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# Community series in mental-health-related stigma and discrimination: Prevention, role, and management strategies, volume II

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# Community series in mental-health-related stigma and discrimination: Prevention, role, and management strategies, volume II

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# Editorial: Community series in mental-health-related stigma and discrimination: prevention, role, and management strategies, volume II

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Editorial on the Research Topic
Community series in mental-health-related stigma and discrimination: prevention, role, and management strategies, volume II

Stigmatizing attitudes towards individuals experiencing mental illnesses, as well as their caregivers, mental health providers, psychotropic medications, mental health institutions, and stakeholders, persist as a prevalent public health concern with global widespread consequences (1). Undoubtedly, despite increased knowledge about mental health, societal misconceptions persevere, resulting in discrimination and the marginalization of those contending with mental health issues (2, 3). This matter is prominently observed in medicine, though, not exclusively, in individuals with mental disorders and its prevalence has intensified in the aftermath of the COVID-19 pandemic (4–6).

In this second volume of the Community Series entitled *Mental-Health-Related Stigma and Discrimination: Prevention, Role, and Management Strategies*, we present 22 new articles exploring various facets of mental-health-related stigma and discrimination, offering diverse perspectives from different countries (7). Through this editorial, we endeavor to encapsulate the key points from these articles and encourage the audience to delve into the comprehensive insights provided in this Research Topic.

Among the works included in this Research Topic, five of them assessed the existing relationship between stigma, mental health care providers, and stakeholders. The qualitative study by Hajebi et al. addresses the impact of stigma on mental health patients in Iran, leading to reluctance in seeking help and discontinuing treatment due to fear and embarrassment. Authors involved purposive sampling and utilized focus group interviews with mental health stakeholders. Thirteen participants, including psychologists, psychiatrists, managers, patients, and a family member discussed challenges, solutions, and successes related to stigma management in Iran. The findings emphasize the importance of raising awareness and providing training to diverse groups, including patients, families, therapists, leaders, policymakers, the public, and the media to change existing stereotypes and reduce stigmas. In another qualitative study lead by Badrfam et al., they examine the stigma experienced by frontline healthcare workers (HCWs) during the initial COVID-19 wave in Iran. The study identified four themes, eight categories, and 33 sub-categories encompassing extrinsic elements like "creating blame and shame" and "discrimination," intrinsic elements like "the desire to be avoided," "feeling depressed and frustrated," and "feeling anxious and scared," as well as perplexity and stigma removal requirements. Factors contributing to stigma among HCWs included low public awareness of COVID-19, insufficient public care, limited protective equipment, inadequate facilities, lack of appreciation, and a deficit in mental health support. Chuen Yu et al. conducted a transnational study, utilizing the Health Stigma and Discrimination framework (HSDF), employing semi-structured informant interviews with non-probability sampling, focusing on public perceptions and reactions to the pandemic in a multicultural context, with specific attention to findings from Singapore in Asia. Twenty-nine participants aged 23 to 80 years were interviewed, and the thematic analysis of coded interviews revealed five major themes: perception and experiences of stigma among respondents, drivers of stigma and misinformation, facilitators for prevention and reduction, and ageist attitudes toward older adults. Through the HSDF, the study provides an exploratory account of COVID-19-induced stigma in an Asian context, highlighting the importance of trust and effective communication in mitigating stigma during public health crises. Still, Huang et al. explored the attitudes and intentions of Chinese HCWs towards seeking professional psychological help amid the COVID-19 pandemic. Authors approached 1,224 participants from 12 hospitals in Hunan province, China, administrating the Attitudes Toward Seeking Professional Psychological Help Scale-Short Form (ATSPPH-SF) and the General Help-Seeking Questionnaire (GHSQ). Results from 1,208 HCWs revealed generally negative attitudes and low intentions regarding seeking professional psychological help during the pandemic. Additionally, psychological learning experience and social support positively influenced intentions to seek professional psychological help, whereas divorced marital status and self-stigma had negative effects. Finally, Kamalzadeh et al. wrote an opinion piece about perspectives from Early Career Psychiatrists (ECPs) Section members of the World Psychiatric Association (WPA), with the aim to explore the influence of stigma on the location and configuration of mental health establishments. The inquiry also investigated its effects on the professional identities and job satisfaction levels of psychiatrists across ten different national contexts, including India, Indonesia, Iran, Italy, Lebanon, Malaysia, Nigeria, Thailand, Tunisia, and the United Kingdom. Recommendations for enhancing the quality and accessibility of mental health care were also provided.

Two articles addressed psychosocial issues in light of stigma in mental health. In the first one Jain et al. ran a review examining the impact of stigma and psycho-socio-cultural challenges on the control of the COVID-19 pandemic. Their findings highlighted the influence of various psychosocial, socio-economic, and ethno-cultural factors on the transmission and control of COVID-19: indeed, stigma and related psychosocial challenges, including anxiety, fear, and stigma-driven social isolation have significantly contributed to mental health issues. Then, Helmert et al. explored variations in the desire for social distancing from individuals with mental illness by analyzing social and spatial information. The study found that stigma levels varied among city districts, and a higher desire for social distance was associated with spatial differences, increased pessimism, heightened shame about mental illness, lower social support, lower socio-economic status, and older age. The results highlight the importance of the geographical context in understanding and addressing mental health stigma.

Two articles that assessed the role of art in combating stigma were included. In the first one, Moeenrad et al. described the experience of the "Art and Psyche Festival", based on the application of protest, education, and/or interpersonal contact with someone affected by mental health issues. Authors concluded that the festivals, aimed at gathering social attention and support, did not formally evaluate the anti-stigma impact. Nevertheless, the organizers hypothesized that incorporating research methods into a third festival can further support the belief in the facilitating role of art in destigmatizing psychiatric disorders. Moreover, El Halabi et al. led a group of 12 ECPs from different countries and cultures collecting data and professional experiences about the role, function, and impact of art in counteracting stigma in mental health in their respective countries. The authors concluded that art can play a decisive role in improving the conditions of treatment and rehabilitation in psychiatry, but a lot still needs to be done, and such potential remains to be enormously enhanced and implemented, almost everywhere in the world.

The stigma associated with substance use disorder (SUD) was explored in depth by four different articles. Sapag et al. proposed a study protocol with the aim to assess the effectiveness of an anti-stigma intervention in reducing stigmatizing attitudes and behaviors among mental health providers toward individuals with mental illness and/or SUD in Chile. This research aimed to advance mental health and stigma research in Chile, contributing to improved access and quality of care for individuals with SUD. Evaluating the intervention's impact and implementation will provide insights for scaling it up to other "Centros de Salud Familiar" across Chile. Henderson et al. published an original research article including 133 individuals under treatment, wherein they assessed the influence of substance use/misuse risk factors and looked at perceived societal stigma and self-stigma. Their findings provide additional insights into the intricate relationship between culture and the individual, emphasizing the role of cultural distance in shaping self-stigma among those under treatment for substance use issues. In another opinion piece, El Hayek et al. proposed a multinational perspective and call for action on stigma toward SUD. Authors highlighted the urgent need for recognizing the significant challenges posed by stigma and reevaluating the language used in discussions about addiction. Additionally, the decriminalization of drug use was emphasized as a crucial step, not only in diminishing stigma but also in reallocating resources toward prevention and treatment, advocating for an approach that prioritizes healing over punishment. Finally, Cunningham et al. aimed to uncover instances of discrimination by clinicians, exploring the role of clinician beliefs and assumptions in the provision of physical health services for individuals with SUD. The study surveyed 253 patients who had accessed physical healthcare services about their experiences. The findings underscored the impact of discrimination based on SUD on the quality of care. The study emphasized the need for health systems and clinicians to prioritize quality improvement processes that ensure equitable access to and delivery of physical healthcare for individuals with SUD.

Focusing on the influence of COVID-19, three studies dedicated more attention to the role of the pandemic. Azman et al. tried to assess posttraumatic growth and its associations with stigma, psychological complications, and sociodemographic factors among COVID-19 patients six months post-hospitalization. Factors predicting posttraumatic growth included a higher level of perceived stigma, Malay ethnicity, retired status, and a history of medical illness. In a nutshell, the study suggested that experiencing stigma contributed to posttraumatic growth in COVID-19 patients, alongside sociodemographic and psychosocial factors. Shah et al. designed a cross-sectional study in Nepal with the goal to assess various aspects related to 395 individuals admitted for COVID-19 or suspected cases, including sociodemographic details, clinical information, COVID-19-related knowledge, perception, internalized stigma, and symptoms of depression and anxiety. Key findings included that 23.3% of patients had anxiety symptoms, 32.9% had depressive symptoms, and 20.3% experienced high COVID-19-related internalized stigma. The third study was an online survey by Hu et al. conducted in China, and covering all provinces, autonomous regions, and municipalities. It aimed to investigate how three dimensions—individual resilience perception, community resilience perception, and government trust perception—mitigate anxiety during COVID-19. Additionally, there was a positive correlation between community resilience perception, government trust, and individual psychological resilience. Government trust perception was found to enhance psychological resilience, leading to a reduction in anxiety. In summary, individual psychological resilience, community resilience perception, and government trust perception played crucial roles in mitigating anxiety during the COVID-19 pandemic, providing valuable insights for understanding mental well-being in challenging times.

Two papers investigated the relationship between mental health-related stigma and students. In one study, Porfyri et al. explored the views of Greek medical students toward mental illness and patients. They conducted a cross-sectional study involving 324 undergraduate students from the Aristotle University of Thessaloniki. While the findings align with previous studies, they suggested an improvement compared to earlier research among Greek student and healthcare populations. The study emphasized the need for ongoing vigilance, educational interventions, and social initiatives to empower current and future healthcare professionals to fulfill their roles effectively. In the study by Zavorotnyy et al., the authors investigated the impact of a psychiatric clerkship on stigmatizing attitudes toward mental disorders among 256 third- and fourth-year medical students in pre- and post-clerkship surveys. The study suggested that a psychiatric clerkship involving direct patient interaction can effectively decrease stigma. The findings support the incorporation of such components in medical education to combat stigma, potentially improving outcomes for individuals with severe mental disorders.

Two publications dealt with psychometric assessments in mental health-related stigma. In the first one, Peng et al. investigated expressed emotion, referring to family members' attitudes and emotional behaviors toward mentally ill relatives. This research successfully translated, adapted, and assessed the psychometric properties of a Chinese version of the Family Questionnaire. The questionnaire demonstrated a consistent two-factor structure (emotional over involvement and criticism), with reliability and validity confirmed through analyses of internal consistency, factor structure, and concurrent validity. In the second study, the research group led by Lu et al. focused on translating the Dementia Public Stigma Scale (DPSS) into standard written Chinese, developing a person-centered translation method, and proposing a tripartite assessment construct for translation quality evaluation. Authors were able to develop a method and an assessment construct for person-centered translation of dementia public stigma scales.

Pokharel et al. were able to collect ECPs' perspectives about mental illness stigma among perinatal women in low- and middle-income countries (LMICs). In this paper authors focused on the need for stigma reduction initiatives specifically targeting perinatal mental disorders in LMICs. They concluded that these programs should integrate effective intervention components, including educational methods such as dispelling myths and increasing knowledge. The implementation of these evidence-based interventions, designed to reduce stigma and discrimination, holds the potential to enhance help-seeking behavior and improve access to appropriate mental health care in LMICs.

Finally, through a series of individual semi-structured interviews (n = 27), Chen et al. aimed to comprehensively examine the impact of the anti-Asian racism within a Chinese community in the greater Boston area. Participants advocated for increased education, community and governmental support, and enhanced allyship among communities of color. These findings offer a cultural context for understanding the trauma experienced by this population and can guide future initiatives aimed at addressing the diverse array of reported health effects.

In conclusion, the articles collected in this editorial focus on the need to develop a comprehensive strategy to overcome mental health-related stigma, encompassing public awareness initiatives, educational efforts, and the use of destigmatizing language. The future of psychiatry should concentrate on creating an atmosphere of empathy, understanding, and open dialogue, empowering individuals to seek help without fear of judgment. Collaborative endeavors involving mental health professionals, policymakers, and communities are vital to dismantle mental health-related stigma, paving the way for enhanced mental health outcomes and a more compassionate society (8–10).

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# Status of stigma on the health care workers related to COVID-19 at the first wave of the pandemic in Iran: A qualitative study

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**Background:** Stigma can be seen as a mark of disgrace that can lead to the separation of one person from another. In this qualitative study, we assess the status of stigma among in front-line health care workers (HCWs) during the first wave of the COVID-19 pandemic in Iran.

**Subjects and methods:** The participants were selected from frontline HCWs related to COVID-19 in Imam Ali and Imam Hossein referral hospitals in Alborz province, Iran. Study was conducted between May and June 2020. The 32-item checklist Consolidated Criteria for Reporting Qualitative Research (COREQ) was used to report this qualitative study. Interview questions were prepared based on the grounded theory method. The thematic approach was used to analyze the data content. Data analysis was based on open and axial coding and after implementing the codes in MAXQDA software.

**Results:** The results of this study included 4 themes, 8 categories and 33 sub-categories. Themes included extrinsic and intrinsic elements of stigma, perplexity and stigma removal requirements. Extrinsic elements included "creating blame and shame" and "discrimination" categories. Intrinsic elements included "the desire to be avoidance," "feeling depressed and frustrated" and "feeling anxious and scared" categories. Perplexity included "feeling loss" category. Stigma removal requirements included "factors causing stigma" and "protective agents against stigma" categories.

**Conclusion:** Low public awareness on COVID-19 and inadequate public care, limited personal protective equipment and inadequate facilities for HCWs along with lack of appreciation for their efforts, lack of proper psychiatric/psychological counseling to identify and treat symptoms associated with mental health and the limitations of training to maintain mental health skills are considered to be factors in the formation of stigma among HCWs related to COVID-19. Health policymakers should implement coherent strategies related to increasing public awareness and providing personal protection needs and counseling care for HCWs in relation to COVID-19.

KEYWORDS

**stigma, health care workers, COVID-19, perplexity, mental health**

## Introduction

Stigma can be seen as a mark of disgrace that can lead to the separation of one person from another (1) and can be evaluated in different layers. Personal stigma can be considered as negative attitudes toward others; just as perceived stigma can be considered as perceived attitudes of others and self-image can be considered as a self-attribution of negative attitudes of others (2).

According to some studies, mental illness stigma has a negative effect on many life domains including housing (3), employment (4), income (5, 6), public perceptions about resource allocation (7) and access to treatment and care (8, 9). Such results underscore the economic usefulness of stigma-reduction interventions (10, 11).

With the emphasis of social aspect, stigma is defined as a process that is used to exclude those who are known as a potential source of disease and may be considered a threat to the effective social living in the society (12). In the meantime, other views on the effect of stigma on the individual, community and state levels in the formation of social inequality have been proposed (13). Experts pay attention to these inequalities in mental health issues, emphasizing the cultural aspect. These cultural issues in this area include concepts such as access and quality of receiving services, family experiences (such as secrecy for the sake of family), specific cultural beliefs and negative emotional responses (self-stigma) (14).

In the health system and in the widespread recent pandemic conditions, especially in case of prolongation of the pandemic time or even after its end, stigma can cause major challenges in the health economy due to the destroying the image of the safety of reference hospitals and the possible decreasing in the number of referrals to these medical centers (15). On the other hand, in addition to the economic aspects of stigma, which are of great attention, other social, psychological, and cultural effects are also noteworthy (10).

In some opinion, stigma related to novel coronavirus disease (COVID-19), like other aspects of the disease, can have a different meaning and can go beyond individual sense (16). This is especially important when it comes to healthcare staff, because of their impact on the care of patients with COVID-19 and pandemic control (17). Both stress in and out of the workplace can play a role in the formation of anxiety among health care workers (HCWs) (18). For this reason, especially in relation to COVID-19, it is important to pay attention to the mental health status of HCWs and its influencing factors (19, 20).

In COVID-19, stigma can mean discrimination against a group of people (for example HCWs, patients, or their families) that can be related to factors such as lack of knowledge about the disease and its spread, along with fear and anxiety related to it (16). Bhanot et al. mentions an example of these cases including people's stigmatizing reactions toward deceased relatives in the context of COVID-19 due to strong irrational fear and threat associated with the virus. They have also mentioned the stigma toward the forefront HCWs in India during the peak of the pandemic by neighbors, landlords, taxi drivers and even family members and have emphasized the equality of all human beings based on nature and avoiding division (12).

Stigmatization of other infectious diseases in the past, such as sever acute respiratory syndrome (SARS), has been prominent in both patients and HCWs. Fear of being stigmatized and of being quarantine-related deprived of various social positions and opportunities has also been seen among this group of people (21). These points, along with other problems with COVID-19-related economic issues, can exacerbate existing problems (22).

The uncertainty associated with COVID-19, due to the unpredictability of various conditions and changes related to infection control methods and public health recommendations, can provide the background for stigma among HCWs (21, 23). On the other hand, caring for patients at high risk of serious infections is associated with significant stigmatization. Meanwhile, it appears to be associated with long-term risks for HCWs, even after the end of quarantine and pandemic conditions (24). Thus, it is important to pay attention to the underlying factors that cause stigma among HCWs during the COVID-19 pandemic.

With various studies on HCWs associated with COVID-19 showing a relatively high prevalence of anxiety and depression symptoms among HCWs, stigma seems to be a worrying trend for this group of workers, especially frontline workers (25–27). In a qualitative study in Nigeria, Kwaghe et al. investigated stigma and traumatic experiences among 19 frontline healthcare workers during the COVID-19 pandemic. They have mentioned themes such as "Early stage of the pandemic" including fear, anxiety and socio-economic effects of the pandemic, "working with COVID-19 patients" including duty stress, "psychological trauma" and "stigmatization" from colleagues, family and friends and its reasons including fear of infection, limited knowledge of the virus and working in the isolated environment as the results of their qualitative study. They have mentioned stigmatization as a big challenge for frontline HCWs in performing their duties. They have also emphasized the psychological impact of stigma experienced by them in reducing the quality of services provided to patients (28). Ramacy et al., in a study involving 260 HCWs in a hospital in southern Italy, examined Social Stigma during COVID-19 and its impact on HCWs Outcomes. They reported stigma as a positive predictor of burnout and a negative predictor of satisfaction (24). In a study in Nepal, Adhikari et al. investigated the prevalence of anxiety, depression, and perceived stigma among HCWs related to COVID-19 and reported the prevalence of anxiety and depression among 213 HCWs, 46.95 and 41.31%, respectively. They mentioned the experience of some form of perceived stigmatization due to COVID-19 among HCWs, 57% and mentioned that frontline HCWs were 6 times more stigmatized than non-front line HCWs (29).

Stigma related to some infectious diseases such as HIV is common among HCWs in Iran (30). After the COVID-19 pandemic, the issue of stigma among HCWs received special attention. In a study in Iran during the peak of the COVID-19 pandemic, which examined posttraumatic stress symptoms and stigma among 894 front-line HCWs in 9 general hospitals, a strong and positive significant correlation was reported between their scores (coefficient: 0.83) (31).

During the outbreak of COVID-19, Iran was affected by this disease early on, and despite the use of existing facilities and the acceptable capacity of primary health care, it faced large waves of outbreaks (32). Meanwhile, HCWs, especially frontline workers, are exposed to mental health problems due to exposure to high workload and caring for patients with serious and highly communicable diseases with the need for long-term hospitalization (33, 34). Azizi et al. reported the prevalence of the physical and psychological anxiety among HCWS 47.9 and 70.5%, respectively. They also reported the prevalence of depression, anxiety, and stress Symptoms among them 44.8, 43, and 34.8%, respectively (35). Rayani et al. also reported significant negative relationship between anxiety and resilience in a study of 550 HCWs related to COVID-19 in Iran (36).

In this way, considering the high prevalence of symptoms of mental health disorders among HCWs in Iran during the COVID-19 pandemic, we hypothesize that in-front line HCWs related to COVID-19 are suffering stigma related to their employment status in the family, occupational, and community environments. Here, based on grounded theory, we discuss the interaction of HCWs with their inner understanding of themselves and its interaction with the surrounding environment, including a set of contacts from close family layers to community levels. Such an approach in this field, in our hypothesis, becomes the basis for the formation of perceived stigma and self-attribution of negative attitudes of others in HCWs during the COVID-19 pandemic. Such experience, along with everyday events and current limitations, presents mental health disorders as a serious challenge among HCWs. In the following, based on the experience gained from these concepts, we will express the solutions to deal with them among this group of people in the society. According to this, in this qualitative study, we assess the status of stigma among "in front line" HCWs during the earliest wave of COVID-19 outbreaks in Iran.

## Materials and methods

### Participants

Participants were selected using convenience sampling method among the personnel involved in the care of COVID-19 patients who worked in various internal medicine and infectious wards and intensive care units (ICU) of the two large general hospitals of Alborz province at the first wave of the COVID-19 pandemic in Iran. They included physicians, nurses, and paramedics. They were invited to participate in an individual interview by sending a text message to them via mobile phone. In addition to requesting a response to agree or disagree to participate in the study by replying to the sent message, one of the interviewers, in accordance with personal protection standards, followed up the receipt of the messages by the participants and their response to voluntarily attend the interview.

The inclusion criteria for the study included all HCWs working in two hospitals of the study site who were older than 18 years and were physicians, nurses and paramedics involved in the care of COVID-19 patients who were working in different wards of the referral hospital for the care of patients with COVID-19. These individuals were HCWs who, after stating the objectives of the study, tended to describe their situations to others. Sampling and coding continued until no new code was obtained and saturation occurred. Thus, on this basis, sampling was completed and the sample size was determined. Exclusion criteria included people who had a previous history of psychiatric disorders under drug treatment in the last year (in the form of self-report).

Finally, the number of participants in this study was 20 [14 females (70%) and 6 males (30%)]. They included 5 physicians (medical doctor), 12 nurses (bachelor's and postgraduate degree) and 3 paramedics (post-diploma degree). Paramedics included radiology and laboratory technicians, social workers, and the like. All these occupational groups had close and direct contact with patients infected with COVID-19 in different departments of the hospital during their stay in the hospital. The mean age of the participants was 33.1 (*SD* = 7.22) years with range of 21–56 years old. Five participants were in the ICU, five in the infectious diseases ward and ten in the internal medicine ward. The average years of work experience of HCWs was 8.1 (*SD* = 6.30) years, which included at least 1 year and a maximum of 22 years (**Table 1**).

All participants and interviewers were Iranian and the interview was conducted in Persian. This study was conducted between May and June 2020.

## Questions and description

The 32-item checklist Consolidated criteria for reporting qualitative research (COREQ) is used to report this qualitative study (37).

Questions asked of HCWs during the interview included the following:

1) Have you been blamed and embarrassed by the working conditions of the Coronavirus pandemic? How did you experience this blame and shame?
2) What are the sources of this blame and shame in the work environment caused by the Coronavirus pandemic?
3) Have you experienced a sense of rejection in the workplace or in everyday life? What were the sources?
4) Have you experienced an inability to understand the environment? Can you explain this feeling?
5) Explain your sources of information about the pandemic. What problems do you feel in the context?
6) During the pandemic period so far, how has your personal and professional life changed?
   How has the recent pandemic affected your personal and professional life?
7) What do you think about your protective equipment in the workplace and your expectations of officials?

TABLE 1 Demographic characteristics of study participants.

| | | Number (percentage)/average (Standard Deviation-SD) |
|---|---|---|
| Gender | Female | 14 (70) |
| | Male | 6 (30) |
| | Total | 20 (100) |
| Job | Physician | 5 (25) |
| | Nurse | 12 (60) |
| | Paramedic | 3 (15) |
| Mean age (years) | | 33.1 (SD = 7.22) |
| The average years of work experience (years) | | 8.1 (SD = 6.30) |

## Research team and reflexivity

### Personal characteristics

The interview was performed by two male and female expert psychiatrists in qualitative research. At the time of the interview, the two interviewing psychiatrists were in charge of the mental health team at a mental health counseling clinic.

### Relationship with participants

Prior to the interviews, the interviewees spoke to HCWs, observing health protocols and using personal protective equipment. This initial talk was conducted for a short period of up to 15 min due to the pandemic conditions. The session was performed in a well-ventilated room outside the ward of patients with COVID-19. Only one interviewer and one HCW were present in the room during each initial interview. These conditions were met for all initial interviews in the same format and under the same conditions. In order to facilitate the conditions of the main interview, a proper rapport was formed with the HCWs in these meetings. This was done in the form of holding a meeting with a friendly approach and in order to create a sense of confidence in trying to improve the personal and working conditions of HCWs.

In this short communication, which was done in order to get acquainted with the people who met the inclusion criteria, the objectives of the study and the reasons for doing so were discussed.

## Study design

### Theoretical framework

The grounded theory method was used to underpin the study (38). Grounded theory is a known methodology in research studies. This method deals with the discovery or creation of theory from data that has been systematically obtained and subjected to comparative analysis (39). The focus here is on discovering patterns of social life that people may or may not be aware of (40). In fact, a diverse approach is considered here, which studies a kind of interaction between the individual and the surrounding environment (41). Grounded theory, especially in triangulation with hermeneutics, is a way to understand complex human phenomena that explains basic social processes at a higher level of abstraction. This path is intended as a framework for planning quantitative interventions (42). In this way, grounded theory and thematic analysis can prevent the bias of the results by using mixed methods and multiple sources and coders and increase the validity of the findings (43).

A grounded theory is produced based on themes. Themes are also formed based on the data and analysis process. In this way, they reveal experiences and achievements from different situations and fields. In this way, it reveals the experiences and understanding of meaning from different situations and contexts (44).

### Participant selection

Sampling was based on convenience and consecutive method (45). The interview was conducted as a face-to-face meeting with appropriate physical distance and in an environment outside emergency department and patients' wards and in a relaxed manner, in the form of a session of about 30 min and at the time intended by the participants. The conditions of the interviews were similar to the initial interviews with the HCWs. The total number of participants in the study was 20, including 5 physicians, 12 nurses and 3 paramedics. While identifying cases to enter the study, two HCWs who met the study criteria, stating that they did not have enough time to participate in the study, but after selecting the final 20, all participated in the study.

### Setting

The study was conducted in Imam Ali and Imam Hossein hospital centers of Alborz province, Iran. These two hospitals are general academic hospitals belonging to Alborz University of Medical Sciences. At the time of the study, a number of internal, infectious and ICU wards in these hospitals were dedicated to the care of patients with COVID-19. Imam Ali and Imam Hossein hospitals have 498 and 150 active inpatient beds, respectively and at the time of the study, 140 and 48 inpatient beds were assigned to patients with COVID-19, respectively. In Imam Ali Hospital, 110 and 30 beds were reserved for isolated COVID-19 wards and ICU for COVID-19 patients, respectively. This number included 36 inpatient beds and 12 ICU beds in Imam Hossein Hospital.

The interview took place in a specific room on one of the floors of each hospital clinic, which was set aside separately during the interview. At the time of the interview, only the interviewer and the HCW were present at the interview site. The interviews were conducted during the first wave of COVID-19 pandemic in Iran, with the aim of familiarizing with the state of stigma among HCWs and the relevant assessment needed to improve the situation.

### Data collection

The questions, questionnaires and guidelines were designed and specified before the study.

Prior to the start of the study, each interviewee conducted an interview with another member of the group who had the inclusion criteria to enter the study but was not a participant in the study. All interviews were conducted in one session and were not repeated.

The work process was such that first and after the initial conceptualization, the desired references were searched in the literature. Previous studies in this field, especially regarding the status of stigma during past pandemics and other related concepts, were evaluated and the results of those studies and their methodology were discussed (46–49). Next, related primary questions were designed and edited several times based on related studies up to that time. The initial pilot study was conducted in the form of three initial interview sessions and recorded for further evaluation. After the end of each session, a discussion was held about the content of the interview with the aim of obtaining the best and most accurate questions related to the interview with HCWs. The holding of these three pilot sessions was accompanied by some changes in the questions and the method of conducting the interview, including trying to make the interviewee-centered sessions.

With the written consent of the participants before starting the interview session, the conversations in the interview session were recorded as audio recording. Each session lasted about 30 min.

## Analysis and findings

### Data analysis

Out of a total of 20 interviews, 142 codes were obtained. These codes were eventually placed in 4 them and 8 categories, which included a total of 33 sub-categories. Based on grounded theory (38), the development of a coding tree was as follows:

With the help of the deductive process, based on the conceptual framework of study and its objectives, first the identification of general data categories was done, and then a correct understanding of the themes and initial data was obtained. Themes were obtained based on the data. Based on these themes and related details, more specific coding categories have been obtained (50). Data analysis was based on open and axial coding and after implementing the codes in MAXQDA software. After presenting the results to the participants, at the appointed time, some of them provided feedback over the phone, and their comments were applied in subsequent settings.

### Reporting

In this report, participant quotations were presented to reveal the themes and findings of the study. Participant quotations were presented in the form of a table according to the themes, categories and subcategories obtained. There was consistency between the data presented and the finding. The main themes were clearly defined. The report also discussed various findings and sub-themes.

## Results

Four themes were extracted in this study. Eight categories and 33 sub-categories were other components of results of the study (**Table 2**).

Themes include "extrinsic elements of stigma," "intrinsic elements of stigma," "perplexity in the ground of stigma" and

TABLE 2 Themes and their categories related stigma over health care workers related to COVID-19.

| Theme | Category | Subcategory | Participant explanatory quotations |
|---|---|---|---|
| **Extrinsic elements of stigma** | **Creating blame and shame** | **Blaming look at the staff** | *My daughter has allergies. She has been coughing for a few days and her eyes were red. During this time, my wife has repeatedly argued with me that it is your fault. "If something bad happens to my child, I will not forgive you." While my daughter has a recurrence of allergies every spring.* |
| | | **Misjudgment and labeling** | *They think that because we are the medical staff, we will definitely get COVID-19; "Oh my God, let your family come to us," said my mother-in-law several times. You deal with the patient every day. Even now, I have heard that you have shortness of breath. You make children sick* |
| | | **Curiosity about getting sick** | *My mother calls every day and asks, "Didn't you and your husband and children get Corona?" It's as if they're waiting for us to get Corona.* |
| | | **Avoidance behaviors** | *Because they know I'm a medical staff, they don't even let their kids play with my kids; My mother-in-law repeatedly told me directly and indirectly, "Don't come to our house.* |
| | **Discrimination** | **Repulsive and cautious behaviors of those around and society** | *I went to the medical goods store to buy. When I told the salesman that I wanted shield and glasses for myself for hospital, he shouted at me and said, "Madam, go back, your bag is hitting the table, now we're all taking Corona."; In the parking lot, the neighbors, who know that I work in the hospital, as soon as they see me, quickly turn their backs on me and run away from me.* |
| **Intrinsic elements of stigma** | **Feeling rejected and the desire to be avoidance** | **Refuse to take leave** | *I can't wait to see anyone. I feel like everyone is looking at me the same way.* |
| | | ***Hide possible symptoms of the disease*** | For *a day or two, I felt dizzy and sometimes itchy in my throat. I really doubted I was sick. I didn't want to talk to anyone, not even my wife. I was both afraid to worry and pessimistic about myself and my job.* |
| | | ***Feeling lonely*** | *My wife and child are reluctant to see me every time I return home. It's as if they're afraid to see me. I really feel lonely and confused. It feels so bad to feel like I have to be in quarantine for days.* |
| | | ***Fear of being fired or unemployed*** | *Honestly, I'm contracted, and if I make a mistake or miss a few days, I'll lose my job.* |
| | **Feeling depressed and frustrated** | **Disappointment with the future** | *No one understands us properly, and soon everyone will forget how much we suffered.* |
| | | ***Sadness*** | *As before, I can't be happy. I feel sad all the time.* |
| | | ***Decreased self-confidence*** | *We are told that you are so exposed and infected that we no longer feel that self-confidence.* |
| | | **Suicide thoughts** | *A few days ago, three patients died in my shift. I felt weak. The loneliness and confusion of those around me was further compounded by the thought of suicide. But I did nothing.* |
| | **Feeling anxious and scared** | **Anxiety caused by sleep disturbances** | *The possibility of rest is low. My sleep conditions are disturbed. I am all asleep and awake. I have nightmares at night. It's as if something very bad has happened.* |
| | | **Feeling tired and exhausted** | *Deaths are also high. These make a person tired and exhausted.; Sometimes I wish I had another job not to deal with the patient.* |
| | | ***Guilt feeling*** | *When my child coughs, I feel guilty. My conscience is really bothering me that I have this job.* |
| | | ***High working pressure*** | *The number of clients is very high and it is difficult to control them and it leads to anxiety in us.* |
| | | ***Physical symptoms and anxiety*** | *I've already had dry coughs before. Now it's more, but I have no other symptoms.* |
| **Perplexity** | **Feeling loss** | **Detachment** | *Sometimes when people around me treat me unnaturally, I feel like I'm confused;*<br>*I don't know how to explain that feeling. I feel like I've loss something.* |
| | | ***Melancholia*** | *Sometimes I feel like I've lost my inner capital; it's a very painful feeling. It's a feeling of emptiness.* |
| **Stigma elimination requirements** | **Factors causing stigma** | **The role of the media** | *TV programs are not complete. What they show is a form of news that often exacerbates stress and takes society's view of medical staff toward those as high risk (for transmitting the infection).* |
| | | **The role of cyberspace** | *The information is still incomplete.*<br>*The role of the Internet is very important. Rumors and stigma may spread through both people and cyberspace.* |

*(Continued)*

TABLE 2 (Continued)

| Theme | Category | Subcategory | Participant explanatory quotations |
|---|---|---|---|
| | | **Lack of knowledge about the disease** | *The disease is still very unknown and even we do not know much about it. I think this is very worrying and misleading.* |
| | | **The role of insufficient information of the people** | *People around us, unwittingly and without accurate information, always think that we must be sick, or that we are sick, or that we are carriers of the disease.* |
| | | **Living and economic issues** | *In society, economic problems abound. People are much more concerned about their own health, especially given the needs of the family. Therefore, those who feel they may be ill may be treated badly.* |
| | **Protective agents against stigma** | **Sufficient equipment** | *Occupational safety and standards are low. Maybe if our safety and equipment is perfectly adequate, people around us will know that we don't have to be sick. The same is true for ourselves.* |
| | | **Adjust hospital attendance** | *Our shifts are too much. The number of staff is small and most of us are on duty one day in between.* |
| | | **Improving the level of care** | *Some are clearly negligent and put themselves and others at risk. Training is very important in this regard.* |
| | | **The presence of psychologists and psychiatrists alongside staff** | *Our job is always stressful. We are always subject to judgment. The situation is much worse now. Psychologists and psychiatrists should really be with us.* |
| | | **Ensuring job security** | *I am a company employee and I am not an official employee and I have not been paid for months.* |
| | | **Pay attention to the positive aspects of the job** | *It feels good to serve patients.* |
| | | **Appreciation of the treatment staff** | *We like to be respected. Finally, one day Corona will be controlled. We must not forget.* |

"stigma removal requirements." Each category has a number of sub-categories.

## Extrinsic elements of stigma

Here we are faced with the concept of being blamed for being in a care setting related to COVID-19 by those close to the HCWs. Also, the wrong beliefs about being infected with infectious disease by taking care of these patients are mentioned by HCWs. Being discriminated against due to job status by sellers and other job groups at the community level is another point worth mentioning.

This theme has two categories. The categories include "creating blame and shame" and "discrimination."

**(1) Creating blame and shame** include the following sub-categories:

**Blaming look at the staff** (Female, nurse, 31 years old: "*My daughter has allergies. She has been coughing for a few days and her eyes were red. During this time, my wife has repeatedly argued with me that it is your fault.")*, **Misjudgment and labeling** (Female, nurse, 31 years old: They think that because we are the medical staff, we will definitely get COVID-19; "*Oh my God! let your family come to us*," said my mother-in-law several times.),

**Curiosity about getting sick** (Female, nurse, 30 years old: "*My mother calls every day and asks: "Didn't you and your husband and children get Corona?" It's as if they're waiting for us to get Corona."*), **Avoidance behaviors** (Female, physician, 35 years old: "*Because they know I'm a medical staff, they don't even let their kids play with my kids").*

**(2) Discrimination** includes the following sub-category:

**Repulsive and cautious behaviors of those around and society** (Female, nurse, 31 years old*: "I went to the medical goods store to buy. When I told the salesman that I wanted shield and glasses for myself for hospital, he shouted at me and said, "Madam, go back, your bag is hitting the table, now we're all taking Corona").*

## Intrinsic elements of stigma

Here we are associated with the concept of worries and fears due to the possibility of being infected with the disease and interpreting the usual symptoms as symptoms of COVID-19. The worry of job loss due to possible infection is one of the other points mentioned in this field. The internal interpretation of the evasive behavior of the family and attributing it to the possibility of being infected due to special working conditions, decreased self-confidence and feelings of sadness and loneliness are mentioned by the HCWs. Also, caregivers report anxiety, excessive worry, and poor sleep due to frequent exposure to a large number of clients and the inappropriate vital condition of patients and their death in inpatient wards.

This theme has three categories. The categories include the desire to be avoidance, feeling depressed and frustrated and feeling anxious and scared.

**(1) Feeling rejected and the desire to be avoidance** includes the following sub-categories:

**Refuse to take leave** (Male, paramedic, 22 years old, *"I can't wait to see anyone. I feel like everyone is looking at me the same way."), **hide possible symptoms of the disease** (*Female, nurse, 42 years old, *"For a day or two, I felt dizzy and sometimes itchy in my throat. I was both afraid to worry and pessimistic about myself and my job."), **feeling lonely** (*Male, physician, 39 years old, *"My wife and child are reluctant to see me every time I return home. It's as if they're afraid to see me"), **fear of being fired or unemployed** (*Male, nurse, 25 years old, *"Honestly, I'm contracted, and if I make a mistake or miss a few days, I'll lose my job").*

***(2) Feeling depressed and frustrated*** includes the following sub-categories:

**Disappointment with the future** (Female, nurse, 40 years old, *"No one understands us properly, and soon everyone will forget how much we suffered."), **sadness** (*Female, nurse, 31 years old, *"As before, I can't be happy. I feel sad all the time."),* **decreased self-confidence** (Male, nurse, 31 years old, *"We are told that you are so exposed and infected that we no longer feel that self-confidence."),* **suicide thoughts** (Female, physician, 31 years old, *"A few days ago, three patients died in my shift. The loneliness and confusion of those around me was further compounded by the thought of suicide").*

**(3) Feeling anxious and scared** includes the following sub-categories:

**Anxiety caused by sleep disturbances** (Female, paramedic, 31 years old, *"The possibility of rest is low. My sleep conditions are disturbed. I am all asleep and awake"),* **Feeling tired and exhausted** (Male, physician, 32 years old, *"Deaths are also high. These make a person tired and exhausted*"), ***Guilt feeling*** (Female, nurse, 31 years old, *"When my child coughs, I feel guilty."), **High working pressure** (*Female, nurse, 21 years old, *"The number of clients is very high and it is difficult to control them and it leads to anxiety in us"), **Physical symptoms and anxiety** (*Female, nurse, 31 years old, *"I've already had dry coughs before. Now it's more, but I have no other symptoms").*

## Perplexity

Here, we are faced with concepts such as a feeling of separation from the environment, confusion and loss among HCWs when faced with the unusual behavior of others and changing environmental conditions.

This theme has one category. This category includes "feeling loss."

**(1) Feeling loss** include the following sub-categories:

**Detachment** (Female, nurse, 31 years old, *"Sometimes when people around me treat me unnaturally, I feel like I'm confused; I don't know how to explain that feeling."*), **Melancholia** (Female, nurse, 26 years old, *"Sometimes I feel like I've lost my inner capital; it's a very painful feeling").*

## Stigma elimination requirements

Here, the causal and protective factors of stigma in HCWs' conversations are considered. They describe the problem of spreading rumors and wrong news in the virtual space and among people on the one hand, and the unknown aspects of the disease on the other hand, as worrying. They emphasize the necessity of having appropriate and complete personal protective equipment and mention that having such protection can reduce people's feeling that they are sick and people's negative attitudes toward them. Also, they emphasize the need to manage their working hours by the hospital officials and reduce related pressures in this field. Emphasizing on stressful working conditions, they point out the need to be supported by psychological and psychiatric counseling systems. They also emphasize the need to extend emotional care and support to them in order to maintain their morale and strengthen their hope and steadfastness in hard working conditions.

This theme has two categories. The categories include "factors causing stigma" and "protective agents against stigma."

**(1) Factors causing stigma** include the following sub-categories:

**The role of the media** (Male, nurse, 56 years old, *"What TV programs show is a form of news that often exacerbates stress and takes society's view of medical staff toward those as high risk for transmitting the infection.*"), **The role of cyberspace** (Female, nurse, 42 years old, "*The information is still incomplete. Rumors may spread through both people and cyberspace.*"), **lack of knowledge about the disease** (Female, physician, 35 years old, *"The disease is still very unknown and even we do not know much about it. I think this is very worrying"),* **The role of insufficient information of the people** (Female, nurse, 31 years old, *"People around us, unwittingly and without accurate information, always think that we must be sick"),* **Living and economic issues** (Male, nurse, 56 years old, "*In society, economic problems abound. People are much more concerned about their own health*").

**(2) Protective agents against stigma** include the following sub-categories:

**Sufficient equipment** (Female, nurse, 35 years old," *Maybe if our safety and equipment is perfectly adequate, people around us will know that we don't have to be sick"),* **Adjust hospital attendance** (Female, paramedic, 29 years old, *"Our shifts are too much. The number of staff is small and most of us are on duty one day in between."),* **Improving the level of care** (Female, physician, 31 years old, *"Some are clearly negligent and* *put themselves and others at risk. Training is very important in this regard."),* **The presence of psychologists and psychiatrists alongside staff** (Female, physician, 35 years old, *"Our job is always stressful. The situation is much worse now. Psychologists and psychiatrists should really be with us."*), **Ensuring job security** (Female, nurse, 26 years old," *I am a company employee and I am not an official employee. I have not been paid for months."),* **Pay attention to the positive aspects of the job** (Female, nurse, 30 years old, *"It feels good to serve patients."*), **Appreciation of the treatment staff** (Female, nurse, 40 years old, *"We like to be respected. We must not forget").*

## Discussion

Being blamed by family and friends in family, professional and social environments, due to their job position as HCWs, is one of the salient points taken from the content of interviews with HCWs in our study. Attributing the non-specific symptoms of this group of staff to the symptoms of the COVID-19 and continuing to ask questions about their possible infection, along with creating some emotional and social deprivations for the HCWs and their families, are the bases for the formation of shame in them. This feeling of shame can induce negative experiences with worthlessness and inferiority that along with guilt, can create and intensify stigma among HCWs (51, 52).

In our study, HCWs also expressed concern about discrimination against them and their families in and out of hospital settings. This sometimes led to attempts to hide some suspicious symptoms of COVID-19, which was due to concerns about losing job opportunities in the face of possible discrimination. Also, the precautionary and repulsive behaviors of those who found out about the job status of the staff were also noteworthy.

This is a major threat to HCWs, which not only expose them to bullying and harassment, but can also be associated with an increased risk of perceived stigma (53). This point in relation to social, psychological and medical variables, along with the loss of respect in society, provides more background for stigma and emotional and physical violence against HCWs and can have many long-term consequences in relation to these variables (54, 55). It seems that attention to all the above variables by health policy makers at different individual and social levels is an undeniable part of COVID-19 pandemic management.

Such variables, both at the level of nations and at the level of governments, emphasize the need to evaluate and determine care strategies. In this regard, the role of policy makers in promoting public awareness and the use of public education with effective methods and the role of HCWs as reference groups in forcing policymakers to take responsibility and creating appropriate physical conditions and financial support, is undeniable (56, 57).

The participants in our study talked about the feeling of loneliness, rejection, feeling of some kind of emotional separation, anxiety about the job situation and fear of being fired from work. These had caused the feeling of rejection and the tendency to avoid in them and finally led to the formation of stigma both in the work and family environment. In a similar study in Italy during the COVID-19 pandemic, a group of nurses experienced stigma in their work environment and stigma in everyday lives, which caused them to avoid being close to others (58).

The content mentioned by the HCWs in our study includes components such as blaming, misjudgment and labeling, curiosity and repulsive behavior. These are associated with a number of intrinsic elements, along with psychological distress, and in some cases with psychiatric symptoms such as anxiety and depression and physical health problems (59). According to some studies, these are conditions that can be more severe in a situation that HCWs have a history of COVID-19 (60). Following the SARS epidemic, Ho et al. examined the status of staff between the two groups with and without a history of the epidemic disease. They cited the fear of infecting their families as one of the common features of the two groups and noted concerns about discrimination among HCWs with a history of SARS and fears of contracting the disease among the second group (61).

Also, during SARS epidemics, the rate of stigmatization, such as psychologic distress, was higher among people who were in the front line (62). In fact, among this group of HCWs, there was not only physical fear of illness, but also anxiety caused by stigma and fear of losing patients, and even the behavior of colleagues could be a source of psychological distress.

Verma et al. also noted the association between stigmatization and psychiatric morbidity among HCWs during the SARS epidemic. They cited a decline in performance and an interpersonal relationship as possible consequences of this situation and emphasized the need to address the psychological needs of HCWs and to identify and treat these disorders (49). This is while, in some studies, stigma is seen as a barrier to mental health interventions (63) and health seeking behavior (64). Other examples of this situation include Ramaci et al.'s study of HCWs in COVID-19 in Italy. They described the stigma as a strong predictor for negative outcomes such as fatigue and burnout (24). In our study, HCWs also introduced fatigue and burnout as one of the elements of stigma.

In our study, according to the symptoms of anxiety and depression in the interviewees and their "frontline" conditions, it seems that trying to reduce stigma can be effective in reducing the above symptoms on the one hand, and controlling the symptoms of depression and anxiety on the other hand can play a role in reducing the feeling of stigma. Thus, it seems that trying to raise the awareness of personnel about mental health problems and the need to pay attention to it and perform related diagnostic and therapeutic measures can help improve the above process and reduce the level of stigma among them.

Also, the need to persuade HCWs to express problems related to mental health, such as attention to sleep problems (65) and physical problems related to mental health disorders (66) can be effective in this regard. In our study, part of stigma's intrinsic elements was anxiety related to sleep disturbances, along with feelings of burnout and anxiety-related physical symptoms. A number of participants also expressed sadness, frustration about the future, and the occasional thought of suicide as part of their mental state.

The participants in our study talk about a sense of loss and perplexity. They mention a feeling like confusion and inability to describe their situation and sometimes they talk about a deep feeling of emptiness. In some similar experiences during the COVID-19 pandemic, it has been reported that the sense of self is affected in terms of detachment and melancholy related to the pandemic. Other similar phenomena have been reported in relation to affecting the sense of self in the context of detachment and melancholy related to the pandemic (67).

According to some experts, this perplexity is a kind of lack of common sense (68). This outward-looking can have similarities with the look "beyond the individual sense" (16). Here perplexity is closely related to the concepts of "detachment" and "melancholia" which were the points we saw in some of the in-front line HCWs who participated in the study.

The impact of media and cyberspace on the intensification of stress related to COVID-19 and their role in the formation of this mindset that HCWs are the source of infectious agent transmission is mentioned by HCWs in our study. In most human cultures, being contaminated and potentially spreading an infectious disease is associated with shame and stigma (69). HCWs in our study also mention incomplete information transmission as one of the salient features of the media during the COVID-19 pandemic. This incomplete information can be associated with many problems related to the performance status of HCWs and cause stigma and discrimination against them in different environments. It can also expose them to the risk of psychological problems (70). A report from Indonesia and Thailand on COVID-19 found that some doctors and nurses were rejected by the community because they were considered a source of virus transmission (71).

In this regard, it seems that in addition to raising awareness at the community level and even in medical service providers to patients with COVID-19, policymakers' efforts should provide a platform for job stability and job security for HCWs. This is even more important given that these people are at greater risk for COVID-19 and is associated with an increased risk of perceived stigma. As in a study in Iran on a group of HCWs with demographic characteristics and working conditions similar to the HCWs participating in our study, the history of COVID-19 was associated with an obvious increased risk of anxiety, depression, and stress (72). These symptoms are bilaterally related to stigma, especially among HCWs. In fact, in such circumstances, in addition to improving the level of public education, it seems that in the face of the crisis ahead, there is a serious need for synergy between central governments, regional decision makers, community leaders and referral hospital officials (73).

As can be seen, the active elements in stigma appear to be intertwined in many cases, and a combination of intrinsic, extrinsic and some other factors can be effective in its formation in various clinical experiments.

In another study by Maunder et al., on the psychological effects of SARS outbreak, fears of infection and anxiety about transmitting the disease to the family with loneliness were some of the highlights. They reported uncertainty and stigmatization as prominent themes, and reported the presence of anxiety and stress associated with uncertainty among HCWs. Here, the use of psychological and psychiatric counseling in HCW mental health care was emphasized (74). In our study, participants also emphasized the need for psychological and psychiatric services to be available in this situation. This can be helpful in managing the symptoms of anxiety, stress, depression and burn out, as well as helping to reduce stigma.

Another point of the report is the abandonment of work by a number of physician and nurses due to lack of appreciation for sacrificing their lives to help others. In our study, the points made by HCWs as a protective factor against stigma are their emphasis on the need to be appreciated and "seen." Supporting HCWs and establishing job security seems to be able to play an effective role in reducing stigma among HCWs.

It seems that removing the stigma requires the influence of various factors, and in the social dimensions, creating solidarity and restoring identity according to the experiences that exist in the field of diseases related to stigma can play an important role in this field. Increasing public awareness can also be an effective factor in reducing the stigma associated with COVID-19 (75).

Appropriate interventions related to coping with the current situation and reconstructing the meaning of life using psychological interventions such as positive psychology and other interventions (76) as well as the use of tele-psychiatry capabilities along with local psychosocial support, which can vary from educational planning to emergency interventions (77, 78), can be used and should be considered as a framework for interventions related to the mental health of HCWs.

The usefulness of such interventions may be considered not only from personal and professional aspects related to HCWs, but also by improving patient care, increasing self-confidence and reducing perceived stigma can lead to direct and indirect economic effects while maintaining HCWs efficiency and improving the human resource status of health systems (79).

Given the global burden of COVID-19, it seems that policy implications need to be achieved so that HCWs and health systems can take steps to ensure safety while providing high quality care for patients with COVID-19 (80). Meanwhile, in the field of public health management, it seems that the sustainable exit strategy from the current conditions (81), given the current pandemic situation, needs to have policies that facilitate the personal and professional needs of HCWs. Accordingly, attention to the financial issues of the health care system will be one of the essential issues in major policy-making in the coming years. Thus, as the pandemic continues, clinical and policy strategies to maintain the mental health of HCWs are increasingly needed (82). Creating suitable occupational and environmental conditions accompanied with psychological interventions and paying attention to all groups related to providing services to patients with COVID-19 seems necessary (83).

At the individual and professional levels, some potential measures to reduce mental health problems in HCWs can include effective communication, providing screening facilities and interventions for mental health problems, financial support, actively limiting rumors and misinformation, and legal protections for disability and retirement benefits (84). An important point in this regard can be the correct modeling of other related initiatives in other countries. Establishing evidence-based strategies and close partnership between the government and the community can help in this regard (85).

### Limitations

This study was evaluated based on cross-sectional data, so it cannot be used to investigate the relationship between cause and effect. Due to the limitations related to personal protection measures and the lack of universal vaccination at the beginning of the pandemic, the interviews were held in the shortest possible time with a minimum number of people in each session (one interviewer and one interviewee).

Focusing on the content of the interview and collecting and reviewing the relevant requirements and references before holding the interview sessions and establishing a proper rapport with the participants, a lot of effort was made so that the sessions have high quality and appropriate content despite the limited number and time of the interviews. Also, this study was carried out at the beginning of the spread of the pandemic. The interviews with the participants were accompanied by restrictions due to the observance of the maximum personal protection coverage, and with the proper cooperation and high motivation of the participants in the study, the follow-up of the meeting progressed properly.

## Conclusion

An interview with a group of in-front line HCWs, related to COVID-19, showed that in addition to intrinsic and extrinsic elements, perplexity in the ground of stigma is a major theme in HCWs-related stigma. Feeling loss was the main category associated with this theme, and was associated with concepts related to lack of common sense and beyond the individual sense. Blame and shame were used as extrinsic elements along with feeling rejected, feeling depressed and frustrated, and feeling anxious and scared as intrinsic elements associated with Stigma.

Health policymakers should implement coherent strategies related to increasing public awareness and providing personal protection needs and counseling care for HCWs in relation to COVID-19. Expanding educational programs related to COVID-19 by using reliable scientific sources with more effective participation of experts in this field and raising awareness about the effective role of health workers in the COVID-19 pandemic along with meeting their personal protection needs is an important part in this field.

At the same time, an important part of public education can be done by reference groups of HCWs, during visits or in structured virtual spaces. The role of awareness campaigns in this field, which can be carried out by spontaneous groups of people with the support of health-oriented institutions, can be important and decisive in providing correct information in times of crisis. Also, the expansion of mental health care related to HCWs by considering telepsychiatry for psychological and psychiatric consultations, which is carried out by psychologists and psychiatrists specializing in this field, can play an important role in dealing with stigma among HCWs.

Considering the nature of the pandemic and the sensitivity of its severity to various aggravating factors such as changing strains leading to increased pathogenicity of the virus and protective factors such as universal vaccination, future studies based on the results of this study can include cases that investigate other factors affecting the formation and persistence of stigma among HCWs. Also, paying attention to the persistence of stigma in HCWs and the long-term effects of stigma on the formation of mental health disorders and its consequences can be effective in identifying different dimensions of stigma in the context of the COVID-19 pandemic.

## Data availability statement

The original contributions presented in this study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

## Ethics statement

The studies involving human participants were reviewed and approved by the Alborz University of Medical Sciences under grant number (IR.ABZUMS.REC.1399.011). The patients/participants provided their written informed consent to participate in this study.

## Author contributions

All authors were equally involved in the study conception and design of the study, searching for articles, and writing the final manuscript, etc.

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## Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

## Publisher's note

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# Assessing the impact of stigma reduction interventions in Iran: A qualitative study from the perspective of mental health stakeholders

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**Introduction:** The fear and embarrassment associated with stigmas discourage patients from help seeking behavior, which may explain why even the patients' loved ones advise them to discontinue treatment to avoid being labeled. In addition, stigmas can lead to personal and family issues, causing patients to disregard their illness. As such, their disease may develop into a chronic condition. This being said, the present study aims to investigate the challenges, solutions, and successes associated with stigmatization in Iran from the perspective of mental health stakeholders.

**Method:** A qualitative study was conducted in the summer of 2022. Purposive sampling was utilized to recruit participants. The primary data collection method involved a focus group interview that lasted 110 min. The project manager monitored the interviews, and all research team members attended the meetings, took notes, and made the necessary preparations. After explaining the study's purpose and ensuring the data's confidentiality, the interviewer led a focus group discussion. The interviews were recorded with the participants' consent. A focus group was used to conduct interviews with 13 individuals until data saturation was reached.

**Findings:** Ten psychologists, psychiatrists, and managers responsible for mental health, two patients, and one patient's family member participated in the current study as eligible participants. Repeated readings led to the emergence of three main classes under the headings of *challenges*, *solutions*, and *successes* of stigma management in Iran, each containing subclasses.

**Conclusion:** The majority of the proposed solutions in this study centered on raising awareness and training diverse individuals and groups to lessen stigmas. The most crucial de-stigmatization measure is to offer training that will cause the current stereotypes to change. This must be taken by patients and their

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families as well as therapists, leaders, policymakers, the general public, and the media. Ideally, younger members of the target groups should be considered for these pieces of training, which must be based on research and derived from cultural and localized needs.

KEYWORDS

**stigmatization, challenges, mental health, Iran, qualitative study, help seeking behavior**

## Introduction

The human body and mind are intimately linked and interdependent. Therefore, the disease affecting one also affects the other. The effects and symptoms of physical diseases are typically perceptible with the eyes and understandable through the five senses. However, mental and nervous diseases typically affect a person's emotions, feelings, and behavior such that in the early stages of the disease, there is a vague feeling and state that the patient cannot understand easily. Initially, a patient with a mental problem feels incompatibility with social expectations and ideals because of the disease's symptoms and complications. As a result, the patient feels ashamed of and disappointed with him/herself. To alleviate this disparity, many patients try to conceal their condition. Nonetheless, they ultimately experience a loss of their civil, social, and human rights. Patients with neurological and mental disorders typically face two major challenges. First, they must manage the symptoms of their illness, which can vary depending on the type of the disease (such as anxiety, delirium, hallucinations, etc.). These symptoms can affect the affected individual's employment, independence, and life satisfaction. Second, the erroneous perception of society can result in (social) stigmas among these individuals (1, 2).

Throughout history, psychiatric diseases have been consistently associated with incorrect beliefs and deviant social reactions to the extent that people with psychiatric diseases were believed to be possessed by the devil. Indeed, the majority of psychiatric disorders provoke a negative impression in the general public, resulting in stigmas and social problems (3).

The word stigma originally referred to a mark applied to Greek slaves to differentiate them from free individuals. As such, stigma was a highly discrediting characteristic. In Persian, however, the word stigma denoted a symbol written on commercial documents. Additionally, Scambler has classified stigmas into two categories: emotional (self-stigmatization) and contractual (discrimination) (4).

A stigma influences the development of mental disorders to such an extent that researchers recognize it as the most significant risk factor and barrier to improving mental health. No aspect of the mental health system is stigma-free; patients, families, and healthcare providers, as well as the diagnosis and treatment of mental illnesses, have always been subject to criticism, protest, and discrimination (2–5).

A stigma is defined as a negative stereotypical view combined with bigoted ideas and discrimination, which results in job, livelihood, and communication losses for the patient and those around the patient due to the unfair perception it creates. The stigmas associated with mental illnesses are the greatest barrier to care provision. Stigmas affect not only patients but also their families and therapists. Even facilities that offer treatment, psychotherapeutic medications, and mental health professionals are not immune to stigmas. Stigmas cause society and decision-makers to dismiss mental illness. Hence, they tend to lack a coherent and purposeful plan to solve the problems of mentally ill patients and are reluctant to seek out and explore resources to assist people with mental disorders. In addition, this stigma results in discrimination when providing services to individuals with both physical and mental disorders (6, 7).

Numerous studies have demonstrated the prevalence of negative beliefs about people with mental health conditions. Stigmas distance individuals from social standing and human dignity. These negative views are prevalent in many nations. In Nigeria, for instance, the general populace holds numerous false beliefs about people with mental health conditions, such as being dangerous, unpredictable, repulsive, and useless to society (8–10).

Also, a stigma exists in every aspect of life, including the workplace and the classroom. It is assumed that patients with severe mental illness (such as psychosis-bipolar disorders and severe depression) are stigmatized to a greater degree. Alonso et al. demonstrated that people with minor psychiatric disorders such as anxiety might also be stigmatized (11, 12).

Unfortunately, patients with mental diseases endure stigma from a variety of sources, including society, surrounding people, and even mental healthcare providers. These negative beliefs about mental illnesses are pervasive throughout society, and they appear to be deeply rooted in culture and reinforced and perpetuated by popular culture and media. Prejudices and biases related to mental health and people with mental illnesses are frequently associated with unrealistic expectations. These unrealistic expectations create conditions for the patient whereby they internalize the stigmas, leading to further stigmatization in society. In this case, people with mental illness are stigmatized not only by society, family, colleagues, and mental healthcare professionals but also by themselves (13–15).

Stigmas also transform a normal individual into one who is unstable and broken. Stigmas cause a person with a mental illness to feel ashamed and to perform less well in society. In addition, the low self-esteem of these individuals leads to difficulties in finding a job and a home, accessing the justice system, and utilizing health support services, ultimately leading to greater social isolation. Various studies demonstrate that stigmas bring about a decline in patients' self-esteem and performance. Furthermore, stigmas negatively affect the treatment process, including help seeking behavior, accepting psychotherapy, and so on. A study conducted in Norway revealed that only 13% of depressed individuals and 25% of those with anxiety disorders seek treatment. According to Corrigan, stigmas are recognized as the most significant barrier to mental patient referral (16–18).

Multiple studies have examined the negative effects of stigmas on patients and their families. In the study conducted by Phillips et al., moderate and severe stigma-related effects were observed in 60% of patients and 26% of families. In Iran, Shahveisi et al. found that 32% of families with schizophrenic members and 12% of families with depressed members concealed the disease from others. In Sadeghi's study, 16% of families with a schizophrenic member, 37% of those with a depressed member, and 26% of families with members suffering from bipolar disorder concealed the family member's illness. In this study, the stigma intensity increased when the disease duration was longer than 2 years and there was more than one hospitalization instance. In the study by Shahveisi et al., 12% of families reported workplace discrimination. In another study, nearly half of adults expressed embarrassment at the prospect of seeing a psychiatrist (13, 19, 20).

The fear and embarrassment of stigma discourage patients from help seeking behavior, which is why even the patient's loved ones may advise them to discontinue treatment so as to avoid being labeled. In addition, stigmas may lead to personal and family issues, causing patients to disregard their illness and experience more chronic conditions over time. To avoid bearing the stigma of mental illness, a patient may seek care from non-psychiatric specialists. Due to stigmas, patients often request that psychiatrists not use their insurance cards for psychiatric drugs. Patients with mental illness may also feel ashamed of their families' financial support for treatment due to the associated stigma (2, 21, 22).

Despite the high number of mental disorders and people in need of counseling in the country, very few people seek counseling and treatment from psychiatrists; this may suggest that Iran bears more stigmas than other countries. A further reason for non-referral could be patients' absence of social support. Additionally, we have observed that patients suffer greatly from the stigma of the disease due to the negative evaluation of patients by some research scholars and social leaders. Lastly, the slow stigmatization process and lagging behind international efforts in terms of stigmatization have exacerbated the situation. As such, the present study aims to investigate stigmatization in Iran. Challenges, solutions, and successes are assessed from the perspective of mental health stakeholders.

## Methods

This research is a qualitative investigation conducted during the summer of 2022. A purposive sampling method was utilized. The primary data collection method involved a focus group interview that lasted 110 min. The project manager monitored the interviews, and all research team members attended the meetings, took notes, and made the necessary preparations. After explaining the study's purpose and ensuring the data's confidentiality, the interviewer led the focus group discussion. The interviews were recorded with the participants' prior consent. A focus group was used to conduct interviews with 13 individuals until data saturation was reached.

The field notes that were recorded immediately after the interviews were reviewed, and the interviews were concurrently transcribed verbatim. Regarding the number of interviews, the primary criterion for the researcher was the use of key informants, the data itself, emerging classes and theory, and theoretical saturation. Field notes, unstructured observations, and written narratives constituted additional data collection instruments. The researchers concurrently collected, coded, and analyzed the data. Corbin and Strauss's coding paradigm (2008) was drawn upon for data analysis. This methodology involved three stages of analysis: open, central, and selective coding. In addition, the constant comparison method was utilized throughout all analysis phases, and differences and similarities between the primary codes were identified. Similar codes were conceptualized and assigned to the same category. The codes were reviewed continuously in a back-and-forth manner and revised as necessary. Comparing data, posing questions, writing the primary storyline, drawing diagrams, and reviewing reminders were among the techniques employed during the coding process.

Before conducting the research, the questions were analyzed to ensure they were congruent with the research objectives. In addition, a consensus was reached on the research context, data collection method, and research ethics. Using the participant confirmation method in the data analysis was one way to ensure the credibility of the present study. In addition, the extracted codes and themes were reviewed and approved by the researcher and two additional university professors who were familiar with the qualitative research approach and were authorities in the field of stigmas.

In this context, the transferability of the extracted codes was discussed and confirmed by the researchers above. The anonymity principle was the most crucial concern for the researchers. Per the ethical codes of the Declaration of Helsinki

(2013) and the American Sociological Association (2001), this study respected the participants' consent to participate, participant anonymity, and the use of alternative names in reports and articles. This study was approved by the Ethics Committee of Iran University of Medical Sciences, Tehran, Iran (code: IR.IUMS.REC.1398.824).

# Results

In accordance with the data saturation criterion, 13 individuals participated in the current study, including 10 psychologists, psychiatrists, and managers in charge of mental health, two patients, and one patient family member. Repetitive readings led to the extraction of three main classes under the headings of *challenges*, *solutions*, and *successes* of dealing with stigmas in Iran. Each of these main classes has sub-classes as displayed in Table 1.

## Challenges

### Beliefs, attitudes, and insufficient awareness

#### Attitude of the general public

Inappropriate attitudes among social strata have contributed to stigmas, leading to the general public's erroneous perception of hospitalized people with mental health conditions. One of the causes of stigmas is, for instance, society's failure to recognize schizophrenia—a condition they have heard about but are unaware of its nature. This lack of recognition strengthens negative attitudes, which is a barrier to changing people's perspectives on mental illness. The absence of a favorable scientific attitude among the general population and society's incorrect reaction to the presentations of mental and atypical diseases, including schizophrenia, create a sense of fear and unpredictability among patients, resulting in increased stigmas toward mental illnesses and the subsequent increased pain and suffering of the patient due to insulting labels.

#### General ignorance of society

The public's ignorance and lack of knowledge regarding mental illnesses are regarded as significant destigmatization barriers. Indeed, in Iran, a significant number of people turn to non-specialists such as fortune-tellers, palm-readers, and magicians rather than mental health specialists to solve mental health problems.

#### Education, children, and mental health

One of the bedrocks of stigmatization in society is the lack of attention to mental health in children's education and the incorrect teaching of mental illnesses to children at the community level.

#### Lack of teaching resources for students

Despite the sensitive role of students in society and the fact that the future of society is infused with them, no curricula or resources are focusing on mental diseases and disorders. Even the Ministry of Science opposes implementing a two-credit mental health course for students at all levels.

### Mental health workers and other professionals

One of the major impediments to stigma reduction in Iran has been the sometimes ineffective role of mental health workers and even professionals working in the mental health field.

#### Negative view of psychiatrists and mental health therapists

The absence of shared literature among mental health therapists, particularly psychologists and psychiatrists, and the entry of non-specialists into the mental health realm are among the obstacles to destigmatizing mental illnesses. The lower income of mental health specialists relative to other health specialties was cited as one of the existing problems, which has led to boredom and even fostered a negative perception among psychiatrists and, more specifically, psychologists.

#### Stigmas among doctors (general and specialist) and paramedics

Inadequate training of physicians regarding mental disorders and negative attitudes among physicians and paramedics have contributed to stigmas associated with mental illnesses. The inappropriate treatment of people with mental health conditions by medical staff and the negative attitudes of doctors and support institutions toward people with mental health conditions are additional obstacles to destigmatization. In addition, the lack of adequate training for paramedics regarding mental health and the disregard of some physicians for mental disorders contribute to the perpetuation of this stigma.

#### Problems of patients and families with the disease

Long-term familial involvement and treatment courses of these patients are among the contributors to society's stigmatization of patients with mental conditions, thereby perpetuating the stigmas.

#### Non-acceptance of patients in general hospitals

General and public hospitals do not admit psychiatric patients, nor do the emergency rooms.

### Structures and policymakers

#### The Ministry of Health, the government, and non-cooperation of organization

Participants cited inadequate cooperation between scientific centers as an impediment to decreased stigmatization. The lack of coordination between organizations pertaining to mental

TABLE 1 Classes, sub-classes, and basic concepts extracted from the data.

| Basic concepts | Sub-classes | Classes |
|---|---|---|
| Attitude of the general public | Beliefs, attitudes, and insufficient awareness | Challenges |
| General ignorance of society | | |
| Education, children, and mental health | | |
| Lack of teaching resources for students | | |
| Negative view of psychiatrists and mental health therapists | Mental health workers and other professionals | |
| Stigmas among doctors (general and specialist) and paramedics | | |
| Problems of patients and families with the disease | | |
| Non-accepting patients in general hospitals | | |
| The government, the Ministry of Health, and the non-cooperation of organizations | Structures and policymakers | |
| Lack of a coherent program | | |
| Problems in (social-therapeutic) structures | | |
| Stigmatization of psychiatry | | |
| NGOs | | |
| Insufficient financial resources of families and economic problems | Insufficient financial resources | |
| Non-cooperation of benefactors | | |
| Lack of insurance support | | |
| Budget | | |
| Culture | Cultural barriers | |
| Media | | |
| Literature and works of art | | |
| Concealment and failure to provide statistics | | |
| Statistics-based needs analysis | Research-based and evidence-based measures | Solutions |
| Modeling successful projects | | |
| The starting point of destigmatization | | |
| Training and changing the attitude of healthcare providers | Emphasis on education and attitude change | |
| Public education and raising awareness | | |
| Beginning of education from childhood | | |
| Using the potential of clerics and scholars | | |
| Using the potential of the media | Cultivation | |
| Training of media personnel | | |
| Use of books and educational materials | | |
| Popular culture | | |
| The role of social networks | | |
| Holding festivals | | |
| The role of prominent people | | |
| Launching a campaign and appointing a support ambassador | | |
| Highlighting and introducing well-managed patients | | |
| Using common literature and creating new literature | | |
| Using the word “nerve” instead of “psychiatrist” in panels | | |
| Budget | Support services and coverage | |
| The necessity of proper pricing for psychiatric and psychological services | | |
| Insurances | | |
| Formation of a committee and a secretariat | Integrated reform of structures -and policies | |
| Demarcation of disciplines and preventing the intrusion of non-specialists | | |
| Integration of psychiatric departments in general hospitals | | |
| Determine the guardian of mental health | | |

*(Continued)*

TABLE 1 (Continued)

| Basic concepts | Sub-classes | Classes |
|---|---|---|
| Emphasis on having a written and comprehensive plan | | |
| Attention to the social rights of patients | | |
| Reforming the public perspective in providing services | | |
| The need to support patients and families | | |
| The necessity of inter-organizational support and coordination and avoiding rework | | |
| Using available resources to destigmatize | | |
| NGOs and independent organizations | The role of different organizations and institutions | |
| The role of the Ministry of Health | | |
| The role of the Ministry of Science | | |
| The role of the Ministry of Guidance | | |
| The role of the Ministry of Education | | |
| The role of the municipality | | |
| The role of Saman advertizing | | |
| The need to use the potential of different organizations | | |
| Office of mental health | Policies | Successes |
| Mental health management | | |
| The link between the private and public sectors | Treatment | |
| Increasing the number of psychologists and psychiatrists | | |
| Placing the board of psychiatrists next to other specialties | | |

health, the limited involvement of the Ministry of Health in mental health, and the absence of unified action among organizations and planners contribute to the stigmatization of mental illness in society. The Ministry of Health has omitted mental health issues from its list of priorities due to a lack of support from policymakers and planners.

### Lack of a coherent program

The absence of a national strategy for stigma reduction and the lack of coordinated anti-stigma efforts at the national level have prevented the development of effective destigmatization initiatives. One of the factors contributing to the persistence of stigmas against people with mental health conditions is the absence of a comprehensive plan and effective actions to combat them.

### Problems in (social-therapeutic) structures

Due to the complexity of urban structures and the prevalence of mental illness, problems are escalating and structural flaws are becoming more apparent. For instance, the absence of halfway houses as a viable treatment method is more apparent now than in the past. On the other hand, the disconnection between medical centers and society leads to the spread of stigmas. Moreover, due to existing limitations and gaps, the inadequate response of medical centers results in the patient's social isolation.

### Stigmatization of psychiatry

The lag in introducing mental health to the general public, the non-socialization of psychiatry, the stigmatization of terms such as psychologist and psychiatrist, the restriction of mental health to clinics, and the vagueness of the institution in charge of mental health in society are among the major problems with mental health promotion in Iran leading to the spread of stigmas.

### NGOs

Another challenge associated with mental health in Iran is the small number of non-governmental organizations (NGOs), the authorities' disregard for them, and the lack of operational power of the NGOs.

## Insufficient financial resources

### Insufficient financial resources of families and economic problems

According to some participants, financial resources play an important role in providing services and reducing the stigma associated with mental illnesses in the contemporary world. Insufficient financial resources, the high cost of psychiatric treatments, and economic issues that prevent people with mental health conditions from receiving treatment are, from a family member's perspective, the most significant problems. Accordingly, there might be non-referrals, whereby the disease deteriorates and takes on a worse presentation. Meanwhile, outpatient and inpatient treatment costs are only partially covered in Iran.

### Non-cooperation of benefactors

Donors and charitable foundations are among the major constituents of the Iranian healthcare system. However, a lack of donor cooperation in the field of mental health is one of the obstacles to destigmatization. Donors have made fewer strides or are unwilling to collaborate in this field.

### Lack of insurance support

Patients and their families are concerned about insurance companies covering the costs of long-term treatment for mental illnesses. Given the large number of patients, insurance companies resist covering medical expenses. In addition to medication and hospitalization costs, insurance companies have partially covered psychotherapy services in the past year, which is a positive development. Insurance companies are not mandated to fully cover mental health problems, giving rise to further stigmas associated with mental illnesses.

## Budget

The appropriate budget line for resolving or mitigating a problem is a trustees' indication of its significance. Participants in the study hypothesized that the reason for concealing the exact number of people with mental health conditions is the constant desire to reduce the mental health budget; they viewed this as a grave injustice against this defenseless portion of society. Among other obstacles, it is possible to mention the inadequate knowledge of actual needs, the inadequacy of the current budget, the economic disorganization and officials' negligence, and the high number of people with mental health conditions, which prevents adequate budgeting for patients.

## Cultural barriers

### Culture

Culture, which functions as a double-edged sword, is a significant factor in reducing or creating stigma in any given society. Most participants viewed culture as a platform wherein a lack of strength tends to increase stigmas. Culture has taken a long time to reach us. Equally reasonable, its transformation will also require considerable time. In addition, perfectionism is one of the defining features of our culture. In this culture that does not tolerate flaws, mental illness is regarded as a major and intolerable shortcoming.

## Media

The media is another influential cultural contributor to mental illness-associated stigmas. The media's insufficient knowledge of psychiatric illnesses is one of the factors that contributes to stigmas in society and causes patients to endure double suffering. The non-scientific nature of some topics raised in the media and the non-specialized terms employed in the media portray people with mental health conditions as frightening and unpredictable. Unfortunately, this misinterpretation of psychiatric illnesses by the media is prevalent in many nations. On the other hand, there have been few successful media campaigns to destigmatize individuals with certain mental illnesses. In Iran, the national media's inability to destigmatize is evidenced by the absence of appropriate scripts and the propagation of false beliefs. In addition, in Iran, programmers rarely use scientific consultants during film production, which has led to bizarre and unrealistic depictions of people with mental health conditions.

### Literature and works of art

Recent years have seen a significant increase in concerns regarding the words of artists and authors concerning mental disorders, particularly the non-scientific use of terms such as schizophrenia in published literature. In our literature, a mental illness diminishes a person's worth, whereas a physical illness does not, and this discrimination between different patients contributes to a negative perception of mental illnesses. In our literary culture, terms such as mental, crazy, and stupid are typical examples of derogatory terminology.

### Concealment and failure to provide statistics

Some authorities' emphasis on the secrecy and concealment of mental illnesses is one of the most significant obstacles to comprehending the true scope of mental problems in society. Society's desire to conceal mental illnesses and the absence of an honest and realistic assessment of the current situation are prime examples of a lack of understanding of the actual needs in this field. The Iranian culture of perfectionism compels families to conceal a loved one's disease and casts doubt on the patient's way of life.

# Solutions

## Research-oriented and evidence-based measures

The foundation of any macro executive action is research. Clearly, an effective strategy to reduce stigma can be achieved by relying on previous research and evidence-based planning.

### Statistics-based needs analysis

The communication of needs based on statistics facilitates precise planning. The available data and studies should be evaluated, and a needs analysis should be conducted. One also needs to pay close attention to the cultural components of society so that an effective plan can be devised to address the enormous stigma problem.

### Modeling successful projects

Using successful models from around the world and neighboring nations, the cooperation with the UNESCO chair in Iran, and the destigmatization of the AIDS program and addiction as examples, it is possible to implement successful programs here as well.

## Emphasis on education and attitude change

Modifying people's attitudes can be cited as an important strategy for reducing stigma. Some participants in the study underlined the importance of belief and attitude shifts prior to providing funding to destigmatize mental illnesses. Among these measures is correcting false beliefs within the medical community and even among mental healthcare providers.

### Training and changing the attitude of healthcare providers

*General physicians, specialists, paramedics, and other therapists.* Evidently, physicians play a key role in the initial assessment of referring patients and in introducing the field of psychiatry. Importantly, too, they are also capable of altering people's attitudes. Appropriate alteration of attitudes appears to be a factor that must be incorporated into studies and curricula. Destigmatizing mental illnesses, therefore, requires working with medical students, correcting the views of general practitioners and specialists, and justifying non-psychologists and non-psychiatrists. It is crucial for medical students not to be influenced by their pre-existing mentality but rather to examine and treat mental illnesses using scientific evidence. In addition to general practitioners, one should be mindful of the beliefs formed in the minds of other specialists, and their attitudes should be assessed during their academic training.

*Psychiatrists and psychologists.* In addition to their well-known function, mental health therapists play an essential role in reducing stigma. Improving the quality of psychiatric services is one measure psychologists and psychiatrists take to lessen the stigmas associated with mental illnesses. Comprehensive and team-based treatment is one of these methods. Holding classes and workshops for the general public and other healthcare workers can help reduce stigmas and their appearance in the media. Effective stigmatization-related measures include providing optimal services for mental health workers, providing effective and immediate treatment to prevent the worsening of patients' conditions for a better presence in society, and providing comprehensive and correct treatment.

### Public education and awareness

Participants in the study highlighted public education and awareness, specialized education during one's studies, and offering a two-credit mental health course to all university students as effective factors in destigmatizing mental illnesses. In addition, the education of kindergarten teachers, patients' families, peers, and the general public; the continuous preparation of brochures and booklets; and the emphasis on the biological etiology of diseases raise the level of literacy and awareness of individuals and special populations and reduce stigmas.

### Beginning of education from childhood

According to the participants, it is possible to shape children's attitudes from an early age by beginning work in preschool and to incorporate life skills lessons into preschool programs. Beginning schooling at a young age reduces the stigmas associated with people suffering from mental health conditions.

### Using the potential of clerics and scholars

An undeniable fact is the influence of clerics and scholars on the general populace, which may benefit destigmatization. Seminaries, the Islamic Propaganda Organization, the Office of Friday Prayer Imams, and congregations are appropriate venues for destigmatization. The use of religious podiums for Friday prayers can be effective for this purpose. Religious elders' religious teachings and traditions demonstrate their leadership in lessoning stigmas against people with mental health conditions.

## Cultivation

The culture of a society, which derives from its customs, traditions, and beliefs, is a fundamental and enduring issue. Basic planning that leads to new cultures will be valuable for reducing the stigma associated with mental illnesses.

### Using the potential of the media

Multiple surveys indicate that the media plays an irreplaceable and undeniable role in promoting or mitigating stigmas. It is possible to utilize the extensive capacity of the media to educate the audience accurately and alter their false beliefs. For instance, by creating educational videos, stigmas can be effectively alleviated. On the other hand, attitudes can be improved by organizing a festival of psycho-friendly films. Conversely, we can improve literature and reduce the stigmas associated with mental illnesses by utilizing artists and media specialists. It is preferable, however, to take this measure under the supervision of experts so that stigmatization does not occur in society due to these programs.

### Training of media personnel

Considering the important role of media in reducing stigmas, it may prove highly beneficial to train planners and program makers. However, the implementation of these programs is associated with problems. The radio and television trustees must be determined to implement it in practice.

### Use of books and education materials

It is expected that steps will be taken to reduce stigmas by preparing a variety of written works, as books and educational materials have a profound and influential effect on the audience. It should be noted, however, that the preparation of these items is not limited to a specific time or day of the year and that professional writers must be requested to create them; mental healthcare professionals are not permitted to pick up a pen themselves.

### Popular culture

Attention to common and general beliefs and cultures is vital to mitigating stigmatization. Consequently, reforming public culture and establishing cultural committees to establish new terms are essential. It is recommended to move forward with those who have worked in this field. Similarly crucial is the participation of various public and private sectors in cultural work.

### Social networks

Given the ever-increasing growth of social networks and their unique impact on the general public, it is expected that a significant portion of the impact on the general public can be achieved through social networks. These networks are widespread and equipped with various facilities, making them an ideal medium for audience education.

### Holding festivals

In order to highlight a certain issue, numerous festivals with the potential for great influence are held around the globe. Thereby, the audience's attention is drawn to these programs, and appropriate stigma-reduction strategies can be implemented. While festivals have proved effective globally, there is room in our country to consider preparations in this area. Participants in the study emphasized the importance of holding various festivals for a variety of general or specialized audiences. These festivities may be cultural, artistic, or athletic. Moreover, it is possible to exhibit works created by patients or works about patients at art festivals. As such, psychological issues become commonplace to the public.

### The role of prominent people and celebrities

Today, many charitable endeavors benefit from the assistance and company of prominent and famous individuals. The support of these individuals will increase social awareness about mental illnesses and effectively change public attitudes. Many participants emphasized the use of this method in destigmatization programs. This way, famous athletes, national heroes, artists, and politicians can contribute effectively.

### Launching a campaign and appointing a support ambassador

Efficient advertizing campaigns are based on research and analysis of consumer needs. The establishment of think tanks and unified organizations will greatly assist these campaigns. In the current study, numerous stakeholders expressed willingness to provide their facilities for stigma reduction campaigns. A further suggestion was to appoint a popular mental health ambassador interested in participating in such programs.

### Highlighting and introducing well-managed patients

Reducing stigma is accomplished by highlighting and utilizing the experiences of successful and well-managed patients. By sharing their experiences, these individuals can serve as a model for other patients, their families, and the public. This will diminish the distorted and disappointing image that has already formed in the minds of the audience.

### Common literature and creation of new literature

Today, one single body of literature and common terminology is utilized within every discipline. Unfortunately, in Iran, due to the negative nature of some words and their valorization, there is a need to form common and new literature among specialists so that the patient is not addressed with words that carry a negative connotation. Further, words such as soul, which is related to religion, should be avoided, and there should be consistency in word usage.

## Supportive services and covers

### Budget

The need for financial support and the allocation of adequate funds, as well as the need for equipment and logistical support in the fight against stigma, necessitates that the authorities allocate sufficient funds to fight stigma.

### Necessity of proper pricing for psychiatric and psychological services

To avoid discipline discrimination and provide appropriate services to patients, the value of psychological services should be recognized on par with the value of other medical services. Even special attention should be directed to psychological services.

### Insurances

It was suggested that the insurance umbrella be made more specific and thorough in order to lessen stigmas and offer patients better services. Chronic people with mental health conditions were specifically suggested to be included in the special patient's category.

## Integrated reform of structures and policies to improve the performance of mental health trustees

### Formation of a committee and a secretariat

Establishing a committee to collect data in accordance with the World Psychiatric Association's plans and emphasizing the formation of a headquarters or a strategic council are among the top stigmatization solutions. This organization has a unique organizational structure that is required for a coordinating team to establish specialized and operational committees that can support patients with mental problems. Participants emphasized the need for a secretariat with a well-defined schedule to avoid duplication and complete a large national undertaking.

### Demarcation of disciplines and preventing the intrusion of non-specialists

It is necessary to clarify and define interdisciplinary boundaries and prevent unqualified and non-specialized individuals from interfering. As long as roles and positions are not clearly defined, the course of events may be derailed.

### Integration of psychiatric departments in general hospitals

Important destigmatization measures include expanding psychiatric units in general hospitals, consolidating psychiatric departments in general hospitals, and establishing psychosomatic (psycho-physical) departments in general hospitals. Iranians are credited with the first integration of psychiatric departments in general hospitals, as evidenced by historical records. Currently, according to the legal resolution allocating 10% of beds in general hospitals to people with mental health conditions, a substantial amount of progress has been made in terms of stigma reduction.

### Determining the guardian of mental health

According to the law, the Ministry of Health, Care, and Medical Education is the official guardian and planner for mental health. Occasionally, however, it is necessary to make this role more distinct and prominent so as to separate responsibilities and define the scope of work.

### Emphasis on having a written and comprehensive plan

With a planned and codified program at the macro level, stigmatization can begin in both fundamental and specialized areas. This work necessitates the presence of a comprehensive and accurate plan, as well as the notification of the relevant institutions. With the right macro-level policy and unity of action, it is possible to develop stigmatization programs that avoid duplication of efforts and parallel work in different organizations.

### Attention to the social rights of patients

The provision of more sophisticated facilities for mentally ill patients will normalize their demands for equal rights in the eyes of the general public, allowing them to be regarded as normal citizens. Since patients require a normal life, it is necessary to modify the structure and relations in order to guarantee their social rights.

### The need to support patients and families

Social acceptance of patients reduces their likelihood of rejection. Support from organizations improves their companionship and acceptance. The establishment of daily service centers staffed by specialists such as psychiatrists, psychologists, occupational therapists, social workers, and psychiatric nurses is crucial for accepting patients and their families. Thus, the programs must be comprehensive enough to encompass all patients from various groups and strata. In the interim, it is essential to respect and safeguard patients' privacy.

### Necessity of inter-organizational support and coordination and avoiding rework

Personnel and operational support, inter-organizational cooperation, observance of material and moral rights, and elucidation of responsibilities are crucial. To reduce stigmas, it would be preferable if the Ministry of Health, Care, and Medical Education took advantage of these facilities while recognizing the personnel-operational potentials in various organizations. Clearly, in these inter-organizational programs, more results could be achieved with a smaller budget by avoiding duplicate work.

## The role of different organizations and institutions

In addition to the Ministry of Health, Care, and Medical Education and the Welfare Organization, this study discovered that numerous and dispersed centers in Iran could assist individuals with mental problems, including the municipality, the Islamic Propaganda Organization, and the Scientific Association of Health Education, among others.

Healthy individuals are the first line of defense in the fight against stigmas. This is necessary for people with mental health conditions due to the presence of non-governmental organizations and support centers for physical insurance. In this context, the *Association of Poets, Artists, and Writers*, the *Centre for Intellectual Development*, the *Book Council*, and NGOs and the organizational formation of NGOs can be effective.

### The role of the Ministry of Health

As the official guardian of mental health, the Ministry of Health should have strong executive arms; as a result, the mental health office should be bolstered, and the mental health structure should be improved and given a greater role.

### The role of Welfare Organization and the Ministries of Guidance, Science, and Education

Together with the Ministry of Health, these ministries and organizations can play a significant role in destigmatization by creating jobs, collaborating in education provision, and publishing books and articles.

### The role of the municipality

Utilizing the potential of the municipality and its close ties and neighborhood-based connections with the people, as well as health houses and centers, is extremely beneficial in destigmatizing mental illnesses.

### The role of the Islamic Propaganda Organization

This organization can hold a unique position in reducing stigmatization, given its wide scope of activities, the presence of clerics in the majority of cities and remote villages, and the availability of suitable facilities and infrastructures for widespread advertizing.

### The need to use the potential of other organizations

Participants emphasized the importance of leveraging the potential of military systems, kindergartens, mosques, seminaries, telecommunications, parliamentarians, and Friday prayer imams.

Successes**:**

We have also made progress in policy and treatment due to the recent practices of the Ministry of Health and the shift in the attitude of managers and government officials over the past decade.

## Policy

- Formation of mental health offices and their independent management.
- Mental health used to be primarily concerned with diagnozing disorders; however, it now also focuses on disease prevention.
- Mental health services cover residents in cities and villages alike.

## Treatment

- More activity of psychologists and psychiatrists.
- Presence of a panel of psychiatrists along with other specialists.
- Links between private and public sector.

# Discussion

This study revealed that stigmas had been the subject of relatively few studies in Iran. Indeed, the literature portrays only a portion of the actual situation. For instance, the study conducted by Ghanean et al. focuses solely on Tehran and not the entire country (23).

As demonstrated by Fiorillo et al.'s study of 27 countries and 108 European organizations, stigma is one of the top treatment priorities for psychiatrists, mental health therapists, medical officials, and non-governmental mental health organizations. In the present study, all participants agreed that addressing stigmas and the resulting discrimination is an essential component of national mental health programs. Since no serious and effective planning has been performed in this regard—destigmatization—there is a strong need to address it. Participants believed that stigmas constituted a major factor in the lack of referrals and discrimination against people with mental health conditions. From the perspective of the participants in this study, who represented important and influential governmental and non-governmental sectors, stigmas are so important that they are willing to cooperate practically, seriously, and actively in national infrastructure programs to reduce stigmas and combat the associated discrimination (24, 25).

No aspect of our psychiatry is stigma-free, according to the study participants. Similar to research elsewhere, this study found that this problem affects not only neurotic or psychotic patients but also their families. Moreover, therapists in this field, such as psychiatrists and other mental illness therapists, are also susceptible to these biases. Moreover, we have observed negative attitudes regarding other aspects of mental health, such as psychiatric diagnoses and classifications, which have always been the subject of discussion and debate (20, 26, 27).

Psychiatric treatments are stigmatized, particularly medication, ECT, electroshock, and hospitalization. In the current study, as in the study reported by Ozman et al., the complications and challenges of the treatment are highlighted, but the treatment's positive effect is not mentioned (28, 29).

Similar to McSwain, we have observed discrimination and stigmas in mental disorder policies, service provision, insurance coverage, and budget allocation. Participants in this project viewed the current study as an example of the steps they expected to be taken in the country's comprehensive fight against stigmas. This study comprehensively examines the intricate and intertwined structure of stigmas in an effort to provide practical solutions to combat them (7, 30).

As in a study by Volpio et al., the participants in the current study, including psychiatrists, officials, families, and patients, reiterated that patients initially seek help from non-psychiatrist therapists for mental health problems. While consultation with non-psychiatrist therapists is less stigmatic, delayed treatment with a psychiatrist can make the disease's progression more chronic and difficult. Indeed, Kolshaw et al. noticed that non-psychiatry specialists do not include medical details on their consultation sheets for psychiatrists (31, 32).

Non-specialists abusing the patient's condition under the guise of prayer writers, fortune tellers, and exorcists complicate the treatment process, according to the participants in the study. The widespread presence of this group of unlicensed and unofficially practicing healers, particularly on the outskirts of cities, is one of the primary causes of delayed patient referral. Apparently, this interest in traditional healers parallels findings from two studies: those conducted by Akighir et al. and Alem et al. (33, 34).

The participants cited the perfectionist and idealistic culture in Iranian society, which hardly tolerates shortcomings, contributing to the intensification of stigmas. This perspective finds more challenging conditions and a more pessimistic outlook concerning mental disorders as typically long-term health problems. This perspective has possibly led to peculiar concealment of information, statistics about the current situation, and even secrecy at the level of families and patients such that patients may even refuse to employ the available treatment facilities. It appears that a portion of the desire to conceal the disease among patients and their families, as well as by some professionals, lies in the cultural characteristics of the society. Moreover, in a culture that views every flaw, no matter how minor, as major and sometimes as an unforgivable sin, it is evident that mental disorders, whether they be a brief anxiety disorder or a severe problem such as schizophrenia, are both looked down upon. Indeed, prior quantitative studies conducted in Iran have discovered that approximately one-third of families tended to conceal the disease from others.

One of the limitations of this research is the interview with the decision makers in this area, so it is recommended to examine the factors affecting stigma from the perspective of patients and their families as well as experts present in the treatment system.

## Conclusion

The majority of the solutions presented in this study centered on raising awareness and training various individuals and groups to reduce stigmas. The most important action, both on the level of therapists, the general public, leaders, policymakers, and the media, as well as among patients and their families, is to provide training that will result in the modification of previously held stereotypes. Ideally, younger members of the target groups should be considered for these pieces of training, which must be based on research and derived from cultural and localized needs.

In addition to official authorities such as the Ministry of Health and the Welfare Organization, this study found that organizations and centers in Iran can indirectly contribute to stigma reduction programs. At first glance, it may seem preferable to consolidate these centers under the supervision of a trustee. However, depending on the policies in place, the presence and company of influential groups can be utilized to develop psychological programs. On the other hand, it was discovered that some locations in Iran are active or potentially willing to cooperate in providing services to psychiatric patients. Therefore, the formation of a committee or office to coordinate various programs and treatments (likely within the Ministry of Health as the primary steward of mental health policy) can be advantageous.

One of the positive effects of destigmatization or the reduction of stigmas is improved quality of life and, hence, higher credibility and elevated dignity of the patients and their families before the general public. As such, these measures will demonstrate that these patients have rights and abilities comparable to those of healthy members of society and that they can express their desires without fear of being judged by others. Under such circumstances, they will live a relatively normal life, legal institutions will value their abilities, the general public will have a more favorable opinion of them, and stigmas will be less visible. Secondly, there are social benefits. Assisting vulnerable patients to demonstrate their abilities and promoting them as successful individuals at the societal level help their abilities to emerge, and society may benefit from their productive presence. Chronic diseases may be prevented, and social problems such as unemployment and delinquency may be reduced to a great extent if this occurs. Thirdly, we may notice economic growth and cost reduction. The successful implementation of stigma reduction programs lowers the financial burden placed on families of mentally ill patients, the economic losses incurred by organizations due to the depreciation of the workforce, and the cost of providing care for people with mental illness. Social and therapeutic measures become more balanced, and the treatment cost cycle improves.

Undoubtedly, an important issue such as the stigma of the disease, which in addition to the individual, the family and the society are also involved in this issue, needs to be investigated and conducted more research to understand its dimensions, characteristics and consequences in order to consider the necessary measures for prevention. and increase the treatment. It is hoped that the findings of this research will be the basis for conducting more research in this field so that a deeper understanding of the concepts of the findings can be carefully determined and used.

## Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding authors.

## Author contributions

AhH and AT have contributed in conducting the research. MK, SH, and AmH has performed the data analysis. AhH, AT, SH, AR, AmH, KA, MA, and MK have contributed to inscribing the main body of the article. All authors contributed to the article and approved the submitted version.

## Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

## Publisher's note

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# Reducing stigma toward mental illness and substance use issues in primary health care in Chile: Protocol of a cluster controlled trial study

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**Background:** Chile is implementing a Community Mental Health Model with a strong role of primary health care (PHC). PHC has great potential to early detection and provision of accessible and coordinated services to people who present mental illness and/or substance use issues (MISUI). However, stigma toward people with MISUI among PHC professionals is a significant barrier to accessing good quality of care. A wealth of literature supports the importance of reducing stigma for this population. The main goal of this research project is to determine the effectiveness of a comprehensive anti-stigma intervention in reducing stigmatizing attitudes and behaviors among PHC providers toward individuals with MISUI in the Chilean context, using Centros de Salud Familiar (CESFAMs) as the point of intervention.

**Methods:** The intervention is based on an initiative that was previously developed in Canada and then also pilot-tested in Lima, Peru, with the Center for Addiction and Mental Health (Ontario, Canada). The model will be culturally adapted with CESFAM PHC provider and user inputs to be relevant and valid to Chile. The 18-month intervention includes five (5) components that are simultaneously implemented in CESFAMs: (1) Develop a Team of Local Champions in each intervention CESFAM, comprising PHC providers and users; (2) Analysis of Internal CESFAM Policies, Procedures, and Protocols to determine areas of improvement in service delivery for individuals with

MISUI; (3) Raising Awareness of stigma toward MISUI using various forms of media within the CESFAM; (4) Innovative Contact-Based Education workshops on anti-stigma and recovery principles, co-lead by academic/clinical trainers and a person with lived experience of MISUI; and (5) Recovery-Based Arts, a multi-week arts workshop for PHC providers and users to produce artwork related to MISUI and recovery, culminating in an exhibition to showcase artwork for the CESFAM providers, users, and community. The expected intervention outcomes are the following: Participation in the experimental group will result in a significant decrease in stigmatizing attitudes among PHC providers toward individuals with MISUI compared with the control group as measured by the Chilean version of the Opening Minds Scale for Health Care Providers Scale (OMS-HC); Participation in the experimental group will result in a significant decrease of PHC users experiences of stigma conveyed by PHC providers compared with the control group as measured by the Internalized Stigma of Mental Illness (ISMI) scale, validated for the Chilean population. The changes in attitudes and behaviors within the experimental group will be sustained over time as measured at 6 months-follow-up. To evaluate the effectiveness of this 18-month intervention, a 4-year, two-arm, cluster-randomized controlled trial is proposed, with CESFAMs being the unit of randomization (or "cluster"). Implementation Science approach will be taken to measure relevant implementation outcomes for each component of the intervention, and through qualitative data collection with CESFAM providers and authorities. Data analysis will be carried out using SAS 9.4 (specifically, using POC MIXED and PROC GENMOD) and R 3.5. Mixed-effect modeling will used for both PHC provider and user data, which will include individuals and CESFAMs as random effects and group (intervention/control) as fixed effects.

