

Title:

An Interpretive Phenomenological Analysis of the Experience of Being Diagnosed with Borderline Personality Disorder

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Summary and Key Words

Summary: IPA study exploring the experience of receiving the highly-stigmatised diagnosis of BPD, using a wider critical lens of psychiatric diagnostic categories and their usefulness.

Keywords: Borderline Personality Disorder; service user perspective, IPA, psychiatric diagnosis, qualitative research, trauma, stigma.

Introduction

Questioning the usefulness of psychiatric diagnoses

There is widespread dissatisfaction with the use of diagnostic categories in conceptualising mental distress. The legitimacy and credibility of these diagnoses has been called into question following the failure of decades of research to reveal specific markers that situate distress biologically or psychologically and genetic abnormalities appear to account for only a small percentage of causal factors (Timimi, 2014). Cromby, Harper and Reavey (2013) argue that it is not possible to produce a set of criteria that transcend culture, history, or place; there cannot be a universal standard against which people's thoughts, emotions and actions can be judged. Diagnostic categories, therefore, are not objective but rather they are moulded by cultural conceptions of normality (Cromby, Harper and Reavey, 2013).

Critiques of the medical model have highlighted the way in which medication fails to address 'symptoms' of psychiatric disorder. In her work critiquing formal psychiatric diagnostic systems, Joanna Moncrieff argues that psychoactive drug treatments can be best conceptualised as inducing states rather than addressing chemical imbalances related to diagnosis (2009). This is reflected in clinical practice where the limited groupings of psychoactive medications are utilised in non-diagnosis specific ways. For example, Selective Serotonin Reuptake Inhibitors (SSRIs) are claimed to be effectual in the treatment of depression, bulimia, obsessive compulsive disorder, among others (Moncrieff, 2009). This is also a reflection of the unclear boundaries - or 'comorbidity' - of diagnostic categories as diagnoses share 'symptoms' with one another, calling into question their validity (Cromby, Harper and Reavey, 2013). In the case of BPD, Zanarini et al. (1998) found that amongst 379 patients with the diagnosis, 96.3%

also met the criteria for a mood disorder, 88.4% for an anxiety disorder, 55.9% for PTSD and 53% for an eating disorder.

Critics argue that psychiatric diagnosis only serve as descriptors, rather than explanation. Thus, when a clinician posits a patient as having a particular diagnosis they are engaging in a process of reification whereby something subjective becomes a dominant narrative that serves to limit other possibilities. As Sami Timimi argues, if someone believes a diagnosis exists in their brain they may begin to act in accordance with this belief (Timimi, 2014). Receiving a diagnosis can interfere with one's identity and sense of self and can induce feelings of enduring vulnerability (Hayne, 2003). In addition, positioning a person as a patient with mental health problems in mental health discourse can have serious repercussions in regard to their sense of agency and credibility (Georgaca, 2013). Thus, receiving a psychiatric diagnosis can become transformative in shaping 'present and future life expectations' (Bjorklund, 1996: 1329).

Critique of personality disorders

Personality disorders are arguably some of the most disputed diagnostic categories. The DSM-V defines personality disorder as 'an enduring pattern of inner experience and behaviour that deviates markedly from the norms and expectations of the individual's culture, is pervasive and inflexible, has an onset in adolescence or early adulthood, is stable over time, and leads to distress or impairment.' (American Psychiatric Association, 2013, p. 689). Thus, personality disorders imply particular cultural values and normative assumptions. Cromby, Harper and Reavey argue that these diagnoses have less to do with mental distress and more to do with the transgression of a behavioural moral code (2013). In their work looking at the

normative assumptions underlying personality disorders, Leising et al (2009) argue that these diagnoses are defined by what a person should *not* be rather than what they should be. Implied is the 'undisordered personality' who, based on the definitions of personality disorders in the DSM-IV, is a person who is able to control their impulses and emotions; displays anger only when appropriate; is able to connect with others and treat them fairly, and exercises self-control, among others (Leising et al, 2009). Thus, one detects a tone of 'moral evaluation' in these categorisations (Cromby, Harper and Reavey, 2013).

