EXPERIENCES OF STIGMA AND DISCRIMINATION IN BORDERLINE PERSONALITY DISORDER: A SYSTEMATIC REVIEW AND QUALITATIVE META-SYNTHESIS

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Individuals with a diagnosis of borderline personality disorder (BPD) typically experience discrimination and stigma, resulting in poor identification and delayed care. We conducted a review to examine and synthesize qualitative studies exploring experiences of stigma and discrimination among individuals with BPD. In August 2021, we systematically searched the following databases: Embase, Medline, Cochrane Library, PsycINFO, and Cinhal . We also hand searched reference lists and Google Scholar. We then synthesized studies using meta-ethnography. We included seven articles in the study, all of high or moderate quality. Five themes were identified: (1) resistance from clinicians (withholding information), (2) othering, (3) negative impact on self-image/esteem, (4) hopelessness surrounding the perceived permanency of BPD, and (5) feeling like a burden. This review highlights the need for improved understanding of BPD across health care services. We also discussed the need to introduce a standardized pathway of care across health services following a BPD diagnosis.

Keywords: borderline personality disorder, stigma, discrimination, mental health care, qualitative systematic review

Borderline personality disorder (BPD), also known as emotionally unstable personality disorder (EUPD), is a complex mental health condition characterized by a pervasive pattern of instability in affect regulation, impulse control, interpersonal relationships, and self-image (Lieb et al., 2004). Of note, the label "EUPD" is no longer included in the *ICD-11*, reflecting a shift toward a dimensional approach to diagnosis of BPD and a move away from the "trait-specific" criterion of ICD-10 (Bach et al., 2022). The prevalence of BPD is approximately 1.4% to 5.9% in the general population (ten Have et al., 2016). BPD is the most common personality disorder diagnosed in clinical practice (The British Psychological Society & The Royal College of Psychiatrists, 2009),

with a prevalence of approximately 10% in psychiatric outpatients and 20% in inpatients (Lieb et al., 2004). Evidence suggests that BPD is stigmatized by both the public and health care professionals (Biskin, 2015) and is perpetuated by unhelpful myths held by clinicians around the intractability of BPD.

Previous research on BPD and stigma has primarily focused on the attitudes of health care professionals, finding that they often view BPD more negatively compared to other mental health conditions, such as anxiety or depression (Bourke & Grenyer, 2010). Moreover, health care professionals tend to be less optimistic about recovery from BPD compared to other personality disorders and mental health conditions, such as schizophrenia (Deans & Meocevic, 2006). Such views can contribute to negative and unhelpful reactions toward BPD. With regard to BPD and stigma, Nehls (1998) outlined the different deprecatory terms used by clinicians, including *not sick*, *manipulative*, and *hateful*, with Hersh (2008) arguing that the use of stigmatizing and discriminatory terminology reflects a lack of empathy toward individuals with BPD.

To establish a shared understanding, Link and Phelan (2001) conceptualize stigma in four parts: labeling; stereotyping; separating "us versus them"; and status loss, with discrimination resulting as a consequence of the four previous components. Stigma can prevent or delay individuals with BPD from disclosing their condition and seeking professional input (Proctor et al., 2021). Stigma can adversely impact different areas of the lives of people with BPD, such as employment (Juurlink et al., 2019), as well as make accessing support more challenging, due to misinformation, assumptions, and invalidation from services and professionals (Carrotte et al., 2019). Individuals with BPD also report downplaying the severity of self-harm and suicidality out of fear of being excluded from services (Carotte et al., 2019). Collectively, this may lead to a vicious cycle of delayed input from health care services, lower treatment effect of interventions, and higher relapse rates, which may reinforce negative attitudes from others and contribute to self-stigmatization (Sartorius, 2007).

If we want to improve clinical care for individuals with BPD and some of the most vulnerable members of society, we need to learn from people who are experts by experience. A greater understanding of the experiences of stigma and discrimination experienced by people with a BPD diagnosis may help in supporting future development of clinical guidelines and addressing variations in practice approaches to individuals with BPD.

AIMS

This review aims to systematically examine and synthesize studies exploring stigma and/or discrimination experienced by individuals with a diagnosis of BPD. This systematic review aims to answer the following:

1. What are the experiences of stigma and discrimination encountered by individuals with a diagnosis of BPD?

2. What, if any, are the potential implications of understanding lived experiences of stigma and discrimination in individuals with a diagnosis of BPD for supporting future clinical guideline development?

METHODS

PROTOCOL

The systematic review was conducted in line with the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA; Moher et al., 2009) statement. The original protocol of this systematic review was registered on PROSPERO in November 2017 (ID: CRD42017076855).