**Discussion:** This study represents a new stage of relevant and innovative research in mental health and stigma in Chile that will contribute to improving access and quality of care for people with MISUI. Evaluating the impact of the intervention model and its implementation will provide the necessary tools to scale the intervention up to other CESFAMs across Chile.

**Clinical trial registration:** [www.ClinicalTrials.gov], identifier [NCT05578066].

KEYWORDS

**stigma, mental illness and substance use issues, protocol, controlled trial study, primary care, healthcare workers, contact-based intervention, implementation science**

## Introduction

Chile presents one of the highest mental disorder burdens in the world, with nearly 38.3% of children and adolescents having had mental illness (1); one third of the population having had a psychiatric disorder in their lifetime, and 22.2% in the past year (2). Alcohol dependence accounts for 7.7% of total DALYs in Chile, and unipolar depression and anxiety disorders are at the top five of DALYs among women (3). The high prevalence of mental illness and substance use issues (MISUI) in Chile is confirmed by the results of the 2016–2017 National Health Survey (4). MISUI account for about 19% of global DALYs (5, 6) and in Chile, the longitudinal study "Mental Health Thermometer in Chile: Fifth Round" (2022) (7) concluded that 21.1% of participants suspected to have or had Mental Health Issue and 45.9% declared that they had a worse or much worse mood than before COVID-19 pandemic (7). There has also been an increase in the "sometime in life" consumption of non-prescription tranquilizers, hallucinogens, and pain relievers without a medical prescription in adults (8).

The adolescent population is in first place in Latin American ranking of consumption of cocaine, marijuana, cocaine base paste and tranquilizers without a medical prescription (1, 5, 9).

Mental Health has been declared as a component of fundamental health human right, but in Latin America less than 40% of people with Mental Health disorders have received treatment (1). There is a global movement to strengthen and support Primary Health Care (PHC) services, including MISUI treatment (10, 11). The high prevalence of mental disorders among PHC patients and the fact that most patients with MISUI will access the health care system through PHC providers makes it an ideal setting to implement early screening and treatment strategies for these health problems (12). Evidence suggests that PHC may resolve up to 90% of mental health issues (13).

The gap in MISUI treatment represents a long-standing neglect of mental health care, with a variety of factors limiting access to care (14), including (1) PHC services lacking the ability to adequately respond to needs for MISUI treatment, and (2) stigma playing a significant role in the hesitancy of people with MISUI to recognize their condition or seek help (15, 16).

Stigma is a phenomenon comprising negative thoughts and actions toward the bearer, in which "elements of labeling, stereotyping, separating, status loss, and discrimination co-occur in a power situation that allows these processes to unfold" (17). Stigma affects multiple health domains such as social relationships, levels of stress, self-perception opportunities or behavior, and can add to the burden of disease or disability (18, 19).

Factors affecting stigma and discrimination are interacting constantly generating complex experiences of stigmatization (20, 21). In recent years, structural discrimination as well as socio-economic and political factors impacting stigmatized people has been described (21, 22). Professional stigma has also been described, as health professionals emulating socially stigmatized lay perceptions of those with mental illness (23).

Stigma toward people with MISUI is a global public health problem (21, 24, 25), and represents a main challenge in the integration of mental health into PHC (12, 26). People with MISUI are exposed to different stigma manifestations components that interact as an interrelated multilevel system, jeopardizing their mental health (20). MISUI stigma-related attitudes can be defined as the predisposition or tendency to respond that is triggered by a marker of illness (27). MISUI stigma-related behaviors refers to the discriminatory acts that result from the negative attitudes and stereotypes (28). Stigma-related attitudes and behaviors can be experienced in health care settings in various forms, such as being threatened with coercive treatment, being provided with insufficient information, being regarded as lacking the capacity for responsible action and being patronized or humiliated (21, 29).

It is important to recognize that there are differences in the way stigma manifests toward mental illness (MI) and substance use issues (SUI) (30–36). Literature suggests that people with SUI may have worse patient experiences when compared with patients without SUI (26). This represents an important challenge for accessing care for people with MISUI in PHC (37).

Stigmatizing attitudes and actions from health professionals toward those with MISUI are barriers to health care (38, 39) and can lead to individuals with MISUI receiving lower-quality physical health care services than others (40, 41). **Figure 1** describes MISUI treatment primary gaps in PHC, which interacts constantly with the sociopolitical and cultural context. There is ample evidence of MISUI stigmatization in health care, such as PHC settings (26, 42), and by health professionals (30–34). Recent (26, 42) studies have found that PHC physicians "don't take mental illness as seriously as other chronic diseases" and negative attitudes toward people with substance use disorder are common among them (35, 36). These experiences of stigma can have detrimental effects on the quality of life of those receiving care (29, 43) and lead to a reduction of treatment adherence and outcomes, as well as perceived health for MISUI (44, 45). Stigma has also been identified as an important limitation in the help-seeking process (46) and mental health care access (23), also, perceived health care provider stigma may lead to worsened clinical and personal recovery (44, 47).

Services for MISUI at the PHC level have potential to minimize stigma and discrimination (23, 46), as people with these conditions are generally treated by the same providers and in the same community-based location as people with other health conditions (48).

There are other health professional-related characteristics limiting the access for optimal mental health care, including (i) poor professional education about MISUI, (ii) lack of training in interpersonal skills, (iii) inadequate time to evaluate and treat mental disorders, (iv) failure to consider psychotherapeutic approaches, among others (39).

The Chilean public health system (**Figure 2**) serves more than 75% of the population with its highest coverage in the middle- and low-income population groups (49, 50). Health service provision is organized by territory, through 29 Servicios de Salud (health districts) (15, 51). These health districts direct and coordinate activities from prevention to treatment and rehabilitation. They are organized through a hierarchical system that includes Tertiary and Secondary health care levels, as well as PHC (15, 52). Tertiary level has a reduced coverage and high complexity services. Secondary level has a medium coverage and complexity services. PHC provides services with high coverage, having diagnosis and treatment access available for most health problems, including MISUI. There are more than 500 PHC centers, in urban and rural areas, in which doctors, nurses, psychologists, social workers, technicians, and other providers work (53). Chilean PHC centers have implemented a Family and Community Health approach (54), becoming family health centers, or Centros de Salud Familiar (CESFAMs).

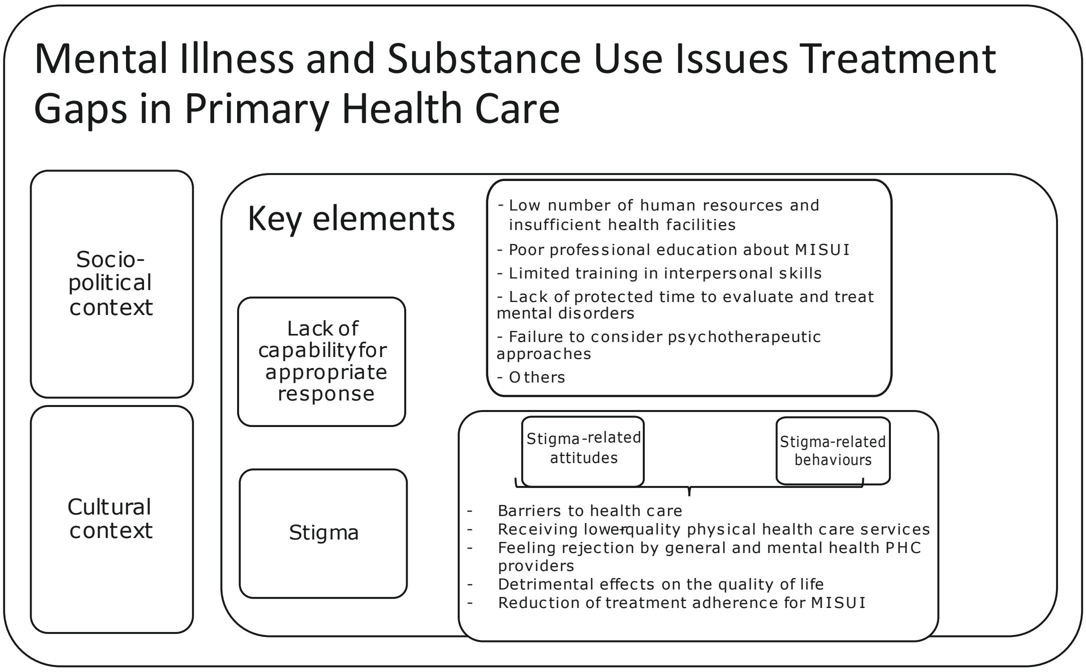


FIGURE 1
Gaps in MISUI treatment in primary health care.

Health professionals within the CESFAM are organized by territorial areas and provide care for the most common diseases. For MISUI, the CESFAM have the role of making a timely diagnosis, providing a set of treatments (based on clinical practice guidelines), or referring patients to a specialized mental health center (55).

Chile has been at the forefront of integration of mental health and PHC in Latin America (49, 52, 55–57). However, a significant gap for MISUI treatment exists, as only 38.5% of patients in Chile with a psychiatric diagnosis receive any kind of mental health care, whether treatment is provided by a specialist or by PHC (15). According to Chile's National Mental Health Plan, up to 2017 Chile's Mental Health budget was close to 2% of the overall Health budget, far below the 5% proposed by World Health Organization (3, 58). Although there has recently been an increase in national interest to enhance Mental Health budget.

The 2017–2025 National Mental Health Plan emphasizes enhancing the community mental health model, with a central role for PHC (3). Chilean PHC has already incorporated effective mental health programs, such as for depression or substance use problems, but there are challenges regarding low adherence levels (51, 53).

It is critical to test context-specific interventions to address stigma in Chilean PHC (2, 59, 60). The 2017–2025 National Mental Health Plan recognizes stigma toward MISUI as an important challenge (3). Evidence based-interventions that can effectively reduce MISUI stigma within health care settings are needed in Chile and worldwide (32, 61). However, a comprehensive, MISUI stigma reduction intervention is required and has not yet been tested or implemented in the Chilean PHC context. This is the first Chilean study to evaluate a comprehensive, multicomponent, anti-MISUI stigma intervention targeting CESFAM providers from an organizational perspective. There was another study specifically aimed at reducing stigma between PHC professional toward people with severe mental disorder diagnosis (62).

One of the projects to address stigma-related attitudes regarding MISUI in the Canadian PHC system was successfully implemented in three Toronto community health centers, resulting in the creation of a comprehensive anti-stigma intervention (21, 63, 64). The intervention proved to be effective at reducing stigmatizing attitudes among health professionals toward people with MISUI. Later on, that intervention was tested in Lima, Peru, after being adapted to the local context (21, 65).

Health care providers are an ideal target group for these interventions, given their clinical interactions with people with MISUI, however, stigma reduction programs for this group are uncommon (66), especially in PHC (61). Interventions comprising training specifically regarding stigma, social contact with users with MISUI, and a focus on recovery are most effective in terms of short-term improvements in stigma (67, 68). There is an important need to follow-up to determine whether positive intervention effects are sustained over time (66, 69). There is a need to actively include those with MISUI in

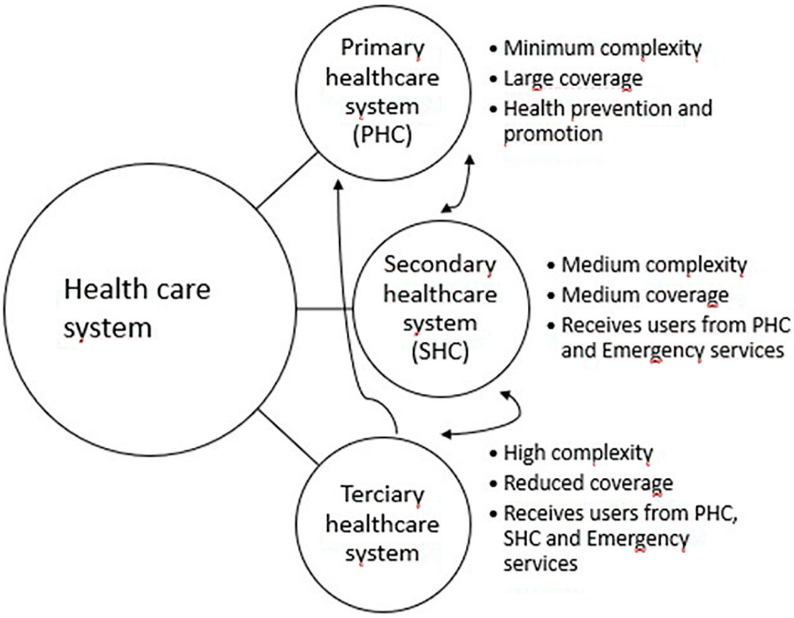


FIGURE 2
Chile's public health care system.

the intervention process and to culturally adapt interventions carried out in settings other than those in which they were designed (70).

A previous related FONDECYT project (34) was just completed, a mixed methods study which sought to examine and understand the phenomenon of stigma toward people with MISUI in the PHC setting of the public health system in Chile. The study confirmed the presence of stigma toward people with MISUI. In addition, it (1) adapted and validated instruments to measure stigma among PHC providers in Chile (71), and (2) identified key elements to be considered for designing an effective intervention to reduce that stigma. In addition, it explored feasibility of the Canadian intervention. This research proposal represents a natural next step aimed at determining the effectiveness of a comprehensive anti-stigma intervention in reducing stigmatizing attitudes and behaviors among PHC providers toward individuals with MISUI in the Chilean context, using CESFAMs as the point of intervention.

## Methods and analysis

### Study design

This two-arm, cluster randomized controlled trial (64) will test the effectiveness of the adapted anti-stigma intervention for MISUI in Chile. As described in **Figure 3**, CESFAMs will be randomized to control and intervention arms of the study. Situational assessments will be conducted at intervention CESFAM, in order to understand their specific characteristics. A cultural adaptation will also be done at these PHC Centers, through a sequential process based on Barrera y Castro framework (72). Data will be collected in intervention and control CESFAMs on relevant stigma outcomes before (baseline), during (mid-point), and after (end-point) the intervention, as well as 6 months post-intervention (follow-up), to determine the effectiveness of the stigma reduction program. Additionally, data will be collected throughout to evaluate intervention implementation. The intervention stage will last a total of 18 months. This will be consist on five components that will be addressed furthermore. After developing the final integrated analysis, the team will disseminate findings and create a scale up intervention.

This research design is useful for non-clinical interventions that are targeted at health providers and patients, and has been used in PHC settings in the past (73, 74). Because an entire group (or "cluster") is randomized to either intervention or control, the risk of contamination across trial groups is minimized (75). In the proposed study, the cluster will be the CESFAM, with eight intervention and eight control sites participating in the study. All PHC providers currently employed at the intervention CESFAMs and some PHC users that have received care there for MISUI in the 3 months prior to study participation are the intervention target groups. The intervention will be conducted in selected CESFAMs by the research team and/or dedicated and trained personnel. CONSORT guidelines for

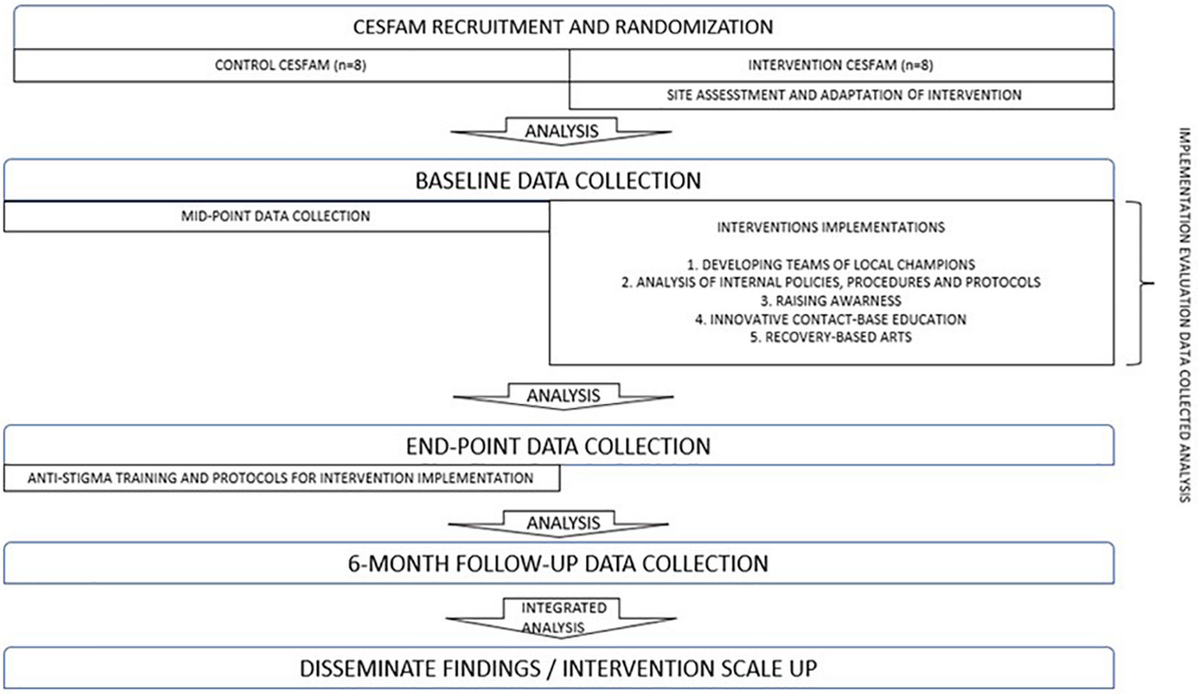


FIGURE 3
Study design.

cluster randomized trials will be followed in all steps of the study (76).

## Inclusion and exclusion criteria

To be eligible for inclusion in the study, CESFAMs must serve a registered population of at least 15,000 people and have at least 50 staff employed. In addition, the following criteria will be considered: (1) geographic location; (2) characteristics of the population served (e.g., size, ethno-cultural profile); (3) rural or urban areas; (4) willingness to participate.

Exclusion criteria: Being part of another anti-stigma program.

## Sample, recruitment, and randomization of Centros de Salud Familiars

*Servicios de Salud* will be approached and invited to participate. CESFAMs that satisfy the inclusion/exclusion criteria within participating *Servicios de Salud* will be progressively invited to participate in the study. About 50% of CESFAMs in the Metropolitan Region will be recruited, 25% in the North and 25% in the South of Chile. Once the 16 CESFAMs that satisfy the criteria are selected, they will be randomly assigned to intervention and control conditions, within each of the three mentioned geographical areas. The nature of the intervention and cluster randomized design of the study requires application to the entire CESFAM (census approach), not to individual PHC providers.

## Intervention program

### Study process

The overall implementation of the intervention process lasts 18 months, in which five main components are to be implemented: raising awareness about stigma and its effects on MISUI PHC users, developing a team of local champions, innovative contact-based education, analysis of internal policies, procedures, and protocols, and recovery-based arts. The entire stigma reduction intervention process will be developed between months 13 and 36 (**Figure 4**).

To exemplify the intervention program and timeline process, they will be described briefly accordingly to its specific objectives and their corresponding components.

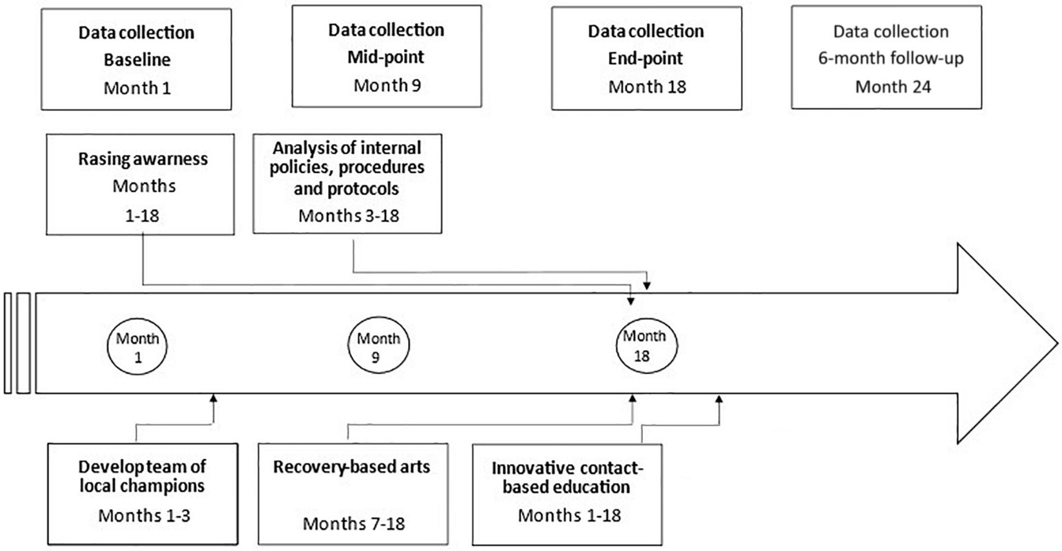


FIGURE 4
Intervention implementation process.

## Specific objective 1: Adapt the anti-stigma intervention with input of primary health care providers and users

An exploratory research and adaptation of the intervention will be developed during months 1–12, before the intervention. Once CESFAMs are recruited, situational assessments will be conducted in order to better understand the specific characteristics of each CESFAM to determine the logistics of implementing the intervention locally. Special emphasis will be placed on identifying the cultural and socio-demographics features of the organizations and the communities being served, to ensure that the intervention is tailored to address their specific needs. The assessment will include requests for the following information: (1) Overview of the CESFAM (history, mission, values, vision, strategic directions), (2) Organizational chart (full description of all services and programs, with an emphasis on MISUI), (3) Demographics of users, (4) Demographics of staff, (5) Challenges and opportunities, (6) Expectations about the intervention.

Based on the framework for cultural adaptation by Barrera and Castro (72), this study includes a sequential process to adapt the anti-stigma/pro-recovery intervention developed in the Canadian setting, the FONDECYT 1160099 project (34) results, and a Community-Based Participatory Research (CBPR) consultation process. CBPR in health is a collaborative approach to research (77), in which community and researchers abilities are acknowledged. CBPR involves the collaborative participation of researchers and the community that will be affected by research in the design and process of an intervention (78). It aims to combine knowledge and action for social change to improve community health and eliminate health disparities (77). This approach is implemented in order to improve the intervention relevance, adaptability and validity for the community. It also allows to access to PHC workers and users valuable information regarding internal processes and dispositions.

## Specific objective 2: Implement a mental illness and/or substance use issues stigma reduction intervention in Centros de Salud Familiar

The comprehensive, 18-month, recovery-oriented anti-stigma intervention is composed of five components: (1) Developing a Team of Local Champions, (2) Analysis of Internal Policies, Procedures and Protocols, (3) Raising Awareness, (4) Innovative Contact-Based Education and (5) Recovery-based Arts. Teams of leaders developed as part of the first component will assist the research team with the implementation of the anti-stigma intervention at their respective CESFAM.

The first component, "Developing a team of local champions," consists of 3–5 PHC providers and 1–2 users at each intervention CESFAM and it will be developed in months 1–3 of the intervention. The teams will comprise some individuals who have provided critical support and input, including participating in the exploratory research phase and the CBPR adaptation of the intervention framework for the Chilean context. The teams of local champions will assist with the data collection process throughout the study by encouraging colleagues to complete questionnaires and recruit users, as well as oversee and implement the intervention at their respective CESFAMs. These teams of champions will receive training to develop their skills as leaders and support the implementation process at their CESFAM. A self-administered evaluation questionnaire will be used to assess the effectiveness of the champion training and teams of local champions will track their activities at their own CESFAM.

Regarding the second component "*Analysis of Internal Policies, Procedures and Protocols*" it will be developed during months 3–18. This component involves evaluating CESFAM policies, procedures, and protocols using an anti-stigma/pro-recovery approach to identify strengths and areas for improvement in service delivery for individuals affected by MISUI. This evaluation will be completed using a policy analysis tool developed specifically for this intervention during the Canadian project; it is based on existing frameworks, such as the *Health Equity Impact Assessment Tool (HEIA)* (79) and the *QualityRights Toolkit* (80). HEIA is a tool that can be used to identify and address potential unintended health impacts (positive or negative) of a policy, program or initiative on specific population groups through five steps; scoping, potential impacts, mitigations, monitoring an dissemination (79). QualityRights Toolkit delivers information and tools for assessing and improving quality and human rights standards in mental health and social care facilities (80). At least five policies, procedures or protocols will be selected by the local champions and then analyzed by the research team. Recommendations concerning health equity, prevention of stigma and recovery-oriented practices promotion for individuals with MISUI will be developed and shared following analysis. It will be expected from each intervention CESFAM to implement at least one recommendation and make the necessary efforts to intend to educate PHC providers about the policy change in months 7–18 of the intervention. The impact of the implemented policy change will be analyzed at end-point data analysis and 6-month follow-up.

The third component *"Raising Awareness"* will be conducted during months 1–18. Various forms of media will be used to raise awareness about stigma related to MISUI among PHC providers and users. This component will be implemented throughout the intervention. Aligned with the premises of the contact-based educational element, local champions at intervention CESFAMs will determine the type of media they would like to use; this may include images, film, music, or a combination of media. This can be posters, web platforms, social media, among others. The research team will work with local champions to develop messaging to include in the media and assist with showcasing these pieces within each intervention CESFAM. This will also depend on the CESFAM's particular resources and media choices. This component impact will be evaluated through its acceptability, adoption, appropriateness and coverage.

The fourth component "*Innovative Contact-Based Education*" will be conducted during months 1–18, trough educational workshops in intervention CESFAM. It will include anti-stigma and recovery principles, along with specific MISUI topics relevant to PHC providers. Topics will be determined by findings from the exploratory phase, current research, best practices, and the perspectives of local champions. Topics may include (1) supporting CESFAM PHC providers in preventing stigma and promoting recovery in their practice and (2) enhancing the competencies of CESFAM PHC providers for discussing MISUI with their users, identifying MISUI signs and symptoms, and referring users to psychosocial centers for treatment. Special emphasis will be placed on cultural beliefs and values that may influence stigma related to MISUI, concurrent disorders, and inter-professional collaboration within CESFAMs and between various health agencies.

The key feature of these workshops is the contact-based educational element (81), where people with lived experience participate in developing and delivering the curriculum to CESFAM PHC providers. mhGAP materials (82) will be used as main curriculum resources. As an incentive and recognition, a diploma will be given to participants. This component will be evaluated by the training team after each workshop to determine feasibility, coverage and perceived workshop usefulness.

Finally, the *"Recovery-Based Arts"* will be developed through months 7–18. Local champions at intervention CESFAMs will select one PHC provider member and recruit one artist to develop an arts curriculum and facilitate the art sessions. The facilitators will select an art form (e.g., painting, sculpting, music, sewing etc.) to use throughout the sessions. The facilitators, in collaboration with local champions, will determine themes related to MISUI to cover in each session. Ten users affected by MISUI and at least three CESFAM PHC providers will participate in the workshops each week. At the end of the 10-week program, each CESFAM will host an exhibition to showcase the artwork that has been produced.

### Specific objective 3: Evaluate the effectiveness of the intervention in primary health care

This part of the interventions is composed by a quantitative and a qualitative component.

1. a Quantitative Component:

All PHC providers at the selected CESFAMs who have direct contact with users will be recruited for the study and will be expected to participate at all data collection time-points. A total sample size of at least 36 PHC providers per CESFAM with a total of 288 per arm its estimate (or 576 per data collection). Sample size for the proposed study was calculated in two steps. First, it was calculated with individual randomization. This calculation was based on the mean ± SD score for the OMS-HC scale was 48 ± 8.3 points, estimated with a sample of 798 PHC providers surveyed in FONDECYT N° 1160099 (34). This should be the average obtained in control CESFAM for the present study. Based on prior interventions in Canada (63), an estimated effect size of 10% in the intervention arm and a placebo effect of 3% in the control arm (from survey application) is expected. Thus, the average OMS-HC score in the intervention arm is expected to decrease to 43.2 ± 8.3 in the intervention group and 46.6 ± 8.3 in the control group (representing a decrease of 4.8 and 1.4 points, respectively). The standard deviation was assumed to remain the same in the intervention and calculations. To detect a statistically significant difference between intervention and control CESFAM, with an $\alpha = 5\%$ and statistical power of 80%, the minimum sample size per arm is 94 individuals. Considering a 10% loss to follow-up in the intervention arm, 105 individuals per arm should be recruited with an individual randomization design. The minimum sample size was also calculated considering cluster randomized controlled design. Two elements were considered: (1) a minimum sample size of 105 and (2) an estimation of the intracluster correlation coefficient (ICC) for the study outcome (OMS-HC scale) (83). In this case, it was assumed the ICC to be $\rho = 0.05$, which is consistent with highest value reported in the literature for outcomes in primary care settings (74) and slightly higher than that reported in a study of a depression program in CESFAMs in Chile (84). Given the required sample size calculated based on individual randomization and the value of ICC = 0.05, the minimum number of clusters required is equal to: [105*0.05] = 5 clusters (75). However, a larger number of clusters would allow recruitment of a smaller number of individuals per cluster, maintaining an $\alpha = 5\%$ and statistical power of 80% to detect differences between the control and intervention groups (85). For example, if 8 clusters per arm is considered (16 CESFAM total), it is necessary to recruit a minimum of 36 professionals per CESFAM. Thus, a minimum of the total sample of PHC providers to recruit would be 288 per arm (576 total). The validated, Chilean version of the Opening Minds Scale for Health Care Providers Scale (OMS-HC) (86), will be used as the primary outcome measure for PHC Professionals in the study. It will be applied at baseline, mid-point, end-point, with an expected 9-month interval between applications, and at 6-month follow-up.

A self-administered questionnaire will be used to examine stigma directed at persons with MISUI among health professionals. Five existing scales to measure stigma toward MISUI were selected to include in the questionnaire because they had been validated in Chile and were recommended by the research team. These scales reflect the current state of knowledge about stigma measurement (with a focus on health providers and persons with MISUI), as well as the feasibility of implementation at CESFAMs. They include: the Opening Minds Scale for Health Care Providers OMS-HC (83, 87, 88), Mental Illness: Clinicians' Attitudes (MICA) (89), Modified Bogardus Social Distance Scale (90, 91) or Grandon Social Distance Scale (92), Recovery Scale for Providers (RS) (93), and the Recovery Self-Assessment-Revised (RSA-R) scale (94).

This questionnaire will be completed at four time-points (baseline, mid-point, end-point, and 6-month follow-up). It will collect data related to two main components: (1) socio-demographic and other relevant general variables; and (2) attitudes toward MISUI stigma and recovery. The end-point questionnaire will also include a third component focusing on the intervention and its implementation. A self-administered questionnaire will be provided to PHC providers at each CESFAM (intervention and control) at a time set aside by CESFAM directors.

CESFAM users will be recruited for participation in baseline and end-point data collection regarding their experiences of stigma by PHC providers. These users must be over the age of 18, have received treatment for MISUI at the CESFAM in the 3 months prior to participation (though not necessarily by a mental health professional), and have a MISUI diagnosis. User MISUI may be diagnosed by a health practitioner or self-diagnosed. Since stigma is a barrier to seeking and receiving help, it is important to include participants who have not been formally diagnosed by a healthcare provider. A research team member will approach users at the waiting room and screen them for inclusion and exclusion criteria. Users in capacity to consent will be invited to sign the consent form and those who sign will be part of the face-to-face survey assisted by a research team member on the same day in the same health facility. To assess capacity to consent, a Spanish adaptation of dimensions and criteria of the Macarthur Competency Assessment Tool for Clinical Research (MACCAT-CR) (95) are used. This process includes the following actions; (1) The interviewer exposes the user to the relevant information of the project after which he/she is questioned about what has been explained (comprehension); (2) Subsequently, they are asked about their appreciation or assessment of the information provided in their specific circumstances; and (3) A reasoned reflection on the decision to be made is promoted, assessing the circumstances and consequences, to end up expressing their choice.

The primary outcome for users will be measured using The Internalized Stigma of Mental Illness (ISMI) scale, validated for the Chilean population (96). The study will collect cross-sectional samples at baseline and end-point data collection and compare average scores between intervention and control groups for baseline and end-point measures.

A minimum sample size of 27 PHC users per CESFAM was calculated (or 216 users per study arm, or 432 users total per data collection). For this sample size calculation, the mean ± SD for the ISMI score was 10.34 ± 4.74 points, estimated based on the results of FONDECYT N° 1160099 (34). A placebo effect of 1% was considered in the control group, and a 15% expected effect size was considered in the intervention group, based on the protocol for a similar intervention study completed in Canada (which estimated a higher effect of 19.5%; a more conservative estimate was selected for this calculation) (64). Thus, the mean of the scale would decrease to 10.23 ± 4.74 in the control group and to 8.79 ± 4.74 in the intervention group (an average decrease of 0.1 and 1.55 points, respectively). No change in the standard deviation was assumed, to be conservative with the calculation. To detect a statistically significant difference of this size between intervention and control groups, with a significance level of α = 5% and statistical power of 80%, 169 individuals are required in each group (intervention and control). Loss to follow-up it is not considered, as individuals recruited at the baseline and end-point data collection will not necessarily be the same, and this will be a cross-sectional sample. In the cluster RCT design, it is expected that the ICC of the ISMI score would be relatively low, as the CESFAM user population is more likely to be heterogeneous than the PHC providers. Assuming an ICC = 0.01, and considering the k = 8 clusters in each arm of the study (from PHC provider calculations), or 16 CESFAM total, it is necessary to recruit a minimum of 27 PHC users per CESFAM, or 216 users in each arm, for a total sample size of 432.

A face-to-face survey assisted by a research team member will be used to examine how users perceive stigmatizing attitudes and behaviors among CESFAM PHC (97) providers. The questionnaire will include four main components: (1) socio-demographic and other relevant general variables; (2) perceived stigmatizing attitudes and behaviors among CESFAM PHC providers; (3) perceived recovery-oriented practices by CESFAM PHC providers; and (4) accessing healthcare at their CESFAM. Subjective experience of stigma as conveyed by CESFAM PHC providers will be measured among patients using validated tools. The Perceived Devaluation-Discrimination Scale will be used to assess the extent to which users believe that other people devalue or discriminate against someone with MISUI. This scale has shown acceptable internal consistency ($a$ = 0.78) (97). The tool is validated in Chile (98). An adapted version of the Discrimination Experience Subscale of the 29-item ISMI scale was designed to measure the subjective experience of stigma, e.g., respondents' perceptions of how they are treated by others. It measures alienation, stereotype endorsement, perceived discrimination, social withdrawal, and stigma resistance. The Cronbach's alpha value of the total score was 0.83 and the Spearman-Brown Coefficient of 0.76 (99). For FONDECYT N° 1160099 (34), a shortened version of the ISMI scale was used, which was validated for use in Chile with an ($a$ = 0.916) (96). The Person in Recovery Version of the RSA will also be considered to assess users' perceptions of recovery-oriented practices in their CESFAMs. Due to the sensitive nature of the study scales, there is some risk of social desirability bias in participants' responses. Both PHC providers and users will complete the Marlowe-Crowne Social Desirability Scale (MCSDS). The MCSDS will allow to measure and control such bias. The scale has 33 items which were defined to be culturally acceptable but unlikely to occur, and to have minimal abnormal implications for either the socially desirable or socially undesirable responses (100).

1. b Qualitative component:

To evaluate implementation of the intervention, qualitative interviews will be held with two PHC providers (local champions) and one CESFAM authority per intervention site at baseline, mid-point, and end-point. In addition, at least one local champion from the community will be interviewed to explore his/her/they experience as a champion, pros and cons of the intervention and how it could be improved. Questions will relate to implementation outcomes for the intervention: acceptability, adoption, appropriateness, feasibility, fidelity, implementation cost, coverage and sustainability (101). In addition, mid-point, end-point, and follow-up questionnaires administered for PHC professionals in experimental CESFAMs will include questions regarding: acceptability, adoption, appropriateness, feasibility, fidelity, implementation cost, coverage, and sustainability. End-point interviews will also include questions regarding key elements needed for scaling up the intervention. In addition, near to the culmination of the project, a Symposium with 20–30 key stakeholders including members from the Ministry of Health, *Servicios de Salud* and CESFAMs, among others, will be held in order to define final recommendations to scale up the anti-stigma intervention on a national level. The discussion process will be guided through ExpandNet & WHO Framework (102) and the recent theoretical recommendations from Greenhalgh and Papoutsi (103) regarding scaling up processes in health, as well as the critical aspects about dissemination of stigma reduction interventions identified by Kemp et al. (69).

*Specific Objective 4* corresponding to "*identify critical barriers and opportunities for its implementation in PHC*" and *Specific Objective 5, "Develop recommendations to scale up the anti-stigma intervention"* will be developed by the qualitative component of data previously mentioned.

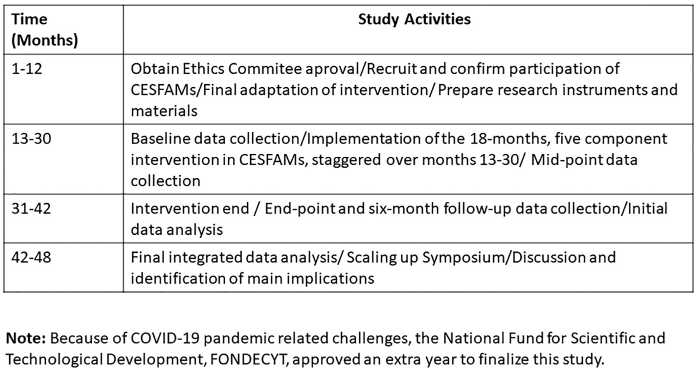
A brief summary of the study's activities is described, correlated with the project timeline in **Figure 5**.

This intervention is expected to promote the following outcomes; Participation in the experimental group will result in a significant decrease in stigmatizing attitudes among PHC providers toward individuals with MISUI compared with the control group as measured by the Chilean version of the OMS-HC; Participation in the experimental group will result in a significant decrease of PHC users experiences of stigma conveyed by PHC providers compared with the control group as measured by the ISMI scale, validated for the Chilean population; The changes in attitudes and behaviors within the experimental group will be sustained over time as measured at 6 months-follow-up.

## Data analysis

The data analysis will be conducted through months 42–48. Post data collection activities consider the following: (1) Data cleaning and evaluation, (2) Creation of derived variables, (3) Response rate calculation and (4) Bias evaluation.

It will be carried out using SAS 9.4 (specifically, using POC MIXED and PROC GENMOD) and R 3.5. Mixed-effect



| Time (Months) | Study Activities |
|---|---|
| 1-12 | Obtain Ethics Commitee aproval/Recruit and confirm participation of CESFAMs/Final adaptation of intervention/ Prepare research instruments and materials |
| 13-30 | Baseline data collection/Implementation of the 18-months, five component intervention in CESFAMs, staggered over months 13-30/ Mid-point data collection |
| 31-42 | Intervention end / End-point and six-month follow-up data collection/Initial data analysis |
| 42-48 | Final integrated data analysis/ Scaling up Symposium/Discussion and identification of main implications |

**Note:** Because of COVID-19 pandemic related challenges, the National Fund for Scientific and Technological Development, FONDECYT, approved an extra year to finalize this study.

FIGURE 5
Study activities.

modeling will used for both PHC provider and user data, which will include individuals and CESFAMs as random effects and group (intervention/control) as fixed effects. The technique is appropriate to analyze cluster randomized controlled trials because these models can account for the possible dependence between responses of users and PHC providers within the same CESFAM. A descriptive analysis will initially be conducted to obtain a general picture of the sample. Time and important covariates (e.g., demographics) as they relate to our outcome variable will be explored. Univariate association tests will be performed to clarify the unconditional effect of these covariates on outcomes.

After the quantitative and qualitative data have been analyzed, summarized, and interpreted independently, the primary focus of the integrated analysis will be on identifying and discussing to what extend and in what ways the qualitative results help to explain the quantitative results (explanatory design). Implementing a "hybrid" approach (104) that will be used for qualitative data.

## Discussion

This study represents a new stage of relevant and innovative research in mental health and stigma in Chile that will contribute to improving access and quality of care for people with MISUI. Evaluating the impact of the intervention model and its implementation will provide the necessary basement to scale the intervention up to other CESFAMs across Chile. This intervention is vital to fight stigma toward MISUI and other conditions in PHC and the Chilean health system overall. Knowledge translation will be a special focus of this study, in order to communicate results to local, national, and international audiences. It is also important to evaluate the feasibility of the intervention scale up, since different studies have reported cultural influences on mental illness-related stigma (105).

Stigma has a detrimental effect on health policies (106), treatment outcomes (107), and efficient and effective recovery from mental health problems (23). Evidence indicates that stigma reduction initiatives must be comprehensive, multifaceted, and able to target various levels within a setting. Different strategies to address stigma have been suggested (66, 69). At the organizational level, specific interventions implemented across entire institutions (e.g., workplaces) (108) may provide supportive environments that encourage anti-stigmatizing practices (109). It has been suggested that reducing stigma interventions with people already in contact with health services, as people with MISUI, needs alternative strategies to deal with self-stigma and cope with experienced stigma to facilitate adherence (46). That reinforces the importance of a collaborative approach, where service users and healthcare practitioners work toward destigmatize PHC. Healthcare professionals stigmatizing behaviors and beliefs may be subtle and denied because of how they are perceived (23) thus, it is important to implement interventions focusing on awareness, internal policies, procedures and protocols. It's also relevant to implement educational approaches, as the one included in this protocol, as adequate information and contact between the public and the stigmatized individuals would lead to diminish stigma (110) in PHC settings.

This study has some particular limitations and potential bias: (a) Non-response bias: A survey of this kind will invariably tend to select the more cooperative and communicative respondents, who may also be more tolerant. Different strategies have been considered to increase the response rate, even among people who might have more stigmatizing attitudes. In particular, it is important to consider potential item non-response as a limitation of this study. The research team will emphasize respondents the importance of trying to answer all the questions and some alternatives, like mean substitution or other imputation methods, will be used if is necessary; (b) Social desirability bias: As with other measurement approaches, there are potential biases measuring stigma attitudes, because it might be considered a sensitive issue. Self-administered questionnaires expect to reduce this bias, as well as the respect for confidentiality and use of the MCSDS (100); (c) Difficulties to measure attitudes: It can be difficult translating untouchable concepts into variables; (d) External validity is threatened by the limitations of the sample, the generalizability of the results are limited to the target population (CESFAM PHC Providers); (e) Inferring behavioral responses from reported intentions; (f) Non-blinding: Participants will not be blinded. Since the intervention is an RCT, this may be a bias source.

Some of the main strengths of this study include: (a) There is a real public health need for this intervention study: stigma is a key factor that affects people with MISUI, resulting in their reluctance to seek health care services. This study will be one of the first to intervene to reduce stigma among PHC professionals in Chile. As discussed in Background, prior stigma reduction intervention work has found that reducing MISUI stigma in PHC has the potential to increase access to care for user with these conditions, improve their quality of life, and contribute to improved treatment adherence for MISUI. (b) The use of a census/organizational approach: seeks to change organizational culture and stigma toward those with MISUI *via* contact-based education, structural policy change, and raising awareness at the CESFAM level. (c) Cultural appropriateness: Special efforts will be made to adapt the intervention for this context, and the stigma instruments were adapted to the Chilean context in FONDECYT 1160099. The mixed methods approach of this research allows addressing many of the limitations of the quantitative stigma measures and facilitates deep understanding of intervention's impact and implementation. (d) The inclusion of both health providers and users in this study: Many studies of stigma in PHC have not included the perspective of users, limiting the impact of their results in the lives of people with MISUI.

After a critical analysis of the proposed study, it is possible to say that its design and internal validity are sufficiently strong and that special measures have been taken to control and reduce its potential limitations. Finally, it is important to remark that "stigma" has many sources and this study will not be able to tacked all of them (e.g., media, social services, the educational system, and legislation). While recognizing stigma as a complex concept, this study seeks to reduce stigma at the health services level by an innovative and collaborative approach. Having that in mind, this will be a unique relevant study to test an innovative anti-MISUI stigma intervention targeting CESFAM providers in Chile from an organizational perspective.

## Ethics and dissemination

a. Research Ethics Approval

This protocol and the template and site-specific informed consent forms, recruitment materials and other requested documents were reviewed, analyzed and approved by the sponsor and the applicable Pontificia Universidad Católica de Chile Ethics Committee (EC) (ID::190603010), Herminda Martin de Chillán Hospital EC, Valparaiso Health Service EC, Coquimbo Health Service EC and Reloncavi Health Service with respect to scientific content and compliance with applicable and intervention research and human subjects regulations. The proposal will follow all ethical guidelines provided for conducting research with human beings. The proposal, interim reports and final reports will be submitted to the EC's at the beginning, middle, and end of the study.

b. Consent

All participants will be required to read and sign an informed consent form outlining the aims and objectives of the study prior to engaging in any aspects of the project, particularly before participating in the data collection process. It will be presented comprehensibly, the opportunity to ask questions will be given, understanding confirmation will be solicited, and voluntarily participation will be re assured. All user participants will also receive an oral explanation of the consent process prior to signing and/or agreeing to participate, and PHC user capacity to consent will be considered.

Informed consent will be conducted by interventors/researchers/PHC workers, guaranteeing adequate training and experience, in order to protect participants moral wellbeing and human rights. The consent process will be conducted by trained professionals.

c. Confidentiality

All participants will be assigned a numerical code, resulting in the anonymization of data. All knowledge translation materials will only include data for groups with 10 members or more to protect confidentiality. Although the quantitative surveys include a question about the participant's CESFAM, reports for each CESFAM will be general and will not include a separate analysis by profession, limiting the potential to identify individual respondents.

d. Ancillary and Post-Trial Care

This study involves minor risk of potential harm (physical, emotional and/or social), however, specific measures will be taken to minimize them: (1) confidentiality, so participants will not be treated differently than other PHC providers/CESFAM as a result of their responses; (2) participation is voluntary and no negative consequences will result for those who decide not to participate; (3) participants may skip any/all questions they do not want to answer as part of the mixed methods approach; (4) information is provided to all participants regarding the institutions conducting the research, the principal investigators, and contact information and active referral for psychosocial support when needed for those who may be emotionally triggered by participating; and (5) final results will be shared with participants.

e. Dissemination Policy

The research team conceptualizes dissemination as a key component of a comprehensive knowledge translation approach (111) in a dynamic ongoing cycle. Special efforts will be made in all the stages of the project to make research results accessible to various audiences (such as research participants, *Servicios de Salud* and CESFAM authorities, Chilean Ministry of Health, and the academic community) through resources such as a research portfolio, reports, at least three academic papers, meetings, and at least two academic conference presentation, as well as to explore possibilities like articles and features in local mass media (e.g., radio, television, and newspapers). There will be a specific budget that supports dissemination efforts. Each academic or research report, will be reviewed by project research committees and by peers, prior to submission to evaluate methodology and implementation and appropriateness merits. The study results will be released to the participating PHC workers and users.

## Ethics statement

This study was reviewed and approved by the Pontificia Universidad Católica de Chile Ethics Committee, Herminda Martín de Chillán Hospital Ethics Committee, Valparaíso Health Service Ethics Committee, Coquimbo Health Service Ethics Committee, and Reloncaví Health Service Ethics Committee. The patients/participants provided their written informed consent to participate in this study.

## Author contributions

JS was the leading researcher. JS and PV conceived the study with the support of other research team members. AK, SB, PC, and JS participated in the design and implementation of a previous initial study in Canada. IB, JS, AK, and SB were part of an earlier similar study in Peru. JS, PV, TA, RA, MA, FP, LV, PB, CÁ-H, AJ, NV-M, SB, IB, AK, PC, and CT were part of the design and/or initial implementation of the protocol in Chile. FP, JS, and LV provided statistical expertise in clinical trial design. LV conducted the primary statistical analysis in the FONDECYT 1160099 study. All authors contributed to refinement of the study protocol and approved the final manuscript.

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## Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

## Publisher's note

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# "Art and Psyche Festival": Utilizing the power of art against the stigma around mental illness

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## 1. Introduction

Despite the great scientific advances in psychiatry and its extensive reflection on society, stigma toward mental health conditions, patients, and even hospitals remains dominant (1). Mental health issues are a double-edged sword; The symptoms, distress, and disability that interfere with individuals' daily lives, along with the surrounding stigma, can make a challenging situation. Stigma toward mental health conditions can be defined as cognitive and behavioral constructs of stereotypes, prejudice, and discrimination (2). People with mental health issues experience different types of stigma from various sources, including public stigma, self-stigma, and structural stigma (2).

Stigmatization attitudes toward psychiatric disorders prevent patients from seeking professional psychological help (3). The fact that individuals with mental health disorders such as depression (4), anxiety (5), and schizophrenia (6) are afraid of being socially labeled by stigmatizing words such as insane or crazy continues to place barriers against obtaining help (7). The results of the Mental Health Million project, which is a survey on global mental wellbeing launched by Sapien Labs, revealed that in 2021, more than 50% of people with clinical mental health risks did not seek psychological help. It also stated that 25% of those not seeking help cited stigma as the leading cause (8).

The stigma toward mental health disorders and help-seeking behavior has altered over time. The study conducted by Leach et al. in 2009 showed a decline in the stigma of seeking mental health counseling and a rise in the acceptance of and the need for mental health services over the past 20 years in Egypt, a Muslim community with a traditional context (9). Another US population-based study published in 2021 reported a significant decrease in public stigma regarding depression but not schizophrenia (10). Taking the progress in destigmatization into account, it seems that the stigma around mental health issues has not been eradicated; rather, some less severe mental health conditions and treatments have become less stigmatized as a result of the destigmatizing efforts (7).

Fighting against stigma is a challenging road. To overcome this challenge, efforts must be made not only on personal levels but also on public levels (2). Various approaches to changing the stigma of mental health issues could be grouped into three categories: *protest*, *education*, and *contact*. **Protest** aims to suppress stigmatizing attitudes by highlighting stigma's injustices and confronting the offenders for negative attitudes and behaviors (2, 11). **Education** aims to raise public awareness and tends to have its best effect among teens and adolescents (2, 12). As another method of fighting against stigma, the literature suggests that interpersonal **contact** with someone with a mental health issue reduces stigma more than either protest or education approaches (2, 11, 12). Anti-stigma movements try to implement these strategies by designing novel, creative, and socially attractive plans and mediums. Among these, art has shown a promising capacity for public engagement in social anti-stigma campaigns.

In this article, we highlight the importance of stigma related to mental health issues as a global problem and review some anti-stigma efforts in the literature. Then, we briefly discuss the relationship between art and mental health and present our experience in an anti-stigma model attracting social attention to psychiatric issues using art as the primary medium.

## 2. The association between psyche and art

Art can be defined as any means for the expression of individual and social values through concrete and artistic activities and processes (13). The rehabilitating impact of art on both mental health and life satisfaction is well-studied (14–17). This can be in the form of music (16, 18), visual arts (19), dance and movement programs (20), expressive writing such as journaling (21), and other alternatives.

Art can also be addressed as a tool for increasing public awareness about mental health and reducing the stigma toward mental health issues (22). Different forms of art, such as visual, literary, and performing arts, can be used as educational approaches to improve relatability, interactivity, and engagement (13). Using multiple art forms, especially in the form of carefully programmed, collaborative, and community-based festivals, can reduce discriminatory behavior toward people living with mental health problems and positively impact stigma around mental issues by constructing shared meanings and engaging audiences on an emotional level (23). Table 1 briefly reviews a number of art-related festivals around the world aiming to increase awareness about mental health disorders and fight the surrounding stigma. Mentioned art-related events were selected using the broad search in Pubmed, Scopus, and Embase. The search strategy was the combination of keywords: (festival OR campaign) AND art AND mental AND stigma. The search yielded a total of 22 results, excluding the duplicates. Finally, seven studies were found to be eligible for this brief review table (24–30).

One of the well-known worldwide artistic festivals aiming to fight mental health-related stigma is the Scottish mental health art festival (SMHAF). SMHAF is an annual festival that aims to fight mental health problems and their surrounding stigma using different types of arts, from music, film, and visual art to theater, dance, and literature (31). Potash et al. stated in an article that the aforementioned art festivals could positively affect the stigma of mental health disorders (29).

In another study, Riches et al. aimed to raise the awareness of the general population and correspondingly reduce the stigma toward mental health issues through a mental health-awareness audio tour co-produced and narrated by young adults with relevant lived experience. Gallery visitors were led on ten stops through the gallery, focusing on artworks, challenging common myths about mental health, and inviting visitors to consider their personal views. The tour increased positive attitudes, indicating the feasibility of arts-based interventions in reducing stigma (32).

Another project, reported by Riches et al., aimed to raise the general population's awareness and reduce the stigma toward psychotic experiences by holding an art exhibition. The developers tried to create a semi-psychotic experience for the visitors by using voice-hearing simulations and video installations with the help of people who have lived the situation and based on their experience. The results showed that the exhibition achieved its aim by raising awareness about mental health (30).

Similarly, the BIG Anxiety Project, a citizen science art project performed in Sydney, Australia, utilized arts to inspect public attitudes toward anxiety. People represented their subjective anxiety experiences through various types of art engagement, such as installation. The project not only led to enhanced knowledge of mental health but also to spreading public participation in research that establish connections to communities (33).

All aforementioned studies confirm that the efficient use of art could help reduce the stigma and raise awareness of mental health issues.

## 3. "Art and Psyche Festival"

Studies have shown moderate to high levels of stigma toward mental health issues in Iran (34–36), a middle eastern country that lacks comprehensive plans to reduce the stigma (37). Taghva et al., in an article aimed to explore the opinions of stakeholders of mental health about the strategies to reduce the stigma toward people with mental disorders in Iran, suggested that cultural, artistic, or athletic festivals with a diverse range of general or specific audiences are of potency to reduce stigma (38). As mentioned in earlier paragraphs, various approaches to changing the stigma of mental health issues could be grouped into three categories: protest, education, and contact (2). Art festivals can offer anti-stigma means in all these categories (23, 39); therefore, considering the current situation of stigmatized attitudes locally, we decided to run an art festival focusing on mental health problems.

The idea of running the "Art and Psyche Festival" was first mentioned during the informal gatherings of the psychiatry department faculties and then developed gradually. Initially, five psychiatry faculties of the Mashhad University of Medical Science (the five latter authors) developed the idea of running the 'Art and Psyche Festival" in the Ibn-e-Sina psychiatric hospital in Mashhad, Iran. They invited psychiatry residents to join them in organizing a committee in august 2019. Eleven psychiatry residents and three medical students formed an executive team. They started to review the available literature on art festivals and destigmatizing programs around mental health issues. They tried to expand their connections and links in many informal gatherings with well-known artists. They also managed to attract financial support from charity departments and governmental/non-governmental organizations.

TABLE 1 A brief review of a number of destigmatizing art festivals with the main goal of increasing awareness about mental health disorders*.

| Campaign/ festival | Aim | Target population | Art tools utilized | Place | Year conducted | References |
|---|---|---|---|---|---|---|
| Mental health arts and film festival | To end mental health stigma and discrimination | Citizens of Glasgow and Lanarkshire | Film, theater, comedy, concert, community event, debate, discussion, and workshop | Scotland | 2007 | (24) |
| "Wellness and Talking Wellness" | To communicate effectively and to decrease the stigma of depression | African-Americans in Los Angles, USA | Poetry, film, and photography | African-American region of the USA | 2004–2005 | (25) |
| "AUSNAHME\|ZUSTAND" (State of Emergency) | To decrease the stigma and social distance of the audience toward people with mental illness | Adolescents | Film, documentary | Germany | 2008–2010 | (26) |
| "Open the Doors" | To improve public knowledge and to reduce the stigma toward schizophrenia and schizophreniform disorders | General and specific target groups such as students, teachers, health professionals, police, and journalists | Workshop, theater, painting, film | 27 countries | 1999-present | (27) |
| Trapped in the Labyrinth | To challenge stigma and increase awareness and understanding of mental illness | General public audiences | Drama and devised performance in theater | United Kingdom | 2016 | (28) |
| "Citizenship, Compassion, the Arts" of Hong-Kong | To help with destigmatizing and to increase "understanding and support" for people living with mental illness | Individuals with mental illness and the general public | Art exhibition and art-making workshop | Hong Kong | – | (29) |
| "Altered States of Consciousness" | To increase public awareness of psychotic experiences | Respondents to advertisements in South-East London, local artists, visitors to the exhibition, the production team | Workshop with people with lived experience, trained actors, artwork, voice hearing simulation, video installation | UK | 2017 | (30) |

*Mentioned campaigns and festivals were selected using the broad search in Pubmed, Scopus, and Embase. The search strategy was the combination of keywords: (festival OR campaign) AND art AND mental AND stigma. The search yielded a total of 22 results, excluding the duplicates. Finally, seven studies were eligible for this brief review table.

The organizing team began to share the invitation to the art festival on social media. As a result of these activities, many individuals and groups, including the general population, artists, art associations, public health charity organizations, private companies, related governmental organizations, NGOs, and authorities, actively got involved in participating and supporting the festival. The executive team organized and categorized the received artistic documents and forwarded them to the jury to rank and select the awardees.

The main goal of the art and psyche festival was to develop an artistic visual exhibition on the campus of a psychiatric hospital to invite every citizen to come to and experience its environment with the aim of challenging some traditional stigmatized beliefs about mental illness and psychiatric hospitals. This festival, with its competitive artistic nature, also encouraged artists to pay closer attention to mental health issues and their related stigmas. Additionally, it aimed to set the ground and promote future research on the potential risks and benefits of such measures in raising mental health and reducing related stigma among communities.

Since 2019, two online mental health art festivals have been organized with a jury committee of well-known artists, critics, and psychiatrists. The first festival, which was a national festival, was performed in three different fields of art, including photography, short movies, and short stories. The participants were asked to send their works of art in the field of mental health diseases in people's daily life. A total of 1,309 artworks (847 photographs, 342 short stories, and 120 films) were received from Iranian artists. The artworks were then reviewed and evaluated by the jury, and the ones with the highest scores in each field were awarded.

In the second festival, we tried to publicize the event globally on social media and invite participants from other countries. In this way, we managed to attract artists from different nationalities and promote the second festival to an international one. The second festival was focused only on photography and covered the following topics: psychological trauma during the COVID-19 pandemic, psychiatric illness and survival, marginalization and mental disorders, positive parenting, effective communication, psychological resilience, acceptance of differences, social emergencies, economy and mental health problems, children and their psychological world, child abuse, and mental health in vulnerable women. Two thousand six hundred and eighty-two photos from 26 countries on all continents were received. The three most participating countries were Iran (1,540 photos), Vietnam (281

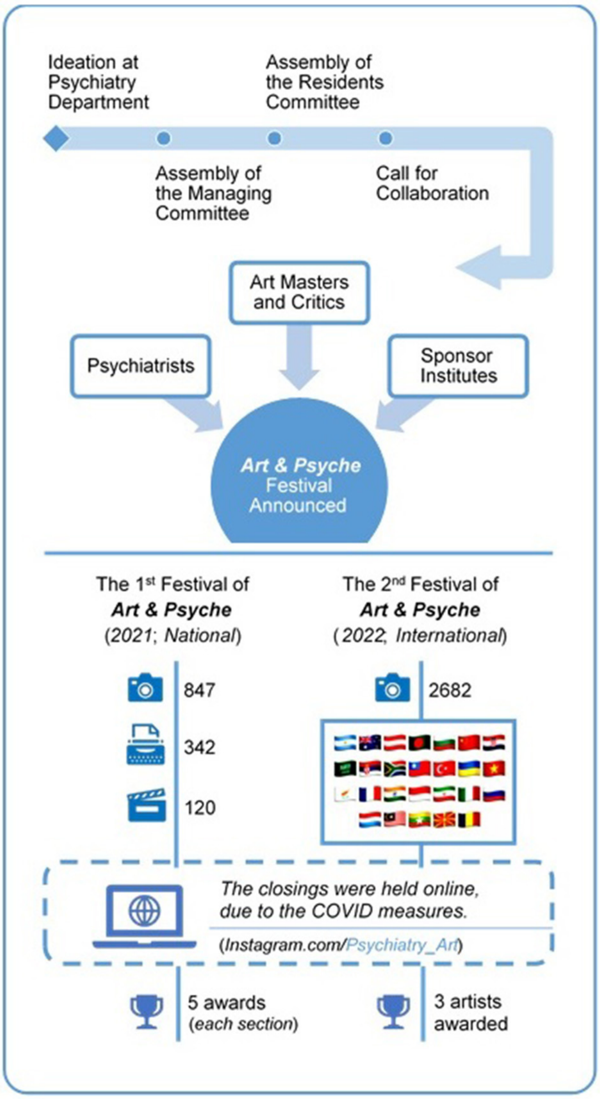

FIGURE 1
Process of organizing the "Art & Psyche Festival" from ideation until the closing event.

photos), and Turkey (238 photos). Artworks receiving the highest scores from the jury were awarded a cash prize. Figure 1 visually summarizes the festivals' ideation and execution process; also, the *artwork booklets are available at: https://doi.org/10.6084/m9.figshare.21747722.v1 and https://doi.org/10.6084/m9.figshare.21747740.v1.*

This festival is among the first faculty-based festivals relating art and psychiatry in Eastern Mediterranean Region. Turning from a national event to an international one in its second year, and doubling the number of artworks, reflects its potential to become a worldwide movement against mental health issues. This festival planned to provide an anti-stigma model coordinated with active public participation, despite some prior art festivals where participants were only visitors of the artworks (30, 32).

As discussed previously, *education*, *protest*, and interpersonal *contact* are three major approaches that can be used to fight the stigma surrounding mental health issues (2, 11). In this festival, we tried to use art as a tool not only for raising awareness but also for connecting participants (citizens and artists) with mental health issues and individuals with such problems. We encouraged participants to depict people with mental health problems and their issues in daily routine life using their artistic and creative perspectives.

According to the available literature, we hypothesize that such an art festival can act as a multi-potent anti-stigma package providing all three main approaches to fighting against mental health stigma, including *protest* (highlighting routine challenges of people with mental illness and how stigma can even worsen their situation), *education* (raising public awareness and implicit psychoeducation about mental illness and its related challenges), and *contact* (connecting citizens with psychiatric care facilities and individuals with mental health issues).

We assume that the anti-stigmatization impacts of this art festival could be more significant if we could perform the closing ceremony at the psychiatry hospital yard, where more people get the chance to be directly engaged; however, due to COVID-19 confinements and limitations, the closing ceremony was performed online. Another limitation of this art festival was the lack of quantitative/qualitative research to support the hypothetical role of this art festival in reducing the stigma related to mental health issues. Therefore, we contemplate re-conducting it in a more intense research design evaluating its potential risks and benefits for the fight against public mental health stigma.

## 4. Conclusion

Although organizing two "*Art and Psych*" festivals in a developing country with moderate to high stigma toward mental health issues (34–36) could not achieve our ultimate goal of gathering people in an art exhibition held in a psychiatric hospital due to COVID-19 limitations, it was a successful experience in gathering social attention and support. Hypothesizing the facilitating role of art in destigmatizing psychiatric disorders, we contemplate running the third festival integrating research methods to support this opinion. We did not assess the actual anti-stigma effect of this festival; however, according to the available body of literature, we firmly believe that popularizing mental health issues using art as an attractive medium and involving social organizations will be effective in destigmatizing psychiatric disorders.

## Author contributions

AS, AT, FF, MF, and MK developed the central idea of the event, led the team through each stage, and collaborated with the jury for the art piece evaluation. AA, AM, BH, FA, FS, HM, MG, NK, NS, SO, ZM, and ZR contributed to the development of the event concept, along with participation in the festival's executive committee. AM, FS, NK, and MG contributed to the public relations and the public promotion of the event and the artworks' reception and indexing. FA contributed to the coordination with various organizations and institutes. AM and NK collaborated to prepare, design, and publish the festival books. SD, AG, HM, and NK composed the manuscript draft and collaborated with the AS, AT, FF, MF, MK, AA, AM, BH, FA, FS, MG, NS, SO, ZM, and ZR for its finalization. AM prepared the figure supplied with the manuscript. SD contributed in designing

Table 1. All authors contributed to the article and approved the submitted version.

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## Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

## Publisher's note

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# A qualitative study on health stigma and discrimination in the first year of the COVID-19 pandemic: Lessons learnt from a public health perspective

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**Background:** Stigmatisation, misinformation and discrimination have been magnified globally due to the COVID-19 pandemic. The healthcare sector was not spared from this. We conducted a transnational study, using the Health Stigma and Discrimination framework (HSDF) to explore public perception and reactions to the COVID-19 pandemic in a multicultural context. Findings from the Asian arm of the study, sited in Singapore, are reported in this paper.

**Methods:** This phenomenological research deployed semi-structured informant interviews using non-probability sampling approaches to recruit members of the public. Interviews were coded independently by two researchers and thematic analysis was used to analyse the responses.

**Results:** Twenty-nine members of the public (23–80 years old) were interviewed between Oct 2020 to Feb 2021. Five major themes were identified: (i) perception of stigma amongst respondents, (ii) experiences of stigma amongst respondents, (iii) views on what drove stigma and misinformation, (iv) facilitators in preventing and reducing stigma and misinformation, and (v) ageist attitudes towards older adults. Overall, construction workers living in dormitories, healthcare workers, and to some extent tourists from China, were perceived to have been stigmatised and shunned by the public. Place-based stigmatisation was common; participants responded by avoiding places that had confirmed cases of COVID-19. Perceived stigma was temporary and not enduring, driven at the outset by fear of being infected. This study also identified the role played by trust in reducing stigmatisation. The relative absence of politicising of issues and high-quality information readily disseminated to the public were reported as factors that could have reduced and prevented stigma and misinformation on the various groups. Ageist attitudes were observed in some participants with older adults being labelled as vulnerable, susceptible to misinformation and being less able to cope during the pandemic.

**Conclusion:** Through the lens of the HSDF, this study provided an exploratory account of the nature of stigma that resulted from the COVID-19 pandemic in an Asian context. It also shed light on facilitators in preventing and reducing stigma during an outbreak especially the role of trust and communications during a public health crisis.

KEYWORDS

**COVID-19, stigma, fear, misinformation, discrimination, public health, ageism, healthcare workers**

# 1. Introduction

In January 2020, the WHO declared the COVID-19 pandemic as an international public health emergency (1). To reduce the rate of infection, governments around the world adopted various policies such as the practise of safe distancing and mask wearing, tight control of population mobility (2), nationwide quarantine measures (3) and other emergency preparedness strategies. While providing guidance and direction to manage a rapidly evolving disease, governments also assumed the responsibility of communicating information, risks, and management strategies to the general public and higher risk groups. In the management of public health emergencies, clear, accurate, and transparent communication is critical (4). However, the uncertainties surrounding a novel disease such as COVID-19 have made information sharing challenging (5).

In a highly connected digital era, many people were quickly exposed to misinformation or conflicting information about the virus such as COVID-19 preventative measures, conspiracy theories about the origins of the virus, or misconceptions about one's perceived susceptibility towards the virus (6–8). This is alarming as the perceived accuracy of a single piece of misinformation could increase even with a single exposure (9). Additionally, one's intention to verify information could also be hindered by motivated reasoning in an attempt to protect existing beliefs (10). A multi-country study comparing the impact of exposure to COVID-19 misinformation in the USA, South Korea, and Singapore found that exposure to misinformation had a significant direct association with information avoidance and heuristic processing (7). While cultural and situational differences may affect response towards and interpretation of misinformation, information-seeking behaviour appears to be similar across cultures (7).

Misinformation, also has the potential to instil fear stigmatisation and discrimination against groups such as patients (11) healthcare workers (12, 13), older adults (14) or individuals of Asian descent (14, 15). Health related stigmatisation, or stigmatisation association with health conditions, can have consequences for public health, for instance leading to affected groups avoiding testing, treatment or other health seeking behaviours (16). Additionally, mental health of those stigmatised could also be affected (11, 17–19). Whilst affected groups may not be excluded or rejected out rightly as a result of discrimination, they can still be subjected to stigmatising behaviours that can fall outside the purview of the law such as verbal abuse or gossip (16). As Singapore was one of the initial countries within the Southeast Asian region where COVID-19 spread, many were potentially exposed to misinformation about the origins of COVID-19 due to its novelty (20, 21). Being a multi-racial and multi-religious city-state with various ethnic groups, the rise of misinformation, fear, and stigma in the face of a pandemic poses a threat to social harmony, as previously seen during the 2003 Severe Acute Respiratory Syndrome (SARS) pandemic in 2003 (22). As social cohesion is important in managing a pandemic such as through positive attitudes towards immigrants (23) and other vulnerable groups, understanding how COVID-19 leads to misinformation, fear, and stigmatisation could inform the development of strategies to alleviate these issues in combating future pandemics.

To address this knowledge gap, a qualitative study was conducted to explore the perceptions and reaction of laypersons, to the COVID-19 pandemic in Singapore. This study was part of an international collaborative effort to further explore how misinformation, fear and stigma are contextualised within a cultural, political and global setting in both Canada and Singapore. The design of this study was guided by elements of the Health Stigma and Discrimination Framework (HSDF) (16). The HSDF helps conceptualise the stigmatisation process across a spectrum of socio-ecological determinants. It considers how individual characteristics (such as race, sex, gender, age) overlap and intersect with organisational biases and power structures with communities, organisations, or systems (16). This framework makes it possible to move away from the dichotomous thinking of "us" vs. "them" with regards to stigma and allows for more comprehensive understanding of the construct. More importantly, the HSDF distinguishes between stigmatised experiences and stigma practises. The former leads to an impact of outcomes such as emotional health, social exclusion, reduced access to treatment, while the latter results in fear or misinformation that perpetuates stereotypes and discrimination (16). Findings from this study could help to catalyse the development of appropriate strategies and tools to combat misinformation, fear, and stigma in response to the COVID-19 outbreak.

# 2. Methods

## 2.1. Study design

Colaizzi's phenomenological method (24) was used for this study. In phenomenology, the subjective experiences of participants are understood by returning to the specific life scenes of the participants and exploring their feelings, perceptions, and reactions to the latter. In the context of this study, the aim of the phenomenological approach was to understand the meaning and essence of the participants' subjective experiences, as they lived through the course and various episodes of the pandemic. As a starting point, phenomenological interviews were conducted using general qualitative interviewing method, which was semi-structured in nature (25). Following Ricoeur (26), a phenomenological researcher is free to use structure in the interviews that enables a thorough investigation. The semi-structured approach was also advocated on grounds for maintaining methodological consistency and trustworthiness (25) especially in a study whereby three interviewers of varying research experience are involved. Due to constraints of the pandemic and for practical considerations, validation of the findings were not sought from the research participants as typically would be expected of the phenomenological method (27). Interviews were conducted in Singapore from October 29, 2020, to February 4, 2021. During this period of data collection, Singapore had no more active COVID-19 clusters of outbreaks. The country entered Phase 3 of re-opening on 28 December, 2020 whereby several restrictions were eased, such as increasing the maximum number of people allowed for social gatherings from five to eight, increasing the capacity limits of premises, and allowing migrant workers to access the community more often (28). This study adhered to the COREQ reporting guidelines.

## 2.2. Participants

Convenience sampling was used to recruit participants, and this was done through word-of-mouth, emails, and advertisements. Additionally, snowball sampling was used to complement recruitment. For instance, the study team mobilised their network in the field of geriatrics to recruit older adults. Potential participants were subjected to screening *via* a phone call before being recruited into the study. Inclusion criteria included English-speaking and able to provide informed consent. Individuals who were not residing in Singapore during the pandemic period and were younger than 18 years old were excluded.

## 2.3. Procedure

All interviews were conducted online using a teleconference platform Zoom due to COVID-19 restrictions and were guided by a topic guide informed by the HSDF. Three researchers consisting of one male research fellow (CC), one female research officer (MK), and one male research officer (BT) conducted hour-long semi-structured interviews. The topic guide (see Appendix A) provided a list of key questions that the interviewers had to follow through, thereby ensuring some degree of consistency across the three interviewers. At the same time, the interviews, being semi-structured in nature, allowed interviewers to follow-up on questions that were deemed important based on the replies of the respondents. Given that adhering to a topic guide may possibly limit the time participants have to adequately express their opinions, the team engaged the participants with two to three follow-up questions in instances where they assessed that the participants had more to share about a particular point. Sub-questions within the topic guide were explored optionally depending on the pace of the interviews. All had educational qualifications in psychology while CC and MK had prior experience in qualitative research. Given the evolving nature of the pandemic, the researchers kept up to date on the local developments of the pandemic by immersing themselves on news updates and actively discussing with each other on issues that arose.

Study materials consisting of an information sheet and topic guide were sent to enrolled participants prior to each interview session *via* email. Study goals and procedures were explained to each participant, and verbal consent was obtained at the beginning of each interview. Each interview consisted of at least two researchers, one to facilitate the interview and the other to take notes. Investigators met after each interview to reflect on the interviews and discuss their findings based on notes taken. Interviews were audio recorded and transcribed verbatim by researchers from a partner institute. To ensure confidentiality, audio recordings were destroyed after checking transcripts for accuracy and transcripts were de-identified. Transcripts were not reviewed by participants and no repeat interviews were conducted. Grocery vouchers worth SGD$25 (USD$19) were offered as an incentive for participation.

## 2.4. Data analysis

Thematic analysis (29) was conducted using QDA Miner Lite to organise the data and identify common themes and sub-themes about fear, stigma, and misinformation. Some preliminary themes aligned with the topic guide were developed based on the HSDF while new themes were generated during the coding process. The domains of HSDF proposed by Stang et al. (16) provided a 'common ground' for researchers to understand health-related stigma and these included (i) personal experiences of stigma, (ii) perception of stigma in society independent of personal experiences, (iii) personal beliefs about what drove stigma and misinformation (iv) factors that facilitate the reduction of stigma and (v) perception of stigmatising behaviours and discriminatory attitudes/behaviours. Two of the three researchers (MK and BT) coded the first three transcripts independently to extract common themes before meeting to refine the codes and cheque for consistency. Any conflicts on a code's content were discussed and refined until a common understanding of the code was achieved. The researchers then came to an agreement on a refined list of codes and continued with coding the rest of the transcripts. Due to a member of the research team leaving the study (MK), BT coded the transcripts with the refined codebook while CC reviewed the coded transcripts. Both researchers then met regularly over 4 months to resolve any conflicting opinions and to discuss themes until no new themes were generated.

## 2.5. Ethical review

Institutional Review Board (IRB) approval was obtained from the National Healthcare Group-Domain Specific Review Board (reference number 2020/00582), based in Singapore. All participants gave verbal consent prior to the start of the interviews and anonymity and confidentiality were maintained according to the IRB-approved study protocol.

# 3. Results

Thirty-one participants were recruited for the study through non-probability sampling. However as one participant did not choose to proceed with the interview after being successfully recruited and another had family members engaging with the responses during the interview, this resulted in a final sample of 29 participants. Participants were aged 23–80 years old and on average 56.45 years old (*SD* = 16.8). Participant demographics are available in Table 1.

Six major themes were generated to explore the effects of the COVID-19 pandemic on misinformation, fear, and stigmatisation: (i) perception of stigma amongst respondents, (ii) experiences of stigma amongst respondents, (iii) views on what drove stigma and misinformation, (iv) facilitators in preventing and reducing stigma

TABLE 1 Participant demographics ($n = 29$).

| Characteristics | *n* (%) |
|---|---|
| **Gender** | |
| Male | 13 (44.8) |
| Female | 16 (55.2) |
| **Age (in years)** | |
| 21–30 | 4 |
| 31–40 | 2 |
| 41–50 | 3 |
| 51–60 | 4 |
| 61–70 | 10 |
| 71–80 | 6 |
| **Ethnicity** | |
| Chinese | 21 (72.4) |
| Malay | 2 (6.9) |
| Indian | 5 (17.2) |
| Others | 1 (3.4) |
| **Employment status** | |
| Full-time | 11 (37.9) |
| Part-time | 5 (17.2) |
| Retired | 11 (37.9) |
| Unemployed | 2 (6.9) |
| **Highest level of education** | |
| Master's/doctorate or equivalent | 5 (17.2) |
| Postgrad diploma/certificate | 1 (3.4) |
| Bachelor's or equivalent | 10 (34.5) |
| Professional qualifications | 3 (10.3) |
| Post-secondary | 2 (6.9) |
| Polytechnic | 2 (6.9) |
| Secondary | 5 (17.2) |
| Primary | 1 (3.4) |

and misinformation, and (v) ageist attitudes towards older adults (see Table 2).

## 3.1. Perception of stigma amongst respondents

Although participants perceived that the virus originated from Wuhan, China, they did not report China visitors (e.g. tourists or students) as being criticised in Singapore. One participant attributed this to the fact that majority of Singaporeans are of Chinese ethnicity. Another participant reported that locals were wary of the virus *per se* rather than the humans (China visitors) that may harbour the virus. One participant was mindful that unlike overseas countries in the West, the label "China Virus" did not exist in the local context and was a political construct. Many participants were aware that the "Chinese origin" narrative originated from the United States.

In Singapore, blue-collar workers typically in the construction field come from overseas and reside in designated large-scale dormitories. The cramped living conditions meant that large infection clusters quickly formed in these dormitories during the initial stage of the pandemic (30). At the time of the outbreak, there were 323,000 dormitory dwellers in Singapore (31). Our interviews showed that many participants were aware that COVID-19 impacted dormitory workers significantly. Beyond facing quarantine measures and movement restrictions, they were perceived to be stigmatised, and shunned by the public. A participant mentioned:

> "I think the foreign workers are stigmatised especially when cases in dormitories are very high, I think Bangladeshi workers, they are pretty much stigmatised… I also do receive complaints from Singaporeans in saying that they have concerns about Bangladeshi cleaners and have they done swab test." (PB13).

This arose from their perception that a large number of dormitory workers had been infected. A participant felt that dormitory workers were potentially shielded from discriminatory behaviour arising from stigmatisation only because they were kept quarantined in their dormitories. Hence, the situation may have been otherwise if they were not quarantined.

Healthcare workers were initially perceived to be at higher risk of being exposed to the virus and many were therefore shunned by the public. In particular, those wearing hospital uniforms were deemed to be stigmatised. A participant mentioned:

> "Earlier, near the start there were some local news about nurses being asked to...leave the public transport or the bus or the train or there were videos of neighbours, you know, spraying alcohol or disinfectant at people who were... nurses who were coming back home." (PB50).

Most participants however did not think this was persistent as it occurred mostly at the start of the pandemic. Although largely confined to healthcare workers, one participant opined that other frontline workers such as teachers and prison staff could have also been targeted given the nature of their work.

## 3.2. Experiences of stigma amongst respondents

Overall, the majority of the participants did not report experiencing stigma or being in a situation whereby they personally witnessed someone else being stigmatised. Most participants also did not experience fear in relation to stigma or discrimination and some mentioned that even if they became infected, they expected that existing family support would reduce the fear of stigmatisation. Strong family support therefore appears to be an important protective factor for many of the participants. However,

TABLE 2 Major themes, sub-themes, and participant quotes.

| Major theme | Sub-theme | Participant quotes |
|---|---|---|
| Perception of stigma amongst respondents | - | "I don't think it's (stigma) widespread simply because Singapore is majority Chinese right by race. I think of it as one race that globally that would be kind of stigmatised. It would be the Chinese for sure, but because we are most of us well, most meaning like I don't know what Singapore is, 60, 70% of the country is Chinese ethnically. I think that that type of racism or stigmatisation is a lot less" -PB05<br>"I've read articles about people not being served in hostels because they're wearing the nurse's uniform or the ambulance driver, stuff like that, and I mean, it's understandable, but like, I feel like that's a bit too much. The way people act is a bit too much. It's to possibly, yeah, like, I think that's more of like a fear of COVID-19 that's just going out of control." -PB11<br>"I don't think we, like, keep away from Bangladeshi man or Indian man but I do hear of friends who say that when they see these people, they will move away in the MRT you know. You come up from the MRT and then they will go to another door or something like that." -PB29 |
| Experiences of stigma amongst respondents | - | "I mean, I guess if it (being stigmatised) happens it happens, but there's no real, like, fear I guess of it." -PB11<br>"…I truly believe that if I have travelled, for example, if I travel to a country where they may think that I'm from mainland China, you know because I've seen those on news, right. I think so but because, you know, and I'm in Singapore. So I don't get that (stigmatised)." -PB70 |
| Views on what drove stigma and misinformation | - | "For example, I have a friend who was working in a hospital, but she's nowhere near any COVID-19 patients or anything like that, and just because she's wearing the hospital uniform, pretty much the only place she can eat without getting stared at is within the hospital food courts and stuff." -PB11<br>"I personally think that no one is to blame because the no one wanted the spread of COVID-19 to happen, but of course, sensationalised news will say China tourists they probably caused this whole thing to happen." -PB13 |
| Facilitators in preventing and reducing stigma and misinformation | Trust in government and local news sources | "I guess if the sources are government or medically backed up by facts from authorities that you can trust, and they know what they're talking about, then it's more trustable. Then I will see that several sources exist and then I'll trust the several sources" -PB30 |
| | Quality of information and timely updates | "My view is, of course, the whole island-wide, they (the government) do announce through media, radio and TV and all that, and they update you actually very, very frequently. And they give advice and guidance as how one should protect oneself and to prevent the spread. I think that is very, very important." -PB34 |
| | Well-educated and informed public | "There is too much information and there are also a number of sensationalised information, be it Singapore or overseas, so I think we will have to be discerning to as to reading such things, as to, whether or not they are factual or distorted information." -PB13 |
| Ageist attitudes towards older adults | - | "…older people, the seniors that you can see in sort of the hawker centres, the seniors between the age of 70 to 80, they just couldn't be bothered. They don't care. They wear their mask under the chin, when I approached them, I say, why don't you pull up (the mask)? They say, I'm already so old, anytime can die. The way they answer you, they do not realise that they can infect other people, they do not know the consequence of infecting their own family, so they just don't care, the attitude is very complacent." -PB35 |

some participants were wary of situations where they could be stigmatised. These included situations such as being infected with COVID-19, having to wear uniforms similar to frontline workers and being mistaken as someone from China while travelling outside Singapore. One participant mentioned that he would fear being Chinese in "Vancouver, United States or United Kingdom" (PB05). A few participants, however, mentioned that they felt avoided or discriminated as illustrated in the following examples: a participant was visibly ill in public, and she felt being "shunned"; another participant mentioned being "called out" by family members due to her job as a frontline worker: "…I've been told please do not carry the virus back home and infect the rest of the household." (PB19).

It was possible that some participants dealt with their fear by avoiding places that had confirmed cases of COVID-19. For instance, some felt that they avoided places out of prudence such as specific shopping malls frequented by dormitory workers, or churches in Singapore with confirmed cases. This was illustrated by a participant:

> "I, was scared to go. You know, for a few days we heard that [shopping mall A] got, [a COVID cluster] you know…we don't go [there] very often unless we really need to go there to get something. We faster go, no distance. We save distance faster get and come. We don't go anyhow, [go shopping mall A] or where. They said even [shopping mall B] have… [and] I stopped going [shopping mall B]." (PB64).

## 3.3. Views on what drove stigma and misinformation

One of the main drivers behind perceived stigma on dormitory workers and frontline workers involved the fear of infection. However, participants clarified that this was not due to some inherent characteristics of the groups but out of fear of the infection itself. It was considered prudent to "protect" oneself through avoidance behaviour, which was not regarded as discriminatory. As one participant remarked: "I would avoid going to places where there is a congregation of dormitory workers. But I wouldn't discriminate against them. I would avoid them, but not discriminate against them. The avoiding and discrimination are two different things." (PB38). There is also an element of risk calculation driving the fear especially for healthcare workers who may have to "subject themselves to COVID-19 (in the care of patients)" (PB17) and that "health care personnel are the high-risk carrier…" (PB17).

Regarding concerns over overseas Chinese at the start of the pandemic, participants' responses suggest that there were initial concerns that Chinese tourists could have been vectors bringing in the virus. However, many also surmised that news about the origin of the virus could have caused this perception, which could have been subsequently amplified by unsubstantiated views promulgated by various information sources. As one participant mentioned:

> "Initially there was all of these conspiracy theories that maybe the US who did it to China, maybe is China, who was researching stuff and they ran out of the laboratory, that kind of stuff. I don't know what to believe anymore…" (PB05).

Another participant said "I did read about accusations flying here and there. Some say Chinese, some say the American soldier, some say animal. Yeah. But, you know, there is no proof of anything..." (PB43). Interestingly, some participants felt that the Chinese were unfairly blamed, and this could possibly have portrayed Chinese excessively negatively. One participant mentioned: "…doesn't really help that the U.S. president has certain opinions about certain groups, especially the China (Chinese) people, so the people who buy into that, that will fuel their misinformation." (PB22). Another participant, as with others, disagreed with the "Chinese/Asian origin narrative" and shared that the association of COVID-19 with one's ethnicity was a misinformed perception that could have been propagated by news or media: "…if you read the news and certain social media outlet…misconstrued that the virus very much has Asian origins" (PB19).

Beyond the perception that older people face significant risk of developing severe illness if they were infected with COVID-19 that could have explained the vulnerability narrative, there were views shared by participants that suggested that older adults were also more susceptible to misinformation. For instance, one participant, PB30, mentioned that older adults tend to spread misinformation on folk remedies to cure COVID-19 (e.g. basking in sunlight, drinking hot water). One participant perceived that older adults "take everything at face value" (PB13).

## 3.4. Facilitators in preventing and reducing stigma and misinformation

### 3.4.1. Trust in government and local news sources

Most of the participants mentioned trusting the Singapore government and local news sources for information. Regarding trust in the government, there was a perception that information communicated to the public tended to be factual and reliable. One participant remarked:

> "In my country, we have to trust the government or the government agency, because I think this is the most reliable source of information, because there is no guarantee that you'll send me whatever on social media that has been proven correct". (PB39).

There were also laws protecting citizens from falsehood as highlighted by a participant: I have seen how my own country managed information, right? So ok, in Singapore we also have got laws very strictly barring against, you know, the spread of falsehoods." (PB70). On local new sources, most participants mentioned trusting the information coming from local news platforms such as Channel News Asia and Straits Times. A participant felt that there is no politicising of issues: "Anything that's from Singapore, I'm inclined to agree. Only some, like if I watch Fox News and the CNN, that sort of news, I'm not too sure, because they seem to be 'pro' certain things". (PB70).

### 3.4.2. Quality of information and timely updates

The manner through which high-quality information was readily disseminated to the public was another possible factor that could have reduced misinformation. Many were familiar with the type and manner of updates that they received. For instance: "When you have daily updates at the time, you know that you will get update on numbers, on developments at that time. So that removes the vacuum of information in which misinformation can spread" (PB 05). Others, e.g., PB13 and PB16, mentioned about the benefits of a "daily/regular press conference and press releases" from the government.

### 3.4.3. Well-educated and informed public

Finally, participants perceived that a well-educated and informed public could have also helped in discerning the information they received, hence reducing stigma and related misinformation. Participants mentioned checking and verifying information that they receive. One participant, PB38 would first establish credibility of who was making the statement before agreeing with it whereas another, PB40, would "fact-check" by using search engines such as "Google". Participants tended to be more cautious if the information they come across was overly negative or if the source was from social media.

### 3.5. Ageist attitudes towards older adults

Expressions of concern were common when participants were questioned about the impact of the pandemic on older adults. There was a general sense that older adults were a homogeneous vulnerable group and were more in need of help than younger people. A participant mentioned: "Number one, they're more susceptible. Number two, they probably are more fearful. Number three, they're probably more susceptible to misinformation as well. So emotionally, economically… I mean, on all fronts, they are the ones who are losing out here." (PB05).

The responses also included perceptions of how older adults were dealing with the pandemic. There was a sense that older adults were less able to cope with changes in their lives: "So there was a lot of unacceptance... and they couldn't accept this at all. They couldn't accept this, all this rules. The old people, …it was very sudden for them, and they couldn't accept it." (PB21). There was also perception of helplessness and the inability of older adults to competently care for themselves. One participant mentioned that the older adults were misinformed: "…the seniors are not getting the exact information from the media and they communicate with their group and that must be a lot of misunderstanding, a misinterpretation of the policy." (PB73). One participant, PB19, a volunteer at a care centre, mentioned that seniors complained that their movements were restricted by their family out of concern for their vulnerability.

Overall, our study showed that younger participants and to some extent, older ones too, tended to subscribe to the vulnerability narrative of older adults. However not all older adults felt this way. Some were unhappy about ageist attitudes that surfaced because of the pandemic:

> "Well I find it like come on, doesn't mean that I am of this age, I am vulnerable, you know. I don't think they should brand us (older adults) that way, which is very, very bad, very hurting. My children also follow along because the news is saying that, you know so they keep cautioning me, don't go out, don't go out, don't go." (PB21).

## 4. Discussion

Adapting elements of the Health Stigma and Discrimination Framework, this study delved into understanding the stigmatisation process that occurred in Singapore during the early phase of the pandemic and not only examined manifestations of stigma in the form of perception, experiences and practises, but also identified the drivers and facilitators behind how stigma is applied to certain groups according to their race or occupation.

Findings from this sample suggest that some groups were perceived to have been stigmatised by the public during the start of the pandemic. These included healthcare workers and dormitory workers with the former being widely reported in existing literature (32–35). As with earlier studies during the SARS outbreak, drivers of stigma against healthcare workers identified in this study was similar as they were shunned and ostracised for fear that they were potential carriers of the virus (36, 37). Initiatives in Singapore to recognise the efforts of healthcare workers as well as a narrative on their sacrifices and contributions as the pandemic progressed, could have had a positive effect in reducing stigmatisation (35).

Stigmatisation of dormitory workers occurred as they formed the vast majority of cases earlier in the pandemic where the virus spread quickly due to their communal living arrangements (38). The main driver behind the pattern of stigmatisation was similar to healthcare workers insofar as this group was perceived to be potential carriers of the virus. There was a general sense that avoidance behaviour was the prudent thing to do, similar to what was observed in the United States and Canada (33). Interestingly, the interviews did not reveal any deep-rooted anger or hatred towards dormitory workers for the large increase in infection numbers. They were also not perceived as "scapegoats" that were to be blamed given their status in society (39). This was in a way surprising given that other studies have shown that ostracism or other forms of discriminatory practises would be expected in a pandemic (40–42).

Prior to the pandemic, attitudes towards dormitory workers were not always positive as revealed in a survey conducted by the International Labour Organisation (ILO) (43). For instance, in 2008, residents of an estate had signed a petition against a foreign workers dormitory situated in their neighbourhood (44). Moreover, these workers are often viewed as a forgotten segment of society whereby their poor living conditions were not a focus of attention until the pandemic hit (44). There was therefore the possibility that some participants in our sample could have offered socially desirable comments. Alternatively, since this study employed the use of convenience and snowball sampling, it was also possible that participants of certain traits and viewpoints may have self-selected themselves to participate in the study. These views therefore reflected the thinking from segments of society that did not hold strong views against dormitory workers.

With regard to relatively absent anti-Chinese national sentiments, a possible reason on why participants in our sample were mindful of the "Chinese origin" narrative of the virus could be in part due to local political leaders actively taking the stand against anti-Chinese sentiments that initially surfaced, largely framing this as a medical issue, staying clear of terms such as "Wuhan virus" that could feed such sentiments (45). To surmise, our findings concurred with earlier studies related to pandemics, where the fear of contracting the virus led to the stigmatising of groups known to be largely infected or suspected to be so due to close contact with the latter (5, 39).

Despite the perceived existence of stigma against groups known to be at high risk of infection, our participants did not reveal much experienced stigma (personally experiencing incidents or knowing of cases from personal networks). There were however views that highlighted how people would fear being mistaken as uniformed frontline workers or as someone coming from China. For the latter group, this fear was driven by the global perception that people of Chinese descent have overwhelmingly been the target of discrimination largely because of the negative portrayal of the Chinese, which was promulgated by overseas news portals, social media, and prominent public figures in the United States. The perception coming from our sample that prominent figures in the United States might have exacerbated the stigmatisation of the Chinese has been surfaced in other studies (14, 46).

Participants mentioned that government and local news outlets in Singapore were trusted sources for accurate information related to the pandemic. This could possibly explain why they were mindful of misinformation surrounding Chinese individuals and other associated stigmatising practises. Indeed, studies have found that lower trust in the government to be a predictor of higher susceptibility to misinformation (7, 47). Views on trust towards the Singapore government in communicating information about COVID-19 corroborated with empirical data provided by a separate study (48). In this pandemic, beyond regular communications and prompt correction of misinformation by the government, fake news law passed have been reported by the home affairs minister in helping to substantially reduce the circulation of misinformation (49). Such proactive approaches in keeping the public informed could also be effective at reducing belief in misinformation through a process known as 'cognitive inoculation' (50). Given emerging evidence suggesting that misinformation can influence people's behaviour negatively during the pandemic, such as lowered willingness to adopt public health guidance measures, more than ever, public institutions involved in fighting the pandemic must continue to gain the trust of the public as reliable sources of information, by providing regular and timely updates so as to limit the spread of misinformation.

The role played by traditional mainstream media is however not always clear. Elsewhere in the United States, it has been found that those who disproportionately consumed right-leaning media were more likely to endorse COVID-19 misinformation (51). Other research showed a positive association between exposure to traditional media and lower misinformation beliefs (52). More recently, exposure to traditional media was found to have a positive association with vaccine acceptance (53). As participants viewed the information coming from news outlets in Singapore to be direct, factual, and non-sensational, and therefore had a level of trust in it, this may have contributed to participants' ability to distinguish between misinformation (e.g., origin of virus, folk remedies) and factual information. In line with recommendations from other research (52), traditional media should continue to adhere to disseminating fact-based information linked to high quality sources such as governmental, healthcare or academic data and reports.

Some studies suggested that education level did not play a role in predicting whether someone will believe in misinformation (53, 54). The evidence on the role of education was not clear as it was not the focus of our study although we uncovered that strategies used by our highly educated sample such as active fact-checking and verification of sources were likely important in combating misinformation. Findings from this study point to the benefits of multi-modal means of messaging during the pandemic by official governmental sources. Future research could examine the role of community leaders and religious leaders in information dissemination efforts as they have been suggested by some of those who were more religiously inclined in our study as possibly playing a role in complementing governmental sources.

Participants' responses also suggested that some may hold certain ageist assumptions of the older population. These attitudes appeared to have been benevolent and paternalistic in nature, stemming from concern towards older adults to care for and protect them (55, 56). Public health messaging therefore needs to be designed in a way that does not further exacerbate benevolent ageism in the community, such as by framing messaging that does not homogenise older adults that could fit paternalistic age stereotypes (57). As the messaging has already been done and protracted, policymakers should focus future communication on dialling down the effects of COVID-19 public health messaging targeting older adults, such as the widely adopted "vulnerability" narrative (56).

Lastly, many participants reported preferring a multi-modal approach with a focus on video and text-based messages (e.g. through platforms such as Telegram and Whatsapp) although some mentioned the latter could take up too much time and may be unsuitable for some segments of the population such as older adults or those with lower health literacy. Infographics were also mentioned as useful ways of conveying important information. Majority of participants prefer receiving information through official sources such as press briefings and government linked websites. Information should also be disseminated through all mediums including print, broadcast, and news media. Regarding messengers, other than through local authorities and news channels, experts such as doctors and other reputable figures have been suggested as figures who could facilitate information dissemination.

## 5. Limitations

This study was not without limitations. Overall, our participants were well-educated, and many were discerning of news and information they receive. Over-representation of particular groups as in our study is not uncommon given the use of non-probability sampling and views on misinformation stigma, and fear during the pandemic may therefore differ should there by greater heterogeneity in education level. Interviews were also all conducted in English *via* Zoom, which meant that participants in our sample also possessed a certain level of digital literacy. This was also the case for the older adults in our sample where digital literacy is typically instead much lower as shown in a recent local study (58). Many of the older adults in our sample were familiar with social media and actively subscribed to various official news platforms in the digital sphere such as Twitter, Facebook, WhatsApp, and Telegram. Therefore, views from older adults in this sample could differ from those in the population with lower digital literacy.

