Thesis

Recovery and Sense of Self for Individuals with a Borderline Personality Disorder Diagnosis

Sarah Davidson

Lancaster University

Doctorate in Clinical Psychology

Submitted October 2015

Word Count

Section	Word Count	Appendices and References	Total
Thesis abstract	277	NA	277
Literature review	7,998	4,561	12,559
Research paper	7,982	5,620	13,602
Critical appraisal	3,089	554	3,643
Ethics section	5,996	7,036	13,032
Total word count	25,342	17,771	43,113

Abstract

Recovery for individuals diagnosed with Borderline Personality Disorder (BPD) is a complex, multifaceted process that remains under researched. The thesis focuses on two elements of recovery for individuals with a BPD diagnosis; elements of mental health services that individuals find therapeutically valuable, and how the concept of recovery affects sense of self. The literature review is a thematic synthesis of therapeutic and non-therapeutic elements of mental health care services for those with a BPD diagnosis and provides a detailed, in depth account of this varied experience. Sixteen studies were selected for inclusion and analysis was completed using thematic synthesis as the chosen approach. The results show that approaches to mental health service delivery and diagnosis at an individual, staff and system level can have huge ramifications for service users. Central to the findings was the importance of the therapeutic relationship. Recommendations include the provision of training around the difficulties associated with the BPD diagnosis and attachment for staff, and using elements of relational models such as Sociotherapy across services. The research paper seeks to ask what the concept of recovery means for the sense of self of individuals with a BPD diagnosis. Six service users were interviewed and the data was analysed using Interpretive Phenomenological Analysis. The resulting analysis produced four themes which showed that recovery is a complex, challenging and seemingly elusive process, understood in the context of ongoing difficulties, ambivalent views on diagnosis, and undeveloped sense of self. Recommendations include identifying difficulties around sense of self as goals for therapy where appropriate, and recognising the effect of attachment relationships. The critical appraisal details reflections on the thesis including the relational nature of the entire process.

Acknowledgements

This thesis is dedicated to the service users who shared their stories with me, and without whom the research would not have been possible. Listening to your experiences was a privilege and has only strengthened my resolve to remain involved with this client group at both a clinical and service development level.

My sincere thanks to both my academic and field supervisors. Your support, knowledge and guidance has been seminal in my development as both a researcher and practitioner. Genuine thanks also to the practitioners associated with the recruitment teams for your enthusiasm, patience and support throughout the research.

A hugely important facet to this research has been the involvement of Experts by Experience. Your contributions have been inimitable, and incredibly valuable, and significant not only in what they add to the study, but in what they represent in terms of growing collaboration between service users and professionals across both research and practice.

To my inspirational placement supervisor, Lis, thank you so, so much - your empathy, kindness and wisdom have kept me in the middle of the see-saw!

To my fellow 2012 colleagues. Your acceptance and comradeship throughout the past three years has been an absolute gift, and I've learnt and smiled because of you. Thank you.

To my parents, family, and friends, old and new, your ongoing love and support over the past fourteen years of my professional development has been incredible.

Finally, to Alex…your unwavering love, and belief in my ability over the past year has been astonishing, and frankly humbling to experience. I am simply a better person because of you. Thank you.

Contents

Ethics

What elements of mental health services are therapeutically helpful and unhelpful for individuals with a BPD diagnosis?

Sarah Elizabeth Davidson

Lancaster University

Abstract

There has been much written about service users with a Borderline Personality Disorder (BPD) diagnosis and their experiences of mental health services. The current thematic synthesis aims to interpret the findings of 15 qualitative studies, to develop a richer understanding of what elements of mental health services individuals with a BPD diagnosis find therapeutically helpful and unhelpful. Through performing a thematic synthesis (Thomas & Harden, 2008), seven analytical themes were derived. Therapeutic value was found in services providing a containing, boundaried and validating experience. The therapeutic relationship was seen as the most powerful tool in bringing therapeutic value to service users and ultimately working towards recovery. Recommendations include making the relationship between staff and service users the key therapeutic tool, the need for increased understanding of this client group, and clinical psychologists providing support and training to staff in order to accomplish this.

Key words: Lived experience, Thematic Synthesis, Borderline Personality Disorder, mental health services, therapeutic alliance

Borderline Personality Disorder (BPD) is understood through the medical model as a personality disorder of emotional dysregulation; the diagnostic criteria include impulsivity, a lack of sense of self, recurrent acts of self-harm, chronic feelings of emptiness, and involvement in intense and unstable personal relationships (APA, 2013). However, these diagnostic terms are not habitually used by clinical psychologists, and do not represent the framework of understanding held by the author. Although accepting of the existence of difficulties that may be associated with the BPD diagnosis, reformulations of these difficulties have been developed (Bateman, Ryle, Fonagy, & Kerr, 2007; Crowell, Beauchaine, & Linehan, 2009; Fonagy, Target, Gergely, Allen, & Bateman, 2003; Ryle, 1997a), with the majority of them drawing on attachment theory as a starting point.

Due to the complex range of mental health and physical health difficulties associated with this diagnosis, individuals with a BPD diagnosis are reported to receive a substantial amount of input from a wide range of both physical and mental health care services (Comtois et al., 2003; Morris et al., 2014; van Asselt, Dirksen, Arntz, & Severens, 2007). From a mental health perspective, individuals with a BPD diagnosis access a wide range of psychological therapies in both inpatient and community mental health care services (Bateman & Fonagy, 2009; Fonagy & Bateman, 2006; Koekkoek et al., 2010). Despite this, mental health services appear to find meeting the needs of this client group challenging, and there appears to be a lack of specialist understanding around this service user group (Morris et al., 2014; NIMHE, 2003).

The National Institute for Mental health in England (NIMHE) documentation “Personality disorder: No longer a diagnosis of exclusion” in 2003 highlighted the inappropriate admissions of individuals with a PD diagnosis to inpatient psychiatric wards (NIMHE, 2003). Studies have shown that 36–67% of inpatients have a BPD diagnosis (NIMHE, 2003), and disproportionately high numbers of individuals with the diagnosis have inpatient admissions (Comtois & Carmel, 2014; Rogers & Dunne, 2011). Similarly, despite the lack of evidence supporting long-term medication use with this service user group, those with a diagnosis of BPD are prescribed significantly more psychotropic medication than those who meet the diagnostic criteria for other PD diagnoses, or other mental health service users, without a PD diagnosis (Broadbear & Rao, 2015; Rogers & Acton, 2012; Sansone, Rytwinski, & Gaither, 2003). This evidence suggests that services misunderstand the needs of this service group.

Koekkoek et al. (2010) in their narrative review of community health care for individuals with ‘severe personality disorder’ recount that not only does frequent or prolonged inpatient psychiatric admission incur the greatest financial cost, in comparison to other interventions for BPD (Fonagy, Target, Gergely, Allen, & Bateman, 2003), but that psychiatric admissions have been found to have numerous potential harmful effects, including a reduction in levels of independence (Koekkoek et al., 2010; Paris, 2004). Koekkoek et al. (2010) also comment that whilst community based services are valuable for this client group, particularly in the light of the stigma faced in inpatient services, they are lacking in structure, require better communication and overlap between their organisation and specialist therapy services, and need to be aware of the risk of iatrogenic damage (Koekkoek et al., 2010).

The National Institute for Health and Care Excellence (NICE, 2009) advise that drug treatment should not be used to treat service users with a BPD diagnosis, except for short-term treatment during a crisis. While NICE (2009) have outlined the treatment recommendations for this client group at a basic level, its guidance remains wedded to a psychiatric understanding of the diagnosis, and does not provide any alternative understanding of this service user group, nor recognition of the deeper therapeutic needs that have the potential to be met by services (Rogers

& Acton, 2012). Thus the issue of diagnosis is of relevance in developing an enhanced understanding of the service user group, and what they require from services.

The personality disorder diagnosis has long been the topic of debate (Alwin et al., 2006; Castillo, Ramon, & Morant, 2013; Gunderson, 2009; Horn, Johnstone, & Brooke, 2007; Nehls, 1999; Stalker, Ferguson, & Barclay, 2005). Pilgrim (2001) has suggested that within the UK National Health Service (NHS), personality disorder has been used as a ‘‘dustbin’’ diagnosis for clients who cannot be adequately described by other diagnostic categories (Pilgrim, 2001). Building on perspectives on the BPD diagnosis, Shedler and Westen (2014) critique personality disorder diagnoses as defined by the DSM, arguing for ways of conceptualising the difficulties associated with these diagnoses that are clinically richer than the DSM categories and place greater emphasis on patients’ mental life or inner experience, as opposed to simple, behavioural accounts (Shedler & Westen, 2014). Horn et al (2007) note that people labelled as ‘mentally ill’ face many consequences in relation to stigma, social isolation and discrimination which arguably have ramifications for the course of the person’s ‘‘illness’’ or distress (Horn et al., 2007), and that this can impact significantly upon people’s recovery (Anthony, 1993).

The issues around diagnosis, stigma and recovery have a particular pertinence for individuals with a BPD diagnosis due to its previously perceived permanence, and due to the potential for re-traumatisation by services. Internalising these views can lead to individuals’ cognitions and behaviours taking on disempowered and devalued attributions consistent with the label (Livingston & Boyd, 2010). As such, the way in which services and staff refer to the difficulties associated with a BPD diagnosis, and subsequently respond to service users, can have considerable impact on their therapeutic value.

This point is demonstrated by the fact that research suggests that mental health professionals may frequently perceive clients with a BPD diagnosis as less deserving of care than clients with a ‘mental illness’ diagnosis, and actually perceive them as having increased levels of dangerousness (Markham, 2003). Stalker, Ferguson and Barclay (2005) suggest that receiving a diagnosis of PD can in itself represent a barrier to obtaining appropriate support from health services (Stalker et al., 2005). Research focusing on the attitudes of health professionals towards individuals with a BPD diagnosis indicates that health staff tend to have strong reactions to individuals with this diagnosis, with more negative attitudes and with less empathy than towards other service users (Bodner, Cohen-Fridel, & Iancu, 2011; Markham, 2003; Westwood & Baker, 2010). Research has repeatedly identified that mental health staff view people with the BPD diagnosis as in control of their behaviour, and thus they display less empathy towards them (Bodner et al., 2015; Clarke, Usick, Sanderson, Giles-Smith, & Baker, 2014). Kling (2014) comments that the use of pejorative language about this client group, such as “manipulative” and “attention seeking”, can also serve to reinforce stereotypes. This may be because they are “constrained to understand and respond to self-harm almost exclusively within a problem saturated discourse” (Walker, 2009). Such issues highlight the difficulties which arise from over-reliance on a medical model of understanding personality issues. If staff and services do not adequately understand the development of the difficulties associated with a BPD diagnosis, and how their interactions impact upon such difficulties, then they cannot possibly understand the true therapeutic needs of this service user group, nor the potential for re-traumatisation and iatrogenic damage (Walker, 2009).

The evidence around service users with a BPD diagnosis and their relationship with services suggests a complex interplay of service user difficulties, inadequate resources, powerful diagnosis, and staff responses to this client group. Given the significant interpersonal and attachment needs of individuals with a BPD diagnosis, and the range of mental health services utilised by such individuals, there is considerable scope for services to either provide real therapeutic benefit, or further compound or cement the difficulties associated with the diagnosis. This thematic synthesis seeks to explore the experiences of mental health care services, from the perspective of individuals with a BPD diagnosis, to provide a rich account of what elements of services are therapeutically helpful and unhelpful.

Method

Methodological Approach

The nature of qualitative data means that approaches to synthesis are required that "understand and transfer ideas, concepts and metaphors across different studies" (Britten et al., 2002, p.210). This review utilised a method called Thematic Synthesis, developed by Thomas and Harden (2008) which was developed out of a need to address questions the answers to which might be gleaned from qualitative methods, without compromising on key principles developed from systematic reviews (Barnett-Page & Thomas, 2009; Harden et al., 2006; Harden & Thomas, 2005; Harden et al., 2004; Thomas & Harden, 2008). The approach has been used across a number of health related fields of research (Bridges, Flatley, & Meyer, 2010; Clarke et al., 2014; Woodman, Baillie, & Sivell, 2015). Barnett-Page and Thomas (2009) provide a comprehensive overview of the difference and similarities between Thematic Synthesis and other qualitative synthesis methods (Barnett-Page & Thomas, 2009). However, whilst Thomas and Harden note the similarities between their method and other established methods such as meta-ethnography (Noblitt & Hare, 1988) and grounded theory, (Glaser & Strauss, 2009) with respect to 'going beyond' the scope of the primary research papers in order to provide a higher order understanding, and completing initial line by line coding, there are some notable differences. Whilst meta-ethnography and grounded theory are arguably best suited to homogenous samples and research methods, Thematic Synthesis can be used across heterogeneous research settings and groups. Thus, this method is well suited to a review that, whilst seeking to understand individual experiences, also seeks to ask specific questions about the therapeutic needs of a service user group, utilising studies of a high quality. In the early stages of the research, the thematic synthesis question was decided as:

'What elements of mental health services are therapeutically helpful and unhelpful for individuals with a BPD diagnosis?'

The Search and Selection Process

The following inclusion criteria were used to identify appropriate papers: (1) the main aim of the paper was to explore experiences of individuals with a BPD diagnosis; (2) the paper used recognised qualitative approaches for data collection and analysis; (3) the data must have been organised thematically; (4) there must be some reference within themes to any mental health care service; (5) the paper was published in a peer reviewed journal; (6) the paper was published in English; (7) the paper contained direct quotes. The following exclusion criteria were applied: (1) papers that focused on forensic experiences; (2) Papers that focused solely on therapeutic models; (3) book chapters.

Having defined these inclusion and exclusion criteria, relevant papers were identified by searching the EBSCO data base (which includes Academic Search Complete, PsycINFO, AMED, CINAHL, Medline, PsyschArticles) ("peer reviewed" box selected). The full text search terms entered were: BPD OR Borderline OR Borderline Personality OR Borderline Personality

Disorder AND experience* OR view* OR opinion* OR journey* OR voice* OR understanding* OR perspective* OR lived experience* OR feeling* OR diagnosis OR stigma AND mental health service* OR mh service* OR psychol* OR psychiatric* OR system OR therap* OR psychotherap* OR CMHT OR specialist OR CPA OR service* OR recovery team* OR case management OR outpatient OR inpatient AND Qualitative* OR phenomenolog* OR IPA OR narrative* OR thematic OR focus group* OR interview* OR discourse analysis OR grounded theory* OR ethno* The search was conducted on the 4th May 2015.

The search strategy yielded a total of 1,085 peer-reviewed articles. The author read each title and then continued to read the abstract if it was felt the paper might meet the remainder of the inclusion criteria. Where suitability for inclusion was unclear, the full text was acquired and reviewed. Thirty nine articles were reviewed as potentially suitable, with 24 subsequently found to be unsuitable. For example a study by Rivera-Segara (2014) was excluded due to its focus on general, societal stigmatisation experiences of BPD as opposed to health care experiences. Finally, 15 papers were chosen for the thematic synthesis and the characteristics of these are outlined in table 1.

[Insert table 1 here]

Appraising Study Quality

Whilst Campbell et al. (2003) view the quality of papers as an important consideration in the exclusion stage of a search strategy, Sandelowski and Barroso (2007) argue the need to balance a rigorous appraisal with creativity and the allowance of individual difference (Ludvigsen et al., 2015). Thomas and Harden (2008) refer to a self-created list of quality appraisal criteria which they follow. However, for the purposes of this study, to ensure rigour, and to make the results more generalizable to the wider qualitative research community, the Critical Appraisal Skills Programme (CASP) (1999) checklist for qualitative research was applied to each paper. This consists of ten items relating to quality, with the first two questions acting as a screening tool. The purpose of using the checklist in this instance was not to exclude studies necessarily, but to establish the quality of each paper understood within the context of an established framework. The CASP analysis for each paper is contained in Appendix B.

Analysing and Synthesising the Selected Studies

Following quality appraisal, Thomas and Harden’s (2008) Thematic Synthesis method was adopted to complete the analysis. This method has three distinct stages of analysis. Firstly, the entire results section, including participant quotes, comments from the authors and interpretations made from each included paper, is initially coded, line by line, according to its meaning and context. This was done by the author, by copying each results section into a word document, and then coding the text line by line. Each code was recorded by hand into a ‘code bank’ and later written onto an individual coloured post-it note, in readiness for the next stage of the process. The second stage involves the development of ‘descriptive themes’ within and between papers, and consisted of amalgamating a number of descriptively similar codes into a series of descriptive themes (Appendix C). These themes generally remain ‘close’ to those generated by the original authors, and Thomas and Harden stress that at this stage, the main aim of a synthesis, of ‘going beyond’ the primary studies, has not been reached. Finally, in the third stage of analysis, overarching, ‘analytical themes’ are created, which should, according to Thomas and Harden, seek to answer the research question, thus representing a stage of interpretation “going beyond” that of the primary studies (Thomas & Harden, 2008). This stage can potentially generate new constructs, as well as produce recommendations and discussion for further research. Thomas and Harden note that this stage is equivalent to Noblitt and Hare's 'third order interpretations' (Noblitt & Hare, 1988). The process of synthesis can be seen in Appendix D.

Characteristics of Included Studies

In total, 15 studies were included in the Thematic Synthesis. All of the studies used participants with a BPD diagnosis. Seven of the studies were undertaken with participants from the United Kingdom, three from the USA, two from Holland, one from Norway, one from New Zealand and one from South Africa, thus representing a number of mental health care systems. A range of qualitative analysis methods were used, including Thematic Analysis (nine studies), Interpretive Phenomenological Analysis (three studies), Grounded Theory (two studies), and a "thematic approach" (Walker, 2009). All the papers, though different in their analytical method, held general epistemological positions that are concerned with how individuals and groups make meaning of their subjective experiences. Although the focus of each paper was slightly different, all of the papers made some reference to client experiences of mental health care, whether that be community or inpatient based, and elements that had been therapeutically helpful or unhelpful.

Results

The Thematic Synthesis produced seven analytical themes: Understand me; If you have to diagnose, don't label; Connect with me; Provide me with Security; Involve me in my care; Believe in me; and Don't abuse power. These themes in turn answer the research question: what elements of services do individuals with a BPD diagnosis find therapeutically helpful and unhelpful?

Analytical Theme One: Understand Me

The first theme to emerge from the data was the need for services and staff members to truly understand their service users. When service users felt that their difficulties were understood, they could begin to derive some therapeutic value from services. Conversely a failure to understand service users' difficulties and needs set a scene for a journey of misunderstanding, which subsequently led to a series of negative decisions and a lack of therapeutic value for service users. This understanding was crucial because it is the framework on which services and staff responses are built.

The data revealed that service users "experienced distressing emotions and thoughts" (Fallon, 2003, p.396), can engage in relationships that are complex, with one participant commenting, "I do not feel normal, going into the same mess again, the same violent men with sexual abnormalities" (Holm & Severinsson, 2011, p.169), and sometimes utilise deliberate self-harm to get "a calming effect" or "as a substitute for experiencing how I'm feeling" (Straker & Waks, 1997, p.195). Service users also recognised, with regard to accessing support and help-seeking, that, "Sometimes I am much too late….I am bad at setting limits or in recognising when I am doing badly" (Helleman, Goossens, Kaasenbrood, & van Achterberg, 2014, p.446) and that "the crisis episode, associated with a loss of emotional control and a greatly increased risk of self-harm was when they sought help" (Fallon, 2003, p.397). When these elements of internal experience, emotional expression, and service seeking were understood, participants felt "She listened and validated what I was experiencing and stuff. And it helped her to like gain an understanding of maybe I was behaving the way I was" (Veysey, 2014, p.27). Here it feels important that the developing understanding around the participant's difficulties is reciprocal and shared, and because understanding was so central to the future direction of support, in fact, being understood was the first therapeutic process for service users.

Participants from several of the included papers felt that services were lacking in specialist understanding. As Mercy describes: “When somebody presents a huge spectrum of problems they don’t know how to deal with them so in the end they just wash their hands of them and leave them to their own devices until a crisis happens” (Morris et al., 2014, p.253). Here, Mercy seems to be saying that services have left her feeling as though she is too complex to deal with. Thus she has interpreted the service response as withdrawing, which she feels has led to an exacerbation of difficulties, and ultimately crisis.

This theme of understanding was particularly pertinent to issues around risk, with participants commenting that they felt their complex risk needs were misunderstood, and that consequently interventions were inappropriate and invalidating. As this participant states:

> They’re [mental health professionals] . . . more interested in protecting the behavior, I guess you would call it, of the borderline . . but not paying attention to the causing of it . . . Oftentimes, what you want is somebody to talk to . . . Basically, you know, I’m here for safety purposes. (Nehls, 1999, p.290).

Here this participant senses a reluctance for services to look past the behavioural aspects of his difficulties. The opportunity for therapeutic benefit is lost, leaving the participant feeling invalidated and not listened to.

Service users not only felt that their difficulties were not adequately understood, but that there was a fundamental sense amongst staff that service users were ‘manipulative’, “you’re just playing up, you’re being a pain in the bum” (Rogers & Dunne, 2011, p.229) , and “that we just do things to gain attention” (Veysey, 2014, p.26), with one participant commenting, “they (clinicians) think that borderline (personality disorder) is more of a behaviour problem or a discipline problem, rather than an actual psychological problem …that you can choose not to feel suicidal" (Nehls, 1999, p.289). This paramount misconstruction of service user difficulty had a profound impact on the way in which service users experienced the support offered to them, which compounded feelings of being "rejected", "criticised" and "blamed" (Morris et al., 2014, p.253), and that ultimately, "I'm a write off as a human being…I just shouldn't be here. Not that I wanted to kill myself but I was just a waste of space and a waste of time" (Veysey, 2014, p.26). The internalisation of staff stereotyping and services' inaccurate interpretations of service user need sullied any opportunity for unconditional positive regard, a key state required for building therapeutic alliance (Steffen, 2013) and any misunderstood behaviours only served to reinforce and exacerbate stereotypes amongst staff groups. Thus, without understanding, the opportunity for any subsequent therapeutic benefit was lost.

Analytical Theme Two: If you have to diagnose, don't label

The second theme to be developed from the data, and linked with Understand Me, centred on service user experiences of the BPD diagnosis, and the experience of being labelled. Whilst service users found a degree of therapeutic value from the diagnosis, the process of labelling was deemed to be profoundly non-therapeutic.

There was ambivalence around the diagnosis itself, with some service users finding some meaning, stating, "After all these diagnoses thrown at me, she sat there within two minutes and told me what was wrong with me" (Rogers & Dunne, 2013, p.42), and "Well, I have to say I do…I do have borderline personality disorder. The criteria fit." (Nehls, 1999, p.288). Others, however, failed to find meaning in their diagnosis, with one participant stating, "If there was a diagnosis that was particularly useful in that it would help me get better by accepting it…I would be more than happy to…But I just didn't feel that BPD was like that at all" (Bonnington & Rose, 2014, p.12).

The way in which the diagnosis was delivered had an impact on how therapeutically diagnosis was viewed, with one participant commenting the diagnosis was helpful because she had "something to recover from" (Morris et al., 2014, p.253), whilst others commented more ambivalently, "They told me…'Your disorder is the reason why you try to kill and harm yourself'. I stayed alive and for this I was grateful, but nobody saw me or spoke to me as a person" (Holm & Severinsson, 2011, p.169). For others, the diagnosis was delivered with very little optimism, with one participant recalling, "What was it they said? Nothing really works for BPD, you're gonna be in and out of hospital, in repeated crisis" (Rogers & Acton, 2012, p.344). This created a sense of hopelessness around the diagnosis, thus the opportunity for therapeutic value to be found through diagnosis was eradicated.

Regardless of how service users viewed the BPD diagnosis, there was a clear view that the process of being 'labelled' was extremely non-therapeutic and unhelpful. Participants were able to express how it felt as though the labelling process had serious ramifications, with one participant commenting,

> I guess it seems like the diagnosis hasn't been used; it's been abused and has become more of just a wastebasket versus something to help direct treatment. I have felt the negative feelings that people have felt towards me, of having that diagnosis, like I felt prelabeled…. (Nehls, 1999, p.288).

Other participants ventured further that is was the labelling process, rather than the diagnosis per se, that caused them additional difficulties, with one participant commenting vehemently,

> I'd struggled for so long not knowing who I was and then suddenly 'here's a label'. Well, what does that tell me then? Am I not part of humanity?…it's made me very insecure about my worth as a person, who I am, because I used to be so capable and now I'm a nothing, a nobody. It's taken everything away from me. (Bonnington & Rose, 2014, p.11).

The process of labelling left participants feeling unworthy of care, thus, once again, service responses further compounded existing difficulties and therapeutic value was lost.

Analytical Theme Three: Connect With Me

The third theme derived from the thematic synthesis highlighted the therapeutic benefit of connection, both with staff members, other service users, and in relation to having a voice heard within services.

The therapeutic process of making a connection began very simply, with the idea that "We're a human being (sic) with thoughts and feelings and shit that's gone on in our lives" (Veysey, 2014, p.27), and "a person rather than…a case number" (Morris et al., 2014, p.253). Whilst this connection could be formed with relatively small gestures, such acts had a profound impact on service users, with one participant recalling, "The nurse talked with me for 30 min; it was a revelation. It removes a rock from your heart. I melted and felt heard, and I told her stuff" (Helleman et al., 2014, p.446). Here this participant demonstrates that this connection enabled them not only to recognise the block in emotion they had been experiencing, but to then go on to disclose further to the staff member, thus gaining further therapeutic value. These relationships also aided in the “containment of distressing emotions” (Fallon, 2003, p.398).

From these connections, participants described that positive relationships with staff members became crucial to daily living, and for many participants in the included papers, the formation of a meaningful relationship within services was their first experience of a secure attachment relationship based on non-judgement, genuine interest and a degree of safety, “In the past every time I did something terrible…that was the end” (Nehls, 2001, p.9). Such relationships helped participants to believe, “I just got that flicker of…maybe…If this person is willing to invest in me, then maybe I’m worthwhile” (Veysey, 2014, p.27), and helped in building self-worth. Thus, the relationship itself is a therapeutic tool. Participants were able to acknowledge that “talking is new, it’s something you have to start learning to do and it wasn’t that easy, trying to explain feelings to people” (Straker & Waks, 1997, p.195), and that building such connections could be a challenge, with one participant commenting,

> It’s taken him a long time to grasp the concept. I’ve finally gotten him to just hear what I have to say and acknowledge how I feel. That’s the biggest thing I want from him…I feel like if I can be in it with someone, then it’s possible to get through it. But like I said, I had to train someone to do that (Nehls, 2001, p.7).

Not only does this quote illustrate the need for understanding between staff member and service user, and the challenges in building such understanding, but also that often participants valued basic connection over action. It also shows the value that the participant garnered from this long-term relationship.

Despite the value that was gained from connection, participants frequently felt as though their own voices were lost within services, as illustrated by reflections such as “It is very important that I feel listened to. If not, I become very cross and begin to cause conflicts" (Koekkoek et al., 2010, p.132). Participants felt as though they were reliant on others to assert their needs, with one service user acknowledging, "I think my last experience was reasonably positive…'Cause my husband wrote an absolutely stonking complaint letter to that psychiatrist" (Rogers & Dunne, 2011, p.229). When service users did not feel heard, connections were not formed in the same way, and thus the therapeutic value of relationships was lessened or non-existent.

Analytical Theme Four: Provide me with Security

The fourth theme to be developed from the thematic synthesis revealed that service users found therapeutic value in services providing security, indeed acting effectively as a 'secure base' (Bowlby, 2005). Linking with earlier themes around understanding and connection, the sense of security incorporated a sense of safety, structure and containment, and was based on accessibility and consistency. The participants reported that consistency within a service was crucial. When participants had a clear understanding of services' expectations of them, and in turn of what they could expect from services, anxiety was lessened, with participants stating, "Discuss with the patient what the expectations of the brief admissions are…what to expect from the clinic. Let this be clear" (Helleman et al., 2014, p.446). This was manifested in clear boundaries both at service and staff level, and although services could sometimes be experienced as paternalistic, participants appreciated the need for both safety and containment. As one participant reflects, "This place was different from other institutions. I felt safe here…This was a turning point for me and my way to freedom" (Holm & Severinsson, 2011, p.168) and another states, "For me it helped to know that I would go again in 4 weeks…" (Koekkoek et al., 2010, p.132). Here, it feels as though the participant recognised the similarities to her previous admissions, in that she was within an inpatient environment, but something fundamentally different about the way the care was delivered allowed her to feel safe and hopeful.

The absence of provision of security for service users, characterised by inconsistent services, or rapid changes in staff members or service provision, was deeply unsettling, and could exacerbate feelings of confusion, abandonment and rejection. As participants commented, “The last thing I’d want is to be shoved off to another service; I’m frightened to death!” (Rogers & Dunne, 2013, p.41), and “a bit confused that the consequences for breaking a limit were not carried out the first time” (Straker & Waks, 1997, p.196).

Analytical Theme Five: Involve me in my care

A fifth theme from the thematic synthesis was concerned with the concept of service users deriving therapeutic value from being involved in their care. This theme harnessed both service user views about the information that was provided to them by services, and experiences of general communication and involvement from services.

