

# Structural stigma and its impact on healthcare for consumers diagnosed with Borderline Personality Disorder: protocol for a scoping review

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## Protocol

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# Abstract

## Background

Structural stigma in health systems experienced by consumers diagnosed with Borderline Personality Disorder (BPD), is a widespread phenomenon that causes health inequities and harm for this population. Structural stigma in this context relates to organisational practices, cultural norms, and institutional policies that limits consumers' access to health services, quality of care, and health and well-being. BPD is a mental illness with high morbidity and mortality, characterised by instability in interpersonal relationships, self-image, and emotional and behavioral deregulation, which stem from significant traumatic childhood/life events, and/or biological etiologies. This scoping review aims to explore the literature on structural stigma in health systems specific to BPD, and to provide an overview of the impact of stigma on healthcare services for BPD consumers, and their carers/families.

## Methods

This scoping review will follow the Joanna Briggs Institute (JBI) guidelines. The search strategy was developed and tested using PsycINFO. A comprehensive search will be conducted across PsycINFO, MEDLINE, CINAHL, Scopus, ProQuest, Cochrane library and JBI Evidence-Based databases; as well as a grey literature search using Google search engine. Studies will be screened by title, abstract and full text articles, by separate reviewers against the eligibility criteria. Selected full text articles will be accessed against the inclusion criteria. Quantitative and qualitative data will be extracted from the selected full text articles. A narrative summary of findings will then be conducted and presented in accordance with the JBI guidelines for scoping reviews, and the Preferred Reporting Items for Systematic Reviews and Meta-Analysis Protocols (PRISMA-P) 2015 checklist. Quality appraisal of the included articles will be assessed using the Mixed Methods Appraisal Tool (MMAT) 2018 version.

## Discussion

This review is anticipated to enhance both identification and understanding of those structures in health systems (i.e., policies, cultural norms, and practices), that manifest and perpetuate stigma experienced by consumers with BPD, and their carers/families. The findings can be used to inform future research, policy and practice relating to stigma reduction strategies that can be adopted to improve the provision of BPD-responsive services and care for this population.

## Scoping review registration

This scoping review was submitted for registration in Open for Science Framework on 11<sup>th</sup> June 2020.

## Background

A dominant stigma discourse perpetuated within health systems towards people with mental illness, [1] continues to undermine the lives of consumers and their carers/families worldwide [2]. Structural stigma

in health systems is the, “societal-level conditions, cultural norms, and institutional policies that constrain the opportunities, resources, and wellbeing of the stigmatized” [5(p742)]. Stigma occurs and is normalized within society [3] through social relationships and interactions, [1] including organizations and institutions that generate and perpetuate notions of difference. It is these social constructs that categorize and attribute a person’s social identity as belonging outside of the norm of what is expected in a given social context or situation. This includes persons deemed to be ‘different from others’ (*sic*), in a manner that is widely discrediting [1]. For example, normative structures within health systems develop and shape expectations regarding what is ‘accepted’ or ‘rejected’ in that context. It is these expectations that create marked differences and perpetuate structural stigma towards people with mental illness [4].

Extant at the macro-social level, [2,5,6] stigma perpetuates deep-seated stereotypes, prejudice, and discriminatory influences on institutions’ organizational culture, practice, and policy [2,3]. This includes, for example, organizational culture and practices that maintain clinicians’ stigmatizing attitudes and behaviors towards consumers with mental illness [7,8]. Policy decisions also play a significant role in limiting the availability of services for people with mental illness. This is evident in the inequitable distribution of resources allocated to mental health services relative to general medical services; [2] analogously, less funding is dedicated to research and treatment of BPD, compared with other mental illnesses [9].