Critique of Borderline Personality Disorder

Since its first appearance in the DSM in 1980, Borderline Personality Disorder (BPD) has been a controversial diagnosis. Derksen describes BPD as 'clinically factual, empirically fictional and theoretically chaotic' (1995: 35).

Feminists have argued that women's life processes are more often subject to medicalisation (Chrisler & Gorman, 2015; Swartz, 2013; Maracek and Gavey, 2013). Historian Susan Cahn states that the relationship between BPD and the feminist movement is an 'intriguing' one which has formed an 'unconscious dialogue' between feminist critiques of psychiatry and psychiatry itself (2014, p. 2). At the time of its establishment as a diagnostic category, BPD appeared as the symbol of a medical narrative that women's sexuality and rage should be rendered 'mental pathology' (Cahn, 2014, p. 4). Since then, feminists have posited BPD as a gendered diagnosis; one that seeks to police femininity and pathologise women's response to trauma while obscuring the widespread abuse of women and girls (Shaw and Proctor, 2005; Showalter, 1985; pp. 3-4). Phyllis Chesler (1972) coined the term 'double-bind' to describe the ways in which women were pathologised for both confirming to, and straying away from, ideas of female passivity. In the case of BPD, feminists have criticised the contradictory way in

which women have been labelled or diagnosed as a result of both not conforming to their gender role, by outwardly displaying anger, and conforming too much, for internalising or repressing this anger, resulting in self-harm. As Wirth-Cauchon (2000) argues, women with a BPD diagnosis embody societal contradictions around femininity. Thus, the diagnosis of BPD itself has been rendered 'anti-feminist'.

Other critiques of BPD have similarly argued that the labelling of certain behaviours as 'disordered' serves to pathologise normal responses to difficulty or trauma, particularly as childhood sexual and physical abuse are associated with a BPD diagnosis (Reavey, Cromby and Harper, 2013). An insecure attachment between the caregiver(s) and the child are associated with the development of BPD 'symptoms', including inadequate interpersonal skills, unhealthy patterns of behaviour and difficulty trusting people (Lyons-Ruth et al., 2005). Furthermore, abuse in childhood can mean individuals go on to see the world through a filter of abuse and as an inherently unsafe place (van der Kolk and Ducey, 1989). Survivors of abuse may develop maladaptive coping strategies, such as engaging in self-harming behaviours, as a way of avoiding dealing with their trauma history (Trippany et al., 2006). Trippany et al. argue that by focusing on the diagnosis, we risk doing a disservice to the individual by focussing on the 'symptoms' and failing to explore what lies behind them (2006).

In addition, BPD remains one of the most highly stigmatised diagnoses. In their book about BPD and its 'stigmatised and overused' nature, Potter and Gunn referred to it as a 'clinical gut punch' and a way in which clinicians can communicate warning to their colleagues about the nature of a patient (2014: 3). Studies have highlighted the way in which mental health professionals view people with a diagnosis of BPD as manipulative, demanding and unresponsive to treatment (Wollaston and Hixenbaugh, 2008: 705; Treloar, 2009: 31). As women make up a far larger proportion of those diagnosed with BPD, this stigma and its effects are gendered. Critics highlight the continued power the psychiatric industry hold over women's lives. As

well as suffering forced hospitalisation or medicalisation, women with a BPD diagnosis may be stripped of their rights as parents or of custody of their children because of their diagnosis (Ussher, 2013, p. 67; Cohen, 2016, p. 140).

Despite the contentious and stigmatised nature of BPD, there is little or no research that explores the experience of receiving a diagnosis of BPD from the individual's perspective. The aim of this research is to fill this gap in literature. In particular, the study aims to explore what impact this diagnosis can have on one's sense of self and how it effects an individual's understanding of their own distress and their ability to access support and services. Thus, the research questions are as follows:

- How do individuals with a Borderline Personality Disorder diagnosis feel the diagnosis has impacted their idea of self and mental well-being?
- How do individuals with a Borderline Personality Disorder diagnosis feel the diagnosis has impacted their access to support services and treatment?

