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**MAJOR RESEARCH PROJECT**

**ZUZANA WINTER BSc Hons**

**IMPACT OF THE DIAGNOSIS OF BORDERLINE PERSONALITY  
DISORDER AND ITS DIAGNOSTIC PROCESS**

**Section A: What are the consequences of the diagnosis of borderline  
personality disorder: A literature review**

**Section B: An exploration of how female service users with the diagnosis  
of borderline personality disorder experience the diagnostic process**

**Section C: Appendices of supporting material**

**Overall word count: 16,000**

A thesis submitted in partial fulfilment of the requirements  
of Canterbury Christ Church University for the degree  
of Doctor of Clinical Psychology

DECEMBER 2015

**SALOMONS  
CANTERBURY CHRIST CHURCH UNIVERSITY**

**CANTERBURY CHRIST CHURCH UNIVERSITY**  
**Doctorate in Clinical Psychology (D.Clin.Psychol.)**

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## **Summary of the MRP portfolio**

**Section A** is a systematic review of the literature regarding the consequences of the diagnosis of borderline personality disorder (BPD). The literature is summarised across three areas: mental health professionals' attitudes towards individuals afflicted with BPD diagnosis, professionals' descriptions of their diagnostic practices, and service users' perceptions of the current level of care. The findings of the review are discussed in light of the existing national clinical guidelines for BPD. Methodological limitations are discussed together with research and clinical implications.

**Section B** reports the findings of a qualitative study investigating the lived experiences of service users with the original diagnostic disclosure of BPD. Semi-structured interviews with eight female service users were analysed using the Interpretative Phenomenological Analysis. Five master themes were identified which were discussed with reference to the existing literature. Methodological limitations are discussed together with suggestions for further research and clinical implications.

**Section C** is a repository of appendices that have been deemed relevant with respect to above sections.

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**MAJOR RESEARCH PROJECT**

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Section A: **Literature review**

**What are the consequences of the diagnosis of borderline  
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DECEMBER 2015

A thesis submitted in partial fulfilment of the requirements  
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**SALOMONS  
CANTERBURY CHRIST CHURCH UNIVERSITY**

## **Abstract**

**Background and aim:** Recent advancement in the understanding of borderline personality disorder (BPD) have led to a dramatic shift towards a recovery orientated healthcare provision, thus cautiously paving way towards a more optimistic outlook for individuals who typically attract this diagnosis. This review aimed to evaluate whether the improved BPD understanding and the concurrent optimism regarding BPD-specific interventions, as reflected by the UK's National Institute for Health and Clinical Excellence (NICE, 2009) guidelines, has led to a concomitant reduction in the degree of negative consequences which might follow the disclosure of BPD diagnosis.

**Method:** Relevant papers were identified using a systematic search of the following databases: ASSIA, PsycINFO, Cochrane Library, SAGE, and Web of Science, and Wiley. Thirty six papers, both within and outside the UK, were identified which depicted experiences of clinicians and service users in various clinical contexts.

**Results and conclusion:** Most studies demonstrated persistently negative diagnostic consequences, including stigmatising attitudes and biased diagnostic practices. Nevertheless, some positive experiences were noted, thus cautiously indicating a positive shift in the healthcare provision for individuals with BPD diagnosis. Methodological concerns were discussed along with clinical recommendations and directions for future research.

**Keywords:** borderline personality, BPD, consequence(s), diagnosis, NICE, stigma\*

## **Introduction**

### **Why focus on BPD?**

‘Borderline personality disorder’ (BPD) has been defined as a pervasive pattern of marked impulsivity and instability of interpersonal relationships, self-image, and affects, which begins by early adulthood and is present in a variety of contexts (American Psychological Association, APA, 2013). The exact BPD prevalence has proved difficult to establish due to large differences in sample sizes, methodology, as well as societal and cultural variations (Gunderson, Weinberg, & Choi-Kain, 2013).

Nevertheless, community sample studies have repeatedly quoted a median prevalence of 1.7% (Torgersen, 2012, in Gunderson et al., 2013); an estimate which is comparable to those of other ‘major mental health (MH) disorders’, such as ‘schizophrenia’ and ‘bipolar disorder’ (BD) (Kealy & Ogrodniczuk, 2010). Owing to the extensive use of MH services by individuals with BPD diagnosis, inflated rates have been reported in clinical settings, with reports of BPD accounting for 20.3% of all psychiatric inpatient admissions (Zimmerman, Chelminski, & Young, 2008) and 11.9% of all psychiatric outpatients (Korzekwa, Dell, Links, Thabane, & Webb, 2008). Lifetime BPD prevalence has been reported between 5.5 and 5.9% (Grant et al., 2004; Johnson, Cohen, Kasen, Skodol, & Oldham, 2008).

BPD has been regarded as a serious mental disorder for several reasons (Ekdahl, Idvall, Samuelsson, & Kent-Inge, 2011; Lieb, Zanarini, Schmahl, Linehan, & Bohus, 2004; Nehls, 1999). These include recurrent crisis presentations and inpatient hospitalisations (Nelson, 2013), high rates of attempted and completed suicide (Oldham, 2006), extreme level of psychological distress, including rage and despair (Bland, Tudor, & Whitehouse, 2007), profound interpersonal difficulties (Nelson, 2013), high levels of self-mutilating behaviours,

extreme mood fluctuation (APA, 2000), as well as severely compromised quality of life (Palmer et al., 2006), and high degree of co-occurring chronic physical conditions (Frankenburg, & Zanarini, 2011). Prospective studies over a ten-year period associated failure to recover from BPD with increased risk of chronic medical disorders, poor health-related lifestyle decisions and expensive health service utilisation (Keuroghlian, Frankenburg & Zanarini, 2013), thus making it an important public health issue.

BPD has historically received a particularly negative reputation within the MH service. More specifically, many have regarded service users with BPD diagnosis as one of the most challenging groups (Cleary, Siegfried, & Walter, 2002; Hersh, 2008; Ma, Shih, Hsiao, Shih, & Hayter, 2009); one which was seen as ‘demanding’, ‘manipulative’, ‘dangerous’ and ‘attention seekers’ (Aviram, Brodsky, & Stanley, 2006). Unsurprisingly, BPD has been the subject of considerable research interest, making it the most heavily researched subtype of ‘personality disorder’ (PD) diagnoses (Dahl, 2008). Thanks to this research, much has been learned about BPD in recent years which has challenged many of the old stereotypes and assumptions, such as those related to untreatability and presumed chronicity, thus cautiously painting a more optimistic picture (Paris, 2012). Some of these findings will be described below.

### **Current psychological understanding of BPD**

Psychological theorising has contributed greatly to improving BPD knowledge, although the original conceptualisation of the term ‘borderline’ has been rather unfortunate. This term was first used by Stern (1938) to describe a borderland state between psychosis and neurosis. Since then, the conceptualisation of BPD has changed dramatically and cognitive symptoms related to psychosis and neurosis are no longer seen as a key feature of the disorder. Instead,



the core aspects of BPD are believed to congregate around an extreme instability across several domains, including the sense of self, interpersonal relationships, and affect, and are accompanied by wide ranging impulsive acts (Paris, Gunderson, & Weinberg, 2007). Nevertheless, the ‘in-between’ concept persists, partly due to the lack of sharing of research outcomes, which are slow to reach the level of health service management and policy makers (Kealy & Ogrodniczuk, 2010).

Regarding aetiology, congruent with other MH disorders, there appears to be no single causal factor implicated in BPD. Instead, developmental, environmental, and genetic factors have all been seen as contributing to presentations leading to the diagnosis, suggesting a complex neuro-bio-psychological BPD aetiology account (Gunderson et al., 2013). Early insecure attachment, especially a combination of disorganised, fearful and preoccupied styles, has long been recognised as the central developmental feature of BPD (Modell, 1963). It is believed that the early insecure attachment is a fairly stable construct, especially in combination with later traumatic or negative life events (Hamilton, 2000), which is believed to subsequently interfere with the individual’s mentalising capacity (i.e. ability to decipher one’s own mental states and those of others in order to interpret actions as meaningful), thought to be a crucial component of successful social integration (Bateman & Fonagy, 2006).

In line with these formulations, the lack of parental validation is presumed to further undermine one’s ability to mentalise and discriminate between one’s own and others’ emotions, thus further exacerbating psychological distress and identity confusion (Fruzzetti, Shenk, & Hoffman, 2005). These factors, with or without added trauma, such as severe neglect, might interfere with the neural mechanisms of arousal and cause structural and functional brain changes (National Institute for Health and Clinical Excellence, NICE, 2009).

In the absence of corrective experiences, the combination of these factors has been presumed to result in the development of BPD (NICE, 2009).

Psychological interventions have been identified as the primary treatment option for BPD (Gunderson et al., 2013). Given the emphasis on insecure attachment and invalidating environment in BPD development, the quality of the therapeutic relationship features as a key factor in most psychological models, including Dialectic Behavioural Therapy (DBT; Linehan, 1993), Mentalisation Based Therapy (MBT; Bateman & Fonagy, 2008), Transference Focused Therapy (TFT; Doering et al., 2010), and Schema Focused Therapy (Giesen-Bloo et al., 2006). In general, the aim is to provide a secure base to allow an exploration of one's inner struggles as well as interpersonal relationships in a gentle and sensitive manner. This importance of the therapeutic relationship has also been highlighted in service users' accounts of helpful practices (Haigh, 2002) and in the NICE (2009) guidelines.

More specifically, the NICE guiding principles stress the importance of working with individuals in an engaging, open, non-judgmental, and reliable manner; by showing sensitivity to their trauma histories, experiences of rejection and stigmatising attitudes. Nevertheless, some have argued that BPD diagnosis, due to its stigmatising properties, interferes with the potential for therapeutic engagement and should therefore be abolished (Coles, 2011). This contested issue will be discussed in the next section. Prior to that, however, it was perceived as important that the reader was aware of the author's own stance on this matter.

## **Author's stance**

The author's own stance is that BPD is as real as any other MH construct, such as 'schizophrenia' or 'major depressive disorder'. It is seen as a construct which has some basis in reality in that it attempts to describe specific difficulties and circumstances which tend to apply to particular groups of individuals. This belief has been shaped by the author's experience of working in a tertiary specialist service for people with BPD diagnosis. Through this work, the author came to appreciate the specificity of the service users' difficulties which seemed unequivocally different from those of other service user groups, in particular the highly fragmented sense of self and the concomitant struggles in most interpersonal areas.

Notwithstanding, the author believes that, similarly to any other diagnostic descriptions, BPD diagnosis is inherently imperfect. As language constructs, all descriptions have the potential to be stigmatising or to be misused for a multiplicity of reasons. The author believes that these issues are likely to be complex and might not be resolved by changing or removing a label. Instead, it might be worth examining the deeper-seated issues which the constructs are likely to represent. In this sense, the author views BPD diagnosis as the top of the iceberg, most of which is hidden from the surface of consciousness and should be uncovered in order to improve the lives of those who attract such labels and the systems within which these exist.

The next section will review some of the benefits and shortcomings of applying BPD label as a diagnostic construct of human distress.

### **What do diagnoses do and what are they meant to do?**

BPD has historically been seen as a “waste-basket diagnostic category” (Hersh, 2008, p.18) due to the prevailing view that BPD was a life-long, ‘treatment-resistant’ disorder, with a heterogeneous array of ‘symptoms’, which overlap with other disorders, such as bipolar affective disorder (BPAD) and post-traumatic stress disorder (PTSD). These issues have affected clinicians’ diagnostic practices, with some proposing that BPD diagnosis should be eliminated (Tyrer, 2009). Unfortunately, this issue continues to persist despite the latest publication of DSM-V (Biskin & Paris, 2012; Gunderson et al., 2013).

Whilst service users’ stance regarding the utility of BPD varies, there is at least one official service-user-led organisation for people who self-identify as having a ‘PD’, including BPD (Emergence, n.d.). These individuals believe that BPD label has helped them to have their difficulties formally recognised and addressed. It therefore seems worth revisiting some of the advantages and problems of applying this diagnosis.

### **Conceptualisation of distress**

The author hypothesised that a diagnosis should ideally help service users make sense of their experiences. Contrary to this, some have suggested that BPD diagnosis should not be used because of its stigmatising labelling properties which do not adequately describe the realities of one’s distress (Coles, 2011). The reliability and validity of BPD diagnosis have also come into question, (Coles, 2011; New, Triebwasser, & Charney, 2008). Nevertheless, it has been proposed that these concerns are not specifically related to BPD; instead they have been seen as problematic for all functional MH disorders due to the ill-fitting application of the medical disease model to expressions of psychological distress (Pilgrim, 2001).

As a consequence of the shortcomings inherently associated with the diagnostic system, some clinicians tended to give the service user the benefit of the doubt before diagnosing BPD, for instance, by diagnosing an Axis-I disorder (Hersh, 2008). Others have considered BPD as an atypical version of an Axis-I disorder, such as BPAD or PTSD (Zanarini, & Frankenburg, 2007). However, recent research has suggested that BPD is not a variant of Axis-I disorders (Paris, Silk, Gunderson, Links, & Zanarini, 2009), but rather should be considered as a distinct disorder in its own right.

### **Access to appropriate services**

Many have argued that one of the main reasons for using diagnostic categories is to offer access to interventions (Paris et al., 2009). With regards to BPD, there has been a surge in wide-ranging psychological therapies that have proved efficacious in relieving BPD-specific distress. The most prominent psychological models include DBT (Linehan, 1993), MBT (Bateman & Fonagy, 2008), Schema-Based Therapy (Giesen-Bloo et al., 2006) and TFT (Doering et al., 2010). Importantly, psychological interventions were reported to be superior when compared to treatment as usual and pharmacotherapy (NICE, 2009).

According to Paris (2012), the main current difficulty regarding BPD management is clinical opinions which fail to regard BPD as separate from Axis-I affect disorders as well as clinicians' inability to provide accurate and timely diagnosis. Without accurately identifying the nature of one's difficulties, the individual's access to effective treatment options may be restricted. Regrettably, many clinicians have been found to refrain from direct diagnostic disclosures for fears that the diagnosis would further discriminate against the service user (Kealy & Ogrodniczuk, 2010). Whilst understandable, this practice has undesirable consequences which, paradoxically, are likely to exacerbate the level of marginalisation of

the service user, such as the consequence of ‘accidental’ disclosure of BPD in discharge letters or in staff’s informal discussions, as well as by perpetuating the view that BPD is ‘bad’ as it has to be kept secret (Kealy & Ogrodniczuk, 2010).

Arguably, failures to openly discuss BPD with service users reduce their potential for recovery by excluding them from accessing appropriate services; instead having to rely on ill-fitting models of traditional psychotherapy or pharmacotherapy that are ineffective for BPD-type difficulties (Gunderson et al., 2013). In this context, it is unsurprising that many individuals who have failed to respond to traditional psychological therapies have been seen as ‘treatment-resistant’ and many have subsequently either disengaged from services or their contact with services has been terminated prematurely (Paris et al., 2009). The following quote exemplifies this point: “When treatment options are not effective, “misfits” might be erroneously labelled as “treatment resistant”” (Diamond & Factor, 1994, p.197).

Withholding diagnostic information has been seen across different branches of medicine, including ‘schizophrenia’ and Alzheimer’s disease (Moran, Oz, & Karnieli-Miller, 2014; Werner, Karnieli-Miller, & Eidelman, 2013). Research in these areas has suggested that withholding practices were linked to concerns over the validity of the diagnosis and the individual’s inability to consider the meaning of the diagnosis, as well as belief that diagnostic disclosures would stigmatise and worsen the individual’s mental and physical health. Such concerns have echoed those of many clinicians regarding BPD disclosure (Gunderson et al., 2013). The diagnostic practices in disorders such as ‘schizophrenia’ and cancer have improved significantly due to improvements in therapy, focus on empowering service users and their families, and the validating impact of psychoeducation.

Similar improvements have been observed in the area of BPD. More specifically, research into the course of BPD and treatment effectiveness has challenged the historical

views of BPD as a lifelong, untreatable disorder by demonstrating considerable responsiveness to appropriate interventions and high rates of remission over time (Sanislow, Little, & Ansell, 2009). Indeed, the NICE (2009) guidelines and other relevant NHS policies (Department of Health, 2003; National Institute for Mental Health in England, 2003) urge clinicians to use this knowledge in their work with service users, by openly and sensitively exploring all treatment options with them, whilst also showing optimism regarding recovery.

### **Rationale and aim of this review**

It seemed important to evaluate whether the improved understanding of BPD and the concurrent optimism regarding BPD-specific interventions, as exemplified by the publication of the NICE (2009) guidelines, has been translated into clinical practice and whether it has led to a concomitant reduction in the degree of negative consequences, including stigmatising perceptions and practices.

The current review aimed to investigate the consequences of BPD diagnosis, as perceived by individuals with BPD diagnosis and those working with them, by reviewing studies which followed the 2009 publication of the NICE. Previous researchers have reported that positive accounts with regards to BPD diagnosis were rare. It was anticipated that the current review would identify a considerable degree of negative consequences of BPD diagnosis, although it was hoped that positive accounts would also be reported.

The following specific questions were posed:

1. What does current research suggest about MH professionals' attitudes?
2. How do MH professionals describe their current diagnostic practices?
3. What do service users' experiences suggest about the current level of care?

## Methodology

A systematic review methodology (Appendix D) was used to search the following databases between January and November 2015: ASSIA, PsycINFO, Cochrane Library, SAGE, Web of Science, and Wiley. The primary search terms were “borderline personality” or BPD. These were combined with the following stigma-related search terms: identity, self\*, “social stigma”/stigma\*, label\*, discriminat\*, stereotyp\*, sham\*, ignor\*, reject\*, fak\*, prejudic\*, approv\*, accept\*, inclu\*/exclu\*/‘social exclu’, perspective\*, perception\*, attitude\*, diagnos\*, ‘mental health’, experience\*, and judg\*. Additional manual searches of reference sections of relevant literature and ‘Google Scholar’ internet search engine were performed.

The inclusion criteria were as follows:

1. Articles published following the publication of the NICE (January, 2009) guidelines.
2. Published, and peer reviewed articles written in English.

The exclusion criteria were as follows:

1. Case studies, dissertations, or academic discussion papers.
2. Studies with a generic focus unrelated to BPD.
3. BPD-specific studies which did not explore the impact of BPD diagnosis, including studies investigating services users’ experiences of living with BPD symptoms or those investigating self-harm in BPD.
4. Literature reviews of studies published prior to the NICE (2009) publication.

The author encountered several challenges during the literature search, which meant that a large number of independent searches were conducted over a lengthy time period. Primarily, the BPD literature was extremely large; however, it was problematic to identify studies which



had investigated issues related to the consequences of BPD diagnosis as opposed to the disorder it was assumed to represent. This, in part, was due to the large heterogeneity of the key terms used by researchers, with most studies refraining from identifying ‘stigma’ as a key search term, despite this having been an identified consequence of the diagnosis. Moreover, accounts of some studies did not provide sufficient details of the participants’ experiences, instead specifying the overall themes only. Finally, despite the initial aim of conducting a review of British research only, this strategy had to be abolished due to a lack of British investigations conducted on this subject.

### **Literature review**

Thirty six papers were included in the review (Appendix F), which were grouped according to the three research questions. Numerous papers contributed information relevant to more than one of these questions. Only findings relevant to the review’s objectives have been documented. Various methodological limitations were noted in the studies. For the purposes of this review, an illustration of some of these was provided for each subsection. The full description of the studies’ limitations was offered in Appendix F. <sup>1</sup>

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<sup>1</sup> Qualitative studies were assessed against Yardley (2000) criteria.

## **1. What does current research suggest about MH professionals' attitudes?**

### **Negative and positive attitudes**

Staff attitudes about individuals with BPD diagnosis are likely to significantly impact the quality of care (Deans & Meocevic, 2006). Akin to previous research, the current papers demonstrated that professionals continued to hold negative attitudes towards service users with BPD diagnosis (Black et al., 2011; Bodner, Cohen-Fridel, & Iancu, 2011; Bodner et al., 2015; Bourke & Grenyer, 2010, 2013; El-Adl & Hassan, 2009; Little, Trauer, Rouhan, & Haines, 2010; McGrath & Dowling, 2012; Stroud & Parsons, 2013; Sulzer, 2015).

Clinicians reportedly found working with individuals with BPD diagnosis challenging, overwhelming, and complex (Bourke & Grenyer, 2010; El-Adl & Hassan, 2009; McGrath & Dowling, 2012; Stroud & Parsons, 2013). Furthermore, many considered their behaviour to be manipulative, destructive, threatening, distrustful, and dangerous (Bourke & Grenyer, 2010; McGrath & Dowling, 2012; Liebman & Burnette, 2013; Sulzer, 2015; Treloar, 2009), as well as resistant and defensive (Bourke & Grenyer, 2013), and preferred to avoid services users with this label (Black et al., 2011). Low levels of empathy were also reported (Black et al., 2011; Bodner et al., 2011; Bodner et al., 2015; McGrath & Dowling, 2012; Treloar, 2009).

Two studies investigating therapists' clinical responses to BPD versus major depressive disorder (MDD) diagnosis (Bourke & Grenyer, 2010, 2013) found that the therapists tended to endorse more negative attitudes towards patients with BPD diagnosis whom they perceived as more 'hostile', 'narcissistic', 'anxious', and 'sexualised' (Bourke & Grenyer, 2013). In contrast, individuals with MDD diagnosis tended to receive more favourable descriptions, including 'friendly' and 'attentive' (Bourke & Grenyer, 2010). In their work with patients

with BPD, therapists further described their lack of confidence, increased levels of emotional distress, and increased need for clinical supervision.

Nevertheless, a minority of studies indicated positive attitudes amongst their clinicians (Bourke & Grenyer, 2010; Bowen, 2013; Giannouli, Perogamvros, Berk, Svigos, & Vaslamatzis, 2009; Hauck, Harrison, & Montecalvo, 2013; Millar, Gillanders, & Saleem, 2012; Sulzer, 2015) and recognition of BPD as a valid diagnosis with an encouraging prognosis (Black et al., 2011; Bowen, 2013; Giannouli et al., 2009). For instance, therapists in Bourke and Grenyer (2010) study viewed clients with BPD diagnosis as likeable, and were optimistic about the possibility of change; furthermore, they appeared to show a commitment in providing stable therapeutic relationships and willingness to explore the underlying processes involved in their clients' presentations and their own reactions to them.