Consumers with a diagnosis of BPD are particularly vulnerable to the effect of structural stigma and indeed report experiencing greater levels of stigma within health systems compared to their counterparts with other mental illnesses [7,10]. BPD is a serious mental illness typically characterized by significant traumatic childhood/life events and/or biological etiology serving to catalyse a pattern of instability in domains of interpersonal relationships, self-image, and emotional and behavioral (de)regulation [11]. People with a diagnosis of BPD also represent a high risk group for suicidality (i.e., suicidal thoughts, self-harm, suicide attempts), with approximately 10% of people with BPD dying by suicide [12].

Recurrent suicidality is often the reason why people with BPD and their carers/families access healthcare services. Help-seeking, including frequent presentations to emergency departments in response to suicidality, is common among consumers with BPD [13]. Although help-seeking has been identified as a healthy coping strategy for assisting consumers with BPD to cope with overwhelming distress [14], current treatment and care responses are often inadequate in meeting the specific needs of this population [13,15]. Findings from a national survey of consumers with BPD and their carers/ families revealed a lack of BPD-related health services and support during times of crisis [16,17]. In addition, over 50% of carers reported instances where the person they were caring for attempted to seek help for suicidality but were refused hospitalization by health providers [17]. These discriminatory experiences can re-traumatize and exacerbate consumers’ distress [18], reinforcing consumers’ intense feelings of anxiety and hopelessness [19], and perpetuating the cycle of problems carers/families and clinicians attempt to manage or treat [20].

Studies examining clinicians' attitudes towards consumers with BPD highlighted the challenges experienced by clinicians' when working with this population [7,21]. A study assessing mental health staff attitudes towards consumers with BPD found that over 80% of staff viewed this population as difficult to work with, and indeed, more difficult to treat than consumers with other mental illnesses [10]. Clinicians reported experiencing strong negative emotional reactions towards consumers with BPD, such as feelings of frustration, anger [22], and powerlessness [21]. In addition, some clinicians' have described consumers with BPD as: manipulative—that is, they have more control of their emotions and behaviors than consumers with other mental illnesses; and they misbehave—rather than their behavior being an expression of mental illness [23,24]. These findings support recommendations for the need for BPD-specific education and training to enhance clinician's knowledge and practice in treating consumers with BPD. Notably, research shows that clinicians *are* interested in attending training to help them to more effectively treat consumers with BPD [7,8,10].

Overall, stigma associated with restricted access to health services [2,6,25] and suboptimal quality of care [24,26] undermine the diagnosis, treatment, and health outcomes of BPD consumers [27]. A recent systematic review exploring stigma at the interface of mental health care identified several fundamental processes contributing to the creation and perpetuation of stigma towards people with BPD. These included: “stigma related to diagnosis and disclosure; perceived untreatability and demand for services; stigma as a response to feeling powerless; stigma due to preconceptions of the BPD patient; and low BPD health literacy” [21(p4-16)]. Recommendations for addressing these complex health inequities and overcoming stigma in mental health settings involved the need to enhance empathy among clinicians through the development of a conceptual framework for understanding the complexities of BPD-based behaviors and the resultant stigma within healthcare interactions [21].

## **Study aims**

To further contribute to the current knowledge in this field, this review seeks to enhance identification and understanding of the structures in health systems, including the policies, cultural norms, and practices, that manifest and perpetuate stigma [5,6] experienced by consumers with BPD and their carers/families. To achieve this, the scoping review aims to explore the extent of the literature on structural stigma specific to BPD in health systems and provide an overview of the current evidence. This will involve assessing how structural stigma impacts on the provision of health services and quality of care for consumers with BPD, their carers/families, and clinicians. Triangulating the perspectives and lived experiences of stigma among consumers, carers/families, and clinicians has been identified as a relatively new approach to conceptualize the complex mechanisms that impact on clinical practice in health systems [28]. Further, this review will inform future research, policy and practice relating to stigma reduction strategies that can be adopted to improve quality patient-centred care and patient outcomes. As this scoping review is one of two intended reviews designed to examine BPD-related stigma in health systems, these findings will also inform a systematic review on the impact of anti-stigma interventions in addressing BPD-related stigma in healthcare settings [23].