SEARCH STRATEGY

A systematic search of published studies related to experiences of stigma and/or discrimination in individuals with a diagnosis of BPD from database inception until the end of July 2021 was performed in early August 2021 using the following databases: Embase (Ovid), Medline (Ovid), Cochrane Library, PsycINFO (EBSCO), and Cinahl (EBSCO).

 The search algorithm included the following terms: borderline personality disorder ("borderline state", BPD, borderline personalit*, emotionally unstable personali*) and stigma ("labelling", "stereotyped attitudes", "attitudes", "social acceptance", "social discrimination", stigma*, stereotyp*, label*, attitude*, discriminat*). The Boolean operator AND was used to search the two categories (borderline personality disorder and stigma), and the operator OR was used to include the variants within categories. Time span was not limited. The search terms were entered into the title, abstract, and keyword fields on Embase (Ovid), Medline (Ovid), Cochrane Library, SCOPUS, PubMed, PsycINFO (EBSCO), Cinahl (EBSCO), and the 'within topic' field on Web of Science. Key words and terms from the search strategy were also entered in Google Scholar to search for additional papers, and reference lists of included studies were hand searched.

INCLUSION AND EXCLUSION CRITERIA

 Inclusion criteria:

- Peer-reviewed journal publications using qualitative methods and analysis to explore experiences of stigma and/or discrimination in individuals with a diagnosis of BPD or EUPD.

 Exclusion criteria:

- Studies using quantitative methods.

- Studies describing experiences of stigma and/or discrimination in non-BPD or non-EUPD populations.

- Studies not published in the English language.

- Unpublished research.

- Studies that have not undergone a peer-review process.

- Studies that fail to provide illustrative quotations.

PROCESS OF STUDY REVIEW

Two reviewers (C.S. and R.B.) independently screened all titles and abstracts for inclusion against the identified eligibility criteria. If an article was deemed relevant, the full-text manuscript was obtained and further screened by three authors (C.S., R.B., and R.G.). Any disagreement regarding eligibility for inclusion was resolved through further discussion between the authors.

QUALITY ASSESSMENT STRATEGY

The Swedish Agency for Health Technology Assessment and Assessment of Social Services' (2016) quality assessment checklist for qualitative research studies was selected as the quality rating tool because it is specific to the perspectives of patients and clients, in line with the main research question of this synthesis. C.S. and R.B. conducted an overall assessment of study quality and categorized studies as high, moderate, or low.

DATA SYNTHESIS

Meta-ethnography was chosen for this systematic review because it is a well-developed method that facilitates the synthesis of research studies that use a variety of qualitative methods (Britten et al., 2002; Ring et al., 2011). Meta-ethnography involves selecting studies aimed at answering a specific research question to be synthesized, reading them repeatedly, and recording key concepts from these original studies. These key concepts, interpretations, and explanations from the original studies then become the raw data for the synthesis (Britten et al., 2002). A seven-step process for carrying out a meta-ethnography allows for new interpretations, as described by Noblit and Hare (1988, pp. 26–29). In line with the meta-ethnographic approach, summaries of original findings using the authors' terms and concepts were compiled for each of the studies. Lists of these summaries were noted side by side on a single sheet of paper to facilitate comparison of relationships between concepts in studies. After identifying key concepts from each study, we completed a systematic search to identify whether these concepts were present in the articles to be synthesized. The synthesis and interpretation of the findings may have been influenced by the lead author's experience of working with young adults with a diagnosis of BPD as part of her major research project for clinical psychology training. To maintain reflexivity as much as possible, we looked at the data and their interpretation for competing conclusions.