Given the sensitive nature of the topic, participants could potentially have withheld or altered their opinions on stigma due to social desirability effect especially when probed about their views relating to foreign workers. Moreover, since foreign dormitory workers were not interviewed in this study, views from participants in this study about the lack of ostracism or discriminatory practises against dormitory workers could not be corroborated. Indeed, whilst the study was able to examine the key domains under the HSDF, namely the manifestations of stigma and the various driver and facilitators, not reaching out to the affected population meant that the impact of stigma on access to justice, uptake of testing, adherence to treatment, resilience and advocacy (16) could be further explored. Future research using the HSDF should therefore pay closer attention to understanding such outcomes beyond the focus on the other domains. Finally, these participants were interviewed at a time when COVID-19 situation was generally under control. Given the evolving nature of the pandemic, attitudes and opinions could differ if the interviews were conducted at an earlier stage of the pandemic whereby there was more uncertainty about the covid-19 cases involving dormitory workers.

## 6. Conclusion

This study explored the perceptions and experience of the laypersons on stigma and identified stigma drivers and facilitators during the COVID-19 pandemic. Perceived stigma existed largely towards dormitory workers and healthcare workers. Personal experiences of stigma were not widespread and while majority of participants reported being unafraid of stigmatisation, some were cautious of situations where they could be stigmatised. Key drivers of stigma and misinformation were identified, such as fear of infection and overseas information sources. Trust in local sources for information, fact-checking, and the manner of information dissemination were suggested to facilitate the prevention or reduction of stigma and misinformation. An important next step would be to utilise the findings to guide development of strategies and tools, such as in public health messaging, to combat the spread of stigma and misinformation in future pandemics.

## Data availability statement

The datasets presented in this article are not readily available because as stipulated by the ethics board, sharing raw data beyond the study team members is not permitted. However, further inquiries can be directed to the corresponding author for clarifications. Requests to access the datasets should be directed to yu.chou.chuen@geri.com.sg.

## Ethics statement

The studies involving human participants were reviewed and approved by the National Healthcare Group Domain Specific Review Board (Reference number 2020/00582). The patients/participants provided their written informed consent to participate in this study.

## Author contributions

JL and CY are the co-investigators of the study and made significant contribution to study design, investigation, and reviewing of this manuscript. CY and BT made significant contribution to study design, investigation, analysis, study administration and writing of this manuscript. CF, MM, and SS made significant contribution to study design and reviewing this manuscript. CY made major contribution to writing this manuscript. All authors have read and approved the manuscript.

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## Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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## Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpubh.2023.1143640/full#supplementary-material

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# Stigma and posttraumatic growth among COVID-19 survivors during the first wave of the COVID-19 pandemic in Malaysia: a multicenter cross-sectional study

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**Background:** Contracting COVID-19 can cause negative and distressing psychological sequelae, but traumatic stressors may also facilitate the development of positive psychological change beyond an individual's previous level of adaptation, known as posttraumatic growth (PTG). As a result, studies have investigated the negative effects of COVID-19 on mental health, but data on PTG among patients who have recovered from COVID-19 remains limited. This study aims to evaluate the level of PTG and its associations with stigma, psychological complications, and sociodemographic factors among COVID-19 patients 6 months post-hospitalization.

**Method:** A cross-sectional online survey of 152 COVID-19 patients was conducted after 6 months of being discharged from Hospital Canselor Tuanku Muhriz, MAEPS Quarantine Center, or Hospital Sungai Buloh, Malaysia. Patients completed a set of questionnaires on sociodemographic and clinical data. The Posttraumatic Growth Inventory (PTGI-SF) was used to assess the level of PTG, the Kessler Psychological Distress (K6) was used to measure the degree of psychological distress, the General Anxiety Disorder-7 (GAD-7) was used to evaluate the severity of anxiety symptoms, the Patient Health Questionnaire (PHQ-9) was used to assess the severity of depression symptoms, and the Explanatory Model Interview Catalog Stigma Scale (EMIC-SS) was used to record the degree of perceived stigma toward COVID-19.

**Results:** The median PTGI SF score of the respondents was 40.0 (Interquartile range 16.0). Multivariable general linear model with bootstrapping (2,000 replications) revealed factors that significantly predicted PTG, which were at the higher level of the perceived stigma score, at 37 ($B=0.367$, 95% CI=0.041 to 0.691, $p=0.026$), among the Malay ethnicity ($B=12.767$, 95% CI 38=7.541 to 17.993, $p<0.001$), retirees ($B=-12.060$, 95% CI=$-21.310$ to $-2.811$, $p=0.011$), and those with a history of medical illness ($B=4.971$, 95% CI=0.096 to 9.845, $p=0.046$).

**Conclusion:** Experiencing stigma contributed to patients' PTG in addition to psychosocial factors such as ethnicity, history of medical illness, and retirement.

KEYWORDS

**posttraumatic growth, stigma, COVID-19, psychological trauma, social stigma**

## 1. Introduction

The world experienced its first pandemic of modern times over a decade ago, with the 2009 H1N1 swine flu outbreak. This was followed by the COVID-19 pandemic in 2020, caused by the SARS-CoV-2 virus, which mutated rapidly into different variants over time. Moreover, asymptomatic individuals were unaware of the possibility of them transmitting the disease. It slowly became obvious that COVID-19-related mortalities were growing in number, especially during the initial phase and when vaccinations were yet to be developed or made available (1). In addition, the course of the illness became unpredictable as some continued to experience what was later referred to as long COVID-19, where symptoms lingered long after a patient no longer produced positive outcomes on test kits. Long COVID-19 was found to occur in the population regardless of age or severity of the initial symptoms (2).

The unique features of COVID-19 posed significant psychosocial impacts on the community as compared to other diseases. Many became more concerned about the safety measures during the pandemic, especially handwashing and social distancing. In addition, self-quarantine and lockdowns were adopted in many countries across the world, including Malaysia. There was also a surge in the hoarding of daily necessities such as food, drinking water, and toilet paper during the pandemic (3, 4). In other words, mankind was pressured to survive during the pandemic, and survival became a matter of major concern in every household.

With the constant pressure to survive, COVID-19 was a traumatic stressor capable of bringing about Post Traumatic Stress Disorder (PTSD) symptomology (5). An increase in PTSD-like symptoms was reported among participants who had COVID-19 infections or when their family members became infected. Moreover, those with no direct contact with the virus were also anxious about becoming infected at any point. Many members of the public lost their source of income, faced lockdown directives, and experienced changes in their financial dependency during the pandemic (5).

Multiple studies have concluded that having experienced COVID-19 poses a high level of negative psychological sequelae; leading to depression, anxiety, and insomnia (6, 7). Fear of the unknown and having limited knowledge regarding COVID-19 additionally culminated in anxiety and distress among the public (8). A local study among healthcare workers found that frontline workers were inclined to be highly cautious toward COVID-19, and thus, were significantly predicted to have higher anxiety scores (9). Concurrently, misleading information caused confusion and increased public anxiety (10).

In addition, the extreme waves of fear of contracting COVID-19 led to prejudicial behavior and discrimination within several communities, particularly among healthcare workers involved in departments managing COVID-19 patients (11). There was also a high level of perceived stigma toward people infected with COVID-19 and their contacts (12). Stigmatization of specific ethnic groups or those living in certain high-risk locations led to delays in or dismissal of seeking medical help (13).

On the contrary, this crisis led to the development of Posttraumatic Growth (PTG). According to Tedeschi and Calhoun (14), PTG arises through a positive adaptation process, in which people cognitively reappraise their traumatic experience to generate a positive psychological change to a level beyond the pre-traumatic state (15). The five main domains of PTG are having an enhanced perception of personal strength, openness to spiritual issues, finding new possibilities in life, greater appreciation of life, and being able to relate to others.

PTG is based on the affective-cognitive processing model, whereby when a traumatic event is encountered, a person's assumptive world of self, others, and the surroundings initially shatters. This leads to emotional distress, but the individual learns to understand the meaning of the traumatic experience and successfully undergoes transformational growth, supported by the assimilation and accommodation process (16). Longitudinal studies have demonstrated that PTG does not occur immediately post-trauma but develops 6 months later (17). As such, individuals surviving a traumatic experience would struggle, sometimes for years, before being able to find meaning and move on with life (18, 19).

According to existing studies, in the presence of positive reappraisal coping as the intermediate variable, a perceived stigma can partially and indirectly affect the development of PTG (20). In another longitudinal study among HIV-positive patients, PTG was found to be predicted by an internalized stigma and other factors including rumination, perceived past resilience, positive thinking, and emotional expression (21). PTG has also been shown to have a positive effect among HIV patients moderated to receive support (22). Adopting a more positive attitude also promotes better adherence to treatment (23), hence the reduction in the rate of HIV progression (24).

Despite the high mortality rate of COVID-19 infections and the risk of those infected becoming traumatized, data on the level of PTG among COVID-19 patients are scarce. To date, the only available research exploring PTG among COVID-19 patients was conducted in China (25, 26). Furthermore, although previous studies have demonstrated that COVID-19 patients experienced stigma and psychological distress (6, 7, 12), the association between these components and PTG among COVID-19 patients is yet to be explored.

Therefore, this study aims to evaluate the level of PTG and its association with stigma, psychological complications, and sociodemographic factors among COVID-19 patients 6 months post-hospitalization. It is hypothesized that COVID-19 survivors who perceived greater stigma would be more likely to develop PTG. The study was conducted during the phase when vaccinations were not available, national lockdowns were enforced, and COVID-19 was spreading rapidly. However, at the time of writing, many countries have survived the peak of the pandemic and are transitioning toward the endemic phase. At this point, many are also more receptive to COVID-19, but we find importance in reflecting on the COVID-19 experience, especially for patients with a profile that means they are likely to develop PTG. Subsequently, the data could provide a basis for appropriate intervention in the future to enhance PTG among patients following pandemic-related trauma.

# 2. Methods

## 2.1. Study design, setting, and population

A cross-sectional study was conducted among patients with confirmed COVID-19 between 1st June 2020 and 31st August 2020. Participants were recruited after they were discharged from any of the three COVID-19 treatment centers, i.e., Hospital Canselor Tuanku Muhriz (HCTM), Hospital Sungai Buloh, and Malaysia Agro Exposition Park Serdang (MAEPS) Quarantine Center via consecutive sampling. These hospitals were among the initially designated centers for handling COVID-19 cases in Malaysia (27). The MAEPS center was selected as it was the first Low-Risk COVID-19 Integrated Quarantine and Treatment Center (PKRC) in Malaysia (28).

All accessible subjects were approached to be recruited in the study and further informed regarding the study via email, phone call, and text message. The eligibility criteria included (i) being aged 18 years old and above, (ii) having been hospitalized due to COVID-19 infection (confirmed via PCR) approximately 6 months prior, and (iii) being able to read and write in English or the Malay language. Foreigners and those who were medically and/ or mentally unstable during their hospitalization were excluded from the study. Participants were engaged by on-site researchers (doctors) during their hospitalization, who assessed the suitability and stability of the participant's general and mental health condition for inclusion in the study. All participants provided their informed consent after reading the survey information sheet in an online Google Form and were assured anonymity and data confidentiality. They were then directed to complete the self-report questionnaire, which takes around 20 min to complete.

The sample size needed for the study (130 subjects) was calculated based on the following formula: $n = Z1 - \alpha/2 \times \sigma2/\Delta2$, where n represents the total estimated sample size; $Z1 - \alpha/2$ is the desired confidence interval value, which was selected at 95%, with a critical value of 1.96; $\sigma$ is the standard deviation (SD), which was 6.5 based on a study of the prevalence of PTG in Chinese COVID-19 frontline workers (29); and $\Delta$ is precision, with a value of 0.8.

## 2.2. Measures

The questionnaire consisted of six components; (a) socio-demographic data, (b) the short form of the Posttraumatic Growth Inventory (PTGI-SF) assessing PTG, (c) the Kessler Psychological Distress Scale (K6) to assess psychological distress, (d) the General Anxiety Disorder-7 (GAD-7) to assess anxiety, (e) the Patient Health Questionnaire (PHQ-9) to identify depressive symptoms, and (f) the Explanatory Model Interview Catalog Stigma Scale (EMIC-SS) to assess perceived stigma experience. The participants were required to complete the questionnaires 6 months post-hospitalization.

## 2.3. Outcome variables

Posttraumatic growth: PTGI is an instrument used to assess the level of PTG or a positive change in a person that occurs following traumatic events. The scale consists of five factors: personal strength, spiritual change, new possibilities in life, appreciation of life, and relating to others (14). PTGI-SF is a shorter version of the original PTGI, which operates with less information (30) and consists of 10 items. The higher the PTGI-SF score, the higher the level of PTG in the individual being assessed.

A Malay version of the PTGI-SF was translated and validated in a Malaysian population. It demonstrated good internal consistency, with a Cronbach's alpha of 0.887 (31). In this study, Cronbach's alpha of the PTGI-SF Malay was 0.966. However, PTGI-SF does not have cut-off values to classify the perceived stigma level as low, moderate, or high, nor lower and upper limits.

## 2.4. Explanatory variables

i. Psychological Distress: K6 is a six-item self-rated psychological screening instrument developed by Kessler to assess psychological distress (32). A cut-off point of $\geq 5$ reflects moderate psychological distress, which may warrant mental health treatment (33). The Malay version of the K6 was validated in a Malaysian population, and it exhibited a Cronbach's alpha of 0.859 (34). In this study, the re-determined Cronbach's alpha of the Malay version was 0.696.
ii. Anxiety: GAD-7 is a seven-item questionnaire used to assess generalized anxiety symptoms (35). It is widely administered in research and clinical settings with a recommended cut-off point of $\geq 10$ as an indication of an anxiety disorder (36). This questionnaire has also been validated in the Malay language and reported a Cronbach's alpha of 0.74 (37). The Cronbach's alpha of the Malay version in this study was 0.918.
iii. Depression: PHQ-9 is a nine-item self-administered questionnaire used for screening depressive symptoms. The recommended cut-off point of $\geq 10$ indicated the presence of major depression (38). A validated and reliable Malay version of PHQ-9 is available with a reported Cronbach's alpha of 0.67 (39). In this study, Cronbach's alpha of the Malay version was 0.815.
iv. Stigma experience: The Explanatory Model Interview Catalog (EMIC) stigma scale has been extensively used to measure the degree of perceived stigma against infectious diseases worldwide. The cross-cultural adaptation of EMIC has been documented for diseases such as leprosy, tuberculosis, onchocercal skin disease, leishmaniasis, HIV/AIDS, and COVID-19. Recently, EMIC underwent adaptation and validation among Malaysian COVID-19 patients with an acceptable internal consistency (Cronbach's alpha of 0.727)

(40). Hence, the EMIC stigma scale was used to measure the perceived stigma of COVID-19 in this study.

The EMIC stigma scale is a 15-item self-rated scale originally designed to specifically measure the degree of stigma among patients with leprosy. As COVID-19 is also a disease that requires isolation, the tool is applicable to this study, whereby the higher the score, the higher the level of perceived stigma. Previous studies have demonstrated good internal consistency with a Cronbach's alpha of 0.897 and 0.88 in EMIC stigma scale items studied in Hong Kong (41) and Ghana (42), respectively. However, EMIC does not have cut-off values to classify the perceived stigma as low, moderate, or high levels and does not have lower or upper limit cut-off values.

v. Socio-demographic and personal characteristics data considered for the study include age, sex, occupation, household income, ethnicity, marital status, education status, presence of medical illness, and the presence of counseling-seeking behavior. The participants' age was recorded as a continuous variable. The answer options for sex were male and female, while the response options for occupation were employed, retired and unemployed, or student. Response options for household monthly income were categorized based on the Malaysian socioeconomic classification of <RM 5,000 (equal to <USD 1,117 based on the currency conversion rate at the time of writing), RM 5,000–RM 10,000, and >RM 10,000, which are also reflective of the bottom 40% (B40), middle 40% (M40), and top 20% (T20) household earners, respectively (43). Ethnicity response options were Malay and non-Malay and marital status options were married, single, divorced, or separated. The options for education status were primary, secondary, or tertiary education. Response options for medical illness presence and counseling-seeking behavior were either yes or no.

## 2.5. Statistical analysis

Statistical analyses were performed using the Statistical Package for Social Sciences, Version 26 (SPSS 26; SPSS Inc., Chicago, Illinois). Descriptive statistics were reported for demographic, personal, and clinical factors, as well as scores for EMIC, K6, PHQ-9, GAD-7, and PTGI-SF. The categorical variables were presented as frequencies and percentages. Continuous variables were presented as median and interquartile range, as the variables were non-normally distributed. There were no missing data. In order to achieve the main objective of the study, a multivariable general linear model with bootstrapping with 2000 replications was computed to assess the association between demographic; clinical; and EMIC, K6, PHQ-9, GAD-7 (independent variables) and PTGI-SF (dependent variable). The statistical significance was set at $p < 0.05$ for the multivariable general linear model.

## 2.6. Ethics statement

This study received approval from the Medical Research Committee of Universiti Kebangsaan Malaysia Medical Cenetr (UKM PPI/111/8/JEP-2020-352) and the Medical Research and Ethics Committee of the Ministry of Health Malaysia (NMRR-20-1,288-55,105). The study abides by the regulations of the 1964 Declaration of Helsinki and its subsequent amendments.

# 3. Results

## 3.1. Respondent characteristics

A total of 152 out of 219 COVID-19 survivors invited to participate completed the online survey, with a response rate of 69.4%. The high drop-out rate was expected as the patients were approached after they had been discharged from hospital. The sociodemographic details, clinical characteristics, and scores from the EMIC, K6, PHQ-9, GAD-7, and PTGI-SF tools are summarized in Table 1.

## 3.2. Associations between socio-demographic and clinical characteristics, perceived stigma, and psychological sequelae in COVID-19 patients 6months after discharge

Table 2 shows a multivariable general linear model (with bootstrapping of 2000 replications) between various factors and total PTG-SF scores. The factors which significantly predicted PTG include Malay ethnicity ($B = 12.767$, 95% CI = 7.541 to 17.993, $p < 0.001$), higher perceived stigma scores ($B = 0.367$, 95% CI =. 0.041 to 0.691, $p = 0.026$), retirees ($B = -12.060$, 95% CI = −21.310 to −2.811, $p = 0.011$), and those with a history of medical illness ($B = 4.971$, 95% CI = 0.096 to 9.845, $p = 0.046$). Malay participants reported a PTG score 12.767 points higher than non-Malay participants. On the contrary, retired COVID-19 patients registered PTGI-SF scores that were 12.060 points lower than employed patients. Participants with a history of medical illness reported a PTG score that was 4.971 points higher compared to those without. Finally, an increase in the perceived stigma score by 1 unit was associated with an increase of 0.367 units in the PTGI-SF score, when all the other independent variables (demographics, clinical variables, PHQ-9, GAD-7, K6 scores) were held constant.

# 4. Discussion

This study investigates the level of PTG and its associations with stigma, psychological complications, and sociodemographic factors among COVID-19 patients 6 months after discharge. The study was conducted after the Malaysian government's decision to lift the Movement Control Order. The study findings confirm the hypothesis that a higher perceived stigma score significantly predicts PTG. In addition, those of Malay ethnicity with a history of medical illness were also significantly associated with higher PTG, but retirees were associated with lesser PTG. No significant associations were found between psychological complications (i.e., anxiety, depression, psychological distress) and PTG.

Relative to other populations measured using the same instrument (the PTGI-SF), the degree of reported PTG in this study was comparable. For example, the median PTG reported in this study was 40.0, while the median PTG reported in a study of Malaysian cancer patients was between 30.0 and 37.5 (44). Moreover, another two

TABLE 1 Sociodemographic and clinical characteristics of participants.

| Variables | N | % |
|---|---|---|
| Age | 34.0[#] | 19.0[$] |
| Sex: | | |
| Female | 54 | 35.5 |
| Male | 98 | 64.5 |
| Ethnicity: | | |
| Malay | 125 | 82.2 |
| Non-Malay | 27 | 17.8 |
| Employment status: | | |
| Retired | 10 | 6.6 |
| Unemployed/housewife/ | | |
| students | 27 | 17.8 |
| Employed | 115 | 75.6 |
| Monthly household | | |
| income: | | |
| B40 (<RM 5,000) | 95 | 62.5 |
| M40 (RM 5000—RM 10,000) | 43 | 28.3 |
| T20 (>RM 10,000) | 14 | 9.2 |
| Marital status: | | |
| Married | 83 | 54.6 |
| Single/divorced/separated | 69 | 45.4 |
| Education status: | | |
| Primary education | 8 | 5.3 |
| Secondary education | 50 | 32.9 |
| Tertiary education | 94 | 61.8 |
| History of psychiatric illness: | | |
| No | 146 | 96.1 |
| Yes | 6 | 3.9 |
| History of medical illness: | | |
| No | 113 | 74.3 |
| Yes | 39 | 25.7 |
| Counseling-seeking behavior: | | |
| No | 86 | 56.6 |
| Yes | 66 | 43.4 |
| Median total EMIC score | 5.5[#] | 8.0[$] |
| Median total K6 score | 10.0[#] | 50.0[$] |
| Median total PTGI-SF score | 40.0[#] | 16.0[$] |
| Depression status of participants | | |
| No | 139 | 91.4 |
| Yes | 13 | 8.6 |
| Median total PHQ-9 score | 2.0[#] | 4.0[$] |
| Anxiety status of participants | | |
| No | 147 | 96.7 |
| Yes | 5 | 3.3 |
| Median total GAD-7 score | 0.5[#] | 5.0[$] |

# = median, $ = interquartile range.

studies on PTG in Malaysian subjects also reported similar degrees of PTG, with the mean ranging from 39.3 to 39.87 (16, 40). While the nature of the trauma in this study was infection as opposed to malignancy, as in the other studies, it is notable that the degrees of PTG across these studies were comparable, further supporting the role of COVID-19 as a traumatic stressor.

This study demonstrates that perceived stigma is associated with higher PTG. Another study in China on COVID-19 survivors 6 months post-discharge also revealed self-stigma as one of the factors positively associated with PTG, in addition to social support and mental health care access during hospitalization (45). As COVID-19 survivors are present globally, stigma has become an additional issue to deal with among communities. Due to stigma, COVID-19 survivors reported being stalked, avoided, and even abandoned by family members (46). Being stigmatized is also a negative experience that may lead to psychological trauma, but it is also probable that affected individuals would eventually engage in a positive adaptation process via cognitive re-appraisal of a traumatic experience. This proactive response would then enhance the development of PTG (15).

An important finding indicates that although negative psychosocial sequelae, such as perceived stigma, contribute to higher PTG, it does not imply that the perceived stigma among COVID-19 survivors should be left unmanaged. This is given the evidenced curvilinear across-time relationship between PTSD and PTG, whereby the increasing degree of trauma initially contributes to increasing PTG, but after a certain level, this effect changes. A further increase in trauma beyond the threshold causes an overwhelming degree of psychological sequelae to occur and may depreciate PTG as they may interfere with the search for meaning outside the traumatic experience (47, 48). A similar occurrence has been demonstrated in a study involving survivors of an earthquake in China, whereby survivors who had experienced moderate levels of disaster exposure had the highest PTG scores, but having higher or lower exposure led to a reduction in PTG scores (49).

As an overwhelming degree of trauma may hinder positive psychological sequelae, close monitoring of the level of stigma experienced is important. They need to be monitored closely to ensure they fall within the mild and moderate levels that may promote PTG. Highly intense trauma leads to failure in the cognitive reprocessing of an event and disrupts the search for new perspectives and the narrative development required in the process of developing PTG (50). Moreover, a recent longitudinal study demonstrated that PTG was associated with COVID-19 patients receiving psychological consultation after discharge (51).

This study also found that Malays had a higher PTG level. As all Malays in Malaysia are Muslims (52), the positive development of PTG among them might be explained by the concept of spiritual coping. Spiritual coping is based on religious beliefs, practices, and teachings (Abu-Raiya and Pargament, 2015 (53). A constructive feeling may be developed when an individual is able to find a sense of spiritual connection. The connection occurs by reflecting on a secure relationship with God to achieve five basic goals, namely meaning, control, comfort, intimacy, and life transformation (54). Empirical studies have demonstrated that spirituality is fundamental in the meaning-making framework, especially following traumatic events that have shattered initial assumptions about oneself and the world, fostering the search for new meaning in life (55). Eventually, a new assumptive world is developed, and this better state helps promote better PTG (56). In another study conducted among

TABLE 2 The association between individual socio-demographic and clinical characteristics, EMIC, PHQ-9, GAD-7, K6 scores, and total PTGI-SF among COVID-19 patients 6months post-hospitalization.

| Variables | *B* | BCa 95% confidence interval | | Standard error | Value of *p* |
|---|---|---|---|---|---|
| | | Lower | Upper | | |
| Age | 0.002 | −0.234 | 0.239 | 0.121 | 0.985 |
| Sex: | | | | | |
| Male | Reference | 1.224 | 7.121 | 1.224 | 0.166 |
| Female | 2.949 | | | | |
| Ethnicity: | | | | | |
| Non-Malay | Reference | 7.541 | 17.993 | 2.667 | <0.001* |
| Malay | 12.767 | | | | |
| Employment status: | | | | | |
| Employed | Reference | −21.310 | −2.811 | 4.719 | 0.011* |
| Retired | −12.060 | −4.738 | 5.748 | 2.675 | 0.850 |
| Unemployed/housewife/ | 0.505 | | | | |
| students | | | | | |
| Monthly household | | | | | |
| income: | | | | | |
| >RM 10,000 | Reference | −4.602 | 10.700 | 3.904 | 0.435 |
| <RM 5,000 | 3.049 | −6.445 | 8.553 | 3.826 | 0.783 |
| RM 5,000—RM 10,000 | 1.054 | | | | |
| Marital status: | | | | | |
| Married | Reference | −6.784 | 3.076 | 2.515 | 0.461 |
| Single/divorced/separated | −1.854 | | | | |
| Education status: | | | | | |
| Tertiary education | Reference | −14.426 | 3.700 | 4.624 | 0.246 |
| Primary education | −5.363 | −4.911 | 4.119 | 2.304 | 0.863 |
| Secondary education | −0.396 | | | | |
| History of psychiatric | | | | | |
| illness: | | | | | |
| No | Reference | −8.661 | 11.068 | 5.033 | 0.811 |
| Yes | 1.203 | | | | |
| History of medical illness: | | | | | |
| No | Reference | 0.096 | 9.845 | 2.487 | 0.046* |
| Yes | 4.971 | | | | |
| Counseling-seeking behavior: | | | | | |
| No | Reference | −0.469 | 7.572 | 2.051 | 0.083 |
| Yes | 3.552 | | | | |
| Total PHQ-9 score | −0.536 | −1.391 | 0.320 | 0.436 | 0.220 |
| Total GAD-7 score | −0.347 | −1.441 | 0.746 | 0.558 | 0.533 |
| Total K-6 score | 0.440 | −0.326 | 1.206 | 0.391 | 0.260 |
| Total EMIC score | 0.367 | 0.043 | 0.691 | 0.165 | 0.026* |

*Statistical significance at $p < 0.05$.

Indonesian tsunami survivors, positive spiritual coping among Muslim survivors predicted PTG (57).

As PTG is shown to arise from highly stressful situations (58), retired participants demonstrated lower PTG scores, which suggests that retirees lacked work stress. It was also probable that employed participants were distracted by daily meaningful and challenging activities that kept them occupied. These activities assisted them in living through difficult circumstances. In Malaysia, the retirement age is 60 (59); hence, nearly all the retired participants were from the elderly age group. Additionally, participants of older age were more 'accepting' of the stressful condition as a natural occurrence in life compared to the younger respondents; hence, the younger group demonstrated a reduced likelihood of developing PTG (60).

In addition, we discovered that participants with co-morbid medical illnesses had higher PTG scores compared to those without a history of medical illness. A previous study reported that the diagnosis of a life-threatening illness can be perceived as an extremely stressful and traumatic experience, but many survivors also reported experiencing various positive changes, referred to in empirical literature as PTG (61).

The current study did not find a significant association between the level of anxiety, depression, and psychological distress and PTG. It is concluded that PTG is a unique positive psychology, which may co-exist with other psychological conditions such as depression and anxiety. Previous prospective studies on PTG have also drawn similar conclusions (62, 63).

### 4.1. Limitations

A few limitations are outlined in this study. Firstly, the cross-sectional approach does not allow the determination of a causal relationship between the variables explored and PTG over time. Secondly, the respondents were not randomly sampled, which limited the complete representation of COVID-19 patients, thus restricting the generalization of the outcome. Thirdly, although sufficient according to the sample size calculation, the number of participants was relatively small. In addition, the lack of data on the clinical stages of COVID-19 was a confounding factor in this study.

### 4.2. Implications of study findings

This study was the first in Malaysia to explore PTG among COVID-19 patients. The data suggest that spiritual coping is potentially an appropriate psychosocial intervention that facilitated COVID-19 survivors to deal with traumatizing experiences. Spiritual coping led to a better spiritual connection with God, and this helped patients to positively live or move on after trauma. Based on the community data, it is also recommended that retirees be more involved in daily activities, as this may enhance their PTG level and improve their mental well-being.

Based on the data collected and understanding of limitations, a longitudinal version of the study is proposed to better elucidate variables that have a causal impact on PTG. The inclusion of a relationship analysis between the development of PTG and the extent of perceived stigma experienced by COVID-19 survivors would have added value to the study.

## 5. Conclusion

In conclusion, experiencing stigma contributed to the PTG of COVID-19 survivors in addition to other sociocultural factors that are influenced by ethnicity, history of medical illness, religion, and work status. No associations were found between PTG and depression and anxiety. The findings provided valuable insights and understanding of the predictors of PTG that may suggest incorporating various psychologically beneficial interventions to improve the well-being of COVID-19 survivors.

## Data availability statement

The original contributions presented in the study are included in the article/Supplementary material, further inquiries can be directed to the corresponding author.

## Ethics statement

The studies involving human participants were reviewed and approved by Medical Research Committee of Universiti Kebangsaan Malaysia Medical Center (UKM PPI/111/8/JEP-2020-352) and the Medical Research and Ethics Committee of the Ministry of Health Malaysia (NMRR-20-1,288-55,105). The patients/participants provided their written informed consent to participate in this study.

## Author contributions

All persons who meet authorship criteria are listed as authors, and all authors certify that they have participated sufficiently in the work to take public responsibility for the content, including participation in the concept, design, analysis, writing, or revision of the manuscript. Furthermore, each author certifies that this material or similar material has not been and will not be submitted to or published in any other publication before its appearance in the Frontiers. NA: acquisition of data, analysis and/or interpretation of data, drafting the manuscript. NN: conception and design of the study, revising the manuscript critically for important intellectual content. ML: analysis and/or interpretation of data, revising the manuscript critically for important intellectual content. NM: conception and design of the study. NA: acquisition of data. MA: acquisition of data. SD: acquisition of data. All authors contributed to the article and approved the submitted version.

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## Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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# Beyond physical health: the role of psychosocial challenges and stigma in tackling the COVID-19 pandemic—A scoping review

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**Background:** The socio-cultural response to the Coronavirus Disease 2019 (COVID-19) and the level of adherence to evidence-based guidelines played a crucial role in determining the morbidity and mortality outcomes during the pandemic. This review aims to evaluate the impact of stigma and psycho-socio-cultural challenges on efforts to control the COVID-19 pandemic and to identify ways to mitigate such challenges in future pandemics.

**Methods:** Using keywords including COVID-19, coronavirus, stigma, psychosocial challenges, and others, the authors searched seven major databases with a time limitation of July 2021, which yielded 2,038 results. Out of these, 15 papers were included in this review.

**Results:** The findings of the review indicated that several psychosocial, socio-economic, and ethno-cultural factors are linked to the transmission and control of COVID-19. The research revealed that stigma and related psychosocial challenges and others, such as anxiety, fear, and stigma-driven social isolation, have resulted in significant mental health problems.

**Discussion:** The review underscores the negative impact of stigma on COVID-19 patients, survivors, and the general population. Addressing stigma and psychosocial challenges is crucial to effectively manage the current pandemic and to prevent similar challenges during future public health crises.

KEYWORDS

**COVID-19, pandemic, psychocultural, psychosocial, stigma, mental health, conspiracy, infodemic**

# 1. Introduction

The COVID-19 pandemic has triggered varying responses from cultures and nations across the world. The emergence of the novel SARS-CoV-2 virus led to the dissemination of information through various media channels in an effort to control its spread. However, the promotion of awareness was accompanied by a significant amount of false or misleading information related to COVID-19, which spread rapidly and had a negative impact on our ability to effectively manage the pandemic. This phenomenon, referred to as an "infodemic" (1), contributed to the development of stigma. Stigma, defined as an attribute that links a person to an undesirable stereotype (2), results in social labeling that hinders full acceptance by society and leads to discrimination, elevated individual stress, and healthcare disparities (2). The instinctual fear response to stigma can foster biases and discriminatory behaviors, particularly when coupled with a lack of knowledge. Despite efforts to mitigate its spread, false and unscientific information about COVID-19 and conspiracy theories continue to persist on the internet (2). The COVID-19 pandemic has led to the dissemination of false information and conspiracy theories through various media channels, which has contributed to stigma associated with the disease. The false information and conspiracy theories, such as the belief that 5G technology is responsible for the spread of COVID-19 (3), have spread quickly and led to significant healthcare disparities (4, 5). A survey conducted in 2020 found that 36% of individuals believed that the pandemic was planned when told so as part of the experiment (5). These conspiracy theories not only contribute to the spread of the virus but also cause significant stigma. To flatten the curve of positive cases and deaths from SARS-CoV-2, governments across the world implemented various isolating measures such as stay-at-home orders, social distancing, quarantining potentially infected individuals, face coverings, shutting down non-essential businesses and social ceremonies at varying levels of strictness. However, the strength of a culture's response to an outbreak and willingness of the people to comply with the public health officials played a significant role in morbidity and mortality outcomes (6). Despite national and global health leaders' insistence on these isolating measures, psychosocial cultural phenomena—stigma, conspiracy theories, individualism, and political agenda—remained obstacles to the containment of COVID-19. Disregarding the nuances of these obstacles and letting science hold complete sway could alienate the cultures and the people. This may compound barriers to managing the pandemic.

Ultimately, the healthiest horizon for all requires a compromise between the medical and the psychosocial-cultural sectors (7). Insufficient knowledge and awareness about the transmission, treatment, and prevention of SARS-CoV-2 can contribute to increased stigma in communities. To mitigate the impact of stigma, effective strategies can be implemented through social media to reduce fear and provide accurate and timely information about the high-risk groups, preventive measures, and treatment modalities. This scoping review aims to analyze the issues related to stigma and psychosocial challenges that have emerged during the COVID-19 pandemic, and to provide recommendations for authorities and healthcare professionals to address them in preparation for future pandemics.

# 2. Materials and methods

A literature search was performed following PRISMA guidelines using the following databases/registers: PubMed, Embase, Litcovid, bioRxiv, medRxiv, Web of Science, and PsychINFO, from January 2020 to July 2021. Gray literature was searched through a web search and Google Scholar. We used combinations of the following keywords applying BOOLEAN logic (AND/OR): "COVID-19, coronavirus, SARS-CoV-2", "COVID- 19 pandemic" "Covid" AND "Stigma" OR "psychosocial challenges" OR "mental health" OR "cultural issues" OR "cultural challenges" OR "stigma" OR "mental health access". The initial search was performed by authors RA and SB through these databases, which generated 2,038 reports. After excluding all duplicates and completely off-topic titles, 549 citations were left. We screened records for inclusion criteria and excluded 342 papers. The remaining 207 publications were manually screened by three authors (SS, HB, VS), any disagreements were mediated by the first author (SA). Studies were removed if they were commentaries, case reports, case series, opinions, workshops, unpublished data, and reviews. A total of 192 papers did not fit the inclusion criteria, resulting in 15 full-text articles that met the inclusion criteria (**Figure 1**). The included 15 studies are summarized in **Table 1**.

# 3. Results

## 3.1. General population

Studies on stigma and COVID-19 have revealed that it affects not only the COVID-19 patients and survivors, but the general population as well. Stigma resulted in delayed health-seeking behavior and preventive efforts (8), with studies identifying anticipated stigma and stereotypes as barriers to COVID-19 testing (9). Herawati et al. (10) conducted a cross-sectional study with a total sample size of 451 respondents consisting of students in the field of health studies and religious studies in West Java, Indonesia. Data was collected using an online questionnaire, which consisted of variables of anxiety, stigma, economic conditions, religiosity, and prevention of COVID-19. The results showed that the most significant influential variable on COVID-19 preventive efforts was the stigma with an Odds Ratio (OR) of 2.256, that is, individuals who experienced high stigma had twice the risk of making a low preventive effort compared to individuals who experienced a low stigma. This study also observed that due to COVID-19, 62% of respondents reported a decrease in income. However, no relationship was seen between levels of religiosity and COVID-19 preventive efforts (10). Another study surveyed 157 German participants regarding their intention to comply with government issued behavioral recommendations. They found that young males were most likely to display low compliance, stressing the need for selective health promotion efforts. They also observed that public stigma had a positive association with compliance (11).

Certain variables are associated with a greater likelihood of one developing a stigma toward COVID-19, including lack of knowledge about the disease, self-employment, financial constraints, and pre-existing depression (9, 12). A cross-sectional survey by Jiang et al. (4) conducted in 31 provinces in China

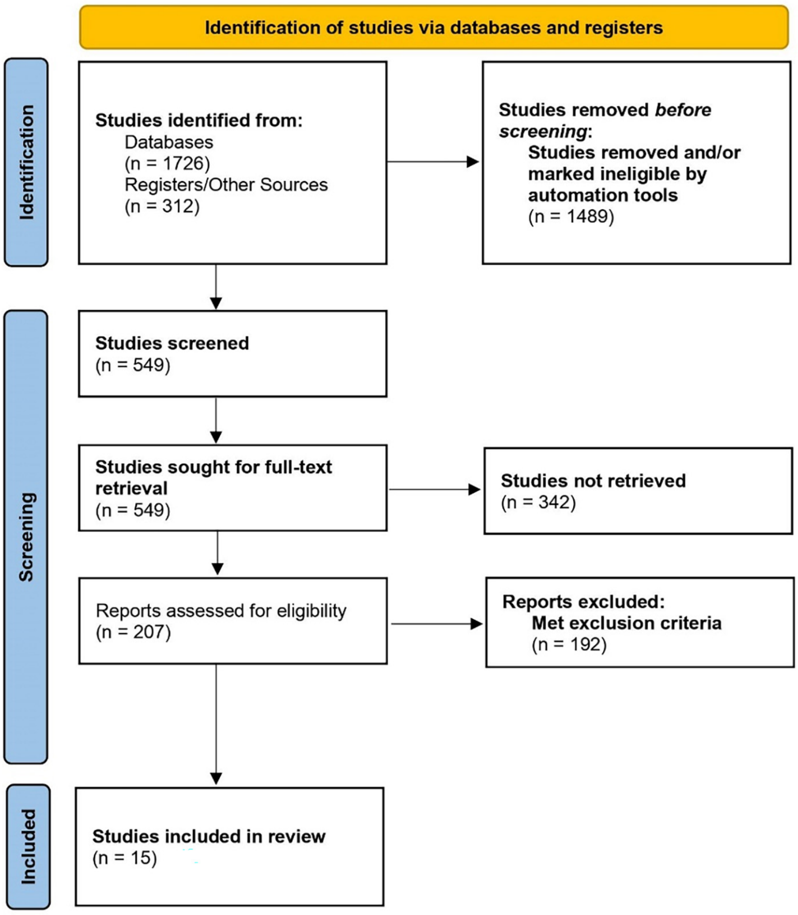

FIGURE 1
PRISMA flow diagram.

covering 5,039 respondents identified various factors related to COVID-19 stigma. This study indicated that participants over the age of 40, who were ethnic minorities and who felt it was difficult to find and understand information were more likely to stigmatize COVID-19 patients (4).

Apart from stigma, COVID-19 transmission led to significant economic, political, social, legal, and cultural challenges. Multiple studies have verified that COVID-19-related lockdown strategies have increased unemployment, leading to poverty, hunger, and restricted access to healthcare (13). This widespread economic instability has led to psycho-social and socioeconomic insecurity (14).

Zakar et al. (15) conducted a qualitative study based on 34 telephone or online in-depth interviews with participants from diverse age groups in the Punjab province of Pakistan. A semi-structured interview guide was used for data analysis, which included questions regarding problems the study participants experienced to observe public health measures in their households, in their neighborhoods, and social spaces. Probing questions were added to ask about social and cultural factors and challenges they faced in implementing COVID-19 protective measures. The study showed that apart from people's poor understanding of the virus and the need for containment measures, false and misleading information about the coronavirus has significant consequences on containing the virus. This study also shed some light on religious practices or beliefs as another obstacle in flattening the COVID-19 curve. This has been observed in developing countries and several African communities (15).

## 3.2. COVID-19 patients and survivors

There are various types of stigma that COVID-19 patients and survivors have to deal with. Social rejection and labeling were among the most notable domains of stigma experienced by these people (16). Lohiniva et al., indicated that respondents did not feel a sense of closure after their isolation and quarantine had ended because of perceived stigma, self-stigma, and worry that they could still infect people around them (8). In addition to this; perceived external stigma, internalized stigma, disclosure stigma, and financial insecurity were commonly reported by the COVID-19 affected population. Yuan et al., conducted a cross-sectional study comprising 154 COVID-19 survivors and 194 healthy controls. COVID-19-related stigma were measured by the Social Impact Scale (SIS) and stigma differences between the two groups were compared. The study results found that COVID-19 survivors experience significantly more overall stigma and heightened stigma in domains of social rejection, financial

TABLE 1 Summary of included references reporting stigma and psychosocial challenges of COVID-19.

| No. | References | Country | Study design | Title of the study | Sample size | Objectives | Results |
|---|---|---|---|---|---|---|---|
| 1 | Herawati et al. (10) | Indonesia | Cross-sectional | Stigma, anxiety, and religiosity on COVID-19 preventative measures | 451 | To determine the effect of stigma, level of anxiety, level of religiosity, and economic condition on COVID-19 preventive efforts among college students | 1. Most dominant influential variable on COVID-19 preventive efforts was *stigma* with OR of 2.256. ($p = 0.000$); 2. *Level of religiosity* had no association with COVID-19 preventive measures ($p = 0.174$); 3. Apart from stigma, *anxiety* ($p = 0.013$) and *economic condition* (0.031) also had significant impact on preventive measures |
| 2 | Ugidos et al. (40) | Spain | Longitudinal | Evolution of intersectional perceived discrimination and internalized stigma during COVID-19 lockdown among the general population in Spain | 1st survey: 3,489; 2nd survey: 1,041; 3rd survey: 568 | To analyze, longitudinally, the evolution of intersectional perceived discrimination and internalized stigma among the general population of Spain, at three points in time throughout the confinement. | 1. From the first to the second evaluation, results show a significant increase in intersectional discrimination and internalized *stigma* ($p < 0.001$); 2. The trends found show that *discrimination and internalized stigma* increase with the evolution of the crisis, decrease with the beginning of recovery and return to normal, although without returning to previous levels |
| 3 | Shokri et al. (41) | Iran | Cross sectional | Stigma and COVID-19 in Iran: A rapid assessment | 1,000 | To investigate the perceived stigma among Iranians following the COVID-19 pandemic | 1. Entirely, 99% of people predicted at least one *stigma-endorsing response* and the mean perceived stigma related COVID-19 was 5.50 (IQR: 3.75–6.87) of 10-point scale; 2. The mean stigma sub-scores were highest for perceived external stigma 6.73 (IQR: 5–8.75) followed by *disclosure stigma* 4.95 (IQR: 0–10); 3. Self-employers were more concerned about *disclosing their illness* than those with governmental jobs (2563.93 vs. 4.3164.14, $P < 0.05$), and also had an *overall higher stigma score*; 5.72 vs. 5.19, $P < 0.05$ |
| 4 | Amir (16) | Uganda | Cross-sectional exploratory | COVID-19 and its related stigma: A qualitative study among survivors in Kampala, Uganda. | 30 (COVID-19 Survivors) | To explore COVID-19 related stigma among survivors in Kampala, Uganda using in depth interviews | The results revealed that a common form of stigma among survivors was *social rejection* followed by *labeling* |
| 5 | Miconi et al. (17) | Canada | Cross-sectional | Ethno-cultural disparities in mental health during the COVID-19 pandemic: a cross-sectional study on the impact of exposure to the virus and COVID-19-related discrimination and stigma on mental health across ethno-cultural groups in Quebec (Canada) | 3,273 | To investigate the association of exposure to the virus, COVID-19-related discrimination and stigma with mental health during the COVID-19 pandemic, in a culturally diverse sample of adults in Quebec (Canada). | 1. *Exposure* to the virus, COVID-19-related *discrimination*, and *stigma* were associated with poorer mental health; 2. Mental health varied significantly based on *socioeconomic status* and *ethno-cultural group*, with those with *lower incomes* and Arab participants reporting higher *psychological distress*; 3. Associations with mental health varied across ethno-cultural groups, with exposed and discriminated Black participants reporting higher *mental distress* |
| 6 | Yuan et al. (12) | China | Case-control | COVID-19-related stigma and its sociodemographic correlates: a comparative study | 154 COVID survivors and 194 healthy controls | To compare differences in stigma experiences of COVID-19 survivors vs. healthy controls after the COVID-19 outbreak peak in China | 1. Compared with healthy controls, COVID-19 survivors reported more overall *stigma* ($p < 0.001$), and stigma in domains of *social rejection* ($p < 0.001$), *financial insecurity* ($p < 0.001$), *internalized shame* ($p < 0.001$), and *social isolation* ($p < 0.001$); 2. *Status* as a COVID-19 survivor, having family members infected with COVID-19, being married, *economic* loss during the COVID-19 pandemic, and *depressive symptoms* were positively associated with higher overall stigma levels (all $p$ values $< 0.05$). |

*(Continued)*

TABLE 1 (Continued)

| No. | References | Country | Study design | Title of the study | Sample size | Objectives | Results |
|---|---|---|---|---|---|---|---|
| 7 | Lohiniva et al. (8) | Finland | Cross sectional based on one to one interviews | Learning about COVID-19-related stigma, quarantine and isolation experiences in Finland | 64 | To review the forms, drivers, outcomes, and impact of social stigma toward those with corona virus and COVID-19 and their family members, and to shed light on their quarantine experience | 1. Respondents did not feel a *sense of closure* after their isolation and quarantine had ended because of perceived *stigma and self-stigma*, and worry that they could still infect people around them; 2. Stigma resulted in *delayed health seeking behavior* among symptomatic patients including testing which can speed the transmission of the virus rapidly; 3. Health officials left out a number of important audiences in communications about the virus: (i) those who cared for sick (caretakers) for critical information and opportunities to discuss and get advice, (ii) children and teenagers did not have a specific channel to communicate with health officials to gain information or share fears and concerns, (iii) asymptomatic household members or those who tested negative received less attention although they seemed to have equally pressing uncertainties |
| 8 | Tomczyk et al. (11) | Germany | Online survey | Social distancing and stigma: association between compliance with behavioral recommendations, risk perception, and stigmatizing attitudes during the COVID-19 outbreak | 157 | To examine patterns of intentions to comply with behavioral recommendations to contain the COVID-19 pandemic in the German population *via* latent class analysis.; tonspect the role of stigma in non-compliance while considering sociodemographic differences, risk perception, and knowledge of adaptive behaviors; to explore intercultural similarities and differences of compliance by focusing on the German population, whereas previous research mostly focused on Asian populations | It discussed the positive association between public stigma and compliance. Compared to high compliance, low compliance was associated with male gender, young age and lower public stigma. |
| 9 | Jiang et al. (4) | China | Cross sectional | COVID-19-related stigma and its' influencing factors: a rapid nationwide study in China | 5,039 | (1) To evaluate the prevalence of stigma during the COVID-19 outbreak in China (2) To assess the association of stigma, health literacy, and sociodemographic characteristics during the COVID-19 epidemic. | 1. People aged over 40, lived in areas with severe epidemics (aOR = 2.15, 95% CI [1.12–4.13]), and who felt it difficult to find and understand information about COVID-19 (aOR = 1.91, 95% CI [1.08–3.27]; aOR = 1.88, 95% CI [1.08–3.29]) were more likely to *stigmatize* COVID-19 patients; 2. People who were male, aged 41–50, and had *difficulty understanding* information (aOR = 2.08, 95% CI [1.17–3.69]) were more likely to stigmatize people from Wuhan |
| 10 | Mahmoudi et al. (19) | Iran | Cross-sectional | A mediating role for mental health in associations between COVID-19-related self-stigma, PTSD, quality of life, and insomnia among patients recovered from COVID-19 | 844 (recovered) | To investigate whether poor mental health may mediate concerns related to infection with COVID-19 (i.e., self- stigma and PTSD) and outcomes such as poor sleep and HRQoL in people having recently recovered from COVID-19 | 1. *Insomnia, PTSD, and COVID-19-related self-stigma* displayed significant direct associations ($r = 0.334–0.454$; $p < 0.01$); 2. Mental health may mediate effects of COVID-19-related *self-stigma and PTSD on quality of life and insomnia* |
| 11 | Earnshaw et al. (9) | USA | Online survey | Anticipated stigma, stereotypes, and COVID-19 testing. | 845 | To explore whether anticipated stigma and stereotypes are associated with likelihood of COVID-19 testing. Knowledge and fear of COVID-19 were included as control variables in analyses | 1. Participants who anticipated greater COVID-19 stigma and endorsed COVID-19 stereotypes to a greater degree reported that they would be *less likely to seek a COVID-19 test* ($p < 0.001$); 2. Participants with *greater COVID-19 knowledge and fear* reported that they would be more likely to seek a COVID-19 test. Participant *sociodemographic variables* were not associated with reported likelihood of testing. The adjusted $R^2$ for the model was 0.26 (SE 0.80, $p < 0.001$) |

*(Continued)*

TABLE 1 (Continued)

| No. | References | Country | Study design | Title of the study | Sample size | Objectives | Results |
|---|---|---|---|---|---|---|---|
| 12 | Kang et al. (18) | Korea | Retrospective analysis of medical records | The psychological burden of COVID-19 stigma: evaluation of the mental health of isolated mild condition COVID-19 patients | 107 | To assess the mental health issues (anxiety, depression, PTSD, and somatic symptoms) of the mild condition coronavirus disease 2019 (COVID-19) patients admitted to a community treatment center (CTC) in Korea; to examine the relationship of COVID-19 stigma with psychiatric conditions | 1. For *depression and anxiety*, previous psychiatric history and stigma of COVID-19 infection were significant risk factors; 2. For *PTSD, previous psychiatric history and stigma of COVID-19 infection as well as total duration of isolation* were found to be significant risk factors |
| 13 | Singh et al. (13) | India | Telephonic survey | Health, psychosocial, and economic impacts of the COVID-19 pandemic on people with chronic conditions in India: a mixed methods study | 2,335 | To assess the health, psychosocial and economic impacts of the COVID-19 pandemic on people with chronic conditions in India | During the COVID-19 lockdowns in India, 83% of participants reported difficulty in *accessing healthcare*, 17% faced difficulties in *accessing medicines*, 59% reported *loss of income*, 38% *lost jobs*, and 28% *reduced fruit and vegetable consumption* |
| 14 | Bodrud-Doza et al. (14) | Bangladesh | Perception based online questionnaire | Psychosocial and socio-economic crisis in Bangladesh due to COVID-19 pandemic: a perception-based assessment | 1,066 | To analyze the psychosocial, socio-economic, and possible environmental crisis based on public perception in Bangladesh due to the COVID-19 outbreak | 1. There was a negative association between the fragile health system of Bangladesh and the government's ability to deal with the pandemic ($p < 0.05$), revealing the *poor governance in the healthcare system*; 2. A positive association of shutdown and social distancing with the fear of losing one's own or a family members' life, influenced by a *lack of healthcare treatment* ($p < 0.05$), reveals that, due to the decision of shutting down normal activities, people may be experiencing mental and economic stress; 3. Positive association of the *socio-economic impact* of the shutdown with poor people's suffering, the price hike of basic essentials, the hindering of formal education ($p < 0.05$), and the possibility of a severe socio-economic and health crisis being aggravated |
| 15 | Zakar et al. (15) | Pakistan | Cross-sectional | Socio-cultural challenges in the implementation of COVID-19 public health measures: Results from a qualitative study in Punjab, Pakistan | 34 | To explore the social and behavioral response to COVID-19 and unveils challenges in the implementation of related public health measures in Pakistan | Lockdown strategy impacting *income* of the population. Adherence to social distancing measures dependent on living conditions. *Misleading information* on COVID-19 |

insecurity, internalized shame, and social isolation compared with healthy controls. Another interesting finding of the study was that married people reported higher levels of stigma than those who were unmarried, which is consistent with earlier reports (12).

The magnitude of the impact of the pandemic was also influenced by the socio-economic and ethnocultural differences among the population. Miconi et al., performed an online survey to investigate the association of sociocultural characteristics and pandemic-specific risk factors (i.e., exposure to the virus, COVID-19-related discrimination, and stigma) with mental health during the COVID-19 pandemic in a culturally diverse sample of 3,273 adults in Quebec (Canada). The results showed that socioeconomic status (in terms of income and household size) and race/ethnicity were both associated with mental health, beyond the contributions of prior mental health, experiences of discrimination not related to COVID-19, and other sociodemographic variables. In comparison to other sociocultural groups, Black participants reported the worst mental health results when exposed to the virus and/or COVID-19-related discrimination (17).

Fear and stigma that accompany the pandemic have adversely affected the mental health of this subgroup in particular (12, 17). Literature on psychological consequences of stigma on this population reported that higher levels of depression, anxiety, insomnia, and Post Traumatic Stress Disorder (PTSD) were attributed to being the victim of stigma (18). Studies demonstrated that being subjected to stigma also had a detrimental effect on the quality of life of the patients (19).

## 3.3. Others

There were special subgroups of the population that have been overlooked during the pandemic and need special attention to alleviate their fears and concerns. Firstly, the caretakers who are ill informed and overly burdened required additional guidance and support. Secondly, children and teenagers were easy targets of stigma, as they do not have adequate opportunities to discuss their apprehension and gain correct information. Thirdly, when compared to those who tested positive, asymptomatic family members or those who tested negative received less care, while having equally significant concerns (8).

## 3.4. Quality appraisal of included studies

Despite the varying objectives and methodologies of the reviewed studies, four aspects merit being discussed to better inform future investigations of stigma and COVID-19. The four aspects were (1) measurement tools, (2) sample selection, (3) use of online platforms, and (4) design of qualitative studies. First, regarding the measurement tools, investigators have used stigma-related questionnaires originally developed for PTSD, AIDS, Ebola, mental health, or general health and Quality-of-Life questionnaires. Although several adaptations and pre-testing have been performed, we should caution that several aspects of the questionnaires might not be appropriate in the context of COVID-19. For example, the behaviors related to the disease transmissions were different for AIDS and COVID-19 (unprotected intercourse vs. not wearing a mask), and the barriers related to their protection efforts are different as well (buying condoms vs. masks). The use of MERS questionnaire by Kang et al. (18) might be more appropriate, given the relative similarity of transmission methods between MERS and SARS-CoV-2 viruses. Ideally, however, we should start developing tools that specifically explore COVID-19-related stigma.

Second, regarding sample selection, in all of the studies reviewed, investigators provided reasonable rationales and criteria for sample selection based on the objectives of the studies. However, we noted one inconsistency in the Herawati et al.'s (10) study, where age above 30 years was an exclusion criterion, but the range of participants was reported as 17–49 years without any explanation (we have sought further clarification from the authors). Despite the small number of participants in the case where consecutive sampling was performed (particularly for qualitative studies), the stopping criteria used were data saturation which we deemed as appropriate considering the objectives.

Third, given the COVID-19 restrictions on face-to-face surveys and interviews, several studies have relied on the use of online survey platforms. However, we found that except for Earnshaw et al. (9) most studies reported insufficient details on the timely completion of the surveys, data quality checks, and duplicate entry prevention measures. These were recommended measures to be taken to minimize bias in online surveys. For example, IP address checks (Internet Protocol address—the label connected to a computer network that uses the Internet) would deter multiple surveys completed by a single person motivated by financial rewards given by the completion of each survey. Similarly, utilizing a platform where durations of surveys were recorded would enable researchers to exclude surveys completed in an unreasonably short time (by automated software's like Chat GPT or copied and pasted) to weed out bad data submitted.

Fourth, for the studies that have qualitative components in them, we found that the themes or ideas presented by the authors were well-supported by actual quotes from the participants. However, we did not find a study where participants provide corrections on the transcriptions and feedback on the findings. These two important aspects were in line with the consolidated criteria for reporting qualitative studies (COREQ) recommendations by Tong et al. (20), to ensure that the themes reported were in line with what the participants' thoughts were. We hope that these steps were performed in future investigations.

We also analyzed the studies with some more merits to check the quality. All the included studies have well-defined research questions and objectives. Almost 50% (7) of the included studies have specified and defined the study population. One study (12) reported that the participation rate of eligible participants was at least 50%, others did not report. The studies (8–11, 13, 14) had included the participants from the same population during the defined period with prespecified inclusion and exclusion criteria, uniformly applied to all eligible participants. Only one study (16) reported justification of sample size, power description/variance, and effect estimates.

# 4. Discussion

This paper aimed to examine the psychosocial and cultural issues associated with the COVID-19 pandemic. We attempted to include as many studies as possible that examined stigma,

TABLE 2 Quality assessment, sample selection, measurement scales, analysis, and interpretation of findings.

| Identifiers and quality assessment | | | Sample selection | | Measurements and analysis | | Results and discussion | |
|---|---|---|---|---|---|---|---|---|
| References | Number | Grade | Selection of participants | Retaining participants/ Compensation | Measurements | Statistical analysis | Interpretation | Discussion |
| Herawati et al. (10) | 1 | Medium | One exclusion criterion was age > 30 years old, however, the table of characteristics of study subjects reported range of 17–49 years. The Snowball Sampling technique is inappropriate, since college student should be easily contactable by their school, therefore voiding the justification of them being "hard to reach population" | Not applicable | The use of Hamilton Anxiety Rating Scale is widely accepted, and the authors mentioned that several local studies have used them. | The use of logistic regression is acceptable, given the binary outcome of interest | The authors seem to interpreted Odds Ratio as Risk, which is problematic. The "event" is not rare, therefore the OR will not estimate RR | Supported by results, however, the comparison to China is quite far-fetched, since the majors are different, and the tools used to measure anxiety are not HARS |
| Ugidos et al. (40) | 2 | High | Recruitments were based on existing database of students and workers, therefore the elderly are less represented. But this was discussed and acknowledged by the authors (i.e., due to impracticalities in recruiting elderly using offline forms) | Significant loss of participants at subsequent time points, due to "loss of interest." The authors did not seem to foresaw this and made some efforts to maintain retention (i.e., through incentives or supports) | The questionnaires used were tailored to match the objectives, which is appropriate → the InDI-D used "Presence of COVID-19" as the condition | The use of Linear Mixed Model is acceptable. The authors did not perform imputation due to the missingness properties not known (quite possible MNAR, Missing Not At Random) | In line with the reported models | It seems that the questionnaires used provide acceptable fit, the Pseudo-R squared (Tables 2, 3) are quite good, given the number of items and the three time points. These supported the interpretation of the models. |
| Shokri et al. (41) | 3 | Medium | There seems to be unclear procedures on participants recruitment. "the questionnaire was shared to participants through email, Instagram direct, WhatsApp direct, and Telegram groups." Did they stop as soon as the recruited participants reached 1,000? Were the methods carried out in parallel? | Not applicable | The Berger HIV stigma scale, modified for Ebola was used. However, the concept of internalized stigma of Berger's and COVID-19 is very distinct. This implication was not discussed. | The use of ANOVA and $T$-test are acceptable. The significance level was set at 0.005, but subsequently at 0.05 in the results (most likely a typo in the method section) | Straight-forward and concise interpretation. | Supported by the data, particularly the context of governmental jobs and self-employed situation were discussed. |
| Amir (16) | 4 | Low | It is highly disturbing that "saturation principle" was used to stop the recruitments, but this was based on a single interpreter/coder, without cross examinations. Thus whether saturation was truly achieved is questionable. | Not applicable | Seven-phase data analysis framework was used but all identifications of themes relied on this single author → very prone to coding bias | Pure qualitative study, without statistical analysis | All of the themes are supported by actual quotes by the participants | Supported by the interviews |

*(Continued)*

TABLE 2 (Continued)

| Identifiers and quality assessment | | | Sample selection | | Measurements and analysis | | Results and discussion | |
|---|---|---|---|---|---|---|---|---|
| References | Number | Grade | Selection of participants | Retaining participants/ Compensation | Measurements | Statistical analysis | Interpretation | Discussion |
| Miconi et al. (17) | 5 | Medium | Based on Leger Opinion Panel. Therefore some degree of selection bias is expected (non-participants of Panel would not be able to participate) | The authors' decision to reward participants based on survey completion time was highly questionable (CAD 0.5–2). This practice has been discouraged by survey guidelines. | The use of Hopkins Symptom Checklist-10 is acceptable, however, to my knowledge it has not been validated in Arab population (which contributes $n$ = 450 in this study) | The use of factor analysis to dimensionally reduce the data complexities of HSCL-10 is acceptable | Supported by the results | The discussion draws comparison to the UK and US which investigated COVID-19 in multi-racial settings. The recommendations (focusing on ethnic minorities) are supported by the findings in the UK and US |
| Yuan et al. (12) | 6 | High | COVID-19 survivors were compared with healthy control of the same city (by convenience sampling). | Not applicable | Fatigue and Stigma were assessed using PHQ-9 and Social Impact Scale (a generic stigma scale). The SIS has been validated in Chinese population previously, but not for COVID-19 | *T*-test, ANOVA, and generalized linear model were used, which are appropriate. | The interpretation were based on the comparison between survivors and healthy controls, appropriate given the study design's limitation of convenience sampling. | The recommendations were based on the findings, however, the decision to not performed matched controls was not explained. Almost half of the survivors were male, but only 20.6% were male in the control group. This imbalance might skew the findings toward the null |
| Lohiniva et al. (8) | 7 | High | Based on maximum variation and data saturation principles, which are standard practices for family-based interviews | Not applicable | Framework analysis following the Health Stigma Framework. Four investigators discussed the coding and framework analysis | Pure qualitative study, without statistical analysis | All of the themes are supported by actual quotes by the participants. Attributions of the quotes were presented consistently | The themes and recommendation being discussed were based on the interview results |
| Tomczyk et al. (11) | 8 | High | Based on online advertisements through Facebook. | Participants received EUR 5 if they finished the set of questions | Mostly based on mental health questionnaires. But some of the adaptation was quite questionable, for example the "Persons with COVID-19 should not be allowed to have a driver's license" question | Since the classes were 3, producing three pairs of 1-2, 2-3, and 1-3, the use of Multinomial Logistic Regression is appropriate. | In line with the reported results | The tailored health promotion efforts targeting youths was supported by the RRR results |
| Jiang et al. (4) | 9 | High | The study has a specific objective of exploring stigma of Chinese people toward people from Wuhan, therefore the recruitment method is acceptable | Not applicable | Adaptation of stigma related to tuberculosis was used. Pre-testing was performed to ensure appropriateness to COVID-19 | Chi-square and logistic regression were used, which are appropriate. | In line with the reported results | There are several inconsistencies in the discussion section. The authors acknowledged that the sampling was not representative and not probabilistic, but they presented and discussed the findings as prevalence. This is clearly inappropriate. |

*(Continued)*

TABLE 2 (Continued)

| Identifiers and quality assessment | | | Sample selection | | Measurements and analysis | | Results and discussion | |
|---|---|---|---|---|---|---|---|---|
| References | Number | Grade | Selection of participants | Retaining participants/ Compensation | Measurements | Statistical analysis | Interpretation | Discussion |
| Mahmoudi et al. (19) | 10 | Medium | Convenience sampling method is deemed acceptable, since they objective of the study was to have PCR test and Chest CT. One minor concern is why the four hospitals were used instead of the others was not properly explained. | Not applicable | PTSD and Self-Stigma Scale-Short (originally was designed for mental health, immigrant, and sexual-orientation minority groups) were used. Adaptation for COVID-19 was performed. Insomnia and MHI-5 were also used | Since the classes were 3, producing three pairs of 1-2, 2-3, and 1-3, the use of Multinomial Logistic Regression is appropriate. | The authors seem to be a bit over optimistic in reporting the goodness of fit. The root mean square error of approximation (RMSEA) value indicated close to mediocre fit, not "satisfactory" as the authors have implied | The mediation analysis were quite acceptable, however, the discussion did not acknowledge that the fit was rather mediocre → some unexplored and unmeasured factors might be necessary to be investigated to improve the current mediation analysis |
| Earnshaw et al. (9) | 11 | Low | Based on Amazon MTurk Panel. Therefore some degree of selection bias is expected (non-participants of MTurk would not be able to participate) | Participants received USD 2 if they finished the set of questions | Chronic Illness Anticipated Stigma Scale was used, but only relevant items for COVID-19 were retained | Linear regression was used for the analysis | The decision to display testing likelihood without confounder adjustment is questionable. Gender and Race (two covariates which were collected in the study) should be included in the analysis. | The interpretation is greatly limited by potential confounders not considered by the authors. |
| Kang et al. (18) | 12 | High | Retrospective analysis of medical record of a community isolation facility | All of the patients analyzed. Time cut-off were used to exclude participants. | The use of MERS questionnaire was appropriate, given the relative similarity of transmission methods between MERS and COVID-19 viruses. | Acceptable. Limited number of participants complicate further analysis of the data. For example, only *n* = 32 have been isolated up to the 4th week. Therefore the absence of further analysis is understandable | In line with the reported results | The authors promoted the CTC model in handling COVID. Notably the comparison to other models were given with careful consideration that they are in other countries with different system and different diseases (H1N1) |
| Singh et al. (13) | 13 | High | Participants were cohort participants of CARRS and India-UDAY. Re-contacted to participate in the current research. | No information was given on the approach to recruit participants, and whether refusal translate to exclusion from cohorts future investigations (which may dis-incentivize participants) | The anxiety was assessed by generalized anxiety disorder questionnaire, an established method. The remaining items are specifically developed by the authors for this study (without adequate validation or pre-testing) | For the qualitative part the authors used "illustrative non-attributable quotations," without any justification. The data collection protocol recruited a diverse set of participants (i.e., not a very specific group of people), therefore attribution should be performed. | Correct interpretation of the Odds Ratios and factors that changes the OR (with specific examples for ease of interpretation) | The tailored health promotion efforts targeting youths was supported by the RRR results |

*(Continued)*

TABLE 2 (Continued)

| Identifiers and quality assessment | | | Sample selection | | Measurements and analysis | | Results and discussion | |
|---|---|---|---|---|---|---|---|---|
| References | Number | Grade | Selection of participants | Retaining participants/ Compensation | Measurements | Statistical analysis | Interpretation | Discussion |
| Bodrud-Doza et al. (14) | 14 | Medium | Email and social platform recruitments (Facebook, WhatsApp, etc.) combined with targeted database of hard to reach group. | Not applicable | The questions were specifically developed for COVID-19 instead of adapting them from previous questionnaires. Expert consultation was used to validate the questions | There were 46 items which the authors attempted to be reduced to a manageable levels of number of variables for easier interpretation. The use of CTT PCA sequentially followed by CA were unusual, but not unheard of. | There is one major concern regarding the Scree Plot and Eigen-cutoff. The alternative of PC1-PC5 seems to be more appropriate, instead of including nine PCs (**Figure 2** and **Table 3**) | The authors provide additional information and suggestion which were reasonable, but not supported by the data, particularly in the "Disadvantaged communities" section. |
| Zakar et al. (15) | 15 | High | A mix of purposive and snowball sampling. This is a bit unusual, but justifiable since the objective was to capture participants from multiple cities. | Not applicable | Theme identifications were performed by multiple analysts, and difference in coding/interpretation were resolved through discussion → considered to follow the recommended practice. | Pure qualitative study, without statistical analysis | All of the themes are supported by actual quotes by the participants. There are inconsistencies in quote attribution, however. For example, several quotes only had "one participant said" but some have age, gender and occupation. This reduces the trustworthiness of the quotes. | The themes and recommendation being discussed were based on the interview results |

mental health access, cultural barriers, myths, and misinformation associated with the COVID-19 pandemic. COVID-19 has resulted in a high level of stigma, anxiety, public confusion, and fear in the setting of many unknowns surrounding this virus. Stigma is a key component of inequalities, but it has been largely ignored in the debate over COVID-19's response. Stopping and controlling pandemics, assisting societies in their recovery from pandemics, and achieving equitable development are all hampered by stigma. For example, African Americans are one of the highest-risk categories when it comes to dying from COVID-19, and yet they may be more resistant to being vaccinated. This mistrust toward people in authority can perhaps be traced back to the dark times of slavery, and has been perpetuated by the violence and apathy, exerted on them ever since. The community remembers, and naturally do not trust any governmental interference in their health, even if it is likely benevolent. The most prominent example of this is the Tuskegee syphilis experiment participants, who were unethically studied in the 1930s through the 1970s by the government in a study on syphilis (21). African American men infected with syphilis were deliberately left untreated to understand what happened to them over time (even when treatment became available and was being prescribed to others). This mistrust also led many African Americans men to fear that racial profiling and police harassment will worsen if they will wear masks (22). Those who choose not to wear a mask in order to not be perceived negatively in the eyes of a racist society can become potential vectors. The failure of the public healthcare system to take these factors into account presents a lose-lose situation.

Common miscomprehensions of what viruses and pandemics are and how they spread lead to resistance in people toward what can help; that being social distancing, temporary but aggressive lockdowns, and the stringent use of face masks. When communities blinded by religion or cultural habits do not look through a scientific lens; they may be more likely to overlook disease symptoms. This was the case in the early days of COVID-19, whose symptoms were deemed akin to those of the common cold or flu (23). An ongoing conflict between culturally appropriate and medically appropriate pandemic practices can cause psycho-cultural trauma. This can hinder the ability of individuals to cope with stressors and can make recovery difficult (24). Collective trauma (trauma that negatively impacts entire societies) leaves even longer-lasting effects with even fewer outlets available to manage despair or allow for cathartic emotional release (i.e., venting). The potential for mass trauma makes it crucial for governmental organizations and public health officials to work together to provide outreach and actively disseminate beneficial coping information.

This "us" vs. "them" dynamic indicates a way in which disease stigma can be viewed as a proxy for other types of fears like xenophobia. The pandemic risk associated with SARS-CoV-2 infection led to the realization of how stigma and discrimination can remain barriers to care for people suspected of being infected; even more if they were frontline healthcare workers or assisting them (2). Recognizing disease stigma; exploring it, and not simply blaming the ignorance of others, can give us insight how these attitudes are formed and how we can disband them. One should keenly reflect on historical evidence to determine what interventions against stigma surrounding infectious diseases has succeeded in the past to determine what may work for COVID-19 pandemic (2).

It is essential to address COVID-19-related stigma to contain the spread of the virus. To overcome this stigma, several agencies, scientific publications, and experts have issued recommendations and taken relevant initiatives. These recommendations have emphasized the usage of inclusive language when talking about the disease, avoiding the spread of misinformation and rumors, being thoughtful and supportive while communicating, and propagating clear, actionable information to support communities affected by this outbreak.

International public health organizations tend to view outbreaks through the lens of epidemiology and hard medical facts. Nevertheless, it could be beneficial to add psycho-cultural nuances to rote medical approaches. For example, during the Ebola crisis, the World Health Organization (WHO) was able to successfully flatten the Ebola transmission rate by melding its treatment strategies with the cultural practices, social norms, and beliefs of affected communities (25). Another example is that Japan's remarkably lower COVID-19 death rates. This was achieved by telling people to avoid the three "Cs"—closed spaces, crowded places, and close-contact settings, rather than solely instructing them to stay at home (26). Their approach also harnessed a long held cultural belief in several Asian countries that people wear facemasks in public during the influenza season with an expectation that it helps prevent infections (27).

Global health organizations should also study how to mitigate cultural taboos as they apply to COVID-19, even if they may not be up to par with the original standard. For instance, if conditions compliant with hospital protocol were followed, the risk of infectious spread would be lowered, and more people could be permitted to attend gatherings like funerals. To this effect, immediate family members, in full personal protective equipment, could be allowed to visit their passing loved ones, say their goodbyes, and perform their final rites. Such solutions are neither meant to be compromises, nor supposed to be perfect. Rather, they sensitively cater to the needs of different cultures so that individuals can engage in at least some form of their cultural practices or religious rituals while also adhering to health prescriptions for the greater good. Only with innovation, cultural sensitivity, and perseverance can these divides be healed, and the mental trauma induced by COVID-19 be diminished. The current pandemic presents us with an opportunity to introspect, educate ourselves, and understand narratives that have been previously misunderstood or underrepresented.

Social isolation, anxiety, fear of contagion, uncertainty, chronic stress, and financial difficulties may lead to the development or exacerbation of stress-related disorders and suicidality in vulnerable populations including individuals with pre-existing psychiatric disorders, low-resilient persons, individuals who reside in high COVID-19 prevalence areas and people who have a family member or a friend who has died of COVID-19 (28). Social disengagement played an important role in the elevated suicide rate during the 2003 SARS epidemic in Hong Kong (29). It is concerning from the suicide prevention perspective that social isolation is the most crucial public health strategy for the COVID-19 pandemic. COVID-19 survivors, particularly those who experienced severe symptoms are at elevated risk of suicide (30). Stressful events such as learning about the diagnosis of COVID-19, fear of spreading the infection to others, symptoms of the illness, hospitalization, especially admission to an intensive care unit, and loss of income may lead to the emergence of anxiety, depression, and PTSD (30, 31). Suicide prevention in the COVID-19 era is an important and difficult issue and policymakers should create well-defined guidelines to help clinician manage such cases.

During the COVID-19 pandemic, the personal liberties embraced by individuals in the western world made it difficult for public health officials and local and federal governments to contain the spread of this disease (32). United States (U.S.) citizens have defied and protested their state's stay-at-home orders out of the belief that public health interventions "have gone too far" and violated their rights. This was exacerbated by misinformation disseminated *via* media (5). For example, some Michigan citizens belonging to working-class population believed that local leaders were "out to get them" by disrupting their local economy, thereby stripping them of their livelihoods and liberty. In April 2020, protesters gathered outside Michigan's capitol building in Lansing, in large crowds without masks and brandished flags, banners and guns outside and inside the building and at the gates of health facilities (32). They demanded that their politicians repeal the stay-at-home order. Their rally defied social distancing and prevented healthcare workers (some of whom passively counter-protested) from getting to work on time. This situation put the Libertarian protesters, their healthcare worker counter-protesters, their patients, and frontline peers at a greater risk of infection (33). This resistance to quarantine and isolation measures in the U.S. contributed to the ineffective mitigation of the COVID-19 pandemic. Numerous studies pointed to the effectiveness of masks and social distancing, thus identifying a lack of adherence to isolation and masking policies being a major factor in intensifying the spread and impact of COVID-19 (34, 35). People's intention to comply with recommendations was also found to be an important factor in the successful containment of the COVID-19 pandemic (36).

Some of these same obstacles were seen when the virus broke out in a less liberal society, but not to the same degree (35). In China people have less private control over their lives and the government controls every psycho-cultural echelon of society, including the healthcare system. China saw fewer protests and petitioning as people may have felt that it will be futile, and there were no citizens occupying government buildings or major hospitals. Not surprisingly, when China imposed a lockdown due to COVID-19, the government's policies were strictly followed. Following the initial outbreak in Wuhan, China implemented "harsh" containment measures, which resulted in a 90 percent reduction in COVID-19 cases in 2 months (37). The doctors who did speak out in the early months of 2020 were summarily suppressed along with their social media accounts, as information spread is tightly regulated (38). Social distancing and the wearing of face masks presented a cultural shock to many communities. Enforcing these guidelines compromised several communal religious events, ceremonies, rituals, and burials. In many communities, people value their rituals and faith as above science and the advice of health experts, and find themselves paralyzed to see their practices being disrupted.

Policymakers and healthcare workers should collaborate in efforts to disseminate factually correct knowledge regarding COVID-19. It is important for governments to consider applying previously established evidence-based stigma reduction strategies to the current pandemic (39), the public should exercise caution in its consumption and response to COVID-19-related media content.

This may help minimize the associated anxiety and decrease the likelihood of succumbing to misinformation and conspiracies, hence contributing to improved COVID-19 preventative efforts. It would be beneficial to enable support groups (*via* the internet if movement restrictions are in place), particularly for COVID-19 affected patients during their confinement and to make mental health services more accessible. All household members of affected patients should receive age appropriate education pertaining to the disease and measures to manage it. Psychological assistance should be specially provided to those traumatized by their experiences, including healthcare workers, caregivers, and victims of COVID-19 hate crimes. Access to healthcare, education, and sustained connectivity to the outside world can help re-establish a sense of "normalcy," and therefore, be crucial to the success of containment facilities during an outbreak.

We should also acknowledge the role that the COVID-19 pandemic has played in exacerbating preexisting social and ethnic-racial inequalities. Policies should focus on improving social inclusion, reducing the discrimination of minority groups, and ensuring that mental health services are accessible and appropriate to the needs of racial, ethnic, and religious minorities, both during and after the pandemic.

Limitations of our scoping review include the heterogeneity in sample sizes (30–5,039) and the type of study conducted. Another limitation of our scoping review is the rapidly evolving nature of the COVID-19 pandemic, which may lead to outdated information as new research and data become available. Additionally, the review may not cover all relevant aspects of psychosocial and cultural factors due to the vastness of the subject matter and potential language barriers in accessing international sources.

## 5. Conclusion

The COVID-19 era requires public health officials and government leaders to consider a broad range of cultural and religious involvement when devising a plan to curb the spread of this virulent disease. Aligning healthcare practices with cultural sensitivities is more likely to help control pandemics like COVID-19. Although science-based approaches have been successful in decreasing the spread of COVID-19, the secondary psycho-cultural effects of the virus on minority communities like Asians and Asian Americans (due to the virus's perceived origins in China) and African American communities (given the racial bias and discrimination prior to the pandemic) remain significant and could persist for years to come. Incorporating more psycho-culturally aware healthcare practices and policies could be advantageous in managing the pandemic and its potentially multilayered aftermath.

## Author contributions

SA and SB determined study design, contributed to developing the original protocol, and revised the manuscript. SA contributed to data analysis and interpretation of results. LJ contributed to the original screening of papers, data extraction, writing the first draft of the manuscript, contributed to the introduction, results, discussion section, and references. LJ and SA reviewed the manuscript. SB, LJ, and SA contributed to writing the manuscript, analyzing data, interpreting data, and writing the introduction. HB, SS, and NN contributed to writing the introduction, discussion, and literature search. AM and AZ contributed to analyzing data, interpreting data, and writing the discussion. NM, MJ, and RA contributed to the literature search, writing some sections of manuscript, and making tables. VS contributed to the literature search and writing some sections of manuscript. All authors contributed significantly to the research, have knowledge of the topic, made a substantial contribution to writing, agreed to the final version of the manuscript, and met all ethical requirements.

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## Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

## Publisher's note

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# Psychometric properties of the Chinese version of the Family Questionnaire among the caregivers of people with schizophrenia

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**Introduction:** Expressed emotion refers to relatives' attitudes and emotional behaviors toward mentally ill family members. It is a robust predictor of patients' illness outcomes and caregivers' wellbeing in a wide range of mental disorders. However, expressed emotion has not been fully explored in the Chinese context. One reason is the lack of reliable and cost-effective measurements. A reliable, valid, and user-friendly instrument is needed to support the research and clinical practice based on expressed emotion in China. This study aimed to translate, adapt, and examine the psychometric properties (factorial structure, measurement invariance, internal consistency reliability, and concurrent validity) of a Chinese version of the Family Questionnaire.

**Methods:** A total of 248 caregivers participated in the study. A translation and back-translation procedure was applied to translate the Family Questionnaire into Chinese. We compared two models to examine the factor structure of the questionnaire by performing confirmatory factor analysis. We also conducted measurement invariance analysis to test whether the factor structure of the tool is invariant across male and female groups. Reliability was evaluated with Cronbach's $\alpha$. The concurrent validity was examined by testing the predictivity of the expressed emotion on relevant outcomes with path analysis. We used the STROBE checklist to report.

**Results:** The item-total correlation coefficients of the scale ranged from 0.375 to 0.752. The confirmatory factor analysis indicated that the Chinese version of the Family Questionnaire displays the original two-factor structure (emotional overinvolvement and criticism; $X^2 = 335.50$, $df = 169$, $X^2/df = 1.985$, RMSEA = 0.063, SRMR = 0.058, CFI = 0.913, and TLI = 0.902). In addition, the two-factor structure was invariant across the male and female groups. The two subscales showed excellent internal consistency, with Cronbach's alpha of 0.92 for both emotional overinvolvement and criticism. The concurrent validity of the Chinese version was supported by the good predictivity of the two subscales to care burden, family function, and quality of life. All path coefficients were significant, and the absolute values of path coefficients ranged from 0.23 to 0.72.

**Conclusion:** The Chinese version of the Family Questionnaire is a valid and reliable measurement of expressed emotion in the Chinese context.

KEYWORDS

**caregivers, expressed emotion, psychometrics, schizophrenia, validation study**

# 1. Introduction

In recent decades, the care for schizophrenia has shifted from institution to community-based, with the belief that community-based care is better for patients' recovery (1). Most schizophrenia outpatients are cared for by their relatives, such as their parents, spouses, and siblings (2). Under this setting, the family environment and the interaction between caregivers and patients significantly impact patients' recovery. As an important family-level stress factor, expressed emotion refers to relatives' attitudes and emotional behaviors toward mentally ill family members. Expressed emotion was conceptualized as an environmental stressor that would increase the probability of psychosis development among people at high genetic risk for mental disorders (3–5). It is a robust predictor of patients' illness outcomes in various mental disorders, including schizophrenia, mood disorders, eating disorders, and dementia (6–11). Over the past decades, meta-analyses and review articles have shed light on its significant impact on mental health disorders (6, 10, 12–15). Despite the substantial empirical research in developed countries and areas, we still need more exploration of expressed emotion from different cultural contexts to expand our understanding of this construct.

Brown (16) first developed the construct of expressed emotion in the 1960's through his clinical practice on people with schizophrenia. Based on Brown and Rutter's work (17), expressed emotion has been studied as an index of family stress to predict symptom relapse in a wide range of mental disorders during the past decades (4, 6, 10–13, 18, 19). In the beginning, expressed emotion comprises five components (20): (1) criticism, which refers to family members' blame or disapproval of the patient's behavior; (2) hostility, which refers to rejection or dislike toward the patient; (3) emotional overinvolvement, which refers to relatives' extravagant/exaggerated emotional responses (e.g., anxiety and worry), and over-protection toward patients; (4) warmth, which reflects empathy and understanding toward the patients; (5) positive remarks, which refer to an appreciation of the patients. Subsequent research found that the first three components (i.e., criticism, hostility, and emotional overinvolvement) showed better predictivity to relapse (5, 6, 21, 22), so the key elements of expressed emotion are considered as criticism (CC), hostility, and emotional overinvolvement (EOI). Given that hostility is associated with high levels of criticism, the ratings of emotional overinvolvement and criticism are most used to classify caregivers into high or low levels of expressed emotion (23–25).

A variety of instruments were developed to measure expressed emotion. The first standardized measurement is the Camberwell Family Inventory (CFI) (26). CFI administration consists of two parts that require trained personnel: interviewing and coding. Interviewing usually takes 1–2 h, and coding takes 2–3 h. The time-consuming administration and coding and the required training of raters limit the use of CFI. Thus, researchers have developed alternative measures with shorter procedures. One alternative is the Five-Minute Speech Scale [FMSS; (27)]. FMSS reduced the administration time by fixing the interview to 5 min and removing the rating of hostility and warmth. However, the FMSS tends to under-identify high-expressed emotion relatives and inflate Type II errors in exploring the relationship between FMSS-rated expressed emotion and any given outcomes (28). Other alternative measures are self-report questionnaires, which are time- and cost-effective ways to measure expressed emotion. Self-report questionnaires also dispense with the dichotomous high/low rating of expressed emotion that has previously been criticized (29).

There are numerous self-report questionnaires used by researchers to measure EE. However, only a few were developed based on the EE construct and validated against the CFI. These self-report questionnaires are the Level of Expressed Emotion Scale (LEE), Family Attitude Scale (FAS), Perceived Criticism Measure (PCM), and Family Questionnaire (FQ). The LEE (30) is a 60-item scale with four subscales. FAS (31) is a unidimensional self-report measure with 30 items. The PCM (32) has only four items with a Likert scale of 10 points to measure criticism. These three scales are all valid measurements and have been used in EE research. In addition to their advantages, these questionnaires also have disadvantages. LEE contains multiple dimensions but is relatively lengthy. FAS is short but cannot measure different elements of EE separately. It is extremely fast and easy to assess PCM, but it only offers information about criticism. Thus, a short valid scale that can assess the main elements of EE to probe high-EE attitudes and is easier to administer and less time-consuming is required. These conditions can be satisfied by the FQ.

The FQ is a cost-effective and research-applicable self-report tool developed by Wiedemann et al. (25). First, the researchers generated 130 items from three different sources: common statements made by relatives of people with schizophrenia and behaviors of such relatives listed by experienced clinicians, expressed emotion-related concepts, and existing questionnaires. Second, based on the theoretical model developed by Vaughn and Leff (26, 33, 34), items were generated for four areas: "intrusiveness," "emotional response," "attribution of illness," and "coping skills." Third, the item pool was evaluated by a team of expressed emotion experts comprised of experienced clinicians familiar with people with schizophrenia, patients' relatives, and the expressed emotion literature. Finally, after a series of psychometric evaluations, 20 items were selected from the 130 preliminary items to measure expressed emotion's two critical elements (criticism and emotional overinvolvement). The FQ is equivalent to the FMSS in terms of validity but is easier to administer and less time-consuming than the CFI or the FMSS (25). In addition, it is suitable for repeated administration because no training is required before use, and the time needed for administration is short. The original version of the FQ showed good validity and was used in many empirical studies. The FQ also showed good psychometrics in other cultural contexts, including Italian (35), Greek (36), Brazilian Portuguese (37), and Spanish (38).

Although expressed emotion has been deeply researched in Western countries, it has not aroused much attention in China. The first batch of Chinese expressed emotion studies was a series of studies (39–43) conducted by Phillips and his cooperators in China around 2000. This team adapted CFI for use in China and evaluated the expressed emotion level of relatives of people with schizophrenia in Beijing. They investigated the relationship between some social demographic factors and expressed emotion, finding that the manifestation of expressed emotion varied in relatives with different sex, roles, educational level, and the length of time contact with the patient (39–42). They also found that relatives' stigma was positively associated with the high level of expressed emotion (41) and expressed emotion mediated the effect of controllable attributions on relapse in the Chinese sample (43). In the following decades, research on expressed emotion in China did not increase much. Several recent studies (44, 45) with samples from Hong Kong and China continue to support that high EE predicts rehospitalization of schizophrenic patients and caregivers' care burden and poor wellbeing. The lack of training opportunities for CFI use, time constraints in Chinese clinical practice, and the time-consuming administration of CFI may be part of the reasons for the lack of research about expressed emotion in China. Thus, time- and cost-effective measurements of expressed emotion that meet local clinical needs would be helpful to research and clinical practice about expressed emotion in China. The FQ could be an appropriate tool to use in China.

The existing valid Chinese version of self-reported expressed emotion measurements are the Level of Expressed Emotion Scale [LEE; (46–50)] and Family Attitude Scale [FAS; (51)]. Using samples of Hong Kong people with schizophrenia and other mental health disorders, Chien et al. (46–48) refined the LEE (Patient Version) into a 52-item Chinese version. Ng and Sun and Ng et al. (49, 50) further developed a 12-item Concise Chinese Level of Expressed Emotion Scale (CCLEES) after taking into account the limitations of Chien's 52-item Chinese LEE. According to Ng and Sun and Ng et al. (49, 50), the 12-item CCLEES is over four times shorter than Chien's but still accurate in assessing three core elements of EE. Chien's 52-item Chinese LEE and Ng's 12-item CCLEES are both measures for patients to report the level of EE they perceived from relatives. Using caregivers' self-reported data, Yu et al. (51) translated and validated a Chinese version of the FAS. However, it was based on a sample of caregivers for people with dementia. The Chinese version of FAS has not been tested on caregivers of people with schizophrenia or other mental health disorders.

While the existing Chinese self-report scales are valid, we believe using the FQ to evaluate EE in China has several advantages. First, it takes little time to administer and evaluate, and it does not require any training to use. Second, the FQ is concise while measuring the two critical elements of EE (i.e., EOI and criticism). The Chinese version of LEE with 52 items is relatively long for clinical and research settings. The FAS focuses on criticism and hostility without much information about EOI. In addition, Phillips and Xiong (39) noticed that the construct of criticism and emotional overinvolvement defined in CFI were more relevant dimensions in the Chinese context than the other three. The empirical studies using the CFI also showed that criticism and emotional overinvolvement were more common in Chinese relatives of people with schizophrenia (40, 42). Third, given the evidence available (35–38), the FQ tends to show a stable factor structure across cultural contexts. This facilitates cross-cultural EE comparisons. Instead, the structure of LEE seems unstable, and the CCLEES was less used in other cultural contexts. In sum, an adapted Chinese version of the FQ (C-FQ) would benefit research and clinical practice about expressed emotion in China.

In this study, we aimed to translate, adapt, and examine the psychometric properties of the C-FQ in a Chinese sample of caregivers of people with schizophrenia. Specifically, we would verify its (1) two-factor structure via confirmatory factor analysis; (2) internal consistency reliability; (3) concurrent validity with constructs related to expressed emotion (family function, care burden, and quality of life); and (4) measurement invariance across sex.

# 2. Methods

## 2.1. Translation of the C-FQ

Translation and back-translation procedure was applied to translate the FQ into Chinese. To start with, two bilingual psychologists who are both native speakers of Chinese and advanced speakers of English independently translated the questionnaire into Chinese (forward translation). Then, a reconciliation meeting was conducted to develop a consensus version (reconciliated Chinese version) with the help of a third reviewer. After that, two psychologists who were blind to the original version translated the reconciliated Chinese version back into English (backward translation). A third reviewer compared the backward translation and the original English version and decided that no significant discrepancies existed between the two versions, thus formulating the revised C-FQ. The English and Chinese versions of the items are listed in the Supplementary material.

## 2.2. Procedure and participants

We recruited relatives of people with schizophrenia from four communities in a district of Shanghai. They are primary caregivers of patients in a public mental health hospital. The participants' inclusion criteria were as follows: participants who (1) were aged 18 years or above; (2) were primary caregivers of the patient; (3) were without a diagnosis of mental health disorder; and (4) were able to read and write Chinese. The sample size estimation was guided by a rule of thumb with at least 10 respondents for each item in factor analysis. Considering the 20 items in the Family Questionnaire, the minimum sample size required was 200 participants.

We collected data for this study between September and October 2019. Data were collected when community doctors from the mental health hospital visited the family for a routine check. First, the doctor would briefly introduce the study to the caregiver, and a research assistant would expand on details about the purpose, procedure, incentive, data confidentiality, and participants' rights. If interested and willing to participate, the caregiver would sign the informed consent and complete a battery of questions.

Finally, 248 caregivers participated in this study. All of them were Chinese speakers. Table 1 summarizes the demographic of the caregivers and patients they care for.

TABLE 1 Demographic information of caregivers and the patients they take care of ($N = 248$).

| Caregivers | % (*n*)/*M* (*SD*) |
|---|---|
| Age | 65.19 (12.41) |
| Gender | |
| Male | 52.42 % (130) |
| Female | 47.58% (118) |
| Educational level | |
| Primary school | 11.29% (28) |
| Junior high school | 42.74% (106) |
| High school | 34.27% (85) |
| Undergraduate | 10.89% (27) |
| Did not report | 0.81% (2) |
| Roles | |
| Father | 35.08% (87) |
| Mother | 36.69% (91) |
| Spouse | 14.92% (37) |
| Siblings | 9.27% (23) |
| Others | 4.03% (10) |
| Living with the patients | |
| Yes | 79.84% (198) |
| No | 19.76% (49) |
| Did not report | 0.40% (1) |
| Contact time with the patients per week (h) | 83.67 (59.29) |
| Household monthly per capita income (CNY) | |
| Under 3,000 | 18.55% (46) |
| 3,001–5,000 | 63.71% (158) |
| 5,001–10,000 | 15.32 % (38) |
| More than 10,000 | 1.61% (4) |
| Did not report | 0.81% (2) |
| Illness duration of patients | 20.17 (8.75) |
| Taking medicine (patients) | |
| Yes | 90.32% (224) |
| No | 9.68% (24) |

## 2.3. Ethics approval and consent to participate

The study was approved by the East China Normal University Committee on Human Research Protection (IRB No: HR 012-2019). Written informed consent was received from all participants. All study details were disclosed to the participants. Participants were free to withdraw from the study at any time.

## 2.4. Instruments

### 2.4.1. Expressed emotion

Expressed emotion of caregivers was measured by the Family Questionnaire (25). This questionnaire was evaluated as a reliable psychometric tool applied to different cultures (35–38). It is composed of two subscales: emotional overinvolvement (10 items) and criticism (10 items). Items were rated on a 4-point Likert scale from 1 (strongly disagree) to 4 (strongly agree), and a higher score indicated a higher level of expressed emotion. The Cronbach's alpha for emotional overinvolvement and criticism was both 0.92 in the current study.

### 2.4.2. Family function

The Chinese version of the Family Assessment Device (52) was used to evaluate family functions. The scale consists of seven subscales: problem-solving, communication, roles, affective responsiveness, affective involvement, behavior control, and general functioning. Items were rated on a 4-point Likert scale from 1 (*strongly disagree*) to 4 (*strongly agree*). Lower scores indicate healthier family functioning. A review (53) summarized the performance of the Chinese version of the Family Assessment Device and found that it has shown good reliability and validity in Chinese participants since its validation. This scale also achieved high reliability (0.79–0.92) in recent studies using Chinese adult samples (54, 55). In this study, Cronbach's alpha for this device was 0.88.

### 2.4.3. Quality of life

Quality of life was measured with the Chinese version of the WHOQOL-BREF (56). Four subscales make up the WHOQOL-BREF, including the physical domain, psychological domain, social relationships, and environmental domain. The number of questions was cut down in this study in case participants get overwhelmed with too many items (57). Finally, items of the environmental domain were excluded from this study, for this domain is more affected by the public environment than the family system. All items were rated on a 5-point Likert scale from 1 to 5. Higher scores indicate a higher level of quality of life. In comparison and review studies (58, 59), WHOQOL-BREF has been shown to be a sound, cross-culturally valid assessment of QOL in various countries (including China). Previous psychometric studies (56, 60, 61) have also indicated its high reliability (Cronbach's $\alpha > 0.88$) in the Chinese adult population. In this study, Cronbach's alpha of the scale was 0.90.

### 2.4.4. Caregiver burden

The burden of caregivers was measured by the Chinese version of the Zarit Burden Interview (62). There are 22 items, rating on a 5-point Likert scale from 0 (never) to 4 (always). Higher scores indicate a higher level of burden. The Chinese version of the Zarit Burden Interview has demonstrated high internal consistency (Cronbach's $\alpha > 0.87$) in psychometric assessment studies based on samples of caregivers of older adults, inpatients, and people with schizophrenia (62–64). The Cronbach's alpha of this scale was 0.96 in this study.

## 2.5. Data analyses

The whole process of statistical analysis was conducted by MPLUS 7.4 statistical program (65) except the association between C-FQ and socio-demographic variables, and clinical characteristics were estimated by SPSS Statistics 25 software. Full information maximum likelihood (FIML) was used to handle missing data, and Maximum Likelihood Robust (MLR) was used in the analyses. Preliminary analyses (skewness, kurtosis, and item-total correlation) were conducted to test the normality of every item in the FQ (66) and to exclude poor-fitting items.

