/31[Date - Publication])	155
LILACS E MEDLINE (VHL)	(patient) OR (patients) OR (client) OR (clients) AND ("social stigma") OR (stereotyping) OR (stigmatization) AND (covid-19) OR (pandemic covid-19) AND (db:("MEDLINE" OR "LILACS") AND la:("en" OR "pt" OR "es")) AND (year_cluster:[2020 TO 2023])	52

SCOPUS	TITLE-ABS-KEY (patient OR patients OR client OR clients AND "social stigma" OR stereotyping OR stigmatization AND covid-19 OR pandemic covid-19) AND (LIMIT-TO (DOCTYPE,"ar")) AND (LIMIT-TO (LANGUAGE,"English") OR LIMIT-TO (LANGUAGE,"Spanish"))	318
SciELO	stigma AND covid-19	16
Web Of Science	(TS=(patient OR patients OR client OR clients) AND ALL=("social stigma" OR stereotyping OR stigmatization) AND ALL=(covid-19 OR pandemic covid-19)) AND (DT=="ARTICLE") AND LA=="ENGLISH" OR "SPANISH"))	164
EMBASE	('patient'/exp OR patient) AND ('social stigma'/exp OR 'social stigma') AND ('coronavirus disease 2019'/exp OR 'coronavirus disease 2019') AND 'article'/it	116
TOTAL		821

Study Extraction and Selection

After the searches, all retrieved studies will be exported through the reference manager²², for the identification and removal of duplicates, as well as the organization of the publications. Next, the studies will be imported into Rayyan Web²³, where they will be re-evaluated and selected according to the eligibility criteria, through the reading of titles and abstracts by two independent reviewers.

Finally, the studies will be submitted to full-text evaluation by these same reviewers. In cases of disagreement, discussions and/or the involvement of a third reviewer will occur. For data extraction, a specific instrument developed for this review will be used, as shown in Table 3.

Chart 3 - Instrument for data extraction. Best Time to See Salvador, BA, Brazil. 2024

STIGMA AND STIGMATIZATION RELATED TO COVID-19 - PROTOCOL FOR INTEGRATIVE REVIEW
Objective: To highlight how stigma and stigmatization of people who became ill due to COVID-19 occur.
PICo: How does the stigma and stigmatization of individuals who became ill due to COVID-19 occur?
Study Characterization
Authorship / Year of publication:
Title:
Country of origin:
Objective:
Methodology:
Participants (sociodemographic characteristics - age, sex, race/ethnicity, sample):

Results and Conclusions
- Aspects of stigma and stigmatization described:
- Conclusions:

All excluded studies will have their respective reasons presented in the review report.

Study Assessment

To assess the quality of the selected studies that will comprise the review corpus, the Research Triangle Institute Item Bank (RTI-Item Bank)²⁴ and the Critical Appraisal Skills Programme (CASP)²⁵ scales will be used, respectively, for those with quantitative and qualitative designs.

Data Analysis

The analysis of data from the studies will be based on the perspective of the constant comparison method, which operates in four phases: data reduction, data display, data comparison, and conclusion drawing and verification^{19,26}.

Data Presentation

This review aims to provide a synthesis regarding the stigma and stigmatization of people who became ill because of COVID-19. The presentation of its report will be both narrative and visual and will be structured according to the recommendations of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2020 checklist²⁷.

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