RESULTS

The search strategy yielded 868 citations. Citations were screened for duplicates, and 37 were removed. The titles and abstracts of the remaining 831 articles were screened, and 713 were excluded. It was evident from the titles or abstracts that these articles were not related to the target population (e.g., other mental health illnesses, nonpsychiatric conditions), were not related to
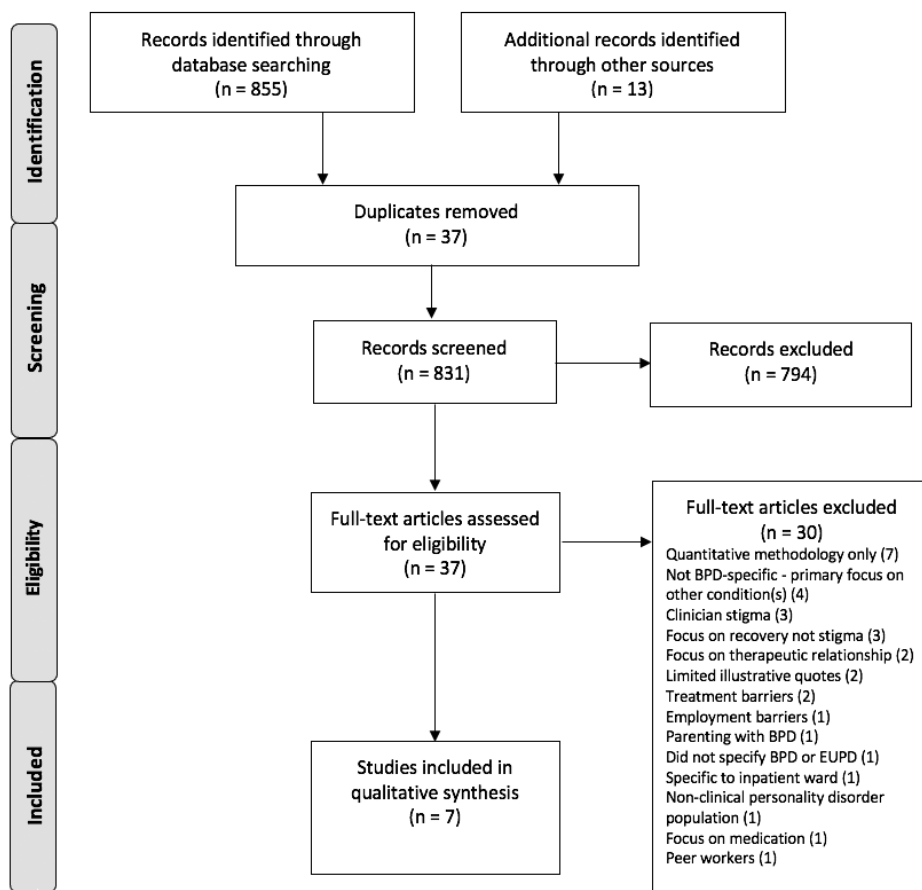
FIGURE 1. Flow diagram of systematic search process and study selection.

stigma or discrimination, or were not qualitative studies (e.g., reviews, feasibility studies, questionnaire studies). Of the remaining 37 articles, the full texts were read and assessed for eligibility, and 30 were excluded. Excluded articles were quantitative studies, not related to the target population, or not related to stigma or discrimination. References of the final seven articles were screened, but no new articles were identified. A PRISMA flow diagram of this process is provided in Figure 1. Table 1 provides details on the seven articles included in this systematic review.

QUALITY APPRAISAL

Two authors (C.S. and R.B.) conducted the quality appraisal for included studies. Of the seven studies reviewed, five met criteria for "high" quality (Bonnington & Rose, 2014; Fallon, 2003; Horn et al., 2007; Nehls, 1999; Veysey, 2014), and two met criteria for "moderate" quality (Fromene & Guerin, 2014; Miller, 1994). It was agreed a priori that the analysis would indicate

TABLE 1. Included Qualitative Research Studies Exploring Experiences of Stigma and/or Discrimination in People With a Diagnosis of Borderline Personality Disorder (BPD)

Authors	Country	Aim	Participants	Design	Key Findings
Bonnington et al. (2014)	United Kingdom	To explore experiences of stigma and discrimination among people diagnosed with borderline personality disorder or bipolar disorder	22 BPD (n = 17 female; n = 5 male) 24 bipolar disorder	Focus Groups Interview Thematic Analysis	Four themes of participants' (BPD) experiences of stigma and discrimination: cultural imperialism; powerlessness; marginalization; violence
Fromene and Guerin (2014)	Australia	To understand the contextual factors underlying the diagnosis of BPD among indigenous clients; experiences of identity; understanding their diagnosis	5 BPD (n = 4 female; n = 1 male)	Interview Thematic Analysis	Themes identified: identity; culture; racism; stereotypes; trauma; family; underlying stigma as a result
Veysey (2014)	New Zealand	To understand experiences of people with a diagnosis of BPD who self-identified as encountering discriminatory experiences	8 BPD (n = 7 female; n = 1 male)	Interview Interpretative Phenomenological Analysis (IPA)	Two thematic areas identified: the impact of the participants' experiences, both helpful and discriminatory; the relationship between stigma and the complaints process
Horn et al. (2007)	United Kingdom	To explore user experiences and understandings of being given the diagnosis of BPD	5 BPD (n = 4 female; n = 1 male)	Semistructured interview IPA	Identified 5 superordinate themes: knowledge as power; uncertainty about what the diagnosis meant; diagnosis as rejection; diagnosis is about not fitting; hope and the possibility of change
Fallon (2003)	United Kingdom	To analyze the lived experiences of people with BPD in contact with psychiatric services	7 BPD (n = 4 female; n=3 male)	Interview Grounded theory thematic analysis	Four categories identified: living with BPD; the service response; relationships; traveling through the system
Nehls (1999)	USA	To generate knowledge about the experience of living with the diagnosis of BPD	30 BPD (n = 30 female)	Interview IPA	Three themes identified: living with the label; living with self-destructive behavior perceived as manipulation; living with limited access to care
Miller (1994)	USA	To learn how patients with a diagnosis of BPD experience the disorder and its treatment	10 BPD (n = 8 female; n = 2 male)	Interview Grounded theory thematic analysis	Reports of their experience differed markedly from clinical descriptions of BPD. Common themes: estrangement, inadequacy, and despair as well as coping strategies, primarily dissociation and avoidance of self-disclosure

