



Duff, C., Kokanovic, R., Flore, J., Thomas, S. D., Callard, F. and Blackman, L. (2020) Perspectives on person-centred care for borderline personality disorder: a critical research agenda. *Health Sociology Review*, 29(1), pp. 1-15. (doi: [10.1080/14461242.2020.1715815](https://doi.org/10.1080/14461242.2020.1715815))

The material cannot be used for any other purpose without further permission of the publisher and is for private use only.

There may be differences between this version and the published version. You are advised to consult the publisher's version if you wish to cite from it.

<http://eprints.gla.ac.uk/233972/>

Deposited on 11 March 2021

Enlighten – Research publications by members of the University of  
Glasgow

<http://eprints.gla.ac.uk>

# **Perspectives on Person-Centred Care for Borderline Personality Disorder: A Critical Research Agenda**

## *Abstract*

Borderline Personality Disorder (BPD) is a highly contentious psychiatric diagnosis with ongoing tensions over nomenclature, aetiology and treatment recommendations. This article examines a number of these tensions and assesses how greater attention to the voices of people living with BPD may help inform the delivery of new modes of person-centred care. To this end, we present a critical social science research agenda for investigating the experiences, social contexts and support needs of people living with BPD. We canvass issues pertaining to the diagnosis of BPD (including its name), the strongly gendered dimensions of BPD, and the pressing need to improve support for people living with this condition. Throughout our analysis, we indicate how critical interdisciplinary inquiry may drive new responses to these challenges. Our analysis is illustrated with reference to experiences of BPD recounted in two Australia-wide surveys conducted in 2011 and 2017. We argue that greater progress towards person-centred care requires novel forms of evidence grounded in critical social inquiry into experiences of treatment and support among people living with BPD, and the varied social, cultural and political contexts underpinning these experiences.

**Keywords:** Borderline Personality Disorder, mental health, sociology of health and illness, person-centred care.

Borderline Personality Disorder (BPD) is a highly contentious psychiatric diagnosis, with ongoing tensions over nomenclature, aetiology, clinical presentations and treatment recommendations (see Lamont and Dickens, 2019 for a review). These tensions partially derive from inconsistencies in psychiatric discourse about the causes and sequelae of BPD, and associated debates about effective means of early diagnosis and intervention (Chanen et al, 2017), and partly from discrepancies between psychiatric accounts of BPD and those advanced by people living with this diagnosis (Donald et al, 2017b; Kerr et al, 2015). At issue are the nosological character of BPD, and its causes and symptomologies, along with the most effective support and treatment approaches for people living with this controversial diagnosis. Despite these tensions, BPD remains frequently diagnosed, just as the category of personality disorders continues to expand in psychiatric manuals (APA, 2013; NHMRC, 2012). Owing to its complex aetiology and interpersonal characteristics, the focus of BPD care has largely been on managing clinical symptoms via structured psychotherapies such as dialectical behaviour therapy (Chanen and Thompson, 2016), with less attention to the psychosocial supports people living with BPD need to engage in meaningful social participation (Donald et al., 2017b; Veysey, 2014). As a result, the social contexts of BPD, and the role of social inclusion in supporting recovery from BPD, are less well understood for this condition than for other mental health diagnoses (see Donald et al, 2017b; Kerr et al, 2015; Gary, 2018).

These oversights arguably follow from the relative absence of the voices and perspectives of people living with a BPD diagnosis, both in critical social science informed mental health inquiry, and in clinical debates and healthcare practice development (Chugani, 2016; NHMRC, 2012). It is striking to observe this absence at a time when mental health service

users, policy makers and health care providers in many parts of the world are calling for greater contributions from people living with psychiatric diagnoses, and their families and supporters, to drive person-centred care and enhance recovery orientations in healthcare delivery (Gask and Coventry, 2012; Donald et al, 2017b). This article explores some of the key controversies in contemporary discussions of BPD across the health and social sciences, and then assesses how greater attention to the perspectives of people diagnosed with BPD may help to resolve these controversies, while contributing to the development of innovative tailored supports. Our efforts are grounded in the conviction that greater sensitivity to, and inclusion of, lived experience is key to improving care and support for people with a diagnosis of BPD. One of the key barriers to service improvements concerns the widespread characterisation of BPD as a “diagnosis of exclusion” from mental health care (Chanen et al, 2017, p. 216), and the extent of the stigma surrounding the condition. Indeed, clinicians and other health care providers have often been accused of treating BPD as a “‘dustbin diagnosis’ for patients considered different or difficult” (James and Cowman, 2007, p. 671), often leading to poor experiences of treatment, mis-diagnosis or changes in diagnosis over time, and conflict between clinical staff, patients and their families. Studies routinely report that health care providers regard individuals presenting with symptoms associated with BPD, such as self-harm and emotional ‘lability’, as “difficult to treat” (Donald et al, 2017a, p. 201), while outcomes of psychiatric treatment (via medication) for BPD are generally poorer than for other personality disorder diagnoses (see Bateman et al, 2015; MacIntosh et al, 2015).