Unfortunately, there was a general feeling across the papers, that despite participants feeling as though “I’d like to explain what I feel is best for me” (Rogers & Dunne, 2013, p.41), information regarding medication, diagnosis and ‘treatment’ options was limited, which left participants with a further sense of being unimportant, and undeserving of care. There was a clear link between a lack of information around service provision and ‘treatment’, and the relationship with diagnosis, with participants commenting, “They don’t say why that particular (drug) or anything – they just give it to you” (Rogers & Acton, 2012, p.345), “If I hadn’t said to my psychiatrist about DBT (Dialectical Behaviour Therapy), then she wouldn’t have said, ‘Oh, there’s one starting up’…”(Rogers & Dunne, 2013, p.42) and

> When he first said “borderline,” I’m like, “Borderline what?” He says, “borderline personality disorder.”…He wouldn’t explain it or anything. He said, “You have a personality disorder. You have a character disorder.” I had to go and research what that meant. I had no idea what he was talking about… (Nehls, 1999, p.287).

In addition, service users reported numerous instances of decision making processes around their care occurring either without them, or feeling as though their involvement was tokenistic, with comments such as, “They’re basically just telling you what they’ve already decided” (Rogers & Dunne, 2013, p.41), and “It was just a waste of time, because I was a waste of time…if I don’t matter, why would what I say matter?” (Veysey, 2014, p.27). This latter quote in particular highlights why such approaches were therapeutically unhelpful for service users. Being excluded from care decisions further internalised feelings of being worthless and unimportant, and was reminiscent of a ‘done to’ experience.

For those who did feel involved in their care and decision making processes, the therapeutic value was clear. Participants were able to express the value of being involved in their care, and appeared to be able to distinguish that this was something different from previous contacts with mental health services, commenting, “The whole CPA [Care Programme Approach] was based on what I wanted…it was a completely different experience” (Rogers & Dunne, 2013, p.41), and,

> He doesn’t tell me, “Well, you need to do this; you need to do that.” Just “Why don’t you try this?” That really makes a difference because, basically, the therapist and the psychiatrists I had before sit there, and you sit there, and you tell them everything that’s going on, and then they tell you what you should do. It doesn’t work for me that way. I don’t like people telling me what to do (Nehls, 2001, p.6).

Here, this participant was able to reflect that previous contacts with mental health professionals have been unsuccessful for them, and directly attributed this to being dictated to about decisions related to their care. Conversely, in this quotation, a clear difference was observed, and therapeutic value was found.

Analytical Theme Six: Believe in me

The penultimate theme relates to the therapeutic value of hope for service users. This theme incorporated hope as related to recovery, and staff views and attitudes, and as such, has links with previous themes on diagnosis and connection.

Participants noted that, particularly when they were struggling with difficult emotions, being believed in was of great therapeutic value, with one service user commenting, “They believed in my ability to heal when I didn’t….thank god they were there, cause (sic) otherwise I wouldn’t be doing this” (Veysey, 2014, p.27), and another reflecting, “They believed I could manage the same things as the others” (Holm & Severinsson, 2011, p.170). Participants commented that it “made all the difference in the world” (Nehls, 2001, p.9) to have a service approach that involved “focusing on strengths”, “started giving me hope and it started me actually focussing on what strengths I had” (Veysey, 2014, p.27).

However, this approach was far from experienced universally, and many of the participants described experiences where they had been met with staff and service feelings of hopelessness, with one participant illustrating perfectly the frustrations associated with hopelessness around diagnosis and a lack of positive future ideation:

> I mean, immediately it puts up a stop sign like, “We’re not going to get anywhere with her anyway…” Borderline personality is looked upon as hopeless, helpless, low-life, no

> sympathy…If someone was given a diagnosis of posttraumatic stress, it appears to me that the health professionals I've been involved with look at that with more concern or care and caring… (Nehls, 1999).

Whilst service users, as illustrated in the previous theme, found therapeutic value in being involved in their care and, as this themes shows, wanted to be believed in, this did not equate to responsibility being passed to them in a spirit of hopelessness, with participants commenting, "And I say, 'What can you do?' They say, 'I'm afraid there's nothing; you'll have to help yourself'" (Nehls, 1999; p.290), and:

> If you say 'you've got this, therefore we can help you with X, Y and Z', that's not as bad as saying 'you've got this [i.e. BPD], we can no longer help you' …'There is no treatment, we're not offering you any therapy, we're not offering you any medication and there's no point of you going into hospital'…they no longer had to bother to make an effort because 'she's one of those we can't help'.

The therapeutic value found in being believed in also extended to concepts of recovery for service users. Some of the papers spoke more explicitly about the concept of recovery than others, with some being published before the concept was prevalent within mental health services, whilst others referred more implicitly to recovery principles, or lack of them. Some participants felt that, "Nobody explained to me what they meant by recovery" (Rogers & Dunne, 2013, p.42), whilst others had their own personal constructs of recovery that included different elements such as coming off medication, "Now I'm not on medication I'm up at seven, go to college, work, I have a social life…" (Rogers & Acton, 2012, p.345), and ceasing to engage in harmful relationships, "I finally took the initiative to leave…later, I managed to leave him" (Holm & Severinsson, 2011, p.169). Prevalent across the theme was a sense that there is a practical journey through the mental health system, in addition to the existential journey through recovery, and that this was unique for each participant. It was accepted by participants that recovery included relapse and was not necessarily a linear construct, but that when services approached the concept with hope and positivity, and focused on participants' quality of life, as opposed to simply symptom reduction, this was most therapeutically helpful for clients. However, in linking with the theme of a 'secure base', recovery needed to be gradual, to avoid feelings of abandonment and anxiety, with one participant commenting,

> I'm moving on from [specific personality disorder service] now, but I'm still a person with BPD and this is what frightens me: when I was at [specific personality disorder service] I could say to the benefits people 'this is what I'm doing', but now I give the appearance of someone who is capable…but, who is still vulnerable and now outside the services (Bonnington & Rose, 2014, p.13).

Thus, being believed in and fostering a sense of hope and recovery for service users was a helpful therapeutic tool, as this participant poignantly states, "I have tried to kill myself over 300 times, but today I manage to tell myself that I will recover and feel better when I wake up tomorrow" (Holm & Severinsson, 2011, p.170).

Analytical Theme Seven: Don't abuse power

The final theme derived from the thematic synthesis encompasses service users' experiences of how power was abused, both within their individual care settings, and within the wider mental health system. The abuse of power was deemed extremely non-therapeutic for servicer users. This theme links also with previous themes relating to being involved in care and having a 'secure base'. Whilst valuing a security, and acknowledging that on occasion, "The goal, of course, is to prevent worsening…to prevent ending up on a slippery slope" (Helleman et al., 2014, p.446), service users were aware of a spectrum of abuse of power. This spectrum ranged from subtle infringements and disregarding actions, such as, “You’re just getting letters, but no actual person really telling you why this is changing or anything” (Rogers & Dunne, 2013, p.43), and “They’d never ever brought medication up unless they’re changing them, and I never got a say in it” (Rogers & Acton, 2012, p.345) to deeply traumatic and damaging abuses of consent and privacy, and in some cases psychological and physical violence, with one participant recounting, “I had to do whatever they [nurses]were doing. I didn’t even have any privacy to put a tampon in. I was followed to the toilet with someone holding the door open all the time watching” (Bonnington & Rose, 2014, p.14).

This abuse of power was felt acutely within the wider system, with issues of consent and sectioning being frequently cited by participants, such as, “She said, ‘you either swallow it, or we give you an injection’, so no choice” (Rogers & Acton, 2012, p.345), and “I had a conversation with the psychiatrist, who said I could either stay voluntarily, or he’d put me under section” (Bertha Rogers & Dunne, 2011, p.229). Similarly, reductions in harmful behaviours, motivated and preceded by fear of reprisal, such as, “being so terrified of being sent back stopped me from doing a hell of a lot of things” (Straker & Waks, 1997, p.194), not only took place at an individual level, but in relation to the wider social system, illustrated by quotes such as, “I’ve been told that if I do self-harm in the form of cutting that my Community Psychiatric Nurse will report me to social services, because I’m the sole carer of my children” (Walker, 2009, p.125).

Some of the papers referred explicitly and implicitly to the process of ‘othering’, whereby belonging to a particular group is considered the ‘right’ way to be human (Walker, 2009; Wright, Haigh, & McKeown, 2007). Within this context, clients with a BPD diagnosis were grouped as ‘other’, producing a dynamic of dominance and subordination between ‘non-BPD’ services and staff members, and clients with a BPD diagnosis at every level of interaction. This abuse of power left participants feeling “…like I was being abused all over again” (Veysey, 2014, p.26). Thus, abuse of power, as it ran throughout individual actions and throughout the wider mental health and social system was deeply non-therapeutic for service users.

Discussion and Conclusions

The main aim of the thematic synthesis was to provide a rich and detailed account of what elements of mental health services individuals with a BPD diagnosis find therapeutically helpful and unhelpful. A thematic synthesis of 15 studies revealed seven analytical themes.

The results of the thematic synthesis build on previous research relating to organisational structure, diagnosis, staff attitudes and understanding of the difficulties associated with the BPD diagnosis. The thematic synthesis found that in keeping with the review completed by Koekkoek et al. (2010), it was therapeutically unhelpful for service users when services were lacking in a clear structure and when services failed to communicate with service users. Papers which focused on specific approaches, for instance case management or the Care Programme Approach (Nehls, 2001; Rogers & Dunne, 2013), reported increased understanding around the need for clear structure, and more specialist knowledge, however, even these services still reported issues related to diagnosis and staff attitudes. The results of the thematic synthesis echo previous research which suggests that there is a fundamental misunderstanding on the part of services and staff about the nature of the difficulties associated with the BPD diagnosis and resulting staff attitudes (Bodner, Cohen-Fridel, & Iancu, 2011; Markham, 2003; Westwood & Baker, 2010). Similarly, in keeping with previous research around the BPD diagnosis, the findings of this thematic synthesis indicate that whilst a degree of basic understanding can be gained from receiving the diagnosis, the process of being diagnosed and feeling labelled is associated with hopelessness and a feeling of being ‘done to’, and does not accord with the concept of recovery (Castillo, Ramon, & Morant, 2013; Gunderson, 2009; Horn et al., 2007; Nehls, 1999; Stalker, Ferguson, & Barclay, 2005; Shedler & Westen, 2014). Cumulatively, these issues result in many therapeutic opportunities being lost for service users, and as such, services are experienced as unhelpful, and potentially causing damage. It was of concern to the author that despite previous research, such long standing and repeatedly reported issues should continue to be found, and really raises the question how far services have really come for individuals with a BPD diagnosis?

Despite some negative findings, the results also show that services can potentially be therapeutically valuable, and thus the recommendations from this thematic synthesis focus on building on the positive findings. Such positive outcomes are dependent on service provision, but most importantly on the reciprocal roles adopted by staff members and manifested in staff and service user relationships (Ryle, 1997a). This indicates that mental health services can pave the way for real therapeutic alliance and recovery, even outside of the therapy room.

The results from the thematic synthesis which centred on developing understanding and creating security, akin to Bowlby’s ‘secure base’ show that participants found great therapeutic value in structured, consistent and boundaried environments. Some of these findings are reminiscent of the work already being undertaken within therapeutic communities, Enabling Environments and the implementation of PIPES standards (Harrison, 2013; Johnson & Haigh, 2010), as part of the Offender Personality Disorder Pathway, in prison and community forensic projects across the United Kingdom. The findings support Morris et al.’s suggestion (2014) that an application of the principles utilised within specialist services across the forensic estate would be advantageous for community services, in creating services that are consistent, and formed around proven attachment based psychological theory. This model not only seeks to provide a secure base for its service users, and one that fosters hope and recovery, but also invests time and resources in providing adequate training and support for staff members. Research has consistently suggested that providing additional training for staff working with this client group can improve negative attitudes (Krawitz, 2004; Westwood & Baker, 2010). The acknowledgment that the opportunity for reflection and support for staff is needed is cited in the recent publication “Meeting the challenge, making a difference: Working effectively to support people with personality disorder in the community” (Bolton, Wood, Lovell, & Morgan, 2014).

Building on the recommendation of increasing understanding and providing staff with a more holistic conceptualisation of the difficulties associated with the BPD diagnosis, that moves away from a medically dominant narrative, this thesis proposes that having a psychological formulation of difficulties provides a shared language for everyone working with the service user, including the service user themselves (Kirkland & Baron, 2014). Psychological formulation provides the opportunity to cite and develop protective factors and thus hope, one of the themes derived from the thematic synthesis. As a collaborative process, this would allow for staff to move away from the ‘doing to’ approach cited so frequently in the results of the thematic synthesis (Steffen, 2013; Wright et al., 2007). Fundamentally, the aim of these recommendations is to place the relationship between the service user and staff member (s) at the heart of services.

The thematic synthesis had several strengths. Notably, the CASP quality analysis showed that the studies utilised in the synthesis were all of a high standard, with none scoring below seven out of ten. This resulted in a synthesis with an abundance of high quality data to draw on.

What particularly impressed the author was the balanced presentation of data within the studies which incorporated both positive and negative service user experiences, regardless of the ‘standpoint’ of the articles. For instance, Rogers and Dunne (2013) presented a varied set of experiences in relation to the Care Programme Approach, and were not swayed in attempting to promote a similar agenda.

A further strength of the thematic synthesis was that it drew on articles from a number of countries, thus providing an international perspective on what elements of services are therapeutically helpful. Similarly, the fact that the included articles focused on slightly different areas of service provision for individuals with a BPD diagnosis means that as an overall synthesis, we are presented with a more complete picture. The range of dates of publication of the included studies also meant that the results appeared to be stable over time, despite the reported changes in services for individuals with a BPD diagnosis. Finally, utilising thematic synthesis as a synthesis approach meant that studies could be included which used a range of qualitative research methods, thus making the synthesis more inclusive. This was crucial in what Thomas and Harden refer to as ‘going beyond’ the scope of the individual studies, to answer the research question (Thomas and Harden, 2008), thus providing a clear set of guidance for services, whilst also providing further evidence for the psychological theories around individuals with a BPD diagnosis, such as attachment theory (Bowlby, 2005) and the paramount importance of the therapeutic relationship.

With regards to future research, it is recommended that it would be beneficial to study the outcomes for individuals with a BPD diagnosis in services where the principles derived from the thematic synthesis are followed, to ascertain the extent to which they make a difference.

Similarly, it would be helpful to further the evidence base around staff wellbeing in relation to working with this service user group when enhanced understanding and training is provided.

References

Alwin, N., Blackburn, R., Davidson, K., Hilton, M., Logan, C., & Shine, J. (2006). *Understanding Personality Disorder: A Report by the British Psychological Society*.

American Psychiatric Association 2013, *Diagnostic and statistical manual of mental disorders*. (5th edition), Arlington, VA: Author.

Anthony, W. a. (1993). Recovery from mental illness: The guiding vision of the mental health service system in the 1990s. *Psychosocial Rehabilitation Journal*, *16*(4), 11–23. http://doi.org/10.1037/h0095655

Aviram, R. B., Brodsky, B. S., & Stanley, B. (2006). Borderline personality disorder, stigma, and treatment implications. *Harvard Review of Psychiatry*, *14*(5), 249–256. http://doi.org/10.1080/10673220600975121

Barnett-Page, E., & Thomas, J. (2009). Methods for the synthesis of qualitative research: a critical review. *BMC Medical Research Methodology*, *9*, 59. http://doi.org/10.1186/1471-2288-9-59

Bateman, A., & Fonagy, P. (2009). Randomized controlled trial of outpatient mentalization-based treatment versus structured clinical management for borderline personality disorder. *The American Journal of Psychiatry*, *166*(12), 1355–1364. http://doi.org/10.1176/appi.ajp.2009.09040539

Bateman, A. W., Ryle, A., Fonagy, P., & Kerr, I. B. (2007). Psychotherapy for borderline personality disorder: mentalization based therapy and cognitive analytic therapy compared. *International Review of Psychiatry (Abingdon, England)*, *19*(1), 51–62. http://doi.org/10.1080/09540260601109422

Bateman, A., & Fonagy, P. (2003) Health service utilization costs for borderline Personality disorder: patients treated with psychoanalytically oriented partial hospitalization versus general psychiatric care. *American Journal of Psychiatry* 2003; 160:169–171

Bodner, E., Cohen-Fridel, S., & Iancu, I. (2011). Staff attitudes toward patients with borderline personality disorder. *Comprehensive Psychiatry*, *52*(5), 548–555. http://doi.org/10.1016/j.comppsych.2010.10.004

Bodner, E., Cohen-Fridel, S., Mashiah, M., Segal, M., Grinshpoon, A., Fischel, T., & Iancu, I. (2015). The attitudes of psychiatric hospital staff toward hospitalization and treatment of patients with borderline personality disorder. *BMC Psychiatry*, *15*(1), 1–12. http://doi.org/10.1186/s12888-014-0380-y

Bolton, W., Wood, H., Lovell, K., & Morgan, L. (2014). *Meeting the challenge, making a difference: Working effectively to support people with personality disorder in the community* . London, Department of Health.

*Bonnington, O., & Rose, D. (2014). Social Science & Medicine Exploring stigmatisation among people diagnosed with either bipolar disorder or borderline personality disorder : A critical realist analysis. *Social Science & Medicine*, *123*, 7–17. http://doi.org/10.1016/j.socscimed.2014.10.048

Bowlby, J. (2005). *A secure base: Clinical applications of attachment theory* (Vol. 393). Taylor & Francis.

Bridges, J., Flatley, M., & Meyer, J. (2010). Older people’s and relatives’ experiences in acute care settings: Systematic review and synthesis of qualitative studies. *International Journal of Nursing Studies*, *47*(1), 89–107. http://doi.org/10.1016/j.ijnurstu.2009.09.009

Britten, N., Campbell, R., Pope, C., Donovan, J., Morgan, M., & Pill, R. (2002). Using meta ethnography to synthesise qualitative research: a worked example. *Journal of Health Services Research & Policy*, *7*(4), 209–215. http://doi.org/10.1258/135581902320432732

Broadbear, J., & Rao, S. (2015). Psychotherapy for Borderline Personality Disorder Reduces the Need for Prescription Medication. *European Psychiatry*, *30*, 1528. http://doi.org/10.1016/S0924-9338(15)31181-0

Campbell, R., Pound, P., Pope, C., Britten, N., Pill, R., Morgan, M., & Donovan, J. (2003). Evaluating meta-ethnography: A synthesis of qualitative research on lay experiences of diabetes and diabetes care. *Social Science and Medicine*, *56*(4), 671–684. http://doi.org/10.1016/S0277-9536(02)00064-3

Castillo, H., Ramon, S., & Morant, N. (2013). A recovery journey for people with personality disorder. *The International Journal of Social Psychiatry*, *59*(3), 264–73. http://doi.org/10.1177/0020764013481891

Castillo, H. (2000). *Personality Disorder: Temperament Or Trauma*? (Vol. 23). Jessica Kingsley Publishers.

Clarke, D., Usick, R., Sanderson, A., Giles-Smith, L., & Baker, J. (2014). Emergency department staff attitudes towards mental health consumers: A literature review and thematic content analysis. *International Journal of Mental Health Nursing*, *23*, 273–284. http://doi.org/10.1111/inm.12040

Comtois, K. A., & Carmel, A. (2014). Borderline Personality Disorder and High Utilization of Inpatient Psychiatric Hospitalization: Concordance Between Research and Clinical Diagnosis. *The Journal of Behavioral Health Services & Research*, (206). http://doi.org/10.1007/s11414-014-9416-9

Comtois, K. A., Russo, J., Snowden, M., Srebnik, D., Ries, R., & Roy-Byrne, P. (2003). Factors associated with high use of public mental health services by persons with borderline personality disorder. *Psychiatric Services*, *54*(8), 1149–1154. http://doi.org/10.1176/appi.ps.54.8.1149

Critical Appraisal Skills Programme, C. (2014) 'CASP Checklists', [online], available: http://www.caspuk.net/#!casp-tools-checklists/c18f8Oxford [accessed 14.05.2015].

Crowell, S. E., Beauchaine, T. P., & Linehan, M. M. (2009). A biosocial developmental model of borderline personality: Elaborating and extending Linehan's theory. *Psychological Bulletin*, *135*(3), 495–510. http://doi.org/10.1037/a0015616

*Fallon, P. (2003). Travelling through the system: The lived experience of people with borderline personality disorder in contact with psychiatric services. *Journal of Psychiatric and Mental Health Nursing*, *10*(4), 393–400. http://doi.org/10.1046/j.1365-2850.2003.00617.x

Fonagy, P., & Bateman, A. (2006). Progress in the treatment of borderline personality disorder. *The British Journal of Psychiatry*, *188*, 1–3. http://doi.org/10.1192/bjp.bp.105.012088

Fonagy, P., Target, M., Gergely, G., Allen, J. G., & Bateman, A. W. (2003). The Developmental Roots of Borderline Personality Disorder in Early Attachment Relationships: A Theory and Some Evidence. *Psychoanalytic Inquiry: A Topical Journal for Mental Health Professionals*, *23*(3). http://doi.org/DOI:10.1080/07351692309349042

Glaser, B. G., & Strauss, A. L. (2009). *The discovery of grounded theory: Strategies for qualitative research*. Transaction Publishers

Gunderson, J. G. (2009). Reviews and Overviews Borderline Personality Disorder : Ontogeny of a Diagnosis. *Am J Psychiatry*, *1666*(5), 530–539. http://doi.org/10.1176/appi.ajp.2009.08121825

Harden, A, Brunton, G., Fletcher, A, Oakley, A., Burchett, H., & Backhans, M. (2006). *Young people, pregnancy and social exclusion: A systematic synthesis of research evidence to identify effective, appropriate and promising approaches for prevention and support*. http://doi.org/ISBN: 0-9551548-4-7 978-0-9551548-4-3

Harden, A., Garcia, J., Oliver, S., Rees, R., Shepherd, J., Brunton, G., & Oakley, A. (2004). Applying systematic review methods to studies of people's views: an example from public health research. *Journal of Epidemiology and Community Health*, *58*(9), 794–800. http://doi.org/10.1136/jech.2003.014829

Harden, A., & Thomas, J. (2005). Methodological issues in combining diverse study types in systematic reviews. *International Journal of Social Research Methodology*, *8*(3), 257–271. http://doi.org/10.1080/13645570500155078

Harrison, T. (2013). *Enabling environments*. Retrieved from http://www.rcpsych.ac.uk/pdf/ee standards - 2013.pdf

*Helleman, M., Goossens, P. J. J., Kaasenbrood, A., & van Achterberg, T. (2014). Experiences of patients with borderline personality disorder with the brief admission intervention: A phenomenological study. *International Journal of Mental Health Nursing*, 442–450. http://doi.org/10.1111/inm.12074

*Holm, A. L., & Severinsson, E. (2011). Struggling to recover by changing suicidal behaviour: Narratives from women with borderline personality disorder. *International Journal of Mental Health Nursing*, *20*(3), 165–173. http://doi.org/10.1111/j.1447-0349.2010.00713.x

Horn, N., Johnstone, L., & Brooke, S. (2007). Some service user perspectives on the diagnosis of Borderline Personality Disorder. *Journal of Mental Health*, *16*(2), 255–269. http://doi.org/10.1080/09638230601056371

Johnson, R., & Haigh, R. (2010). Social psychiatry and social policy for the 21st century - New concepts for new needs: The “psychologically-informed environment.” *Mental Health and Social Inclusion*, *14*(4), 30–35. http://doi.org/10.5042/mhsi.2010.0620

Kirkland, J., & Baron, E. (2014). Using a cognitive analytic approach to formulate a complex sexual and violent offender to inform multi-agency working: developing a shared understanding. *Journal of Sexual Aggression*, (March 2015), 37–41. http://doi.org/10.1080/13552600.2014.939596

Kling, R. (2014). Borderline Personality Disorder, Language, and Stigma. *Ethical Human Psychology and Psychiatry*, *16*(2), 114-119.

*Koekkoek, B., van der Snoek, R., Oosterwijk, K., & van Meijel, B. (2010). Preventive psychiatric admission for patients with borderline personality disorder: A pilot Study. *Perspectives in Psychiatric Care*, *46*(2), 127–134. http://doi.org/10.1111/j.1744-6163.2010.00248.x

Koekkoek, B., van Meijel, B., & Hutschemaekers, G. (2010). Community mental healthcare for people with severe personality disorder: narrative review. *The Psychiatrist*, *34*(1), 24–30. http://doi.org/10.1192/pb.bp.108.022426

Krawitz, R. (2004). Borderline personality disorder: Attitudinal change following training. *Australian and New Zealand Journal of Psychiatry*, *38*(7), 554–559. http://doi.org/10.1111/j.1440-1614.2004.01409.x

Livingston, J. D., & Boyd, J. E. (2010). Correlates and consequences of internalized stigma for people living with mental illness: A systematic review and meta-analysis. *Social Science and Medicine*, *71*(12), 2150–2161. http://doi.org/10.1016/j.socscimed.2010.09.030

Ludvigsen, M. S., Hall, E. O. C., Meyer, G., Fegran, L., Aagaard, H., & Uhrenfeldt, L. (2015). Using Sandelowski and Barroso's Metasynthesis Method in Advancing Qualitative Evidence. *Qualitative Health Research*. http://doi.org/10.1177/1049732315576493

Markham, D. (2003). Attitudes towards patients with a diagnosis of "borderline personality disorder": Social rejection and dangerousness. *Journal of Mental Health*, *12*(6), 595–612. http://doi.org/1360-0567

* Miller, S. G. (1994). Borderline Personality Disorder From the Patient's Perspective. *Psychiatric Services, 45*(12), 1215-1219.

*Morris, C., Smith, I., & Alwin, N. (2014). Is contact with adult mental health services helpful for individuals with a diagnosable BPD? A study of service users views in the UK. *Journal of Mental Health*, *23*(5), 251–255. http://doi.org/10.3109/09638237.2014.951483

*Nehls, N. (1999). Borderline personality disorder: The voice of patients. *Research in Nursing and Health*, *22*(4), 285–293. http://doi.org/10.1002/(SICI)1098-240X(199908)22:4<285::AID-NUR3>3.0.CO;2-R

*Nehls, N. (2001). What is a case manager? the perspective of persons with borderline personality disorder. *Journal of the American Psychiatric Nurses Association*, *7*(1), 4–12. http://doi.org/10.1067/mpn.2001.113132

National Institute of Clinical Excellence (NICE). (2009): *Borderline personality disorder: The NICE guideline on treatment and management*. ISBN: 978-1-85433-477-0. Retrieved from http://www.nice.org.uk/guidance/cg78/resources/cg78-borderline-personality-disorder-bpd-full-guideline3

NIHME (National Institute for Mental Health in England). (2003). *Personality disorder: No longer a diagnosis of exclusion.* London: Department of Health.

Noblit, G. W., & Hare, R. D. (1988). *Meta-ethnography: Synthesizing qualitative studies* (Vol. 11). Sage.

Pilgrim, D. (2001). Disordered personlaities and disordered concepts. *Journal of Mental Health*, *10*(3), 253–265. http://doi.org/10.1080/09638230020023877

*Rogers, B., & Acton, T. (2012). “I think we”re all guinea pigs really’: A qualitative study of medication and borderline personality disorder. *Journal of Psychiatric and Mental Health Nursing*, *19*(4), 341–347. http://doi.org/10.1111/j.1365-2850.2011.01800.x

*Rogers, B., & Dunne, E. (2011). “They told me I had this personality disorder: all of a sudden I was wasting their time”: personality disorder and the inpatient experience. *Journal of Mental Health (Abingdon, England)*, *20*(3), 226–233. http://doi.org/10.3109/09638237.2011.556165

*Rogers, B., & Dunne, E. (2013). A Qualitative Study on the Use of the Care Programme Approach with Individuals with Borderline Personality Disorder: A Service User Perspective. *Journal of Psychosocial Nursing & Mental Health Services*, *51*(10), 38.

Ryle, A. (1997a). The structure and development of borderline personality disorder: a proposed model. *The British Journal of Psychiatry: The Journal of Mental Science*, *170*, 82–87. http://doi.org/10.1192/bjp.170.1.82

Sandelowski, M., & Barroso, M. (2007). Handbook for synthesizing qualitative research. New York: Springer.

Sansone, R. A., Rytwinski, D., & Gaither, G. A. (2003). Borderline Personality and Psychotropic Medication Prescription in an Outpatient Psychiatry Clinic. *Comprehensive Psychiatry*, *44*(6), 454–458. http://doi.org/10.1016/S0010-440X(03)00147-0

Shedler, J., & Westen, D. (2004). Refining personality disorder diagnosis: integrating science and practice. *The American Journal of Psychiatry*, *161*(8), 1350–1365. http://doi.org/10.1176/appi.ajp.161.8.1350

Stalker, K., Ferguson, I., & Barclay, A. (2005). It’s a horrible term for someone: Service user and provider perspectives on personality disorder, (April 2015), 37–41. http://doi.org/10.1080/09687590500086443

Steffen, E. (2013). Both “being with” and “doing to”: Borderline personality disorder and the integration of humanistic values in contemporary therapy practice, *28*(1).