which articles contributed to each theme in addition to identifying their level of quality (Table 2). All seven studies were considered eligible for synthesis based on their quality rating, and those in the "moderate" category were further considered within the context of limitations. Ratings from both assessors were highly concordant; five of the seven articles received the same rating. Discrepancies regarding the sixth and seventh articles occurred because of different interpretations of some of the appraisal questions; this was resolved through discussion among C.S., R.B., and R.G., and ratings were agreed on.

SYNTHESIS

Meta-synthesis started with the five methodologically strongest articles before the remaining two studies were incorporated into the synthesis. The purpose of this was to assess for data saturation and to search for any additional data that confirmed or disconfirmed initial interpretations (Sattar et al., 2021). The quality appraisals did not make a significant difference in the findings of the meta-ethnography, as themes were found to be similar across the studies, irrespective of article quality.

Table 2 provides an overview of five key concepts that were identified by the synthesis, in addition to which articles contributed to each theme; these are:

1. Resistance from clinicians (withholding information)

2. Othering

    i. From clinicians/health care professionals

    ii. From the public

3. Negative impact on self-image/esteem

4. Hopelessness surrounding the perceived permanency of BPD

5. Feeling like a burden

RESISTANCE FROM CLINICIANS (WITHHOLDING INFORMATION)

Five articles (Bonnington & Rose, 2014; Fallon, 2003; Fromene & Guerin, 2014; Horn et al., 2007; Nehls, 1999) highlighted a sense of reluctance from health care professionals to diagnose and provide information on BPD. Fallon (2003) described this as most evident for participants when first entering the mental health system via their general practitioner, highlighting variability across explanations that were given by various mental health professionals. It is unclear whether this was for those who had already received a diagnosis of BPD, but the author felt that despite the participants' distress and concern, "some received no explanations concerning the roles of the individuals they were seeing, or of their function" (p. 398).

Bonnington and Rose (2014) described participants' experiences of health care as one that left the individuals in a "disempowered limbo for long periods" (p. 13), whereby their diagnosis and treatment were withheld, or they were given the diagnosis but told no treatment was locally available. The authors

TABLE 2. Themes From Synthesis of Selected Studies, Categorized by Quality Rating

Themes From Synthesis	Studies (Quality Rating: High)				Studies (Quality Rating: Moderate)		
	Bonnington and Rose (2014)	Veysey (2014)	Horn et al. (2007)	Fallon (2003)	Nehls (1999)	Fromene and Guerin (2014)	Miller (1994)
Resistance from Clinicians (Withholding Information)	✓		✓	✓	✓	✓	
Othering From Clinicians/Health Care Professionals	✓	✓	✓	✓			✓
From the Public	✓				✓	✓	✓
Negative Impact on Self-Image/Esteem		✓	✓	✓	✓	✓	✓
Hopelessness Surrounding the Perceived Permanency of BPD	✓	✓	✓		✓		✓
Feeling Like a Burden			✓		✓	✓	✓

further noted a sense that BPD patients felt as if they were "being held at arm's length" (p. 13), which often led to disengagement from mental health services. Horn et al. (2007) highlighted the same sentiment, stating "that all participants reported that initially they were given little information or explanation about the diagnosis" (p. 260). The authors explained that a participant described how many questions were met with "No, this is definitely what you have. We are 100% sure" (p. 261). That sense of power or the "expert role" was further highlighted by Fromene and Guerin (2014); one of their participants stated:

> I didn't really know anything about it [BPD]. I would have liked a lot more information. She just gave it to me and said "you have got BPD." And I said, "Okay what is that?" and she said "Ah, well, that is what you have got." (p. 575)