In light of these findings, our key claim is that improvements in care and support for people diagnosed with BPD requires deeper critical inquiry into personal experiences of this

diagnosis, including greater recognition of experiences of *coming to a BPD diagnosis* and the effects this may have on individuals' subjectivity and identity (that is to say, what it means to live 'under' a diagnosis of BPD), and keener awareness of the key social and cultural factors underpinning these experiences, particularly gender and socio-economic status (Kerr et al, 2015; Hughes et al, 2008). Importantly, these interests suggest the need for novel critical social science understandings of the lived trajectories of BPD diagnoses, and the complex interactions between 'expert' and 'lay' knowledges that shape these trajectories (Author B et al, 2010). More broadly, it suggests the need for renewed interest in the "processes and categories" (Blaxter, 1978) by which disease states like BPD emerge in medicine and related fields, along with the "conceptual models" and "clinical practices" by which these states are converted into formal diagnoses and treatment plans (Brown, 1995; see also Jutel, 2009; Jutel and Nettleton, 2011). With these interests in mind, this article offers a critical research agenda to guide this work, informed by our reading of diverse literatures in the sociology of health and illness, medical anthropology, medical humanities, and psychology, and illustrated by the findings of two Australia-wide studies into the lived experiences of individuals diagnosed with BPD conducted in 2011 and 2017 by a large Australian NGO that supports people living with this diagnosis. Featuring 82 'open' and 'closed' survey items exploring diverse questions of diagnosis, treatment, care and support, the two online surveys attracted a total of 577 people diagnosed with BPD with experiences of using mental health services, and 296 self-identified 'carers' (see Lawn et al, 2017 for details regarding sampling, methods and key findings). The results offer rich insights into experiences of diagnosis and treatment, along with indications of mental health service users' preferences for the design of clinical and social supports for BPD. Insights into the contradictions and synergies of personal and professional (medical and psychological)

knowledge of BPD are central, in our view, to these service improvements, and enhanced quality of life for people living with this diagnosis.

Contradictions and inconsistencies are evident throughout the social and clinical literature on BPD. In our view, three central controversies stand out, both for their salience in the literature, and for their significance in terms of the design and delivery of person-centred care for people living with a BPD diagnosis. The first controversy concerns the nosological character of BPD, and the notion that it describes a stable, knowable health condition. The second pertains to the gendering of BPD and the sociocultural, intimate and emotional contexts in which women in particular encounter BPD diagnoses and their effects. The third controversy concerns the nature of care for BPD, when care is initiated, and by whom. We briefly review each controversy as it manifests across diverse fields of inquiry, with additional reference to responses to open-ended questions in the Australian surveys described above. We close with recommendations for ongoing critical social science research into how BPD is conceptualised and experienced, and for improving the organisation of care for people living with the condition, including social, material and community supports and services.

### **Controversies in the Study and Treatment of BPD**

International studies indicate considerable variance in the incidence and prevalence of BPD across geographical regions and populations (Temes et al, 2017). Global prevalence estimates range from 1-4% within a given population (NHMRC, 2012), with regional discrepancies likely revealing the diagnostic difficulties that BPD can present (Biskin and Paris, 2012; Stapleton and Wright, 2019). In Australia, prevalence rates between 1%

(Jackson and Burgess, 2000) and 3.5% (Moran et al, 2006) have been reported, though more recent estimates are unavailable, with females significantly outnumbering males in clinical settings (Chanen and Thompson, 2016). In the 5<sup>th</sup> edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5), the diagnostic criteria for BPD encompasses a range of volatile affective states including ‘excessive’ impulsivity and sensitivity, and self-injurious behaviours (APA, 2013, p. 663). Research has further highlighted that people diagnosed with BPD are likely to also have other psychiatric diagnoses (Chanen and Thompson, 2016). The combination of suicide ideation and self-harm, often taken as hallmarks of BPD (Leichsenring et al, 2011), mean that those diagnosed with the condition tend to frequently access mental health services (Temes et al, 2017). Individuals accessing care report mixed experiences, with evidence that healthcare providers regard people with BPD as “difficult and disruptive” (Stapleton and Wright, 2019, p. 445). They often endure highly stressful interactions in the healthcare system (Lamont and Dickens, 2019) and report feeling judged, neglected or otherwise mistreated by healthcare practitioners (Donald et al, 2017b). It may be that part of the reason for these difficulties is the enduring struggle to identify effective approaches for people diagnosed with BPD, and a corresponding over-reliance on acute psychiatric inpatient care (Stapleton and Wright, 2019). A range of ‘evidence-based’ treatments are presently recommended, including dialectical behaviour therapy (Linehan, 1993), mentalisation-based therapy (Bateman et al, 2015), and transference-based therapy (Clarkin et al, 2007), although questions of treatment effectiveness and access remain largely unresolved (Sisti et al, 2016).

Our purpose in restating these features of the lived experience and clinical presentation of people diagnosed with BPD is to emphasise from the outset the controversies that surround

discussions of this diagnosis. These encompass the diagnostic accuracy and/or clinical utility of BPD, including confusion over diagnostic boundaries (Bourne, 2011); the nature and prevalence of key symptomologies and the varieties of their manifestation (Paris and Lis, 2012); the sociocultural contexts of BPD, including most strikingly their gendered nature, and the 'gendering' of personality disorders more broadly (Shaw and Proctor, 2005); as well as the efficacy of available treatments, including indications for pharmacotherapies (Chanen and Thompson, 2016). Debates endure around these controversies, with important implications for how BPD is understood in the wider community, how it is treated, and how people experience this diagnosis in their everyday social and emotional lives. More directly, these controversies reveal discrepancies between lived experiences of BPD and its clinical considerations, including diagnosis and treatment (Donald et al, 2017a; Chugani, 2016). It also suggests a gap between what people presenting for treatment for BPD want or need, and what mental health treatment services are currently able to deliver (see Chanen et al, 2017).