Furthermore, Bowen (2013) demonstrated that staff working in a specialist BPD service, using residential therapeutic community model, generally maintained more positive attitudes regarding recovery, with emphasis on inclusion, negotiation, and holistic approach to care. Moreover, problematic behaviours were seen as opportunities for learning. This study offered a positive example of recovery-focused service that maintained many of the NICE principles (2009) of good practice.

### **Factors impacting on attitudes**

In parallel with previous research (Westwood & Baker, 2010), several papers identified specific factors that were associated with improved attitudes of MH professionals (Black et al., 2011; Bodner et al., 2011; Bourke & Grenyer, 2013; Hauck et al., 2013; Lebowitz & Woo-kyoung, 2012; Liebman & Burnette, 2013; Little et al., 2010; Stroud & Parsons, 2013).

These were synthesised into the following sub-themes: profession, age and clinical experience, BPD knowledge and training.

### **Profession**

Not all MH professionals harboured equally pessimistic attitudes (Black et al., 2011; Bodner et al., 2011; Liebman & Burnette, 2013; Little et al., 2010). The studies compared diverse professional groups on several measures, with mixed results which did not lend themselves easily to generalisations. Authors reported that staff nurses scored lowest regarding overall caring attitudes (Black et al., 2011), empathy (Black et al., 2011; Bodner et al., 2011; Bodner et al., 2015) and optimism regarding treatment interventions. Comparative to nurses and psychiatrists, psychologists tended to score lowest on antagonistic judgments (Bodner et al., 2011; Bodner et al., 2015). Regarding treatment optimism, social workers and psychiatrists obtained the highest scores (Black et al., 2011). Unsurprisingly, differences regarding intervention effectiveness were found, with psychiatrists rating medication, and social workers and psychologists rating psychotherapy as the most effective intervention option (Black et al., 2011).

### **Age and clinical experience**

Age, BPD-specific clinical experience, and years of experience were all independently associated with enhanced attitudes in several studies (Black et al., 2011; Hauck et al., 2013; Liebman & Burnette, 2013). As above, the studies were heterogenous in terms of sample characteristics and measures, and some findings were conflicting, making conclusions difficult to draw. For instance, Liebman and Burnette (2013) found that self-reports of younger clinicians and those with more BPD experience tended to indicate more empathetic attitudes towards to the individual. Hauck et al. (2013) found that nurses with more years of

nursing experience reported more positive attitudes, although age and level of education failed to show a significant association with positive attitudes. Black et al. (2011) found that clinicians with more psychiatric experience scored higher on items of competence. Furthermore, this study identified higher self-ratings of positive attitude in those practitioners who cared for more patients with BPD diagnosis in the last year.

### **BPD knowledge and training**

Ten studies examined the impact of existing knowledge and BPD-specific training on attitudes (Black et al., 2011; Bodner et al., 2011; El-Adl & Hassan, 2009; Furnham & Dadabhoy, 2012; Giannouli et al., 2009; Hauck et al., 2013; Lebowitz & Woo-kyoung, 2012; Shanks, Pfohl, Blum, & Black, 2011; Stroud & Parsons, 2013; Treloar, 2009). Generally, there was a consensus about the positive impact of knowledge and training on the participants' expressed attitudes. For instance, Stroud & Parsons (2013) found that the nurses' attitudes tended to be more positive if they had a knowledge framework for explaining the behaviour of their clients. Those without such knowledge appeared to hold more pejorative views, to embrace conflicting explanations, and reported feeling more disconnected from their clients. According to the authors, these positions were not fixed; rather they appeared to change depending on how the client's behaviour was interpreted in the moment.

The effects of formal training on people's attitudes had previously been documented (Treloar & Lewis, 2008). The current review adds to this evidence-base by demonstrating that those with BPD-specific training exhibited more positive attitudes, compared to individuals without such training (Liebman & Burnette, 2013). Two studies evaluating the impact of different types of training programmes reported immediate post-training attitudinal gains in their volunteers (Shanks et al., 2011; Treloar, 2009). In addition, two studies

demonstrated some maintenance effects with regards to a psychoanalytic training (Treloar, 2009) and MBT training (Warrender, 2015). Whilst encouraging, several limitations need to be considered, including unknown length of the maintenance effect (Warrender, 2015) as well as large attrition rates, the comparatively higher baseline scores in the psychoanalytic group, author acting as the trainer for both education programmes, and the possible impact of the author's psychoanalytic theatrical lens on data interpretation (Treloar, 2009).

In summary, concurrent with previous research, the prevalence of stigmatising attitudes towards those with BPD diagnosis was confirmed in the majority of studies. However, some findings described positive attitudes of their respondents; hence possibly indicating an attitudinal shift. Akin to previously reported findings, several different variables were associated with improved attitudes in the respondents, suggesting that negative attitudes regarding BPD diagnosis were not inevitable but were subject to change. Of these, education and BPD knowledge appeared to be the most salient factors that were associated with enhanced attitudes. Whether such gains in attitude could be maintained long-term would be a question for future research. Irrespectively, the results support the view that the impact of BPD diagnosis is a complex issue that is unlikely to be understood in simply dichotomous terms.

The results need to be considered with caution due to various limitations. The ability to make inter-study comparisons was limited due to the heterogeneity of the samples and means by which attitudes were evaluated. Further shortcomings included small sample sizes, use of self-report designs without a control group, missing basic demographic and statistical information (e.g. power, reliability, and validity coefficients), social desirability and sampling bias.

The next section will consider studies of MH professionals' existing diagnostic practices. This issue is important to consider in the current climate of service organisation which is based on the application of the diagnostic model.

## **2. How do professionals describe their diagnostic practices?**

Four studies addressed the question of diagnostic practices (Koehne, Hamilton, Sands, & Humphreys, 2013; Liebman & Burnette, 2013; Treloar, 2009; Treloar & Lewis, 2009). These suggested that the diagnostic process was highly heterogeneous and subject to various influences, including work setting, clinician's age, degree of direct contact and specific training, as well as service user characteristics (e.g. age and gender). For instance, clinicians in Liebman and Burnette's (2013) study read through a vignette depicting an individual meeting the DSM-IV criteria for BPD. They were asked to assign one of seven possible diagnoses to the individual. The vignettes were identical although age and gender was manipulated to create four experimental conditions. Using DSM criteria, respondents were more accurate in diagnosing BPD in a female rather than a male client. Furthermore, there were interactions between gender and age in that adult females and adolescent males were the most likely to be assigned BPD diagnosis.

In Treloar and Lewis's (2009) study, comparing emergency and MH staff in their use of the DSM-IV diagnostic criteria, most respondents tended to rely on the presence of impulsive behaviours when making the diagnosis. Group comparisons revealed that emergency staff tended to rate impulsive behaviour as the most characteristic of BPD whilst MH professionals considered unstable interpersonal relationships' pattern as the hallmark of BPD. Conversely, emergency staff rather than MH professionals, tended to consider family history of mental

disorders, psychosocial causality factors of family environment and abuse history. Contrary to Liebman and Burnette (2013), no associations were found between the use of the diagnostic criteria and profession, years of experience, and specific BPD education respectively.

Findings from another study (Koehne et al., 2013) from specialist adolescent services, one inpatient and one community, indicated that the issue of diagnostic disclosure was not black-and-white and the fallible nature of the current diagnostic system directly impacted how professionals used the diagnosis. In particular, clinicians in both settings tended to avoid frank use of the BPD diagnostic label with the clients; instead they tended to describe the problematic behaviours because they believed that behaviours were changeable whilst BPD diagnosis would position “the adolescent with a totality” and would give little cause for optimism (p.53). In addition, they tended to use ‘hedging words’, such as ‘traits’ or ‘emerging’ when talking about BPD. Informal ‘borderline talk’ was perceived negatively by most interviewees, but nevertheless took place at both sites.

The particular work setting appeared to influence the extent to which it was acceptable for staff to use the diagnostic label with each other, with inpatient staff believing that only the psychiatrist was allowed to use the term openly and directly. However, all community-based clinicians were expected to use the diagnostic term as every client was required to be given a formal diagnosis. This appeared to have caused diagnostic dilemmas for most community-based professionals.

In summary, stereotypes are likely to be damaging for therapeutic relationships and to negatively impact the quality of the diagnostic experience (Dinos, Stevens, Serfaty, Weich, &



King, 2004). The above-described studies demonstrated that such biases operate at a diagnostic level. The findings highlighted the fragility of the diagnostic system which is subject to personal, clinical and client-related influences. As Treloar and Lewis (2009) proposed, the diagnostic system exists to guide treatment efforts, but “this framework is only as effective as the diagnostician using it” (p.123).

The studies suffered from several methodological limitations, including the use of survey designs with no control groups, unknown response rates, and unknown characteristics of non-respondents. The studies’ recommendations centred around increased training and BPD specific experience (Treloar, 2009; Treloar & Lewis, 2009) to reduce the impact of the diagnostic stereotypes on the diagnostic process. The use of qualitative diagnostic interviews was recognised as fundamental in order to obtain a comprehensive clinical picture of the individual developmental trajectory (Treloar & Lewis, 2009).

The final section will focus on service users’ experiences of the current level of care, including the perceived interpersonal relationship quality, diagnostic label, and diagnostic process.

### **3. What do service users’ experiences suggest about the current level of care?**

#### **Interpersonal relationships**

In line with previous research (Haigh, 2002), the relationship quality between staff and service users was seen by many service users as key to good quality care (Helleman, Goosens, Kaasenbrood, & van Achterberg, 2014; Morris, Smith, & Alwin, 2014; Rogers & Dunne, 2011). Although examples of positive interactions with staff were difficult to find, a

minority of studies gave specific examples. These included the professional's ability to actively listen (Morris et al., 2014; Rogers & Dunne, 2011) and to regard the service user as "a person rather than . . . a case number" (p.253). With respect to inpatient admissions, service users described the importance of being "seen, heard, and accepted" (Helleman et al., p.446).

Contact with the nurse was identified as the most important aspect of the admission, as it was likely to influence their ability to overcome the 'crisis'. Participants reported particularly valuing nurses who sought to actively understand their difficulties by informally enquiring about the nature of their problems, thoughts, and feelings. It was reported that this approach helped the interviewees reduce the level of tension and conflict which had typically prevented them from initiating conversations and opening up with staff for fears of "abandonment and rejection" (Morris et al., 2014, p.253) should their care be subsequently withdrawn.

A considerable proportion of the participants' accounts described negative interactions with staff. These included perceptions of being "criticised" and "blamed" (Morris et al. 2014, p.253), as well as staff showing distancing attitudes, and focusing on co-ordinating care rather than psychological and emotional support. This had reportedly intensified the service users' feelings of emptiness and estrangement.

### **General aspects of care**

Whilst no specific details were provided by the researchers, some positive accounts were identified. These related to service users' experiences with specialist PD services, (Bonnington & Rose, 2014; Rogers & Acton, 2012; Wehne-Alamah & Wolgamott, 2014), and carers and family members' reports of being included in the provision of inpatient care for their loved ones (Dunne & Rogers, 2013).

Most recounted experiences, however, seemed negative in nature. These included service user and carer reports of significant exclusion and discrimination (Lawn & McMahon, 2015a, 2015b), service users reports of being let down by services with services being perceived as providing reactive rather care (Morris et al., 2014), rapid admission/discharge cycle with inadequate discharge planning, and practical difficulties, including unavailability of separate male/female wards and unavailability of activities during admission (Rogers & Dunne, 2011).

Accounts of service users in two studies suggested an overemphasis on medication as a treatment of choice (Richardson & Tracy, 2015; Rogers & Acton, 2012); a concern which echoed in another study, investigating the level of compliance with the NICE guidelines on treatment and management of BPD using a questionnaire design with 31 care-coordinators of service users with BPD diagnosis (Dunne & Rogers, 2011). The findings indicated generally poor standards of care, including an overemphasis on medication (61 percent of service users) with three quarters of service users receiving no psychological interventions. Furthermore, 50 percent reportedly received no information about BPD diagnosis and available or recommended treatment, and three quarters of care-coordinators failed to receive regular supervision.

### **Diagnostic label**

Similarly to previous literature exploring service users' perceptions of BPD-related stigma and discrimination (Horn, Johnstone, & Brooke, 2007; Nehls, 1999), BPD-related stigma was clearly evident in the clinicians' accounts (Lam, Salkovskis, & Hogg, 2015; Sulzer, 2015) as well as service users' accounts (Bonnington & Rose, 2014; Lovell & Hardy, 2014; Morris et al., 2014; Richardson & Tracy, 2015; Rogers & Dunne, 2011; Wehne-Alamah & Wolgamott, 2014). For instance, respondents in Dunne and Rogers (2011) study reported that simply

having BPD diagnosis appeared to prevent the MH professional from considering their problems as real or serious. In Bonnington and Rose's (2014) study, comparing the accounts of individuals with BPD versus Bipolar Affective Disorder (BPAD) diagnosis, both participant groups described professionals' negative practices. These included normalisation, stereotyping, and pathologising the individuals' expressions of 'normal' psychological and behavioural states, which in turn led to the individual rejecting the diagnosis; hence suggesting that similar stigmatising attitudes accrued to both diagnostic labels.

Nevertheless, some notable group differences emerged. For instance, whilst stigma experiences were reported by most participants, reportedly for those with BPAD diagnosis the stigma predominantly occurred within employment, whilst for individuals with BPD diagnosis it was mostly encountered within the healthcare system. Moreover, the BPAD label was reported to attract more positive stereotypes, which, in part, was explained by the media's positive portrayals of BPAD; whilst BPD was seen as attracting more negative labels, such as attention-seeker, manipulative, childlike, malingerers, untreatable, pathologically violent.

Two other studies demonstrated that BPD diagnosis attracted both positive and negative descriptions. More specifically, Lovell and Hardy (2014) interviewed eight females in a forensic setting about their experiences of living with the BPD diagnosis. Several interviewees reportedly accepted BPD "as their identity" (p.233) and as an accurate explanation of their experiences, whilst at the same time they viewed the label as a shameful diagnosis that was given to them against their will. The researchers suggested that BPD diagnosis could help one to define one's identity whilst it was also possibly detracting from their sense of identity.

Similarly, Richardson and Tracy (2015) interviewed eight volunteers who had been given BPD diagnosis after they sought a medical review of their original diagnosis, including BPAD. The interviewees described their belief that people with BPD diagnosis were more likely to be perceived as “creators of their problems” whilst those with the BPAD label were more likely to be seen as “victims” (p.4). Moreover, they described having limited BPD-specific knowledge, with some stating never having heard of BPD prior to being diagnosed. Nevertheless, all respondents reportedly noted a sense of relief when BPD was explained adequately to them as it “made sense” (p.3) and allowed them to contextualise their long-term difficulties within a framework that had previously been missing. Some interviewees believed that the diagnosis actually served to reduce the self-blame by legitimising their difficulties. Such accounts indicated that the impact of the label is not exclusively negative but can simultaneously incorporate both positive and negative elements.

### **Diagnostic process**

Two investigations of the perceived quality of the BPD diagnostic process were supportive of the above conclusions. More specifically, the participants in the Morris et al. (2014) study seemed more positive about BPD when they felt that the diagnostic process was well managed by the staff and was seen as helpful for them, and believed that how a service user was told about the BPD diagnosis was likely to play a significant role in how the diagnosis was subsequently perceived. This view echoed in the accounts of participants in another study (Richardson & Tracy, 2015), who identified appropriate discussions about BPD diagnosis with service users to be paramount to good-quality care. These data suggest that the meaning of BPD diagnosis is unlikely to be understood in linearly dichotomous terms of either positive or negative connotations. It would appear that service users are looking for

comprehensive explanations of their difficulties and some view the diagnostic process as crucial in this regard.

Regrettably, service users' experiences with the diagnostic process identified in this review appeared largely negative (Bonnington & Rose, 2014; Lovell & Hardy, 2014; Morris et al., 2014; Richardson & Tracy, 2015; Rogers & Acton, 2012; Wehne-Alamah & Wolgamott, 2014). The reported inadequacies included a lack of diagnostic disclosure and consequent exacerbation of power differentials and limited explanations regarding BPD (Bonnington & Rose, 2014), lack of opportunity to explore the meaning of the diagnosis with the service users (Richardson & Tracy, 2015), delayed diagnosis, and misdiagnosis (Wehne-Alamah & Wolgamott, 2014). Furthermore, many interviewees described a general lack of access to expert MH professionals who could provide early and accurate diagnosis and appropriate interventions, as well as exclusion from services (Bonnington & Rose, 2014; Lovell & Hardy, 2014; Rogers & Acton, 2012; Sulzer, 2015; Wehne-Alamah & Wolgamott, 2014), premature discharge for being "too risky" (Morris et al., 2014, p.253), and lack of effective interventions locally (Bonnington & Rose, 2014; Wehne-Alamah & Wolgamott, 2014).

Specific recommendations were put forward by the researchers. To tackle the undesirable effect of BPD diagnosis, researchers highlighted the importance of involving individuals in the diagnostic process (Lovell & Hardy, 2014) and care planning (Helleman et al., 2014). The diagnostic process should involve the provision of adequate information (Wehne-Alamah & Wolgamott, 2014) and service user discussions about BPD meaning (Lovell & Hardy, 2014), whilst demonstrating sensitivity during diagnostic disclosures and optimism regarding effective interventions (Morris et al., 2014). The diagnostic dialogue was seen as important in tackling the power differentials between staff and service users,

particularly in forensic and other such settings where the unequal distribution of power is likely to even more salient (Lovell & Hardy, 2014).

In summary, research in this section suggested that BPD diagnosis could have both positive consequences (e.g. having a framework for understanding difficulties, validation, enhanced sense of identity, and access to appropriate care) and negative consequences (e.g. stigmatising attitudes of staff or others particularly in those lacking BPD-specific knowledge, inadequate diagnostic process, limited access to care, and rejection from services). The quality of the diagnostic process was viewed as imperative in this regard for it appeared to influence how BPD diagnosis was perceived by the service users.

Concurrent with the previous sections depicting MH professionals' views, the service users' accounts identified several gaps between the desired and actual care. These related to interpersonal experiences with staff, lack of knowledge and awareness of BPD, faulty diagnostic process, and lack of access to care. These practices appeared contrary to the standards as set out by the NICE (2009) guidelines. The recommendations seemed related to the need for increasing BPD awareness and BPD-specific education in order to improve diagnostic accuracy to facilitate access to appropriate care and to improve the overall quality of care and interpersonal relationships of staff and service users.

Whilst important, these results need to be considered with caution due to several methodological limitations. For instance, the response rates in several studies were poor or remained unspecified, hence raising questions about sampling bias. Although most studies chose to use qualitative methodologies which were judged appropriate for the research

purpose, the research quality (e.g. context sensitivity, rigour, completeness, and transparency) seemed poorly demonstrated in numerous studies.

## **Discussion**

This review summarised literature regarding the consequences of BPD diagnosis, as perceived by service users and clinicians working with individuals with this diagnosis. Negative experiences were evident in the accounts of both participant groups. Importantly, however, positive accounts were also identified in a minority of studies; a finding which seemed contrary to previously identified literature (Deans & Meocevic, 2006). Such findings are encouraging as they suggest a slow shift in the perceptions of BPD diagnosis and those afflicted by this diagnosis.

The first research question was concerned with evaluating MH professionals' attitudes towards individuals with BPD diagnosis. The research revealed overwhelmingly negative attitudes, with professionals' describing high levels of emotional distress, lack of confidence and distancing attitudes towards individuals with BPD diagnosis. Nevertheless, some positive attitudes were reported. These included attitudes of hopefulness, holistic, and recovery-orientated approach to healthcare. In line with previous research (Westwood & Baker, 2010), the attitudes did not appear fixed; instead several factors (e.g. years of experience, intensity of clinical contact, existing BPD knowledge, and formal training) seemed associated with attitudinal improvements.

The studies of MH professionals' diagnostic practices revealed largely negative and heterogeneous practices, which were subject to various biases. These included work setting, clinician's age, degree of direct contact and specific training, as well as service user characteristics. Finally, research investigating service users' accounts of current level of care



indicated several gaps, including the overreliance on medication as the treatment of choice, lack of information regarding BPD diagnosis and treatment, as well as negative interpersonal relationships with staff, who were perceived by service users as judgmental, avoidant, and task-orientated. Studies investigating BPD diagnosis revealed a mixture of positive and negative connotations. Negative ones included service users' descriptions of BPD as a shameful label, and MH professionals' tendency to perceive individuals with this diagnosis as disingenuous and difficult rather than genuinely unwell. Nevertheless, positive impact of BPD was also reported by service users, which included a sense of relief, accurate description, and validation for their struggles.

Research investigating the nature of the diagnostic process seemed indicative of numerous gaps in the process, such as a lack of diagnostic disclosure, limited diagnostic discussions, delayed diagnosis, misdiagnosis, exclusion from services, and lack of access to specialist services. Several recommendations were put forward, including increased involvement of service users in the diagnostic process and overall care planning, provision of adequate BPD information, honest and comprehensive discussion with service users about BPD and its meaning, and optimistic recovery-orientated attitude.

### **Research limitations**

The Critical Appraisal Skills Programme (CASP, 2013) was used to evaluate the methodological soundness of the identified studies. The CASP revealed numerous methodological concerns, hence posing threats to the internal validity and generalisability of the current findings. For instance, all studies used volunteers, the overwhelming majority of whom were females. Together with low or unspecified response rates and missing basic demographic information these shortcomings raise the potential for a sampling bias.

Moreover, information on the timing of the original BPD diagnostic disclosure was frequently missing. This was seen as a notable drawback as the timing of the disclosure was likely to have impacted the subjective quality of the service user experience. For instance, it is possible that individuals with a more recent diagnostic disclosure might have had insufficient opportunity to consolidate the impact of the experience, hence giving rise to more negative recollections.