# Methods

The scoping review methodology will be conducted in accordance with the JBI guidelines for scoping reviews [29] and Arksey and O'Malley's [30] five-step process for scoping reviews. The PRISMA-P 2015 checklist (Additional file 1) will ensure adherence to rigorous standards are met [31].

## Identifying the research question

The primary research question for this scoping review is as follows:

How does structural stigma associated with a diagnosis of BPD impact on access to health services and care for people with BPD, their carers/families, and clinicians?

Additional sub-questions will be explored to facilitate a deeper understanding of the key factors, barriers, and mechanisms contributing to the maintenance of structural stigma in health systems experienced by this population, as follows:

- What are the perspectives and experiences of structural stigma among consumers with BPD, their carers/families, and clinicians?
- What are the specific drivers and facilitators influencing the manifestation and maintenance of structural stigma in health systems towards consumers diagnosed with BPD, and the implications for research, policy and practice?

This review will be founded on the Population, Concept and Context framework [29], as follows:

### *Population*

Studies focusing on stigma in health systems will be included in this review if consumers are aged 12 years or older and have a diagnosis of BPD; carers/families of people with BPD; or clinicians working in clinical outpatients, inpatients, or community-based services.

### *Concept*

This review will focus on structural stigma; this will subsume stigma maintained by some clinicians in relation to consumers with BPD and their carers/families within the context of crisis care. These studies must include stigma as an outcome to enable the current review to identify and map the key outcomes of structural stigma relevant to a diagnosis of BPD in health systems. Included studies will also be BPD-specific, examining:

- Participants perspectives and experiences of stigma in healthcare
- Impact of stigma on access to health services and quality of care
- Identification of contributing factors associated with the creation and maintenance of structural stigma in health systems

- Policy and funding allocation associated with BPD-related services in healthcare settings.

### *Context*

Studies included in this review must examine structural stigma associated with BPD in healthcare settings such as outpatients, inpatients, primary health care, or community-based facilities.

### **Identify relevant studies**

The search strategy will identify published and unpublished studies relating to stigma experienced by consumers with BPD, carers/families, and/or clinicians in healthcare systems. Study designs consisting of mixed methods, qualitative, and quantitative approaches will be included in this review. Preliminary searches were executed in PsycINFO to test the search text word terms and subject heading combinations (Additional file 2). The search strategy was further refined following analysis of relevant articles key words, resulting in a comprehensive search strategy to identify all existing peer-reviewed articles relating to the topic of interest. The search was further tested to ensure that at least 10% of the citations were relevant to the topic and that the 10 test articles used to ensure that the search was sensitive enough to locate key citations were, in fact, located in the final search. The following database sources will be searched: PsycINFO (Ovid), MEDLINE (Ovid), and Scopus (Elsevier), CINAHL (EBSCO Connect), ProQuest, Cochrane library (Wiley), and JBI Evidence-Based Database (Ovid). A research librarian with expertise in sourcing literature guided the design of the search strategies. A grey literature search (Additional file 3) using Google search engine will then be conducted to identify other relevant citations such as, clinical practice guidelines, and other government reports.

### **Eligibility criteria**

Rationale justifying the inclusion and exclusion criteria will be articulated in the final scoping review paper.

#### Inclusion criteria

Studies included will meet the following criteria:

- Written in English language only
- Peer-reviewed journal articles and reviews
- Non peer-reviewed literature including clinical practice guidelines and other government reports relating to the treatment of consumers with BPD in healthcare services
- No limitations to the publication date will be imposed.