A key feature of mental health care reforms, as advocated by those with lived experience, is the claim that improvements in service provision require fresh insights into how people navigate mental health services, and how they experience psychiatric treatment and its contexts (Davidson, 2016, pp. 1091-93: also Knight et al., 2018). However, there is little empirical, qualitative research regarding personal experiences of BPD in Australia (or elsewhere), and what research is available points to significant problems with the reporting, diagnosis and treatment of BPD. This, in turn, perpetuates suffering and stigma for people diagnosed with BPD and members of their social networks supporting them (Veysey, 2014; Treloar, 2009). Despite emerging evidence highlighting the complex sociocultural



dimensions of the experience of BPD and diagnosis (Paris and Lis, 2012; Agnew et al, 2016), the current literature is dominated by reports based on biomedical studies of the phenotypic structure, neurobiology, social cognition and treatment of BPD. Studies rarely examine experiences of BPD within broader social, economic and cultural contexts, and/or how to explore the relationships between body, culture and identity among people living with this diagnosis (see Author F, 2007, Author A, 2014). Moreover, available treatments are largely designed such that people living with BPD are expected to adapt to the treatment, rather than the treatment being tailored to their individual needs, which are often unknown or misunderstood (see Treloar, 2009; Donald, et al, 2017b). Although collaborative care approaches among practitioners are recommended for BPD (Bateman et al., 2015), there is little experiential or clinical knowledge to guide such efforts. It is largely to inform and underpin the ongoing development of these collaborative approaches that we propose a novel research agenda for critical social science accounts of the lived experience of BPD in the conclusion to this article.

While scarce, studies of experiences of BPD suggest that the diagnosis can have a profound impact on an individual's sense of self, their relationships with others, and their uptake and use of mental health services (Shaw and Proctor, 2005). It has been reported, for example, that staff often lack effective strategies and techniques to work with people diagnosed with BPD (Agnew et al, 2016), which sometimes results in patients being refused care, and may, in turn, perpetuate stigma (Chugani, 2016). A key reason for these difficulties is the risk of self-harm associated with a BPD diagnosis (Rao et al, 2017), and the challenges this risk presents in clinical settings. Inadequate community mental health service responses often cause people to turn to emergency departments and/or be admitted to secure inpatient

units, which may exacerbate their distress (NHMRC, 2012). Indeed, qualitative studies paint a grim picture of dissatisfaction, experiences of discrimination and conflict over the design and delivery of clinical care (Gary, 2018; Donald et al., 2017b; Lamont and Dickens, 2019). Much of this dissatisfaction derives from clinical and diagnostic confusion over the nosological character of BPD, and the claim that it describes a stable health condition. This, then, is the first of the key social controversies in discussions of BPD that we wish to draw out.

### *BPD and its (Uncertain) Diagnostic Boundaries*

Our first broad agenda for critical social science research on the lived experience of BPD takes questions of diagnosis and diagnostic reliability as key interests. Our goal is to devise an agenda for social science research that unpacks the complex relationships between diagnosis and care, and asks how matters of diagnosis, treatment, care and support could be organised differently to offer more meaningful person-centred care for people diagnosed with BPD. A key source for much of this agenda derives from recent work in the ‘sociology of diagnosis’ (see Jutel, 2015; Jutel and Nettleton, 2011; Author B, 2013 for reviews), which asks cognate questions about the processes, methods, contexts and relations by which formal disease diagnoses are established. Phil Brown’s (1990; 1995:34) early contributions to this work describe aspects of the “social construction” of diagnosis and illness, emphasising the specific “effects of class, race, gender, language, technology, culture, political economy, and institutional and professional structures and norms” on this construction. Brown (1995:34) was equally alert to the ways “assumptions about the prevalence, incidence, treatment and meaning of disease” come to inform formal disease categories and their attendant diagnostic criteria. Later work explores how these

assumptions “frame the social reality of the healthy and the ill” by organising and distributing roles, functions and identities (including ‘normal’ and ‘deviant’, ‘healthy’ and ‘ill’) within a social field (Jutel, 2015:844-5). This work treats diagnosis as a social, cultural, political and technical achievement that relies for its maintenance on a series of mobile practices and relations. Jutel (2015) reminds us that diagnoses are labile effects of this maintenance, remaining vulnerable to revision as a result.

Aspects of this vulnerability are clearly visible in recent discussions of BPD diagnosis, along with the social, cultural and technical practices that sustain it. For example, discussions of the clinical validity of BPD and the effects and utility of the term ‘borderline’ (Gunderson, 2009) partially underscore BPD’s changing classification in the *International Classification of Diseases* and the DSM-5 (Lamont and Dickens, 2019; see also Wykes and Callard, 2010). As this diagnostic category has evolved, it is evident that some clinicians have become reluctant to diagnose BPD (Sisti et al, 2016; Paris, 2018), particularly in the case of younger people (Chanen et al, 2017). It has also been reported that people may receive treatment for BPD without the diagnosis being discussed due to clinicians’ concerns about stigmatising patients (Sisti et al, 2016; Donald et al., 2017a). While many clinicians hold the view that BPD is a “valid and reliable diagnosis with effective treatments” (Sisti et al, 2016, p. 848), there has long been the counter-view that, like all personality disorders, the diagnosis of BPD suffers from poor construct validity, high rates of diagnostic co-occurrence, poor clinical specificity, and a lack of clarity regarding its underlying neurobiology (Gunderson, 2009; Bourne, 2011; Pilgrim, 2017). Personality disorders are sometimes described as a ‘catch-all’ or “residual” (Pilgrim, 2017, p. 389) category, lacking the nosological clarity of formal disease classifications, and belonging instead to a remaindered cluster of ‘troubling’

traits, qualities and conditions. Common within debates across the social sciences is the view that BPD encompasses a set of socially disavowed behavioural traits that reflect the medicalisation of responses to trauma and discrimination, particularly women's responses, rather than any underlying neuropathology (see Donald, et al., 2017a). This is another reason why recent work in the sociology of diagnosis is so pertinent to our interests, casting fresh light on the social and cultural processes that continually shape BPD's diagnostic trajectories (see Bendelow, 2004).

