

‘Service-Users’ and Professionals’ Views of the Borderline Personality Disorder
Diagnosis: A Q-methodological Study’

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Preface

This preface is intended as a guide for the reader. Paper one is a review of the literature regarding factors implicated in recovery from Borderline Personality Disorder (BPD), above and beyond remission. The focus for this is specifically upon influences outside of, or as complements to, therapeutic modality. This paper will be submitted to the *Journal of Psychology and Psychotherapy: Theory, Research and Practice*.

Paper two delineates a piece of empirical research with the aim of accessing staff and service-user perspectives on the diagnosis of BPD. This is intended for publication in *Personality Disorders: Theory, Research, and Treatment*.

Paper three is a reflective account of the research process and whilst it is not intended for publication it naturally follows from the preceding two chapters.

To facilitate navigation through the thesis, the formatting of the thesis is consistent throughout with changes made for publication purposes.

Thesis word count: 19445

Thesis Abstract

Borderline Personality Disorder (BPD) is a contentious diagnosis due in part to the abstract nature of personality, as well as the controversies surrounding the current classification systems. Individuals with this diagnosis make up a significant proportion of mental health services, but what the label means to people is unclear.

The first paper is a literature review about recovery from BPD, distinct from the process of remission. Ten papers were included, and the range of themes synthesised into an overview about recovery. The second, empirical, paper examined service-users' and professionals' perspectives of the BPD diagnosis. Q methodology was selected to gather an appreciation and objective understanding of subjective beliefs about recovery, treatment and stigma. This will identify the key factors underpinning these perspectives. The following factors were found: 'Stigma, Internalisation and Social Construction'; 'Essentialism, Acceptance and Compassion'; and, 'Change, Externalisation and Shared Understandings.'

The personal meanings attributed to the BPD diagnosis are important and, to respect the subjectivity and idiosyncrasies of people who may meet the criteria for this diagnosis, should be explored before the diagnosis is made.

The third paper is a reflective piece about the overall research process.

Abstract word count: 189

“...the whole concept of “recovery” brings up some painful questions. What do I recover? ... What if you simply don’t have a solid self to return to—if the way you are is seen as basically broken? And what if you can’t conceive of “normal” or “healthy” because pain and loneliness are all you remember? “You were such a happy child,” my mother says. But I don’t remember that. So what do I recover?”

Kiera van Gelder (2010)

‘Beyond Remission: Recovery from Borderline Personality Disorder’

Paper 1

Literature Review

The following paper is intended for publication in, *Psychology and Psychotherapy: Theory, Research and Practice* (see Appendix A for journal guidelines).

Supplementary material is included for thesis purposes and will be removed for publication.

Word count: 8821

Abstract

There is an ever-increasing body of research into the factors underpinning remission from Borderline Personality Disorder (BPD), including the role of different therapeutic modalities. This review looks beyond remission and treatment model to establish what is involved in personal and clinical recovery.

The Healthcare Database and Web of Science were searched to identify research involving BPD and recovery. Following this initial search, abstracts of relevant papers were read and either rejected or accepted according to specified criteria.

Ten papers met the inclusion criteria and revealed five themes delineating the added value of recovery over remission from BPD. Relationships, meaningful occupation, empowerment, understanding the self and clinical chronicity constituted the 'added value' of personal and clinical recovery above and beyond remission.

The review highlights the abstract and subjective nature of recovery, as well as the differences between the processes of remission and recovery. Future research should explore service-user and professional understandings of BPD and the extent to which they believe it is possible to recover from the diagnosis.

Practitioner Points:

- Recovery from BPD is possible and should be conveyed to clients.
- Specific factors are implicated in moving beyond remission and into recovery.
- Clinical and personal recovery are both valid and should be attended to in clinical practice.
- Recovery is an idiosyncratic journey.

Abstract word count: 211

‘Beyond Remission: Recovery from Borderline Personality Disorder’

Borderline Personality Disorder (BPD) is a complex disorder, characterised by emotional instability, high suicide rates and a tendency towards deliberate self-harm (Gratz & Gunderson, 2006). To diagnose BPD certain criteria must be met as defined by the American Psychiatric Association’s Diagnostic and Statistical Manual-5 ([DSM], 2013; Appendix B), including impairments in personality (such as a poor and unstable self-image) and interpersonal functioning (such as difficulties with empathy or intimacy). The American Psychiatric Association (APA) report a prevalence rate of 2% of BPD in the general population, with 10% of outpatients and 20% of inpatients meeting the diagnostic criteria (2000). Until relatively recently BPD was considered untreatable (Biskin, 2013) with high comorbidity with other psychological difficulties further complicating treatment (Stone, 2006). This nihilistic attitude towards recovery has led to difficulties for both service-users and staff (Paris, 2005).

Moving Towards a Recovery Model

Recently, there has been a shift in how BPD is understood, with the realisation that recovery is achievable (Jørgensen et al., 2013). This is due to a move away from a medicalised understanding of BPD, towards a more psychologically informed, formulation driven approach in accord with the recovery model (Division of Clinical Psychology [DCP], 2011). This is partly because of the increasing evidence base for the treatment modalities specifically indicated for BPD (Barnicot, Katsakou, Bhatti, Fearn, & Priebe, 2012).

The National Institute for Health and Care Excellence (NICE) guidelines (2009) state that the optimum treatments for BPD, also known as Emotionally Unstable Personality Disorder (EUPD) in the International Classification of Mental and Behavioural Disorders (ICD-10; World Health Organization [WHO], 1992; Appendix C)¹, are principally Dialectical Behaviour Therapy (DBT), Schema Therapy (ST) or Mentalization Based Therapy (MBT). These psychological models have demonstrated that recovery is possible (Fonagy & Bateman, 2005). NICE guidelines support the psychological shift which looks beyond remission and towards recovery, stating that when working with people with BPD, treatment planning must be discussed from a

¹ The acronym BPD will be used to represent both terms for the purposes of this review.

hopeful position, informing the client that recovery is achievable (2009).

Remission

There is a distinction between recovery and remission from BPD. Remission is quantifiable in that people no longer meet the diagnostic criteria for BPD over a period of at least two years (Zanarini, Frankenburg, Reich, & Fitzmaurice, 2012). One study suggests that 93% of participants with BPD achieved remission lasting at least two years, and 86% achieved remission lasting at least four years (Zanarini, Frankenburg, Reich, & Fitzmaurice, 2010). Linked to remission is relapse, which has been operationalised as someone remitting then experiencing at least five of the criteria for BPD for at least two months following their initial improvement (Gunderson et al., 2011).

Clinical Recovery

Recovery goes beyond remission with a distinction between clinical and personal recovery (Slade, Amering, & Oades, 2008). The former addresses more concrete elements of recovery, viewing it as a dichotomous, measurable goal. The latter is borne out of service-user perspectives with a focus on subjective beliefs about living a meaningful life, even if problems associated with BPD remain.

Key studies (Plante, Frankenburg, Fitzmaurice, & Zanarini, 2013; Reed, Fitzmaurice, & Zanarini, 2012a; Zanarini et al., 2014) define recovery as symptom remission coupled with two years of adequate social and vocational functioning, socially and vocationally. A Global Assessment of Functioning (GAF) score of at least 61 has been shown to demonstrate good psychosocial functioning and an increase in score to at least this level is used as evidence of recovery from BPD (Plante, et al., 2013; Zanarini et al., 2014). Clinical recovery has been evidenced as fully achievable, with 50% of participants achieving recovery after ten years, in one longitudinal study of people with BPD (Zanarini et al., 2010).

Psychosocial functioning is a key factor in clinical recovery and combines social and occupational functioning. Zanarini et al. (2010a) define it as involving one enduring, supportive relationship in which there is at least weekly contact with a loved one who is not a family member. Vocational effectiveness incorporates competence at school, work or as a houseperson, with consistent and full-time attendance (at least half of the time over the course of follow-up).

Personal Recovery

Many of the qualitative studies regarding service-user views on recovery involve the clinical definitions, and incorporate more abstract, subjective elements; recovery seems to be idiosyncratic (Kelly & Gamble, 2005). “Recovery is a personal process of growth that involves hope, self-identity, meaning in life and responsibility” (Huguelet et al, 2016, p.1). Jessica Gray discusses how recovery is a lifelong journey rather than something to be achieved (2011). Similarly, Rachel Reiland talks about her recovery from BPD as a journey, achieved through a commitment to recovery that goes beyond being symptom free, that involved facing her fears and forging healthy relationships (2004). These concepts allude to a process which by its very nature, is difficult to operationalise but important to understand.

There is a clear distinction between remission and recovery, the latter bringing ‘added value’ associated with improvements in domains of functioning rather than clinical symptoms alone. Reviews of the BPD literature promote the shift towards a more hopeful prognosis for the course of BPD (Barnicot et al., 2012; Barnicot, Katsakou, Marougka, & Priebe, 2011; Links & Heslegrave, 2000). These reviews are a useful synthesis of factors influencing symptom *change* but do not differentiate between remission and recovery. This distinction is important because explicitly examining factors influencing recovery will promote it as a realistic outcome. Other reviews that do make this distinction (Zanarini et al., 2014; Biskin, 2015) focus on clinical recovery, quantitatively defining remission and recovery, without acknowledging personal recovery. Whilst this research is clinically helpful in identifying tangible factors to assess, they do not capture a holistic conceptualisation of recovery from BPD.

Review Rationale

There is a paucity of information regarding the factors that contribute towards both clinical and personal recovery, above and beyond remission. This review aims to identify these factors. As there is an ever increasing evidence base into treatment models for BPD this review will not examine these. The clinical utility and generalisability of the findings will be critically appraised.

Method

The search strategy is detailed below and was run on 26th June 2016.

Search Strategy

Key words involved in recovery were identified via an initial scoping search of the literature and a search string was created to encompass recovery factors. The website www.evidence.nhs.uk was accessed to explore several electronic databases within the Healthcare Databases Advanced Search which were: AMED, British Nursing Index (BNI), CINAHL, EMBASE, HMIC, MEDLINE, PsycINFO and Health Business Elite. Following this, ProQuest Hospital Collection, PsycARTICLES, The Cochrane Library Database and The Web of Science. Each database was searched on an individual basis in order to be as thorough and rigorous as possible. The search terms used were to be found in the title and/or abstract and/or topic, and were:

("borderline personality disorder" OR "emotionally unstable personality disorder")

AND

(remiss* OR recover* OR relaps* OR remit* OR "symptom change*" OR "symptom decrease" OR "symptom reduc*" OR "symptom improve*" OR "symptom elim*")

Inclusion criteria. Limiters were applied to capture the most relevant research. Papers were included if they were peer reviewed, published since 2000, written in English and relating to adults diagnosed with BPD and their recovery. A ‘traffic light’ system was used to screen titles retrieved from databases that met all of the inclusion criteria. Studies that were clearly not relevant to the review were coded as red, titles that may be relevant were coded as amber, and titles that appeared highly relevant were coded green.

Exclusion criteria. Abstracts of ‘amber’ and ‘green’ titles were read to determine the relevance of each paper. To these, the following exclusion criteria were applied:

- Studies that focused on physiology (such as medication or medical illness),
- Studies that did not go beyond remission (i.e. did not mention personal or clinical recovery and only looked at ‘change’ or ‘outcome’).

- Studies that focused on evaluating the treatment model.
- Clinicians' accounts.

This resulted in 10 articles. The reference lists for these were hand searched which did not reveal any further studies for inclusion in the review (see Appendix D for the search strategy flow chart). The 10 papers were critically appraised which involved assessing the quality and validity of research to determine the extent to which generalisations can be made. The quality of research is contingent on various scientific standards being met which indicate the robustness of the acquired data and determines the extent to which the evidence applies (Lohr, 2004).

Results

Overview of Studies

Ten studies met the inclusion criteria, five were quantitative, four were qualitative and one was a personal account of recovery. The data extraction table (Appendix E) shows the key details for each study, the basic demographic information, a summary of the findings, how BPD was diagnosed, the study's clinical implications, limitations and if and how recovery was defined. The five quantitative studies were prospective in design and part of the McLean Study of Adult Development ([MSAD] Zanmarini et al., 2005²; Reed, Fitzmaurice, & Zanmarini, 2012a; Reed, Fitzmaurice, & Zanmarini, 2012b Zanmarini, Frankenburg, & Fitzmaurice, 2013; Zanmarini et al., 2014; Zanmarini et al., 2015). In this research, questionnaires were administered over contiguous two-year follow-ups to compare people who had recovered with those who had not to identify the mediating or moderating factors. Recovery was operationalised as remission of symptoms as well as good social and vocational functioning for the past two years.

The qualitative papers (Agnew, Shannon, Ryan, Storey, & McDonnell, 2016; Holm & Severinsson, 2011; Katsakou et al., 2012; Larivière et al., 2015), and personal account (Wright & Jones, 2012) explored service-users' perspectives on recovery via interviews and thematic analysis to establish broader themes across participants. They used abstract criteria, focusing on service-users' personal meaning of recovery and as such, do not specify a concrete definition.

² The MSAD is the first study to be funded by the National Institute of Mental Health (NIMH) that examines the longitudinal trajectory of BPD (Zanmarini, Frankenburg, Hennen, Reich, & Silk, 2005).

Zanarini, Frankenburg and Fitzmaurice (2013) found that humour predicts a faster route to recovery, which was attributed to enabling psychosocial adjustment. In contrast, the findings suggested that emotional hypochondriasis, projection and acting out inhibited recovery because such defence mechanisms would hinder psychosocial functioning.

Zanarini et al. (2014) found six predictors of recovery: no previous hospital admissions, higher IQ, good vocational functioning in the two years preceding the index admission, no comorbid anxious personality disorder, and high agreeableness and extraversion. Contrary to previous studies, childhood sexual abuse did not significantly predict time to recovery, suggesting that assumptions about a poor trajectory for people who have been abused may be unfounded. The significance of prior admissions is related to chronicity, suggesting that the less chronic the BPD, the greater the chances of recovery. IQ and work record are related to an ability to learn ways of managing difficulties and underpin good psychosocial functioning. They relate the other three variables to temperament which impacts upon social functioning, with the person being more empathic and outgoing. The researchers recommend that reduced avoidance may be a key factor in improving psychosocial functioning, leading to recovery. In turn, this may improve their ability to function vocationally. They distinguish between variables that may lead to remission but not recovery such as traumatic experiences, demographics and family history of mental illness, reinforcing the knowledge that recovery is distinct from remission.

Zanarini et al. (2015) propose that functioning as a parent and partner is strongly related to recovery. People who had recovered were significantly more likely to be in a stable relationship and to be a parent, and less likely to separate or lose custody. Those who had recovered were older when entering this relationship and becoming parents, suggesting that they addressed their difficulties before taking on these responsibilities. The possibility that the relationship may have aided recovery is not discussed; the study therefore can only highlight a link between recovery status and relationship stability.

Reed and Fitzmaurice (2012a) suggest that positive affective, cognitive and mixed states are predictors of recovery from BPD, with recovered people experiencing positive states more frequently than those who had not recovered. As with the first study mentioned (Zanarini et al., 2015) the researchers do not discuss how or why people recovered and others did not, only making the link between states and recovery status. They found that positive states increased at a greater rate for people with BPD

compared to the Axis II comparison cohort, suggesting that people with BPD may be adept at building on positive experiences. This provides clinical utility and hopefulness and they recommend that clinicians familiarize themselves with these positive states to aid the client in shoring up these strengths. Similarly, Reed, Fitzmaurice and Zanarini (2012b) discuss the relationship between dysphoric affective and cognitive states and recovery, with people who have not recovered from BPD experiencing more severe dysphoric states than those who had recovered. They suggest that such enduring painful experiences and beliefs may hinder functioning. The researchers relate these findings to psychosocial functioning in that pervasive dysphoric states may reduce confidence and increase emotional exhaustion; self-belief and energy are imperative in finding sustained occupation.

Holm and Severinsson (2011) conclude that hope, trust and safety underpin recovery which come about when the person assumes responsibility for their own life by working through past traumas and discovering a sense of identity. This study revealed the many nuances in recovery rather than overarching factors and highlights the individual nature of the concept. Similarly, Katsakou et al. (2012) and Larivière et al. (2015) explicitly mention that recovery is subjective, and that for some the term is fraught with difficulty because it implies a polarisation between recovery and non-recovery. Larivière et al. (2015) organised recovery factors in terms of the Person-Environment-Occupation mode, suggesting that recovery is linked to improvements across all three domains, including reflection (Person), a good support network (Environment) and vocational fulfilment (Occupation). Katsakou et al. (2012) found that increased confidence and self-acceptance, improved emotional regulation, a reduction in symptoms (such as self-harming) and improved psychosocial functioning were integral to their recovery, which calls for a more holistic approach to BPD. Agnew et al., (2012) found that conceptualizing the self as a multiple, dynamic person rather than unitary and inflexible can be empowering, strengthening the healthy parts of their identity which will lead to recovery. They identified the following major themes as underpinning recovery: ‘connecting to myself’, ‘distance between us’ and ‘hurt and healing’, and suggest that empowerment, autonomy and forging new connections with the self and others underpin recovery.

Wright and Jones (2012) reinforce the subjectivity of the recovery process. The report is written by a service-user and mental health nurse and lecturer, who state that

recovery is created through, “mutual honesty, respect and decency”, an environment that fostered hopefulness in the client and enabled her to move forwards.

The quality of the papers varies and this impacts upon the degree to which the conclusions drawn can be applied clinically and to a wider population. The evidence hierarchy (Evans, 2002; Appendix F) reflects the strength of the evidence in a paper. In this review, the five prospective, quantitative studies (Reed et al., 2012a; Reed et al., 2012b; Zanarini et al., 2013; Zanarini et al., 2014; Zanarini et al., 2015) constitute the highest quality standard followed by the qualitative studies (Agnew et al., 2016; Holm & Severinsson, 2011; Katsakou et al., 2012; Larivière et al., 2015). Below these is the personal account (Wright & Jones, 2012).

The five quantitative papers were appraised according to a tool specifically designed to assess the quality of longitudinal, observational research which befits all five (Tooth, Ware, Bain, Purdie & Dobson, 2005; Appendix G). The qualitative papers were evaluated according to the Critical Appraisal Skills Programme Checklists (CASP). The CASP is a tool for appraising the trustworthiness, relevance and validity of a piece of research (Public Health Resource Unit, 2006; Appendix H). As can be seen from these tools, the papers were of a high quality; the qualitative research in particular. The appraisal of the papers follows this hierarchical structure.

Aims and Objectives

All 10 studies clearly state the research aims, identifying the link between recovery and another factor/s to be studied. This enabled the extraction of the themes (see p.28). The quantitative papers focus on clinical recovery, examining factors that may contribute to this, whilst the qualitative studies and the personal account lean towards personal recovery and its constituents. All studies discussed their findings in relation to their aims and objectives.

Sample Characteristics

The characteristics of the sample are significant, particularly as there is often comorbidity, such as between bipolar and BPD (Marčinko & Vuksan-Ćusa, 2009). All participants had a diagnosis of BPD. The five quantitative studies involved the same cohort of people from the MSAD: 290 people with BPD who had initially been inpatients at the McLean Hospital (Reed et al., 2012a; Reed et al., 2012b; Zanarini et al., 2013, Zanarini et al., 2014; Zanarini et al., 2015). This does not allow for a

representative sample of BPD across cultures and age, and highlights the possible overuse of one sample in trying to understand the mechanisms underlying BPD. However, this is a large sample which somewhat mitigates the difficulties in using one cohort of participants in several studies as it is likely that differences between recovered and non-recovered groups would be detectable.

Altogether, 441 people diagnosed with BPD were involved in the studies. It is important that the sample size is large enough to yield differences if they exist – that there is enough power (Dorey, 2011). None of the studies included power calculations so there is some uncertainty that they were sufficiently powered to detect differences between recovered and non-recovered cohorts. All studies used purposive sampling, possibly justifying the lack of power calculations in the quantitative studies.

The ages ranged across studies, with the quantitative studies only reporting the mean age ($m = 27$) and stating that participants had to be between the ages of 18-35. Omitting people older than 35 does not encompass adulthood in its entirety and may therefore miss important data that could be sought from adults over 35, such as stability of recovery. There was no rationale given for this cut-off point. One qualitative study (Holm & Severinsson, 2011) reported an age range of 25-53 ($m = 39$). Agnew et al. (2016) reported the age range only (30-45), with Katsakou et al. (2012) and Larivière et al. (2015) reporting the average age ($m = 36.5$ and 37.2 respectively). Wright and Jones (2012) did not state the age of the service user. BPD is most often diagnosed in early adulthood (Macfie, 2009) and there is evidence to suggest that age can influence remission (Biskin, 2015). Therefore, these reported age ranges are relatively generalisable to the adult population diagnosed with BPD.

Recruitment

The quantitative studies took place in America (Reed et al., 2012a; Reed et al., 2012b; Zanarini et al., 2013; Zanarini et al., 2014; Zanarini et al., 2015). Of the other studies, one is Canadian (Larivière et al., 2015), two were English (Katsakou et al., 2012; Wright & Jones, 2012), one is Norwegian (Holm & Severinsson, 2011) and one was Irish (Agnew et al., 2016). The five quantitative studies involved inpatients at the Mclean Hospital. Two studies recruited through Community Mental Health Centres, (Agnew et al., 2016; Katsakou et al., 2012), one via mental health nurses, therapists and a mental health organization (Holm & Severinsson, 2011), and one via a specialized BPD program (Larivière et al., 2015). Whilst this demonstrates diversity across the

sample, it may be difficult to generalise the findings to a UK sample because different countries may have varied understandings of BPD, its treatment and treatment provision.

Inclusion and Exclusion Criteria

The MSAD studies had stringent inclusion criteria. The participants were initially inpatients and aged between 18 and 35. Exclusion criteria were: symptoms of schizophrenia, schizoaffective disorder, bipolar I disorder or an organic problem that could manifest as a psychological difficulty. This stringent criterion increases the validity of the studies, because there can be greater confidence that they are measuring symptoms of BPD rather than those of other disorders. The people in this cohort were all initially inpatients which suggests they were severely ill at baseline. This sampling bias has some ramifications as it excludes people with less severe presentations who may have different experiences of recovery. One study only included women with the justification that women are more likely to be diagnosed with BPD (Larivière et al., 2015). This sampling bias omits information about males with BPD that could contribute to the evidence base and denies that men can be diagnosed with BPD.

Attrition

Attrition is important because it affects the strength of findings. Overall, attrition was relatively low. Three of the MSAD studies had an 87.5% retention rate for all eight follow-up waves (Zanarini et al., 2013; Zanarini et al., 2014; Zanarini et al., 2015). Two MSAD studies had a 90.1% retention rate over all five follow-up waves (Reed et al., 2012a; Reed et al., 2012b). Attrition was not applicable to the qualitative studies because they did not involve follow-up.

Data Collection: Quantitative

A variety of primary and secondary measures were used in the studies to assess diagnosis and outcomes (Appendix I) and were clearly described. The range of measures may impact upon the generalisability of the findings and the cross comparisons.

Interviews. All of the MSAD studies used the Structured Clinical Interview (SCID), the Revised Diagnostic Interview for Borderlines (DIB) and the Diagnostic Interview for Personality Disorders, to capture the participants' diagnoses and

psychosocial level of functioning. The inter-rater (level of agreement amongst raters) and test-retest reliability (how consistent the scores are over time) of the Background Information Schedule (BIS), the SCID, and the diagnostic interviews were measured to be good to excellent, as was the concurrent validity of the BIS (Zanarini et al., 2014). The follow up version – the Revised Borderline Follow-up Interview (BFI-R) was used in one study (Zanarini et al., 2015) which also has good to excellent psychometric properties. However, a recent systematic review of the reliability and validity of the diagnostic interviews for BPD and PD propose that further work is needed to establish their validity, so conclusions drawn using these measures should be tentative (Carcone, Tokarz, & Ruocco, 2015).