Materials and methods

Methodology

Interpretative Phenomenological Analysis (IPA) was chosen due to its firm rooting in its phenomenological foundations and the way in which it attends to how humans experience their world and gain knowledge (Smith, Flowers and Larkin, 2021). IPA seeks to undergo a detailed examination of human lived experience on its own terms rather than according to predefined categories, which connects to the central values of phenomenological philosophers (Smith, Flowers and Larkin, 2021). Whilst recognising that we can never truly gain access to another's

universe and understanding (Willig, 2008), IPA seeks to do research which is 'experience close' (Smith et al., 2009).

IPA concerned with what occurs when the everyday experience becomes particularly significant, which usually happens when something of importance has occurred in a person's life (Smith, Flowers and Larkin, 2021). Thus, IPA is appropriate for this study, which is focused on participants' experiences of receiving a psychiatric diagnosis. It is widely agreed that a psychiatric diagnosis has a profound effect on recipients (Abbott et al., 2012; Callard, 2014; Parker et al., 2014). This goes beyond the acquisition of knowledge about how one functions: a diagnosis serves to shape 'present and future life expectations' (Bjorklund, 1996: 1329). IPA allows for multiple participants who have similar experiences to share their stories without misrepresentation while drawing out the commonalities within these experiences (Cresswell, 2013). Thus, IPA is not a process of description but one of detailed examination and interpretation of the phenomenon the research aims to explore.

According to some critical psychologists, there is a risk when adopting IPA of reduction to the individual, overemphasising the internal and losing sight of how what is 'inside' is dependent on what is 'outside' (Parker, 2005). Accompanying this is a danger of allowing dominant cultural understandings of distress to dominate (Harper, 2013; Parker, 2005). If naïve realism is to be avoided, interrogating assumptions implicit in narratives is essential – participant accounts cannot be treated as simple empirical truth (Parker, 2005). However, it is equally important to take selves and phenomenal factors seriously (Cromby & Standen, 1999) if we are to avoid reducing human existence to nothing but discourse. Thus, this research has actively sought to challenge preconceptions of BPD, whilst simultaneously attempting to understand the lived experiences of our participants..

Data collection

IPA requires the researcher to find a reasonably small and relatively homogenous sample to conduct an in-depth analysis (Smith, Flowers and Larkin, 2021). For this research, people were approached who had lived experience of being diagnosed with BPD. To be eligible for the study, it was specified that participants had to meet the following criteria:

1. They must have received a formal diagnosis of BPD
2. They must not currently reside in a detained setting e.g a psychiatric hospital or mental health hospital
3. They must not have had a mental health crisis in the past 6 months

Participants were recruited through social media to ensure the widest possible scope and diversity of interviewees. This was achieved through a Facebook search of peer-support groups for people who had a diagnosis of BPD. We posted on these groups outlining our research study and the eligibility criteria. We were contacted by ten people who met the criteria and wanted to know more about the study and how to take part. Four of these participants stopped engaging prior to arranging interviews. Six of these participants continued to engage and were scheduled for interviews. The demographic information of the participants can be found below in Table 2.

Table 2: Demographic information of the participants in this research

Pseudonym	Age	Gender/Sexuality	Ethnicity
Ana	28	Female/Queer	White other
Eleanor	29	Female/Queer	Any other Mixed/Multiple ethnic background

Pseudonym	Age	Gender/Sexuality	Ethnicity
Grace	23	Female/Bisexual	White other
India	28	Genderqueer/Pansexual	Mixed-race
Julie	26	Female/Bisexual	White British
Sharon	32	Female/Heterosexual	White British

Data was gathered via semi-structured interviews conducted via Microsoft Teams, taking several precautions to address the power imbalance of the interviewer/interviewee dynamic.

The participants were emailed the interview questions prior to their interview, for them to familiarise themselves and not feel caught off guard during the interview. This was particularly important with this research as the topic was especially sensitive. Participants were also informed that they were under no obligation to answer any of the questions and could pass at any time. In line with IPA guidance, all of the questions were open so that the participant could lead the interview in a way that felt comfortable and authentic for them. For example, ‘How did it feel to receive this diagnosis?’. Sub-questions or prompts were used if participants felt stuck. For example, ‘what emotions were present at the time and in the immediate aftermath?’. All interviews were recorded via the inbuilt MS Teams recording function and later transcribed verbatim.

