Review

Exploring and Mapping the Lived Experiences of Stigma Among People Living with a Mental Illness: A Scoping Review of Qualitative Studies

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Correspondence: Andrea Poliani – Center for Nursing Research and Innovation, Faculty of Medicine and Surgery, Vita-Salute San Raffaele University, Milan, Italy;
Mail: poliani.andrea@unisr.it

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Miriana D'Andrea[1], Giulia Villa[2], Andrea Poliani[2], Ilaria Marcomini[2], Debora Rosa[2], Duilio F. Manara[2]

[1] Monzino Cardiologic Center - IRCCS, Milan, Italy
[2] Center for Nursing Research and Innovation, Faculty of Medicine and Surgery, Vita-Salute San Raffaele University, Milan, Italy

Abstract

Introduction. Stigma affects a large proportion of people with mental health conditions and it can be a potent social stressor, presenting persistent challenges to individuals' coping abilities. The present study aimed at mapping and exploring the direct experiences of stigma encountered by individuals with mental health conditions.

Methods. A scoping review was conducted according to Joanna Briggs Institute guidelines. Searches of PubMed, PsycINFO, EmBASE, and CINAHL led to 18 eligible qualitative studies.

Results. Four primary themes emerged: self-stigma, involving the internalization of societal stereotypes; descriptions of social and public stigma; lack of knowledge in mental illnesses' course; and the consequences of stigma for individuals' lives.

Discussion. Results highlight the deeply negative and exclusionary impact of stigma surrounding mental disorders, outlining its manifestation and repercussions for social life. Future research is needed to identify a direct approach to the issue and to detect the most appropriate approaches in facing it. To help limiting the experience of stigma, healthcare providers should ensure an individualized care relationship, in a secure and empathetic environment filled with elements of understanding, consent and informativeness.

Keywords: Mental Disorders, Mental Health, Nursing, Stigma.

Introduction

Stigma can be defined as a set of negative beliefs held by individuals, groups or society about a specific characteristic.[1] There are various approaches to understanding the concept of stigma, yet most acknowledge four essential elements: 1) distinction and labelling of others' differences, 2) association between these differences and harmful attributes/ stereotypes, 3) group separation between 'us' and 'them', and 4) discrimination and loss of social status.[2] Theories suggest that the strong connection between stigma and stereotyping is rooted in a tendency to identify, recognize, and label different characteristics in others.[3,4] This process appears to be a way used by individuals to understand the world around them.[3,4] Stigma affects a large proportion of people with mental health conditions[5] and it can be a potent social stressor, presenting persistent challenges to individuals' coping abilities.[6,7] According to the Canadian Mental Health Association, 10–20% of young adults in Canada suffer from mental illnesses such as anxiety and depression.[8] In Europe, mental health conditions affect around 84 million people and are among the leading causes of non-fatal health loss.[9] In England, it is estimated that almost half the population will present a mental health condition at some point in their life, while nine out of ten people who live with a mental illness experience stigma on a social and institutional level.[10] In China, there is emerging evidence of increased personal guilt and shame related to the experience of mental illness.[11] Understanding perceptions of individuals experiencing mental illness related stigma is important to implement targeted care, help direct resources, remove barriers to help-seeking, and improve coping among this population. Preliminary searches of available literature indicate heterogeneity in existing studies' methods of data collection and analysis. The choice to conduct a scoping review was based on the breadth and heterogeneity of the available evidence concerning lived experiences of stigma in people with mental illness or poor mental health. The topic encompasses diverse populations, contexts, and methodological approaches, making it necessary to map and synthesize the range of existing knowledge rather than to focus on narrowly defined outcomes. A scoping review was therefore the most appropriate design to provide a comprehensive overview of the extent, nature, and characteristics of the literature, to identify research gaps, and to guide future qualitative evidence syntheses or primary studies. The aim of this scoping review is to map and explore the lived experiences of stigma by people with mental illnesses, independently of context and geographic region.

Methods

This scoping review was conducted following the Joanna Briggs Institute (JBI) methodology for scoping reviews.[12,13] The Preferred Reporting Items for Systematic Reviews and Meta-Analysis extension for Scoping Reviews (PRISMA-ScR) Checklist[14] was used to report this review. The following research question was formulated: *"How do people with mental illness experience stigma?"* Then, the sub-question: *"How does the experience of stigma impact daily life?"* The research question was structured following the Participant-Problem/Concept/Context (PCC) framework, as reported in Table 1.

Table 1. PCC Framework.[12]

PCC	
Population	People suffering from mental illness
Concept	1. Social stigma
	2. Lived experience
Context	No geographical or place distinction were made

Inclusion and exclusion criteria

The inclusion criteria encompassed articles that addressed the research questions and followed the PCC framework, written in English and/or Italian, and published from 2012 to the present. This date was chosen to capture the period following growing international policy attention to mental health[15] and the years immediately preceding the DSM-5 publication,[16] which together marked a turning point in stigma research.Given that the review specifically aimed to map the lived experiences of stigma, only qualitative research was included, as

this methodological approach provides the most appropriate evidence to capture such experiences. Participants needed to be at least 13 years old (i.e.; for individuals' capability of autonomously narrating their experience) and living with a diagnosis of mental illness and/or having poor mental health. Grey literature publications, and publications not focused on review's research questions were excluded.

Search strategy and database searching

In accordance with guidance by Aromataris and Munn (2020)12, a three-step search approach was employed. The first step entailed conducting an initial limited search on two relevant online databases: MEDLINE via PubMed and the Cumulative Index to Nursing and Allied Health Literature - CINAHL. This preliminary search permitted to identify words in titles and abstracts of relevant articles as well as index terms used to describe these articles. In the second step, a comprehensive search was carried out using all keywords and index terms identified in the first step. This expanded search was conducted across MEDLINE via PubMed, CINAHL, PsycINFO, and Excerpta Medica DataBASE - EmBASE. The search strategy, including all identified keywords and index terms, was adapted for each database and can be consulted in Supplementary Materials (Table S1).

