Lived experiences of adults with borderline personality disorder: a qualitative systematic review protocol

Teresa McDonagh[1] • Agnes Higgins[1] • Jenny Archer[2] • Eoin Galavan[3] • Greg Sheaf[4] • Louise Doyle[1,5]

[1]School of Nursing and Midwifery, Faculty of Health Sciences, Trinity College Dublin, The University of Dublin, Dublin, Ireland, [2]The Open University, Milton Keynes, UK, [3]School of Psychology, Faculty of Arts, Humanities and Social Sciences, Trinity College Dublin, The University of Dublin, Dublin, Ireland, [4]The Library of Trinity College Dublin, Trinity College Dublin, The University of Dublin, Dublin, Ireland, and [5]The Trinity Centre for Practice and Healthcare Innovation: a Joanna Briggs Institute Affiliated Group

ABSTRACT

Objective: The objectives of this review are: to explore the lived experiences of individuals with a diagnosis of borderline personality disorder (BPD) and to present recommendations for policy, practice, education and research.

Introduction: Borderline personality disorder is a mental disorder characterized by poor capacity to engage in effective relationships, intense and sudden mood changes, poor self-image and emotion regulation, significant impulsivity and severe functional impairment. Studies estimate the prevalence of BPD at 15% to 22% and identify a predominantly negative attitude among health professionals towards individuals with BPD. This review will examine the lived experiences of people with a diagnosis of BPD in order to better understand this condition.

Inclusion criteria: This review will include peer-reviewed qualitative studies on adults with a diagnosis of BPD in all settings and from any geographical location.

Methods: A three-step search strategy will be used. A search strategy has been developed for MEDLINE. A second search using all identified keywords and index terms will be conducted across MEDLINE, CINAHL, PsycINFO and Embase. Studies will be screened by title and abstract by two independent reviewers against the review inclusion criteria. The full text of selected citations will be assessed against the inclusion criteria and for methodological quality. Qualitative data will be extracted from included papers using a standardized data extraction tool. Qualitative research findings will be pooled using the meta-aggregation approach. The final synthesized findings will be graded according to the ConQual approach and presented in a Summary of Findings.

Systematic review registration number: PROSPERO CRD42019141098.

Keywords Borderline personality disorder; meta-synthesis; emotional instability

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Introduction

The epidemiology of borderline personality disorder (BPD) has been studied in a variety of large-scale population-based surveys.[1] A national comorbidity survey (n = 5692) in the United States reported a prevalence of 1.4% for BPD.[2] A British study (n = 626) reported a lower population prevalence rate of approximately 0.7%.[3] Data from a large scale mental health survey (n = 5303) in the Netherlands[1] found that 3.8% of the study population experienced three to four symptoms of BPD and 1.1% experienced more than five symptoms, which the authors point out meets the criteria for a BPD diagnosis, according to Diagnostic and Statistical Manual of Mental Disorders, 4th edition (DSM-IV).[4] However, the National Epidemiological Survey on Alcohol and Related Conditions, a US survey of more than 40,000 people conducted from 2000 to 2010, reported finding a higher lifetime prevalence of BPD of 5.9%.[5] Some consensus has therefore been reached that the population prevalence for BPD may be conservatively estimated at 1%.[1-3] Consistent with most epidemiological surveys, but not clinical studies,[1,6] the results demonstrated no significant difference in the prevalence of BPD between men and women.[5] This finding

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Correspondence: Teresa McDonagh, mcdonate@tcd.ie

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contradicts the DSM and other writings that assert that BPD occurs more commonly in women than in men by a ratio of 3:1.[1,4,6] From a feminist perspective, BPD is therefore considered to be a gendered diagnosis.[7,8] Higher rates of BPD diagnosis in women has been attributed to a number of factors, including assessment bias, increased treatment-seeking among women, sampling bias and sociocultural differences; however, these potential explanations require further research.[9-11]

Studies estimate that the prevalence of BPD in people experiencing mental health problems and attending mental health outpatient clinics is 15% to 22%.[12,13] A 2008 two-phase cross-sectional study conducted in a Canadian general adult outpatient university clinic with 360 patients demonstrated a BPD prevalence rate of 22.6%.[12] A 2012 cross-sectional study conducted in two Shanghai psychiatric outpatient clinics ($n = 3075$) found the that prevalence of BPD among the psychiatric outpatients was 5.8%, with a prevalence of 3.5% among males and 7.5% among females.[13] The prevalence among outpatients in this Chinese study is notably lower than that reported in North America. The prevalence in mental health inpatient settings is further estimated to be in excess of 20%.[4,14,15]