*Straker, G., & Waks, B. (1997). Limit setting in regard to self-damaging acts: The patient's perspective. *Psychotherapy*, *34*(2), 192–200. http://doi.org/http://psycnet.apa.org/doi/10.1037/h0087846

Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, *8*, 45. http://doi.org/10.1186/1471-2288-8-45

Van Asselt, A. D. I., Dirksen, C. D., Arntz, A., & Severens, J. L. (2007). The cost of borderline personality disorder: societal cost of illness in BPD-patients. *European Psychiatry*, *22*(6), 354–361. http://doi.org/10.1016/j.eurpsy.2007.04.001

*Veysey, S. (2014). People with a borderline personality disorder diagnosis describe discriminatory experiences. *Kōtuitui: New Zealand Journal of Social Sciences Online*, (November), 1–16. http://doi.org/10.1080/1177083X.2013.871303

*Walker, T. (2009). “Seeing beyond the battled body” – An insight into selfhood and identity from women’s accounts who self-harm with a diagnosis of borderline personality disorder.

Counselling and Psychotherapy Research, *9*(2), 122–128. http://doi.org/10.1080/14733140902909174

Westwood, L., & Baker, J. (2010). Attitudes and perceptions of mental health nurses towards borderline personality disorder clients in acute mental health settings: A review of the literature. *Journal of Psychiatric and Mental Health Nursing*, *17*(7), 657–662. http://doi.org/10.1111/j.1365-2850.2010.01579.x

Woodman, C., Baillie, J., & Sivell, S. (2015). The preferences and perspectives of family caregivers towards place of care for their relatives at the end-of-life. A systematic review and thematic synthesis of the qualitative evidence. *BMJ Supportive & Palliative Care*, 1–12. http://doi.org/10.1136/bmjspcare-2014-000794

Wright, K., Haigh, K., & McKeown, M. (2007). Reclaiming the humanity in personality disorder. *International Journal of Mental Health Nursing*, *16*(4), 236–246. http://doi.org/10.1111/j.1447-0349.2007.00480.x

Table 1: Features of included papers

Paper No.	Author and Year of Publication	Country	Sample	Qualitative Approach	Primary Aim
1	Miller (1994)	USA	n = 10 (8 women) with a BPD diagnosis Age range = 21-50 years	Grounded Theory	To understand the lived experience of having a BPD diagnosis and how it is treated.
2	Straker & Waks (1997)	South Africa	n = 5 women with BPD diagnosis Age range = 22-25 years	Thematic Analysis	To explore the phenomenological experiences of limit setting regarding self-damaging acts
3	Nehls (1999)	USA	n = 30 women who met the criteria for BPD Age range not specified	Interpretive Phenomenology	To understand the lived experience of BPD
4	Nehls (2001)	USA	n = 18 (17 women) who met the criteria for BPD Age range = 33-57 years	Interpretive Phenomenology	To explore the experiences of case management services for individuals with a BPD diagnosis
5	Fallon (2003)	UK	n = 7 (4 women) Age range = 25-45 years	Grounded Theory	To gain an understanding of how participants experience mental health services
6	Walker (2009)	UK	n = 4 women with a diagnosis of BPD and a history of self-harm Age range not specified	A performance and thematic approach	To explore the experiences of self-harm in women with a BPD diagnosis
7	Koekkoek et al. (2010)	Holland	n = 8 women with a BPD diagnosis Age range = 24-61 years	Thematic Analysis	To determine the impact of short-term psychiatric admission on individuals with a BPD diagnosis
8	Holm & Severinsson (2011)	Norway	n = 13 women with a BPD diagnosis Age range = 21-43 years	Thematic Analysis	To understand how the recovery model affects suicidal behaviour in individuals with a BPD diagnosis
9	Rogers & Dunne (2011)	UK	n = 7 (5 women) with a BPD diagnosis Age range = 21-61 years	Thematic Analysis	To explore the inpatient experiences of individuals with a diagnosis of BPD
10	Rogers & Acton (2012)	UK	n = 7 (6 women) with a BPD diagnosis	Thematic Analysis	To explore the perspectives of individuals with a BPD diagnosis, who are treated with

			Age range 21-43 years		medication
11	Rogers & Dunne (2013)	UK	n = 7 (5 women) with a BPD diagnosis Age range = 21-61	Thematic Analysis	To explore the experiences of individuals with a BPD diagnosis, in relation to the CPA approach
12	Bonnington & Rose (2014)	UK	n = 22 (17 women) plus focus groups of individuals with a BPD diagnosis Age range not specified	Thematic Analysis	To explore the experiences of stigma and discrimination amongst individuals with a BPD and Bi-Polar Disorder Diagnosis
13	Helleman et al. (2014)	Holland	n = 17 (16 women) Age range = 28-59 years	Thematic Analysis	To explore the experiences of a brief admission as a crisis intervention for individuals with a BPD diagnosis
14	Veysey (2014)	New Zealand	n = 8 (7 women) with a BPD diagnosis Age range = 25-65	Interpretive Phenomenological Analysis	To explore the self-identified discriminatory experiences of individuals with a BPD diagnosis.
15	Morris, Smith & Alwin (2014)	UK	n = 9 (7 women) with a BPD diagnosis Age range = 31-47 years	Thematic Analysis	To understand the experiences of adults with a BPD diagnosis in accessing mental health services

Appendix A

Author Guidelines for The Journal of Qualitative Health Research

Manuscript Submission Guidelines: Qualitative Health Research (QHR)

4. Preparing your manuscript

4.1 Word processing formats

Preferred formats for the text and tables of your manuscript are Word DOC, RTF, XLS. LaTeX files are also accepted. The text should be double-spaced throughout and with a minimum or 3cm for left and right hand margins and 5cm at head and foot. Text should be standard 10 or 12 point. Word and LaTex templates are available on the Manuscript Submission Guidelines page of our Author Gateway.

4.2 Artwork, figures and other graphics

For guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's Manuscript Submission Guidelines. Please refer to clause 4.5 for information on SAGE Language Services.

Figures supplied in colour will appear in colour online regardless of whether or not these illustrations are reproduced in colour in the printed version. For specifically requested colour reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

4.3 Supplementary material

This journal is able to host additional materials online (e.g. datasets, podcasts, videos, images etc) alongside the full-text of the article. These will be subjected to peer-review alongside the article. For more information please refer to our guidelines on submitting supplementary files, which can be found within our Manuscript Submission Guidelines page.

4.4 Journal layout

In general, QHR adheres to the guidelines contained in the Publication Manual of the American Psychological Association [“APA”], 6th edition (ISBN 10:1-4338-0561-8, softcover; ISBN 10:1-4338-0559-6, hardcover; 10:1-4338-0562, spiral bound), with regard to manuscript preparation and formatting. These guidelines are referred to as the APA Publication Manual, or just APA. Additional help may be found online at http://www.apa.org/, or search the Internet for “APA format.”

4.5 Reference style

QHR adheres to the APA reference style. Click here to review the guidelines on APA to ensure your manuscript conforms to this reference style.

4.6 English language editing services

Authors seeking assistance with English language editing, translation, or figure and manuscript formatting to fit the journal’s specifications should consider using SAGE Language Services. Visit SAGE Language Services on our Journal Author Gateway for further information.

Appendix B

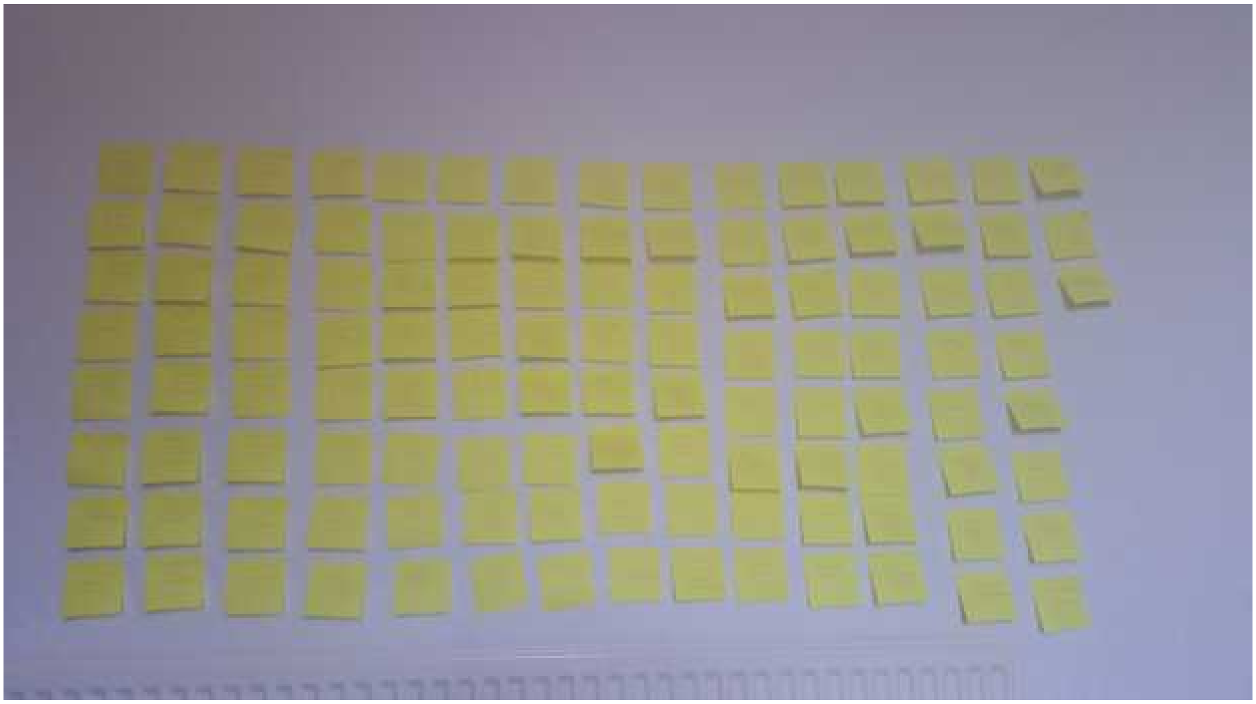
CASP Quality Appraisal for Included Papers

CASP Q	Miller (1994)	Straker & Waks (1997)	Nehls (1999)	Nehls (2001)	Fallon (2003)	Walker (2009)	Koekkoek et al. (2010)
1	Y	Y	Y	Y	Y	Y	Y
2	Y	Y	Y	Y	Y	Y	Y
3	Y	Y	Y	Y	Y	Y	N
4	Y	Y	Y	Y	Y	Y	Y
5	Y	Y	Y	Y	Y	Y	Y
6	N	N	N	N	N	N	N
7	N	?	N	N	Y	Y	Y
8	Y	N	Y	Y	N	Y	Y
9	Y	Y	Y	Y	Y	Y	Y
10	Y	Y	Y	Y	Y	Y	Y
Total	8	7	8	8	8	9	8

CASP Q	**Holm & Severinsson (2011)**	**Rogers & Dunne (2011)**	**Rogers & Acton (2012)**	**Rogers & Dunne (2013)**	**Bonnington & Rose (2014)**	**Helleman et al. (2014)**	**Veysey (2014)**	**Morris et al. 2014**
1	Y	Y	Y	Y	Y	Y	Y	Y
2	Y	Y	Y	Y	Y	Y	Y	Y
3	Y	N	N	N	Y	Y	Y	Y
4	Y	Y	Y	Y	Y	Y	Y	Y
5	Y	Y	Y	Y	Y	Y	Y	Y
6	Y	Y	Y	Y	N	N	Y	N
7	Y	N	Y	N	Y	Y	Y	Y
8	Y	Y	Y	Y	Y	Y	Y	Y
9	Y	Y	Y	Y	Y	Y	Y	Y
10	Y	Y	Y	Y	Y	Y	Y	Y
Total	10	8	9	8	10	9	10	9

Appendix C

Photographs to Illustrate Stages 1 and 2 of the Thematic Synthesis



Appendix D

Process of Thematic Synthesis

Initial Code	**Descriptive Theme**	**Analytical Theme**
Feelings of abandonment	Emotional difficulties associated with BPD diagnosis	Understand Me
Feelings of suicidality		
Feelings of inadequacy		
Feelings of hopelessness		
Feelings of estrangement		
Dissociation as coping		
My pain is overwhelming		
Paranoid ideation		
Interpersonal relationships characterised by violence or abuse		
Service user understanding of BPD different from clinical description		
Self-harm releases tension	The function of self-harm	
Self-harm to feel pain		
Self-harm improves mood		
Self-harm works when language fails – there and then experience		
Self-harm does need to be limited		
Sense of failure if medication doesn't fix difficulties	The role of medication	
Over-reliance on medication		
Self-harm scores determine treatment	The impact of self-harm	
Self-harm affects how I'm treated		
Self-harm linked to self-destruction and rejection		
Too much pressure increases desire to self-harm		
Self-harm scars affect my identity		
Needing to enhance self-development	How I seek help	
Struggling to assume responsibility		
I seek help when in crisis		
I am poor at recognising my own needs and when things are going wrong		

Difficulties beginning in adolescence	Origins of difficulties	
Formulation improves client experience by linking to abusive past events	Services can provide understanding	
CPA system helpful		
CPA as improving communication		
Evidence based practice		
Specialist services most helpful		
Lack of understanding of client need	Staff's lack of understanding	
Staff misunderstanding of BPD – discipline problem not a psychological problem		
Lack of shared understanding		
Notoriety of clients with BPD diagnosis goes before them	Staff stigma and stereotyping	
Manipulation viewed as core component of BPD diagnosis for staff		
Behaviours with misunderstood meaning exacerbate stereotyping by staff		
Withdrawal during crisis – contradiction		
Misunderstanding of risk issues		
More interest in reducing risk than the real cause?	Risk management	
Judgement is internalised	Impact of service response on service users	
Amplified emptiness		
Clients learn to predict negativity		
Avoidance of self-disclosure in therapy setting		
Clients feel undeserving of care		
Clients made to feel stupid		
Ambivalence around containment		
If they see strength, I see strength		
Diagnosis as meaningless	Service user view of BPD diagnosis	If you have to diagnose, don't label
Knowledge around diagnosis increases power		
Diagnosis only provides superficial explanation of difficulties		
Diagnosis can provide light and hope		
Diagnosis is damning		

Diagnosis equals isolation		
Diagnosis has the potential to help plan care	Usefulness of diagnosis	
Diagnosis criteria ‘fits’ client difficulties		
Homogeneity of client experience		
Timeliness of diagnosis affects feelings about it		
Optimism about diagnosis affects feelings about it		
Reluctance of professionals to share diagnosis with service user	BPD as a labelling process	
Labelling perpetuates being marginalised and mistreated		
BPD not as worth of care as ‘other’ diagnosis		
Labelled not diagnosed		
Ramifications of the label, not the diagnosis itself		
Pathologisation as discrimination		
When all else fails diagnosis		
Containment related to having a team	Making a connection	Connect with me
Respond from inside		
Quality of relationship makes seeking care more likely		
More than just a member of staff		
Sticking with me through difficult times		
Lifeline and connection to the world		
True therapeutic relationships take time and effort		
Good staff are central to daily living		
Contact based on trust can increase disclosure		
First experience of a meaningful relationship	Treating service users like people	
No judgement and genuine interest		
Small gestures can equal huge human meaning		
Being interested		
Treated like an individual worth of respect and companionship solidifying identity		
Sometimes just listening is enough		
Therapeutic relationship increases		

desire to recover		
Client has no voice	I have no voice	
Clients not listened to		
Clients treated as objects		
Making decisions without service user involvement (CPA)		
Client experience not valued		
Voice of carers and families lost		
Contact with other BPD service users increases self-awareness of difficulties	Service users as a therapeutic tool	
Contact with other BPD service users increases emotional support		
Unlimited accessibility	Accessibility of services	Provide me with a secure base
Approachability equals accessibility		
Flexibility increases accessibility		
Limitations to services – time and dialogue		
Inconsistent services		
Named person increases trust and accessibility		
Hospital is a safe haven	Services can provide safety	
Limits increase safety		
Ambivalence towards A&E		
Admission as a ‘time out’		
Planned admission can reduce crisis		
Brief admission can reduce negative outcomes – prevent the slippery slope		
The quality of the relationship equals safety		
Safety associated with the relationship, not just the setting		
Contact with nurse can prevent crisis		
Limits create structure	Services can provide containment and structure	
Consistency as crucial		
Proximity not as vital as perceived accessibility		
Limit setting does contain symptoms when feelings not intense		
Limits can increase internal control		
Structure and occupation helpful		

Lack of contact leads to feelings of rejection and abandonment increasing	Abandonment	
Lack of follow up – reinforces abandonment		
Lack of rationale for medication	Lack of information from services	Involve Me in My Care
Guinea pig approach to medication		
Lack of information about medication side effects		
Lack of explanation regarding diagnosis		
Aetiology of difficulties unknown by clients		
Lack of treatment options		
Lack of information about services		
Prevent crisis without loss of control	Communication and involvement	
Collaboration		
Partners in care		
Contact crucial in preventative admissions		
Individualised service		
Brief admissions plan crucial in planning stay		
No clarity regarding expectations of clients		
Being included in decision making process		
Consultation before ‘treatment’ action		
Worries over confidentiality		
No copy of care plan		
Recovery means letting me take responsibility for myself – being involved in decisions	What recovery means	Believe in me
Being understood as who I am – with all my limitations		
Recovery can mean medication		
Recovery means refusing to be violated		
Increasing acceptance decreasing self-loathing		
Service context affects notion of		

recovery		
Moving on from services		
Lack of understanding about what recover is		
Recovery is personal to each individual		
I see recovery as a permanently ongoing thing		
Recovery in a journey – travelling through the system		
Movement through the system		
Navigation of the system		
Recovery is a full time job		
Recovery includes relapse		
Recovery means searching for inner strength		
Recovery by feeling safe and trusted		
BPD as permanent – there’s no cure	Staff hopelessness	
Practitioners re-enact and embody past experiences		
Over vs under involvement		
Diagnosis breeds hopelessness in staff		
Staff avoid meaningful contact due to difficult emotions	Staff views of BPD	
BPD is merely an attitude problem – “pull yourself together”		
Blaming attitude of staff when seeking care		
Over-pathologising of behaviour “typical BPD”		
Service users have to fight misconceptions		
Limit setting equal fear of reprisal as deterrent	Limit setting	Don’t Abuse Power
Limits impact on identity		
Limits remove control and is stigmatising		
Limit setting feels shaming		
Limits increase rebelliousness		
Subjective experience of limit setting is negative and punishing		
Humane and appropriate imposition of limits is challenging		
Practical difficulties around work	Stigma of BPD in the wider system	

and benefits – constructive dismissal		
Cultural imperialism		
Media stereotypes		
BPD diagnosis represents a moral judgement		
Societal expectation around gender and BPD – anger not allowed		
Being treated differently within other healthcare services as a result of BPD diagnosis		
Lack of avenues for questioning diagnosis	Power in the wider system	
Power of sectioning and coercion		
Paternalistic care		
Progression versus consistency		
The process of othering – dominance and subordination		
Lack of real consent		
Mental health funding marginalised		
Staff work within a medical model		
No place for BPD within service structure – admissions mixed with other service users		
Challenges in making complaints		
Services repeat cycles of abuse	Abuse by services	
Punitive and rejecting use of contracts		
Physical and psychological violence towards service users		

What does the concept of recovery mean for the sense of self of individuals with a Borderline Personality Disorder Diagnosis?

Sarah Elizabeth Davidson

Lancaster University

Abstract

The concept and diagnosis of Borderline Personality Disorder (BPD) is contentious, has previously led to many service users seemingly being denied support and care, and is experienced by many as labelling and stigmatising. One of the diagnostic criteria for BPD is an unstable and unclear sense of self. The current research seeks to expand on the evidence base by developing an understanding of how the concept of recovery impacts on service users' sense of self. Interpretive Phenomenological Analysis (IPA) was used to develop four Master Themes: I see my life with BPD as a jagged edge; BPD: The dialectical diagnosis; I'm lost inside; and It'll never be better: The rocky road to recovery. The participants described ongoing difficulties associated with the BPD diagnosis, ambivalence over their diagnosis, and a complex relationship with identity and recovery. Recommendations from the research include a further emphasis on sense of self within the therapy setting, and the adoption of principles utilised by Therapeutic Communities.

Key words: Borderline Personality Disorder, Recovery, Sense of self, identity, Interpretive Phenomenological Analysis.

Within a medical model of understanding, Borderline Personality Disorder (BPD) is considered to be a serious condition associated with a pervasive pattern of instability in emotional regulation, interpersonal relationships, and identity (Lieb, Zanarini, Schmahl, Linehan, & Bohus, 2004). This diagnosis is widely regarded as contentious (Alwin et al., 2006) in regard to its reliability and validity as a clinical construct, (Castillo, 2003), in its explicit suggestion of permanence in terms of recoverability, attributions around complexity, (Barnicot, Katsakou, Marougka, & Treatment, 2011), and in relation to how service users are denied services and stigmatised as a result (Markham & Trower, 2003; Rivera-Segarra, Crespo-Ramos, & Marqués-Reyes, 2014; Stalker, Ferguson, & Barclay, 2005; Veysey, 2014).

The focus of this research is sense of self as it relates to a BPD diagnosis. For the purposes of this research, sense of self is defined as “the experience of oneself as unique, and as having a clear distinction between oneself and others” (Bateman & Krawitz, 2013), though there are many other philosophically driven definitions. Solberger (2013) provides a rich and detailed history of the concept and relates the work of many authors on the subject to the BPD diagnosis, highlighting a lack of sense of self as a core difficulty (Clarkin, Yeomans, & Kernberg, 2006; Jørgensen et al., 2013; Jørgensen, 2006; Kernberg, 2006; Sollberger, 2013).

Despite the theoretical literature on lack of sense of self, research directly investigating the construct, and how it affects this service user group remains sparse. Jørgensen (2009), found that, in comparison to a group of psychology students, individuals with a BPD diagnosis showed evidence of a more “diffuse identity”, meaning their sense of self was less stable (Jørgensen, 2009). Wilkinson-Ryan and Westen (2000) concluded that identity disturbance is a multifaceted construct that differentiates clients with a BPD diagnosis from other mental health service users, following research which identified four identity disturbance factors, cited by the authors as:

"role absorption", "painful incoherence", "inconsistency" and "lack of commitment" (Wilkinson-Ryan & Westen, 2000). Similarly, Adler et al (2012) applied a life story interview approach to understand the sense of self in individuals with a BPD diagnosis, and discovered that in comparison to a control group, themes of a lack of agency, a lack of fulfillment with attachments and relationships, known as 'communion fulfilment' and a lack of narrative coherence were more prominent in the narratives of individuals with BPD "features" (Adler, Chin, Kolsetty, & Oltmanns, 2012).

Whilst some of these concepts reported in the literature can appear to be somewhat abstract, the problems associated with an undeveloped, or fractured sense of self are multitudinous. (Gunderson, 2009; Lieb et al., 2004). This means that the real life impact of this psychological phenomenon may include a constantly changing view of what someone wants to achieve in life, an inability to maintain relationships due to not knowing what kind of person they would like to have a relationship with and rapidly shifting values, a difficulty in maintaining different 'selves', and in extreme cases even a difficulty knowing that one exists. As such, a lack of sense of self can be seen to be a core difficulty for service users with a BPD diagnosis as it can infiltrate all areas of functioning, and should be an important focus of psychological approaches. However, the lack of research into these real life effects suggests that further research relating to sense of self and the BPD diagnosis is required.

Castillo and colleagues have conducted extensive research into the experience of being diagnosed with a personality disorder (Ramon, Castillo, & Morant, 2001; Castillo, 2003). This work raises important issues around the impact of a BPD diagnosis both at an individual and societal level (Battle et al., 2004; Briere, Hodges, & Godbout, 2010; Macintosh, Godbout, & Dubash, 2015; Martín-Blanco et al., 2014; Van Dijke, Ford, van Son, Frank, & van der Hart, 2012), and suggests that a reframing of the difficulties associated with this diagnosis is required, with a more helpful understanding arguably being found in attachment theory (Castillo 2003).

Attachment theory and the concept of a ‘secure base’ (Bowlby, 2005) posits that in order to survive, an infant will attach to their main caregiver, for physical, emotional and psychological support. The theory continues that internalised early experiences continue into adult life, on both an emotional and neurobiological level (Fonagy, Luyten, & Strathearn, 2011). The theory has been developed (Fonagy & Target, 1997; Fonagy, 2000) to argue that an individual’s ‘sense of self’ is developed by repeatedly internalising the representation that their main caregiver gives them through their interactions. Several psychological interventions designed to aid with the difficulties associated with the diagnosis base their understanding of the difficulties as a disorder of early attachment (Agrawal, Gunderson, Holmes, & Lyons-Ruth, 2004; Clarkin, Lenzenweger, Yeomans, Levy, & Kernberg, 2007; Fonagy, Target, Gergely, Allen, & Bateman, 2003; Fonagy, 2000; Ryle, 1997a).

A modest but increasing amount of research has begun to challenge the view that improvements are not possible for this population (Paris & Zweig-Frank, 2001). It has been demonstrated that core features of BPD, such as relational instability, and emotional dysregulation can decrease over time (Perry, Banon, & Ianni, 1999; Verheul & Herbrink, 2007; Zanarini et al., 2014; Zanarini, Frankenburg, Reich, & Fitzmaurice, 2010), and that psychological interventions for the BPD diagnosis can be relatively successful (Bateman & Fonagy, 2009; Bateman, Ryle, Fonagy, & Kerr, 2007; Clarke, Thomas, & James, 2013; Clarkin, Levy, Lenzenweger, & Kernberg, 2007; Jørgensen et al., 2013; Montgomery-Graham, 2015; Ryle, 2004). Psychological intervention in the United Kingdom is now favoured over medication within National Institute of Health and Care Excellence Guidelines (NICE, 2009;

DoH, 2009), however, there remains a tendency in the psychiatric literature towards reporting ‘symptom remission’, as opposed to more personal constructs of change (Zanarini et al., 2014), which may suggest that the concept of recovery for this client group is complex and under researched. Furthermore, a specific focus on improved sense of self as a possible outcome of therapy is notably lacking (Brazier et al., 2006; Sollberger et al., 2014).

The concept of recovery in mental health has been prominent for some time, initially as a protest by service users against the ‘illness’ conceptualisation of mental health (Onken, Craig, Ridgway, Ralph, & Cook, 2007). In the UK, policy makers recognised this concept with the paper “The Journey to Recovery” (DoH, 2001), which stated that recovery should be central to service delivery, and subsequently “Making Recovery a Reality” (Shepherd, Boardman, & Slade, 2008). However, there are different perspectives with regard to the concept of recovery and thus a lack of unanimity regarding how recovery is understood and defined (Slade, 2009). There is an established distinction between the more traditional notion of ‘clinical recovery’, and ‘personal recovery’. The latter is viewed as a more personal, holistic concept, defined initially by the survivor movement, and most recognisably by Anthony (1993) as "a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by the illness.” (Anthony, 1993).

A recent systematic review identified five core recovery processes as identified by service users: Connectedness; hope and optimism about the future; identity; meaning in life; and empowerment (Leamy, Bird, Le Boutillier, Williams, & Slade, 2011). Thus, there is particular pertinence in applying the concept of personal recovery to individuals with a BPD diagnosis, based on the aforementioned tensions around diagnosis and stigma. However, the application of recovery informed processes to personality disorder, particularly because of these issues, is not without its complexities.

Turner, Lovell and Brooker (2011) argue against prescribing a too generic notion of recovery when developing personality disorder services and that the complex attachment related difficulties experienced by those with the diagnosis mean that a focus on personal recovery is all the more necessary. In services which remain focused on the reduction of the harmful behaviours often associated with the BPD diagnosis, such as deliberate self-harm, and where diagnosis is used to indicate that service users' patterns of relating to the world are at odds with cultural norms (Jørgensen, 2006), there is considerable potential for tension between meaningful notions of recovery for service users and service providers.

In an effort to avoid these problems, by involving service users in developing a framework for understanding the concept of personal recovery, Castillo and The Haven Project aim towards what they have termed 'Transitional Recovery', a hierarchy of progress in the journey of recovery for people with a personality disorder diagnosis, which is represented by a pyramid (Castillo et al., 2013).

Further qualitative research in this area has echoed the need for trust and a secure attachment, recovery as dynamic, sometimes elusive process, a sense of coming to terms with perpetual difficulties, and most notably for this research, an emphasis on a less fractured sense of self and increased autonomy (Holm & Severinsson, 2011; Jones, 2014; Katsakou et al., 2012; Larivière et al., 2015; Shepherd et al., 2015).