Later, confirmatory analyses were conducted to test the validity of the Chinese version of FQ (C-FQ). The fit of the model was tested with several indices, including $\chi^2$, the comparative fit index [CFI; (67)], Tucker and Lewis index [TLI; (68)], root mean square error approximation [RMSEA; (69)], and the standardized root mean square residual [SRMR; (70)]. A model can be considered satisfactory with the CFI and the TLI both over 0.90 (71) and the values of the RMSEA and the SRMS $< 0.08$ (72). We also compared two models to examine whether the structure of C-FQ was similar to the original one. Specifically, one was a single-factor model where all items load onto the general factor of expressed emotion (Model 1). The other was a model with two intercorrelated factors (critical comments and emotional overinvolvement) as in previous research (25, 36, 38) (Model 2). In addition, we used Satorra-Bentler scaled chi-square difference test (73) to compare the fitness of the two models.

Then, the measurement invariance of factor structure (configural invariance), factor loadings (metric invariance), and intercepts (scalar invariance) across gender were examined using the whole sample. ΔCFI and ΔTLI were used to investigate measurement invariance. Comparing models where loadings and thresholds were held equal vs. free to vary, a reduction in CFI (ΔCFI) and TLI (ΔCFI) of $< 0.01$ suggests that the model is scalar and metric invariant (74, 75). Cronbach's alpha was calculated to evaluate the internal consistency reliability of the scale. Moreover, concurrent validity was evaluated by path analysis, where all variables were specified as explicit ones. Concurrent validity is usually determined by correlation coefficients between criterion and target scores (76). Based on the most common guidelines, a strong correlation is defined as $r$ between 0.75 and 1, while a moderate correlation is defined as $r$ between 0.30 and 0.70 (77). The non-parametric test was used to examine the association of C-FQ with socio-demographic variables and clinical characteristics since the Kolmogorov–Smirnov test revealed a non-normal distribution of C-FQ. Specifically, univariate associations between C-FQ and categorical variables were tested by Mann–Whitney and Kruskal–Wallis tests. The strength of the association between C-FQ and continuous variables was estimated via Spearman's rho correlation coefficient.

# 3. Results

## 3.1. Preliminary analyses

In preliminary analyses, item 17 presented a slightly non-normal distribution, with a kurtosis over 2 (66, 78). The item-total correlations for all items present acceptable values, so no item was deleted. Given the non-normal distribution of item 17, further data analyses were conducted using the MLR estimator (66). Table 2 shows all C-FQ items' mean, standard deviation, skewness, kurtosis, and item-total correlations.

## 3.2. Confirmatory factor analyses

As stated above, the confirmatory factor analysis was conducted using the MLR estimator. Reported in Table 3 are the fit indices of two models, which manifests that the single-factor model (Model 1) was not acceptable. In contrast, the two-factor model (Model 2) was a preferable structure, with satisfactory fit indices, all factorial loadings being significant ($p < 0.001$), and a significant improvement in model fit compared to Model 1. Moreover, the dimension of emotional overinvolvement and criticism is positively correlated with each other ($p < 0.001$; see Figure 1).

## 3.3. Measurement invariance

We conducted configural measurement invariance by a multi-group model based on sex, and the model fit was acceptable [$\chi^2(338) = 537.40$, $p < 0.001$, CFI = 0.902, TLI = 0.890, RMSEA = 0.069, and SRMR = 0.068]. We further investigated metric invariance by constraining the factor loadings to be equal, and the model fit was reduced [$\chi^2(356) = 565.823$, $p < 0.001$, CFI = 0.897, TLI = 0.890, RMSEA = 0.069, SRMR = 0.085, ΔCFI = 0.005 (below the threshold of 0.010), and ΔTLI = 0.000 (below the threshold of 0.010)]. Finally, we investigated scalar measurement invariance by constraining the intercepts to be equal across sex, and it similarly yielded a reduced model fit [$\chi^2(374) = 585.675$, $p < 0.001$, CFI = 0.896, TLI = 0.894, RMSEA = 0.068, SRMR = 0.083, ΔCFI = 0.001 (below the threshold of 0.010), and ΔTLI = 0.004 (below the threshold of 0.010)]. Thus, configural, metric, and scalar invariance of C-FQ across sex were all supported.

## 3.4. Internal consistency reliability of C-FQ

We conducted an alpha reliability analysis to examine the internal consistency of emotional overinvolvement and criticism. Two subscales had excellent (>0.70) internal consistency, with Cronbach's alpha of 0.92 for both emotional overinvolvement and criticism.

TABLE 2 Mean, standard deviation, skewness, kurtosis, and item-total correlations of all C-FQ items.

| | *M* | *SD* | Skewness | Kurtosis | Item-total correlation |
|---|---|---|---|---|---|
| Item 1 | 2.46 | 0.385 | −0.388 | −0.410 | 0.636 |
| Item 2 | 2.36 | 0.417 | −0.065 | −0.298 | 0.661 |
| Item 3 | 2.78 | 0.455 | −0.647 | 0.731 | 0.691 |
| Item 4 | 2.47 | 0.426 | −0.315 | −0.293 | 0.752 |
| Item 5 | 2.55 | 0.513 | −0.349 | −0.169 | 0.745 |
| Item 6 | 2.57 | 0.487 | −0.245 | −0.151 | 0.723 |
| Item 7 | 2.29 | 0.466 | 0.017 | −0.273 | 0.717 |
| Item 8 | 2.44 | 0.464 | −0.049 | −0.247 | 0.651 |
| Item 9 | 2.47 | 0.460 | −0.046 | −0.233 | 0.597 |
| Item 10 | 2.31 | 0.457 | 0.331 | 0.106 | 0.545 |
| Item 11 | 2.53 | 0.436 | −0.393 | −0.163 | 0.703 |
| Item 12 | 2.63 | 0.468 | −0.343 | 0.001 | 0.736 |
| Item 13 | 2.68 | 0.451 | −0.411 | 0.189 | 0.705 |
| Item 14 | 2.14 | 0.402 | 0.069 | −0.140 | 0.542 |
| Item 15 | 2.42 | 0.504 | −0.121 | −0.323 | 0.660 |
| Item 16 | 2.40 | 0.419 | −0.242 | −0.395 | 0.663 |
| Item 17 | 2.88 | 0.342 | −0.828 | 2.021 | 0.375 |
| Item 18 | 2.52 | 0.395 | −0.256 | −0.250 | 0.735 |
| Item 19 | 2.58 | 0.431 | −0.493 | −0.006 | 0.742 |
| Item 20 | 2.26 | 0.313 | 0.266 | 0.040 | 0.580 |

TABLE 3 Model fit indices for confirmatory factor analyses.

| | $X^2$ | *df* | Scaling correction factor | CFI | TLI | RMSEA | SRMR | CD | TRd | △ *df* |
|---|---|---|---|---|---|---|---|---|---|---|
| Model 1 | 417.781 | 170 | 1.206 | 0.871 | 0.855 | 0.077 | 0.065 | 2.727 | 37.495 | 1 ($p < 0.001$) |
| Model 2 | 335.502 | 169 | 1.197 | 0.913 | 0.902 | 0.063 | 0.058 | | | |

Model 1, one-factor model; Model 2, two-factor model; CD, difference test scaling correction; TRd, Satorra-Bentler scaled chi-square difference.

## 3.5. Concurrent validity

Concurrent validity can be established with moderate-to-high correlations with other reliable instruments. We chose family function, quality of life, and caregiver burden as the benchmark in this study. Both dimensions of emotional overinvolvement and criticism are good predictors of the three chosen criteria. It is shown that the emotional overinvolvement dimension had a moderate negative correlation with family function [$\beta = -0.25$, 95% CI = (−0.21, −0.05), $p = 0.001$] and quality of life [$\beta = -0.24$, 95% CI = (−0.36, −0.07), $p = 0.003$], as well as a moderate positive correlation with care burden [$\beta = 0.37$, 95% CI = (0.40, 0.76), $p < 0.001$]. As for the criticism dimension, it had a high positive correlation with family function [$\beta = 0.72$, 95% CI = (0.28, 0.50), $p < 0.001$] and moderate positive correlation with care burden [$\beta = 0.39$, 95% CI = (0.41, 0.83), $p < 0.001$], as well as a moderate negative correlation with the quality of life [$\beta = -0.23$, 95% CI = (−0.36, −0.05), $p = 0.008$].

## 3.6. Associations of the C-FQ with socio-demographic and clinical characteristics

We examined the influence of socio-demographic and clinical characteristics on the two subscales of the C-FQ. Table 4 displays the statistical results. The results indicated that caregivers living with patients tended to score higher in EOI than those not living with patients. Additionally, EOI scores demonstrated significant differences in caregiving roles. The *post-hoc* test (the Dunn test) revealed that parents or spouses scored higher in EOI than siblings, but no significant difference existed between fathers, mothers, or spouses. Meanwhile, CC scores showed significant differences in education levels. The Dunn test revealed that caregivers with primary or college education reported higher CC scores than those with junior high school education. However, there were no significant differences between other education levels. Notably, contact time with patients per week showed a significant

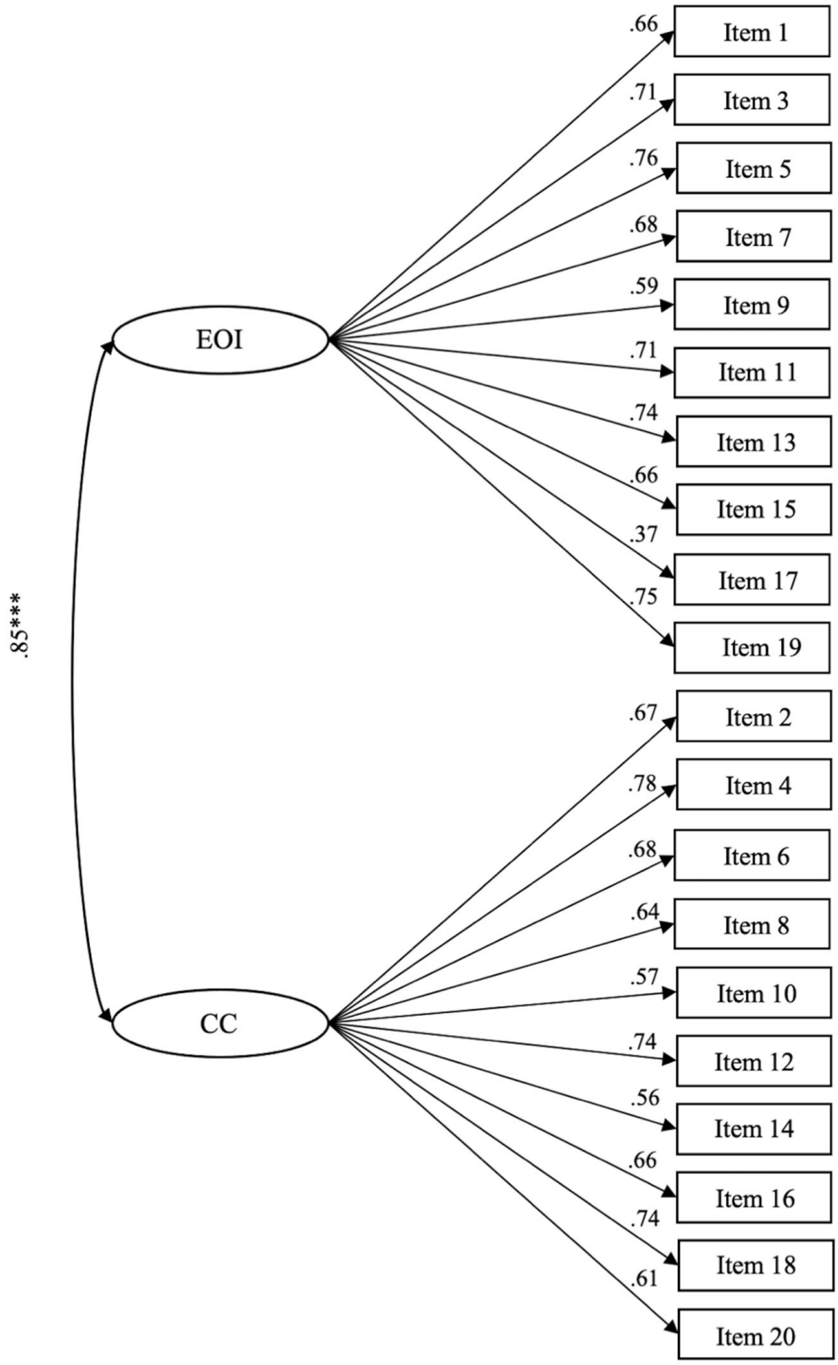

FIGURE 1
Standardized solution of the factor structure of the C-FQ. CC, criticism; EOI, emotional overinvolvement; the R-SQUARE values of all items vary from a minimum of 0.135 to a maximum of 0.603; ***$p < 0.001$.

positive correlation with both EOI and CC scores. As for clinical characteristics, caregivers of patients taking medicine reported higher EOI scores than caregivers of patients not taking medicine. No significant differences were found concerning caregivers' age, gender, household monthly per capita income, and patients' illness duration.

## 4. Discussion

The primary aim of this study was to adapt the FQ into the Chinese version and evaluate its psychometric properties in a sample of family relatives of people with schizophrenia. Expressed emotion has been widely studied in many cultural

TABLE 4 Univariate analysis of the association between C-FQ and socio-demographic characteristics.

| Caregivers' characteristics | EOI | | | CC | | |
|---|---|---|---|---|---|---|
| | *M (SD)* | z/H/*r* (df) | *p* | *M (SD)* | z/H/*r* (df) | *p* |
| **Age** | 2.56 (0.47) | *r* (246) = *0.07* | 0.252 | 2.41 (0.46) | *r* (246) = −*0.02* | 0.734 |
| Gender | | | | | | |
| Male | 2.57 (0.49) | *z* (246) = −*0.30* | 0.767 | 2.42 (0.46) | *z* (246) = −*0.40* | 0.689 |
| Female | 2.55 (0.46) | | | 2.39 (0.47) | | |
| Educational level | | | | | | |
| Primary school | 2.74 (0.37) | H (3) = 7.74 | 0.052 | 2.55 (0.50) | **H (3) = 13.84** | **0.003** |
| Junior high school | 2.50 (0.44) | | | 2.31 (0.41) | | |
| High school | 2.56 (0.51) | | | 2.43 (0.50) | | |
| Undergraduate | 2.63 (0.53) | | | 2.58 (0.45) | | |
| Roles | | | | | | |
| Father | 2.63 (0.48) | **H (4) = 11.12** | **0.025** | 2.44 (0.47) | H (4) = 5.56 | 0.234 |
| Mother | 2.60 (0.43) | | | 2.41 (0.45) | | |
| Spouse | 2.54 (0.39) | | | 2.42 (0.42) | | |
| Siblings | 2.26 (0.62) | | | 2.22 (0.55) | | |
| Others | 2.44 (0.41) | | | 2.46 (0.45) | | |
| Living with the patients | | | | | | |
| Yes | 2.60 (0.45) | ***z* (246) = −*2.82*** | **0.005** | 2.43 (0.45) | *z* (246) = −*1.68* | 0.093 |
| No | 2.42 (0.53) | | | 2.33 (0.49) | | |
| Contact time with the patients per week (h) | 2.56 (0.47) | ***r* (246) = *0.27*** | **<0.001** | 2.41 (0.46) | ***r* (246) = *0.17*** | **0.009** |
| Household monthly per capita income (CNY) | | | | | | |
| Under 3,000 | 2.64 (0.53) | H (3) = 5.39 | 0.145 | 2.46 (0.50) | H (3) = 5.37 | 0.147 |
| 3,001–5,000 | 2.58 (0.45) | | | 2.42 (0.48) | | |
| 5,001–10,000 | 2.43 (0.50) | | | 2.33 (0.36) | | |
| More than 10,000 | 2.68 (0.19) | | | 2.45 (0.39) | | |
| Illness duration of patients | 2.56 (0.47) | *r* (246) = −*0.09* | 0.155 | 2.41 (0.46) | *r* (246) = −*0.07* | 0.303 |
| Taking medicine (patients) | | | | | | |
| Yes | 2.58 (0.47) | ***z* (246) = −*2.14*** | **0.032** | 2.41 (0.46) | *z* (246) = −*0.72* | 0.469 |
| No | 2.37 (0.49) | | | 2.35 (0.54) | | |

Statistically significant differences at $p < 0.05$, based on Mann–Whitney U-test for two independent samples, Kruskal–Wallis one-way analysis of variance by ranks, and Spearman's rho correlation coefficient. EOI stands for emotional overinvolvement; CC stands for criticism.

contexts. However, there were not many empirical results from the Chinese sample. The lack of appropriate measurements could hinder studying expressed emotion in China. Thus, as a time- and cost-effective instrument, the C-FQ would be beneficial for research about expressed emotion and clinical practice based on expressed emotion theory in China, as well as the cross-cultural comparison of expressed emotion theory between the Chinese context and other cultures. Overall, the C-FQ presents good psychometric properties, including good structure validity, reliability, and concurrent validity.

The original FQ displayed a two-factor structure: emotional overinvolvement and criticism. Our CFA results indicated the same two-factor structure of the C-FQ. Specifically, the one-factor model showed a poor model fit to the data (CFI and TLI $< 0.9$), while the two-factor model showed a good model fit (CFI and TLI $> 0.9$). Using Satorra-Bentler scaled chi-square difference test to compare the fitness of these two models, we found that the fit of the two-factor model was significantly better than the one-factor model. This two-factor solution is in line with the factor structure of other non-English FQ versions (i.e., Spanish, Italian, and Brazilian Portuguese). Based on that, it would be essential to distinguish different aspects of the emotional experience of family members of people with mental illness.

Generally, C-FQ items showed good factor loadings in the two-factor model. However, item 17 showed a low factor loading (0.37), while the loadings of other items ranged from 0.56 to 0.78. The low factor loading of item 17 may be due to its contents ("He/she is an important part of my life"). Most caregivers are close family members of people with schizophrenia, such as fathers, mothers, and spouses. Thus, a feeling that sons/daughters/spouses are an essential part of parents'/spouses' life could be an expected condition among them. Considering that this feeling is common and natural among close family members, it cannot reflect the overinvolvement of emotions. In addition, it may be unable to discriminate between family relationships with and without people with mental illness. The low factor loading of item 17 was also found in other translated versions of the FQ, including the Greek version [loading is 0.42; (36)] and the Spanish version [0.14 in a sample of mothers, 0.22 in a sample of fathers; (38)]. The Italian version deleted item 17 because of its extremely low value (0.16) of item-total correlation and non-significant loading (35). Given that, item 17 may need an amendment to achieve better measurement validity. To modify it as "He/she is the *most* important part of my life" might be helpful.

In this study, we further test the stability of the C-FQ's factorial structure across sex by the analysis of measurement invariance. Our results showed that the configural, metric, and scalar invariance of C-FQ across sex were all supported, which indicated that male and female caregivers had the same C-FQ factor structure and interpretation of the scale items. As far as we know, this is the first study to examine the measurement invariance of the FQ across sex. In previous studies, caregivers' levels of emotion are compared without testing the factorial structure consistency of the measurement [e.g., (35, 38)]. A different examination of sex, however, would be meaningless if the scale did not measure the latent construct equally for men and women. Thus, our findings gave evidence to support the examination of sex differences in expressed emotion. We also conducted an alpha reliability analysis to examine the internal consistency of the two C-FQ subscales. The results indicate that emotional overinvolvement and criticism showed excellent reliability indexes with Cronbach's $\alpha$ coefficient.

Finally, we examined the concurrent validity of C-FQ by testing its ability to predict constructs related to caregiving experience, family function, and wellbeing. The two subscales are both effective predictors of care burden, family function, and caregiver's quality of life. Specifically, caregivers who are over concerned with the patient or show a higher level of criticism toward the patient tend to experience a higher level of care burden, poorer quality of life, and poor family function. These results are in line with existing research on expressed emotion across different cultures (4, 6, 10). The good concurrent validity of C-FQ suggests that expressed emotion in Chinese contexts can be well-measured with a self-reported method.

Despite the interesting findings of our study, several limitations should be noted. First, we did not examine the test–retest reliability of this instrument. Many family intervention studies would examine changes in expressed emotion before and after the intervention. Therefore, a deep exploration of the test–retest reliability of the C-FQ would help researchers decide whether to use it for measuring intervention effects. Second, we only successfully recruited caregivers of people with schizophrenia to participate in this study. Future research could examine the psychometric properties of the C-FQ by collecting data from different clinical samples (e.g., depression, eating disorders, and dementia) to examine its generalizability. Third, we are unable to validate the cutoff scores of the C-FQ to distinguish high and low levels of expressed emotion. This is limited by the lack of trained psychiatrists to conduct the Camberwell Family Inventory (CFI) for comparison. Future studies could validate the cutoff scores of expressed emotion in the Chinese context by using the CFI for comparison and taking possible cultural differences into account. In addition, future research should also (1) collect data on symptoms and rehospitalization to test the C-FQ's predictive power in clinical outcomes and relapse of patients; (2) further evaluate C-FQ psychometric properties with diverse samples of caregivers from different socio-cultural backgrounds; and (3) consider developing a valid patient report version of C-FQ that enables researchers to explore the interaction between patients and their caregivers using dyadic data (i.e., the EE caregivers expressed and the EE the patients perceived). Finally, although the self-report measure is easy to administer and less time-consuming, its methodological disadvantages should also be acknowledged. Self-report data may be affected by social desirability. Given the negative connotation of the high-EE construct, most FQ items are negatively worded. Participants might be reluctant to give a strong agreement response to those items due to the impact of social desirability. Therefore, short self-report measures are best viewed as probing for high-EE attitudes rather than a replacement for the full CFI.

## 5. Conclusion

Overall, the Chinese version of the Family Questionnaire is a reliable and valid measurement to assess the expressed emotion of caregivers of people with schizophrenia in the Chinese context. The C-FQ presents good reliability, construct validity, and concurrent validity. Our results also indicated that C-FQ has the same factor structure across sex, which supports the future researcher to compare the expressed emotion level among male and female groups in the Chinese context. Despite its short length, the C-FQ effectively measures two core elements of EE and requires no special training for the administrator. Thus, given the time constraints and shortage of training resources in Chinese clinical settings, it could be a preferred tool. A simple and short measure would also reduce respondents' burden, thereby increasing their willingness to respond. The C-FQ results can inform healthcare professionals about EE levels in family members in terms of critical comments and emotional overinvolvement. By obtaining clinical information on these aspects, healthcare professionals can develop timely and tailored interventions to improve the family environment of patients. The intervention on caregivers' EE levels may also help patients combat the negative impact of self-stigma. Evidence indicates that caregivers' high-EE levels may contribute to patients' self-stigmatization (79, 80). The reduction of caregivers' EE levels may keep people with mental health disorders from internalizing stigma attitudes and allow them to live more fulfilling lives. Except for clinical implications, the C-FQ can be used to advance our understanding of how EE manifests in China and how it affects patients and their caregivers through empirical research. In turn, these empirical studies would benefit the cross-cultural investigation of EE.

## Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

## Ethics statement

The studies involving human participants were reviewed and approved by the East China Normal University Committee on Human Research Protection (IRB No: HR 012-2019). The participants provided their written informed consent to participate in this study.

## Author contributions

YP was responsible for formulating research aims and designs, data collection, data analysis, and draft writing and revising. EX was involved in data analysis and original draft writing. YL and LS were responsible for the data collection. JX supervised this study and made critical revisions to the study. All authors contributed to the article and approved the submitted version.

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## Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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## Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpubh.2023.1200130/full#supplementary-material

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# HEAR US: a qualitative study of racial discrimination in Boston's Chinatown and empowering change from within the community

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**Objective:** To qualitatively explore the impact of anti-Asian racism in a Chinese community in the greater Boston area.

**Methods:** Individual semi-structured interviews (n = 27) were conducted between June and September 2021. Eligible participants were ethnic Chinese immigrants living in the Boston area, who were recruited through a community-based organization and by word-of-mouth. Interviews were conducted in Mandarin and Cantonese and translated into English. Data were coded and analyzed using a directed approach to content analysis.

**Results:** The majority of participants reported personal experiences of anti-Asian racism, ranging from microaggressions to violent attacks. Although lockdown and isolation during COVID-19 affected all communities, the Chinese community suffered unique and prolonged trauma stemming from the fear of violent attacks against Asians. The older person/people, in particular, were severely isolated due to fear of exposure to anti-Asian hate crimes. Participants reported a variety of emotional, mental, and physical health effects associated with feelings of fear, anxiety, isolation, and powerlessness. Many preferred to engage in self-protective behavior changes rather than relying on external resources.

**Conclusion:** Participants advocated for more education, community, and governmental support, and increased allyship between communities of color. These findings provide cultural context on the trauma this population faces and can inform further actions to address the wide range of reported health effects.

KEYWORDS

**Asian, Chinese, racial discrimination, stigma, mental health, COVID-19, qualitative study**

## Introduction

The COVID-19 pandemic placed a stark spotlight on social and racial disparities in the U.S., with Black, Indigenous, and People of Color (BIPOC) communities suffering disproportionately from the health and economic effects of the disease. People of Asian descent faced unique challenges and barriers during this time, stemming from the rise in racist rhetoric sparked by the reporting of initial cases of COVID-19 in Wuhan, China. However, bigotry toward Asian Americans is not a new phenomenon. Since Asians first arrived in the United States during the late 19th century, they have faced racial discrimination that has persisted over time. The oppressive policies aimed at Asian immigrants, coupled with conflicts between the Western and Eastern worlds in the 20th century, have deepened the animosity toward this community in the U.S. (1). The use of racist rhetoric to assign blame to specific ethnic groups for disease outbreaks is also not without precedence. Just as the Bubonic plague in the 19th century and the 2003 SARS outbreak triggered xenophobia, the advent of COVID-19 once again thrust Asian Americans into the spotlight due to widespread scapegoating (2, 3). This unfair targeting of Asian Americans can be attributed to the enduring stereotype that portrays them as "perpetual foreigners," regardless of nationality or immigration status (4–6).

Since March 2020, tens of thousands of racist incidents against Asian Americans and Pacific Islanders (AAPIs) across the U.S. have been reported to *Stop AAPI Hate*, an online reporting center established by a group of AAPI civil rights organizations (7). A large proportion (70%) of the reported cases were verbal attacks including racial slurs, name-calling, and profanities, while a smaller proportion (9%) of them were physical attacks (7). Several nationwide surveys have been conducted during the past three years revealing the oppressive and stressful environment faced by members of Asian communities. Statistics from a collection of survey data demonstrated increases in hate incidents targeting Asian American and Native Hawaiian/Pacific Islanders (AANHPIs) in 2020 and 2021 (8). Nearly 30% of AANHPI participants from the California Health Interview Survey reported having witnessed unfair treatment toward another AANHPI person, while 75% of Asian participants in the AA & NHPI COVID-19 Needs Assessment Project believed that the living environment in the US had become more threatening for their race (8, 9). The National Asian Pacific American Women's Forum (NAPAWF) survey revealed that more than two-thirds of AAPI women experienced racism or discrimination in 2020, with East Asian women reporting a much higher propensity to feel insecure compared to other Asian ethnic groups (51% vs. 33%) (10). Results from the Understanding America Study showed that Asians were more likely to perceive COVID-19-associated discrimination compared to non-Hispanic Whites (adjusted odds ratio = 3.2), and that perceived discrimination was related to a 30% increase in mental distress points based on the 4-item Patient Health Questionnaire score (11). Furthermore, an analysis of the 2020 Healthy Minds Study (HMS) found that over 60% of AAPI student respondents who experienced COVID-related racial discrimination met the criteria for at least one mental health condition (12).

The plethora of articles on the resurgence of anti-Asian racism in the U.S. following the pandemic has primarily been quantitative in nature (7–18). To date, only two qualitative studies have been published on this topic – one in Asian healthcare workers in Canada and the other in international students (16, 19). No studies have documented the lived experiences of a largely immigrant population of Asians in a community setting. The purpose of this study is to provide richer context to the numbers and types of experiences reported in quantitative surveys. Using in-depth qualitative interviews, this study further explores the thoughts, emotions, and reactions around personal experiences of anti-Asian hate, explores access and availability of local community support and resources, and solicits solutions to inform further actions by community organizations and governments.

# Methods

Our research team consists of a female Professor and epidemiologist with extensive global health experience in conducting mixed-methods research studies; a female Associate Professor with a professional interest in addressing healthcare access to reduce health inequities in vulnerable populations; three female research assistants pursuing Master's degrees in public health related fields with research experience and a passion for community health advocacy; and two community-based organization leaders, one male and one female, who have worked closely with the population being studied. All team members are Asian and committed to ensuring that the research is respectful and responsive to the needs of the community.

We conducted in-depth interviews with Chinese immigrants living in the Greater Boston area to explore their experiences and perspectives on anti-Asian racism during the height of the COVID-19 pandemic. We partnered with the Boston Chinatown Neighborhood Center (BCNC) to recruit participants using a convenience sampling approach and word-of-mouth referrals. BCNC is a longstanding community-based organization (founded in 1969) focused on empowering disadvantaged Asians and new immigrants to build healthy families, achieve greater economic success, and contribute to a thriving community. The majority of clients served by BCNC are Chinese. Information about this study was shared by the research team and BCNC via digital flyers and in hard copy. Bilingual research assistants contacted those who were interested to screen for eligibility. Eligibility for the study included individuals who self-identified as ethnic Chinese; were able to converse in Cantonese, Mandarin, or English; were 18 years of age or older; were knowledgeable about the needs of the local Chinese community; and were able to participate in a one-on-one interview via Zoom. Eligible participants were scheduled for an individual in-depth interview and received the consent script in their preferred language to review on their own before the interview.

Interviews were conducted between June and September 2021 via Zoom or by using the phone feature embedded within Zoom. One research assistant conducted the Mandarin interviews and one research assistant conducted the Cantonese interviews. Both research assistants were trained in qualitative interviewing techniques by the faculty researchers on the project. A verbal consent process was conducted at the beginning of each interview and any questions were answered. For participants who did not agree for their interview to be audio-recorded ($n = 1$), the interviewer took notes. The semi-structured interview guide focused on the impact of Anti-Asian racism on health and well-being during the pandemic. Although the study was conducted during the height of the COVID-19 pandemic, not all of the incidents reported were a direct result of the pandemic. The interview guide also included sociodemographic questions related to age, gender, education, household size, occupation, and years living in the U.S. Each interview lasted approximately 40 min. All participants received a $30 electronic gift card to compensate for their time. This study received ethical approval from Tufts University Social Behavioral & Educational Research Institutional Review Board (ID: STUDY00001487).

## Data analysis

A directed content analysis approach was used to analyze the qualitative data (20). Interviews were analyzed in Chinese (before translation to English) to ensure that the meaning behind codes and key themes would not be lost in translation. Prior to analysis, a list of overarching domains was created to guide the analyses, including effects of the COVID-19 pandemic on individuals, households, and communities; personal experiences of anti-Asian racism; effects of anti-Asian racism; resources for overcoming challenges; barriers to accessing these resources; and recommendations for improving community support. Two research assistants coded each transcript independently and met to discuss and ensure a shared understanding of each code and consistency in its application. All transcriptions and codebooks were subsequently translated into English so that codes and themes could be discussed among the entire study team and issues addressed.

# Results

Twenty-seven participants were recruited from the Chinese immigrant population living in the Greater Boston area. Table 1 shows the sociodemographic characteristics of the participants. Participants ranged in age from 25 to 73 years old and worked in various industries. The majority of participants (92.6%) were female, 70.4% were married, and 66.7% had a high school education or less. The two male participants both worked in the tech industry. Thirteen interviews were conducted in Cantonese, 13 in Mandarin, and one in English.

## Lived experiences of anti-Asian racism

A majority of participants shared personal incidents of racism and discrimination experienced by themselves, family members, or friends. Table 2 shows the types of discrimination described by community members, with microaggressions being the most frequently discussed type. Research participants often felt they were treated unfairly, stigmatized, or ignored while they were using public services or shopping. In addition, research participants reported several experiences of workplace racism or discrimination. Some participants felt that their opinions were not respected because of their race, while others shared about prejudiced treatment from their supervisors. One participant expressed particular concern over Chinese working in the information technology (IT) industry.

Many participants felt strongly that Asians or Chinese were stigmatized due to COVID-19 and mask-wearing. Blaming the Chinese for the pandemic was linked to *"leaders' remarks"* (ID 22) and *"misconceptions led by the media"* (ID 4). One participant noted that new COVID-19 variants had been found in other countries, but the Chinese were the ones that were stigmatized. Some participants also reflected on how they were avoided or discriminated against by others when wearing masks.

Another common type of discrimination shared by participants was verbal assaults. Research participants reported insults thrown at them when merely walking down the street. One participant further shared how she worried about her friend, a Chinese restaurant worker, who was constantly being harassed by unknown people calling the restaurant during the pandemic. In addition, two participants described violent attacks on older person/people Asians who were severely harmed and hospitalized. One of them shared that the grandmother of her daughter's friend *"was hit on her way back home from a walk, and her face was severely hurt."* (ID 3).

Our participants reported on a wide range of discriminatory incidents, both experienced or observed, but we did not note any associations between participants' characteristics and the type of discriminatory experiences they reported.

## Isolation

While social distancing and quarantine reduced everyone's connection at the beginning of the COVID-19 pandemic, members of the Chinese community appeared to experience more extreme isolation over a longer period. Some participants expressed that the Chinese community, in general, tends to be more cautious about COVID-19 compared to others and are therefore more inclined to reduce contact with other people, even when restrictions were lifted. In addition, several participants shared that they were especially scared to go out given their awareness of specific anti-Asian racism incidents taking place in the community and across the country. *"Trapped at home"* was the term used by one participant (ID 12) to describe the situation. Several participants mentioned that they specifically directed the older person/people in their households to not take public transportation, go grocery shopping, or even walk outside.

> *"I think I've never before felt scared for my parents the way I do now, especially because the older person/people were being attacked so blatantly and they still are. So, I've never had to have the conversation with my parents, like don't go outside [until now]." (ID 17)*

## Coping strategies

More than half the participants reported modifying their own behaviors to adapt to the challenging environment. Different types of strategies were described including isolation, avoidance, staying alert, and preparing themselves with defensive tools or weapons.

Many participants chose to avoid going to public spaces where incidents were likely to occur.

Others avoided going out at night and were extra careful when taking the subway, staying away from the edge of platforms. For safety reasons, younger adults also reported changing their daily routines and becoming more alert when outdoors.

> *"I will avoid areas … like a subway station or a place where many homeless people gather. It was unsafe already and could be even more dangerous during these turbulent times. It feels like violent people or people with bad behaviors may be more likely to be in those places." (ID 7)*

Some participants expressed the importance of being advocates and speaking up for themselves and others against discrimination.

> *"I just think it is my responsibility … I hope more people will understand. If I can do something and you can do a little bit, and we tried to stop it from getting worse, then why not?" (ID 7)*

However, most of our participants were hesitant or afraid to speak up, primarily due to concerns about personal safety. For example, one participant expressed:

TABLE 1 Characteristics of interviewees ($n = 27$).

| ID | Language | Age | Gender | Education | Marital status | Household Size | Occupation | Years in the U.S. |
|---|---|---|---|---|---|---|---|---|
| 1 | Cantonese | 53 | Female | < High school | Married | 9 | Homecare Worker | >10 |
| 2 | Cantonese | 73 | Female | < High school | Married | 3 | Retired | 13 |
| 3 | Cantonese | 55 | Female | < High school | Married | 4 | Home Help Aid | 21 |
| 4 | Cantonese | 57 | Female | Some College | Married | 4 | Stay home mom | 13 |
| 5 | Cantonese | 58 | Female | High school | Married | 3 | Home Help Aid | 10 |
| 6 | Mandarin | 27 | Female | College | Single | 2 | Accountant | 11 |
| 7 | Mandarin | 25 | Female | Master's degree | Single | 3 | Accounting Analyst | 14 |
| 8 | Mandarin | 49 | Female | Associates Degree | Single | 2 | Personal Care | 7 |
| 9 | Mandarin | 54 | Female | High school | Divorced | 3 | Stay home mom | 10 |
| 10 | Cantonese | 42 | Female | Associates Degree | Married | 4 | Retail | 6 |
| 11 | Cantonese | 35 | Female | High school | Married | 5 | Unemployed | 7 |
| 12 | Cantonese | 33 | Female | High school | Married | 5 | Home Help Aid | 9 |
| 13 | Cantonese | 37 | Female | High school | Married | 3 | Nursing | 15 |
| 14 | Mandarin | 48 | Female | < High school | Divorced | 3 | Certified Nursing Assistant | >8 |
| 15 | Mandarin | 50 | Male | College | Single | 4 | Software Programming | 25 |
| 16 | Mandarin | 31 | Male | Master's degree | Separated | 2 | Software Engineer | 9 |
| 17 | English | 46 | Female | Master's degree | Married | 4 | Stay home mom | Born in U.S. |
| 18 | Mandarin | 43 | Female | High school | Married | 3 | Assembly line worker | 5 |
| 19 | Mandarin | 38 | Female | High school | Married | 4 | Stay home mom | 10 |
| 20 | Mandarin | 43 | Female | High school | Married | 4 | Personal care (older person/people) | 9 |
| 21 | Mandarin | 35 | Female | High school | Married | 7 | Stay home mom | 21 |
| 22 | Mandarin | 34 | Female | High School | Married | 6 | rental assistance coordinator | 10 |
| 23 | Mandarin | 33 | Female | College | Single | 4 | Hospital financial analyst | 17 |
| 24 | Cantonese | 31 | Female | High school | Married | 5 | Stay home mom | 11 |
| 25 | Cantonese | 51 | Female | Middle School | Single | 2 | Helper | 20 |
| 26 | Cantonese | 32 | Female | High School | Married | 4 | Stay home mom | 9 |
| 27 | Cantonese | 46 | Female | High School | NA | 4 | Stay home mom | 13 |

*NA = Not ask.

> *"I am afraid that if I argue with the person, it will escalate the issue into a physical conflict and threaten my physical safety." (ID 16).*

Many weighed the potential costs and benefits of fighting back when encountering racist events, but in most cases, they felt the costs outweighed the benefits and that prevented them from defending themselves. Participants felt that they were in a helpless situation and believed that keeping silent was the best option for them. As one participant reflected:

> *"Many Chinese do not know what to do when they encounter these problems. They do not speak English and it is difficult to ask for help. Moreover, many Chinese are unwilling to help out when they see this kind of thing." (ID 27)*

Consequently, most parents of school-age children instructed their children to *"not have conflicts"* (ID 26) and *"stay away from people"* (ID 25) in order to avoid problems.

When discussing incidents of workplace discrimination, participants mentioned some actions that were taken by the victims against unfair treatment. One reported success after getting support from the workplace.

> *"… then she [participant's daughter] went to [her boss], and then her [workplace] had a multi-ethnic and multi-racial meeting, and*

TABLE 2 Anti-Asian racism incidents reported by participants – illustrative quotes by code.*

| | |
|---|---|
| **Microaggressions/Discrimination in various situations** | |
| In accessing public services | “We thought that was discrimination since we have some other friends who had completed the application for the same housing location, and they had not been asked to provide as many materials as this person had been asked for. And those extra materials were hard to obtain so this friend finally lost the housing opportunity.” (ID 10) |
| | “When I called the services department, they usually called me back very slowly, but when others who were able to speak English made the call, they usually called back much sooner.” (ID 12). |
| | “When I went to apply or get things, their attitude toward Chinese was not very good. They felt that we did not understand English, so we were not willing to apply for things.” (ID 20) |
| In stores | “I was …at the cashier line at [retail store]. There was a staff calling people in line to check out at a new open counter. And the Chinese person behind me was trying to remind two non-Asian people [who were standing in front of me] to move to the new line but was verbally attacked by them saying that he [the Chinese guy] had no right to ask them to move.. [one] person looked so aggressive that he looked like he was ready for a fight..” (ID 1) |
| | “When I was waiting in line for the check-out, one person jumped the queue and stood right in front of me. And he kept staring at me … even as he left the store. I did not dare to look back at him because I was freaked out…” (ID 2) |
| | “I heard the child ask the father, ‘Why are WE not wearing masks as they do?’ They referred to me and my family…His father said, ‘Because they are Asian’…I was very angry when I heard that at the time.” (ID 7) |
| | “Recently, when I went to [name of store], the salesperson ignored me and my family for more than 10 or 20 min. She excused herself when I reported her disrespectful behaviors…I feel like we were being treated like air. They ignore our existence. We are treated unfairly, and it seems like we are not welcomed here.” (ID 13) |
| In the workplace | “My colleague’s son works in the IT industry. He has mentioned the increasing mistrust of the Chinese in this industry…It is basically the conflict between governments, but it is just so unfair to us and our next generation..This will definitely limit their job choices in the future.” (ID 4) |
| | “…but because he felt he was Asian, if he brought this up, the company would not be willing to listen to his advice” (ID 7) |
| | “..*[supervisor]* speaking with a tone or a facial expression that is insulting…because it is not once or twice, many times are not ok.” (ID 9) |
| | “Their [supervisor’s] attitude made me feel like I was causing trouble, and in the end, my attitude was to give up.” (ID 15) |
| | “I’ve experienced microaggressions throughout my career, throughout school… blatant racism throughout higher-ed, even though my master’s program, microaggressions within family circles at birthday parties for kids, at the school setting from teachers, from other parents that we playdate with.” (ID 17) |
| Stigmatization | “My family all wore masks and went [shopping]. There was a father and son. That son was very young, he was only eight or nine years old. “I heard the child ask the father, ‘Why are WE not wearing masks like they do?’ They referred to me and my family…His father replied, ‘Because they are Asian.’” (ID 7) |
| | “At the beginning of the pandemic, even my good friends also asked if this was ‘your Asian virus’ (ID 21) |
| | “I took the elevator to go downstairs. There was a person in the elevator who saw that I was wearing masks and did not want to be the same elevator with me… The person’s attitude was not asking and I felt discriminated against.” (ID 23) |
| | “Asians wear masks, people of other races will avoid us when passing by.” (ID 26) |
| **Verbal attacks by strangers** | |
| | “[*My friend’s*] family runs a restaurant.. many unknown people called to his restaurant to curse him, because everybody knows that it is a Chinese restaurant. They called to scold my friend…” (ID 7) |
| | “Once I was walking on the road, there was a person who said “Chin-English,” but he passed by quickly” (ID 8) |
| | “Once in Boston, there was a homeless person on the street. It was relatively late. When there was no one on the road, he would ask for money when you pass by. I said, ‘oh sorry, I do not have one’, he said something such as, ‘go back to your country’, or other words.” (ID 16) |
| | “…as early as March 2020 I heard friends getting verbally assaulted in NY City on public subway, and then in different parts of the tri-state.” (ID 17) |
| | “Someone spit on me and shouted, ‘shut the [expletive] up, your Asian virus go away’” (ID 21) |
| | “During the lockdown I was scolded by others for no reason in the supermarket parking lot.” (ID 22) |
| **Violent attacks on older person/people Asians** | |
| | “…something that happened to my granddaughter’s classmates’ grandma. She was robbed by a [man] when she came out from [retail store]. She did not allow the robber to take her bag so she was beaten by the robber and she needed to go to the hospital. I have seen her photos that her face was badly hurt (swollen and bruised). It makes me so scared to go out at night, not even after 6 pm..” (ID 2) |

*(Continued)*

TABLE 2 (Continued)

| Violent attacks on older person/people Asians | |
|---|---|
| | "The grandmother of my daughter's friend got hit a few days ago, around May 20th. Her face was seriously hurt and she needed to go to the hospital. It was said that the grandma was hit on her way back home from a walk, and her face was severely hurt. But she was attacked randomly, you know." (ID 3) |
| | *[Referring to a previous incident where an aunt was beaten]* "It was so panic and painful in my heart. After all, a person who is such a close family member.. I feel that such a person who harms the older person/people for no reason is really inhumane and excessive." (ID 14) |

*A participant can report multiple types of racism experienced.

> *then finally she felt that she won because the boss was transferred." (ID 9)*

Other participants, however, were not as successful:

> *"… the [supervisor's] attitude made me feel like I was causing trouble, and in the end, my attitude was to give up." (ID 15)*

The feeling of living in *"someone else's country"* (ID 15) further constrained this participant from asking for equality and respect.

Some emphasized the importance of learning self-defense and being physically prepared for attacks. Tools like security cameras, pepper spray, and other weapons provided them with a sense of security to be able to defend themselves in case of an attack.

## Health effects

Health and safety concerns significantly impacted the mental and emotional well-being of community members. Worry, stress, fear, anger, depression, and sleep disturbances were commonly reported by community members. Participants felt strongly that anti-Asian racism experiences continued to have negative effects on mental health.

Participants expressed feeling very conflicted because although they were angry at being targeted, they were also worried about escalating the situation. Several participants discussed how they did not feel secure and were constantly worried about being hurt by people around them.

> *"You worry about going out, you must be more careful, you are going to be paranoid, and you need to be highly vigilant. You think about whether the person around you may hurt you. In the long term, you are overly nervous." (ID 8)*

Unstable mood was another manifestation resulting from worry – not only about their own circumstances but also about the safety and isolation of their older person/people parents.

> *"Because I live in a senior house and take care of my father, I can especially feel that the quality of life of the older person/people has changed a lot. They stay at home and are afraid of going out. They are very nervous, so as their offspring … I am a lot more irritable than before, and my mood is not very stable, because you don't go to work, you have less money, there are a lot of messes, and I have to worry about what happens to my father." (ID 9)*

In addition to their own mental health, some spoke of the negative effects of racism on the younger generation and the views that children were developing about themselves and the world. One participant stated,

> *"… any toxic environment will affect the victims' mental health. If this phenomenon is very common, then many Asian children will be traumatized. Because discrimination, no matter what form, time, or context, will have a negative impact on people's mental health." (ID 6)*

Although most parents stated that their children had not encountered anti-Asian racism, they still worried about how their children might be bullied or attacked at school. Parents believed that *"children are impacted by their parents' ideas"* (ID 21). The influence that parents have on their children's attitudes is highlighted by the story shared previously from the participant who overheard a non-Asian father explaining to his child in the store aisle that the reason the participant's family was masked was *"because they are Asian"* (Table 2, Stigmatization, ID 7).

## Resources and barriers to accessing resources

Community members pointed out some of the existing resources that they found helpful to combat the rising crisis of anti-Asian racism. Support from the workplace was mentioned most frequently. For some, their workplace offered support by having regular and open discussions about racial justice or providing individual support through HR departments. One participant shared her experience at the workplace:

> *"In my company, there is an HR department. There are no support groups dedicated to this, but if you have anything [race-sensitive experiences], you can go to them." (ID 6)*

A few parents commented about the schools' approach to racial justice. Some schools held meetings for faculty on a regular basis to discuss racial equity issues. Many parents trusted the ability of teachers and schools to handle conflicts and incidents. Family liaisons at schools and in the Department of Education were mentioned several times by parents as a resource.

Participants mentioned several types of social media and other platforms used to disseminate information to the community. "Stop Asian Hate"-related YouTube campaigns, WeChat petitions, online and in-person community meetings, flyers with safety information, and "Stop Asian Hate" signs in the community all contributed to increasing awareness of racial injustice in the Asian community. Participants were also aware of several local organizations in Chinatown and the Greater Boston area that were dedicated to supporting Asians.

Although resources exist and are helpful in supporting the community, not all participants were able to easily access them. Some of the major barriers preventing people from getting help included a lack of knowledge about existing resources, language barriers, financial constraints, and limitations of the existing programs. Some participants indicated that they were either not aware of community resources or did not know how to access the resources they heard about. One participant shared,

> *"I think such an organization definitely exists [for mental health counseling], but I don't actually know how to access it. So, I think it would be very helpful if someone can find this resource very simply when they have needs." (ID 6)*

Individuals with limited English proficiency found it especially challenging to request help, and it often took extra effort and money to access simple social services. One participant provided an example about contacting the police during emergencies,

> *"The older person/people know the phone number to dial [911] but they are not able to communicate with police when they encounter problems." (ID 14)*

Language and cultural barriers also limit the services available to immigrants. Participants commented that they had to rely on organizations that speak their language. One participant was struggling to find a culturally competent therapist who would understand her perspective. Some expressed such difficulties in overcoming these barriers that they lost trust in their community's ability to support their needs. One participant expressed disappointment when asked about which community resources they accessed – *"Nothing. I can only do my part by myself"* (ID 24).

## Proposed solutions

Community members were asked to provide suggestions on how to fight against anti-Asian racism. Five main suggestions were identified from the responses: (1) improve education on racial equity, (2) enhance support within the AAPI community, (3) encourage social advocacy to make AAPI voices heard, (4) create alliances with other BIPOC communities, and (5) improve government support and protection for the community.

(1) Improve education on racial equity.

Participants mentioned that they hoped to see more education on racial justice. Increasing awareness of racial justice comprehensively, regardless of age and background, would be a fundamental strategy for improving racial justice. As one participant stated, *"it begins with education and there is not an age that's too young"* (ID 17). Another participant suggested, *"the school can provide a brochure telling children what to do* [when they are bullied]*"* (ID 28).

(2) Enhance support within the AAPI community.

Although participants felt it was important for Asians to shift from avoidance to advocacy, the importance of having empathy and support was also recognized. Establishing community support groups and providing safe spaces for people to communicate thoughts, share experiences, and discuss difficulties was suggested as a potential way to provide direct help to community members. One participant suggested:

> *"… just provide them [Chinese community] with such a forum … a safe place to express their unhappiness or whatever they encountered, that will be good". (ID 9)*

Another suggestion was for community organizations to provide counseling services targeted at racism-related issues. Specifically, one participant commented:

> *"It would be good for organizations to hold meetings for educational purposes about equal rights. And also, they [organizations] can help the victims who suffered from racist incidents. They will provide us with emotional support as a group". (ID 2)*

(3) Encourage social advocacy to make AAPI voices heard.

Participants shared similar opinions about the importance of speaking up and raising awareness within and outside the Asian community. Participants felt that not everyone may be aware of the severity of the racial injustice facing the Asian community, so people should speak out about their racist experiences in community forums and through awareness campaigns. One participant used the Black Lives Matter and the LGBTQ movements as examples of successful campaigns that helped to draw society's attention.

> *"Like LGBTQ groups, and then the black community, they have been successful in getting their voice out, and the public has heard it. For example, June is now Pride Month. So I think that LGBTQ groups can stand up for themselves, and at the same time, they can show their true faces to everyone, not be demonized or treated with prejudice, and then let everyone correctly understand who they are as groups. So this is a successful campaign that I think is relatively healthy." (ID 6)*

Publicizing the issue through newspapers, on TV, and in social justice campaigns was also recommended. However, as mentioned previously, the lack of a sense of security was a major concern preventing people from speaking up individually about racial encounters. In many cases, people were aware of the injustices and wanted to make changes, but perceived threats prevented them from speaking up. Cultural barriers were also mentioned as a reason why people did not speak up.

> *"There's a whole Saving Face thing, like you know a lot of people within our culture just aren't going to broadcast it. Even if it's dire and terrible and people should know for their own safety, I think that's just like an ingrained part of our overall Asianness – to keep quiet and low-key." (ID 17)*

(4) Create alliances with other BIPOC communities.

Building upon social advocacy, community members hope to improve cross-ethnic collaboration and communication to reduce misunderstanding and increase appreciation of different cultures and perspectives. As one participant believed, *"It's really powerful when there are alliances and community between each other, whether it's across ethnicities or across gender … Groups need to talk"* (ID 17) Such connections can also foster empathy and trust, as well as make individuals and communities feel more included. One participant shared that *"a lot of friends around me were not Asian, but when they heard about my experience or the experience of my Asian friends around me, they were willing to offer help"* (ID 7).

(5) Improve government support and protection for the community.

Furthermore, participants spoke about their wish for more government-level effort to be devoted to helping address the difficulties faced by Asians. One community member hoped that *"the government will make a correct statement, not to say that this is a Chinese virus"* (ID 21).

Specifically, participants wanted to see increased police presence and response to enhance their sense of security in the community, such as having more police patrols. One participant suggested that:

> *"for places where these things [physical attacks] frequently happen, patrol cars should move around more often. We must increase efficiency and adopt such measures". (ID 14)*

Another participant shared:

> *"For my robbery experience, I waited for more than twenty minutes to have the police arrive to help me although the police station was only a 5-minute walk to the place where I was robbed." (ID 1)*

Improving legislation on hate crimes to support minorities with legal protection was also strongly desired. More than one participant pointed out the importance of having strong leadership that represents the voice of minorities. Participants hoped that:

> *"… in the future, there will be more Asians or people of Chinese descent who can enter politics or reach a higher level in society, a higher position. And if they can make use of their social resources, they will be influential. People will respect them, listen to them, and then they can make our voices heard." (ID 16)*

## Discussion

The HEAR US study reveals multiple effects of anti-Asian racism on a community of Chinese immigrants during the COVID-19 pandemic. Although we do not have any historical comparisons, our data captured the heightened fear and anxiety of attacks that participants associated with the amplification of anti-Asian hate crimes during that period. Compared to previous studies on this topic which were primarily conducted using quantitative surveys, our qualitative results provide more vivid and nuanced descriptions of the lived experiences of this community, depicting the overt and inner struggles of the community and its effects on health. Our qualitative interviews went further to solicit ideas and solutions from participants that would be helpful to the community, information that previous quantitative surveys did not provide.

For the most part, the major themes obtained from our interviews agree with results from previous quantitative surveys and are not unique to the Greater Boston area. Our findings suggest that anti-Asian racism was widely experienced by community members, with microaggression being the most reported type of incident followed by verbal assaults and physical attacks. The extensiveness of racist incidents that we discovered locally resonate with the findings from surveys that explored the discrimination experience of the AAPI population nationally (10, 12, 14). For example, the COMPASS Study, a nationwide community-based survey, showed that 60.7% of its participants reported discriminatory experiences, and the NAPAWF revealed that 74% of the AAPI women who participated reported such experiences (10, 14). For the types of racism incidents, our findings align with another interview-based study that explored the discrimination experience among Asian healthcare workers, which highlighted the common occurrence of microaggressions against Asian healthcare workers in both the hospital setting and outside environment during the height of the COVID-19 pandemic (16). Our study also finds that verbal assaults and physical attacks are two other types of incidents that are commonly reported by the research participants.

Although many participants felt that Boston was safer compared to other areas, such as New York and California, all 27 participants were easily able to share incidents of perceived racism experienced personally or by friends and family members (14). It was noted in a prior national survey that hate crimes are usually underreported since people often lack the literacy, resources, or simply courage to report such events (13). Although the racism incidents reported in our study are mainly microaggression and verbal assaults, and not physical attacks, reports of violence against Asians elsewhere can still have significant effects on individuals, especially on their sense of security.

The health effects reported by our participants encompass emotional, mental, and physical health effects. Our results align with findings from both regionally and nationally representative surveys and demonstrate the negative association between discrimination and well-being (8, 21, 22). A cross-sectional study that surveyed Chinese and South Asian adults in Chicago found that the prevalence of depressive symptoms among these groups had doubled since the pandemic began (23). Other survey-based studies found that high proportions of participants reported feeling stressed, anxious, depressed, or distressed about discriminatory experiences (10, 12, 15). Among our participants, fear, anxiety, stress, helplessness, a sense of insecurity, and anger are all mentioned as emotional and mental health effects resulting from experiences of racism and discrimination. These negative psychological effects are similar to findings from qualitative studies conducted in other populations of Asians. The qualitative study by Shang et al. in Asian healthcare workers in Canada and the US reported that experiences of threats of violence or actual physical assault linked to COVID-19 resulted in a range of negative emotions and cognitive processes, such as despair, rumination, and hypervigilance among the victims (16). In a study of Asian international students in the U.S., participants reported similar mental health challenges facing this ethnic group during COVID-19, mainly attributed to the rise of anti-Asian racism, the lack of sense of belonging and social support, and the uncertainties around immigration status related to the unexpected lockdown (19).

Chronic mental stress can lead to changes in physical health, as reported by our participants (24, 25). Sleep disturbance and deterioration of sleep quality are the major physical manifestations of the stress experienced by participants during this period. A similar observation was made in a prior online survey among Asian American adults as well as in a longitudinal study among Asian American adolescents, demonstrating the association between racism-related experiences and poor sleep quality (21, 26).

Many of the health effects mentioned by the participants, such as anxiety and sleep disturbances are symptoms of depression. However, few of the participants specifically used the Chinese word for "depressed" or "depression" in their descriptions. For cultural reasons, many Asian immigrants are hesitant to link their experiences to psychological changes and to seek mental health services (15, 18, 27). They are generally afraid to bring stigma and shame upon themselves and their families due to the perceived discrimination associated with mental health conditions (28). In other words, although mental health impacts were mentioned in interviews, it may be just the tip of the iceberg. Culturally, people of Asian descent may unconsciously downplay or ignore the impact of the challenging events on their health and not realize the long-term consequences. This issue is further compounded by the lack of culturally competent mental health providers, as shown in the literature (27, 29, 30). Improving access to culturally and linguistically appropriate mental health services is urgently needed in this population.

When asked about the resources that Asian immigrants can access to address challenges and the barriers they faced when seeking help, participants indicated that they were either not aware of community resources or did not know how to access the resources they heard about. Only a few community organizations were named as being helpful in addressing the issue of anti-Asian racism.

When asked for suggestions on how services can be improved, participants mentioned building social support as one of the key strategies. Participants suggested that local communities set up support groups to develop interpersonal connections, enhance racial identity and pride, and provide guidance for people in need. They noted that community organizations can help improve access to existing resources and provide a forum to build emotional support and courage to speak up for their rights. Where possible, to build collective efficacy, organizations should hold conversations about how to implement emotional support services more effectively, ensuring such services are easily accessible to community members and safe spaces are available for discussion around sensitive topics like racism. Teaching community members to advocate for themselves to speak up against racism may be necessary to address cultural norms of staying silent and avoiding conflicts. Recognizing the limited funding and capacity of many organizations, it is important to have cross-sector learning and to invest in local community-based organizations so that they can provide linguistically and culturally responsive services. Community members also expressed interest in building alliances across ethnic groups to foster inter-racial communication and understanding to strengthen the respect between racial groups. A nationally representative survey conducted by the NAPAWF also emphasized the role of community partnerships as being the crucial bridge between individuals and societal resources (10). Finally, education on racial equity in school-age children is another important strategy mentioned by participants which will help to address the issue from a young age. Family-oriented interventions to teach both parents and kids how, when, and to whom incidents of bullying and discrimination should be reported can also help foster communication about racial injustice between parents and their school-age children.

From the systems level, developing culturally and linguistically appropriate resources and tools will be necessary to support Asian immigrants' health, and such a strategy is also applicable to assist other minority groups. More governmental level support is desired as well, to ensure basic social security and fundamental justice against discriminatory events. Although federal-level hate-crime legislation was enacted in 2021, more support from local governments is crucial to maximize the effect of the federal law (31).

Our study has several strengths. The qualitative nature of this study allows participants to share their stories more deeply and reflect on their culture and identity. The use of the interpretive paradigm in this study is another strength, which helps value the social contexts when understanding human behaviors (32). In addition, our study is unique in that bilingual interviewers helped to facilitate trust building with participants, which allowed for deeper narratives as participants could more easily express their thoughts and opinions in their native language.

Although our study provides us with an in-depth understanding of the effects anti-Asian racism, there were some limitations to our study. Firstly, due to the qualitative nature of this study, we are not able to quantify the prevalence and severity of racist events, which could be helpful in determining the intensity of anti-Asian racism specifically in the Greater Boston area. Nevertheless, the primary purpose of our study was not to measure the extent of anti-Asian discrimination, but rather to offer context and amplify the voices of those affected. By exploring their thoughts, emotions, and reactions to these incidents and proposing solutions from the community, our findings still have significant implications for society.

Secondly, since this study is cross-sectional in design and cannot establish a causal relationship or indicate whether discrimination increased during the pandemic. We did not ask these questions directly in our interview and no pre-pandemic studies are available for comparison. Although we can't directly attribute discrimination and racial hate to the pandemic, it is important to acknowledge that the COVID-19 outbreak acted as the major catalyst for the collective awakening and reporting of anti-Asian racism across the country, making this issue worthy of investigation.

Thirdly, participants were purposefully recruited to share their observations and personal struggles with anti-Asian racism, which could introduce some bias in the stories and opinions expressed during the study. Being aware of this potential bias can help contextualize and interpret the narratives provided. For example, the majority of participants were female, so male perspectives were lacking. Also, our study included only Chinese immigrants, which limits our understanding of what other Asian ethnic groups experienced during the pandemic. However, within these subgroups, we were able to obtain perspectives from a diverse group with respect to language (Cantonese vs. Mandarin), age, education, marital status, and occupation.

The HEAR US study showcases the unique struggles the Chinese community faced during the COVID-19 pandemic amid the rise of anti-Asian racism in the U.S. and reveals just how common experiences of racism and discrimination are in people's daily life. To effectively restore and better support the well-being of this minority group, future actions can be taken such as improving education on racial justice; improving self-efficacy to speak out against racism; encouraging social advocacy; reinforcing collective discussion between groups; enhancing community and government support of culturally and linguistically appropriate services; and having representative leaders that speak in the voice of the community. The HEAR US team will continue to work with local community-based organizations to develop resources and programs to provide targeted support. As society becomes more diverse and connected, more studies to understand the challenges faced by immigrants will be helpful to promote health equity and healthy lives.

## Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

## Ethics statement

The studies involving humans were approved by Tufts University Social Behavioral and Educational Research Institutional Review Board (ID: STUDY00001487). The studies were conducted in accordance with the local legislation and institutional requirements. The ethics committee/institutional review board waived the requirement of written informed consent for participation from the participants or the participants' legal guardians/next of kin because the interviews were conducted remotely during COVID-19, and the participants provided verbal consent.

## Author contributions

The authors confirm that AT, KD, YY, and BH contributed to the conception and design of the study. SC, YL, and SL were involved in data collection and analysis. All authors discussed and contributed to interpretation of results. SC and YL drafted the manuscript. All authors contributed to the manuscript revision, read, and approved the submitted version.

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## Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

## Publisher's note

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# Attitudes and intentions toward seeking professional psychological help among Chinese healthcare workers during the COVID-19 pandemic

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**Background:** It has been suggested that healthcare workers (HCWs) are experiencing massive stressors that threaten their mental health during the COVID-19 pandemic, but little is known about their attitudes and intentions toward seeking professional psychological help. This study aimed to investigate the attitudes and intentions of Chinese HCWs toward seeking professional psychological help during the COVID-19 pandemic and the associated factors.

**Methods:** A total of 1,224 Chinese HCWs working in hospitals were recruited online from 12 hospitals in Hunan province in China for a survey conducted in November 2022. The Chinese version of the attitudes toward seeking professional psychological help scale-short form (ATSPPH-SF) and the general help-seeking questionnaire (GHSQ) were separately used to assess the attitudes and intentions of the respondents toward seeking professional psychological help. Demographic and socio-psychological data were collected using a self-developed questionnaire, the perceived social support scale, the self-stigma of seeking help scale, and the patient health questionnaire-9 scale.

**Results:** The 1,208 HCWs in the final analysis showed relatively negative attitudes and low intentions toward seeking professional psychological help during the COVID-19 pandemic. Results of the multiple linear regression analysis showed that female sex ($p = 0.031$), experience of psychological learning ($p < 0.001$), and social support ($p < 0.001$) had a positive predictive effect on the attitudes of these HCWs toward seeking professional psychological help, whereas self-stigma of seeking help ($p < 0.001$) and depressive symptoms ($p < 0.001$) exerted negative effects. Moreover, experience of psychological learning ($p = 0.004$) and social support ($p < 0.001$) had a positive predictive effect on the intentions of these HCWs toward seeking professional psychological help, whereas divorced marital status ($p = 0.011$) and self-stigma of seeking help ($p < 0.001$) exerted negative effects.

**Conclusion:** The overall attitudes and intentions of HCWs toward seeking professional psychological help were not optimistic. Effective interventions targeted at influencing factors should be formulated to promote the professional psychological help-seeking attitudes and intentions of HCWs who are at risk of developing mental health problems.

KEYWORDS

**attitudes, intentions, healthcare worker, help-seeking, psychological help**

## Introduction

COVID-19 has been a significant global public health problem since late 2019 (1–3). During the COVID-19 pandemic, healthcare workers (HCW) all over the world have experienced massive psychosocial burden and mental health problems (4). A meta-analysis of 65 studies involving 79,437 participants worldwide reported that the overall prevalence rates of anxiety, depression, stress, post-traumatic stress syndrome, insomnia, psychological distress, and burnout among HCW were 34.4%, 31.8%, 40.3%, 11.4%, 27.8%, 46.1%, and 37.4%, respectively, all of which exceeded their corresponding levels before the COVID-19 outbreak (5). A recent survey also showed that 819 (10.5%) of 7,795 frontline Australian HCWs thought about suicide or self-harm during the second wave of the pandemic (6). These data highlight the need to take appropriate measures for addressing COVID-19-related mental health problems.

Since the start of the COVID-19 outbreak, mental health professionals and health authorities in several countries started offering telehealth mental health services, such as telephone hotlines, online 24/7 psychological counselling, synchronous video conferencing, SMS text messaging services, and online psychological self-help interventions, for HCWs and other individuals experiencing psychological crises during the pandemic (7–9). On-site professional psychological services were also provided in designated isolation hospitals. These services were crucial to alleviating the psychological symptoms experienced by HCWs during the crisis (10). However, large-scale studies revealed that only few HCWs actively seek help for their mental problems. For instance, only 2.3% to 18.3% (11–14) of HCWs experiencing mental distress sought professional support, and less than half [388 out of 819 (6)] of those HCWs with thoughts of suicide or self-harm reported professional mental help-seeking behavior during the pandemic.

While the factors associated with the delays, decreases, or deficits in the help-seeking behavior of HCW have been explored in the literature, these studies have mainly focused on demographic (e.g., age and sex), knowledge and structural (e.g., psychological training and time), and social psychological factors (e.g., social support level, depression, anxiety, and stigma) (12, 13). The most commonly reported barriers included confidentiality concerns, lack of time, stigma, lack of awareness about the availability of support, and negative career implications (12, 15, 16). HCWs with previous psychological training experience, high level of social support, depression, and anxiety were more likely to demonstrate mental help-seeking behavior, which can be further promoted by positive work environments and availability of support services; meanwhile, some demographic factors associated with help-seeking behavior remain debated (6, 11, 12, 17).

Psychological help-seeking is an adaptive coping process where individuals seek external assistance from health professionals and others to deal with their mental health problems (18). This process includes three key components, namely, general attitude toward obtaining assistance, future behavioral intentions, and observable behavior. According to theory of planned behavior action, attitudes can strongly influence intentions, which in turn affect actual help-seeking behaviors (19). Therefore, identifying help-seeking attitudes and intentions can help predict actual help-seeking behavior and support those interventions that are aimed toward improving psychological help-seeking. However, previous research on the psychological help-seeking behavior of HCWs has largely ignored their attitudes and intentions toward seeking professional psychological help (20).

While most countries have canceled their strict public health measures over time, China has maintained its long-term "dynamic zero-COVID policy" as an overarching strategy that takes restrictive measures to quickly "zero out" the infected people at the social level and to stop the spread of the virus in a region (21). Accordingly, Chinese HCWs continue to experience massive challenges, psychosocial burden, and suffering in their mental health. The gap between the high prevalence of mental health problems and low rates of actual professional psychological help-seeking behaviors as well as the significant impact of help-seeking attitudes and intentions on actual help-seeking behavior only underscore the significance of investigating the attitudes and intentions of Chinese HCWs toward seeking professional psychological help. Therefore, this paper aims to investigate the level of attitudes and intentions toward seeking professional psychological help among Chinese HCWs who are at risk of experiencing mental health problems during the COVID-19 pandemic and to identify the potential influencing factors associated with such attitudes and intentions. Results of this study can guide the development of targeted interventions and improve the early diagnosis and treatment of HCWs mental health problems.

## Materials and methods

### Study design and participants

A cross-sectional survey was conducted in November 2022 at a time when the participants were experiencing huge psychosocial burden due to the pandemic. The participants were recruited online from 12 hospitals in Hunan Province. These hospitals were selected by convenience sampling. The inclusion criteria for the participants were: aged 18 years or above; HCWs working in hospitals as either doctors or nurses; and were willing to take part in the study voluntarily.

An electronic questionnaire was designed by using a commonly used questionnaire star web/app in China, and an online survey link was initially distributed by the director of the nursing department of the selected hospitals to HCWs through WeChat, which is one of the most commonly used social media applications in China. All participants clicked on the online survey link voluntarily and were informed about the research aims, design, methods, risks, benefits, and how their personal data would be handled. They were also advised that returning the completed questionnaire was equivalent to giving their informed consent. Each participant can only fill out the questionnaire once. The collected data were kept strictly confidential and used only for research purposes. Ethics approval was provided by the medical ethics committee of the Hunan University of Medicine (2022/H120020).

The sample size was determined based on the findings of previous surveys conducted in four European countries (22). With a standard deviation ($\sigma = 5.7$), permissible error ($\delta = 0.475$), and significance level ($a = 0.05$), the required sample size was calculated to be 553 by using an online Chinese sample size calculator. A total of 1,224 HCWs completed the questionnaires, of which 16 questionnaires were discarded for not being filled out by either a doctor or nurse. A total of 1,208 questionnaires were retained for the analysis.

## Measures

### Socio-demographic characteristics

The sociodemographic characteristics of the participants included their age, sex, marital status, education level, working years, occupation, employment title, department, frontline or non-frontline staff in epidemic prevention and control work, sleeping time, and psychological learning experience.

### Attitudes toward seeking professional psychological help

The attitudes of HCWs toward seeking professional psychological help was assessed using the Chinese version of the attitudes toward seeking professional psychological help scale-short form (ATSPPH-SF) (23), which comprises 10 items divided into 2 dimensions, namely, openness to seeking treatment for emotional problems and value and need in seeking treatment. Each item was rated on a 4-point Likert scale ranging from 0 (disagree) to 3 (agree). The total scores ranged from 0 to 30, with higher scores indicating more positive attitudes toward seeking professional help. The attitude of a respondent was deemed positive when the total score was ≥20 and when the score for each dimension exceeded 10. Items 2, 4, 8, 9, and 10 were reverse scored. This scale had a Cronbach's alpha of 0.681, item content validity (I-CVI) of 0.833 to 1.000, and scale content validity index (S-CVI) of 0.932 among community residents in China (23). In this study, ATSPPH-SF obtained a Cronbach's alpha of 0.651.

### Intentions toward seeking professional psychological help

The general help-seeking questionnaire (GHSQ) (24) was used to assess the intentions of HCWs to seek help from various sources, such as partners, parents, friends, and mental health professionals. GHSQ can be used as an overall scale that includes all sources of help, or each source can be used as a separate scale. Only one source (mental health professionals) was used in this study to rate the likelihood for HCWs to seek professional psychological help for their mental health problems. The participants were asked a question, "If you were to experience symptoms of depression, how likely would you be to seek psychological help from mental health professionals?" The item was rated on a 7-point Likert scale ranging from 1 (never) to 7 (very likely), with ≥5 indicating possible professional help-seeking intentions and higher scores indicating greater help-seeking intentions. This scale reported a Cronbach's alpha of 0.85 (24).

### Social support

Social support was assessed using the perceived social support scale (PSSS) (25), which comprises 12 items divided into 3 dimensions, namely, family support, friends support, and other support. Each item was rated on a 7-point Likert scale ranging from 1 (strongly disagree) to 7 (strongly agree). The total score ranged from 12 to 84, with scores of 12–36 indicating low support, 37–60 indicating moderate support, and 61–84 indicating high support from multiple sources. The Chinese version of the PSSS was validated among Chinese cancer patients, and its coefficients for family support, friend support, other support, and full scale were 0.87, 0.85, 0.91, and 0.88, respectively (26). In this study, PSSS obtained a Cronbach's alpha of 0.967.

### Self-stigma of seeking help

The 10-item self-stigma of seeking help scale (SSOSH) was used to measure how much the respondents felt that their self-esteem would be threatened when they seek professional psychological help (27). Each item was rated on a 5-point Likert scale ranging from "strongly disagree" (1) to "strongly agree" (5). Items 2, 4, 5, 7, and 9 were reverse scored. The total score ranged from 10 to 50. High scores indicate greater self-stigma. The Chinese version of the SSOSH was validated among a sample of college students and reported an acceptable internal consistency (Cronbach's alpha =0.81) (28). In this study, SSOSH reported a Cronbach's alpha of 0.762.

### Depression symptoms

The patient health questionnaire-9 (PHQ-9) was used to measure the depressive symptoms felt by the respondents over the past 2 weeks (29). Each item in PHQ-9 was rated on a 4-point Likert scale ranging from 0 (not at all) to 3 (almost every day). The total score ranged from 0 to 27, with scores of 0–4 indicating no depression, 5–9 indicating mild depression, 10–14 indicating moderate depression, 15–19 indicating moderate to severe depression, 20–27 indicating severe depression. The Chinese version of PHQ-9 was validated among patients and reported an acceptable internal consistency (Cronbach's alpha = 0.851) (30). In this study, PHQ-9 obtained a Cronbach's alpha of 0.929.

### Data analysis

All data analyses were performed using SPSS version 22. The characteristics of participants were presented as frequencies or proportions, and the levels of social support, self-stigma, depression symptoms, help-seeking attitudes and intentions were characterized using means and standard deviations. An independent student's $t$-test was conducted to analyze the statistical differences between different sex, occupation, frontline or non-frontline staff, and psychological learning experience in terms of their professional psychological help-seeking attitudes (the mean ATSPPH-SF sum score) and intentions (the mean GHSQ sum score). Also, one-way ANOVA test were performed to test if the mean ATSPPH-SF sum score and the mean GHSQ sum score differed between the age, marital status, education level, Working years, employment title, department, and sleeping time per day. Pearson correlation analysis was performed to analyze the relationship between professional psychological help-seeking attitudes (ATSPPH-SF sum score) or intentions (GHSQ sum score) and the three continuous variables (social support sum score, self-stigma of seeking help sum score, and depression symptoms sum score). Multiple linear regression models (stepwise) were used to examine the factors that influence professional psychological help-seeking attitudes and intentions. Professional psychological help-seeking attitudes (ATSPPH-SF sum score) or intentions (GHSQ sum score) were analyzed as dependent variable separately and all variables related to professional psychological help-seeking attitudes and intentions in the univariable analysis ($t$-test/one-way ANOVA test) and Pearson correlation analysis were included as independent variables. A $p$-value of <0.05 was considered statistically significant (two-sided test).

# Results

## Characteristics of participants

The 1,208 HCWs participating in this study were aged between 19 and 60 years ($M = 32.49$ years, SD = 7.13 years). The majority of these HCWs were female ($n = 1{,}091$, 90.3%), 71.1% ($n = 859$) of them were married, and 881 were holding a bachelor's degree. In addition, 45.1% ($n = 545$) have been working for more than 10 years, and 48.4% ($n = 585$) had junior employment titles. Most of these respondents were nurses ($n = 1{,}055$, 87.3%) and non-frontline medical workers ($n = 885$, 73.3%), only 26.7% ($n = 323$) were frontline medical workers, and 75.1% ($n = 907$) were working in inpatient departments. Table 1 presents the characteristics of the participants.

On average, the participants reported moderate to high levels of social support ($M = 61.04$, SD = 13.84), moderate levels of self-stigma of seeking help ($M = 25.77$, SD = 5.20), and mild to moderate levels of depressive ($M = 7.51$, SD = 5.72).

TABLE 1 Characteristics of eligible participants ($N = 1{,}208$).

| Sociodemographic characteristics | Frequency | % |
|---|---|---|
| *Age (years)* | | |
| 19–30 | 522 | 43.3 |
| 31–40 | 533 | 44.1 |
| 41–50 | 125 | 10.3 |
| >50 | 27 | 2.2 |
| *Sex* | | |
| Male | 117 | 9.7 |
| Female | 1,091 | 90.3 |
| *Marital status* | | |
| Married | 859 | 71.1 |
| Unmarried | 325 | 26.9 |
| Divorced | 24 | 2.0 |
| *Education level* | | |
| College diploma and below | 290 | 24.0 |
| Bachelor's degree | 881 | 72.9 |
| Master's degree and above | 37 | 3.1 |
| *Working years* | | |
| <3 | 162 | 13.4 |
| 3–5 | 165 | 13.7 |
| 5–10 | 336 | 27.8 |
| >10 | 545 | 45.1 |
| *Occupation* | | |
| Doctor | 153 | 12.7 |
| Nurse | 1,055 | 87.3 |
| *Employment title* | | |
| Junior | 585 | 48.4 |
| Intermediate | 522 | 43.2 |
| Senior/deputy senior | 101 | 8.4 |
| *Department* | | |
| Emergency department | 117 | 9.7 |
| Outpatient department | 116 | 9.6 |
| Inpatient department | 907 | 75.1 |
| Others | 68 | 5.6 |
| *Frontline or non-frontline workers*[a] | | |
| Frontline | 323 | 26.7 |
| Non-frontline | 885 | 73.3 |
| *Sleeping time per day (hours)* | | |
| <6 | 346 | 28.6 |
| 6–8 | 792 | 65.6 |
| >8 | 70 | 5.8 |
| *With psychological learning experience* | | |
| Yes | 400 | 33.1 |
| No | 808 | 66.9 |

[a] Frontline workers have a high risk of being exposed to COVID-19 patients and body fluids during their epidemic prevention and control work. These workers include those medical staff who are directly involved in the treatment of COVID-19 patients, field nucleic acid collection, COVID-19 fever clinics, or come in contact with the body fluids of COVID-19 patients.

## Attitudes toward seeking professional psychological help and the associated factors

The total scores of ATSPPH-SF ranged from 2 to 30, with a mean score of 18.88 (SD = 4.74), thereby indicating that the participating HCWs had relatively negative help-seeking attitudes.

Table 2 presents the univariable analysis of the characteristic factors related to attitudes toward seeking professional psychological help, whereas Table 3 presents the correlations between the continuous variables and ATSPPH-SF. The statistically significant categorical variables (i.e., sex, sleeping time per day, and psychological learning experience) in Table 2 and continuous variables (i.e., social support, self-stigma, and depression symptoms) in Table 3 were included in the multivariable analysis of attitudes toward seeking professional psychological help. Professional psychological help-seeking attitudes (ATSPPH-SF sum score) was analyzed as dependent variable in the multiple linear regression analysis.

Results of the multiple linear regression analysis (Table 4) revealed that having a more positive attitude toward seeking psychological help from professionals was significantly associated with being female ($\beta = 0.053$, $p = 0.031$), having psychological learning experience ($\beta = 0.098$, $p < 0.001$), receiving higher social support ($\beta = 0.131$, $p < 0.001$), having lower self-stigma of seeking help ($\beta = -0.370$, $p < 0.001$), and having less severe depression ($\beta = -0.105$, $p < 0.001$). The multiple linear regression model for help-seeking attitudes was statistically significant ($F = 70.313$, $p < 0.001$), with 29.1% of the variance explained by the predictors.

## Intentions toward seeking professional psychological help and the associated factors

The total scores of GHSQ ranged from 1 to 7, with a mean score of 4.06 (SD = 1.69), thereby indicating that the participants had a relatively low intention to seek professional psychological help.

TABLE 2 **Univariable analysis characteristics factors related to attitudes and intentions toward seeking professional psychological help.**

| Characteristics | Help-seeking attitudes | | | Help-seeking intentions | | |
|---|---|---|---|---|---|---|
| | *M* (SD) | *t*/*F* | *p* | *M* (SD) | *t*/*F* | *p* |
| Age (years) | | 1.915 | 0.125 | | 0.746 | 0.525 |
| 19–30 | 18.91 (4.74) | | | 4.11 (1.67) | | |
| 31–40 | 19.02 (4.60) | | | 4.07 (1.66) | | |
| 41–50 | 18.52 (4.85) | | | 3.86 (1.92) | | |
| >50 | 16.88 (3.64) | | | 4.04 (1.58) | | |
| Sex | | −2.006 | **0.045** | | 0.031 | 0.975 |
| Male | 18.05 (4.75) | | | 4.07 (1.85) | | |
| Female | 18.97 (4.73) | | | 4.06 (1.67) | | |
| Marital status | | 0.193 | 0.825 | | 3.142 | **0.044** |
| Married | 18.89 (4.74) | | | 4.08 (1.70) | | |
| Unmarried | 18.90 (4.73) | | | 4.09 (1.64) | | |
| Divorced | 18.29 (5.26) | | | 3.21 (1.76) | | |
| Education level | | 0.442 | 0.643 | | 0.165 | 0.848 |
| College degree and below | 18.67 (4.51) | | | 4.02 (1.66) | | |
| Bachelor degree | 18.96 (4.82) | | | 4.08 (1.70) | | |
| Master degree | 18.70 (4.60) | | | 4.14 (1.81) | | |
| Working years | | 1.854 | 0.136 | | 0.782 | 0.504 |
| <3 | 19.19 (4.48) | | | 4.15 (1.65) | | |
| 3–5 | 18.33 (5.03) | | | 3.99 (1.70) | | |
| 5–10 | 19.25 (4.70) | | | 4.15 (1.62) | | |
| >10 | 18.73 (4.74) | | | 4.01 (1.74) | | |
| Occupation | | 0.316 | 0.752 | | 1.648 | 0.241 |
| Doctor | 19.00 (5.12) | | | 4.27 (1.75) | | |
| Nurse | 18.87 (4.69) | | | 4.03 (1.68) | | |
| Employment title | | 1.850 | 0.158 | | 0.042 | 0.959 |
| Junior | 18.86 (4.73) | | | 4.06 (1.71) | | |
| Intermediate | 18.74 (4.79) | | | 4.06 (1.67) | | |
| Senior/deputy senior | 19.73 (4.48) | | | 4.11 (1.69) | | |
| Department | | 1.695 | 0.166 | | 0.412 | 0.744 |
| Emergency department | 18.08 (4.38) | | | 3.98 (1.66) | | |
| Outpatient department | 19.37 (4.76) | | | 4.22 (1.81) | | |
| Inpatient department | 18.90 (4.76) | | | 4.06 (1.68) | | |
| Others | 19.22 (5.00) | | | 4.03 (1.71) | | |
| Frontline OR non-frontline staff | | 0.543 | 0.587 | | −0.445 | 0.657 |
| Frontline | 19.00 (4.69) | | | 4.03 (1.66) | | |
| Non-frontline | 18.84 (4.76) | | | 4.08 (1.70) | | |
| Sleeping time per day (hours) | | 9.562 | **<0.001** | | 0.415 | 0.661 |
| <6 | 18.07 (4.95) | | | 3.99 (1.75) | | |
| 6–8 | 19.10 (4.57) | | | 4.09 (1.65) | | |
| >8 | 20.40 (4.96) | | | 4.14 (1.84) | | |
| With psychological learning experience | | 6.761 | **<0.001** | | 5.235 | **<0.001** |
| Yes | 20.17 (4.58) | | | 4.42 (1.68) | | |
| No | 18.24 (4.69) | | | 3.89 (1.67) | | |

*M*, mean; SD, standard deviation; *t*, independent sample *t*-test; *F*, ANOVA-test. Bold = significant predictor.

**TABLE 3** Correlations between continuous variables and attitudes or intentions toward seeking professional psychological help.

| Variables | Help-seeking attitudes | | Help-seeking intentions | |
|---|---|---|---|---|
| | *r* | *p* | *r* | *p* |
| Social support | 0.377 | **<0.001** | 0.329 | **<0.001** |
| Self-stigma of seeking help | −0.495 | **<0.001** | −0.298 | **<0.001** |
| Depression symptoms | −0.300 | **<0.001** | −0.054 | 0.062 |

Bold = significant predictor.

**TABLE 4** Multivariable analysis of attitudes toward seeking professional psychological help.

| Variables | Help-seeking attitudes | | | | |
|---|---|---|---|---|---|
| | *B* (SE) | *β* | *t* | *p* | 95% CI |
| Female | 0.848 (0.392) | 0.053 | 2.165 | 0.031 | 0.080, 1.617 |
| Male (ref.) | — | — | — | — | — |
| With psychological learning experience | 0.987 (0.251) | 0.098 | 3.932 | < 0.001 | 0.495, 1.480 |
| Without psychological learning experience (ref.) | — | — | — | — | — |
| Social support | 0.045 (0.010) | 0.131 | 4.544 | <0.001 | 0.026, 0.064 |
| Self-stigma | −0.338 (0.027) | −0.370 | −12.722 | <0.001 | −0.390, −0.286 |
| Depression symptoms | −0.087 (0.022) | −0.105 | −3.916 | <0.001 | −0.133, −0.046 |

Attitudes: $R^2 = 0.291$, adjusted $R^2 = 0.287$, $F = 70.313$, $p < 0.001$. *B*, unstandardized coefficients; SE, standard error; $\beta$, standardized coefficients; 95% CI, 95% confidence interval.

Table 2 presents the univariable analysis of the characteristic factors related to intentions toward seeking professional psychological help, whereas Table 3 presents the correlations between the continuous variables and GHSQ. The statistically significant categorical variables (i.e., marital status and with psychological learning experience) in Table 2 and continuous variables (i.e., social support and self-stigma of seeking help) in Table 3 were included in the multivariable analysis. Professional psychological help-seeking intentions (GHSQ sum score) were analyzed as dependent variable in the multiple linear regression analysis.

The multiple linear regression analysis results in Table 5 show that those participants with greater help-seeking intentions tended to having psychological learning experience ($\beta = 0.078$, $p = 0.004$), and having higher social support ($\beta = 0.229$, $p < 0.001$). Having a lower intentions toward seeking psychological help from professionals was significantly associated with divorced marital status ($\beta = -0.068$, $p = 0.011$) and having lower self-stigma of seeking help ($\beta = -0.170$, $p < 0.001$). The regression model for help-seeking intentions was significant ($F = 39.984$, $p < 0.001$), with 14.3% of the variance explained by the predictors.

## Discussion

The main findings of this study were as follows: (1) the mean score of ATSPPH-SF and GHSQ were 18.88 (SD = 4.74) and 4.06 (SD = 1.69) respectively, indicating that Chinese HCWs have a relatively negative attitude and low intention toward seeking professional psychological help for their mental health problems. (2) Being female, having psychological learning experience, and social support were positively associated with the total scores of ATSPPH-SF, whereas self-stigma of seeking help and depression symptoms were negatively associated with the total scores of ATSPPH-SF. (3) Having psychological learning experience and social support were positively associated with the total scores of GHSQ, whereas divorced marital status and self-stigma of seeking help were negatively associated with the total scores of GHSQ.

Chinese HCWs had relatively negative attitudes toward psychological help-seeking from professionals during the COVID-19 pandemic, that is, these workers had a low acceptance of seeking treatment for their mental health problems. The scores of ATSPPH-SF were relatively lower than the those of surveys involving 262 Chinese nurses working in an emergency department before the COVID-19 outbreak ($M = 21.33$, SD = 4.72) (31), patients in the US ($M = 20.45$, SD = 5.51) (32) and the general public in four European countries ($M = 20.0$, SD = 5.7) (22). The low personal help-seeking intentions among Chinese HCWs echoed the findings from other populations (33, 34). These indicated that there are still gaps compared with the more positive help-seeking attitudes and intentions people. Therefore, the attitudes and intentions of HCWs toward seeking professional psychological support should be further improved.

Several influencing factors in the multiple linear regression model were significantly associated with negative attitudes and intentions toward seeking professional psychological help.

Female HCWs held more positive attitudes toward seeking professional psychological help compared with their male counterparts, and this result was consistent with those of studies involving people in the medical profession people and the general public (22, 35–40). Masculinity may limit the ability of men to express their grief (41), and men are more likely to alleviate their pain through alternative solutions, such as alcohol consumption (37). Divorced marital status HCWs had a lower intention toward seeking professional psychological help compared with their married counterparts. A study with analysis of 2,853 cases of psychological assistance hotline help-seekers reported similar findings, that is, the largest number of calls came from married people and fewer (9.7%) from divorced people (42). This may be because divorced people are mainly stressed by work issues, while married people are stressed by both family and work issues, and are more likely to feel anxiety, depression than divorced people (42). Therefore, the need and willingness of divorced people for psychological help are lower than those of married people. Other demographics characteristics, such as age, education level, and occupation, were not associated with the attitudes and intentions of HCWs toward seeking professional psychological help.

Psychological learning experience was positively associated with help-seeking attitudes and intentions, by which an individual's knowledge/literacy of mental health problems, awareness of mental disorders, and beliefs about effective treatments can be improved (43). Having sufficient knowledge/literacy of mental health problems was also positively associated with help-seeking attitudes and

TABLE 5 Multivariable analysis of intentions toward seeking professional psychological help.

| Variables | Help-seeking intentions | | | | |
|---|---|---|---|---|---|
| | *B* (SE) | *β* | *t* | *p* | 95% CI |
| Divorced | −0.830 (0.325) | −0.068 | −2.551 | 0.011 | −1.468, −0.192 |
| Married (ref.) | — | — | — | — | — |
| With psychological learning experience | 0.280 (0.098) | 0.078 | 2.849 | 0.004 | 0.087, 0.473 |
| Without psychological learning experience (ref.) | — | — | — | — | — |
| Social support | 0.028 (0.004) | 0.229 | 7.336 | < 0.001 | 0.021, 0.035 |
| Self-stigma of seeking help | −0.055 (0.010) | −0.170 | −5.491 | < 0.001 | −0.075, −0.036 |

Intentions: $R^2 = 0.143$, adjusted $R^2 = 0.139$, $F = 39.984$, $p < 0.001$. *B*, unstandardized coefficients; SE, standard error; *β*, standardized coefficients; 95% CI, 95% confidence interval.

intentions as revealed in other studies focusing on HCWs (38) and other populations (e.g., adolescents and community-dwelling residents) (38, 40, 44). By contrast, having poor knowledge of mental health problems decreases one's willingness and need to seek professional psychological help (45). However, most HCWs in this study did not report any psychological learning experience. Moreover, the general population has a relatively low mental health literacy due to the lack of psychological education (46, 47). Psychological education about mental illnesses, including their recognition, prevention, and treatment, may influence the help-seeking attitudes and intentions of HCWs who are at risk of developing mental health problems.

Social support positively predicted attitudes, intentions, and help-seeking behavior (12, 48, 49). The participating HCWs reported moderate to high levels of social support from their families, friends, or others. Consistent with the previous literature (48–51), social support from society was positively associated with psychological help-seeking attitudes and intentions. People usually choose their families, friends, or other social networks as their first source of help when facing emotional problems (48, 52). These social networks often play the role of a presenter with lived experience to facilitate the flow of information and advice (53). Individuals interacting with these presenters show less mental-health-related stigma and are more open to seeking treatment (54, 55). Moreover, social support increases the self-efficacy and sleep quality of individuals, which in turn reduce their psychological stress and prompt them to seek help (56). Therefore, social support need to be strengthened to promote people's positive attitudes and intentions toward seeking mental health help. Social-contact-based interventions can be useful in influencing the psychological help-seeking of HCWs who are at risk of developing mental health problems (54, 55).

The total SSOSH scores of the participating HCWs pointed toward their moderate levels of self-stigma of seeking professional psychological help. Such self-stigma refers to one's internalization of negative public views toward people who seek professional psychological help, which is one of the most common barriers reported by HCWs who try to seek psychological help (15). Self-stigma has also been strongly associated with the participating HCWs' negative attitudes and intentions toward receiving psychiatric help in current study. A survey of 8,875 Swiss adults reported similar findings, that is, those people with more negative attitudes toward seeking psychological help also expressed a higher level of self-stigma (40). Another study reported that self-stigma influences the attitudes of college students toward seeking mental health services and is associated with an increased likelihood of having sought mental health services in the past (34). Self-stigma, which is particularly prevalent among HCWs, could instill in them the fear that being diagnosed with a mental health problem would negatively affect their career prospects and highlight their failures in their respective roles (57). The presence of self-stigma decreases the willingness of HCWs and their need to seek psychological help. Therefore, stigma reduction programs (e.g., to offer training that will cause the current stereotypes to change) (58) targeted at HCWs should be organized to encourage positive help-seeking attitudes and intentions, and increase the possibility for these workers to receive mental health treatment.

Mild to moderate levels of depressive was found among the participating HCWs. This physical and mental health indicators was significantly associated with psychological help seeking in the multivariable analysis. Those HCWs with more severe depressive symptoms held more negative attitudes toward seeking professional help, which was consistent with the findings of previous studies focusing on pregnant women and adolescents (35, 48, 59). However, these results also contrasted those of other studies. For instance, one study revealed that public health workers with depression and anxiety were more likely to report actual help-seeking behavior during the COVID-19 pandemic (12), and another study reported that the presence of depression and psychological distress may increase one's likelihood to seek professional help (60). Such differences can be ascribed to abnormalities in behavioral activation (BAS) and behavioral inhibition (BIS) systems, in which depressed people are more likely to face behavioral inhibition (61) and are more introverted, pessimistic, evasive, and less likely to maintain social interaction compared with non-depressed people (13, 60, 62). If these people are not severely depressed, then they are more likely to rely on themselves to cope with their psychological problems (63) and become willing to seek help. Moreover, having severe symptoms of anxiety, depression, or prior mental health issues can encourage people to utilize the available professional support (13).

## Strengths and limitations

To the best of the authors' knowledge, this study is the first to investigate the professional psychological help-seeking attitudes, intentions, and associated factors of a large sample of Chinese HCWs during the COVID-19 pandemic. The results of this study could guide mental health providers in developing targeted interventions that can improve the attitudes and intentions of HCWs toward seeking psychological help.

This study also has several limitations that should be acknowledged. First, this study adopts a cross-sectional survey, which makes it impossible to infer causal pathways among attitudes and intentions toward seeking professional help and their influencing factors. Second, nurses comprised 87.3% of the sample, and most of the participating HCWs were female. Therefore, doctors or other HCWs and males were underrepresented in this study.

## Implications

This study offers significant implications for improving the attitudes and intentions of HCWs toward seeking professional psychological help. Chinese HCWs who are at risk of developing mental health problems held relatively negative attitudes and had a low intention to seek professional psychological help, which largely contrasted the high prevalence of mental health problems among this population during the COVID-19 pandemic. The more positive their attitudes and intentions toward seeking help, the more likely these HCWs will demonstrate help-seeking behavior, which in turn can alleviate their work pressure and improve their mental health (19). Therefore, the attitudes and intentions of HCWs toward seeking professional psychological support should be improved.

The significantly positive impact of social support on the help-seeking attitudes and intentions of HCWs highlights the importance of strengthening the role of informal psychological support sources in encouraging HCWs to disclose their feelings, promote their utilization of mental health services, and improve their self-belief in successfully demonstrating a professional psychological help seeking behavior with the desired result. The significantly negative impact of self-stigma on the help-seeking attitudes and intentions of HCWs implies that stigma reduction programs should be developed to reduce the self-stigma associated with mental illness and professional psychological help-seeking behavior. The participating HCWs in this study with depressive symptoms were less willing to seek psychological help from professionals. Therefore, the early recognition of at-risk HCWs, early treatment of their depressive symptoms, and their timely referral to psychological professionals are all critical. Psychological learning experience also has a positive impact on help-seeking attitudes and intentions. Therefore, HCWs should be given essential training to instill in them the knowledge, attitudes, and skills that would lead to positive changes in their help-seeking process.

## Conclusion

The attitudes and intentions of Chinese HCWs toward seeking professional psychological help during the COVID-19 pandemic are relatively negative and low. Positive factors affecting such attitude include being female, having psychological learning experience, and having better social support. Meanwhile, those factors that positively affect these HCWs' intentions toward seeking psychological help include having psychological learning experience and having better social support. The negative factors affecting attitudes include self-stigma of seeking help and higher level of depression. The negative factors affecting intentions include divorced marital status and self-stigma of seeking help. Interventions that target these factors should be designed to enhance the professional psychological help-seeking attitudes and intentions of HCWs.

## Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

## Ethics statement

The studies involving humans were approved by the Medical Ethics Committee of the Hunan University of Medicine, in Hunan Province, China. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

## Author contributions

RH, XP, SY, and CG conceived, planned, and designed the study. RH and SY wrote the original draft of the manuscript, analyzed the data, and revised the manuscript under the supervision of CG and XP. CG and XP administrated the project, interpreted the data, and oversaw the writing of the paper. RH, SY, and YT performed this experiment, supervised the execution of the study, and checked the quality of data. All authors contributed to the article and approved the submitted version.

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## Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

## Publisher's note

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# It's not in my head: a qualitative analysis of experiences of discrimination in people with mental health and substance use conditions seeking physical healthcare

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**Introduction:** Clinician bias contributes to lower quality healthcare and poorer health outcomes in people with mental health and substance use conditions (MHSUC). Discrimination can lead to physical conditions being overlooked (diagnostic overshadowing) or substandard treatment being offered to people with MHSUC. This research aimed to utilise experiences of people with MHSUC to identify discrimination by clinicians, including the role of clinician's beliefs and assumptions in physical health service provision.

**Methods:** We surveyed people with MHSUC who accessed physical healthcare services. Of 354 eligible participants, 253 responded to open-ended questions about experiences of those services. Thematic descriptive analysis of survey responses was completed using existing stigma frameworks and inductive coding.

**Results:** One dominant theme from survey responses was that diagnostic overshadowing by clinicians was driven by clinician mistrust. Another theme was that clinicians assumed respondent's physical symptoms, including pain, were caused by MHSUC. This influenced decisions not to initiate investigations or treatment. Respondents perceived that clinicians focused on mental health over physical health, contributing to suboptimal care.

**Discussion:** Discrimination based on MHSUC leads to poor quality care. Health systems and clinicians need to focus quality improvement processes on access to and delivery of equitable physical healthcare to people with MHSUC, address stereotypes about people with MHSUC and improve integration of mental and physical healthcare.

KEYWORDS

**discrimination, health care, mental health, quality of care, overshadowing, severe mental disorder, substance use disorder**

## 1. Introduction

People with mental health and substance use conditions (MHSUC) experience worse outcomes from physical health conditions than those without MHSUC (1–4). This can be attributed in part to poorer quality physical healthcare, including lower rates of timely, appropriate diagnosis and treatment (5, 6).

People with MHSUC presenting to a health service with a physical complaint commonly experience the complaint being dismissed or ignored (7–10). When physical symptoms are misattributed to MHSUC, with subsequent missed or incorrect diagnoses, this is described as diagnostic overshadowing (11, 12).

Even when physical conditions are recognized, differential outcomes may still occur if clinicians provide different treatments or fail to address barriers to care for people with MHSUC (11). Therapeutic pessimism or overshadowing can contribute to clinicians developing inferior treatment plans for people with MHSUC, driven by negative beliefs about a person's capacity and ability to comply or respond to treatment (11, 13).

Bias from clinicians plays an important role in both diagnostic and therapeutic overshadowing (11, 14, 15). Bias encompasses a range of factors, from lack of experience or knowledge about mental health (ignorance), negative beliefs about people with MHSUC (stereotypes), negative attitudes and emotions towards people with MHSUC (prejudice) and discriminatory behavior (discrimination) (16, 17). Bias can also be unconscious or implicit, and bias against people with MHSUC occurs in clinicians at similar high levels to the general population (18, 19).

Previous research in Aotearoa New Zealand (NZ) reported that 23% of people with MHSUC experienced discrimination from health services (20). Examples of discrimination include acting on stereotypes and prejudice, such as clinicians avoiding patients with MHSUC due to unwarranted fear of violence or discomfort with mental illness (21) and patients with MHSUC being denied weight loss surgery due to unsubstantiated assumptions they will have poorer outcomes (22). Discrimination from clinicians can also deter people from seeking treatment (23), creating further barriers to appropriate diagnosis and treatment of physical conditions.

Although qualitative research has examined reasons for overshadowing from the perspective of clinicians (10, 21, 24), exploring discrimination from the perspective of people with MHSUC is less common and usually limited to describing discriminatory behavior without identifying underlying stereotypes (25–28). We surveyed people with MHSUC in NZ who had accessed healthcare for a physical health condition, drawing on methodology that also used patient perspectives to critique service quality issues (29, 30).

The aims of the research were:

- To describe how people with MHSUC experienced discrimination in physical health services, including diagnostic and therapeutic overshadowing.
- To use the observations and reports of people with MHSUC to explore likely underlying beliefs of clinicians that lead to discrimination in physical healthcare.

## 2. Materials and methods

Experiences of physical healthcare in people with MHSUC were collected through an anonymous online Qualtrics survey that included both closed and open-ended questions and ran from 31 January to 1 April 2022.

### 2.1. Recruitment and sample

People were recruited through snowballing methods using digital media, starting with social media outreach through Facebook and Twitter by the researcher team and research advisory group and distribution through online newsletters and email lists from other organizations (e.g., Government and non-governmental organizations and services, Māori health networks and providers).

The survey site was accessed 488 times. Four-hundred-and-eight people agreed to participate, and 354 eligible individuals were included in the final dataset. Eligibility criteria were:

- Use of primary or secondary healthcare services for MHSUC in the past 5 years
- Engagement with any health care service for a physical health issue in the past 5 years
- Age 18 or over.

People who did not answer any questions about physical healthcare services were excluded, as was one duplicate response. The analysis sample for this paper included only those who answered at least one of the open-ended questions ($n = 253$).

### 2.2. Survey content

The survey was divided into four sections covering mental health and addiction service use, physical health service use (across five types of services), stigma and discrimination, and demographics. Demographic questions included age, gender, ethnicity, sexual orientation, and MHSUC diagnoses. The survey questionnaire was reviewed by a research advisory group, which included clinicians and people with lived experience of MHSUC. The responses to ten open-ended questions formed the basis of the qualitative analysis (Table 1).

Ethics approval was granted by the Southern Health and Disability Ethics Committee (21/STH/216). Information about the survey, including maintenance of privacy and confidentiality, and contact details for support was provided in the survey introduction. Informed consent was assumed once participants engaged with the online survey. Where identifying information was provided by participants (in order to volunteer for participation in interviews or to receive study results) this information was removed prior to analysis and stored separately and was not accessible to study authors conducting analyzes.

### 2.3. Data analysis

Responses to the open-ended questions were imported into NVivo v1.6.1 (QSR International) in an anonymised form. We used

TABLE 1 Open-ended questions for analysis.

| Open-ended questions |
|---|
| Please tell us more about your experiences of physical healthcare from general practice (GP) services |
| Please tell us more about your experiences of physical healthcare from emergency departments |
| Please tell us more about your experiences of physical healthcare in hospital services |
| Please tell us more about your experiences of physical healthcare from chemists or pharmacies |
| Please tell us more about your experiences of physical healthcare from other health services (e.g., kaupapa Māori health service, physiotherapy, dietetic service, naturopath service) |
| Please tell us more about being accompanied by a mental health or addiction staff member to an appointment for your physical health |
| Please tell us more about deciding not to seek help and/or continue with treatment for a physical health problem, in case you were treated unfairly due to your experience of mental health or addiction |
| Please tell us more about about being treated unfairly due to your ethnicity, age, gender, sexual orientation or disability when seeking help for a physical health problem |
| How do you think physical health care could be improved for people with mental illness or addiction issues? |
| Do you have any other comments you wish to make about the topics raised in this survey? |

TABLE 2 Project team expertise and background.

| Team member | Expertise/background |
|---|---|
| CL | Psychiatry, mental health research, Māori health |
| DP | Mental health research, qualitative research, lived experience |
| FI | Public health/epidemiology, mixed methods research |
| HL | Mental health and substance use research, practice and policy |
| RC | Public health/epidemiology, mental health research |
| SE-P | Psychiatry, mental health research |
| TH | Psychology, mental health research, Māori health, qualitative research |

theory-driven thematic analysis (31), starting with deductive coding using pre-existing frameworks on stigma (16, 17) to classify experiences of discrimination. Investigators (FI and DP) independently reviewed survey responses to identify sections of text that described discrimination, prejudice and stereotypes. These sections were analyzed inductively to infer clinicians' underlying assumptions as perceived and reported by respondents, drawing on the respondents' observations of clinician demeanor and behavior and their interpretations of these, particularly within the context of delayed, missed or incorrect physical health diagnoses, but also where physical health diagnoses were unknown or unclear. The investigators discussed and developed themes based on respondents' common experiences as an iterative process with team input and review (Table 2). Quotes to demonstrate themes were inserted verbatim with grammatical corrections to aid clarity and identifiers indicating age range (NA = no age given) and gender (W = woman, M = man).

# 3. Results

## 3.1. Respondent characteristics

Respondents were predominantly female and compared to the general population were younger and more likely to identify with the rainbow community (Table 3). Depression and anxiety were the most frequently reported MHSUC diagnoses and multiple diagnoses were common.

## 3.2. Overview of themes

Three themes (clinician's beliefs) were evident from the descriptive analysis of factors that people with MHSUC considered led to discrimination from clinicians when seeking physical healthcare. Themes included that in people with MHSUC, MHSUC is responsible for physical symptoms (with sub-themes around physical symptoms being psychosomatic, caused by anxiety and pain as an unreal symptom), that people with MHSUC are untrustworthy (particularly those who need controlled drugs or pain management) and that mental and physical healthcare were competing priorities (either mental or physical health takes the focus).

## 3.3. In people with MHSUC, MHSUC is responsible for physical symptoms

A predominant theme from survey respondents centered around the experience of clinicians assuming that their MHSUC was responsible for or explained their physical symptoms. As a result, respondents reported that their physical symptoms were dismissed, leading to delayed investigations, diagnosis and treatment – or no investigation despite an underlying physical cause. Respondents reported that they were not treated in the same way as someone without a history of MHSUC.

> I had to argue with a doctor about the cause of dehydration and difficulty swallowing. He put it down to depression and a history

TABLE 3 Characteristics of respondents.

| Characteristic | *n* (%) for total survey sample | *n* (%) for those who responded to open-ended questions |
|---|---|---|
| *Age* | | |
| 18–25 years old | 57 (16%) | 43 (17%) |
| 26–35 years old | 91 (26%) | 65 (26%) |
| 36–45 years old | 65 (18%) | 49 (19%) |
| 46–54 years old | 51 (14%) | 42 (17%) |
| 55+ years old | 42 (12%) | 37 (15%) |
| Missing | 48 (14%) | 19 (8%) |
| *Gender* | | |
| Female | 228 (64%) | 172 (68%) |
| Gender diverse | 15 (4%) | 13 (5%) |
| Male | 59 (17%) | 44 (17%) |
| Prefer not to answer | 4 (1%) | 4 (2%) |
| Missing | 48 (14%) | 20 (8%) |
| *Ethnicity* | | |
| Māori | 58 (16%) | 47 (19%) |
| Non-Māori | 245 (69%) | 185 (73%) |
| Missing | 51 (14%) | 21 (8%) |
| *Sexual orientation* | | |
| Heterosexual | 197 (56%) | 149 (59%) |
| LGBQA+ | 107 (30%) | 83 (33%) |
| Missing | 50 (14%) | 21 (8%) |
| *Diagnosis*[a] | | |
| Addiction | 58 (16%) | 44 (17%) |
| Anxiety | 225 (64%) | 168 (66%) |
| Bipolar disorder or schizophrenia | 59 (17%) | 50 (20%) |
| Depression | 241 (68%) | 181 (77%) |
| Personality disorder | 41 (12%) | 35 (14%) |
| Post-traumatic stress disorder | 54 (15%) | 42 (17%) |
| *Number of diagnoses* | | |
| 1 | 43 (12%) | 36 (14%) |
| 2 | 114 (32%) | 85 (34%) |
| 3 | 79 (22%) | 58 (23%) |
| 4+ | 53 (14%) | 44 (17%) |
| Missing | 65 (18%) | 30 (12%) |
| Total | 354 | 253 |

[a] This percentage is for all those who reported a diagnosis in the whole sample; the proportions are higher if people who did not report any diagnosis are excluded from the denominator.

> of eating disorders. Turned out I had thrush in my mouth and oesophagus after being on antibiotics. (W, 36–45)

Within this theme, sub-themes emerged relating to physical symptoms in people with MHSUC being ascribed as psychosomatic, or due to anxiety and stress, and the physical symptom of pain being not real or caused by MHSUC.

### 3.3.1. Physical symptoms in people with MHSUC are psychosomatic

Respondents reported that clinicians assumed their physical health symptoms were either psychosomatic or not real. Whether clinicians distinguished between psychosomatic conditions and “feigning” was unclear, but respondents were left with the impression that their symptoms were imagined.

> I was in for cardiac issues. When ECGs were done because of chest pain and came back normal it was suggested it could be because of my bipolar by nurses again. It was in fact my Duromine that I was on for weight loss, so it wasn't in my head at all. (W, 55+)

Although respondents frequently experienced clinicians telling them that physical complaints were psychosomatic or due to their MHSUC, they were not told what this meant or what to do about the symptoms they were experiencing, leaving them unclear how to manage and reluctant to raise the same or other concerns in the future. Respondents experienced this as a bind, where the onus was on them to prove their symptoms were not caused by their MHSUC, and if they could not, they were left without treatment or support.

> In some instances, my mental health issues are blamed for my physical health issues but it is never explained why my [mental health] is to blame. I leave feeling hopeless and confused. (W, 26-35)

### 3.3.2. Physical symptoms in people with MHSUC are due to anxiety and stress

Respondents reported that anxiety and stress were the primary reasons given by clinicians to explain physical symptoms, and the reasons for not investigating further. Examples of this spanned both primary and secondary healthcare settings. Several respondents who were initially told that their physical symptoms were due to anxiety or stress were later diagnosed with significant health conditions, including lupus, a kidney infection, a viral liver infection, endometriosis, brachial neuritis and postural tachycardia syndrome.

> My GP often tries to blame any physical problem I have on my anxiety. I know my own anxiety pretty well now, I know what it feels like and how it behaves. It frustrates me when my GP is not willing to investigate my symptoms and just says "it could be your anxiety." (W, 26–35)

### 3.3.3. The physical symptom of pain in people with MHSUC is not real or is caused by MHSUC

A special category within this theme related to pain as a physical symptom. People with MHSUC complaining of pain experienced an even stronger sense that their clinicians believed the pain to be imaginary or fabricated and did not warrant treatment. People were given the impression that their MHSUC caused or exacerbated pain, or they could not achieve pain control unless their MHSUC was better managed.

> In the last 5 years I have been struggling to get a diagnosis and get treatment for on-going pelvic and back pain as a result of adenomyosis, a pars defect and a few other factors. My mental health would be brought up in every appointment and often blamed for my inability to control my pain levels. [This was] despite already seeing a psychologist and psychiatrist, being on medication, and being in decent control of my mental health. (W, 26–35)

Poor treatment of the symptom of pain could relate to mistrust of people with MHSUC (and reluctance to prescribe pain medication, see below) and/or lack of knowledge about the nature and management of pain. One respondent reported her experience: "I was told that I could not possibly be in pain as my car accident was years ago. The woman told me to repeat after her, 'tissue damage repairs itself after 3 months so I am not in pain.'" (W, 46–54) That this occurred at a pain clinic suggests that ignorance was not the root cause of this dismissal, as such clinics routinely assess people with pain that persists in the absence of tissue damage.

## 3.4. People with MHSUC are untrustworthy

Respondents recounted how they were not believed when they reported physical health symptoms, with an implicit or sometimes explicit assumption that they were making the symptoms up, exaggerating or even outright lying. The presence of an MHSUC diagnosis was presumed to indicate an unreliable narrator.

> I broke my tailbone and sacrum I was called a liar, I'm faking it, etc etc. Turns out was so serious, my insides were prolapsed, tailbone removed, sacrum has 3 pins in but took me 2 years, lots of tears … hundreds of pain meds for them to believe me. (W, 46–54)

Respondents felt ignored, dismissed and not listened to. Respondents wanted their physical health concerns to be taken seriously, independently from their MHSUC diagnosis, and without fear of their symptoms being pre-determined as having a psychological aetiology.

> Doctors have been quite dismissive, I've felt, of the physical symptoms I'm experiencing, almost always putting it down to my mental health challenges which at times is frustrating. I just wish they would listen a bit more and not immediately discount physical health complaints because I have a mental health diagnosis. (W, NA)

The experience of being disbelieved and dismissed could have negative consequences for people's mental health, making it even harder to seek help for physical health issues.

> I find seeing a new doctor a very stressful experience now, especially if they already have my patient notes, because I have to prepare to not be listened to, talked down to, or entirely dismissed. (W, 26–35)

### 3.4.1. People with MHSUC who need controlled drugs or pain management are particularly untrustworthy

Within this theme, the experience of being untrustworthy was intensified for people with addiction or taking controlled medication. Mistrust was most evident in relation to pain management and pain medication, and particularly affected people with addiction or perceived to be at risk of addiction, who could be labeled as drug seeking. They found it difficult to access pain relief and even routine investigation or treatment for symptoms.

> Referred to mental health labeled as an attention/drug seeker. I had heart failure. (W, 55+)

The experience of mistrust extended beyond people with a history of addiction. People with mental health conditions but no history of addiction still felt they risked being labeled as a 'drug seeker' if they presented with pain. The consequence of this mistrust was that some people did not receive pain relief and others did not even ask for it, due to lack of confidence and a mutual lack of trust in clinicians and the health system.

> I'm on a controlled drug for ADHD and feel that often I am treated as a criminal and a drug seeker both by my GP service and my regular pharmacy. Makes me loath to disclose any issue with pain or my anxiety as I know they will judge it as drug seeking behavior. (W, 36–45)

## 3.5. Mental and physical healthcare are competing priorities

People with MHSUC experienced two apparently conflicting assumptions related to the intersection between mental and physical healthcare, depending on the context and the focus of the clinician, which could be at odds with what the patient wanted to focus on.

### 3.5.1. Mental healthcare takes the focus over physical health

The first assumption was that mental health issues must be attended to first before any physical health concerns could be addressed. The MHSUC was the primary or sole focus, even when people presented only with physical health concerns. Sometimes this was to the extent that clinicians appeared to be unable to deal with physical health conditions when there was co-existing MHSUC.

> I went to seek help for a sore ankle, the Dr replied with a "tell me about your bipolar disorder." Turns out I had a torn ligament, diagnosed by someone else. My treatment was delayed and I felt humiliated. (W, 36–45)

Respondents wanted to be seen as people, not as "mental health cases." They wanted their physical symptoms to be treated as important and to be addressed fully and actively. They wanted physical causes to be ruled out first, rather than the MHSUC to dominate the consultation.

> My mental health becomes a significant distraction and delays getting actual treatment for the issue I was there for. I wanted to know about my baby, but the conversation always went back to my mental health. I was stressed because I wanted to enjoy and understand my pregnancy, but no-one talked to me about my baby. I thought that's what I was there for. (W, 36–45)

### 3.5.2. Physical healthcare takes the focus over mental health

The second assumption pertaining to the relationship between physical and mental healthcare was that a person's MHSUC had no impact on their physical health and that mental health concerns could be left to some other clinician or service. This appears to contradict the assumption that mental health takes the focus but demonstrates how mutually exclusive beliefs can exist within the same system.

Most descriptions of this assumption related to physical health services not understanding or accounting for stress and anxiety related to procedures, treatment or health settings or MHSUC being overlooked when it was relevant to physical healthcare.

> I have Type 1 diabetes and am an outpatient at the diabetes clinic. Mental health is not addressed as a component of diabetes care, but in my experience, there is a lot of connection between my diabetes management and mental health. (M, 36–45)

Some of the tension between whether mental health or physical health was prioritized related to a lack of clarity over who was responsible for each domain of health. Holistic care, where physical and health issues were both treated as important and the interdependencies between them were recognized, was an ideal that respondents felt was rarely achieved.

> The focus with some services is only on one thing – they do not take a holistic approach to wellbeing. If I am there for a physical issue then my mental health is not discussed and vice versa. (W, 26–35)

Short appointment times in primary care meant that some respondents felt that mental, addiction and physical health concerns could not both be adequately addressed in a single consult – this may have been dependent on service attributes of the practice and clinician. Although mental health was often assumed to be the cause of physical symptoms, the impact of physical health on mental health was seldom raised by clinicians.

# 4. Discussion

Respondents in this study provided many examples of how the demeanor and responses of clinicians would change or differ depending on their awareness of the respondent's MHSUC, and the ways in which their MHSUC led to diagnostic and treatment overshadowing, contributing to delayed treatment and prolonged suffering.

Although research into the prevalence and impact of overshadowing is lacking (32), previous studies have documented adverse outcomes from diagnostic and treatment overshadowing (7, 10, 12). For example, in a qualitative study of clinicians working in the ED, clinicians recalled two patients with MHSUC who died and five who experienced irreversible long term damage due to delayed investigation or treatment (10). From the clinicians' perspective, factors that contributed to overshadowing included difficulties in taking a detailed history, frequent attendances for unexplained symptoms and patients refusing to consent to an examination, procedure or treatment (10, 21). Poor interpersonal skills and lack of collaborative care from health providers were additional contributing factors (7, 21).

These studies convey how features of the patient and how they present contribute to overshadowing, explicitly or implicitly focusing the blame on the person. Treating patients differently because of any characteristic is discriminatory behavior, whether due to an individual clinician's prejudice (33) or a system failure to accommodate the needs of patients (25, 28, 32, 34). By taking the perspective of the patient, we sought to focus on the clinicians' actions, in order to shift responsibility onto services and systems to provide non-discriminatory care.

## 4.1. Addressing the psychosomatic assumption

Many respondents in this study reported that physical symptoms were attributed to their MHSUC almost by default, with no apparent consideration of a somatic cause. Without access to patient notes and records, we were unable to verify whether any or some appropriate investigations or examinations were conducted, but in many cases, the stories spoke for themselves – physical health conditions, including broken bones and infections, were missed.

This indicates not only discrimination but a failure in the duty of care, as presenting symptom(s) in all patients should be thoroughly investigated, regardless of previous history, which may include interviewing family or other contacts to gather additional information (10).

The assumption that MHSUC can cause physical symptoms may be true, as medically unexplained symptoms are extremely common, particularly in primary care (35). However, even in these situations, this does not mean that symptoms are not real and does not excuse a clinican from investigating for an organic cause and offering treatment or a referral if this is outside their expertise (36, 37). In the face of unexplained symptoms, clinicians are encouraged to reflect on the number of medical conditions throughout history that have been considered "psychosomatic" but subsequently found to have a biological basis (38).

## 4.2. Addressing stereotypes

Addressing the stereotype that people with MHSUC are untrustworthy involves more than one-off education sessions or increased awareness. From research on interventions to address unconscious bias, some strategies show promise (including exposure to counter-stereotypical examples, identifying with the outgroup and emphasizing the recovery from MHSUC) but positive effects may wane with time due to ongoing exposure to bias entrenched in society and discriminatory workplace cultures (13, 39). Interventions may need to be organization-wide and repeated, with ongoing assessment, reflection and deliberate practice (40, 41) using objective monitoring methods (e.g., internal audits against best practice standards, comparing treatment plans for people with and without MHSUC).

It is not only patients with MHSUC who are disbelieved and mistrusted. People reporting persisting symptoms after COVID infection were initially discounted, as "unreliable informants of their own illness experiences." (42) People with MHSUC also experience discrimination in health care services due to belonging to other stigmatized groups, including female, ethnic minorities, sexual minorities and gender diverse people, which can worsen physical and mental health (43–46).

Not believing or taking a patient's symptoms seriously is the antithesis of patient-centered care, a critical dimension of high-quality healthcare (40, 47, 48). A revised commitment to patient-centered care, with an explicit focus on respect, partnership, listening to and developing a trusted relationship with the patient, may be needed to improve quality of care for people with MHSUC.

## 4.3. Addressing mind–body dualism

The conflicting experiences of mental health taking precedence over physical health in some consultations and vice versa in others underscores the artificial and stigmatizing separation of mind and body within health systems (49, 50). Better integration between mental health, substance use and physical health services in order to improve outcomes for people with MHSUC is an ongoing challenge but a priority for health systems (51, 52). Characteristics of successful integration models include case management, care co-ordination and joint assessment/planning, shared information systems, co-location, clear accountabilities and strong leadership (51, 53–56). Physical health services, particularly primary care services which are often at the forefront of assessment, treatment and referral of people with MHSUC, need to have the requisite mental health and addiction training and skills (57, 58). Conversely, mental health and addiction services need to be aware of physical health risks associated with MHSUC and treatment and ensure that physical health needs are addressed (59).

## 4.4. Strengths and limitations

One limitation of this research was a relatively small sample size, but responses to the open-ended questions were high (71% of survey respondents gave textual answers), including some extensive narratives. However, we were unable to clarify ambiguous responses since the data were collected anonymously online. In this paper we focused on the worst experiences of physical healthcare for people with MHSUC. Respondents also recognized *non*-discriminatory behavior and provided exemplars of when they were treated well, which will be published separately. Responses to closed questions about quality and experience of healthcare services are published elsewhere (60). From this paper, 10% of respondents reported experiencing discrimination due to MHSUC always or most of the time, and this was significantly more prevalent in people with severe mental illness (schizophrenia or bipolar disorder), those with four or more diagnosis and LGBQA+ individuals. In addition, 20% of respondents reported diagnostic overshadowing always or most of the time, and this was experienced more often by Māori, people with severe mental illness or addiction and those with four or more diagnoses (60).

The underlying assumptions we have described are based on reports from respondents, and their interpretations of the clinician's attitudes and behavior. We are unable to ascertain the beliefs and assumptions from the clinician's perspective but regard the perceptions of respondents to be more valuable than clinician's self-report in this context. Unconscious and social desirability biases are likely to lead to under-recognition and under-reporting of clinician bias against people with MHSUC. Taking the patient perspective, we are unable to disentangle whether unfair treatment is solely due to MHSUC or caused or compounded by other biases, such as racism, sexism or homophobia. More research should be done to examine the interactive impacts of belonging to more than one stigmatized group.

We were unable to quantify the impact or relative importance of assumptions that lead to discrimination against people with MHSUC. However, it is well established that people with MHSUC have worse outcomes from physical health conditions, including premature mortality (5). Further research is needed to quantify the extent of overshadowing and its causative factors and develop effective interventions to reduce it. One Australian survey found that 11% of people with MHSUC had experienced discrimination by a clinician in the previous 12 months (27).

The underlying assumptions identified in this research are consistent with findings from other studies on bias against people with MHSUC in clinicians (32), suggesting that these are not unique to NZ. However, in countries with different healthcare structures, particularly with higher levels of mental and physical healthcare integration, the competing priorities of mental and physical health may be less acute.

Respondents were self-selecting, recruited through social media and health service connections, hence may not reflect the experiences of people who are not engaged with health services or able to participate in online research. On the other hand, groups who might be more likely to experience other forms of discrimination such as women and people from the rainbow community were over-represented in our sample. However, although we would expect that more marginalized individuals would experience higher levels of discrimination, the stereotypes and underlying assumptions are likely to be similar.

## 5. Conclusion

Experiences of overshadowing in people with MHSUC are experiences of discrimination from individual clinicians, which may be exacerbated by personal and system factors, but are inherently healthcare quality issues. Interventions to change the way we support and manage the physical health of people with MHSUC are urgently needed.

## Data availability statement

The datasets presented in this article are not readily available because due to the nature of the research, respondents of this study did not agree for their data to be shared publicly, so supporting data are not available. Requests to access the datasets should be directed to ruth.cunningham@otago.ac.nz.

## Ethics statement

The studies involving humans were approved by Southern Health and Disability Ethics Committee. The studies were conducted in accordance with the local legislation and institutional requirements. Written informed consent for participation was not required from the participants or the participants' legal guardians/next of kin because this was an online survey. Detailed information about the survey and contact details for more information was provided at the start of the survey. Informed consent was assumed when participants chose to engage with and complete the survey.

## Author contributions

RC: Conceptualization, Funding acquisition, Methodology, Project administration, Writing – review & editing. FI: Formal analysis, Methodology, Writing – original draft, Writing – review & editing. TH: Methodology, Writing – review & editing. SE-P: Methodology, Writing – review & editing. CL: Methodology, Writing – review & editing. HL: Conceptualization, Funding acquisition, Methodology, Writing – review & editing. DP: Conceptualization, Formal analysis, Funding acquisition, Methodology, Writing – review & editing.

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## Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

## Publisher's note

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# Mental illness through the perspective of undergraduate medical students in Greece: a cross-sectional study at Aristotle University of Thessaloniki

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**Introduction:** Numerous studies reveal that mental health-related stigma, stereotypes, and prejudices negatively affect the patients, jeopardizing their health, prognosis, and social opportunities. Healthcare professionals, who are in the first line of combating mental disease, are expected to play a significant role in drastically changing discriminatory and stigmatizing attitudes toward psychiatric patients and in diminishing the existing healthcare and social disparities. In this study, we aimed to explore and highlight the views of Greek medical students—that is of the future physicians—toward mental illness and people suffering from it.

**Materials and methods:** It is a cross-sectional, observational study, in which 324 undergraduate students from the most populous Greek medical school of the Aristotle University of Thessaloniki, participated online, during the spring semester of 2022. The tools used were the Opinions about Mental Illness Scale (OMI) that assesses one's viewpoints about mental illness, the Social Distance Scale (SDS) that captures the desired degree of social distancing from patients with mental disorders, and the Level of Contact Report (LCR-12) that estimates the level of familiarity with them.

**Results:** Participants displayed rather positive attitudes regarding the etiology of mental illness, social integration, and discrimination toward psychiatric patients [as evaluated with the respective OMI subscales; Etiology mean score ($\mu$):8.87 ± 4.68, Social Integration ($\mu$):17.79 ± 5.42, Social Discrimination ($\mu$):13.54 ± 11.17], and more clearly favorable opinions concerning the need for social provision or the enactment of restrictive measures [as expressed with the relative OMI subscales; Social Care ($\mu$):22.74 ± 4.56, Social Restriction ($\mu$):13.27 ± 8.98], while claiming to be quite familiar with mental disorders and individuals experiencing them (as assessed with LCR; $\mu$: 8.71 ± 2.16), and relatively willing to interact with them (as measured with SDS; $\mu$:8.95 ± 4.23). Degree of familiarity with mental illness was directly proportional to the desire for contact with patients living with it, while the higher both were, the more improved most of the aforementioned OMI sectors were found to be. Female sex, clinical medical education, previous clinical psychiatric training, and living with or being a person with a mental disorder were the factors that defined a statistically refined profile in many of the aspects above.

**Conclusion:** Our findings are in accordance with many prior and recent studies, while showing improved opinions compared to those of previous research in Greek student and healthcare population. They are calling for vigilance, rather than complacency, as well as educational and social interventions, in order to enable current and future healthcare professionals to perform their function to its fullest extent. Implications of our results and further research suggestions are included.

KEYWORDS

**stigma, mental health, mental illness, stigma reduction, students' stigma, medical students' stigma, Greek medical stigma, Greek students' stigma**

## Introduction

Mental health-related stigma constitutes a global issue; there is no nation, community or culture where the psychiatric patients are treated as of equal societal worth to those considered mentally healthy (1). Historically, only rare health conditions like leprosy—with its alarming sight and contagiousness—had social effects comparable to those of mental health illnesses (2). Numerous studies reveal that attitudes toward psychiatric patients are often influenced by religion, ethnicity, and racial differences (3–6), by political characteristics and population density (7–10), as well as by culture, social norms, and values (11).

Accordingly, it should not be forgotten that individuals suffering from a mental disorder are forced to give an uneven battle not only against the condition itself but also against a "second disease": the social stigma (12). This "social disease" is probably favored by the nature and intensity of acute psychiatric symptoms and is mainly based on the wide ignorance, the traditional superstitions (13) or even the misrepresentation of patients' profile in the media and the arts and the subsequent fear created by these factors. The existence of stereotypical views—like the belief that psychiatric patients are unpredictable or menacing—contributes to the discrimination against them and the deprivation of their basic human rights, resulting in their repetitive exposure to major social disparities and isolation (14, 15).

In addition, the presence of stigmatizing perceptions concerning mental health disorders creates barriers for patients seeking care, due to their efforts to avoid the mentally ill's label (16). As a result, stigma affects the self-esteem of psychiatric patients, prolongs their recovery, and burdens their physical health as well (17, 18), thereby jeopardizing their prognosis (19).

Healthcare professionals, who are on the frontline in the fight against mental illness ignorance and stigma, are expected to play a significant role in drastically changing discriminatory and stigmatizing attitudes toward people suffering from mental diseases (20). This includes advocating for these patients, by helping them on their anti-stigma efforts and campaigns, by co-educating with them the public that consider their opinion as expert (21, 22), by pressuring governments and organizations, and—last but not least—by supporting them actively in terms of accessibility and care of their mental and physical health. However, for them to successfully play this role, they should have received an anthropocentric, patient-centered education since the years of their studies (23). Same goals refer to medical students, who given their appropriate training, their extensive presence in social media world and the rush of their youth are expected to participate in the aforementioned actions since the years of their studies, while forming alongside a promising and conscious next generation of doctors.

However, following numerous studies medical students may have stereotypical opinions regarding psychiatric patients similarly to the general population (24, 25), and often feel awkward when in contact with them (26), believing that they have a poor prognosis (27), and considering that collaborating with them will be extremely stressful (28), emotionally overwhelming (29, 30), and even menacing (31). Even though this negative approach could have been present prior to medical training, it could also have been influenced and shaped through stigmatizing viewpoints expressed by their own instructors (24). Research also reveals that after graduation from medical schools, physicians can exhibit increased stigmatizing perceptions regarding mental illness' social aspects, such as patients' both social integration and personal socialization (32).

These medical students' perceptions are crucial as they directly associate with psychiatric patients' treatment. More specifically, most health professionals, regardless of specialty, systematically treat patients with co-occurring mental disorders. Graduated medical students who finish their studies without having improved their antecedent perceptions of psychiatry will eventually transform into medical practitioners who feel incompetent or reluctant to address mental illness, therefore sustaining stigmatization, misinformation, and the resulting limited care (33, 34).

Factors such as a higher social life enjoyment among medical students have been linked to increased stigmatizing perceptions (35), while a personal or family history of mental disease seems to incite their compassion toward individuals with a mental health condition (35–37). Surprisingly, it has been further reported that medical students in distress tend to adopt more frequently stigmatizing behaviors toward psychiatric patients than their non-distressed classmates (35). In a survey conducted at the University of Michigan

Medical School, students with high scores of self-identified depression repeatedly expressed the opinion that they are viewed as less competent and appeared less likely to seek treatment compared to students with low scores of depression (38, 39).

These findings—except for being the outgrowth of mental distress or disorder—could possibly further reflect the pressure upon medical students by the public's general perception and high expectation of them supposedly being confident and resilient. This misconception could result in self-stigma that is the incorporation of others' stereotypes about mental conditions into one's convictions about oneself (40). Consequently, mental illness and self-stigma, besides affecting the quality of life of medical students, may also result in long-term consequences in regards to the treatment of their future patients (41): as data indicate, medical students with previous psychiatric problems tend to be unwilling to refer patients for treatment if they believe the stigmatization will overshadow the benefits (42).

Finally, a specific question arises: to what extent medical students themselves—the future physicians—are prepared to face the stigma that is hidden behind mental illness and support those suffering from it and calling for respect. Their knowledge, experience, and humanistic opinions about mental health related stigma can serve as veritable tools to fight against this social "disease." Our study seeks to make an approximate measurement of the presence and degree of this kind of stigmatization among a group of healthcare students, which is expected to play a significant role in the equal perception and treatment of every patient regardless their mental state, as their aspiring physicians (20) whose opinion is publicly perceived as expert (23, 43, 44). It also aims to highlight the areas that call for critical action, both educationally and socially. To achieve these objectives, we employed widely used questionnaires, the analysis of which gave us the chance to detect specific problematic areas and needs for the population studied, as well as to compare them with previous studies on students, healthcare professionals and the general population. This way the researchers of the current study and future researchers have the opportunity to come up with targeted suggestions for further investigation, and educational and social anti-stigma interventions.

# Materials and methods

## Study design

This is a cross-sectional, observational study, aiming to (a) explore the attitudes of undergraduate medical students about mental illness, (b) investigate possible differentiations among them regarding their special characteristics (e.g., demographics, training, and familiarization with mental disorders), and (c) compare them with previous studies on students or on populations with similar characteristics (e.g., similar age, occupational, or educational level). This way, questions will arise about the sufficiency and evaluation of students' training and the probable impact of labor or contact with patients to one's attitudes.

In the present study, 324 undergraduate medical students from Aristotle University of Thessaloniki (AUTh), Greece, participated. The School of Medicine of AUTh constitutes the medical school with the highest attendance in the country, counting more than 4.000 registered students in its undergraduate and postgraduate programs (45–47), and bringing together students from all over the country and Cyprus and a minority of foreigners as well, including military medical students.

Notably, the undergraduate curriculum is of 6-year duration, with the initial 2 years principally focused on basic sciences, while contact with clinical experience begins in the spring semester of the third year (sixth semester). During their studies, students receive psychiatric training through a considerable number of elective lessons (available since the first year of education), and—mainly—through mandatory clinical psychiatric practice in their eighth academic semester and optionally in their sixth year of studies as well.

The study was conducted during the spring semester of 2022 from February 1 to May 25 (where third year students had just been introduced into clinical training, fourth year students had just started their psychiatric clinical training and students in their sixth- or higher-year of studies had already completed one or two semesters in clinical Psychiatry), during a difficult time period, where students had to face the personal and training limitations of the COVID-19 pandemic. The relative permission was granted by the headmaster of the School of Medicine of AUTh, after officially informing—via written letter—the general secretary of the school. The questionnaires were distributed mainly through email sent by the general secretary to every single undergraduate student, as well as via a social media platform. Medical students were invited to participate in the research voluntarily and anonymously, having provided informed consent through the initial briefing for the survey on the online platform. The sample of our study was formed from all the answers collected via the electronic questionnaire.

Ethical approval was received from the Scientific Committee of the General Hospital of Thessaloniki "Papageorgiou" Review Board before the collection of data.

## Questionnaires/tools

### Sociodemographic questionnaire

Participants were invited to provide anonymous demographic information on their gender, family status, and year of medical studies, as well as prior training in clinical psychiatry (Supplementary Table 5).

### Opinion about Mental Illness scale (OMI)

Respondents were also asked to complete the Opinions about Mental Illness Scale (OMI) (48), originally created by Cohen and Struening in 1959, aiming to assess the viewpoints of healthcare professionals concerning mental illness. The current form of the OMI—which was obtained from profound factor examination of its primary shape of 200 items by more than 8,000 mental health experts—contains 51 statements demonstrated via a six-point Likert-type scale (49). Responses range from 1 (Entirely Agree) to 6 (Entirely Disagree). Factor analysis of the 51 items exposed the following five subscales for the initial English version: A: Authoritarianism, B: Unsophisticated Benevolence, C: Mental Hygiene Ideology, D: Social Restrictiveness, and E: Interpersonal Etiology (48, 49).

The Greek OMI version (Supplementary Table 1), was standardized for the Greek population by Madianos et al. (50), who reported its validity and reliability as well. It follows a modified evaluative scheme (Supplementary Table 2), which stresses the following five factors (20):

- Factor 1: Social Discrimination (SD; 16 items): this factor refers to the identifying features of mental health patients, who are mostly treated as second-class individuals in comparison to those perceived as "normal." It also contains a hidden belief that psychiatric patients should be treated in an authoritarian manner.
- Factor 2: Social Restriction (SR; 13 items): It portrays the tendency that precautionary actions should be adopted by the society concerning mental health patients. It implicates rejective and coercive convictions referring to penalizations in the course or following a psychiatric hospitalization.
- Factor 3: Social Care (SC; 8 items): This factor contains favorable perspectives about the treatment principles, proposing improvement of quality of care and social assistance.
- Factor 4: Social Integration (SR; 8 items): This one describes the urge to favor equal opportunities in social inclusion of mental health patients in every single facet of public life.
- Factor 5: Etiology (E; 6 items): This factor mentions the opinions about the cause of psychiatric disease, portraying an inclination to assign that to the patients' relatives.

Statements of OMI are demonstrated in Supplementary Table 1, while those included for the assessment of each of the above factors are presented at Supplementary Table 2 (20).

For each factor, the final score is calculated by adding the scores of all the items contained and subtracting them from a constant number (20, 51). Higher scores demonstrate that the participant inclines more toward the attitude illustrated by every factor (51). In particular, higher scores for factors 1, 2, and 5 represent more stigmatizing and stereotypical beliefs. On the contrary, higher scores for factors 3 and 4 indicate more positive opinions regarding mental disorders and patients suffering from them (20).

The OMI scale has been widely used—both spatially and temporally—among healthcare professionals' categories, as well as in various populations like undergraduate students, the general population, and psychiatric patients' relatives (48, 49, 52, 53). Furthermore, the OMI scale has been commonly used in Greece, both for the general population (50, 54), and for subpopulations, including students (51, 55–58) and mental healthcare professionals (20, 25, 59, 60).

### Social Distance Scale (SDS)

Respondents were invited to complete the Social Distance Scale (SDS) as well (61, 62), a tool often used in stigma research, with good reliability and validity (56, 61–63). It includes seven items (Supplementary Table 3) answered via a four-point Likert-type scale. Example items: "How willing would you feel about working with someone with a mental illness?" "How willing would you feel about renting a room in your home to someone with a mental illness?" The options for the Greek version used range between 0 (Entirely Unwilling) and 3 (Entirely Willing) (63). However, it is noted that the scores were reversed for the statistical analysis process, to be comparable with the results from international literature (20). Total scale scores vary between 0 and 21, by summing the individual scores of all the answers. This scale estimates the social distance the interviewee wishes to keep from a person suffering from a certain condition; in the current study, it calculates the distance that the medical students wish to keep from psychiatric patients (63, 64) with higher scores indicating a stronger will to do so (20).

### Level of Contact Report (LCR)

The last questionnaire respondents were invited to complete was the Level of Contact Report (LCR-12), a scale initially created by Holmes et al. (64, 65). It is a psychometric self-report test that estimates acquaintance with mental illness. LCR-12 includes 12 statements (Supplementary Table 4) that were derived from other scales employed in stigma research (30) and holds well-reported reliability and validity (65, 66). Each of the statements equates to a particular score (from 1 to 12), depending on the increasing degree of familiarity with mental disorders that it portrays (20, 66). Example items: "I have never observed a person that I was aware had a mental illness." (rank order score 1), "I have watched a documentary about mental illness." (score 4), "I suffer from a mental disease" (score 12). Concerning the completion of the scale, participants can select one or more of the 12 declarations, in case they have experienced them before (52, 63). The final score for each respondent is equal to their highest-scoring answer, that is, to the one exhibiting the highest level of familiarity (20, 65, 67).

For all the above questionnaires, the validated Greek version was used (50, 51, 63).

## Statistical analysis

Data were checked for deviations from normality by Kolmogorov–Smirnov test. Comparison of mean scores at OMI subscales (Social Discrimination, Social Restriction, Social Care, Social Integration, and Etiology), SDS, and LCR between categories in sex (male vs. female), year of studies (a. 1, b. 2, c. 3, d. 4, e. 5, f. 6, and g. >6), family status (h. Married, i. Single, and j. Other), and previous clinical Psychiatry training (k. one semester, l. two semesters, and m. None) were performed with parametric tests in case of normal distribution (*t*-test, ANOVA). Otherwise, non-parametric tests were applied (Mann–Whitney U Test, Kruskal-Wallis test). In case of statistical significance, *post-hoc* analyses were performed, in order for differences in demographics between specific groups to be identified. The same analysis was carried out for some selected items of high interest (items 4, 24, 29, 41, and 51) of the OMI scale. Cronbach's alpha was also calculated in each subscale of OMI, as well as in SDS scale, in order to assess the influence of each one on the subscales' internal consistency. Spearman's correlation was performed in order to assess the relationship between subscale of OMI, SDS, and LCR. An alpha error of 5% ($p < 0.05$) was considered as statistical significance threshold for all analyses. The statistical analyses were performed with SPSS (Version 29, IBM, Armonk, NY, United States).

# Results

## Sample characteristics

In total, 324 subjects were recruited. The subsequent distribution was based on gender: 62% female, 38% male; year of studies: 20.4% 1st, 10.2% 2nd, 13.3% 3rd, 23.3% 4th, 8.3% 5th, 21.0% 6th, and 3.4% >6th; family status: 92.3% single, 1.5% married, and 5.3% other; and previous clinical Psychiatry training in semesters: 38.3% 1 s, 7.4% 2 s, and 54.3% none. Detailed sample characteristics are presented at Supplementary Table 5.

## Cronbach's alpha

The internal consistency was excellent (>0.7) for Social Discrimination, Social Restriction, and Social Care OMI's subscales, and SDS and acceptable for Social Integration (0.675) and Etiology (0.654). Deletion of one item did not change the results, with exception of Item 2 (excellent) and Item 3 (unsatisfactory) for Social Integration, as well as Item 1 (excellent) and Item 20 (unsatisfactory) for Etiology. Results are presented at Supplementary Table 8 and Supplementary material 2.

## Spearman correlation

Spearman correlation revealed that Social Discrimination, Social Restriction, and Etiology were positively correlated with SDS. This finding implies that being more willing to interact with people with mental disorders is associated with less discriminative and restrictive attitudes and less stereotypical ideas about the origin of mental illness. Conversely, it indicates that less authoritarian attitudes, and less prejudiced notions regarding the genesis of mental diseases leads to greater readiness to associate with people suffering from them.

Furthermore, Social Discrimination and Social Restriction were negatively correlated with LCR, which means that a higher level of familiarity with mental disorders and patients is linked to a lower presence of discriminative attitudes or approval of restrictive measures, and vice versa. Social Care and Social Integration were positively correlated with LCR. That is, the more one is familiarized with mental disease, the more he endorses the development of an improved social net for psychiatric patients, and the reverse as well. Finally, SDS was negatively correlated with LCR, which indicates that the desire to associate with individuals with mental disorders is directly proportional to the level of intimacy with mental disease and patients.

Respective results are presented at Supplementary Table 8.

## Comparison of OMI subscales

Results are presented at Supplementary Table 6, while the scoring intervals of each subscale are provided in Supplementary Table 11.

### Social Discrimination (SD)

Analysis for mean scores regarding Social Discrimination revealed statistically significant associations for sex, year of studies and previous Psychiatry training, with males, students in the 1st year and those with no previous Psychiatry training to have the higher (more discriminative) scores. Women presented a quite refined profile compared to men, within the limits of sufficient contradiction to the discriminative notions, while students above the 4th year of studies showed a less authoritarian character more clearly. Notably, all the examined groups in general expressed their strong or only partially doubtful disagreement to the expressed notions that could be considered as a rather satisfactory fact.

### Social Restriction (SR)

Analysis for mean scores regarding Social Restriction revealed statistically significant associations only for sex, with males having the higher (more restrictive) scores. Nonetheless, it is worth noting that all groups expressed their generous and undoubted disagreement to restrictive measures.

### Social Care (SC)

Analysis for mean scores regarding Social Care revealed no statistically significant difference in mean scores between groups. This factor was found to be more consistent among the participants, who expressed their explicitly positive attitude about the urgency for better providence for those suffering from mental diseases (mean scores above or below the threshold between "agreement" and "full agreement").

### Social Integration (SI)

Analysis for mean scores regarding Social Integration revealed statistically significant associations for year of studies and previous clinical Psychiatry training: sophomores and first year students, and those with no previous clinical Psychiatry experience had the lower scores, indicating the more negative attitude toward patients with mental disorders. All groups demonstrated cautiously supportive beliefs concerning the social inclusion and equal treatment of individuals with mental disorders, while students from the 5th year and above, singles, and those with higher clinical Psychiatry experience appeared slightly more daring in a positive way (mean scores within the spectrum of "agree" with the items included).

### Etiology (E)

Analysis for mean scores regarding Etiology revealed statistically significant associations for sex, year of studies and previous Psychiatry training, with males, students in the second year and those with no previous Psychiatry training having the higher scores (expressing more stereotypical attitudes). All groups remained rather willing to avoid misconceptions on mental disorders' etiology (mean scores ranged in the spectrum of "rather disagreement" with the statements under consideration), while students who had completed their 6-year education appeared less prejudiced and only singles stood out more decisively in a more positive way (by entering the spectrum of "disagreement" with the stereotypical beliefs examined).

## Comparison of SDS

Analysis for mean scores regarding SDS revealed statistically significant associations for year of studies, with students in the second year having the higher scores—depicting poorer willingness to associate with people suffering from mental disorders. All groups displayed their probable willingness to interact with psychiatric patients, with sophomores tending to be more ambivalent, in contrast with those with the maximum clinical psychiatric education and even more those who had completed their 6-year educational program, who appeared more decisive to do so. Results are presented at Supplementary Tables 3, 6.

## Comparison of LCR

Analysis for mean scores regarding LCR revealed statistically significant associations for year of studies, with students in the 2nd year having the lower scores (μ:7.70), indicating they are less familiarized with mental illness and patients. Remarkably, all other groups showed a great level of intimacy (rated over 8), which corresponds—at least—to the belief that their job involves providing services and treatment for persons with a mental disease, with questions given a higher rating referring to one's friends/relatives/family/oneself with a psychiatric history. The higher the year of study and the level of clinical education in Psychiatry, the more intimate (or probably the braver to mention it) the participants appeared. Furthermore, a respective total percentage of 52.6% declared that providing services to psychiatric patients is part of their job, while >41% mentioned a friend or relative with mental health problems and 9% of the participants presented themselves suffering from a mental condition (that constitutes the highest degree of contact report:12). Results are presented at Supplementary Tables 4, 6.

Stereotypical opinions (as measured with OMI) and willingness to interact with people with mental problems (as expressed by SDS) are separately reported for each LCR item at Supplementary Table 7. In terms of Social Care and Etiology, all 12 groups of LCR choices remained quite consistent, while those suffering from a mental problem (item 12) and even more those having a family member with a mental disorder (item 11) displayed more positive and less stereotypical attitudes regarding Social Discrimination, Social Restriction, and Social Integration, and appeared more willing to interact with patients. It was interestingly reported that those who declared to have taken a course on mental illness (item 7), showed the second most favorable opinion about the etiology of mental disease (after the aforementioned group of item 11).

## Comparison of selected items 4, 24, 29, 41, and 51 of OMI scale

The items below were specifically and separately examined (at Supplementary Table 9), due to their distinctness to detect more problematic and stereotypical views (4). They appear to capture major social issues: firstly by broaching essential democratic values and great ethical dilemmas, in which nowadays medical students and future physicians will be called to provide scientific answers (items: 4, 29, and 51); secondly by highlighting the importance of medical confidentiality and the understanding of the dire need to fight social ignorance as medical scientists and mental health experts, in order to dispense people who have suffered from a mental health problem from the burden of hiding it and having to prove themselves and their capacities repeatedly (items: 24, 41).

### Item 4 ("*Even if psychiatric patients may seem to be okay, they should not be allowed to get married*.")

It belongs to the items assessing social discrimination. Analysis for mean scores regarding Item 4 revealed statistically significant difference based on previous training on Psychiatry, with the lower scores—which correspond to beliefs more approving of the statement and, as a result, more stigmatizing—to be for those with no training. Nevertheless, all groups expressed a considerable level of disagreement to the statement ($\mu > 4.76$), that is a less discriminative opinion, with singles being slightly more cautious to do so.

### Item 24 ("*It would be foolish for a woman to marry a man who once had a serious mental illness, even if he appeared to be fully mentally restored*.")

It is included in items of social discrimination. Analysis for mean scores regarding Item 24 revealed no statistically significant associations. Nonetheless, the individual groups of the participants expressed, in general, quite clearly their disagreement to the above declaration.

### Item 29 ("*Anyone who is hospitalized in a psychiatric unit should not be allowed to vote*.")

It constitutes one of the social restriction items. Analysis for mean scores regarding Item 29 revealed statistically significant associations for sex, with the higher scores (which express a greater disagreement to the item) to be for the females. Yet, all the examined groups displayed their disapproval of the above statement, more or less (mean scores within the spectrum of "rather disagree" and "disagree"), while singles appeared a little more reluctant and restrictive compared to others.

### Item 41 ("*Most women who have been hospitalized in a psychiatric unit should be trusted to look after children*.")

It is indicative of social integration items. Analysis for mean scores regarding Item 41 revealed no statistically significant difference in mean scores between groups, which ranged in moderate scores (between "rather agree" and "rather disagree") and preferred safer waters. Students who completed their education (>6th year of studies) seemed slightly more troubled about this item.

### Item 51 ("*All patients in psychiatric units should be prevented from having children with sterilization*.")

It is included among the items of social restriction factor. Analysis for mean scores regarding Item 51 revealed no statistically significant difference in mean scores between groups. However, all the individual populations were strongly against the aforementioned notion, expressing their great assurance and respect for patients and democratic principles.

## Presentation of the OMI items with the extreme mean scores and standard deviations

Mean scores and standard deviations for each one of the 51 items of OMI are presented at Supplementary Table 1. The following tables present the items that stood out in the total population by their mean score or their standard deviation (Tables 1, 2).

As shown on the tables, participants expressed positive opinions in a more explicit way regarding people with mental disorders, in matters of social care (with the lowest mean scores that express their agreement with the items) and social restriction (highest mean scores that correspond to one's disagreement with the statements). They were also found to have given more convergent answers about these factors (as shown by their low standard deviations), but more divergent about some discriminative matters (as expressed by their higher standard deviations).

TABLE 1 Items of minimum and maximum mean scores in OMI analysis.

| Items of OMI | Mean score* | Std. deviation | OMI factor |
|---|---|---|---|
| 12. Even though patients in mental hospitals behave in funny ways, it is wrong to laugh at them. | **1.21** | 0.68 | SC |
| 22. Anyone who tries hard to better himself deserves the respect of others. | **1.45** | 0.81 | SC |
| 47. Our mental hospitals should be organized in a way to make the patient feel as much as possible as if they are living in their home. | **1.57** | 0.89 | SC |
| 40. No matter how you look at it, people with serious mental illnesses are no longer real people. | **5.48** | 0.87 | SR |
| 32. Being hospitalized in a psychiatric clinic is tantamount to failing in real life. | **5.52** | 0.9 | SR |
| 31. The best way to handle patients in mental hospitals is to keep them behind locked doors. | **5.62** | 0.73 | SR |

*Answers rating scale from 1 (Fully Agree) to 6 (Fully Disagree). SD, Social discrimination; SR, Social restriction; SC, Social care; SI, Social integration.

TABLE 2 Items of minimum & maximum SDs in OMI analysis.

| Items of OMI | Mean score* | Std. deviation | OMI factor |
|---|---|---|---|
| 12. Even though patients in mental hospitals behave in funny ways, it is wrong to laugh at them. | 1.21 | **0.68** | SC |
| 31. The best way to handle patients in mental hospitals is to keep them behind locked doors. | 5.62 | **0.73** | SR |
| 22. Anyone who tries hard to better himself deserves the respect of others. | 1.45 | **0.81** | SC |
| 19. A heart patient has just one thing wrong with him/her, while a mentally ill person is completely different from other patients. | 3.57 | **1.39** | SD |
| 48. One of the main causes of mental illness is the lack of moral strength or willpower. | 4.01 | **1.58** | SD |
| 2. Mental illness is an illness like any other. | 3.05 | **1.67** | SI |

*Answers rating scale from 1 (Fully Agree) to 6 (Fully Disagree). SD, Social discrimination; SR, Social restriction; SC, Social care; SI, Social integration.

## Discussion

The present study aimed to evaluate the attitudes on mental illness of medical students at Aristotle University of Thessaloniki, the most populous Medical School of Greece, which students are expected to be the next generation of physicians that will staff the Hellenic National Health System, and other—basically European—health systems as well. Medical students are charged with high expectations for the future of healthcare systems and the establishment of equal provision for all patients, so the evaluation of their current beliefs and the outcomes of their education are of high importance for the following steps.

In Greece, an improvement in the perception of people experiencing or living with a mental disorder has been recorded throughout the last decades among the general public and healthcare population (4), alongside the modernization of the mental healthcare system (68, 69), yet both still lacking. Our study's goal, apart from presenting medical students' attitudes toward psychiatric patients, was also to compare them to previous similar studies in student populations (51, 55, 67, 70, 71) and current studies of healthcare personnel (20), and to explore areas for intervention, as well.

In total, our study describes a certain degree of positive attitudes toward people with a mental disorder among medical students of the biggest University of Greece, who interestingly reported a quite high level of contact with mental illness, as well. More specifically, they appeared to almost completely agree with the necessity for measures of high social provision and disagreed with restrictive notions, providing respective answers of high congruency. On the other side, they reported less satisfactorily positive attitudes regarding social discrimination, where their opinions were essentially divergent. Similarly, they expressed themselves less positively concerning the etiology of mental disease, the integration of patients experiencing a mental disorder, and the willingness to interact with them.

In the section below, we summarize the specific features of stigmatization based on participants' characteristics. Regarding the different groups of medical students, we observe that:

- Sex appeared statistically significant in terms of Social Discrimination, Social Restriction, and Etiology. That indicates that women seemed more sensitive, expressing less stigmatizing notions in the fields more linked to authoritarianism, prejudice, stereotypes, and lack of awareness.
- Year of studies was not considered a statistically significant factor regarding Social Restriction and Social Care, but preclinical students (below the third year) expressed more cautious and less positive opinions concerning Social Discrimination, Social Integration, and Etiology of mental illness. Students of the last years of studies (and students not having yet graduated after the completion of their sixth year education) showed higher desire for interaction with psychiatric patients (as was captured by SDS), while appearing braver and more sensitive in terms of familiarity with mental illness (as shown by LCR).
- Family status did not affect any of the sectors studied in a statistically significant way, yet it should be noted that the vast majority of the participants (>92%) were single.
- Clinical psychiatry training seems to have significantly determined in a more positive and less stigmatizing way the beliefs of the participants, regarding Social Discrimination, Social Integration, and Etiology. It is remarkable that those who declared to have taken a course on mental illness (LCR item 7) appeared to have the second-best opinion regarding the origin of mental illness (after those who stay with a person with a mental disease).

These results should be interpreted cautiously, as prior research has reported the following questionings: the expressed attitudes may differ from the real ones, either due to the factor of social desirability that derives from the implied professional ethos and tends to present less stigmatizing opinions (25), or due to an increased uneasiness for social health and safety (as a result of the professional responsibility "burden") mixed with insufficient knowledge and familiarity with mental illness that can lead to the choice of expressing more reserved notions (49).

Prior research of Greek and international student populations has reported similar findings to ours: women tend to show a more humanitarian and less stigmatizing profile (37, 70), lower years of studies present more negative attitudes (70), previous contact with psychiatric patients leads to a more friendly and favorable attitude toward them (32, 35, 37, 70, 72) and to a less strong desire for social distance (56). However, few studies of the past described the opposite influence of the factor of sex (57) or of previous personal experience and contact specifically with schizophrenia (25, 67) to one's opinions and willingness to associate with people living with it.

Comparing our results to previous research of Greek medical students using the same tools and evaluation method, we have reported an increased level of familiarity with mental disease and patients, significantly improved opinions regarding discrimination, less restrictive notions and prejudice regarding the etiology of mental illness, and slightly improved profile regarding social provision and integration (51). These findings are consistent with international literature that describes generally positive beliefs among medical students' and their amelioration with time (24, 32, 36).

In comparison with a recent study that was conducted in a tertiary University Hospital of Thessaloniki during the same time period (by the same main authors and editor, using the same tools) (20) and had already demonstrated less stigma and prejudices compared to Greek data from previous decades (50, 51, 54, 73–75), we mention the following conclusions, contrasting them with the groups of healthcare professionals with similar characteristics—that is physicians, young people, and those of higher/tertiary education—that showed a more refined, and less stigmatizing profile as well (Supplementary Table 10).

In terms of Social Discrimination and Social Restriction, students showed a significantly better profile than the previous groups, with statistical proximity to the beliefs of the physicians' group, while they expressed the most positive attitudes among all groups regarding Social Care. Concerning Social Integration and Etiology, students' attitudes were found within the limits of the scores of the aforementioned groups, with statistical closeness to the beliefs of physicians and higher education graduates for the first factor and to those of physicians and young employees for the latter. Regarding the familiarity with mental illness and people suffering from it, medical students reported a quite high degree of intimacy, yet the level of contact for the specific groups above and the total population of healthcare professionals of the examined study was higher. Nevertheless, medical students appeared significantly more willing to interact with people with mental disease.

The aforementioned conclusions could imply the following points, hypotheses, and suggestions for interventions (educational, occupational, and social), as well as for further research:

More and appropriate educational programs need to take place in healthcare faculties, in order to fight ignorance (as expressed with the scores of Etiology OMI subscale). Education that incorporates useful theoretical knowledge (not a sterile only genetic-based one that is associated with pessimism for one's prognosis), technological means, and more importantly the experiential learning and interaction with people who can narrate their successful story of recovery from a mental disease (19, 21, 22, 62, 76–79) with emphasis to those healthcare professionals who have experienced a mental disorder (21, 80) is required. As it has been specifically reported by previous research for medical students' psychiatric education, its frequency and quality characteristics are of high importance (36), as different outcomes have been described for different kinds of psychiatric training (81); education including the beneficial characteristics mentioned above can lead to an improvement of students' opinions, neutralizing stigma and promoting integration (55, 67, 71, 81), while an obsolete and inappropriate one can result in zero or even negative impact to one's beliefs (25).

Moreover, light should be shed in additional reasons forming the declined opinions of students (especially in terms of Social Discrimination), as personality, psychopathology, or other characteristics or one's history could be revealed as significant factors. It would also be of great interest to study separately the opinions of military students (the medical population of whom was included in our study), in order to detect possible differences and reasons behind it.

As for doctors' more negative opinions compared to medical students' ones (32), they could have arisen due to their stress and fatigue level, as well as their wider contact with psychiatric patients in their mental or somatic acute phase. The finding could also imply a modification of the previous psychiatric training to a more effective one currently or be indicative of increased understanding and romanticism by younger generations. A possible bias in the comparison between our two studies is the fact that psychiatrists were excluded from the first study—with unclear implications for the results, while potential next-generation psychiatrists were included in the students' population. In any case, investigating the factors that lead healthcare professionals to adopt more stigmatizing views compared to students, as well as providing opportunities for stress relief, suitable educational methods, and anti-stigma interventions is particularly required.

Considering that the—less positive—attitudes of medical students of the first years may reflect those formed during the secondary education or in public life, further research on minors and general population could bring about useful results. Based on them, an appropriate introduction and familiarization with mental illness in the mandatory education could be adopted, and targeted social campaigns (that make good use of media participation and arts as well) could be effectively organized (82–84).

## Limitations of our study

The study was conducted during the COVID-19 pandemic, the impact of which on students' health and education needs to be taken into consideration, albeit not being somehow measured; it drastically reduced the clinical education of the students and the interaction with patients, alongside inducing other quarantine restrictions and consequences on their daily life and health (such as sleep and mood disorders or even suicidal ideation). Additional social phenomena that have overwhelmed the Greek current affairs, such as the increasing incidents of violence against women and children during the COVID-19 era, the "Me too" movement, the over decennial financial crisis and the refugee crisis could possibly distress medical students as well and some of them even raise important questions about the mental state of the abovementioned groups or individuals, presumably providing fertile ground for developing mental health stigma notions.

Regarding the sample characteristics, we should mention that the participation rate of military students was not assessed, and their subpopulation—of special characteristics and interest about their views—was not evaluated separately. As for "Family status" factor, we highlight that it was not equally distributed among the available choices (majority of >92% were single).

Concerning the statistical analysis and interpretation, a correction for multiple comparisons was not performed. Lastly, most previous studies were compared descriptively, due to the lack of same tools, evaluation or presentation published.

## Conclusion

It is widely accepted that healthcare professionals and especially doctors are—universally and over time-perceived as the ones who determine the public opinion regarding the formation of mental health-related stigma (23, 43, 44). With an eye to the future generation of physicians, we conducted the current study in medical students of Greece, who expressed clearly approving ideas mainly about social provision and certain disapproval of restrictive measures for psychiatric patients. They appeared rather willing to interact with them, a willingness increasing especially among females, those with clinical experience and psychiatric clinical training. Even though our results indicate an improvement in the perception of people with a mental disorder among the Greek medical students when compared to previous data for students and healthcare professionals, they should not be interpreted in an absolute way, but rather as a tendency. Even though there is hope that the still progressing psychiatric modernization in Greece (68, 69, 81) is followed by a progression in attitudes about mental illness, the slow pace of both (20, 68) could no way bring about complacency, as international literature consistently reports the dangerous—and even fatal—outcomes of poor healthcare access resulting from stigma (22, 25, 85–92). Consequently, the present study is rather a reminder for what needs to be done for current and future doctors in order to "benefit their patients, not to harm or injustice them, and to keep pure and holy both their life and art" as was captured in the Hippocratic Oath thousands of years before (93).

## Data availability statement

The original contributions presented in the study are included in the article/Supplementary material, further inquiries can be directed to the corresponding authors.

## Ethics statement

The studies involving humans were approved by Institutional Review Board of the Neurology Clinic, "Papageorgiou" General Hospital of Thessaloniki, Greece (protocol code: 120 /date of approval: 19/02/2021). The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

## Author contributions

G-NP, GD, JR, AK, and ID: conceptualization. G-NP, GD, JR, AK, ID, and VS: methodology. VS and ED: software. VS, G-NP, MA, ED, GD, JR, AK, and ID: validation. VS, MA, ED, and JR: formal analysis. G-NP, KA, SS, S-CZ, MA, GD, AK, and ID: investigation. G-NP, KA, MA, SS, S-CZ, and AK: resources. VS, MA, ED, AK, and JR: data curation. G-NP, MA, KA, SS, and S-CZ: writing-original draft preparation. G-NP, MA, KA, AK, and ID: writing-review and editing. G-NP, VS, MA, SS, and S-CZ: visualization. ID, AK, JR, and GD: supervision. AK, ID, G-NP, GD, and JR: project administration. All authors contributed to the article and approved the submitted version.

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## Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

## Publisher's note

## Supplementary material

The Supplementary material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpsyt.2023.1228539/full#supplementary-material

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# Explorative analyses on spatial differences in the desire for social distance toward people with mental illness in a diverging city

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**Introduction:** Stigma is an individual and societal process based on attitudes and power and relates to both spatial disparities and social distinction. In this study, we examined differences in desire for social distance toward people with mental illness within a city using social and spatial information.

**Methods:** ANOVAs and Scheffé *post-hoc* tests analyzed varying desires for social distance toward people with mental illness within Leipzig (East Germany). Joint Correspondence Analyses (JCA) explored correspondences between desire for social distance, socio-economic status, age, life orientation, social support, duration of living in Leipzig, and shame toward having a mental illness in five city districts of Leipzig in LIFE study participants (by Leipzig Research Center for Civilization Disease, data collected 2011–2014 and 2018–2021, $n = 521$).

**Results:** Stigma varied among Leipzig's districts ($F(df = 4) = 4.52$, $p = 0.001$). JCAs showed that a higher desired social distance toward people with mental illness corresponded with spatial differences, high levels of pessimism, high shame of being mentally ill, low social support, low socio-economic status, and older age (75.74 and 81.22% explained variances).

**Conclusion:** In terms of stigma, where people with mental illness live matters. The results identified target groups that should be addressed by appropriate intervention and prevention strategies for mental health care.

KEYWORDS

**social distance, stigma, stigmatization, mental health, joint correspondence analysis, urban, public mental health**

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## 1. Introduction

Stigma is embedded in its cultural context and influences decisions and behavior; it shapes and is shaped by society through processes of beliefs, power, inclusion, and exclusion (1, 2). Stigma toward people with mental illness refers to "labeling, stereotyping, separation, status loss, and discrimination" (1), aggravating the consequences of mental illness and posing a barrier to mental health care (3, 4). Staiger et al. (5) investigated the double stigma of unemployment and mental illness and found that intersectionally stigmatized people reported more distress compared to singularly disadvantaged people. Else-Quest et al. (6) emphasized the importance of investigating many facets of social structures to gain information on the complex characteristics of stigma. Thinking further, intersectional approaches condense not only determinants of social inequality like gender and age but also spatial aspects, such as neighborhood, negative representations of places, and accessibility to infrastructure. These aspects additionally represent a part of health disparities and stigmatization processes (7–11). In detail, Wacquant investigates with quantitative data (for instance, from local community fact books), in-depth interviews, and ethnographic observation of territorial stigma over time (7). He points out that increasing inequalities in social determinants interrelate with spatial segregation processes and negative representation of places. People feel ashamed of living in a so-called "bad neighborhood" (for instance because of people with low socioeconomic status living there). Based on this, Halliday et al. make clear that these neighborhoods lack further in accessibility and social isolation, so they are of remarkable interest for public health research (and nevertheless under-represented in the body of research) (8). As mentioned above and the fact that intersections of stigmatized characteristics lead to stronger distress for people, it is of particular relevance to understand and overcome complex stigmatization processes.

Nevertheless, there is sparse knowledge about correspondences of spatial and social aspects and stigma toward people with mental illness. Current research seeking to close the research gap about stigma within cities provides perspectives on spatial (8) or territorial stigmatization (7, 12) as well as social dimensions of stigma. Therefore, we aim to investigate the desire for social distance toward people with mental illness in cities.

Space is shaped by people and influences people's behavior (13). Hence, cities are realms of experience (14). Leipzig is a major city in East Germany and has areas teeming with opportunities, but it also showcases spaces marked by inequality and disadvantage (15). With more than 600,000 inhabitants in 63 city districts (16), Leipzig is one of the German cities with the fastest-growing populations (17). It is known for its art and culture scenes (18) and also for its heterogeneity (15), with the latter quality rendering Leipzig suitable for the current research question. To this end, we chose five selected city districts to portray the diversity of Leipzig's social and cultural atmosphere: The City Center around Leipzig Central Station and the marketplace is characterized by a flow of people in shopping malls, historical buildings, and renowned concert halls; Connewitz in the South is the district with the highest proportion of forest (19) and has a flourishing independent culture scene with a history of the left-wing activist movement (20); Gohlis-North in the North of the city's periphery has classical modern houses and a growing population (19). Grünau-North in the West of Leipzig is characterized by large-panel system buildings, and Heiterblick is an industrial area with green space.

The focus on districts as smaller units is especially important for research on the progression of social connections, distance, and networks (21). To supplement spatial data, the current study additionally investigates social features, which determine and constitute spatial varieties among individual city districts. Current analyses explore and condense past research on associations between stigma toward people with mental illness and socioeconomic status (SES) (22), social support (23), and life orientation (24), as well as associations between social distance, SES (25, 26), and social support (27). Life orientation is operationalized through pessimism regarding recovery potential in people with mental illness (28). As mentioned above, social disparities interrelate with space and mental health.

Furthermore, it is well established that cities are characterized by a higher prevalence of mental illness (29, 30) and lower stigma (31) when compared to rural areas.

Little is known about how social and spatial features correspond with stigmatization toward people with mental illness, especially within cities in Germany. We attempt to close this research gap by condensing ongoing research and adding insights into relevant features that interrelate with stigma toward people with mental illness through explorative analyses. To this end, this paper investigates characteristics associated with a desire for social distance as an expression of mental health stigma in different city districts in Leipzig.

## 2. Research questions

The current paper aims to explore possible cohesiveness and disparities in the five city districts of Leipzig mentioned above, focusing on desired social distance toward people with mental illness by combining social and spatial information on city districts. This led to the following research questions:

Are there differences in the desire for social distance toward people with mental illness between Leipzig's city districts?

Which aspects (SES, life orientation, social support, duration of living in Leipzig, and shame of having a mental illness) constitute and correspond with the desire for social distance toward people with mental illness in different city districts of Leipzig?

## 3. Materials and methods

### 3.1. Sample

The LIFE-Adult-Study is a longitudinal cohort study by the Leipzig Research Center for Civilization Diseases (LIFE) evaluating a broad spectrum of common diseases in 10,000 randomly selected people residing in Leipzig (for further information about the LIFE-study please see (32–34)). The LIFE-study includes data on psychological and medical examinations, laboratory studies, interviews, questionnaires, and cognitive tests collected during the first wave of the study from 2011 to 2014 (32). During the second wave

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Abbreviations: ANOVA, Analysis of variances; JCA, Joint Correspondence Analysis; LIFE, Leipzig Research Center for Civilization Diseases; M, Mean; Max, Maximum; Min, Minimum; SD, Standard Deviation; SES, Socio-Economic Status.

from 2018 to 2021 (34), new items, including items concerning the desire for social distance toward people with mental illness, were added ($n = 2{,}993$). Inclusion criteria were being of legal age (≥18y) and being a resident of Leipzig (32), a major city in eastern Germany with nearly 600,000 inhabitants (35). Written informed consent of all participants was obtained before data collection. The ethics committee of the Medical Faculty of Leipzig University approved the study (approval numbers 263–2009-14122009, 263/09-ff, 201/17-ek). The responsible data protection officer approved the data privacy and safety concept. (32, 34).

Urban differences were mapped to investigate inner city's differences in attitudes and stigma (36). Leipzig has 63 city districts within nine superordinate areas. City districts as smaller, homogenous, spatial units were chosen for analyses and selected by two criteria: First, city districts had to be part of a superordinate area named after cardinal points or the city center. The second criterion was the cities with the highest number of cases. One exception is Connewitz instead of Südvorstadt for the south of Leipzig, as the participant number was nearly identical to Connewitz but not directly adjacent to the City Center. Comparing these two districts in the desire for social distance toward people with mental illness, no significant differences were found ($t(df = 212) = -0.292$, $p = 0.770$), justifying city districts. Finally, analyses include five of 63 city districts ($n = 521$): Leipzig's City Center, Connewitz in the south, Gohlis-North in the north, Grünau-North in the west, and Heiterblick in the east of Leipzig.

## 3.2. Data and variables

Research data were drawn from two waves of the LIFE-adult-study (32, 34) and open-source shape files for additionally visualized maps (37).

The following measures were elicited in the first wave of the LIFE-study (2011–2014) (32): SES was operationalized according to Lampert et al. (38) through summed educational and professional status and income as social deprivation. The scale's calculated quintiles were summarized into three categories: low, middle, and high SES (38). As life orientation is related to stigma (39, 40), dispositional and generalized pessimism and optimism were rated on a five-point Likert scale (1 "strongly disagree" to 5 "strongly agree") as part of the Life Orientation Test (for instance "In uncertain times, I usually expect the best") (41, adapted by 42, 43). Higher sum scores on respective instruments indicated higher levels of optimism or pessimism (44). Optimism and pessimism were seen as stable traits (41). Both scales were dichotomized at the sample's median to depict higher and lower-than-average optimism or pessimism. Social support was operationalized by Likert-scaled answers (1 "none of the time" to 5 "all of the time") on five items of the ENRICHD-Social Support-Instrument (ESSI) (45 adapted for a German sample by 46, 47). Analogous to Cordes et al. (47), scores were analyzed dichotomously: when two items scored less than four, participants were operationalized as lacking social support, while all other results indicated high social support. Personal master data and spatial information about the city districts the participants resided in completed the dataset.

The second LIFE survey (34) elicited the stigma variables (shame and desire for social distance) toward people with mental illness and the duration of living in Leipzig. The desire for social distance was measured using three questions that referred to acceptance regarding renting a flat to working with and living in a neighborhood with a person with mental illness, each on a five-point-Likert-scale (0 "definitely willing" to 4 "definitely unwilling," with high values indicating a higher desired social distance) (48–50). To describe the desire for social distance, the sum scale was calculated and dichotomized using the sample's median due to a lack of standardized reference values. Values ranged from 0 to 12, with higher scores again indicating higher social distance. An additional question investigated anticipated shame when experiencing mental illness using a Likert scale (0 "Not at all" to 4 "strongly") (51). Shame as the emotional equivalent of self-stigma is known to be associated with the desire for social distance toward people with mental illness (52, 53). Data on the duration of each participant's residency in Leipzig was part of the analysis, taking the known association between residential stability and the prevalence of depression into consideration (54).

We utilized Joint Correspondence Analyses (JCA) to combine social and spatial or environmental information for a multifaceted approach to stigma (55).

## 3.3. Analysis

After testing for normal distribution using the Kolmogorov–Smirnov test and homoscedasticity using the Levene test, an analysis of variance compared city district-specific mean values of desire for social distance toward people with mental illness to examine area-specific differences (56). For non-normal distributed variances, the Kruskal Wallis test compared city district-specific mean values (56). The significance level was set to 95% ($\alpha = 0.05$) (56). Scheffé's test analyzed and compared *post-hoc* contrasts (57, 58).

We created a map of reported desire for social distance toward people with mental illness in different city districts of Leipzig by combining information from the LIFE-study sample with spatial data in the City of Leipzig (37).

To explore cohering and diverging variables for these variations in desire for social distance toward people with mental illness in city districts, two JCAs were calculated (55). Ordinal and nominal data (city districts, SES, and social support) were chosen, and metric items were condensed to quartiles (referring to the sample's distribution: age and duration of living in Leipzig) or dichotomized (referring to the sample's median: life orientation; desire for social distance toward colleagues, neighbors, and subtenants with mental illness; and shame) (59). JCA followed a weighted least-squared algorithm with steps comparable to factor analyses for non-metric variable categories (60, 61). Data were principal-normalized as recommended for correspondence analysis with more than two variables to compare categories (62). The variable category frequencies were listed in a multiway contingency table (similar to chi-squared statistics) (63). The centroid marked the average row and column profiles (64). JCA reduces errors of diagonal values, which would depict correspondences of the same categories (55). Results were variances, inertias ($\lambda$, averaged frequencies) (55, 65), and masses (or weights, w; explaining the categories' contributions to related variables for the whole matrix) (55, 66). By decomposing JCA's inertia, distinct dimensions were identified and represented outlined deviations from numerical independence (64). These factors or axes were extracted; they structure the matrix of category frequencies. Explained variance for two dimensions reached more than 70%, so using more principal components was not conducive (67). For each dimension, the categories' eigenvalues as contributions ($ctr_k$%) to dimension were calculated (64).

JCAs helped to find out about characteristics corresponding with varying desired social distance toward people with mental illness and referred to five districts: City Center, Heiterblick in the east, Grünau-North in the west, Connewitz in the south, and Gohlis-North in the north of Leipzig. The first JCA included desire for social distance as a sum score and the second JCA investigated three items of the desire for social distance scale separately.

JCA results were graphically represented by a matrix that mapped the resulting dimension 1 (horizontal axis) and dimension 2 (vertical axis) (64) with data points as variable categories. The latter can be interpreted as correspondences (or distances) from the centroid (average) between each category as well as categories and axes (62, 63).

Cases with missing values were excluded from analyses as inherent in the JCA calculation procedure. Overall, there were $n = 261$ (8.72%) missing values in merged datasets on city district retrieval and $n = 107$ cases (3.58%) with missing values on the desire for social distance. We take this as a reference point to rely on van Buuren (68) to assume completely missing random data instead of imputation methods. Additionally, Diaz-Bone recommends excluding missing values in JCAs to keep analyses interpretable (59).

### 3.4. Software

All calculations were performed with Stata SE 16.0 (69) with additional packages 'SPMAP' to visualize spatial data (70) and 'grc1leg' to combine similar graphs with one legend (71).

## 4. Results

### 4.1. Sample

Of all respondents in the first wave of the LIFE-study ($n = 10{,}589$, 51.69% women, age: $M = 57.61$y, SD = 12.51y, Min: 18.24y, and Max: 87.83y), information on the desire for social distance was available from those additionally included in the second wave ($n = 2{,}993$, 51.35% women; age at the time of the second survey: $M = 62.72$y, SD = 12.97y, Min: 26.00y, and Max: 86.00y). In our sample, 15.50% ($n = 464$) reported low SES, 51.19% ($n = 1{,}532$) middle SES, and 22.69% ($n = 679$) high SES. The life orientation test resulted in a mean optimism score of 12.03 (SD = 2.39, Min: 3, Max: 15) and a mean pessimism score of 7.21 (SD = 2.29, Min: 3, Max: 15). ESSI score indicated low social support for 11.16% ($n = 334$) and high social support for 85.87% ($n = 2{,}570$) of participants. The sample included participants from 53 city districts in Leipzig who had lived there, on average, since 1988 (SD = 21.94y, Min: since 1928, Max: since 2020), while data was missing for 10 city districts.

Participants from the five districts described in the Introduction and Methods sections were included in the analysis ($n = 521$): Leipzig's City Center with $n = 117$ participants (47.86% women; age: $M = 61.43$y), Heiterblick in the east ($n = 91$, 57.14% women; age: $M = 64.12$y), Connewitz in the south ($n = 101$, 51.49% women; age: $M$: 61.72y), Grünau-North in the west ($n = 91$, 47.86% women; age: $M = 66.44$y), and Gohlis-North in the north ($n = 121$, 53.72% women; age: $M = 64.41$y). Differences to 100% are missing values. For all descriptive information, please see Table 1.

The desire for social distance varied toward subtenants ($M = 2.96$, SD = 1.20), neighbors ($M = 1.33$, SD = 1.20), and colleagues ($M = 1.03$, SD = 1.15) with mental illness. Supplementary Figures S2, S3 show city districts' social distance toward subtenants, Supplementary Figures S4, S5 toward neighbors, and Supplementary Figures S6, S7 toward colleagues with mental illness. Comparing selected city districts resulted in varying sum scores in desire for social distance: Grünau-North ($M = 6.18$, SD = 2.71) showed the highest social distance toward people with mental illness compared to City Center ($M = 4.89$, SD = 2.34), Connewitz ($M = 5.02$, SD = 2.85), Gohlis-North ($M = 5.10$, SD = 2.97), and Heiterblick ($M = 5.94$, SD = 2.61) (ANOVA: $F(df = 4) = 4.52$, $p = 0.001$, Levene-Test: $F(df = 4) = 1.95$, $p = 0.100$). ANOVA ($F(df = 4) = 3.20$, $p = 0.013$, Levene-Test: $F(df = 4) = 1.102$, $p = 0.355$) resulted in significant variations in the desire for social distance toward neighbors with mental illness between city districts (Heiterblick: $M = 1.58$, SD = 1.19; Grünau-North: $M = 1.61$, SD = 1.19; City Center: $M = 1.26$, SD = 1.05; Gohlis-North: $M = 1.25$, SD = 1.13; Connewitz: $M = 1.14$, SD = 1.21). Desire for social distance toward subtenants with mental illness also revealed significant differences (ANOVA: $F(df = 4) = 5.35$, $p = 0.002$, Levene test: $F(df = 4) = 4.95$, $p < 0.001$, Grünau-North: $M = 3.38$, SD = 1.04, Heiterblick: $M = 3.23$, SD = 1.04, Connewitz: $M = 2.97$, SD = 1.13, Gohlis-North: $M = 2.85$, SD = 1.31, and City-Center: $M = 2.84$, SD = 1.10). *Post-hoc* tests revealed that Grünau-North, City Center, and Gohlis-North were especially important for these differences. Please see Supplementary Table S2 for detailed results. No significant differences could be reported in the desire for social distance toward colleagues with mental illness between city districts. All results are listed in Table 1. Scheffé *post-hoc* tests can be found in Supplementary Tables S1, S2.

### 4.2. Joint correspondence analyses for the desire for social distance toward people with mental illness

As Figure 1 shows, high desire for social distance toward people with mental illness corresponded with living in Heiterblick or Grünau-North, low optimism, high pessimism, and high shame of having a mental illness. Compared to other city districts, study participants living in Grünau-North reported low social support, low SES, and high social distance toward people with mental illness. Low social distance toward people with mental illness corresponded with high social support, high optimism, low pessimism, low shame, high SES, and living in Connewitz or City Center.

Figure 1 shows JCA's graphical results ($n = 521$) with the closest fitting of data on the first dimension (horizontal axis), which explained 52.51% ($\lambda_1 = 0.015$) of the total variance, and the second dimension (vertical axis), which explained 23.23% ($\lambda_2 = 0.007$) of the total variance (75.74%, $\lambda = 0.029$). For a more precise distinction, contributions to the first axis were mainly described by pessimism ($ctr_{\%} = 20.10\%$). The second dimension was based on participants' age ($ctr_{\%} = 56.70\%$) and duration of living in Leipzig ($ctr_{\%} = 26.60\%$). Among age categories, the two extreme quartiles, oldest and youngest adults, explained most of the matrix's variance (75–86: $\lambda_{\%} = 10.30\%$, 26-52y: $\lambda_{\%} = 7.40\%$). Supplementary Tables S3, S4 include all results

TABLE 1 Sociodemographic characteristics for each of the five exemplary city districts of Leipzig and the whole sample, frequencies by column, and distributions ($n = 2,993$).

| Variables | | | | | Leipzig's exemplary city districts | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | Descriptives | | Sample | Missings | *City Center* | *Heiterblick* | *Connewitz* | *Grünau-North* | *Gohlis-North* |
| *Total* | | *N* (%) | 2,993 | 261 (8.72) | 117 (3.91) | 91 (3.04) | 101 (3.37) | 91 (3.04) | 121 (4.04) |
| Sex | Men | *N* (%) | 1,407 (47.401) | 113 (43.30) | 61 (52.14) | 39 (42.86) | 49 (48.51) | 46 (50.55) | 56 (46.28) |
| | Women | *N* (%) | 1,537 (51.35) | 99 (37.93) | 56 (47.86) | 52 (57.14) | 52 (51.49) | 56 (47.86) | 65 (53.72) |
| | Missings | *N* (%) | 49(1.64) | 49 (18.77) | 0 | 0 | 0 | 0 | 0 |
| Age | | Median (Range) | 64.00 (26–86) | 55.50 (26–83) | 61.00 (26–84) | 63.00 (31–82) | 60.00 (27–86) | 67.00 (47–85) | 66.00 (33–86) |
| | | *M* (±SD) | 62.72(±12.96) | 57.18(±14.07) | 61.43(±14.93) | 64.12(±11.38) | 61.72(±13.80) | 66.44(±9.70) | 64.41(±12.62) |
| SES[a] | Low | *N* (%) | 464 (15.50) | 23 (8.81) | 10 (8.55) | 16 (17.58) | 12 (11.88) | 19 (20.88) | 16 (13.22) |
| | Middle | *N* (%) | 1,532 (51.19) | 109 (41.76) | 49 (41.88) | 60 (65.93) | 56 (55.45) | 51 (56.04) | 74 (61.16) |
| | High | *N* (%) | 679 (22.69) | 61 (23.37) | 40 (34.19) | 7 (7.69) | 24 (23.76) | 18 (19.78) | 25 (20.66) |
| | Missings | *N* (%) | 318 (10.62) | 68 (26.05) | 18 (15.38) | 8 (8.79) | 9 (8.91) | 3 (3.30) | 6 (4.96) |
| Living in Leipzig since … | | Median (Range) | 1994 (1928–2020) | 2003 (1941–2020) | 1995 (1936–2020) | 1990 (1928–2019) | 1996 (1941–2019) | 1987 (1940–2019) | 1987 (1938–2019) |
| | | *M* (±SD) | 1987.84 (±21.94) | 1996.61 (±21.40) | 1989.19 (±21.18) | 1987.69 (±23.56) | 1986.62 (±21.81) | 1986.73 (±20.08) | 1986.28 (±23.75) |
| Optimism (LOT-Subsc) | | Median (Range) | 12 (3–15) | 12 (6–15) | 13 (3–15) | 12 (3–15) | 12 (5–15) | 11 (3–15) | 12 (3–15) |
| | | *M* (±SD) | 12.03 (±2.39) | 12.11 (±2.33) | 12.36 (±2.41) | 11.90 (±2.25) | 12.16 (±2.33) | 11.19 (±2.38) | 12.22 (±2.24) |
| | Low (3–12) | *N* (%) | 1,544 (51.59) | 106 (40.61) | 54 (46.15) | 56 (61.54) | 50 (49.50) | 62 (68.13) | 59 (48.76) |
| | High (13–15) | *N* (%) | 1,339 (44.74) | 102 (39.08) | 61 (52.14) | 35 (38.46) | 49 (48.51) | 29 (31.87) | 56 (46.28) |
| | Missings | *N* (%) | 110 (3.68) | 53 (20.31) | 2 (1.71) | 0 | 2 (1.98) | 0 | 6 (4.96) |
| Pessimism (LOT Subscale) | | *Median (Range)* | 7 (3–15) | 7 (3–14) | 7 (3–14) | 8 (3–13) | 7 (3–13) | 8 (3–11) | 7 (3–13) |
| | | *M (±SD)* | 7.21 (±2.29) | 7.00 (±2.19) | 6.96 (±2.23) | 7.43 (±2.18) | 6.95 (±2.29) | 7.7 (±2.21) | 7.22 (±2.20) |
| | Low (3–7) | *N (%)* | 1,630 (54.46) | 128 (49.04) | 72 (61.54) | 48 (52.75) | 58 (57.43) | 40 (43.96) | 65 (53.72) |
| | High (8–15) | *N (%)* | 1,251 (41.80) | 81 (31.03) | 45 (38.46) | 43 (47.25) | 42 (41.58) | 50 (54.95) | 54 (44.63) |
| | *Missings* | *N (%)* | 112 (3.74) | 52 (19.92) | 0 | 0 | 1 (0.99) | 1 (1.10) | 2 (1.65) |
| Social Support (ENRICHD-SSI) | | *Median (Range)* | 24 (5–25) | 24 (8–25) | 24 (5–25) | 22 (7–25) | 23 (12–25) | 23 (7–25) | 24 (9–25) |
| | | *M* (±SD) | 22.37 (±3.41) | 22.81 (±2.71) | 22.67 (±3.39) | 21.27 (±4.20) | 22.47 (±2.70) | 21.04 (±4.58) | 22.63 (±3.03) |
| | Low | *N (%)* | 334 (11.16) | 14 (5.36) | 11 (9.40) | 16 (17.58) | 9 (8.91) | 19 (20.88) | 14 (11.57) |
| | High | *N (%)* | 2,570 (85.87) | 197 (75.48) | 106 (90.60) | 75 (82.42) | 91 (90.10) | 72 (79.12) | 106 (87.60) |
| | *Missings* | *N* (%) | 89 (2.93) | 50 (19.16) | 0 | 0 | 1 (0.99) | 0 | 1 (0.83) |
| Soc. Dis. subt. | | Median (Range) | 3 (0–4) | 3 (0–4) | 3 (0–4) | 4 (0–4) | 3 (0–4) | 4 (0–4) | 3 (0–4) |
| | | *M* (±SD) | 2.96 (1.20) | 2.93 (1.23) | 2.84 (1.10) | 3.23 (1.04) | 2.97 (1.13) | 3.38 (1.04) | 2.85 (1.31) |

*(Continued)*

TABLE 1 (Continued)

| Variables | Descriptives | Sample | Missings | Leipzig's exemplary city districts | | | | |
|---|---|---|---|---|---|---|---|---|
| | | | | City Center | Heiterblick | Connewitz | Grünau-North | Gohlis-North |
| Soc. Dis. coll. | Median (Range) | 1 (0–4) | 1 (0–4) | 1 (0–4) | 1 (0–4) | 0 (0–4) | 1 (0–4) | 1 (0–4) |
| | *M* (±SD) | 1.03 (±1.15) | 1.04 (±1.17) | 0.81 (±0.91) | 1.09 (±1.18) | 0.90 (±1.14) | 1.21 (±1.19) | 1 (±1.19) |
| *Soc. Dis. neigh.* | Median (Range) | 1 (0–4) | 1 (0–4) | 1 (0–4) | 2 (0–4) | 1 (0–4) | 1 (0–4) | 1 (0–4) |
| | *M* (±SD) | 1.33 (±1.20) | 1.23 (±1.19) | 1.26 (±1.05) | 1.58 (±1.19) | 1.14 (±1.21) | 1.33 (±1.10) | 1.25 (±1.13) |
| Shame | Median (Range) | 1 (0–4) | 1 (0–4) | 1 (0–4) | 1 (0–4) | 1 (0–3) | 1 (0–4) | 1 (0–4) |
| | *M* (±SD) | 1.22 (±1.04) | 1.31 (±1.03) | 1.30 (±0.98) | 1.38 (±0.96) | 1.09 (±1.11) | 1.19 (±1.05) | 1.19 (±1.05) |
| Soc. Dis. Sum | Median (Range) | 5 (0–12) | 5 (0–12) | 5 (0–11) | 6 (0–12) | 5 (0–12) | 6 (1–12) | 4 (0–12) |
| | *M* (±SD) | 5.32 (±2.84) | 5.19 (±2.91) | 4.89 (±2.34) | 5.94 (±2.61) | 5.02 (±2.85) | 6.18 (±2.71) | 5.10 (±2.97) |

[a]operationalized as described in 38.

concerning the first JCA with sum scales on the desire for social distance items and all variables.

Figure 2 shows that a high desire for social distance toward subtenants but also toward neighbors and colleagues with mental illness corresponded with a high shame of having a mental illness. Living in Heiterblick or Grünau-North, high pessimism, low optimism, low social support, and low SES as well as older age corresponded with high social distance toward subtenants with mental illness. Conversely, a low desire for social distance toward colleagues and neighbors with mental illness related to low shame, whereas a low desire for social distance toward subtenants with mental illness corresponded with high optimism, low pessimism, living in Connewitz or City Center, high SES, and high social support.

JCA explained a total variance of 81.22% through two dimensions (horizontal axis: $\lambda_1 = 0.024$, 66.26%; vertical axis $\lambda_2 = 0.006$, 14.96%). The desire for social distance toward neighbors ($ctr_{\%} = 32.20\%$), colleagues ($ctr_{\%} = 28.70\%$), and subtenants ($ctr_{\%} = 9.60\%$) with mental illness notably describes the horizontal axis. The second dimension can be explained by pessimism ($ctr_{\%} = 15.00\%$) and age ($ctr_{\%} = 14.80\%$). Inertias describe contributions of each variable's categories: high desire for social distance toward colleagues ($\lambda_{\%} = 14.20\%$) and neighbors ($\lambda_{\%} = 13.30\%$) with mental illness explained most of the JCAs' variance. Supplementary Tables S3, S5 show results on JCA with all included variables.

## 5. Discussion

Results indicate that it matters where people with mental illness live and in what socioeconomic circumstances they are embedded. We found variations in the desire for social distance toward people with mental illness corresponding to both social and spatial characteristics. The desire for social distance toward people with mental illness was lower in Leipzig's City Center compared to other districts. Results support that there still is a stigma in cities even if urban spaces have been connoted as representing postmodern heterogeneity, diversity, and fluidity (72). Current analyses support that cities and city districts are more than spatial units: districts combine social features, which are particularly relevant when investigating social distance toward people with mental illness. Encouraged by Link and Phelan's (1) proposal on multifaceted and multilevel approaches and Staiger et al. (5) and Else-Quest et al.'s (6) call for intersectionality in stigma research, micro (individual) and macro (urbanity-related) level factors might help understand, reflect on, and cope with stigma and desire for social distance toward people with mental illness. Investigating districts as socially constructed concepts adds insight into territorial (7, 12) and spatial stigmatization processes (8).