Another example of this diagnostic confusion concerns discussions about the relationship between BPD and trauma, and whether diagnoses such as post-traumatic stress disorder (PTSD) are more clinically valid and reliable than the category of BPD (Frías & Palma, 2015). At issue here is the relationship between diagnosis, the delivery of treatments and a subsequent reduction in suffering, and the difference particular diagnoses makes to treatment outcomes. Some researchers argue that diagnoses like PTSD may involve less stigma for people than BPD, insofar as *trauma* is regarded as the cause of psychological distress in the case of PTSD, and not aberrant features of the patient's own personality (Lee, 2017), while others argue for the complete abandonment of the diagnosis of BPD (MacIntosh et al, 2015). To demonstrate how the uncertainties of diagnosis impact care we offer illustrative accounts from participants from the national Australian surveys on BPD:

*It's difficult when professionals have different views on your diagnosis, one says yes you have borderline the other says no, so that was really unhelpful for my treatment. Trauma therapy was horrific. I almost suicided going over my abuse with someone who said I had dissociative identity disorder instead of BPD (respondent to the 2011 survey).*

*If I had been properly assessed when I was first diagnosed with a mental health condition, I wouldn't be in this situation now, people might take me seriously, and I could have started ACT and DBT [BPD treatment programs] much sooner. I was 17 at the time, and no psychiatrist would diagnose me with BPD, and I feel like it has delayed my recovery. I got diagnosed [with BPD] by my GP last year, but I've known within myself for a long time (respondent to the 2017 survey).*

As these reports begin to indicate, enduring misgivings about the nosological clarity and clinical utility of the BPD diagnosis undermine the delivery of person-centred care by entrenching confusion about the nature of the condition for which individuals may need support. This raises interrelated questions: is BPD a brain disorder; an idiocentric function of a 'maligned personality'; a maladaptive response to trauma and/or emotional neglect, particularly experienced during childhood; a socially constructed category of power and gendered discrimination; or a combination of some or all these factors? (Sulzer, 2015; Stapleton and Wright, 2019). Compounding this confusion, there is much current debate about the extent to which BPD might be more effectively understood and treated as a form either of "complex PTSD" (Lee, 2017), or bi-polar spectrum disorder (Gary, 2018), even as others argue for the diagnostic discreteness and enduring clinical utility of BPD (Paris, 2018). It is not surprising that people accessing care for BPD report such mixed experiences in light of these debates. It is unlikely that these debates will be resolved anytime soon pointing again to the urgent need for new critical social science evidence to inform service improvements.

### *The Social and Cultural Lifeworlds of BPD: Gender and Power*

Our second proposed area of research emphasises the social and cultural contexts of BPD diagnosis and treatment, and the ways such contexts shape pathways into and out of care. Gender and power are especially important aspects of critical inquiry into BPD. The gendered dimensions of personality disorders have long been a focus of scrutiny in feminist critiques of psychiatry and clinical practice in mental health care (Wirth-Cauchon, 2001; Shaw and Proctor, 2005; Tseris, 2013). Feminist critiques ordinarily proceed from the still unexplained over-representation of women diagnosed with and in treatment for BPD, with studies around the world routinely finding that women comprise around 70-80% of patients in care (Ussher, 2013). In the absence of any compelling neurobiological explanation for this ratio, feminist scholars have mainly harnessed social, cultural and political arguments, with a focus on power and the pathologisation of trauma and suffering (see Author F, 2017; Author B et al, 2008; Author B et al., 2009). In our view, the gendering of BPD is yet to be adequately accounted for, just as there is still considerable work to be done investigating *how* gender (and intersecting dimensions such as sociocultural background and sexuality) mediates the ways BPD is experienced, diagnosed, and treated. Feminist literature provides several key orientations for critical social studies of BPD, with ongoing work exploring the pathologisation of women's experiences of trauma and suffering (Paris and Lis, 2012; Veysey, 2014; Jones et al, 2015), along with historical research exploring the construction of women's personalities in psychiatric accounts of the manifestations of psychopathology (Ussher, 2013; Sulzer, 2015).

Another significant research strand is the problematisation of behaviours or acts often associated with BPD such as self-harm. Drawing on qualitative research, this important body

of research has interrogated the affective states that have come to constitute BPD in clinical settings, highlighting the inextricability of self-harm from sociocultural and economic contexts (Chandler, 2016). This literature focuses on how certain acts, traits and temperamental characteristics have been pathologised in psychiatric research and practice, and gendered as 'essentially' feminine (Tseris, 2013; Agnew et al, 2016). In this respect, BPD is taken to describe a kind of "exaggerated femininity" (Ussher, 2013, p. 65) in which behaviours such as impulsivity, self-harm, anger and emotionality are pathologised and gendered. Feminist analysis has considered how these traits and behaviours are understood in contexts involving male patients, compared with those involving women, pointing to inexplicable contradictions and discrepancies in the delivery and experience of care (Shaw and Proctor, 2005).

The following excerpts from the 2011 national survey illustrate why renewed social science analysis of the gendering of BPD is so urgent:

*It was my Social Worker who asked if I knew what was wrong with me, and then she told me I had BPD. I found this diagnosis extremely offensive as I thought it meant that there was something wrong with my personality...and my personality is who I am...so therefore 'who I am' is all wrong. That was awful and I'll never forget that moment (respondent to the 2011 survey).*

*I've found that in certain times and places I've felt a very strong sense of stigmatisation within the medical system, like having my actions interpreted as being acts of manipulation rather than a way to self-medicate (in a very private way) in the only way that really works for me. Rather than getting to know me as an individual,*

*I've found that I've been seen by some professionals through the "lens" of BPD and some of the negative assumptions that have become so intertwined with that diagnosis (respondent to the 2011 survey).*

These statements reflect the layered and multiple enactments of the BPD diagnosis beyond “the primal scene of the clinical encounter” (Viney, Callard and Woods, 2015, p. 2). The circulation of BPD and its gendering in plural contexts necessitates interrogation, with particular sensitivity to the social and gendered contexts of BPD diagnosis and treatment.