The third step involved searching reference lists of selected sources to identify any additional relevant studies. A research expert at the university assisted with development of the search strategy. Search terms comprised a combination of Medical Subject Headings (MeSH), text words, and variations of words related to mental illness, stigma, and lived experience. The database search was first conducted in October 2022 and updated at the end of April 2023.

Selection and screening

Study selection was conducted based on the PRISMA Flow Diagram 2020.[17] Selection was divided into two steps using the RAYYAN web application.[18] First, title-abstract selection was conducted by two authors working independently. Screening involved evaluation based on inclusion criteria and attempted retrieval of full texts. Secondly, two authors working independently assessed the full texts of selected studies against the inclusion criteria. Divergences were resolved through discussion with a senior reviewer. Eligible texts were systematically collected and sorted. Deduplication was conducted using the reference manager Zotero.[19] Subsequently, documents were manually sorted.

Data extraction

Metadata such as title, year of publication, authors, publication type, and publication name were extracted using Zotero.[19] These data were manually checked upon import. Data were extracted from included papers using standardized data extraction tools as reported in the JBI Manual of Evidence Synthesis.[12] Reviewer disagreements were resolved through discussion. The data extraction form consisted of the following variables: author(s), year of publication, country of origin (i.e.; where the source was published or conducted), purpose, population, sample size, type of mental pathology, data extraction and re-elaboration model, and key findings related to the scoping review's question. The JBI template showing sources of evidence, study characteristics, and results of extraction 13 can be consulted in Supplementary Materials (Table S2).

Presentation of findings

The results of the scoping review were shown using a combination of narrative, tables, and figures. The synthesis of findings followed a thematic analysis approach.[20] After data extraction, two reviewers (M.D., A.P.) independently coded the qualitative findings from the included studies. Codes were then compared, discussed, and grouped inductively into categories. Through iterative discussion, these categories were further refined into four overarching themes and corresponding subthemes. Any disagreements were resolved through consensus or by involving a third reviewer (G.V.).

Results

Sources of evidence

The database search retrieved a total of 1,407 articles. After deduplication, 982 remained. From title and abstract screening, 205 articles were judged potentially eligible. Of these, 32 records were impossible to retrieve in full-

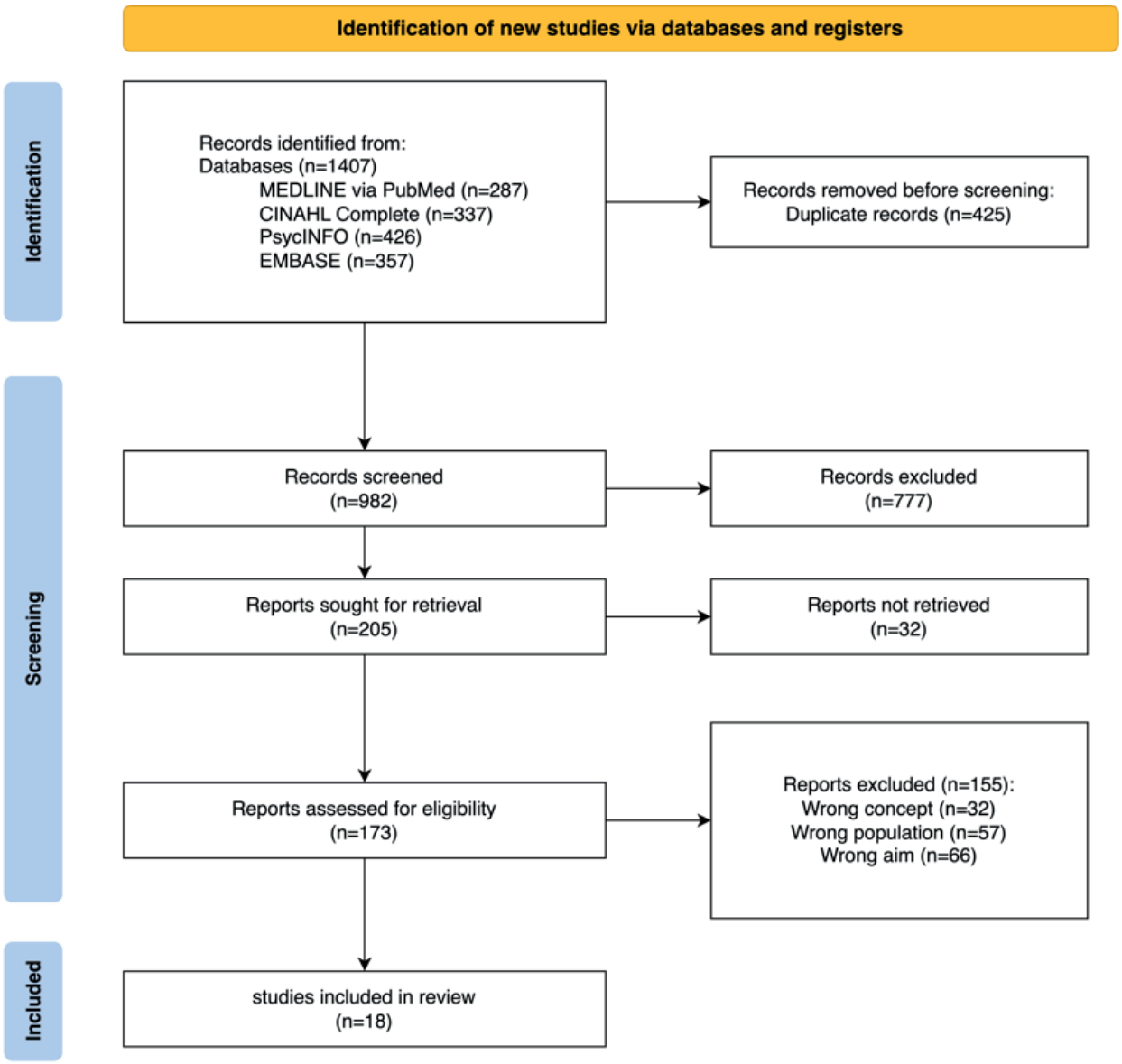

Figure 1. PRISMA Flow Diagram 2020.[17]

text, leaving 173 articles for full-text screening. Finally, 18 articles were included. Figure 1 shows the PRISMA Flow Diagram 2020 17 illustrating the selection process.