We will exclude publications reporting the following:

- editorials, commentaries, books, theses, conference abstracts, abstracts without full-text available, and presentations

- Studies with a focus on mental illnesses that do not include BPD
- Studies on brain abnormalities relating to BPD
- Studies on structural stigma in non-clinical settings

## **Study selection**

All citations identified from the search will be collated and uploaded into EndNote v.9. Citations will be uploaded into Covidence and deduplicated. Two independent reviewers (PK and AKFS) will screen the titles and abstracts against the defined selection criteria to identify relevant studies. Full text articles of selected studies will be retrieved via Covidence and assessed against the inclusion criteria. Full text articles that are deemed ineligible will be excluded in accordance with the exclusion criteria and reported in the final scoping review paper. Any discrepancies in decisions regarding the inclusion of studies will be accessed and resolved by a third reviewer (SL) with clinical expertise in the field of mental health. Results of the search will be presented in a PRISMA Flow Diagram [32] generated by Covidence and reported in full in the final scoping review paper.

### *Assessment of methodological quality*

Separate reviewers (PK and AKFS) will assess the full text studies for methodological validity prior to conducting the inclusion process of the review, using the MMAT v.2018 [33]. Discrepancies in decisions regarding methodological quality will be discussed by the research team and resolved by a third reviewer (SL). All studies, including those of lower methodological quality, will be included in this review.

## **Charting the data**

Separate reviewers (PK and AKFS) will extract the data from the included studies to populate the summary table. A data extraction tool will be used to capture key information in tabular form that is relevant to the objectives and questions of the review (Additional file 4). This will include information on the population groups, concept, and context. The following key headings, for example, will be included to structure the extraction of relevant data: author, year, country; population type/sample size; clinical area/setting; study design; data collection/methods; and main findings.

## **Collating, summarizing and reporting results**

Results of the extracted quantitative and qualitative data will be presented in tabular form, accompanied by a narrative summary of key findings relating to the scoping review objective and questions. Descriptive statistics will be used to describe and summarize key characteristics of the studies, present percentages, frequencies and any patterns emerging from the data in relation to, for example, professional type/clinical area/healthcare setting, BPD, and structural stigma. Implications for future research, policy and practice in addressing structural stigma towards consumers diagnosed with BPD, and their carers/family in health systems will also be discussed.

## Discussion

The purpose of this scoping review is to map existing literature on structural stigma in health systems specific to BPD and summarize the findings on the impact of stigma on accessing and delivering quality healthcare services for consumers with BPD, and their carers/families. Evidence has indicated that institutionalized stigma affects consumers with BPD, particularly those who present to health services in crisis, more so than consumers with other mental illnesses [3,7,16,19]. By completing this review, we hope to gain a better understanding of consumers, their carers/families, and clinicians experiences of stigma, and the mechanisms perpetuating stigma in the health system. Understanding the lived experiences of consumers with BPD, and their carers/families can help to identify the specific needs of this population as well as the current gaps in healthcare services [16,19]. Exploring clinicians experiences of working with consumers diagnosed with BPD will also be beneficial in broadening our understanding of the specific challenges, barriers, and gaps in knowledge/skills experienced by various healthcare providers [8,10]. This can assist in identifying recommendations for BPD-related education and training for clinician's to enhance the delivery of effective services that meet the needs of consumers with BPD, and their carers/families [21]. In conclusion, these findings can make a valuable contribution towards identifying potential solutions to addressing BPD-related stigma in health systems to improve access to patient-centred care and health outcomes for this population [8,34]. Findings from this scoping review will also inform a systematic review accessing the impact of anti-stigma interventions on addressing institutionalized BPD-related stigma in healthcare settings.

## Abbreviations

BPD, Borderline Personality Disorder; JBI, Joanna Briggs Institute; (MMAT) Mixed Methods Appraisal Tool; PRISMA-P, Preferred Reporting Items for Systematic Reviews and Meta-Analysis Protocols.

## Declarations

### Ethics approval and consent to participate

Not applicable.

## Consent for publication

Not applicable.

### Availability of supporting data

Not applicable.

### Competing interests



The authors declare that they have no competing interests.

## Funding

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## Authors' contributions

PK, AKFS and SL conceptualised the study. PK drafted the initial protocol. AKFS, SL, HS and PC critically reviewed the protocol. All authors (PK, AKFS, SL, HS, PC) contributed to manuscript revisions and approved the final version.

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