Unfortunately, 12 of the 14 quantitative studies used a self-report questionnaire design with only one of these employing a control group. Such designs undermine the reliability of the finding due to the potential influence of extraneous variables. Furthermore, it makes it difficult to evaluate the specificity of the findings for volunteers with BPD diagnosis against those with other diagnoses. It is possible, for instance, that similar diagnostic practices operate with other diagnostic categories.

It was noted that the studies documenting the professionals' perspective appeared on the whole more positive than those depicting the accounts of service users. These differences could potentially reflect the social desirability of the MH professionals. The differences might also reflect the participants' demand characteristics to provide responses presumed to be in keeping with the hypothesised aim of the study rather than their own experiences. Nevertheless, 17 studies (mostly investigating service users' perspective) used qualitative design, hence significantly reducing this bias with the service user samples.

The studies of service users' experiences predominantly used UK volunteers, hence allowing for direct comparisons against the UK national guidelines (NICE, 2009). Regrettably, the studies of MH professionals included numerous studies from outside the UK, thus not allowing for any direct comparisons against to the NICE guidelines. Nevertheless, the studies were deemed important and relevant on the premise that the vast majority were

conducted in developed countries, such as Australia, Ireland, and USA. The author hypothesised that the medical conceptualisations of MH, which was likely to operate in the identified western countries, was likely to act as a significant unifying factor across the different national healthcare systems.

### **Clinical implications**

Several clinical implications could cautiously be extrapolated from the current results. For instance, it would appear that attitudes towards BPD diagnosis and those afflicted by the diagnosis are slowly improving. Furthermore, instead of being fixed entities, attitudes seemed subject to numerous biases and positive shifts in response to concrete interventions, such as specific training. Such findings are encouraging as they indicate that the BPD-specific stigmatising impact should not automatically be presumed; tangible ways (e.g. BPD-specific training) could be employed to potentially reduce such impact.

The quality of the therapeutic relationship seemed highly regarded by service users. In addition, many of the reported positive experiences seemed to have come from specialist services, where the quality of the therapeutic relationship seemed a prerequisite to good clinical practice; a finding which seemed understandable in the context of the assumed disturbances in primary attachments of individuals who typically attract the BPD label (Bateman & Fonagy, 2006). In line with the NICE (2009) guidelines, it would be important that those working in specialist services continue to share their working practices and specific psychological knowledge with professionals from generic healthcare settings in order to continue to work towards improved healthcare provision across different settings.

Diagnostic accuracy improvements are crucial in facilitating access to adequate interventions (NICE, 2009). The current findings suggest practices which are at odds with

these recommendations. Despite improvements in BPD knowledge and the concurrent optimism regarding BPD-specific interventions, it is striking that MH professionals seem comparatively slow to embrace this and other important NICE (2009) messages. Numerous reasons for this could be postulated, including the lack of appropriate services locally and lack of BPD-specific knowledge. It could also be hypothesised that the application of psychological BPD models might seem uncomfortable and perhaps even disempowering to those who embrace a more medical approach to relieving human distress.

### **Research implications**

The current findings offer several directions for future research. The research indicated that negative attitudes towards and assumptions about those carrying BPD diagnosis continue to dominate in healthcare settings. Although specific training seemed effective in changing these attitudes, long-term maintenance effects of such interventions remain unknown. Furthermore, more UK-based studies would be welcome in order to evaluate general adherence to the national guidelines.

Future research should ideally examine stigma at different levels, not just in terms of attitudes. For instance, only a few studies have hitherto been published which touched on the nature of the diagnostic process. These studies indicated that a good-quality diagnostic process is an important aspect of care provision; one which has numerous consequences depending on how well it is managed by the clinician. The focus of future research could be to learn more about the realities of the diagnostic process and service users' perceptions of its helpful and unhelpful aspects.

## **Conclusion**

This review summarised literature evaluating the consequences of the BPD diagnosis. The research indicated several gaps in the current care provision, including the prevalence of stigmatising attitudes which also operate at the diagnostic level, hence minimising the quality of the diagnostic experience and concomitant lack of access to specialist services. Several biases, including personal, clinical and client-related influences, were identified which highlight the fragility of the existing healthcare system. Equally, some variables, such as increased BPD knowledge and genuine therapeutic approach were identified as strong contestant for improved quality of care. These results have specific research and clinical implications.

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**MAJOR RESEARCH PROJECT**

**ZUZANA WINTER BSc Hons**

Section B: **Empirical paper**

**An exploration of how female service users  
with the diagnosis of borderline personality disorder  
experience the diagnostic process**

Word count: **8,000**

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**SALOMONS  
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## Abstract

**Background and aim:** Contrary to the long-held assumptions, borderline personality disorder (BPD) is now considered a treatable disorder. Timely assessment has been recognised as one of the key treatment enablers and basic assessment standards have been stipulated by the UK's National Institute for Health and Clinical Excellence (NICE). The current study was the first to have specifically investigated the quality of the diagnostic process in light of the government recommendations.

**Methods:** Interpretative phenomenological analysis was used to analyse semi-structured interviews with eight female service users about their lived experiences with the original diagnostic BPD disclosure.

**Results:** Five master themes and several subthemes featured in the majority of the participants' experience: a) answer with a question mark; b) if only...; c) BPD like a star sign; d) star signs are not enough; it's what happens afterwards!; e) being at the mercy of the system.

**Conclusion:** Most participants' experiences suggested that the original diagnostic process was largely negative and did not follow the national guidelines. Nevertheless, a minority of positive views emerged. The findings are discussed with reference to the existing literature, whilst also detailing the study's limitations, clinical and research implications.

Keywords: borderline personality disorder, BPD, diagnostic process/assessment/experience, NICE, stigma\*

## **Introduction**

### **BPD – no cause for celebration**

‘Borderline personality disorder’ (BPD) has been defined as “a pervasive pattern of instability of interpersonal relationships, self-image, and affects, and marked impulsivity that begins by early adulthood and is present in a variety of contexts” (American Psychological Association, APA, 2013, p.664). BPD has been recognised as a serious mental disorder (Ekdahl, Idvall, Samuelsson, & Kent-Inge, 2011) which has been associated with some of the highest rates of recurrent crisis presentations, inpatient hospitalisations (Nelson, 2013), attempted and completed suicide (Oldham, 2006), as well as extreme level of psychological distress, including rage and despair (Bland, Tudor, & Whitehouse, 2007), profound interpersonal difficulties (Nelson, 2013), severely compromised quality of life (Palmer et al., 2006), and high degree of co-occurring chronic physical conditions (Frankenburg & Zanarini, 2011).

BPD aetiology is complex and includes developmental, environmental, and genetic factors, although research evidence has thus far proved inconclusive (Gill & Warburton, 2014). Nevertheless, attachment-based psychological models have been seen as central to understanding the principal struggles associated with BPD (Levy, Beeney, & Temes, 2011). In brief, it has been postulated that insecure attachment interferes with the individual’s mentalising capacity (i.e. ability to decipher one’s own mental states and those of others in order to interpret actions as meaningful), thought to be a crucial component of successful social integration (Bateman & Fonagy, 2006). Additionally, persistent signs of parental invalidation are thought to further undermine one’s ability to mentalise and discriminate between one’s own and others’ emotions, thus exacerbating psychological distress and identity confusion (Fruzzetti, Shenk, & Hoffman, 2005). These factors, with or without added

trauma, including severe neglect, might interfere with the neural mechanisms of arousal and cause structural and functional brain changes (National Institute for Health and Clinical Excellence, NICE, 2009). In the absence of corrective experiences, these factors have been presumed to result in the development of BPD (NICE, 2009).

BPD has been one of the most heavily contested diagnostic categories, which has long been criticised for its questionable validity and reliability (Alwin, Blackburn, Davidson, Hilton, Logan, & Shine, 2006, in Morris, Smith, & Alwin, 2014). Many have gone as far as to propose that BPD is nothing more than a ‘dustbin diagnosis’ for those service users who cannot satisfactorily fit within other diagnostic labels (Pilgrim, 2001). Furthermore, BPD has traditionally been regarded as an ‘untreatable’ disorder with negative therapeutic outcomes (Stalker, Ferguson, & Barclay, 2005), giving little hope to individuals with this label.

The BPD name itself has been seen by many as a highly stigmatising label, one reserved for those individuals whom psychiatrists disliked the most. Indeed, previous research showed that most mental health (MH) professionals tended to maintain highly negative views about individuals with this diagnosis, describing them as ‘dangerous’, ‘manipulative’, and ‘attention-seekers’ (Aviram, Brodsky, & Stanley, 2006). Furthermore, service users with BPD diagnosis have expressed their negative experiences with regards to self-perceptions of BPD and how, based on their diagnostic status, they were treated by others (Bonnington & Rose, 2014).

### **The changing picture of BPD**

In recent years, BPD has been the subject of a considerable research interest. Consequently, new knowledge has emerged which has challenged some of the long-standing negative views and historical assumptions about BPD. In particular, BPD is no longer viewed as an ‘untreatable’ disorder, as the core symptoms associated with BPD appear to be equally

responsive to an array of structured, long-term psychotherapeutic interventions, such as Dialectic Behavioural Therapy (DBT; Linehan, 1993) and Mentalisation based Therapy (MBT; Bateman & Fonagy, 2008). The significant success of psychological therapies has been recognised by the national guidelines (NICE, 2009), which recommend psychological interventions to be the primary treatment options for BPD.

The overarching message from the guidance is a positive one, installing a sense of optimism and hope that recovery is possible and attainable (NICE, 2009). As such, healthcare professionals are urged to work in partnership with service users and openly explore all available treatment options in an atmosphere of hope and trust, whilst continuously demonstrating sensitivity to the service users' trauma histories, experiences of rejection and stigmatising attitudes.

### **BPD and assessment process**

Prevention, early intervention, and timely BPD assessment have been identified as key treatment enablers (NICE, 2009). When conducting BPD assessment, the following guiding principles have been specified. The assessment process should be explained clearly, and BPD diagnosis and its meaning should be discussed openly, using clear non-technical language. Post-assessment emotional support should also be available.

Whether such assessment standards are being upheld in practice is currently difficult to ascertain as no study to date has specifically investigated the quality of the diagnostic process in light of the government recommendations. Nevertheless, a few existing studies touched on the issue indirectly (Bonnington & Rose, 2014; Lovell & Hardy, 2014; Morris et al., 2014; Richardson & Tracy, 2015; Rogers & Acton, 2012; Wehne-Alamah & Wolgamott, 2014). Their findings highlighted several insufficiencies in the care received by the service users, thus painting an alarmingly inadequate picture in this area.

The inadequacies included a lack of BPD diagnostic disclosure and consequent exacerbation of power differentials, limited explanations regarding BPD (Bonnington & Rose, 2014), as well as lack of opportunity to explore the meaning of the diagnosis with service users (Richardson & Tracy, 2015), delayed diagnosis, and misdiagnosis (Wehne-Alamah & Wolgamott, 2014). Many service users described exclusion from services and a general lack of access to MH specialists who could provide early, accurate diagnosis and appropriate interventions (Bonnington & Rose, 2014; Lovell & Hardy, 2014; Rogers & Acton, 2012; Wehne-Alamah & Wolgamott, 2014).

These practices appeared contrary to the NICE (2009) guidelines. The studies' recommendations emphasised the need for increasing BPD awareness and BPD-specific education to facilitate diagnostic accuracy, access to appropriate care, and to improve the overall quality of care and interpersonal relationships of staff and service users. Furthermore, the findings of two studies (Morris et al., 2014; Richardson & Tracy, 2015) indicated that the quality of the diagnostic process affected the degree to which BPD was perceived as useful and meaningful by the service users.

For instance, the participants in the Morris et al. (2014) study seemed more positive about BPD when they perceived the diagnostic process as well managed and helpful. Moreover, they believed that how they were told about the diagnosis impacted their subsequent perceptions of the diagnosis. These data suggest that BPD diagnosis is unlikely to be understood in linearly dichotomous terms as either positive or negative. It would appear that service users consider the diagnostic process to be crucial in this regard.

Taken together, the appropriate BPD diagnostic assessment seems essential to timely access to effective psychological treatment. Furthermore, the above findings suggest that the diagnostic process is likely to significantly impact how BPD is perceived by service users,

with an appropriate diagnostic disclosure possibly acting to reduce the stigma inherently associated with the label.

### **Rationale and aims**

Despite its recognition as a key treatment enabler, no study to date has specifically investigated service users' experiences with the BPD diagnostic process. The few studies which looked at this aspect of care indirectly pointed towards poorly managed diagnostic processes. The current research aimed to build on this preliminary evidence by obtaining a detailed qualitative account of service users' experiences with the BPD diagnostic process. This information was seen as paramount to understanding how the diagnostic practices operate and how they can be improved in the future.

A unique feature of the research was that, in addition to their original BPD diagnostic experience at some point in the past, all recruited participants would have learned about BPD during a specific psychoeducation programme, which they completed prior to embarking on an 18-month MBT programme. The programme closely followed the NICE (2009) guidance on diagnostic assessment in providing service users with a structured, comprehensive process where care was taken to explain the diagnosis and its impact on one's functioning. It aimed to help service users improve their understanding of the main aspects of BPD to help them adjust to the diagnosis, hence minimising its potentially stigmatising effect.

The author hypothesised that recruiting participants with this experience could represent a unique opportunity to learn about their diverse diagnostic experiences and to gather views about the specific aspects of this process and their perceived meaning for service users. Learning about these aspects of the diagnostic process was seen as important to enhance its quality. Furthermore, it is these aspects which might ultimately need to be incorporated into the formal diagnostic process to transform it into a process that will increase healthcare



professionals' confidence in routinely sharing BPD diagnosis with service users with the aim to reduce the BPD stigma.

The specific research questions were as follows:

1. How did the participants experience the original diagnostic process?
2. How did the participants make sense of their experiences with the diagnostic process?

## Methods

### Participants

A purposive sample of eight white British female volunteers, aged 20 to 52 (Mean=30.50 years, S.D.=10.50) was recruited from a pool of service users under the care of one of three assessment and treatment teams (ATTs) within a South London NHS Foundation Trust. The sampling method and size were in line with those recommended for IPA (Smith, Flowers, & Larkin, 2009). See Table 1, summarising participants' characteristics.

**Table 1. Summary of participants' characteristics.**

Number	Pseudoname	Age*	BPD first diagnosed by	Time since original diagnosis**	Previous diagnosis(es)	Type of psychological therapy
1	Gwen	30	psychiatrist	5 years	Yes	MBT including art
2	Celine	52	psychiatrist	2 years	Yes	MBT including art
3	Rosie	37	several psychologists ***	3 years	Yes	CBT & MBT
4	Eve	32	psychiatrist ***	1.5 years	Yes	MBT including art
5	Michaela	29	clinical psychologist	1.5 years	Yes	MBT including art
6	Roxy	20	psychiatrist	1 year	Yes	MBT including art
7	Megan	20	GP	2 years	Yes	MBT including art
8	Yvette	24	psychiatrist	5 years	Yes	MBT including art

\* mean = 30.50 years; SD = 10.50

\*\* mean = 2.63 years; SD = 1.58

\*\*\* described a comprehensive approach to the diagnostic process

Table 2. summarises the inclusion criteria. Participants who did not meet one or more of these criteria were not considered for the study. All participants had originally learned about the BPD diagnosis within the past five years (Mean=2.63 years; S.D.=1.58). The participants reported varied direct and indirect methods of disclosure, such as during an inpatient ward round, in a discharge letter, or a meeting with a MH professional.

**Table 2. Summary of inclusion criteria.**

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*	Working age adults;
*	Original diagnosis of BPD within the past five years;
*	Completion of 6-week BPD psychoeducation programme;
*	Good command of English;
*	Full capacity to consent to the study; and
*	Emotional stability of the participants verified by the responsible clinician.

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In addition to the original diagnostic experience, all participants received a formal confirmation of BPD diagnosis as part of an 18-month MBT programme, specifically designed to be delivered to service users with the diagnosis of BPD. As an introduction to the MBT programme, all participants had undergone a six-week-long psychoeducation programme, intended to enhance their understanding of BPD and in so doing to hopefully improve their subsequent individual psychosocial adjustment.

## **Design**

Interpretative Phenomenological Analysis (IPA) “is a qualitative research approach committed to the examination of how people make sense of their major life experiences. IPA is phenomenological in that it is concerned with exploring experience in its own terms” (Smith et al., 2009, p.1). In line with IPA, the author was interested in developing a detailed experiential account of how service users made sense of their experiences with the BPD

diagnostic process. Therefore, IPA was chosen as a suitable method to guide the research design.

### **Measures**

A semi-structured interview schedule (Appendix J) was devised in line with the IPA standards for data collection (Smith et al., 2009). Open-ended, non-leading questions and follow-up, prompting questions were developed in collaboration with the academic supervisor and clinical supervisor, each with respective experience in the area of research and clinical work with individuals with BPD diagnosis.

### **Service user involvement**

Service user involvement at the stage of research proposal was seen as necessary. Therefore, the author shared the proposal at a service-user-led research meeting. Furthermore, the author had several informal discussions with some of the service users many of whom identified themselves as having BPD diagnosis and all had experience using NHS services. The author was particularly keen to gather their views on the relevance of the research question and appropriateness of the interview schedule, as well as seeking their advice on potential ethical issues that might arise in the course of the research.

### **Procedure**

The author first conducted a bracketing interview (Roulston, 2010) with the clinical supervisor. The aim was to explore the author's own attitudes, experiences and biases.

Following the discussion with service users, the interview schedule was piloted with the clinical supervisor to test the appropriateness of the interview questions.

The responsible clinician provided the participants with the information sheet (Appendix G). Following this, the author, who acted as the researcher for the duration of the research, made contact with the participants to schedule the interviews at a mutually convenient time. All interviews took place in a therapy room in one of the three ATT sites. The interviews lasted between 45 and 70 minutes.

Prior to the commencement of the interview, the nature of the study was discussed with the participants who were also given an opportunity to ask questions or discuss any concerns. The participants then signed the consent forms. The first two interviews acted as further piloting. Following a discussion with the supervisors, it was decided that these data were of adequate quality and were therefore included in the main analysis.

## **Analysis**

Interviews were transcribed and analysed using IPA (Smith et al., 2009). The transcripts were read and re-read to achieve the necessary data submersion. On the second reading, exploratory descriptive, linguistic, and conceptual comments were made on the right transcript margin. These comments were then used to make emerging themes on the left transcript margin (Appendix K), which were then listed chronologically in a separate word document. Emerging themes were subsequently clustered together in another document in order to develop initial super-ordinate themes. Suitable quotes were identified for each super-ordinate theme and were highlighted in the original transcripts (Appendix K). This process was repeated for each transcript.

The next stage involved detecting overarching themes across cases to develop master themes and super-ordinate themes across cases. The author tried various methods to achieve this, including the laying out of colour-coordinated cuttings of all super-ordinate themes (Appendix L) and using Excel spread sheets (Appendix M). This process involved a continual cycle of switching, renaming and regrouping of the themes, whilst simultaneously moving between the individual and general. This process was terminated when a good-enough themes' abstraction was achieved which seemed to maintain sufficient authenticity of the raw data. Finally, transcripts and emerging themes were re-read to ascertain that the authenticity of the individual transcripts was maintained.

### **Quality assurance checks**

Yardley's quality criteria were followed throughout the research process to maintain the quality standards for IPA (Yardley, 2008, in Smith, 2008). These included 'sensitivity to context', 'commitment and rigour', and 'transparency and coherence'.

The 'sensitivity to context' criterion was demonstrated in several ways. This included the choice of IPA to understand the idiographic conditions of the diagnostic process, awareness of possible ethical issues and relevant literature, commitment to representing the rawness of each participant's unique perspective, and offering general interpretations with cautions.

'Commitment and rigour' was the second criterion. Commitment was adhered to by paying close attention to the raw data in the interview and analysis. Rigour was maintained by attempting to match the sample homogeneity to the research questions and following IPA analysis guidelines.

The 'transparency and coherence' was demonstrated by the inclusion of a coded interview transcript (Appendix K), research diary extracts (Appendix P), service user

consultation, bracketing interview and piloting of the interview schedule with the clinical supervisor so as to enhance the author's awareness of some of the biases and personal experiences which might have influenced the choice of the research topic, the author's approach to the research and the interpretative lens used by the author in data. Finally, the 'impact and importance' criterion will be considered in the discussion section for it relates to the study's usefulness and significance.

### **Researcher reflexivity**

The author was a white, 36-year-old female trainee clinical psychologist in her final year of training who had an interest in working with individuals with complex trauma histories. For six months of the research, the author worked with service users with BPD diagnosis, using MBT and psychodynamic approach. The service users were accepted onto the programme after they fulfilled the criteria for BPD diagnosis during a structured diagnostic interview.

The author assumed that this work experience had impacted her approach to the research, including the stance on the reliability and validity of BPD, and the importance of this psychological approach to understanding BPD. Equally, this working experience arguably enhanced the author's ability to tune into the service users' struggles, to recognise and work with their transferences, whilst providing containment and empathy. As such, this experience had potentially improved the 'sensitivity' of the research interviews.

The bracketing interview highlighted some of the author's preconceptions, including personal experiences with past diagnostic disclosures. The author attempted to be mindful of these potential biases throughout the research process.

## **Ethical considerations**

Ethical approval was obtained from the National Research Ethics Committee and the Research and Development Department at the corresponding NHS trust (Appendix A). Participants were informed that their participation was voluntary, they could discontinue the interview at any point, and that this decision would have no bearing on any aspect of their care, offered by the respective MH team. Participants were informed that the interview might potentially be upsetting. A discussion with the participants took place about how best to address this, should the interview raise difficult issues for them. All participant data were kept anonymous and confidential.

## **Results**

The analysis resulted in five master themes and 14 super-ordinate themes (Appendix N), which are described below. Quotes have been chosen to illustrate the richness, complexity and contradiction of the raw data whilst also reflecting the overarching generic theme. For additional quotes see Appendix O.

### **1. Answer with a question mark**

This master theme featured strongly across all eight cases. It corresponded to the participants' conflicting reactions to the way BPD diagnosis was first shared with them. In particular, whilst providing some answers and a sense of validation, the diagnostic experience appeared for many to be a source of further confusion, anxiety, and uncertainty.