Studies characteristics

All 18 articles included in this scoping review were qualitative studies and all analyzed stigma from the direct experiences of people with mental health conditions. Most of the studies were from the United Kingdom,[8,21–25] and from the USA and South America.[26–30] The remaining studies were from Europe,[31–33] the Asian continent,[32,34,35] and the African continent.[1,32,36]

The studies included were published between 2012[23] and 2021,[27,32] with details and connections with the geographical area of publication shown in Figure 2.

The included studies cover diverse continents, including Europe, Asia, Africa, and North and South America, and involve participants from a variety of cultural, social and economic backgrounds. In the European and United Kindgom context stigma is narrated as an isolating experience, affecting help seeking behaviours and influencing negatively self-perception.[31,33] In the studies exploring the African context is reported social rejection and the association between mental illness and religious or spiritual

cause.[1,36] In studies exploring stigma in the Asian context, mental illness stigma is rooted in societal expectations, leading individuals not to want to disclose their mental illness.[34,35] Lastly,

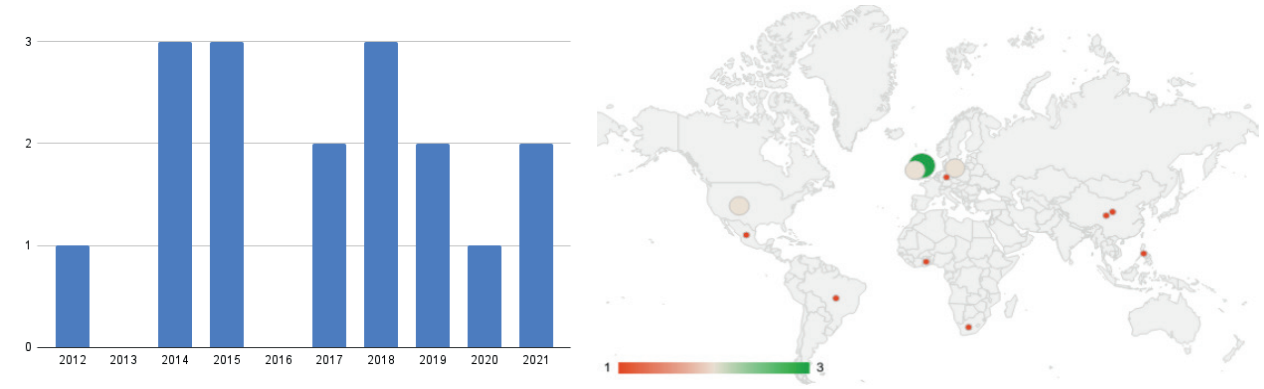

Figure 2. Publication year of included studies and geographical context of publication.

in USA and South America stigma appears to be connected to labeling and self-identification with the mental illness,[26,27] and emerges a focus on stigma experienced in social and institutional structures.[28,29]

The majority of the studies analyzed stigma in people between the ages of 18 and 69. One study focused on adolescents[8] and two focused on the elderly.[25,27] Mental illnesses most commonly investigated were schizoid personality disorder, depressive, bipolar and anxiety disorder, psychosis and borderline personality disorder. Most studies included participants with more than one mental illness, one study[31] did not specify the mental health conditions taken into account. Regarding data collection, seven studies used semi-structured interviews, four studies open-ended interviews, in three studies were used focus groups, and structured interviews in two studies. Information gathering and analysis were conducted using thematic analysis in nine studies, content analysis in three studies, grounded theory in three studies, framework analysis in one study, and lastly inductive analysis in one study.

Main findings

Four themes emerged from the review:

1. Self-Stigma, as the internalization of stereotypes and external prejudice.
2. Social and Public Stigma: exploring distancing, stigmatizing and discriminatory behaviour that can permeate relationships with family, friends and peers, the work environment and the institutional substrates.
3. Lack of Knowledge about Mental Illness's Course: exploring lack of skills and willingness to understand mental illnesses, as perceived by people with mental health conditions in their everyday life.
4. Direct Experiences and Consequences of Stigma: exploring how experiences of discriminant and stigmatizing behaviours can lead to restricted social lives, loss of social status, and overall estrangement towards surroundings.

Characteristics and data extraction of included studies are presented in Table 2.

Summary of findings

Included articles were analyzed to identify common themes that described the experiences and stigma faced by individuals with mental health disorders. The analysis allowed for the identification of four main themes previously descripted and eight consequential sub-themes. A graphic representation of these results is shown in Figure 3.

Of the four main themes, each was directly connected with sub-themes that helped to explain the main theme.

Table 3 summarizes the frequency and percentage that each theme occurred in included articles.