The previously cited research shows that both attachment difficulties, and the resulting undeveloped sense of self, are key issues for individuals with a BPD diagnosis, which can either be exacerbated or aided by the approach of services. Thus, qualitative research that links the inherently personal concept of recovery for individuals with a BPD diagnosis to how the core issue of sense of self features, or is affected by this concept is valuable in developing an understanding of the relationship between these two experiences, and in determining how services can best shape their practices to foster recovery. The current research seeks to develop the evidence base by drawing on participants' personal narratives to develop an understanding of what the concept of recovery means for the sense of self for individuals with a BPD diagnosis.

Method

Design

The study utilised a qualitative research design, using Interpretative Phenomenological Analysis (IPA), as this method focuses on the individual's experience and perception of a particular phenomenon (Biggerstaff & Thompson, 2008) and allows exploration of how the meanings of experiences are constructed by individuals, making it particularly useful for developing an understanding of how people understand their sense of self and how this may or may not relate to their individual construct of recovery. IPA's theoretical roots are in phenomenology, which is the study of being and experience; hermeneutics, which refers to the theory of how information is interpreted and understood (Smith, Flowers & Larkin, 2009); and ideography, which focuses on the specific meaning for an individual, as opposed to establishing a collective understanding (Smith, Jarman & Osborn, 1999). The approach also acknowledges the interpretive role of the researcher.

Procedure

Sample: size, strategy and characteristics

As Smith, Flowers and Larkin (2009) suggest recruiting between four and ten participants for a doctoral level study, in order to gain a rich understanding of each individual's experiences, six participants were interviewed. As referred to above, the goal of IPA is to describe and interpret, at a rich level of detail, the experiences and understanding of a specific group of people, rather than to represent a global perspective (Smith, Jarman & Osborn, 1999). Therefore, a purposive sampling method was used. There has been a move towards personal recovery as an aim for mental health services. Thus services which harnessed recovery principles were chosen in order to gauge whether such an approach had an impact on how or if participants conceptualise recovery, and to ascertain what impact they felt this had on, or what relationship it had, with their sense of self. It was concluded that a group with a shared diagnosis, within one NHS Trust, would allow for a range of recovery experiences to be gleaned, whilst remaining homogenous to the degree required to remain true to the principles of IPA. Such a rationale is supported by Smith *et al.* (2009).

Participant demographics can be found in Table 1.

INSERT TABLE ONE HERE

All participants were Caucasian, with an age range of 30-59 years. Participants were eligible for the study if they met the following inclusion criteria: Adults aged over 18 years; having received a diagnosis of BPD; currently using NHS services through the teams identified; having English as a first language or being fluent; and currently being deemed by themselves and a member of their recovery team to have a level of psychological wellbeing consistent with being able to take part, without increasing risk.

The participants were all involved currently with the Recovery Team, and whilst several of the participants had been involved in mental health services for 16-20 years, only two had had their BPD diagnosis for that time. Four of the participants had had their diagnosis for less than five years.

Recruitment

Participants were recruited through Recovery Teams in a NHS Trust in North West England. The researcher initially liaised with the Consultant Clinical Psychologist at each of the teams, to discuss the project and initiate recruitment. Professionals were informed about the study and asked to approach appropriate potential participants with an initial contact letter and an Information Sheet. Individuals who wished to participate were asked to either contact the researcher or to communicate their interest to their clinician, who would relay the information to the researcher.

Data collection

The study utilised semi-structured interviews, chosen as they allow the researcher to have a broad structure of topics to follow, ensuring that there is some consistency in the focus of the interviews, but also allow for flexibility (Biggerstaff & Thompson, 2008).

Interviews were conducted at the Recovery Team premises. The researcher informed participants about the research, revisited the information sheet, and invited questions before obtaining their informed written consent. Some brief, demographic information was also collected before beginning the interview. Interviews were audio-recorded and subsequently transcribed by the researcher.

Ethical Considerations

Ethical approval was sought and obtained from a NHS Research Ethics Committee and the Research and Development Department at the Trust. A support plan was designed in the case of any participants becoming distressed, which included up to two debrief sessions with the field supervisor, a consultant clinical psychologist. Each of the participants chose a pseudonym, which was used across the transcripts and throughout the analysis to ensure anonymity.

To enhance quality and validity, two of the transcripts, with initial notations and emergent themes, and the resulting superordinate themes were read by the Academic Supervisor, and constructively checked and questioned, engaging with the reflexive nature of an IPA supervision process. Feedback on the themes was incorporated in the resulting amendments of interpretation and themes. Care was taken to ensure that the resulting themes remained close to the data and that they could be traced back to the original transcripts. An example of this can be seen in Appendix B.

Analysis

The guidance provided by Smith *et al*. (2009) was followed whilst conducting the analysis. Each transcript was analysed according to these stages, before the data set was analysed as a whole: Initially, the researcher read the transcript several times to become familiar with the participant's account. The researcher then moved on to making initial linguistic, conceptual and descriptive comments on the transcript. The transcript and initial notes were then used to actively develop emergent themes which were given titles and placed in a separate Word document. Emergent themes were then clustered together, by interpreting their conceptual similarities and commonalities, to develop a set of superordinate themes for the participant, which were tabulated by the researcher, as is recommended by Smith et al for sample sizes up to six (Smith et al, 2009). The researcher then compared across the whole sample, until a full representation of the data set was complete, and superordinate themes clustered into master themes, to reflect an overall interpretation and understanding across the data set. Clustering of the subthemes into master themes, in addition to participants' emergent and superordinate themes can be seen in

Table 2. Although the analysis resulted in four discrete themes, and their subthemes, there were inevitably instances where themes shared commonalities.

Analysis

Overview of Themes

The aim of this study was to explore what the concept of recovery means for the sense of self for individuals with a BPD diagnosis. Following analysis, four master themes were created, each of which contained between two and four subthemes.

INSERT TABLE 2 HERE

1. “I see life with BPD as a jagged edge; like a 50p piece”: Living with BPD

The first master theme refers to the participants’ historical and present experiences of daily living with difficulties associated with the BPD diagnosis. These difficulties were comprised of their internal experience, their relationships, and the pervasive nature of their experiences, to form a whole world view of life with a BPD diagnosis.

1.1.“I am broken”: The internal experience

All six participants spoke openly about the difficulties they experienced, both historically and presently, frequently beginning with an awareness of an inner experience that felt different from others’. The participants were able to relate this to their development, using phrases such as, “I’ve always had this from when I was little…” (Claire), “And I was always, you know, like the black sheep…” (Sandra), and “And, I’ve always felt like that” (Ol).

All six of the participants reported that their negative internal experiences had led them to extreme ways of coping, such as dissociation, acts of deliberate self-harm, and suicide attempts. Poe describes, “The overdosing and the self-harming…I slit my throat in front of the staff…I’ve got scars on my stomach, scars on the tops of my legs”. Although the participants were able to describe these difficulties, their detached and slightly clinical tone indicate that they may be maintaining some emotional distance between themselves and their experiences, perhaps to protect themselves from the impact of such experiences.

1.2. Unequal Relationships

All of the participants discussed intense difficulties in relationships, which extended into the present day. One participant, Adam, referred directly to his interpersonal history in the context of trauma, using phrases such as “my abuser”, and describing his previous experiences as directly relating to his current difficulties:

> That person has won, because they’ve made you ill, they’ve made you go down to the bottom of the barrel that you’ll never be able to get up… You might be able to get halfway up but you’ll never be able to get to the top… They’ve basically molded you into that one person that is that much of a mess, they’ve still got control.

Adam uses the metaphor of being trapped in a barrel to illustrate the arduousness of the challenges he’s faced. He also uses the medical term “ill” to denote an end point; a level of function not associated with being ‘well’, and views the deterioration in his mental health and the need to access mental health services as a virtual continuation of the control and abuse he experienced. Other participants were aware of the impact of their early attachment experiences on their development, with Ol stating, “My dad was an old-fashioned dad. And it was quite brutal at times….And very condescending and mentally cruel”.

These early experiences now manifested themselves for many of the participants in extreme difficulties in forming and maintaining pro-social and secure relationships with others, with Poe commenting, “I’m terrible with relationships. I can’t trust anyone…my ex, was with him two and a half years. He killed himself", and James explaining, "I always think people think the worst of me…That there is some ulterior motive to everything".

1.3. Pushing On – life as existing not living

The final subtheme in the first master theme is concerned with the way in which participants felt their experiences associated with the BPD diagnosis had created a life that seemed to be focused on existing rather than living. Participants shared reflections that their lives had been profoundly altered by their experiences and resulting difficulties, and that "I didn't want my life to turn out this way" (James). The participants all felt exhausted by their difficulties, commenting, "And I think, how long can I keep the front on for? I can't do it for ever, because it drains me" (Sandra), "I've fought for that many years or thought I was fighting for that many years, so I've got nothing in me…" (Adam). Adversarial words such as "fighting" were used frequently by the participants throughout the transcripts, to indicate that they had come to make sense of their lives as a battle. This subtheme was summarised most eloquently by James, who reflected,

> I don't see things like smoothly and circular…My life doesn't revolve and just move smoothly…I see my life with borderline as a jagged edge…Like a 50p piece… I don't move from one, like, in a circle like a smooth…(gesticulates to indicate the shape of a circle)…I see mine as a (gesticulates to indicate an edge)…And then another (gesticulates to indicate another edge)

The author interpreted that the unrelenting nature of the participants' difficulties impacted adversely on how meaningful a term the participants felt recovery was for them, which was more evident in Master Theme Four.

2. BPD: The dialectical diagnosis

This master theme was concerned with the extremely mixed and at times contradictory views and understandings the participants held regarding both the process of diagnosis and their BPD diagnosis itself. The theme incorporated the experiences of feeling both validated and simultaneously labelled, and out of the data came suggestions of stigma at both an individual and societal level. In this respect the diagnosis had a dialectical quality, in that there were elements of both positives and negatives to it.

2.1. I Had a Title – Diagnosis as validation?

All of the participants reported that their diagnosis had been given following crisis, most commonly referred to as a "breakdown", and for some, it was interpreted that the diagnosis provided the beginnings of developing a rationale for why this had happened. Perhaps more importantly, the diagnosis served to validate and confirm their experiences. As Sandra comments, "I felt in some ways like I had a title…I have got something now wrong with me, I'm not just losing the plot", and Ol further illustrates, "It's not entirely my fault…it's something that people with this disorder do". The diagnosis provides perhaps not only validation, but the opportunity to distance and dissolve some responsibility for difficult emotions and behaviours, and increase self-compassion, which appeared from the data to be one of the first steps necessary to engage with the idea of recovery as a concept. However, at other points in the interviews these participants also stated that diagnosis meant "nothing really" (Claire), and "I still feel worthless, not wanted" (Sandra), demonstrating both the dialectical nature of the diagnosis, and the continuation of difficulties following the diagnosis being given.

2.2. Labeling – diagnosis as meaningless

Whilst some of the participants had experienced some benefit to their diagnosis, Adam and James felt vehemently that their diagnosis had not been of any value to them whatsoever, with Adam commenting, “It’s just a label. That’s all it is, it’s just a label. It’s just a label that can excuse your acts for, for doing…” Of note here, is that Adam seems to be suggesting his distaste at the opportunity to absolve himself of responsibility, whereas Claire and Ol valued this. Other participants highlighted that the diagnosis was lacking in true meaning for them, with James contemplating,

> And the word borderline personality what does that even mean? Are you borderline normal or borderline not? Have you got a personality disorder? It doesn’t really self-describe does it? You say borderline personality disorder, but borderline is like…Are you, or aren’t you? It’s hard to understand what it is.

Here, James is acknowledging not only the difficulties with the actual language pertaining to the diagnosis, but that the label lacks any real description and is open to a number of interpretations. Similarly, Poe noted ambivalence towards her diagnosis, stating, “I ended up accepting it about five years ago, if not less…I still sometimes think it now…I haven’t got a personality disorder”. There was a suggestion here that meaning making in diagnosis may involve acquiescence, being ‘done to’, to “slap a label on me” (Adam), which is arguably the very opposite of validation. Starting to emerge here, are deeper issues around mental health and personal and societal stigma which lead into subtheme 2.3.

2.3. I’m too busy trying to be normal: denial and fear of stigma

Subtheme 2.3 describes how, in almost all of the participants’ accounts, a level of fear and stigma was associated both with mental health issues in general, and specifically with the BPD diagnosis. For some participants, such as Poe, her rationale for initially rejecting her diagnosis was linked quite explicitly to beliefs around mental health in general, as she commented, “I thought there was nothing wrong with me…mental health wasn’t known about in our family, it was never talked about". However, she later commented, "I've just had depression, to me, I just had a big nervous breakdown". These repeated statements of ambivalence suggest that there is something about the BPD diagnosis specifically which caused distress for Poe.

James described receiving his diagnosis and recounted, "And I was just gutted. Really disappointed". Linking back to the previous theme, James also made connections between the stigma he had internalized, and his early experiences, stating, "My dad used to say that (mental health) wasn't real and people like that were just moaning". The concept of 'not normal' was a repetitive theme throughout James' account, and he applied it also at a wider, societal level, reflecting,

> …And I don't want people to know even less…Because I feel…You see things on television, high-profile killers, Fred West or Myra Hindley, and you always hear personality disorder…Or you know…So it makes me feel I couldn't tell anybody at all, because they might think, you just get blanket, don't you, blanketed stigma of you're the same.

The theme of stigma also ran through Adam's account, though perhaps in a more subtle manner. He made references to societal stigma, commenting that people judged him as a "scrounger" for being currently unable to work.

Overall, the overriding sense of this master theme was that "diagnosis has left me with more questions than it hasn't left me with" (James).

3. "I'm Lost Inside"

The third master theme to emerge from the research was participants' difficulties with their sense of self and identity. Participants were aware that they had difficulties describing themselves or making sense of their identity, and this impacted on how they related to others and how they viewed the concept of recovery.

3.1. Am I real? Lifelong struggles with identity

Subtheme 3.1 captured the participants' severe difficulties associated with not having a clear sense of who they were and these were issues shared amongst all the participants. Claire stated, "I've always had this since I was little, but I'm not actually, I can't explain it, like, not actually, here…Like I'm some kind of experiment". "Some kind of experiment" suggests that not only is Claire unsure of her physical presence in the world, but almost feels as though she is not human. James also used language with reference to being almost alien like, when he commented that he refers to other people as "humans", as though suggesting he is not. Here, Adam seems to be struggling to make sense of all his experiences, is questioning his various identities and is unable to synthesise them into one coherent self when he says:

> Was that life a lie? When I was in school I was a joker, I was always, I always put myself in the middle because I didn't wanna put myself at the top boys and obviously I didn't wanna be down low…And not knowing who I was…I was still a joker and that, but was that me?

Participants described cognitive difficulties with identity, such as, "I don't have thoughts and feelings" (Poe), and three of the participants described issues which centered around questioning their sexuality. Moreover, there were also occasions where they questioned their physical presence, with Claire commenting, "I mean, I know my name's Claire and I know my age…I get panicky…I don't know, it affects everything". Here, Claire is reliant on factual information to convince herself of her existence. Similarly, Adam describes his experiences of dissociation when he comments:

> …sitting in the room, I know there's lights and know you're here, but I don't feel real, my arms don't feel real, my legs don't, my voice doesn't even sound like my own…And then I look in the mirror, and I go is that me, am I seeing what I'm seeing?

3.2. Identity and Others

Subtheme 3.2 captures the relational dimension of identity; how the sense of self of participants is understood through their relationships with others. This theme incorporated both the mental and physical manifestations of this experience. In the first instance, the participants viewed themselves through the eyes of others, and this often meant their views were negative. Poe commented, "Just think I'm this divvy person…I'm just this thick person…even the kids think I'm thick…They'll say, Oh Mom, you're thick (laughs shyly)". Here Poe repeats the words used by her children, having internalised them, which appears to played a role in low self-esteem.

In the second instance, participants relayed accounts of taking on the characteristics and viewpoints of others, both as a way of piecing together a sense of self, but additionally to maximize the likelihood of being accepted and minimizing rejection, a state that had become familiar and feared. For James contact with others and adopting a role, serves to create an identity:

> …I wanted to join the army when I was about 22…Anyway I used to like, assume, well I still do, assume a role, and be that role (laughs)…So when I came out I came out marching, well I felt like I was marching, and felt that, proud of me self, marching everywhere then..…Because I've just been in there I felt like people will recognise me and I'll kind of be a soldier…

Notably, in this example, the role he adopted was a stereotypically masculine, ‘strong’ character, which contrasted with James’ own perception of himself as, “I’ve got this impression of bigness, but inside I’m little”.

A lack of clear identity, and a sense of needing to fit in appeared to be linked to participants developing a strong sense of empathy, “I’m a caring person, and I’d do anything for anybody” (Sandra). However, this led to difficulties in assertiveness, “Because I don’t like conflict, and because I can’t put my point of view across” (Ol).

4. It’ll never be better: The Rocky Road to Recovery

The final master theme captures participants’ complex relationships with recovery, with particular emphasis on their sense of self. The theme has a number of dimensions to it: how participants view recovery, how their sense of self is impacted on by their construct of personal recovery, and how diagnosis features within the construct of personal recovery.

4.1 Building bricks – Recovery as a process

Common to all the participants was the idea that recovery was a process, combining elements of what could be described as ‘symptom reduction’ with changes in sense of self-worth, and attempting to build a meaningful existence. Far from being a linear, chronological process, recovery was often challenging, with Adam commenting:

> But self-harming wise, cutting, I’ve still haven’t cut, but the suicidal thoughts are still there…Everything still there…And it still, so wouldn’t say it’s had a huge…It’s helped slightly but I wouldn’t say a massive amount.

Here Adam highlights the complex nature of the difficulties associated with the BPD diagnosis, and the perceived need to reach a further stage in his recovery. The participants associated specific changes, in building a therapeutic alliance, and behavioural and cognitive changes, with what they felt were the first stages of recovery. For example, “I get out more places and that now” (Poe), “And it’s only the last 12 months, but I haven’t self-harmed” (Sandra). Equally, participants had some sense of where they wanted to make further improvements, with Claire stating, “Well, it’s probably impossible, but trying to get those thoughts out of my head…”, and, “I shouldn’t, I shouldn’t, but I’ve kind of got my hopes up that I might be able to get a job helping people with mental health problems. But I don’t know if I’ll be allowed to have that, paid employment” (James). Although superficially aspirational, the caveats within these phrases suggest that such goals may be unachievable, and that ‘full recovery’, as an end point, may not be possible.

Regardless of where participants saw themselves in terms of recovery, they all had a personal construct of what recovery meant to them, which encompassed elements of both clinical and personal recovery, with conceptualisations such as, “That I don’t have to…stay in the same place” (Ol), “My life would be totally different…just easier to cope with” (Claire), “Recovery is getting better, isn’t it? And that’s my aim, to get better” (Poe). In this sense, although the participants saw their recovery as a process, they all had some idea of an eventual end point they would like to reach, regardless of whether they thought this would be possible.

4.2. The First Step – Recovery as acceptance

Following on from conceptualizing recovery, participants had developed understandings of what was required to bring about recovery, in its initial stages, namely gaining a sense of validation, acceptance, and starting to build some self-compassion. Linked with subtheme 2.1, it was felt that these processes were essential in establishing a sense of hope, before any further progress could be made. As Ol illustrates, “I am entitled to certain emotions, and anger”, and

Poe states, “I’ve been punished enough by my abusers, and I was just punishing myself…But it wasn’t my fault”.

Aiding in building acceptance and compassion was increased understanding, which for the majority of the participants came from psychological understanding. It was felt that this provided an additional layer of understanding which was not gleaned from diagnosis alone. Comments such as this rather poignant quote from Adam, encapsulate the understanding and acceptance gained from this:

> But, for someone to say that to you or notice something that I’ve gotten through, they can see, for example that I was the middle child…So for somebody to sit there and believe me and say that…I’m like (indicates fist pump) so it’s not just me.…that’s much more helpful than somebody saying oh, you’ve got this.

Interestingly he also compares this process with diagnosis “you’ve got this”, which feels reductionist and lacking in the qualities he describes here. He associates this process with a degree of recovery, whereas he did not with diagnosis.

4.3. Recovery through Relationships

Perhaps not surprisingly, given the relational elements that have run throughout the themes thus far, a central theme for participants in moving towards recovery was the importance of building positive relationships. Participants cited their relationships with key staff members in terms of making human connections that were safe, healthy and allowed for trust and disclosure, as James recounts, “the psychologist people…who were more on a personal level, so I felt more comfortable…I disclosed something that was really, really bad… ”, and Sandra confirms, whilst acknowledging that trusting is challenging “I can talk to (CPN) about it, but sometimes, I, I don’t tell her, and I don’t know why, because I know she is there to help me…And then there’s other times where I phone because I'm desperate for help". Here Sandra emphasizes not only that the relationship itself is important, but that it is synonymous with gaining support, which is crucial in terms of beginning the process of recovery.

4.4 Recovery – "Right term, wrong meaning"

This final subtheme describes the relationship between the participants' constructs of recovery, and their ambivalence about a term that did not appear to fully reflect their experiences. Participants were able to acknowledge very small improvements relating to confidence, being "empathic now" (James), and "a better person" (Claire), but they reported that these improvements had not (at this stage of recovery) enabled the development of a sense of self. Concerningly, this appeared to create a sense of hopelessness around difficulties that participants felt were unlikely to abate. Adam was left with the view:

> I'd say there's a recovery to a set point…Knowing how to deal with things, knowing how to soften the blow as such…I'd say…Because you'll never be better… (Long pause) you'll never be what you was, because if you have a mental breakdown, it's happened through reason…

This view seemed to be shared across the data set, with participants commenting, "I can't see myself going forward. Because I still feel, like I shouldn't be here" (Sandra), and "I sort of know who I am, when I'm doing something busy…But when I'm not, the feelings sort of…" (Claire).

Moreover, most of the participants felt that, due to their BPD diagnosis, 'full' or 'clinical' recovery was not possible. Thus, it was interpreted that, even in cases where some initial validation had been experienced, recovery, as the participants personally constructed it, was not possible, with comments such as "And how could someone with *that* possibly recover and be normal?" (James). It seems as though in developing and envisaging their personal constructs, participants had perhaps not begun to explicitly widen their conceptualisations to encompass elements of personal recovery, leaving them with a sense of pessimism.

A lack of knowing who they were remained the most difficult to cope with core difficulty, with Adam stating, "Like with the dissociativeness, being dissociative, you don't know, who you are as a person that's the worst one", and James poignantly reflecting:

> …I wouldn't be able to cope with this borderline personality…That makes me feel this way. It makes me see things, makes me really feel things…things, maybe they're real maybe they're not…Makes me assuming…assume roles…

Discussion and Conclusions

The master themes that emerged from the data, following IPA analysis show that service users engaged with a service adopting personal recovery principles have personal understanding of the difficulties associated with their diagnosis, have made mixed meanings of the diagnosis itself and stigma, have complex difficulties associated with their sense of self, and have personal concepts of recovery which relate to their sense of self. The results suggest that the concept of recovery has not, at this stage, impacted on their sense of self and that issues with identity remain.

The participants all described significant difficulties with sense of self, at a physical, mental, and metaphysical level, reporting dissociative experiences, questioning their physical existence, issues with sexuality, forming and maintaining belief systems and developing a sense of agency (Lieb et al., 2004), as was illustrated by Adam's quote, "I don't feel real, my arms don't feel real, my legs don't, my voice doesn't even sound like my own". The results from this study echo previous findings relating to issues with sense of self for this service user group as a core difficulty both theoretically and clinically (Adler et al.. 2012: Clarkin, Yeomans, & Kernberg, 2006; Jørgensen et al., 2013; Jørgensen, 2006; Kernberg, 2006; Sollberger, 2013). Some of the narratives were more developed than others, with a higher level of agency, where others felt chaotic, in that they were not consistent with their use of tense, they did not follow a chronological template, and there was a sense of events happening around the participants, with very little autonomy.

The findings from this study echo previous research (Horn, Johnstone, & Brooke, 2007) that suggest that whilst providing some initial validation and a framework of understanding, and certainly a pathway into services, service users found receiving a “dialectical” diagnosis of BPD to be challenging. Participants had issues with its meaning, its relation to recovery, stating, “I still don’t know what it means” (Claire), and there was evidence that participants perceived themselves to be stigmatised at a societal level. This strongly suggests the role of social context requires further consideration when applying a diagnostic framework, as does the potential for re-enacting abusive and powerful reciprocal roles (Castillo, 2003; Horn et al., 2007; Jørgensen, 2006; Markham & Trower, 2003; Pilgrim, 2001; Shepherd et al., 2015; Stalker et al., 2005).

The results from this study share similarities with previous research in the area, in terms of what recovery means to individuals with a BPD diagnosis. The results suggest that personal recovery is exactly that; an individualised and bespoke journey, perhaps without an endpoint, which has to account for ongoing difficulties (Katsakou et al., 2012; Larivière et al., 2015). In this respect the findings echo that of Turner et al (Turner, Lovell, & Brooker, 2011), in the need to be cautious in applying too generic attributions about recovery. Participants cited constructs of recovery that arguably encompassed both clinical and personal recovery, though this distinction was not explicitly cited, and their feelings of hopelessness seemed to be linked to being unable, as they perceived it, to reach “full” recovery. Ongoing difficulties related to a fractured sense of self, including dissociation, doubting one’s existence, and adopting roles appeared to be strongly connected to this sense of hopelessness. The pivotal finding from the research indicates that recovery and sense of self have a complex correlating, almost symbiotic relationship, with one unable to fully occur without the other. Thus, the findings suggest the importance of services working more closely with service users in developing an individualised recovery construct that focuses on the importance of personal recovery, in order to alleviate feelings of hopelessness, and foster positivity for the future, which may aid in developing a more stable sense of self. However, the findings also mirror previous qualitative studies which have shown some similarities in personal recovery constructs and what is necessary to achieve recovery (Leamy et al., 2011). Although the participants described recovery as “being better”, they also described their constructs as a process, which built on initial changes to form larger ones, reflecting previous research (Katsakou et al., 2012; Larivière et al., 2015; Shepherd, Sanders, Doyle, & Shaw, 2015). In this respect the research provides further evidence for Castillo et al’s, transitional recovery model (Castillo et al., 2013).

The study was the first, to the author’s knowledge, to seek the experiences of sense of self, specifically as it relates to personal recovery for service users with a BPD diagnosis. The findings suggest that although participants recognised sense of self as a core difficulty, and stated that they would like to see improvements in this area, mirroring other research (Holm & Severinsson, 2011; Jones, 2014; Katsakou et al., 2012; Larivière et al., 2015; Shepherd et al., 2015), they did not feel that their sense of self had been affected by their recovery journey thus far, commenting “I still don’t know who I am” (Claire). There are several possible reasons as to why this may be the case. Castillo, Gregory and Maslow (Castillo et al., 2013; Gregory, 1994;

Maslow, 1943) all hypothesise recovery to be a hierarchical process that encompasses a number of stages, with each stage being met before the next one can begin. For instance, Castillo et al's model includes changes in sense of self within the 'highest' level of the pyramid, following the completion of the first six stages. Similarly Maslow refers to 'self-actualisation' as the highest level of human need, and Gregory refers to a more stable sense of self emerging in his final therapeutic stage 'Am I ready to leave?' Each participant in this study was at their own stage in their recovery journey. However, more generally, it could be that although they were building a sense of safety and building trust, feeling cared for, starting to develop a sense of belonging and community, learning the boundaries and even containing experiences and developing skills, stages of Castillo's model (Castillo et al., 2013), they had not yet reached the stage of building hopes and dreams, or achievements.

Another possibility is related to the aforementioned goals of the therapeutic modalities accessed by the service users. Therapeutic communities also have at their heart core principles of attachment, containment, communication, inclusion and agency (Haigh, 2013) and are recommended in recent documentation as an appropriate intervention for individuals with complex personality difficulties (Bolton, Wood, Lovell, & Morgan, 2014; Haigh, 2013). In this respect, not only do they offer the factors that lead to initial basic hierarchical stages of recovery but they include elements that foster the latter stages of recovery, which may perhaps have been missing for this participant group. It is proposed that services consider such an approach in the future. Similarly, co-production of services (Slay & Stephens, 2013), could provide an outlet for development for service users with a BPD diagnosis, that may help to build a more coherent sense of self (Cooke, Daiches & Hickey, 2015), as such a venture may also connect with the latter 'stages' of recovery proposed, particularly 'agency' or Castillo's 'achievements'. An avenue for further research may be to assess the impact of such therapies and approaches on service users' conceptualizations of recovery, and its impact on their sense of self, paying particular attention to the seemingly dialectic nature of recovery and diagnosis, as was raised in the current research. Similarly, it may be advantageous to ascertain the degree to which issues of diagnosis affect the concepts of recovery and the subsequent effect on sense of self, in services that reject a diagnosis led approach.

Strengths and Limitations

Although not the first study to explore the experiences of recovery described by individuals diagnosed with BPD (Heather Castillo et al., 2013; Katsakou et al., 2012; Larivière et al., 2015; Shepherd et al., 2015) this is the first study to date which focuses specifically on how the concept of recovery affects the sense of self for this client group. Whilst other studies have made reference to sense of self as it relates to recovery, this is the first study which places this core difficulty related to the BPD diagnosis at its forefront, allowing a detailed and rich exploration of identity and its relationship to both the BPD diagnosis and recovery. A further major strength of the study is the involvement of Experts by Experience throughout the study process, not only as this constitutes an example of clinical and research staff, and service users, working together collaboratively, but also as the EBEs were able to help shape the research in such a way that it is current, necessary and relatable for service users as well as researchers.