Data analysis procedure

The detailed procedure outlined by Smith, Flowers and Larkin (2022) was followed to analyse the interview transcripts in detail. Their procedure specifies seven stages of analysis which are displayed in Table 3.

Table 3: The seven stages of Interpretative Phenomenological Analysis

Step 1	Starting with the first case: Reading & re-reading
Step 2	Exploratory noting
Step 3	Constructing experiential statements
Step 4	Searching for connections across experiential statements (creating personal experiential themes [PETs])
Step 5	Naming the PETs & consolidating & organising them (e.g., in a table)
Step 6	Continuing the individual analysis of other cases (i.e., steps 1-5 for each transcript)
Step 7	Working with PETs to develop group experiential themes across cases.

The themes that arose are detailed below in Table 4.

Table 4: Superordinate and subordinate themes

Superordinate themes	Subordinate themes
1. 'Opening the can of worms': A lack of support following the diagnosis	2.1 The diagnostic process not being what was expected
	2.2 'How bad do I have to get?': Wanting to act out or hurt themselves in order to get desired care
	2.3 Comorbidity or dual diagnosis: stuck between two systems
2. Stigma	

Ethical Considerations

Ethics approval was gained from the University of East London School of Psychology Research Ethics Committee. Participants were given pseudonyms and any other identifiable information was removed or changed. All participants gave written consent to be part of this research. All participants were also given details of available support services.

Results and discussion

1. Superordinate theme: 'Opening the can of worms': A lack of support following the diagnosis

Despite most of the participants expressing feelings of relief and validation following the initial diagnosis, all of the participants described the contradictory feeling of being lost or 'left to their own devices' in the period afterwards.

I was like wow what the fuck it just felt like this of can of worms had been opened and there was no one there to like help me close it [lines 39-41]

Participants spoke about their experience in a binary way: while it legitimised and validated their suffering, the diagnostic label also created more problems due to a lack of support and the stigma of the label.

1.1 Subordinate theme: The diagnostic process not being what was expected

Participants spoke about the diagnostic process not living up to their fantasies. For many of them, they had a longstanding sense of something being 'wrong' so had investigated the process of receiving a formal diagnosis and built-up ideas of what it would look like and what care might follow it. The actual process and that followed felt anti-climactic.

it didn't really like announce it to me like I kind of imagined it to be like they'd be like we think you have this this very like serious personality thing [laughs] [lines 33-34]

but I think like I was kind of hoping that at the end she'd be like this is your diagnosis and this is what we're going to do about it and that didn't happen it was just kind of like cool yeah well I hope life goes well bye [lines 37-39]

Participants used sarcasm to convey their hurt feelings and a sense that they had been disregarded due to a lack of follow-up support. They spoke to the reality of many people who are diagnosed with BPD in the UK, where treatment is only available to those with 'moderate to severe symptoms' which forms a serious barrier to support for many sufferers (NHS, n.d). Those that do qualify for treatment often have to wait years for specialised treatment. For many of the participants in this study this triggered feelings of abandonment and neglect from childhood and early adult experiences.

I haven't had family around I guess to receive help from or anything when I was younger I was always received help from like services and like for the first time they were kind of leaving me to my own devices in a way I felt (...) and I kind of expected it to be a lot different like I expected — I don't know a lot more care I guess [lines 132-135]

1.2 'How bad do I have to get?': Wanting to act out or hurt themselves in order to get desired care

Participants spoke about the process of diagnosis and subsequent lack of follow up or support serving to exacerbate and intensify their BPD 'symptoms' (which often relates to feelings of abandonment and loneliness) and leading them to self-harm as a cry for help.