## **PS: You've got BPD**

This theme featured across six cases and related to the strong sense that the MH professionals treated the exchange as something routine, as though they were “Passing out the Daily Post.

*It was just like, “Oh, there you go. This is what’s wrong with you”” (Celine, 5, 176)<sup>2</sup>.*

Many described a sense of dishonesty in which they learnt about their diagnosis as if by accident. For instance, Yvette (2, 7) said:

*There wasn't an exact point that I know of that I got the diagnosis cause it was . . . pretty much given to me in my absence (...)<sup>3</sup> I saw it on a correspondence between my psychiatrist and my GP [general practitioner].. on a piece of paper.*

## **You can't argue against it**

Six participants described a distinct lack of collaborative discussion and support during and following the diagnostic disclosure:

*Nobody really discusses, you know, “This is what this is, this is how it will impact on your life, this is what we're gonna do for you” There's never really been a sort of MEETING to explain all of that (Megan, 3, 47).*

For several participants, there was a sense that the sharing of the diagnosis seemed something of a pointless exercise as nothing appeared to have changed following the diagnosis. As Celine (8, 316) put it: *“They diagnosed me, they didn't tell me anything about it and then it wasn't actually mentioned at any time whilst I was there [psychiatric ward] by any other staff”.*

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<sup>2</sup> (Transcript page number, line number)

<sup>3</sup> (...) Text omitted to aid clarity



Despite its seeming pointlessness, this experience appeared to have had a significant impact, as judged by the strong emotions reported by many participants. Although some relief was present, negative reactions, such as rage, confusion, and resignation, seemed to dominate the participants' experiences.

Roxy (6, 193) said: *“Who the hell are you, you know, I don't even know you”. Erm, yeah, I wasn't very comfortable there [psychiatric ward] at all. So I guess I just accepted the BPD as getting help”*. Yvette (5, 163) explained:

*It just left me feeling on my own with this diagnosis and “Ok, well, now what do I do next? Do I just try and get on with life knowing that I've got this, not really knowing exactly what it is or how it's gonna affect me or, you know, what, er is this element of my personality what's wrong or is this the real me?”*

### **Here we go again...**

For five participants, there was a sense that they have had numerous disappointing experiences with MH professionals in the past. In this sense, the negative BPD diagnostic experience appeared just another let down. Gwen (2, 9) described that:

*Most of my diagnoses I've never really been told face to face, what they think I have. Maybe they'll say what depression or something but they won't go into detail what kind or what they think it is or anything and then when you get it written in, you know, have different, so many different diagnoses, it's weird.*

Two participants described more favourable BPD diagnostic experiences. Interestingly, their experiences seemed to differ from those of the other interviewees in that they described a relatively comprehensive diagnostic process. Eve (12, 530) said: *“Erm, I don't think there's anything wrong with the way it was explained to me”*, although she explained that there should have been more emphasis *“on a case of it not just being physical or sexual abuse (...)*

because I think those that have experienced like an emotional neglect may feel slightly out of place” (12, 535).

## **2. If only ...**

This master theme represented another seeming contradiction. Whilst most participants perceived the diagnostic process as flawed, many expressed a wish that the BPD diagnosis had been shared with them years ago.

### **... It was done differently**

Seven participants expressed clearly what was missing from the diagnostic experience. Most believed that they were not asking for much, “just to have someone that you could discuss it with properly that kind of knew what *they were talking about*” (Gwen, 29, 1337), “*just someone there to talk to you . . . listen*” (Celine, 10, 407) who would give a person “*time to explore it and explaining it*” (Yvette, 23, 24) and “*link it to stuff that you’ve said . . . that matches it*” (Michaela, 20, 854). This was felt important because:

*Then it would make me say, “Right, you know what you’re talking about, you’ve listened to me, you’ve acknowledged certain areas of my life where it applies, erm, based on what I’ve told you and what behaviours I’ve had, erm, rather than just from text books*  
(Michaela, 20, 860).

Two participants believed that the diagnostic meeting should have been planned with them in advance to help contain the fear and worry they had experienced during the meeting. Celine (4, 116) said:

*I think it was quite frightening (...) because you're in this setting and you've, they all of a sudden throw this label on you . . which no one seems to know about. Nobody's actually TALKING to you about . . and you don't know where this is gonna lead to.*

### **... It was done years ago**

This sentiment was detected across five cases. It was related to the appreciation for the psychological help that eventually followed the diagnostic disclosure. As Megan (20, 825) put it, "I would rather be *labelled a crazy person and have the help than, . . "No, you're fine to go away" sort of thing, so yeah {gently laughs}*".

Rosie was the only participant who appeared to have had no regrets about the diagnostic process. She described several positive aspects of the interview which the rest of the participants felt were missing: "*They explained it well to me and they got to know me and (...) it was quite, it was in simple terms and it sort of helped me understand what was going on really*" (26, 1209).

### **3. BPD like a star sign**

This master theme occurred in some format across all eight cases. It reflected views about the benefits and shortcomings of using BPD to make sense of one's experiences. One participant likened this to the practice of using star signs as a way of understanding individuals.

### **A scary star sign that fits**

Across most cases, the participants seemed to prefer to have the BPD diagnosis. For many, BPD fitted better than any other diagnosis “*cause there’s more links to that than any other thing that I’ve been told before, than the other sort of illnesses*” (Gwen, 21, 976).

For some, the appreciation for how BPD related to their struggles was not instantaneous; instead it came only “*after it was explained to me a hundred per cent [in therapy] I could identify with it more than anything else I could have identified with*” (Eve, 11, 456). For three participants, it was felt that any diagnosis had the potential to be useful even though it might have been a misdiagnosis. As Roxy (28, 1277) put it:

I would rather be diagnosed with something than nothing. Because you feel like . . . you *feel like you’re up in the air. You don’t know what’s wrong with you, you don’t know WHY this is happening to you.*

Four participants shared their initial impressions of what BPD meant to them Yvette (3, 61) said: “*Well, you’re saying my whole personality is disordered*”. Celine (7, 233) explained:

*Although I didn’t talk about it, it was probably, I know it was probably niggling at the back of my head. “Hmm, personality flaw (...), then I’m thinking, “Oh, do other people see, do other people see a flaw in my personality? Is there something wrong with me?”*

Some turned to the Internet for answers; however, what they found seemed difficult to contemplate. Yvette (14, 577) said: “*When I read, what I read online, erm, . . . I hated myself for the diagnosis*”. Megan (11, 446) said:

*It’s quite frightening to discover information on your own and not really have anyone to then discuss it with and reassure you almost that everything will be ok sort of even if it won’t but, you know, so quite frightening, I think.*

### **A star sign that fits anyone**

Six participants believed that criteria for BPD diagnosis were too generic and could easily apply to anyone, especially in cases where previous diagnoses have failed. Michaela (22, 954) said:

*I feel it's like a star sign (...) Every single Libra in the world can read the same . . . daily horoscope and it fits everyone because they read it but it's because they make it fit. Because it could be saying, "Oh, you're gonna have great love today" and then somebody loves their cat, somebody loves chocolate, and then they can both get the same, (...) it can fit anyone, so with the BPD you go, "Oh, I've got that" and you can apply it to EVERY single person in the street.*

A few others touched on the problems of using arbitrary diagnostic labels (e.g. BPD, Bipolar Disorder [BD], Emotionally Unstable Personality Disorder [EUPD]) as a means of making sense and validating human experience. For Megan, the only participant with a dual BPD and BD diagnosis, this created an extra layer of confusion: *"They're [BPD vs BD] quite, they're quite mutually exclusive almost sort of. On one hand, you can get better but on the other hand we can manage this but you won't get better sort of thing"* (5, 144).

Two participants believed that EUPD rather than BPD was more validating, although each stated a seemingly opposing reason for this. Roxy (29, 1132) said: *"BPD is a huge thing, you know, everyone's bumbled in it. (...) So yeah, I prefer saying I have emotional unstable personality disorder than just borderline personality, it's just sounds, it SOUNDS non-important, really"*.

Conversely, Eve (14, 598) stated: *"I've never felt like it's [BPD] a wishy washy label if you like. Erm, I think Borderline Personality Disorder sounds more, something more*

*sociopathic, like it's something more dangerous than an Emotional Instability or Personality Disorder”.*

### **I'm more than just the star sign**

Six participants believed that following the BPD diagnosis, it was difficult for others, especially MH professionals, to see past the diagnosis. Gwen (22, 993) said:

*You've now got that label and then they started to sort of ignore the things like the post traumatic side of things and, and the depression even sometimes (...) so it was, instead of being a mixture of things it was, it's BPD and BPD and that's it.*

Some believed that this negatively affected their medical treatment. For instance, Michaela (3, 54) said:

*Well, borderline personality, so you, you need mood stabilisers.” . . . And it's like, “Well, you don't know me, you don't know my situation, you don't, you haven't even asked what med, medication I'm on. And so it's just, didn't really make me very trusting of them at all.*

### **It takes an astrologist to get it**

Many believed that *“unless you understand it [BPD] completely the, the, what it entails, where it comes from, there's a lot of stigma (...)”* (Yvette, 14, 572). This related to a wider issue of MH stigma; something that was explicitly expressed by two participants. Roxy (22, 974) said:

*I know they trying to push the whole campaign about mental illness not being worry and talk about mental illness and stuff but people still have, you know, ideas of what mental*

*illness and it's not quite right, so if I say that I have a mental illness they're gonna be like, "Oh, my God", you know.*

Many expressed a strong belief that it takes time and special knowledge to understand BPD.

Yvette (6, 201) said:

*It was in those eighteen months [of therapy] (...), not with my doctor that I learnt what BPD was. How to recognise the, the symptoms in myself and you know and understand why it was given to me, you know {gently smirks}.*

The lack of BPD knowledge seemed particularly problematic when the participants attempted to explain BPD to their friends and relatives, or when seeking professional help:

*If you have to go to A&E, even there, they don't even understand what BPD is, erm . . . there, I usually get asked, "Is it like Bipolar?" (...) when you're in crisis you can't even explain it yourself. It's not even thinking straight, so it's really hard . . . {long pause}*  
(Celine, 9, 377).

#### **4. Star signs are not enough; it's what happens afterwards!**

This master theme featured across all cases. It related to the participants' conviction that simply diagnosing somebody with BPD was insufficient, as was an attempt to treat BPD symptoms with medication. Most participants believed that it was therapy, which not only provided a meaningful interpretation of BPD but which, for many, represented the long-sought-after psychological help.

### **Magic pills won't fix me**

Six participants voiced their impression that many medical professionals, such as GPs or psychiatrists, seemed helpless in their attempts to provide adequate help to the participants.

Gwen (10, 440) said: *“He couldn't fix me with his magic pills so, so that he could just toss his hands off and doesn't want nothing to do with me”*. Megan (9, 356) said:

*I think mental health tends to scare your average GP because it's, it's, . . . it's not a broken toe, you know, bandage it up and take some pain killers . It's, it's more in-depth, isn't it (...) Just in its very nature it's very undefined, so, I think a lot of them just sort of, you know, try the bog standard antidepressants and we'll see how you go and that's it.*

### **Therapy changed my life**

Most participants believed that psychological therapy represented a positive aspect of NHS care. Various therapeutic benefits were noted by the participants, including a life transformation, validation, enriched self-understanding, self-acceptance, improved interpersonal relationships, and renewed sense of direction.

Several participants believed that therapy has saved their lives. Eve (7, 246) said:

*It felt like a last chance for me. I was so sick of life, I was sick of waking up, sick of everything (...) I hate to think it but if I hadn't gone through X [therapy] now I would . . . doubt very much whether I'd necessarily be here.*

Meeting others with BPD diagnosis seemed a source of validation for many, including Eve (10, 426):

*I was quite convinced for a long time that I was literally beyond crazy and beyond help. Erm, and between the teams here and the groups and everything it was a convincing process to know that actually I wasn't crazy at all and I was completely legit in the way*



*that I felt which was nothing that I'd experienced from anywhere including the other side, X [MH team in London] if you like . . . {tails off}.*

Some participants believed that therapy had given them hope and new life direction. Yvette (16, 650) said:

*It was a long process of therapy but sitting here now a year or so afterwards I can see such a change and I CAN see a future for myself and . . . erm, not worry so much about . . . ever . . . erm, I suppose having a breakdown again or anything like that.*

Some participants described less favourable therapy outcomes. In particular, for three participants, daily life continued to represent a struggle and future appeared less certain.

Michaela (17, 709) explained:

*My future's always bleak, it's not anything really going on in the future and I don't make any plans and stuff, it's kind of just like go with the flow and just wait around and see what happens. So I don't really make plans.*

A minority of participants, including Michaela (26, 1148), found group environment difficult:

*Because he [art therapist]'s trying to push for something that isn't there. Or something that I'm not willing to talk about there and then. Maybe next week but maybe not there and then and then it feels like you're trespassing on something.*

## **5. Being at the mercy of the system**

This theme featured in varied ways across all eight cases. It related to the participants' increasingly helpless migration through the MH system, and taking whatever help was available to them in a hope of that, eventually, the right kind of help would be found.

### **You take what you're given**

Across seven cases, there was a strong sense that, due to the lack of any real alternatives, participants accepted whatever opinion and service they were given. This included taking on a MH diagnosis, such as BPD *"because there's not, er, much else out there to help you with"* (Michaela, 12, 473). It also involved reluctantly accepting inpatient admission at times of crisis. As before, Rosie (3, 83) was the only participant with a positive inpatient experience, who also seemed afraid of managing on her own after discharge: *"I thought, "My goodness me", I thought, "I hope I'm gonna be alright". But I've actually, I've proved that I am alright cause I've managed and I've done quite well on my own"*.

Three participants described themselves as neither completely well nor ill enough; something that seemed to tap into their identity struggle. Yvette (23, 980) said:

Well. . I must be them [in-patients], you know, I must be and all I saw in THEM was, *erm, no hope, no future, you know. So that and when I got out I didn't fit in, I didn't feel like I fit in.*

### **The MH migrant – can anyone help?**

Most participants expressed long-standing search for answers and help with their internal struggles. Their general sentiment was that despite being in the MH system, it has seemed difficult to find adequate help, with several participants describing that they were *"going round in circles for quite a few years"* (Gwen, 3, 83). Some described their initial sense of

*“confidence in the doctors that they knew what they were doing”* (Yvette, 12, 487). At the same time, it seemed that MH professionals were viewed as the only decision makers whose expertise gave them the power to *“play God with your life”* (Megan, 8, 304). Roxy (27, 1174) expressed this conflict as follows:

They are medical professionals and stuff and you, you DO trust 'em instantly because you think, *“Oh, they know what they’re talking about”*, so to say that you think that they’re wrong contradicts the whole thing so, like, if he turned round and said to me, *“Oh, ok if you don’t have BPD what do you have?”* I wouldn’t have a clue what to say.

Some participants expressed their belief that the only way to receive appropriate help was by speaking up or by finding someone else who was able to speak on their behalf. Gwen, (23, 1056) said:

*If that psychologist back at the hospital didn’t sort of write the letter and everything and kind of keep writing letters every few months to find out what was happening, it wouldn’t have happened, d’you know what I mean. So, it needed take to, someone to take the actual reins and take control.*

Encouragingly, this positive experience with a particular staff member seemed to echo the experiences of six other participants, who described some positive experiences with the NHS staff. Eve (7, 275) said:

I got an appointment I think it within . . . about six weeks of being referred by my GP, so I was quite lucky in that sense from what I can gather, erm, my very first interaction with the psychiatrist at X [Location within another London MH Trust] was . . . I felt very positive from it.

## **Discussion**

The current research aimed to obtain a first-hand account of service users' lived experiences with the BPD diagnostic process. The IPA analysis of eight interview transcripts revealed a clear sense that for most participants the original diagnostic experience was largely negative, although a minority of positive views emerged. The findings will be discussed below with reference to relevant literature and an outline of clinical and research implications.

### **Original diagnostic experience**

The original diagnostic BPD disclosure was described negatively by all but one participant. Many felt that BPD was simply given to them in a rush with no opportunity to discuss how, and why it was given to them, or to discuss with them their views about BPD and what it meant to them. More alarmingly, some participants first learnt about the diagnosis in a letter correspondence.

This seemed to have increased their sense of suspicion in the MH professionals' motives; something that the participants had already experienced many times before. Unsurprisingly, strong emotional reactions were reported by many. Most participants perceived themselves as powerless agents whose voice carried no weight in this process. These disempowering experiences are consistent with previous literature (Bonnington & Rose, 2014; Lovell & Hardy, 2014; Richardson & Tracy, 2015), which urged clinicians to explore BPD meaning with service users (Lovell & Hardy, 2014).

Notably, two participants in the current research reported relatively more favourable experiences with the original diagnostic process. Their narratives seemed indicative of a comprehensive and well-managed assessment, where time was taken to explain and discuss BPD honestly and collaboratively where a clear action plan or referral to appropriate psychological service was promptly made. In contrast, those with less positive experiences

described a much more haphazard process, where aspects of good diagnostic disclosure, such as active listening skills, compassion, and BPD knowledge, were missing. Again, previous literature has voiced similar shortcomings (Rogers & Acton, 2012).

### **BPD meaning is not fixed**

There was a clear sense that participants had been looking for explanations to their fundamental struggles and were prepared to have diagnostic discussions with healthcare professionals in a hope of finding an answer which would adequately explain and validate their struggles. BPD, however badly managed, seemed to give most participants a peace of mind as it seemed to fit better than any other previous diagnosis.

The BPD meaning seemed a highly fluid concept, however. For some, the diagnosis provided an instant validation. For others, BPD was a stigmatising label until it was explained to them comprehensively (usually as part of the psychoeducation programme or in therapy) in an atmosphere of hope, cooperative discussion, and compassion. These results echo those of previous research (Morris et al., 2014), which suggested that meaning of BPD is not a fixed entity and how one is told about BPD will impact one's understanding of the label. Furthermore, it seems that with increased knowledge about BPD, its stigmatising message can be replaced by a more meaningful, validating construct. Similarly to previous literature (Bonnington & Rose, 2014), participants spoke of the negative aspects of applying the BPD label, such as the potential for BPD to pathologise or minimise the severity of their experiences, and losing curiosity and appreciation for the individuality of human experience.

Participants believed that BPD represented a highly complex concept, one which was difficult to understand without having specific knowledge or training. Many expressed their beliefs that BPD continues to be a largely unknown and misunderstood label in many healthcare settings, including Accident & Emergency departments, or crisis admissions.

Participants believed that more training should take place to improve diagnostic practices and overall healthcare experience.

Unsurprisingly, personal circumstances of the participants at the time of the diagnostic disclosure seemed to influence their interpretations of BPD and the diagnostic process. For instance, one participant with a criminal conviction was ready to accept the diagnosis as it meant she was not a “criminal”, rather she was mentally unwell. Another participant was a teenager at the time of the diagnosis who struggled to see any future. She struggled to take on the diagnosis and the help that was on offer for it meant she was mentally unwell and her life was over.

Despite their negative experiences, most participants reported that they preferred to have BPD diagnosis, even if it represented a misdiagnosis, as long as it meant they were given the appropriate psychological help. Several participants even described their wish that BPD diagnosis had been made many years ago. This seemed to represent a powerful message that any diagnostic label or language construct has the potential to be personally meaningful and useful if it provided access to help.

### **Access to help**

Access to psychological therapy and professionals willing to listen appeared a precious commodity and something of a post-code lottery. This was in line with existing literature (Department of Health, 2014). In many cases, it seemed, such help only occurred following many years of migrating through the NHS system, with participants desperately accepting whatever help was available. Most described their negative experiences with the NHS staff. Nevertheless, most participants also described some positive experiences, which seemed to have painted a more encouraging picture of good practice by some professionals.

Typically, these experiences were linked to having contact with an interested and compassionate professional and where MH contact resulted in the provision of psychological help. As stated in previous literature (Helleman, Goosens, Kaasenbrood, & van Achterberg, 2014; Rogers & Dunne, 2011), the quality of interpersonal relationship seems to be the foundation of good-quality care for service users with BPD diagnosis. Such findings have been documented for several years and seemed a testament to the attachment-based psychological understanding of BPD, which emphasises the importance of providing a secure base and containment to the individual (Bateman & Fonagy, 2006; Hamilton, 2000).

### **Limitations and research implications**

Several limitations were considered. Although attempts were made to find participants with equal characteristics, this proved difficult to achieve. The participants' age range was large and there were variations in time since diagnosis, which reduced the sample's homogeneity, and possibly affected how the individuals perceived the diagnostic process. Nevertheless, the sample was limited to white British females from one particular location, with an experience of diagnostic disclosure and psychoeducation prior to embarking on MBT. Due to these characteristics, the findings cannot be generalised to the population as a whole.

Notwithstanding these limitations, the author aimed to increase the quality of the research by adhering to the quality assurance checks for qualitative research.

To the author's awareness, this was the first study which interviewed participants about their experiences with the diagnostic process. Future research could be conducted to strengthen or refute the current findings, in particular the impact of the diagnostic process on the meaning of the BPD diagnosis. Furthermore, it would be important to examine the mental health professionals' experiences with the diagnostic process in order to learn about

the obstacles to successful implementation of the NICE guidelines and how professionals might be empowered to improve their practices.

### **Clinical implications**

Numerous clinical implications could be stipulated with caution. The NICE (2009) principles of good practice seemed largely missing in the participants' accounts. If such practices were to be demonstrated more generally, this could potentially paint an alarming picture of substandard care. For now, it seemed reasonable to hypothesise about the possible reasons for the lack of appropriate diagnostic disclosures as experienced by the current sample of participants.

Several mechanisms might contribute. For instance, healthcare professionals might believe that disclosing BPD would negatively impact the individual or that the diagnostic dilemmas might be too complex for service users to comprehend. However, the current research suggested evidence to the contrary. The participants appeared intuitively aware of the uncertainties of the diagnostic process, and seemed ready to have open diagnostic discussions with professionals who considered them equal partners in the process. Perhaps, the lack of adequate disclosures reflected the clinicians' own assumptions about the potential burden of the diagnosis or about their judgments over service users' immaturity, fragility, and lack of readiness for frank diagnostic discussions.