Because Leipzig is a growing city regarding both population and cultural diversity (15), there are still variations and progressions in and between Leipzig's city districts (see Supplementary Figures S8–S14 in the Supplementary material for the depiction of additional characteristics of Leipzig). The five selected city districts differ not only in desire for social distance toward people with mental illness but also in SES, age, and social support implicating detailed urban and suburban research and comparisons (73). Residents in Heiterblick and Grünau-North reported low SES corresponding with high pessimism, low social support, and a high desire for social distance toward people

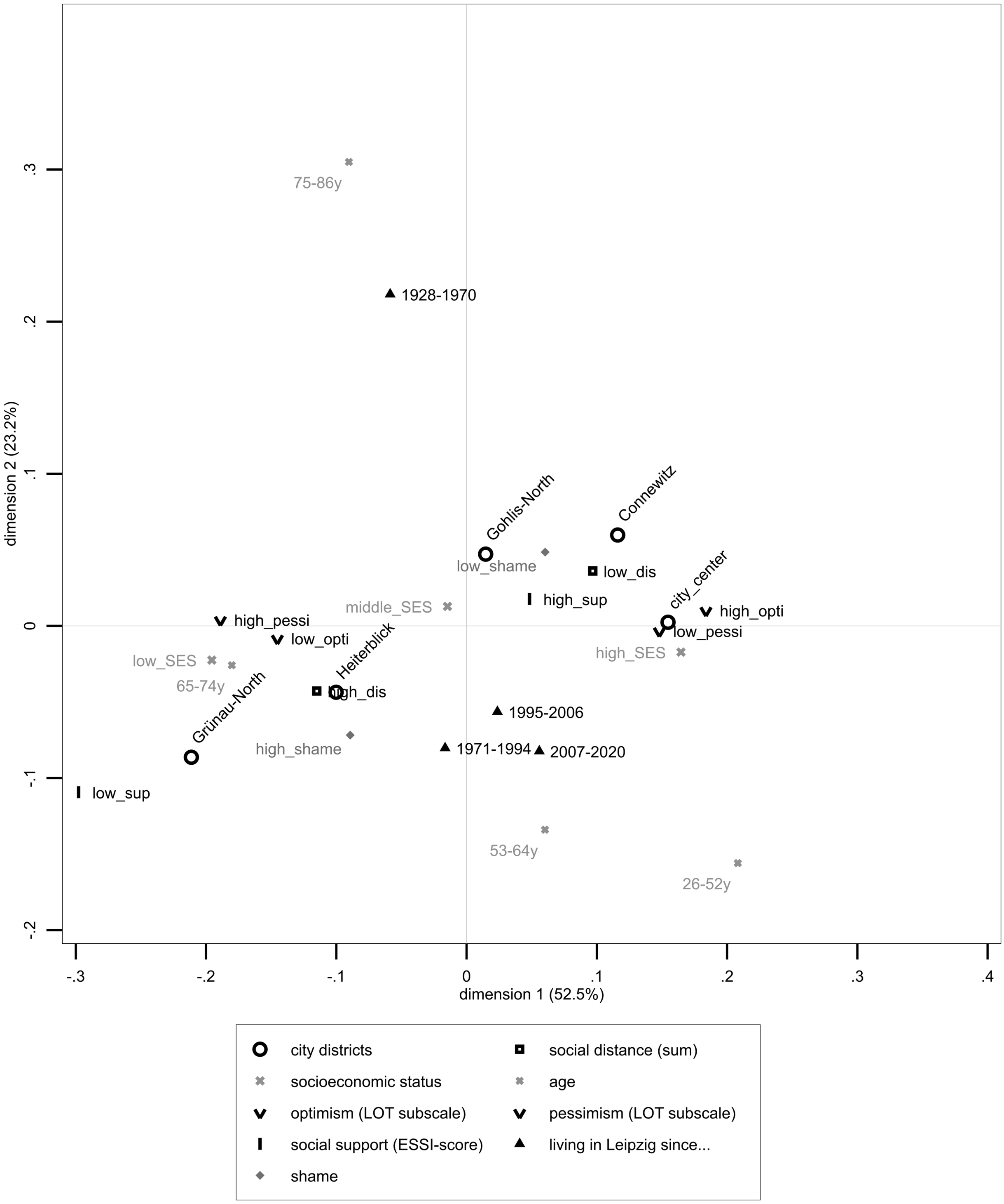

FIGURE 1
Joint Correspondence Analysis depicting sum scale on the desire for social distance toward people with mental illness, Leipzig's exemplary districts (City center, Heiterblick, Connewitz, Gohlis-North, and Grünau-North), SES, age, life-orientation scales including dichotomized optimism and pessimism scales, dichotomized ENRICHD-Social-Support-Instrument, duration of living in Leipzig, and shame of having a mental illness based on LIFE data (*n* = 521).

with mental illness. These correspondences of disadvantages are supported by double stigma research (5) and by Else-Quest et al.'s (6) concept of intersectional, socially constructed categories interfering with mental health stigma. Furthermore, results condensed past findings on higher social distance toward people with mental illness to be associated with higher age (74), lower SES (22), pessimism (24), lower social support (23), and higher shame of having a mental illness (52).

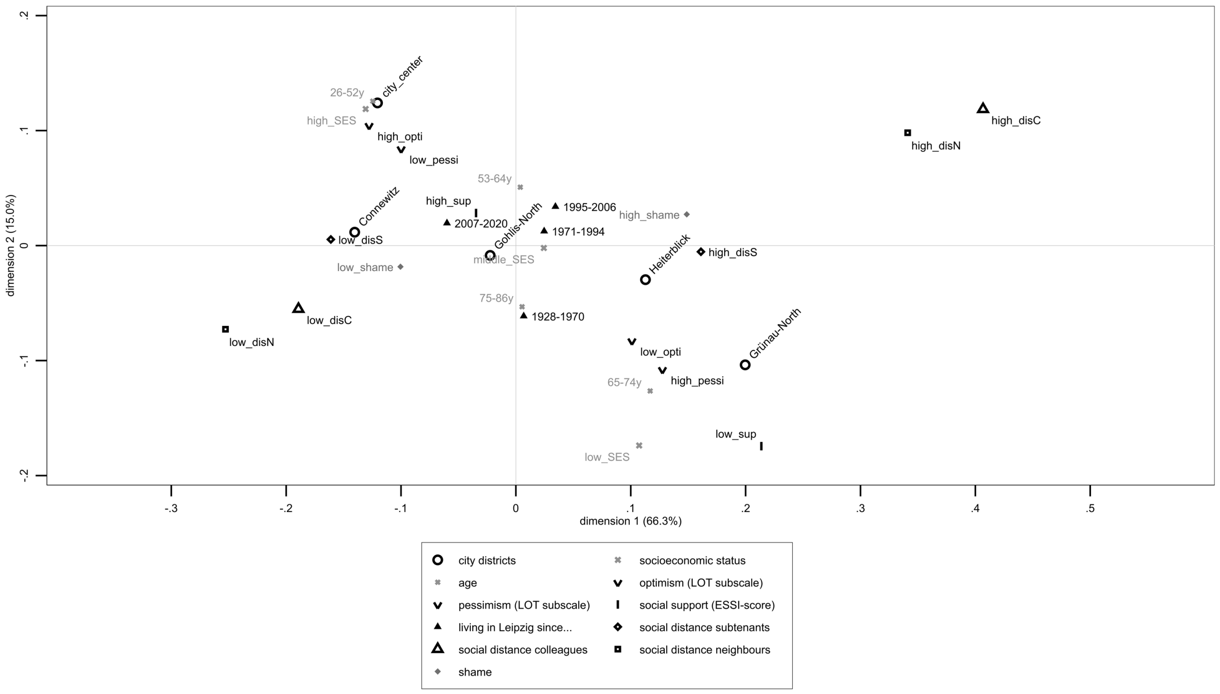

FIGURE 2
Joint Correspondence Analysis including single items on desire for social distance toward colleagues, neighbors, and subtenants with mental illness, Leipzig's exemplary districts (City center, Heiterblick, Connewitz, Gohlis-North, and Grünau-North), SES, age, life-orientation scales including dichotomized optimism and pessimism scales, dichotomized ENRICHD-Social-Support-Instrument, duration of living in Leipzig, and shame of having a mental illness based on LIFE-data (*n* = 521).

Distinctions between city districts represent a self-selection bias as people choose where to live not only based on pragmatic aspects (75). Moving in different city districts as habitats might influence one's identification with prevailing characteristics and habitus such as values and cultural diversity, as well as socioeconomic characteristics of inhabitants (76, 77). This association can be exemplarily demonstrated through Leipzig's city district Connewitz with its long-term, leftist inhabitants (20). In the past, Connewitz was occupied by squatters who established a habitat for left-wing people (please see the election result in Supplementary Figure S13) and space for leftist discourses (78, 79). Current analyses showed high social support as well as low levels of desire for social distance toward neighbors with mental illness, accentuating a district-specific cohesion in Connewitz, regarding, for instance, shared values or lifestyles. These assumptions are consistent with past research on social segregation processes [in Leipzig: (80); but also as a postmodern phenomenon: (21)], neighborhood cohesion, and health status (81). These inner-city processes endorse interrelating social and spatial aspects as experience realms in Leipzig and other cities. Results may help establish destigmatization efforts and support people with mental illness when seeking to gain access to health care.

To conceptualize stigma, we compared a sum scale with single items of desire for social distance toward neighbors, colleagues, and subtenants with mental illness. The latter led to a more explained variance of the JCA. These results were consistent with previous research which states that items measuring the desire for social distance refer to different areas of life and that ranges of desire for social distance toward colleagues, neighbors, and subtenants cannot easily be summarized (27).

# 6. Strengths and limitations

## 6.1. Data collection

The LIFE-adult-sample was collected in two different waves. While life orientation is recognized as a stable personality trait (41), possible changes in other data, such as participants moving between city districts, could not be depicted. Due to different questionnaires and information between the two waves, longitudinal analyses and reflections were not possible. Additionally, there were dropouts over time (34).

Despite anonymized data collection, social desirability might influence participants' response behavior to possibly objectionable questions regarding the desire for social distance toward people with mental illness. Furthermore, the desire for social distance labeled people with mental illness in general while research has shown varying desires for social distance between different disorders (26, 82), for instance, for depression and schizophrenia (27).

Sample representability is limited as participants have higher social and health status compared to recruited non-participants (33). As the sample's health status is above average, possible results concerning mental illnesses or other health-related risk factors may be underestimated (33). Leipzig has a unique history as a city of fairs with significant influence of infrastructure and diverse perspectives from other countries (83). Additional research about past and current sociopolitical progress may help in understanding ongoing developments and problems, for instance, housing shortages because of bought-up flats or dead industries (84). Migration processes, spatial distribution, the density of schools in the city, and culturally used areas additionally reshape a district's social structure. Leipzig currently registers remarkable demographic growth compared to other cities, especially in the East but also throughout Germany (85, 86).

### 6.2. Methodological aspects

As variables were not all distributed normally, we reported results of a non-parametrical Kruskal Wallis test. JCA allows for explorations of cross-sectional data structure and frequencies although the direction of associations or causality cannot be determined (59). Additionally, data was dichotomized and categorized, referring to the sample's median because there was no reference data for normalization. As with all statistical calculations, correspondence analyses reduced complexity (59). The number of cases in different city districts varied; therefore, generalizations and comparative conclusions were limited (33).

## 7. Future directions

Future research should be aware of milieus or lifestyles in cities. Taking target groups into consideration, especially for anti-stigma interventions, may help to overcome social distance and support mental health literacy in marginalized groups, for instance, groups with low SES, low social support, high pessimism, and high shame toward having a mental illness.

Leipzig, with its remarkable history and current diversity, enables many possibilities for further investigations such as comparing Leipzig's population with other urban areas. Future studies should include data over a longer period of time to gain information on fluid and stable markers of social distance and social structure in cities to detect causes and predict consequences for progressions in stigma toward people with mental illness (87, 88).

As the term 'social distance' refers to interpersonal and spatial information, future research should follow interdisciplinary approaches by combining historical knowledge with political, sociological, psychological, epidemiological, and geographic knowledge (89). Factors that might relate to stigma within cities are higher population densities, access to health care, or intersectional aspects (6, 90).

These approaches may help to identify target groups as well as spaces and areas that should be addressed by appropriate intervention and prevention strategies for mental health care (91, 92), like district-specific health care centers addressing spatial and social help-seeking barriers (93).

## Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

## Ethics statement

The studies involving humans were approved by the Ethics Committee of the Medical Faculty of the Leipzig University (approval numbers 263–2009-14122009, 263/09-ff, 201/17-ek). The responsible data protection officer approved data privacy and the safety concept. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

## Author contributions

CH: Conceptualization, Data curation, Formal analysis, Methodology, Visualization, Writing – original draft, Writing – review & editing. SS: Writing – review & editing. TF: Writing – review & editing. DO: Writing – review & editing. CK: Writing – review & editing. EB: Writing – review & editing. HM: Writing – review & editing. LA: Writing – review & editing. SH: Writing – review & editing. SS: Conceptualization, Writing – review & editing. MR: Writing – review & editing. HG: Writing – review & editing. AH: Writing – review & editing. NR: Writing – review & editing. KW: Writing – review & editing. CE: Writing – review & editing. GS: Conceptualization, Writing – review & editing. CU: Conceptualization, Data curation, Writing – review & editing.

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## Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

## Publisher's note

## Supplementary material

The Supplementary material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpubh.2023.1260118/full#supplementary-material

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# Insights from China: understanding the impact of community resilience and government trust in psychological resilience and anxiety during COVID-19

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**Background:** COVID-19 has the potential to greatly impact an individual mental well-being. However, an individual's psychological resilience, combined with support from their community and government disaster relief efforts can aid individuals in confronting crises with a positive mindset. The purpose of this study is to investigate how individuals, across three dimensions of individual resilience perception, community resilience perception, and government trust perception, mitigate individual anxiety during COVID-19.

**Methods:** This study employed an online survey method that was not restricted by geographical location. Data collection took place from January 2022 to June 2022, and the valid questionnaires covered all 31 provinces, autonomous regions, and municipalities in China. The assessment of community resilience was conducted employing the Conjoint Community Resilience Assessment Measure-10 (CCRAM-10). Structural Equation Modeling (SEM) was also used to examine the relationship between community resilience, government trust, individual psychological resilience, and anxiety.

**Results:** The SEM results reveal that individual psychological resilience is significantly negatively correlated with anxiety ($b = -0.099$, $p < 0.001$), while there is a significant positive correlation between community resilience perception ($b = 0.403$, $p < 0.001$) and government trust ($b = 0.364$, $p < 0.001$) with individual psychological resilience. Furthermore, government trust perception enhances psychological resilience, consequently reducing anxiety ($b = -0.036$, $p < 0.001$). The results also revealed that women and increasing age had a mitigating effect on individual anxiety during COVID-19.

**Conclusion:** Individual's mental state is influenced on multiple dimensions during COVID-19. Not only can individual psychological resilience better cope with anxiety, but support at the community and government dimensions has a significant impact on individual psychology. These resources can enhance the resilience of both individuals and communities, helping them better cope with stress and difficulties.

KEYWORDS

**COVID-19, anxiety, psychological resilience, community resilience, government trust, mental well-being**

## Introduction

Ulrich Beck's risk society thesis underscores that contemporary society is characterized by an awareness of risk and uncertainty (1). During a pandemic outbreak, individuals may experience heightened levels of anxiety, fear, helplessness, and stress related to the possibility of getting sick or dying (1–3). No individual can easily avoid exposure to public risks. Moreover, with many countries implementing stay-at-home measures to reduce the spread of the novel coronavirus, social interactions among residents have decreased. During this time, individuals may experience increased social isolation and loneliness, leading to more pronounced levels of anxiety and depression (4–7). Research has unveiled that psychological resilience plays a pivotal role in enabling individuals to adapt to their psychological, emotional, and physical environments while facilitating self-recovery and rejuvenation following periods of duress. This intrinsic psychological resilience is instrumental in an individual's capacity to confront diverse stressors and challenges, thereby augmenting self-assurance, optimism, and overall life quality (8–10).

However, during a crisis, vulnerable individuals have limited capacities to cope with risks and have limited access to human an economic resource that can be mobilized (11). In such circumstances, the importance of external support in reducing an individual's vulnerability to further trauma becomes paramount (12). Primarily, communities first become the buffer point under the impact of public crises. Social support from neighbors and friends within residential communities significantly reduces the negative impact of major disasters on individual mental health (13). In addition, citizens' confidence in local government can diminish the public perception of crisis-related risks and future apprehensions, thus augmenting their perceived control over the crisis and effectively safeguarding their mental health (11, 14).

Research related to resilience have attracted the attention of numerous disciplines (15). However, current research on community resilience primarily concentrates on the resilience capacity at the community level (9, 16–18). Secondly, previous studies have often examined pairwise relationships, such as the impact of community resilience on psychological resilience or the relationship between trust in government and mental health. Using SEM, a commonly used tool in psychological research. It better allows for the examination and identification of the correlations and the proportion of mediating effects among variables. This study employs SEM to examine how assessments in three dimensions, namely individual resilience, perceived community resilience, and perceived government trust, affect mental health during COVID-19.

## Anxiety and psychology resilience during crisis

Anxiety is a common human psychological emotion, typically triggered by both internal and external stimuli. In appropriate circumstances, anxiety responses can help individuals better cope with stress and challenges. However, excessive anxiety can lead to various psychological disturbances, subsequently affecting an individual's physiological and behavioral well-being (19). During a pandemic outbreak, individuals may experience fear and a sense of helplessness regarding illness or death (20, 21). Feelings of social isolation and loneliness may intensify, and the levels of anxiety and depression may become more pronounced (5–7).

Psychological resilience explains why certain individuals are better able to process traumatic internal injuries than others (22), achieving better psychological and emotional balance (23, 24), and being more likely to respond positively during crises (25). Psychological resilience can be seen as a malleable capability, which is a person's capacity to adapt and recover when facing difficulties, setbacks, and stress. This capability can change with changes in the environment (26). This ability can be learned and developed by anyone (27). Many studies have confirmed that this inherent psychological resilience is crucial for an individual's ability to confront diverse stresses and challenges, contributing to increased self-confidence, motivation, and quality of life (8, 10, 28).

Prior literature has demonstrated a negative relationship between psychological resilience and anxiety. For instance, studies on events such as Hurricane Katrina in Louisiana and the Deepwater Horizon oil spill have shown that lower levels of psychological resilience in individuals are associated with higher rates of depression and anxiety (29). Another example is the aftermath of intensive terrorist attacks in Israel, where individual resilience serves as a protective factor, effectively reducing individual anxiety levels (17).

## Community resilience during crisis

The development of individual psychological resilience is not only associated with individual characteristics but also closely related to one's social support network. A positive and supportive peer group can provide necessary support and assistance, thereby enhancing an individual's psychological resilience (12). While individual resilience plays a role in coping with crises, individuals in crisis situations, especially vulnerable groups, are often more susceptible to risk, making external support crucial in minimizing the risk of further trauma. During public crises, communities become a buffer in the face of crisis impacts, serving as the frontline units in dealing with the crisis directly, responding to it, and managing it (30).

Community resilience is an ability that encompasses both resilience and protection (31). Researchers have pointed out that resilience plays a role in maintaining stability, recovering, and reconstructing (32). These abilities and functions stem from the community itself and are reflected in its members (33). A resilient community not only helps prevent or minimize loss or damage to life, property, and the environment but also has the capacity to respond quickly and recover normal operations, even when critical parts of the community are severely affected (34). Communities can increase their resilience, reduce risk, and overall vulnerability through sustainable development policies, effective intervention measures, increased social support and resources (35, 36).

Communities are the refuge for residents, especially resilient communities that can effectively reduce the impact of disasters on residents, provide timely assistance and support, and help people gradually return to normal life. Resilient communities can provide emotional support, material assistance, and social connections, offering strong support for individual resilience during crises (37). When communities successfully resist risks, people's psychological stress is relieved (38), thus reducing the trauma caused by risks and communication errors (39). Social support from neighbors and friends in residential communities also significantly reduces the negative impact of major natural disasters on individuals' mental health (13). Braun-Lewensohn and Sagy (40) found that community resilience is closely related to the reduction of anxiety levels among rural residents during missile attacks. Williams and Merten's research (41) discovered that community interactions among teenagers have a positive impact on the long-term mental health of teenagers.

## Government crisis management and trust

Government's governance actions during disasters and citizens' trust in the government can also have a positive impact on the development of psychological resilience (14). Behavioral public administration applies psychological theories to introduce government trust as a factor influencing individual psychology in public crises (42, 43). The logic behind how government trust alleviates individual anxiety during crises is as follows: firstly, citizens' trust in the government can reduce the public's perception of crisis-related risks and future concerns, enhance their perception of crisis controllability, thus effectively protecting their mental health (14, 44, 45). Studies have pointed out that local governments played a crucial role in issuing policies, communicating information, and organizing resources during the Covid-19 crisis (30). During the outbreak of the SARS virus in 2003, the trust of residents in the Hong Kong region in the government and healthcare institutions effectively mitigated the harm caused by personal anxiety (14). Under the influence of government and media protective measures, residents' trust reduces their perceived risk, weakening the sense of crisis (46). When the public has trust in the government, they are more likely to accept the information and measures provided by the government, thus reducing unnecessary panic and worry (44).

Moreover, as a mechanism for reducing complexity, public trust in the government can also increase cooperation and coordination between the government and the public, maintaining people's ability to act in complex environments, thereby better addressing crises (47). Because crisis events provide opportunities that require close social cooperation to address them, positive outcomes in crisis interventions can lead to a "unity effect" in public psychology (48). Therefore, trust is a key element in resolving collective action dilemmas (49). Government trust also increases community cooperation, thus enhancing community resilience.

Secondly, the policies issued by the government are mainly implemented at the community dimension, with communities in China designed as the basic administrative units. Community resilience plays a supportive role in individual resilience, and the construction of community resilience also requires support and efforts from various stakeholders. This includes support and assistance from local governments, non-governmental organizations, and other relevant stakeholders (50). Community resilience requires sufficiently strong and fast resources to facilitate functional recovery in response to changing environments (15). Some researchers have pointed out that resilient communities are successful in lobbying the government to provide resources for community reconstruction (51). The higher the level of material preparedness, the higher the perception of residents regarding the connections, resources, and potential for change within the community (52). When resources and characteristics are sufficient to generate resistance or resilience, the community can maintain its functionality (36).

## Framework and hypotheses

The above literature emphasizes the impact of community resilience and government trust on individual psychological resilience and anxiety. Based on the literature, we have established a theoretical framework for anxiety, psychological resilience, community resilience, and government trust (Figure 1). First, researchers have pointed out that psychological resilience explains why some individuals are better able to cope with traumatic injuries than others (22), making it easier to achieve psychological and emotional balance (23, 24, 53). Therefore, we propose the hypothesis:

> *Hypothesis 1 (H1)*: Individual psychological resilience mitigates individual anxiety emotions.

Furthermore, research indicates that community resilience has a positive impact on individual psychological resilience. The stress-buffering hypothesis confirms that social support may positively affect individuals' psychological ability to resist risks during crises, thereby moderating the impact of stress on pathological stress responses (54). The more support from external sources, the stronger an individual's ability to cope with stressful situations (37).

In addition to the influence of community resilience on psychological resilience, research also suggests the role of community resilience in psychological well-being. Personal social support enhances an individual's ability to cope with external challenges, and the individual's sense of anxiety during crises is reduced (55). Social support from neighbors and friends in residential communities also significantly reduces the negative impact of major natural disasters on individual mental health (13). Zhang et al.'s (56) study found that international students in Wuhan, during the lockdown, experienced reduced anxiety through the indirect impact of perceiving community resilience on community communication and support. Zhang et al.'s (18) research found that community resilience alleviated mental health stress among the older adults through the perception of community prevention effects. Based on the literature mentioned above, we propose the following hypotheses:

> *Hypothesis 2 (H2)*: Community resilience increases individual psychological resilience.

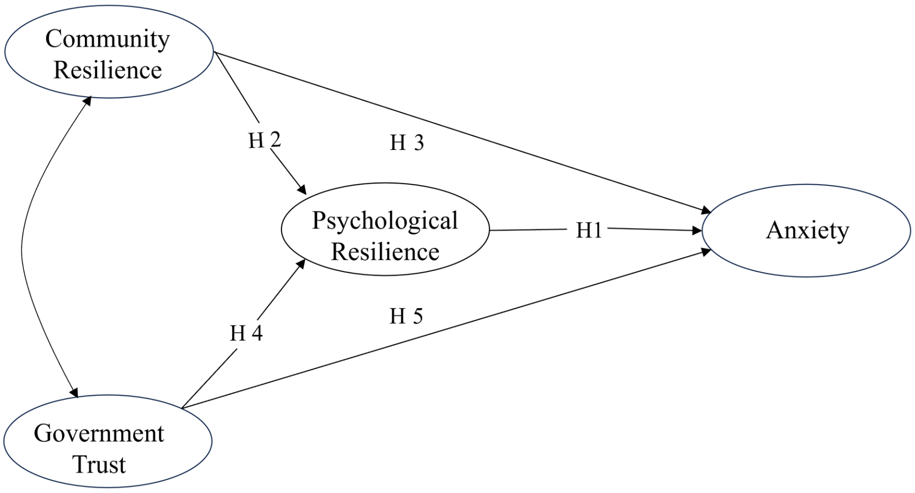

FIGURE 1
The theoretical framework that encompasses the relationships between interconnects anxiety, psychological resilience, community resilience, and government trust.

> *Hypothesis 3 (H3)*: Community resilience alleviates anxiety by enhancing individual psychological resilience.

Individual trust in the government can have a positive impact on the development of psychological resilience (11). When the public has trust in the government, it enhances their perception of crisis controllability and can further effectively protect their mental health (14, 46). Previous research has often not strictly distinguished psychological well-being from psychological resilience and anxiety. We believe that trust in the government not only enhances individual resilience and reduces individual anxiety but also alleviates anxiety through the enhancement of individual resilience. Based on this, we propose the following hypotheses:

> *Hypothesis 4 (H4)*: Citizens' government trust enhances individual psychological resilience.
>
> *Hypothesis 5 (H5)*: Government trust alleviates anxiety by enhancing individual psychological resilience.

Furthermore, community resilience builds a stable institutional environment that encourages the formation of trust beliefs and trust behaviors. Similarly, trust is conducive to the occurrence of cooperative behavior (57), and when such cooperative behavior occurs within a community, community resilience is also enhanced. Trust and community resilience mutually influence each other, leading to co-variation effects and impacting individual resilience. Zhang's (58) study treated trust in the government as a moderating variable for community resilience and anxiety. Community resilience reduced anxiety in older adults during COVID-19, but this association weakened in older adults with low trust in the government. In another study by Zhang, governance efficacy was treated as an intermediate variable for community resilience (18). We believe that communities and higher-level local governments are different government levels that residents can typically distinguish and perceive their subjective feelings. Therefore, we consider the perceived community resilience at the community dimension and the perceived trust in the government at the government dimension as two independent variables. The subjective feelings of these two government dimensions will have co-variation effects.

# Methods

## Variables and measurement

The first section of the questionnaire comprises demographic information about residents, including gender, age, marital status, household registration, political affiliation, educational level, and annual income. The second section assesses anxiety, psychological resilience, community resilience, and government trust.

### Anxiety

Drawing from the model of the Generalized Anxiety Disorder-7 (GAD-7) scale (59), we measured anxiety using a 7-item anxiety subscale from the Depression Anxiety Stress Scales. Participants were asked to indicate how much time, in the past 2 weeks, they have been troubled by specific issues presented in 7 questions. The seven questions are: "1. Feeling tense, anxious, or restless." "2. Unable to stop or control worries." "3. Excessive worry about various things." "4. Finding it difficult to relax." "5. Unable to calm down due to unease." "6. Easily getting upset or irritable." "7. Feeling something dreadful is going to happen." Responses were scored on a scale from 1 to 4, with higher scores indicating greater levels of anxiety.

### Psychological resilience

Psychological resilience refers to an individual's ability to adapt to external environmental changes when faced with adversity, threats, or challenges through self-regulation or external support (12). This study assessed participants' self-perceived level of psychological resilience under emergency circumstances using two questions: "1. I can adapt to change" and "2. I tend to recover quickly after illness or difficulties." Responses were rated on a scale from 1 to 5.

### Community resilience

Community resilience capacity is defined as a social system's preparedness, response, and recovery capabilities when faced with destructive disaster events (31). Assessment indicators for community resilience encompass a community's ability to resist, respond to, recover from, and rebuild after crisis events (36). We adopted the CCRAM-10 assessment framework, which serves as a comprehensive indicator reflecting a community's crisis response and recovery capabilities. It assesses community resilience from five aspects. Leadership: "1. The local government of my community functions well" and "2. The decision makers in the local government handle matters appropriately." Collective efficacy: "3. There are mutual assistance and people care for one another. "and "4. I count on my community to assist and share essential information." Preparedness: "5. Community has well-established infrastructure for emergency situation "and 6. Residents are aware of their roles in an emergency and respond promptly ". Place attachment: "7. I am proud to tell others where I live and participate community issues "and "8. I have a sense of belonging to my community." Social trust: "9. Good relationships exist between various groups "and "10. Residents in my community trust each other and community develop well ". This framework is a well-established tool for assessing urban community resilience (60).

Specifically, leadership covers the cognitive perception of positive support provided by community leaders from the top down. Collective efficacy represents the level of mutual assistance and concern among neighbors. Preparedness involves the awareness of the community's ability to respond to emergencies. Local attachment represents residents' identification with their own community. Social trust reflects mutual trust and relationships among community residents (60). In this study, a 5-point Likert scale was used to measure the 10 items, with higher scores indicating a stronger perceived sense of community resilience.

### Government trust

Government trust refers to the trust and reliance that the public places in the government. This trust is based on the belief in the government's ability, goodwill, and integrity (61). To assess residents' trust in the government during emergencies, we employed a 5-point Likert scale and asked:"1. Are you satisfied with the central government? "and "2. Are your satisfaction with the local government?" These items assessed the degree of trust residents had in government, with higher scores indicating greater trust.

## Sample and data collection

This study used a questionnaire survey method, and data collection took place from January 2022 to June 2022, collecting a total of 2,316 questionnaires. During the COVID-19 pandemic, due to the widespread implementation of social distancing measures, conducting in-person surveys became challenging. Therefore, this study employed an online survey method that was not limited by geographical location. Participants were contacted using a snowball sampling method through the internet and social media, and data collection was conducted through anonymous online questionnaires. To select participants, we used the general characteristics of the entire online population as a reference. We chose four main demographic variables, including gender, region, educational level, and household registration, as sampling criteria. Researchers on social media selected respondents who met these criteria and distributed online questionnaires to them to obtain the sample. Valid questionnaires covered all 31 provinces, autonomous regions, and municipalities in China. Since we conducted an online convenience survey, the participants were relatively younger, but their characteristics were similar to those of Chinese internet users. After excluding invalid questionnaires, we obtained 2,279 valid questionnaires.

## Data analysis

We commenced by conducting a descriptive statistical analysis of socio-demographic characteristics among our 2,279 participants, covering variables such as gender, age, marital status, residence, political affiliation, education, and income. Secondly, we conducted a correlation analysis to investigate potential associations between socio-demographic factors and our measurement variables. Finally, we employed SEM to examine the mediating role of psychological resilience in the relationships between anxiety and both community resilience and government trust. This analytical process encompassed model development, parameter estimation, and model fit testing, all executed using STATA 15.1 software.

# Results

## Descriptive statistics

The study included 2,279 participants, with a higher proportion of female participants ($n = 1{,}334$, 58.53%) compared to male participants ($n = 945$, 41.47%). The mean age was 28.66 years, with a median age of 24 years. Regarding marital status, 65.60% were unmarried, while 34.40% were married. In the context of political alignment, 21.59% were identified as members of the Chinese Communist Party (hereinafter referred to as CCP Members), while the vast majority, constituting 78.41%, were non-members of the Chinese Communist Party (hereinafter referred to as Non-CCP Members). Household registration was categorized as urban ($n = 1{,}200$, 52.65%) and non-urban ($n = 1{,}079$, 47.35%). Education levels were divided into three categories: high school and below ($n = 297$, 13.03%), college and bachelor's degree ($n = 1{,}697$, 74.46%), and postgraduate or higher ($n = 285$, 12.51%; see Table 1).

The measurement of the four variables, anxiety, psychological resilience, community resilience, and government trust are carried out using 5-Likert scales. Firstly, Cronbach's alpha was employed to examine the reliability of anxiety ($\alpha = 0.968$), psychological resilience ($\alpha = 0.840$), community resilience ($\alpha = 0.973$), and government trust ($\alpha = 0.836$). The Cronbach's alpha values for the core variables were all greater than 0.80, which validates the high internal consistency of the relevant items on this scale, indicating good reliability. When we do correlation analysis and SEM later, we normalize the variables of 1–5 or 1–4 (Table 2).

TABLE 1 Demographic characteristics of the participants.

| Variables | The meaning and assignment of variables | Mean | SD | N | Percent (%) | Min/Max |
|---|---|---|---|---|---|---|
| Gender | Female (0) | | | 1,334 | 58.53 | |
| | Male (1) | | | 945 | 41.47 | |
| Age | | 28.66 | 10.64 | 2,279 | 100 | 18/72 |
| Marital Status | Singl (0) | | | 1,495 | 65.6 | |
| | Married (1) | | | 784 | 34.4 | |
| Household registration | Non-urban (0) | | | 1,079 | 47.35 | |
| | Urban (1) | | | 1,200 | 52.65 | |
| Political status | Non-CCP Member (0) | | | 1787 | 78.41 | |
| | CCP Member (1) | | | 492 | 21.59 | |
| Education Level | Below high school | | | 297 | 13.03 | |
| | Associate and bachelor's degree | | | 1,697 | 74.46 | |
| | Postgraduate | | | 285 | 12.51 | |
| Annual income | Below 50,000Yuan | | | 1,398 | 61.34 | |
| | 50,001–100,000 Yuan | | | 487 | 21.37 | |
| | 100,001–200,000 Yuan | | | 269 | 11.8 | |
| | 20,001–500,000 Yuan | | | 94 | 4.12 | |
| | More 500,001 Yuan | | | 31 | 1.36 | |

## Analysis of SEM results

In this study, we employed SEM for analysis. The model's fit indices are as follows: the chi-square value is 4038.35 with 323 degrees of freedom, the Comparative Fit Index (CFI) is 0.934, the Tucker-Lewis Index (TLI) is 0.928, the Standardized Root Mean Square Residual (SRMR) is 0.041, and the Root Mean Square Error of Approximation (RMSEA) is 0.071. All these indicators meet the relevant standards and requirements, indicating a good model fit.

The results (see Figure 2; Table 3) show a significant negative correlation between anxiety and psychological resilience ($b = -0.099$, $p < 0.001$), confirming hypothesis H1. The enhancement of psychological resilience mitigates the negative impact of anxiety.

There is a significant positive correlation between community resilience and psychological resilience ($b = 0.403$, $p < 0.001$), confirming hypothesis H2. This suggests that a stronger community resilience is associated with higher individual psychological resilience in the face of risks. The construction of community resilience has a positive effect on individuals in risk situations. Community resilience has a positive and significant effect on anxiety ($b = 0.169$, $p < 0.001$). Although community resilience reduces anxiety by increasing psychological resilience ($b = -0.040$, $p < 0.001$), the overall effect remains significantly positive ($b = 0.129$, $p < 0.001$), and hypothesis H3 is not supported.

Individual government trust is significantly positively correlated with psychological resilience ($b = 0.364$, $p < 0.001$), confirming hypothesis H4. Residents with high trust in the government exhibit greater psychological resilience. Government trust not only reduces anxiety ($b = -0.136$, $p < 0.001$) but also alleviates anxiety by enhancing individual psychological resilience ($b = -0.036$, $p < 0.001$). The total effect of government trust on anxiety is $-0.172$ ($p < 0.001$), confirming hypothesis H5.

The results of the covariate relationship between community resilience and government trust indicate a significant association between the two. There is a positive relationship between community resilience and government trust, with a standardized coefficient of $b = 0.71$ ($p < 0.001$), highlighting the significant positive correlation between increased community resilience and higher levels of government trust. This underscores the important connection between community resilience and government trust.

Regarding demographic variables, males were found to be more anxious than females ($b = 0.063$, $p < 0.001$). Increasing age ($b = -0.110$, $p < 0.001$) significantly mitigated anxiety and had a positive impact on psychological well-being. Educational level ($b = -0.036$, $p = 0.147$), household registration ($b = 0.022$, $p = 0.339$), marital status ($b = -0.018$, $p = 0.581$), and income ($b = 0.013$, $p = 0.604$) had no significant impact on anxiety.

## Discussion

During times of crises, individuals consistently endeavor to establish supportive connections with others. When self-reliant individuals become part of a collective entity, it substantially contributes to the accomplishment of objectives previously unattainable on an individual basis (13). Integration into social networks can aid an individual in avoiding adverse experiences, thereby augmenting the likelihood of psychological resilience (55), subsequently bolstering one's psychological resilience. This assimilation into social networks progressively nurtures a communal

TABLE 2 Investigation items of core variables in questionnaire.

| Variables | Items of questionnaire survey | Mean(SD) normalization | α |
|---|---|---|---|
| Anxiety (GAD-7) | 1. Feeling tense, anxious, or restless. | 0.511(0.239) | 0.968 |
| | 2. Unable to stop or control worries. | 0.466(0.239) | |
| | 3. Excessive worry about various things. | 0.488(0.235) | |
| | 4. Finding it difficult to relax. | 0.467(0.239) | |
| | 5. Unable to calm down due to unease. | 0.429(0.239) | |
| | 6. Easily getting upset or irritable. | 0.460(0.235) | |
| | 7. Feeling something dreadful is going to happen. | 0.426(0.237) | |
| Psychological resilience | 1. I can adapt to change. | 0.865(0.153) | 0.840 |
| | 2. After difficulties, I tend to recover quickly. | 0.830(0.172) | |
| Community resilience (CCRAM-10) | 1. The local government of my community functions well. | 0.834(0.195) | 0.973 |
| | 2. The decision makers in the local government handle matters appropriately. | 0.846(0.184) | |
| | 3. There is mutual assistance and people care for one another. | 0.836(0.191) | |
| | 4. I count on my community to assist and share essential information. | 0.857(0.180) | |
| | 5.Community has well-established infrastructure for emergency situation. | 0.845(0.183) | |
| | 6. Residents are aware of their roles in an emergency and respond promptly. | 0.836(0.187) | |
| | 7. I am proud to tell others where I live and participate community issues. | 0.821(0.203) | |
| | 8. I have a sense of belonging to my community. | 0.838(0.178) | |
| | 9. Good relationships exist between various groups. | 0.829(0.191) | |
| | 10.Residents in my community trust each other and community develop well. | 0.842(0.183) | |
| Government trust | 1. Are you satisfied with the central government? | 0.918(0.137) | 0.836 |
| | 2. Are your satisfaction with the local government? | 0.881(0.165) | |

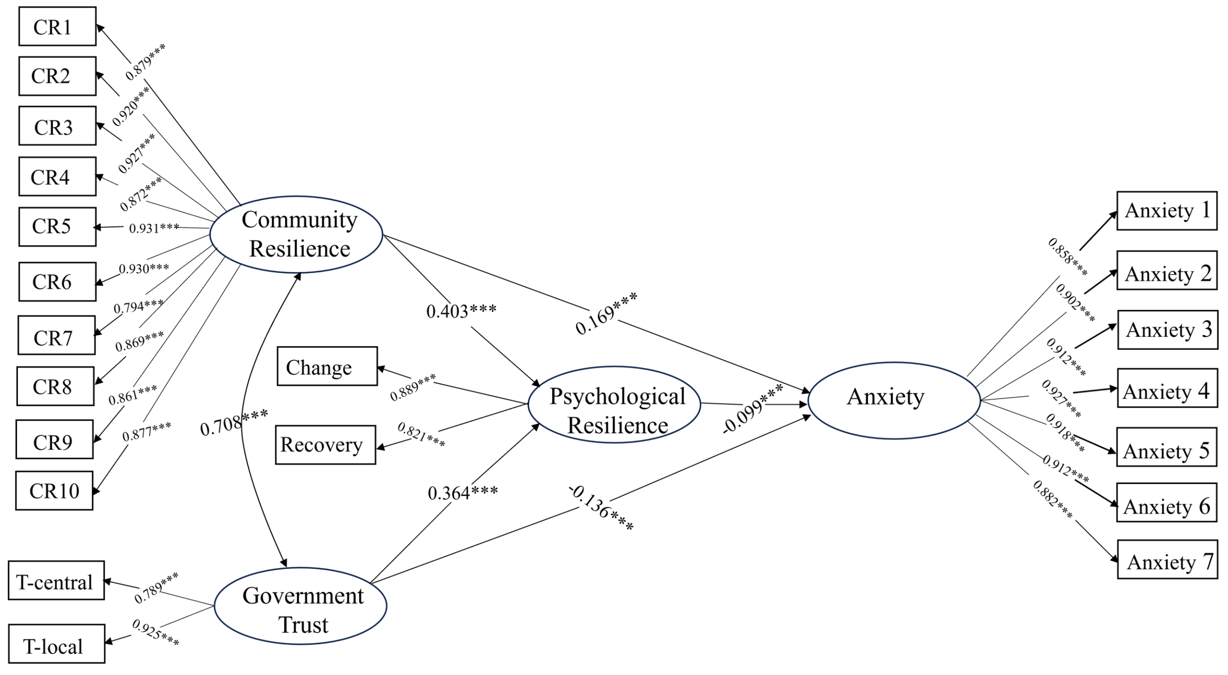

FIGURE 2
The results of SEM.

**TABLE 3** The results of direct, indirect, and total effects of demographic variables, anxiety, psychological resilience, community resilience, and government trust.

| | | Direct effects (SE) | Indirect effects (SE) | Total effects (SE) |
|---|---|---|---|---|
| Psychological resilience | Community resilience | 0.403***(0.022) | | 0.403***(0.022) |
| | Government trust | 0.364***(0.037) | | 0.364***(0.037) |
| Anxiety | Psychological Resilience | −0.099***(0.053) | | −0.099***(0.053) |
| | Community Resilience | 0.169***(0.042) | −0.040***(0.018) | 0.129***(0.039) |
| | Government Trust | −0.136***(0.070) | −0.036***(0.025) | −0.172***(0.065) |
| | Male | 0.063***(0.009) | | 0.063***(0.009) |
| | Age | −0.110***(0.001) | | −0.110***(0.001) |
| | Married | −0.018(0.014) | | −0.018(0.014) |
| | City | 0.022(0.009) | | 0.022(0.009) |
| | CCP Member | 0.021(0.012) | | 0.021(0.012) |
| | Educational Level | −0.036(0.014) | | −0.036(0.014) |
| | Annual Income | 0.013(0.006) | | 0.013(0.006) |

*$p < 0.05$; **$p < 0.01$; ***$p < 0.001$.

sense of efficacy, laying the groundwork for an individual's psychological flexibility and recovery (12). Social support encompasses emotional, informational, material, and cognitive facets, among others. These resources have the potential to fortify the resilience of both individuals and communities, enabling them to better cope with and adapt to stress and adversity (62). Our research demonstrates that individual resilience during COVID-19 is influenced by community resilience and government trust, thereby affecting individual psychological well-being.

## Individual dimension – psychological resilience can alleviate anxiety

Psychological resilience acts as a safeguarding element for residents and augmenting psychological resilience can mitigate the adverse effects of anxiety. In times of peril, "fear and apprehension" are common manifestations among individuals navigating a state of existential risk. Concerned about their "ontological security," individuals may grapple with "existential anxiety," prompting them to either vacate the hazardous zone or mitigate harm (63). Psychological resilience is crucial for an individual's ability to cope with various stressors and challenges, promoting overall adaptation and mental well-being (8, 10). This implies that individuals in adversity can overcome difficulties through their own efforts. Our findings also reinforce previous research conclusions that high psychological resilience fosters the development of positive cognitions about oneself, the world, and the future, reducing anxiety during COVID-19.

## Community resilience – its impact on individual resilience and anxiety

The pressure-buffering hypothesis suggests that social support has a positive impact on individuals' ability to resist risk during crises (54). Crises hold a dual significance for communities. When managed effectively, crises can activate advantages and exhibit a diminishing effect; conversely, mismanagement can lead to amplification within a disaster chain reaction (64). Communities, serving as buffers during crises, play two crucial roles in crisis periods. Firstly, they constitute the fundamental unit of governance, and their performance in emergency functions directly extends and supplements the government's crisis management capabilities, underpinning the overall crisis management of society (65, 66). Researchers have also pointed out the role of communities in soft mobilization during crises. Public crisis management represents an extraordinary mode of governance, where the administrative and political mobilization methods effective in routine management may become less efficient. Effective self-mobilization within society can transmit government decisions and crisis-related knowledge to grassroots and individuals, aiding in dispelling panic induced by crises and enhancing societal and individual crisis resilience (67).

The construction of community resilience encompasses the accumulation of diverse social capital, which provides support to individuals during risks. The more social support individuals receive during risks, the stronger their psychological resilience against risks becomes. Our data results reveal that community resilience also acts as a 'protective umbrella' for individuals. Resilient communities develop their own resources in social, political, cultural, and psychological aspects to mitigate the impact of risks on the community (68). They may even utilize crises in reverse, strengthening their pre-existing resilience and perpetuating a self-enhancing environment for the community (31). Given that communities are on the frontline of risk, the construction of their resilience is particularly essential in supporting individuals. Individuals facing risks can seek external assistance through community social networks to acquire risk information and leverage community resources to enhance their adaptability to risks, thus reducing panic and anxiety arising from a lack of control or understanding of external circumstances.

Our results indicate a positive and significant relationship between community resilience and anxiety, with community resilience not mitigating anxiety through individual resilience. Previous research has often confirmed the positive relationship between community resilience and individual mental health, such as Zhang's study (18), which found that community resilience alleviated mental health stress among the older adults by perceiving community preventive effects. Nevertheless, most studies have not directly demonstrated the relationship between community resilience and anxiety. Another study by Zhang (56) found that international students in Wuhan during the lockdown period were indirectly influenced by community resilience perception through community communication and support to alleviate anxiety, but community resilience perception did not have a direct effect on anxiety. Lee et al. (9) found that community resilience could enhance individual psychological resilience, but the relationship between community resilience and anxiety was not significant. Lyons et al. (51), through correlation analysis, identified a positive relationship between community resilience and higher psychological well-being but did not control for other variables using multiple regression. Williams and Merten's research (41) revealed that increased community interactions among adolescents fostered their agency and significantly reduced depressive symptoms, but the direct impact of community interactions on anxiety symptoms was positively significant. Our results confirm the substantial effect of communities on individual resilience but do not alleviate anxiety. Given the multifactorial nature of anxiety, variables such as trust in the government and individual resilience play a significant role in mitigating anxiety. The SEM analysis clearly demonstrates the contributions of variables to anxiety relief, both indirectly and directly.

## Government trust – its impact on individual resilience and anxiety

The conclusion reveals that government trust not only significantly positively influences individual psychological resilience but also plays a constructive role in alleviating anxiety. When individuals encounter difficulties, seeking assistance and collaborating with others can help them better cope with challenges and enhance their survival and recovery capabilities. In situations with a high level of external pressure controllability, individuals facing risks become more resilient in terms of risk tolerance and recovery capabilities. Trust is a key factor in individuals' actions during risk, and higher levels of trust lead individuals to actively seek external support to gain greater pressure controllability. This sense of unity can be achieved through the establishment of trust and common goals, thereby assisting individuals and groups in coping with stress and challenges (12, 69).

Mutual trust and dependence between the government and residents are among the political characteristics of emergency management in China (70). Firstly, in China, disaster management power is largely concentrated in the hands of the central government, which plays a crucial role in disaster reduction, preparedness, and response. Secondly, under the influence of cultural factors related to legitimacy, residents' trust in the government significantly influences their risk perception. This trust and confidence are primarily affected by the government's ability and performance in crisis prevention and management. When the government is well-prepared, efficient, and responsive, citizens do not excessively worry about crises, and they are less critical of related crisis management decisions (30). Furthermore, local governments can provide necessary resources and support to enhance community disaster preparedness, response, and resilience. Community resilience built on the foundation of robust community resources is beneficial for community resistance to external crises and can serve as a "safe haven" for individuals during public crises.

In times of crisis impact, mutual trust, and a sense of solidarity among people play a crucial and positive role in subsequent disaster management (38). Good crisis governance by the government enhances citizens' trust in the government during crises (47). When the public has trust in the government, they are more likely to accept the information and measures provided by the government, thereby reducing unnecessary panic and worry. Additionally, public trust in the government can also increase cooperation and coordination between the government and the public, enabling a better response to crises. These factors contribute to improving individual psychological resilience and alleviating anxiety. Previous research has pointed out the "unity effect," (48) which is attributed to the belief that being part of a group can provide individuals with many benefits. As a member of a group, an individual can access social support and resources, thereby increasing their chances of survival and psychological recovery. Our research confirms this. Specifically, government trust is a protective factor for individuals. Enhanced trust in the government strengthens the impact of individual psychological resilience on mental health.

## The mutual influence between community resilience and government trust

The construction of community resilience also requires support and efforts from various stakeholders, with many resources relying on local and central government provision for community rebuilding (15, 36, 52). Our findings underscore the close relationship between community resilience and government trust. Highly trusted communities often form bonds of mutual assistance, which can provide residents with robust emotional support and reduce their fear of risks (71). A resilient community, by definition, implies strong social support, a sense of trust, and robust stability and rebuilding capabilities. Residents coexisting in a public crisis within such a community can utilize the abundant social capital and social networks within the community to regulate their own anxiety in the face of unexpected situations, thereby enhancing their individual psychological resilience.

# Limitations

The limitations of this study are as follows. Firstly, due to the convenience sampling method used in the study, the representativeness of the questionnaire survey participants was affected, limiting the generalizability of the conclusions. Secondly, the heterogeneity of communities has a significant impact on individuals residing within them, and community resilience is related to the type and characteristics of the community, which can clearly influence individuals living in the community. Whether this influence has structural characteristics is a variable that was not addressed in this study and therefore cannot be analyzed. Inequality in residence and its impact on individuals is a topic worthy of future attention.

## Conclusion

In this study, the factors influencing individual anxiety in a major crisis were examined, and the research distinguished how evaluations at the individual, community, and government dimension interacted and affected mental health. The results indicate that in a super crisis, individual psychology is impacted on multiple dimensions. Not only does individual psychological resilience better cope with anxiety in the crisis, but support at the community and government dimensions also significantly affects individual psychology. For more vulnerable individuals in times of risk, enhanced trust, and sense of belonging among community members facilitate the effectiveness and quality of social support, thereby strengthening self-regulation and self-recovery capabilities at both the community and individual dimensions. Additionally, trust during risk contributes to the formation of cooperative behaviors, allowing individuals to mitigate the impact of risk and subsequently alleviate anxiety, enhancing psychological resilience. Our study reinforces this conclusion. Particularly in the context of China, government governance actions and public trust in the government are strong influencing factors on individuals' psychology. Trust in the government during risk enhances individual psychological resilience, thus mitigating anxiety. This expands our understanding of the impact of community and government governance as external environmental factors on mental health in the context of major crises. Thirdly, the study employed SEM, which helped us to delineate the interrelationships among subjective variables and their contributions to the dependent variable.

## Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

## Ethics statement

The studies involving humans were approved by Academic Ethics Committee of School of Politics Science and Public Administration, Guangxi Minzu University. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

## Author contributions

YHu: Data curation, Investigation, Methodology, Software, Writing – original draft, Writing – review & editing. YHua: Data curation, Methodology, Writing – original draft, Investigation, Software. HZ: Data curation, Methodology, Writing – original draft, Conceptualization, Funding acquisition, Supervision, Writing – review & editing. MF: Conceptualization, Data curation, Methodology, Writing – review & editing. GC: Data curation, Software, Writing – review & editing.

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## Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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# Mental illness stigma among perinatal women in low- and middle-income countries: early career psychiatrists' perspective

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## Introduction

Perinatal mental disorders (PMDs) are prevalent among women in low- and middle-income countries (LMICs), constituting the most frequently encountered complications during the perinatal period, affecting almost 20% of perinatal women (1). The PMDs are associated with adverse obstetrics outcomes (e.g., increased risk of pre-eclampsia, antepartum and postpartum hemorrhage, placental abruption and still-births) and neonatal outcome (e.g., preterm births and fetal growth impairments) (2). PMDs are among the commonest morbidities of pregnancy, associated with high rates of maternal mortality and adverse outcomes, however, these conditions are often remains underdiagnosed and undertreated in LMICs. Lack of access to perinatal mental health services is mainly due to a lack of adequate resources (human, financial), inadequate knowledge among health care workers, stigma, a negative attitude toward mental disorders, a lack of evidence-based integrative or collaborative models of care, and being overlooked by stakeholders (3, 4). Mental illness stigma is also a major barrier to help-seeking, and it contributes to poor quality of life and social withdrawal among person with mental illness. Addressing the stigma associated with perinatal mental disorders has the potential to improve perinatal mental care inclusive of screening, and intervention and thus preventing the complications. However, stigma among perinatal women remains largely unexplored in LMICs (5). In this article, we-a team of early-career psychiatrists (ECPs) attempted to explore stigma toward mental illness among perinatal women residing in LMICs, its impact, and interventions to reduce it using a theoretical model. Table 1 summarizes the stigma associated with perinatal mental illness, its types, possible impact, and interventions. The theme-based approach was used to describe the types of stigma among perinatal women and to propose interventions (8).

## Impact of stigma toward perinatal mental illness on mother and baby

Few studies attempted to investigate stigma toward perinatal mental illness in LMICs (9, 10). In our experience, perinatal women with mental illness are frequently stigmatized for seeking treatment, refusing treatment, being on medications, and being associated with a husband or family member (e.g., mother) with a mental illness in LMICs. This frequently results in social withdrawal of perinatal women with mental health conditions, financial burden on the family, and family disruption (e.g., divorce). These negative consequences exacerbate mental health issues and perpetuate the stigmatization cycle. Stigma leads to non-treatment of common perinatal mental disorders. This increases the risk of suicide and substance use among perinatal women and is linked to poor infant outcomes (e.g., preterm delivery, developmental and cognitive delays, and attachment and bonding problems between mother and child) (9, 11, 12) (Table 1). Furthermore, secondary to stigma, it becomes difficult for a mother to understand healthy emotional reactions during the motherhood transition and this can worsen the degree of empathy and the relationship with the child, fueling the vicious circle of postpartum depression (13). Alternatively, many mothers are hesitant to disclose their illness out of fear of losing custody of their child (14). Lastly, cultural factors related to gender preference (e.g., preference for male children) and expectations around social behaviors of mothers often affect treatment-seeking behaviors and worsen stigma toward perinatal mental illness (13, 15).

## Interventions to reduce stigma toward perinatal mental illness

Perinatal women with mental illness require supportive care. Despite this, the majority of women are hesitant to discuss their illness with family members and health care workers (HCWs) due to stigma (16). The lack of knowledge about the spectrum of perinatal mental disorders not only increases the stigma associated with the illness, but also limits access to appropriate care for these conditions (6, 16). Although, Electroconvulsive therapy (ECT) is recommended as safe for women with clinical emergencies of perinatal mental disorders (e.g., catatonia, no food or fluid intake, suicide risk) (17). There is a scarcity of data from LMICs on ECT use and its effectiveness for perinatal disorders. ECT is often considered as the least helpful/harmful and inhumane treatment by the general public in LMICs (18). Both ECT and psychotropic medications are stigmatized as primary treatments for psychiatric conditions in pregnant women (6, 19, 20).

An intervention aimed at mitigating the mental illness stigma has been developed and evaluated for its effectiveness in LMICs. These interventions have been shown to be effective in enhancing the knowledge of healthcare professionals (HCWs) and the general community. However, they are minimally effective in improving the attitudinal and behavioral outcomes (21).

## Discussion

We found that there is a dearth of research pertaining to the epidemiology, impact, and interventions of mental illness stigma among perinatal women in LMICs. The determinants of mental illness stigma among perinatal women are more likely to differ from other groups of people. This is primarily due to prevailing myths and misinformation regarding the effect of psychotropic medications and ECT on mothers and child across the world including LMICs (6). Moreover, there is a dearth of targeted interventions that specifically address the perinatal mental illness stigma. The collaborative or integrative models [e.g., Brief Psychological intervention during pregnancy BIND-P model (22), Task sharing model (23), Stepped care model (24)] developed in LMICs with the goal of providing screening for common mental disorders (22, 25), and psycho-education have the potential to reduce stigma (inclusive of knowledge, attitude and behavior) and improve access to care for perinatal mental disorders (21). Thus, there is an urgent need to develop HCWs-based psychosocial interventions (including psychoeducation, and training) for stigma reduction (6, 26) (Table 1).

The cultural factors, such as collectivism, Confucianism, face concern and familism, religion, and supernatural beliefs, have a role in shaping stigmatizing behavior and attitudes toward perinatal mental health. Therefore, it is crucial to promote culture-specific mental health services and interventions for reducing stigma, which is a significant barrier to recovery. We used a basic theme-based approach to explore different types of stigma, assess their impact, and offer intervention. The approach has potential to guide for future research and collaboration, as well as the development of targeted theme-based interventions.

## The way forward

Due to significant disparities in mental health infrastructure across the world (27), a collaborative framework to address stigma toward perinatal mental illness across countries is required. Such framework should consider cultural, social, and health system-related factors while developing and adopting a psycho-social intervention for stigma toward perinatal mental illness. The existing infrastructure (e.g., community mental health model) of each country should be explored to develop such models of care or interventions. Further, there is an immediate need to undertake cross-country research to explore variations in stigma toward perinatal mental illness and develop tailored interventions to improve access to perinatal mental health services. These efforts have a potential to reduce the burden of perinatal mental health conditions and infant mental disorders across the world. There is a need for ECPs to work together and explore innovative methods to tackle the stigma associated with perinatal mental health in LMICs, such as digital strategies. The digital strategies can expand the reach of or complement the proposed interventions (Table 1). There are, however, several factors that need to be considered when proposing interventions and digital strategies: cultural adaptation to diverse contexts and settings, consideration of reliable measurement of stigma related to mental illness, and the

TABLE 1 **Stigma toward perinatal mental illness: types, potential impact, and interventions.**

| Type of stigma | Potential impact | Potential interventions |
|---|---|---|
| Public stigma/experienced stigma: Perinatal women face discrimination or prejudice as a result of their mental illness. The negative attitude of medical professionals toward taking any psychiatric medications during pregnancy (6). | • Social isolation and avoidance, lack of help-seeking behavior.<br>• Increase in psychiatric morbidities.<br>• Decrease self-esteem, quality of life, and self-efficacy. | • Peer Educator intervention.<br>• Providing social support.<br>• Role play<br>• Lecture-based education.<br>• Brief training or longer training intervention.<br>• Training sessions through the media (Anti-stigma movies) (7) |
| Self-stigma/internalized stigma: Mothers with mental illnesses apply negative/judgmental attitudes displayed by others to themselves (8, 9). | | |
| Associated stigma: Family members of a perinatal woman with a mental illness are stigmatized for being associated with her. | | |
| Structural stigma: Perinatal women with mental illness are denied from infant care and community participation. | | |
| Label avoidance: Perinatal women may avoid seeking mental health care as it will automatically label them as having a mental illness. | | |

risk that digital media could exacerbate stigma related to mental illness and spread misinformation.

## Conclusion

Stigma reduction programs that explicitly address perinatal mental disorders in LMICs are needed.

Effective intervention components, such as educational methods (knowledge, myth-busting), should be incorporated into these programs. Further, there is an urgent need to develop evidence based or culturally adapted interventions to reduce the stigma of perinatal mental disorders in LMICs. The implementation of evidence-based interventions aimed at reducing stigma and discrimination has the potential to improve help-seeking behavior and facilitate access to suitable mental health care in LMICs.

## Author contributions

AP: Conceptualization, Investigation, Writing—original draft. SP: Conceptualization, Investigation, Writing—original draft. MK: Conceptualization, Writing—original draft. SE: Writing—review & editing. RF: Writing—review & editing. RR: Conceptualization, Funding acquisition, Supervision, Writing—original draft, Writing—review & editing. MH: Writing—review & editing. MO: Writing—review & editing. MS: Conceptualization, Supervision, Writing—review & editing.

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## Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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# The effects of a psychiatric clerkship on stigmatizing attitudes toward mental disorders as held by German medical students

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**Background:** According to the United Nations, access to medical care is a fundamental human right. However, there is widespread stigmatization of severe mental illnesses and this appears to seriously hamper the quality of healthcare in people with psychiatric co-morbidity. Thus, interventions that help reduce stigma among healthcare providers are urgently needed.

**Purpose:** The objective of the current study was to investigate the effects of a psychiatric clerkship on stigmatizing attitudes toward mental disorders held by medical students.

**Methods:** Between 2018 and 2019, a total of 256 third- and fourth-year students from Marburg University Medical School (Germany) completed two surveys—one before and one after a 2 week clerkship program that was designed to prioritize direct interaction with the patients. For measuring stigma, the questionnaires contained questions about students' attitudes toward psychiatry (ATP), including the Opening Minds Scale for Healthcare Providers (OMS-HC), Community Attitudes Toward the Mentally Ill (CAMI), and measurements according to the Stereotype-Content Model (SCM). We conducted pre-vs.-post comparisons using the Wilcoxon signed rank test with continuity correction or paired $t$-test and employed the Spearman method for correlational analysis. We considered $p < 0.05$ significant and adjusted all $p$-values reported here using the Benjamini-Hochberg procedure to account for family-wise error.

**Results:** After the clerkship, a significantly reduced stigma was found, as assessed with ATP (mean $p < 0.001$), OMS-HC (sum and subscale "attitudes" $p < 0.001$; subscale "disclosure" $p = 0.002$), and both SCM subscales ($p < 0.001$). Moreover, we observed significant associations between stigma expression (e.g., OMS-HC sum) and the willingness of students to choose psychiatric residency after finishing medical school (before clerkship: $p < 0.001$; $\rho = -0.35$; change after clerkship: $p = 0.004$; $\rho = -0.2$).

**Conclusion:** Our findings indicate that a psychiatric clerkship that involves students in direct interaction with patients may effectively reduce stigma. Therefore, we advocate the incorporation of components of direct interaction in medical education to combat stigma and unequal treatment, as this could improve outcomes in patients with severe mental illnesses.

KEYWORDS

**Germany, mental disorders, psychiatry, social stigma, stereotyping, undergraduate medical education, vulnerable populations, clinical clerkship**

## 1 Introduction

Access to medical care is recognized by the United Nations as a fundamental human right (1) and should therefore be provided to all groups of patients in accordance with general standards, and must avoid systematic discrimination against minoritized populations. However, there is a dramatic mortality gap in people with severe mental illness in high-income countries (2, 3) and this cannot only be explained by factors related to the mental illness itself or its treatment, or to the patients' lifestyle. Besides all these factors, this mortality gap must, at least in part, be a consequence of the difficulties that people with mental illness experience in accessing appropriate health care and may be associated with stigmatization by healthcare professionals (4, 5). Furthermore, social stigmatization can be a significant barrier to suicide prevention, particularly in low- to middle-income countries (6).

According to international studies, psychiatric disorders are estimated to have a lifetime prevalence of ∼30% and a 12-month prevalence of 17.6% (7). At the national level in 2010, mental conditions were Germany's fourth most prevalent disease group in terms of disability-adjusted life years (8). At the same time, misinformation and misconceptions about stigmatizing attitudes to psychiatric illnesses prevail in the population [e.g., (9)]. Since stigmatization of people with mental illness is both a risk factor and a consequence of mental illness, it seems to be a significant obstacle to seeking help for recovery. Thus, mechanisms that help reduce this stigmatization need to be systematically studied. Effective mechanisms should be implemented in our daily practice as a matter of urgency.

### 1.1 Stigma among healthcare provides

The phenomena of stigmatization do not only affect the general population and people with mental illness, but are also prevalent among healthcare providers such as physicians or medical students, social workers, and nursing staff, whether they work in somatic or psychiatric care (10). For example, there is a less willingness to treat people with mental illness, especially those diagnosed with schizophrenia, due to concerns about an increased predisposition to violence (11–14). Additionally, working in psychiatry is often considered by medical students unsatisfying and stressful (15). Therefore, expressions such as "emotionally stressful," "overwhelming," "clerkship with mentally disturbing images," or "working with crazy people makes you crazy" are widely used in evaluations of psychiatric training among medical students (15). Although psychiatry does not have a bad reputation among medical students, they are less likely to opt for post-residence training in psychiatry, and this leads to a shortage of young psychiatric staff (11, 15–17). Possible reasons include fear of criticism from family and friends, due to the negative image of psychiatry compared to other specialties, and a potential risk of being stigmatized as "neurotic" or "weird." In addition, there is a misconception that psychiatry is unscientific and inaccurate (16).

Stigmatizing attitudes also seem to influence treatment-relevant decisions. For example, the recommendation of a weight reduction program was not even made in patients with schizophrenia, mainly due to the preconception of reduced motivation, difficulties in information intake, and reduced personal responsibility (18). Additionally, the false attribution of physical symptoms to a mental condition—also known as "diagnostic overshadowing"—is also a significant medical problem attributable to stigma (19). Not unexpectedly, a large body of evidence shows that stigma among medical providers seriously decreases the quality of care (5). However, there are promising retrospective data that demonstrate that stigma in medical providers has tended to decrease over the past 30 years (20). Furthermore, previous research indicates that stigma expression can depend on individual characteristics and professional education. For example, in an evaluation using a case vignette (21), the level of stigma and the tendency to greater social distance were lower in students who reported previous personal contact with people with mental illness and in those who had participated in relevant professional training in healthcare.

### 1.2 Role of psychiatry training in stigma reduction

A clerkship in psychiatry is an essential part of medical training. In addition to teaching specialized knowledge and communication skills, the reduction in stigma toward mental illness is a necessary goal of the psychiatric degree program (11, 13, 17). Personal contact with people with mental illness seems crucial in helping to reduce stigma (22–24). The importance of personal contact has already been demonstrated, for example, by its favorable effects on attitudes toward the benefits of psychopharmacology, prognosis, and explainability of mental illness (25). In addition to personal contact, the length and quality of the clerkship appear to influence stigma reduction (26). Furthermore, the motivation of the practitioner or teacher—as a role model—must be mentioned as a further relevant influencing factor (27).

In general, most studies show a reduction in stigma after a psychiatric clerkship (16). However, there are reports of unaffected and even increased stigma after a psychiatric clerkship (11, 28–30). Aside from methodological and intercultural aspects, these conflicting results may be associated with differences in the way students perceived their trainers and hospital staff, and in how the clerkship was organized, (31, 32). Furthermore, it could be assumed that the participation of students in direct patient interaction during the curricular program may differ in different medical school programs. However, there is emerging evidence that shows that contact between members of different groups leads to a significant reduction in prejudice (33, 34), as first postulated by Gordon Allport and known as the intergroup contact theory (35).

### 1.3 Rationale for the study and hypotheses

Since a direct interaction between students and patients is an essential compound of the psychiatric clerkship at the Marburg University Medical School, the objective of the current study was to evaluate our program in terms of its effectiveness in reducing stigma in the context of intergroup interaction. For this purpose, we included the measurement according to the stereotype-content model (36), that recently demonstrated its reliability in testing stigmatizing stereotypes between groups [e.g., (37)]. As our *a priori* hypothesis, we assumed a reduction in stigma after our clerkship in psychiatry.

Given the increasing need and current shortage of mental health professionals, we were interested to see how stigma and its change after the clerkship influence the desire to become a psychiatrist in the future. Therefore, we hypothesize that a high level of expressed stigma is associated with a lower willingness to complete specialist training in psychiatry after finishing medical school. Additionally, we assumed that a stronger increase in willingness to complete specialist psychiatry training is associated with a more prominent reduction in stigma.

## 2 Materials and methods

We conducted an interventional cohort study using opinion surveys. Initially (T1) and after completing (T2) the psychiatric clerkship, medical students were asked to answer a multiple choice questionnaire. The item count varied between baseline ($N^{\mathrm{T1}}_{\mathrm{items}} = 80$) and follow-up due ($N^{\mathrm{T2}}_{\mathrm{items}} = 76$) to the static nature of certain measures—e.g., Big-Five personality traits—, and the time-specific relevance of others such as post-clerkship student perceptions.

### 2.1 Participants

A total of 256 students completed the psychiatry clerkship in the summer semester of 2018 ($n = 118$) and the winter semester of 2018/19 ($n = 138$) and participated in the present study. For 73 subjects (29%), the survey data were incomplete in T1 or T2, so we excluded these cases as non-completers. Thus, 183 data sets were available for a completer analysis. All students were in their third and fourth year at the time of the study. Table 2 provides an overview of our cohort.

### 2.2 Intervention

The clerkship in psychiatry—obligatory clinical part of the medical school curriculum—takes place between the sixth and tenth semesters (3rd and 5th year of medical school training), parallel with the other so called “head subjects” (e.g., neurology, otolaryngology, 1 week in psychosomatic medicine, and 1 week in child psychiatry). Together with psychiatry, the complete psychiatric-psychosomatic training block lasts four weeks. In the first or second pre-clinical year of study, students have two 1.5-h teaching sessions with patient videos and theoretical presentations of the psychopathological findings.

Our psychiatric internship spans the weekdays in two weeks. On average, students spent 8.8 of the scheduled ten days at the department. The internship is divided into a practical part from 8:00 to 11:30 a.m. on the ward and a theoretical part from 2:30 to 4:15 p.m. There are no classes during weekends or on holidays. One day of absence is allowed. Attendance is certified and is a prerequisite for taking the final exam and obtaining the certificate. At 8:00 a.m., the students attend the morning briefing, where the reports of previous inpatient admissions and the planning of the upcoming day occur. Twice a week, this meeting includes specific continuing education, case presentations, or journal clubs. Lectures with psychiatric topics can be attended from 11:30 a.m. to 2:30 p.m. In the afternoons, from 2:30 to 4:30 p.m., students participate in disease-specific seminars, including patient presentations and case discussions. Internal and external lecturers are responsible for the seminars. The external lecturers must be qualified as experienced therapists trained in medical didactics.

The students are divided into small groups of three to five participants and assigned to one of the six wards with different disease focuses, e.g., elderly psychiatry, depression, psychosis, anxiety and obsessive-compulsive disorders, addiction, or urgent psychiatry. Students spend the entire internship on the assigned wards and participate in their activities, including psychotherapy groups and individual sessions, as well as occupational or movement therapies. Each small group has an assigned academic mentor—a physician or psychologist. Furthermore, each student is assigned a patient with whom he or she conducts a medical history interview, accompanies during therapies, and writes a case discussion. During the training, students discuss different aspects of patient contact with their mentors. Finally, each student presents his or her case to the senior physician of the ward, who grades the student’s work with the patient.

Successful completion of the clerkship requires fulfilling three criteria:

- sufficient attendance (defined as having <1 day of absence)
- accomplished presentation and discussion of the patient’s case with the senior physician of the ward
- achieving a minimum score of 60% in the final multiple-choice test

The failure rate for the final multiple-choice examination varies from semester to semester but is typically below 5%. Overall, the psychiatry training is rated as average by students in the faculty ranking.

### 2.3 Procedure and recruitment

At the beginning of the study, the participating students received a subject information sheet and signed an informed consent form. Participants completed two anonymous questionnaires—before (T1) and after finishing the clerkship (T2). To identify the corresponding pairs of baseline and follow-up sheets, we instructed participants to generate a unique code that was used consistently on both questionnaires (T1 and T2). To avoid responses affected by conflicts of interest or social desirability, completion of the questionnaire was mandatory. The Marburg University Ethics Committee approved our study protocol.

### 2.4 Measurement tools

In the baseline questionnaire, we assessed the basic characteristics of participants (age, gender, semester assignment),

TABLE 1 Measurement tools and time points.

| Measurement tools | Time points | |
|---|---|---|
| | T1 | T2 |
| **Baseline only** | | |
| Age, gender, semester assignment | + | – |
| Completed clerkship in child psychiatry | + | – |
| Big five personality traits | + | – |
| Level-of-contact report | + | – |
| **Baseline and follow-up** | | |
| Attitude toward Psychiatry | + | + |
| Stereotype-content model | + | + |
| Opening minds scale for health care providers | + | + |
| Community attitudes toward the mentally ill | + | + |
| **Follow-up only** | | |
| Number of days of clerkship | – | + |
| Clerkship evaluation questionnaire | – | + |

whether or not the student had accomplished the clerkship in child psychiatry, and the previously experienced contact with people with mental disorders, employing the Level-of-Contact Report [LOCR; (38)]. We also briefly assessed the personality profiles using the Big Five personality traits model (39, 40). To evaluate the expression of stigma at baseline and after the clerkship, we asked the participants about their attitudes toward psychiatry (ATP) and used established measuring tools such as the Stereotype-Content Model [SCM; (36)], Opening Minds Scale for Health Care Providers [OMS-HC; (41)], and Community Attitudes Toward the Mentally Ill [CAMI; (42)]. Finally, we assessed the number of days the participants attended the clerkship and asked them to evaluate it. Table 1 provides an overview of the measured parameters and the time points. For a brief description of the measurement tools, see the Supplementary material.

## 2.5 Statistical analysis

For statistical analyzes, we used IBM® SPSS® Statistics 29 (43) and R software (44).

For the assumption of a normal distribution, we used the Shapiro-Wilk test and additionally considered density and quantile-quantile plots. To estimate the internal consistency of the scales used in our questionnaire, we applied the Cronbach $\alpha$ test.

To check for possible bias, we compared the group of "non-completers" (participants who completed the T1 questionnaire only) and "completers" (available T1 and T2 data), using the unpaired Wilcoxon rank sum test with continuity correction for categorical and metric-scaled variables if normal distribution cannot be assumed. For normally distributed variables, we performed the Student or Welch $t$-test. For comparisons of categorical variables, we used the $\chi^2$ test and, if required, the Fisher exact test.

To test our hypothesis of a reduction in stigma after the clerkship, we applied Student $t$ or Wilcoxon rank sum paired tests to compare the SCM, OMS-HC, and CAMI values at visit T1 vs. T2. Since we assumed an effect of reduction, we performed these tests one-sided. This analysis was only conducted for the completers.

To test for the association between willingness to complete psychiatric specialist training and stigma, we performed a correlational analysis. Since the variable "willingness…" was categorical and we assumed directed effects, we applied one-sided Spearman rank correlations. Since the these data was available at baseline in completers and non-completers, this analysis was conducted for all participants.

To test our hypothesis of an association between increase in "willingness…" and reduction in stigma after clerkship, we calculated increments ($\Delta$) representing changes in variables. Since high values of the items we tested here may represent higher or lower expression, depending on the scale, we calculated $\Delta$ using two distinct methods:

- For all variables testing the "attitude toward psychiatry", the "stereotype-content model" as well as the CAMI subscales "benevolence" and "community mental health ideology," we assumed that the values at T2 are higher than at T1. Therefore, we calculated increments using Formula 1.

$$\Delta = \text{Value}_{\text{T2}} - \text{Value}_{\text{T1}} \tag{1}$$

- For all variables testing the "OMS-HC" as well as the CAMI subscales "authoritarianism" and "social restrictiveness", we assumed that values at T1 are higher than at T2. Therefore, we calculated increments using Formula 2:

$$\Delta = \text{Value}_{\text{T1}} - \text{Value}_{\text{T2}} \tag{2}$$

In the next step, we performed a further correlational analysis with the calculated increments ($\Delta$) using the one-sided Spearman rank correlation for the completers only.

We assumed statistical significance at $p < 0.05$. However, since multiple tests were performed, we used the False Discovery Rate (FDR), according to the Benjamini-Hochberg procedure, to take the family-wise error (FWE) into account.

# 3 Results

All internal consistencies are adequate ($\alpha_{\text{Cronbach}} > 0.7$) except for the subscale competence of the SCM (complete cohort at T1: SCM competence $\alpha = 0.68$), OMS-HC attitudes ($\alpha > 0.6$ and $< 0.7$); ATP (completers at T2: $\alpha = 0.59$), OMS-HC disclosure ($\alpha < 0.6$), CAMI authoritarianism (completers at the beginning of the study: $\alpha = 0.65$), CAMI social restrictiveness ($\alpha < 0.6$), and the CAMI community mental health ideology ($\alpha < 0.6$).

TABLE 2 Descriptive statistics and comparisons between completers and non-completers at baseline (T1).

| Characteristic | *N* | Overall, *N* = 256[a] | Completers, *N* = 183[a] | Non-completers, *N* = 73[a] | *p*-value[b] | *q*-value[c] |
|---|---|---|---|---|---|---|
| Sex | 254 | | | | 0.14 | 0.25 |
| Male | | 166 (65) | 124 (68) | 42 (58) | | |
| Female | | 88 (35) | 58 (32) | 30 (42) | | |
| Age in years | 254 | 24.36 (2.64) | 24.40 (2.68) | 24.25 (2.56) | 0.77 | 0.77 |
| Internship in child psychiatry | 252 | 106 (42) | 81 (45) | 25 (35) | 0.17 | 0.25 |
| **Level-of-contact report** | | | | | | |
| Sum | 255 | 26 (13) | 26 (13) | 27 (14) | 0.74 | > 0.99 |
| Yes by LOCR_5 | 254 | 16 (6.3) | 12 (6.6) | 4 (5.5) | > 0.99 | > 0.99 |
| Yes by LOCR_10 | 254 | 23 (9.1) | 16 (8.8) | 7 (9.7) | 0.82 | > 0.99 |
| **Big five personality traits** | | | | | | |
| Extraversion | 255 | −0.90 (2.67) | −1.03 (2.64) | −0.56 (2.72) | 0.25 | 0.35 |
| Agreeableness | 255 | 1.99 (2.20) | 2.10 (2.15) | 1.71 (2.30) | 0.16 | 0.35 |
| Conscientiousness | 255 | −2.32 (2.25) | −2.51 (2.11) | −1.83 (2.51) | 0.040 | 0.20 |
| Neuroticism | 255 | 2.24 (2.17) | 2.30 (2.21) | 2.10 (2.06) | 0.28 | 0.35 |
| Openness | 255 | −2.56 (1.84) | −2.57 (1.87) | −2.53 (1.77) | 0.81 | 0.81 |
| **Attitude toward psychiatry** | | | | | | |
| Mean | 254 | 2.48 (0.76) | 2.45 (0.74) | 2.53 (0.82) | 0.36 | 0.69 |
| Willingness to complete specialist training in psychiatry | 254 | 1.94 (1.03) | 1.90 (0.97) | 2.06 (1.17) | 0.11 | 0.45 |
| Level of personal knowledge | 256 | 2.38 (0.78) | 2.37 (0.75) | 2.40 (0.85) | 0.87 | 0.87 |
| Level of personal interest | 256 | 3.13 (1.07) | 3.11 (0.99) | 3.18 (1.25) | 0.52 | 0.69 |
| **Stereotype-content model** | | | | | | |
| Competence | 249 | 3.68 (0.82) | 3.70 (0.81) | 3.64 (0.85) | 0.93 | 0.93 |
| Warmth | 249 | 4.11 (0.83) | 4.08 (0.80) | 4.18 (0.90) | 0.24 | 0.47 |
| **Opening Minds Stigma Scale for Health Care Providers** | | | | | | |
| Sum | 256 | 45 (9) | 45 (8) | 46 (9) | 0.62 | 0.76 |
| Attitudes | 256 | 16.0 (4.2) | 15.9 (4.0) | 16.2 (4.7) | 0.76 | 0.76 |
| Disclosure | 254 | 14.0 (3.7) | 13.9 (3.7) | 14.3 (3.7) | 0.50 | 0.76 |
| **Community attitudes to mental illness** | | | | | | |
| Authoritarianism | 256 | 2.17 (0.34) | 2.17 (0.33) | 2.18 (0.39) | 0.84 | 0.98 |
| Benevolence | 256 | 3.92 (0.42) | 3.93 (0.40) | 3.91 (0.47) | 0.98 | 0.98 |
| Social restrictiveness | 256 | 1.77 (0.39) | 1.74 (0.37) | 1.82 (0.43) | 0.32 | 0.98 |
| Community mental health ideology | 256 | 3.88 (0.51) | 3.89 (0.50) | 3.85 (0.54) | 0.60 | 0.98 |

[a] *n* (%); Mean (SD). [b] Pearson's $\chi^2$ test; Wilcoxon rank sum test; Welch Two Sample *t*-test. [c] False discovery rate correction for multiple testing.

## 3.1 Complete sample at baseline

A total of 256 medical students participated in the survey, 166 (65%) of whom were women. Forty-two percent of the participants ($n = 106$) had previously completed a child psychiatry clerkship. Sixteen participants (6%) reported having had a mental illness themselves (LOCR item 5), and 23 (9%) reported living with at least one person who had a mental illness (LOCR item 10). See Table 2 for more descriptive data. Although participants showed an average (Value = 3) personal interest (Mean = 3.20, [SD] = 0.92), their

TABLE 3 Evaluation after the finishing of the clerkship (T2).

| Items | *N* | *N* = 183[a] |
|---|---|---|
| **Staff motivation** | | |
| mot1: Motivation of doctors and psychologists | 180 | 2.17 (1.36) |
| mot2: Motivation of nurses | 179 | 2.92 (1.65) |
| mot3: Motivation of social workers and occupational therapists | 153 | 2.86 (1.72) |
| **Organization** | | |
| org1: How educational was it to experience daily life on the ward by being always present? | 180 | 2.94 (1.62) |
| org2: How educational was it to do the patient exams myself? | 179 | 2.22 (1.40) |
| org3: How educational was it to care for my patients? | 176 | 2.23 (1.41) |
| org4: How educational was it to follow patients over 2 weeks? | 178 | 3.06 (1.65) |
| org5: How educational was it to be able to have one-on-one conversations with patients? | 180 | 1.82 (1.13) |
| **Overall impression** | 180 | 2.74 (1.32) |
| **Contact with patients** | | |
| con1: The patient took an active part in the discussions with me | 181 | 1.98 (1.12) |
| con2: I felt comfortable in my interaction with the patient | 181 | 1.78 (1.04) |
| con3: Me and the patient understand each other | 180 | 1.56 (0.91) |
| con4: I find the patient difficult to interact with | 181 | −1.28 (1.49) |

[a] Mean (SD).

TABLE 4 Stigma measurements before (T1) and after (T2) the clerkship: completers only analysis.

| Characteristic | *N* | T1, *N* = 183[a] | 95% CI[b] | T2, *N* = 183[a] | 95% CI[b] | *p*-value [c] | *q*-value[d] |
|---|---|---|---|---|---|---|---|
| **Attitude toward psychiatry** | | | | | | | |
| Mean | 363 | 2.45 (0.74) | 2.3, 2.6 | 2.78 (0.69) | 2.7, 2.9 | < 0.001 | < 0.001 |
| Level of personal interest | 364 | 3.11 (0.99) | 3.0, 3.3 | 3.20 (0.92) | 3.1, 3.3 | 0.13 | 0.19 |
| Level of personal knowledge | 364 | 2.37 (0.75) | 2.3, 2.5 | 3.08 (0.66) | 3.0, 3.2 | < 0.001 | < 0.001 |
| Willingness to complete specialist training in psychiatry | 363 | 1.90 (0.97) | 1.8, 2.0 | 2.06 (1.13) | 1.9, 2.2 | 0.023 | 0.037 |
| **Stereotype-content model** | | | | | | | |
| Competence | 357 | 3.70 (0.81) | 3.6, 3.8 | 4.09 (0.86) | 4.0, 4.2 | < 0.001 | < 0.001 |
| Warmth | 357 | 4.08 (0.80) | 4.0, 4.2 | 4.80 (0.91) | 4.7, 4.9 | < 0.001 | < 0.001 |
| **Opening minds stigma scale for healthcare providers** | | | | | | | |
| Sum | 366 | 45 (8) | 44, 46 | 43 (8) | 42, 44 | < 0.001 | < 0.001 |
| Attitudes | 363 | 15.9 (4.0) | 15, 16 | 14.2 (3.5) | 14, 15 | < 0.001 | < 0.001 |
| Disclosure | 365 | 13.9 (3.7) | 13, 14 | 13.3 (3.5) | 13, 14 | < 0.001 | 0.002 |
| **Community attitudes to mental illness** | | | | | | | |
| Authoritarianism | 365 | 2.17 (0.33) | 2.1, 2.2 | 2.19 (0.35) | 2.1, 2.2 | 0.35 | 0.38 |
| Benevolence | 365 | 3.93 (0.40) | 3.9, 4.0 | 3.90 (0.44) | 3.8, 4.0 | 0.65 | 0.65 |
| Social restrictiveness | 365 | 1.74 (0.37) | 1.7, 1.8 | 1.73 (0.46) | 1.7, 1.8 | 0.35 | 0.38 |
| Community mental health ideology | 365 | 3.89 (0.50) | 3.8, 4.0 | 3.93 (0.52) | 3.9, 4.0 | 0.23 | 0.29 |

[a] Mean (SD). [b] CI, confidence interval. [c] Wilcoxon signed rank test with continuity correction; Paired *t*-test. [d] False discovery rate correction for multiple testing.

knowledge (2.08 [0.66]) and willingness to complete psychiatric specialist training (2.06 [1.13]) was below the average level at the start of the study. For the Stereotype-Content Model, the baseline means that the domains "warmth" (4.11 [0.83]) and "competence" (3.68 [0.82]) were also above average, corresponding to a moderate level of stigma, as measured with OMS-HC and CAMI (see Table 2).

Our comparisons between the completer ($n = 183$) and non-completer ($n = 73$) groups revealed no significant differences. Interestingly, the expression of the big-five traits of conscientiousness was higher in the completers, but this finding missed the significance level after the FWE correction ($p_{\text{FDR-adjusted}} = 0.20$; see Table 2).

## 3.2 Evaluations after finishing the clerkship

As depicted in Table 3 and Supplementary Figure 1A, the evaluation values vary in the upper range, indicating relatively high satisfaction with the psychiatric clerkship. Regarding staff motivation, physicians and psychologists achieved the highest scores for involving medical students in the treatment process (Mean = 2.17 [SD = 1.36]), ahead of occupational therapists, social workers (2.86 [1.72]), and nursing staff (2.92 [1.65]). Among all clerkship evaluation ratings, the items "Conducting face-to-face conversations with patients" ([1.82 1.13]) and "Experience of daily life on the ward…" (2.94 [1.62]) were rated the highest and lowest, respectively. Among the four items that addressed perceived aspects of contact with patients (see Supplementary Figure 1B), "Me and the patient understand each other" (1.56 [0.91]) and "I find the patient difficult to interact with (−1.28 [1.49]) were rated the highest and lowest, respectively.

## 3.3 Effects of the intervention (completer analysis)

As depicted in Table 4, Figures 1, 2, we measured a significant reduction in stigma after psychiatry clerkship.

With respect to the measurement of attitude toward psychiatry, we observed a more positive rating after the clerkship:

- Attitude toward psychiatry (ATP mean: $\Delta_{\text{Mean}} = -0.33$; 95% CI $[-\infty, -0.25]$, $t_{(179)} = -7.14$, $p < 0.001$; $d_{\text{Cohen}} = -0.53$, 95% CI $[-\infty, -0.40]$; see Figure 1C).
- Level of personal knowledge (ATP knowledge: $W = 384.00$, $p < 0.001$; $\hat{r}^{\text{rank}}_{\text{biserial}} = -0.89$, 95% CI $[-1.00, -0.86]$; see Figure 1A).
- Willingness to complete specialist training in psychiatry (ATP willingness: $W = 905.50$, $p = 0.037$; $\hat{r}^{\text{rank}}_{\text{biserial}} = -0.29$, 95% CI $[-1.00, -0.16]$; see Figure 1B).

However, we did not measure any significant changes in the level of personal interest in psychiatry (ATP interest), which remained in the neutral range.

Similarly to the measurement of ATP, we observed a significant reduction in the sum and both subscales of the OMS-HC:

- OMS-HC sum ($\Delta_{\text{Mean}} = 2.32$, 95% CI $[1.58, \infty]$, $t_{(182)} = 5.18$, $p < 0.001$; $d_{\text{Cohen}} = 0.38$, 95% CI $[0.26, \infty]$; Figure 1D).
- OMS-HC attitudes ($W = 9229.50, p < 0.001$; $\hat{r}^{\text{rank}}_{\text{biserial}} = 0.57$, 95% CI $[0.46, 1.00]$; Figure 1E).
- OMS-HC disclosure ($W = 7801.00, p < 0.001$; $\hat{r}^{\text{rank}}_{\text{biserial}} = 0.31$, 95% CI $[0.18, 1.00]$; Figure 1F).

As depicted in Figure 2, we measured a statistically significant and strong increases in both SCM domains:

- Competence ($W = 2193.00$, $p < 0.001$; $\hat{r}^{\text{rank}}_{\text{biserial}} = -0.55$, 95% CI $[-1.00, -0.44]$).
- Warmth ($W = 979.00$, $p < 0.001$; $\hat{r}^{\text{rank}}_{\text{biserial}} = -0.80$, 95% CI $[-1.00, -0.74]$).

Visual analysis of the two-dimensional density plot (Figure 2B) demonstrated that there were almost no observations with extreme negative ratings (below −1.5) affecting both SCM domains.

Surprisingly, our pre-vs.-post comparisons in all CAMI subscales did not reveal any significant differences (see Table 4).

## 3.4 Associations between the willingness to complete specialist training in psychiatry and the stigma measurements

### Before clerkship

As depicted in the first correlation matrix (Supplementary Figure 3A), all stigma measurements correlated with the willingness to complete psychiatry specialist training after finishing medical school. These correlations demonstrate an association between lower stigma expression and more prominent "willingness…"; the effect size range ranged from low (e.g., OMS-HC disclosure: $\rho_{\text{Spearman}} = -0.14$) to very large (OMS-HC attitudes: $\rho_{\text{Spearman}} = -0.43$). The second most prominent correlation was with the OMS-HC sum, see Figure 3A. Our further analysis used ANOVA to test the differences between subgroups of medical students with willingness "non-present," "low," "some," and "high or very high" showed significant differences between the groups. *Post-hoc*, we observed significant differences between the groups, with the exception of the comparison between students with "some" and "high or very high" rating in the willingness at T1, see Figure 3B.

### Changes (Δ) after clerkship

As depicted in the second correlation matrix (Supplementary Figure 3B), the increments of only two stigma measurements (Δ OMS-HC sum and the subscale attitudes) correlated with the increment willingness to complete specialist training in psychiatry. These direct correlations demonstrate an association between a more prominent stigma reduction (measured using OMS-HC and attitudes) and a more prominent increase in

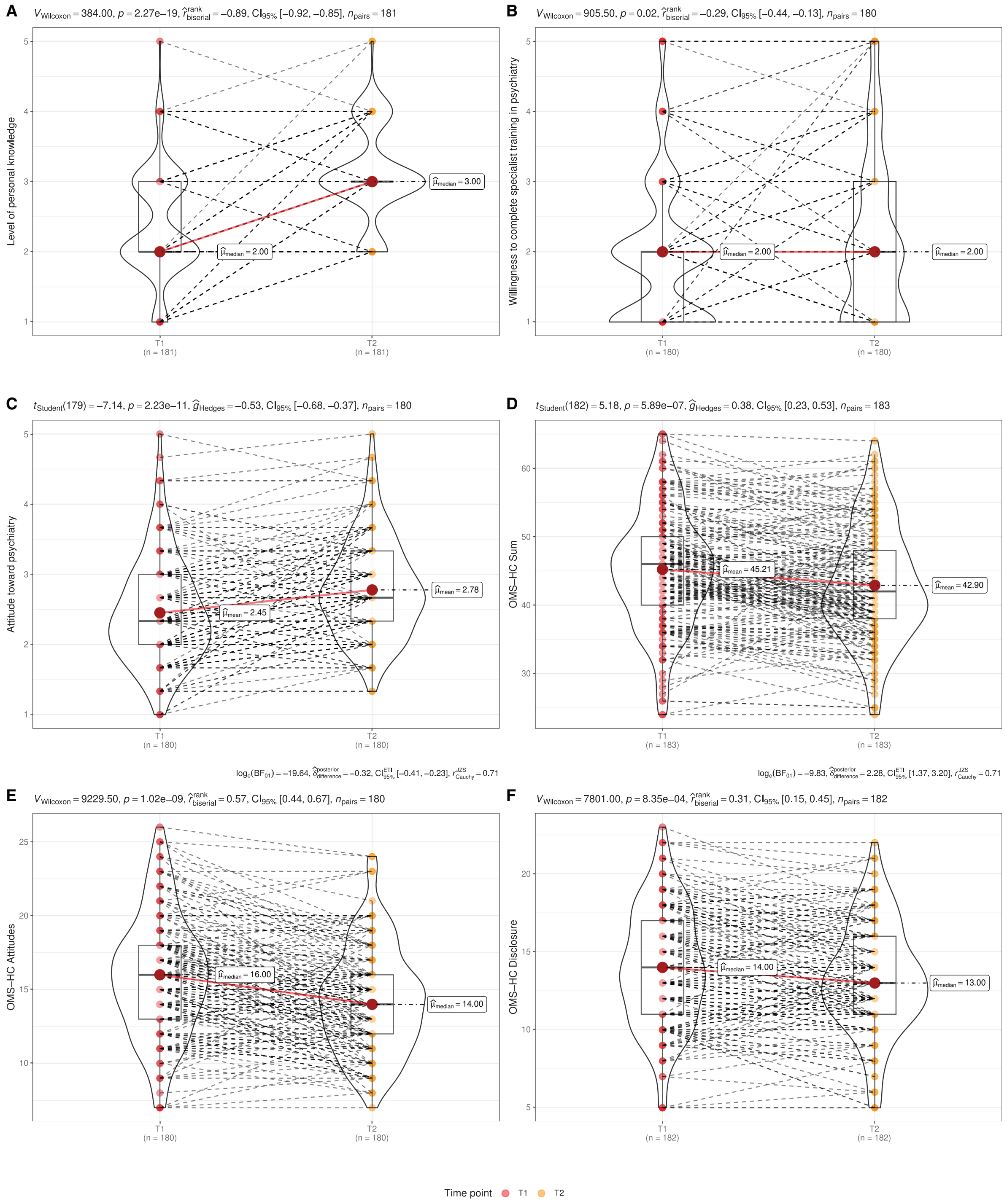

FIGURE 1
Combined violin-/ boxplots represent stigma reduction after the psychiatry clerkship —as measured using the questionnaire addressing the attitude toward psychiatry (ATP) and the Opening Minds Scale for Healthcare Providers (OMS-HC). Significant higher ratings in ATP **(A)** "personal knowledge", **(B)** "willingness to complete specialist training in psychiatry", and **(C)** mean ATP value. Significant lower ratings in OMS-HC **(D)** sum and subscales **(E)** "attitudes" and **(F)** disclosure after the clerkship.

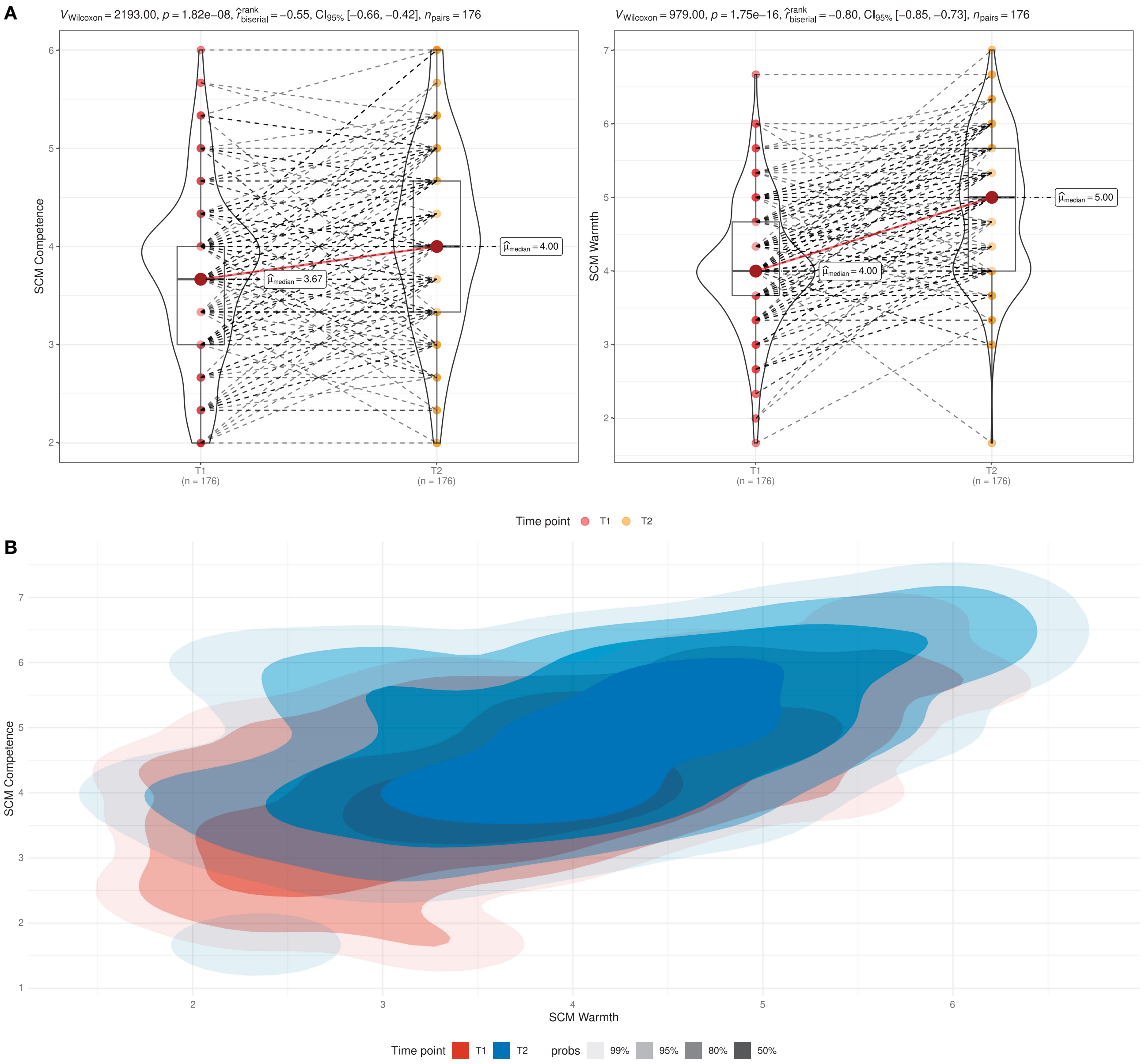

FIGURE 2
Stigma reduction after the psychiatry clerkship, as measured using the stereotype-content model (SCM). **(A)** Combined violin-/ boxplots represent significant higher ratings in SCM domains "competence" and "warmth" after the clerkship. **(B)** The effect of stigma reduction after the psychiatry clerkship was measured using the stereotype-content model presented in a two-dimensional density plot.