When I heard that I was like do you wanna know about attention seeker? I'll give you attention seeker I mean I'll do it properly though like it pushed me (...) it was just like a cry for help like I'm not I'm not doing well at the moment I don't know how to deal with how I'm feeling and I just need to be looked after a bit. [lines 330-333]

Participants spoke about feeling dismissed and acting out in order to be taken seriously. Many of them felt that they had to get worse to be considered for professional support. This often came across as childlike or adolescent.

and it's like you have to be on your deathbed or like sectioned for them to actually do something [lines 491-492]

1.3 Comorbidity or dual diagnosis: stuck between two systems

Many of the participants had been diagnosed with one or more additional psychiatric diagnoses alongside BPD. They spoke to the feeling of being stuck between systems that saw different diagnoses as distinct whereas they felt they were inherently connected (e.g., addiction and BPD). They spoke of feeling passed around between services but not being able to access support anywhere.

what I will say is they said they won't refer me to other services until I stop self-harming so it's kind of held onto as a contract for them giving me more support as I had to stop self-harming so essentially what I did was I lied [laughs] [lines 17-19]

Participants often found themselves in a double bind of being asked to stop self-harming behaviours (e.g., cutting or using drugs or alcohol) before they could access BPD support, which felt impossible as they used these behaviours to cope with difficult feelings relating to their BPD. This often led to participants lying in order to access support.

2. Superordinate theme: Stigma

All of the participants described feeling stigmatised as someone with a BPD diagnosis. There was a general feeling among participants that individuals with a BPD diagnosis weren't taken seriously, were viewed as attention seekers or as a nuisance, as Julie put it "I was just pissing everyone off by going to hospital' [line 158].

One participant, Grace, described the interaction she had with the psychiatrist at age 16 who first diagnosed her with BPD. During the meeting, the psychiatrist disclosed some upsetting and stigmatising opinions to Grace, in which she told her she had an 'incurable' illness and wouldn't be able to function as a healthy adult.

and she decided that I was never going to be able to succeed in the world and that at 21 I would have failed relationships and I wouldn't be able to have a career in this, this and that and that's a lot to hear at 16. [lines 57-60]

Participants spoke about internalising stigmatising views about their diagnosis, particularly when they came from healthcare professionals who they felt were authority figures. Grace spoke 5 years on from this exchange, but she continued to feel upset by it and often questioned herself as a result.

he blocked me from getting support and help to the point where I was banned from [redacted] London Borough] mental health services I wasn't allowed to access any help — mental health help because this psychiatrist we just didn't get on personally
[lines 280-283]

This exchange highlighted the powerlessness that people with a BPD diagnosis may feel in having a diagnosis that they are conscious of having such negative connotations. It also makes us acutely aware of the way in which many of the participants had become accustomed to being stigmatised at the hands of their doctor or other healthcare professionals.

*I also had colleagues in that same office space who would literally rant and rave about BPD diagnosis and how shitty people are how manipulative they are how nasty they are and I was sat there like they don't know that I'm sat there with this and it's this question of what do you say? And sometimes in those instances I would dissociate because it's a real stressful situation because yeah they're literally bitching about you and they just don't know it so um yeah it was really difficult [laughs] **[lines 233-238]***

Sharon continued to feel deeply disturbed and hurt by this incident at her workplace, a mental health service in the NHS. It was clear how her diagnosis formed a central part of her identity. While her colleagues were making mean comments about patients, Sharon felt so in tune with

the patients as a result of her diagnosis that she experienced the episode as if they were talking about her.

The power of the stigma associated with BPD was evident when participants spoke about the difficulty of disclosing their BPD diagnosis to loved ones in fear of being judged and stigmatised by their friends and family. Many participants spoke about feeling fearful of rejection, judgement or being seen as 'crazy'. For others, disclosing their BPD diagnosis to their friends and family served as a way of challenging the stigma they had faced. One participant, India, described this disclosure as a 'coming out'; they wanted to be visible to challenge the negative connotations surrounding the label.

Discussion

The following section will situate the current research within existing theory and literature, recognise the current study's contribution and identify directions for future research.

Opening the can of worms': A lack of support following the diagnosis

There is little existing research on service users' experience of being diagnosed with BPD and how it impacts on their sense of self. The primary contribution of the current paper is to begin to fill this gap. Existing studies found that participants had been given little or no information following their diagnosis and found that what was given was predominantly negative (Horn et al, 2009). The current study's findings supported this and further explored the contradictory experience of individuals feeling initially validated by the diagnostic label but then let down by the lack of information and support that followed, despite often high expectations that a diagnosis would open doors to support and treatment.