These interviews were carried out by assessors blind to their clinical diagnosis. Assessors blind to baseline diagnosis also carried out post baseline assessments. Blinding the assessors reduces the possibility of biased outcomes when there may be an unconscious desire for a particular result (Karanicolas, Farrohyar, & Bhandari, 2010).

One study (Zanarini et al., 2014) used semi-structured interviews, the Childhood Experiences questionnaire, the Revised Family History Questionnaire and the Abuse History Interview, to identify childhood history, all of which have good to excellent inter-rate reliability. Zanarini et al. (2015) incorporated a brief interview into the assessment battery to assess relationship and parenting status, thus enhancing validity.

Clinician rated measure. The quantitative studies used the Global Assessment of Functioning ([GAF]; Aas, 2010), a scale used by clinicians to rate a person's psychosocial functioning. One study used the GAF to assess at baseline only (Zanarini et al., 2013) with a mean score of 39.8 indicating severe impairment in many areas of life. Repeating the assessment at the end of the study could have provided useful data regarding recovery factors. A score of at least 61 indicated recovery because it describes a reasonable level of functioning across social, psychological and occupational domains. There are issues with the reliability and validity of the GAF, which have implications for the accuracy of scores and sensitivity to change (Aas, 2010). These difficulties are highlighted with the replacement of the GAF with the World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0; World Health Organization, as cited in Gold, 2014). The subjective nature of the GAF could affect reliability as different professionals may reach different conclusions.

Self-report measures. One paper used the Positive Affect Scale ([PAS]; Reed et al., 2012a) and another used the Dysphoric Affect Scale ([DAS]; Reed et al., 2012b). These are both self-report measures which raises issues with reliability and validity, as, possibly in an attempt to please, participants may not respond accurately. This results in skewed data which is not a true reflection of the assessed phenomena. However, both measures have excellent psychometric properties, and both measures involved gaining consensus from five psychologists and psychiatrists regarding the properties in the measures.

Zanarini et al. (2013) used the Defense Style Questionnaire, which is internally consistent and has criterion validity. They concede that using this measure results in less clinically descriptive information than other methods.

Zanarini et al. (2014) used the Neuroticism-Extraversion-Openness Five Factor Inventory and the Shipley Institute of Living Scale to assess temperament and IQ, both of which have strong support for their psychometric properties.

Data Analysis: Quantitative Studies

Methodologies. All five studies provided detailed statistical analyses and gave details of follow-up waves of assessments at varying time intervals. Three of these had eight contiguous two-year follow-up periods, two studies had five follow-up waves, two years apart. Four of the studies used regression which is appropriate in identifying predictors of recovery (Reed et al., 2012a; Reed et al., 2012b; Zanarini et al., 2013; Zanarini et al., 2014). Three of these (Reed et al., 2012a; Reed et al., 2012b; Zanarini et al., 2013) used multiple imputation to account for missing data, overcoming the threat to validity that can be caused by an incomplete data set (Sterne et al., 2009). One study used Chi-squared tests and Student's *t* tests, an appropriate choice as this study compared two groups on continuous and categorical variables (Zanarini et al., 2015). All were thorough and would allow for replication.

Alpha values. All quantitative studies reported alpha values, with all but one (Zanarini et al., 2015) reporting confidence intervals, an estimate of the parameters within which the 'true value' lies. Reporting alpha values and confidence intervals enhances the accuracy of the study and informs the reader of the level of significance of the results.

Effect size. Two of the quantitative studies reported effect sizes (Zanarini et al., 2014; Zanarini et al., 2015), which is essential to understand the magnitude of significant results. Large effects indicate not only that the results are significant, they are substantially so. Effect sizes will therefore influence the conclusions drawn from the studies (Coe, 2002). Zanarini et al. (2013) reported percentages to show the impact of defences on recovery which is helpful in understanding how significant they are in predicting recovery. For every one-point increase in humour score, there was an 18% greater likelihood of recovery. A one-point increase in scores for acting out, emotional hypochondriasis and projection resulted in a reduced chance of recovery by 19%, 18% and 36% respectively.

Confounds. As all of the quantitative studies involve the same group of participants, they all state identical limitations. Whilst these are discussed, none of the potential confounds are addressed and could have a significant effect on outcome. The majority of participants in the MSAD studies were in individual therapy and taking psychotropic medication. This remained the case at all follow-up waves and could have mediated or moderated the relationship between recovery and the mechanism under investigation.

Data Collection: Qualitative Studies

The principal method of data collection was semi-structured interviews which were then thematically analysed. This is appropriate to the study objectives as they aim to explore personal perceptions of recovery.

Semi-structured interviews. All studies used interviews to capture information. One study developed a topic guide for in-depth interviews, involving two researchers and two service-users, adding to the rigor of the method. The use of open questions supported a flexible approach, allowing the participants to reveal their personal views (Katsakou et al., 2012). Agnew et al., (2016) ensured that the interviews in their study were carried out by a researcher who was unaware of the results of the screening interview and had no clinical involvement with participants, reducing the possibility for bias. Holm and Severinsson (2011) stated the questions put to participants, which is helpful in understanding the responses.

Picture collages. Participants in Larivière et al.'s study (2015) were asked to create a collage that would represent their life with BPD and were subsequently interviewed about its links to the concept of recovery. This study used interviews, collages and examined medical records; using different methods of data collection is a form of triangulation that increases the validity of the study. In addition, participants were contacted one month after this interview to discuss any developments in their thoughts on their recovery. This is helpful in consolidating and triangulating the results and a method that is especially helpful for those who struggle to communicate.

Data Analysis: Qualitative Studies.

Methodologies. For Katsakou et al., (2012) grounded theory was appropriate in attempting to reach saturation regarding views on recovery. This study thematically analysed the data, and this iterative processes allows for thorough and holistic analysis. Part of this process involved the development of a coding frame and this too was created by researchers and service-users. Following coding, the analysis was reported back to four service-users to allow for further refinement, enhancing the validity of the findings.

Holm and Severinsson (2011) demonstrated rigour by discussing the findings and reaching a consensus regarding the factors important in recovery. They also describe thematic analysis which acts as a useful aid for readers who are less knowledgeable in this methodology.

In one study (Katsakou et al., 2012) the interviews were transcribed by a professional transcriber which does not allow for the researcher to fully engage with the service-users' views. Agnew et al., (2016) transcribed and re-read the interviews several times which allows for immersion in the data (Braun & Clarke, 2006). Larivière et al. (2012) transcribed the interviews verbatim. A thematic grid was then developed by two of the researchers independently and then discussed with the wider team which increases the validity of the themes.

Agnew et al., (2016) and Holm and Severinsson (2011) use participants' quotes to evidence their themes, helping the reader to understand how they arrived at them. Holm and Severinsson (2011) do not use excerpts from all participants which makes it more challenging for the reader to identify how they arrived at their major themes.

Reflexivity. Agnew et al. (2016) and Holm and Severinsson (2011) were the only papers to consider reflexivity; how their personal beliefs and epistemological positions might influence data collection and interpretation. The former state that their epistemological position was acknowledged throughout the data collection and analysis stages, and credibility checks carried out by other members of the research team. Doing so enhances the validity of the resulting themes. This study justifies the use of their chosen methodology by relating it to the researcher's epistemological position. The latter study mentions how experience as psychiatric nurse might have significantly impacted upon the interpretation of participants' views.

Clinical Utility

All of the studies presented their findings very clearly with all but one suggesting potential future research (Zanarini et al., 2015). Whilst the majority discuss the clinical implications of their findings, two do not (Zanarini et al., 2014; Zanarini et al., 2015). Doing so is helpful in guiding treatment and ensuring that clinical guidelines relate to empirical evidence. The qualitative studies discuss how their findings can help shape treatment, demonstrating that even small-scale studies have clinical utility, with results that can be broadly generalisable. For example, Larivière et al., (2015) suggest incorporating meaningful occupation into therapy for BPD. This consolidates findings from larger scale studies – such as MSAD papers – that acknowledge the role of occupation in recovery. Similarly, Katsakou et al. (2012) embed their findings in the wider literature base, as well as linking them to the recommended treatments for BPD.

Ethical Considerations

Holm and Severinsson (2011), Katsakou et al., (2012), Larivière et al., (2015) and Agnew et al., (2016) summarised the ethical approval process so the reader can be certain that participants made an informed decision to take part in the study. The quantitative research states that participants provided informed consent following a description of the study. It is noteworthy that all inpatients consented to be in the study. There is the possibility that as inpatients they may have found it difficult to refuse which would suggest an ethical issue. The researchers do not discuss this issue.

There are a number of strengths and weaknesses in the reviewed literature, leading to variable quality as can be seen with the application of appraisal tools

(Appendices G & H). The quantitative studies are of a reasonably high quality, and are mainly compromised by the lack of acknowledgement about other factors that may have impacted on recovery, such as medication, therapy and severity at baseline. The qualitative papers are of a very high quality, increasing the validity of their findings, and meaning that they are more applicable to clinical work. All of the studies contribute to the knowledge base regarding BPD, and highlight the importance of looking at recovery from both a clinical and a personal perspective to provide the most holistic and respectful conceptualisation for service-users. A synthesis of the findings from these papers shall now be presented in order to show its breadth of coverage.

Themes across the Literature

Papers were read and themes highlighted by the researcher. This was facilitated by the authors of the selected papers stating the link between recovery and the factor under scrutiny. These were then examined holistically to identify commonalities across papers. Five main themes emerged which are important in recovery: socialisation, meaningful occupation, empowerment, understanding the self and clinical chronicity.

Socialisation

An individual's ability to form healthy, sustainable relationships seems integral to recovery. Several of the studies suggest that relationships play a fundamental role in recovery and this includes professionals and other service-users as well as well as friends and family (Agnew et al., 2016; Holm & Severinsson, 2011; Katsakou et al., 2012; Larivière et al., 2015; Wright & Jones, 2012; Zanarini et al., 2015). Relational difficulties include a person's intrapersonal skills, as problems with the self and identity are often associated with BPD (Agnew et al., 2016).

Zanarini et al. (2015) found that people who had recovered from BPD were significantly more likely to have married or lived with a partner and to have become a parent than people who had not recovered. These relationships were also significantly more stable for those who had recovered from BPD. Furthermore, these relationships tended to be supportive and sustained, providing stability for the person. These results may indicate that people who have recovered have the necessary energy and skills required to form and sustain a supportive relationship. Recovered people were significantly less likely to lose custody of their children, supporting the hypothesis that recovery can be equated with some intrapersonal resolution. The finding that those who

had recovered tended to be older when starting a relationship or having children may be because they had resolved many of the difficulties that had previously impaired their functioning. It is difficult to know which comes first: recovery or a healthy relationship. It may be that each reinforces the other, with people learning to feel safe, nurtured and validated when in a healthy relationship. Having children may enable recovery as the individual is focussed on the needs of the child more than their own distress, helping regulate their emotions.

Agnew et al. (2016) identified a theme about connections with others, labelled 'Distance between us' and a subordinate theme of 'A different way' that discussed the importance of positive relationships that allow for nurturing and intimacy. The researchers found that despite BPD criteria relating to difficulties sustaining relationships (APA, 2013) this was not the case for all participants, with some able to connect intimately with others. They link this healthy aspect of the self to recovery. It may be that nurture and intimacy strengthen an individual's self-belief and provide a validating and secure base allowing them to explore difficulties, and experience and tolerate distress.

Holm and Severinsson (2011) found that feeling validated and trusted by others are key to recovery from BPD, with the discovery that dependency in relationships was hindering their recovery. Taking responsibility for this meant leaving unhealthy relationships, leading the women to define themselves as recovered. This reinforces the importance of healthy relationships in order to feel both independent and connected. This is supported by Katsakou et al.'s study (2012) in which improving relationships was a significant part of recovery due to the added support and decreased isolation relationships bring. Participants reflected on how healthy relationships foster trust, allowing them to feel less vulnerable when revealing their feelings and manage fears of rejection and abandonment, a criterion for BPD (APA, 2013).

Larivière et al. (2015) support the importance of maintaining and creating healthy relationships as part of recovery. Moreover, not only do healthy relationships positively impact upon recovery, unhealthy ones had a deleterious effect. It may be that these maintain difficulties and any low sense of worth which in turn affects recovery. Functional relationships include professionals and community organisations as well as more personal relationships, and therapeutic relationships may therefore have an important role in recovery. The case studies strengthen these findings, especially the importance of the therapeutic alliance which is known to be a valuable part of recovery

(Barnicot et al., 2012). The service-user in one case study discusses how her keyworker was integral to her recovery, showing her kindness and compassion (Wright & Jones, 2012). The strength of this validating relationship enabled the service-user to enhance her self-belief and understand herself better whilst regaining control over her life.

Meaningful Occupation

Occupational activity is part of the recovery process and refers to an individual's ability to function in the work place or academic setting. Two studies (Katsakou et al., 2012; Larivière et al., 2015) highlight the importance of meaningful activity in the recovery process as this increases confidence and a sense of connectedness with the world. It would also help establish relationships which are integral to recovery. Occupation was often discussed in relation to employment, although people did not necessarily believe that this had to be full time to ensure recovery (Larivière et al., 2015). It may be that the quality of the work, the sense of purpose, the confidence it brings and connectedness with others, not the 'quantity, is sufficient in achieving recovery. This study used the Person-Environment-Occupation model which describes interactions between the three domains, to organise recovery factors, highlighting the relationship between the person and their occupation and the people around them. Zanarini et al. (2014) found that full time vocational functioning in the two years before hospitalisation was predictive of recovery over remission, and suggest that this may be because the person has reduced their avoidance of different experiences, perhaps fostering resilience.

Empowerment

Several of the studies related recovery to increased empowerment, a sense of growing in confidence and competence. Holm and Severinsson (2011) found that the search for strength was part of taking responsibility for themselves and others, which was in turn part of recovery. For some people, attempting suicide was actually a way of taking responsibility for by trying to escape from the world. They talked about feeling powerless and having to find their own ways of recovering. 'Enhancing self-development' was a theme across participants, with recovery linked to making the decision to do something meaningful with their lives. This suggests a shift from dysfunctional methods towards healthier ways of empowering the self as part of the recovery process.

Katsakou et al. (2012) provide support for the role of empowerment in recovery, with participants reporting that taking control of their feelings and thoughts and moving away from dichotomous thinking is part of recovery. Being able to hold balanced views may lead to less intense emotion and more considered responses which may then empower the individual as they react in healthier ways.

Being hopeful about the future is empowering and signaled recovery. This is linked to other dimensions of empowerment such as taking responsibility: choosing not to give up and to make changes with the possibility that a meaningful life will come to fruition (Holm & Severinsson, 2011; Larivière et al., 2015). In one case study, the participant talks about hope coming from understanding her diagnosis and knowing that she was not alone in her difficulties (Wright & Jones, 2012). This may decrease an individual's isolative feelings and increase their sense of connectedness. This may in turn encourage the formation of relationships as they discover that they are not as different as they had previously believed, increasing their self-acceptance.

Understanding the Self

There seems to be a change in how people understand themselves which is connected to recovery. One qualitative study highlights the importance of identity in recovery and change, with participants overcoming a sense of fragmentation through making connections with others (Agnew et al., 2016). This study suggests that recovery is aided by understanding the self as dynamic, relational and multiple rather than static and dichotomous. This would enable the individual to nurture the healthy aspects of the self and promote recovery. This links to empowerment and thinking in less extreme ways in order to accept the complexity of the self. Agnew et al. (2016) suggest that moving away from a singular identity towards a multiple, relational self means that people can focus on nurturing healthy aspects of their identity, thus helping them recover. People could see themselves as multidimensional and move away from 'good' or 'bad' conceptualisations of personhood.

Individuation is integral to recovery for some (Larivière et al., 2015) and refers to the ability to carve out an identity distinct from other people, to discover the self, personal interests and values. Improved self-knowledge may pave the way for greater acceptance in acknowledging the complexity and diversity of people. For the women in Holm and Severinsson's study (2011), recovery was about reframing their sense of identity and definitions of self, allowing them to accept their limitations. Thinking of

the self as fluid and dynamic is supported by Katsakou et al.'s finding (2012) that recovery is a fluctuating process rather than a linear one. Similarly, people talked about accepting the past in order to let go and move on from it as a significant aspect of recovery (Larivière et al., 2015). Acceptance can also refer to the importance in feeling accepted by others as this can impact upon recovery (Wright & Jones, 2012). This links with relationships as they can provide validation for the individual.

Clinical Chronicity

Several of the studies provide evidence that the complexity of a person's presentation – i.e. the more BPD criteria they meet and the strength of these criteria – will impact on their recovery status (Reed et al., 2012a; Reed et al., 2012b; Zanarini et al., 2014). All of the quantitative studies viewed symptom remission as part of recovery. Some of the women in Larivière et al.'s study (2015) viewed recovery as healing from an illness by overcoming symptoms, such as self-harm and suicidality. It stands to reason that the more symptoms present, the harder it is to recover, so the number of symptoms and comorbidity will inhibit recovery. Zanarini et al. (2014) found that the absence of a comorbid anxious cluster personality disorder significantly increases the chances of recovery from BPD as does a more extroverted, agreeable nature.

Zanarini et al. (2014) also found that IQ predicts recovery over remission, linking this to the individual's ability to learn new ways of coping. People may be able to implement skills and receive positive reinforcement. They also found that no prior admissions to psychiatric hospital were predictive of recovery over admission with recovered individuals less likely than the non-recovered cohort to have ever been admitted because of their mental health difficulties. It may be that previous admissions lead to nihilistic, defeatist beliefs about the future.

The findings suggest that positive cognitions and emotions as well as certain defence mechanisms may help mitigate the chronicity of the disorder. This links to thinking style and how people respond to their difficulties. Reed et al. (2012a; 2012b) found that people who had recovered from BPD had an increased number of positive states, such as 'Assertive' and 'That things around me are real'. Non-recovered participants experienced greater severity of dysphoric states, such as 'I cannot trust other people' and 'I have to be on guard at all times', than the recovered cohort, suggesting that dysphoria negatively affects functioning in general. An increase in positive cognitive and affective states, and a decrease in dysphoric states, may affect

recovery because they lead to the individual forming trusting relationships and a willingness to interact with the world. Cognitions and affect are inextricably linked, as is the basic premise of Cognitive Behavioural theory (Hoffman, Asnaani, Vonk, Sawyer, & Fang, 2012), so a change in one may positively impact upon the other. Freud proposed that people have certain protective mechanisms to help them cope whenever there is a threat to the perceived sense of self, or the ego and these mechanisms were termed 'defences' (Baumeister, Dale, & Sommer, 1998). How people manage distress may affect its intensity and impact upon recovery. The defences people use to protect themselves from this distress will affect these responses. Zanarini et al. (2013) found that there are four defences that influence the time it takes to recover from BPD: acting out (overt destructive behaviours), emotional hypochondriasis (transforming intolerable pain into attempts to get others to recognise this pain; Zanarini & Frankenburg, 1994), projection (attributing personal feelings and beliefs to others) and humour (such as joking about emotional pain), suggesting that the first three manifest in interpersonal and vocational difficulties. The predictive strength of humour was attributed to ego strength and as such leads to a greater ability to manage the distress and instability that characterises BPD. These defences will affect their relationships with others. Acting out, emotional hypochondriasis and projection imply a level of difficulty for people around the individual. The greater the difficulty the fewer opportunities there are to sustain relationships and feel validated and secure. These defences also imply a level of dependency on others and as has been identified, autonomy is part of recovery as well as healthy relationships. Humour may mitigate these difficulties.

Discussion

The review has identified a number of influential factors regarding recovery from BPD, defined as: 'Socialisation', 'Meaningful Occupation', 'Empowerment', 'Understanding the Self' and 'Clinical Chronicity'. It supports Kelly and Gamble's statement that recovery from mental health difficulties is highly individual (2005), and identifies factors that may unite people to different degrees. It also synthesises quantitative and qualitative methodologies which allows for a holistic review. The quantitative papers were of a relatively high quality with the qualitative papers even more so. This suggests that the findings regarding personal recovery may carry more weight than findings related to clinical recovery.

The synthesis of both qualitative and quantitative research is representative of recovery: there are measurable elements, such as symptom remission, and purposeful occupation, and more abstract, subjective elements, concerning identity and empowerment. It is not necessary to view recovery from either a clinical or personal position; each complements the other with a contextual approach leading to personalised care planning and measurable outcomes allowing for evidence based treatment.

This review reinforces the theory proposed by Slade, Amering and Oades (2008) that recovery consists of both clinical and personal factors. In focusing on clinical recovery, the quantitative studies do not further explore individual meaning in their studies. Paradoxically, the qualitative papers do not tend to acknowledge more concrete definitions of recovery. Both clinical and personal recovery have meaning and value for service-users and professionals and the review is a reminder of the importance of exploring both forms concurrently. This is reinforced in the synthesis of findings, in which there is distinct overlap between domains; an individual may feel more empowered when employed, or have a more stable sense of identity when in a healthy relationship. Giving weight to subjective views on BPD recovery as well as clinical factors may be more empowering for the service-user, helping them discover and maintain some autonomy over their difficulties. This would also help explain why evidence suggests that admissions to hospital are particularly unhelpful for a person with a diagnosis of BPD (Paris, 2004), hindering recovery, as hospitalisation significantly compromises their autonomy, creating passivity (Krawitz & Watson, 1999).

The studies raise the issue of nomenclature when discussing recovery, with some participants saying that the concept is dichotomous and others believing it to be a continuum based journey; this might indicate a difference between values and goals in recovery. It cannot be assumed that the term 'recovery' will always be positively perceived: some participants believed that recovery meant losing an element of themselves, a part that they have accepted as fundamental to their identity. If someone cannot recall a time when these difficulties were absent from their lives, it stands to reason that the thought of recovery would be akin to becoming someone else. Not all of the qualitative studies defined recovery, and this needs to be explored with service-users to ensure that clinicians' assumptions are not impacting on goal setting and treatment options.

Apart from the promulgation of a holistic conceptualisation of recovery, this review supports a positive trajectory for BPD. It was particularly important to focus on recovery as distinct from remission to further embed the knowledge that the prognosis is far less chronic and enduring than once believed. Understanding BPD from a purely medical approach does not account for contextual factors. A biopsychosocial approach demands a restructuring of the power differentials within services, with professionals needing to acknowledge the role that we all play in shaping mental illness and how it is understood.

Strengths and Limitations of the Review

This literature review encompasses views on both clinical and personal recovery, which means that both qualitative and quantitative papers have been included, as well as a personal account, adding another dimension to the findings. In focusing on recovery over remission, the review helps promote recovery as an achievable outcome for people with BPD and acknowledges that this can have different meanings to different people. The search terms and inclusion criteria ensured that papers focusing on symptom change or remission were examined, to check whether this constituted recovery for some individuals. The findings reinforce the importance of exploring recovery with service-users whilst being aware of personal assumptions about what this may look like.

There are limitations to the review. Grey literature was excluded from the research to ensure quality, but this neglects a sizable proportion of literature and may result in a bias towards studies with statistically significant findings. Including personal recovery was an attempt to mitigate this. Whilst the review was carried out systematically there is still room for subjectivity and another researcher may have included/excluded different papers.

Ten papers were included due to the inclusion/exclusion criteria and a larger number could have resulted in greater clinical utility, but this was beyond the scope of the review. This must be acknowledged when considering clinical implications.

Recommendations for Future Research

All participants had some involvement – past or present – with mental health services. Whilst this is understandable due to recruitment obstacles, it may be beneficial to research recovery for outpatients or people with BPD who have no contact with services to control for treatment effects. This could be achieved by working in conjunction with

outreach services. It would also be interesting to understand why some people remit but cannot achieve full recovery through discussions with service-users who have been discharged from services for some time due to reaching a level of consistent stability. The review has highlighted some possibilities: focusing on symptom reduction may only provide short-term benefits, unwittingly evoking a sense of despair in client and therapist. Whilst the review has contributed to this understanding, further research is required.