Participants from three studies (Fromene & Guerin, 2014; Horn et al., 2007; Nehls, 1999) explicitly stated that they had to engage in their own research to find out further information about BPD:

> He wouldn't explain it or anything. He said, "You have a personality disorder. You have a character disorder." I had to go and research what that meant. I had no idea what he was talking about. (Nehls, 1999, p. 287)

> [I had] to try and find out more about it. . . . it was almost as though I had to be quite challenging to professionals, by being persistent and for quite a large part of the response in that was. . . . (Horn et al., 2007, p. 261)

Fromene and Guerin (2014) stated that all the individuals in their study had wanted more information about BPD and potential treatments: "I still feel that it needs to be explained to me more. . . . If I've got a better understanding of it, I might be able to change it and become a better person" (p. 575), with three out of five individuals in their study stating that they had not been given any information or psychoeducation about BPD.

OTHERING (FROM CLINICIANS, HEALTH CARE PROFESSIONALS, AND THE PUBLIC)

Five of the seven articles (Bonnington & Rose, 2014; Fallon, 2003; Horn et al., 2007; Miller, 1994; Veysey, 2014) described participants feeling othered by clinicians/health care professionals due to their BPD. Participants described themselves being perceived by health care professionals as "liars, attention-seeking, unreasonable/difficult, manipulative, and taking resources from other patients" (Veysey, 2014, p. 26); another participant was told that she was "undeserving of inpatient care" (Fallon, 2003, p. 397). Attention-seeking was highlighted on numerous occasions (Bonnington & Rose, 2014; Nehls, 1999; Veysey, 2014), with one participant stating: "Well of course I'm seeking attention. I need help; I'm terribly depressed . . . [but] I've done dozens of mutilations and not told anyone" (Nehls, 1999, p. 289). Another participant explained: "You walk into the emergency room, and they don't want to treat you because you did this to yourself . . . they think it's just attention-seeking. But that's not what it's about" (p. 287). Nehls argued that

by viewing manipulation as being an inherent part of a borderline disorder, health care providers were responding negatively to the individual with BPD.

Some individuals felt diagnosis was an opportunity for clinicians and health care professionals to discriminate by rejecting them from services: "I think, to be honest, they were glad to be shot of me" (Horn et al., 2007, p. 261). Bonnington and Rose (2014) affirm this, stating, "The use of it [diagnosis] to the doctors was that it meant they no longer had to bother to make an effort because 'she's one of those we can't help'" (p. 13). Nehls (1999) outlined one participant's perception that clinicians think "no matter what we do, it's not enough, therefore we'll just put an end to it [services]" (p. 290), with another stating, "We're not going to get anywhere with her anyway" (p. 288).

Four articles described participants as feeling othered by the public, including family/friends in relation to their BPD (Bonnington & Rose, 2014; Fromene & Guerin, 2014; Miller, 1994; Nehls, 1999). Bonnington and Rose (2014) stated that many participants "anticipated/experienced stigma in public relating to visible signs of their distress, such as scars or 'challenging behaviour' which made them 'discredited'" (p. 14). Some individuals felt their mental health was dismissed by friends or family, and others felt there was an absence of accurate information about BPD in general public awareness. Others recounted experiences of physical and psychological violence as a result of their diagnosis, particularly when first entering into health care settings (p. 14). A participant in the Nehls (1999) study explained:

> I've had a lot of negative experiences as a result of what I consider more of a label than a diagnosis. I've learned from experience not to give that diagnosis . . . because it just has a lot of negative ramifications. I mean, immediately it puts up a stop sign, like "oh here, you know she has borderline. She's going to be difficult to work with." (p. 288)

Miller (1994) echoed a sense of participants feeling inadequate and estranged from others because of their diagnosis, particularly with regard to meeting perceived social standards.

NEGATIVE IMPACT ON SELF-IMAGE/ESTEEM

Six of the included seven studies (Fallon, 2003; Fromene & Guerin, 2014; Horn et al., 2007; Miller, 1994; Nehls, 1999; Veysey, 2014) described how a BPD diagnosis negatively impacted self-image and/or self-esteem, including how the participants viewed themselves: "not as human, as others" (Veysey, 2014, p. 26). For some, diagnosis led to a reinforcement of both implicit and explicit negative judgment:

> You're this . . . you're a sod, you're a slimey. I was already in the mindset where I was a bit of a failure . . . a freak . . . because I had no explanation. . . . My nature is that I do internalise, sort of, my problems. . . . And you know, you're this, you're a sod. (Horn et al., 2007, p. 261)

Some individuals felt the diagnosis meant they would now be labeled as a difficult client (Horn et al., 2007), which inadvertently reinforced their own self-beliefs: "I had no self-respect. . . . I'm a reject" (p. 262).