Borderline personality disorder was first introduced in the 1980s as a diagnostic category in the DSM-III.[15] Through the evolution of each version of the manual, the DSM maintains a narrow view from the medical model perspective on the problems experienced by people labeled as having BPD. The dominance of the medical model is much criticized and contested in mental health as an approach that is paternalistic, illness-focused and reductionist.[16] The medical model reduces human distress to a list of symptoms to be formulated into diagnosis without consideration of the "patient as a person." Scott,[17] in questioning the medicalization of mental distress, decries the seemingly endemic diagnostic labeling in mental health. Remaining firmly entrenched in the medical model, the current manual DSM-5[18] demonstrates a particular understanding of BPD that continues to medicalize human distress. Similarly, within practice, many clinicians persist in labeling complex human experiences with features of emotional dysregulation, impulsivity and social-interpersonal difficulties, using the DSM-5 definition and nomenclature of BPD. This is also the terminology that appears most commonly in the literature. DSM-5[18] defines BPD as a "mental disorder" characterized by poor capacity to engage in effective relationships, intense and rapid changes in mood and affect, poor self-image and emotion regulation, significant levels of impulsivity and severe functional impairment. Within this framework, "symptoms" of BPD are said to normally emerge in adolescence or early adulthood. Symptom severity ranges from mildly impairing to severely disabling.[19] In a book that challenges the medical perspective, Gunn and Potter describe the nomenclature surrounding BPD, particularly that of the DSM, as that which "reduces this human struggle to a list of concrete symptoms."[7(p.112)] The authors argue that this diminishes the individual concerned and results in complex human behaviors being examined out of context. Steffen[20] considers BPD from a humanistic standpoint and extols a holistic view of the individual as capable of self-actualization and growth in accordance with the Rogerian theory.[21] This view rejects clinical diagnosis as a means of labeling and pigeon-holing individuals into prescribed categories within a rigid system of classification.

The BPD label is particularly attributed to individuals who self-harm, especially women.[22] Consequently, individuals with a diagnosis of BPD frequently present in general hospital emergency departments for treatment following acts of self-harm, substance abuse and attempted suicide.[23-25] A meta-analysis of studies that examined gender differences in the prevalence of non-suicidal self-injury (NSSI) found that the rate of NSSI was slightly higher in women than in men.[26] A US study that examined the relationship between NSSI and borderline symptoms among college students found that participants who engaged in NSSI were more likely to be female χ^2 $(1, N = 723) = 11.22$, $P < .001$.[27] While those experiencing and living with any mental health diagnosis experience stigma, the term "surplus stigma" has been assigned to BPD.[28] Gunn and Potter describe BPD as "one of the most stigmatized and overused diagnoses in existence."[7(p.3)] Some studies have explored the subjective experiences of stigma and discrimination endured by people with a diagnosis of BPD. One such study reveals that the experience can be separated into two categories: the stigma surrounding diagnosis and the BPD label, and the experience of stigma from within the healthcare context related to the negative attitudes of staff.[29] Further, Bonnington and Rose[29] describe the experiences of individuals with a diagnosis of BPD as being stereotyped, enduring psychological abuse and having their diagnosis withheld, resulting in exclusion from appropriate treatment.

People who experience significant mental distress that manifests as symptoms of emotional dysregulation and impulsivity often have a long history of complex trauma. Frequently, the distress that results from these traumatic experiences is subsequently categorized as BPD. Grant[30] emphasizes that the use of the term "distress" in this context does not mean "disease" or disorder" and discusses the need for a change of language to better conceptualize, research, understand and relieve "human misery." People diagnosed with BPD report such distress as a form of intense emotional pain.[31] Such distress can impact on an individual's education, employment and social engagement leading to isolation, which in a circular manner, can exacerbate the individual's distress.[32] In addition, exclusion by society and health services has been the norm for people with a diagnosis of BPD for many years.[33-35] Yet national and international research studies, government policies and guidelines challenge the historical assumption that people with a diagnosis of personality disorders are untreatable.[31,36,37] Following a review of the literature, Biskin[38] concludes that BPD, once considered a lifelong medical condition, now carries a more positive prognosis. Mental health services worldwide have an obligation to provide appropriate services for quality care and management to improve outcomes for individuals with a diagnosis of BPD.[32,36,37]