The relationship between a BPD diagnosis and self-harm has been well-documented in existing literature, including how self-harm is used as a means of self-soothing (Zanarani et al., 2011; Reichl & Kaess, 2021; Sansone, Gaither & Songer, 2002). However, little has been written on the use of self-harming behaviours to cope with the diagnosis itself. A key finding of this study was participants' accounts of using self-harm as a form of communication and a plea for help in both coming to terms with the diagnosis and for treatment of the disorder. Further research is necessary to look at the ways in which individuals with a BPD diagnosis use self-harm or the threat of self-harm and/or suicide as a way of exerting agency over their treatment and care within healthcare settings and as a way of communicating to healthcare professionals, a setting within which they often feel powerless or out of control.

All the participants in the current study discussed experiencing the comorbidity of a BPD diagnosis with another psychiatric diagnosis and they described how this made them feel stuck or pushed between services in a system that treats these issues as distinct and separate. The comorbidity of a BPD diagnosis with other psychiatric diagnoses has been well recorded (Zanari et al, 1998; Fyer et al, 1988; Choate et al, 2021). However, little has been written about the subjective experience of feeling 'stuck' in the system because of multiple diagnoses. The current study begins to fill this gap as participants spoke to the impact these systemic issues had on their sense of self, particularly as BPD is often defined by an acute fear of real or perceived abandonment or neglect. Future research could further explore this and could lend itself to service improvement and delivery and the development of more holistic ways of working with people with complex mental health difficulties that are holding and containing.

Stigma

All the participants spoke about feeling stigmatised within healthcare settings. Existing research has routinely found that mental health staff see individuals with a BPD diagnosis as 'bad' rather than 'mad' (Horn et al., 2009; Deans and Meocevic, 2006). The current study supported existing research in this regard. Participants described being called 'attention seekers' or 'manipulative' and this study served to explore the long lasting impact of this stigma, as participants spoke about feelings of self-doubt or self-blame. The participants also spoke about not wanting to disclose their BPD diagnosis to people outside of healthcare professions, in fear of being on the receiving end of stigmatising views. In this instance, the stigma of a BPD diagnosis loomed large and often acted as a deterrent to them opening up. Potter and Gunn referred to the diagnosis of BPD as 'the scarlet label', claiming it was one of the most stigmatising diagnoses that an individual can receive (2014, p. 3). Building on the work of Foucault (1978), we aim to fill a current gap in the existing literature by looking at the way that the internalisation of stigma serves to morally and socially regulate, where individuals within society begin to voluntarily govern themselves (Foucault, 1978). Many of the participants spoke of their diagnosis as something they were reluctant to share, even with those close to them, for fear of being judged or seen as 'crazy'. Also evident in the current study were examples of reappropriation of discourse, where marginalised labels are embraced to empower. Foucault (1978) spoke about the way in which this happened in the case of homosexuality: 'homosexuality began to speak on its own behalf, to demand that its legitimacy or "naturalness" be acknowledged, often in the same vocabulary, using the same categories by which it was medically disqualified' (1978, p. 101). In the current study, India spoke about their 'coming out' for having BPD and the way in which they used visibility to actively challenge the stigma that they felt very conscious of. Further research could further explore the power in reclamation of the BPD label and how this has served to ease or exacerbate the negative connotations associated with the label.

Conclusion

Due to the lack of existing research on individuals' experience of being diagnosed with BPD, the current research has useful implications for the psychological treatment of people who display BPD 'symptoms'. First, this research highlighted the importance of clear communication from practitioner to patient during the diagnostic process. Second, this research showed that receiving a diagnosis was only helpful if it opened the door to much needed support and treatment. Third, this research highlighted the importance of incorporating a relational, compassionate, trauma-informed approach to BPD, which remains a highly stigmatised diagnostic label.

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Disclosure statement

The authors have no conflicts of interest to declare.

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