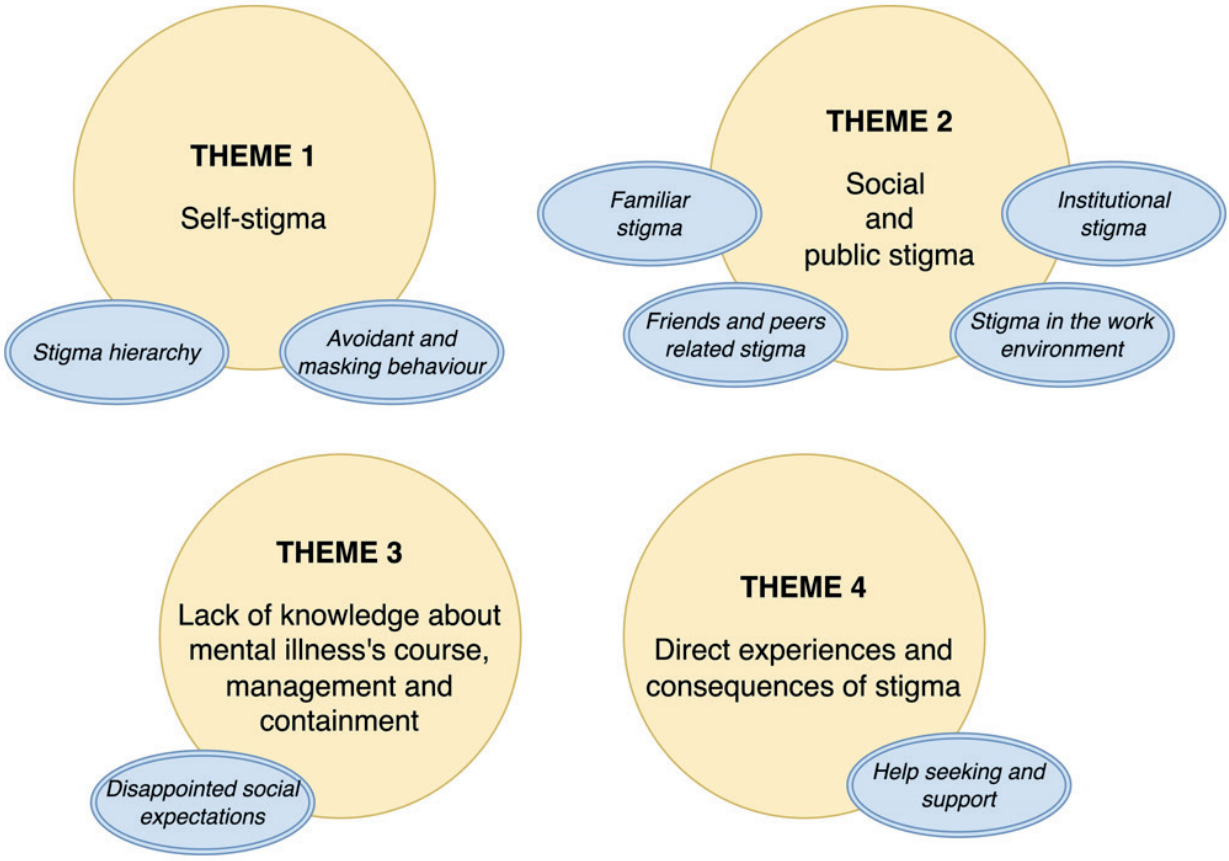

Figure 3. A graphic representation of themes emerged from the review.

Table 3. Summary of search strings (part 1).

Citation	Theme 1†	Theme 2‡	Theme 3§	Theme 4¶
Axelsson et al., 2020		X		X
Bluhm et al., 2014			X	
Campbell et al., 2016	X	X	X	X
Chung et al., 2019	X	X		X
Eads et al., 2021	X	X		
Egbe, 2015		X		X
Gyamfi et al., 2018	X	X	X	
Hamilton et al., 2014		X	X	
Huggett et al., 2018	X	X		X
Koschorke et al., 2021		X		X
Lakeman et al., 2012		X		X
McKeague et al., 2015		X		X
Mizock et al., 2015			X	
Mora-Rìos et al., 2014		X		
Oexle et al., 2019	X	X		X
Tanaka et al., 2018	X	X	X	X
Tzouvara et al., 2018	X			
Vedana et al., 2017		X	X	
Frequency (n.) and percentage (%) of occurrence	n.9 (50%)	n.15 (83.33%)	n.7 (38.89%)	n.10 (55.56%)
† T1= Theme 1; ‡ T2= Theme 2; §T3= Theme 3; ¶ T4= Theme 4				

Table 3. Summary of search strings (part 1).

Author(s) and year.	Title	Study Design	Study location	Aim	Sample	
Huggett C, et al. (2018)	A qualitative study: experiences of stigma by people with mental health problems	Qualitative study	England	To investigate the stigma experienced by people with mental illnesses	13 participants. Age range 21–69 years old, 46% females and 54% males	
Lakeman R, et al. (2012)	A qualitative study exploring experiences of discrimination associated with mental-health problems in Ireland	Qualitative study	Republic of Ireland	To perform an in-depth exploration of people's understanding, experience and the impact of discrimination as a consequence of being identified with mental-health problems	30 participants. Age range 23–62 years, 63% males and 37% females	
Tanaka C, et al. (2018)	A qualitative study on the stigma experienced by people with mental health problems and epilepsy in the Philippines	Qualitative study	Philippines	To investigate the factors related to experiences of stigma and the lived experience of discrimination of people with mental health problems in the Philippines	39 people with mental health problems, age range 19–69 years, 66.7% males and 33.3% females	
Chung KF, et al. (2019)	Changes in Stigma Experience Among Mental Health Service Users over Time: A Qualitative Study with Focus Groups	Qualitative study	China	To explore how Chinese mental health service users perceived the changes in social stigma and stigma coping	22 participants, mean age was 55 years, 68.2% females and 59.1% were males	
Hamilton S, et al. (2014)	Discrimination against people with a mental health diagnosis: qualitative analysis of reported experiences	Qualitative study	England	To explore experiences of reported discrimination described by mental health service users in England	537 mental health service users randomly selected from five National Health Service Trusts in England. A subsample of 23 interviews was available in the record: 7 males, 16 females, age range 26–60	
Catherine E. (2015)	Experiences and effects of psychiatric stigma: monologues of the stigmatizers and the stigmatized in an African setting	Qualitative study	North West Province of South Africa	To explore the experiences and effects of psychiatric stigma among mental healthcare services users and healthcare providers	77 participants, 32 healthcare service providers and 45 mental health service users, over the age of 18 37 participants (27 females and 10 males), age range 16–25 years	
Chung KF, (2019)	"I Just Have to Stick with It and It'll Work": Experiences of Adolescents and Young Adults with Mental Health Concerns	Retrospective observational study	England	To address the experiences of mental health problems in an adolescent/ young adult population	37 participants (27 females and 10 males), age range 16–25 years	
Gyamfi S, et al. (2018)	Individual factors that influence experiences and perceptions of stigma and discrimination towards people with mental illness in Ghana	Prospective observational study	Ghana	To examine perceptions of stigma and discrimination and self-stigma in individuals diagnosed with a mental illness	12 participants (9 males and 3 females), age range 18–50 years	
Mizock L, Russinova Z. (2015)	Intersectional stigma and the acceptance process of women with mental illness	Qualitative case narrative research	United States	To demonstrate the impact of intersectionality stigma on the process of acceptance for women with mental illnesses	20 European American participants, 3 African American participants, 3 Asian participants, 2 biracial participants, 1 Latino participant, 1 Native American participant. Age range 19–72 years	
Axelsson M, et al. (2020)	Lived experiences: a focus group pilot study within the MentALLY project of mental healthcare among European users	Focus group pilot study	Europe	To describe experiences of mental healthcare among adult Europeans with mental health problems	50 participants, age range 29–69	
Koschorke M, et al. (2021)	Perspectives of healthcare providers, service users, and family members about mental illness stigma in primary care settings: A multisite qualitative study of seven countries in Africa, Asia, and Europe	Multi-site qualitative study	Africa, Asia and Europe	To document perspectives of PCPs and people with mental illness who use primary care services	248 participants: 64 primary care providers, 11 primary care facility managers, 111 people with mental illness, and 60 family members of people with mental illness	