Conclusions

The key findings from this review are that recovery from BPD goes beyond remission, and there are several factors that may account for or moderate this process. Clinical and personal conceptualisations of recovery must be considered together to provide a holistic and thorough understanding. Examining different definitions of recovery has highlighted the fact that for many it is a highly personal process. As with the quantitative definition of recovery, social and vocational functioning were important, but incorporating qualitative research has allowed for a closer analysis and understanding of these domains. Symptom remission has been identified as part of recovery, and this has been further analysed, identifying factors that may affect chronicity and thus recovery or lack thereof. The qualitative research highlights the importance of less concrete factors, such as empowerment. The overlap between the different elements – such as acceptance affecting social functioning – is a timely reminder that recovery is best viewed holistically.

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DOI:http://doi.org/10.1521/pedi_2014_28_147

Appendix A

Journal Guidelines

Psychology and Psychotherapy: Theory, Research and Practice

Retrieved from: [http://onlinelibrary.wiley.com/journal/10.1111/\(ISSN\)2044-8341](http://onlinelibrary.wiley.com/journal/10.1111/(ISSN)2044-8341)

Psychology and Psychotherapy: Theory Research and Practice (formerly The British Journal of Medical Psychology) is an international scientific journal with a focus on the psychological aspects of mental health difficulties and well-being; and psychological problems and their psychological treatments. We welcome submissions from mental health professionals and researchers from all relevant professional backgrounds. The Journal welcomes submissions of original high quality empirical research and rigorous theoretical papers of any theoretical provenance provided they have a bearing upon vulnerability to, adjustment to, assessment of, and recovery (assisted or otherwise) from psychological disorders. Submission of systematic reviews and other research reports which support evidence-based practice are also welcomed, as are relevant high quality analogue studies. The Journal thus aims to promote theoretical and research developments in the understanding of cognitive and emotional factors in psychological disorders, interpersonal attitudes, behaviour and relationships, and psychological therapies (including both process and outcome research) where mental health is concerned. Clinical or case studies will not normally be considered except where they illustrate particularly unusual forms of psychopathology or innovative forms of therapy and meet scientific criteria through appropriate use of single case experimental designs.

1. Circulation

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

2. Length

All articles submitted to PAPT must adhere to the stated word limit for the particular article type. The journal operates a policy of returning any papers that are over this word limit to the authors. **The word limit does not include the abstract, reference list, figures and 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 (e.g., a new theory or a new method). The authors should contact the Editors first in such a case.

Word limits for specific article types are as follows:

- Research articles: 5000 words
- Qualitative papers: 6000 words
- **Review papers: 6000 words**
- Special Issue papers: 5000 words

3. Brief reports

These should be limited to 1000 words and may include research studies and theoretical, critical or review comments whose essential contribution can be made briefly. A summary of not more than 50

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words should be provided.

4. Submission and reviewing

All manuscripts must be submitted via <http://www.editorialmanager.com/paptrap/>. The Journal operates a policy of anonymous peer review. Before submitting, please read the terms and conditions of submission and the declaration of competing interests.

5. 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 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.**
- **Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use.** Unnecessary background patterns, lines and shading should be avoided. Captions should be listed on a separate sheet. The resolution of digital images must be at least 300 dpi. All figures must be mentioned in the text.
- For articles containing original scientific research, a structured abstract of up to 250 words should be included with the headings: Objectives, Design, Methods, Results, Conclusions. Review articles should use these headings: Purpose, Methods, Results, Conclusions.
- **All Articles must include Practitioner Points – these are 2-4 bullet points, in addition to the abstract, with the heading 'Practitioner Points'. These should briefly and clearly outline the relevance of your research to professional practice.**
- **For reference citations, please use APA style.** Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full and provide DOI numbers where possible for journal articles.
- SI units must be used for all measurements, rounded off to practical values if appropriate, with the imperial equivalent in parentheses.
- In normal circumstances, effect size should be incorporated.
- Authors are requested to avoid the use of sexist language.
- Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations, etc. for which they do not own copyright.
- Manuscripts describing clinical trials must be submitted in accordance with the **CONSORT statement on reporting randomised controlled trials** (<http://www.consort-statement.org>).
- Manuscripts describing systematic reviews and meta-analyses must be submitted in accordance with the PRISMA statement on reporting systematic reviews and meta-analyses (<http://www.prisma-statement.org>).

For guidelines on editorial style, please consult the APA Publication Manual published by the American Psychological Association.

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6. Multiple or Linked submissions

Authors considering submitting two or more linked submissions should discuss this with the Editors in the first instance.

7. Supporting Information

PAPT is happy to accept articles with supporting information supplied for online only publication. This may include appendices, supplementary figures, sound files, videoclips etc. These will be posted on Wiley Online Library with the article. The print version will have a note indicating that extra material is available online. Please indicate clearly on submission which material is for online only publication.

Please note that extra online only material is published as supplied by the author in the same file format and is not copyedited or typeset. Further information about this service can be found at

<http://authorservices.wiley.com/bauthor/suppmat.asp>

Appendix B

DSM-5 Criteria for Borderline Personality Disorder

The essential features of a personality disorder are impairments in personality (self and interpersonal) functioning and the presence of pathological personality traits. To diagnose borderline personality disorder, the following criteria must be met:

A. Significant impairments in **personality functioning** manifest by:1. Impairments in **self functioning** (a or b):

- a. **Identity:** Markedly impoverished, poorly developed, or unstable self-image, often associated with excessive self-criticism; chronic feelings of emptiness; dissociative states under stress.
- b. **Self-direction:** Instability in goals, aspirations, values, or career plans.

AND

2. Impairments in **interpersonal functioning** (a or b):

- a. **Empathy:** Compromised ability to recognize the feelings and needs of others associated with interpersonal hypersensitivity (i.e., prone to feel slighted or insulted); perceptions of others selectively biased toward negative attributes or vulnerabilities.
- b. **Intimacy:** Intense, unstable, and conflicted close relationships, marked by mistrust, neediness, and anxious preoccupation with real or imagined abandonment; close relationships often viewed in extremes of idealization and devaluation and alternating between over involvement and withdrawal.

B. Pathological personality traits in the following domains:

1. **Negative Affectivity**, characterized by:

- a. **Emotional liability:** Unstable emotional experiences and frequent mood changes; emotions that are easily aroused, intense, and/or out of proportion to events and circumstances.
- b. **Anxiousness:** Intense feelings of nervousness, tenseness, or panic, often in reaction to interpersonal stresses; worry about the negative effects of past unpleasant experiences and future negative possibilities; feeling fearful, apprehensive, or threatened by uncertainty; fears of falling apart or losing control.
- c. **Separation insecurity:** Fears of rejection by – and/or separation from – significant others, associated with fears of excessive dependency and complete loss of autonomy.

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d. **Depressivity:** Frequent feelings of being down, miserable, and/or hopeless; difficulty recovering from such moods; pessimism about the future; pervasive shame; feeling of inferior self-worth; thoughts of suicide and suicidal behavior.

2. **Disinhibition**, characterized by:

a. **Impulsivity:** Acting on the spur of the moment in response to immediate stimuli; acting on a momentary basis without a plan or consideration of outcomes; difficulty establishing or following plans; a sense of urgency and self-harming behavior under emotional distress.

b. **Risk taking:** Engagement in dangerous, risky, and potentially self-damaging activities, unnecessarily and without regard to consequences; lack of concern for one's limitations and denial of the reality of personal danger.

3. **Antagonism**, characterized by:

a. **Hostility:** Persistent or frequent angry feelings; anger or irritability in response to minor slights and insults.

C. The impairments in personality functioning and the individual's personality trait expression are relatively stable across time and consistent across situations.

D. The impairments in personality functioning and the individual's personality trait expression are not better understood as normative for the individual's developmental stage or socio-cultural environment.

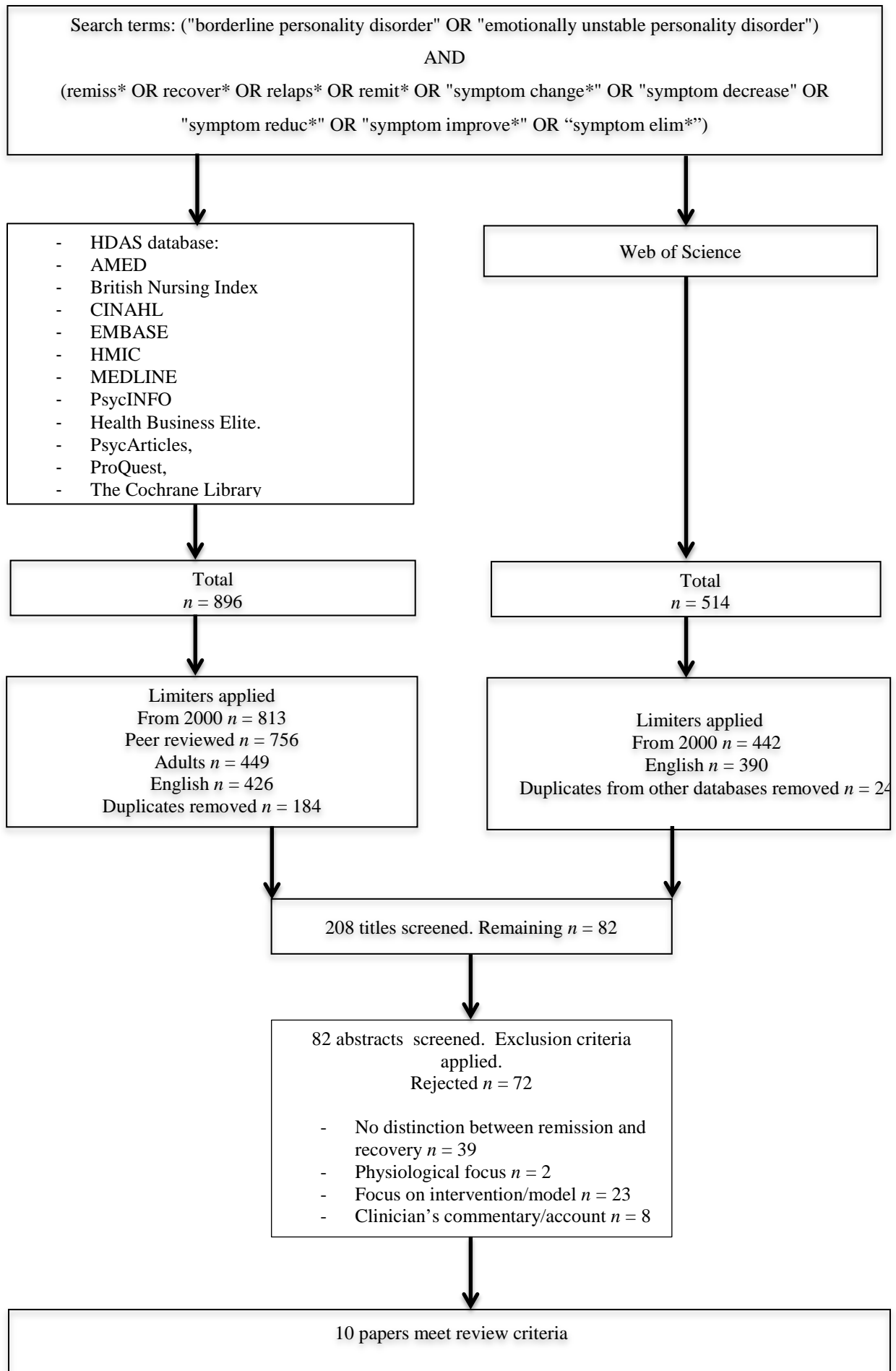
E. The impairments in personality functioning and the individual's personality trait expression are not solely due to the direct physiological effects of a substance (e.g., a drug of abuse, medication) or a general medical condition (e.g., severe head trauma).

Appendix C

ICD-10 Disorders of Adult Personality and Behaviour

F60.3 Emotionally unstable personality disorder	A personality disorder in which there is a marked tendency to act impulsively without consideration of the consequences, together with affective instability. The ability to plan ahead may be minimal, and outbursts of intense anger may often lead to violence or "behavioural explosions"; these are easily precipitated when impulsive acts are criticized or thwarted by others. Two variants of this personality disorder are specified, and both share this general theme of impulsiveness and lack of self-control.
F60.30 Impulsive type	<p>The predominant characteristics are emotional instability and lack of impulse control. Outbursts of violence or threatening behaviour are common, particularly in response to criticism by others.</p> <p>Includes: explosive and aggressive personality (disorder)</p> <p>Excludes: dissocial personality disorder (F60.2)</p>
F60.31 Borderline type	<p>Several of the characteristics of emotional instability are present; in addition, the patient's own self-image, aims, and internal preferences (including sexual) are often unclear or disturbed. There are usually chronic feelings of emptiness. A liability to become involved in intense and unstable relationships may cause repeated emotional crises and may be associated with excessive efforts to avoid abandonment and a series of suicidal threats or acts of self-harm (although these may occur without obvious precipitants).</p> <p>Includes: borderline personality (disorder)</p>

Appendix D – Literature Search Flow Chart



Appendix E

Table E1.
Data Extraction Table

Number	Journal Title, Author(s), Date.	Objective(s)	Sample	Methodology	Measures Use	Identified Recovery Factors	Clinical Implications	Limitations	Definition of Recovery
1.	Defense mechanisms reported by patients with borderline personality disorder and axis II comparison subjects over 16 years of prospective follow-up: Description and prediction of recovery. Zanarini, Frankenburg, & Fitzmaurice. (2013)	Assess defensive functioning of people with BPD; assess the relationship between time-varying defences and recovery from BPD.	290 inpatients with BPD participating in the McLean Study of Adult Development. Between ages 18-35 IQ >71 Fluent in English. 72 patients with other forms of axis II psychopathology. Mean age = 27. 279 = female, 315 = white.	Quantitative. 16-year prospective follow-up. Part of the McLean Study of Adult Development. Semi-structured interviews and questionnaires.	SCID-I for DSM-III-R BIS-R DIB Diagnostic Interview for DSM-III-R Personality Disorders	Four defence mechanisms predict time to recovery: humour, acting out, emotional hypochondriasis and projection.	Could guide treatment, use defences to track progress, work with the patient's sense of humour to strengthen psychosocial adjustment.	Self-report measure = less rich info re: defences, socially acceptable answers. Generalisability issues as all initially inpatients. Large proportion of participants were in outpatient treatment too.	Not stated
2.	The course of marriage/sustained cohabitation and parenthood among borderline patients followed prospectively for 16	To determine the rate of marriage/sustained cohabitation and parenthood reported	290 inpatients with BPD participating in the McLean Study of Adult Development.	Quantitative. 16-year prospective follow-up. Part of the McLean	BIS SCID-I for DSM-III-R	Stable functioning as a partner and as a parent is strongly associated with	BPD patients can have stable relationships. Focus on	All patients were seriously ill at the start of the study. Majority of	During the 2 year interval participants must have: GAF score of

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	years. Zanarini, Frankenburg, Reich, Wedig, Conkey, & Fitzmaurice. (2015)	by recovered and non-recovered borderline patients.	Between ages 18-35 IQ >71 Fluent in English. 72 patients with other forms of axis II psychopathology. Mean age = 27. 279 = female, 315 = white.	Study of Adult Development. Semi-structured interviews.	DIB-R Diagnostic Interview for DSM-III-R Personality Disorders	recovery status.	relationships as part of treatment.	patients in therapy and taking psychotropics at baseline.	61 or more, symptomatic remission, at least one good relationship with a friend or partner, the ability to go to work/school full-time, and be competent when there.
3.	Prediction of time to attainment of recovery for borderline patients followed prospectively for 16 years. Zanarini, Frankenburg, Reich, Wedig, Conkey, & Fitzmaurice. (2014)	To determine the most relevant predictors of time-to-recovery from BPD.	290 inpatients with a diagnosis of BPD participating in the McLean Study of Adult Development. Between ages 18-35 IQ >71 Fluent in English. Mean age = 26.9. 233 = female, 253 = white.	Quantitative. 16-year prospective follow-up. Part of the McLean Study of Adult Development. Semi-structured interviews, questionnaires, self-report measures.	BIS SCID-I for DSM-III-R Revised DIB Diagnostic Interview for DSM-III-R Personality Disorders	Aspects of temperament: no comorbid anxious cluster personality disorders, higher levels of extraversion and agreeableness.	Suggests developing treatments focused on helping borderline patients learn to cope with temperamental symptoms or personalities that are less than helpful	All Pps were seriously ill inpatients and 90% in therapy and taking medication at baseline. How generalisable to non-outpatients.	During the 2 year interval participants must have: GAF score of 61 or more, symptomatic remission, at least one good relationship with a friend or partner, the ability to go to work/school

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									full-time, and be competent when there.
4.	The course of positive affective and cognitive states in borderline personality disorder: A 10-year follow-up study. Reed, Fitzmaurice, & Zanarini. (2012a)	To identify and define the course of positive affective and cognitive states in BPD, and compare the positive affective and cognitive states of borderline patients who recovered to those who did not.	290 inpatients with BPD participating in the McLean Study of Adult Development. 72 patients with other forms of axis II psychopathology. Mean age = 27. 279 = female, 315 = white.	Quantitative. 10-year prospective follow-up. Part of the McLean Study of Adult Development. Self-report scales, structured clinical interviews.	SCID-I for DSM-III-R DIB-R Diagnostic Interview for DSM-III-R Personality Disorders	Higher frequency of positive affective and cognitive states.	Clinicians can try to understand these states to build on the client's strengths.	Patients were severely ill, so results may not generalise. Measure only administered to 33% of sample at baseline. 90% of patients also in therapy and on medication at baseline, 70% after baseline.	Symptom remission combined with good social and vocational functioning over the two year interval.
5.	The course of dysphoric affective and cognitive states in borderline personality disorder: A 10-year follow-up study. Reed, Fitzmaurice, & Zanarini. (2012b)	To assess dysphoric states among people with BPD.	290 inpatients with BPD participating in the McLean Study of Adult Development. 72 patients with other forms of axis II psychopathology. Mean age = 27. 279 = female, 315 = white.	Quantitative. Part of the McLean Study of Adult Development. Structured clinical interview, self-report measures.	SCID-I for DSM-III-R DIB-R Diagnostic Interview for DSM-III-R Personality Disorders	Severity of dysphoric states. Dysphoric cognitive beliefs and feeling states may inhibit recovery.	Addressing patients' sense of competence needed to focus on negative cognitive states to increase likelihood of recovery. Highlights the importance of subjective internal states.	Inpatient sample – how generalisable to less severely ill patients? The Dysphoric Affect Scale only administered to 48% at baseline. Majority in therapy and using medication.	Symptom remission combined with good social and vocational functioning over the two-year interval.
6.	Struggling to recover by	To explore how a	13 women with a	Qualitative	None	Feeling	Focus on	Small sample.	Stated as

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	changing suicidal behaviour: Narratives from women with borderline personality disorder. Holm & Severinsson. (2011)	recovery process facilitated change in suicidal behaviour in people with BPD.	diagnosis of BPD. Mean age = 39, range = 25-53.	Exploratory design. Interviews. Thematic analysis.	identified	confirmed, safe and trusted.	building and maintaining trust. Understand the lived experience of the client through self-reflection groups, supervision and training.	being a subjective process; 'reclaiming of personhood, roles, responsibilities, and self-knowledge.'	
7.	Recovery, as experienced by women with borderline personality disorder. Larivière, Couture, Blackburn, Carbonneau, Lacombe, Schinck, Shella-Ann; David, St-Cyr-Tribble. (2015).	To enrich our understanding of recovery by qualitatively capturing the experience of recovery in women with BPD.	Twelve women, aged between 18-65, with a diagnosis of BPD, have completed at least 2 years in a program for people with BPD.	Qualitative. Interviews, Thematic analysis, Person-Environment-Occupation model framework used.	N/A	A process towards stability and wellbeing.	Letting go of the past, meaningful occupation and being in healthy relationships.	Small sample so problems with generalisability.	Recovery is about personal interpretation – the term 'recovery' is not ideal to describe the process.
8.	Recovery in borderline personality disorder (BPD): A qualitative study of service-users' perspectives. Katsakou, Marougka, Barnicot, Savill, White, Lockwood, & Priebe. (2012).	To explore what service-users with BPD view as recovery.	Forty-eight service-users from CMHT services, all with a diagnosis of BPD.	Qualitative. Semi-structured interviews, grounded theory and thematic analysis.	N/A	Developing self-confidence, emotional regulation, better relationships, employment, occupational activity, improved	Developing individual recovery plans, focusing on personal goals.		

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						symptoms such as self-harm.			
9.	Self and identity in women with symptoms of borderline personality: A qualitative study. Agnew, Shannon, Ryan, Storey, & McDonnell. (2016).	To explore the concept of self/identity from the perspective of the person with BPD.	Five women, aged between 30-45, diagnosis of BPD.	Qualitative. Life story interviews. Thematic analysis.	N/A	Support for theories that conceptualise the self as multiple and relational, empowering healthy parts of the self as part of recovery.	Thinking of identity as dynamic and multiple, not static. Focusing on empowering healthy aspects of the self.	Small sample. Recovery not defined.	None given.
11.	Therapeutic alliances in people with borderline personality disorder. Wright & Jones. (2012).	To show how important the therapeutic relationship is for recovery.	One woman with a long history of BPD.	Qualitative. Case study.	N/A	Being able to trust the clinician, and feel validated by them, clinician with knowledge of BPD, and hopefulness about recovery.	Clinicians to be hopeful about recovery, give some choice and control to clients, to focus on the person not just the difficulties.	Case study is low in quality, no definition of recovery.	None given.