There were a number of limitations to the study. One potential limitation is that recruitment took place from a single North West England NHS recovery team. Although recruitment was open to three recovery teams from within that Trust, eventually all the participants that took part came from within one team. Whilst IPA studies place emphasis on understanding and interpreting individual experiences and those of a small, homogenous group, thus the findings remain valid, it would be useful for future research, to explore the views of service users using different contexts and populations.

References

Agrawal, H. R., Gunderson, J., Holmes, B. M., & Lyons-Ruth, K. (2004). Attachment studies with borderline patients: a review. *Harvard Review of Psychiatry*, *12*(2), 94–104. http://doi.org/10.1080/10673220490447218

Alwin, N., Blackburn, R., Davidson, K., Hilton, M., Logan, C., & Shine, J. (2006). *Understanding Personality Disorder: A Report by the British Psychological Society*.

Anthony, W. a. (1993). Recovery from mental illness: The guiding vision of the mental health service system in the 1990s. *Psychosocial Rehabilitation Journal*, *16*(4), 11–23. http://doi.org/10.1037/h0095655

Barnicot, K., Katsakou, C., Marougka, S., & Treatment, P. S. (2011). Treatment completion in psychotherapy for borderline personality disorder – a systematic review and meta-analysis, 327–338. http://doi.org/10.1111/j.1600-0447.2010.01652.x

Bateman, A., & Fonagy, P. (2009). Randomized controlled trial of outpatient mentalization-based treatment versus structured clinical management for borderline personality disorder. *The American Journal of Psychiatry*, *166*(12), 1355–1364. http://doi.org/10.1176/appi.ajp.2009.09040539

Bateman, A. W., Ryle, A., Fonagy, P., & Kerr, I. B. (2007). Psychotherapy for borderline personality disorder: mentalization based therapy and cognitive analytic therapy compared. *International Review of Psychiatry (Abingdon, England)*, *19*(1), 51–62. http://doi.org/10.1080/09540260601109422

Battle, C. L., Shea, M. T., Johnson, D. M., Yen, S., Zlotnick, C., Zanarini, M. C., … Morey, L. C. (2004). Childhood maltreatment associated with adult personality disorders: findings from the Collaborative Longitudinal Personality Disorders Study. *Journal of Personality Disorders*, *18*(2), 193–211. http://doi.org/10.1521/pedi.18.2.193.32777

Biggerstaff, D., & Thompson, A. R. (2008). Interpretative phenomenological analysis (IPA) : a qualitative methodology of choice in healthcare research, (April 2015), 37–41. http://doi.org/10.1080/14780880802314304

Bolton, W., Wood, H., Lovell, K., & Morgan, L. (2014). *Meeting the challenge, making a difference: Working effectively to support people with personality disorder in the community* . London, Department of Health.

Bowlby, J. (2005). A secure base: Clinical applications of attachment theory (Vol. 393). Taylor & Francis.

Brazier, J., Tumur, I., Holmes, M., Ferriter, M., Parry, G., Dent-Brown, K., & Paisley, S. (2006). Psychological therapies including dialectical behaviour therapy for borderline personality disorder: A systematic review and preliminary economic evaluation. *Health Technology Assessment*, *10*(35), 1–61.

Briere, J., Hodges, M., & Godbout, N. (2010). Traumatic stress, Affect dysregulation, and Dysfunctional Avoidance: A Structural Equation Model. *Journal of Traumatic Stress*, *23*(6), 767–774. http://doi.org/10.1002/jts.

Castillo, H. (2003). A dangerous Diagnosis. *Mental Health Today*, *2*, 27–30.

Castillo, H., Ramon, S., & Morant, N. (2013). A recovery journey for people with personality disorder. *The International Journal of Social Psychiatry*, *59*(3), 264–73. http://doi.org/10.1177/0020764013481891

Clarke, S., Thomas, P., & James, K. (2013). Cognitive analytic therapy for personality disorder: Randomised controlled trial. *British Journal of Psychiatry*, *202*(2), 129–134. http://doi.org/10.1192/bjp.bp.112.108670

Clarkin, J. F., Lenzenweger, M. F., Yeomans, F., Levy, K. N., & Kernberg, O. F. (2007). An object relations model of borderline pathology. *Journal of Personality Disorders*, *21*(5), 474–499. http://doi.org/10.1521/pedi.2007.21.5.474

Clarkin, J. F., Levy, K. N., Lenzenweger, M. F., & Kernberg, O. F. (2007). Evaluating three treatments for borderline personality disorder: A multiwave study. *American Journal of Psychiatry*, *164*(6), 922–928. http://doi.org/10.1176/appi.ajp.164.6.922

Clarkin, J. F., Yeomans, F., & Kernberg, O. . (2006). *Psychotherapy for Borderline Personality: Focusing on Object Relations*. *American Journal of Psychiatry* (Vol. 163). http://doi.org/10.1176/appi.ajp.163.5.944

Cooke, S., Daiches, A., & Hickey, E. (2015). Narratives of experts by experience: the impact of delivering training in partnership on the subject of personality disorder. *The Journal of Mental Health Training, Education and Practice*, *10*(4), 234-244.

Department of Health. (2001). *The Journey to Recovery – The Government's vision for mental health care*. London, Department of Health.

DoH. (2009). *Recognising complexity: Commissioning guidance for personality disorder services*. Retrieved from www.personalitydisorder.org.uk

Fonagy, P., Luyten, P., & Strathearn, L. (2011). Mentalisation and the neurobiology of attachment. *Infant Mental Health Journal*, *32*(1), 47–69. http://doi.org/10.1002/imhj.

Fonagy, P. (2000). Attachment and borderline personality disorder. http://doi.org/10.1177/00030651000480040701

Fonagy, P., & Target, M. (1997). Attachment and reflective function: their role in self-organization. *Development and Psychopathology*, *9*(4), 679–700. http://doi.org/10.1017/S0954579497001399

Fonagy, P., Target, M., Gergely, G., Allen, J. G., & Bateman, A. W. (2003). The Developmental Roots of Borderline Personality Disorder in Early Attachment Relationships: A Theory and Some Evidence. *Psychoanalytic Inquiry: A Topical Journal for Mental Health Professionals*, *23*(3). http://doi.org/DOI:10.1080/07351692309349042

Gregory, R. J. (2004). Thematic stages of recovery in the treatment of borderline personality disorder. *American Journal of Psychotherapy*, *58*(3), 335–348.

Gunderson, J. G. (2009). Reviews and Overviews Borderline Personality Disorder: Ontogeny of a Diagnosis. *Am J Psychiatry*, *1666*(5), 530–539. http://doi.org/10.1176/appi.ajp.2009.08121825

Haigh, R. (2013). The quintessence of a therapeutic environment. *Therapeutic Communities: The International Journal of Therapeutic Communities*, *34*(1), 6–15. http://doi.org/10.1108/09641861311330464

Holm, A. L., & Severinsson, E. (2011). Struggling to recover by changing suicidal behaviour: Narratives from women with borderline personality disorder. *International Journal of Mental Health Nursing*, *20*(3), 165–173. http://doi.org/10.1111/j.1447-0349.2010.00713.x

Horn, N., Johnstone, L., & Brooke, S. (2007). Some service user perspectives on the diagnosis of Borderline Personality Disorder. *Journal of Mental Health*, *16*(2), 255–269. http://doi.org/10.1080/09638230601056371

Jørgensen, C. R. (2006). Disturbed sense of identity in borderline personality disorder. *Journal of Personality Disorders*, *20*(6), 618–644. http://doi.org/10.1521/pedi.2006.20.6.618

Jørgensen, C. R. (2009). Identity style in patients with borderline personality disorder and normal controls. *Journal of Personality Disorders*, *23*(2), 101–112. http://doi.org/10.1521/pedi.2009.23.2.101

Jørgensen, C. R., Freund, C., Bøye, R., Jordet, H., Andersen, D., & Kjølbye, M. (2013). Outcome of mentalization-based and supportive psychotherapy in patients with borderline personality disorder: A randomized trial. *Acta Psychiatrica Scandinavica*, *127*(4), 305–317. http://doi.org/10.1111/j.1600-0447.2012.01923.x

Katsakou, C., Marougka, S., Barnicot, K., Savill, M., White, H., Lockwood, K., & Priebe, S. (2012). Recovery in borderline personality disorder (BPD): A qualitative study of service users' perspectives. *PLoS ONE, 7*(5). http://doi.org/10.1371/journal.pone.0036517

Kernberg, O. F. (2006). Identity: recent findings and clinical implications. *The Psychoanalytic Quarterly*, *75*(4), 969–1004.

Larivière, N., Couture, É., Blackburn, C., Carbonneau, M., Lacombe, C., Schinck, S.-A., … St-Cyr-Tribble, D. (2015). Recovery, as Experienced by Women with Borderline Personality Disorder. *Psychiatric Quarterly*. http://doi.org/10.1007/s11126-015-9350-x

Leamy, M., Bird, V., Le Boutillier, C., Williams, J., & Slade, M. (2011). Conceptual framework for personal recovery in mental health: Systematic review and narrative synthesis. *British Journal of Psychiatry*, *199*(6), 445–452. http://doi.org/10.1192/bjp.bp.110.083733

Lieb, K., Zanarini, M. C., Schmahl, C., Linehan, M. M., & Bohus, M. (2004). Borderline personality disorder. *Lancet*, *364*(9432), 453–461. http://doi.org/10.1016/S0140-6736(04)16770-6

Macintosh, H. B., Godbout, N., & Dubash, N. (2015). Borderline Personality Disorder: Disorder of Trauma or Personality , a Review of the Empirical Literature. *Canadian Psychology*, *56*(2), 227–241.

Markham, D. (2003). Attitudes towards patients with a diagnosis of “borderline personality disorder”: Social rejection and dangerousness. *Journal of Mental Health*, *12*(6), 595–612. http://doi.org/1360-0567

Markham, D., & Trower, P. (2003). The effects of the psychiatric label “borderline personality disorder” on nursing staff’s perceptions and causal attributions for challenging behaviours. *The British Journal of Clinical Psychology / the British Psychological Society*, *42*(Pt 3), 243–256. http://doi.org/10.1348/014466503360703366

Martín-Blanco, A., Soler, J., Villalta, L., Feliu-Soler, A., Elices, M., Pérez, V., … Pascual, J. C. (2014). Exploring the interaction between childhood maltreatment and temperamental traits on the severity of borderline personality disorder. *Comprehensive Psychiatry*, *55*(2), 311–318. http://doi.org/10.1016/j.comppsych.2013.08.026

Maslow, A. H. (1943). A theory of human motivation. *Psychological Review*, *50*(4), 370–396. http://doi.org/10.1037/h0054346

Montgomery-Graham, S. (2015). DBT and Schema Therapy for Borderline Personality Disorder: Mentalization as a Common Factor. *Journal of Contemporary Psychotherapy*, 1–8. http://doi.org/10.1007/s10879-015-9309-0

National Institute of Clinical Excellence (NICE). (2009): *Borderline personality disorder: The NICE guideline on treatment and management*. ISBN: 978-1-85433-477-0. Retrieved from http://www.nice.org.uk/guidance/cg78/resources/cg78-borderline-personality-disorder-bpd-full-guideline3

Onken, S. J., Craig, C. M., Ridgway, P., Ralph, R. O., & Cook, J. a. (2007). An analysis of the definitions and elements of recovery: a review of the literature. *Psychiatric Rehabilitation Journal*, *31*(1), 9–22. http://doi.org/10.2975/31.1.2007.9.22

Paris, J., & Zweig-Frank, H. (2001). A 27-year follow-up of patients with borderline personality disorder. *Comprehensive Psychiatry*, *42*(6), 482–487. http://doi.org/10.1053/comp.2001.26271

Perry, J. C., Banon, E., & Ianni, F. (1999). Effectiveness of psychotherapy for personality disorders. *American Journal of Psychiatry*, *156*(9), 1312–1321.

Pilgrim, D. (2001). Disordered personlaities and disordered concepts. *Journal of Mental Health*, *10*(3), 253–265. http://doi.org/10.1080/09638230020023877

Ramon, S., Castillo, H., & Morant, N. (2001). Experiencing Personality Disorder: The research partnership. *International Journal of Social Psychiatry*, *47*(4), 1–15. http://doi.org/doi: 10.1177/002076400104700401

Rivera-segarra, E., Crespo-ramos, G., & Marqués-reyes, D. (2014). Stigmatization Experiences among People Living with Borderline Personality Disorder in Puerto Rico Stigmatization Experiences among People Living with Borderline Personality Disorder in Puerto Rico. *The Qualitative Report*, *19*(15), 1–18.

Ryle, A. (1997). The structure and development of borderline personality disorder: a proposed model. *The British Journal of Psychiatry: The Journal of Mental Science*, *170*, 82–87.

Ryle, A. (2004). The contribution of cognitive analytic therapy to the treatment of borderline personality disorder. *Journal of Personality Disorders*, *18*(1), 3–35. http://doi.org/10.1521/pedi.18.1.3.32773

Shepherd, A., Sanders, C., Doyle, M., & Shaw, J. (2015). Personal recovery in personality disorder: Systematic review and meta-synthesis of qualitative methods studies. *International Journal of Social Psychiatry*. http://doi.org/10.1177/0020764015589133

Shepherd, G., Boardman, J., & Slade, M. (2008). *Making Recovery a Reality*. Retrieved from http://www.scmh.org.uk/pdfs/Recovery_lived_experience_perspective.pdf

Slade, M. (2009). *Personal Recovery and Mental Illness: a guide for mental health professionals*. Cambridge University Press. http://doi.org/10.1017/CBO9780511581649

Smith, J., Flower, T., Larkin, P. (Eds) *Interpretative Phenomenological Analysis: Theory, Method and Research* London. Sage Publishing

Sollberger, D. (2013). On identity: from a philosophical point of view. *Child and Adolescent Psychiatry and Mental Health*, *7*(1), 29. http://doi.org/10.1186/1753-2000-7-29

Sollberger, D., Gremaud-Heitz, D., Riemenschneider, A., Agarwalla, P., Benecke, C., Schwald, O., Dammann, G. (2014). Change in Identity Diffusion and Psychopathology in a Specialized Inpatient Treatment for Borderline Personality Disorder. *Clinical Psychology & Psychotherapy*, n/a–n/a. http://doi.org/10.1002/cpp.1915

Stalker, K., Ferguson, I., & Barclay, a. (2005). It’s a horrible term for someone: Service user and provider perspectives on personality disorder, (April 2015), 37–41. http://doi.org/10.1080/09687590500086443

Turner, K., Lovell, K., & Brooker, A. (2011). “… and They All Lived Happily Ever After”: “Recovery” or Discovery of the Self in Personality Disorder? *Psychodynamic Practice*, *17*(3), 341–346. http://doi.org/10.1080/14753634.2011.587604

Van Dijke, A., Ford, J. D., van Son, M., Frank, L., & van der Hart, O. (2012). Association of Childhood-Trauma-by-Primary Caregiver and Affect Dysregulation With Borderline

Personality Disorder Symptoms in Adulthood. *Psychological Trauma: Theory, Research, Practice, and Policy*, *5*(3), 217–224. http://doi.org/10.1037/a0027256

Verheul, R., & Herbrink, M. (2007). The efficacy of various modalities of psychotherapy for personality disorders: a systematic review of the evidence and clinical recommendations. *International Review of Psychiatry (Abingdon, England)*, *19*(1), 25–38. http://doi.org/10.1080/09540260601095399

Veysey, S. (2014). People with a borderline personality disorder diagnosis describe discriminatory experiences. *Kōtuitui: New Zealand Journal of Social Sciences Online*, (November), 1–16. http://doi.org/10.1080/1177083X.2013.871303

Wilkinson-Ryan, T., & Westen, D. (2000). Identity Disturbance in Borderline Personality Disorder: An Empirical Investigation. *American Journal of Psychiatry*, *157*(4), 528–441. Retrieved from http://ajp.psychiatryonline.org/doi/10.1176/appi.ajp.157.4.528

Zanarini, M. C., Frankenburg, F. R., Reich, D. B., & Fitzmaurice, G. (2010). Time to Attainment of Recovery From Borderline Personality Disorder ... *The American Journal of Psychiatry*, *6*(167), 663. http://doi.org/10.1176/appi.ajp.2009.09081130

Zanarini, M. C., Frankenburg, F. R., Reich, D. B., Wedig, M. M., Conkey, L. C., & Fitzmaurice, G. M. (2014). Prediction of time-to-attainment of recovery for borderline patients followed prospectively for 16 years. *Acta Psychiatrica Scandinavica*, 205–213. http://doi.org/10.1111/acps.12255

Table 1. Participant Demographic Information

Participant	Sandra	Claire	Poe	Ol	James	Adam
Gender	Female	Female	Female	Female	Male	Male
Age	51	35	43	59	45	30
Ethnicity	White British	White British	White British	White British	White British	White British
Employment	Unemployed	Unemployed	DLA	DLA & ESA	Unemployed	PIP
Diagnosis	BPD (16years) Depression (18years)	BPD (5years) Depression (6years)	BPD (16years) Post-natal Depression	BPD (1 year) Depression (18 years)	BPD (18 months) Depression (20 years)	BPD (<1 year)
Length of time in Services	18 years	6 years	16 years	20 years	20 years	18 months
Previous or current psychological therapy/intervention	SCM Art Therapy Just starting MBT	SCM MBT Individual Psychotherapy	SCM CBT DBT Individual Psychological intervention	SCM MBT	SCM MBT Individual Psychotherapy	SCM Individual Psychotherapy

Table 2: Clustering of Participant Emergent and Superordinate Themes

Participant	Emergent Theme	Superordinate Theme
Sandra	Difficulties with BPD go on and on	Life with BPD
	Difficult thoughts lead to difficult feelings	
	I feel worthless and unwanted – I was a mistake	
	Relationships continue in the same way	
	Life is surviving and existing, not living	
	I’ve always been the black sheep	
	I just didn’t want to be here	
	I cut off to protect myself	
	Life is draining	
	Medical approach to diagnosis	BPD – The Dialectical Diagnosis
	“I had a title” – diagnosis as validation	
	Diagnosis – I’m still not a hundred percent sure what it means	
	Diagnosis came from crisis	
	I put a front on	My sense of self is understood through others
	Other people are the reason for my progress	
	I only exist through others	
	I’m just another person	
	If others don’t need me, there’s no point me being here	
	Staff using recovery terms is helpful	The Road to Recovery? I can’t see myself

	I’ve made a connection with my worker	moving
	Recovery is forward and I’m stuck	
	Progress feels hollow	
	I’m only at the first stage of recovery	
	I see my progress through others	
	Unsure of the helpfulness of Recovery	
Claire	I still feel like I don’t know what’s wrong with me	Life with BPD
	Higher and Lower order difficulties	
	I have “extra” mental health needs	
	That was my own fault	
	I want a better life for my children than I had	
	My diagnosis doesn’t mean anything to me	BPD – The Dialectical Diagnosis
	My diagnosis provides some explanation	
	Diagnosis has helped me see it’s not my fault	
	Crisis led to diagnosis	
	Am I real? Lifelong struggle with identity	Am I real? Struggles with self-image
	I don’t know who I am except through facts	
	I understand my identity through others	
	My identity is lost when I’m inactive	
	Recovery has helped me contain my difficult feelings	The road to recovery
	Recovery has increased empathy towards myself	
	Recovery as life changing	
	Recovery as an ongoing process	
	Recovery is increasing my self worth	
	Recovery and diagnosis are separate	
	Recovery as providing a framework of understanding that diagnosis could not	
	Recovery has helped me to perspective take	
	Strong sense of future aspiration	
	I’m starting to think differently about things	
Poe	I’m utterly confused at life	Life with ‘BPD’
	Difficulties with BPD go on and on and round and round	
	My illness had a clear trigger	

	I suddenly got in touch with my anger	
	I don’t deserve to be loved	
	I harmed myself to gain control and punish myself	
	I haven’t got any relationships – I’m terrible at them	
	I denied my problems and my diagnosis	BPD – I denied my diagnosis and I’m still unsure
	Fear of mental health issues	
	Other diagnosis were more acceptable	
	My diagnosis came from crisis	
	My diagnosis was punishing and shameful	
	I’m still ambivalent	
	I’m lost inside – don’t know who I am	I’m lost inside
	I hate my physical image	
	I have no thoughts or feelings	
	Understanding of myself through others	
	Understanding of my improvement through others	
	Conflict between my progress and my ongoing problems	Rocky road to Recovery
	Recovery is thinking differently	
	Medication plays a role	
	My relationship with my key worker is key	
	I’ve gradually started to accept my difficulties	
	Recovery is removing the label	
	Recovery is a process with an end point – I’ve got the basics	
	Recovery is blaming myself less and understanding past events	
	Recovery is being less scared	
Ol	Previous Experiences of being ignored	Life with BPD
	I don’t want them to view me as having a mental disorder	
	My adult relationships are like my early experiences	
	Distanced from myself	
	I’ve formed an understanding of my difficulties	Diagnosis – Permission to….
	Diagnosis = I feel justified. These ARE my feelings	
	Diagnosis as a framework of understanding - validating	
	Diagnosis as permission to seek help	
	Fear of stigma	

James	My sense of self is voiceless and powerless Self-development has been kept childlike I’ve been living a lie I still struggle to establish an identity	I see myself as a child
	Recovery means I can do something about it Recovery is going forward You don’t feel quite as alone Recovery = I am entitled to feel emotions Recovery as a step by step process Recovery as an additional framework of understanding difficulties Recovery as a thinking/change process It’s still early days for me Better at managing emotions Self-forgiveness in starting recovery	On my way towards recovery
	I didn’t want my life to turn out this way There is some ulterior move to everything I don’t see life past my kids Relationships remind me too much of past experiences “I’ve got the impression of bigness, but inside I’m little” I see my fears in a physical form I see my life with borderline as a jagged edge – like a 50p piece I am broken	I see life with borderline as a jagged edge
	Previous abusive care Diagnosis came from looking deeper Diagnosis as process of elimination My diagnosis was gutting I struggle to connect with my diagnosis – I’m trying to be normal BPD label is permanent I reject the medical model 100% recovery is unattainable Diagnosis means I’m pigeon holed as that weird guy – it’s like half a person Diagnosis has left me with more questions than it’s not left me with	BPD – A damaging diagnosis

Adam	Blanketed stigma	Stigma
	Stigma through my family's eyes	
	Stigma leads me to harmful acts	
	I only exist through adopting the roles of others	Adopting a Role
	My imagined selves are strong	
	I see improvement in others	
	I can see myself AS others	
	Maybe I come from a different race	
	Recovery as feeling normal – 'losing all the…'	Does Recovery exist? A Road to nowhere?
	Does recovery exist? Understanding breeds doubt	
	Recovery has made me talk about it	
	I'm more rational now	
	Recovery has helped me be stronger	
	1st level of recovery	
	I feel empathy now	
	Trauma caused my difficulties	The profound scars of trauma
	Needing mental health services as a sign of weakness	
	Mental health difficulties are a continuation of abuse/trauma	
	"Nobody ever did believe me"	
	Relationships have continued to be abusive	Life as a battle with BPD
	I can't connect	
	I just always felt horrible	
	I question my value and judgement	
	I can't make sense of nothing	
	I haven't got it in me anymore	
	My responsibility to my children is a reason for living – trying not to repeat mistakes	
	Diagnosis came from crisis	It's just a label - diagnosis
	Diagnosis is making excuses	
	Diagnosis is the opposite to recovery – static	
	It's just a label – diagnosis is meaningless	
	Was my life beforehand really me?	Who am I?
	The problems were in growing up – where do I go?	

	I questioned my sexuality	
	I couldn’t put my identities together	
	I exist through others	
	Dissociation makes me question everything	
	Not knowing who you are is the most difficult thing	
	Now I’m being believed and validated but also raw and exposed – they’ve opened a door	Recovery – right term, wrong meaning
	Day to day coping but you’ll never be better	
	Recovery – right term, wrong meaning	
	The role of medication	
	CPN’s don’t have the specialist knowledge	
	Psychology has added a layer of understanding – individual and validating	
	Having a positive relationship has been powerful	
	The power of being believed	

Table 3: Clustering of Superordinate Themes into Master Themes

Cluster of Superordinate Themes	**Master Theme**	**Subtheme**
Life with BPD Life with BPD Life with BPD I see my life with BPD like a jagged edge Life as a battle with BPD The profound scars of trauma	1. I see my life with BPD as a jagged edge – like a 50p piece	1.1 I am Broken – the internal experience 1.2 Unequal Relationships 1.3 Pushing On – life as existing not living
BPD – The dialectical Diagnosis BPD – The Dialectical Diagnosis BPD – I denied my diagnosis and I'm still	2. BPD: The Dialectical Diagnosis	2.1 I Had a Title – Diagnosis as validation

unsure Diagnosis – Permission to…. BPD – A damaging diagnosis Stigma It’s just a label - diagnosis		2.2 Labelling – diagnosis as meaningless 2.3 I’m too busy trying to be normal – Denial and fear of stigma
My sense of self is understood through others Am I real? - Struggles with self-image I’m lost inside I see myself as a child Adopting a Role Who am I?	3. I’m Lost Inside	3.1 Am I real? Lifelong struggles with identity 3.2 Identity and Others
The Road to Recovery? I can’t see myself moving The road to recovery Rocky road to Recovery On my way towards recovery Does Recovery exist? A Road to nowhere? Recovery: Right term, wrong meaning	4. It’ll never be better: The Rocky Road to Recovery	4.1 Building bricks – Recovery as a process 4.2 The First Step – Recovery as acceptance 4.3 Recovery Through Relationships 4.4 Recovery - Right

	term, wrong meaning

Appendix A

Author Guidelines for The Journal of Qualitative Health Research

Manuscript Submission Guidelines: Qualitative Health Research (QHR)

4. Preparing your manuscript

4.1 Word processing formats

Preferred formats for the text and tables of your manuscript are Word DOC, RTF, XLS. LaTeX files are also accepted. The text should be double-spaced throughout and with a minimum or 3cm for left and right hand margins and 5cm at head and foot. Text should be standard 10 or 12 point. Word and LaTex templates are available on the Manuscript Submission Guidelines page of our Author Gateway.

4.2 Artwork, figures and other graphics

For guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's Manuscript Submission Guidelines. Please refer to clause 4.5 for information on SAGE Language Services.

Figures supplied in colour will appear in colour online regardless of whether or not these illustrations are reproduced in colour in the printed version. For specifically requested colour reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

4.3 Supplementary material

This journal is able to host additional materials online (e.g. datasets, podcasts, videos, images etc) alongside the full-text of the article. These will be subjected to peer-review alongside the article. For more information please refer to our guidelines on submitting supplementary files, which can be found within our Manuscript Submission Guidelines page.

4.4 Journal layout

In general, QHR adheres to the guidelines contained in the Publication Manual of the American Psychological Association [“APA”], 6th edition (ISBN 10:1-4338-0561-8, softcover; ISBN 10:1-4338-0559-6, hardcover; 10:1-4338-0562, spiral bound), with regard to manuscript preparation and formatting. These guidelines are referred to as the APA Publication Manual, or just APA. Additional help may be found online at http://www.apa.org/, or search the Internet for “APA format.”

4.5 Reference style

QHR adheres to the APA reference style. Click here to review the guidelines on APA to ensure your manuscript conforms to this reference style.

4.6 English language editing services

Authors seeking assistance with English language editing, translation, or figure and manuscript formatting to fit the journal’s specifications should consider using SAGE Language Services. Visit SAGE Language Services on our Journal Author Gateway for further information.