Arguably, avoidant diagnostic practices seem counterproductive as they could potentially increase the feared stigma. Without a frank dialogue, service users can be left alone with their initial impressions of BPD (e.g. 'There's something wrong with my personality', 'Am I dangerous?') and have no means of testing the reality of these assumptions. Consequently, inadequate diagnostic process may actually serve to reinforce stigma that is inherently attached to the BPD label.



The current research is encouraging because it suggests that stigma attached to BPD is not fixed. Instead, it seems that having better understanding of BPD directly acts to increase a sense of validation whilst also reducing BPD's stigmatising associations. Therefore, clinicians should facilitate an open collaborative dialogue with service users about the diagnosis. Related to this is the importance of sharing BPD-specific knowledge. BPD appears to represent a complex concept. Without fully understanding it, the likelihood is that one will cling onto the initial impressions and stereotypes of what BPD means. The current research indicated some real gaps in knowledge-base of some healthcare professionals. The importance of knowledge sharing has been highlighted by many researchers (Treloar, 2009). It is an ongoing quest; one which will hopefully empower professionals to have open discussions about BPD with service users.

Finally, the lack of specialist services for people with BPD diagnosis is a real obstacle; one which is encountered in all NHS services. However, this lack of resources should not be used as a reason for not disclosing the diagnosis as such practice is likely to be more damaging. After all, the current research evidence suggests that considerable gains can be achieved just by having appropriate diagnostic discussions with services users.

## **Conclusion**

This was the first study to specifically explore the experiences of service users with the BPD diagnostic process. The findings pointed towards numerous gaps in the quality of the diagnostic experience as depicted by the current sample, something that would be at odds with the NICE (2009) guidelines. The importance of the diagnostic process was seen as multi-fold and related to the participants' conviction that a comprehensive and open diagnostic process with a knowledgeable individual was directly linked to a sense of validation of one's struggles, whilst reducing the power imbalance inherently associated with the process in which mental health professionals would typically be viewed as expert decision makers. Furthermore, such process appeared to immediately reduce the stigmatising aspects of BPD, especially if it was followed by access to appropriate psychological help. These findings added to the preliminary findings from previous research. Further qualitative research would be required in the first instance to learn more about the diagnostic practices and how these could be improved.

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Wehne-Alamah, H., & Wolgamott, S. (2014). Uncovering the mask of borderline personality disorder: Knowledge to empower primary care providers. *Journal of the American Association of Nurse Practitioners*, 26, 292-300.

**MAJOR RESEARCH PROJECT**

**ZUZANA WINTER BSc Hons**

**Section C: Appendices of supporting material**

DECEMBER 2015

A thesis submitted in partial fulfilment of the requirements  
of Canterbury Christ Church University for the degree  
of Doctor of Clinical Psychology

**SALOMONS**  
**CANTERBURY CHRIST CHURCH UNIVERSITY**

Please note that any identifying features have been removed to ensure anonymity and confidentiality of the submitted material.

**Appendix A: NHS REC - Acknowledgment of conditions met**

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**Appendix B: NHS REC - Favourable with conditions**

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## **Appendix C: NHS REC - Provisional opinion**

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## **Appendix D: Literature search strategy for part A**

### **Inclusion criteria**

The following inclusion criteria were applied:

4. Articles published following the publication of the National Institute for Health and Clinical Excellence guidelines (NICE, January, 2009).
5. Published, and peer reviewed articles written in English.

### **Exclusion criteria**

The exclusion criteria were as follows:

5. Case studies, dissertations, or academic discussion papers.
6. Studies with a generic focus unrelated to BPD.
7. BPD-specific studies which did not explore the impact of the diagnosis of BPD, such as studies investigating services users' experiences of living with BPD symptoms or those investigating self-harm in BPD.
8. Literature reviews of research papers published prior to the NICE (2009) publication.

### **Search strategy**

A systematic review methodology was conducted between January 2009 and November 2015. In line with the rationale and aims of the research, the particular start date was chosen in order to identify journals that have been published following the publication of the NICE guidelines. The following databases were searched: ASSIA, PsycINFO, Cochrane Library,

SAGE, Web of Science, and Wiley. Additional manual searches of reference sections of relevant literature and 'Google Scholar' internet search engine were performed.

The primary search terms were "borderline personality" or BPD. These were combined with the following search terms related to stigma: identity, self\*, "social stigma"/stigma\*, label\*, discriminat\*, stereotyp\*, sham\*, ignor\*, reject\*, fak\*, prejudic\*, approv\*, accept\*, inclu\*/exclu\*/'social exclu', perspective\*, perception\*, attitude\*, diagnos\*, 'mental health', experience\*, and judg\* . .

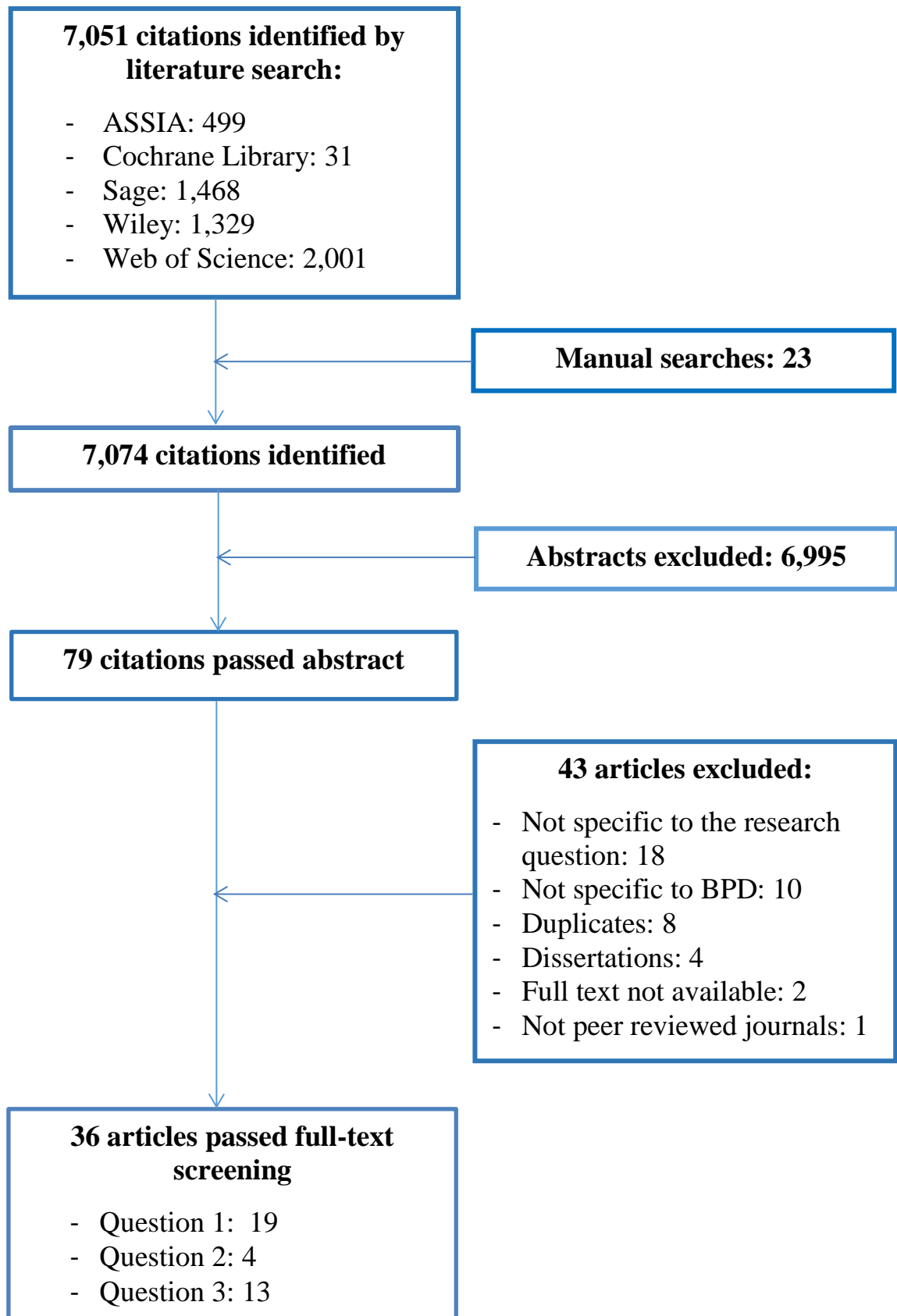
### **Study selection process**

Research abstracts of search results were first screened to establish the degree of relevance to the topic area. Full articles were accessed in all cases that broadly fitted the identified topic area. The reference sections of the collated journals were also screened for additional articles not identified in the database search.

### **Study categorisation**

Studies were categorised into the following topic areas: general knowledge regarding BPD, current issues in diagnosis of BPD, current psychological understanding of BPD, and consequences of the diagnosis of BPD. Numerous journals contribution information to more than one of these domains.

## Appendix E: Flow chart



**Appendix F: Summary table of studies identified and included in the review**

**1. ATTITUDES OF MENTAL HEALTH PROFESSIONALS AND GENERAL PUBLIC**

Author(s) (year) country	Subjects				Results			
	n (study group only); Response rate	Sector	BPD specific experience	Sex; Age range or mean age (years)	Measures	Control group	Main relevant finding	Critique *
Black et al. (USA) 2011	706;  48%	9 academic centres	unknown	Overrepresentations of F (%) in 6 of 7 occupational subcategories;  unknown	31-item self-report questionnaire	none	overall MH clinicians endorsed negative attitudes, low ratings on empathy, comfort & treatment and overall prognosis. Almost 1/2 preferred to avoid pt with BPD diagnosis. Most Ss perceived it at a valid diagnosis. Staff nurses=the lowest self-ratings on overall caring attitudes, social workers=the highest. Social workers and psychiatrists=the highest ratings on treatment optimism. Social workers and psychologists=most optimistic about psychotherapy effectiveness, while psychiatrists were most optimistic about	social desirability? Self-report; reliability of the measure?, characteristics of those who didn't take part/took part; no comparison group; no age information

							medication effectiveness. Staff nurses=lowest self-ratings on empathy and treatment optimism. Overall, caring attitudes, empathy, and treatment optimism were all higher among care providers who had cared for a greater number of pts with BPD diagnosis in the past 12 months.	
Bodner, Cohen-Fridel & Iancu (Israel) 2011	57; unknown	public psychiatric institutions	unknown	64.9% F & 35.1% M; range = 25-65; mean = 41.40 (SD = 8.54)	20 item self-report questionnaire designed to evaluate cog & emotional responses	none	psychologists scored lower than psychiatrists & nurses on antagonistic judgements; nurses scored lower than psychologists & psychiatrists on empathy; most negativity related to self-harm; all groups interested in learning more	non-random sample; no controls; unknown response rate; self-report measure; ? Power analysis not given; not clear why recruitment continued for 10 months; questionnaire invented by the authors (conflict of interest), unsure about validity & reliability coefficients although factor analysis was performed to provide a measure of

								construct validity;
Bodner, Cohen-Fridel, Mashiah, Segal, Grinshpoon, Fischel, & Iancu (Israel) 2015	710; unknown	public psychiatric wards	unknown	440F & 249 M;  mean = 44.62 (SD = 9.78)	5-point Likert scale cognitive and emotional attitudes inventories; implicit attitudes assessment (vignette with varied diagnosis BPD/MDD/GAD)	none	nurses and psychiatrists reported more negative attitudes and less empathy than social workers and psychologists; negative attitudes were positively correlated with greater number of SUs with BPD in the past month and past 12 months; nurses expressed interest in learning more about treatment for BPD	positive points: inclusion criteria specified; large sample; group differences were assessed and controlled for in the analysis; description of dev of the questionnaire negative points = unsure how the different professions were assigned to different vignette conditions took place; lack of control group; self-report questionnaire design --> report bias?
Bourke & Grenyer (Australia) 2013	20; unknown	CMHTs	all had treated at least 2 pts with BPD diagnosis in past year	13 F & 3 M;  mean = 34 (SD=7.52)	semi-structured interview using Relationship anecdotes paradigm; Psychotherapy relationship questionnaire to index therapists' perceptions of pt's relational patterns;	n/a	therapists expressed greater emotional distress and increased need for supportive supervision in their clinical work with pts with BPD diagnosis; perceived them as presenting with higher hostile, narcissistic, compliant, anxious &	snowball method --> non-representative sample; retrospective accounts of therapists --> increase recall bias; not blind to diagnostic status --> stereotype bias; participants asked to choose pts they felt were 'representative of their caseload' - -->



					computerised content analysis Leximancer		sexualised dimensions of interpersonal responses than pts with MDD diagnosis; Years of experience & theoretical orientation did not account for significance variance; authors argued that therapists must be able to manage their transference pattern and their own countertransference responses	subjective judgement
Bourke & Grenyer (Australia) 2010	20; unknown	CMHTs	all had treated at least 2 pts with BPD diagnosis in past year	17 F & 3 M; mean = 34 (SD = 7.52)	semi-structured Interviews using Relationship Anecdotal Paradigm interview method which; interview scored using Core Conflictual Relationship Theme-Leipzig/Ulm (CCRT-LU) method as a measure of cognition and emotional valence & emotional	none	overall therapists expressed supportive attitude towards all patients regardless of diagnosis; However, pts with MDD diagnosis=perceived as more friendly, attentive and generally harmonious; pts with BPD diagnosis=perceived as disharmonious; therapists expressed more confidence working with MDD diagnosis; negative valence reported in	using snowballing --> reduces representativeness; participants not blind to diagnostic status --> stereotype bias; participants asked to choose pts that they felt were 'representative of their caseload' --> subjective judgement; unclear why the patient characteristics were provided and the patients were deemed to be 'participants';

					measure; GAF		relation to BPD	MDD vs BPD - not so clear cut; social desirability effect?; retrospective accounts --> recall bias
Bowen (UK) 2013	9; unknown	specialist PD service	work experience at the unit of 1 to 25 years	6 F & 3 M; unknown	semi-structured interviews	n/a	four themes: shared decision making, use of social roles, peer support and open communication; in contrast to literature on staff attitude, the staff attitudes were optimistic a belief that change was possible & behs that had often been viewed as difficult to managed have been used by the interviewees as opportunities for learning; it was seen as important to avoid acting impulsively and thoughtlessly; also it was viewed as important to show compassion to each other and appreciation of each other; acting as a 'container' was viewed as important	small sample; specific service --> reduced generalisability; purposive sampling & research bias as to who gets to be selected

El-Adl & Hassan (UK) 2009	185	various MH sectors	unknown	Unknown; unknown	cross sectional survey	none	most reported individuals with BPD diagnosis as challenging and agreed that training was needed; 1/3 of respondents believed they were mentally ill (the majority of them were from inpatient staff); survey suggested that it was not so much the problem of recognition of BPD but rather a problem of not knowing how to provide adequate help and care	survey design; unsure how this study contributes NEW knowledge - no research gap identified; characteristics of non-respondents; no acknowledgement of limitations; study results do not match the aims (no suggestions for what training needs were identified) - possibly b/c the survey design not able to answer this question; confusion about generalisability - is this meant for Arab practitioners or for those practicing in UK
Furnham & Dadabhoy (UK) 2012	102; averaged at 60%	general population	unknown	54 F & 48 M; 18-66; mean = 31.83 (SD = 12.40)	mean nr of correct identification responses given to the 4 vignettes (vignette identification task that required Ss to answer open-ended questions	none	recognition rate for BPD was very low amongst Ss, with Ss more likely to identify depression, schizophrenia or psychopathy; Ss favoured psych & sociological treatments & early	problems with convenience sample & generalisability to others; if some of them had formal education in psych, medicine, or psychiatry how were they considered 'lay' people?; small

					about hypothetical pts with 4 psych problems, one of which was BPD); mean responses to each of the 50 50 attitude statements		trauma/stress as possible causes of the symptoms of pts described in the BPD vignette; Authors argued for more educational programmes & steps to improve general awareness of BPD	sample; restrictions of quantitative method - forced to make a choice whilst missing the quality of the response; not sure if these views relate specifically to BPD or to MI in general; no control group
Giannouli et al. (Greece) 2009	69; 54.3%	15 wards from general psychiatry and psychiatric hospitals	36.2%=contact >1/month; 20.3%=daily contact; 8.7%=no contact	48 F & 22 M; range =30-50	questionnaire by Cleary et al. (2002)	none	staff self-reported good enough knowledge re: diagnosis & treatment; the majority believed that the management of pts was moderate to difficult; most believed that the management of BPD pts was inadequate; 26.1% reported that the main reason was lack of education rather than BPD-specific difficulties; 73.9% believed educational programmes would help in pt management & 58% responded that they need information as to	non-random sampling, no evidence of matching procedure; questionnaire design; no report on reliability & validity coefficients; 8.7% of respondents reported no experience with p with BPD diagnosis ->? Impact on results; no limitations acknowledged by authors

							where they can refer pt; in general there was willingness for education - all reporting willingness to take part in a 1-h/month educational seminar and 95.6% wished to take part in 2h/month programme. 8.7% believed that not informing pts about their diagnosis was reason for inadequate treatment. They also believed that they played an important role in their pt management 72%, assessment 47%, educating and informing 59%, and referral 47%	
Hauck, Harrison, & Montecalvo (USA) 2013	83; 50.3%	behaviour health inpatient units	unknown	75 F & 8 M; range = 21 - 65; mean = 47	demographic & Educational Needs Information Questionnaire; Adapted version of the Attitudes towards DSH Questionnaire	none	nurses self-reported positive attitudes tws pts; those with more years of psychiatric experience & self-reported need for further BPD education had more positive attitudes	using questionnaire design with non-standardised questionnaire; Inter-rater reliability and validity of the measure?; only attitudes that were questioned were revealed; M v F ratio; not enough

								demographics regarding the sample e.g. age range of F & M; level of BD-specific experience; descriptive design --> correlations; convenience sample characteristics; no control group; 50% of those approached did not reply; reduced generalisability due to the sample population and response rate
Lebowitz & Woo-kyoung (USA) 2012	249; unknown	general population	unknown	101 F & 62 M (86 = no gender provided); unknown	vignettes describing a p with BPD symptoms & p with schizophrenia symptoms; social distance scale to judge attitudes	none	pairing biological explanations of mental disorders with treatment information can diminish negative attitudes toward persons with mental disorders.	characteristics of Ss unknown; no info on how they dealt with missing data (e.g. demographic questionnaire was optional and some info e.g gender, was missing); ? Generalisability; no CI info; no power analysis; no controls; only one aspect of stigma i.e. social distance was examined here --> ? How about effect on

								other types of stigma
Little et al. (Australia) 2010	378; 97.67%	Various incl public sector	unknown	27% F & 73% M; unknown	35-item Questionnaire (developed by the authors) evaluating knowledge about diagnostic criteria & concept of chronic suicidality, emotional reactions, concerns & management	none	different agencies respond in different ways towards people with diagnosable BPD. E.g. police adopted conservative & safe approach. These differences reflected ideological splits between agency groups.	self-selected sample -> ? validity of results; Overrepresentations of police whilst underrepresentation of others; lack of comparison for significant difference of groups; questionnaire design; unable to verify diagnosis of BPD; Differences in motivation e.g. police required to attend; welfare staff attended b/c of personal interest
McGrath & Dowling (Ireland) 2012	17; 54.85%	MH community service	10 Ss=daily contact with p with BPD diagnosis; 4 Ss=2-3times/week; 3 Ss=<5/month; 1 S= one-day workshop in BPD	12 F & 5 M; unknown	semi-structured interviews using the staff-patient interaction response scale (SPIRS) for empathy	n/a	4 themes: challenging & difficult (e.g. not taking responsibility for their beh; beh deemed as difficult to manage); manipulative, destructive & threatening beh; (e.g. having hidden agenda; resorting to self-harming beh if needs not met);	age info missing; some Ss asked for their transcripts to be amended after reading them (concerned over lack of empathy) --> ?impact on results; demand characteristics & social desirability?; quotations not numbered -->

							preying on the vulnerable resulting in splitting staff & SUs; boundaries & structures (e.g. the need to have strict boundaries and firm limit setting). Also low levels of empathy in majority of Ss	researcher bias?; no validation strategy; unsure about how this study contributed new information; characteristics of sample & generalisability
Millar, Gillanders , & Saleem (UK) 2012	16; 70%	adult clinical psychology department	12 had direct clinical experience with patients with BPD diagnosis	16 F & 0 M; unknown	focus groups	n/a	reported less negative perceptions reported about the BPD client group; commitment to providing stable therapeutic rels, recognition of challenges inherent in this work, attempts to understand processes involved in their clients' presentations and their own reactions. More experience --> more positive perceptions; 8 themes : negative perceptions (odd, different, controlling, manipulative), undesirable feelings in participants (confusion, low self-efficacy, frustration,	only 12 had direct clinical experience with this client group; impact of focus group - social desirability?; purposive sample & low generalisability; no males



							complexity, overwhelmed), 'positive perceptions (likable; possibility of change), desirable feelings in participant (empathy, interest, reward), awareness of negativity (awareness of negative perceptions; avoidance of being unhelpful; exploring why), trying to make sense of the chaos (searching for explanations, providing structure, normalising, working on engagement, working on diff levels), working in contrast to the system (problems with diagnosis, limited impact of psychology) & improving our role (desire to learn more, value of experience & support, potential for psychology)	
Shanks et al. (USA) 2011	271;	general MH	mean number of years treating p	77.5% F& 22.5% M;	questionnaire (completed before	none; although pre	clinicians endorsed having significantly	no follow up to evaluate long-term

	unknown		with BPD diagnosis = 8; median = 6	unknown	and after the STEPPS workshop)	and post scores collected	greater empathy, greater awareness of distress & low self-esteem associated with BPD; significant improvements also seen in attitude tws pts and also desire to work with them; significantly less likely to express dislike for pts with BPD diagnosis; feeling more competent	maintenance effects of this intervention ; limitations of questionnaire design; no controls; characteristics of those who responded cs non-respondents e.g. more F, lack of generalisability to other groups of professionals and general public; unsure about the reliability and construct validity of the questionnaire; does this change in attitude lead to a change in outcomes for pts with BPD diagnosis?
Stroud & Parsons (UK) 2013	4; unknown	CMHT	daily experience of working with BPD, overall experience of BPD work between 1 and 10 years; 1 S = a specialist BPD training	3 F & 1 M; range = 30-59	semi-structured interviews	n/a	4 themes: knowledge of BPD (lack of knowledge --> negative views); attitudes tws BPD (knowledge base affected attitudes reported, although all perceived the work as challenging & complex); interactions with clients; service	Semi-structured interview - researcher bias in interpretation; social desirability; not enough detail regarding sensitivity to context, transparency and rigour as process of data analysis not exemplified (e.g. example of

							context. Nurses' explanations for certain behs --> more positive in their attitude, less pejorative; more nurturing terms used; no explanations --> more pejorative; attitudes were not static but tended to shift according to how the client presented in the moment; importance of supervision; attitudes are impacted upon by the prevailing culture (e.g. focus on risk and litigation --> more guarded attitudes tws clients; positive risk taking --> improved working with client group)	transcribed interview; summary table of themes; themes' evolution)
Sulzer (USA) 2015	22; unknown	various MH settings	n/a	unknown; unknown	semi-structured interviews, manual and N Vivo data analysis		SUs with BPD diagnosis continue to be labelled as "difficult" and responsible for their behaviour and as untreatable; in turn these assumptions contribute to their	potential for interpretative bias as unsure whether independent checks of coding had been performed; unknown characteristics of participants (age, gender); quotes not

							experiences of being excluded from care either directly or indirectly	accompanied by pseudonyms/page & line numbers --> reduced rigour and transparency of report
Treloar (Australia) 2009	140; control = 41; CBT = 50; psychoanalytic = 49;  response rates: 31.46% ( but 16% left service before the 6 month follow-up!) = 118 (84%) clinicians participated; 65% of these responded to follow up - of these 25 (38%) were from psychoanalytic experimental condition; 18 28% were from CBT; 22 34% were from control group	emergency & MH clinicians	unknown	39 (60%) F; 26 (40%) M;  unknown	Attitudes tws DSH questionnaire (completed before and after educational training using either CBT or psychoanalytic programme); demographic questionnaire	yes (Ss who where not provided with educational session)	compared with participants in control g, the in the CBT & in psychoanalytic educ. programme showed significant improvement in attitudes immediately after attending the programme. At 6-month follow up only those in the psychoanalytic group maintained signif changes in attitudes; Suggestions that clinicians might benefit from learning about the unconscious processes underlying DSH	large attrition rate; sample size; unequal sample sizes; using questionnaire design that forces one to make a decision; longer-term maintenance effects? 140 (16% left services before the 6 month follow-up!); higher baseline ratings for those in the psychoanalytic group; author was the trainer - conflict of interest; author - psychoanalytic theoretical interest
Warrender (UK) 2015	9;	acute MH wards in	unknown	unknown;	focus groups	none	overall, following MBT-S 2-day	positive points: demonstrating