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Data Extraction Table Key:

SCID = The Structured Clinical Interview for DSM Disorders

BIS = The Background Information Schedule

BIS-R = The Background Information Schedule - Revised

DIB = The Diagnostic Interview for Borderlines

DIB-R = The Diagnostic Interview for Borderlines - Revised

DSM = The Diagnostic and Statistical Manual of Mental Disorders

Appendix F
Hierarchy of Evidence

Hierarchy of evidence: a framework for ranking evidence evaluating healthcare interventions:

	Effectiveness	Appropriateness	Feasibility
Excellent	<ul style="list-style-type: none"> • Systematic review • Multi-centre studies 	<ul style="list-style-type: none"> • Systematic review • Multi-centre studies 	<ul style="list-style-type: none"> • Systematic review • Multi-centre studies
Good	<ul style="list-style-type: none"> • RCT • Observational studies 	<ul style="list-style-type: none"> • RCT • Observational studies • Interpretive studies 	<ul style="list-style-type: none"> • RCT • Observational studies • Interpretive studies
Fair	<ul style="list-style-type: none"> • Uncontrolled trials with dramatic results • Before and after studies • Non-randomized controlled trials 	<ul style="list-style-type: none"> • Descriptive studies • Focus groups 	<ul style="list-style-type: none"> • Descriptive studies • Action research • Before and after studies • Focus groups
Poor	<ul style="list-style-type: none"> • Descriptive studies • Case studies • Expert opinion • Studies of poor methodological quality 	<ul style="list-style-type: none"> • Expert opinion • Case studies • Studies of poor methodological quality 	<ul style="list-style-type: none"> • Expert opinion • Case studies • Studies of poor methodological quality

Appendix G

Table G1

Quality of Reporting of Observational Longitudinal Research

Criterion	Paper 1	Paper 2	Paper 3	Paper 4	Paper 5
1. Are the objectives or hypotheses of the study stated?	Y	Y	Y	Y	Y
2. Is the target population defined?	Y	Y	Y	Y	Y
3. Is the sampling frame defined?	Y	Y	Y	Y	Y
4. Is the study population defined?	Y	Y	Y	Y	Y
5. Are the study setting (venues) and/or geographic location stated?	Y	Y	Y	Y	Y
6. Are the dates between which the study was conducted stated or implicit?	N	N	N	N	N
7. Are eligibility criteria stated?	Y	Y	Y	Y	Y
8. Are issues of "selection in" to the study mentioned?	Y	Y	Y	Y	Y
9. Is the number of participants justified?	Y	Y	Y	Y	Y
10. Are numbers meeting and not meeting the eligibility criteria stated?	Y	Y	Y	Y	Y
11. For those not eligible, are the reasons why stated?	Y	Y	Y	Y	Y
12. Are the numbers of people who did/did not consent to participate stated?	Y	Y	Y	Y	Y
13. Are the reasons that people refused to consent stated?	N/A	N/A	N/A	N/A	N/A
14. Were consenters compared with non-consenters?	N/A	N/A	N/A	N/A	N/A
15. Was the number of participants at the beginning of the study stated?	Y	Y	Y	Y	Y
16. Were methods of data collection stated?	Y	Y	Y	Y	Y
17. Was the reliability (repeatability) of measurement methods mentioned?	Y	Y	Y	Y	Y
18. Was the validity (against a "gold standard") of measurement methods mentioned?	N	N	N	N	N

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19. Were any confounders mentioned?	Y	Y	Y	Y	Y
20. Was the number of participants at each stage/wave specified?	Y	Y	Y	Y	Y
21. Were reasons for loss to follow-up quantified?	P	P	P	N	N
22. Was the missingness of data items at each wave mentioned?	N	N	N	N	N
23. Was the type of analyses conducted stated?	Y	Y	Y	Y	Y
24. Were “longitudinal” analysis methods stated?	Y	Y	Y	Y	Y
25. Were absolute effect sizes reported?	Y	N	N	N	N
26. Were relative effect sizes reported?	Y	N	N	Y	Y
27. Was loss to follow-up taken into account in the analysis?	N	N	N	N	N
28. Were confounders accounted for in analyses?	N	N	N	N	N
29. Were missing data accounted for in the analyses?	Y	N	N	Y	Y
30. Was the impact of biases assessed qualitatively?	N	N	N	N	N
31. Was the impact of biases estimated quantitatively?	N	N	N	N	N
32. Did authors relate results back to a target population?	Y	Y	Y	Y	Y
33. Was there any other discussion of generalizability?	Y	Y	Y	Y	Y
Quality Index Score (%)	23.5 (76)	20.5 (66)	19.5 (63)	22 (71)	22 (71)

Note. Y = 1, ‘Partially’ = .5, N = 0.

Appendix H

Table H1

CASP Qualitative Checklist and Index Score

Question	Paper 6	Paper 7	Paper 8	Paper 9
Was there a clear statement of the aims of the research?	Y	Y	Y	Y
Is a qualitative method appropriate?	Y	Y	Y	Y
Was the research design appropriate to address the aims of the research?	Y	Y	Y	Y
Was the recruitment strategy appropriate to the aims of the research?	Y	Y	Y	Y
Was the research collected in a way that addressed the research issue?	Y	Y	Y	Y
Has the relationship between researcher and participants been adequately considered?	N	Y	N	Y
Have ethical issues been taken into consideration?	Y	N	Y	Y
Was the data analysis sufficiently rigorous?	Y	Y	Y	Y
Is there a clear statement of findings?	Y	Y	Y	Y
Is the research valuable? *	Y	Y	Y	Y
Quality Index Score (%)	90	90	90	100

Note. Y = Yes, N = No,*Amended from 'how valuable is the research?' for scoring purposes

Appendix I

List of Measures Used

N.B Self-report format can be assumed unless otherwise indicated.

- Defense Style Questionnaire
- Structured Clinical Interview for DSM–IV Personality Disorders
- Structured Clinical Interview for DSM-III-R Axis I Disorders
- Revised Diagnostic Interview for Borderlines
- Diagnostic Interview for DSM-III-R Personality Disorders
- Background Information Schedule
- Revised Borderline Follow-up Interview
- Revised Childhood Experience Questionnaire (semi structured interview)
- Revised Family History Questionnaire (semi structured interview)
- Abuse History Interview (semi structured interview)
- NEO Five Factor Inventory
- Shipley Institute of Living Scale
- Global Assessment of Functioning (GAF) (completed by clinicians)
- Dysphoric Affect Scale (DAS)
- Occupational Performance History Interview (semi structured interview)
- State-Trait Anger Inventory (STAXI)
- Dissociative Experiences Scale
- Positive Affect Scale

“We have to remember that what we observe is not nature in itself but nature exposed to our method of questioning.”

(Heisenberg, 1962, as cited in Mckeown & Thomas, 2013).

Service-users' and Professionals' Perspectives on the Borderline Personality
Disorder Diagnosis: A Q-methodological Study

Paper 2
Empirical Report

The following paper is intended for publication in *Personality Disorders: Theory, Research, and Treatment*, a peer-reviewed journal. (See Appendix A for journal guidelines). Supplementary material is included for thesis purposes and will be removed for publication.

Word count: 8444

Abstract

Borderline Personality Disorder (BPD) is a particularly contentious diagnosis. There is a bias towards a medical model, a lack of qualitative understanding about BPD and the meaning and implications attributed to the diagnosis (Division of Clinical Psychology [DCP], 2013). This suggests a fundamental lack of understanding from a psychologically informed position. This is juxtaposed with a recent positive shift in guidelines and documents towards hopefulness and recovery, highlighting the complex nature of BPD. This research investigates the varied understandings of the BPD diagnosis for staff working with clients with the label and the service-users themselves. What are the common and distinctive understandings of the diagnosis between service-users and professionals?

Q methodology was used to investigate the primary research question. An initial Q set was developed, drawing on existent literature, a focus group with service-users and individual interviews with professionals. Service-users and professionals then completed Q sorts to reveal their subjective positions on the subject matter. Results were analysed using the PQ method and the factors interpreted by the primary researcher.

The following three factors were found: 'Stigma, Internalisation and Social Construction'; 'Essentialism, Acceptance and Compassion'; and 'Change, Externalisation and Shared Understandings.'

These three factors show that views on the BPD diagnosis are complex and varied, highlighting the importance of identifying people's beliefs to understand how we might most effectively help those with the label.

Abstract word count: 224

Key words: Borderline Personality Disorder, diagnosis, service-users, perspectives, Q methodology.

‘Service-Users’ and Professionals’ Views of the Borderline Personality Disorder
Diagnosis: A Q-methodological Study’

The Borderline Personality Disorder (BPD) label stems from the psychoanalytical branch of psychotherapy and was used by Stern in 1938 (The National Institute for Health and Care Excellence [NICE], 2009) who applied the label to patients whose presentations could not be explained by a diagnosis of neuroticism or psychosis. It was recognised as a disorder and defined by the American Psychiatric Association’s (APA) Diagnostic Statistical Manual of Mental Disorders (DSM) in 1980 and was a contentious diagnosis, due to concerns that the label did not adequately capture the person’s experience (Ramon, Castillo, & Morant, 2001). Due to the same concerns regarding its validity, it remains a controversial diagnosis (Paris, 2007b). It is estimated that BPD affects between 1%-5.9% of the population (Coid, Yang, Tyrer, Roberts, & Ullrich, 2006) and service-users with this diagnosis account for a significant proportion of psychiatric inpatients (National Alliance on Mental Illness, 2015).

Defining BPD

The DSM (5th ed.; DSM-V; APA, 2013) defines BPD as a personality problem reflected in inter and intrapersonal difficulty with functioning. To meet the criteria for a BPD diagnosis a client must exhibit significant impairment in their identity, manifest through enduring feelings of emptiness and an unstable sense of self, or a fluctuating sense of future direction. The client must also have interpersonal problems, such as difficulties empathising or with intimacy, oscillating between idealising others and rejecting them. The DSM states that these personality traits are characterised by intense, unstable emotions, extreme anxiety, a feeling of not being in control, high dependency on others with an associated fear of rejection or abandonment. A BPD diagnosis is indicative of a lack of inhibition, with impulsive behaviours and risky behaviours, and an absence of consequential thinking. The person may be hostile towards others. To meet the diagnostic criteria for BPD, impairments need to be stable across time and contexts and unrelated to culture or developmental stage. Furthermore, the client’s difficulties cannot be rooted in physiological conditions, substance misuse or head injury. The ten different personality disorders (PD) have been further refined into three clusters. Cluster A (labelled ‘Suspicious’) is comprised of paranoid, schizoid and schizotypal. Cluster B (‘Emotional and impulsive’) is comprised of borderline,

histrionic, narcissistic and antisocial PD. Cluster C ('Anxious') is comprised of avoidant, dependent and obsessive compulsive PD (APA, 2013).

Controversy Surrounding Diagnosis

In 2013, a position statement released by the Division of Clinical Psychology (DCP) asserted that the controversy around psychiatric diagnosis is largely due to the application of disease models to psychological domains. Whilst the DCP acknowledge the contribution diagnostics make to the psychological field (such as the general acceptance of classifications by service-users, professionals and the public), it highlights its flawed basis, especially for diagnoses such as PD where there are concerns about validity and cross over with other disorders. These concerns, combined with the reliance upon clinical judgment during assessment, leave some professionals reluctant to make a diagnosis of personality disorder (Paris, 2007a). The DCP (2013) reiterate this subjective position of diagnosis and its roots in a Westernised discourse of wellness, with such ethnocentricity failing to appreciate other cultures and traditions (Shaw & Proctor, 2005).

There has been longstanding debate surrounding the BPD label as particularly stigmatising, with calls to rename it due to the nebulous nature of the term, to address the often traumatic ontogeny and reduce the internalisation of the damaged self (Castillo, 2000). Gunderson (2009) points out the irony of the term 'borderline' because it reflects the disorder's lack of clarity and the ever-changing nature of psychiatric disorders and their associated boundaries. In other research, the diagnosis evokes strong feelings with both professionals and service-users feeling hopeless, rejected, judged by services, and confused as to the exact meaning of the label (Horn, Johnstone, & Brooke, 2007). Whilst professionals use the academic arena to debate the BPD label, service-users may not have such opportunities (Horn, et al., 2007). To get a clear understanding of the meaning of the diagnosis for people it is essential to elicit the views of the wider community on BPD.

Views on Diagnosis

People with a diagnosis of BPD are often involved with mental health services (NICE, 2009) and helping people with this diagnosis can be challenging, with professionals often feeling overwhelmed and lacking the skills to help them (Darongkamas, 2013). One study explored good practice amongst professionals working with BPD and

identified four key themes: shared decision-making, social roles, peer support and open communication (Bowen, 2013). Sansone and Sansone (2013) reviewed the literature examining mental health clinicians' perceptions of clients with BPD. They found that the vast majority focused on psychiatric nurses, indicating a lack of diversity that makes generalisability difficult. They found that attitudes towards patients with BPD were overwhelmingly negative due to their perceptions of the diagnosis and the interpersonal difficulties associated with BPD, such as idealising or devaluing others.

Where previously a diagnosis of BPD signalled lifelong difficulties and a sense of hopelessness in clients and professionals alike (Paris, 2005), more recently there has been a gradual shift towards a more hopeful outcome. There is some recognition that the diagnosis can be validating, giving some tangibility to a set of difficulties. This validation can stem from the perception that a person's problems can be understood as an illness and not a reflection of character flaws (Craddock & Mynors-Wallis, 2014).

A significant increase in research, an evidence base demonstrating positive outcomes and support for a range of psychotherapeutic models such as Dialectical Behaviour Therapy (DBT) has highlighted the potential for change (Brodsky & Stanley, 2013; Winston, 2000). Seminal documents include: 'Personality disorder: No longer a diagnosis of exclusion' (National Institute for Mental Health in England [NIMH], 2003), and 'Meeting the Challenge, Making a Difference' (Department of Health [DoH], 2014). Despite the evidence supporting positive outcomes, there remain some negative perceptions about the diagnosis. This warrants research that looks at the differing perspectives about the BPD label.

Aims of the Current Research

There is a paucity of investigation into peoples' views of the BPD diagnosis from the perspectives of both service-users and professionals, with little understanding as to its meaning, criteria and utility (Ramon et al., 2001). This research will examine service-users' and professionals' viewpoints about the BPD diagnosis.

Method

Ethical Approval

Ethical approval was granted by the sponsor (Staffordshire University; Appendix B) and the NHS Health Research Authority, West Midlands (Appendix C). Research and Development approval was obtained from the North Staffordshire Combined Healthcare

Trust (see Appendix D). A further substantial amendment was made to the research which received favourable opinion (Appendix E).

Methodology

Design. The study used Q methodology. Q methodology enables researchers to systematically study subjectivity and to analyse social perspectives (van Exel & de Graaf, 2005). It allows subjective opinion to be organised into a smaller number of factors, bringing less dominant positions to the fore,³ by exploring opinions about “complex and socially contested concepts... from the point of view of the group of participants involved” (Watts & Stenner, 2012; Watts & Stenner, 2005, p.70). Q methodology incorporates self-reference, examining the internal rather than external framework (McKeown & Thomas, 2013). Quantitative methods purportedly examine data independent of a “consideration of social reality as characterized by intersubjective and common meaning” (Taylor, 1971, p.32), and could be considered as antithetical to the study of intrasubjectivity. Diametrically opposed to this is the idea that personal meaning cannot be quantified: Q methodology dispels both of these myths in doing precisely that (McKeown & Thomas, 2013). In this study, Q methodology gives a voice to those people affected by the BPD diagnosis – the service-user and the people working with them.

The concourse. The concourse is the breadth of opinion about a topic and is a central part of Q methodology (van Exel & de Graaf, 2005). To capture views about the BPD diagnosis a focus group was held for five service-users, and five staff were interviewed individually (see Appendix F for a list of research questions). This led to the development of the Q set (see below; Appendix G).

Participants

Recruitment. There were two consultations with a support group for people with a diagnosis of PD within a local NHS Trust. The researcher attended one of the groups to talk about the project and to facilitate a focus group. After these consultations, a focus group was carried out at the end of the next monthly meeting, with five people who had opted-in at the previous meeting. These five people also

³ Q Methodology is in keeping with the researcher’s epistemological position.

carried out Q sorts. The group facilitator then contacted other group members to ask if they wished to participate in a Q sort. The first five to opt-in were included.

Staff were identified by the researcher attending meetings at local CMHT bases, delivering a brief presentation about the research and handing out information sheets. Staff emailed the researcher to opt-in. The clinical supervisor provided staff on their team with information about the study. Staff emailed the researcher if they wanted to take part. The first five to respond were interviewed on a 1:1 basis to help develop the Q set. They also carried out Q sorts. The next five to opt-in carried out a Q sort. A risk assessment form (see Appendix H) was given to all participants. Participants were asked to inform the researcher should they feel distressed and the process would be halted. All participants received an information sheet and signed a consent form (Appendices I & J).

Study population. Recruitment yielded ten service-users and ten members of staff from a variety of professional groups, including a social worker, a community psychiatric nurse, a psychologist and a support worker.

Demographics. Appendix K presents the demographic information for all participants ($n = 20$). All of the staff members had between two and 25 years of experience in working with people with a diagnosis of BPD. All of the service-users had a diagnosis of BPD and were in various stages of recovery.

Procedure

Step one: The Q set. The focus group and interviews were recorded and transcribed. Journals and internet sites about the BPD diagnosis were accessed to gather opinion and to ensure that the themes captured the public feeling about BPD. Process notes and the transcriptions from audio recordings from the interviews with staff and the service-user focus group were examined in detail to identify themes across the concourse (Appendix L). Online statements were added to the ones generated via the focus group and interviews. Initially this resulted in 147 statements pertaining to the BPD diagnosis. These were further examined to check for any overlap amongst statements and to ensure that all themes were represented. Similar statements were then combined resulting in sixty statements representing all themes and creating the Q set. Each statement was transposed onto a piece of white card and numbered (to aid with

recording the final distribution). The statements were discussed with the research supervisor and a Q methodology working group for validation.

Step two: The Q sorts.

Piloting. A trainee psychologist carried out a pilot Q sort to enhance rigour and validity.

Statement ranking. Participants (the P set) were asked to separate the statements (the Q set) into three piles: ‘most like my view’, ‘neutral’ and ‘most unlike my view’. They were asked to rank order statements relating to their personal views of the BPD diagnosis. A condition of instruction was provided (Appendix M).

The distribution grid. Participants were presented with a forced choice normal distribution grid (Figure 1). Each participant was asked to place the statements onto a 10-point grid (from -5 to +5). Participants were asked to select the two statements that were most like their view on the BPD diagnosis and these were placed on the outermost boxes on the grid. Then they were asked to select the next four that were most like their view and so on until there were no cards left in that pile. The same process was applied to the statements placed in the ‘most unlike my view’ pile. When all the statements were on the grid, they were asked to review it and make any changes. The final distribution was recorded by the researcher onto a smaller, blank grid.

Correlation

The intercorrelations between sorts were calculated (Appendix N) to show the extent of the relationship between sorts i.e. the level of concurrence and disparity between them. Seven of the participants did not correlate with any other, suggesting that their views were different to all other participants'. The remaining 13 all correlated with at least one other sort. Intercorrelations were between both professionals and service-users with no obvious distinction between the two. This suggests that service-users were just as likely to have similar views as other service-users or professionals and vice versa.

Factor Loadings

The potential number of factors within the data was identified using Principal Component Analysis (PCA). Ideally, the model determines the least number of factors that can account for the most variance within the model. PCA initially identified 20 components, determined by factors with an eigenvalue (an indication of the strength of the factor) over one in accordance with the Kaiser-Guttman criterion (Watts & Stenner, 2012). Six factors meet this criterion.

Table 2 shows the eigenvalues and cumulative percentages for components as well as the amount of variance explained by each one.

Table 1

Initial PCA Factor Analysis Results

Component	Eigenvalues	As Percentages	Cumulative Percentages	Variance Explained %
1	4.2800*	21.4001	21.4001	21
2	2.4786*	12.3928	33.7929	12
3	2.1480*	10.7402	44.5331	11
4	1.5202*	7.6012	52.1343	8
5	1.1850*	5.9252	58.0595	6
6	1.1384*	5.6921	63.7516	6

Note. *Significant factor

Initial Analysis

The results of this PCA initially suggest a six-factor model, explaining 64% of the variance. A manual rotation was performed to check that there were factor loadings for all six factors, and automatic pre-flagging was selected. A three-factor model

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accounted for 19 sorts, with a minimum of two people loading onto each factor. As such, a three-factor model was considered most appropriate and Humphrey's rule (Brown, 1980) was applied to Factor 3 to confirm that a three-factor model was preferable to a two-factor model. If the cross production of the two highest loadings on a factor are greater than twice the standard error, then the factor can be included. The following equation determined that this was the case:

$$1/\sqrt{\text{(number of statements in the Q set)}} = \text{standard error. Loading Pp1} \times \text{loading Pp7} \\ = \\ 1/\sqrt{60} = 0.13 \times 2 = .26. .63 \times .80 = .50$$

Appendix O shows the factor loadings for each Q sort on the three extracted factors. The loadings reflect the degree to which each sort is typical of the factor. Factor exemplars are Q sorts that load significantly onto a factor. Overall, this three-factor model explains 45% of the variance, in line with suggestions that a representative model should explain at least 35% of the variance (Watts and Stenner, 2012). Factor 2 is a bipolar factor, with three positively loading sorts and two negatively loading sorts.

Correlation between Factors

Table 3 confirms that there is minimal correlation between factors and so each can be seen as distinct from the others.

Table 3

Correlations between factor scores

Factor	1	2	3
1	1.00	0.22	0.23
2	0.22	1.00	0.19
3	0.23	0.19	1.00

Crib Sheets

To help with the abductive process, crib sheets were created to systematically highlight items ranked higher and lower for each factor over any other factor (see Appendix P) thus further organising the statements to help with the interpretation. Thoroughly going through these sheets meant that nothing was overlooked and each factor's viewpoint was closely attended to.

Consensus and Distinguishing Statements

There were several consensus statements and these are of particular interest as they are ranked similarly across factors – they are not specific to any one factor and are discussed shortly (Appendices Q & R).

Interpretation

Three factors were identified. The factor which explained the greatest amount of variance (18%) was factor one, which seems to represent the negative internalisation of a socially constructed diagnosis, factor two (12%) is a bipolar factor and represents the diagnosis as an essentialist phenomenon and factor three (15%) represents an externalised, socially constructed diagnosis. Factor arrays were created to enable a sound, rigorous and holistic interpretation of the factors. An array represents the viewpoint of the specified factor and emerges from the average loading of the Q sorts onto each individual factor (Appendices S & T).

Factor 1

Stigma, Internalisation and Social Construction. Factor one explains 18% of the variance, with seven Q sorts loading significantly: five were service-users and two were staff. The definition of Factor 1 can be best understood when the qualitative feedback is considered in conjunction with the entire configuration. The idea of a ‘them and us’ dichotomy is exemplified; a separateness between the public and the person with the diagnosis. With regards stigma, Participant (Pp) 2 stated that this is “Reducing for some people with BPD but not in the general public”, “Most people don’t know what it means – they look bemused when you tell them”, and “People think BPD means ‘nutjob’ – the public, not the patients”. This aspect of Factor 1 highlights the need for a new framework for understanding BPD may be required (a distinguishing statement for Factor 1). This idea was endorsed by the majority of participants whose views define Factor 1. Pp 11 stated, “We need a new model because people’s views are so different about BPD so everyone gets treated differently.”

Pp 2 suggested that when the diagnosis is conveyed it needs to be explained not just to the person but also to those around them; as a standalone concept it is devoid of meaning. Pp 3 stated, “The people around me think it means that [the borderline between having a PD and not having one] but I don’t.... People don’t understand.” Pp15 said “BPD? People don’t know what it means.” When considering the items

ranked higher in Factor 1 than any other, the statement ‘People focus on the diagnosis more than the person’ supports a lack of context and understanding of BPD. This idea may explain the disagreement with the statements: ‘Guidelines help reduce the stigma’ and ‘Getting the diagnosis means discharge from services.’ As Pp11 stated, “I haven’t seen all the guidelines and documents but of all the mental illnesses this is the worst – people are sarcastic about BPD and there’s been no change there. They are in services forever – so it’s the opposite of being discharged. It’s rare that they’re discharged.” This indicates a nihilistic conceptualisation of BPD, that it is severe and enduring, reinforcing the stigma. A distinguishing statement that further supports this for Factor 1 is ‘the BPD diagnosis is for life.’

This factor identifies strong views about trauma and BPD, with the majority of participants disagreeing with the idea that a person has to have experienced a major trauma in life to receive this diagnosis. Pp11 said, “People are often surprised if I hand over someone with BPD and there’s no trauma”. Pp8 considered the subjectivity of trauma; “How do we define major trauma? It doesn’t have to be something obvious – it could be subtle. They may not be aware. They may not know. We can’t make generalisations.”

In terms of making sense of difficulties, items ranked lower on Factor 1 than any other factor include: ‘The BPD diagnosis explains a lot’, ‘It’s important to keep a diagnosis of some sort for these problems’, ‘Having the BPD diagnosis provides a shared understanding of BPD’, and ‘The words that make up the label are important’. As Pp 3 stated: “It’s so subjective, it depends on who you see so there’s no point in having a name for it.” This excerpt ties in with the strongly agreed with statement that the helpfulness of the diagnosis depends upon how it’s conveyed, highlighting the subjective responses to receiving this diagnosis, the meaning it is given and the views of the person making the diagnosis.