Health professionals have a critical role in working with individuals who have a diagnosis of BPD experiencing distress, whether in a hospital, forensic, outpatient clinic, primary healthcare or community setting. However, published literature reveals prevailing negative attitudes, lack of empathy, stigma, reluctance to engage and low levels of optimism for recovery among health professionals in relation to people with a BPD diagnosis.[39-41] In an Australian survey[39] on the experiences of emergency medicine and mental health clinicians ($N = 140$) working with BPD, many reported experiencing an "uncomfortable personal response" and feelings of frustration, anger and inadequacy when working with this cohort. Many participants believed people with a diagnosis of BPD to be more in control of their adverse behaviors such as self-harm than people with other psychiatric diagnoses.

In an Israeli study,[40] mental health clinicians ($n = 710$) from four professions (psychiatry, psychology, social work and nursing) completed two questionnaires, one measuring attitudes toward patients with a BPD diagnosis, and another measuring attitudes either toward patients with a BPD diagnosis, patients with major depressive disorder (MDD) diagnosis or patients with generalized anxiety disorder (GAD) diagnosis, using a short narrative. Nurses and psychiatrists encountered a greater number of patients with a BPD diagnosis and demonstrated more negative attitudes and lower levels of empathy toward these patients than the other two professions. Negative attitudes were positively correlated with caring for a higher numbers of patients with a BPD diagnosis. Nurses were most highly motivated to learn short-term methods for treating patients diagnosed with BPD and a lower percentage of psychiatrists demonstrated interest in improving their professional skills in treating this cohort.

An Irish study[41] that explored interactions and levels of empathy among psychiatric nurses ($n = 17$) found that overall the participants perceived people with a diagnosis of BPD in a negative way and found it difficult to deliver good quality care to this cohort. Studies from the consumer perspective reveal that individuals with a diagnosis of BPD commonly perceive health professionals as holding negative and stigmatizing attitudes and lacking in empathy.[42-43] Studies further indicate that prevailing negative attitudes of health practitioners and stigma act as barriers to people accessing services, resulting in exclusion of service users from care pathways.[44,45]

Understanding the lived experience of people with a diagnosis of BPD, demonstrating empathy and the ability to relate to them in a humanistic way are key elements in the therapeutic relationship. Knowledge and understanding of that lived experience enables health professionals to promote individualized care and assist individuals experiencing mental distress to engage in personal reflection, thus leaning them towards self-care and mindful behavior change.[46] The evidence on negative attitudes among healthcare professionals and demonstrable lack of understanding and empathy for individuals with a diagnosis of BPD point to the need for further comprehensive research. This will be used to establish an evidence base from which improvements can be made, and services and health professionals developed to respond appropriately to the care needs of individuals with a diagnosis of BPD. This review will contribute to that evidence base.

Over the past four decades, many studies have been dedicated worldwide to examining the etiology, epidemiology, pathophysiology, costs, treatments and outcomes of this complex human condition.[47,48] The perspectives of people diagnosed with BPD have also been explored in the literature in respect of their lived experience of diagnosis, stigma and treatment.[49-51] A preliminary search of PROSPERO, MEDLINE, the Cochrane Database of Systematic Reviews and the *JBI Database of Systematic Reviews and Implementation Reports* was conducted and no current or underway systematic reviews on the topic of the lived experiences of adults with a diagnosis of BPD were identified. A related review, as yet unpublished, was identified that explores experiences of stigma and discrimination in BPD.[52] This review is confined to examining the experience of stigma and/or discrimination experienced by individuals with a diagnosis of BPD or emotionally unstable personality disorder, including self-stigma. The principal outcomes are to understand to what extent individuals with the diagnosis experience stigma and discrimination and to establish the nature of those stigmatizing and discriminatory experiences endured by individuals diagnosed with BPD. A systematic review and meta-synthesis that examines the experiences of people diagnosed with BPD admitted to acute psychiatric inpatient wards has also recently been published.[53] In that review, the focus is specifically on "exploring the experiences of people with BPD in acute psychiatric wards."[52(p.2)] The specific focus of this review is to explore the lived experience of individuals with a diagnosis of BPD, whether they have been hospitalized or not. This review differs in scope from the identified existing systematic reviews in that it is not solely concerned with the experiences of stigma and discrimination for individuals with a diagnosis of BPD but rather the broad spectrum of their lived experiences, and neither is the review confined to the inpatient setting but any setting in which the individuals lives. Studies included in the identified existing reviews may be included in the proposed review if they meet the inclusion criteria.