Appendix B

Excerpt of Participant Transcript To Show Analytic Process

Behavioural and affective components of the difficulties associated with a BPD diagnosis **Lack of clarity around the diagnostic process – did this happen for Ol without her knowing or being involved in the process? Similarly it sounds as though Poe feels her mental health issues are external and out of her control. She lists her difficulties as though reading case notes in very clinical terms.**	[0:00] Participant: I've had a history of attempted suicides, a history of depression. And don't really know how I became with the diagnosis of borderline personality disorder. (Pause). So it's difficult for me to say, when I was diagnosed, really.	
	Researcher: okay, okay. So you said about history of suicide attempts and depression. What other kinds of difficulties would you describe yourself as having that might have led to that diagnosis?	
Does this pause indicate more than what Ol actually goes on to say? Or maybe highlight her uncertainty when asked for her own opinion on her difficulties	Participant: a feeling of… I felt very insecure… And self-loathing… And… (Pause) and… Thought I wasn't a very nice person.	Distanced from self and diagnosis/difficulties
	Researcher: okay and how did you come to be referred to the recovery team?	
Self-loathing – a part of a self Ol seeks to destroy? **Factual, taleological account of referral – slightly detached tone**	Participant: when I took my first overdose. It was quite serious. I was admitted to the (inpatient mental health ward)… for a while.	
	Researcher: okay. So you said a little bit about the kind of difficulties, and how you thought about yourself. How did those difficulties affect kind of, your sense of identity, or how you know who you are, do you think?	
How has this understanding come about – is this a clinican's account of Ol's difficulties. It sounds like a formulation. **I've always classed myself as a child – is this Ol's representation of herself, as seen and mirrored by her early care givers? Has remaining in this child state become a necessary survival strategy for her? A re-enacted reciprocal role which meets her needs, but prevents her from asserting or developing an adult self? Poe sounds like she has no voice or has been told her voice is wrong**	Participant: one of my problems is… Is that I've always classed myself as a child. And I don't think of myself as an adult… I have problems with asserting myself, putting my views across… Because I don't feel I've got the right… Because I'm a child. (Pause) so… I'm a people pleaser… Because I don't like the conflict and because I can't put my point of view across… And then I then I tend to see myself as ineffectual, as I say like a child… And I've always felt like that.	Sense of self as a child – voiceless and powerless
	Researcher: so you say you associate as being a child. Does that affect how you see your identity. Kind of difficult to establish an identity?	
understanding of difficulties – people pleaser – feels unimportant	Participant: yeah. Yeah. Because, I don't talk about myself. I don't talk about what my views are… And I feel… Ignored… And I'm not important.	
Feels ignored, unimportant	Researcher: when you say you don't talk about your views, do you feel you know what your views are and what you believe in?	
This is quite an indirect response though it is really relevant –is Ol avoiding engaging in the real question here? **Vivid descriptions of past experiences, and rich language used – does this suggest that Ol has developed insight into how her difficulties have developed and as such is able to give quite a mentalised and coherent narrative? Or has this account come from clincian's?**	Participant: no not really, because when I was younger my dad was an old-fashioned dad. And it was quite brutal at times. And not very supportive. And very condescending and mentally cruel (Pause.) And, I was always trying to appease him so he didn't get angry, and it didn't get violent, and as a family, we were there to be the old-fashioned thing, to be seen and not heard. And as far as I can remember, my parents never had any friends round, so I was never… I was never in the company of adults. So I have never learned how to speak as an adult (Pause). I have had quite a bit of problems regarding that.	Understanding of early experiences in keeping her self-development childlike
Has formulated difficulties outside of the diagnostic/medical framework –	Researcher: so it sounds like establishing an identity for yourself wasn't particularly encourage,…(tails off)	Formulation of difficulties – through treatment
Is this "normally" in reference to the fact that Ol agreed to take part in the research? **Again, shows understanding of history although the accounts are a little contrary – being kept childlike versus having to set herself independently to everything**	what I do, but it's helpful,… It's not entirely my fault… It's something that people with this disorder do… I mean I'm not making excuses as to the reasons, but it's nice to know, well not nice to know, but helpful to know that… I can do something about it. With impulsivity, because you do it as I say, on impulse, you feel like you've got no control over it, and that's what I used to feel… But since coming to the group and that, I'm learning how to control my impulsivity… You know… by thinking… Yes, I can do something about it… rather than just letting the situation develop.	

"It's something that people with this disorder do" – diagnosis has provided some understanding in tandem with self-responsibility – or is this Poe's way of being able to distance herself from her behaviour and experiences. Her dad is cited as the cause of all difficulties and is the diagnosis the end point of this? **"You feel like you've got no control over it"** **Recovery has increased self-efficacy and reduced impulsivity** **"I don't question what I do" – Ol is removed from her experiences?** **Diagnosis as helpful in giving permission to ask for help** **These sound more like Ol's own words. Is that why the pauses punctuate them to indicate uncertainty?** **"You don't have to think, suffer" – is Ol giving a reason for her detachment here? To avoid suffering?** **Does this view come from Ol's early experiences?** **"I don't have to stay in the same place" – Recovery equates with movement** **Recovery equates with self-efficacy** **"Its how you view what you think" – is Ol starting to take a slightly different perspective?** **Recovery equates with connection and shared experience – does hearing other people's stories help Ol with her own forgiveness and distancing a little?** **You don't feel quite as alone** **Ol doesn't answer, she just keeps going – has the previous question resonated with her?** **"It say that", not "I say"** **I wonder if realising she is entitled to certain emotions has come from initially distancing herself, and using the diagnosis to do this** **"And gosh, it was terrible" – sounds like St Trinian's – British and girly** **Increased perspective taking** **Recovery has given Ol permission to feel** **"To be told that I have a right…" This is Ol still listening to an authority figure and not quite developing her own opinion?**	Researcher: okay, so it sounds like been given the diagnosis was the first part of that. The first step of that. Okay, so having the diagnosis, did it change how you view yourself? You identity? Participant: it's difficult to say because, I don't, I don't question, what I do… But, in a way I feel its helpful… To have the diagnosis… (Long pause)… Because… What I used to do, I've always felt that, I should be able to deal with this on my own… Shouldn't need, need all the help that I'm getting you know, because it's in your head, you think, well you don't have to think, suffer. Should be able to deal with it by [0:05] myself… Researcher: and has having the diagnosis change that? Participant: it has a bit yeah… Because I am now getting the help… Which is good. Researcher: okay. So when we think about the term recovery… What does that term mean to you? What does it individually mean to you? Participant: that I don't have to do to… Stay in the same place… I can work towards doing something about it myself… And that there is help out there, that, I'm not on my own… And then when we going to the group and people… It's how you view what you think… Things I think of as petty, you know, that other people, deal with this, why can't I deal with it? And then talking with people in group, they are on the same wavelength. So,… You don't feel quite as alone. Researcher: so there's a sense of unity there are almost the sense of belonging to something? Participant: and then the thing that it says is that, I am entitled to certain emotions, and anger, and all that, because I'm not an angry person, and at one stage I was in the centre, and I don't know where it came from, but this anger just… Erupted… And gosh, it was terrible… Because before, I was never allowed to be angry. And even now, I hold it all back. Researcher: so difficult emotions to allow yourself to feel? Participant: yeah. Researcher: so when you think about recovery has that changed how you feel about these things? Participant: yeah it has. To be told that I have a right to be angry… Okay… I go from one extreme to the other, I go from being really placid, to absolutely manic… But I'm now trying… To learn how to control my anger. Not stop it, but to be able to put across, why I'm feeling angry, without… Doing something stupid, like drinking, or jumping off a bridge (laughs)… You know… Researcher: so how does it apply to you in terms of things like relationships, and feelings and self-harm and things like that, how does recovery affect how you see those things? Participant: it's difficult with regards to things like the family, because even now, I don't want them to view me as having a mental disorder. (Pause) and I must admit I'm very, very lucky that I've got a husband and a son that, look after me (Pause). And I don't know if my son is….	Diagnosis as providing an explanatory framework of understanding – validating Self-forgiveness in helping recovery? Recovery means I can do something about it Diagnosis as providing permission to ask for help Recovery as movement You don't feel quite as alone Recovery = I am entitled to feel certain emotions

Critical Appraisal: Reflections on a Relational Research Process

Sarah Elizabeth Davidson

Lancaster University

The completed thesis contains three papers. The first, a literature review using a qualitative synthesis methodology known as Thematic Synthesis seeks to understand what elements of services service users with a Borderline Personality Disorder (BPD) diagnosis find therapeutically helpful and unhelpful. The second, empirical paper utilises Interpretive Phenomenological Analysis (IPA) to understand what the concept of recovery means for the sense of self for individuals with a BPD diagnosis. Cumulatively, the thesis contributes to the literature around the BPD diagnosis, by furthering understanding relating to how service users experience their diagnosis, how they interact with and value services, what their personal constructs of recovery are, and how their sense of self is impacted on by the concept of recovery.

This third paper seeks to provide some reflections by myself on the research process, giving particular consideration to the relational dimension of the research. This perspective has been taken due to the overarching theme of relationships that permeated both the content and the process of the literature review and the empirical paper, and caused me to reflect frequently on this phenomenon. Whilst I had, perhaps, anticipated the papers to contain a relational aspect, given the types of difficulties associated with a BPD diagnosis, I was surprised to discover how prominent patterns of relating appeared to be across the entire research process. Additionally, I became aware of how personal and involved a process the thesis became, and reflected on how this phenomenon fit within a relational framework.

Across the two previous papers, Attachment Theory has featured heavily, which posits that babies are born with a biological drive to seek proximity to their main caregiver for survival (Bowlby, 2005). The response from their caregiver in terms of providing both physical and emotional safety provides a ‘blue print’ from which children learn about the world, themselves, and others, and their attachment is believed to direct their subconscious needs, beliefs and behaviours into adult life. Thus, regardless of the quality of early experiences, everyone has an attachment style.

The basis of Cognitive Analytic Therapy (CAT) (Ryle, 1997) builds on attachment theory by observing that early relational patterns are dyadic, and states that these internalised dyadic relationship patterns are repeated over and over within an individual’s life time, on a subconscious level, often without awareness. Thus, an individual builds a subconscious repertoire of relating towards others, and towards one’s self, ensuring survival by finding ways to elicit care. In CAT these relational patterns are known as Reciprocal Roles. In individuals with a healthy, secure attachment, frequently these reciprocal roles are helpful, as the early experiences of the child will hopefully have taught them a repertoire of eliciting and showing care to others and the self that is based on being loved, cared for and accepted. In children with traumatic histories, however, the child is more likely to develop patterns of relating that are self-defeating and damaging (Ryle, 2004). The notion of Reciprocal Roles has been important throughout this research on several levels, and for varying reasons. Firstly, the relational patterns of individuals with a BPD diagnosis are thought to be associated with trauma and profoundly negative early experiences (Agrawal, Gunderson, Holmes, & Lyons-Ruth, 2004; Clarkin, Yeomans, & Kernberg, 2006; Fonagy, Target, Gergely, Allen, & Bateman, 2003) and can go some way to explaining both the inter and intrapersonal difficulties they experience. This has huge implications for the way services are delivered, and the need for a relational approach has been evidenced frequently in this research. Secondly, because everyone has an attachment style, and their own reciprocal roles, any one interacting with any other individual will always have an intra and interpersonal response to them based on their own patterns of relating. Individuals with a BPD diagnosis, may elicit unusually strong emotional reactions, dependent on the other individual’s own reciprocal roles. Hamilton (2010) describes the responses that individuals may have to individuals with a personality disorder diagnosis, and how these responses may represent shifts or transgressions in appropriate and healthy boundaries, using the Boundary See-Saw Model. The model suggests that to adopt either an overly punitive/withholding approach or an overly involved and rescuing position is in fact, abusive, and that a truly therapeutic and appropriately boundaried relationship is found by staying within the ‘middle’ of the see-saw, as an open care giver with explicit limits. These ‘ends’ of the see-saw can also be understood in terms of reciprocal roles. These points are relevant in considering within this research, the way service users with a BPD diagnosis have interpreted, responded to, and been responded to within services. It is also relevant when considering my own responses to the research, the participants, and my feelings surrounding diagnosis. Thirdly, Ryle (2010) and Ahmadi (2011) observe that reciprocal roles also occur at a wider collective, service, and societal/political level. As such, the narrative and discourse around individuals with a BPD diagnosis, and diagnosis as a political issue, can become entrenched, with little conscious awareness, making the likelihood of re-enacting previously abusive experiences, and moving too far down one ‘end’ of the Boundary See-saw model all the more likely.

The first time I began to develop a sense of potential patterns of relating in relation to individuals with a BPD diagnosis, was during the literature search procedure for the literature review. On the Lancaster University Doctorate in Clinical Psychology, the thesis is explicitly designed to encompass a literature review, an empirical paper, and this critical appraisal. Although deciding on an appropriate literature topic is an accepted challenge for any thesis, I found this process particularly difficult for one specific reason: It seemed that there was either a profusion of literature within an appropriately narrow and relevant topic field, to the extent that several qualitative reviews had already been completed, or, there was such scarcity of literature within a topic field that there was insufficient data to complete a qualitative synthesis. I began to reflect that this could potentially mirror approaches to working with individuals with a BPD diagnosis, and echoed the approaches exemplified in the Boundary See-Saw Model. For example, I was able to identify a glut of literature pertaining to Recovery, which may indicate an arguably slightly over-involved approach of researchers and practitioners seeking to, quite understandably, improve outcomes for service users with this diagnosis. I would admittedly place myself towards this end of the 'see-saw', which was partly the motivation for the research. In contrast, when interested in considering the literature on the experiences of carers and families around service users with a BPD diagnosis, I was dismayed to find only a select few articles, and certainly not sufficient literature to complete a qualitative review. It occurred to me that whilst of course researchers naturally have interests and expertise in specific areas, this may represent a more withholding, detached approach to this area of research, and, given the relationship between attachment theory and BPD, was perhaps linked to stigmatizing or negative attributions about the parents or family members of those with a BPD diagnosis. In this respect, by either under or over researching particular aspects of the experiences of service users with a BPD diagnosis, I reflected that researchers are at risk of potentially re-enacting reciprocal roles present not only at an interpersonal level, but at service level also.

Within the empirical paper, there was a clear emphasis on relationships, and in supervision I actually created a CAT formulation from the data gleaned from the IPA analysis. Issues such as diagnosis, interpersonal relationships, sense of self and concepts of recovery were all heavily influenced by attachment and relationships, and each of these issues could have been mapped out, for each participant, using Reciprocal Roles as a method of understanding the dynamics which took place at both an individual and systemic level.

Havercamp (2005), in a seminal article on ethical perspectives in qualitative research, notes that for psychologists, the “expansion permitted in one’s role as a researcher may be experienced as a heady and bewildering freedom” (Havercamp, 2005, pg.146), and I was certainly mindful of number of relationally based ethical issues that arose throughout the thesis. It was of particular interest to me that Havercamp’s general perspective on ethics is guided so heavily by relationships, as this is in keeping with my position, and I felt such an approach integrated beneficially with the relational and CAT informed way of considering the thesis as a whole. I feel that many of the points raised by Havercamp could be reframed using a relational model such as CAT, particularly with regard to Reciprocal Roles, and this is evidenced throughout this paper.

Aware of my tendency to sit along the slightly over involved end of the boundary see-saw, or indeed, re-enact reciprocal roles, I reflected constantly throughout the recruitment and interviewing process on the relational procedures occurring perhaps subconsciously, using a reflective diary as an aid (Malacrida, 2015). When considering accessing this service user group, with regard to recruitment, I reflected that participants consent to research for many different reasons. Indeed Dew (2007) noted that consenting to take part in research, for individuals with a BPD diagnosis, can be part of procedures either associated with forming connection and rapport, and therefore, attachment and care with a researcher, or with procedures associated with being abused or dominated by an authority figure (Dew, 2007). Furthermore, Havercamp (2005) recognises that there is an inherent power imbalance between researcher and participant that requires careful negotiation (Haverkamp, 2005), despite best intentions to recruit participants as “co-researchers” (Haverkamp, 2005; pg 146), in the sense that the participants’ contributions are as valuable as the researcher’s. Given the early experiences of service users with a BPD diagnosis, and the issues raised by Dew (2007), it was of paramount importance that potential participants did not feel in any way coerced into taking part in the research. Such an experience for potential participants may not only have been re-enacting individual reciprocal roles, but may also have been reminiscent of their experiences of mental health services; a ‘done to’ procedure. One such example of these considerations was that, on discussion with the recruitment teams, it was deemed appropriate, following a group discussion within a Mentalisation Based Therapy Group that I could attend at the end of the group, to answer any questions potential participants may have about the research. In this circumstance it was vital that the decision whether or not to take part in the research lay with individuals, and that my role was simply to answer questions, not to ‘seek’ recruitment from the group. However, given that recruitment took place in services, despite assurances that not taking part in the research would not affect clinical care, it is difficult to determine how truly ‘consensual’ agreeing to participate can ever be. Equally, it was crucial that the opportunity to take part in research was not proffered as anything other than that, and that participants did not misinterpret the research as therapy.

Qualitative research seeks to reduce the power imbalance inherently created in Quantitative research (Karnieli-Miller, Strier, & Pessach, 2009). As many individuals with a BPD diagnosis have experienced powerful service led dynamics previously, and may have had abusive experiences in the past, this makes it ideal for developing an understanding of the experiences of service users with a BPD diagnosis in a less threatening environment. It attempts to do this by giving participants a space to share their experiences, based on the information that they feel is most valuable and important, rather than have a narrow set of questions, dictated by the researcher, imposed on them. Havercamp (2005) notes that qualitative research can be particularly useful for participants whose experiences have been historically overlooked by traditional research, and I believe this of great pertinence for individuals with a BPD diagnosis, given the absence of qualitative research in this area, and the absence of service user perspectives within services. Once again, this can be illustrated by a dominant-dominated or ignoring-ignored reciprocal role. Furthermore, there is no set hypothesis to test, reporting instead a degree of phenomenological experience, which again places the judgment of value with the participant, not the researcher. This approach was particularly important to be, as I felt, both as a researcher and a clinician, that it was vital that the research data was “co-created through the lens of each one’s experience” (Havercamp, 2005, p.147). I would acknowledge a critical realist epistemological stance across the whole of the thesis, and I believe that a relational approach suits this wholly. Whilst it has been accepted through this research that some shared language with regard to the BPD diagnosis, and a degree of shared experience has been identified, there is also a strong focus on individual meaning making, both in terms of sense of self, and in relation to the concept of recovery and therapeutic need from services. As such, there is a rejection of traditional notions of absolute truths within ontology (Havercamp, 2005), and a move towards a more post modern qualitative paradigm, which has particular pertinence when considering issues such as diagnostic categories and the BPD diagnosis. It could be argued that this demonstrates a sharing-shared or curious-listened to Reciprocal Role.

Nonetheless, qualitative research brings with it its own set of complex dynamics, specifically around appropriate boundaries and the role of the researcher, and thus, it was crucial that I be mindful of both the issues of power and boundaries (Havercamp, 2005) throughout the data collection process. During this time I listened to and transcribed the accounts of the participants, an experience that I considered to be something of a privilege, but that was nonetheless, often an emotive and challenging experience. During the interviews themselves, I would frequently feel pulled into wanting to respond therapeutically, as would be more natural, given my clinical background, and yet ethically, of course, this was not suitable, thus, in being mindful of this pull and reflecting on it, I was able to respond and act appropriately. This issue was particularly prominent towards the end of the interviews, whereby I felt a strong desire to end the interview positively, acutely aware of the difficulties the participants had discussed at interview, and the potential impact of this on their mood on leaving. Again, the process of reflexive journaling throughout this time was extremely useful, as was utilising supervision with the academic and field supervisors. Listening to the interviews multiple times, in order to complete the transcription process was subjectively the most emotively impactful period of the research, and it was important that the author utilised self-care during this time, such as taking regular breaks, during which I would undertake mindful walking or spending time in the garden (Lalor, Begley, & Devane, 2006).

Similarly, in locating appropriate data to illustrate the themes gleaned from the Thematic Synthesis, I became aware of the emotional impact of reading accounts which frequently revealed that service users with a BPD diagnosis had been disenfranchised, alienated and at times, re-traumatised by services and the staff within them. Again, perhaps due to my own Reciprocal Roles and tendency to adopt a rescuing role, or perhaps, simply as a clinician, I felt intense sorrow and regret, and a passionate desire to bring about change for this service user group. Not only do I feel that research with this client group can be used to strengthen and advance clinical practice (Silverstein, Auerbach, & Levant, 2006), but that, given the political and societal issues around diagnosis, and the BPD diagnosis in particular, research such as this can be utilised to effect social and service level change in the wider climate for service users with a BPD diagnosis (Skodol et al., 2007).

A further relational dimension to this particular research process was the involvement of Experts by Experience (EBEs), (Raptopoulos, 2010a) who added an additional layer of richness to the research, by sharing their own experiences in relation to thinking about the interview process, diagnosis and recruitment. There is an absence of service users with personality disorder diagnoses being actively involved in research (Montgomery & Donnelley, 2014), and I very much wanted to take steps to remedy this, by paralleling some of the progress made in the co-production of services for personality disorder (Cooke, Daiches & Hickey, 2015; Slay & Stephens, 2013). Whilst I would argue that having EBE involvement in the research process had overwhelming advantages, there were some relational dilemmas that required clear thought and management. It was crucial that the EBE’s were afforded the same respect, openness and professionalism as other professionals involved in the research, whilst still taking into account the difficulties openly discussed as being experienced by the EBE’s related to their own diagnoses, and the author frequently utilised supervision around this (Read & Maslin-Prothero, 2011). For example, despite their involvement as service users within the services used for recruitment, it was decided that EBE’s should not take part in the research as participants. The EBE’s were included in all group correspondence, as were other professionals, and their input into interview materials such as consent forms was equal to that of others. I was mindful that, whilst I would not expect a supervisor to respond to emails over a weekend or outside of office hours, an EBE may do, and it was essential that I set appropriate boundaries to maintain a healthy and professional working environment. The author regularly reflected on her boundaries with the EBE’s and worked hard to manage the balance been service user and professional relationship, for example, collaboratively agreeing to and sticking to deadlines for feedback. In this sense, I hope I managed to maintain a respecting-respected and valuing-valued Reciprocal Role.

In conclusion, this Critical Appraisal seeks to reflect on the relational elements that have run throughout this thesis, and which I believe are pertinent in thinking about both the process and the findings, at a theoretical and clinically applicable level. Cognitive Analytic Therapy has been presented as a way of understanding the relational factors presented, both in terms of the data and recommendations, and as a way of reflecting on my experiences with the thesis. Furthermore, Havercamp's 2005 seminal article has been discussed, amongst others, as a method of evidencing that such issues are relevant in relation to the ontology, epistemology and methodology of qualitative research. When considering the research with, services for, and interactions with individuals with a BPD diagnosis, I would argue that it is of paramount importance to utilise a relational approach and that value can be found in communicating understanding around this service user group through both qualitative research and a relational model such as CAT.

.

References

Agrawal, H. R., Gunderson, J., Holmes, B. M., & Lyons-Ruth, K. (2004). Attachment studies with borderline patients: a review. *Harvard Review of Psychiatry*, *12*(2), 94–104. http://doi.org/10.1080/10673220490447218

Ahmadi, J., 2011. What are the most dominant Reciprocal Roles in our society? *Reformulation,* Summer, pp.13-17.

Bowlby, J. (2005). A secure base: Clinical applications of attachment theory (Vol. 393). Taylor & Francis.

Clarkin, J. F., Yeomans, F., & Kernberg, O. (2006). *Psychotherapy for Borderline Personality: Focusing on Object Relations*. *American Journal of Psychiatry* (Vol. 163). http://doi.org/10.1176/appi.ajp.163.5.944

Cooke, S., Daiches, A., & Hickey, E. (2015). Narratives of experts by experience: the impact of delivering training in partnership on the subject of personality disorder. *The Journal of Mental Health Training, Education and Practice*, *10*(4), 234-244.

Dew, R. E. (2007). Informed consent for research in Borderline Personality Disorder. *BMC Medical Ethics*, *8*, 4. http://doi.org/10.1186/1472-6939-8-4

Fonagy, P., Target, M., Gergely, G., Allen, J. G., & Bateman, A. W. (2003). The Developmental Roots of Borderline Personality Disorder in Early Attachment Relationships: A Theory and Some Evidence. *Psychoanalytic Inquiry: A Topical Journal for Mental Health Professionals*, *23*(3). http://doi.org/DOI:10.1080/07351692309349042

Hamilton, L. (2010). The boundary seesaw model: Good fences make for good neighbours. In *Using time, not doing time: Practitioner perspectives on personality disorder and risk* (pp. 181-194). John Wiley & Sons, Ltd.

Haverkamp, B. E. (2005). Ethical Perspectives on Qualitative Research in Applied Psychology. *Journal of Counseling Psychology*, *52*(2), 146–155. http://doi.org/10.1037/0022-0167.52.2.146

Karnieli-Miller, O., Strier, R., & Pessach, L. (2009). Power relations in qualitative research. *Qualitative Health Research*, *19*(2), 279–289. http://doi.org/10.1177/1049732308329306

Lalor, J. G., Begley, C. M., & Devane, D. (2006). Exploring painful experiences: Impact of emotional narratives on members of a qualitative research team. *Journal of Advanced Nursing*, *56*(6), 607–616. http://doi.org/10.1111/j.1365-2648.2006.04039.x

Malacrida, C. (2015). Topics: Ethical Issues for Team Researchers. *Qualitative Health Research*, *17*(10), 1329–1339. http://doi.org/doi: 10.1177/1049732307308948

Montgomery, L., & Donnelley, M. (2014). A scoping review of the literature on the involvement of service users in personality disorder services. *Irish Journal of Psychological Medicine*, *31*(4), 233–243. http://doi.org/DOI: 10.1017/ipm.2014.46

Raptopoulos, A. (2010a), “Becoming an expert by experience”, in Weinstein, J. (Ed.), *Mental Health, Service User Involvement and Recovery* , Jessica Kingsley Publishers, London, pp. 73-87.

Read, S., & Maslin-Prothero, S. (2011). The involvement of users and carers in health and social research: the realities of inclusion and engagement. *Qualitative Health Research*, *21*(5), 704–713. http://doi.org/10.1177/1049732310391273

Ryle, a. (1997). The structure and development of borderline personality disorder: a proposed model. *The British Journal of Psychiatry: The Journal of Mental Science*, *170*, 82–87.

Ryle, A. (2004). The contribution of cognitive analytic therapy to the treatment of borderline personality disorder. *Journal of Personality Disorders*, *18*(1), 3–35. http://doi.org/10.1521/pedi.18.1.3.32773

Ryle, T., 2010. The Political Sources of Reciprocal Role Procedures. *Reformulation*, Summer, pp.6-7.

Silverstein, L. B., Auerbach, C. F., & Levant, R. F. (2006). Using Qualitative Research to Strengthen Clinical Practice. *Professional Psychology: Research and Practice*, *37*(4), 351–358. http://doi.org/10.1037/0735-7028.37.4.351

Skodol, A. E., Bender, D. S., Pagano, M. E., Shea, M. T., Yen, S., Sanislow, C. a., … Gunderson, J. G. (2007). Positive childhood experiences: Resilience and recovery from personality disorder in early adulthood. *Journal of Clinical Psychiatry*, *68*(7), 1102–1108. http://doi.org/10.4088/JCP.v68n0719

Slay, J., & Stephens, L. (2013). Co-production in mental health: A literature review. *New Economics Foundation, London*.

Ethics File Ready for PDF 01.07.2015.pdf

S0415 - Trust Permission letter.pdf

Ethics Section

Sarah E. Davidson

[redacted] University

Ethics

Research Protocol

What does the concept of recovery mean for the sense of self of people with a Borderline Personality Disorder Diagnosis?

Research Protocol Version 1.1

Name of Applicant: Sarah Davidson

[redacted]

Email: [redacted]

Academic Supervisor: [redacted]

[redacted]

Tel: [redacted]

Field Supervisor: [redacted]

[redacted]

[redacted]

1.1 Aims

The aims of the study are to explore the experiences of service users who have been given a diagnosis of personality disorder (PD) and to understand how the concept of recovery has impacted on their sense of self.

1.2 Rationale

The Diagnostic and Statistical Manual (DSM-IV) IV defines PD as: "an enduring pattern of inner experience and behaviour that deviates markedly from the expectations of the individual's culture, is pervasive and inflexible, has an onset in adolescence or early adulthood, is stable over time, and leads to distress or impairment" (American Psychiatric Association, 2013).

Several high profile criminal cases in the 1990's brought the concept of personality disorder into the public domain. This led to an increase in funding in forensic services for 'Dangerous and Severe Personality Disorder', and the implementation of The National Personality Disorder Development Programme, which ran from 2002 to 2011, and extended the government's interest to mainstream mental health and preventative work for young people. It was launched with the publication of "No Longer a Diagnosis of Exclusion" to support service development (NIMH, 2003). Castillo (Castillo, 2000; Castillo, Ramon, & Morant, 2013) has written at length about the experience of being diagnosed with a personality disorder, and how this impacts on service users' views of mental health treatment provision in the UK. Haigh (2006) also utilised this research and incorporated it, along with the input of a service user advisory group, when consulting on the Policy Implementation Guide Personality Disorder: No Longer a Diagnosis of Exclusion, with respect to service development for individuals with a personality disorder. This contentious diagnosis has previously led to many service users seemingly being denied support and care, and was experienced by many as labelling and stigmatising (Castillo, 2003; Haigh, 2008). This movement led to specialist services being deployed to support service users with a PD diagnosis, utilising the evidence base that suggests that a slightly different approach is required than that for other mental health diagnoses (Castillo et al., 2013). Despite this, the diagnosis does remain contentious, and views on its efficacy, utility and meaning vary widely in both service users and professionals (Alwin et al., 2006).