### *Care Pathways and Caring for People with BPD*

The third major area for critical social analysis concerns pathways into and out of care for people diagnosed with BPD. As mentioned earlier, the views of those with lived experiences and informal carers and supporters are central to the realisation of person-centred care (Hughes et al, 2008; Gask and Coventry, 2012) although, again, there is very limited lived experience research related to being diagnosed with BPD, compared to other diagnoses such as depression (Donald et al, 2017b). The goal now must be to move from small scale studies of lived experiences in specific settings – as helpful as these studies have been in pointing to key areas for future research – to more systematic qualitative studies of *how* individuals experience a diagnosis of BPD, the care pathways available, their preferences for treatment and social support, the role of informal carers and social networks in support and treatment, and the ways recovery ought to be understood in the context of BPD (see Author A, 2014; Donald et al, 2017b; Knight et al, 2018). While there is encouraging evidence on the effectiveness of treatments such as dialectical behaviour therapy and mentalisation-based therapy (Bateman et al., 2015), pressing questions remain regarding access to these treatments, and the contexts in which they are most effective and for whom. How questions



of social and material support can be addressed in care are equally critical. Addressing these questions will require renewed attention to the relationship between the provision of psychosocial therapies, acute clinical responses including for those presenting with self-harm, the design of outpatient/inpatient care, the importance of continuity of care, and the place of peer delivered services and trauma-informed care provision (Donald et al, 2017b).

Respondents to the two Australian surveys made recurrent mention of the promise of psychotherapies like DBT, while expressing frustration at the absence of DBT trained specialists in their area, and the challenge of having to travel long distances to access more effective treatment and support. Others spoke of the costs involved and long waiting lists:

*DBT! It's either a 2 year waiting list for a public spot or a \$70 gap for weekly visits. I don't know anyone with borderline who can wait that long or afford that much. We all want DBT and the friends I know who have managed to get on a stream have improved immensely (respondent to the 2017 survey).*

Another salient feature of discussions of care in the Australian surveys concerned the importance of brief periods of respite and support, particularly through acute inpatient admissions. Such was the mixed experience of care in community-based mental health services, numerous survey respondents emphasised the importance of having access to more intensive support to help manage key periods of risk or vulnerability:

*My problem has been when I feel distressed and know that I am on the path to self-harm or suicide. There are no supports available then, except Lifeline and Suicide line, neither of which are ongoing supports. This feels crazy! I am doing the right things in developing self-awareness, but I am having to do so with utterly inadequate*

*supports. So that's when I feel like the hospital is my only option. Like I just need that support right away (respondent to the 2017 survey).*

Despite this perceived urgency, many respondents expressed frustration at being excluded from emergency care because of assessments that their needs were not acute enough:

*The more work I have done on myself, the more I am excluded from services, which are reserved for "serious" patients. I feel as if I have to escalate my self-harm or suicidality to get any services, which I am not willing to do. This is a terrible situation (respondent to the 2011 survey).*

Even so, responses at hospitals often reinforced unhelpful stigmas about BPD:

*Hospital is a bad option for people with BPD because it can become a self-harm competition. This is callous and harmful [but staff] say things like this; Your overdose wasn't bad enough; you only needed stitches and more self-control, not hospital. We are over-run by people with real mental illness; You are in control of your actions, we are here to help real people who don't have the luxury of that control; It's just behavioural. We know you lie all the time it is written all over your file notes, so why should we take any notice of you now (respondent to the 2011 survey).*

It is not clear how widespread these kinds of experiences might be among Australians living with a BPD diagnosis, and we are cautious about drawing strong conclusions from these data. Nevertheless, these reports do indicate the need for ongoing critical research into the

lived experiences of BPD and its treatment. It is equally clear that this kind of research needs to be driven by those directly affected, to provide a stronger evidence base for implementing new and more effective treatments and social supports for people living with a BPD diagnosis.

## **Discussion and Conclusion**

The controversies identified in this article call for a more sophisticated and nuanced understanding of living with a BPD diagnosis to drive person-centred care by inspiring innovative social support and healthcare to improve treatment outcomes for people diagnosed with this condition. Our analysis warrants novel social science research in three areas. Firstly, investigations of the nosology and symptomologies of BPD that consider the mutability of the diagnosis and examines the repertoire of acts and behaviours associated with BPD over time. This work ought to be guided by the rich body of research within the social sciences and humanities that examines the social and historical contexts of psychiatric diagnoses (see Jutel, 2015; Bendelow, 2004); the character of self-injurious acts and behaviours and the ways they are linked to specific diagnostic categories like BPD (Millard, 2015); and the deluge of emotions that can become named 'BPD' (Tseris, 2013; Chandler, 2016; Donald et al, 2017b). Secondly, we would stress the need for greater attention to the sociocultural contexts of BPD diagnosis, with a particular focus on ways BPD is *gendered* in the myriad affects and events that constitute treatment in clinical realms (see Author F, 2007). Enriched by the diverse accounts of people with direct experiences of a BPD diagnosis, this work may begin to map how this diagnostic category emerges, evolves and functions in clinical and social contexts, while also exposing its ambivalences, slippages and contingencies. Finally, we have emphasised the importance of critical studies of care among

people living with BPD. For people living with a diagnosis of BPD, the research we have proposed should help overcome difficulties encountered when seeking support, including: pessimism about outcomes of care; supporting efforts to reduce stigma; outlining new options for care and encouraging people to seek support; and, addressing social isolation among individuals living with a diagnosis of BPD. Being better equipped to support people with BPD should assist those living with the diagnosis, clinicians and informal carers and supporters to help reduce discrimination and improve access to healthcare services and other critical social supports.