	50%	one hospital		unknown			workshop, there was an increase in hope and optimism compared to baseline; also increase in empathy and appropriate response to self-harm; increased ability to tolerate risk; improved attitudes tws SUs with BPD diagnosis (e.g. not seeing SUs as intentionally difficult)	awareness of impact of own beliefs & preconceptions; reasons for non-participation given (but this was a purposive sample i.e. the assumption was that all invited participants shared important characteristics); data analysis described; negative points: small sample size; lack of demographic information re: Ss; unknown maintenance effects (could be 6 months, could be less); unknown numbers of those who reported improved post-training attitudes/responses
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## 2. MH PROFESSIONALS' DESCRIPTIONS OF THEIR DIAGNOSTIC PRACTICES

Author(s) (year) country	Subjects				Results			Critique *
	n (study group only); Response rate	Sector	BPD specific experience	Sex; Age range or mean age (years)	Measures	Control group	Main relevant finding	
Koehne et al. (Australia) 2013	23 (15 from community; 8 from inpatients);  unknown	specialist CAMHS (inpatient & community)	unknown	unknown  unknown	semi-structured interviews	n/a	"complexity, contradictions and flaws inherent in the BPD diagnostic label seemed to have driven the practices identified in the research. The setting in which one works (i.e. inpatient vs community) influences how diagnosis is thought about/talked about. Inpatient = only psychiatrist can formally diagnose BPD, although informal talking about BPD amongst staff was okay. At both sites = little scope for frank use of the diagnostic label; instead clinicians tended to talk to clients in terms of symptoms/problems/behs. At both sites = diagnosis was viewed as necessary and unnecessary, helpful and unhelpful, contributing to and detracting from the ability to know the pt; overall = diagnosis viewed	not enough demographic information on the respondents' characteristics; not demonstrating critical evaluation of the research by e.g. failing to describe limitations of research, such as awareness of biases in interpretations --> reducing research quality; nevertheless some quality demonstrated by paying attention to the theoretical underpinnings of the discourse analysis & showing sensitivity to context by e.g. learning about the particular work settings, incl norms and roles, to enhance

							as imperfect/fallible; decisions to not talk to the pt about the emerging BPD diagnosis was fuelled by the clinician's view that the diagnostic category was fallible rather than by them disregarding the adolescent position; clinicians wanted to avoid positioning the adolescents with a totality; instead they relied on beh descriptions (b/c beh is seen as fleeting)	understanding of their impact on talking about BPD with adolescents; also completeness achieved
Liebman & Burnette (USA) 2013	560; unknown	residential, outpatient & private setting	varied	407 F & 147 M; mean = 50	online survey questionnaire, including questions regarding countertransferences and presumed dangerousness, plus demographic data	none	clinicians more accurate in diagnosing female client with BPD diagnosis than a male client; the clinician's reactions differed as a function of client age and clinical experience (ADOLESCENT clients viewed as less ill, untrustworthy, more dangerous; MORE CLINICAL EXPERIENCE associated with more positive attitude). The diagnostic classification system exists as a framework to guide treatment efforts, but this framework is only as effective as the	survey questionnaire = ? appropriateness to evaluate presence of countertransference (e.g. distrust, empathy, chronicity; conduct problems; interpersonal efficacy; dangerousness) why not other client and clinician-level characteristics chosen as candidates for negative countertransference reactions?; unknown characteristics of nonrespondents &

							diagnostician using it. Suggests that the diagnostic system is faulty and is subject to personal, clinical and client-related influence; it also has consequences for treatment decisions	unknown response rate --> selection bias? ; unequal sample sizes; no control although 4 conditions created
Treloar (Australia & New Zealand) 2009	104; 73.57%	emergency staff & MH professionals	unknown	92 F & 48 M; unknown	demographic questionnaire (gender, service setting, primary occupation/discipline, BPD training); open-ended question on experiences in working with BPD	n/a	4 themes: BPD pts generate an uncomfortable personal responses (manipulative; excusing bad beh; feelings of inadequacy, anger, powerlessness; CLINICIANS UNSURE AS TO HOW TO RESPOND --> CONFLICT WITHIN TEAM); specific characteristics of BPD that contribute to negative response (being seen as manipulative; waste of clinical time; scepticism about responsiveness to treatment; how a clinician perceives the BPD pt and how they respond affects the level of therapeutic engagement); inadequacies of the health system in addressing BPD pt needs (clinicians described that since labelled as BPD, it is hard for the pt to be given an objective assessment;	no exclusion criteria given (e.g. level of BPD experience) --> sample might not be appropriately matched to the aims of the study (i.e. experiences of working with p with BPD diagnosis); unknown characteristics of non-respondents?; self-reported demographic questionnaire - problems with this; also questionnaire included a space for a comment on "your experience or interest in working with pts diagnosed with BPD - ? unsure whether this addresses the study's aim to explore WHY negative



							decline of services and provision of biased clinical assessment of the pt needs - ALARMING!); techniques & strategies needed to improve service provision (provision of regular access to training & education & supervision; using crisis plans to manage beh difficulties; using less staff in order to standardise clinical response)	attitudes might persist? Lack of awareness demonstrated about the limitations of the design/other characteristics of the study (despite demographics taken, there is not enough information about this e.g. age range)
Treloar & Lewis (Australia & New Zealand) 2009	108; 90.9%	emergency depts & MH services	BPD specific training=53; no training=55; contact frequency: daily=31, weekly=42; fortnightly=12; >monthly =23	72 F & 36 M; unknown	purpose designed survey	none	participants tended to rely on observable beh symptoms (e.g. DSH & impulsive beh) when screening for BPD; there were differences between emergency medical staff & MH clinicians in using diagnostic indicators of BPD	using survey method - limitations e.g. difficult to judge the completeness of response; social desirability characteristics; demand characteristics as this was a purpose-designed survey; also unable to evaluate results against clinician based characteristics (e.g. level of experience with BPD); however a good response rate & authors attempted to minimise selection bias

### 3. CURRENT LEVEL OF CARE AS PERCEIVED BY SERVICE USERS

Author(s) (year) country	Subjects				Results			Critique *
	n (study group only); Response rate	Sector	BPD specific experience	Sex; Age range or mean age (years)	Measures	Control group	Main relevant finding	
Bonnington & Rose (UK) 2014	46 (BPD = 22; BD = 24);  unknown	general population (recruited via various methods)	unknown	BPD = 17 F & 5 M; BD = 16 F & 8 M;  18-51 +	5 mini-focus groups (with 3-4 Ss) & 29 in-depth interviews (with 15 pts with BPD diagnosis & 14 BD with diagnosis)	n/a	Themes: cultural imperialism (as PATHOLOGISATION - i.e. pathologising what the Ss viewed as normal psych & beh states; many BPD pts rejected the diagnosis as a misrepresentation of their experiences/themselves and as something that "cast a negative moral . . . judgment" p 12; NORMALISATION - many BPD pts felt their "illness" was being dismissed as illegitimate by staff, friends and families; & STEREOTYPES - used by others erroneously - e.g. BPD pts felt that the gen population was unaware of the diagnosis, apart from "unsympathetic Hollywood portrayals; whilst BD appeared to have attracted both positive & negative stereotypes, BPD appeared to have attracted only negative ones e.g. "attention-seeker, manipulative, trouble-maker, dishonest, childlike, irresponsible, malingerers, untreatable, & pathologically violent/angry/confrontational"; however some BPD pts had positive experiences - no details given - and reportedly these Ss felt that there were no stereotypes related to BPD); POWERLESSNESS - E.g perception that as a patient they had little power to influence healthcare treatment and for those with BPD	transparency and coherence issues e.g. results not explained in depth in relation to their aims of examining the experiences of stigma/discrimination using the critical realism perspective; instead it criticises other studies' inability to do this; not clear why only 29 Ss chosen to do in-depth interviews and how they were chosen; reduced generalisability; unclear how diagnosis verified; unclear inclusion/exclusion criteria; Ss aware of the study's focus on stigma --> demand characteristics; ? characteristics of non-volunteers; lack of

							<p>diagnosis, they felt powerless to resist <b>EXCLUSION FROM TREATMENT, MARGINALISATION/DISCRIMINATION</b> - E.g. BPD pts felt that they were disempowered / their diagnosis was withheld from them --&gt; no access to treatment or they were told the diagnosis but were also told there was no treatment available (locally); Also described that the diagnosis was not explained appropriately to them and treatment was seen as too short-term and irregular and impersonal --&gt; disengagement from services. BPD pts who had experienced specialist PD interventions tended to be more positive about their experiences; <b>VIOLENCE</b> - many BPD pts reported having experienced physical and psych violence as a consequence of being pathologised or stereotyped by the healthcare system and their families; <b>STIGMA</b>. All Ss anticipated stigma &amp; discrimination and the majority experienced it; BD = mostly within employment, BPD = mostly within the healthcare system; Both groups experienced stigma within both of these system and also within family/friendships/neighbourhood/education/civil society relations</p>	<p>transparency and completeness in data analysis e.g. extracts without pseudonyms and page numbers; nevertheless - good points e.g. creating rationale for the theoretical approach; awareness of some limitations and critical thinking; importance of study</p>
Dunne & Rogers (UK) 2011	31 care-coordinators of Sus with the diagnosis of BPD;  36%	coordinators of 85 service users with BPD diagnosis	n/a	unknown;  unknown	questionnaire	none	<p>4 themes: shared decision making, social roles, peer support &amp; open communication; general finding: standards put forward by NICE for BPD were not being met by care coordinators</p>	<p>identification of Ss with BPD diagnosis based on ePJS system (possibly an underrepresentation of the real sample of BPD within that trust); small response rate; questionnaire design --?</p>

								demand characteristics & response bias; no descriptive stats for the responding care coordinators; whilst some limitations acknowledged, others were missed by the authors
Dunne & Rogers (UK) 2013	8 carers (8 in first focus group; 5 in the second focus group);  unknown	community PD service	n/a	unknown;  unknown	2 focus groups (1 - role of MH services; 2 - experiences in the community)	n/a	10 themes: carers' needs (not knowing what BPD was; not having successful carers' assessment; not being given understanding about possible financial support; interest in option of respite but unclear over whether they would be granted it; no carers' group for PD); CPA (tick boxing exercise); MH services (lack of understanding by staff e.g. oh, it's just his/her beh; MH tel lines - both helpful and unhelpful; specialist service for PD given positive feedback; questions regarding crisis accommodation); SU & carer rel (stressful role; wanting more information on how to deal with it); support (on-line support; but no other support available); life changing (as a result of becoming a carer); financial (unable to work); accessing information (not enough information about services available for carers); professionals' awareness of carers (carers overlooked and un-involved by MH professionals); understanding PD (lack of understanding by family/friends/wider public)	Inadequate descriptions of pts e.g. age, gender, whether the person they care for has a PD or BPD label; unknown details of those who didn't take part; poor sensitivity to context; lack of rigour and completeness (e.g. no summary of themes for each participant, no line numbers/pseudonyms); good points: attempts at minimising interpretative bias by using independent researchers, inter-rater reliability checks
Helleman et al. (Netherlands)	17; 62.96%	brief inpatient admission	yes	16 F & 1M; range =	semi-structured interviews	n/a	4 themes: (i) organization of the brief admission - e.g. conversation with the nurse at the start of the admission important; ability to call care co-	M v F ratio; specificity of the Dutch sample --> reduced

2014				28-59; mean = 42.1			ordinator important; (ii) quality of contact with a nurse affected the perceived quality of the admission; importance of active approach with the BPD Ss e.g. enquiring about feelings/wishes/etc and not expecting Ss to come to them necessarily; (iii) time out from daily life; and (iv) experienced value for the patient.	generalisability; interviewer - first author --> ?demonstration of possible bias and how this was dealt with? good point - sensitivity to context demonstrated by e.g. using interview methodology which encourages 'bracketing'; rigour and completeness demonstrated in detailing the process of analysis; inclusion criteria specified; awareness of limitations
Lam, Salkovskis, & Hogg (UK) 2015	265; unknown	CMHTs	n/a	170 F & 95 M; range = 20 - 60; mean = 38.8	Clinical Assessment Questionnaire (to elicit attitudes) pre/post viewing a video	yes (Ss provided with only background clin and family info)	BPD label was associated with more negative ratings of the SU's problems and her prognosis than both information alone and a beh description of 'BPD symptoms' --> diagnostic label can have a negative effect on judgments; more negative than beh descriptions of clin presentation	Negative points: overrepresentations of Fs; unsure how equal/unequal the diff conditions were e.g. age, gender, occupation; positive points: randomised allocation; control condition; well described study; large sample
Lovell & Hardy (UK) 2014	8; 66.66%	forensic setting (private secure)	yes	8 F & 0 M; 24-55	semi-structured interviews; Depression	n/a	4 themes: IDENTITY (all Ss; also evidence of polarity = either BPD was accepted as their identity); POWER (all Ss = oscillation between perceiving the power of others over their lives	heterogeneity of sample --> against IPA; credibility ? --> interview schedule not

		units)			Anxiety Stress Scale (DASS-21, Lovibond and Lovibond)		and attempts at gaining power by e.g. keeping up a front, remaining distinct from others, acts of DSH --> confusion in experiences), PROTECTION & CONTAINMENT (all Ss = Oscillation b/w needing others to protect them and relying on themselves b/c of lack of trust in others --> confusion; ways of protection included detachment from others and DSH to stop them from committing more serious harm to themselves), and CONFUSION (7 Ss = confusion about articulating their experiences; unsure about future, unsure about identity, self harm). The themes of identity, power and protection and containment represented polarised positions which in turn contributed to the theme of confusion. Clinical implication = to explore meaning of BPD diagnosis with clients; meaning is unlikely to be black and white/clear-cut (diagnosis is both + and -) --> the diagnosis will have an impact on identity and work to balance power differentials; power struggle (e.g. "manipulative" beh) might be seen more as an attempt at regaining a sense of self-agency	available; good points: limitations acknowledged (heterogeneous sample); inclusion criteria given; rationale for IPA use given; author's theoretical stance on interpretation of data; transparency & reflexivity demonstrated e.g. using research diary, revisiting original transcript at the end of analysis, researcher showed awareness of own background and theoretical stance and their potential impact on the study; sensitivity to forensic context
Morris et al. (UK) 2014	9; unknown	adult MH services	yes	7 F & 2 M; 31-47	semi-structured / thematic analysis	n/a	3 themes - a) diagnostic process influences how service users think about BPD (e.g. optimism, sensitivity, opportunity for discussion); b) non-caring care (let down by services withdrawing, reactive rather than proactive, discharged by therapist b/c of being too risky; following diagnosis perceived as difficult rather than unwell or distressed; psychotic experiences no longer viewed as genuine); c) it's all about the relationship (positive experiences - person-centred care; active listening; negative	inclusion criterion - "significant" period of contact with adult MH services - ? how is this evaluated; reliance on self-reports of BPD diagnosis; other axis II and also axis I disorders reported by the interviewees (although this is expected for

							experiences - criticised, blamed, little interest in listening, focus on co-ordinating care; struggling to open up for fears of abandonment and rejection if care withdrawn).	those with the BPD diagnosis, it is problematic); good points: SUs consulted on the interview material; attempts to increase the validity of the study by e.g. using reflective diary; inter-rater checking; using negative cases; attempt to get feedback from Ss
Richardson & Tracy (UK) 2015	8; 53.33%	secondary MH services	yes	8 F & 0 M;  range = 27-56; median = 35	semi-structured interviews	n/a	6 themes: public information on illnesses (described knowing more about BPAD than BPD & never having heard of BPD prior to being diagnosed; confusion with BD); delivery of the diagnosis (not one S wanted to be diagnosed with BPAD; not given enough time to ask questions, talk through what it meant to have BPD diagnosis; all 8 stated that they felt a sense of relief when BPD was explained properly to them); illness causes (BPD perceived more nurture; BPAD more nature); illness management (BPAD = seen medication to be more appropriate; BPD = frustration that medication was primary treatment option); stigma and blame (All felt that all MIs were subject to stigma; 4 described BPD label as stigmatising; BPD = seen as creator of their problems whilst BPAD = seen more as a victim); and relationships with others (BPAD seen as more easily conceived from others)	transparency poor e.g. quotes without pseudonyms/line nr, interviews conducted by both researchers --> how did they demonstrate awareness of a potential bias?; unknown characteristics of non-respondents --> selection bias; good points: high study relevance as found a gap in research; sensitivity to research (previous research shaped interview questions)
Rogers & Acton (UK)	7;	specialist PD service	yes	6 F & 1 M;	semi-structured	n/a	Themes: staff knowledge and attitudes (negative attitudes and lack of knowledge about BPD),	unknown response rate --> selection bias?;

2012	unknown			21-43	interviews		lack of resources for BPD (Lack of knowledge - -> Ss feeling let down and rejected and feeling that it was their fault that the medication was not working; also overemphasis on the use of medication; generally reporting that the specialist service provided a positive change and was more helpful to the SS)and the recovery pathway for BPD (Ss felt the need to be involved in decisions about their care & whether they wanted medication or not). Overall, p felt that BPD diagnosis had had a negative impact on their care, with staff either refusing treatment or focusing on medication as a treatment option; this research found that despite NICE guidelines, medication continues to be the primary treatment of choice/rather than psych therapies	researcher a member of the team (although not involved in care co- ordination of the Ss); nevertheless - attempts at increasing quality of research by e.g. triangulation, demonstrating sensitivity to the professional's impact on the research, taking measures to minimise interpretation biases
Rogers & Dunne (UK) 2011	10; 15.38%	acute inpatient admissions	yes	9 F & 1 M; 21-45	focus group	n/a	5 themes: practicalities of ward life; having a voice; revolving door patients; the power of sectioning and the 'PD' label.	only included Ss with a BPD diagnosis - limited generalisability; small response rate and unknown characteristics of those who declined -- > sampling bias; unsure how many with BPD diagnosis/other PD diagnoses --> not in line with study aims; poor rigour in analysis - not enough information to evaluate completeness, transparency, coherence of data analysis; good



								points - group facilitators were ex-service users with experience of running focus groups; % of inter-rater reliability demonstrated to reduce bias in data analysis; some limitations acknowledged
Wehne-Alamah & Wolgamott (USA) 2014	1109 postings; unknown	general population	unknown	unknown; unknown	1109 blogs	n/a	4 themes: (a) a reliance on online blogging to cope; (b) a quality of life that is impacted by debilitating effects of condition; (c) coping mechanisms that encompass healthy and destructive measures; and (d) social injustices that include stigmatization & prejudice (from gen public and health-care professionals), delayed diagnosis (e.g. wish that the diagnosis was given to them earlier on), misdiagnosis (of depression), limited healthcare access (described by many; especially access to specialist support which could facilitate early & accurate diagnosis & treatment), and being desperate for a 'cure').	lack of clear rationale & aims; self-reports; analysis of blog postings; not enough data on data analysis (how the analysis proceeded and how data were collected); lack of reflexivity and demonstration of steps taken to maximise the quality of the research; no details of literature review strategy
Lawn & McMahon (Australia) 2015a	153; unknown	general population	self-reported	87.8% F & 12.2% M; range = <18-65+	specific survey developed by the Private MH Consumer Carer Network	n/a	results indicate ongoing discrimination when in contact with MH professionals, including refusal of hospital admission during crisis and unresponsiveness of professionals during crisis, and blasé response to self-harm at emergency departments	negative points: using self-report measures --> response bias; unknown reliability & validity of the questionnaire; missing data/incomplete questionnaires; no measures taken to guard against Type I error due

								to the multiple comparisons; unknown response rate; overrepresentations of female respondents and those living in rural areas
Lawn & McMahon (Australia) 2015b	121; unknown	general population	n/a	78F & 24M; range = 18-65+	specific survey developed by the Private MH Consumer Carer Network	n/a	family carers reported experiences of significant exclusion and discrimination when attempting to interact with generalist health and MH services (e.g. lack of explanations of BPD diagnosis; lack of choice of services and support services; lack of involvement in decision making); authors urged further education and importance of carers having access to specialist support	negative points: using self-report measures --> response bias; unknown reliability & validity of the questionnaire; missing data/incomplete questionnaires (60% completed all questions); no measures taken to guard against Type I error due to the multiple comparisons; unknown response rate; overrepresentations of those from rural areas and of female respondents; difficult to ascertain the degree to which the data reflect the respondents' current/recent experiences with services; difficult to establish the degree to which the data reflect the SUs current/recent

								experiences as over 50% of respondents reported BPD diagnosis was given in the past 5 years
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\* Generic guidelines used in the evaluation of the research quality:

a) qualitative research = using Yardley (2000)

b) quantitative research = using Critical Appraisal Skills Programme (2013)

## Appendix G: NHS participant information sheet

### Information about the research

#### **How do people diagnosed with Borderline Personality Disorder experience the diagnostic process?**

Hello. My name is Zuzana Winter and I am a Trainee Clinical Psychologist at Canterbury Christ Church University. I would like to invite you to take part in a research study. This study has been reviewed and approved by [REDACTED] Research Ethics Committee.