Whilst previously being viewed as an unrecoverable and highly disabling diagnosis, the development of services such as those set up as part of the National Personality Disorder Programme pilots, and more recent research around the efficacy of therapy for PD has led to the concept of Recovery coming to increasing prominence in approaches to personality disorder (Katsakou et al., 2012; Zanarini, Frankenburg, Reich, & Fitzmaurice, 2010). Conceptual clarity is necessary when applying the idea of recovery to personality disorder, as to other mental health diagnoses, as the definition of Recovery for PD differs from the traditional medical notion of recovery as a cure from an illness (Slade, Amering, & Oades, 2015). The personal definition of recovery which has emerged from service user narratives emphasises that recovery means more than simply the absence of illness, and includes building a future, and giving value to life. It is also viewed more as a journey than a finite point (Castillo et al., 2013). Castillo and The Haven aim towards what they have termed ‘Transitional Recovery’, a hierarchy of progress in the journey of recovery for personality disorder, which emerged from service user interviews, and is represented by a pyramid. The recovery concept debate is complex (Turner, Lovell, & Brooker, 2011), and as with many clinical concepts, it is vital that the definition of recovery remains owned by and meaningful to service users, and is not hijacked by service planners and health politicians (Castillo et al., 2013).

Identity is “the experience of oneself as unique, and as having a clear distinction between oneself and others” (Bateman & Krawitz, 2013). A fractured, or unclear sense of self, or identity disturbance, is one of the diagnostic criteria for Borderline Personality Disorder, and can lead to difficulties such as accuracy and appraisal of self-esteem, self-direction and sense of self, understanding the motivations and perspectives of others and fluctuating emotional intensity with regard to making sense of what is desired in life. This may occur due to emotional intensity and lack of containment, or as a result of shutting down emotions as a coping strategy, without which much learning about values and beliefs is lost (Bateman & Krawitz, 2013). Several treatment modalities for BPD, such as Mentalization Based Therapy, Cognitive Analytic Therapy and Dialectical Behaviour Therapy understand these difficulties as a disorder of early attachment, during which time an individual’s sense of self is formed, or not, by the mirroring of emotion and containment from the attachment figure. Resolving these attachment difficulties and aiding a client in developing a more coherent and stable sense of self is an important facet of treatment. Also, as identity disturbance is a diagnostic criteria for BPD, the successful resolution of such difficulties means that, in thinking about the concept of recovery, progression in this area could lead to a reduction in diagnostic symptoms, if not a removal of the diagnostic label altogether.

Previous qualitative research in this area has focused on the impact of a personality disorder diagnosis with regard to service exclusion and service provision, and the creation of services such as the ones the current study seeks to recruit from suggests that the evidence base has resulted in some progress in the area. The current research seeks to expand on the evidence base by listening to participants' personal narratives, and developing an understanding of how the concept of recovery impacts on service users' sense of self, the way they relate to others, and on how they view and relate to the world around them.

As services quite rightly begin to diversify and alter their practice in order to best meet the needs of this client group, clinical psychologists, both as individual therapists and as consultants within multi-disciplinary teams (MDTs) need to a) be more aware of how having a diagnosis of personality disorder affects service users and how this might impact on their engagement in therapies and other services, b) develop a better understanding of how concepts like recovery impact on the world view and sense of self of such individuals; and c) potentially need to be able to communicate formulations to MDTs through consultation, which may include facilitating an understanding of interpersonal difficulties. Models of therapy used in the 'treatment' of personality disorder, such as Cognitive Analytical Therapy, Dialectical Behaviour Therapy and Mentalisation Based Therapy make clear reference to individuals with personality disorder frequently having experienced disordered attachments, invalidating environments, and trauma, and struggling with issues around an unclear sense of self, dysregulated emotions and forming relationships. It is important for therapists to be aware of these issues when establishing a therapeutic rapport with clients and creating validating and helpful services for them. Equally, although Recovery as a concept is now used as a service model within some specialist services, if the conception, as defined by service commissioners, is incompatible with how service users value and ascribe meaning to the term, then the real worth and significance of such a development is arguably lost, and better understanding of how service users understand this term, and what it means for their sense of self, a crucial element of treatment, is necessary in order to maximise the benefits of such services.

1.2.1 Research Question

What does the concept of recovery mean for the sense of self for people with a Borderline Personality Disorder Diagnosis?

1.3 Design

This is a qualitative study. The purposive sample will be comprised of individuals who have been given a personality disorder diagnosis and currently receive support within a secondary care NHS psychology service that uses a personal recovery-based approach. A research methodology based on Interpretive Phenomenological Analysis (IPA) (Smith, Flowers & Larkin, 2009) will be used to address the research question. IPA is an idiographic method that is suited to research topics where an in-depth understanding of how individuals make sense of particular experiences is needed, thus it will facilitate the development of a rich understanding of the meaning of the concept of recovery and its impact on sense of self for participants. Data will be collected using semi-structured interviews, which will ensure that key areas are covered in all interviews. Data will subsequently be analysed using the analytic method described by Smith et al (2009).

1.4 Participants

8-12 participants will be recruited from any of three Recovery Teams within the chosen NHS Trust, all of which operate within a ‘Recovery based’ model. **Inclusion** criteria for the study are as follows:

- Participants must have received a diagnosis of borderline personality disorder, either historically, or on entry to the service, in order that their narratives link diagnosis and recovery with how they view themselves and the world around them;
- Participants must be aware of their personality disorder diagnosis;
- Participants must be engaged with the Recovery Team, either undergoing personal therapy or accessing support through Structured Clinical Management;
- Participants must have English as their first language, or be fluent in English.

The safety, both physical and psychological of participants is of paramount importance for the study. Potential participants will be excluded from the study if it is deemed that inclusion will increase risk.

1.5 Materials

A number of materials will be required in order to undertake the research, and they can be found in the Appendices section. They include: 1) A consent form and information sheet for each participant; 2) the interview schedule for each participant.

1.5.1 Interview Schedule

Using a semi-structured interview facilitates a degree of consistency in terms of topics covered, whilst also providing scope for unanticipated facets of the topic area to be explored, enabling us to obtain rich and complex data.

1.6 Procedure

1.6.1 Ethical Considerations

This research has been submitted to the NRES system, in accordance with governance on research involving interviewing NHS patients. The research will also be submitted to [redacted] NHS Trust R&D Department.

Individuals diagnosed with a borderline personality disorder diagnosis frequently experience a level of emotional sensitivity and dysregulation. Thus it is of the upmost importance that every attempt is made to ensure that the interview process is as reassuring as possible. Participants will be offered the choice of a service or home visit. They will be offered a comfortable and confidential interview space, and will be offered refreshments where possible. It is essential that the study is explained in as much detail as possible to potential participants and that consent is checked throughout the process. Breaks can be provided as and when they are required by the researcher, and the researcher will be observing the participants' levels of distress at all times throughout the interview process. Despite these measures, however, the impactful nature of the interviews mean that it is possible that participants may experience distressing memories, and an increase in uncomfortable emotions. Should a participant experience distress at any time, they can withdraw from the interview process. Confidentiality around interview content will be explained clearly before the interview begins. Should a participant disclose any information which suggests that the participant is at increased risk, such as a desire to self-harm, the researcher will be obliged to contact a member of the participant's care team, in order that they can access the appropriate support. The Consultant Psychologist attached to the service has also offered to support any participant who may become distressed as a result of engaging in the research, with up to two face to face debrief sessions, following interview.

It is deemed to be unlikely that the researcher faces any risk to themselves in undertaking the study. However, they will observe service protocol in ensuring their own personal safety before, during and after interview, and will implement [redacted] University's Lone Worker Policy if undertaking home visits.

1.6.2 Recruitment

Lead Clinicians within each Recovery Team will be asked to send introductory materials outlining the project to all potential participants who meet the inclusion criteria, and are not excluded by risk issues, inviting them to take part in the study. This approach will ensure that all potential participants are given the opportunity to take part, and will reduce the likelihood of participants with positive experiences of a recovery model being 'cherry picked'. This contact will be supplemented by an Information Sheet, detailing the study, and a covering letter providing the principal investigator's contact details. The introductory material will invite potential participants to contact the principal investigator directly in order to find out more about the project, or to arrange a mutually convenient interview time.

Interviews will be held at team office locations when it is convenient for participants. Visits at other approved public premises for interviews will be given consideration if it is felt that such an arrangement would be beneficial for the participant's emotional wellbeing, in which case [redacted] University's Lone Worker Policy will be used.

1.6.3 Interview Process

An interview room will be booked by the principal investigator at the service, and they will ensure that the environment is as conducive to the interview process as is possible.

Prior to the interview starting, the participant will be informed that the content of the interview will remain confidential, under the caveats in the Participant Information Sheet and Consent Form. The participant will be given an opportunity to read the information sheet again, and to ask any questions of the principal investigator, prior to giving their written consent to take part in the study.

When the interview itself begins, the interview schedule will be used to guide the interview process, ensuring that key issues are covered whilst still allowing exploration of other issues that emerge as important to participants' experience and understanding of the topic, and for the interview to remain relatively informal and reflective. It is of utmost importance to the researcher that the interview is a safe space for participants to discuss personal experiences. On completion of the interview, the participants will be thanked for their involvement in the study, and informed that there will be an opportunity to receive and provide feedback on a summary of the research findings, should they wish. The participant has the right to withdraw from the research at any time, up until the point where the data have been anonymised and included in the overall analysis.

1.6.4 Transcription and Data Storage

All interviews will be digitally recorded using [redacted] University digital recording equipment. The recordings will be transcribed by the principal investigator. Pseudonyms will be used in all transcripts, chosen by the participants if they wish, in order to maintain confidentiality and anonymity.

All data, including scanned consent forms, digital recordings, and transcribed interviews, will be stored on the [redacted] University server, where they can be accessed securely via virtual private network (VPN). Personal contact details and hard copies of consent forms will be stored securely in a locked cabinet in the Academic Supervisor's office, and destroyed at the end of the study.

Following completion of the project, the data will be stored for 10 years by the [redacted] University DClin Psychology Administration Team. All data will be saved electronically, and encrypted. It will then be transferred securely using ZendTo file transfer software to the Research Coordinator who will save the files in password-protected file space on the university server.

1.6.5 Analytic Procedure

The data collected from the semi-structured interviews will be analysed using IPA.

Interpretative Phenomenological Analysis is an approach to psychological qualitative research with an idiographic focus, which means that it seeks to offer insights into how a given person makes sense of particular experiences. IPA is phenomenological in that it is interested in individual perceptions and experiences, rather than making an objective statement (Biggerstaff & Thompson, 2008; Smith, 2004). However, it also recognises that the research process is a dynamic one on the part of the researcher, and that in order to access participants' 'personal worlds', the conceptions of the researcher are required in order to complete an interpretive analysis. IPA, therefore seeks to combine both the phenomenological and interpretative, hence the term IPA (Smith, 2004).

1.7 Time Scale

August 2014 – Submit to NHS Ethics and Research and Development

September 2014 – January 2015 – Collect data

October 2014 – February 2015 – Analyse data

February-April 2015 – Complete write up

June 2015 – Submit Thesis

1.8 Distribution of Results and Recommendations

On completion of the analysis and the research overall the results will be written up as part of the principal investigator's Doctoral Thesis in Clinical Psychology, and subsequent presentations will be given on campus as appropriate. The study will also be submitted to appropriate journals for publication. A report will also be written and disseminated to the services involved in data collection, and a presentation at the local PD Hub meeting will also be offered.

References

Alwin, N., Blackburn, R., Davidson, K., Hilton, M., Logan, C., & Shine, J. (2006). *Understanding Personality Disorder : A Report by the British Psychological Society*. . Retrieved from http://www.bps.org.uk/content/understanding-personality-disorder-report-british-psychological-society

Bateman, A. W., & Krawitz, R. (2013). *Borderline personality disorder: an evidence-based guide for generalist mental health professionals*. Oxford University Press.

Biggerstaff, D., & Thompson, A. R. (2008). Interpretative phenomenological analysis (IPA) : a qualitative methodology of choice in healthcare research, (April 2015), 37–41. http://doi.org/10.1080/14780880802314304

Castillo, H., & Mind, C. (2003). A dangerous diagnosis. *Mental Health Today*, 27-30. PDF available from thehavenproject.org.uk

Castillo, H., Ramon, S., & Morant, N. (2013). A recovery journey for people with personality disorder. *The International Journal of Social Psychiatry*, *59*(3), 264–73. http://doi.org/10.1177/0020764013481891

Katsakou, C., Marougka, S., Barnicot, K., Savill, M., White, H., Lockwood, K., & Priebe, S. (2012). Recovery in borderline personality disorder (BPD): A qualitative study of service users' perspectives. *PLoS ONE*, *7*(5). http://doi.org/10.1371/journal.pone.0036517

NIMH. (2003). *Mental Health in England Personality disorder : No longer a diagnosis of exclusion*. London, Department of Health, National Institute for Mental Health.

Slade, M., Amering, M., & Oades, L. (2015). Recovery: an international perspective. *Epidemiologia E Psichiatria Sociale*, *17*(2), 128–137. http://doi.org/10.1017/S1121189X00002827

Smith, J. a. (2004). Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative Research in Psychology*, *1*(1), 39–54. http://doi.org/10.1191/1478088704qp004oa

Turner, K., Lovell, K., & Brooker, A. (2011). "… and They All Lived Happily Ever After": "Recovery" or Discovery of the Self in Personality Disorder? *Psychodynamic Practice*, *17*(3), 341–346. http://doi.org/10.1080/14753634.2011.587604

Zanarini, M. C., Frankenburg, F. R., Reich, D. B., & Fitzmaurice, G. (2010). Time to Attainment of Recovery From Borderline Personality Disorder ... *The American Journal of Psychiatry*, *6*(167), 663. http://doi.org/10.1176/appi.ajp.2009.09081130

Introductory Letter

Version 1.2

Faculty of
Health & Medicine

[redacted]

[redacted]

Introductory Letter for potential Participants

Hello,

My name is Sarah Davidson and I am a third year Trainee Clinical Psychologist at [redacted] University. I am completing this study for my thesis and am interested in hearing from individuals who have been given a diagnosis of Borderline Personality Disorder, and are currently using the services of the Recovery Teams across [redacted] NHS Trust.

The idea of Recovery is one that is used frequently now in services for people with personality disorder diagnosis. I am interested in hearing what this term actually means to service users with the diagnosis and how this may or may not affect how you view yourself or your identity. This research hopes to better understand how service users view the term recovery, in order to shape and improve services in the future.

If you decide to take part in the study, you will be asked to talk for about an hour, about your experiences of Recovery and how this has impacted on how you view yourself. The interview will be confidential and will take place at your service building. The Information Sheet which comes with this letter provides more detail about the project.

If you are interested in taking part, please contact me using the details below and I will be happy to explain more about the project and what taking part would involve. Alternatively, you can ask a member of your care team to contact me, if you are happy for me to have your contact details. **Please note that contacting me DOES NOT commit you to taking part in the study**, it is simply to discuss it further. You will be given further opportunity to decide whether you would like to take part, before being asked to sign a consent form.

Many thanks for taking the time to read this letter.

Kind Regards,

Sarah Davidson Trainee Clinical Psychologist, [redacted] University

[redacted] [redacted]

Information Sheet

Version 1.2

[redacted]

[redacted]

Participant Information Sheet Version 1.2

What does the concept of recovery mean for the sense of self of people with a Borderline Personality Disorder Diagnosis?

My name is Sarah Davidson and I am conducting this research as part of my Clinical Psychology Doctorate training at [redacted] University, United Kingdom. I am interested in how the concept of recovery impacts on the sense of self of people with a Borderline Personality Disorder diagnosis. This may mean their identity, their view of themselves, or how they think of their diagnosis.

Who is involved in the study?

I am the Principal Investigator for the study, which is part of my Clinical Psychology Doctorate at [redacted] University. An academic supervisor from the university, [redacted], will supervise my work. A Consultant Psychologist from [redacted] Trust, Dr[redacted], is also involved to help me organize the project and provide extra support to those individuals who participate if they need it.

What is the study about?

The study aims to look at what the concept of recovery means to individual service users and their sense of self. Being diagnosed with a personality disorder can be a hugely affecting life event. Some research has already been undertaken on the experience of actually being diagnosed with a personality disorder and I would like to extend that by looking at how the fairly recent recovery approach to treatment of people with this diagnosis has changed or affects how they see and feel about themselves, how they relate to others and how they think and feel about the world. The results will be useful for increasing understanding about how the way we use and talk about recovery affects service users, and how we can improve services for this client group. Previous research has suggested that people with a diagnosis of personality disorder need a different approach from traditional mental health services. However, in this study I want to listen to the stories of service users, and get a better understanding of how this diagnosis impacts on them across their lives and how services can better help them manage that.

Why have I been approached?

You have been approached because the study requires information from people who have been diagnosed with Borderline Personality Disorder and are involved in services. People with a diagnosis of personality disorder, who have been referred by or accessed support from the Recovery Teams within [redacted] are being approached to see if they would like to take part in the study.

Do I have to take part?

Not at all. You have the right to choose whether to participate in the research, it is voluntary. If you choose not to take part it will in no way affect your treatment, or your journey through services.

What will I be asked to do if I take part?

- If you decide to take part in the study, I will arrange a date and time to best suit you, to carry out an interview. You will be asked to sign a consent form to confirm you agree to take part.

- You will be asked to take part in an interview lasting about 1 hour. This will be carried out by me and will be audio recorded onto a digital audio recorder. You can stop the recording at any time, and asked for words to be deleted. This interview is designed to allow you to tell your story, and to speak freely and openly about your experiences of diagnosis. After the interview I will type up what you have said on the recording into a transcript. This will be put together with the transcripts from other participants in the study and the information from all the transcripts will be analysed so that we can identify common themes. There will be the opportunity for a further interview if information needs to be checked or clarified.

- You will be able to claim travel expenses of up to £10.

If you decide to take part in the study, a member of your recovery team will be informed. This is purely to ensure that there are no current concerns about your mental well-being. The content of the interview is confidential, and will only be listened to by me and my academic supervisor. The only exception to this would be if you were to disclose anything in the interview that might indicate that you or someone else was at risk. If for any reason your confidentiality needed to be broken, I would try to discuss this with you first.

- You are entitled to withdraw from the study at any time, without giving a reason.

Will my data be Identifiable?

The information you provide is confidential. The data collected for this study will be stored securely and only my academic supervisor and I will have access to this data:

- Audio recordings will be saved to secure, password protected file space on the [redacted] University computer server and will be deleted once the project has been examined.
- The files on the computer will be encrypted (that is no-one other than the researcher will be able to access them) and the computer itself password protected. This information will be permanently deleted after 10 years.
- The transcript of your interview will be made anonymous by removing any identifying information including your name. Anonymised direct quotations from your interview may be used in the reports or publications from the study, so your name will not be attached to them.
- All your personal data will be confidential and will be kept separately from your interview transcript.

There are some limits to confidentiality: if what is said in the interview makes me think that you, or someone else, is at significant risk of harm, I will have to break confidentiality and speak to a member of staff about this. I will tell you if I have to do this.

What will happen to the results?

The results will be summarised and reported in a thesis and may be submitted for publication in an academic or professional journal. You will be given the opportunity to receive feedback on the overall results of the study. If you are still accessing the Recovery Team at that time, this can be done in person. If you have been discharged you can receive written feedback if you provide a contact address.

Are there any risks?

The study is not designed in any way to cause any emotional distress to participants. However, being diagnosed with a personality disorder and the life events that may have led up to this may have been challenging experiences, and talking about this could bring up some strong emotions. You will be given the space to talk about this during the interview. If you feel at any time during the interview that you need a break, or that it is becoming too distressing for you, the interview will be halted until you feel able to continue, or can be rearranged for another time. Following the interview, anyone who feels distressed by the experience can be supported by [redacted] [redacted], Consultant Psychologist by telephone, and in up to 2 face to face support sessions.

If you have any questions following the interview, or at any time during the study, you can ask to speak with [redacted] [redacted] from [redacted] Recovery Team [redacted]

Are there any benefits to taking part?
Although you may find participating interesting, there are no direct benefits in taking part.

Who has reviewed the project?
The study has been reviewed for ethical issues by the [redacted] – [redacted] and by [redacted] NHS Trust's internal permissions system.

Where can I obtain further information about the study if I need it?
If you have any questions about the study, please contact me:

Sarah Davidson
[redacted]
United Kingdom

[redacted]

[redacted]

Complaints
If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

[redacted] – Research Director
[redacted]

[redacted]

If you wish to speak to someone outside of the Doctorate Programme, you may also contact:

[redacted]

Thank you for taking the time to read this information sheet.

Consent Form
Version 1.2

Faculty of
Health & Medicine

[redacted]

[redacted]

PARTICIPANT CONSENT FORM

To accompany Participant Information Sheet.

Short title of study: What does the concept of recovery mean for the sense of self of people with a Borderline Personality Disorder Diagnosis?

The aim of the research is to better understand how the concept of recovery affects the sense of self of people with a Borderline Personality Disorder diagnosis.

Researchers: Sarah Davidson, Trainee Clinical Psychologist, [redacted] University
Supervisors: [redacted] [redacted], [redacted] University and [redacted] [redacted], [redacted] Partnership

Please read this form carefully. Please tick and initial each box.

I have read and understood the Participant Information Sheet Version 1.2 06.04.2015 for the above study. I have had time to think about the study and ask questions and I agree with the answers provided............. ☐

I understand that the interview will be audio recorded and then made into an anonymised written transcript............... ☐

I understand that direct quotes may be used in the write up but these will be anonymised and I will not be identified........... ☐

I understand that data from the study may be looked at by regulatory authorities or by persons from the Trust where it is relevant to my taking part in this research. I give permission for these individuals to have access to this data…… ☐

I understand that my participation is voluntary and I can withdraw at any time, without giving a reason and with no adverse consequences to my treatment, or my journey through services ☐

I understand that once my data have been anonymised and incorporated into themes it might not be possible for it to be withdrawn, though every attempt will be made to extract my data, up to the point of publication. ☐

I consent to [redacted] University keeping written transcriptions of the interview for 10 years after the study has finished. ☐

I understand that any information I give will remain strictly confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the principal investigator will/may need to share this information with his/her research supervisor. ☐

I agree to take part in the above study ☐

Name of participant ***Date*** ***Signature***

--------------- ---------- -----------------------

Name of Person taking consent Date Signature

--------------- ---------- -----------------------

Interview Schedule

Version 1.1

Faculty of
Health & Medicine

[redacted]

Clinical Psychology Doctorate Programme,
[redacted]
[redacted]
[redacted]

Interview Schedule

1. **Could you start by telling me a little bit about how you came to be given a Borderline Personality Disorder Diagnosis? How did you come to be referred to the Recovery Team?**
2. **What kind of difficulties were you experiencing?**
3. **How was your sense of self or your identity affected by your difficulties (use prompts/examples around identity if needed e.g. how well do you know who you are, what you believe in etc.)?**
4. **How did your diagnosis affect your sense of who you are? Did it change, or alter, or even clarify or explain how you view yourself?**
5. **What does the term 'Recovery' mean to you? How do you feel about the term? (Prompts: How does the term apply, for you, to things like services, feelings, self-harm, relationships, coping strategies etc. Dependent on answers already given).**
6. **How, if at all, has Recovery as a way of thinking about your diagnosis, helped you?**
7. **How has it impacted on how you view your diagnosis? Services? Therapy?**
8. **How does Recovery affect how you see yourself now? Has it, or how has it, impacted on your identity/sense of self?**

Research Ethics Committee Form

NHS REC Form Reference: IRAS Version 3.5

15/NW/0237

Welcome to the Integrated Research Application System

IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please enter a short title for this project (maximum 70 characters)
Recovery, Sense of Self and Borderline Personality Disorder

1. Is your project research?

● Yes ○ No

2a. Please answer the following question(s):

a) Does the study involve the use of any ionising radiation?	Yes ○	No ●
b) Will you be taking new human tissue samples (or other human biological samples)?	Yes ○	No ●
c) Will you be using existing human tissue samples (or other human biological samples)?	Yes ○	No ●

3. In which countries of the UK will the research sites be located? *(Tick all that apply)*

☑ England
☐ Scotland
☐ Wales
☐ Northern Ireland

3a. In which country of the UK will the lead NHS R&D office be located:

● England

○ Scotland

○ Wales

○ Northern Ireland

○ This study does not involve the NHS

4. Which review bodies are you applying to?

☑ NHS/HSC Research and Development offices
☐ Social Care Research Ethics Committee
☑ Research Ethics Committee
☐ National Information Governance Board for Health and Social Care (NIGB)
☐ National Offender Management Service (NOMS) (Prisons & Probation)

For NHS/HSC R&D offices, the CI must create Site-Specific Information Forms for each site, in addition to the study-wide forms, and transfer them to the PIs or local collaborators.

5. Will any research sites in this study be NHS organisations?

● Yes ○ No

5a. Are all the research costs and infrastructure costs for this study provided by an NIHR Biomedical Research Centre, NIHR Biomedical Research Unit, NIHR Collaboration for Leadership in Health Research and Care (CLAHRC) or NIHR Research Centre for Patient Safety & Service Quality in all study sites?

○ Yes ● No

If yes, NHS permission for your study will be processed through the NIHR Coordinated System for gaining NHS Permission (NIHR CSP).

5b. Do you wish to make an application for the study to be considered for NIHR Clinical Research Network (CRN) support and inclusion in the NIHR Clinical Research Network (CRN) Portfolio? Please see information button for further details. Yes No

○ ●

If yes, NHS permission for your study will be processed through the NIHR Coordinated System for gaining NHS Permission (NIHR CSP) and you must complete a NIHR Clinical Research Network (CRN) Portfolio Application Form immediately after completing this project filter and before completing and submitting other applications.

6. Do you plan to include any participants who are children?

○Yes ●No

7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?

○Yes ●No

Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the NIGB Ethics and Confidentiality Committee to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?

○ ●

9. Is the study or any part of it being undertaken as an educational project?

●Yes ○No

Please describe briefly the involvement of the student(s):
Research is being undertaken as part of the Chief Investigator's thesis for the Doctorate in Clinical Psychology.

9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?

○Yes ●No

10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?

○Yes ●No

11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?

○Yes ●No

NHS REC Form Reference: IRAS Version 3.5

15/NW/0237

Integrated Research Application System

Application Form for Research involving qualitative methods only

---

Health Research Authority

Application to NHS/HSC Research Ethics Committee

The student should complete this form on behalf of the Chief Investigator. Guidance on the questions is available wherever you see this symbol displayed. We recommend reading the guidance first. The complete guidance and a glossary are available by selecting Help.

Please define any terms or acronyms that might not be familiar to lay reviewers of the application.

Short title and version number: (maximum 70 characters - this will be inserted as header on all forms) Recovery, Sense of Self and Borderline Personality Disorder

Please complete these details after you have booked the REC application for review.

REC Name:
[redacted]

REC Reference Number:	**Submission date:**
15/NW/0237	04/03/2015

PART A: Core study information

1. ADMINISTRATIVE DETAILS

A1. Full title of the research:

What does the concept of recovery mean for the sense of self for people with a Borderline Personality Disorder Diagnosis?

A2-1. Educational projects

Name and contact details of student(s):

Name and contact details of academic supervisor(s):

Academic supervis
1

	Title	Forename/Initials	Surname
	Dr	[redacted]	[redacted]
Address	[redacted]		
Post Code	[redacted]		
E-mail	[redacted]@[redacted].ac.uk		
Telephone	[redacted]		

Fax

Please state which academic supervisor(s) has responsibility for which student(s):
Please click "Save now" before completing this table. This will ensure that all of the student and academic supervisor details are shown correctly.

Student(s)	Academic supervisor(s)

A copy of a current CV for the student and the academic supervisor (maximum 2 pages of A4) must be submitted with the application.

A2-2. Who will act as Chief Investigator for this study?

● Student
○ Academic supervisor
○ Other

A3-1. Chief Investigator:

	Title	Forename/Initials	Surname
	Miss	Sarah	Davidson
Post	Trainee Clinical Psychologist		
Qualifications	MSc Forensic Psychology BSc Honours Psychology		
Employer	[redacted]/[redacted] University		
Work Address	[redacted] [redacted] University [redacted]		
Post Code	LA1 4YG		
Work E-mail	s.davidson@[redacted].ac.uk		
* Personal E-mail	[redacted]		
Work Telephone	[redacted]		
* Personal Telephone/Mobile	[redacted]		
Fax			

** This information is optional. It will not be placed in the public domain or disclosed to any other third party without prior consent.*
A copy of a current CV (maximum 2 pages of A4) for the Chief Investigator must be submitted with the application.

A4. Who is the contact on behalf of the sponsor for all correspondence relating to applications for this project?
This contact will receive copies of all correspondence from REC and R&D reviewers that is sent to the CI.

Title Forename/Initials Surname

[redacted]

Address [redacted]
[redacted],
[redacted] University, [redacted]

Post Code [redacted]
E-mail ethics@[redacted].ac.uk
Telephone [redacted]
F

ax

Fax

A5-1. Research reference numbers. *Please give any relevant references for your study:*

Applicant's/organisation's own reference number, e.g. R & D (if available):
Sponsor's/protocol number:
Protocol Version:
Protocol Date:
Funder's reference number:
Project website:

Additional reference number(s):

Ref.Number Description	Reference Number

Registration of research studies is encouraged wherever possible. You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you have registered your study please give details in the "Additional reference number(s)" section.

A5-2. Is this application linked to a previous study or another current application?

○Yes ●No

Please give brief details and reference numbers.