"willingness…"; the effect sizes were low (both $\rho_{\text{Spearman}} = 0.2$). The correlation with the OMS-HC sum is visualized in Figure 4A.

Our further analysis used ANOVA to test the differences between subgroups of medical students whose rating of the "willingness…" decreased, stayed unchanged, increased "some" and "high or very high" willingness showed significant differences between groups. *Post-hoc*, we observed that the reduction in the OMS-HC sum after the clerkship was significantly higher in students who reported a strong increase (Likert $\geq$ 2) compared to those whose "willingness…" remained unchanged or decreased after the clerkship (see Figure 3B).

## 4 Discussion

In our cohort, we observed that completion of the training was associated with a reduction in stigmatizing attitudes held by medical students toward mental disorders and psychiatry in general. Furthermore, their average willingness to become a psychiatrist in the future was reinforced in association after the clerkship in psychiatry, with a positive correlation with the degree of reduction in stigma.

We measured stigma using the stereotype-content model (36), in which both domains "warmth" and "competence" were estimated using a Likert scale, we observed that the ratings in the domain "warmth" were marginally positive and for the

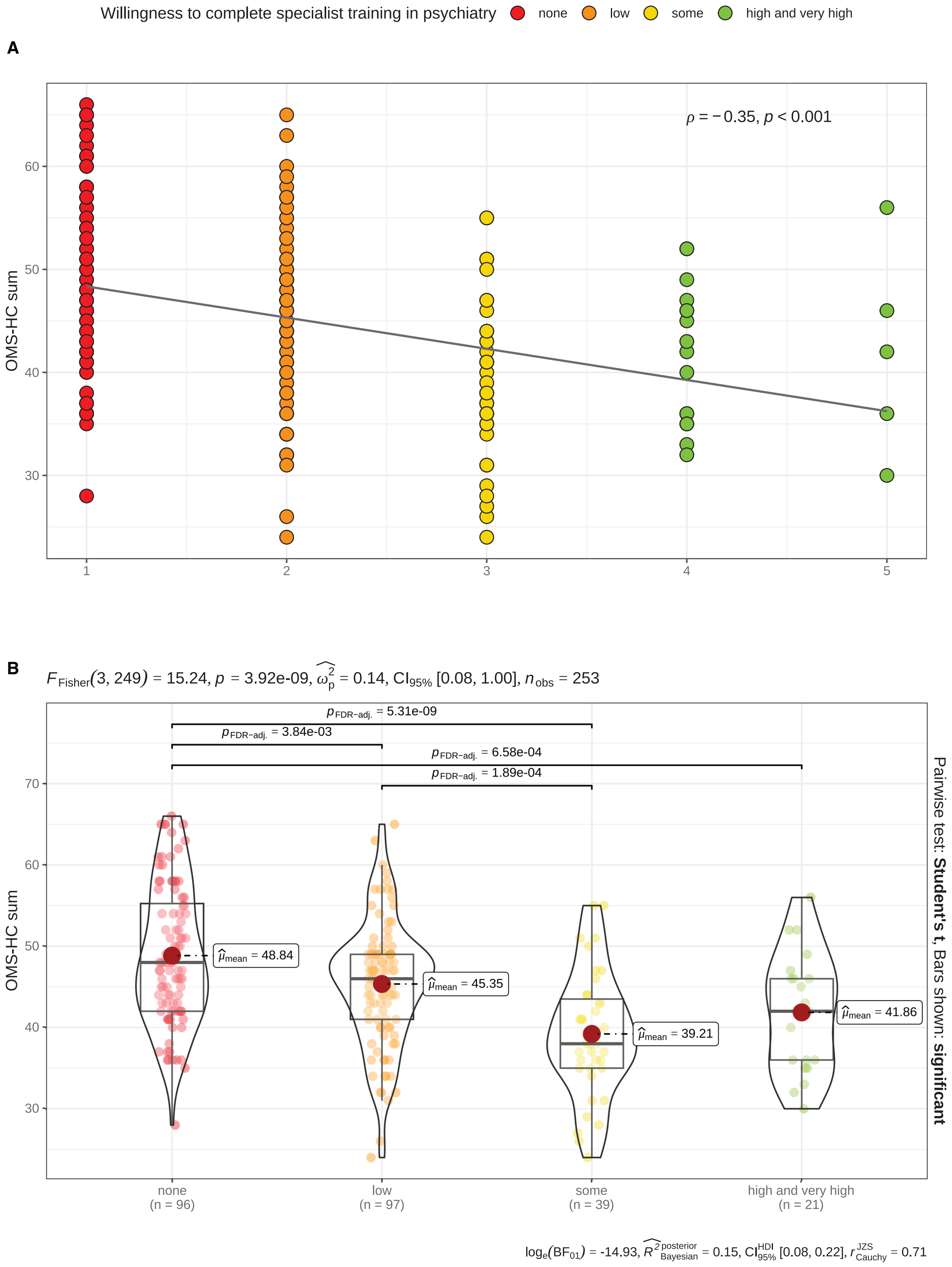

FIGURE 3
Significant association between stigma expression before the psychiatry clerkship (T1) —as measured using the Opening Minds Scale for Health Care Providers; OMS-HC sum score— and the "willingness to complete specialist training in psychiatry". **(A)** Scatterplot demonstrates a significant inverse correlation (Spearman). **(B)** Combined violin-/ boxplot demonstrates the differences of the OMS-HC sum scores depending on the level of the "willingness"... before the clerkship. Color coding represents the ratings in "willingness"... at baseline —as measured using a 5-items Likert scale: red Value = 1 [none]; orange Value = 2 [low]; yellow Value = 3 [some]; green Value > 3 [high and very high].

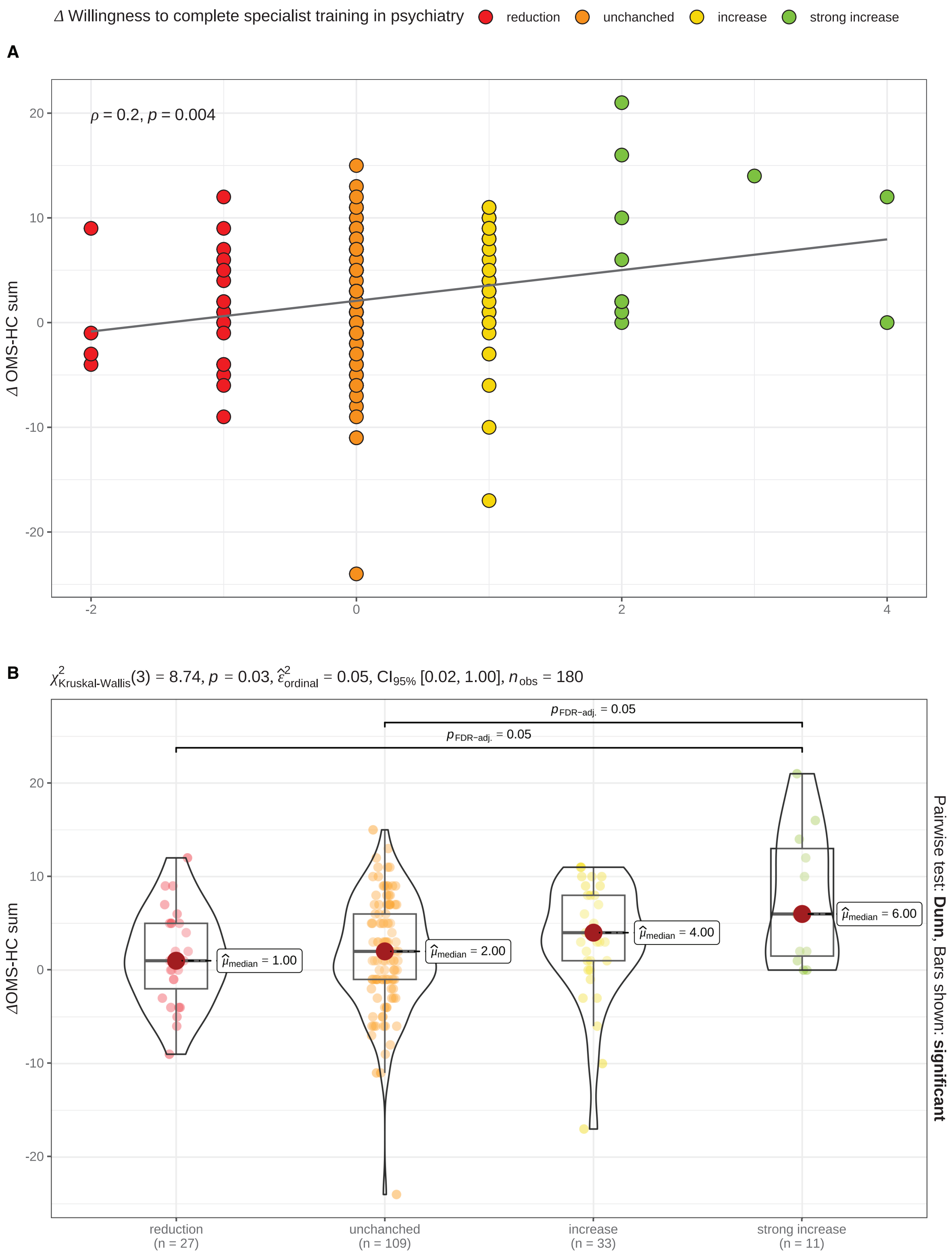

FIGURE 4
Significant association between degrees of changes in "willingness to complete specialist training in psychiatry" and stigma —as measured using the Opening Minds Scale for Health Care Providers; OMS-HC sum score— after the psychiatry clerkship. **(A)** Scatterplot demonstrates a significant correlation (Spearman). **(B)** Combined violin-/ boxplot demonstrates the differences of the OMS-HC sum scores depending on the degree of the "willingness"... changes after the clerkship. $\Delta = \text{Value}_{T2} - \text{Value}_{T1}$. Color coding represents the degrees of changes in "willingness"... measured using a 5-items Likert scale: red $\Delta < 0$ [reduction]; orange $\Delta = 0$ [unchanged]; yellow $\Delta = 1$ [increase]; green $\Delta > 1$ [strong increase].

"competence" lightly negative at the baseline. Although this pattern might initially appear to be an expression of the healthcare professionals' social awareness, prior publications indicate its negative connotation (45, 46). This SCM pattern describes a condescending relationship with a group of benign subordinates, eliciting pity and sympathy. This attitude implies an inequality, suggesting it as a form of stigmatization (46).

After the clerkship, we observed highly significant changes in absolute Likert scale scores for both domains, as consistent with our *a priori* hypothesis. However, the increase in "warmth" was more prominent than in "competence". Thus, the baseline pattern "warm but incompetent" remained. A possible explanation might be that the clerkship gave students the opportunity to learn that psychiatric patients are less dangerous than they expected and may thus contribute—by reducing anxiety—to higher "warmth" ratings, as previously supposed (45, 47). Simultaneously, impaired cognition and social functioning deficits accompanying severe mental illnesses can in principle hinder higher ratings in the SCM domain "competence", and thus lead to the persistence of the baseline pattern after the clerkship. However, we interpret these results as a correlate of stigma reduction, one reason being the prominent reduction in the high levels of expressed stigmatization—and corresponding to the lowest ratings in both SCM domains simultaneously—, as depicted using the two-dimensional density plot in Figure 2.

For a proper interpretation of our results, it is relevant to mention that baseline ratings in both SCM domains were relatively high compared to previously published data (48), which argues for a rather low initial level of stigmatization in our cohort. Therefore, a possible floor effect that decreases the strength of stigma reduction should be considered. Similarly to baseline ratings in the SCM domains, we observed a comparatively low baseline stigma expression measured with the OMS-HC, a tool to test stigmatization among medical providers (41). However, we still observed a significant reduction in the mean values of the OMS-HC sum and its subscale "attitudes" scores after the clerkship, in support of our *a priori* hypothesis. These findings are in line with the recent observation in a cohort of Canadian medical students (49).

Furthermore, we observed a reduction in the OMS-HC subscale "disclosure", which explicitly addresses the attitude toward personal mental health of participants, and which represents "self-stigma" tendencies among healthcare professionals (50). Healthcare providers may associate their professional image with alleged "invulnerability" and "omnipotence", and may thus lead to self-stigmatization due to a mismatch with an irrationally high benchmark reference; they might then avoid help seeking and delay adequate support (51). This may be a reason for the increase in burnout rates among medical students (52, 53). Our findings indicate that a psychiatry clerkship may reduce "self-stigma" and, therefore, can contribute to better mental health among medical students and healthcare providers.

The other stigma measurement tool we used was the Community Attitudes to Mental Illness (CAMI) scale, that measures social stigma (42, 54). Although we observed several significant correlations between baseline values or increments in CAMI subscales and other stigma measurements (see Supplementary Figure 3), no significant effects of clerkship could be found in our cohort. Since the mean values of the CAMI subscales "authoritarianism" and "social restriction" were lower in our cohort than in previously published results (55, 56), we speculate that the lack of clerkship effect could also be due to a "floor/ceiling effect" associated with a comparatively low baseline level of stigma in the current cohort, as recently assumed (27). Furthermore, the lack of significant intervention effects may also be associated with limitations of the CAMI questionnaire, which was originally designed to be applied in the general population, but which is not specific to healthcare professionals. Moreover, a recent systemic review has revealed that, since the first introduction of CAMI in 1981, only few longitudinal studies with CAMI have been published, and these possibly indicate that this measure exhibits limited temporal stability (54).

In further analysis, we compared self-assessed levels of personal knowledge, interest, and willingness to work as a psychiatrist in the future before and after the clerkship. We hypothesized that these items would increase significantly after the clerkship. At baseline, the mean values of the Likert scale for "interest" were rated neutral, "knowledge" neutral to negative and "willingness" negative. After the clerkship, the levels of "knowledge" and "willingness" increased significantly. However, the mean values for "willingness" remained in the negative range of the Likert scale. Furthermore, there were no significant changes in personal "interest" after the clerkship. Since our cohort's baseline level of "interest" was relatively high, this could explain the lack of a significant increase, and corresponds to previous findings (17, 57). The most prominent growth was measured in the subjective evaluation of "knowledge", which is not surprising, as this is the primary objective of the intervention.

In addition, we found an association between the willingness to complete psychiatric specialist training and the level of stigmatization measured using the OMS-HC scale, which demonstrated lower stigma in students who rated their "willingness" as above average; see Figure 3. Furthermore, we observed a similar trend in changes in the rating after the clerkship. As seen in Figure 4, growth in "willingness" was associated with a more prominent reduction in stigma. These findings align with our *a priori* hypothesis and the previously published results (17).

## 4.1 Limitations

In general, it is necessary to take into account that the fundamental methodical challenges of questionnaires—e.g., biasing due to "social desirability" and "tendency to the center"—limit the interpretation of current findings. In addition, Likert scales are inherently limited by the specification of response options and the restriction of multiple responses. Specifically for the current cohort, the relatively low expression of stigma before training must be regarded as a limitation. As mentioned above, the possible floor and ceiling effect may potentially lead to underestimation of the intervention effects and therefore need to be taken into account during the interpretation of the results. The direct interaction between medical students and patients is an essential component of our training. However, no data on the diagnoses and severity of mental conditions by patients were evaluated, although these may have an impact on stigma, and may enhance stigma after interactions with very severely ill patients [e.g., (45)]. Similarly, only limited differentiation was possible of the influencing characteristics of the staff or the previously completed clerkship. Finally, the lack of a control group should be considered as another limitation.

Future research should be aware of the limitations mentioned here and continue to address the role of direct student-patient interaction in stigma reduction, compare clerkship programs across various medical schools and countries, and consider the effects of patients' characteristics (e.g., diagnoses, severity of symptoms, social functioning level) and the perceived teaching skills, motivation, and personality profiles of academic mentors. Additionally, future studies should address the development and implementation of novel interventions that help reduce stigma (58, 59).

## Conclusion

Prior research underscores the widespread nature of stigma associated with severe mental illnesses and its detrimental impact on access to adequate healthcare. Stigma can lead to suboptimal treatment, shortened life expectancy, and indirect discrimination against patients. Our current findings provide additional evidence that direct student-patient interaction is highly effective in reducing stigma, as shown by the significant reduction in prejudice observed among medical students after a psychiatry training program. Furthermore, we identified a correlation between reduced stigma and increased willingness to pursue a psychiatric residency after medical school. These results align with previous studies, and emphasize the importance of addressing stigma in healthcare-related educational programs. Therefore, we advocate the incorporation of components of direct interaction in medical education, in order to combat stigma and improve patient outcomes.

## Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

## Ethics statement

The current study was approved by Marburg University Ethics Committee and conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

## Author contributions

MZ: Conceptualization, Data curation, Formal analysis, Methodology, Visualization, Writing—original draft. SK: Conceptualization, Investigation, Methodology, Project administration, Writing—review & editing. YY: Data curation, Formal analysis, Methodology, Writing—review & editing. WL: Conceptualization, Data curation, Formal analysis, Methodology, Validation, Writing—review & editing. UW: Conceptualization, Supervision, Writing—review & editing. TK: Conceptualization, Project administration, Resources, Supervision, Writing—review & editing.

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# Impact of stigma on the placement of mental health facilities: insights from early career psychiatrists worldwide

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KEYWORDS

**mental health, mental disorders, psychiatry, art, social stigma, health facilities, psychiatric hospital**

## Introduction

In the realm of mental health care, the placement and organization of facilities have long been intrinsically linked to prevailing societal and cultural attitudes and the persistent stigma surrounding mental illness (1). Psychiatric hospitals, known as "asylums", were often located in remote areas due to safety concerns, driven in part by misconceptions and stigma (2). The mid-twentieth century marked the emergence of the deinstitutionalization movement, aimed to reintegrate patients with mental illnesses into the community by placing mental health facilities within or close to urban areas and providing community mental health care (3). Despite these positive movements, traces of stigma continue to influence the geographical positioning and structure of mental care facilities (4). We synthesized the viewpoints of some Early Career Psychiatrists (ECPs) Section members from the World Psychiatric Association (WPA) (5), who were within the age bracket of 30–47 years. Our inquiry aimed to examine the influence of stigma on the location and configuration of mental health establishments, as well as its effects on the professional identities and levels of job satisfaction among psychiatrists. This exploration spanned across 10 distinct national contexts, including: India, Indonesia, Iran, Italy, Lebanon, Malaysia, Nigeria, Thailand, Tunisia, and the United Kingdom, as summarized in Tables 1A, B. We also provided recommendations for improving the quality and accessibility of mental health care.

## Segregation in placement of psychiatric hospitals and wards

In most of the countries where we collected the views of psychiatrists, standalone psychiatric hospitals still comprise a significant portion of psychiatric beds, with diverse geographical distribution patterns influenced by factors such as population density, urbanization, and healthcare infrastructure. However, the specter of stigma noticeably affects the geographic placement of psychiatric facilities in various nations. For instance, Indonesia and Iran have predominantly located their psychiatric hospitals in the countryside. This choice stems from misconceptions about mental illness, with the assumption that remote locations with stringent security measures will prevent patients from wandering or posing threats to the community (6, 7). Conversely, in places like India, Tunisia, Lebanon, and Nigeria, psychiatric hospitals are predominantly situated in large urban centers. Malaysia initially constructed psychiatric hospitals in suburban areas but later shifted them to city centers with urban expansion. The UK and Thailand exhibit variable rural and urban placement patterns, while Italy underwent significant transformations due to anti-stigma efforts initiated by "Basaglia's Law" in 1978, resulting in the closure of psychiatric asylums (usually located in peripheral areas), the organization of psychiatric assistance through the creation of territorial psychiatry departments and the integration of psychiatry wards (with a limited number of bed seats) for the management of acute phases of psychiatric diseases, within general hospitals in medium and large cities (8).

On a more positive note, some psychiatrists highlighted potential benefits of locating psychiatric hospitals in areas distant from urban centers. These benefits include reduced exposure to urban noise and pollution and reduced transport costs for individuals residing in rural areas. Additionally, the case of the Aro Village Project in Nigeria was mentioned. This innovative initiative, led by Prof. Thomas Adeoye Lambo, established a community-based mental health care system that prioritized affordability, accessibility, and cultural appropriateness. The project involved villagers in the accommodation and treatment of psychiatric patients, integrating family members and traditional healers into the care process. This initiative transformed social perceptions of madness and evolved from a rural mental hospital into a community situated in an urban center (9).

Regarding the placement of psychiatric units or wards within general hospitals, over half of the respondents reported that psychiatric wards in their respective countries were situated in specific locations, such as separate buildings, lower floors, or isolated wings. These wards often feature specialized facilities, security measures, and unique ward architecture, including closed walls and security guards. While these security measures primarily aim to ensure patient safety and prevent suicides, this segregation inadvertently perpetuates stigma by communicating separation between physical and mental healthcare. Patients' restricted access to outdoor spaces due to security concerns fosters feelings of isolation and marginalization. Moreover, disparities in resource allocation are observed, with specialists from other fields often exhibiting a negative view or even fear of psychiatric patients. In some cases, these specialists refuse to accept patients with psychiatric disorders into their departments.

## Use of stigmatizing language

Many countries still use stigmatizing terms for psychiatric hospitals, wards, or locations. Terms like "crazy" and "psycho" label patients, while references to "asylums" further perpetuate institutional stigma. For example, "Tanjung Rambutan" is the location of Malaysia's first psychiatric hospital, but it is also used as a derogatory and discriminatory term for someone who is not accepted and should be locked up in an asylum. Similarly, some countries, like Thailand, consistently use "neuro" instead of "psycho" (or neuro-psycho) in official terms, hospitals, and institutes (10). Such stigmatizing terminology may reflect and reinforce societal prejudice (11).

## Integration of medical services

Opinions on the establishment of medical inpatient wards or outpatient clinics of various specialties, such as neurology, internal medicine, or emergency care, within psychiatric hospitals as means to reduce stigma diverged. Some believed that such integration reduced stigma by fostering frequent interactions between psychiatrists and non-psychiatry practitioners, challenging stereotypes and discrimination. However, others argued that stigma persisted across various fields, often stemming from professionals' own understanding of mental illness.

## Impact of stigma on employment choices

Perspectives varied on how stigma associated with psychiatric hospitals affects psychiatrists' employment choices. Some observed willingness among younger generations to foster positive change through such positions. However, stigma appears to deter others from these career paths. Improved infrastructure can increase desirability of psychiatric hospital employment. Overall, individual attitudes likely involve multiple factors like past training experiences and job availability.

## Implementation of destigmatization programs

Psychiatrists also highlighted the implementation of destigmatization initiatives in their regions. These efforts encompassed the expansion of Liaison-Consultant Psychiatry, the establishment of off-site centers for adolescents with mental distress, the training of primary care physicians and specialists from various fields, the introduction of CBT-based anti-stigma

TABLE 1A Presence and location of psychiatric facilities and stigma.

| Country | Presence of psychiatric hospitals | Location of psychiatric hospitals | Specific location of psychiatric wards in general hospitals | Stigma influence | Stigmatizing terms |
|---|---|---|---|---|---|
| India | Yes | Large cities | Yes | Significant | "Mental," "Psycho," "Pagal" |
| Indonesia | Yes | Countryside | Yes | Significant | "Crazy" |
| Iran | Yes | Countryside | Yes | Significant | "Timarestan," "Divaneh," "Ravani" |
| Italy | No, closed in 1978 | - | Yes | Previously high, now lower although present | "Manicomio" (asylum), "Ospedale dei pazzi o dei matti" (hospital of the fools), "Madhouse" |
| Lebanon | Yes | Formerly isolated, now central | No | Significant | "Majnoun," "Akhwat" |
| Malaysia | Yes, integrated | Within city hospitals | Yes | Significant | "Tanjung Rambutan" |
| Nigeria | Yes | Large Cities | Yes | Significant but improving | "Yaba left" |
| Thailand | Yes | Large Cities | Yes | Variable | None |
| Tunisia | Yes | City centers | No | Previously high, now low | Famous stigmatizing terms |
| UK | Yes | Variable | Yes | Variable | "Asylum" |

TABLE 1B Programs, integration, and views on psychiatric care.

| Country | Benefits of remote locations | Destigmatization programs | Medical integration | Employment views | Deinstitutionalization |
|---|---|---|---|---|---|
| India | No benefits | Training of primary care physicians and health care professionals | Can help reduce stigma | Mixed based on hospital | Supported |
| Indonesia | Dignity and privacy of patients | Expansion of Liaison-Consultant Psychiatry | Can help reduce stigma | Positive employment views | Supported |
| Iran | No benefits | Mental health education for health care workers and the public | Experience shows benefits | Mixed attitude | Supported but challenges remain |
| Italy | Not applicable | Considered (e.g., Establishment of youth-friendly hubs) | Experience shows it reduces stigma | Lingering stigma remains | Strongly supported |
| Lebanon | No benefits | Conducted by major hospitals and educational institutions, as well as non-governmental organizations | Helps reduce stigma | No employment effect | Supported |
| Malaysia | No benefits | No sustained anti-stigma program | No effect | No stigma effect | Supported |
| Nigeria | Reduced cost, easy access | Awareness programs | Helps reduce stigma | Mixed attitude | Supported but with caution regarding practicability, models, etc. |
| Thailand | Some benefits | Community-based psychiatric care (Village health volunteer training) | Helps reduce stigma | Mixed attitude | Caution adapting western models |
| Tunisia | Remoteness from the noise and the pollution | National programs, hospital closure advocated | Did not reduce stigma | No employment effect | Strongly supported |
| UK | None described | "Choose psychiatry" campaign | Potentially positive | Possible stigma effect | Not a priority currently |

programs for caregivers of psychiatric patients, and initiatives to raise awareness about mental health issues among children, and youths. Additionally, community-based psychiatric care programs involving Village Health Volunteers (VHVs) were mentioned. However, despite these endeavors, the absence of comprehensive, sustainable, and long-term destigmatization programs, coupled with financial constraints and inadequate support from authorities, remains a significant challenge in this regard.

## Deinstitutionalization considerations

Respondents' opinions on the deinstitutionalization movement also vary. Many express supports for deinstitutionalization, citing reasons such as reducing stigma, increasing access to care, respecting patient preferences, enhancing family and social support, and saving costs. Some mention that modern mental health hospitals offering high-quality services may render deinstitutionalization less urgent. Others emphasize the importance of considering social welfare and contextual culture when implementing deinstitutionalization.

## Discussion

In summary, despite notable advancements in the deinstitutionalization movement and the incorporation of mental health care into mainstream healthcare systems, the enduring impact of stigma continues to shape the placement and structure of psychiatric facilities. It is crucial to acknowledge and actively address these persistent stigmatizing influences to ensure comprehensive and inclusive healthcare for individuals with psychiatric disorders, thereby enhancing their wellbeing and alleviating the societal burden of mental illness. Future research and policy endeavors should prioritize the dismantling of these barriers and the cultivation of a more compassionate and integrated approach to mental health care. A balanced strategy is recommended: (1) Foster the development of accessible community-based care by allocating adequate resources and implementing anti-stigma initiatives; (2) In cases where psychiatric hospitals are still deemed necessary, introduce internal destigmatization programs while concurrently devising transitional plans to gradually shift toward community-based models when sustainability allows.

## Author contributions

LK: Conceptualization, Data curation, Investigation, Project administration, Writing—original draft. RdF: Conceptualization, Data curation, Writing—review & editing. SE: Conceptualization, Data curation, Writing—review & editing. MH: Data curation, Writing—review & editing. CJ: Data curation, Writing—review & editing. EK: Data curation, Writing—review & editing. AL: Data curation, Writing—review & editing. IN: Data curation, Writing—review & editing. MO: Data curation, Writing—review & editing. LO: Data curation, Writing—review & editing. MP: Conceptualization, Data curation, Supervision, Writing—review & editing. RR: Data curation, Writing—review & editing. MAS: Data curation, Writing—review & editing. MS: Conceptualization, Data curation, Investigation, Project administration, Supervision, Writing—review & editing.

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# Distance from a cultural model of substance use risk, internalization, and self-stigma in urban Brazil

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**Introduction:** A cognitive theory of culture as socially distributed cultural models has proven useful in research. Cultural models exist in two forms: the model shared by individuals in a social group, and individual versions of that model modified by personal experience. In previous research we documented a shared cultural model of substance use risk among a general population sample in urban Brazil. Here we examine how this model is distributed among persons under treatment for substance use/misuse and the implications for perceived and self-stigma.

**Methods:** A convenience sample of 133 persons under treatment rated the influence of risk factors for substance use/misuse. The configuration of those ratings and the cultural distance of persons under treatment from the general population model were calculated. Degree of stigma perceived in the wider society and degree of self-stigma were also assessed.

**Results:** Persons under treatment aggregate risk factors to a greater extent than the general population. Using a cultural distance metric, the more distant persons under treatment are from the general population model, the lower their self-stigma regarding substance use.

**Discussion:** Some individuals under treatment separate their understanding of substance use/misuse from shared perspectives in the wider society, which in turn reduces self-stigma. These findings add an additional perspective on the relationship of culture and the individual.

KEYWORDS

**cultural models, cultural distance, substance use disorder, self-stigma, Brazil**

## Introduction

One of the enduring theoretical and empirical questions in the social sciences in general, and in anthropology specifically, is the relationship between culture and the individual (Dressler, 2018). Are we merely "cultural dopes" whose thought and action are determined by our culture of upbringing; or, are we independent agents who forge our own paths in life irrespective of cultural influences?

The real empirical question, of course, lies somewhere between these statements. The set of cultural models that inform thought and action certainly shape our understanding of the world; at the same time, individuals incorporate the knowledge encoded in cultural models with their own experience and goals in life. These "subjectivities" in turn guide interpretations of and action in the world (Strauss, 2018a).

Our aim in this paper is to explore these questions in a particular context: cultural influences on stigma in relation to substance use and misuse in urban Brazil. Previous research has shown that there is a shared but relatively nonspecific model of the risk of substance misuse in Brazil that, as a result of drug education and media focus, is centered within a specific demographic: young adults in the general population (Henderson and Dressler, 2020). Here we explore how this model is configured and internalized by persons occupying a different social position: those who are under treatment for substance use. We find that persons under treatment tend to make fewer distinctions among risk factors than do general population young adults. Furthermore, the greater the distance between individuals under treatment and the young adults in terms of the cultural model, the less likely persons under treatment are to self-stigmatize as a result of their substance use. These findings offer a novel perspective on the relationship of culture and the individual.

## Theoretical background

The nature of the relationship between culture and the individual has been a question debated since the beginnings of anthropology. In the early days of the field, Kroeber (1917) thought that individuals should be ignored in favor of the study of culture as an entity external to them, while Sapir (1917) countered that such an external entity was of no theoretical use and questionable empirical status, and that the observed behavior of individuals was where culture was manifest.

Much later both Goodenough and Schwartz attempted to reconcile the external quality of culture with the undeniable fact that persons incorporate culture into their own subjective experience of the world and employ it in their everyday interactions. They posited individual versions of culture [the "propriospect" for Goodenough (1981) and the "idioverse" for Schwartz (1978)] that reflected a combination of culture in the aggregate with personal experience, although neither of these constructs provided much empirical guidance. Spiro's (1997) concept of "internalization" is also relevant here, in that it describes a step-wise process by which individuals proceed from a mere passing knowledge regarding some cultural domain to actively incorporating that knowledge into a personal belief system that they then use to guide their own actions. Still, an effective way of describing and operationalizing both culture in the aggregate and the subjective experience of culture has eluded researchers.

In part, the ways in which culture is internalized and becomes a part of individual subjectivity depends on how culture itself is conceptualized. Here we rely on a cognitive theory of culture, starting with Goodenough's (1956) definition of culture as that which one must know in order to act acceptably in a given social group. In contemporary cognitive culture theory, this knowledge is understood to be encoded in the form of cultural models. A cultural model is a schematic outline of some salient cultural domain (itself a focus of discourse within the group) that includes the elements that make up the domain, along with the semantic, functional, and causal relations that are understood to distinguish among and link those elements. Cultural models contain one or more prototypes that can be either some kind of abstract type that represents that domain, or an actual member of the domain thought to represent a best example (D'Andrade, 1995; Bennardo and de Munck, 2013).

Examining cultural models requires that an emic approach be adopted. The term "emic" is derived from linguistics and phonemic analyses, a phoneme being the smallest unit of sound that makes a difference in the meaning of word. An emic approach in ethnography requires that the focus of research is on the meaningful distinctions that members of a community themselves make in understanding the world around them, as opposed to an etic approach in which categories and distinctions are imposed on community members by the researcher (Lett, 1996). An emic approach focuses on "the insider's view" of specific cultural domains.

Cultural models are most profitably investigated using a mixed-methods approach. In-depth interviewing (including traditional ethnographic interviews, person-centered interviews, and free lists) is essential for eliciting the elements that make up an hypothesized cultural model and for describing how those elements are linked and distinguished (Dengah et al., 2021). Then, a quantitative analysis employing cultural consensus theory (Romney et al., 1986) can be used to verify that the model is shared and hence a cultural model (see Weller et al., 2023). Cultural consensus analysis can also be used to estimate how much of the knowledge encoded in the model is shared within a social group, and it can be used to estimate the most likely content encoded in the model. One of the advantages of the combination of cultural model theory and cultural consensus theory is that culture can be understood, non-mysteriously, as an emergent property of social groups, in that it cannot be reduced to what any given individual knows, but rather is a weighted average of individual knowledge, in which individuals who command more of that knowledge contribute more to the aggregate keeping in mind that, in cultural consensus theory, "to know" something means to agree more with others about it (Dressler, 2018).

Understanding cultural models and individual subjectivities, or how persons incorporate that knowledge into their own thought and action, requires another step. Dressler's (2018) concept of cultural consonance describes the link between cultural knowledge and individual behavior. Traditionally, this work has focused on the individual's ability to "live-up" to the expectations encoded in widely shared cultural models and the effects of that "success" or "failure" on measured health outcomes. As Dressler (2018) has argued, there must be an aspirational component to the cultural model that drives one to be culturally consonant. A separate question, however, pertains to how individuals utilize their understandings of shared cultural models to recursively inform and modify their own personal models, or, their subjective experience of the world. This question has been less well investigated.

Strauss has been particularly interested in this question. Her research on economic mobility (Strauss, 1990), political orientations (Strauss, 1997), and poverty (Strauss, 1990) has focused on how individuals take their shared knowledge of cultural models and their own experiences and mold them into ways of thinking about and coping with the world around them. Her approach to this work has emphasized person-centered interviewing and a thick description or interpretive analysis of those narratives to demonstrate how individuals incorporate culture into their daily lives.

This work is rich and illuminates carefully how culture lives in persons. At the same time, the ways that varying subjectivities are socially distributed within the community in question is missing from these analyses [although Strauss (2018b) correctly points out how the description of varying subjectivities described in individual case studies illuminates intracultural variation]. It might be argued that cultural consensus analysis itself achieves this goal by describing variation in cultural competence, the measure of how much knowledge an individual shares with others. But cultural competence does not describe whether or not that knowledge is salient for the individual and incorporated into their experience of the world or, put more simply, whether that knowledge matters individually. In Gatewood's terms, it may simply be "knowledge of" but not actual "knowledge for" (Gatewood, 2011).

An added complication in conceptualizing the relationship of cultural models and individual experience has been highlighted by Chentsova-Dutton and Ryder (2020): most research on the topic has focused on cultural models that are normalized or valorized within a community. That is, they describe thought and action that is at least understood to be ordinary and perhaps is a life goal for community members (e.g., Dressler et al., 2017). But what of cultural models of domains that are disvalued or encode what is culturally constructed as deviant within that society? One such domain is substance use and misuse. Persons who use or misuse substances are often the objects of stigma. This stigma can take several forms, including attributed and enacted stigma coming from other persons, and/or perceived and self-stigma felt by the persons using substances themselves (Paquette et al., 2018). Perceived and self-stigma, two foci of this paper, can be particularly problematic in that these forms of stigma can inhibit seeking treatment and lead to comorbid mental health problems. Furthermore, recent reviews suggest that understanding of factors underlying these forms of stigma remains limited (Milan and Varescon, 2022).

Here we present research that helps to address these issues. In a study of the stigma associated with substance use and misuse in Brazil, we first documented a cultural model of the risk of substance use among young adult Brazilians in the general population that in turn informed their tendencies to stigmatize—or not—substance users, by labeling them as untrustworthy and dangerous (Henderson and Dressler, 2020). Next, a sample of persons under treatment for substance misuse rated the influence of the same risk factors for substance use based on their own individual experiences. We thus can determine the similarity and differences in cultural models of substance use risk between the general population and those under treatment. This is a particularly interesting example of the relationship between culture and the individual because the cultural model of the general population is, in essence, imposed on the treatment sample in the sense that in everyday interaction they encounter persons who know and/or adhere to that model and expect them to do the same. The proximity or distance of persons under treatment from this model in their own evaluations of risk factors will contribute to an understanding of how cultural models are put to use by individuals, with the added advantage of describing the distribution of models in use.

Furthermore, the idea of "cultural distance" will be employed operationally here, not just metaphorically. There is evidence that in some cultural domains, people experience culture as a space they navigate (Lakoff and Johnson, 1980; Dressler et al., 2023), determining their position in that space relative to prototypes encoded in cultural models. Actually measuring the distance of persons under treatment from a general population model in a multidimensional array will allow us to explore this theoretical orientation further, especially in terms of how this might influence their subjective well-being, as measured by their experience of stigma.

By comparing the treatment sample to the general population sample, we can examine the following research questions:

a. how proximate are persons in the treatment sample in their thinking to the general population sample?
b. how are the elements of the cultural model of substance use risk reconfigured by persons sharing the status of substance user?; and,
c. what are the implications of proximity to or distance from the general population sample for stigma experienced by the substance user?

## Ethnographic setting

Research was conducted in the city of Ribeirão Preto, a community of over 700,000 persons in the north of the state of São Paulo. It sits in a rich agricultural region originally devoted to coffee production and more recently emphasizing sugar cane and citrus. The city itself has become a regional center in manufacturing, finance, and education.

Many sources identify Brazil as a leading consumer of drugs (INPAD, 2012). Approximately 50% of the population engages in recreational alcohol use, 2–3% in cannabis use, and 1–2% in cocaine/crack use (CICAD, 2019). Despite seemingly low prevalence rates, Brazil is the second largest consumer of cocaine in the world (CICAD). Nearly 4% of the adult Brazilian population experiments with cocaine at some point in their lives, and of those nearly half (48%) become dependent on the substance (Pillon et al., 2017). Substance use is particularly popular among young adults and those attending university (Andrade et al., 2010). Houvèssou et al. (2021) found that 92% of undergraduate students surveyed in southern Brazil consumed alcohol, while 13% of students combined alcohol use with the use illicit substances.

The rates of substance use in Ribeirão Preto are also estimated to be relatively high (de Freitas and de Moraes, 2011). Alcohol use is common, fueled in part by the historic beer industry of the city (arguably one of the most famous bars in all Brazil serving *chopp* or draft beer is located there). Cannabis use is common, especially within the large university student population of the city, and there are several well-known local scenes for drug use where crack cocaine users convene to buy and consume the drug (LECUCA, 2020).

While there have been attempts to move public policy in Brazil away from the criminalization of substance use to prevention and treatment, incarceration rates for even casual users remain high (Boiteux and Wiecko, 2009), a trend exacerbated under the Bolsonaro presidency. Despite this, there are several avenues that the individual can take to receive treatment. Most treatment is provided through the Unified Health System (SUS), which offers free health care to all Brazilian citizens, mainly through primary care clinics. With respect to mental health, within SUS there is a system of *Centros de Atenção Psicosocial* (CAPS) or Psychosocial Care Centers, and more specifically there are the CAPS-AD, or centers devoted to the treatment of alcohol and drug abuse. These community-based centers provide a continuum of multidisciplinary outpatient care, with the goal being a reduction in psychiatric hospitalization, including for drug abuse (Ferreira-Furegato et al., 2012).

Another major source of treatment for substance misuse are the *communidades terapeúticas* or therapeutic communities (CT). While CAPS-AD is purely outpatient, persons attending the CTs are required to live for several months in the community, usually tending gardens and small animals and participating in both group and private therapy sessions. In Brazil CTs are generally associated with religious organizations, and typically with evangelical or Pentecostal protestant churches (Lucchetti et al., 2016).

In Ribeirão Preto there is one CAPS-AD and several CTs. The CAPS-AD is somewhat unique in that, prior to the establishment of SUS, it was a mental health treatment center associated with the Spiritist movement in the state of São Paulo. Briefly, the Spiritist movement is associated with the writings of the 19th century figure Allan Kardec, who developed a belief system centered around the continuing moral evolution of the spirit after death, the ability of some to communicate with those spirits, and a commitment to social welfare (Greenfield, 2008). The CAPS-AD began as one such center and was the established in 1996 in accordance with changing legislation for mental health care in Brazil.

Of the several CTs in the city, we focused on two that were well outside the city center. The CTs consisted of fairly large *chácaras* (a term used in Portuguese to describe small farms or country houses), and patients live on-site for three to nine months of treatment. One CT was associated with the Catholic Church while the other was Pentecostal, and all residents were required to participate in religious study. Residents lived in dormitory-style buildings with several residents to a room and communal bathrooms. They were required to make their beds and clean the bathrooms, as well as work in the kitchens, tend the gardens, and take care of domestic animals. Opportunities for recreation included fishing in small ponds on the property and playing *fútebol* (soccer). During their stay, patients were allowed outside visitors only infrequently and under controlled conditions, the rationale being that separation encourages greater concentration on treatment. In addition to religious study, treatment consisted of group discussions as well as individual counseling sessions.

## Cultural models of substance use and stigma

An initial study of cultural models of substance use and attributed stigma was carried out sequentially in mid-2017 among a general population sample consisting of young adults (Henderson and Dressler, 2020). Participants were recruited through professors and students at two local universities and also at popular young adult hangout locations, such as a local shopping mall in Ribeirão Preto. It was reasoned that this age group was where the cultural model was socially "located" (i.e., most salient). There were several reasons to suspect this, including the fact that this group had most recently been the focus of drug education programs in secondary school while, at the same time, only beginning experimentation with substance use. Furthermore, they are high consumers of popular media that portray substance use and misuse. For these reasons, they serve as a kind of social repository of the schema that frame substance use and its evaluation.

A convenience sample of 16 young adults were asked to list factors associated with the risk of substance use, although data saturation (i.e., minimal generation of novel terms) was achieved with only 12 individuals. Twenty-nine items were retained for further analysis. Next, a second convenience sample of 35 respondents performed an unconstrained pile sort of these items. Multidimensional scaling and cluster analysis of the pile sort data indicated that the 29 risk factors were grouped into four categories: (1) social life (such as the influence of friends and going to parties or clubs); (2) the family (such as a family history of substance use and family problems); (3) self-medication (such as using drugs to seek relief, feeling anxious or depressed, wanting to feel better); and, (4) hedonism (having a lot of money, having a "weak head"). Additionally, 48 young adults rated each of the 29 risk factors on a 4-point scale from the risk factor having no influence on the risk of substance use to the risk factor being very influential (Henderson and Dressler, 2020).

Using cultural consensus analysis, the pile sort configuration was found to be highly shared; that is, there was strong agreement on the allocation of each risk factor to each of the four major categories. When the ratings of the influence of the risk factors were analyzed with cultural consensus analysis, however, there was no consensus. Further analysis with the internal consistency model for cultural consensus indicated that there was substantial agreement among respondents [respondent reliability = 0.871; see Weller (2007) for a discussion of different models for analyzing cultural consensus]. There were two reasons for the difference in these results between the cultural consensus model and the internal consistency model. First, the young adults tended to rate every risk factor as having potential influence on substance use, and cultural consensus analysis does not work well with these kinds of skewed ratings. Second, there was substantial residual agreement (Dressler et al., 2015) in the sample. One subgroup of respondents tended to rate psychosocial problems and self-medication as more important risk factors, while the other subgroup of respondents tended to rate social and hedonistic factors as more important.

What this means substantively is that, while there is an underlying cultural model of substance use risk, the model itself is not very specific. There is fairly high agreement on the elements of the model (risk factors) and their configuration; then, all the risk factors within that model are thought to be potential influences. In other words, nearly any path can lead to substance misuse.

A further finding of this preliminary study was the association between knowledge of the cultural model and the attribution of stigma to drug users. The residual agreement analysis was important in this respect: respondents who rated psychosocial problems and self-medication as more important also stigmatized drug users more, while respondents who rated social aspects of drug use and hedonism higher were less likely to stigmatize drug users (Henderson and Dressler, 2020). The "self-medicator" was deemed to be more untrustworthy and dangerous than the "feckless partier."

With these results as a foundation, we initiated a study of persons under treatment for substance use. Of the factors likely to be influenced by cultural distance from the general population sample, here we focus on perceived stigma and self-stigma (Corrigan et al., 2017). Perceived stigma refers to the degree to which persons under treatment understand stigma to be prevalent in the society around them. Self-stigma, on the other hand, is the degree to which persons under treatment themselves stigmatize persons, including themselves, with substance use disorders. How do individuals under treatment view the risk of substance use relative to the general population? What are the implications of being proximate versus being distal from the general population sample in terms of perceptions of risk? We next turn to these questions.

## Materials and methods

Human subjects approval was received from the University of São Paulo-Ribeirão Preto (Approval No. 3.008.0012) and from The University of Alabama (Approval No. 17-OR-082-R1).

### Sampling

As noted above, research focused on individuals under treatment at the CAPS-AD (psychosocial treatment center for alcohol and drugs) in the community and in two of the CTs (therapeutic communities). Convenience sampling methods were utilized and all interviews were conducted in 2019. In the CAPS-AD, the lead author and a research assistant spent virtually every weekday in the clinic for close to nine months. All new patients were invited to participate in the research and made up about half of the sample from that clinic. Continuing patients made up the other half, who were interviewed when they attended the clinic for activities. Data were gathered in a semi-structured interview that lasted 60 to 90 min. Given that access to the CTs was much more limited, specific days (usually a Saturday) were designated for interviewing. This continued until all persons under treatment who agreed to participate in the research were interviewed. This resulted in a sample of 133 individuals.

Descriptively, the sample was predominately male (85%), although the CT samples skewed this due to the fact that they were male-only facilities. The sample was made up of adults ($m = 38.14$, s.d. = 11.85, range = 18–71), 62.4% of whom were single, 65.4% had children, and slightly over one-third (33.9%) had graduated from secondary school. Sixty-nine percent ($n = 91$) of the sample were drawn from CAPS-AD, while 31% ($n = 41$) were drawn from the CTs.

### Variable measurement

Interviews focused on the patient's personal experience with the initiation and continuation of alcohol/drug use, their perceptions of the importance of the risk factors for substance use identified in the study of young adults in the general population, and structured scales to assess perceived social stigma and internalized self-stigma, the former referring to patient perceptions of stigma directed toward them and the latter referring to stigma directed inward.

With respect to the rating of the influence of risk factors, the young adults in the general public sample were primed to think about how community members broadly understood risk factors associated with addiction. In contrast, persons under treatment were specifically primed to report their *personal beliefs* regarding substance use risk. They rated each potential risk factor on a 4-point scale (1 = no influence; 2 = a little influence; 3 = some influence; 4 = a lot of influence) in terms of how that factor had affected their own personal drug use, or how they had seen that risk factor influence other substance users in their personal social network. These ratings capture individuals' internalized beliefs about risk. When analyzed in terms of similarities and differences between the general population and treatment group samples, these data are used to plot the distribution of respondents in a space defined by cultural models of substance use risk. A cultural distance metric is then calculated using this array (see below).

A 14-item scale of perceived stigma was employed (Link et al., 2004). This scale, which had previously been translated into Portuguese, included items such as "Did any of your friends reject you after they found out about your alcohol or drug use?," which was one of 6 dichotomous items, and "Most people believe that people who use drugs or alcohol cannot be trusted," which was one of 8 items rated on a 4-point rating scale. This scale had acceptable reliability (alpha = 0.74).

Self-stigma was measured with an adaptation of Oliveira et al. (2015) Brazilian translation of the Internalized Stigma of Mental Illness Scale, which was originally designed to measure the experience of self-stigma broadly among persons with mental illness. For our use, "alcohol or drug use" was substituted for the term "mental illness." Sample items include: "I am embarrassed or ashamed that I use alcohol or drugs;" "I feel inferior to other people because I use drugs or alcohol;" and, "Negative ideas or stereotypes about people who use drugs or alcohol apply to me." This scale also had acceptable reliability in this sample (alpha = 0.89).

## Analysis and results

Both Q-mode and R-mode analyses were employed with these data. First, a Q-mode (case-by-item) analysis was performed to measure and visualize the distance of individuals in the treatment group (henceforth TG) from the general population sample (henceforth GPS). Data were pooled for the two studies, with individuals as columns and the 29 ratings of the influence of risk factors on substance use as the rows. Then, following Garro (1986) and Chavez et al. (1995) nonmetric multidimensional scaling (MDS) was employed to scale a full symmetric matrix of profile dissimilarities. A two-dimensional solution (stress = 0.24) for this analysis is acceptable (see Sturrock and Rocha, 2000) and provides a visual representation of the distribution of cases (see Figure 1).

The members of the GPS are clustered toward the center of the graph, indicating both their relatively strong agreement on how the risk factors are configured and that all of the risk factors are influential with respect to substance use. The members of the TG, on the other hand, are widely distributed relative to the members of the GPS; some members of the TG are proximate to the GPS, while others are quite distant. This demonstrated that there were not two distinct cultural models for the two sample types as there was no indication that patients were moving toward the development of their own subcultural model. Rather, the young adults form a clear "cultural core" of the model, and the patients vary from this model in alternative ways. While there are differences in the way that members of the general public understand substance misuse risk, there are far more differences in terms of the ways that the patients come to internalize and believe in the influence of particular risk factors. In other words, the patients are not starting from scratch, but rather are

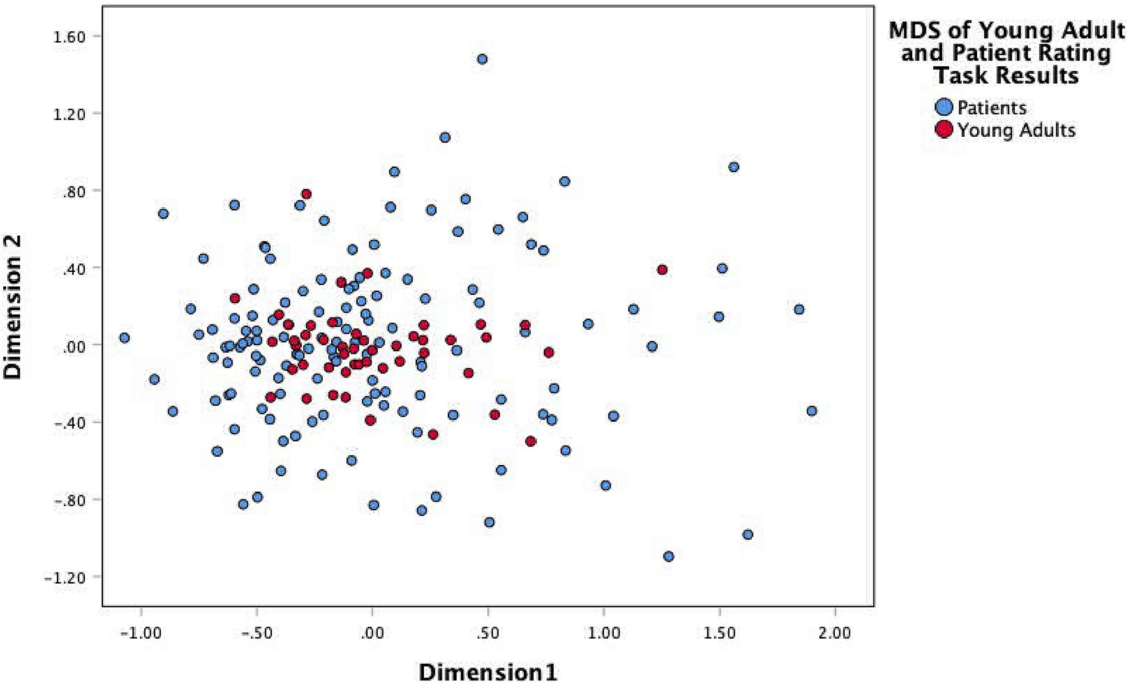


FIGURE 1
Nonmetric multidimensional scaling of distance of members of the treatment group (blue markers) from the general population sample (red markers).

beginning from the shared cultural model and using their personal experience to guide their shifts away from or toward the center of the cultural model.

At this point, the implications of the cultural distance of individuals in the TG from the GPS were explored to identify the extent to which the individual patient's internalized beliefs differed from the "cultural core." First, the distances of TG members from the GPS were calculated by subtracting the GPS centroid (or geometric center) from each individual TG member's multidimensional scaling coordinates, then squaring and summing that difference. This provided a squared Euclidean distance metric for each TG member from the GPS as a whole, or:

$$\text{Cultural distance} = \left(TG_{\text{dim.1}coord.} - GPS_{\text{dim,1}centroid}\right)^2 + \left(TG_{\text{dim.2}coord.} - GPS_{\text{dim.2}centroid}\right)^2.$$

Next, we turned to an R-mode (item-by-case) analysis of the TG ratings of risk factor influence. Like the GPS, the TG tended to rate most of the items as influential. Using exploratory factor analysis (varimax rotated principal components analysis), a 2-factor solution was obtained for the ratings. The 2-factor solution was selected primarily on the basis of a scree plot. Given the skewed values of the ratings, the correlations among the ratings of the risk factors were attenuated, resulting in a number of eigenvalues hovering around 1.0; however, the "elbow" in the scree plot clearly indicated a 2-factor solution, shown in Table 1. While the amount of variance explained by the two factors was modest (28%, again a result of the skewed ratings), the solution clearly indicates two distinct sets of risk factors as important from the perspective of the TG. The first factor combines risk factors that were distributed across all four of the risk factor clusters employed by the GPS. The dominant risk factors on Factor I include having a weak head, to rebel, easy access, influence of friends, emotional problems, going to parties and clubs, and desire for acceptance, as well as many others. Factor II includes only the items related to the basic sensations engendered by substance use. Keeping in mind that respondents in the TG rated items on the basis of their own experience and beliefs, we refer to Factor I as "Internalized Psychosocial Model of Risk" (IPSMR), and Factor II as "Internalized Experiential Model of Risk" (IEMR). The raw scores for each set of variables were summed to provide measures of each factor (and each has acceptable reliability, alpha = 0.84 and alpha = 0.68 respectively).

The cultural distance measures were highly skewed to the right, so a log transform was applied; descriptive statistics for all variables are shown in Table 2.

Correlations of cultural distance with IPSMR, IEMR, perceived stigma, and internalized stigma were examined. Linear correlations of cultural distance with IPSMR ($r = -0.38$, $p < 0.001$) and IEMR ($r = 0.23$, $p < 0.01$) were small to moderate and inverse, while these correlations with both measures of stigma were close to zero; however, when nonlinear associations were examined, the addition of both quadratic and cubic components to the correlations were statistically significant for all variables, with the exception of perceived stigma ($p \leq 0.03$).

To display these associations more easily, cultural distance was divided into quartiles. Figure 2 shows the association of quartiles of cultural distance with the internalization scales and each of the stigma outcome variables; Table 3 shows means (± s.d.) for each scale by quartile of cultural distance, along with the analysis of variance for each scale. The associations of cultural distance quartile with IPSMR

TABLE 1 Factor analysis of perceived influence of risk factors in the treatment group.

| Risk factor | Factor 1 | Factor 2 |
|---|---|---|
| Weak head | **0.626** | 0.055 |
| To rebel | **0.578** | 0.079 |
| Easy access | **0.565** | 0.017 |
| Influence of friends | **0.538** | 0.060 |
| Emotional problems | **0.533** | 0.336 |
| Going to parties/clubs | **0.525** | 0.025 |
| Desire for acceptance | **0.511** | 0.123 |
| Depression | **0.499** | 0.218 |
| Financial problems | **0.491** | 0.277 |
| Family history of addiction | **0.487** | 0.076 |
| Curiosity | **0.482** | 0.113 |
| Lonely or isolated | **0.482** | 0.370 |
| Stress | **0.480** | 0.302 |
| Addictive properties of alcohol/drugs | **0.459** | 0.000 |
| Lack of family structure/dialog | **0.450** | 0.072 |
| Predisposition to addiction | **0.431** | 0.177 |
| Believe that have control over use | **0.406** | 0.326 |
| Friends that use alcohol/drugs | 0.353 | −0.019 |
| Family problems | 0.372 | 0.110 |
| Environment | 0.350 | 0.123 |
| A lot of money | 0.133 | 0.201 |
| Search for relief | 0.286 | 0.270 |
| Lack of god | 0.250 | 0.272 |
| Lack of knowledge | 0.224 | 0.365 |
| To escape reality | 0.265 | **0.555** |
| To feel better | 0.118 | **0.575** |
| To relax | −0.215 | **0.657** |
| Search for pleasure | −0.127 | **0.690** |
| Good sensation | 0.024 | **0.708** |

Factor loadings > 0.40 are in bold.

TABLE 2 Descriptive statistics for variables included in the analysis.

| Variable | Total sample ($n = 133$) |
|---|---|
| IPSMR* | 51.1 (± 9.8) |
| IEMR** | 15.8 (± 3.6) |
| Self-stigma | 40.9 (± 10.1) |
| Perceived stigma | 19.1 (± 4.1) |
| Cultural distance | −0.55 (± 0.59) |

*Internalized psychosocial model of risk.
**Internalized experiential model of risk.

(eta = 0.583, $p = 0.001$) and IEMR (eta = 0.4045, $p = 0.001$) describe how the cultural model of substance misuse risk is reconfigured by distance from the GPS cultural model. While the members of the TG more proximate to the GPS have similar and high ratings of potential risk factors, the distal quartile reports significantly lower ratings of potential risk factors; furthermore, for both IPSMR and IEMR, the variance in the culturally distal quartile is higher than it is in any other group ($p = 0.001$).

Turning to the outcome variables, internalized stigma (eta = 0.262, $p = 0.013$) differs across the quartiles and deviates from linearity; the association of cultural distance quartile and perceived stigma is essentially zero (eta = 0.114, $p = 0.461$).

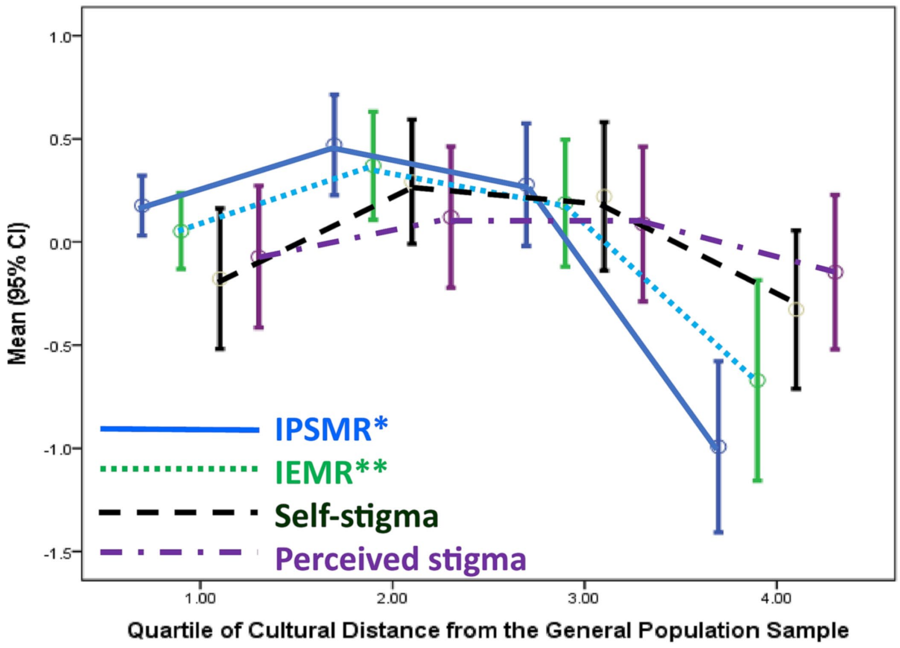
Post-hoc tests for IPSMR, IEMR, and internalized stigma indicate that the culturally distal quartile is significantly lower on those measures than the other three groups ($p = 0.001$).

## Discussion

In this study we examined how a group under treatment for substance use disorder in urban Brazil resembled a general population sample in their ratings of the influence of risk factors for substance use. Two forms of analysis were used. First, using a Q-mode, or case-by-variable analysis, we examined the profile similarity of each member of the treatment group to the general population sample in terms of the influence ratings. In this form of analysis, individual differences in the magnitude of the ratings of influence are ignored in favor of concentrating on patterns of similarity and difference. This analysis indicated substantial variation in the pattern of ratings among the members of the treatment group, relative to the general population sample. When visualized using nonmetric multidimensional scaling, this indicated that, while the general population sample was clustered together in their agreement on the potential influence of risk factors, the treatment group was widely scattered in terms of the profile similarity of their ratings to the general population sample. It is worth keeping in mind here that, in the general population sample, essentially all of the risk factors were considered to be at least a potential influence on the development of substance use disorder. The results of the Q-mode analysis show that there are distinct differences in this pattern among some of the members of the treatment group. From this analysis we derived our cultural distance metric, calculated as the distance of individual members of the treatment group from the center of the general population group configuration.

Second, using an R-mode, or variable-by-case analysis, we examined the differences in magnitude [or what Cronbach and Gleser (1953) originally described as "elevation" of scores] of ratings of the influence of risk factors relative to the distance of the members of the treatment group from the general population sample. This was done in terms of the two factors representing how the variables clustered for the treatment group, one factor composed of psychosocial risk factors, the other composed of the hedonic experience of drugs. In terms of both these factors, the further a member of the treatment group was from the general population sample, the lower they rated risk factors as influential in terms of substance misuse. This was especially true of the treatment group members most distal from the general population sample. Furthermore, within this distal group, the variability in ratings was significantly higher.

In our results we presented this in terms of mean values of the two factor scales. It is instructive, however, to look at this in a slightly different way. In a follow-up analysis, we dichotomized the ratings as influential (a rating of 3–4 on the Likert-response scale) versus not influential (ratings of 1–2 on the Likert-response scale), using all 29 items. The mean number of items rated as influential by quartile of



*Internalized Psychosocial Model of Risk
**Internalized Experiential Model of Risk

FIGURE 2
Association of internalized psychosocial model of risk, internalized experiential model of risk, self-stigma and perceived stigma with distance from the cultural model of substance misuse risk for members of the treatment group.

TABLE 3 **Means (± s.d.) of internalized psychosocial model of risk, internalized experiential model of risk, self-stigma, and perceived stigma by quartiles of cultural distance from the general population cultural model of substance misuse, with analysis of variance.**

| Quartile of distance from the general population cultural model | Internalized psychosocial model of risk | Internalized experiential model of risk | Self-stigma | Perceived stigma |
|---|---|---|---|---|
| 1 | 52.8 (± 4.0) | 15.9 (± 1.9) | 39.1 (± 9.7) | 18.8 (± 3.9) |
| 2 | 55.0 (± 6.6) | 17.0 (± 2.5) | 43.9 (± 2.5) | 19.6 (± 3.8) |
| 3 | 54.2 (± 8.3) | 16.5 (± 2.9) | 43.2 (± 10.1) | 19.5 (± 4.2) |
| 4 | 41.4 (± 11.4) | 13.4 (± 4.7) | 37.6 (± 10.9) | 18.5 (± 4.3) |
| Overall F-ratio (df = 3,129) | 22.1** | 8.4** | 3.1* | 0.6 |
| F-ratio Linear Effect (df = 1,129) | 33.1** | 10.6** | 0.5 | 0.7 |
| F-ratio Nonlinear Effect (df = 2,129) | 16.5** | 7.3** | 4.4* | 0.4 |

*$p < 0.05$, **$p < 0.001$.

distance from the general population sample was as follows: 22.2, 23.2, 20.6, and 14.5 ($p < 0.001$). As members of the treatment group diverge from the general population sample in the pattern of their ratings of influence, the actual number of items that they rate as influential drops from about 22 of 29 to about 14 of 29. In other words, the distal members of the treatment groups are making more distinctions among the potential risk factors, rather than viewing them as generally potent influences on the risk of substance misuse (It is worth noting, too, that members of the distal quartile of the treatment group who approach two standard deviations below the mean rating for that group are actually rating only 3–4 potential risk factors as influential).

The importance of distance from the general population sample in terms of beliefs about the influence of risk factors is further highlighted by the relationship with self-stigma. The members of the treatment group most distant from the general population cultural model are significantly less likely to stigmatize themselves and other substance users for their substance use, even though they are equally likely to perceive stigma against substance users as prevalent in the society around them.

As we noted earlier, unlike much research on cultural models that examines positively valued life goals or basic features of everyday life, we are examining here a cultural model of culturally constructed deviance. Substance use can be positively valued by some for its recreational, therapeutic, or spiritual value; substance misuse, however, is considered deviant. Chentsova-Dutton and Ryder (2020) suggested that cultural models theory could be profitably applied to the study of culturally constructed deviance. In their framework, they see this culturally constructed deviance as a kind of reflection of normalized cultural models, and for each kind of model the behavior that is culturally scripted can be valued, "unmarked" (by which they mean neither valued nor disvalued), or disvalued. They present this model as a 2 × 3 contingency table with normalized versus deviant models on the rows, and valued, unmarked, and disvalued presentations of those models in the columns. For example, with respect to drugs, psychoactive drugs can be valorized or simply normalized (i.e., unmarked) with respect to their use in orthodox medical practice to achieve the alleviation of common symptoms of anxiety or depression; on the other hand, even individuals who are under formal treatment for mental health disorders can be thought of as overly dependent on psychoactive drugs (i.e., the practice is disvalued).

With respect to the culturally scripted practices associated with substance misuse, while we did not examine this directly, the Chentsova-Dutton and Ryder (2020) model suggests that even deviant behavior can be valorized. In Brazil, heavy drinking and cocaine use are often associated with highly successful, wealthy, and powerful individuals, both because they can afford such expensive psychoactive recreation, and because as persons of higher social status they can avoid penalties in the criminal justice system for their behavior. Hence, while considered deviant, such individuals are ruefully granted social status.

More directly relevant to our results are Chentsova-Dutton's and Ryder's categories of unmarked and disvalued cultural scripts for substance misuse. What we found among the general population sample to be a prototype of the "feckless partier" is considered to be fairly common among college-age young adults, given that substance use is widely practiced at social events. While some people regard this as problematic, many simply shrug their shoulders and say that is just the way it is. This could represent the unmarked category in the Chentsova-Dutton/Ryder model. As we found, too, this prototype of substance use is not stigmatized in Brazil (Henderson and Dressler, 2020).

The cultural script for deviant and disvalued practices, then, is the "self-medicator:" the individual who seeks relief through substance use from the mental distress associated with social and family problems. And for the general population sample, this is the prototype of the substance user that is stigmatized (Henderson and Dressler, 2020).

The treatment group, however, seems less sanguine about the distinction between the partier and self-medicator in that in their configuration of risk factors both sets are combined as a single factor. What is more important with respect to alleviating their self-stigma is refining, and, we think, personalizing the inventory of risk factors. As this segment of the treatment group distances themselves from the cultural model of substance use in the general population, and as they narrow down the number of risk factors they regard as truly influential, they in turn suffer less self-stigma.

These results are consistent with Strauss's conceptualization of the "subjectivities" of cultural models, and they complement, using a mixed-methods approach, her argument (Strauss, 2018a). While those members of the treatment group most proximate to the general population sample appear to simply take that cultural model as given (although they do aggregate risk factors in a way the general population does not), treatment group members who are distal from the general population appear to be reconfiguring the potential risk factors in novel ways, given their own experiences with substance use and, no doubt, other contextual factors. It is worth emphasizing here that the general population and the treatment group are operating with a common information pool of what constitutes risk factors. How they differ is in how they configure those risk factors, with the general population neatly compartmentalizing the factors into four groups (we think influenced strongly by their secondary school drug education), while the treatment group integrates the risk factors in novel ways (we think based on experience).

The results are consistent, too, with Spiro's (1997) theory of internalization. The students and other young adults in the general population sample certainly know about substance misuse risk factors. The members of the treatment group, especially those who are distal from the general population sample, are using their combined cultural and personal models to understand the world and their lives in a particular way, which in turn is associated with their subjective well-being, in the sense of self-stigmatizing, or not.

We do not, however, have data on the process by which personal cultural models or "models in use" are constructed, although we suspect that Archer's (2010) arguments regarding the importance of reflexivity are relevant here [see Caetano (2015) for a useful summary]. While reflexivity with respect to cultural models, meaning raising such models to full consciousness, has long been considered to be important for understanding culture and the individual, Archer has suggested that reflexivity can be considered a kind of individual difference variable, with individual variation in how persons achieve such a reflexive understanding of cultural models. For Archer, internal dialogue is an essential part of the process. This would suggest that individuals under treatment for substance misuse who are more distal from the general population may engage in an internal dialogue regarding substance misuse risk in which they are able ultimately to raise the general population model to consciousness and compare it to their own experience. Furthermore, Archer (2010) labels one mode of this internal dialogue as "communicative reflexivity," suggesting that individuals who practice it seek confirmation of their thinking from others.

This is certainly consistent with activities in the CAPS-AD and therapeutic communities where treatment took place. Individual therapy was available, but group therapeutic groups were particularly important. The discussions in these groups could certainly be the locus of communicative reflexivity where individuals could share their experiences and receive confirmation of interpretations that both personalized those experiences and leavened the social stigma felt by the participants. This in turn would reinforce the perception of stigma in the larger society, while helping reduce the felt self-stigma. We are reminded of one of our respondents in the treatment group who, when asked to rate the influence of the risk factors, commented: "These are the sorts of things that people who do not abuse drugs think causes it."

We collected some data on the treatment process and examined these in relation to cultural distance, perceived stigma, and self-stigma. The variables included: time in treatment, participation in treatment groups, participation in other activities, and individual treatment sessions with a psychologist. There was a weak tendency for persons participating in treatment groups and having individual sessions with the psychologist to have smaller cultural distance scores (i.e., to be closer to the general population model) and to report greater perceived stigma ($p < 0.10$). We suspect these are a function of being relatively new patients. A problem with these data is that they are simply self-reports of participation or not, with no indication of the actual degree of participation nor the quality of the interactions, and the self-reports of time spent in treatment are somewhat unreliable. Examination of the importance of reflexivity in this process would require carefully coded data regarding interaction and discourse in these treatment activities, and this should be examined more closely in future research.

These results are a further example of the utility of what Dressler et al. (2023) call a "spatial representation of culture." In this conceptualization, we as individuals are seen as inhabiting a cultural space, defined by the parameters of the cultural model for any specific domain. In an analysis of culturally constructed adult developmental life goals, Dressler et al. found that individuals who were distant from the prototype of one achieving those life goals reported higher psychological distress, due to their perceived (by self and others) difficulty in navigating that social space.

The results presented here examine the other side of achieving normalcy, in Chentsova-Dutton and Ryder's (2020) sense. The prototypes for substance misuse are the partier and the self-medicator, with the latter stigmatized in the general population cultural model. The more that the substance user under treatment can distance themselves from this prototype, the less they engage in self-stigma. In this case, being culturally marginalized appears to ameliorate the distress they experience. Conceptualizing this in spatial terms is thus useful.

It is worth noting, too, that this analysis and the measurement of cultural distance are based on an emic approach; that is, the terms that make up the cultural model of risk factors for substance misuse were elicited from members of the community and knowledge of these risk factors was shown to be shared both in the general population sample and the treatment group. The measure of cultural distance between members of the treatment group and the general population sample can thus be said to have high "emic validity" (Dressler and Oths, 2014) in that it locates individuals along a continuum defined in the terms that they themselves use to talk about substance use. This emic validity thus lends credence to the findings.

There are of course limitations to this study. First, the sample from which the data were collected is a convenience sample and individuals self-selected into the study. Testing hypotheses derived from our study with a sample of persons under treatment for substance misuse that better reflects the larger population of persons under treatment would be useful. Second, it is also noteworthy that model construction among the general public occurred in mid-2017, while interviews and data collection with patients occurred throughout 2019. Although the authors do not have reason to believe that understandings of substance use/misuse shifted significantly during this time, they may have. Third, as noted above, the measure of cultural distance of persons from the cultural model of risk as defined by the general population has high emic validity, based as it is on a careful cultural domain analysis carried out in this particular community. This raises the question, however, of how widely this cultural model might be distributed. Brazil is a heterogeneous society with distinct regional differences in history and society that might influence how cultural models of substance use/misuse are configured. Future research on this question would also be useful.

This line of inquiry can be extended in future research to understand better how persons who are considered marginal and are stigmatized use cultural models that are imposed upon them to reconstruct personal models supporting, we hope, their well-being.

## Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

## Ethics statement

This study was carried out with the recommendations of the Institutional Review Board for the Protection of Human Subjects of The University of Alabama and the Ethics Committee of the Faculty of Nursing of the University of São Paulo-Ribeirão Preto. All subjects gave written consent in accordance with the Declaration of Helsinki. The studies involving humans were approved by Institutional Review Board for the Protection of Human Subjects, The University of Alabama, Tuscaloosa, Alabama, USA Committee for Ethics in Research, Faculty of Nursing, University of São Paulo-Ribeirao Preto, Brazil. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

## Author contributions

NH: Conceptualization, Formal analysis, Methodology, Writing – original draft, Writing – review & editing, Data curation, Funding acquisition, Investigation. WD: Writing – review & editing, Conceptualization, Formal analysis, Methodology, Writing – original draft. NP: Writing – review & editing, Project administration, Supervision. AF: Investigation, Writing – review & editing. SP: Investigation, Project administration, Supervision, Writing – review & editing.

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## Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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# Development of a method and an assessment construct for person-centered translation of dementia public stigma scales

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**Background:** With the number of people with dementia dramatically increasing over time and dementia becoming a major health concern worldwide, scales have been developed to assess the stigma socially attached to this neurodegenerative disorder. There are, however, almost no available methods and assessment constructs for person-centered translation of dementia public stigma scales.

**Objective:** To develop such a method and such an assessment construct by translating the Dementia Public Stigma Scale (DPSS) into standard written Chinese.

**Methods:** We translated the DPSS following three major steps: (1) literal translation and mistranslation identification; (2) panel discussions of items with problematic translations; and (3) the final checking of the translated scale. Informed by the translation and adaptation process, we then developed a method for person-centered translation of dementia public stigma scales. Based on this method and our panel discussions, we finally proposed a tripartite assessment construct for quality evaluation of the translation of dementia public stigma scales.

**Results:** Forward and backward translation did not work sufficiently in dementia public stigma scale translation. Mistranslations were induced by three major causes, including confusion caused by multiple Chinese meanings of the immediate Chinese direct translation, the lack of immediate Chinese direct translation because of varying positive/negative emotions attached to multiple translations, and the lack of culture-specific idioms in Chinese. Based on these factors, we proposed a tripartite dementia translation assessment construct. Following this assessment tool, we determined the best Chinese version that could further be tested for its psychometric properties among the public.

**Conclusion:** A method and an assessment construct for person-centered translation of dementia public stigma scales were developed. Such a method and such an assessment construct could be followed in the translation of dementia public stigma scales and the translation evaluation of such scales.

KEYWORDS

**development, method, assessment, construct, person-centered, translation, dementia, stigma**

# Introduction

## Prevalence of dementia and dementia-related stigma

With the number of people with dementia dramatically increasing over time (1), dementia is regarded as a major health concern worldwide (2). About 50 million individuals are currently diagnosed with dementia globally and without a medical breakthrough, this is projected to rise to 131.5 million by 2050 (3). Of this amount, an apparently increasing proportion will be identified in Latin America, Africa, India, China, South Asia, and the Western Pacific region (4), due to some reasons, including health and care systems often providing limited or no support to people with dementia or their families in these low-and middle-income countries and regions, much higher increasing proportions of older people in low-and middle-income countries compared with that in higher-income countries, etc. (3). The number of people living with dementia in China has been estimated to be 9.5 million in the population aged 60 years or older (1). Despite the high prevalence and growing trend of dementia in China, this neurodegenerative disorder is conceptually stigmatized in contemporary Chinese society (5). In the Chinese context of cultural, social, and political undesirabilities characterizing such a disorder, it is increasingly stigmatized in China (5). The increased public awareness that the mind constitutes a key concern in maintaining a high quality of life in contemporary China reinforces the persistence of dementia-related stigma in the public, which manifests itself in the form of silencing, indifference, or ignorance in memory clinics or other public settings (5). In this background of research, it is imperative to provide a scale assessing dementia public stigma in China to deliver targeted education and interventions and launch dementia stigma reduction initiatives.

Growing evidence has shown that dementia is regarded as one of the most feared health conditions (6). Some people with dementia experience social stigmas (7) caused by fear and the lack of public awareness and understanding of dementia (8). These stigmas include dementia-related stereotypes, negative prejudices and emotional reactions, and discriminatory behaviors (9). Dementia-related stigmas bring about a potential barrier to care and support (10, 11) that can manifest itself in such behaviors as excluding individuals with dementia in healthcare decisions (12) or shunning family members of individuals living with dementia (13). However, there is limited research focusing on dementia stigma and few evidence-based interventions specifically targeting dementia stigma (14), although reducing dementia stigma can contribute to better care access, greater support engagement, and ultimately higher life quality for individuals with dementia and their families (7).

## Stigma as a social construct

Stigma is a perspective "generated in social contexts" (15), where a socially salient group difference is identified, devalued, and used as a source of discrimination against individuals or groups (16). Stigma consists mainly of public stigma, affiliated stigma, and self-stigma (16). Both public and self-stigma include three components: stereotypes, prejudice, and discrimination. Public stigma consists of negative beliefs about a group, agreement with belief and/or negative emotional reaction, and behavioral response to prejudice (16). Public stigmatizing views are not limited to uninformed members of the general public, and even well-trained professionals from most mental health disciplines subscribe to stereotypes about mental illness (16). Self-stigma comprises negative beliefs about the self, agreement with beliefs and negative emotional reactions, and behavioral responses to prejudice (16). Affiliated stigma has been shown to limit the social support and social opportunities available to family members who come to share some of the shame, blame, and loss associated with their family members' stigma(s) (17). As observed by Jones and Corrigan, public stigma underpins affiliated stigma and self-stigma (18). Based on this observation, we believe that it is imperative to study public stigma before examining affiliated and self-stigmas.

Stigma has been widely viewed as a social construct in the literature. Goffman regards stigma as "spoiled identity," a gap between "virtual social identity" (how a person is characterized by society) and "actual social identity" (the attributes possessed by a person) (15). As such, the stigmatizing process is relational: the social environment defines what is deviant and provides the context where devaluing evaluations are expressed (19). According to the Modified Labeling Theory, stigma is a social construct in which powerful groups in society impose negative stereotypical labels on those who are deemed undesirable and subsequently devalued and subjected to discrimination (20). Crocker et al. (21) also define stigma socially. They claim that stigma occurs when a person is believed to possess an "often objective" characteristic conveying a particular devalued social identity in a specific social context (21). Such an identity is socially constructed by defining who belongs to a specific social group and whether an attribute will lead to a given devalued social identity in a particular social context (22). Like Goffman (15), Crocker et al. (21) define stigmas as an essentially "devaluing social identity" that occurs within a particular social context that defines a feature as devaluing. Since stigma is socially constructed and dependent on relationship and context (23), the sociocultural environment where stigma occurs (20) and the myriad societal forces that shape exclusion from social life (24) need to be considered in stigma-related studies. Considering the sophistication of stigma as a complex social construct, we think it advisable to explore public stigma before investigating affiliated and self-stigma when it comes to dementia.

## Developing socioculturally-relevant dementia public stigma scales

### The relevance of the worldwide study and translation of dementia public stigma

Despite the high prevalence of 131.5 million individuals living with dementia worldwide by 2050 (2), negative attitudes toward and discrimination against people with dementia are quite common (25, 26). Dementia-related stigmas bring about wide-ranging consequences, such as low self-esteem, poor psychological well-being, social isolation, and poor quality of life (9). It is, therefore, imperative to develop psychometrically sound scales to measure dementia knowledge and dementia-related stigma. The Dementia Knowledge Assessment Scale has been developed to support dementia knowledge evaluation in diverse populations and inform educational intervention development, and it has been proven valid and reliable for assessing knowledge deficiencies and change in those caring for and treating people with dementia (27). Such instruments are essential for providing knowledge about how to develop interventions for dementia-related stigma reduction in the community (9).

Some dementia stigma scales have been developed to assess such stigma. Stigma Questionnaire (28), STIG-MA (29), and Dementia Stigma Questionnaire (30) were adapted from multiple sources. However, these instruments have been rarely adopted till now (9). The validated Family Stigma in Alzheimer's disease Scale reflects caregiver stigma, lay public stigma, and structural stigma (31). It was designed to assess family members' perceptions of the stigma held by the public rather than lay public attitudes toward people living with Alzheimer's disease (9). The validated Dementia Attitudes Scale (32) assesses people's positive attitudes to people with dementia rather than common stereotypes or negative attitudes toward dementia and people with dementia (9). It is also not designed to measure structural discrimination or perceived personhood (e.g., enjoying life and interaction) that might be regarded as an essential aspect of dementia stigma underlying and impacting individual stigmatizing attitudes and behaviors (33). Originally developed and validated as a tool assessing perceived stigma against HIV/AIDS and cancer (34), the Stigma Impact Scale was revised to measure stigma perceived by persons with dementia and their caregivers (35). Although it has been proven effective among its target respondents, it was not designed to assess dementia public stigma. The Perceived Psychiatric Stigma Scale (36) was suitable and effective for measuring perceived public stigma in Chinese social and cultural settings, but it is designed to measure stigma attached to mental illnesses rather than to the neurodegenerative disorder of dementia. To better capture dementia public stigma, stereotypes of people with dementia, such as being dangerous (37), being a burden to family and the health care system, being incapable of speaking for themselves, being unreliable, and being unable to contribute to the society (38), need to be covered in dementia public stigma scales.

## Established methods for health survey language translation

There are many approaches to health survey language translation methodology (39), including forward translation, back-translation, team-based translation, pretest of the translated scales, etc. Among these approaches, back translation is regarded as the most common persisting methodology used to translate mental health materials (40). Back-translation prioritizes equivalence between the source and target texts (41). However, this approach cannot truly ensure equivalence. A translation may be assumed equivalent when the back-translated text is not equivalent to the source text because of problematic translation that may not be identified during the translation process (41), especially when many mental health-related terms are particularly challenging or even impossible to translate directly (40).

Another widely adopted approach is the TRAPD (translation, review, adjudication, pretesting, and documentation) model (42, 43). Although there is no consensus on research standards to evaluate the quality of a translation, the TRAPD is considered the gold standard for questionnaire translation and adaptation. This model advocates a team-based approach through which a team of researchers (translators) with diverse expertise jointly produce an optimal version of the tool, as translation skills alone are not sufficient in a survey context (44). The TRAPD focuses on cultural equivalence rather than on word-or entity-level literal equivalence (45). Due to its general design purpose, this translation approach is not perfectly applicable to the translation of dementia public stigma scales because it is not sufficiently person-centered. Drawing on the team-based approach proposed by the TRAPD, we took a little step forward by fully considering the personhood of people with dementia in our team-based translation process in this study.

## Developing a method and an assessment construct for the translation of dementia public stigma scales by translating the DPSS into Chinese

Herrmann et al. (7) reviewed worldwide evidence on dementia stigma over the past decade, focusing on how stigmatizing attitudes may present themselves in various ethnic subgroups, stigma assessment instruments, and prospective or experimental approaches to stigma assessment and management. As they discovered, only one cross-sectional study was conducted by Cheng et al. in China (7). Cheng et al. (28) found lower levels of stigma in participants with relatives or friends living with dementia and in younger and more educated individuals using 11 English assessment items derived from other stigma scales (34, 46–48). The assessment tool of Cheng et al. developed through synthesizing diverse currently available evaluation instruments may, to some extent, be neither sufficiently systematic in assessment nor adequately relevant to the target sociocultural context. A scale appropriate to the Chinese language and culture is needed to assess dementia public stigma among Chinese populations. Currently, there is no available dementia public stigma scale developed in the Chinese language to adopt targeted approaches to countering or eliminating dementia-related stigma, including protest, education, and contact (49). In this context, translating already-developed tools for use is a rapid and practical approach to assessment (50) before delivering more tailored stigma-mitigating interventions or launching more targeted stigma-reducing initiatives.

Given painstaking efforts as well as considerable time and cost investments involved in developing new instruments (50) and the purpose of establishing international comparability across different studies, well-developed, available, and reliable instruments need to be adapted and validated cross-linguistically (51, 52). As such, there is a pressing need to translate quantitative scales into the language of the culture in which these tools are adopted (53). In the development of well-established and scientifically validated instruments available in various languages, scientific standards must be meticulously followed during translation, adaptation, and comprehensive psychometric evaluation. To this end, strategies need to be used in the whole translation and adaptation process to ensure semantic equivalence and cultural appropriateness, including "forward translation, semantics evaluation and consolidation of the translated version, back translation, translation equivalence testing, and further adaptation" (54). Based primarily on the forward-backward translation approach, these strategies are designed to adapt an instrument in "a culturally relevant and comprehensible form" without changing its original meaning and intent (55). Such strategies are informative and helpful for the translation of the original English version of the DPSS into Chinese, but they are probably not sufficient in such a translation mainly for two reasons. The first reason is concerned with the different lexical systems, different language registers, and distinct cultural expression repertoires between the source and target languages and cultures. The second factor relates to cultural differences (56) in both perceived and experienced stigma (10) between Chinese and English cultural settings. To ensure a successful translation of this scale and help develop a dementia public stigma reduction initiative (7) in China, we aimed to develop a person-centered translation method that could produce culturally acceptable dementia public stigma scales by achieving semantic closeness and accuracy and cultural relevance and to develop an assessment construct for evaluating the translation of dementia public stigma scales. In the context that stigmatizing attitudes can be displayed in various ethnic subgroups, stigma assessment instruments, and prospective or experimental approaches to stigma assessment and management worldwide (7), the method and the assessment construct for person-centered translation of dementia public stigma scales we proposed in this study could directly help reduce dementia public stigma that presents itself in stigma assessment scales and stigma assessment and management approaches.

Our development of such a translation method was inspired by Kitwood (57), who attaches great importance to the "personhood" of people with dementia and defines it as "a standing or status that is bestowed upon one human being by others in the context of relationship and social being" (57). However, malignant social psychology undermines the personhood of individuals with dementia (57). As such, Kitwood (57) proposes person-centered care and underpins good dementia care within relationships, interconnectedness, and communication between people, by postulating that nurses need to serve as role models to enable family and the public who contact the person with dementia to replicate person-centered practices. Our proposal and development of a method and an assessment construct for person-centered translation of dementia public stigma scales can somehow contribute to the reduction of malignant social psychology or socially attached stigma toward the person with dementia and to the popularization of person-centered dementia care.

# Design and methods

## Overall design

This study was conducted at Jiaxing University, China, and the University of Sydney, Australia from February 1 to May 8, 2023. First, we translated and adapted the DPSS following three major steps. Informed by the translation and adaptation process, we then developed a method for person-centered translation of dementia public stigma scales. Based on this method and our panel discussions during translation and adaptation, we finally proposed a three-item assessment construct for the quality evaluation of the translation of dementia public stigma scales.

## The dementia public stigma scale

To address the need for assessing dementia-related public stigma, Kim et al. (9) drew on the Attribution Theory to develop and validate the DPSS that comprises the three components of the tripartite model of stigma (cognitive, emotional, and behavioral) (58, 59). Social-psychologically oriented, the Attribution Theory proposes that public stigma comprises three components: stereotypes, prejudice, and discrimination (58). Within the framework of this theory, stereotypes refer to generalized negative beliefs about a specific group, prejudice means the negative emotional reactions to these stereotypes, and discrimination is a negative behavioral reaction caused by prejudice (58). Based on the Attribution Theory (58), the DPSS can facilitate understanding the formative factors underpinning stigma and allow for a more nuanced exploration of dementia stigma and its impacts across or within populations. To our knowledge, the DPSS is the latest and most systematic scale for assessing dementia public stigma.

The DPSS is a five-factor, 16-item construct. The five factors are Fear and Discomfort (Items 1–4), Incapability (Items 5–9), Personhood (Items 10–12), Burden (Items 13–14), and Exclusion (Items 15–16). Responses to the 16 items are measured through a seven-point Likert scale ranging from 1 (strongly disagree) to 7 (strongly agree). The total scores achievable for this tool, therefore, vary from 16 to 112. Six items are reverse-scored (1, 2, 3, 10, 11, and 12). As regard the other items, a higher score indicates a more negative attitude toward dementia. The DPSS displayed moderate to high reliability in all five factors (Cronbach's $\alpha = 0.805$ for Factor 1, 0.738 for Factor 2, 0.743 for Factor 3, 0.796 for Factor 4, and 0.743 for Factor 5). The whole scale also showed high reliability (Cronbach's $\alpha = 0.818$). Item analysis also indicated that removing any of the 16 items would not increase Cronbach's Alpha value. Capturing the cognitive, emotional, and behavioral domains of stigma, Kim et al. (9) have effectively validated the factor structure of the DPSS that underpins dementia pubic stigma among their study participants (9).

As found by Kim et al. (9), the DPSS is a comprehensive, valid, and reliable tool among community-dwelling adults in the Australian sociocultural context, which can not only be used to measure the public stigma of dementia among adults but also be used to develop and evaluate interventions for dementia-related stigma reduction. However, the DPSS may not be completely applicable to other sociocultural contexts, considering that there is no accepted "gold standard" for assessing dementia-related stigma (7) as stigma is a complex social construct shaped by the sociocultural environment (20) and various social forces (24). As such, it is relevant to translate and adapt the DPSS and other systematic scales, if any, to diverse languages and cultures and study dementia public stigma in these linguistic-cultural contexts for intervention purposes. The translated and adapted scales then need to be validated through psychometric evaluation to test their validity and reliability. However, such psychometric evaluation is out of the purview of the current study and will be conducted in future studies.

## Developing the Chinese version of the DPSS

Based on our analysis of the studies reported by Herrmann et al. (7), particularly Cheng et al. (28), the dementia-related expertise of four authors (L-FL, SK, AB-W, and SS) of our study, and our consultations with some mental health professionals working at the Hospital Affiliated with Jiaxing University and Qilu Hospital of Shandong University, we believed that the brief, user-friendly, and quick-to-complete assessment instrument of the DPSS could reveal dementia public stigma in the Chinese sociocultural context if well translated and adapted to the Chinese language and culture.

Drawing on and developing the methodologies adopted in previous studies (53–55, 60–62), we developed the Chinese version of the DPSS following three major steps below.

1. First, three translators (Meng Ji, Yi Shan, and Weiwei Chu) translated the DPSS into Chinese.

2. A panel comprising bilingual health educators, bilingual translators, the scale author, and content experts met to discuss items with problematic translations and corresponding root causes by double-checking the target version against the source version. Discussion of the meaning of the items and possible translations was undertaken until consensus was obtained. An adapted English item was sometimes written in conjunction with the Chinese translation. The consequences of forced literal translation and their implications for translation were also worked out through panel discussion.
3. The final translated scale was sent back to all panel members for checking.

## Developing a method and an assessment construct for person-centered translation of dementia public stigma scales

The development of a method and an assessment construct for person-centered translation of dementia public stigma scales was informed conceptually by the translation and adaptation guidelines reported in relevant studies (53–55, 60–62) and practically by the accumulated health translation experience of three authors of this study (MJ, YS, and WC) and the translation process above. Thus informed, we focused on panel discussions after literal translation, making full use of the potential advantages of the panel members: the language proficiency of native Chinese speakers (MJ, YS, and WC) and native English speakers (L-FL, SK, AB-W, and SS); the health translation experience of bilingual translators (MJ, YS, and WC); and the expertise of the scale author of the DPSS (SK) and content experts (L-FL, AB-W, and SS) who are engaging in studies on mental health with a special focus on dementia. Such penal discussions ensured not only the linguistic appropriateness and comprehensibility as well as cultural relevance and accessibility of the translated scale but also the maintenance of the original meaning and intent of the source scale (54). The method developed was presented schematically in the RESULTS section. Based on this method and our panel discussions, we finally proposed a three-item assessment construct for the quality evaluation of the translations of dementia public stigma scales, which was also provided in the RESULTS section.

Kim (63) proposed a people-centered theory of translation by advocating a focus on "what people need, what people can do, and what people think and feel" in translation. Informed by this proposal and Kitwood's (57) advocacy of person-centered care, we tentatively developed a method of person-centered translation of dementia public stigma scales by mainly considering the dignity and self-esteem of persons with dementia and showing understanding of and sympathy for them from multiple perspectives of the health translators, the DPSS author, and dementia experts who well understand persons with dementia. We were thus concerned with upholding the personhood of people with dementia and catering to linguacultural appropriateness and relevance in the Chinese sociocultural context while maintaining the original meaning and intent of the DPSS when we addressed mistranslations and agreed upon the final Chinese version of the DPSS. We also put forth three items of evaluation from the perspective of persons with dementia when proposing the assessment construct. Overall, such a person-centered orientation was implemented throughout the entire process of our study.

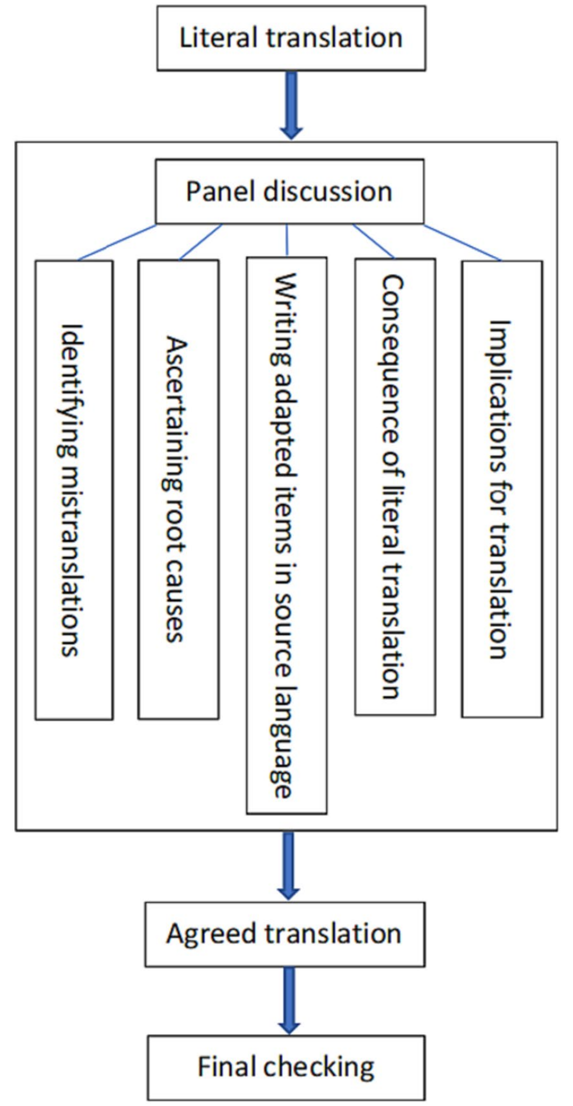

FIGURE 1
Method for person-centered translation of dementia public stigma scales.