Statements about how helpful the diagnosis is for the individual and their autonomy were rated neutrally, including, ‘If someone recovers they should still have the diagnosis on their records’, and ‘Getting the diagnosis doesn’t make that much difference’. This further supports the idea that Factor 1 is concerned with others’ perceptions, stigma and poor communication of meaning. It is not that it is a ‘Horrible diagnosis’ or that it is ‘Ingrained so people cannot recover’ (both rated as 0) that matters; people felt that the diagnosis is subjective, that their personal feelings were not always heard, or misunderstood.

Factor 2

Essentialism, Acceptance and Compassion. Factor 2 explains 12% of the variance and captures the viewpoints of two service-users and three professionals. It is a bipolar factor with two negative loadings (Pps 10 and 14). This factor represents the view that the diagnosis of BPD is an intrinsic part of the person, that they are indistinguishable from it and as such would never be considered as ‘recovered’. Participants 10 and 14 agreed with the remaining three sorts with a compassionate view towards people with this diagnosis, but felt that it could only be validating and empowering if services were better designed to help service-users with BPD. They felt that BPD was a ‘Horrible diagnosis’ because it is not used in an appropriate way. Participants 10 and 14 are professionals working in the service and talked about their frustrations with the system. From their position, service-users are not given an adequate service and this impacts upon their feelings about the diagnosis. Pp 10 did not believe that the diagnosis was for life but made a distinction between the diagnosis and the associated difficulties, agreeing with the statement that problems are ingrained and that the diagnosis indicates an essentialist quality. Pps 10 and 14 strongly disagreed with the idea that the diagnosis should be kept on a person’s records because of how disempowering this could be, even if the problems will always be present at some level. For these two participants, there was a sense of needing to protect the service-user. Pp10 talked about how services promote a sense of learned helplessness in the person with the diagnosis, “You can’t cope we’re saying really.” Pp 14 considered the diagnosis from an attachment perspective and talked about the importance of a strong therapeutic bond to help the client feel contained; “Which is less easy now than it was.” Pps 6, 17 and 20 viewed the service-user as less fragile than this, and had a more positive view of services and professionals.

This view is fundamentally positive and accepting, compassionate towards the person and how the diagnosis might affect them. This is initially evident in the distinguishing statements for Factor 2 that strongly disagrees with the ideas that BPD is a ‘Horrible diagnosis’ and that the ‘Personality disorder part of the label causes problems.’ There is a strong sense of acceptance within Factor 2, and that this is part of moving forwards. The diagnosis is seen as ‘validating’, helping people accept and start dealing with their difficulties. The statement ‘Getting the BPD diagnosis is a relief for patients’ was ranked higher in Factor 2 than any other, further supporting this validation.

Factor 2 captures some positive experiences of services with neutral opinions about others' understandings of the label, whether professionals know what to do and how empathic they are. There was strong disagreement with the statement that 'People focus on the diagnosis more than the person', supporting the positive experience.

The idea that the person and the diagnosis cannot be separated is further supported by the strong disagreement that everyone has BPD to a degree and that the term EUPD can be used for everybody. As Pp20 stated, "yes we're all unstable, but to say everyone has it gives the person with BPD a disservice. In a 'normal' person, they have control, they realise it's harmful. But people with BPD we don't have that switch. It's like saying we've all got dyslexia." The perspective that the diagnosis is intrinsic also implies some reduction in autonomy for the diagnosed person; that they surrender themselves to their diagnosis. There was relatively strong overall disagreement with the idea that the diagnosis takes away some of the responsibility from the person, suggesting that people do not feel disempowered. Distinguishing statements including 'BPD is for life' and 'If someone recovers they should still have the diagnosis on their records because it's part of who they are' communicate lifelong difficulties. This factor may be somewhat pessimistic with regards prognosis but does so in a validating way. Initially, the strength of agreement with 'the BPD diagnosis is not based on a true picture of somebody' seemed to contradict this view. When looked at holistically with qualitative feedback in mind, this may be because people believed that a true picture of anybody is difficult to ascertain – it does not make the diagnosis any less valid for them. Service-users and professionals discussed the short time that clients spend with their psychiatrist, but there was a sense of trusting the professional. Pp20 stated, "You may always need support – people are trying to feel safe. You don't know who you are."

Just as with Factor 1, the idea that BPD signifies a major trauma was rejected. People represented by Factor 2 strongly disagreed with these ideas. This is because people felt that the BPD diagnosis delineated more innate difficulties. As Pp 6 stated, "Lots of people experience trauma but most of them don't get a diagnosis of BPD." Whilst Factor 1 drew out ideas about shame and stigma, Factor 2 represents a more compassionate view of the meaning behind the diagnosis. Pp6 talked about how judgmental others can be, but that "that's their misconception – they shouldn't judge." Pp20 talked about how the diagnosis is part of the person but "That's ok – you're always in recovery, you can't forget or you'll make the same mistakes, but there's more

to people than their disorder”. Pp 14 stated, “It’s not about fault, it’s the result of past experiences.”

Factor 3

Change, Externalisation and Shared Understandings. Factor 3 explains 15% of the variance and consists of the views of three service-users and four professionals. Initially Factor 3 seemed to have much in common with Factor 2; on further examination, there are some fundamental differences. Whilst both factors depict a relatively positive view of the diagnosis, Factor 2 suggests passivity in sharp contrast to the more proactive views captured in Factor 3. Within this factor is a strong sense of the possibility of change over acceptance. As Pp4 said in response to the statement, “Getting the BPD diagnosis means people can start dealing with their problems better”, “That’s what it’s all about! That’s me!” whilst Factor 2 also strongly agreed with this, it ranked ‘Accepting difficulties’ more highly than Factor 3 did, reinforcing the idea that the latter takes a more proactive view of the diagnosis. This is exemplified in the distinguishing statement: ‘If they can get appropriate treatment most people recover from BPD’. This factor suggests a positive experience with regards how others understand the diagnosis denoted by strong agreement that ‘It provides a shared understanding’, and strong disagreement that ‘The diagnosis is given because of what people do, not what they feel’ and ‘If someone has this diagnosis then all their problems are attributed to it.’ Within this factor is some agreement that self-discovery is more important than recovery, possibly because of the more accepting nature of this factor. Pp18 said, “even if someone doesn’t recover it doesn’t mean they’ve failed, self-discovery is more important.”

Factor 3 disagreed with the statement ‘Getting the diagnosis doesn’t make much difference’ more than any other factor. When looked at holistically, it suggests that the diagnosis may be empowering. As Pp5 said, “We’ve [people with the BPD diagnosis] been through a lot but our choices are still our choices....Stuff happens in life, life goes on, you don’t always have control, but not every problem is because of having that diagnosis.” There is a sense of a ‘temporary diagnosis’ here; that the usefulness stems from providing a shared understanding and changes how people think of themselves in a *positive* sense – especially as there is strong agreement that the diagnosis is conveyed more positively than it used to be - and disagreement that people should have the diagnosis on their file after they have recovered. Pp12 said that, “It seems to change

VIEWS ON THE BORDERLINE PERSONALITY DISORDER DIAGNOSIS

how people think about themselves and makes them think they have a fighting chance – if that’s what it [a diagnosis] takes then that’s good.” There is a strong sense of autonomy within Factor 3 in line with an empowering perspective. Pp13 said, “I don’t think people with BPD are consulted enough about what they need, it’s the culture, it’s very frustrating.” This factor rated the statement, ‘Having a name makes it a ‘real thing’ or ‘more real’ higher than the other two factors, with Pp 4 saying, “It’s a shared understanding, it’s given me a community. It’s a strength and it reduces the stigma, having a name. I can like myself.” Similarly, Pp5 said, “There’s a reason – it’s not just that I’m dysfunctional, it explains, validates, I’m less alone.” Pp1 said, “Because you’re wondering....am I a bad person? Is there anything wrong? It [the diagnosis] helps to make sense.” It stands to reason then that for Factors 2 and 3 there is disagreement that a new model is needed for understanding the diagnosis – at odds with the view captured in Factor 1.

As Factor 3 suggests that people see the diagnosis as separate from the person, it also highlights how people see this stigma as having less of a negative impact upon the service-user; ‘You still hear things like ‘typical borderline’ or ‘raging borderline PD’ was strongly agreed with and ‘The stigma around the BPD diagnosis is reducing’ was rated neutrally. Pp12 discussed this distinction, saying, “Having the diagnosis has a lot of positives but there’s still stigma around. Sometimes it’s how it’s said not what’s said.” They also said, “I very much disagree that it means something is wrong with the person”, a shared view within this factor. Similarly, Factor 3 slightly disagreed with the statement ‘BPD is a horrible diagnosis’, which may be because it doesn’t have the power to be thought of in this way. As Pp18 said, “I can see how some people might say that but I wouldn’t say that just as I wouldn’t say it was a horrible disorder – there’s lots of elements to it so you can’t generalise.”

The people within this factor had certain opinions about trauma and its relationship to the BPD diagnosis with Pp12 stating, “Well it depends on what you mean by trauma – it could mean anything”, and Pp13: “It just means something’s happened and they didn’t learn to cope”. In keeping with this hypothesis is the strong disagreement with the ideas that BPD and EUPD can be used for anybody: not everybody has it to a degree, it is less intrinsic than that statement would suggest. As Pp4 said, “If people think that [that anyone can have BPD and we all have EUPD to a degree] then they’re just not getting it. It is a bit subjective and there might be elements....but it’s not the same.” This fits in with the overall view that the service-

user understands their diagnosis and can move forwards with it – even if those around them may not – and that that is the most important aspect of diagnosis.

Consensus Statements

The view that services are not set up to help people with the BPD diagnosis was a statement that people tended not to have a strong opinion about, although this was a distinguishing statement for Factor 2. This may be because people felt that relative to other statements this was not something they held strong views on, or that they felt this to be somewhat untrue. The majority of people, when considering this statement felt that they simply did not know whether this was true or not and therefore could not hold a strong opinion about it either way.

The strong disagreement with the statement ‘BPD means the borderline between psychosis and normality’ reinforces the idea that people with the diagnosis and those working with them have a good understanding as to the origins of the BPD label, with strong views about what it does *not* mean.

There was consensus across factors that the medical model does not rule with BPD. This statement was drawn directly from an interview with a member of staff and was somewhat ambiguous with most people checking the meaning behind it. The theory underpinning this statement was that BPD should be viewed as a medical issue. Some people were uncertain and rated this neutrally, but the vast majority disagreed with this – including the psychiatrist.

People agreed that the label makes BPD more ‘real’ and disagreed that EUPD would be a preferable label. The consensus here was that EUPD is ‘just as bad’. Pp5 stated, “I don’t think there is a right label for it.” This statement was ranked particularly highly in Factor 3, reinforcing its pragmatic nature: the diagnosis helps people to recover and move on, so anything that increases the tangibility of this process would be welcomed. Conversely, this statement was only agreed with slightly for Factor 2, befitting the idea that as the person and the diagnosis are so closely linked, having a name may be helpful but it is already very ‘real’ for people with the diagnosis.

People agreed that the diagnosis is a double-edged sword; a statement encompassing all three factors as whilst all acknowledged the advantages and disadvantages to different degrees and in different guises, the contentious nature of the polemic remains central for most people.

Whilst not a consensus statement, the lacklustre response to ‘We need to keep a diagnosis of some sort for these problems’ is noteworthy, with neutrally clustered rankings across factors. This statement taps into a fundamental issue: should a diagnosis for this particular set of presenting problems be kept at all? The neutrally clustered ranking depicts strong feelings that this should be a personal choice, and does not highlight an ambivalence of any sort. As Pp13 stated, “There’s always room to be kind, they still need the human side, people can be too rigid about diagnosis to the point of being cruel.” Pp18 summarised their opinion with, “Regardless of the label it’s about their experience and distress, they might have a symptom that doesn’t fit the diagnosis. Same as if they have the diagnosis but they might be ok – the diagnosis wasn’t needed. We need to ask ‘how can we help them, label or not?’”

Discussion

Three factors explained 45% of the variance and sorts. Factor one was ‘*Stigma, Internalisation and Social Construction*’, Factor two was ‘*Essentialism, Acceptance and Compassion*’ and Factor three was ‘*Change, Externalisation and Shared Understandings*’. Factor one links into past research that highlighted the negative attitudes exhibited by mental health services towards people with a diagnosis of BPD (Markham & Trower, 2003). More positively, professionals would like to improve these apparently strained relationships (Woollaston & Hixenbaugh, 2008). The answer to this may lie in the fundamental finding encapsulated in this factor: a systemic idea of a contextual self needs to be promulgated. Essentially, this factor highlights how society maintains the positions of the more vulnerable members of society by locating the difficulties in the individual.

The idea of a divide between public perception and personal understanding highlights the misrepresentation of those with BPD as fundamentally different. The distinguishing statement ‘Professionals don’t know what to do for people with BPD’ supports this position. This sense of polarisation perpetuates the stigma and is internalised by the vulnerable individual, as supported by the views that most people do not recover. The stigma associated with mental health problems is a longstanding and well-established relationship that impacts upon the well-being of individuals with a disorder (Couture & Penn, 2003). The implications of a mental health diagnosis are often deleterious to the sufferer, affecting their environment (such as employment) and leading to a negative internalised sense of self, with increased shame (Knight, Wykes,

& Hayward, 2003). Flanagan and Davidson (2007) draw attention to the paradox that if people are defined by their diagnosis then recovery becomes an impossibility, finding that whilst there is a decline in classifying people a trend towards this still remains. Factor 2 ultimately validates this theory for there seems to be a relationship between the degree to which a person identifies with their diagnosis and the degree to which they believe they can ever recover. In many respects, Factor 2 could be summarised with the flowing quote: *“Your label is a reality that never leaves you; it gradually shapes an identity that is hard to shed”* (Leete, 1989, p.199). If the diagnosis is integrated into the person, it may well be that whilst they may think recovery is impossible, they may not want to ‘shed’ part of who they are.

The rejection of the idea that a person has to have a major trauma to receive a BPD diagnosis may explain why the statement that emotion regulation difficulties would be a better name was strongly agreed with (and is a distinguishing statement), and the rejection of the word ‘trauma’ in the label was strongly agreed with. People felt it was subjective and generalisations cannot be made. The idea of generalisations is central to diagnosis because it implies certain shared characteristics. This issue is raised in Factor 1 as it captures the view that because of a perceived basic lack of understanding about BPD, people do not believe that the label is helpful as it does not accurately communicate what they would wish it to. The idea of the distinction between person and diagnosis may explain the different understandings of trauma in Factor 3, with the statement ‘It’s hard to understand if someone has this diagnosis but has no major trauma in their life’ rated neutrally. Factor 3 suggests a certain complacency about this angle – it does not matter either way, some people have had a trauma, others have not, but as the diagnosis is not bound up tightly with the person’s sense of self then this issue is not seen as particularly important.

Factor 3 can be considered in light of research suggesting that promoting biological explanations for mental health problems would distinguish the person from the disorder meaning that the person is not ‘at fault’. Conversely, Goldstein and Rosselli (2003) suggest that physiological conceptualisations of mental illness may increase stigma in implying a fundamental flaw in the person’s makeup. Read, Sayce and Davies’ review of the literature up to 2004 found that biogenetic models of distress increase stigma, with professionals more likely to view a patient as ‘ill’ and less likely to involve them in their care (2006). Factor 3 suggests that this debate is too simplistic with people able to separate the disorder from the person without requiring

physiological explanations. The view that the medical model does not rule with BPD indicates that people felt that BPD is better explained with a psychological model, a hypothesis that is bolstered by the qualitative data from the post sort discussions.

The wide variety of opinions about the BPD diagnosis captured in the research highlights the idiosyncratic relationship between a person and the label. Whilst this could be said of all diagnoses, BPD is arguably one of the most controversial making it even more important to explore subjective beliefs around it. Doing so requires the requisite skills, and is a reminder of the importance of the therapeutic relationship. It is widely acknowledged that the relationship between client and therapist is fundamental to the success of the therapy, regardless of treatment model, affecting several areas of treatment including clinical outcome (Leach, 2005). Given the current knowledge base about the interpersonal difficulties associated with the BPD diagnosis, the role of the therapeutic alliance may be particularly important in creating the optimum environment for the client. When a client experiences a non-judgmental, empathic, genuine relationship with their therapist, they are safe to explore intolerable feelings (Millar, Gillanders, & Saleem, 2012). This links in with supervision to help the professional maintain these Rogerian core conditions (1951) regardless of their personal feelings and beliefs.

Exploration is a fundamental part of clinical supervision, a mandatory part of working psychologically and the findings from this research are a reminder of its importance, particularly in light of the differing opinions of staff as to the meaning of the diagnosis. Supervision allows for the acknowledgment and exploration of these views, providing a forum in which the diagnosis itself is not necessarily of paramount importance. Supervision must be prioritised even in the current testing economic climate, to fortify the psychological understandings of the BPD diagnosis, evident across participants in the current research. With such a loaded diagnosis, it is particularly important that supervision is offered and maintained for all disciplines. This research involved psychologists, social workers, support workers and psychiatric nurses amongst other professions, all of whom work in community settings with people with a BPD diagnosis.

Since 2010, the service from which all of the participants were drawn started to offer 'Knowledge and Understanding Framework Training' (KUF), designed to support effective working with people with personality disorder and to enhance the experiences of service-users. The qualitative feedback from this research indicated a strong

preference for maintaining this training with regular refreshers. This latter point is particularly important in ensuring that any negative attitudes about and towards the BPD label that can become pervasive in the culture of any organisation are identified and challenged. When viewed holistically, this research reinforces this suggestion, highlighting an understanding as to the origins of the BPD label. As the label is seen as pejorative by some, with others feeling uncertain about recovery, such training remains of paramount importance. As KUF training is service-user led, the potential for empowerment must also be borne in mind in the rationale for its dissemination.

This research reinforces that of Horn et al. (2007) whose IPA study found that service-users experience the BPD diagnosis in conflicting ways, as both validating and rejecting. Whilst Horn et al. (2007) recommend a social constructionist conceptualisation of BPD, this could be invalidating for those that view their diagnosis as fundamental to them, part of their identity that has been integrated and accepted. The following recommendations are ways to try to resolve diametrically opposed views, such as constructionism and essentialism:

- When a client enters services it cannot be assumed that they are seeking a diagnosis. Therefore, before they reach this point (usually an appointment with a psychiatrist) this needs to be ascertained during the assessment process,
- Before a diagnosis is given it would be helpful to discuss the service-user's ideas about diagnosis as a tool, what they would hope to gain from receiving one, their fears around being given a label – such as stigmatisation - what their beliefs are about recovery, and their opinion about the stability and fluidity of the label,
- If the client meets the criteria for a diagnosis of BPD, then their difficulties must be formulated collaboratively. No client should receive this diagnosis without a formulation to help them make sense of their difficulties,
- Changing the words in the label does not get to the crux of the debate around BPD and is not the area to focus upon. Having formulated their difficulties, the client can be explicitly informed about the controversy about the BPD label, with statements such as: “looking at your formulation, the difficulties you have had in the past and how they affect you now, might mean that you would receive this diagnosis...”
- If the service-user has made the informed decision to receive a diagnosis then they must be provided with information pertaining to how it is currently understood,
- Service-users must be given information about the retractable nature of BPD and that

recovery is possible,

- Staff must be transparent about the power differential in the room to help empower the client and move towards a more heuristic stance, “you know yourself far better than I ever could so what would be most helpful to you at the moment?”
- Supervision must be prioritised for all staff working with people with a diagnosis of BPD not least to challenge assumptions and prejudices that they may or may not be aware of, to consider the impact of the diagnosis for the service-user and to ensure that they are up to date with guidelines and research.

Study Strengths and Limitations

Although the intention with this research was not to discover an underlying theory about views of the BPD diagnosis, the methodology means that there are issues with generalisability. It is unlikely that a generic perspective about the BPD diagnosis exists. As the research is underpinned by a social constructionist ontology, the sample size is of little significance as there is no ‘truth’ waiting to be discovered, only a complex set of interactions between people. The nature of the research in terms of sample size and design also means that the role of the researcher is integral to the process. This is in keeping with the epistemology and the idea that meaning is created *between* rather than *within* people, and means that a different researcher is likely to have different interpretations of the factors and would emphasise different aspects of the study.

A strength of the research is in the originality because it has captured the views of the diagnosis of BPD from service-users with the label and the staff who work with them. Q methodology has not previously been used to identify these perspectives and this is particularly important as it is well placed to identify underrepresented views and unacknowledged beliefs.

The existing literature regarding views on the diagnosis focuses on either service-users or staff; one aim of this study was to synthesise both sets of opinion and identify any significant divergence. The fact that none existed helps shore up a more collaborative position on diagnosis, looking for similarity and shared views rather than difference. This is reinforced by the inclusion of various professional disciplines to capture a range of views. An equal number of staff and service-users with the BPD diagnosis were included; whilst this was a challenge, it was imperative if the study was to achieve its aim of hearing the voices of people often marginalised. Unfortunately,

despite this equal representation, the inclusion of men and women, and a relatively broad age range, all of the participants identified their ethnicity as ‘white’, highlighting a lack of cultural diversity.

An unexpected strength of the study was the impact upon service-users who all fed back directly or indirectly that they had very much enjoyed the research and had learned from it, felt listened to, and realised that their opinions really mattered. The service-users were all keen to hear the outcome of the research and were curious as to how it could be used to help increase understanding of the BPD label. It is hoped that to some degree and in some format this research will contribute to furthering understanding and challenging assumptions associated with the BPD diagnosis.

Future Research

It would be interesting to capture the views of people who have received a diagnosis but have chosen not to engage with services and/or treatment to identify whether they have different views on the label. This may go some way to help identify ways to engage people who are particularly hard to reach – perhaps because of derogatory connotations the diagnosis has for them or due to the severity of their difficulties.

It would be enlightening to carry out a Q-methodological study to capture views on other diagnoses, and reveal opinions that may have been missed. This applies to other controversial diagnoses such as ‘schizophrenia’ as well as those that have greater acceptance in the public domain, such as bipolar.

Lastly, as KUF training is rolled out across Trusts within the NHS, Q methodology is a systematic way of identifying subjective views, and thus evaluating what impact this training has upon perception.

Conclusion

Evidently, the BPD diagnosis remains controversial, dividing people as to its utility. On the one hand, diagnosis can help with sense making and inform treatment, yet on the other, pathologises behaviour and may reduce treatment options (Wykes & Callard, 2010). With these tensions in mind, it is important to consider the benefits of diagnosis for people within the present study. It would be an oversimplification to say that it invalidates experience, locates the difficulty in the person and stigmatises individuals. Whilst this is certainly the position for some, for others a diagnosis can be validating, a

way of making sense of a life often beset by instability. A diagnosis can liberate the patient, enable them to research recovery and treatment, and connect with others.

These findings mirror what may well be the broader reality of the BPD diagnosis outside of this study; there are no clear divides with regards its utility. This research highlights the dangers with making assumptions based on personal political standings, it may be a dramatic oversimplification to be ‘antipsychiatry’ or pro a recovery model for example. Jørgensen et al. (2013) stated that there is no ‘one size fits all’ treatment for BPD, and whilst this may be because the optimum treatment has yet to be discovered, it may be due to the highly personal nature of diagnosis.

This research fulfilled its aim of exploring staff and service-users’ views of the BPD diagnosis. The research aimed to identify whether there was any significant divergence in terms of views on the diagnosis, and discovered a unity across service-users and staff. There was no notable polarisation or sense of ‘them’ and ‘us’; the key here was individual opinion over cohort.

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Appendix A
Journal Information and Guidelines

ISI Impact Factor: 3.221

Personality Disorders: Theory, Research, and Treatment ® (PD:TRT) publishes a wide range of cutting edge research on personality disorders and related psychopathology from a categorical and/or dimensional perspective including laboratory and treatment outcome studies, as well as integrative conceptual manuscripts and practice reviews that bridge science and practice.