	Participant's mental concerns	Data collection and extraction method	Main findings
	Depression, schizophrenia, anxiety, borderline personality disorder, psychosis	In depth focus groups Thematic analysis	Participants identified their mental health diagnosis as labels, which brought self-stigmatization as they identified with it and a perception of stereotyping by others: not only in the form of social stigma but also within family members and friends. Participants felt like there was a hierarchy of stigma, resulting in being seen more as a threat depending on the mental illness concern
	Bipolar disorder, major depression, anxiety, schizophrenia	Structured questionnaire exploring discrimination and in-depth interviews Inductive analysis, semantic themes, thematic map	Participants provided examples of discrimination in the work environment; disclosure of mental illness was something they were very ambivalent on doing in fear of being stigmatized. They also brought examples of stigma in personal relationships and related to accessing healthcare
	Schizophrenia, anxiety, depression	In depth interviews Constructivist grounded theory approach (theoretical framing)	Participants described personal experiences of public stigma, familial stigma, and the ignorance of people that lacked the ability of understanding a normal course of mental illness. They also reported direct consequences of stigma such as isolation, aggravated mental health, self-identification with mental illness
	Schizophrenia, bipolar disorder, major depressive disorder, anxiety disorder	Focus groups Grounded theory approach	Participants divided between believing some improvements in public stigma and acceptance were made, and having reservation about such changes. Stigma coping and learning how to interact with society is something all participants stated they had to do in order to not aggravated their sense of isolation
	Schizophrenia, bipolar disorder, depression, anxiety disorder, personality disorder	Structured telephone interviews using the Discrimination and Stigma scale (DISC-11) Qualitative content analysis	Participants described their perception of discrimination in four major areas: family, friends, neighbours and work environments. A common point was the lived experience of being distanced by society and losing contact with people they were once connected to
	Depression, schizophrenia, bipolar disorder	Focus groups Thematic analysis with the aid of the software NVivo 10.1	Participants described being treated as if they were different citizens, with distancing, forced social isolation and societal disapproval. People with mental illness felt like they were blamed for their condition and experienced stigma perpetrated by family, friend and society in general
	Depression disorder, anxiety disorder	Semi-structured interviews Coding and identifying concepts and related emerging themes	Participants stated that self-stigma was a high component of social distancing, and that the fear of disclosing their mental health status made them distancing from new acquaintances. Family and peers are reported to be a large component of stigma
	Schizophrenia, bipolar disorder	Semi-structured interviews Thematic content analysis	Participants described direct experiences of stigma and mostly reported negative interactions with the public and society. In result, self-stigma became predominant and isolation from social interaction a natural conclusion
	Bipolar disorder, major depression, schizophrenia spectrum disorder	Semi-structured qualitative interviews Thematic analysis to develop case narratives	Women in this study experience intersecting levels of oppression linking mental health stigma with sexism for their gender. This can progressively interfere with the woman's acceptance of their mental health status, bringing identification with such mental illnesses and social withdrawn
	Not specified	Focus groups Thematic analysis	Stigma was present in all of the Countries included in the report. It was in the form of social stigma, stigma from peers and self-stigma. It affected the ability and the courage to seek mental health help and it was an ultimate obstacle for recovery when present
	Common mental disorder, severe mental disorder, diagnosis not known	Qualitative interviews Framework analysis	Participants reported direct experiences of stigma, in particular regarding interactions with social members, healthcare workers, public in general, friends and peers. Some were physically attacked, some were verbally abused, others suffered from isolation and loss of credibility and significant role in the society and in the family status

Table 3. Summary of search strings (part 2).

Author(s) and year.	Title	Study Design	Study location	Aim	Sample	
McKeague L, et al. (2015)	Retrospective Accounts of Self-Stigma Experienced by Young People With Attention-Deficit/ Hyperactivity Disorder (ADHD) or Depression	Qualitative study	Republic of Ireland	To investigate the experiences of self-stigma in childhood and adolescence	16 participants, age range 18–30 years. 56,25% females and 43,75% males	
Tzouvara V, et al. (2017)	Self-stigma experienced among older adults with mental health problems residing in long-care term facilities: a qualitative study	Qualitative study	England	To explore experiences of self-stigma among institutionalized older adults with mental health problems	10 participants over the age of 60, 5 males and 5 females	
Oexle N, et al. (2019)	Stigma and suicidality among suicide attempt survivors: A qualitative study	Qualitative study	Germany	To explore the consequences of mental health stigma and suicide stigma among a sample of suicide survivors	13 participants, 7 females and 6 males, age range 23–65)	
Mora-Rios J, Bautista N. (2014)	Structural stigma, gender and intersectionality. Implications for mental health care	Qualitative study	Mexico	To describe the commonest forms and manifestations of structural stigma from the perspective of a group of service users and providers at three treatment centers of third level	95 health care providers and 68 service users, age ranged to 21–64 years	
Vedana KGG, et al. (2017)	The meaning of stigma for people with mental disorders in Brazil	Qualitative study	Brazil	To understand the meaning of stigma for people with mental disorders	46 participants with mental illnesses, 91.3% females, 8.7% males	
Eads R, et al. (2021)	The power of perception: lived experiences with diagnostic labeling in mental health recovery without ongoing medication use	Qualitative study	United States	To explore the lived experience of diagnostic labeling and self-perception among persons in sustained recovery without ongoing medication use	19 participants, 10 females and 9 males, age range 27–70 years	
Campbell RD, Mowbray O. (2016)	The stigma of depression: Black American experiences	Qualitative study	United States	To explore the mental health stigma experienced by Black Americans	17 participants, age range 21–57, 13 females and 4 males	