Central to the achievement of such goals is the work of supporting people living with a BPD diagnosis to have their voices heard in policy and clinical discussions of person-centred care. We recognise that the notion of ‘patient-centredness’ has generated much interest across the health and social sciences, with many regarding the approach as a paradigmatic improvement on earlier approaches to psychiatric care (see Gardner, 2017; Delaney, 2018), just as others remain cautious, concerned that a focus on ideas like ‘supported decision making’ and care preferences risks displacing responsibility for treatments outcomes from clinicians to patients and their carers (see Gardner, 2017; Author A, 2014). Whilst mindful of these nuances, we would note how greater participation of people diagnosed with BPD, including members of their extended social networks, is fundamentally changing how BPD support and care are organised by ensuring that services are more effectively tailored to patients’ needs (Author E et al., 2011; Donald et al, 2017b). There are also important lessons to learn from mental health reform advocacy led by people with experience of living with this diagnosis. Accounting for their often-marginalised voices requires critical engagement with an array of potentially conflicting perspectives from various sources. For example,

qualitative studies among those with lived experiences of BPD have pointed to the emergence of strong counter-narratives of BPD, and personality 'disorders' more broadly, that typically contest the strongly gendered characterisation of the 'disorder', and the view that it describes a somehow damaged subject (see Martin, 2010 for a review). These studies provide insights into how consumer voices may be included in discussions about care and support in ways that lead to significant service improvements (Treloar, 2009; Donald et al., 2017b; Vesey, 2014).

The critical social science research agenda promoted here offers important conceptual and methodological innovations too. Grounded in a review of contributions across the social sciences, medical humanities, psychiatry, clinical practice and research, service user research and psychology, our proposed research agenda should inspire new theoretical and practical contributions by incorporating scholarship based on intersectionality, plural medical epistemologies, and person-centredness. Our goal is to generate a critical evidence base for health, government and carer and community groups to effect more equitable and inclusive responses to BPD by multiplying the kinds of evidence used to inform this work (see Author A, 2014). Our analysis indicates the need for novel responses to BPD through intersectional accounts of gender, sexuality, age, ethnicity, socioeconomic status and relationships, grounded in novel participatory methodologies (see Collins and Bilge, 2016). Intersectional perspectives are needed to secure more comprehensive understandings of the diversity of experiences of BPD, and the intertwined effects of sociocultural dynamics and medical institutions on these experiences. Intersectionality contributes to these understandings by addressing issues of recognition, parity and participation, and the ways gender, age, sociocultural positioning and other environmental factors shape all aspects of

experiences called BPD. As our analysis has indicated, sensitivity to these factors should inspire new insights into institutional barriers in mental health care, and experiences of stigma and powerlessness across the complex intersections of class, gender, sexuality, dis/ability, race, ethnicity and age. The analysis we have presented in our critical review of the literature points both to how urgent this kind of research is, and unfortunately, how rare it still remains.

Of course, as all existing discussions of intersectionality demonstrate (Collins and Bilge, 2016), sensitivities to power and context require a commitment to epistemological multiplicity of the kind often evinced in critical health and social research across the medical humanities (see Author A, 2014; Fitzgerald and Callard, 2016). It requires a commitment to troubling questions of method and epistemology that open novel modes of knowing (and knowing about) BPD. We would argue that simply adding the voices of people living with a BPD diagnosis to existing discussions is insufficient, for doing so will do nothing to undermine existing epistemological hierarchies across the health and social sciences. A commitment to intersectionality requires not a suspension of knowledge claims but a flattening of the ontological and epistemological ground on which these claims appear (Collins, 2015). This approach acknowledges that *all* knowledge claims are partial and contingent, such that neuroscience, for example, may stake a partial and contingent claim to a provisional truth about the neurobiology of BPD, just as advocacy led by those diagnosed with BPD, their carers and supporters may generate its own partial claims to provisional truths about the everyday experience of living with this diagnosis. Consequently, a plurality of methods and approaches is required to arbitrate between these claims, both in terms of their pragmatic utility and their sensitivity to the shifting contexts of BPD

(Fitzgerald and Callard, 2016). It is to stress that people living with BPD are active agents in the generation of different forms of expertise about the condition, an insight that lies at the heart of person-centred care, and the drive for greater peer and carer support in the delivery of care (Sweeny et al, 2009; Delaney, 2018).

We acknowledge the persistent struggle within medicine and psychiatry to adequately conceptualise and achieve genuine person-centredness (Gask and Conventry, 2012). The research agenda outlined in this article seeks to shed light on what is valued or has salience in service settings across varied lived experiences of BPD, and how people seek and receive care for BPD. Our intervention is grounded in the recognition that valuing the lived experiences of being diagnosed with BPD is central to the accomplishment of genuine person-centredness in clinical and non-clinical settings (see Delaney, 2018). Of course, this requires that the voices of people living with a diagnosis of BPD are listened to and valued. Addressing the personal and social implications associated with BPD is clearly urgent. This is a challenge for researchers as much as clinicians and policymakers, which is why we have been so persistent on the nature of the research tasks confronting social scientists interested in BPD.