Manuscripts presenting empirical findings may be submitted as full-length articles. Full-length articles should not exceed 36 pages total (including cover page, abstract, text, references, tables, and figures), with margins of at least 1 inch on all sides and a standard font (e.g., Times New Roman) of 12 points (no smaller). The entire paper (text, references, tables, etc.) must be double-spaced.

Prepare manuscripts according to the *Publication Manual of the American Psychological Association* (6th edition). Manuscripts may be copyedited for bias-free language.

Use Word's Insert Table function when you create tables. Using spaces or tabs in your table will create problems when the table is typeset and may result in errors.

All manuscripts must include an abstract containing a maximum of 250 words typed on a separate page. After the abstract, please supply up to five keywords or brief phrases.

List references in alphabetical order. Each listed reference should be cited in text, and each text citation should be listed in the References section.

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Appendix B
Independent Peer Review Approval letter



Faculty of Health Sciences

INDEPENDENT PEER REVIEW APPROVAL FEEDBACK

Researcher Name Philippa Smith
Title of Study Service users and professionals views of the BPD Diagnosis: A Q-Study
Award Pathway DClinPsy
Status of approval: **Approved**

Thank you for forwarding the amendments requested by the Independent Peer Review Panel (IPR)

Action now needed:

You must now apply to the Local Research Ethics Committee (which serves the Trust within which you intend to complete your study) for approval to conduct your study. You must not commence the study without this second approval. To seek approval you will need to complete the application form for the committee and forward copies of your proposal.

Please forward a copy of the letter you receive from the L.R.E.C. to Andrea Boardman at the Science Centre as soon as possible after you have received approval. Once you have received L.R.E.C. approval you can commence the implementation phase of your study. You should note that any divergence from the approved procedures and research method will invalidate any insurance and liability cover from the University. You should, therefore, notify the Panel of any significant divergence from this approved proposal.

It is now possible to begin writing your dissertation and you may wish to consult with your supervisor on this matter.

A Boardman

PP **Signed:** Dr E Boath
Chair of the Faculty of Health Sciences IPR Panel

Date: 18th February 2015

Appendix C

Research Ethics Committee Letter of Favourable Opinion

NRES Committee West Midlands - The Black CountryRoyal Standard Place
Nottingham
NG1 6FSTelephone: 0115 8839435
Fax: 0115 8839294

18 May 2015

MISS PHILIPPA SMITH
C/O STAFFORDSHIRE UNIVERSITY
THE SCIENCE CENTRE
STOKE ON TRENT
ST4 2DE

Dear MISS SMITH

Study title:	Service Users' and Professionals' Views of the Borderline Personality Disorder Diagnosis: A Q Study
REC reference:	15/WM/0120
IRAS project ID:	174250

Thank you for your letter of , responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager, Miss Georgia Copeland , nrescommittee.westmidlands-blackcountry@nhs.net. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

VIEWS ON THE BORDERLINE PERSONALITY DISORDER DIAGNOSIS

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publicly accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra_studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from NRES. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

VIEWS ON THE BORDERLINE PERSONALITY DISORDER DIAGNOSIS

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Certificate of Employers' Liability Insurance]	1	10 March 2015
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance Certificate]		29 May 2014
Interview schedules or topic guides for participants [Focus Group Questions]	1	22 February 2015
IRAS Checklist XML [Checklist_07052015]		07 May 2015
Letters of invitation to participant [Email to staff]	1	22 February 2015
Other [Risk Assessment V1]	1	22 February 2015
Participant consent form [Consent form V2]	2.0	01 May 2015
Participant information sheet (PIS) [PIS V2]	2.0	01 May 2015
REC Application Form [REC_Form_31032015]		31 March 2015
Research protocol or project proposal [Study protocol]	1	22 February 2015
Summary CV for Chief Investigator (CI) [CV]	1	10 March 2015
Summary CV for supervisor (student research) [Supervisor CV]	1	10 March 2015
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Overall Process Flow Chart]	1	22 February 2015

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical reviewReporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

VIEWS ON THE BORDERLINE PERSONALITY DISORDER DIAGNOSIS

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at

<http://www.hra.nhs.uk/hra-training/>

15/WM/0120

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely

A handwritten signature in black ink, appearing to be 'PP' followed by a stylized, cursive signature.

**Dr Hilary Paniagua
Chair**

Email: nrescommittee.westmidlands-blackcountry@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to: DR HELEN COMBES

MS LOUISE ALSTON, North Staffordshire Combined Healthcare NHS Trust

Appendix D
Research and Development Approval Letter

North Staffordshire Combined Healthcare 
NHS Trust

RESEARCH AND DEVELOPMENT DEPARTMENT
Trust Headquarters (Lawton House)
Bellringer Road, Trentham, Stoke-on-Trent, ST4 8HH
Telephone: 01782 441687/651 : Fax: 01782 441637/624
Email: r&d@northstaffs.nhs.uk : Twitter: @nschtresearch

08 June 2015

R&D Ref: CHC0112/RD

Miss Philippa Smith
Trainee Clinical Psychologist
North Staffordshire Combined Healthcare NHST
c/o Staffordshire University
The Science Centre
Stoke-on-Trent ST4 2DE

Dear Philippa

Study Title: Service Users' and Professionals' Views of the Borderline Personality Disorder Diagnosis – A Q Study
Chief Investigator: Miss Philippa Smith
Sponsor: Staffordshire University

I can confirm that the above project (R&D application) has been reviewed and given NHS Permission for Research by the Research & Development Department for North Staffordshire Combined Healthcare NHS Trust, and the details have been entered onto the R&D database.

I note that this research project has been approved by West Midlands – The Black Country Research Ethics Committee [15/WM/0120].

NHS permission for the above research has been granted on the basis described in the application and supporting documentation. The documents reviewed were:

Document	Version Number	Date
Protocol	1.0	22/02/2015
Participant Information Sheet	1.0	22/02/2015
Consent Form	1.0	22/02/2015
Email Invitation to Staff Participants	1.0	22/02/2015
Overall Process Flowchart	1.0	22/02/2015
Focus Group Questions	1.0	22/02/2015
Risk Assessment	1.0	22/02/2015

Chairman: Mr Ken Jarrold CBE

Chief Executive: Mrs Caroline Donovan

Working to improve the mental health and wellbeing of local communities



R&D-TMP-001

Version 4.1 (03/12/2013)

 @nscht1
www.combined.nhs.uk

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The research Sponsor, Chief Investigator, or the local Principal Investigator at a research site, may take appropriate urgent safety measures in order to protect research participants against any immediate hazard to their health or safety. The R&D Office should be notified of any such measures, the reasons for the action and any further action required. The R&D Office should also be notified within the same time-frame as that of the research ethics committee and other regulatory bodies.

Approval by the R&D Department therefore assumes you have read, understand and agree to comply with:-

- ❖ Research Governance Framework (www.doh.gov.uk/research)
- ❖ ICH Guidelines on Good Clinical Practice
- ❖ Data Protection Act 1998
- ❖ Mental Capacity Act 2007
- ❖ Medicines for Human Use (Clinical Trials) Regulations 2004
- ❖ Human Tissue Act 2004
- ❖ All applicable Trust policies & procedures

In line with these requirements, may I draw your attention to the need for you to provide the following documentation/notifications to the R&D Office throughout the course of the study, and that all amendments (including changes to the local research team) need to be submitted to, and approved by R&D, in accordance with IRAS guidance:-

- ❖ Annual Progress Report (form sent by this R&D Office)
- ❖ End of Study Declaration Form (available via IRAS)
- ❖ End of Study Report (produced by the Chief Investigator)
- ❖ Changes to study start and end dates
- ❖ Changes in study personnel

Please note that this NHS organisation is required to monitor research to ensure compliance with the Research Governance Framework, and other legal and regulatory requirements. This will be achieved by random audit conducted by this department.

I would like to take this opportunity to wish you well with your research. If you need any further advice or guidance please do not hesitate to contact us.

Yours sincerely



Dr Richard Hodgson
Associate Director for R&D

Copies to:
Dr H Combes, Academic Supervisor
Dr C O'Callaghan, Clinical Supervisor
Dr D Okolo, Clinical Director
Dr E Boath, Sponsor Rep.

Chairman: Mr Ken Jarrold CBE

Chief Executive: Mrs Caroline Donovan

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R&D-TMP-001


Version 4.1 (03/12/2013)

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Appendix E

Research Ethics Committee Amendment Approval Letter

	
Health Research Authority	
West Midlands - The Black Country Research Ethics Committee	
Royal Standard Place Nottingham NG1 6FS	
Tel: 0115 883 9435	

04 November 2015

Miss Philippa Smith
Staffordshire University
The Science Centre
STOKE ON TRENT
ST4 2DE

Dear Miss Smith

Study title:	Service Users' and Professionals' Views of the Borderline Personality Disorder Diagnosis: A Q Study
REC reference:	15/WM/0120
Amendment number:	1
Amendment date:	15 October 2015
IRAS project ID:	174250

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Discussion

There were no ethical issues raised.

Approved documents

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Notice of Substantial Amendment (non-CTIMP)	1	15 October 2015
Participant consent form	3	13 October 2015
Participant information sheet (PIS)	3	13 October 2015
Research protocol or project proposal	3	13 October 2015

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.



Health Research Authority

West Midlands - The Black Country Research Ethics Committee

Attendance at Sub-Committee of the REC meeting on 30 October 2015

Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Dr Joseph Arumainayagam	Consultant and Honorary Senior Clinical Lecturer in HIV and GUM	Yes	
Dr Hilary Paniagua (Chair)	Senior Lecturer	Yes	

Also in attendance:

<i>Name</i>	<i>Position (or reason for attending)</i>
Miss Lindsey Wallace	REC Assistant

Appendix F
Research Questions

Interview questions: Professionals

- What is your experience of working with clients with BPD?
- What is your opinion of BPD as a diagnosis?
- What is your opinion of the words that make up the label?
- How do you feel about working with clients with this diagnosis?
- What do you think about recovery from this diagnosis?
- What do you think is most helpful about this diagnosis for clients?
- What is less helpful?
- What do you think about the guidelines for BPD diagnosis and management?
- Is there anything that you would to change about the current treatment and management of people with BPD in your service?
- What difference does the diagnosis make for you and service-users?

Focus group questions: Service-users

- What is your opinion of BPD as a diagnosis?
- What is your opinion of the words that make up the label?
- What do you think about recovery from this diagnosis?
- What has been your experience of treatment and management for this diagnosis in services?
- Which specialties have you worked with because of your disorder? E.g. psychiatry, psychology.
- What are the similarities and differences of working with different specialities in your opinion (If any)?
- What have you found most helpful about the diagnosis?
- What have you found less helpful?
- What difference does the diagnosis make for you and staff?
- What did getting the diagnosis mean for you?

Appendix G

The Q Set

1. In services people focus on the BPD diagnosis more than the person
2. Services are not set up to help people with the BPD diagnosis
3. The stress professionals are under makes them less empathic towards people with the BPD diagnosis
4. Guidelines and documents have helped reduce the stigma of the BPD diagnosis
5. Professionals don't think people can recover from BPD
6. You still hear things like 'typical borderline' or 'raging borderline PD'
7. Professionals do not know what to do for people with the BPD diagnosis
8. To have a diagnosis of bipolar is more acceptable than a diagnosis of BPD
9. Professionals don't know how to explain the BPD diagnosis to someone
10. The stigma around the BPD diagnosis is reducing
11. Getting the BPD diagnosis means more access to treatment and services
12. If someone has the BPD diagnosis then all their problems are attributed to it
13. Getting the BPD diagnosis leads to discharge from services
14. The BPD diagnosis is not based on a true picture of someone
15. People don't understand the difference between the BPD diagnosis and other personality disorder diagnoses
16. The BPD diagnosis means someone is like Jekyll and Hyde
17. Everyone has BPD to a degree – having the diagnosis is just about the severity or degree z
18. The BPD diagnosis means that something is wrong with the person
19. The majority of people don't know what the BPD diagnosis means
20. The 'personality disorder' part of the BPD diagnosis causes problems
21. The BPD diagnosis is given because of what people do, not what they feel
22. The BPD diagnosis changes how people think about themselves
23. BPD means the borderline between psychosis and normality
24. Having the BPD diagnosis means a person has experienced a major trauma in their life
25. It's hard to understand if someone has this diagnosis but has no obvious trauma in their life
26. BPD means the borderline between not having a PD and having one
27. BPD diagnosis says nothing about severity of difficulties

VIEWS ON THE BORDERLINE PERSONALITY DISORDER DIAGNOSIS

28. A BPD diagnosis means problems are ingrained so people can't recover
29. Recovery from BPD is less realistic because of the current economic climate and pressures of services
30. Self-discovery is more important than recovery from BPD
31. If someone recovers from BPD they should still have the diagnosis on their records because it's part of who they are
32. If they can get appropriate treatment, most people recover from BPD
33. Patients should be the judge of whether they should still have the BPD diagnosis or not
34. The BPD diagnosis is for life
35. Having the BPD diagnosis provides a shared understanding of BPD
36. How helpful the BPD diagnosis is depends on how it's conveyed
37. The BPD diagnosis is conveyed more positively to clients than it used to be
38. The diagnosis of BPD is validating
39. Getting the BPD diagnosis means people can start accepting their difficulties
40. Getting the BPD diagnosis means people can start dealing with their problems better
41. Getting the BPD diagnosis doesn't make that much difference
42. Getting the BPD diagnosis is a relief for patients
43. Getting the BPD diagnosis means people can stop hunting around for explanations
44. The BPD diagnosis explains a lot
45. The BPD diagnosis guides the professional down the right path
46. People think it's hard to treat because there's no medication for BPD
47. We need a new model for understanding the BPD diagnosis
48. The medical model rules with BPD
49. The BPD diagnosis doesn't fit a medical model
50. It's important to keep a diagnosis of some sort for these problems
51. Having a name makes it a 'real thing' or more 'real'
52. Having the word trauma in the label would be unhelpful because people's experiences are so different
53. Emotionally Unstable Personality Disorder is a better name than BPD
54. The term Emotionally Unstable Personality Disorder can be used for everybody – we're all unstable sometimes
55. The words that make up the label are important
56. The BPD diagnosis is a double edged sword
57. The BPD diagnosis takes some of the responsibility away from the person

VIEWS ON THE BORDERLINE PERSONALITY DISORDER DIAGNOSIS

58. If someone with a diagnosis of BPD re-enters services they are reassessed
59. BPD is a horrible diagnosis
60. Emotional regulation difficulties would be a better name for BPD

Appendix H
Risk Assessment Form

Risk Assessment

Name:

Date:

All participants are required to complete this assessment tool. Should any concerns arise please see the 'what if there is a problem?' section of the Participant Information sheet.

SUICIDE

- Previous attempts on their life
- Previous use of violent methods
- Misuse of drugs and/or alcohol
- Major psychiatric diagnoses
- Expressing suicidal ideas
- Considered/planned intent
- Believe no control over their life
- Separated/widowed/divorced
- Unemployed/retired
- Recent significant life events
- Major physical illness/disability
- Helplessness or hopelessness
- Expressing high levels of distress
- Family history of suicide
- Other (please specify)

NEGLECT

- Previous history of neglect
- Failing to drink properly
- Failing to eat properly
- Difficulty managing physical health
- Living in inadequate accommodation
- Lacking basic amenities (water/heat/light)
- Pressure of eviction/repossession
- Lack of positive social contacts
- Unable to shop for self
- Insufficient/inappropriate clothing
- Difficulty maintaining hygiene
- Experiencing financial difficulties
- Difficulty communicating needs
- Denies problems perceived by others
- Other (please specify)

AGGRESSION/VIOLENCE

- Previous incidents of violence
- Previous use of weapons
- Misuse of drugs and/or alcohol
- Male gender, under 35 years of age
- Known personal trigger factors
- Expressing intent to harm others
- Previous dangerous impulsive acts
- Paranoid delusions about others
- Violent command hallucinations
- Signs of anger and frustration
- Sexually inappropriate behaviour
- Preoccupation with violent fantasy
- Admissions to secure settings
- Denial of previous dangerous acts

VIEWS ON THE BORDERLINE PERSONALITY DISORDER DIAGNOSIS

OTHER

- Self-injury (e.g. cutting, burning)
- Other self-harm (e.g. eating disorders)
- Stated abuse by others (e.g. physical, sexual)
- Abuse of others
- Harassment by others (e.g. racial, physical)
- Harassment of others
- Risks to child(ren)
- Exploitation by others (e.g. financial)
- Exploitation of others
- Culturally isolated situation
- Non-violent sexual offence (e.g. exposure)
- Arson (deliberate fire-setting only)
- Accidental fire risk
- Other damage to property.....

The Sainsbury Centre for Mental Health 2000.

CLINICAL RISK MANAGEMENT TOOL

Retrieved from:

<http://www.bcpft.nhs.uk/documents/policies/c/771-care-programme-approach-cpa-documentation-clinical-risk-tool-2-sainsburys/file>

Appendix I
Participant Information Sheet



Staffordshire & Keele
Universities
*DOCTORATE IN CLINICAL
PSYCHOLOGY*



Participant Information Sheet

Study title: “Service-users’ and Professionals’ Views of the Borderline Personality Disorder Diagnosis: A Q-methodological Study.”

Investigator: Philippa Smith

Invitation and brief summary

You are invited to take part in a research study. Before you decide, you need to understand why the research is being done and what it would involve for you. Please take the time to read the following information carefully. Talk to others about the study if you wish.

(Part 1 tells you the purpose of the study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study).

Please ask the researcher if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Part 1

What is involved?

Research tells us that people with a diagnosis of Borderline Personality Disorder (BPD) (also known as Emotionally Unstable Personality Disorder) are often involved with mental health services. However, less is known about people's perceptions of BPD and what it means to them. This research aims to find out exactly that: what do service-users and clinicians think about BPD as a diagnosis? This might help increase our understanding of the disorder, which may, in the long term, benefit services and service-users.

What will happen to me if I take part?

You MAY be asked to attend a 1:1 interview or focus group to talk about what you think of the BPD diagnosis. This would take about half an hour to an hour. Information discussed is confidential and will not be discussed outside elsewhere. You will then be asked to do something called a 'Q Sort' whereby you sort printed statements about BPD according to how much you agree or disagree with them. There are no right or wrong answers – it is about your opinion. The sort will take about twenty minutes. On completion of the sort the researcher can discuss it with you if you wish to.

Do I have to take part?

No. It is entirely up to you to decide. The researcher will describe the study and go through this information sheet, which they will give you to keep. If you choose to participate, the researcher will ask you to sign a consent form to confirm that you have agreed to take part. You will be free to withdraw at any time (up until the point of analysis), without giving a reason and this will not affect you or your circumstances in any way.

What are the possible disadvantages and risks of taking part?

Participation involves thinking about your views on BPD and this may be distressing for

VIEWS ON THE BORDERLINE PERSONALITY DISORDER DIAGNOSIS

some. Any difficulties you have as a result of the study or any concerns you have about the process will be addressed. Please see Part 2 for details of this.

What are the possible benefits of taking part?

Some people like having the opportunity to discuss their views on a topic, and I hope that that may be the case here. The information from the study will also help to further our understanding into BPD.

Expenses and payments

Participants will not be paid for taking part in this study. However, travel expenses for attending the interview and/or the 1:1 Q sort will be reimbursed.

What will happen when the study ends?

On completion of the project all data will be securely stored for five years and then destroyed thereafter.

Will my taking part be kept confidential?

Yes. We will follow strict ethical and legal practice and all information about you will be handled in confidence. Further details are included in Part 2.

What if there is a problem?

Any concerns about the way you have been dealt with during the study or any possible harm that you might suffer will be addressed. Detailed information is given in Part 2.

This concludes 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

Who is organising and funding the study?

The researcher is organising the study as a trainee at Staffordshire and Keele Universities and will be supervised by Dr Helen Combes and Dr Catherine O'Callaghan. It is for the Professional Doctorate in Clinical Psychology course. It has also been reviewed by the West Midlands- Black Country Research Ethics Committee.

What will happen if I don't want to carry on being part of the study?

Participation in this study is entirely voluntary. If you choose not to participate then this will not affect you in any way. If you decide to take part in the study, you will need to sign a consent form, which states that you agree to participate.

If you agree to participate, you may withdraw from the study at any time (up until the point of analysis) without affecting you in any way. You have the right to withdraw from the study completely and decline any further contact by study staff after you withdraw.

What if there is a problem?

Should you find that you are in any way negatively affected by taking part then please contact your key worker, your GP or the supervisor of this research. Their name is: Dr Helen Combes and she will be happy to speak to you if you are distressed as a result of the study. She is available Monday – Friday between the hours of 9-5pm and can be contacted through the university on: 01782 294000. You may also wish to talk in confidence to The Samaritans. Their contact details are: **Stoke:** 01782 213555 and **National:** 08457 909090. You can also email them at: jo@samaritans.org. If you have any concerns about the overall process, you may wish to contact Patient Advice and Liaison Services (PALS) on: 0800 389 9676. Should I feel that you are at risk to yourself or others as a result of your participation then we can discuss what to do next. This is the only instance that confidentiality may be breached. If you have a key worker then they will be informed as will the supervisors involved in the research.

Will my taking part be kept confidential?

Yes. Analysis will take place on university premises using the appropriate software and by the researcher. Data will be stored on a password-protected personal computer and password protected memory stick. No data will be traceable to participants as no names or details will be included. On completion of the project all data will be securely stored for five years and then destroyed thereafter. Only members of the research team (i.e. the principal investigator and supervisors) will have access to the data.

The only time that confidentiality will be breached is if I feel that you are not safe. If this is the case then I will inform you that I need to break confidentiality and speak to my clinical supervisor about what to do next. We may then need to speak to your key worker (if you have one).

What will happen to the results of the study?

The findings of this study will be published in a journal. All data will be used anonymously which means that your name – or anything that identifies you – will not be used. You are welcome to find out about the outcome of this research. To do so please inform the researcher.

Who has reviewed the study?

This study has been reviewed and given favourable opinion by Staffordshire University Research Ethics Committee.

Further supporting information:

You have the right to ask questions about the research and should you have any questions about this research please contact the researcher prior to the start of the study. The contact details are as follows:

Name of researcher: Philippa Smith

Address: c/o Staffordshire University, The Science Centre.

Email: sj262529@student.staffs.ac.uk

Academic Supervisor's name: Dr Helen Combes

Academic Supervisor's email: H.A.Combes@staffs.ac.uk

Patient Advice and Liaison Service (PALS): 0800 389 9676

Thank you for taking the time to read this participant information leaflet.

Appendix J
Consent Form



Staffordshire & Keele
Universities
*DOCTORATE IN CLINICAL
PSYCHOLOGY*



CONSENT FORM

Title of Project: “Service-users’ and Professionals’ Views of the Borderline Personality Disorder Diagnosis: A Q-methodological Study.”

Name of Researcher: Philippa Smith

Please initial boxes

1. I confirm that I have read the information sheet dated.....13/10/2015..... (Version 3) for the above study. I have had the opportunity to consider the information, ask questions and have these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time up until analysis without giving any reason, without my medical care or legal rights being affected.
3. I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with the supervisors involved.
4. I understand that confidentiality may be breached in the event of a disclosure during the interview and/or post sort discussion.
5. I agree to my quotes being used anonymously on publication.
6. I agree to the audio recording of the focus group OR interview and post sort discussion.