Main Theme 1: Self-stigma

Self-stigma can occur when negative stereotypes are progressively introjected by individuals with mental illness, causing their perceptions of themselves and their mental health problems to change over time, making increasingly difficult to separate themselves from the pathology.[22] Negative stereotypes about mental illness can be amplified by diagnosis. Oexle et al.[33] articulate how stereotypes related to mental illnesses are deeply ingrained at the societal level. Mental health labeling and the stigma perpetuated through labels can have devastating effects.[27] Societal rejections can increase individuals' perception of being inadequate, leading to an idea of mental pathology and reinforcing the association between self-identity and external judgments.[34] This can lead to strained interpersonal relationships and a negative self-perception of being someone who needs to be 'fixed'.[24]

Subtheme 1.1: Stigma Hierarchy

Hierarchies of stigma arise from the complexity of mental illnesses, creating a need for simplification and categorization. This can lead to pessimistic views regarding mental illness.[35] Individuals with mental health conditions often feel linked to their diagnosis, and to the label attached to it, leading to internalized stigma.[22] Different categorizations of mental illness, and the concurrent translation of them into the individual diagnosed with it (e.g.; behaviours, emotional responses), can result in a differential perception of dangerousness of people with

	Participant's mental concerns	Data collection and extraction method	Main findings
	ADHD and depression	Open-ended interviews Thematic analysis	Participants described stigma in the primary form of peer stigma, with examples of negative attitudes received by friends and peers in general. This has led to feelings of being "broken" of "damaged" of "weak" and to operate selected disclosure of mental illness in fear of being stigmatized
	General mental health illnesses	Semi-structured interviews Content analysis	Participants experienced self-stigma in terms of sense of rejection, inferiority and ultimate isolation. They also stated to feel internalized feelings of guilt and shame regarding being mentally ill
	Affective disorders, schizophrenia spectrum disorders, dissociative disorders	Individual in depth interviews Qualitative content analysis (Mayring, 2000) within MAXQDA 12 to analyze the data	Participants reported lived experiences of stigma and discrimination toward their mental illness and around the theme of suicide and being a suicide attempter. They reported avoidant behaviors from peers, feeling unsupported, unfair treatment and loss of opportunities. They also reported feeling of profound loneliness and hopelessness
	Schizophrenia, bipolar disorder, obsessive compulsive disorder and dual disorder	In depth interviews Thematic analysis with inductive method	Participants described experiences of stigma and discrimination, how it determined a barrier to help seeking and how it presented in many spheres such as family, clinical and social events. This lead to social vulnerability and social inequalities
	Mood disorder, bipolar affective disorder, depression, borderline personality disorder, schizophrenia, first psychotic episode, psychogeriatric disorder, psychoactive substance abuse disorder	Semi-structured interviews Thematic analysis with symbolic interactionism	Participants described stigma as a "hurtful misunderstanding". Social stigma is described as the inability of people to sympathize, understand and tolerate differences. It enlightened self-stigma when the sub-tone implied that it was the mentally ill person's fault that they had the condition. A considerable finding is that emerged that also mentally ill people have stigmatizing behavior toward people with more severe mental disorders
	Schizophrenia, bipolar disorder, and major depression	Grounded theory with semi-structured in depth interviews Constant comparative method	Participants stated that "diagnostic labeling" could have two different sides: one in which the person externalize their disease, finding explanation for symptoms and making help seeking easier. On the other hand though, participants felt the "diagnostic label" was limiting and led to a stigmatized identity and self-stigma
	Depression	In depth semi-structured interviews Thematic analysis	Participants enlightened the cultural form of social stigma as a major barrier of help seeking. Some attributed the stigmatization to a form of ignorance and to a lack of education on the matter. Self-stigma and self-identification with the disease was predominant. Participants masked and distanced from peers and family, knowing there was no space for acceptance and for understanding of their disease in a deep cultural way

mental health conditions.[22] Individuals with schizophrenia, borderline personality disorder, bipolar disorder, and psychosis are often perceived by the general population as aggressive, unpredictable, potentially violent, and therefore to be avoided and feared.[34–36] Conversely, people suffering from depression and exhibiting suicidal thoughts are typically viewed as frail, having suicidal instincts, or being weak, and can be labeled as selfish, and self-referential.[26,33]

Subtheme 1.2: Avoidant and Masking Behavior

Self-stigma can lead people with mental health conditions to a progressive distancing from social groups, friendships, and families. They often experience anticipatory fear of reactions and repercussions[26] and this process often begins with the decision of not disclosing their mental health condition due to fear of discrimination.[33]

Main Theme 2: Social and Public Stigma

Individuals with a mental health condition frequently experience fear, distrust, estrangement from others, and sometimes violence,[22] as a result of stereotypes and prejudice. Discrimination was also commonly reported.[35] To be avoided and feared by the social environment raises feelings of disconnection and dehumanization.[27]

Subtheme 2.1: Familiar Stigma

Familiar stigma can be defined as stigma perpetrated by family members of individuals with mental health conditions.[21,22] Stigmatized individuals often reported dismissiveness,

lack of attention, and underestimating of disorders' severity by others, which led to feeling unwelcomed and unseen.[21] Verbal abuse was reported in many cases, as was physical abuse and violence.[29,32] Taboos and lack of knowledge regarding the characteristics of mental pathology can lead subjects to feel abandoned and frustrated, particularly the more they introject these harmful experiences. [6,35]