## Ethical considerations

This study was approved by the Academic Committee of the College of International Studies, Jiaxing University, China. We conducted this research among all authors of this paper without involving study informants.

## Results

The method for the person-centered translation of dementia public stigma scales we developed could be displayed schematically in Figure 1. We conducted six rounds of translation (see Table 1 in the *Identification of the best translation among* various *translation options* subsection below), each of which followed the processes described in Figure 1, to produce the best-translated version of the DPSS. In the development of such a method, we (1) used inclusive, non-offensive words that were friendly to people with dementia and their families,

TABLE 1 Dementia public stigma scale translation assessment.

| Translation variants | Semantic meaning closeness to the English words (SMC) | Perceived cultural familiarity/ acceptability to target readers (PCF) | Perceived psychological harm to target readers (PPH) |
|---|---|---|---|
| Explanations | How close is the meaning of the translation to the English word? There is no 100% matching translation to an English word, so literal translation is impossible in most cases, but we can strive to get the closest meaning in Chinese as much as possible. | Is this translation the most natural way to convey the meaning? The translation cannot be too formal or too vulgar, which will reduce the cultural trust, affinity, and acceptability of the translation. | Does the translation have strong negative connotations that would stigmatize dementia? |
| 1 | Yes | No | No |
| 2 | No | No | Yes |
| 3 | Yes | No | Yes |
| 4 | No | Yes | Yes |
| 5 | Yes | Yes | No |
| 6 | Yes | Yes | Yes |

(2) centered on the person rather than on the neurodegenerative disorder or the social care system by considering "what people need, what people can do and what people think and feel" (63), and (3) focused on practice and cognition to enhance translatability (63). The following subsections of this section illustrate with examples how we produced the person-centered version of the DPSS to avoid stripping individuals of their dignity and self-esteem, reinforcing inaccurate stereotypes, and heightening the fear and stigma surrounding dementia (64). We will revisit the concept of "person-centered translation" and how to achieve it in detail in the section "Discussion."

Revolving around the schematic diagram in Figure 1, we presented the results of this study in the following subsections.

## Mistranslations arising from the literal translation

We found the literal translation of Items 1, 2, 5, 9, and 16 problematic. Table 2 shows the specific literal translations and meanings of the literal translations of these items. It can be seen that the problems lay in the multiple meanings of the literal translation of "feel confident" in Item 1 and "touching" in Item 2, the possibilities of translating "supervise" in Item 5 and "ignore" in Item 16 into different Chinese phrases that have diverse meanings, and the lack of matching sayings in Chinese for "no longer themselves" in Item 9.

## Root causes of mistranslations, implications for translation, and consequences of forced literal translations

The three factors identified as causes of the aforementioned mistranslations included: (1) The immediate Chinese direct translation can cause confusion because it has multiple Chinese meanings, (2) There is no immediate Chinese direct translation—multiple translations are possible with varying positive/negative emotions attached, and (3) There is the lack of counterpart culture-specific idioms in Chinese. In the final analysis, what underlay these three causes were three root causes, as listed in Table 3. Each of these root causes could provide an essential implication for translation, as shown in Table 3. Regardless of these implications, forced literal translations would incur severe consequences for the readers, as reported in Table 3. It follows that the forward-backward translation method proposed in previous studies (53–55, 60–62) did not work effectively in dementia stigma scale translation.

## An assessment construct for person-centered translation of dementia public stigma scales proposed

Based on the analysis above, we proposed a construct that could facilitate translating the DPSS into Chinese, as shown in Figure 2. This construct consists of three components: semantic meaning closeness (SMC), perceived cultural familiarity (PCF), and perceived psychological harms (PPH). It could be used as a model to guide the assessment of the Chinese translation of dementia stigma scales.

## Identification of the best translation among various translation options

Table 1 illustrates how our research team arrived at an agreed Chinese version of the DPSS before testing it for public use. A translated version was subjected to assessment in light of the three components comprising the construct shown in Figure 2. As can be seen from Table 1, we conducted six rounds of translation before finally agreeing on the best version of translation that satisfied these three components. During the repeated translating processes, we managed to achieve semantic meaning closeness to the English wordings of "feel confident" in Item 1 and "touching" in Item 2 by avoiding such possible literal translations as listed in Table 2 in rounds 1, 3, 5 and 6, as shown in Table 1. Similarly, we avoided using such Chinese phrases with diverse negative meanings listed in Table 2 when translating "supervise" in Item 5 and "ignore" in Item 16. Translating "supervised" and "ignore" into "bèi rén kānguǎnzhe" (watched over) and "Duǒ kāi" (avoid), respectively could ensure accuracy in the meaning that we conveyed through the translation and meanwhile possibly prevent perceived psychological harm to target readers in rounds 2, 3, 4, and 6, as shown in Table 1. As "are no longer themselves" in Item 9 has no corresponding culture-specific idioms in Chinese,

TABLE 2 Mistranslations of items 1, 2, 5, 9, and 16.

| Problematic items | Original English phrasing | Literal translation | Meaning of the literal translation in Chinese culture |
|---|---|---|---|
| Item 1 | Feel confident | Xìnxīn | A feeling of trust (in someone or something) |
| | | | A state of confident hopefulness that events will be favorable |
| | | | Any cognitive content held as true |
| | | | Belief in yourself and your abilities |
| | | | A strong belief in a supernatural power or powers that control human destiny |
| Item 2 | Touching | Jiēchù | Deal with |
| | | | Close interaction |
| | | | Perceive via the tactile sense |
| | | | Come in contact with |
| | | | In physical contact |
| Item 5 | Supervise | guǎnlǐ | The act of managing something—(neutral) |
| | | kānguǎn | Keep tabs on, keep an eye on (slightly negative, informal language: adults to children) |
| | | jiāndū | Watch and direct, oversee (moderately negative, formal language: authorities to individuals) |
| | | jiānshì | Keep under surveillance, monitor (strongly negative) |
| Item 16 | Ignore | hūshì | The trait of neglecting responsibilities and lacking concern |
| | | mòshì | Willful lack of care and attention, disregard |
| | | bù lǐcǎi | Fail to acknowledge, give little or no attention to |
| | | qīngshì | Treat with contemptuous disregard |
| | | lěngyù | A refusal to recognize someone you know |
| | | mièshì | Look down on with disdain |
| | | páichì | Marginalize, relegate to a lower or outer edge, as of specific groups of people |
| Item 9 | No longer themselves | No matching sayings in Chinese | |

TABLE 3 Root causes of mistranslations, implications for translation, and consequences of forced literal translations.

| | Root causes | Implications for translation | Consequences of forced literal translations |
|---|---|---|---|
| 1 | English and Chinese have different lexical systems. | One-to-one linear lexical matching is impossible since two large scenarios have been captured in our study:<br>• One English word was translated into one Chinese word with multiple meanings (See Questions 1 and 2) which could cause potential confusion.<br>• One English was translated to multiple competing words with distinct emotional and cultural connotations (see Questions 5 and 16) that could stigmatize dementia. | Misunderstanding and confusion to readers |
| 2 | Language registers (formality, abstractness) are different for health information in English and Chinese. | Adapting English formal expressions to more natural, informal Chinese words | Lowered cultural believability, trustworthiness, and communicative effectiveness to readers |
| 3 | Cultural expression repertoires in two cultures are distinct. | Using cultural equivalents in the target language to carry over the meaning (See Question 9, "people with dementia are no longer themselves"—changed to "changed into a different person") | Meaningless translation to readers |

we rendered it into a neutral wording of "Hǎoxiàng biànle yīgè rén" (appear to become another person) to achieve perceived cultural familiarity and acceptability to target readers, in rounds 4, 5, and 6, as shown in Table 1. In the six rounds of translation, only round 6 satisfies all three translation variants of SMC, PCF, and PPH. Therefore, the translation produced in round 6 was deemed as the best-translated version, that is, the final Chinese version of the DPSS, as shown in Supplementary Table S1.

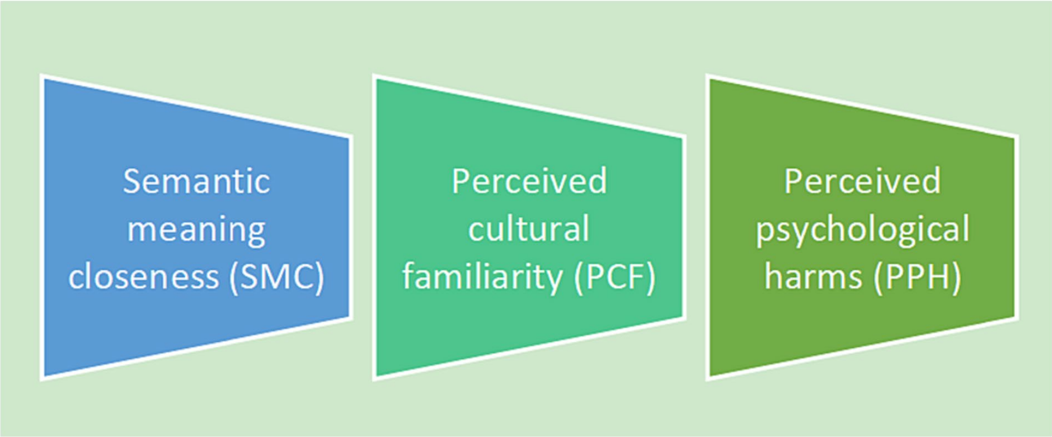

FIGURE 2
Assessment construct for the translation of dementia public stigma scales.

## Discussion

We tentatively developed a method for person-centered translation of dementia public stigma scales in this study. The translator needs to discuss the meaning of the original text with someone with content knowledge to avoid misinterpretations and optimize word choice when there are multiple possible translations. To this end, we proposed an assessment construct for the translation of dementia public stigma scales that incorporates three major components: semantic meaning closeness (SMC), perceived cultural familiarity (PCF), and perceived psychological harms (PPH). Such a construct could help minimize mistranslations involved in the translation of dementia public stigma scales due to the differences in lexical systems, language registers, and cultural expression repertoires between the source and target languages. It can be used as a guide to help health translators navigate the translation of dementia public stigma scales. Translations following the method and the assessment construct we developed could facilitate understanding and measuring dementia public stigma.

We found that the forward and backward translation method did not work effectively in the translation of the DPSS into Chinese, detrimental to the understanding and measurement of dementia public stigma. Chang et al. (50), Zhao et al. (51), Mohamad et al. (52), Maneesriwongul and Dixon (53), Shan et al. (48), Sperber (55), Guillemin et al. (60), Sousa and Rojjanasrirat (61), and Sidani et al. (62), among many others, adopted forward and backward translation to adapt the English versions of some health-related measures into different languages. Although they concluded that this method was effective in their studies, we found it insufficient in our study. English and Chinese have different lexical systems, language registers, and cultural expression repertoires, which challenged the English-to-Chinese translation of the DPSS. These differences made it extremely difficult to forward-translate this scale into Chinese. For example, if "ignore" in Item 16 were forward-translated into "hūshì" (the trait of neglecting responsibilities and lacking concern), "mòshì" (willful lack of care and attention, disregard), "bù lǐcǎi" (fail to acknowledge, give little or no attention to), "qīngshì" (treat with contemptuous disregard), "lěngyù" (a refusal to recognize someone you know), "mièshì" (look down on with disdain), or "páichì" (marginalize, relegated to a lower or outer edge, as of specific groups of people), different degrees of discrimination or negative emotions would be induced, which is not intended in the original English scale. These translations would naturally lead to misleading backward translations, making translation equivalence testing (54, 55) considerably challenging. Translations thus produced could not effectively explore the cognitive, emotional, and behavioral domains of stigma held by the general public, therefore failing to gain a better understanding of dementia public stigma. Besides, the DPSS was written in a dementia-friendly language, in response to the appeal of Alzheimer's Australia (64) in Dementia Friendly Language Position Paper 4, which advocates that "Language is a powerful tool" and "The words we use can strongly influence how others treat or view people with dementia." Considering this appeal, we believed that the forward and backward translation method would possibly distort the original meaning and intent of the DPSS, bringing additional stigma to individuals with dementia. As a result, such translated scales could not objectively solicit and measure public attitudes toward people with dementia. As "a true translation proceeds by the motions of understanding and sympathy" (65, p. 211), a health translator needs to keep "constantly examining the relationship between word and experience, i.e., signifier and signified" (63). To this end in our translation process, we attached great importance not merely to "the relationship between word and experience" to achieve linguistic appropriateness and cultural relevance from the perspective of health translators but also to the understanding of and sympathy for those with dementia from the perspectives of the DPSS author and dementia content experts. It can be said that our translation team played the role of "a powerful agent for cultural change," and our translation functioned as "a bridge-building space between the source and the target" (66). As a result, the dementia pubic stigma scale translation in our study could ensure a translated scale that could effectively measure dementia public stigma and facilitate our understanding of such stigma. It is well-known and widely published that translation and back-translation often present challenges. As Brislin (67) has pointed out, back-translation may lead to three potential pitfalls. Specifically, the back-translated text may support equivalence between the source and target texts although problematic translation may exist, when (1) the forward-and back-translators share a set of rules for translating words or phrases that are not truly equivalent, (2) the back-translator can infer what is meant by a poorly translated target text and reproduce the source text, or (3) the forward-translator retains the grammatical structure of the source text in the target text, therefore making it easy to back-translate while making it incomprehensible or awkward to monolingual target language speakers (67, 68). Therefore, it is crucial to rely on a team-based process, as described in this manuscript.

We proposed a better alternative, a method for person-centered translation of dementia public stigma scales, to reveal and measure such stigma more objectively. This method was effective in facilitating the translation of the DPSS in a culturally relevant and appropriate manner (54). It allowed us to use words friendly to people with dementia and their families, those that are "normal, inclusive, jargon-free, non-elitist, clear, straightforward, non-judgmental" (69), and those that center on the person rather than on the neurodegenerative disorder or the social care system (69). Such wording can avoid stripping individuals of their dignity and self-esteem, reinforcing inaccurate stereotypes, and heightening the fear and stigma surrounding dementia (64). Translated scales using such wording are most likely to assess stereotypes, prejudice, and discrimination among the general population, revealing their generalized negative beliefs, negative emotional reactions to stereotypes, and negative behavioral reactions resulting from prejudice (49). Our protocol can, therefore, be seen as an initiative counteracting the prevalent phenomenon that inappropriate language used in the literature, the media, and the community creates wrong descriptions, prescriptions, misconceptions, and stigma of individuals with dementia (69). A good case in point is such derogatory, stigmatizing, and discriminatory words as "demented," "sufferers," "subjects," and "victims" used by most researchers and presenters at the 2014 Alzheimer's disease International Conference (69). In the context that the language being used remains stigmatizing, negative, and disempowering (70), there is a pressing need to use "inclusive non-offensive language that supports the whole person positively, rather than negative demeaning language that stigmatizes and separates us" (69). In this case, the protocol we proposed in this study can contribute to the promoted use of person-centered, dementia-friendly language, especially in the translation of dementia public stigma scales. Counteracting inaccurate stereotypes and the resulting prejudice and discrimination against dementia, translated scales using such language could help us understand and assess the public attitudes toward dementia more objectively.

Our study also points to the need to construct a person-centered theory of translation (63) of dementia-related materials or in health care and medical domains in general. To this end, health translation studies should be taken away from purely linguistic and cultural analysis. Health translation in specific social and cultural circumstances needs to fulfill its expected social and cultural roles. As such, before engaging in translating health materials and constructing health translation theories, health translators and translation theorists should ask themselves the following question: "In whose terms, to which linguistic constituency, and in the name of what kind of intellectual authority does one translate?" (71). To answer this question, health translators and translation theorists need to adopt a person-centered approach advocated by Robinson (72) and Hoffman (65) to consider "what people need, what people can do and what people think and feel" (63). In the context of the prevalent social stigma attached to dementia, health translators and translation theorists need to spare no efforts to center on people with dementia and their relatives in their translation practices and theory construction to "change views of and about people with dementia," "include them in the research and conversations about them" (63), and "remove the stigma which we hear of every day in dementia" (63). The language being used about individuals with dementia is a powerful tool (73) for inclusion, reducing stigma, and increasing education and awareness as the way forward in reducing stigma (74). Provided that a people-centered theory of translation in health care and medical domains can be established, the disadvantaged position of patients could be improved through dementia-friendly, inclusive, non-offensive language in the translated materials about dementia to some extent. Such a translation theory is "true to life" (63). Such translation theories are urgently needed, especially when considering that "Language creates the particularly human kind of rapport, of being together, that we are in a conversation together" (75).

To establish a person-centered theory of dementia translation, we need to highlight the importance of the translator's role, which has already been stressed by famous translation scholars such as Bassnett (66), Robinson (72), Venuti (76), and Snell-Hornby (77). To be qualified in health and especially dementia translation, translators should be equipped with essential "literacies," which include the ability to understand "what people need, what people can do and what people think and feel" (63), in addition to bilingual and bicultural competences (77). They also need to enhance translatability by focusing on practice and cognition (63) to make dementia translation "a humanizing process" (72).

## Strengths and limitations

To develop a method and an assessment construct for person-centered translation of dementia public stigma scales, we formed a research team comprising bilingual health educators, bilingual translators, the scale author, and content experts. Such a composition could ensure the quality of translation from different perspectives of experts in relevant domains, especially considering the interdisciplinary nature of dementia translation. Another strength lay in the bilingual translators' experience in community-based health translation for many years. Their rich health translation practice could enable them to gain a keen, sensitive sense of cross-cultural and-lingual differences both from the perspective of language and from the perspective of health care. This is beneficial to ascertaining the key steps of the person-centered translation method and the core elements of the translation quality assessment construct we tried to develop. The translation method and the assessment construct we developed may be used as a guide to help navigate the translations of dementia public stigma scales that can be used to develop and evaluate interventions aimed at dementia public stigma reduction in the public.

To our knowledge, they are the first method and the first assessment construct for person-centered translation of dementia public stigma scales that have been developed. Without relevant studies for reference, our translation method and assessment construct may not be perfect. Their reliability and efficacy need to be validated in future studies. Their applicability to other dementia-related materials than dementia public stigma scales needs to be further attested. As stigma is a complex social construct and the DPSS was developed in English-speaking populations in Australia, the Chinese version of the DPSS we developed may not be perfectly specific to the Chinese language and culture although we made great efforts to adapt it linguistically and culturally. In the following stage of research, we would conduct a pretest (pilot study) to obtain initial psychometric results for the Chinese DPSS. During this process, participants would be invited to comment on the wording and comprehensibility of the question items to identify potential issues in the Chinese DPSS. Based on the findings from the pilot study, we would make adjustments to obtain the final Chinese version of the DPSS.

## Conclusion

The translation method and the assessment construct we developed are designed to facilitate the person-centered translation of dementia public stigma scales. They can help health translators navigate dementia translation to destigmatize people with dementia and their relatives while maintaining the original meaning and intent of the source text in a culturally relevant and appropriate manner in the target text. The best Chinese version of the DPSS we translated could be used for further evaluation with the public to test its psychometric properties. The translation method and the assessment construct we developed could be further validated for their reliability and efficacy in dementia public stigma scale translation and dementia translation in general.

## Data availability statement

The original contributions presented in the study are included in the article/Supplementary material, further inquiries can be directed to the corresponding author.

## Author contributions

JL, YS, and MJ: supervision, conceptualization, and methodology. MJ and WC: scale translation. YS and JL: writing—original draft, review, and editing, investigation, and formal analysis. YS and MJ: formal analysis, data curation, visualization, and project administration. JL, L-FL, SK, AB-W, and SS: critical review and commentary. JL: funding acquisition. All authors contributed to the article and approved the submitted version.

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## Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

## Publisher's note

## Supplementary material

The Supplementary material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpubh.2023.1233400/full#supplementary-material

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# Stigma toward substance use disorders: a multinational perspective and call for action

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## 1 Introduction

The stigma surrounding persons living with substance use disorders (SUDs) is a ubiquitous phenomenon that has had detrimental effects on affected individuals, their families, healthcare providers, treatment outcomes, research, policies, and society as a whole (1). Studies suggest that the stigma toward SUDs exceeds that of other mental health conditions (2) and is a common obstacle to help-seeking behavior among individuals with SUDs (3, 4). One systematic review found that healthcare professionals typically hold negative attitudes toward people with SUDs, resulting in patients experiencing reduced empowerment and poorer treatment outcomes (5). As healthcare professionals are often the gatekeepers to treatment, they must be adequately trained and educated about managing SUDs. Medical bodies, educational institutes, and various governmental and non-governmental organizations are recognizing that substance use treatment, policies, and language need to evolve to provide better support for affected individuals (1).

In this opinion piece that brings the wisdom and experience of a multinational group of adult and addiction psychiatrists, we highlight the different sources of stigma faced by individuals with SUDs and how it impacts treatment-seeking and related outcomes. More importantly, we provide recommendations for holistic interventions to address stigma toward addiction and enhance the delivery of optimal care.

## 2 Stigma toward addiction and its impact on treatment

### 2.1 Where does stigma originate from?

Stigma toward SUDs comes from many sources including society, individuals living with SUDs themselves, their families, and healthcare professionals (6). Many factors can play a role in perpetuating this stigma, especially the longstanding societal view of addiction as a personal or moral failure (6, 7). In different societies and cultures, it is not uncommon for the community to label individuals with SUDs as worthless, weak, dangerous, criminals, incapable of holding jobs or forming families, and having deliberately chosen addiction. Some specific stereotypes faced by individuals with SUDs can be related to disadvantaged and vulnerable populations, such as those living in poverty or homelessness, minorities, and those who allow "peer pressure" to influence their drug use (8). In Nepal, individuals with a history of SUD continue to be perceived as lacking moral values, despite undergoing treatment, which can lead to relapse (9). One systematic thematic analysis of Indian newspaper articles explored online media's attitudes and perceptions toward individuals with SUDs. Results showed that many articles propagated public stigma by using stigmatizing language, identifying people who use drugs with negative and unwanted qualities (10). Similarly, the media in New Zealand had often used terms such as "meth head" and "drug addict" when discussing individuals with SUDs (11). In Italy, schools, universities, and media outlets rarely convey the medical aspects of addictions, and SUDs are typically perceived as vices rather than diseases. Along the same lines, addiction treatment centers tend to be isolated and external to the general hospital setting (12, 13). Criminalizing drug use further fosters public stigma toward individuals with SUDs, through social and economic marginalization. Criminalization also diverts attention from the medical and public health models of addiction to a moral and punitive model. In India, for instance, this translates in the latest Narcotic Drugs and Psychotropic Substances policy limiting the access to evidence-based treatment, such as opioid agonist maintenance treatment and harm reduction strategies, by imposing restrictions on the duration and settings of treatment (14). Similarly, in Nepal, current laws remain harsh and add to the perception that individuals with SUDs are criminals who should be referred to the criminal justice system (15).

Individuals with SUDs and their family members experience significant internalized and affiliate stigma. Across cultures, internalized stigma is correlated with poorer quality of life (16) and delay in seeking treatment (17), especially in the initial stages of the illness (18). The Arab, Iranian, and Indian societies are collectivistic societies where family plays an essential role in fostering support and individuals' decision-making. Hence, if one family member is affected by a SUD, others would attempt to provide support. However, families would also try hard to shield the affected member from the neighborhood and society to avoid stigma, which can lead to delays in treatment. In general, affiliate stigma tends to prevent families from providing the necessary medical support to their loved ones (19).

Healthcare professionals also hold negative perceptions and implicit biases toward individuals with SUDs. One study among primary care providers in New Zealand found that people who misuse prescription medications can be often stigmatized and offered limited harm reduction interventions (20). A systematic review of studies conducted in Western countries found that negative attitudes of healthcare professionals toward individuals with SUDs are common and contribute to suboptimal care (5). The general attitude of healthcare providers toward people with lived experience of mental illness is not positive in Iran, and attitudes toward those living with SUDs seem to be worse (21, 22). In many countries, including the Arab world and India, little enthusiasm is noted among psychiatry trainees to take up addiction psychiatry as a career option. Minimal exposure during residency, non-availability of evidence-based treatments and limited awareness about them, and significant public stigma might contribute to this. For similar reasons, practicing psychiatrists are sometimes uncomfortable with treating individuals with SUDs and are reluctant to initiate medications, perceiving this population as "challenging" and "difficult".

### 2.2 How does stigma impact treatment?

Stigma is a negative driver for recovery from addiction. As previously mentioned, individuals who are stigmatized are less willing to engage in or seek medical treatment. Moreover, they may have to deal with associated fear, anger, isolation, trauma, or comorbid mental health disorders. This leads to care avoidance, self-directed early hospital discharge, and hesitance to call medical help or accept transport to a hospital after an overdose, all secondary to the fear of stigma and legal consequences (4). Stigma also impacts treatment availability, with a noted scarcity in the workforce that caters to the needs of individuals with SUDs, insufficiency in the number of treatment centers and available interventions, and limited support groups. Along the same lines, research into the treatment of addictions tends to be less prioritized than that of other mental illnesses. The stigmatizing language used to describe substance use behaviors, individuals with SUDs, and substance use treatment also creates other types of barriers for individuals who are on the road to recovery and re-integration into society, including at the level of their general healthcare, housing, employment, and insurance policies.

In many parts of the world, this translates into inappropriate and potentially hazardous treatment methodologies. For instance, in India, some privately owned rehabilitation centers deliver unethical and punitive treatments that lack evidence- and right-based medical approaches (23). In Iran, families can push their relatives with SUDs for involuntary admissions to "Campus", which represents mandatory residence places that fail to provide proper treatment. In Nepal, people with SUDs have been traditionally treated out of health systems, in shoddy rehabilitation centers run by people with no experience and no standardized treatment protocol (15). In the Arab world, drug use can still be seen as a form of breakdown, possession by an evil spirit, or shortcoming of individual religious faith; and people may pursue a religious healer instead of a professional mental health practitioner to address this problem (24). But even when individuals seek professional help from psychiatrists or other allied medical health professionals, they can certainly be subject to inaccurate treatment approaches, highlighting the need for improving the awareness of the different stakeholders about the available evidence-based interventions.

## 3 Discussion

There is an urgent need to combat the stigma surrounding SUDs. Research on stigma interventions for providers who treat individuals with SUDs increased in recent years, indicating greater worldwide attention to the negative impact of stigma (25). Table 1 presents a comprehensive summary of potential interventions and strategies to decrease stigma toward addiction and individuals living with SUDs. By recognizing the enormous challenge that stigma poses to communities, and by revising the words and terms used when discussing matters of addiction and the people living with it, major reforms can occur. Decriminalizing drug use is another pivotal step that can guide the way. This measure not only decreases stigma but also allows for a shift in resources toward prevention and treatment, promoting an approach that prioritizes healing over punishment.

TABLE 1 Strategies to reduce stigma related to addiction and individuals with SUDs.

| | |
|---|---|
| Introducing training on SUDs in medical and nursing schools. | Promoting destigmatizing language when communicating with people with lived or living experience of addiction, their families, and the community:<br>- Utilize "person-first" language, emphasizing the individual rather than their condition.<br>- Replace terms such as "substance abuser", "drug abuser", "addict", "alcoholic", "drunk", "junkie", and "user" with "person with substance use disorder" and "person in active use of".<br>- Replace "clean person" and "ex-addict" with "person in recovery" and "person who previously used drugs".<br>- Replace "stayed clean" with "maintained recovery".<br>- Replace "habit" with "substance use disorder" and "drug addiction".<br>- Replace "abuse" with "use" for illicit drugs and "misuse" or "used other than prescribed" for prescription medications.<br>- Replace "clean/dirty" toxicology results with "positive/negative" toxicology results.<br>- Replace "drug offender" with "person arrested for drug use or drug violation".<br>- Replace "refused" and "non-compliant" with "chose not to at this point".<br>These changes emphasize that the person "has" a problem, rather than "is" the problem and help avoid negative connotations, punitive attitudes, and individual blame. |
| Increasing training and engagement in addiction psychiatry during post-graduation psychiatry residency, as well as in other residencies such as emergency medicine and family medicine. | |
| Encouraging research in the field of SUDs, with a particular focus on generating more evidence for culturally validated and accepted psychosocial treatments for SUDs. | |
| Making evidence-based treatment widely available and accessible to individuals with SUDs. | |
| Introducing courses that explain the biological elements and the concept of SUDs in educational bodies, such as schools and universities. | |
| Developing social media guidelines for reporting individuals with SUDs, using destigmatizing language. | |
| Implementing social media awareness campaigns to encourage discussions about addiction and help-seeking. | |
| Educating high-profile individuals and influencers, including religious leaders, on available evidence-based treatments to enable them to provide referrals when encountering individuals with SUDs. | |
| Increasing stakeholder and community engagement in both research and awareness campaigns to facilitate conversations and raise awareness about the topic. | |
| Improving the social inclusion of individuals with SUDs through better access to job opportunities and health insurance, among other measures. | |
| Decriminalizing substance use (excluding possession, sale, or drug dealing). | |

On this path of improvement, it is necessary to highlight some of the extensive efforts, campaigns, and work-in-progress initiated to battle the stigma against SUDs. For instance, in the United States, the Substance Abuse and Mental Health Services Administration (SAMHSA) and the National Institute on Drug Abuse (NIDA) continue to make widespread efforts to educate and break the stigma. In Egypt, the Ministry of Health has re-launched its "You Can, Without It" campaign for the fifth year in a row to aid individuals in recovery in avoiding relapse. Erada Center for Treatment and Rehabilitation in Dubai has launched for the past four years the "Masmooh" Campaign, a television/radio initiative that aims to educate the community about the nature of SUDs and promote greater understanding of the role of forgiveness in helping individuals recover. "Masmooh", which means "permitted", seeks to promote forgiveness in society to help re-integrate individuals with SUDs into their communities and give them a sense of hope. New Zealand has a strong history of health promotion, prevention, and anti-discrimination advocacy, with various campaigns targeting non-behavioral addictions, such as "Say Yeah, Nah", "Go the distance", and 'Changing Minds'. Worldwide, several countries, governments, institutions, and educational bodies have shared online material to promote SUD-related anti-stigma campaigns and provide training and workshops for policymakers, healthcare professionals, educators, employers, faith leaders, youth, and the public. Equally important, major medical journals have been more keen on publishing about the topic of stigma toward SUDs in a compounded effort to educate the public (26).

Still, more work is needed. We, as psychiatrists, advocate for a stigma-free approach when treating individuals with SUDs. Such an approach includes actively listening to the person's story, using destigmatizing language (27, 28), avoiding medical jargon, and ensuring to ask every individual how comfortable they feel talking about their substance use and how ready they are to change their use. Treatment should be provided in an individualized manner. Importantly, the approach should be free from judgment and prejudice, building trust by respecting the person's rights for confidentiality and choice of treatment strategies, and respecting their dignity, beliefs, and culture. Autonomy and freedom to choose or not choose treatment or any particular treatment is essential. While using a motivational interviewing approach, providers should actively work on offering evidence-based treatments, including pharmacological interventions and prompt referral to medication-assisted treatments, individual and group therapies, and referral to peer support groups, such as Alcoholics Anonymous (AA) and Narcotics Anonymous (NA) meetings. Emphasis is on the adoption of a harm-reduction approach, including the provision of a naloxone rescue kit and encouragement of safe injecting practices. This helps to highlight that the problem is substance use-related harm, not the person nor the substance use. Of equal significance is the incorporation of a trauma-informed care approach for all individuals with SUDs (29). Alternatively, using analogies of chronic non-communicable diseases (e.g., hypertension, diabetes mellitus) can be helpful for individuals to understand their condition. Lastly, instilling hope is of utmost importance, through educating people and their families that SUD is a treatable medical condition, not a choice, and that the person is never defined by their drug use. In the end, fostering a more accepting society involves numerous avenues, yet it always starts with grassroots initiatives, such as our language choices in everyday clinical discourse.

## Author contributions

SEH: Conceptualization, Data curation, Investigation, Writing – original draft. WF: Conceptualization, Data curation, Writing – original draft. RdF: Conceptualization, Data curation, Writing – review & editing. AG: Data curation, Writing – review & editing. NK: Data curation, Writing – review & editing. AMMK: Data curation, Writing – review & editing. SP: Data curation, Writing – review & editing. VP: Data curation, Writing – review & editing. RR: Data curation, Writing – review & editing. HT: Data curation, Writing – review & editing. MS: Conceptualization, Data curation, Supervision, Writing – review & editing.

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# Internalized stigma related to COVID-19 and its psychosocial and mental health correlates: a multicentric health facility based observational study from Nepal

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**Introduction:** The COVID-19 pandemic has led to physical and psychological complications and social consequences in the form of illness-related stigma. This study aimed (1) to assess the sociodemographic and clinical variable, as well as COVID-19 related knowledge and perception of persons admitted for COVID-19/Suspected COVID-19 in Nepal, (2) to determine their levels of COVID-19- related internalized stigma, depression, and anxiety symptoms, and (3) to evaluate the correlates of COVID-19- related internalized stigma.

**Materials and methods:** It was a cross-sectional exploratory study with a convenience sample of 395 participants (306 confirmed cases, 89 suspected cases) conducted between July–October 2020 in four health facilities in Madhesh and Lumbini provinces of Nepal. We used a semi-structured questionnaire to assess sociodemographic details, clinical information, COVID-19-related knowledge, perception, COVID-19-related internalized stigma, and the Hamilton Anxiety Depression Scale (HADS) in Nepali language. Descriptive statistics, correlation analyses, and linear regression analyses were performed. The level of statistical significance was considered at $p < 0.05$.

**Results:** Around 23.3% of the patients had anxiety symptoms, 32.9% had depressive symptoms, and 20.3% had high COVID-19-related internalized stigma (mean ISMI score: 2.51–4.00). Linear regression analyses showed a significant positive association of COVID-19-related internalized stigma total score, with the following eight factors, i.e., no income in the past one month ($p = 0.013$), below average socioeconomic status ($p = 0.004$), anxiety symptoms ($p = <0.001$), depressive symptoms ($p = <0.001$), recent testing positive for COVID-19 ($p = <0.001$), involuntary admission ($p = <0.001$), prior experience of being in isolation and quarantine ($p = 0.045$), and those who blame others for COVID-19 ($p = 0.025$).

**Conclusion:** COVID-19 survivors and suspects are vulnerable to symptoms of depression, anxiety, and COVID-19-related internalized stigma. For the first time from Nepal, our data suggests that COVID-19-related internalized stigma is associated with anxiety and depression symptoms, perceived below-average socioeconomic status, involuntary admission, prior experience of being in isolation and quarantine, recent COVID-19 positive report, self-blame, below-average socioeconomic status and no income in the past one month. Mitigating and preventing internalized stigma associated with a public health crisis such as COVID-19 is imperative by diagnosing and treating such mental health issues early and designing interventions and policies especially targeting vulnerable populations focusing on their economic background and socio-cultural beliefs.

KEYWORDS

**internalized stigma, anxiety, depression, stigma, COVID-19, Corona virus, mental health, Nepal**

## 1 Introduction

The Coronavirus disease 2019 (COVID-19) pandemic, since its emergence in December 2019 in Wuhan, China, has transformed from a global health emergency to a humanitarian crisis worldwide of unprecedented magnitude. Because of its high infectivity rate and widespread morbidity and mortality, nations worldwide were compelled to enforce lockdowns, quarantine, and isolation, leading to several adverse psychosocial and economic consequences. Moreover, lack of knowledge about the illness, misconceptions, health anxiety, public hysteria triggered by infodemics, led to a psychosocial crisis and adverse mental health consequences (1).

The COVID-19 pandemic has also resulted in stigmatizing attitudes and beliefs followed by discrimination toward those suffering from COVID-19, health workers, and first responders involved in their management. Stigma has different facets. It has been further observed that persons who have been diagnosed with COVID-19 may not only suffer societal discrimination, but they are also at risk of internalizing these beliefs, developing feelings of inferiority and self-anger, eventually applying to themselves and behaving as stigmatized individuals (for instance, thinking that the disease is their responsibility or that because of it, they may be dangerous to others) (2–4). This internalized stigma can lead to devaluation of self and generate emotions of self-prejudice, guilt, or shame, which would further affect their behavior and lead to adverse mental health consequences such as depression and anxiety (3, 4). Stigma hampers diagnosis, treatment, prevention, and control of diseases as individuals tend to hide their identity, avoid social interaction, and follow health guidelines and healthy preventive adaptive behaviors. Thus, internalized stigma affects the health of not just an individual but society at large (5, 6).

Yuan and colleagues conducted a systematic review and meta-analysis on the prevalence of stigma in infectious diseases, including COVID-19 in 2022 and estimated the prevalence of COVID-19 stigma (enacted stigma and perceived stigma) as 35% [95% CI, 26–44%] among the affected individuals, indicating COVID-19 is stigmatizing. People from lower education and lower and middle countries were more vulnerable to contagious disease-related stigma (7). Moreover, various factors increased infection-related stigma such as place of living, being minorities (due to ethnicity, sexual orientation, gender identity), having contagious infection, the lethality of the disease, social isolation due to quarantine and physical distancing, elderly age group, physical comorbidities, fear aggravating factors such as insufficient knowledge about illness, unavailability of effective treatment (8–13). Despite similarities in stigma in various infectious diseases, each disease had different features of stigma. Hence, it is pertinent to understand the factors contributing to stigma in each infectious disease outbreak separately so that specific interventions to prevent and eliminate stigma can be designed (11). Further, COVID-19 stigma affects both suspected and infected individuals and it is associated with particular race, religion, and occupations, such as healthcare professionals and police officers, minorities (migrant workers), lower education, and those working in quarantine hospitals (14, 15). However, research on internalized stigma is minimal worldwide (16–20). It is difficult to compare the studies due to methodological differences such as the use of heterogeneous instruments to measure internalized stigma. Therefore, it necessitates understanding COVID-19-related internalized stigma and its associated factors even more.

## 1.1 The COVID-19 situation in Nepal

The first case of COVID-19 was diagnosed on the 23rd of January 2020 in Nepal. The country underwent the first lockdown from 24 March to 21 July 2020, prohibiting domestic and international travel.

The first wave of COVID-19 cases occurred from July 2020 to February 2021. But vaccination for COVID-19 began in Nepal only on 27 January 2021. The second wave occurred between the end of March 2021 and July 2021, which was the most devastating of all the three waves. For the second time, the country underwent lockdown for four months, i.e., from April 29, 2021 to Sep 1, 2021 (21–23). The third wave began from Dec 2021 to Jan 2022, with multiple surges in COVID-19 cases (24). Like most developing nations, Nepal has faced its share of adverse consequences of the COVID-19 pandemic on its economic and public health care systems. With a population of 29.16 million, as of July 28, 2023, the country has reported 1,003,382 COVID-19 PCR positive, 153,972 COVID-19 Antigen positive and 112,031 deaths (25, 26). Measures like nationwide lockdowns, social distancing, travel restrictions, 76.5% of the population vaccinated with double doses as of February 2023, and booster intake of about 27% as of December 2022 have been adopted in Nepal (27). COVID-19 has affected mental health in Nepal and worldwide (3, 28). Studies from Nepal have documented that people living in quarantine centers, COVID-19 survivors, those with lower socioeconomic status, healthcare workers, and especially nurses were found vulnerable to mental comorbidities, social stigma, and discrimination during the COVID-19 pandemic in Nepal (22, 29–32).

However, there has not been a study that has specifically explored the internalized stigma of COVID-19 among the Nepalese population to date. We conducted a multicentric health facility-based observational study from Nepal to study internalized stigma related to COVID-19 and its psychosocial and mental health correlates. We hypothesize a potential relationship between internalized stigma related to COVID-19 with psychosocial factors and depressive and anxiety symptoms in patients suffering or suspected to be suffering from COVID-19. The purpose of the present study was three-fold: 1) to assess the sociodemographic and clinical variables, as well as COVID-19-related knowledge and perception of persons admitted for COVID-19/Suspected COVID-19 in Nepal, 2) to determine their levels of COVID-19- related internalized stigma, depression, and anxiety symptoms, and 3) to evaluate the correlates of COVID-19-related internalized stigma.

# 2 Materials and methods

## 2.1 Participants and procedures

This study was designed as an exploratory cross-sectional observational study conducted in COVID-19 cases, and suspects admitted to Narayani Hospital, Birgunj, Narayani Temporary Special Corona Hospital, Birgunj of province two and Corona Special Hospital, Beljhundi, Dang, Bheri Hospital and Primary Health Centre, Bankatawa of province five in Nepal. The study was conducted over five months (July-Nov2020) during the first wave of the COVID-19 pandemic in Nepal.

The sampling method employed for the study was convenience sampling based on the set inclusion criteria. We included all patients fulfilling the following inclusion criteria: 1) COVID-19 suspects or cases admitted to Narayani Hospital, Birgunj, Narayani Temporary Special Corona Hospital, Birgunj, and Corona Special Hospital, Beljhundi, Dang, Bheri Hospital and Primary Health Centre, Bankatawa 2) aged between 18–65 years 3) not suffering from any severe co-morbid physical illness 4) willing to provide informed consent.

## 2.2 Sample size estimation

The reference study used for the purpose was the only study conducted in Nepal to evaluate the prevalence of anxiety and depression among COVID-19 patients (34.0 and 31.0%, respectively) until our study was designed (32). Assuming absolute error or precision at 0.05 and an expected non-response rate of 10%, the study's sample size was estimated to be 380.

## 2.3 Data collection

The participants were recruited at the time of their discharge from their respective health facilities or within the first week of their discharge if missed, once they provided written consent. The interviews were in-person using WHO precautions and physical distancing or telephonic interviews. The discussions were followed by psychoeducation about COVID-19 and referral to psychiatrists if mental health issues were identified in the participants. Four hundred twelve participants were approached for the study; six refused to participate. 11 questionnaires were not filled and removed. A total of 395 complete questionnaires were used for the analyses.

## 2.4 Assessments

We collected the participant's data using the following measures:

### 2.4.1 Sociodemographic sheet

It included participants' age, gender, marital status, religion, ethnicity, education, occupation, employment status, source of income, perceived socio-economic status, type of family, place of stay, living status, address, name of the health facility where admitted, method of admission, if was in quarantine/isolation facility before access in the current setting.

### 2.4.2 Clinical profile sheet

It included the source of possible COVID-19, current COVID-19 status, symptomatic or not, history of medical illness, history of diagnosed psychiatric illness at present and in the past, substance use history, and pattern in the past month.

### 2.4.3 Semi-structured questionnaire on COVID-19 related knowledge and perception

Questions were made about the local context, dealing with the perception of COVID-19 concerning its dangerousness, ideas of self-blame, situations where stigmatized the most, reasons for worry and knowledge about the cause of COVID-19, ways of its transmission, and recovery. The questionnaires were translated into Nepali using the WHO translation-back-translation methodology (33). Then, the research team reviewed the content. Further, out of the three questions related to knowledge about the cause of COVID-19, mode of transmission, and recovery from COVID-19 infection, if responses in at least two questions were correct, it was labeled adequate knowledge.

### 2.4.4 COVID-19-related internalized stigma scale

Since there was no scale to study internalized stigma to COVID-19 at the time of the study, the Internalized Stigma of Mental Illness (ISMI) scale was adapted for this study. It is a 29-item self-report that includes subscales: Alienation, Discrimination Experience, Social Withdrawal, Stereotype, Endorsement, and Stigma Resistance (34). Items were developed initially in participants diagnosed with a severe mental illness (SMI) (34). Answers were coded on the following 4-point Likert scale: 1 (strongly disagree), 2 (disagree), 3 (agree), and 4 (strongly agree). It has high internal consistency reliability (0.90), high test–retest reliability, and good evidence of construct validity (34). There are two methods of score interpretation (34). The 2-category method divides scores according to whether they are above or below the midpoint: 1.00–2.50 (does not report high internalized stigma) and 2.51–4.00 (reports high internalized stigma) (35). The score can also be used as a continuous variable. Permission was taken to use the author's scale and translate it into Nepali. The English and Nepali versions of the scale are available in Figure 1.

The ISMI scale was adapted for this study by following a four-stage procedure similar to (36).

1. The first stage consisted of modifying the wording of the items so that these would be relevant for COVID-19 suspects and cases. Accordingly, "mental illness" was replaced by "Corona suspect and cases."
2. The scale was translated to Nepali using the WHO translation-back-translation methodology.
3. The research team reviewed content through group discussions to reach a consensus regarding the face validity of the instrument.
4. Pilot testing to assess feasibility and comprehensibility among the participants was done among 40 cases and suspects in Bheri Hospital and PHC, Bankatawa. The items were comprehensible in all scales and semi-structured performa. Patients understood all points except item 10 on the internalized stigma scale. Hence, "like others" words were added for clarification in item 10.

### 2.4.5 Hospital anxiety and depression scale

It is a psychiatric screening instrument to identify and assess anxiety and depression. Due to the absence of somatic symptoms, it is acceptable in hospital populations. The original English version of HADS contains 14 items in two subscales: anxiety (HADS-A) and depression (HADS-D), each with seven items (A1 to A7; D1 to D7) (37). Each item is rated on a four-point scale from 0–3 (3 indicating maximum symptom severity), and the scores are summed (five items on the depression subscale and one on the anxiety subscale are reversed before adding) (38). Each subscale, therefore, has a summed score with a potential range from 0 to 21. According to the original English version, a summed score of ≥11 on either subscale indicates caseness concerning the relevant psychiatric morbidity. Summed scores from 8–10 are "borderline" cases and 0–7 signifies the normal range (38). The Nepali version developed by Rijal and colleagues (24) will be used. Cronbach's alpha was 0.76 for anxiety (HADS-A) and 0.68 for depression (HADS-D). All seven HADS-A items showed at least good item-to-factor correlations (range 0.44–0.74), and full construct validity was achieved for this subscale. Item-to-factor correlations for six HADS-D items were also at least acceptable (range 0.42–0.70); one thing (D4) had persistently low correlations throughout all trials, although construct validity was still satisfactory (39). Permission was taken to use the scale from the author.

## 2.5 Statistical analyses

Statistical analyses were performed using the Statistical Package for Social Sciences Version 26 (SPSS, Chicago, Illinois, USA). Descriptive statistics were calculated for socio-demographic and clinical characteristics and other relevant assessment instruments. As appropriate, data are presented as means and standard deviations (SD) or frequencies and percentages (%). A Spearman's correlation analysis was performed to test the correlation between internalized stigma score, anxiety, and depression scale score. A combination of statistical association with the outcome, as well as theoretical importance, was considered while choosing predictors for the regression model. Among all theoretically important predictors, those with a univariate value of $p$ <0.05 were considered for inclusion. If a variable was deemed theoretically very important, a value of $p$ <0.2 was considered acceptable for inclusion. Care was taken not to include two theoretically redundant variables. Finally, a bidirectional stepwise selection was employed to choose the final set of variables for the multivariable model to determine the most parsimonious model. The level of statistical significance was kept at $p < 0.05$ for all the tests.

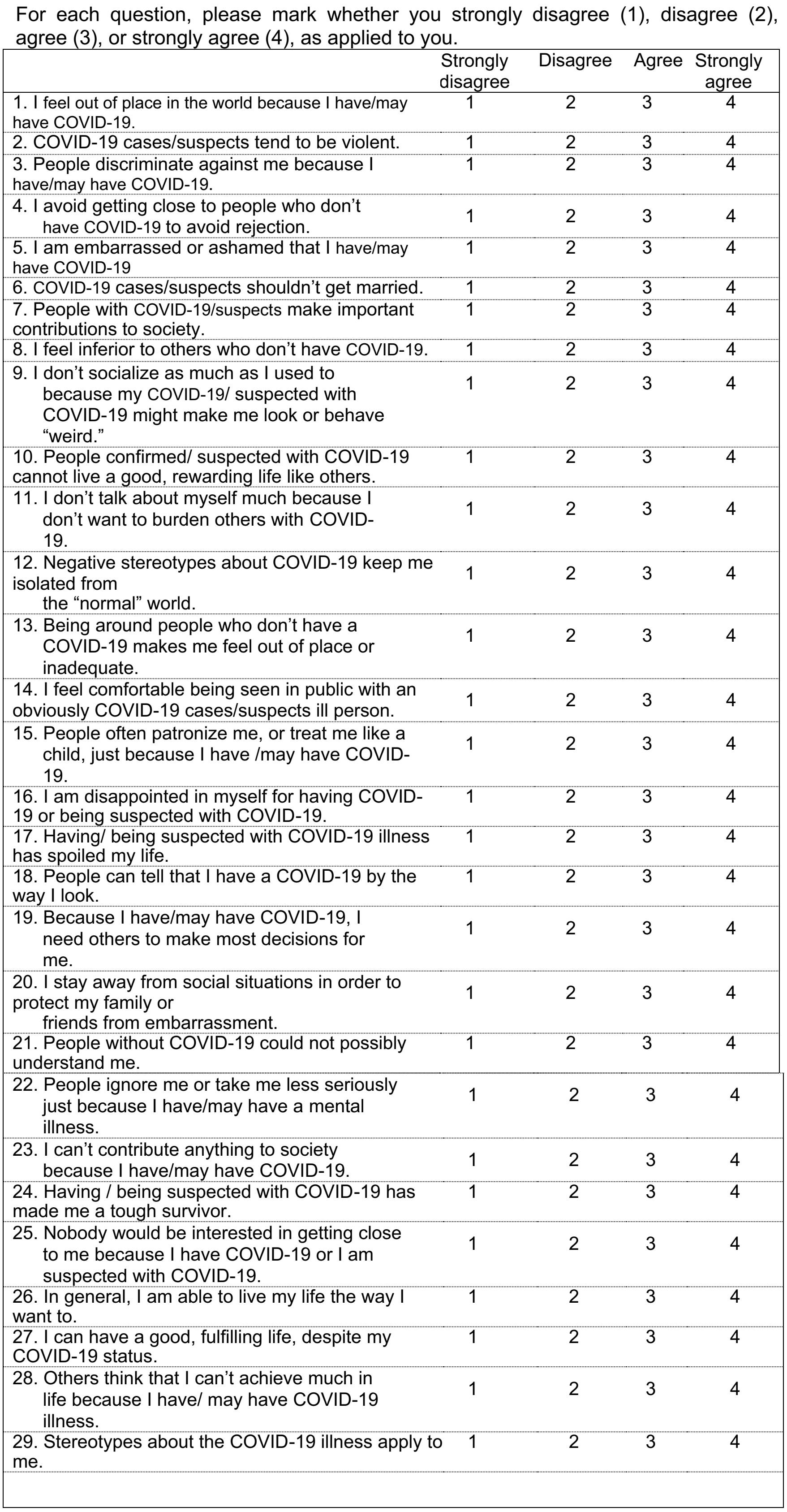
# 3 Results

## 3.1 Sociodemographic and clinical profiles

The demographic and clinical characteristics are summarized in Tables 1, 2. The mean age of the participants was 32.5 (±11.0) years, 68.1% belonged to the 18–35 years age group, 26.1% were from Madhesi ethnicity, 70.4% were females, 71.4% were married, 65.1% were educated less than or up to class 10, and 36.5% were partially employed. Similarly, 55.2% did not have a source of income in the past one month, 56.2% perceived average socio-economic status, while majority stayed currently with family (78%), owned a house (74.2%). 20% of the participants were health workers, and 17% had involuntary admission to the health facilities (17%). 77.5% were COVID-19 cases and 22.5% were COVID-19 suspects. Most of them were from Province Five (81.8%), with no prior experience of staying in isolation or quarantine facilities before current admission (52.4%), did not get their COVID-19 test done recently (38.6%), asymptomatic (75.4%), with no history of medical illness (94.9%), and no current (99.2%), nor history of psychiatric illness (99.2%). The most common substance used in the past month was tobacco (23.8%), followed by alcohol (16.2%). Among the tobacco users, 45.8%used tobacco products mostly daily, but among alcohol users, they mostly used alcohol for more than half a week (78.1%).

## 3.2 COVID-19 infection-related knowledge, perception, and internalized stigma related to COVID-19

As shown in Table 3, more than half of the participants did not know that COVID-19 infection was caused by the COVID-19 virus



For each question, please mark whether you strongly disagree (1), disagree (2), agree (3), or strongly agree (4), as applied to you.

| | Strongly disagree | Disagree | Agree | Strongly agree |
|---|---|---|---|---|
| 1. I feel out of place in the world because I have/may have COVID-19. | 1 | 2 | 3 | 4 |
| 2. COVID-19 cases/suspects tend to be violent. | 1 | 2 | 3 | 4 |
| 3. People discriminate against me because I have/may have COVID-19. | 1 | 2 | 3 | 4 |
| 4. I avoid getting close to people who don't have COVID-19 to avoid rejection. | 1 | 2 | 3 | 4 |
| 5. I am embarrassed or ashamed that I have/may have COVID-19 | 1 | 2 | 3 | 4 |
| 6. COVID-19 cases/suspects shouldn't get married. | 1 | 2 | 3 | 4 |
| 7. People with COVID-19/suspects make important contributions to society. | 1 | 2 | 3 | 4 |
| 8. I feel inferior to others who don't have COVID-19. | 1 | 2 | 3 | 4 |
| 9. I don't socialize as much as I used to because my COVID-19/ suspected with COVID-19 might make me look or behave "weird." | 1 | 2 | 3 | 4 |
| 10. People confirmed/ suspected with COVID-19 cannot live a good, rewarding life like others. | 1 | 2 | 3 | 4 |
| 11. I don't talk about myself much because I don't want to burden others with COVID-19. | 1 | 2 | 3 | 4 |
| 12. Negative stereotypes about COVID-19 keep me isolated from the "normal" world. | 1 | 2 | 3 | 4 |
| 13. Being around people who don't have a COVID-19 makes me feel out of place or inadequate. | 1 | 2 | 3 | 4 |
| 14. I feel comfortable being seen in public with an obviously COVID-19 cases/suspects ill person. | 1 | 2 | 3 | 4 |
| 15. People often patronize me, or treat me like a child, just because I have /may have COVID-19. | 1 | 2 | 3 | 4 |
| 16. I am disappointed in myself for having COVID-19 or being suspected with COVID-19. | 1 | 2 | 3 | 4 |
| 17. Having/ being suspected with COVID-19 illness has spoiled my life. | 1 | 2 | 3 | 4 |
| 18. People can tell that I have a COVID-19 by the way I look. | 1 | 2 | 3 | 4 |
| 19. Because I have/may have COVID-19, I need others to make most decisions for me. | 1 | 2 | 3 | 4 |
| 20. I stay away from social situations in order to protect my family or friends from embarrassment. | 1 | 2 | 3 | 4 |
| 21. People without COVID-19 could not possibly understand me. | 1 | 2 | 3 | 4 |
| 22. People ignore me or take me less seriously just because I have/may have a mental illness. | 1 | 2 | 3 | 4 |
| 23. I can't contribute anything to society because I have/may have COVID-19. | 1 | 2 | 3 | 4 |
| 24. Having / being suspected with COVID-19 has made me a tough survivor. | 1 | 2 | 3 | 4 |
| 25. Nobody would be interested in getting close to me because I have COVID-19 or I am suspected with COVID-19. | 1 | 2 | 3 | 4 |
| 26. In general, I am able to live my life the way I want to. | 1 | 2 | 3 | 4 |
| 27. I can have a good, fulfilling life, despite my COVID-19 status. | 1 | 2 | 3 | 4 |
| 28. Others think that I can't achieve much in life because I have/ may have COVID-19 illness. | 1 | 2 | 3 | 4 |
| 29. Stereotypes about the COVID-19 illness apply to me. | 1 | 2 | 3 | 4 |

FIGURE 1
COVID-19 internalized stigma scale in English version. For each question, please mark whether you strongly disagree (28), disagree (13), agree (62), or strongly agree (31), as applied to you.

TABLE 1 Sociodemographic of the participants (*N* = 395).

| Sociodemographic variables | Frequency (%) | |
|---|---|---|
| Age categories | 18–35 years<br>36–55 years<br>56 years and above | 269 (68.1)<br>106 (26.8)<br>20 (5.1) |
| Age (in years)[a] | 32.5 ± 11.0 | |
| Gender | Male<br>Female | 117 (29.6)<br>278 (70.4) |
| Marital status | Unmarried<br>Married<br>Widow/widower | 106 (26.8)<br>282 (71.4)<br>7 (1.8) |
| Religion | Hindu<br>Buddhist<br>Muslim | 350 (88.6)<br>4 (1.0)<br>41 (10.4) |
| Ethnicity | Brahmin<br>Kshettri<br>Dalit<br>Janajati<br>Madhesi<br>Others | 54 (13.7)<br>97 (24.6)<br>65 (16.5)<br>64 (16.2)<br>103 (26.1)<br>12 (3) |
| Education completed | Less than and up to class 10<br>Above class 10 | 257 (65.1)<br>138 (34.9) |
| Health care workers | | 79 (20) |
| Current Employment status | Unemployed<br>Partially employed<br>Fully employed | 115 (29.1)<br>114 (36.5)<br>136 (34.4) |
| Income source in past 1 month | Present<br>Absent | 177 (44.8)<br>218 (55.2) |
| Perceived Socioeconomic Status | Below average<br>Average<br>Above average | 41 (10.4)<br>222 (56.2)<br>132 (33.4) |
| Current Stay | Alone<br>With family<br>With friends | 75 (19.0)<br>308 (78.0)<br>12 (3.0) |
| Place of Stay | Own house<br>Rent<br>Hostel and quarter | 293 (74.2)<br>83 (21.0)<br>19 (4.8) |
| Method of admission | Voluntary<br>Involuntary | 328 (83.0)<br>67 (17.0) |
| Names of centers | Narayani Hospital<br>Dang Hospital<br>Bheri Hospital<br>PHC, Bankatawa | 72 (18.2)<br>103 (26.1)<br>145 (36.7)<br>75 (19.0) |
| History of prior admission in isolation or quarantine center | Yes<br>No | 192 (48.6)<br>203 (52.4) |

a = Mean ± SD.

TABLE 2 Clinical profile of the participants (*N* = 395).

| Clinical variables | | Frequency (%) |
|---|---|---|
| Suspects<br>Cases | | 89 (22.5)<br>306 (77.5) |
| Recent COVID-19 test result | Positive<br>Negative<br>Report awaited<br>Not done | 90 (22.8)<br>133 (33.7)<br>22 (5.6)<br>150 (37.9) |
| Presentation | Symptomatic<br>Asymptomatic | 97 (24.6)<br>298 (75.4) |
| History of medical illness | Yes<br>No | 20 (5.1)<br>375 (94.9) |
| *Type of Medical illness<br>1 DM<br>2 HTN<br>3 Asthma<br>4 Hypothyroidism<br>5 Congenital Heart Disease<br>6 Pulmonary TB | | <br>8 (40.0)<br>6 (30.0)<br>5 (25.0)<br>1 (5.0)<br>1 (5.0)<br>1 (5.0) |
| History of a diagnosed psychiatric illness | Yes<br>No | 3 (0.8)<br>392 (99.2) |
| Current diagnosed psychiatric illness | Yes<br>No | 3 (0.8)<br>392 (99.2) |
| Substance use profile | | |
| | Yes [Frequency (%)] | No [Frequency (%)] |
| Tobacco products | 94 (23.8%) | 301 (76.2) |
| Alcoholic beverages | 64 (16.2%) | 331 (83.8) |
| Cannabis | 8 (2.0%) | 387 (98.0) |
| Sedatives | 2 (0.5%) | 393 (99.5) |
| Opioids/ Others | 0 (0%) | 395 (100.0) |

| | Frequency of substance use | | |
|---|---|---|---|
| | Daily | More than half a week | Less than half a week |
| Tobacco products (*N* = 94) | 43 (45.8) | 13 (13.8) | 38 (40.4) |
| Alcoholic beverages (*N* = 64) | 1 (1.6%) | 13 (20.3) | 50 (78.1) |
| Cannabis (*N* = 8) | – | 2 (25.0) | 6 (75.0) |
| Sedatives (*N* = 2) | – | – | 2 (100.0) |

*Multiple response questions.

(51.6%). The majority knew that COVID-19 was a communicable disease (97%), only two-fifths attributed contact transmission (40.8%), and one-twenty-fifth mentioned vehicle-borne transmission (3.3%). However, most reported air transmission as the mode of transmission (66.1%), and four people attributed it to even fate for getting infected with COVID-19. One-fourth assumed friends as the possible source of information. More than one-fifth attributed home remedies as the way to recover from the infection, and only one in ten participants reported that COVID-19 illness is self-limiting. Most reported COVID-19 as dangerous (70.6%), and most attributed complications and death to its dangerousness (46.1%). More than one-fifth had inadequate knowledge (21.3%) of COVID-19 infection, and more than one-fourth blamed self for being infected with COVID-19 (25.1%). The participants were primarily worried about illness and health complications (64.2%), followed by social stigma (35.8%), being in isolation and quarantine (27.7%), the health of the family

TABLE 3 COVID-19 infection related knowledge, perception and stigma perceived due to COVID-19 ($N = 395$).

| Variables | | Frequency (%) |
|---|---|---|
| Causes of COVID-19 infection | COVID-19 virus | 191 (48.4) |
| | Others | 161 (42.0) |
| | Unknown | 42 (10.6) |
| Is COVID-19 a communicable disease? | Yes | 383 (97.0) |
| | No | 7 (1.8) |
| | Unknown | 5 (1.3) |
| *Modes of its transmission | Air | 259 (66.1) |
| | Contact | 150 (40.8) |
| | Vehicle borne | 12 (3.3) |
| | Due to fate | 4 (1.0) |
| | Unknown | 32 (6.8) |
| Source of transmission of COVID-19 | Family member | 34 (8.6) |
| | Friend | 99 (25.1) |
| | Neighbor | 68 (17.2) |
| | Patients | 10 (2.5) |
| | Do not know | 207 (52.4) |
| *How can someone recover from COVID-19 infection? | Self-limiting | 48 (10.4) |
| | Medical management | 105 (22.7) |
| | Boosting immunity | 85 (18.4) |
| | Better hygiene | 45 (11.4) |
| | Separation from others | 45 (9.7) |
| | Religion | 2 (0.4) |
| | Positive mental health | 3 (0.6) |
| | Unknown | 36 (7.8) |
| | Home remedies | 95 (20.5) |
| Is COVID-19 dangerous? | Yes | 279 (70.6) |
| | No | 116 (29.4) |
| COVID-19 infection related Knowledge | Adequate | 311 (78.7) |
| | Inadequate | 84 (21.3) |
| *Why is COVID-19 dangerous? | No Medical cure | 43 (10.9) |
| | Complications and death | 182 (46.1) |
| | Communicable to others | 22 (5.6) |
| | No Vaccination | 1 (0.3) |
| | Heard from others | 13 (3.3) |
| | No idea | 135 (34.2) |
| Self-blame for infected with COVID-19 | Yes | 99 (25.1) |
| | No | 296 (74.9) |
| *Major concern | Illness and health complications | 204 (64.2) |
| | Social Stigma | 114 (35.8) |
| | Isolation and quarantine | 88 (27.7) |
| | Health of the family | 54 (17.0) |
| | Transmission to others | 12 (3.8) |
| | Financial | 20 (6.3) |
| | Infodemics | 6 (1.9) |
| | Education, work & future | 6 (1.9) |
| *Most stigmatizing situation faced by the patient since the pandemic | On the day of the diagnosis | 129 (32.7) |
| | During isolation and quarantine | 129 (32.7) |
| | Not felt stigmatized | 93 (23.5) |
| | While utilizing health services | 17 (4.3) |
| | In neighborhood | 3 (0.8) |
| | Abroad | 4 (1.0) |
| | When symptomatic | 1 (0.3) |
| | Do not know | 20 (5.1) |

*Multiple response questions.

(17.0%), financial aspects (6.3%), transmission to others (3.8%), infodemics (1.9%), and education, work, and future (1.9%). Most of the participants felt that they were mostly stigmatized on the day of the diagnosis (32.7%), followed by during isolation and quarantine (32.7%), when utilizing health services (4.3%).

## 3.3 Measures of COVID-19- related internalized stigma, anxiety, and depression in participants

The mean HADS-anxiety scale score was 7.2 (±4.2), and the mean HADS-depression score was 7.0 (±4.8), where scores between 8 and 10 were considered "borderline" and a score of $\geq 11$ on either subscale indicates caseness (Table 4). More than one-fifth of the participants were anxiety cases (23.3%) and one-third were depression cases (32.9%). The majority of them were classified as "normal" for both anxiety (53.2%) and depression (53.2%). The mean value of the COVID-19-related internalized scale score of the participants was 2.2 (±0.4), where the maximum scale score is 4. One-fifth had high internalized stigma (20.3%). Among the internalized stigma-specific subdomains, the participants scored the most on stigma resistance subscale ($2.4 \pm 0.4$), followed by social withdrawal ($2.3 \pm 0.6$), discrimination experience ($2.2 \pm 0.5$), alienation ($2.1 \pm 0.6$), and stereotype endorsement ($2.0 \pm 0.6$).

## 3.4 Correlation and regression analysis

Spearman's correlation revealed significant positive correlations between the ISMI total score and HADS-anxiety score ($\rho$- 0.6, $p < 0.001$) and HADS-depression score ($\rho$- 0.5, $p < 0.001$) (Tables 5, 6). Except for stigma resistance, the other four sub-domains of the COVID-19-related internalized scale were significantly associated with HADS-Anxiety and HADS-Depression scores. Stigma resistance was only primarily related to the HADS-Anxiety score. Further, linear regression analyses showed a significant positive association of internalized stigma total score with eight factors, i.e., no income in the past one month ($p = 0.013$), below average socioeconomic status ($p = 0.004$), anxiety symptoms ($p = <0.001$), depressive symptoms ($p = <0.001$), recent testing positive for COVID-19 ($p = <0.001$), involuntary admission ($p = <0.001$), prior experience of being in isolation and quarantine ($p = 0.045$), and those who blame others for COVID-19 ($p = 0.025$). The model predicted 49% of the variance.

# 4 Discussion

This study demonstrated the sociodemographic, clinical variables, and COVID-19-related knowledge and perception of persons admitted for COVID-19/Suspected COVID-19 in Nepal. It also assessed their levels of internalized stigma to COVID-19, depression and anxiety symptoms and evaluated the correlates of internalized stigma to COVID-19. The present study, conducted during the first wave of the pandemic, is the first study from Nepal that has attempted to delineate the correlates of internalized stigma related to COVID-19.

The majority of the participants in the present study belonged to the age group of 18–35, were women (70.4%) and married (71.4%). This result is in contrast to a study conducted with 441 participants living in 9 selected quarantine centers across the provinces of Nepal, wherein among the 441 participants, 180 (40.9%) were aged 20–29 years, majority of the respondents were males (426/441, 96.6%) and labor workers (90%, 395/441) (29). One of the reasons for the difference in the gender distribution of the sample could be that, in the latter study, the majority of the sample constituted returnee migrants and health workers who were more likely to be men.

In our present study, the majority of the participants were not educated beyond class 10. This finding was similar to the previous study, where only 2% of the participants had a higher education (>12th Grade). A study in India, conducted in multiple centers like ours, had a comparable monthly income. However, the mean age of the participants was 38 years, which was higher than ours, the majority were males and educated above class 12 (40). In both studies, the majority of the participants knew about the cause of COVID-19 infection but a lesser number of participants knew about the mode of transmission in our study than in the Indian study. Even though Nepal and India share similar sociocultural backgrounds and both studies were conducted in the first wave of COVID-19, the discrepancies in the result of knowledge may be because the two provinces selected in our study are not the most developed provinces of Nepal. However, the seven states, which were selected in the Indian study, are one of the developed states with the majority of the participants from urban areas and with good education and monthly income. Further, the use of different questionnaires on knowledge related to COVID-19 in both studies makes it difficult to compare results. Similarly, two studies on self-stigma, the construct of our focus, conducted in Lebanon and China had similar profiles of participants like ours.

The majority of participants in China had similar educational profiles, perception of socioeconomic, and health status, and most lived with their families. But they were mostly males and the mean age of the participants was 42.2 years (20). The majority of the Lebanese population were females with low or no income like ours. However, unlike ours, majority were singles, highly educated and only 10% were COVID-19 positive (16).

In our study, more than one-fifth of the participants were found to be suffering from anxiety (23.3%), and one-third were found to be suffering from depression (32.9%). This was significantly more than that reported from the previous study conducted in quarantine center in Nepal, where around 13.6% (60/441) of individuals kept in the quarantine centers were suffering from depression and 20.9% (92/441) of respondents were suffering from anxiety (29). However, it is important to note that, these respondents were not all cases or suspected cases of COVID-19 and were residing in quarantine centers because they were returnee migrants. The findings of the prevalence of depressive and anxiety symptoms are in sharp contrast to the literature among other studies conducted in Nepal (41), India (42, 43) and Korea (44). The differences may be because of heterogeneity in instruments used to measure anxiety and depression, time frames in which research was carried out, patients' profiles- whether asymptomatic or recovered, general population or health care workers, etc.

During the COVID-19 pandemic, people have experienced stigma related to COVID-19 illness in various spectra: social stigma (16, 19, 45, 46) perceived stigma (15, 18–20, 29, 40, 42, 44, 47–50)

TABLE 4 Measures of internalized stigma, anxiety, and depression in participants ($N = 395$).

| Variables | Mean ± S.D. or Frequency (%) |
|---|---|
| HADS-A score | |
| Categories: | |
| Normal | 210 (53.2) |
| Borderline | 93 (23.5) |
| Anxiety cases | 92 (23.3) |
| Mean ± SD | 7.2 ± 4.2 |
| *HADS-D Score* | |
| Categories | |
| Normal | 210 (53.2) |
| Borderline | 55 (13.9) |
| Depression cases | 130 (32.9) |
| Mean ± SD | 7.0 ± 4.8 |
| *ISMI score* | |
| Severity | |
| 1 No high stigma | 315 (79.7) |
| 2 High Stigma | 80 (20.3) |
| Mean ± SD | 2.2 ± 0.4 |
| Subtypes | |
| 1 Alienation | 2.1 ± 0.6 |
| 2 Stereotype endorsement | 2.0 ± 0.6 |
| 3 Discrimination experience | 2.2 ± 0.5 |
| 4 Social withdrawal | 2.3 ± 0.6 |
| 5 Stigma resistance | 2.4 ± 0.4 |

TABLE 5 Spearman correlation analysis between internalized stigma, anxiety, and depression scores ($N = 395$).

| | | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
|---|---|---|---|---|---|---|---|---|---|
| 1 | ISMI total score | 1 | – | – | – | – | – | – | – |
| 2 | ISMI alienation sub score | **0.811*** | **1** | – | – | – | – | – | – |
| 3 | ISMI stereotype endorsement sub score | **0.849*** | **0.621*** | **1** | – | – | – | – | – |
| 4 | ISMI Social Withdrawal Sub score | **0.602*** | **0.421*** | **0.418*** | **1** | – | – | – | – |
| 5 | ISMI discrimination experience sub score | **0.799*** | **0.640*** | **0.616*** | **0.449*** | **1** | – | – | – |
| 6 | ISMI stigma resistance sub score | −0.013 | **−0.171*** | **−0.038*** | **−0.456*** | **−0.127*** | **1** | – | – |
| 7 | HADS anxiety sub score | **0.6*** | **0.645*** | **0.448*** | **0.451*** | **0.446*** | **−0.211*** | **1** | – |
| 8 | HADS depression sub score | **0.511*** | **0.550*** | **0.416*** | **0.342*** | **0.385*** | −0.079 | **0.755*** | **1** |

*Correlation is significant at the 0.001 level (2-tailed).

TABLE 6 Linear regression.

| Dependent: Stigma Score | | Mean ± SD | Coefficient (univariable) | Coefficient (multivariable) |
|---|---|---|---|---|
| Age | 18–35 Years | 2.2 ± 0.4 | – | – |
| | >35 Years | 2.2 ± 0.3 | 0.03 (−0.05 to 0.11, $p = 0.442$) | – |
| Gender | Male | 2.2 ± 0.4 | – | – |
| | Female | 2.3 ± 0.3 | 0.07 (−0.01 to 0.15, $p = 0.067$) | – |
| Marital status | Married | 2.2 ± 0.4 | – | – |
| | Not Married | 2.2 ± 0.4 | 0.03 (−0.05 to 0.11, $p = 0.523$) | – |
| Education | Above 10 | 2.2 ± 0.4 | – | – |
| | Up to 10 | 2.2 ± 0.3 | 0.04 (−0.04 to 0.11, $p = 0.365$) | – |
| Employment | Employed | 2.2 ± 0.4 | – | – |
| | Unemployed | 2.2 ± 0.4 | 0.02 (−0.06 to 0.10, $p = 0.706$) | −0.06 (−0.12 to 0.01, $p = 0.096$) |
| Income in past 1 Month | No | 2.3 ± 0.4 | – | – |
| | Yes | 2.1 ± 0.4 | −0.13 (−0.20 to −0.06, $p < 0.001$)*** | −0.08 (−0.15 to −0.02, $p = 0.013$)* |
| Health care professional | No | 2.2 ± 0.4 | – | – |
| | Yes | 2.1 ± 0.4 | −0.16 (−0.25 to −0.07, $p < 0.001$) *** | – |
| Current place of residence | Own House | 2.2 ± 0.4 | – | – |
| | Hostel/ Quarter/Rent | 2.2 ± 0.3 | 0.03 (−0.05 to 0.11, $p = 0.507$) | – |
| Perceived SES | Average/ Above Average | 2.2 ± 0.4 | – | – |
| | Below Average | 2.4 ± 0.4 | 0.27 (0.15 to 0.38, $p < 0.001$)*** | 0.13 (0.04 to 0.23, $p = 0.004$)** |
| Current tobacco use | No | 2.2 ± 0.4 | – | – |
| | Yes | 2.2 ± 0.4 | 0.01 (−0.07 to 0.10, $p = 0.745$) | – |
| Anxiety symptoms | No | 2.1 ± 0.3 | – | – |
| | Yes | 2.6 ± 0.4 | 0.47 (0.40 to 0.54, $p < 0.001$)*** | 0.33 (0.26 to 0.40, $p < 0.001$)*** |
| Depression symptoms | No | 2.1 ± 0.3 | – | – |
| | Yes | 2.5 ± 0.4 | 0.38 (0.31 to 0.45, $p < 0.001$)*** | 0.18 (0.12 to 0.25, $p < 0.001$)*** |
| Recent COVID-19 Positive result | No | 2.2 ± 0.4 | – | – |
| | Yes | 2.3 ± 0.4 | 0.11 (0.02 to 0.20, $p = 0.012$)* | 0.12 (0.06 to 0.19, $p < 0.001$)*** |
| Isolation and quarantine | No | 2.2 ± 0.3 | – | – |
| | Yes | 2.4 ± 0.4 | 0.20 (0.11 to 0.28, $p < 0.001$)*** | 0.07 (0.00 to 0.13, $p = 0.045$)* |
| Mode of hospital admission | Self | 2.1 ± 0.3 | – | – |
| | Forced | 2.5 ± 0.4 | 0.41 (0.32 to 0.50, $p < 0.001$)*** | 0.21 (0.13 to 0.29, $p < 0.001$)*** |
| Symptomatic at admission | No | 2.2 ± 0.4 | – | – |
| | Yes | 2.3 ± 0.3 | 0.08 (−0.01 to 0.16, $p = 0.072$) | – |
| Knowledge of COVID-19 | Inadequate | 2.2 ± 0.3 | – | – |
| | Adequate | 2.2 ± 0.4 | 0.03 (−0.06 to 0.12, $p = 0.466$) | – |
| Considers COVID-19 dangerous | No | 2.1 ± 0.3 | – | – |
| | Yes | 2.3 ± 0.4 | 0.18 (0.10 to 0.25, $p < 0.001$)*** | – |
| Self-blame for COVID-19 | No | 2.2 ± 0.3 | – | – |
| | Yes | 2.1 ± 0.5 | −0.11 (−0.19 to −0.02, $p = 0.013$)* | −0.07 (−0.13 to −0.01, $p = 0.025$)* |

*$p < 0.05$.
**$p < 0.01$.
***$p < 0.001$.

and internalized stigma (15–20). The relationship between social and internalized stigma has been widely discussed (2, 51–53). The socio-cognitive model of internalized stigma in mental illness explains the cognitive processes involved in its development from social stigma: an individual is aware of the negative stereotype of the health condition and holds their attitude toward the state (stereotype awareness and social stigma), then as he agrees with the assumption (agreement) and eventually applies those stereotypes to themself (application) (2, 53). Internalized stigma has been consistently linked with poor outcomes such as poor self-esteem, severe psychiatric symptoms, and poor recovery from the health condition (51, 52). But very few studies have studied internalized stigma or self-stigma related to COVID-19 (15–20). In our study, about one-fifth (20.3%) of the participants admitted for COVID-19 had a high internalized stigma to COVID-19. This proportion is in sharp contrast to the higher proportion of self-stigma in an online survey conducted on the Lebanese population (65.9%) using the Self-Stigma Scale (16) and the lower prevalence of internalized shame of 2.7% in Chinese population (20). The latter study used the Social Impact Scale in which overall stigma was 12.9% (20). The difference in participants' profiles as described above, methodologies, and scales for measuring internalized stigma explain the variation in the result. Therefore, it warrants the need to study internalized stigma among people with COVID-19 systematically. It requires excellent concern, attention, and awareness at national and global levels.

Our study reported that those who recently tested positive for COVID-19, involuntarily admitted, blamed others for COVID-19, with below average perceived socioeconomic status, no income in the past month, and prior experience of being in isolation and quarantine were significantly associated with internalized stigma to COVID-19. A growing body of literature has also suggested various other societal, structural, and personal factors aggravating the stigma of COVID-19. To name a few, fear and blame of transmitting the infection to others and being responsible for other's deaths, social exclusion and social distancing during isolation and quarantine, physical violence and abuse, mental health issues, loss of livelihood, insensitive treatment by health care professionals, false information about COVID-19, social media as source of information, involvement of police in contact tracing and isolation, and legitimization of segregation by forced public health interventions, poor educational status, social support, and income have been widely discussed in the qualitative studies (18, 45, 48) and quantitative studies (16, 17, 19). However, as we have extensively assessed psychosocial factors associated with internalized stigma, similar work has not been carried out in other studies. In our research, we have identified additional factors positively associated with internalized stigma to COVID-19, i.e., involuntary admission and recent COVID-19 positive test report result. People admitted to hospitals and quarantine centers often share uncertainty, health concerns, boredom, and bad experiences in the form of insensitive behavior by staff and other colleagues and poor management in Nepal (29, 54) and elsewhere (15, 43, 45). So, forceful isolation and quarantine as a public health intervention acted as a double- edge sword and increased public stigma toward those with the illness (55). This could be why most of the participants in our study felt stigmatized on the day of the diagnosis and during isolation and quarantine. Also, in our research, internalized stigma was positively associated with having recent COVID-19 positive test results. Such a result can be easily explained by the same effect of isolation or quarantine for fear of being contagious. Hence, it can lead to more social withdrawal, discrimination, and internalized stigma among the cases and suspects. Additionally, in our study, other social and clinical factors contributed to internalized stigma, highlighting their roles as risk factors for internalized stigma. Hence, when they are timely identified, we can take measures to prevent and manage the internalized stigma of COVID-19. However, due to the different scales to measure internalized stigma and methodologies used while conducting the research, it is a great challenge to study their correlates among the available studies (56).

Internalized stigma to COVID-19 was significantly positively associated with depression and anxiety symptoms in our study. The findings are similar to other studies (17, 42, 44). In a pandemic, uncertainty about the future can result in anxiety (57). Social discrimination, exclusion, fear of rejection and abandonment lead to a negative appraisal of oneself and result in anxiety (58). Further, such concerns about a disease can result in negative behaviors toward others and a higher stigma (16), Similarly, the relationship between depression and stigma is based on several theoretical models of stigma and infectious disease or disability (59–63). The key features of depression are reduced self-esteem, ideas of guilt, and self-blame, which are also components of internalized stigma (64, 65). Depression can impair a person's judgment and make a person agree and endorse negative stereotypes. Those with mental comorbidities have or tend to perceive poor social support and avoid interaction due to anhedonia. Such isolation and poor socioeconomic status reduce their sense of belonging to the group; they feel more alienated, discriminated against due to their condition, and socially withdrawn (66). Moreover, poor socioeconomic status and socio-occupational functioning, as seen in those with mental comorbidities, delay recovery and treatment-seeking, resulting in more social withdrawal, alienation, and discrimination (66).

The stigma of COVID-19 has led to difficulty in contact tracing as people fear disclosing the infection (18). Such people delay treatment seeking or not adhering to treatment, leading to medical complications. Also, they become more vulnerable to mental illnesses. Among healthcare professionals, such self-stigma toward their condition makes them demotivated toward their profession (66). Therefore, treatment and management of COVID-19 illness and the health system suffer due to stigma due to COVID-19. Hence, mitigating the internalized stigma of COVID-19 at the multidisciplinary level and among stakeholders such as the government, the public, healthcare providers, and religious leaders is of utmost importance (26). Early screening and identification of people for mental health issues such as anxiety and depressive symptoms with risk factors, especially among those who are socioeconomically disadvantaged, under isolation or quarantine repeatedly, COVID-19 positive test reports despite isolation and quarantine, and involuntarily admitted, and their timely treatment can reduce how they internalize stigma to COVID-19. Providing some financial support to those with poor socioeconomic status, employment sick leave, access to testing, and health insurance may address social inequalities and reduce stigmata. Similarly, home isolation may be encouraged rather than involuntary admission in mild cases. Attention to human rights by public health authorities and hospitals in COVID-19 wards is necessary. Providing clear information and addressing myths about COVID-19 can lead to reduced stigma (68). Anti-stigma education for the public, health professionals, cases, suspects, and their families is paramount. There exists the role of social support in moderating the effects of internalized stigma to COVID- (17). So, social support in the form of instrumental support (e.g., task assistance), informational support (e.g., guiding copying or problem-solving), and emotional support should be encouraged during such a pandemic.

We are aware of our limitations. It was a cross-sectional study conducted in only two provinces of Nepal during the first wave of the COVID-19 pandemic and only admitted COVID-19 confirmed or suspected persons were included. Hence, there are questions about the generalizability of the findings in the Nepalese population or other population profiles. Moreover, the result is not applicable to other time frames and at the current moment since COVID-19 is no longer a pandemic. Now that COVID-19 vaccines are available, we cannot verify the causal relationship of COVID-19 stigma-related variables. We used the ISMI scale for measuring internalized stigma to COVID-19 illness. Though it was translated and adapted using the WHO translation method and there was no scale to measure internalized stigma to COVID-19, the scale is not validated for the COVID-19 confirmed or suspected persons. There was no clinical diagnosis of anxiety and depression used. Though the HADS scale is valid and reliable for measuring anxiety and depressive symptoms, both the HADS scale & substance use history were self-reported. The study also had certain potential biases, such as convenience sampling method, psychosocial stressors, social and perceived stigma, unrecognized medical illnesses, social support, personality factors, and undiagnosed psychiatric comorbidities by clinicians. Therefore, future studies with a longitudinal study design addressing the potential biases can help us understand the COVID-19 stigma-related variables in a better way.

## 5 Conclusion

A significant proportion of COVID-19 survivors & suspects experience psychological morbidities such as depression and anxiety symptoms and internalized stigma. For the first time, our data suggest that internalized stigma of COVID-19 is associated with anxiety and depressive symptoms, perceived below-average socioeconomic status, involuntary admission, prior experience of being in isolation and quarantine, recent COVID-19 positive report, self-blame, below-average socioeconomic status and no income in the past one month. Therefore, it is imperative to diagnose and treat mental health issues early. The interventions, practices, guidelines, and public health policies should target vulnerable populations with a focus on their economic background and socio-cultural beliefs to mitigate and prevent internalized stigma related to COVID-19 in isolation and quarantine facilities.

## Data availability statement

The raw data supporting the conclusion of the article will be made available. Any inquiry can be directed to the corresponding author.

## Ethics statement

This study involving human participants were reviewed and approved by National Health Research Council, Nepal (registration number: 436/2020). The participants provided their written informed consent to participate in the study.

## Author contributions

BS: Conceptualization, Data curation, Formal analysis, Methodology, Project administration, Supervision, Validation, Visualization, Writing – original draft, Writing – review & editing. AM: Conceptualization, Formal analysis, Methodology, Validation, Visualization, Writing – original draft, Writing – review & editing. US: Conceptualization, Methodology, Project administration, Supervision, Writing – original draft. VM: Conceptualization, Methodology, Project administration, Software, Writing – original draft, Writing – review & editing. SD: Methodology, Project administration, Writing – original draft, Writing – review & editing. RP: Project administration, Supervision, Writing – review & editing. MN: Methodology, Project administration, Supervision, Writing – review & editing. AB: Methodology, Visualization, Writing – original draft. CK: Methodology, Project administration, Supervision, Writing – review & editing. TK: Methodology, Project administration, Supervision, Writing – review & editing. RM: Methodology, Project administration, Supervision, Writing – review & editing. SP: Visualization, Writing – review & editing. RG: Formal analysis, Visualization, Writing – review & editing. KG: Formal analysis, Visualization, Writing – review & editing.

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## Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

## Publisher's note

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# The role of arts in moderating mental health-related stigma: views of early career psychiatrists and trainees from different parts of the world

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## 1 Introduction

Stigma was first defined by Goffman in 1963 as a "spoiled identity that discredits a person in society" (1).

In the mental health context, stigma can be categorized as two-fold, internal stigma and public stigma. Public stigma occurs when members of the public endorse stereotypes about mental illness and act based on these stereotypes. It refers to a group of negative attitudes and beliefs that motivate the public to fear, reject, avoid, and discriminate against people with mental illness (2). Self-stigma is public stigma that is internalized (2). We cite these two types of stigma as a means of simplification, which is not to say that they summarize all forms of stigma, particularly as they pertain to their most-studied outcome of interest to mental health, reduction in help-seeking behavior (3).

The impact of stigma is difficult to overstate. Stigma against mental illness has been noted in multiple studies to be highly prevalent globally (4–6), and the fear of being subject to stigma has been shown to be one of the most significant barriers to accessing mental health care among a variety of populations (7–9). Meaningful methods to combat stigma and improve access to mental health resources are therefore direly needed. In the literature, different forms of art and artistic expression have been the subject of study as one possible means of combatting mental health stigma (10–15). A systematic review showed that interventions co-employing multiple art forms, including documentary, music, radio, and visual arts, are effective in combatting stigma (10). Cinema has generally been shown to be the single most effective art form in combating stigma (10, 11). Theater has also been shown to be effective (12, 13). Music has also been discussed in the literature as a tool for ameliorating stigma in public consciousness (14).

In this opinion article, we bring together perspectives from early career psychiatrists and trainees with various cultural backgrounds practicing in nine different countries, who met through their common work in a global mental health think tank. The authors were further unified by their common interests in discussing stigma against mental illness and some of the available avenues, through art, to combat that stigma on both local and national levels. The authors fall back on their own experiences in their countries of practice, and, with that, also supplement their observations, when necessary, with literature that pertains to these experiences. While the literature in this work might not be all comprehensive, it is meant to reflect on the various experiences of authors in their countries of practice.

## 2 Stigma in different countries

Authors reported that stigma against people with mental illness persists in their countries of practice, underscoring the global prevalence of this problem. The author from Italy noted that in his country, deep-seated societal misconceptions and prejudices contribute to a climate of fear, shame, and discrimination, discouraging individuals from seeking help for mental health concerns (16–18). He further stated that this stigma not only hinders early intervention and timely treatment but also perpetuates a culture of silence, making it challenging for individuals to openly discuss their mental health struggles (16–18). The author practicing in New Zealand noted that in that country, one in five individuals with mental illness have changed their behavior in some way to avoid discrimination (19). The author from Iran noted that stigma against the mentally ill originates not only from the general Iranian population (20) but also from healthcare workers (21, 22). He noted that internal medicine and cardiology trainees had shown particularly stigmatizing attitudes towards those suffering from mental illness (21).

For at least one contributor – practicing in Hungary – a paucity of research on the subject of mental health and stigma is a significant issue in Eastern European countries (23). The author did note, on the positive side, that Hungary recently initiated a national anti-stigma program. A recent research study found that medical practitioners (24) and the general public (25) in Hungary have positive and non-stigmatizing attitudes and behaviors towards patients with mental illness.

Stigma against people with mental illness was noted to be related to a reluctance to seek care in Iran, Lebanon, India, Italy, and the UK. As an example, our author from Lebanon stated that due to cultural stigma people with mental illness are often hesitant to visit mental health professionals and seek psychiatric assistance, resulting in delayed diagnosis and treatment. This reluctance to seek treatment is even more pronounced among men, who are expected to be emotionally strong, and any display of emotional distress is viewed negatively by the community. Similarly, our author from India stated that people with mental illness are reluctant to seek help due to the fear of being judged or discriminated against. People with mental illness often prefer to seek help of non-psychiatrists (e.g. general physician, neurologist) doctor, alternative medicine doctor, and faith healers due to stigma related to mental illness and by extension, psychiatrists.

Stigma may be particularly visible in certain settings. For example, authors from the UK and New Zealand noted the widespread existence of stigma in places of work and education (15, 19).

The reports by our contributors echoed trends in the global literature. Professor Sartorius, former president of the WPA, EPA and the WHO division of mental health, in an article in 2007 wrote that stigma is the central obstacle towards provision of care for people with mental illness (4). Similarly, a systematic review studying stigma in Latin America and the Caribbean found public stigma towards individuals with mental illness as well as stigma from mental health professionals in the community but less so in university settings (6).

## 3 Stigma in different languages

Many authors pointed out the pervasive use of stigmatizing language by the general public in different countries and languages, when referring to people living with mental illness, including derogatory terms like “crazy”, “nuts” or “unstable”.

In Lebanon people with mental illness may be referred to by the term “Majnoun”, a dismissive expression encapsulating any behavior outside the norms of society. In Portuguese one would state that one “has little monkeys in the attic” or “Has a screw missing” or that they “Do not play with a full deck” to refer to someone with mental illness. In Hungarian, similar words are used to describe mental illness albeit the author refers to diagnostic labels as a more common way of using stigmatized language. As an example, in Hungary, the author noted that stigma manifested itself in the frequent use of disparaging language like “schizophrenic” as opposed to “people with schizophrenia “among medical professionals, despite publication manuals of the APA and AMA recommendations suggesting the use of the latter, more humanizing term (26, 27). Our authors from Iran noted that people with mental illness are compared to the supernatural and described as devils.

On the other hand, authors from the United States of America commented on more widespread issues related to public stigma such as its relationship to race. In America, studies showed that racial and ethnic minority groups often expressed greater public and self-stigma compared to white American groups (28). They noted that similar stigma was frequently encountered in rural populations (29).

## 4 Arts to address stigma

While all authors highlighted the presence of stigma in their countries, their experience of the use of art in their local hospitals to address stigma differed substantially. Many of the authors cited art as a healing intervention for patients with mental illness, but very few noted specific efforts by their local hospital system to target mental health stigma in the local population. The exceptions were the authors from UK and New Zealand hospitals who noted local art projects such as art installations and utilizing creative arts for health promotion and to combating stigma.

Most countries exhibited a national effort to combat stigma albeit through different means. For example, the UK, India, and New Zealand cited governmental efforts to alleviate stigma through the arts. In others, there are civilian-led campaigns. In Hungary for example, the national art festival Psychart24 whose goal was to encourage people with mental illness to paint alongside members of the general population and showcase their work to promote equality. In the US, "This Is My Brave" a storytelling theatre show where individuals with mental illness highlight their stories. In the Spring of 2020, this later developed into BraveTV to bring stories of hope online during the COVID-19 pandemic. In Lebanon, there are localized efforts through various NGOs that encourage the facilitation of community mental health art projects aiming to showcase the artistic work of individuals with mental illness in the community. In Tunisia there was a famous play "Jonoun" centered on the lived experience of a patient with schizophrenia. Furthermore, in the wake of the revolution in Tunisia art has gained greater prominence within the public eye. The question of how culture influences art and its potential to mitigate stigma, both locally and nationally, prompted diverse viewpoints among the authors. This underscores the cultural diversity of the multiple nations from which our authors hail. In the USA focus was primarily on Hollywood's cinematic depictions of mental illness. In other countries such as Italy and Hungary the relationship between architecture and culture and artworks and culture is instrumental. For example, the artworks of *Laocoön and His Sons*, the madness of Herakles and Dying Gaul were all cited. In New Zealand, Maori art forms include wood carving, weaving, tattooing, and painting. In Lebanon music, dance and literature are expressions of culture. Despite these varied perspectives, authors generally did not perceive a significant relationship between celebrating culture and mitigating the stigma against mental illness.

## 5 Conclusions

Mental illness-related stigma still exists throughout the world, but efforts are underway to combat it. These efforts take place at a variety of levels - local, civic, federal - and are as unique as the locales from which they originate. The arts have an important and growing role to play in aiding those who seek to combat the stigma against mental illness throughout the world. The authors hope that by discussing the power of art and its multiple uses throughout the world, especially with regards to its relationship to culture, that readers can be made aware of mental health stigma and the role that art can play in helping to combat it.

## Author contributions

SarE: Conceptualization, Data curation, Investigation, Methodology, Writing – original draft, Writing – review & editing. EF: Writing – original draft, Writing – review & editing. MB: Data curation, Writing – review & editing. RF: Conceptualization, Data curation, Writing – review & editing. SamE: Conceptualization, Data curation, Writing – review & editing. AL: Data curation, Writing – review & editing. DO: Data curation, Writing – review & editing. MP: Conceptualization, Data curation, Supervision, Writing – review & editing. RoR: Data curation, Writing – review & editing. RaR: Data curation, Writing – review & editing. FR: Data curation, Writing – review & editing. MS: Conceptualization, Data curation, Methodology, Supervision, Writing – review & editing.

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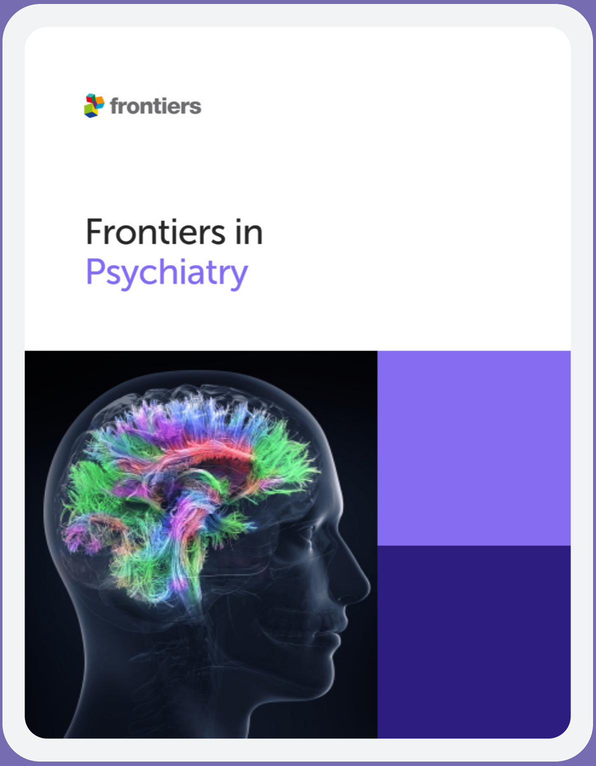

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