7. I agree to take part in the study.

Name of Participant

Date

Signature

Name of Person
taking consent

Date

Signature

Appendix K

Table K1

Demographic Information

Professional (P) or Service-user (SU)	Job Role	Age	Ethnicity	Gender
SU	N/A	50	White British	Male
SU	N/A	43	White British	Female
SU	N/A	41	White British	Female
SU	N/A	40	White British	Female
SU	N/A	40	White British	Female
SU	N/A	37	White British	Female
SU	N/A	31	White British	Male
SU	N/A	45	White British	Male
SU	N/A	28	White British	Female
SU	N/A	63	White British	Female
P	Social Worker	26	White British	Female
P	Cognitive Behavioural Therapist	40	White British	Female
P	Psychiatrist	60	White British	Female
P	CPN	35	White British	Female
P	3 rd year Clinical Psychology Trainee	33	White British	Female
P	Assistant Psychologist	26	White British	Female
P	1 st year Clinical Psychology Trainee	27	White British	Female
P	STR Worker	45	White British	Female
P	Carer's Assessment Worker	35	White British	Female
P	Senior Clinical Psychologist	40	White Irish	Female

Note. SU = Service-user, P = Professional

Appendix L
Themes from the Concourse

Experiences of mental health professionals and services

- Positive experiences
- Negative experiences
- Professionals' knowledge
- Treatment
- Discharge from services

Shame, stigma and perception – self and others

- Decreasing stigma
- Persistence of stigma
- Reflecting the person
- Difference between BPD and other PDs
- BPD as the 'norm'
- Intrinsic 'wrongness'
- Behaviours over feelings
- Internalising stigma

Understanding the meaning

- Understanding a person's history
- Trauma
- Severity

Recovery

- How realistic is recovery?
- Dependence on services
- Life long?
- Self-discovery
- Patient insight

Helpful or unhelpful

- Shared understanding

VIEWS ON THE BORDERLINE PERSONALITY DISORDER DIAGNOSIS

- Validation
- Moving forward
- Explanations
- Guidance
- Hindrance

Model

- Medical model
- New model
- Importance of diagnosis
- Medication

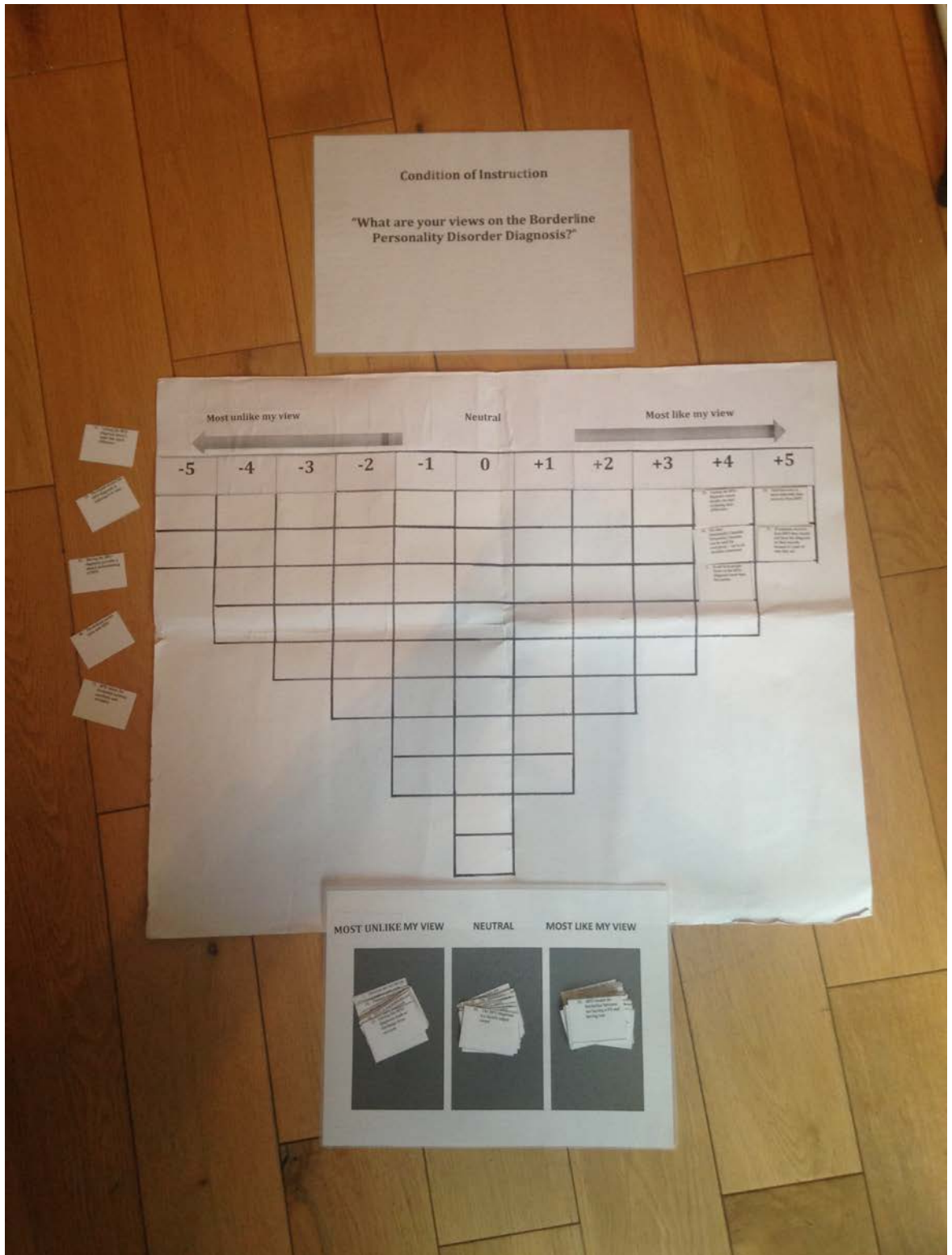
The importance of words

- EUPD vs. BPD
- Responsibility
- Making the abstract tangible

VIEWS ON THE BORDERLINE PERSONALITY DISORDER DIAGNOSIS

Appendix M

Q Sort Materials



Appendix N

Table N1

Correlation Matrix

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
1	1.00	0.05	-0.20	0.38	0.15	0.29	0.35	-0.002	0.10	0.06	0.13	0.21	0.30	-0.13	0.22	0.09	0.10	0.19	-0.10	0.15
2	0.05	1.00	0.13	0.27	0.32	0.38	0.18	0.44	0.16	-0.05	0.20	0.09	0.42	0.17	0.25	0.15	0.12	0.19	0.34	0.07
3	-0.20	0.13	1.00	0.06	0.05	0.11	-0.08	0.28	0.00	0.01	0.46	-0.09	0.09	0.21	0.10	0.11	0.16	0.05	0.37	0.34
4	0.38	0.27	0.06	1.00	0.18	0.30	0.58	0.28	0.04	-0.19	0.32	0.10	0.33	-0.08	0.08	0.13	0.47	0.46	0.05	0.37
5	0.15	0.32	0.05	0.18	1.00	0.15	0.28	0.06	0.16	0.11	0.07	0.14	0.29	0.14	0.07	0.29	0.03	0.14	0.10	0.03
6	0.29	0.38	0.11	0.30	0.15	1.00	0.16	0.25	-0.20	-0.03	0.13	0.23	0.12	-0.23	0.26	-0.01	0.32	0.14	0.14	0.21
7	0.35	0.18	-0.08	0.56	0.28	0.16	1.00	0.10	0.16	0.01	0.17	0.31	0.34	-0.08	0.13	0.14	0.14	0.40	-0.32	0.08
8	-0.00	0.44	0.28	0.28	0.06	0.25	0.10	1.00	0.41	0.03	0.50	0.10	0.38	0.16	0.35	0.23	0.34	0.30	0.37	0.21
9	0.10	0.16	0.00	0.04	0.16	-0.20	0.16	0.41	1.00	0.13	0.31	0.01	0.37	0.40	0.09	0.35	-0.05	0.18	0.16	-0.08

10	0.06	-0.05	0.01	-0.19	0.11	-0.03	0.01	0.03	0.13	1.00	-0.02	0.11	0.23	0.29	0.14	-0.06	-0.24	0.00	0.17	-0.27
11	0.13	0.20	0.46	0.32	0.07	0.13	0.17	0.50	0.31	-0.02	1.00	-0.01	0.32	0.16	0.26	0.18	0.29	0.33	0.19	0.34
12	0.21	0.09	-0.09	0.10	0.14	0.22	0.31	0.10	0.01	0.11	-0.01	1.00	0.27	-0.09	0.02	0.05	0.13	0.18	-0.12	0.01
13	0.30	0.42	0.09	0.33	0.29	0.12	0.34	0.38	0.37	0.23	0.32	0.27	1.00	0.30	0.21	0.34	0.04	0.33	0.07	0.05
14	-0.13	0.17	0.21	-0.08	0.14	-0.23	-0.08	0.16	0.40	0.29	0.16	-0.09	0.30	1.00	0.04	0.15	-0.04	0.16	0.31	-0.21
15	0.22	0.25	0.10	0.08	0.07	0.26	0.13	0.35	0.09	0.14	0.26	0.02	0.21	0.04	1.00	-0.01	0.18	-0.08	0.14	0.25
16	0.09	0.15	0.11	0.13	0.29	-0.01	0.14	0.23	0.35	-0.06	0.18	0.05	0.34	0.15	-0.01	1.00	0.28	0.16	0.05	0.28
17	0.10	0.12	0.16	0.47	0.03	0.32	0.14	0.34	-0.05	-0.24	0.29	0.13	0.04	-0.04	0.12	0.28	1.00	0.12	0.06	0.51
18	0.19	0.19	0.05	0.46	0.14	0.14	0.40	0.30	0.18	0.00	0.33	0.18	0.33	0.16	-0.08	0.16	0.12	1.00	0.13	0.03
19	-0.10	0.34	0.37	0.04	0.10	0.14	-0.32	0.37	0.16	0.17	0.19	-0.12	0.07	0.31	0.14	0.05	0.06	0.13	1.00	-0.02
20	0.15	0.07	0.34	0.37	0.03	0.21	0.08	0.21	-0.08	-0.27	0.34	0.01	0.05	-0.21	0.25	0.23	0.51	0.03	-0.02	1.00

Note. *Correlation coefficients between sorts. Significant correlations are emboldened; $r \geq 0.38$, $p < 0.01$ (calculated using the equation $2.58 \times (1/\sqrt{60})$; Watts & Stenner, 2012).

Appendix O
Varimax Rotated Factor Matrix

Table O1

Varimax Rotated Factor Matrix

	Factor 1	Factor 2	Factor 3
Participants			
1SU	-0.0468	0.1521	0.6282X
2SU	0.531X	0.0073	0.2713
3SU	0.6161X	0.1827	-0.3142
4SU	0.2679	0.4530	0.5868X
5SU	0.2216	-0.1599	0.4195X
6PRO	0.2039	0.4687X	0.2825
7PRO	-0.0091	0.1101	0.7980X
8PRO	0.7544X	0.0874	0.1455
<i>9PRO</i>	<i>0.4537</i>	<i>-0.4636</i>	<i>0.2448</i>
10PRO	0.0957	-0.5583X	0.1030
11PRO	0.6705X	0.1916	0.1307
12PRO	-0.0733	0.0201	0.5201X
13PRO	0.4577	-0.2551	0.5906X
14PRO	0.4776	-0.5829X	0.0568
15SU	0.3707X	0.1387	0.1182
16SU	0.3767X	-0.0093	0.2547
17SU	0.3492	0.6356X	0.1354
18PRO	0.3000	-0.0172	0.5060X
19SU	0.6310X	-0.1481	-0.2817
20SU	0.3266	0.7047X	0.0347
% of variance explained	18	12	15

Note. X indicates a defining sort SU = Service-user PRO= Professional

Italics indicates no factor loadings

Appendix P

Crib Sheets

Crib Sheet for Factor 1**Items at +5**

#47: We need a new model for understanding the BPD diagnosis

#46: People think it's hard to treat because there's no medication for BPD

Items ranked higher in Factor 1 array than other factor arrays

#1 In services people focus on the BPD diagnosis more than the person +4

#5 Professionals don't think people can recover from BPD +1 'some do, some don't'

#7 Professionals do not know what to do for people with the BPD diagnosis +2

#8 To have a diagnosis of bipolar is more acceptable than a diagnosis of BPD +2

#12 If someone has the BPD diagnosis then all their problems are attributed to it +3

#20 The 'personality disorder' part of the BPD diagnosis causes problems +3

#27 BPD diagnosis says nothing about severity of difficulties+4

#30 Self-discovery is more important than recovery from BPD +2

#36 How helpful the BPD diagnosis is depends on how it's conveyed+4

#52 Having the word trauma in the label would be unhelpful because people's experiences are so different +3

#56 The BPD diagnosis is a double edged sword +3

#59 BPD is a horrible diagnosis 0 *does not signify indifference but a firm yes and no stance.

#60 Emotional regulation difficulties would be a better name for BPD +3

Items ranked lower in Factor 1 array than in other factor arrays

#4 Guidelines and documents have helped reduce the stigma of the BPD diagnosis -4

#11 Getting the BPD diagnosis means more access to treatment and services -2

#13 Getting the BPD diagnosis leads to discharge from services -4

#18 The BPD diagnosis means that something is wrong with the person -3

#23 BPD means the borderline between psychosis and normality -4

#32 If they can get appropriate treatment, most people recover from BPD -4

#35 Having the BPD diagnosis provides a shared understanding of BPD -1

#42 Getting the BPD diagnosis is a relief for patients-2

#45 The BPD diagnosis guides the professional down the right path -3

#48 The medical model rules with BPD -3

#50 It's important to keep a diagnosis of some sort for these problems -1

#55 The words that make up the label are important -3

#58 If someone with a diagnosis of BPD re-enters services they are reassessed -1

Items at -5

#10 The stigma around the BPD diagnosis is reducing. -5

#26 BPD means the borderline between not having a PD and having one -2

Omitted Statements

29 out of 60 statements included – 31 omitted

Statements omitted from factor 1:

2

3

6

14 ' the bpd diagnosis is not based on a true picture of someone' - +2

15

16

17

19 'the majority of people don't know what BPD means.' +4

21

22 the BPD diagnosis changes how people think about themselves.' 0

24 having the BPD diagnosis means a person has experienced a major trauma in their life - 2

25 it's hard to understand if someone has this diagnosis but has experienced no obvious trauma in their life.-3 These 2 together suggest that people recognized that trauma takes many forms and that a traumatic experience for one is not necessarily as traumatic for another. This is backed up with post sort feedback.

28 a BPD diagnosis means problems are ingrained so people can't recover – 0

29

31 if someone recovers they should still have the diagnosis on their records because it's part of who they are. 0 – doesn't communicate much so doesn't matter?

33

34 is for life - +1 – for some people

37

38 is validating -1 – depends!

39 accepting their problems - +1

40dealing with problems +1
 41 doesn't make that much difference 0
 43
 49
 51 makes it more real. +2
 53
 54
 57

Crib Sheet for Factor 2

Items at +5

#31: If someone recovers from BPD they should still have the diagnosis on their records because it's part of who they are
 #44 The BPD diagnosis explains a lot
 #28: A BPD diagnosis means problems are ingrained so people can't recover

Items ranked higher in Factor 2 array than other factor arrays

#9 Professionals don't know how to explain the BPD diagnosis to someone +2
 #11 Getting the BPD diagnosis means more access to treatment and services +2
 #14 The BPD diagnosis is not based on a true picture of someone +3
 #15 People don't understand the difference between the PDs +3
 #16 The BPD diagnosis means someone is like Jekyll and Hyde 0
 #18 The BPD diagnosis means that something is wrong with the person +3
 #21 The BPD diagnosis is given because of what people do, not what they feel +2
 #34 The BPD diagnosis is for life +4
 #38 The diagnosis of BPD is validating +2
 #39 Getting the BPD diagnosis means people can start accepting their difficulties +4
 #40 Getting the BPD diagnosis means people can start dealing with their problems better +4
 #42 Getting the BPD diagnosis is a relief for patients +2
 #43 Getting the BPD diagnosis means people can stop hunting around for explanations +3
 #44 The BPD diagnosis explains a lot +4
 #45 The BPD diagnosis guides the professional down the right path +1
 #48 The medical model rules with BPD -2

#49 The BPD diagnosis doesn't fit a medical model +3

#50 It's important to keep a diagnosis of some sort for these problems +1

Items ranked lower in Factor 2 array than in other factor arrays

#2 Services are not set up to help people with the BPD diagnosis -1

#3 The stress professionals are under makes them less empathic towards people with the BPD diagnosis -3

#5 Professionals don't think people can recover from BPD -1

#19 The majority of people don't know what the BPD diagnosis means 0

#20 The 'personality disorder' part of the BPD diagnosis causes problems

#22 The BPD diagnosis changes how people think about themselves 0

#24 Having the BPD diagnosis means a person has experienced a major trauma in their life -4

#25 It's hard to understand if someone has this diagnosis but has no obvious trauma in their life -4

#29 Recovery from BPD is less realistic because of the current economic climate and pressures of services -2

#30 Self-discovery is more important than recovery from BPD -2

#32 If they can get appropriate treatment, most people recover from BPD -4

#33 Patients should be the judge of whether they should still have the BPD diagnosis or not -3

#36 How helpful the BPD diagnosis is depends on how it's conveyed 0

#37 The BPD diagnosis is conveyed more positively to clients than it used to be +1

#46 People think it's hard to treat because there's no medication for BPD 0

#47 We need a new model for understanding the BPD diagnosis -1

#51 Having a name makes it a 'real thing' or more 'real' +1

#52 Having the word trauma in the label would be unhelpful because people's experiences are so different +1

#53 Emotionally Unstable Personality Disorder is a better name than BPD -1

#55 The words that make up the label are important -1

#56 The BPD diagnosis is a double edged sword +1

#57 The BPD diagnosis takes some of the responsibility away from the person -3

#59 BPD is a horrible diagnosis -3

#60 Emotional regulation difficulties would be a better name for BPD -1

Items at -5

#17 Everyone has BPD to a degree – having the diagnosis is just about the severity or degree

#54 The term Emotionally Unstable Personality Disorder can be used for everybody – we're all unstable sometimes

Omitted Statements

46 out of 60 included - 14 omitted

Statements omitted from factor 2:

1 people focus more on the diagnosis than the person - -3 -

4

6 you still hear things like typical PD – 0 is this because this factor represents more professionals?

7 professionals don't know what to do.....0

8

10 stigma reducing -2

12 problems all attributed to BPD – 0 positive

13

23

26

27

35 shared understanding + 2

41 doesn't make that much difference -1

Crib sheet for Factor 3

Items at +5

#19 The majority of people don't know what the BPD diagnosis means

#32 If they can get appropriate treatment, most people recover from BPD

Items ranked higher in Factor 3 array than other factor arrays

#2 Services are not set up to help people with the BPD diagnosis 0

#3 the stress professionals are under makes them less empathic towards people with the BPD diagnosis 0

#4 Guidelines and documents have helped reduce the stigma of the BPD diagnosis +3

#6 you still hear things like 'typical borderline' or 'raging borderline PD' +three

#10 the stigma around the BPD diagnosis is reducing.0

- #11 getting the BPD diagnosis means more access to treatment and services +2
- #22 The BPD diagnosis changes how people think about themselves +3
- #24 having the BPD diagnosis means a person has experienced a major trauma in their life -1
- #25 it is hard to understand if someone has this diagnosis but has no obvious trauma in their life 0
- #29 Recovery from BPD is less realistic because of the current economic climate and pressures of services +2
- #30 Self-discovery is more important than recovery from BPD +2
- #35 having the BPD diagnosis provides a shared understanding of BPD +4
- #36 how helpful the BPD diagnosis is depends on how it has conveyed four
- #37 The BPD diagnoses is conveyed more positively to clients than it used to be +4
- #40 getting the BPD diagnosis means people can start dealing with their problems better +4
- #45 The BPD diagnosis guides the professional down the right path +1
- #48 the medical model rules with BPD -2
- #51 having a name makes it a 'real thing' or three that are more 'real'
- #55 the words that make up the label are important +1
- #56 The BPD diagnoses is a double edged sword +3
- #58 if someone with a diagnosis of BPD re-enters services they are reassessed one

Items ranked lower in Factor 3 array than other factor arrays

- #5 Professionals don't think people can recover from BPD -1
- #7 Professionals do not know what to do for people with the BPD diagnosis -2
- #8 To have a diagnosis of bipolar is more acceptable than a diagnosis of BPD 0
- #9 Professionals don't know how to explain the BPD diagnosis to someone -1
- #12 If someone has the BPD diagnosis then all their problems are attributed to it -2
- #14 The BPD diagnosis is not based on a true picture of someone -2
- #15 People don't understand the difference between the BPD diagnosis and other personality disorder diagnoses +1
- #18 The BPD diagnosis means that something is wrong with the person -3
- #21 The BPD diagnosis is given because of what people do, not what they feel -4
- #23 BPD means the borderline between psychosis and normality -4
- #28 A BPD diagnosis means problems are ingrained so people can't recover -2

#31 If someone recovers from BPD they should still have the diagnosis on their records because it's part of who they are -1

#33 Patients should be the judge of whether they should still have the BPD diagnosis or not -1

#34 The BPD diagnosis is for life -3

#41 Getting the BPD diagnosis doesn't make that much difference -4

#43 Getting the BPD diagnosis means people can stop hunting around for explanations
0

#47 We need a new model for understanding the BPD diagnosis -1

#49 The BPD diagnosis doesn't fit a medical model 0

#53 Emotionally Unstable Personality Disorder is a better name than BPD -2

#57 The BPD diagnosis takes some of the responsibility away from the person -3

Items at -5

#16 The BPD diagnosis means someone is like Jekyll and Hyde

#54 The term Emotionally Unstable Personality Disorder can be used for everybody – we're all unstable sometimes

Omitted Statements

45 statements out of 60 included – 15 omitted:

1

13

17 everyone has it to a degree – it's about severity -3

20

26

27 says nothing about severity +2

38 validating - 0

39

42 a relief - +1

44 explains a lot +1

46

50 important to keep a diagnosis - 0

52

59 horrible diagnosis -1

60 emo reg is a better name 0

Appendix Q
Consensus Statements

Table Q1

Consensus Statements

Number	Statement	Factor 1 – Q-sort Value	Factor 2 - Q-sort Value	Factor 3 - Q-sort Value
2	Services are not set up to help people with the BPD diagnosis	0	-1	0
15*	People don't understand the difference between the BPD diagnosis and other personality disorder diagnoses	1	3	1
23*	BPD means the borderline between psychosis and normality	-4	-2	-4
33	Patients should be the judge of whether they should still have the BPD diagnosis or not	-2	-3	-1
48*	The medical model rules with BPD	-3	-2	-2
51*	Having a name makes it a 'real thing' or 'more real'.	2	1	3
53*	Emotionally unstable personality disorder is better name than BPD	-1	-1	-2
56*	The BPD diagnosis is a double edged word	3	1	3

Note. All listed statements were insignificant at $p > .01$ *Insignificant at $p > 0.05$.