Before you decide it is important that you understand why the research is being done and what it would involve for you.

I would like to encourage you to take time to read the following information, think about the study and perhaps even talk it over with others before you decide whether to take part in it. If there is anything that is not clear or if you would like more information, do not hesitate to contact me; you can find my details at the end of the information sheet.

#### **What is the purpose of the study?**

The purpose of the study is to interview people with a recent diagnosis of borderline personality disorder (BPD) about their experiences of the diagnostic process. There is relatively little research in this area but the existing research findings suggest people's experiences are mixed.

It is hoped the study will offer insight into people's experiences of the diagnostic process of BPD. The information gained from this research will be used to make recommendations for best clinical practice to improve experiences of people with the diagnosis of BPD.

#### **Why have I been invited?**

I understand that you have been given a diagnosis of BPD. I am interested in hearing about people's experiences of this and would like to hear about how the process went for you.

The study will involve up to twelve participants with a recent diagnosis of BPD, who will be all interviewed separately.

#### **Do I have to take part?**

It is entirely up to you to decide to join the study. If you agree to take part, I will then ask you to sign a consent form. The original signed consent form will stay with me and you will receive a copy of the signed consent form. You are free to withdraw at

any time without giving a reason. A decision not to take part will not affect in any way the standard of care you receive.

### **What will happen to me if I take part?**

If you decide to take part in the study, I will organize a one-off meeting with you at a time and location convenient to you. The meeting will last between 60 to 90 minutes. There will be an opportunity for a break during this time.

The meeting will take a form of a semi-structured interview, which means I will have a few questions prepared beforehand to keep us focused on the research question. It will be an opportunity for you to tell me about your experiences of being diagnosed with BPD and aspects related to this experience. The interview will be fairly informal with the aim being to help me learn about your experiences, good or bad. After the interview, I would like to arrange to meet with you once more in order for us to share our experiences of the interview. This will also be a good opportunity to discuss the overall findings of the research and how the findings relate to your experiences.

### **What are the possible disadvantages and risks of taking part?**

Talking about your experiences with the diagnostic process and issues related to it may be upsetting for you. You are free to pause or stop the interview at any time if you do not wish it to continue by signalling using a hand gesture or another appropriate signal which we can agree on beforehand. If you choose to opt out of the interview or after you have completed the interview, there will be an opportunity for you to discuss the interview and/or any concerns you might have either with me or with a member of staff that you would have nominated prior to taking part in the research. I will discuss this aspect of the interview thoroughly before we commence the interview.

### **What are the possible benefits of taking part?**

I cannot promise the study will help you but information obtained from this study might help us improve the process by which people are given their diagnosis of BPD.

### **What will happen with the information that is collected?**

The interview will be audio-taped so that an accurate record of your story is retained. The data will then be transcribed onto a computer. The audio recording will be anonymised to ensure confidentiality. All identifiable information, potentially revealed in the process of the interview will be removed. The audio tapes will be securely stored in a locked location at all times. They will be destroyed at the end of the study. All electronic data will be password protected.

The data will be reviewed and analysed by myself. Anonymous quotations from the interview might be used in the study. At the end of the study, I will write a report about the results, present the data at a research meeting with other service users and also at research conferences. It is hoped the results will be published in a peer reviewed journal. The anonymous records of each interview will be stored for 10 years at Canterbury Christ Church University. It is possible that an examiner for my research project might wish to look into one transcript from the interviews in order to check that I have reported accurately on the content of the interviews I conduct.

### **Will my taking part in the study be kept confidential?**

Throughout the study, I will follow ethical and legal practice and all information about you will be handled in utmost confidence. If you decide to take part, you will be identifiable only by a code number or false name(s). You can request a copy of the interview transcript if you wish. No research participant will be identifiable from the publication or in any of the other stages of research dissemination. The only time I would pass on information from your interview to another person is if I felt concerned for the safety of yourself or someone else as a result of something you say in the interview. If this happened I would discuss it with you first if possible.

### **Expenses and payments**

Unfortunately, there will be no monetary reimbursements for your participation in the study. However, travel expenses of up to £10 will be reimbursed if you have to travel to the interview.

### **What if there is a problem?**

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

This completes part 1.

*If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.*

## **Part 2 of the information sheet**

### **What will happen if I don't want to carry on with the study?**

You are free to withdraw at any time without giving a reason. A decision not to take part will not affect in any way the standard of care you receive. If you decide to withdraw from the study, I would like to use the data that is collected up to time of your withdrawal.

### **What if there is a problem?**

If you have a concern about any aspect of this study, you could ask to speak to me and I will do my best to address your concerns. Alternatively, you could speak to the Research Director at my University (details provided below). If you remain unhappy and wish to complain formally, you can complain to the Complaints Department, [REDACTED] NHS Foundation Trust.

### **Contact details for making a complaint:**

#### **My contact details:**

Address: [REDACTED]

Tel: [REDACTED] (a 24-hour voicemail service). Please ensure you say the

message is for me [REDACTED] and leave your contact number.

**Contact details of the research director at my university:**

Address:

[REDACTED]

**[REDACTED] NHS Foundation Trust**

Address: **Head of Complaints**

**[REDACTED] NHS Foundation Trust**

[REDACTED]

Tel:

Fax:

Email:

[REDACTED]

**Will my taking part in this study be kept confidential?**

Throughout the study, I will follow ethical and legal practice and all information about you will be handled in utmost confidence. If you decide to take part, you will be identifiable only by a code number or false name(s). You can request a copy of the interview transcript if you wish. No research participant will be identifiable from the publication or in any of the other stages of research dissemination.

The interview will be audio-taped so that an accurate record of your story is retained. The data will then be transcribed onto a computer. The audio recording will be transcribed and anonymised to ensure confidentiality. The audio tapes will be destroyed after they are transcribed into a written format. The transcriptions of the tapes will be securely stored in a locked location at all times. They will be destroyed after the completion of the study. All electronic data will be password protected. The data will be reviewed by myself and analysed by myself. Anonymous citations from the interview might be used in the study.

**Involvement of the General Practitioner/Family doctor (GP)**

The involvement of your GP is not required for the study. However, if you would like your GP to be informed of your involvement, you can do so by indicating your agreement when signing the consent form.

**What will happen to the results of the research study?**

At the end of the study, I will write a report about the results, present the data at a research meeting with other service users and also at research conferences. It is hoped the results will be published in a peer reviewed journal. As mentioned above, anonymous citations from the interview might be used in the study. I can provide you with a summary of the results, which will be likely to be available after the completion of the study, if you indicate to me at the time of interview that you would like this.

**Who is organising and funding the research?**

Canterbury Christ Church University.

**Who has reviewed the study?**

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the [REDACTED] Research Ethics Committee.

**Thank you for taking the time to read this information sheet****Further information and contact details**

If you would like to speak to me and find out more about the study or have questions about it answered, you can leave a message for me on a 24-hour voicemail phone line at [REDACTED].

Please say that the message is for me [Zuzana Winter] and leave a contact number so that I can get back to you.



## Appendix H: Participant consent form

Centre Number: 01

Study Number: [REDACTED]

Participant Identification Number for this study:

### CONSENT FORM

Title: *How do people diagnosed with Borderline Personality Disorder experience the diagnostic process?*

Name of Researcher: *Zuzana Winter*

Please initial box

1. I confirm that I have read and understand the information sheet dated.....  
(version 2.0) for the above study. I have had the opportunity to consider the information,  
ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time  
before data is analysed without giving any reason, without my medical care or legal  
rights being affected.
3. I agree for the interview to be audio-taped and for the data to be transcribed onto a  
computer.
4. I agree that anonymous quotes from my interview may be used in published reports of  
the study findings.
5. I agree to take part in the above study.
6. I would like to be kept informed of the results of the study.
7. **I would like my GP to be informed of my involvement in the study.**

Name of Participant \_\_\_\_\_ Date \_\_\_\_\_

Signature \_\_\_\_\_

Name of Person taking consent \_\_\_\_\_ Date \_\_\_\_\_

Signature \_\_\_\_\_

## Appendix I: GP information letter

Zuzana Winter



Date:

Dear Dr [INSERT SURNAME],

**Re: [INSERT PATIENT NAME, SURNAME, AND ADDRESS]**

**Study Title: How do people with the diagnosis of Borderline Personality Disorder experience the diagnostic process?**

**REC reference: [REDACTED]**

I am writing to inform you that your patient, [INSERT TITLE, NAME, AND SURNAME], has agreed to take part in the above research study. This study has been reviewed and approved by the [REDACTED] Research Ethics Committee.

The purpose of the study is to interview people with a recent diagnosis of borderline personality disorder (BPD) about their experiences of the diagnostic process. There is relatively little research done in this area, with mixed results. It is hoped the study will offer insight into people's experiences of the diagnostic process of BPD. Furthermore, it is hoped this information will ultimately be used to make recommendations for best clinical practice to improve experiences of people with the diagnosis of BPD.

The interview, which will last between 60 to 90 minutes, will be audio-taped and transcribed for the purpose of qualitative statistical analysis. Following the analysis, participants will be invited to meet with the researcher (myself) to share the themes identified in the analysis. Those choosing to take part in commenting on themes will be in the project for up to a year but direct involvement time will be less than five hours.

At the end of the study, the findings will be written up in a report, and disseminated at a service-user led research meeting as well as at various research conferences. It is hoped the results will be published in a peer reviewed journal.

If you have any questions regarding any of the above, please feel free to contact me on [REDACTED] (a 24-hour voicemail service).

Yours sincerely,

*Zuzana Winter*  
*Trainee Clinical Psychologist*

### Appendix J: Interview schedule

Area	Interview questions & probing questions
<b>Original diagnostic process</b>	<ul style="list-style-type: none"> <li>• When/How were you told for the first time you had BPD?</li> <li>• What was it like to be told for the first time you had BPD?               <ul style="list-style-type: none"> <li>- What was it like being in the room in that moment and hearing the other person talk?</li> <li>- Can you tell me how the meeting finished? And what happened immediately afterwards?</li> </ul> </li> <li>• If not told explicitly (but heard it indirectly/read it in the letter etc.), how did this come about?</li> </ul>
<b>Impact of diagnostic process</b>	<ul style="list-style-type: none"> <li>• What did you think (make) about THE WAY you were told about your diagnosis?               <ul style="list-style-type: none"> <li>- What was your first reaction after you were told/read/heard about it?</li> <li>- What was going through your mind?</li> <li>- If vague response, e.g. I don't know/can't remember, then.. Have you thought about the meeting since? What would you make of the way you were told about the BPD diagnosis now?</li> </ul> </li> <li>• Could you describe how this experience affected you?               <ul style="list-style-type: none"> <li>- if vague ask about (relationships, future, outlook)</li> </ul> </li> <li>• What was life like at the time? (at the time of being given the diagnosis)               <ul style="list-style-type: none"> <li>- e.g. life outside the hospital, home life, social life</li> </ul> </li> </ul>
<b>Changes to diagnostic process</b>	<ul style="list-style-type: none"> <li>• Based on your experience of being about BPD diagnosis, do you think there might have been a different (better) way of being told about the diagnosis?</li> <li>• What would it look like?</li> </ul>

**Appendix K: Coded interview transcript**

This has been removed from the electronic copy.

**Appendix L: Identifying master themes (paper cuts example)**





## Appendix N: Theme development process

Number	Master theme / super-ordinate theme	Frequency	Candidate	Contrasting theme	Frequency	Candidate
<b>1</b>	<b>AN ANSWER WITH A QUESTION</b>	<b>8</b>				
<b>1a</b>	<b>PS - YOU'VE GOT BPD</b>	<b>6</b>	1, 2, 5, 6, 7, 8	<b>IT WAS OKAY HOW I WAS TOLD</b>	<b>2</b>	
	A dishonest fob-off	6	1, 2, 5, 6, 7, 8	BPD kind of fitted me straightaway (positive experience)	1	3
<b>1b</b>	<b>YOU CAN'T ARGUE AGAINST IT</b>	<b>6</b>	1, 2, 4, 6, 7, 8	What about emotional neglect though?!		4
	A cocktail of emotions	5	1, 2, 5, 6, 7			
<b>1c</b>	<b>HERE WE GO AGAIN...</b>	<b>5</b>	1, 5, 6, 7, 8			
<b>2</b>	<b>IF ONLY...</b>	<b>7</b>				
<b>2a</b>	<b>... IT WAS DONE DIFFERENTLY</b>	<b>7</b>	1, 2, 4, 5, 6, 7, 8	It was done right the first time	1	3
<b>2b</b>	<b>... IT WAS DONE YEARS AGO</b>	<b>5</b>	1, 4, 5, 7, 8			
<b>3</b>	<b>BPD LIKE A STAR SIGN</b>	<b>8</b>				
<b>3A</b>	<b>A SCARY STAR SIGN THAT FITS</b>	<b>8</b>	1, 2, 3, 4, 5, 6, 7, 8	Positive experience of having a MH diagnosis	1	3
	It fits	8	1, 2, 3, 4, 5, 6, 7, 8			
	It's scary	4	2, 5, 7, 8			
<b>3B</b>	<b>A STAR SIGN THAT FITS ANYONE</b>	<b>6</b>	1, 2, 4, 5, 6, 7			
<b>3C</b>	<b>IN THE END, ALL THEY SEE IS YOUR STAR SIGN</b>	<b>6</b>	1, 4, 5, 6, 7, 8			
<b>3D</b>	<b>IT TAKES AN ASTROLOGIST TO GET IT</b>	<b>6</b>	1, 2, 4, 5, 6, 8			
<b>4</b>	<b>STAR SIGNS ARE NOT ENOUGH; IT'S WHAT HAPPENS AFTERWARDS!</b>	<b>8</b>				
<b>4A</b>	<b>MAGIC PILLS WON'T FIX ME</b>	<b>6</b>	1, 3, 4, 5, 7, 8			
<b>4B</b>	<b>THERAPY CHANGED MY LIFE</b>	<b>7</b>	1, 2, 3, 4, 5, 7, 8	<b>THINGS HAVE BEEN A STRUGGLE</b>	<b>5</b>	
	It saved my life	5	3, 4, 5, 7, 8	Groups - I didn't fit in	3	3, 5, 7
	Finally, I wasn't alone	6	1, 2, 3, 4, 5, 8	I'm still struggling	2	2, 6
	Finally, a new perspective	6	1, 2, 3, 4, 5, 8	I don't know what the future holds	3	2, 5, 6
	Finally, I have a future	4	1, 3, 4, 8			
<b>5</b>	<b>BEING AT THE MERCY OF THE SYSTEM</b>	<b>8</b>				
<b>5A</b>	<b>YOU TAKE WHAT YOU'RE GIVEN</b>	<b>8</b>	1, 2, 4, 5, 6, 7, 8	Positive experience of inpatients	<b>1</b>	3
<b>5B</b>	<b>THE MENTAL HEALTH MIGRANT - CAN ANYONE HELP?</b>	<b>6</b>	1, 4, 5, 6, 7, 8	They're not all bad	<b>7</b>	1, 3, 4, 5, 6, 7, 8



## Appendix O: List of additional quotes

**Answer with a question mark:** PS: You've got BPD

*"Oh, I think it might be (...) what we called Borderline Personality Disorder. Here's a piece of paper" and that was sort of it. It wasn't, "I am dising\*, diagnosing you with; these are the symptoms, this is what we can do". It was sort of, "Well, it might be this, read this bit of paper and we'll, you know, we'll come back to it next time". And then in the, the GP report it definitely says "suffering from" and yeah (Megan, 6, 216)*

*"I don't think, I was actually told verbally . . . I think, the first time I found out was, you know when those letters that psychiatry sort of team of doctors sends to your GP" (Gwen, 2, 5).*

*And I bumped into X [name of therapist] into the reception and I said "Look, I'm just really upset, I'm not liking what's been like chosen for me", erm, and then, she then agreed to make an appointment for me to come in and see her and that's when I think she sort of said like, "Ok, this is the situation and we can put you on a Borderline Personality Disorder group" (Michaela, 4, 114).*

*"You have this, you have this, erm, off you go" sort of thing (hm). And that's basically what it was (hm). I was given the leaflet and like "Right, see you later" sort of thing. I was like, "ok" {smirks sarcastically} (Roxy 5, 180).*

**Answer with a question mark:** You can't argue against it

*Yeah, it was anger, and it was just, just the fact it felt like, it just feels like the psychiatrists don't really wanna talk what they're thinking of through with you properly. They don't mind dictating it to someone else to put on a bit of paper to post to you though but they won't sit there face to face and talk it through with you which is kind' a crazy (Gwen, 7, 273)*

*"Okay, you're giving me a new diagnosis, telling me I'm not . . . Bipolar but now you're actually telling me in a way that it is still my fault for being a cannabis user and"* (Eve, 4, 136)

*It was good to kind of know that, I don't know really, like I already knew I had it kind of thing, but it was nice to have it sort of confirmed. But at the same time it annoyed me cause of all the other crap that's written on there (Gwen, 21, 948).*

**Answer with a question mark:** Here we go again...

*It feels like a big let-down and again I was NEVER told that he thought I had postnatal depression. It was, "Have these anti-depressants and go away" rather than, "Ok postnatal depression, it involves this and this"* (Megan , 9, 348).

*"Same when I was diagnosed with PTSD, I was like, "Well, why do you think that, what's your reasons?""* (Michaela, 5, 146).

*I didn't FEEL with that particular doctor that she listened to me very much at all whenever I saw her (...) so I just {smirks as she speaks} felt just as disappointed as I had whenever I'd seen her before just as not listened to and brushed away ( Yvette, 4, 113).*

**If only...:** It was done differently

*As I'm coming more to terms with that I'm starting to realise that actually I haven't been given a lot of information, I haven't been given a chance really to explore that with a doctor. (...) I find, I think NOW I find that quite frustrating I think because you know, if you have a chance to discuss it and apply to yourself then it's easier to accept and start putting, throwing yourself wholeheartedly into what treatment options you've been given (Megan, 13, 515).*

*"I think because of the lack of information I was given initially with the Borderline diagnosis ... Erm, it wasn't explained to me about sort of emotional neglect" (Eve, 3, 81).*

*"I would probably say more information, a bit more time (hm). Make it a bit more personal (hm) not just ticking boxes because it doesn't, it annoys you" (Roxy, 27, 1222)*

**If only...:** It was done years ago

*I think . . if, IF I'd been given a dig-+ diagnosis, that diagnosis at that time . . if it had been explained to me and, and MASSIVELY if I'd got therapy for it I may not have ended up in hospital (Yvette, 27, 1163).*

*"The way I see it is if I was given this help 15 years ago I wouldn't have, well, I didn't live the last 15 years, literally" (Eve, 6, 217).*

*"Yeah, could have been done ten years ago {laughs}. I could be a psychologist by now, you never know" (Gwen, 26, 1220).*

*"Maybe the BPD thing has to be, maybe the first thing people do before as a last resort, because otherwise it's not as helpful" (Michaela, 24, 1042).*

**BPD like a star sign:** A scary star sign that fits

I think it was good to know what was wrong when you was wondering what was wrong . . . cause I thought everything, like, my life was great. So I thought when I ended there [psychiatric unit], and ended up there and they *were saying all this I thought*, “*Well, at least I know what’s wrong now*” (Rosie, 5, 192).

*So, yeah, I was confused before, erm {clears her throat} getting the diagnosis. I’m still confused but in a different way but at the same time, like I say, was kind of thinking, “Well, at least I might have answers soon. Might have an answer to why I’m the way I am”* (Michaela, 9, 337).

*“NOW it feels nice to know that I’m not Bipolar and it feels nice to know, not that you could ever want to be Borderline, but it’s quite comforting. Erm, I find it quite comforting diagnosis these days”* (Eve, 10, 438).

I say, I switched off from it, which I probably do well, switching off of things, But I think, still there (um hmm), it was *nagging, obviously*, “*Hm, BPD, flawed personality {laughs}*”, *it’s like, uhmmm (hmm). Yeah . . . suppose it does stay with you . . .* (P02, 2, 145).

**BPD like a star sign:** A star sign that fits anyone

*I’ve read all through these and I can remember saying, like, saying to my mum and to my ex-husband, saying, “BUT I DON’T HAVE THIS, I DON’T HAVE THIS”, “Look”, and I actually said to them, “Right, read through that and see which one that you feel I belong to.” And they read through and they actually kind of, they couldn’t see that I was actually fitted with any of those groups. It didn’t seem to . . . marry up* (P02, 2, 17).