Subtheme 2.2: Friend- and Peer-related Stigma

Individuals reported being the object of teasing from friends or peers and expressed that the avoidant attitudes of others had long-term impacts.[23,36] Progressive estrangement was a particularly concerning observation.[21,33] Such experiences frequently cause those with mental illness not to attempt to join or form peer groups and cement an unwillingness to disclose their mental condition.[23,33]

Subtheme 2.3: Stigma in the Work Environment

Many individuals reported not disclosing their illness in the workplace due to fear of consequences (e.g.; not obtaining a position, losing their job, experience harassment).[23] Stigma at work was also connected to negative interactions, lower salaries, less responsibility.[34,36] Work performance was often affected, with loss of opportunities for career growth widely reported.[32] Stigma in the workplace[22] thus manifests as direct or indirect (i.e.; present but not openly manifested) discrimination and prejudice regarding mental pathology.[21]

Subtheme 2.4: Institutional Stigma

The analysis showed a structural stigma at the level of institutions such as schools, police stations, and hospitals . Particularly concerning was stigma within healthcare services. Individuals reported experiencing dismissiveness when needing medical attention, feeling disempowered, not heard, misunderstood, and general disengagement.[22,23,32] There was a feeling of not being prioritized by health professionals as individuals with mental illnesses. This was characterized by longer waiting lists, shorter visits, fewer objective assessments requiring physical contact, and less willingness to listen.[27,29,31] Women with mental conditions reported experiencing an intricated form of discrimination, that was related both to gender and to mental health, and exacerbated in their dealings with public healthcare services.[28] Moreover, Lakeman et al.[23] reported that people with mental illness were less likely to have access to a bank account or loan facility, and less able to buy or rent a home.

Main Theme 3: Lack of knowledge about Mental Illness's Course and Management

Stigma around mental illness reflects stereotypes and prejudices, which can arise when something is poorly understood.[35] Individuals frequently reported feeling that people around them alternated between passive or dismissive behavior, to an overprotective stance that prevented them from making their own choices.[21] It should be noted that people with mental conditions are not always able to recognize signs and symptoms, which can extend the time taken to seek clinical help.[8] Lack of knowledge about mental illness appears to pervade every aspect of everyday life, leading some individuals to lament a lack of mental health conditions' management and willingness to understand, even among healthcare professionals.[30]

Subtheme 3.1: Disappointed Social Expectations

Individuals with mental health issues often felt that others oversimplificated the course of mental illness, or were overly optimistic or pessimistic regarding prognosis and symptoms, and had high expectations about how individuals should behave.[35] That could cause relational detachment, particularly when others realized their expectations could not be met.[21] Cultural factors were also an influence. Cultural grounds in which mental illness is linked to weakness, lead more often to unrealistic expectations about fighting the illness. This can leave individuals feeling inadequate.[26] Expectations can also be gender-specific, with women finding themselves strongly stigmatized when facing mental illness, with help denied and their value diminished socially and culturally.[28]

Main Theme 4: Direct Experiences and Consequences of Stigma

According to Tanaka et al.[35], key consequences of stigma experience are reduced social network, estrangement - whether due to circumstances or individuals' desire to reduce social contact, loss of social roles and opportunities for personal and professional development, and economic difficulties. Egbe[1] notes how individuals with mental illness are often dehumanized

through being treated as inadequate or lower citizens, without the rights of others. Studies by Koschorke et al.[32] and Campbell and Mowbray[26] explored how the experience of stigma created an anticipatory fear of discrimination, leading to restricted social lives and a sense of emotional detachment from those around them.

Subtheme 4.1: Help Seeking and Support

Experiencing stigmatizing events can cause mentally ill people to modify the ways in which they seek help. Self-stigma appears to be a primary obstacle, leading individuals to lose hope in receiving assistance and develop a profound sense of loneliness in their struggle.[22,23,33] In certain instances, enhancing resilience to stigmatization and strengthening coping mechanisms has been successful in encouraging individuals to access care, achieve self-acceptance, and lead a more serene life.[34] The assistance of family and friends/peers can help drive change among individuals, especially concerning the ability to seek clinical assistance.[24,31]

Discussion

In this scoping review, a broad view of available literature describing nature of stigma and discrimination experienced by people suffering from mental conditions was carried out. The experience of stigma was intensely negative and described as alienating and isolating.[1,33] It was viewed as a widespread social issue with minimal progress being made, such that individuals who had experienced stigma over long periods held little hope for resolving the problem.[34] Particularly concerning was the issue of self-stigma, whereby stigmatized individuals begin to adopt the harmful stereotypes they have experienced as part of their self-concept.[22] Results reveal that the most painful sources of stigma are often one's closest relationships. Individuals in need of acceptance from their families and peer groups often reported unmet expectations, discriminatory attitudes, and a lack of support.[21,26,31] Indicative of the all-encompassing nature of stigma around mental conditions is the fact that experiences of stigma were similar irrespective of age, place of residence, or type of mental pathology.[25,32] Nevertheless, it was experiences in different ways: it seems that very young (13–18 years of age) and very old (>70 years of age) individuals experience self-stigma and internalization of others' prejudices more frequently,[24,25] while young adults and adults (18–65 years of age) find greater difficulties in working life, relationships, contact with family, and interacting with the healthcare system.[22,23,32] Suffering from being the target of others' prejudices was therefore present in all age groups.[8,22,25] For many, the experience of stigma creates a need to hide one's mental pathology.[22] The consequences of doing so include an increased sense of burden and a reduced likelihood of accessing support.[8] Indeed, results highlight that stigma is a profound barrier to seeking help.[8,22,26,33] Regarding experiences with health professionals and healthcare facilities, studies reported concerning instances of stigma, with resulting experiences of rejection, feelings of not being taken seriously, and a perception that one's mental pathology obscures one's physical symptoms.[22,32] Moreover, individuals reported unsatisfactory care relationships, unclear or incomplete information, their opinions not being considered, and inadequate explanations of treatment plans and health.[31,32] These experiences inevitably lead to reduced interaction with facilities and a decreased tendency to seek treatment and assistance.[1,35] Notably, however, the theme of health professionals, and society more broadly, lacking sufficient knowledge about the management of mental illnesses received relatively little attention across the articles included in this scoping review. This suggests further investigations are required to improve knowledge on this issue and highlight areas for intervention.