Appendix R
Distinguishing Statements

Table R1
Distinguishing Statements for Factor 1

Statement number	Statement	Factor 1 z score
47	We need a new model for understanding the BPD diagnosis	(5) 1.86*
46	People think it's hard to treat because there's no medication	(5) 1.64*
1	In services people focus on the BPD diagnosis more than the person	(4) 1.62*
27	The BPD diagnosis says nothing about severity of difficulties	(4) 1.52
20	The 'Personality disorder' part of the BPD diagnosis causes difficulties	(3) 1.04*
12	If someone has the BPD diagnosis then all their problems are attributed to it	(3) 1.04*
60	Emotion regulation difficulties would be a better name	(3) 1.03*
7	Professionals do not know what to do for people with the BPD diagnosis	(0) 0.83*
34	The BPD diagnosis is for life	(1) 0.73
5	Professionals don't think people can recover from BPD	(1) 0.66*
39	Getting the BPD diagnosis means people can start accepting their difficulties	(-1) 0.43
29	Recovery from BPD is less realistic because of the current economic climate	(1)0.32
25	It's hard to understand if someone has this diagnosis...	(-4) -1.70
40	Getting the BPD diagnosis means people can start dealing with their difficulties	(1) 0.31*

Note. (p < .05 ; Asterisk (*) Indicates Significance at P < .01)

Table R2
Distinguishing Statements for Factor 2

Statement number	Statement		Factor 2 z score
31	If someone recovers from BPD they should still have the diagnosis on their records	(5)	1.95*
28	A BPD diagnosis means problems are ingrained so people can't recover	(5)	1.74*
39	Getting the BPD diagnosis means people can start accepting their difficulties	(4)	1.63
34	The BPD diagnosis is for life	(4)	1.44
44	The BPD diagnosis explains a lot	(4)	1.28
18	The BPD diagnosis means that something is wrong with the person	(2)	1.26*
9	Professionals don't know how to explain the BPD diagnosis to someone	(2)	0.85*
21	The BPD diagnosis is given because of what people do not what they feel	(2)	0.76*
35	Having the BPD diagnosis provides a shared understanding	(2)	0.72*
50	It's important to keep a diagnosis of some sort	(1)	0.55
16	The BPD diagnosis means someone is like Jekyll and Hyde	(0)	.49*
19	The majority of people don't know what the BPD diagnosis means	(0)	.40*

36	How helpful the BPD diagnosis is depends on how it's conveyed	(0)	.23*
13	Getting the BPD diagnosis means discharge from services	(0)	-.24*
7	Professionals don't know what to do for people with the BPD diagnosis	(0)	-.28*
12	If someone has the BPD diagnosis then all their problems are attributed to it	(0)	-.33*
60	Emotional regulation difficulties would be a better name	(-1)	-0.46
4	Guidelines and documents have helped reduce the stigma	(-1)	-.53*
2	Services are not set up to help people with the BPD diagnosis	(-1)	-.55
55	The words that make up the label are important	(-1)	-.57
30	Self-discovery is more important than recovery from BPD	(-2)	-.76*
29	Recovery from BPD is less realistic because of the current economic climate	(-2)	-.82*
10	The stigma around BPD is reducing	(-2)	-.96*
3	The stress professionals are under makes them feel less empathic	(-3)	-1.02*
59	BPD is a horrible diagnosis	(-3)	-1.02
1	In services people focus on the BPD diagnosis more than the person	(-3)	-1.07*
20	The 'personality disorder' part of the BPD diagnosis causes problems.	(-4)	-1.20*
24	Having the BPD diagnosis	(-4)	-1.58

	means a person has experienced a major trauma		
17	Everyone has BPD to a degree – having the diagnosis is just about severity	(-5)	-2.09
54	The term EUPD can be used for everyone...	(-5)	-2.24

Note. ($p < .05$; Asterisk (*) Indicates Significance at $P < .01$)

Table R3

Distinguishing Statements for Factor 3

Statement number	Statement	Ranking	Factor 3 z score
32	If they can get appropriate treatment most people recover from BPD	5	1.63*
35	Having the BPD diagnosis provides a shared understanding	4	1.53*
37	The BPD diagnosis is conveyed more positively than it used to be	4	1.52*
4	Guidelines and documents have helped reduce the stigma	3	1.10*
6	You still hear things like 'typical borderline'	3	1.08*
22	The BPD diagnosis changes how people think about themselves	3	1.05
39	Getting the BPD diagnosis means people can start accepting their difficulties	2	0.98
29	Recovery from BPD is less realistic because of the current economic climate	2	.90
55	The words that make up the label are important	1	.69*
44	The BPD diagnosis explains a lot	1	.53*
20	The 'personality disorder' part of the BPD diagnosis causes problems	1	.35*
10	The stigma around BPD is reducing	0	.29*
49	The BPD diagnosis doesn't fit a medical model	0	.22
25	It's hard to understand if	0	.18*

	someone has this diagnosis but has no obvious trauma in their life		
60	Emotional regulation difficulties would be a better name	0	.13
8	To have a diagnosis of bipolar is more acceptable than BPD	0	-.08
50	It's important to keep a diagnosis of some sort for these problems	0	-.11
1	In services people focus on the BPD diagnosis more than the person	-1	-.17*
24	Having the BPD diagnosis means a person has experienced a major trauma	-1	-.19*
31	If someone recovers they should still have the diagnosis on their file	-1	-.60
14	The BPD diagnosis is not based on a true picture of someone	-2	-.91*
7	Professionals do not know what to do for people with this diagnosis	-2	-1.11*
12	If someone has the BPD diagnosis then all their problems are attributed to it	-2	-1.11*
28	A BPD diagnosis means problems are ingrained	-2	-1.15*
34	The BPD diagnosis is for life	-3	-1.21*
17	Everyone has BPD to a degree	-3	-1.37
21	The BPD diagnosis is given because of what people do not what they feel	-4	-1.46*
41	Getting the BPD diagnosis doesn't make much difference	-4	-1.46*

54	The term EUPD can be used for everyone....	-5	-1.54
16	The BPD diagnosis means someone is like Jekyll and Hyde	-5	-2.37*

Note. (p < .05 ; Asterisk (*) Indicates Significance at P < .01)

Appendix S
Factor arrays for Factors 1, 2 and 3

Table S1
Factor Arrays for Factors 1, 2 and 3

Statement	Factor 1	Factor 2	Factor 3
In services people focus on the BPD diagnosis more than the person	4	-3	-1
Services are not set up to help people with the BPD diagnosis	0	-1	0
The stress professionals are under makes them less empathic towards people with the BPD diagnosis	0	-3	0
Guidelines and documents have helped reduce the stigma of the BPD diagnosis	-4	-1	3
Professionals don't think people can recover from BPD	1	-1	-1
You still hear things like 'typical borderline' or 'raging borderline PD'	0	0	3
Professionals do not know what to do for people with the BPD diagnosis	2	0	-2
To have a diagnosis of bipolar is more acceptable than a diagnosis of BPD	2	1	0
Professionals don't know how to explain the BPD diagnosis to someone	-1	2	-1
The stigma around the BPD diagnosis is reducing.	-5	-2	0
Getting the BPD diagnosis means more access to treatment and services	-2	2	2
If someone has the BPD diagnosis then all their problems are	3	0	-2

 attributed to it

Getting the BPD diagnosis leads to discharge from services	-4	0	-3
--	----	---	----

The BPD diagnosis is not based on a true picture of someone	2	3	-2
---	---	---	----

People don't understand the difference between the BPD diagnosis and other personality disorder diagnoses	1	3	1
---	---	---	---

The BPD diagnosis means someone is like Jekyll and Hyde.	-2	0	-5
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Everyone has BPD to a degree – having the diagnosis is just about the severity or degree	0	-5	-3
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The BPD diagnosis means that something is wrong with the person	-3	3	-3
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The majority of people don't know what the BPD diagnosis means	4	0	5
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The 'personality disorder' part of the BPD diagnosis causes problems	3	-4	1
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The BPD diagnosis is given because of what people do, not what they feel	0	2	-4
--	---	---	----

The BPD diagnosis changes how people think about themselves.	0	0	3
--	---	---	---

BPD means the borderline between psychosis and normality	-4	-2	-4
--	----	----	----

Having the BPD diagnosis means a person has experienced a major trauma in their life	-2	-4	-1
--	----	----	----

It's hard to understand if someone has this diagnosis but has no obvious trauma in their life	-3	-4	0
---	----	----	---

BPD means the borderline between not having a PD and having one	-5	-2	-4
---	----	----	----

BPD diagnosis says nothing about severity of difficulties	4	1	2
---	---	---	---

A BPD diagnosis means problems are ingrained so people can't recover	0	5	-2
--	---	---	----

Recovery from BPD is less realistic because of the current economic climate and pressures of services	1	-2	2
Self-discovery is more important than recovery from BPD	2	-2	2
If someone recovers from BPD they should still have the diagnosis on their records because it's part of who they are	0	5	-1
If they can get appropriate treatment, most people recover from BPD	-4	-4	5
Patients should be the judge of whether they should still have the BPD diagnosis or not	-2	-3	-1
The BPD diagnosis is for life	1	4	-3
Having the BPD diagnosis provides a shared understanding of BPD	-1	2	4
How helpful the BPD diagnosis is depends on how it's conveyed	4	0	4
The BPD diagnosis is conveyed more positively to clients than it used to be	1	1	4
The diagnosis of BPD is validating	-1	2	0
Getting the BPD diagnosis means people can start accepting their difficulties	1	4	2
Getting the BPD diagnosis means people can start dealing with their problems better	1	4	4
Getting the BPD diagnosis doesn't make that much difference	0	-1	-4
Getting the BPD diagnosis is a relief for patients	-2	2	1
Getting the BPD diagnosis means people can stop hunting around for explanations	1	3	0
The BPD diagnosis explains a lot	-2	4	1
The BPD diagnosis guides the professional down the right path	-3	1	1

People think it's hard to treat because there's no medication for BPD	5	0	1
We need a new model for understanding the BPD diagnosis	5	-1	-1
The medical model rules with BPD	-3	-2	-2
The BPD diagnosis doesn't fit a medical model	2	3	0
It's important to keep a diagnosis of some sort for these problems	-1	1	0
Having a name makes it a 'real thing' or more 'real'	2	1	3
Having the word trauma in the label would be unhelpful because people's experiences are so different	3	1	2
Emotionally Unstable Personality Disorder is a better name than BPD	-1	-1	-2
The term Emotionally Unstable Personality Disorder can be used for everybody – we're all unstable sometimes	-1	-5	-5
The words that make up the label are important	-3	-1	1
The BPD diagnosis is a double edged sword	3	1	3
The BPD diagnosis takes some of the responsibility away from the person	-1	-3	-3
If someone with a diagnosis of BPD re-enters services they are reassessed	-1	0	1
BPD is a horrible diagnosis	0	-3	-1
Emotional regulation difficulties would be a better name for BPD	3	-1	0

Appendix T
Factor Array Grids

Factor 1 Factor Array

The distribution grid for factor one's factor array would look as follows:


Most unlike my view			Neutral				Most like my view			
										
-5	-4	-3	-2	-1	0	+1	+2	+3	+4	+5
10	32	45	16	50	17	34	51	52	1	47
26	13	48	33	57	28	5	8	56	27	46
	23	55	42	53	6	15	7	20	19	
	4	25	24	58	22	43	30	12	36	
		18	44	9	2	37	14	60		
			11	38	3	39	49			
				35	31	29				
				54	41	40				
					59					
					21					

Figure 2. Factor Array for Factor 1

Statements most like the view:

#47: We need a new model for understanding the BPD diagnosis

#46: People think it is hard to treat because there is no medication for BPD

#1: In services people focus on the BPD diagnosis more than the person

#27: The BPD diagnosis says nothing about severity of difficulties

#19: The majority of people don't know what the BPD diagnosis means

#36: How helpful the BPD diagnosis depends upon how it's conveyed

Statements least like the view:

#10: The stigma around BPD is reducing

#26: BPD means the borderline between not having a PD and having one

#32: If they can get appropriate treatment most people recover from BPD

#13: Getting the BPD diagnosis means discharge from services

#23: BPD means the borderline between psychosis and normality

#4: Guidelines and documents have helped reduce the stigma of the BPD diagnosis

Factor 2 Factor Array

The distribution grid for factor two's factor array would look as follows:

Most unlike my view			Neutral				Most like my view			
-5	-4	-3	-2	-1	0	+1	+2	+3	+4	+5
17	20	57	30	4	16	45	42	43	39	31
54	32	3	29	60	19	27	9	15	40	28
	24	59	48	4	2	50	38	49	34	
	25	1	23	47	46	8	21	14	44	
		33	10	53	36	51	35	18		
			26	5	58	37	11			
				2	6	56				
				55	13	52				
					7					
					12					

Figure 3. Factor Array for Factor 2

Statements most like the view:

#31: If someone recovers from BPD they should still have the diagnosis on their records because it's part of who they are

#28: A BPD diagnosis means problems are ingrained so people can't recover

#39: Getting the BPD diagnosis means people can start accepting their difficulties

#40: Getting the BPD diagnosis means people can start dealing with their problems better

#34: The BPD diagnosis is for life

#44: The BPD diagnosis explains a lot

Statements least like the view:

#17: Everyone has BPD to a degree – having the diagnosis is about severity or degree

#54: The term Emotionally Unstable Personality Disorder can be used for everybody – we're all unstable sometimes

#20: The 'personality disorder' part of the BPD diagnosis causes problems

#32: If they can get appropriate treatment, most people recover from BPD

#24: Having the BPD diagnosis means a person has experienced a major trauma in their life

#25: It's hard to understand if someone has this diagnosis but has no obvious trauma in their life.

Factor 3 Factor Array

The distribution grid for factor three's factor array would look as follows:

Most unlike my view			Neutral			Most like my view				
-5	-4	-3	-2	-1	0	+1	+2	+3	+4	+5
54	21	13	53	1	10	42	39	4	36	19
16	23	18	14	24	38	55	52	6	35	32
	41	34	48	47	49	44	27	22	37	
	26	57	7	9	25	45	29	56	40	
		17	12	59	60	15	30	51		
			28	33	2	46	11			
				5	43	58				
				31	8	20				
					3					
					50					

Figure 4. Factor Array for Factor 3

Statements most like the view:

- #19: The majority of people don't know what the BPD diagnosis means
- #32: If they can get appropriate treatment, most people recover from BPD
- #36: How helpful the BPD diagnosis is depends upon how it's conveyed
- #35: Having the BPD diagnosis provides a shared understanding of BPD
- #37: The BPD diagnosis is conveyed more positively to clients than it used to be
- #40: Getting the BPD diagnosis means people can start dealing with their problems better

Statements least like the view:

- #54: The term Emotionally Unstable Personality Disorder can be used for everybody – we're all unstable sometimes
- #16: The BPD diagnosis means someone is like Jekyll and Hyde.
- #21: The BPD diagnosis is given because of what people do, not what they feel
- #23: BPD means the borderline between psychosis and normality
- #41: Getting the BPD diagnosis doesn't make that much difference
- #26: BPD means the borderline between not having a PD and having one

“The perspective of the observer and the object of observation are inseparable; the nature of meaning is relative; phenomena are context-based; and the process of knowledge and understanding is social, inductive, hermeneutical, and qualitative.”

(Sexton, 1997, as cited in Raskin, 2002)

Paper 3

Commentary and Reflective Review

Word count: 2180

Working in adult mental health for several years piqued an interest in personality disorders – especially BPD – for several reasons: the disparaging remarks about clients with this diagnosis, the disconnect between medical and psychological positions, the negative ramifications for the client in terms of services and treatment, and the divide between those that welcomed the diagnosis and those that rejected it. This experience, combined with personal development from clinical training, resulted in an ambivalent position towards this label. This research was part of my journey towards holding a stronger position on diagnosis.

During this past year, I have been particularly fortunate to work in adult mental health in a Dialectical Behaviour Therapy (DBT) service. Many of the discoveries I made as a result of working to a new model and placement experiences have helped shape my research experience and beliefs as a psychologist. Most significantly has been appreciating the extent of my dichotomous ways of thinking, and how much I struggle to walk a ‘middle path’. I have seen my views about diagnosis, the medical model and psychology shift, becoming less fixed and increasingly fluid. I completed a Q sort of my own and as I did so I was aware of how much I have changed. With ideas about synthesising extremes underpinning this, it seemed fitting to use a dialectical framework to shape and inform the first part of this reflective piece. I shall then explore how the process has impacted upon my epistemological position and how I have come to think of diagnosis as a result.

Emotion Regulation and Distress Tolerance

Talking to people with a diagnosis of BPD and learning about DBT has given me some insight into how overwhelming emotions are for some people and put my own anxieties into perspective. It is very disconcerting to feel uncertain and the opportunity to experience increased anxiety and expose my vulnerabilities has been pivotal. The research process revealed how the BPD diagnosis does not reveal much about the extent of someone’s difficulties, nor operationalise a subjective concept about wellbeing. One of the main messages I heard from service-users reinforced for me how much more helpful it is to think on a continuum, to realise that I can reconcile polarised feelings.

Just as with learning to manage emotions and tolerate distress I have had to identify with the clients I work with and service-users I have met as part of this research. It was only when I acknowledged that we are all fallible and I could be the client in front of me that I began to walk the middle path and not defend against feeling

unsure. I hope that as a result this past year has given me a better level of insight into myself, my anxieties and defences and how vulnerable clients can feel.

Mindfulness

As I have allowed myself to sit with difficult emotions I have been able to appreciate the act of mindfulness as more than just a strategy. I realise that people can live in a paradox; something does not have to be fact or have scientific 'evidence' to make it real. Observing conflicting feelings without judgment or action is a powerful position to take. In DBT – which reflects the human condition of being both deeply flawed yet thoroughly acceptable – the idea of the 'middle path' is a principle component and this resonates with me at this stage in my life and my career.

A Bio-social Approach

Thinking about my beliefs on diagnosis whilst speaking to service-users about theirs has enabled me to really appreciate that I can see both the value in it yet believe diagnosis to be fundamentally antithetical to psychological understanding. Once I would have struggled with this contradiction and sought a definitive stance but I have come to see it as dialectical. Many of the service-users I met struggled with their diagnosis but disliked the idea of removing it and this is something I can now understand. Not embracing a medical model does not mean rejecting it. DBT is based upon a bio-social understanding of emotional dysregulation and different parts of this appeal to different people, with people emphasising different elements. I think that because of the people I have met and the discussions we have had, I can see the appeal of both together. What is important is not solely based on my personal, political views, but the purpose of this project: what are the views of people who do not get the opportunity to air them? I can synthesise my own beliefs to find a way to accept the way things are whilst wanting to change them. This is in essence the cornerstone of mindfulness and DBT and a way of being that I find helpful.

Interpersonal Effectiveness

Reflecting upon position and ontology is inextricably linked to power. I came to realise over the course of the research how defined we are by others' constructions of ourselves. This leads me to wonder about the role we must all play in shifting this imbalance to empower people (especially many in the mental health system who have

long been subjugated) to assert their identity in the face of others who dictate it to them. Giving a voice to marginalised groups maintains this as we decide whose voices to hear, how actively we listen and what we do with what we have heard. We are asking people to explore their sense of self whilst covertly defining their identity for them: as someone with a disorder who is in need of psychological help, someone who is ‘disordered’ because the person ‘treating’ them is not.

Diagnosis and Context

Looking at the literature on recovery from BPD is sobering – I had assumed it would elicit too many papers for contemplation. Certainly there are a lot of papers about BPD, there are a lot of papers about remission, there are quite a lot about treatment. This outcome tells us more than the research content ever could: we are pursuing a particular path, one that moves away from the knowledge available to us in the post-modern era of psychology. I found the literature review the most challenging aspect of this process for this reason. My reflective journal showed that when I thought of the literature review as promoting personal recovery I discovered a way to enjoy it and it began to feel as if it had some meaning.

Thinking about this process alongside the variety of placements I have had leads me to truly appreciate the role of context in people’s difficulties and the systems I am embedded within. I have become increasingly aware of my position in postmodern society and the Psychology I want to work with: how influenced I am by the covert politics of society and western culture as it currently stands. This ontological position is woven throughout my research and within me as part of that experience, moving away from faith and reasoning but not dismissing it, towards constructionism and the belief that we can never fully, objectively know a truth outside of our personal and private realities. This leads me further away from a diagnostic model in psychology and reinforces my allegiance to formulation whilst acknowledging that other people’s realities will lead them to different beliefs. Ultimately, there are no truisms, something that has been brought home to me by using Q methodology. Understanding how people’s realities are created rather than a futile search for an objective understanding is central to this constructionist, postmodern ontology (Sexton, as cited in Raskin, 1997). Operant subjectivity reflects my beliefs about truth, the world, and the power structures within this better than any other theory.

Person-Centred Care

Person-centred care means idiosyncratic care plans and collaborative working but whatever language we use – and this research has brought home to me how integral semantics and words are and how powerful the rhetoric - we cannot claim person-centred approaches to individuals when those same people have to be diagnosed to receive a service. These two poles cannot be synthesised whilst that structure is in place and people view a personality disorder diagnosis as a core construct of the individual. This process leads me to question the idealised notion of person-centred care because it is this narrow gaze that does not fully embrace context

The answer to this might lie in the lessons that Q methodology has taught me: to use a methodological metaphor we can marry quantitative and qualitative methods and maximise our understandings of one another. Postmodern psychology has taught us that they are complementary not antithetical. This could mirror the bio-psycho-social relationship rather than a purely medical one.

This ontological position mirrors my experience of synthesising two distinct poles in terms of my beliefs, and befits the DBT model that is the current model of choice. It may be that it is the model of choice precisely *because* it is in keeping with postmodern thinking about illness and treatment, bringing together idealism and realism whilst compromising neither (Chiari & Nuzzo, 1996, in Raskin, 2002). In particular, it is this epistemology that best depicts my position and that I maintain. These constructions create the schemata we use to make sense of our worlds, just as clients with a diagnosis of BPD and the people that work with them create. Perhaps it is the constructions we create about mental illness, mental health, personality, disorder and diagnosis that we need to examine socially and politically rather than assuming that these phenomena provides us with any real objective truth. This research provided me with an insight into others' worlds and I do not believe that I could have achieved that through any other method.

Other Methodologies and the Epistemological Position

I considered using PCP (Paszkowska-Rogacz & Kabzińska, 2012) as an alternative to Q because of its roots in constructivism, the ontology being that we come to understand ourselves and our worlds through dichotomous poles – which was very similar to my own thinking. PCP particularly appealed because of its acknowledgement of the autonomous individual who continually reassesses and develops their constructs. However, PCP views the self as constructed (Burr, Butt, & Epting, 1997, in Raskin,

2002) and I am reluctant to let go of the idea of self-discovery which is antithetical to constructivism. I began to appreciate what self-discovery really means when I was talking to people who have been defined by their diagnosis by others and themselves. It is one of life's great levellers – some people are trying to recover from illness – but we are all on a journey of self-discovery. I think that therein lies the dialectic that appeals to me; to hold a constructionist position whilst on a journey of discovery. Q further appealed to the discoveries I was making. The idea of the biopsychosocial model is difficult to reconcile with my stance when it sits within a medical discourse. Diagnosis of course fits within this and is seemingly very dichotomous. However, to look at difficulties and diagnoses on a continuum could be seen as minimising the validation diagnosis can give. I have been wondering how psychology might contribute to this conundrum without seeking to develop yet another model. Although I have no solutions I have found my own way through the time I spent with the service-users who were the foundation for this research.

Conclusion

What I have found most revealing has been the assumptions that I and so many of the professionals make about diagnosis and BPD specifically. Many people had strong views related to the negative implications of BPD, the checklist approach to diagnosis and the meaning they took from the label. Extremely experienced, person-centred members of staff talked passionately about their dislike of the label. Several did not understand or could not remember the origins of the label, some thought that recovery was not truly possible and others felt that we should rename it. These beliefs come from good intentions, a sense of wanting to protect vulnerable service-users, but these views are still embedded in a political context in which people are either pro diagnosis or they are against it.

It is a fundamental human desire to make sense of ourselves and our stories. This is perhaps the quest for self-actualisation, whether it is achievable or not, and we all continue along this journey in some way. I think that diagnosis takes advantage of this striving for certainty and self-awareness so even in the value it provides it is embedded in a political context that promotes striving. We should all be trying to be better and do better, without knowing quite how to. Saying someone has a diagnosis regarding their mental health implies that their difficulties make sense and they can strive to do something about it. This hints at an objectivist view of human knowledge,

that there is something wrong and if we ask the right questions we might discover what that is. By trying to create a label we are going against that meaning making, disempowering the client, and creating too much power for the psychiatrist, psychologist and every other profession in mental health services by imposing positivistic, so-called scientific meaning onto others.

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