As Miller (1994) outlined, participants often held a view of themselves as estranged from others and "inadequate in the face of perceived social standards" (p. 1216), but Miller also found that rather than having an impaired sense of self (*DSM-5* BPD diagnostic criteria, American Psychiatric Association [APA], 2013), participants instead identified their sense of self as intact but recognized that they may have impairments in behaviors.

HOPELESSNESS SURROUNDING THE PERCEIVED PERMANENCY OF BPD

A sense of hopelessness around the perceived permanency following a diagnosis of BPD was evident across five of the studies (Bonnington & Rose, 2014; Horn et al., 2007; Miller, 1994; Nehls, 1999; Veysey, 2014). Participants recounted their feelings on the permanency of the diagnosis, not believing things could change for them: "The best we [BPD clients] can do is the least amount of damage to ourselves as possible and this is going to be our lives" (Veysey, 2014, p. 26). This perspective was echoed by Nehls (1999) through a participant's description of diagnosis as something "you can never get rid of" (p. 288), while other participants explicitly stated their sense that the word *disorder* implied permanency (Horn et al., 2007, p. 263). Internalized stigma experienced by these individuals appeared, to some degree, to be rooted in their experience of receiving a diagnosis of BPD without any sense of hope being instilled about future prognosis or outcome. Some individuals described diagnosis as the "killing of hope . . . it almost feels like, well, your hands are tied, your cards laid and your fate set" (p. 262), and furthermore:

> But to have a diagnosis means you are just screwed. Once you have that on a piece of paper in a medical file, it's over. It's just over. No one will touch me with a ten-foot pole. It's like you got the plague. (Nehls, 1999, p. 287)

Another participant within the Horn et al. (2007) cohort appeared to be resigned to the fact that there was nothing they could change about their diagnosis, stating: "Well, okay, that's what I've got. Y'know? There's nothing I can do about it. Got to accept it" (p. 263). Another participant stated: "I didn't have a positive outlook of my future for quite a number of years" (p. 262). Miller (1994) stressed a sense of estrangement that followed diagnosis, highlighting that a number of the participants felt unable to meet society's standards, which led to feelings of inadequacy and despair. This was echoed by Nehls (1999), who quoted participants as feeling blamed and undeserving of treatment (p. 288).

FEELING LIKE A BURDEN

Four of the seven included studies (Fromene & Guerin, 2014; Horn et al., 2007; Miller, 1994; Nehls, 1999) highlighted that a sense of burden was experienced by individuals with BPD, where they often described feeling they were a "burden to everyone" (Horn et al., 2007, p. 261). Others "did not want to burden anyone" (Miller, 1994, p. 1218). Fromene and Guerin (2014) reported

a participant who particularly feared being a burden to their children and was therefore concentrating on being a good role model for them and attempting to no longer be absent from their lives. A sense of fear was also noted by individuals with BPD that others, including health care professionals, would tire of hearing them repeat the same issues. As one participant explained:

> They [health care professionals] hear from me quite often, and, I suppose, I'm the little boy that cries wolf, and they're kind of tired of it. But I'll call, and I'm legitimately having what I would consider a crisis. (Nehls, 1999, p. 288)

DISCUSSION

This systematic review synthesized qualitative studies exploring experiences of stigma and discrimination in individuals with a diagnosis of BPD to facilitate greater understanding of their views and experiences. Five themes were identified through the meta-synthesis: (1) resistance from clinicians (withholding information), (2) othering, (3) negative impact on self-image/esteem, (4) hopelessness surrounding the perceived permanency of BPD, and (5) feeling like a burden.

This review found that individuals with BPD tend to experience resistance from clinicians to provide adequate psychoeducation regarding their diagnosis. It was noted that for some individuals this experience first occurred when they were moving into a mental health service via their general practitioner, with many individuals finding the explanations provided to be highly variable (Fallon, 2003). Participants often had to conduct their own research to gather additional information, with others sensing they were being held at "arm's length," which led to their subsequent disengagement from services (Bonnington & Rose, 2014; Fromene & Guerin, 2014; Horn et al., 2007; Nehls, 1999). This could be because clinicians and health care professionals hold to myths around BPD, and their knowledge of BPD symptoms is poorly understood. Indeed, BPD is often equated with a social or relational difficulty until the person is in extreme distress, and a small proportion of those repeatedly accessing crisis services are subsequently diagnosed.