The geographical location of included studies can allow us to explore how different cultural aspects are linked to the stigma experience. Stigma appears to be a transversal experience for individuals with mental illnesses, however tends to be deeply influenced by cultural, societal and institutional contexts. In the Western context, stigma appears more internalized, with self-stigmatization and identification with the illness being predominant. This leads more often to social isolation, a tendency to avoid disclosure of mental illness for fear of discrimination, and difficulty in help-seeking.[21–23] Whereas in context like South America and Africa, where, based from the included studies, mental illnesses seem to be connected to individual and societal value, or linked to religious and spiritual causes, individuals report distance and isolation from family and peers, leeding to a feeling of profound

misunderstanding.[1,30] In the Asian context, lastly, stigma is silent and internalized, with individuals with mental illnesses who tend to conceal their diagnosis, leading to high emotional distress and burden from society's expectations.[34,35]

Overall, the results of this scoping review offer clarity regarding the experiences and perceptions of stigma by individuals suffering from mental illness. Findings outline the various forms in which stigma occurs and some commonly observed reactions, as well as the encompassing presence it has in all aspects of people's lives. Recognising that stigma experiences can vary across cultures highlights the importance of tailoring mental health interventions to specific social and cultural contexts.

Limitations

This review has some limitations. First, our search did not identify any secondary sources of evidence, such as systematic reviews of qualitative studies, which limited opportunities for comparison with synthesized findings. Second, restricting inclusion to studies written in English and/or Italian may have led to the exclusion of relevant research published in other languages. In addition, the majority of included studies focused on young adult and adult populations; while this allowed for a comprehensive mapping of their experiences, further research is needed to explore stigma in adolescents and older adults. Finally, we did not conduct a methodological quality appraisal of the included studies, as this is not required in scoping reviews, and are therefore unable to assess their risk of bias. Clinical implication for nursing practice

By examining factors that individuals with mental illness consider crucial during their healthcare experience and outlining the impediments to care they encounter, our results can help nurses identify deficient areas in healthcare systems. In response to the stigmatizing experiences reported by individuals with mental illness, nurses and healthcare providers should ensure a secure and empathetic environment filled with trust and understanding. Factors related to consent and informativeness are also relevant. A caring relationship centered on the needs of the individual can help limit the experience of stigma and its impact. In practical terms, individualized care can create a reciprocal relationship between nurses and patients that can improve trust and reliability. This goal can be obtained through consistent patient-provider relationships such that patients see the same healthcare provider whenever possible, and through training for healthcare providers about stigma and its effects on patients.

Implications for Future Research

Our findings highlight the important need of examining stigma that can arise from interactions with healthcare institutions and staff. Research should focus on ways to limit this phenomenon and on how to enhance individuals' coping and resilience strategies. Meta-synthesis or meta-summaries could achieve this aim. Focusing on stigmatizing experiences in healthcare settings and comparing these experiences by sociodemographic factors such as age could inform improvements in care for those with mental illness.

Conclusion

Lived experiences of those with a mental health condition highlight the deeply negative and exclusionary impact of stigma. Prejudices around mental illness progressively becomes internalized, leading to self-stigma. Sufferers commonly experience insufficient support from peers, friends, and family members with limited understanding of mental illness. Lack of trust in institutions leads to reduced help-seeking and difficulty accessing services. There is a need to continue exploration of this topic so that approaches to remedy the effects of stigma can be developed. Addressing stigma and its effects is an important step to helping individuals with mental illness feel accepted and supported in their lives.

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Supplementary Materials **1.** Comparison of the primary outcomes.

Date of search execution	Biomedical database	Adverse Events
26.10.2022 to 30.04.2023	PubMed	("Mental Health"[Mesh] OR ("mental health"[TIAB]) OR ("mental wellbeing"[TIAB]) OR ("mental hygiene"[TIAB]) OR ("Mental Disorders"[Mesh]) OR ("mental illness*"[TIAB]) OR ("behaviour disorder*"[TIAB])) AND ("Social Stigma"[Mesh] OR (stigma [TIAB]) OR ("social stigma"[TIAB]) OR (prejudice*[TIAB]) OR (stereotyp*[TIAB])) AND (experienc*[TIAB] OR ("lived experience*"[TIAB])) AND ("qualitative stud*")
28.10.2022 to 30.04.2023	CINAHL	(MH "Mental Health" OR MH "Mental Disorders" OR "mental health" OR "mental wellbeing" OR "mental hygiene" OR "mental disorder*" OR "mental illness*") AND (MH "Stigma" OR "stigma" OR "social stigma" OR "prejudice*" OR "stereotyp*") AND (MH "Life Experiences" OR "experienc*" OR "lived experience*") AND ("qualitative stud*")
28.10.2022 to 30.04.2023	PsycINFO	(DE "Mental Health" OR DE "Mental Disorders" OR "mental health" OR "mental wellbeing" OR "mental hygiene" OR "mental disorder*" OR "mental illness*" OR "behaviour disorder*") AND (DE "Stigma" OR DE "Mental Health Stigma" OR "stigma" OR "social stigma" OR "prejudice*" OR "stereotyp*") AND ("experienc*" OR "lived experience*" OR "personal experienc*") AND ("qualitative stud*")
28.10.2022 to 30.04.2023	EMBASE	('mental health'/exp OR 'mental disease'/de OR 'behavior disorder'/de OR 'mental health':ab,ti OR 'mental wellbeing':ab,ti OR 'mental hygiene':ab,ti OR 'mental disorder*':ab,ti OR 'mental illness*':ab,ti OR 'behaviour disorder*':ab,ti) AND ('social stigma'/de OR 'stigma'/de OR 'stigma':ab,ti OR 'social stigma':ab,ti OR 'prejudice*':ab,ti OR 'stereotyp*':ab,ti) AND ('personal experience'/de OR 'experienc*':ab,ti OR 'lived experience*':ab,ti) AND ('qualitative stud*')