Human experience is necessarily at the core of qualitative research; however, the notion of "lived experience," which comes from the German verb *erleben* meaning "to live through something," has specific methodological significance. As Smith[54] explains, the term "lived experience" indicates an intention to explore directly the original and immediate meaning of phenomena in people's lives prior to any interpretation. In contemporary human scientific inquiry, exploring the "lived experience" aims to elicit critical insights into the meaning of phenomena in people's lives.[55] It is envisaged that in synthesizing the qualitative research that broadly explores the lived experiences of people with a diagnosis of BPD, this complex mental health problem may be better understood.

Review objectives

The aim of this systematic review is to synthesize available evidence on the lived experiences of adults with a diagnosis of BPD. The specific objectives of this review are:

- To explore the lived experiences of individuals with a diagnosis of BPD
- To present recommendations for policy, practice, education and research.

Inclusion criteria

Participants

The review will consider studies where the data are obtained directly from adults (18 years of age and older) who are defined by the primary study authors as having a diagnosis of BPD.

Phenomenon of interest

The review will consider studies that examine the lived experiences of individuals with a diagnosis of BPD.

Context

The context for this review is all settings, including, but not limited to, the home, primary health care, inpatient, outpatient, forensic and community mental health settings. The review will take an international perspective, aiming to capture all data relevant to the lived experiences of adults with a diagnosis of BPD. The review will consider publications from any geographical location (e.g. urban, rural and remote) in any country. Differences in culture and healthcare systems may be evident in some studies.[56]

Types of studies

The current review will consider peer-reviewed studies published in English that focus on qualitative data including, but not limited to, designs such as phenomenology, grounded theory, ethnography, action research and feminist research. Mixed methods studies may be included where the qualitative element elicits rich descriptions and where there is a well described and recognized method of qualitative data analysis.

Exclusion criteria

Studies will be excluded where the reviewers find difficulty in extracting the qualitative data, for example, mixed methods studies where the qualitative data are not clearly separated out or studies with mixed participant groups where data on the experiences of individuals with a diagnosis of BPD cannot be separated out. Studies whose participants are younger than 18 years will be excluded. Studies that include participants both over and under the age of 18 years will be excluded if responses from the adult participants are not explicit in the findings. Conference abstracts, commentaries and opinion pieces will not be included. Studies whose participants are not attributed a diagnosis of BPD will be excluded.

Methods

The proposed systematic review will be conducted in accordance with the JBI methodology for systematic reviews of qualitative evidence.[57] This review has been registered in PROSPERO (CRD42019141098).

Search strategy

The search strategy aims to find published and unpublished studies that examine the phenomenon of interest. A three-step search strategy will be used in this review. An initial limited search of MEDLINE via PubMed will be undertaken, followed by an analysis of the text words contained in the title and abstract and the index words used to describe each article. A search strategy has been developed for MEDLINE (Appendix I). A second search using all identified keywords and index terms will then be conducted across all included databases. The reference list of all studies selected for critical appraisal will be screened for additional studies. Studies published in English from 1980 to the present will be included as BPD first appeared as a diagnostic entity in the DSM-III published in 1980.[15]

Information sources

The databases to be searched include MEDLINE, CINAHL, PsycINFO and Embase. Initial keywords to be used in the search will be borderline personality disorder, experience, perspective, perceptions, qualitative research, phenomenology, grounded theory, ethnography, action research, feminist research and mixed methods. Sources of unpublished studies will include ProQuest Dissertations and Theses, and relevant government websites such as the National Institute of Mental Health (US), the National Health Service (UK) and RIAN (Ireland). Where necessary, authors of studies will be contacted for missing information, if possible, using the contact information provided in the article.