Given that mental health practitioners are the next point of contact after general practitioners, they may be the first people to diagnose BPD and by doing so are fundamental to how individuals understand and interpret their diagnosis (Lester et al., 2020). As such, the clinician may inadvertently reinforce stereotypes or the individual's lack of self-esteem or worth by withholding, or not providing, adequate information (Lester et al., 2020). Indeed, this review identified that individuals who received a diagnosis of BPD found that the information they were provided often instilled a sense of hopelessness; clinically, this could have implications for how clinicians provide information or diagnosis of BPD.

Previous research highlights the stigma that clinicians and health care professionals sometimes hold toward individuals with BPD (e.g., Dickens et al., 2016). This review substantiates those findings, with participants detailing their experiences of discrimination from health care providers. This included treatment being withheld and difficulties accessing support when an individual presented with a BPD diagnosis. This discrimination is not exclusive to BPD

and has been demonstrated toward mental health problems more broadly (Corrigan, 2005), but there is evidence to indicate that individuals with BPD especially experience discrimination (Biskin, 2015), with the diagnosis itself becoming a barrier to care. Biskin argues that this may be due in part to many clinicians' views of BPD as an "untreatable" condition, and that clinicians often encounter individuals with BPD in crisis settings, which is not where they would receive treatment, resulting in a biased perspective of the clients.

Individuals with BPD described othering from others, due to the diagnosis itself and as a result of the *symptoms* of their diagnosis. That is, individuals with scars on their arms as a result of self-harm or those engaged in behaviors deemed challenging felt "othered" by the public due to their visibility and experiences they felt were not always entirely in their control. This highlights that stigma and discrimination may not be exclusively linked to the internal label provided, but is also the result of the individuals' physical and/or external presentation.

This review identified that individuals who have experienced BPD stigma felt that the diagnosis had a negative impact on their self-esteem and self-image. This is consistent with previous research that examined the impact of having a mental illness diagnosis on self-image (Horn et al., 2007), with the label itself leading to an internalized and disempowered view of self (Knight et al., 2003; Quenneville et al., 2020). This further emphasizes the need for both patients and clinicians to be provided with accurate information as early as possible. Chanen et al. (2017) have already produced such recommendations, which include encouraging training programs (e.g., medical schools) to address "clinician-centred discomfort with the label, mistaken beliefs, and prejudicial and discriminatory attitudes and behaviours" (p. 215). Clinicians often associate BPD either with social difficulties until self-harming behaviors escalate or with suicidal behavior, whereas the actual primary early indicators of BPD are difficulties with self-identity, impulsivity, and fear of abandonment. It is also common for individuals with a BPD diagnosis to have a history of major trauma. This highlights the need for improved understanding of the development and early indicators of BPD in order to lead to earlier identification, improved care pathways, and possibly a reduction of internalized stigma.

Hayne (2003) notes that clients who received a psychiatric diagnosis found the use of medical language destructive, stating that clients' distress was due to "pure knowing; hearing a medical term that is taken as absolute and irrefutable fact" (p. 725). This sentiment was echoed across this review, with participants explicitly stating that their sense of the word *disorder* suggested permanency (Horn et al., 2007). Participants linked their sense of hopelessness to internalized stigma associated with the perceived permanency of a diagnosis, with little hope for their future (Veysey, 2014), a sense of all hope being taken away (Horn et al., 2007), and diagnosis increasing their sense of marginalization and estrangement from society in general (Miller, 1994; Nehls, 1999).

Despite the perceived *permanency* of BPD noted above, there is strong evidence to indicate that BPD is not lifelong, with a reduction in symptoms over time (Biskin, 2015). This links to participants' experiences of clinicians' explanations of BPD and the limited provision of psychoeducation. It may be that clinicians are not aware of the long-term prognosis and longitudinal

course of BPD and therefore are unable to provide this information to individuals when they are first diagnosed. This has clinical implications for how individuals view themselves and how they engage with services, society, and their families going forward, potentially contributing to a sense of hopelessness, as evidenced by participants' experiences in this synthesis.

This review highlighted that some individuals with BPD have concerns around being a burden on others, including their children (Fromene & Guerin, 2014; Horn et al., 2007; Miller, 1994; Nehls, 1999). Parental concern about their mental health being burdensome on their children is not exclusive to individuals with BPD alone but expands to mental illness more broadly; in their systematic review, Wahl et al. (2017) found that parents with mental ill-health had three primary concerns: the need for being a good parent, worries about the child's well-being, and the need for practical help. Additional research indicates variable findings regarding the evidence around the impact of parental mental illness on children (Gladstone et al., 2011); however, providing psychoeducation and peer support to family members of individuals with mental illness may be indicated (Ditlefsen et al., 2021; Grenyer et al., 2019). This could contribute to a reduction in parents' concern about the perceived burden they may be placing on their children, leading to improved well-being.