*And because there's some parts of my personality that do meet the criteria of BPD I think it was just easy for them to follow the DSM and say, "Yes, yes, she's got five out of ten points, give her this." (hmm) . . . is how it seemed (Michaela, 3, 85).*

*And when I come out [of the assessment], I remember coming out of the room and they [other inpatients] were like "Let me guess, you have some sort of personality disorder" and I was like "How the hell do you know?" "Oh, we all get diagnosed with it" (Roxy, 26, 1146).*

*Well, there was stuff there about like excessive cannabis use cause I've used cannabis sort of quite a long time now and that's also another reason I felt they were blaming my being unwell on cannabis use when I knew personally that it wasn't due to that (I see) (...) I know that you can cause illness and I have become ill from smoking too much but I kind of know the signs now. So I don't smoke like that . . . (Gwen, 4, 142).*

*"Answer this set of questions, I will then diagnose you, prescribe you whatever and send you on your way until next time", so (uh-um) which is understandable, there's a lot of people to see same as, as GP, you know, it has to be done quickly, erm, but it kind of feels like a diagnosis is sort of well, "You meet most of these so we'll give you that one" rather than comprehensively and SLOWLY (Megan, 7, 258).*

**BPD like a star sign:** I'm more than just the star sign

*I think just like a lot of things, people, people just have it in their heads that like this person got BPD that means they're emotionally unstable, that means I can't trust them. Or they'll . . . be, erm, hot and cold with me and stuff like that (Yvette, 19, 786).*

*"They're coming from BPD stance they tend to sort of fit everything into the BPD (within that) diagnosis rather than (Um hmm) exploring the possibility that this might be, er, a bipolar situation" (Megan, 6, 187).*

*“Oh, you have this, here’s a leaflet and these are the drugs that I’m putting you on” and I’ve been on those drugs ever since. The levels have changed up and down but those are the ones I’ve been on (Roxy, 6, 201).*

He [a new psychiatrist] made quite an emphasis on the whole point that I thought that I was agitated purely because I had to wait in reception (Eve, 9, 369).

**BPD like a star sign:** It takes an astrologist to get it

*“With my own family they would, they could never understand that. They’d never give me the back up to say, “Well, actually no, it wasn’t necessarily right, erm, we can understand where you’re coming from”” (Eve, 6, 200).*

*I’ve explained it to some of my friends loads of times and they still don’t take it into account . . . So it’s kind of like they, they, I don’t know, they just don’t understand it cause it is a very hard topic to explain (Michaela, 19, 804).*

*Being fairly new to the workplace I wasn’t, you know, I didn’t know who I could trust and who, you know, I think with mental health, there’s always a lot of fear that people don’t believe you, you’re just making it up (Megan, 14, 576).*

**Star signs are not enough; it’s what happens afterwards!:** Magic pills won’t fix me

*I was really upset because they were just waving tablets under my nose and I said “I don’t wanna be on tablets, I wanna see what my mood is like without them now cause I’ve been on them for long (Michaela, 4, 110).*

*“I had, had help before and it hadn’t worked and I think it was the medication was wrong or they, I wasn’t getting the psychological help I NEEDED” (Rosie, 3, 93).*

*I wasn’t receiving any therapy or anything, I was just in, in the institution and I was on tablets which I believed at the time and, and still do they, they weren’t working, you know, erm, and instead of adjusting them they just kept putting the dose up (Yvette, 7, 259).*

*It’s [having BPD diagnosis] changed my personality in a way that drugs just wasn’t doing because whatever drugs I was given when Bipolar, erm, didn’t make a difference, they just didn’t allow me to do anything physically Erm, whereas being Borderline helped me see a lot of why I, I understood a lot of why I was doing things, the things I was doing, if that makes sense (Eve, 11, 446).*

**Star signs are not enough; it’s what happens afterwards!:** Therapy changed my life

*“I feel good now. I feel my life is good. I feel like . . . I’ve, I am better now. My, I’ve gone out of that stage of being ill now with a lot of help I had” (Rosie, 23, 1065).*

[Reply to a question about what made the difference in terms of help]. The therapy, *I’d say making the changes that I needed to make and you know, with my dog, getting the responsibility for something (...) being on the course and achieving what I wanna sort of see that I can maybe achieve, don’t know, achieve. So sort of turn a dream back into sort of a reality, really. Making it sort of happen (Gwen, 28, 1295).*

[Reply to a question what was helpful about having other people to speak to in group therapy] *Very helpful, very helpful because . . . you don’t feel like you’re on your own, you’re not the only person (uh huh) . . . dealing with it. It’s, it’s SO helpful. Cause otherwise you feel like you’re*

*really weird, you're really strange cause you've got these ideas, these thoughts. And all of a sudden it's like, "Other people are doing it as well"* (P02, 10, 425).

*"I thought, "I can't take this anymore!" I think that's why I used to harm myself. But I think once I've started getting the talking therapy then I was getting it all out of my head"* (Rosie, 24, 1111).

*Although I can understand or WHY I've done certain things in the past . . . {long pause} it's still . . . I'm still not happy that they . . . that I did them . . . But I can see now, possibly, why it wasn't my fault I suppose* (P02, 11, 472).

*I wanna try and push through and I'm gonna keep pushing through until I can't push through anymore. And at the moment it's working and it has worked for most of my life. Erm, you know and I, I do get bad days sometimes but then I think, well most people get bad days* (Roxy, 25, 1117).

**Being at the mercy of the system:** You take what you're given

*I'd been in and out of the mental health system for, since I was 11, roughly, on and off. Firstly, I was diagnosed with Depression and then through X [South London MH Trust] I was diagnosed as Bipolar for many years and medicated for Bipolar. Erm, but it didn't necessarily ring true with me because I was, I wasn't overly convinced that I was actually Bipolar* (Eve, 2, 4).

*The only good thing that's come out of it [crisis inpatient admission] is that whenever I do feel sad or suicidal the fear of going back to that place stops me . And it shouldn't BE really like that but that's what it is* (Roxy, 9, 359).



In and out of hospital, like I say. It felt like I was in *there for a few days. After a few days, I'd kind of wake up out of whatever, really bad sort of* crisis I was in and be so angry by what I saw around me that it would make them, felt like they needed to get me out of hospital to cover their arse because I saw *the shit that they do wrong in there and they didn't like that* (Gwen, 12, 492).

*I think that's the biggest difficulty for me, is having to, to work and I'm the only mother in there [group therapy] at the moment as well. So having those normal every day responsibilities that (...) everyone in the group doesn't have makes it a bit difficult to . . . validate myself* (P07, 19, 797).

**Being at the mercy of the system:** The MH migrant – can anyone help?

If you were to see any registrar or consultant you just sort of *nod and say "Yes, sir, no sir"* and accept what they say *{gently laughs}* and then come out and it takes a little time to sink in and think, *"Oh, I should have asked this" or "I should have said that"* (Megan, 7, 239).

*"I've only actually, like, thought about it NOW, I thought and how it happened. "What would have happened, what would they have done? Would they have just left me in the system [had I not pestered them]?"* (Michaela, 21, 884).

*I'm very grateful to the staff that helped me, you know, I had a lot of help with X [name of Psychologist] and X [name of another Psychologist]. If they hadn't been there then I wouldn't be here today. . So it's been a lot of help but I've had loads of people supporting me and staff at X [NHS respite centre for MH patients] were great as well, minus one* (Rosie, 23, 1074).

*“I got a lot more of the information and stuff that (...) from day treatment team and stuff but not through like the psychiatrists or the nurses or anything like that” (Gwen, 3, 57).*

*Felt fobbed many times and then felt like they’ve [NHS staff] actually done stuff to help and bend over backwards to get me some help. Erm, so sometimes, there’s good things about X [name of MH trust] and other times there’s not so much help (Michaela, 2, 13).*

*“It’s, I think it’s down to the person as well though isn’t it. You know, you could, . . because the doctors I’ve seen some of them are very different and will give the time . . but others won’t” (Yvette, 24, 1048).*

## Appendix P: Extracts from research diary

20<sup>th</sup> February 2012

Service user-led meeting – presented my research proposal. Very keen to hear their views on the project, its' presumed validity, ethical issues, and their views on the interview schedule. What an inspiring meeting; feel a lot more confident about the research. Really didn't appreciate just how important the psychoed experience had been for them. ? perhaps – recruit participants with psychoed experience ? Also, struck by the variety of diagnostic experiences and impressions of the diagnosis itself - ? how to reflect this in the interview schedule and in the inclusion criteria that I will be using?

12<sup>th</sup> June 2012

Just completed the bracketing interview with [REDACTED] [REDACTED]. I was so amazed to have identified some key potential biases e.g. why I selected the topic in the first place and the potential importance I ascribed to the value of 'good' diagnostic experience. I am determined to keep this in mind throughout the research.

16<sup>th</sup> October 2012

Started to familiarise myself with the IRAS application process; so much to do but think I can do this! Only two weeks before baby due – really wanna do as much now before the baby comes! Quite hard to keep motivated though...

9<sup>th</sup> December 2013

Getting ready for the NHS Ethics Panel meeting. I feel confident in the value of the research. Keep thinking back to the meeting with service users who felt there was a massive gap in research.

20<sup>th</sup> June 2014

Met with my first participant (pilot interview). What a relief; the interview questions seemed to work; hitting the mark. Following the interview, I felt that the first question (WHEN were you first told you had BPD should be kept and asked first; also felt that perhaps it would be useful to have some more opening questions for a "warm up" (e.g. involvement with the

service user led research group). A new question identified – “If not told directly,…” “How did this come about?”

10<sup>th</sup> July 2014

What an emotional reaction, in comparison to the previous interview. It seemed that the interview made [REDACTED] think for the first time about some of the impact of the diagnostic disclosure on her personal life. The interview questions appeared appropriate. The original question, “When were you first told…” worked well as the first interview question.

11<sup>th</sup> July 2014

Meeting with [REDACTED] [REDACTED]. Discussed the interviews and the pilot. I really tried to adhere to the IPA standards, whilst also getting a detailed account of the experiences that were addressing the research questions. It was a relief to learn that I could include the pilot interviews in the IPA.

17<sup>th</sup> July 2014

My first transcription of the first interview. Noticed that it felt difficult to summarise what was said without imposing / affecting what the person would have otherwise said. The question of the impact of the diagnostic experience on relationships seemed a bit difficult and perhaps unexpected for the participant; but she appeared to want to think about it.

?Appropriateness of the question?

26<sup>th</sup> August 2014

Interview with [REDACTED]. She came in with her father who was ready to come in with her. A sense of feeling overwhelmed and drained by the end of the interview. [REDACTED] was the first person who seemed to have had a completely different experience from the other interviewees. She seemed to have accepted the diagnosis straightaway. I was struck by the circumstances which had led to her being given the diagnosis and which seemed to have impacted the readiness with which she was able to just take the diagnosis on without a question (committing a crime → I’m a criminal; validation → I’m not a criminal; I’m just unwell). I was also struck by the completeness of the whole process which seemed so different from the experiences of the previous interviewees (being “ordered” to undergo psychological assessment and therapy → it was ‘properly done’; it felt comprehensive).

7<sup>th</sup> October 2014

Interviewed [REDACTED]. Struck by her willingness to help with the research; this very much mirrored the willingness of all of the other four participants. Is the diagnostic process important to them? Do they feel that things can improve?

13<sup>th</sup> October 2014

Just started my specialist placement in an MBT service for service users who had all been through the formal diagnostic process of BPD. I am interested to learn how/if in any way will this experience colour my own ideas about the diagnostic process/value of MBT/the use of BPD label.

21<sup>st</sup> November 2014

I am noticing my stance on the utility of BPD diagnosis and the value of having a comprehensive diagnostic dialogue are changing. I am quite surprised by this as initially, I saw BPD as a very wishy washy label and I couldn't quite see how BPD could represent a distinct category. I think I'm starting to understand the core difficulties of the service users who had been given the diagnosis much better now and I can see that perhaps the diagnosis is a much clearer entity.

18<sup>th</sup> December 2014

I've been doing some preliminary research reading on part A since May, hoping that I will soon be able to get to a point where the structure becomes clear. However, I am starting to feel increasingly concerned as the literature is not only extremely vast but the search terms which I had identified do not seem to work – there's more than 5,000 articles for each search with no way of narrowing it down. I'm starting to realise that I will have to combine more than 15 search terms in order to identify some studies. I am concerned that I'm running beyond schedule.

17<sup>th</sup> March 2015

Have analysed six interviews. It is very difficult to know where the analysis is heading and how I will combine all the themes in a way that will still maintain the originality of the

interviewee's experiences. I'm noticing that I'm finding it difficult to move to a more abstract level of analysis. I read this is a normal stage ... hopefully I will get past it.

7<sup>th</sup> August 2015

Finally, the stage that I've been anticipating. I managed to put all the themes together and write the results section. It feels like a great achievement and actually I feel a lot more confident in the authenticity of my data. Nevertheless, I noticed that I've been very conscious to read and re-read the original transcripts alongside the newly arrived master themes and kept switching constantly between them. It still feels difficult to know when enough [abstraction] is enough. I do feel though that I was able to achieve the continuity between the individual experience and the overriding message.

8<sup>th</sup> September 2015

What a relief; [REDACTED] supervisor gave me some feedback on part B. It seems that the analysis was appropriate and in keeping with IPA as were the other parts of the report.

### **Appendix Q: Audit trail process**

The following documents were reviewed by the research supervisor:

- 1) Two annotated interview transcripts complete with exploratory comments and emerging themes.
- 2) Two excel spreadsheets listing the superordinate themes for the two respective participants together with all equations identified for each theme.
- 3) Theme process development table with the final themes for all participants.

The above documents were discussed in three individual meetings with the research supervisor. Based on the supervisor's feedback, the author regrouped and renamed some of the themes in order to avoid overlap between the themes and to provide themes' names which were not too abstract whilst retaining the originality of the raw data.

## Appendix R: NRES End of study form

### DECLARATION OF THE END OF A STUDY

(For all studies except clinical trials of investigational medicinal products)

*To be completed in typescript by the Chief Investigator and submitted to the Research Ethics Committee (REC) that gave a favourable opinion of the research within 90 days of the conclusion of the study or within 15 days of early termination.*

*For questions with Yes/No options please indicate answer in bold type.*

#### 1. Details of Chief Investigator

Name:	<b>Zuzana Winter</b>
Address:	[REDACTED]
Telephone:	[REDACTED]
Email:	[REDACTED]
Fax:	<b>n/a</b>

#### 2. Details of study

Full title of study:	<b>How do people with the diagnosis of borderline personality disorder experience the diagnostic process</b>
Research sponsor:	[REDACTED]
Name of REC:	<b>NRES Committee</b> [REDACTED]
REC reference number:	[REDACTED]

#### 3. Study duration

Date study commenced:	<b>13/02/2014</b>
Date study ended:	<b>05/02/2016</b>
Did this study terminate prematurely?	<b>No</b> <i>If yes, please complete sections 4, 5, 6, &amp; 7. If no, please go direct to section 8.</i>



#### 4. Recruitment

Number of participants recruited	n/a
Proposed number of participants to be recruited at the start of the study	n/a
If different, please state the reason or this	n/a

#### 5. Circumstances of early termination

What is the justification for this early termination?	n/a
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#### 6. Temporary halt

Is this a temporary halt to the study?	n/a
If yes, what is the justification for temporarily halting the study? When do you expect the study to re-start?	<i>e.g. Safety, difficulties recruiting participants, trial has not commenced, other reasons.</i>

#### 7. Potential implications for research participants

Are there any potential implications for research participants as a result of terminating/halting the study prematurely? Please describe the steps taken to address them.	n/a
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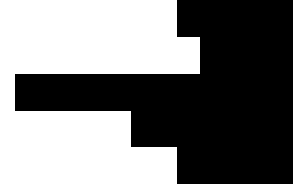
#### 8. Final report on the research

Is a summary of the final report on the research enclosed with this form?	<b>Yes</b> <i>If no, please forward within 12 months of the end of the study.</i>
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**9. Declaration**

Signature of Chief Investigator:	
Print name:	
Date of submission:	

**Appendix S: Provisional research summary for  
a) Ethics Panel and b) Research and Development**



Date

Dear [REDACTED],

**END OF STUDY NOTIFICATION**

**Study title:** How do people with the diagnosis of Borderline Personality Disorder experience the diagnostic process?

**REC reference:** [REDACTED]

**Protocol number:** [REDACTED]

**IRAS project ID:** [REDACTED]

I am writing to inform you of the completion of my project: “How do people with the diagnosis of Borderline Personality Disorder experience the diagnostic process?”

**Background and aim:** Contrary to the long-held assumptions, BPD is now considered a treatable disorder. Timely assessment has been recognised as one of the key treatment enablers and basic assessment standards have been stipulated by the UK’s National Institute for Health and Clinical Excellence (NICE). The current study was the first to have specifically investigated the quality of the diagnostic process in light of the government recommendations.

**Methods:** Interpretative phenomenological analysis was used to analyse semi-structured interviews with eight adult female service users about their lived experiences with the original diagnostic disclosure of BPD.

**Findings:** The following five master themes featured in the majority of the participants' experience:

**a) Answer with a question mark**

The diagnostic practices described by most participants appeared largely negative. Most participants reported conflicting reactions to the way BPD diagnosis was first shared with them. Whilst providing some answers and a sense of validation, the diagnostic experience appeared for many to be a source of further confusion, anxiety, and uncertainty.

A minority of positive views were noted which were indicative of a comprehensive and well-managed assessment, where time was taken to explain and discuss BPD in an honest and collaborative way and where a clear action plan or referral to appropriate psychological service was promptly made.

**b) If only...**

Whilst most participants perceived the diagnostic process as flawed, many expressed a wish that the BPD diagnosis had been shared with them years ago. Most participants believed that little things would have made a huge difference to them at the time of the original diagnostic disclosure, including active listening and discussion with a knowledgeable clinician.

**c) BPD like a star sign**

BPD, however badly managed, seemed to give most participants peace of mind as it seemed to fit better than any other previous diagnosis. At the same time, many participants believed that criteria for BPD diagnosis were too generic and could easily apply to anyone, especially in cases where previous diagnoses have failed. Participants believed that BPD represented a highly complex concept, one which was difficult to understand without having specific knowledge or training.

**d) Star signs are not enough; it's what happens afterwards!**

All participants believed that simply diagnosing somebody with BPD was insufficient, as was an attempt to treat BPD symptoms with medication. Most participants believed that it was therapy, which not only provided a meaningful interpretation of BPD but which, for many, represented the long-sought-after psychological help.

**e) Being at the mercy of the system**

Access to psychological therapy and healthcare professionals willing to listen appeared a precious commodity and something of a post-code lottery. In many cases, it seemed, such help only occurred following many years of migrating through the NHS system, with participants desperately accepting whatever help was available.

## **Recommendations**

Several recommendations were cautiously drawn from the results, including the following:

- BPD label is not inevitably stigmatising. BPD and its meaning appear to be highly flexible entities and how one is told about BPD is likely to impact one's understanding of the label.
- Frank and comprehensive diagnostic discussions with service users appear to be vital in this regard. Namely, they have the potential to validate service users' experiences whilst minimising the stigmatising effect of BPD.
- It is vital that health professionals across healthcare settings continue to increase their knowledge of BPD and competency in discussing the diagnosis with service users.
- Furthermore, it is important that professionals working in specialist services continue to share their knowledge with those from generic healthcare settings.
- Lack of specialist services for service users with BPD diagnosis should not stop clinicians from having frank diagnostic discussions with service users. The current research suggests that service users are ready to have such discussions and welcome a clinical shift towards a more transparent BPD dialogue with knowledgeable clinicians.

Thank you very much for your support with this project.

Yours sincerely,

Zuzana Winter

Trainee Clinical Psychologist  
Canterbury Christ Church University

## **Appendix T: Author guideline notes for chosen journal British Journal of Clinical Psychology**

Retrieved from

<http://onlinelibrary.wiley.com/journal/10.1111/%28ISSN%292044-8260/homepage/ForAuthors.html>

### **Author Guidelines**

The British Journal of Clinical Psychology publishes original contributions to scientific knowledge in clinical psychology. This includes descriptive comparisons, as well as studies of the assessment, aetiology and treatment of people with a wide range of psychological problems in all age groups and settings. The level of analysis of studies ranges from biological influences on individual behaviour through to studies of psychological interventions and treatments on individuals, dyads, families and groups, to investigations of the relationships between explicitly social and psychological levels of analysis.

All papers published in The British Journal of Clinical Psychology are eligible for Panel A: Psychology, Psychiatry and Neuroscience in the Research Excellence Framework (REF).

The following types of paper are invited:

- Papers reporting original empirical investigations
- Theoretical papers, provided that these are sufficiently related to the empirical data
- Review articles which need not be exhaustive but which should give an interpretation of the state of the research in a given field and, where appropriate, identify its clinical implications
- Brief reports and comments

#### 1. Circulation

The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

#### 2. Length

The word limit for papers submitted for consideration to BJCP is 5000 words and any papers that are over this word limit will be returned to the authors. The word limit does not include the abstract, reference list, figures, or tables. Appendices however are included in the word limit. The Editors retain discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length. In such a case, the authors should contact the Editors before submission of the paper.

#### 3. Submission and reviewing

All manuscripts must be submitted via [Editorial Manager](#). The Journal operates a policy of anonymous (double blind) peer review. We also operate a triage process in which submissions that are out of scope or otherwise inappropriate will be rejected by the editors without external peer review to avoid unnecessary delays. Before submitting, please read the [terms and conditions of submission](#) and the [declaration of competing interests](#). You may also like to use the [Submission Checklist](#) to help you prepare your paper.

#### 4. Manuscript requirements

- Contributions must be typed in double spacing with wide margins. All sheets must be numbered.
- Manuscripts should be preceded by a title page which includes a full list of authors and their affiliations, as well as the corresponding author's contact details. A template can be downloaded from [here](#).
- The main document must be anonymous. Please do not mention the authors' names or affiliations (including in the Method section) and refer to any previous work in the third person.
- Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript but they must be mentioned in the text.
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