Study selection

Following the search, all identified citations will be collated and uploaded into EndNote X8.2 (Clarivate Analytics, PA, USA) and duplicates removed. Titles and abstracts will then be screened by two independent reviewers for assessment against the inclusion criteria of the review. Potentially relevant studies will be retrieved in full and their citation details imported into the JBI System for the Unified Management, Assessment and Review of Information (JBI SUMARI; JBI, Adelaide, Australia). The full text of selected citations will be assessed in detail against the inclusion criteria by two independent reviewers. Reasons for exclusion of full text studies that do not meet the inclusion criteria will be recorded and reported in the systematic review. Any disagreements that arise between the reviewers at each stage of the study selection process will be resolved through discussion, or with a third reviewer. The results of the search will be reported in full in the final systematic review and presented in a Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) flow diagram.[58]

Assessment of methodological quality

Each paper selected for retrieval will be assessed independently by two reviewers for methodological quality prior to inclusion in the review using the JBI Critical Appraisal Checklist for Qualitative Research.[57] Authors of papers will be contacted to request missing or additional data for clarification, where required. Any disagreements that arise between the two reviewers will be resolved through discussion or in consultation with a third reviewer. The results of critical appraisal will be reported in narrative form and in a table. All studies, regardless of the results of their methodological quality, will undergo data extraction and synthesis (where possible).

Data extraction

Qualitative data will be extracted from papers included in the review using the standardized data extraction tool from JBI SUMARI.[57] The data extracted will include specific details about the populations, context, culture, geographical location, study methods and the phenomena of interest relevant to the review objective. The level of congruency between the findings and the supporting data will be graded for credibility using three levels: unequivocal, credible or unsupported. Any disagreements that arise between the reviewers will be resolved through discussion, or with a third reviewer. Authors of papers will be contacted to request missing or additional data, where required.

Data synthesis

Qualitative research findings will, where possible, be pooled using JBI SUMARI with the meta-aggregation approach.[57] This will involve the aggregation or synthesis of findings to generate a set of statements that represent that aggregation through assembling the findings rated according to their quality and categorizing those findings based on similarity of meaning. These categories will then be subjected to meta-synthesis to produce a single comprehensive set of synthesized findings that can be used as a basis for evidence-based practice. Where textual pooling is not possible, the findings will be presented in narrative form.

Assessing confidence in the findings

The final synthesized findings will be graded according to the ConQual approach for establishing confidence in the output of qualitative research synthesis and presented in a Summary of Findings.[59] The Summary of Findings includes the major elements of the review and details how the ConQual score is developed. Included in the Summary of Findings will be the title, population, phenomena of interest and context for the specific review. Each synthesized finding from the review will be presented along with the type of research informing it, a score for dependability and credibility, and the overall ConQual score.

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Appendix I: Search Strategy for MEDLINE

Search run: 12-02-2018

Results retrieved: 574

1. MH “borderline personality disorder” OR TI (“borderline personality disorder∗” OR “emotionally unstable personality disorder∗”) OR AB (“borderline personality disorder*” OR “emotionally unstable personality disorder*”)
2. TI (attitude* OR awareness OR belief* OR comprehension OR experienc* OR feel* OR opinion* OR perceiv* OR perception* OR perspective* OR thought* OR understanding OR value* OR view*) OR AB (attitude* OR awareness OR belief* OR comprehension OR experienc* OR feel* OR opinion* OR perceiv* OR perception* OR perspective* OR thought* OR understanding OR value* OR view*)
3. MH (“anecdotes as topic” OR “focus groups” OR “grounded theory” OR “hermeneutics” OR “interviews as topic” OR “narration” OR “nursing methodology research” OR “observational study as topic” OR “personal narratives as topic” OR “qualitative research” OR “tape recording” OR “video recording”) OR TI (“action research” OR “case stud*” OR “content analysis” OR descriptive OR ethnograph* OR “exploratory stud*” OR “feminist research” OR “focus group*” OR “grounded theory” OR hermeneutic* OR “interpretative analysis” OR interview* OR “mixed design*” OR “mixed method*” OR “mixed model*” OR multimethod* OR “multiple method*” OR narrative OR phenomenolog* OR “qualitative research” OR “qualitative stud*” OR “thematic analysis” OR “thematic coding” OR triangulat*) OR AB (“action research” OR “case stud*” OR “content analysis” OR descriptive OR ethnograph* OR “exploratory stud*” OR “feminist research” OR “focus group*” OR “grounded theory” OR hermeneutic* OR “interpretative analysis” OR interview* OR “mixed design*” OR “mixed method*” OR “mixed model*” OR multimethod* OR “multiple method*” OR narrative OR phenomenolog* OR “qualitative research” OR “qualitative stud*” OR “thematic analysis” OR “thematic coding” OR triangulat*)