STRENGTHS AND LIMITATIONS

Unpublished and gray literature studies were excluded, and it may be that inclusion of these would have added to the breadth and depth of studies. To counter this selection bias, the included studies were peer-reviewed, which provided support to the overall quality of methodologies. A decision was made not to exclude studies on the basis of quality because there is no consensus on the application of quality criteria to qualitative research (Atkins et al., 2008). All studies were critically appraised prior to beginning the meta-synthesis, and themes identified in the two methodologically weaker studies were largely consistent with themes in the five methodologically stronger studies. It is important to recognize that the included studies incorporated a range of different methodologies (i.e., thematic analysis, interpretive phenomenological analysis, and grounded theory methodology), which contributed to the development of the overall meta-synthesis.

A limitation of this review is that sampling bias may have impacted the findings, as the participants who chose to take part in the research may have been motivated to share their experiences, whereas those who chose not to take part may not have experienced stigma and/or discrimination. The studies selected for this review were conducted in Europe, the United States, and Australia; therefore, the results of the review may not fully reflect the experiences of participants from other geographical locations and cultural backgrounds. It is important to consider that different health care services and provisions may also have impacted the findings presented. Limiting the search to studies published in the English language meant that studies in different cultural contexts may have been missed. Qualitative research is rarely published in high-ranking journals (Gagliardi & Dobrow, 2011); this finding, combined with the exclusion of unpublished research from this review, may have limited

our understanding of the topic area. More qualitative studies in this field could allow for crucial learning from, and dialogue with, experts with experience so that we can begin to address the conscious and unconscious biases that impact the assessment and treatment of BPD, and build on the foundations of research being carried out around BPD and stigma in mental health care over the past few decades (Aviram et al., 2006).

CLINICAL AND RESEARCH IMPLICATIONS

A key finding of this review was that individuals felt they were not provided with adequate information regarding their diagnosis. It may be that a standardized pathway of care following diagnosis could be introduced across health services that would indicate that mandatory psychoeducation should be provided. Participants in this review felt a sense of hopelessness as a result of their belief in the permanency of a BPD diagnosis; therefore, clearer psychoeducation could encourage a sense of empowerment in patients and lead to a reduction in hopelessness, which in turn may improve their overall well-being.

To facilitate collaborative and informed BPD diagnoses, specialized training is needed for clinicians to improve their understanding of the symptomatology of BPD and longer-term outcomes following diagnosis. In addition, access to current BPD research and time within one's job set aside to digest this knowledge could supplement this training and foster greater confidence among clinicians to provide a holistic and accurate diagnosis that acknowledges the challenges identified in this review. Further research on how best to make this information more accessible to mental health providers is warranted.

This review has highlighted a need for mental health professionals and services alike to consider the validity of a diagnosis of BPD. Current *DSM-5* diagnostic criteria for BPD include a pervasive pattern of instability of self-image (APA, 2013), and Miller (1994) summarized clinicians' understanding and descriptions of BPD as including identity disturbance and an impaired sense of self. However, this review found that patients with BPD described themselves as having a cohesive identity; rather than having an *impaired* sense of self, they had a sense of *an impaired self* (i.e., they felt inadequate in the face of perceived social standards and behavioral impairments), perhaps relating to internalized stigma. It is important to recognize that this may not apply to all individuals with a diagnosis of BPD, but it does highlight that further research may be warranted to investigate the real-life validity of these criteria for a diagnosis that can in fact show a reduction in symptoms over time (Biskin, 2015). Seeking the perspectives of experienced experts on the recent paradigm shift seen in the *ICD-11* is perhaps a first step in investigating their validity (Hackmann et al., 2019).

CONCLUSION

To our knowledge, this is the first qualitative meta-synthesis of experiences of stigma and discrimination in individuals with a diagnosis of BPD. This review has provided an opportunity to gain a greater understanding of their experiences and has shown that individuals report experiencing stigma and

discrimination as a direct result of receiving a diagnosis of BPD. This review has highlighted areas for further research that may contribute to a reduction in stigmatization and discrimination of individuals with BPD and improve health care providers' understanding of the longer-term prognosis following diagnosis. It may be that significant work needs to be devoted to breaking barriers and exposing myths around BPD identification and treatment. This may include a pathway for early identification and treatment of BPD to care that could stipulate a level of psychoeducation that must be provided to health care providers and newly diagnosed individuals when they first enter mental health services.

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