## REFERENCES

- Agnew, G., Shannon, C., Ryan, T., Storey, L., & McDonnell, C. (2016) Self and identity in women with symptoms of borderline personality. *International Journal of Qualitative Studies of Health and Well-being* 11: 1-9.
- American Psychiatric Association (2013) *Diagnostic and Statistical Manual of Mental Disorders*, 5<sup>th</sup> edition. Arlington: American Psychiatric Publishing.
- Author A (2014). Omitted for peer review.
- Author B et al (2008). Omitted for peer review.
- Author B et al (2009). Omitted for peer review.
- Author B et al (2010). Omitted for peer review.
- Author B et al (2013). Omitted for peer review.
- Author E et al (2011). Omitted for peer review.
- Author F (2007). Omitted for peer review.
- Author F (2017). Omitted for peer review.
- Bateman, A.W., Gunderson, J. and Mulder, R. (2015) Treatment of personality disorder. *The Lancet* 385(9969): 735-743.
- Bendelow, G. (2004). Sociology and concepts of mental illness. *Philosophy, Psychiatry, & Psychology*, 11(2), 145-146.
- Biskin, R. and Paris, J. (2012) Diagnosing borderline personality disorder. *Canadian Medical Association Journal* 184(16): 1789-1794.
- Bourne, J. (2011) From bad character to BPD: the medicalization of 'personality disorder'. In M. Rapley, J. Moncrieff and J. Dillon (eds). *De-Medicalizing Misery: Psychiatry, Psychology and the Human Condition*. London: Palgrave Macmillan, pp 66-85.
- Blaxter, M. (1978). Diagnosis as Category and Process: The Case of Alcoholism. *Social Science & Medicine*. 12:9-17.
- Brown, P. (1990). The name game: Toward a sociology of diagnosis. *The Journal of Mind and Behavior*, 11(3/4):385-406.
- Brown, P. (1995). Naming and Framing: The Social Construction of Diagnosis and Illness. *Journal of Health and Social Behaviour*. Extra Issue: Forty Years of Medical Sociology: The State of the Art and Directions for the Future, pp. 34-52.
- Chandler, A. (2016) *Self-injury, Medicine and Society: Authentic Bodies*. London: Palgrave Macmillan.



- Chanen, A., C. Sharp, P. Hoffman, and Global Alliance for Prevention. (2017) Prevention and early intervention for borderline personality disorder: a novel public health priority. *World Psychiatry* 16(2): 215-216.
- Chanen, A.M. and Thompson, K.N. (2016) Prescribing and BPD. *Australian Prescriber* 39(2): 49-53.
- Chugani, C. (2016) Recovered voices: experiences of BPD. *The Qualitative Report* 21(6): 1016-1034.
- Clarkin, J.F., Yeomans, F.E. and Kernberg, O.F. (2007) *Psychotherapy for borderline personality: focusing on object relations*. London: American Psychiatric Publishing.
- Collins, P. (2015). Intersectionality's definitional dilemmas. *Annual Review of Sociology*, 41, 1-20.
- Collins, P.H. and Bilge, S. (2016) *Intersectionality*. London: John Wiley & Sons.
- Davidson, L. (2016) The recovery movement: implications for mental health care and enabling people to participate fully in life. *Health Affairs* 35(6): 1091-1097.
- Delaney, L. J. (2018). Patient-centred care as an approach to improving health care in Australia. *Collegian*, 25(1), 119-123.
- Donald, F., Duff, C., Lawrence, K., Broadbear, J., & Rao, S. (2017a) Clinician perspectives on recovery and BPD. *Journal of Mental Health Training, Education & Practice* 12(3): 199-209.
- Donald, F., Duff, C., Lawrence, K., Broadbear, J., & Rao, S. (2017b) Consumer perspectives on personal recovery and BPD. *Journal of Mental Health Training, Education & Practice* 12(6): 350-359.
- Fitzgerald, D. and Callard, F. (2016) Entangling the medical humanities. In: A. Whitehead and A. Woods (eds.) *Edinburgh Companion to the Medical Humanities*. Edinburgh: Edinburgh University Press, pp. 35-49.
- Frías, Á. and Palma, C. (2015) Comorbidity between post-traumatic stress disorder and borderline personality disorder: a review. *Psychopathology* 48(1): 1-10.
- Gardner, J. (2017). Patient-centred medicine and the broad clinical gaze: Measuring outcomes in paediatric deep brain stimulation. *BioSocieties*, 12(2), 239-256.
- Gary, H. (2018) A diagnosis of "Borderline Personality Disorder" Who am I? Who could I have been? Who can I become?, *Psychosis*, 10(1):70-75:

- Gask, L. and Coventry, P (2012) Person-centred mental health care. *Epidemiology and Psychiatric Sciences* 21(2):139-44.
- Gunderson, J. (2009) BPD: ontogeny of a diagnosis. *American Journal of Psychiatry* 166(5): 530-9.
- Hughes, J. C., Bamford, C. and May, C. (2008) Types of centredness in health care: themes and concepts. *Medicine, Health Care and Philosophy* 11(4): 455-463.
- Jackson, H. and Burgess, P. (2000) Personality disorders in the community: Australian National Survey of Mental Health and Wellbeing. *Social Psychiatry and Psychiatric Epidemiology* 35(7): 531-538.
- Jutel, A. (2009). Sociology of diagnosis: a preliminary review. *Sociology of health & illness*, 31(2), 278-299.
- Jutel, A. (2015). Beyond the sociology of diagnosis. *Sociology Compass*, 9(9), 841-852.
- Jutel, A. and S. Nettleton. (2011). Towards a Sociology of Diagnosis: Reflections and Opportunities. *Social Science & Medicine*. 73:793-800.
- Kerr, I. B., Finlayson-Short, L., McCutcheon, L. K., Beard, H., & Chanen, A. M. (2015) The 'self' and BPD: conceptual and clinical considerations. *Psychopathology* 48(5): 339-48.
- Kerr, L. (2004) The 'borderline' as the sociocultural origin of BPD. *Ethical Human Psychology & Psychiatry* 6(3): 201-15.
- Knight, F., Kokanović, R., Ridge, D., Brophy, L., Hill, N., Johnston-Ataata, K., & Herrman, H. (2018). Supported Decision-Making: The Expectations Held by People With Experience of Mental Illness. *Qualitative Health Research*, 28(6), 1002-1015.
- Lamont, E. & Dickens. (2019). Mental health services, care provision, and professional support for people diagnosed with borderline personality disorder: systematic review of service-user, family, and carer perspectives. *Journal of Mental Health* DOI: [10.1080/09638237.2019.1608923](https://doi.org/10.1080/09638237.2019.1608923)
- Lawn, S., McMahon, J. and Zabeen, S. (2017) *Foundations for Change: Experiences of Consumers with the Diagnosis of Borderline Personality Disorder (BPD) 2017 Update*. South Australia: Private Mental Health Consumer Carer Network (Australia) Ltd.
- Lee, D. (2017) A person-centred political critique of current discourses in post-traumatic stress disorder and post-traumatic growth. *Psychotherapy and Politics International* 15(2): 1411-1420.

- Leichsenring, F., Leibing, E., Kruse, J., New, A. S., & Leweke, F. (2011) Borderline personality disorder. *The Lancet* 377(9759): 74-84.
- Linehan, M. (1993) *Cognitive-Behavioral Treatment of Borderline Personality Disorder*. New York: Guildford Press.
- Martin, E. (2010) Self-making and the brain. *Subjectivity* 3(4): 366-381.
- MacIntosh, H.B., Godbout, N. and Dubash, N. (2015) Borderline personality disorder: disorder of trauma or personality, a review of the empirical literature. *Canadian Psychology/Psychologie Canadienne* 56(2): 227.
- Millard, C. (2015) *A History of Self-Harm in Britain: A Genealogy of Cutting and Overdosing*. London: Palgrave Macmillan.
- Moran, P., Coffey, C., Mann, A., Carlin, J. B., & Patton, G. C. (2006) Personality and substance use disorders in young adults. *The British Journal of Psychiatry* 188(4): 374-379.
- NHMRC. (2012) *Clinical practice guideline for the management of BPD*. Canberra: NHMRC.
- Paris, J. (2018) Clinical features of borderline personality disorder. In: W.J. Livesley and R. Larstone (eds.) *Handbook of Personality Disorders: Theory, Research, and Treatment*. New York: Guildford Press.
- Paris, J. and Lis, E. (2012) Can sociocultural and historical mechanisms influence the development of BPD? *Transcultural Psychiatry* 50(1): 140-51.
- Pilgrim, D. (2017) Incurable conduct and incurable diagnoses: the case of personality disorder. *Social Theory & Health* 15(4): 388-406.
- Rao, S., Broadbear, J. H., Thompson, K., Correia, A., Preston, M., Katz, P., & Trett, R. (2017) Evaluation of a novel risk assessment method for self-harm associated with Borderline Personality Disorder. *Australasian Psychiatry* 25(5): 460-465.
- Shaw, C. and Proctor, G. (2005) Women at the margins: a critique of the diagnosis of BPD. *Feminism and Psychiatry* 15: 483-90.
- Sisti, D., Segal, A. G., Siegel, A. M., Johnson, R., & Gunderson, J. (2016) Diagnosing, disclosing, and documenting borderline personality disorder: a survey of psychiatrists' practices. *Journal of Personality Disorders* 30(6): 848-856.
- Stapleton, A. and Wright, N. (2019) The experiences of people with borderline personality disorder admitted to acute psychiatric inpatient wards: a meta-synthesis. *Journal of Mental Health*. 28(4):443-457.

- Sulzer, S. (2015) Does “difficult patient” status contribute to de facto demedicalization? The case of borderline personality disorder. *Social Science & Medicine* 142: 82-89.
- Temes, C. M., Magni, L. R., Fitzmaurice, G. M., Aguirre, B. A., Goodman, M., & Zanarini, M. C. (2017) Prevalence and severity of childhood adversity in adolescents with BPD, psychiatrically healthy adolescents, and adults with BPD. *Personality and Mental Health* 11(3): 171-178.
- Treloar, A. (2009) BPD: patient perspectives of mental health and emergency medicine service. *Psychotherapy in Australia* 15: 24-30.
- Tseris, E. (2013) Trauma theory without feminism? Evaluating contemporary understandings of traumatized women. *Affilia* 28(2): 153-164.
- Ussher, J.M. (2013) Diagnosing difficult women and pathologising femininity: Gender bias in psychiatric nosology. *Feminism & Psychology* 23(1): 63-69.
- Veysey, S. (2014) People with a borderline personality diagnosis describe discriminatory experiences. *Kōtuitui: New Zealand Journal of Social Sciences* 9(1): 20-35.
- Viney, W., Callard, F. and Woods, A. (2015) Critical medical humanities: embracing entanglement, taking risks. *Medical Humanities* 41: 2–7.
- Wirth-Cauchon, J. (2001) *Women and Borderline Personality Disorder: Symptoms and Stories*. New Brunswick: Rutgers University Press.
- Wykes, T. and Callard, F. (2010) Diagnosis, diagnosis, diagnosis: towards DSM-5. *Journal of Mental Health* 19(4): 301-304.