2. OVERVIEW OF THE RESEARCH

To provide all the information required by review bodies and research information systems, we ask a number of specific questions. This section invites you to give an overview using language comprehensible to lay reviewers and members of the public. Please read the guidance notes for advice on this section.

A6-1. Summary of the study. *Please provide a brief summary of the research (maximum 300 words) using language easily understood by lay reviewers and members of the public. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, this summary will be published on the website of the National Research Ethics Service following the ethical review.*

Borderline Personality Disorder is defined as a disorder of personality characterised by unstable self-image, emotional dysregulation, unstable mood and frequently self-harm. Having previously been seen as a negative and treatment resistant diagnosis, considerable change in policy since the 1990's and a shift in services for this client group has led to an increase in research which suggests that BPD is treatable, and as such, a move towards a 'Recovery' model. As a fractured or unstable 'sense of self' is one of the defining features of the diagnosis, this research seeks to understand what the concept of recovery means for the sense of self of people with a Borderline Personality Disorder diagnosis.

A6-2. Summary of main issues. *Please summarise the main ethical, legal, or management issues arising from your study and say how you have addressed them.*

Not all studies raise significant issues. Some studies may have straightforward ethical or other issues that can be identified and managed routinely. Others may present significant issues requiring further consideration by a REC, R&D office or other review body (as appropriate to the issue). Studies that present a minimal risk to participants may raise complex organisational or legal issues. You should try to consider all the types of issues that the different reviewers may need to consider.

Purpose & Design

deviates markedly from the expectations of the individual’s culture, is pervasive and inflexible, has an behaviour that deviates markedly from the expectations of the individual’s culture, is pervasive and inflexible, has an onset in adolescence or early adulthood, is stable over time, and leads to distress or impairment” (American Psychiatric Association, 1994).

As one of the defining diagnostic criteria of the BPD diagnosis, an unstable sense of self may or may not be altered by treatment and the recovery process. How the concept of recovery affects how service users view their self-image is of great interest to service providers as a shift in sense of self may actually render the diagnosis invalid, and the client 'recovered'. Alternatively, regardless of recovery, this key facet of the individual may remain fractured or delicate. Despite varying approaches across the different health professions, it is likely that all NHS professionals will work within some remit with clients who have a diagnosis of personality disorder, both within mental health services, and in physical health settings. As services quite rightly begin to diversify and alter their practice in order to best meet the needs of this client group, clinical psychologists, both as individual therapists and as consultants within multidisciplinary teams (MDTs) need to a) be more aware of how having a diagnosis of personality disorder affects service users and how this might impact on their engagement in therapies and other services, b) develop a better understanding of how concepts like recovery impact on the world view and sense of self of such individuals; And c) potentially need to be able to communicate formulations to MDTs through consultation. It is important for therapists to be aware of these issues when establishing a therapeutic rapport with clients and creating validating and helpful services for them.

Previous qualitative research in this area has focused on the impact of a personality disorder diagnosis with regard to service exclusion and service provision, and the creation of services such as the ones the current study seeks to recruit from shows that the evidence base has resulted in some progress in the area. However, the current research seeks to expand on the evidence base by listening to participants’ personal narratives, and studying how the concept of recovery has impacted on service users’ sense of self, the way they relate to others, and how they view and relate to the world around them. For these reasons it is vital that we develop a better understanding of what this diagnosis means to service users, and how it influences their views on life.

The transcripts will be analyzed using Interpretive Phenomenological Analysis. This form of analysis was chosen as it was decided that it would best capture the experiences of this client group. It was also felt that that it best represented the epistemological position of the researcher.

This research proposal has been developed in conjunction with the academic thesis supervisor at [redacted] University, and a Clinical Psychologist from one of the Recovery Teams identified for recruitment. The proposal also received critique and input from a joint peer and staff group in its early stages. More recently, Experts by Experience within the main NHS trust recruitment site have been consulted on the idea for the research, the protocol, and the interview materials.

Recruitment

Introductory materials including an Information Sheet will be sent via key workers to all potential participants who meet the inclusion criteria, to reduce any selection bias. Willing participants will then be able to contact the Chief Investigator directly if they wish to take part. It will be made clear to potential participants that taking part in the study is entirely voluntary, and that consenting/non-consenting will in no way affect the individual's pathway through services or their treatment. There are no incentives offered to take part, as this would be considered as coercive, however, travel expenses will be reimbursed. If potential participants contact the researcher, the researcher will then arrange a time for a face to face semi-structured interview to be completed, either at the chosen service, or at the individual's home, if this is deemed to be less stressful for the participant. On the date of interview, the researcher will explain the project in detail once again, and will seek written consent from the participant.

Inclusion/Exclusion

This is a qualitative study using a purposive sample, comprised of individuals with a Borderline Personality Disorder diagnosis, who are currently engaged in some form with an NHS community mental health team that adopts a recovery model for working with this client group (Recovery Teams). Participants must be aware of their diagnosis. As their model for working with this client group(Recovery Teams). Participants must be aware of their diagnosis. As their physical and psychological well-being of is of paramount importance, any potential participant who is currently in crisis, or is deemed to be at risk by taking part in the study will be excluded.

Consent

Valid consent will be sought from each individual participant, by the researcher. It is important that each participant has the capacity necessary to give valid consent, and this will be assessed on each occasion consent is sought. If, on the day of the arranged interview, it is thought that capacity has diminished, advice will be sought from Recovery Team staff, and another appointment arranged if required.

Risks & Benefit

The potential risks of this project to both participants and the researcher have been discussed in detail with both the project and field supervisor, the peer and staff feedback group, and with service user representatives.

It is not envisaged that the study will cause any harm to its participants, however, all steps possible to minimise any adverse emotional effects will be taken. The research team are mindful that this client group are potentially vulnerable and emotionally labile, and that sharing their experiences of their diagnosis and recovery may be an involved and draining process. Participants will have the opportunity to speak to the field supervisor for up to two face to face debrief sessions following the research if they feel they require support.

The issue of risk to the researcher, in relation to interviewing this client group has been discussed. It is not envisaged that the client group present any unexpected risk to the researcher, however, the researcher will implement the Trust's Lone Worker Policy should home visits take place.

Confidentiality

Confidentiality will be held in accordance to The Caldicott Principles.

Interviews are to be transcribed and will be stored, along with all other participant data, on a secure server at [redacted] University.

There may be circumstances under which confidentiality may have to be broken, for example, should risk of harm to the participant or others, or the researcher be disclosed. Under such circumstances, the Trust Confidentiality Policy and Procedure will be adhered to. Participants will have been made aware of the level of confidentiality available to them prior to giving consent and this will be referred back to in the eventuality of any kind of disclosure being made.

On completion of the study, a dissemination strategy will be implemented, to share the results of the research.

A6-3. Proportionate review of REC application *The initial project filter has identified that your study may be suitable for proportionate review by a REC sub-committee. Please consult the current guidance notes from NRES and indicate whether you wish to apply through the proportionate review service or, taking into account your answer to A6-2, you consider there are ethical issues that require consideration at a full REC meeting.*

○ Yes - proportionate review ● No - review by full REC meeting *Further comments (optional):*

Note: This question only applies to the REC application.

3. PURPOSE AND DESIGN OF THE RESEARCH

A7. Select the appropriate methodology description for this research. *Please tick all that apply*:

- ☐ Case series/ case note review
- ☐ Case control
- ☐ Cohort observation
- ☐ Controlled trial without randomisation
- ☐ Cross-sectional study
- ☐ Database analysis
- ☐ Epidemiology
- ☐ Feasibility/ pilot study
- ☐ Laboratory study
- ☐ Metanalysis
- ☑ Qualitative research
- ☐ Questionnaire, interview or observation study
- ☐ Randomised controlled trial
- ☐ Other (please specify)

A10. What is the principal research question/objective? *Please put this in language comprehensible to a lay person.*

What does the concept of recovery mean for the sense of self for people with a Borderline Personality Disorder Diagnosis?

A11. What are the secondary research questions/objectives if applicable? *Please put this in language comprehensible to a lay person.*

A12. What is the scientific justification for the research? *Please put this in language comprehensible to a lay person.*

Zanarini (2003, 2010) has evidenced that a form of recovery is possible for individuals with a diagnosis of personality disorder. Previous qualitative research in this area has focused on the impact of a personality disorder diagnosis with regard to service exclusion and service provision, and the creation of services such as the ones the current study seeks to recruit from shows that the evidence base has resulted in some progress in the area. However, the current research seeks to expand on the evidence base by listening to participants' personal narratives, and studying how the concept of recovery has impacted on service users' sense of self, the way they relate to others, and how they view and relate to the world around them.

A13. Please summarise your design and methodology. *It should be clear exactly what will happen to the research participant, how many times and in what order. Please complete this section in language comprehensible to the lay person. Do not simply reproduce or refer to the protocol. Further guidance is available in the guidance notes.*

The research is qualitative in nature and uses Interpretive Phenomenological Analysis (Smith, 1996) to analyse the data.

Each potential participant will be given an Information Sheet in the first instance by a member of their care team. This will provide the researcher's contact details, enabling the participant to register their interest.

When the participant contacts the researcher, the researcher will then explain the project in more detail, and if appropriate, arrange a mutually agreeable date for interview. This will be held either at the offices of the Recovery Team with which the participant is engaged, or at the participant's home, if this is felt to be more appropriate.

On the date of interview, the researcher will seek verbal and written consent form the participant, after explaining in detail the consent form and confidentiality. The semi structured interview is expected to take approximately one hour. It is envisaged that each participant will be interviewed on one occasion only.

Following interview, audio recordings will be transcribed by the researcher and analysed using Smith's IPA analysis.

A14-1. In which aspects of the research process have you actively involved, or will you involve, patients, service users, and/or their carers, or members of the public?

☑ Design of the research
☑ Management of the research
☐ Undertaking the research
☐ Analysis of results
☑ Dissemination of findings
☐ None of the above

Give details of involvement, or if none please justify the absence of involvement.
The [redacted] University Public Involvement Network [redacted] have been involved in the initial design stages of the project, by way of a proposal review panel of which [redacted] members were a part. Experts by Experience from the primary NHS trust recruitment site have been consulted on the research design, interview materials and interview procedures, and it is hoped they will continue to be involved throughout the research process.

4. RISKS AND ETHICAL ISSUES

RESEARCH PARTICIPANTS

A17-1. Please list the principal inclusion criteria (list the most important, max 5000 characters).

- Potential participants must have received a diagnosis of borderline personality disorder, either historically, or on entry to the service through which they have been recruited, in order that they are able to explicitly link diagnosis and recovery with how they view themselves and the world around them;
- Participants must be aware of their personality disorder diagnosis;
- Participants must be engaged with the Recovery Team, either undergoing personal therapy or accessing support through Structured Clinical Management;
- Participants must have English as their first language, or be fluent in English.

A17-2. Please list the principal exclusion criteria (list the most important, max 5000 characters).

Potential participants will be excluded from the study if:
- It is deemed that inclusion will increase risk;
- They are deemed to lack capacity to give informed consent.

RESEARCH PROCEDURES, RISKS AND BENEFITS

A18. Give details of all non-clinical intervention(s) or procedure(s) that will be received by participants as part of the research protocol. *These include seeking consent, interviews, non-clinical observations and use of questionnaires.*

Please complete the columns for each intervention/procedure as follows:

1. Total number of interventions/procedures to be received by each participant as part of the research protocol.
2. If this intervention/procedure would be routinely given to participants as part of their care outside the research, how many of the total would be routine?
3. Average time taken per intervention/procedure (minutes, hours or days)
4. Details of who will conduct the intervention/procedure, and where it will take place.

Intervention or procedure	1	2	3	4
Consent process	1	n/a	10 mins	Written consent will be taken by the Chief Investigator at the start of each interview. Interview to be held either on Recovery Team premises, or participant's home.
Semi structured interview	1	n/a	60 mins	Interview to be undertaken by Sarah Davidson, Chief Investigator. Interview to be held either on Recovery Team premises, or participant's home.

A21. How long do you expect each participant to be in the study in total?

It is envisaged that each participant will be interviewed on one occasion. The time elapsed between giving consent

It is envisaged that each participant will be interviewed on one occasion. The time elapsed between giving consent and receiving a dissemination report may total 6 months.

A22. What are the potential risks and burdens for research participants and how will you minimise them?

For all studies, describe any potential adverse effects, pain, discomfort, distress, intrusion, inconvenience or changes to lifestyle. Only describe risks or burdens that could occur as a result of participation in the research. Say what steps would be taken to minimise risks and burdens as far as possible.

Individuals diagnosed with borderline personality disorder frequently experience a level of emotional sensitivity and dysregulation. Thus it is of the upmost importance that every attempt is made to ensure that the interview process is as reassuring as possible. Participants will be offered the choice of being interviewed in the service from which they have been recruited or at home. Where they are interviewed in an NHS site, the Chief Investigator will ensure that the interview space is comfortable and confidential, and that refreshments are offered where possible. It is essential that the study is explained in as much detail as possible to potential participants and that consent is checked throughout the process. Breaks can be provided as and when they are required, and the researcher will be observing the participants' levels of distress at all times throughout the interview process. Despite these measures, however, the impactful nature of the interviews mean that it is possible that participants may experience distressing memories, and an increase in uncomfortable emotions. Should a participant experience distress at any time, they can withdraw from the interview process. Confidentiality around interview content will be explained clearly before the interview begins. Should a participant disclose any information which suggests that the participant is at increased risk, such as a desire to self-harm, the researcher will be obliged to contact a member of the participant's care team, in order that they can access the appropriate support. The Consultant Psychologist attached to the service has also offered to support any participant who may become distressed as a result of engaging in the research, with up to two face to face debrief sessions, following interview.

A23. Will interviews/ questionnaires or group discussions include topics that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could occur during the study?

● Yes ○ No

If Yes, please give details of procedures in place to deal with these issues:

The interviews will be asking individuals to reflect on their life experiences and sense of self. It is possible that this will include interpersonal relationships, identity, sexuality and relationship with the self, all of which could potentially be sensitive. The interview will not be designed to be deliberately embarrassing or upsetting, but will cover some rather personal issues. There may be disclosures of historical self-harm, abuse or other criminal involvement. It is unlikely that new disclosures of these issues would be made in the interview. In the unlikelihood that such disclosures are made, [redacted] confidentiality policy would be adhered to, and advice sought from the Field Supervisor.

A24. What is the potential for benefit to research participants?

Although there are no clear direct benefits to taking part for the individual, it is hoped that the data gleaned from the research will help to further improve services for this client group by increasing understanding about how sense of self is affected by recovery, and what this means for future treatment and diagnosis.

A26. What are the potential risks for the researchers themselves? *(if any)*

It is deemed unlikely that there will be any direct risks to the researcher. [redacted] Foundation Trust Lone Worker policy will be followed if home visits are arranged. There is the possibility that listening to the detailed, personal accounts of individuals who may have experienced difficult circumstances could be an emotive experience, and the researcher will undertake good self-care mechanisms in order to minimise the impact of this, and access support from both the academic and field supervisor where appropriate.

RECRUITMENT AND INFORMED CONSENT

In this section we ask you to describe the recruitment procedures for the study. Please give separate details for

different study groups where appropriate.

A27-1. How will potential participants, records or samples be identified? Who will carry this out and what resources will

A27-1. How will potential participants, records or samples be identified? Who will carry this out and what resources will be used? *For example, identification may involve a disease register, computerised search of GP records, or review of medical records. Indicate whether this will be done by the direct healthcare team or by researchers acting under arrangements with the responsible care organisation(s).*

Lead Clinicians within each Recovery Team will be asked to send introductory materials outlining the project to all potential participants who meet the inclusion criteria, and are not excluded by risk issues, inviting them to take part in the study. This approach will ensure that all potential participants are given the opportunity to take part, and will reduce the likelihood that participants with positive experiences of a recovery model being 'cherry picked'. This contact will be supplemented by an Information Sheet, detailing the study, and a covering letter providing the Chief Investigator's contact details. The introductory material will invite potential participants to contact the Chief Investigator directly in order to find out more about the project, or to arrange a mutually convenient interview time. Alternatively the introductory material will give potential participants the opportunity to inform their clinician that they would like the clinician to make contact with the Chief Investigator on their behalf. The Chief Investigator will not have access to the names and contact details of anyone invited to take part in the study until the point at which they contact her.

A27-2. Will the identification of potential participants involve reviewing or screening the identifiable personal information of patients, service users or any other person?

● Yes ○ No

Please give details below:
Identification of potential participants will be undertaken by the field supervisor and key members of the Recovery Teams, in that anyone who meets the inclusion criteria will be offered introductory materials. No additional information will be required by staff members and the researcher will not require information to patient details.

A27-4. Will researchers or individuals other than the direct care team have access to identifiable personal information of any potential participants?

○ Yes ● No

A28. Will any participants be recruited by publicity through posters, leaflets, adverts or websites?

○ Yes ● No

A29. How and by whom will potential participants first be approached?

Introductory materials will initially be given to all potential participants who meet the inclusion criteria, by key workers within the Recovery Teams. This material will contain the researcher's contact details, through which participants can then elect to take part in the study. Alternatively, potential participants can inform their clinician that they would like to take part, and can give permission for their details to be passed to the Chief Investigator.

A30-1. Will you obtain informed consent from or on behalf of research participants?

● Yes ○ No

If you will be obtaining consent from adult participants, please give details of who will take consent and how it will be done, with details of any steps to provide information (a written information sheet, videos, or interactive material). Arrangements for adults unable to consent for themselves should be described separately in Part B Section 6, and for children in Part B Section 7.

If you plan to seek informed consent from vulnerable groups, say how you will ensure that consent is voluntary and fully informed.

The Chief Investigator will take consent from participants. When potential participants contact the researcher, having already been given an Information Sheet, initial verbal consent will be taken over the telephone and documented by the researcher, in order to arrange an interview.

On the date of interview, the researcher will explain the Information Sheet again with the participant, and will then explain each stage of the Consent Form. Participants will be asked to sign the consent form, thus giving their written consent.

This client group are recognised as vulnerable adults, thus it is vital to ensure that consent is voluntary and that each participant has full capacity to give informed consent. Consideration will be given at every stage of the interview process as to the capacity status of the individual and advice will be sought, with the participant's permission, from the client's care team and field supervisor if it is felt at any time that capacity is not present or has diminished.

If you are not obtaining consent, please explain why not.

Please enclose a copy of the information sheet(s) and consent form(s).

A30-2. Will you record informed consent (or advice from consultees) in writing?

● Yes ○ No

A31. How long will you allow potential participants to decide whether or not to take part?

As introductory materials will be handed to all potential participants, with an invitation for them to contact the researcher, there is a considerable amount of time to decide consent allowed.

A33-1. What arrangements have been made for persons who might not adequately understand verbal explanations or written information given in English, or who have special communication needs?*(e.g. translation, use of interpreters)*

It is part of the inclusion criteria that participants are fluent in English. Where written communication needs are present, the researcher will explain all information in a verbal format.

A35. What steps would you take if a participant, who has given informed consent, loses capacity to consent during the study? *Tick one option only.*

● The participant and all identifiable data or tissue collected would be withdrawn from the study. Data or tissue which is not identifiable to the research team may be retained.

○ The participant would be withdrawn from the study. Identifiable data or tissue already collected with consent would be retained and used in the study. No further data or tissue would be collected or any other research procedures carried out on or in relation to the participant.

○ The participant would continue to be included in the study.

○ Not applicable – informed consent will not be sought from any participants in this research.

○ Not applicable – it is not practicable for the research team to monitor capacity and continued capacity will be assumed.

Further details:

Because of the high levels of emotional distress often associated with this client group, it is necessary for the researcher to continue to monitor participants' capacity to consent throughout the research process. The researcher will liaise where appropriate with staff members around client well-being. If at the time of interview capacity is not present, the researcher will endeavour to arrange a subsequent meeting. If it is felt that the participant has lost capacity to consent following a subsequent meeting, it will be discussed with the Field Supervisor as to whether the participant should be withdrawn from the study.

CONFIDENTIALITY

In this section, personal data means any data relating to a participant who could potentially be identified. It includes

pseudonymised data capable of being linked to a participant through a unique code number.

Storage and use of personal data during the study

A36. Will you be undertaking any of the following activities at any stage (including in the identification of potential participants)?*(Tick as appropriate)*

☐ Access to medical records by those outside the direct healthcare team
☐ Electronic transfer by magnetic or optical media, email or computer networks
☐ Sharing of personal data with other organisations
☐ Export of personal data outside the EEA
☑ Use of personal addresses, postcodes, faxes, emails or telephone numbers
☑ Publication of direct quotations from respondents
☐ Publication of data that might allow identification of individuals
☑ Use of audio/visual recording devices
☐ Storage of personal data on any of the following:

- ☐ Manual files including X−rays
- ☐ NHS computers
- ☐ Home or other personal computers
- ☑ University computers
- ☐ Private company computers
- ☐ Laptop computers

Further details:
Use of personal addresses will only be necessary if the participant requests a home visit for interview. Personal telephone numbers will be required to contact participants to arrange interview dates.
A university issued audio recording device will be used to record the interview.
All identifiable ad non-identifiable data will be stored on the researcher's personal password protected file space on the secure university server.

A38. How will you ensure the confidentiality of personal data? *Please provide a general statement of the policy and procedures for ensuring confidentiality, e.g. anonymisation or pseudonymisation of data.*

Pseudonyms will be used in all transcripts, chosen by the participants, in order to maintain confidentiality and anonymity. All data, including scanned consent forms, digital recordings, and transcribed interviews, will be stored on the [redacted] University server, where it can be accessed securely via VPN. Personal contact details and hard copies of consent forms will be destroyed as soon as possible after they have been uploaded for long term storage (consent forms) or after the information is no longer required (participant contact details).

A40. Who will have access to participants' personal data during the study? *Where access is by individuals outside the direct care team, please justify and say whether consent will be sought.*

The Chief Investigator will have access to participants' consent forms and anonymized transcripts. The academic supervisor will have randomised access to a small proportion of the transcripts and sections of the analysis, in order to provide supervisory support, and ensure analytical rigor.

Storage and use of data after the end of the study

A43. How long will personal data be stored or accessed after the study has ended?

● Less than 3 months
○ 3 – 6 months
○ 6 – 12 months
○ 12 months – 3 years
○ Over 3 years

15/NW/0237

INCENTIVES AND PAYMENTS

A46. Will research participants receive any payments, reimbursement of expenses or any other benefits or incentives for taking part in this research?

● Yes ○ No

If Yes, please give details. For monetary payments, indicate how much and on what basis this has been determined. Travel expenses to the interview location can be reimbursed by the [redacted] University Doctorate in Clinical Psychology Research Budget

A47. Will individual researchers receive any personal payment over and above normal salary, or any other benefits or incentives, for taking part in this research?

○ Yes ● No

A48. Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g. financial, share [redacted], personal relationship etc.) in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest?

○ Yes ● No

NOTIFICATION OF OTHER PROFESSIONALS

A49-1. Will you inform the participants' General Practitioners (and/or any other health or care professional responsible for their care) that they are taking part in the study?

○ Yes ● No

If Yes, please enclose a copy of the information sheet/letter for the GP/health professional with a version number and date.

PUBLICATION AND DISSEMINATION

A50. Will the research be registered on a public database?

○ Yes ● No

Please give details, or justify if not registering the research.
The research will be written up as a doctoral thesis and submitted for publication in peer-reviewed academic journals. The research team are not aware of any other suitable public database.

Registration of research studies is encouraged wherever possible.
You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you are aware of a suitable register or other method of publication, please give details. If not, you may indicate that no suitable register exists. Please ensure that you have entered registry reference number(s) in question A5-1.

A51. How do you intend to report and disseminate the results of the study? *Tick as appropriate:*

☑ Peer reviewed scientific journals
☑ Internal report
☐ Conference presentation
☐ Publication on website
☐ Other publication
☐ Submission to regulatory authorities
☐ Access to raw data and right to publish freely by all investigators in study or by Independent Steering Committee on behalf of all investigators
☐ No plans to report or disseminate the results
☐ Other (please specify)

A53. Will you inform participants of the results?

● Yes ○ No

Please give details of how you will inform participants or justify if not doing so.
Written feedback will be provided to participants in the form of a report detailing general themes and findings.

5. Scientific and Statistical Review

A54. How has the scientific quality of the research been assessed?*Tick as appropriate:*

☐ Independent external review
☐ Review within a company
☐ Review within a multi−centre research group
☑ Review within the Chief Investigator's institution or host organisation
☑ Review within the research team
☐ Review by educational supervisor
☐ Other

Justify and describe the review process and outcome. If the review has been undertaken but not seen by the researcher, give details of the body which has undertaken the review:

This research was reviewed at its early stages by a panel comprised of peer group members, staff team members, and service user representatives. The proposal was then reviewed by the thesis academic supervisor and course research supervisor.

For all studies except non-doctoral student research, please enclose a copy of any available scientific critique reports, together with any related correspondence.

For non-doctoral student research, please enclose a copy of the assessment from your educational supervisor/ institution.

A59. What is the sample size for the research? *How many participants/samples/data records do you plan to study in total? If there is more than one group, please give further details below.*

Total UK sample size: 10
Total international sample size (including UK):
Total in European Economic Area:

Further details:
As this is a qualitative study using IPA for analysis, an appropriate sample size is 6-10.

A60. How was the sample size decided upon? *If a formal sample size calculation was used, indicate how this was done, giving sufficient information to justify and reproduce the calculation.*

This is the sample size cited as appropriate for an IPA study.

A62. Please describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative research) by which the data will be evaluated to meet the study objectives.

The data collected from the semi structured interviews will be analysed using Interpretive Phenomenological Analysis.
Interpretative Phenomenological Analysis (IPA) is an approach to psychological qualitative research with an idiographic focus, which means that it seeks to offer insights into how a given person makes sense of particular experiences. IPA is phenomenological in that it is interested in individual perceptions and experiences, rather than making an objective statement (Smith, Jarman & Osbourn, 1999). However, it also recognises that the research process is a dynamic one on the part of the researcher, and that in order to access participants' 'personal worlds', the conceptions of the researcher are required in order to complete an interpretive analysis. IPA, therefore seeks to combine both the phenomenological and interpretation, hence the term IPA (Smith, 1996).

6. MANAGEMENT OF THE RESEARCH

A63. Other key investigators/collaborators. *Please include all grant co-applicants, protocol co-authors and other key members of the Chief Investigator's team, including non-doctoral student researchers.*

	Title Forename/Initials Surname Dr [redacted] [redacted]
Post	Lecturer in Health Research
Qualifications	
Employer	[redacted] University
Work Address	[redacted] [redacted] University, [redacted]
Post Code	[redacted]
Telephone	[redacted]
Fax	
Mobile	
Work Email	s.[redacted]@[redacted].ac.uk
	Title Forename/Initials Surname Dr [redacted] [redacted]
Post	Consultant Clinical Psychologist
Qualifications	
Employer	[redacted] Partnership NHS Trust
Work Address	[redacted]
Post Code	[redacted]
Telephone	[redacted]
Fax	
Mobile	
Work Email	[redacted].[redacted]@[redacted].[redacted]

A64. Details of research sponsor(s)

●
○
○
○
○
○

Contact

Given
Family
A
To
Post
C
Telep

○ ●

Sp

Lead

○ NHS or HSC care organisation

Commercial status:

Pharmaceutical industry
Medical device industry
Local Authority

Other social care provider (including voluntary sector or private organisation) Other

If Other, please specify:

Name of organisation [redacted] University
[redacted]
[redacted]
[redacted]
[redacted] [redacted] University
[redacted]
[redacted]

[redacted]

ethics@[redacted].ac.uk

Is the sponsor based outside the UK? No

Under the Research Governance Framework for Health and Social Care, a sponsor outside the UK must appoint a legal representative established in the UK. Please consult the guidance notes.

A65. Has external funding for the research been secured?

☐ Funding secured from one or more funders
☐ External funding application to one or more funders in progress
☑ No application for external funding will be made

What type of research project is this?

● Standalone project
○ Project that is part of a programme grant
○ Project that is part of a Centre grant
○ Project that is part of a fellowship/ personal award/ research training award
○ Other

Other – please state:

A67. Has this or a similar application been previously rejected by a Research Ethics Committee in the UK or another country?

○Yes ●No

Please provide a copy of the unfavourable opinion letter(s). You should explain in your answer to question A6-2 how the Please provide a copy of the unfavourable opinion letter(s). You should explain in your answer to question A6-2 how the reasons for the unfavourable opinion have been addressed in this application.

A68-1. Give details of the lead NHS R&D contact for this research:

	Title	Forename/Initials	Surname
	Ms	Anna	Pearson

Organisation	[redacted] Partnership NHS Trust
Address	[redacted]
Post Code	[redacted]
Work Email	[redacted]
Telephone	[redacted]
Fax	[redacted]
Mobile	[redacted]

Details can be obtained from the NHS R&D Forum website: http://www.rdforum.nhs.uk

A69-1. How long do you expect the study to last in the UK?

Planned start date: 01/04/2015 Planned
end date: 01/10/2015
Total duration:
Years: 0 Months: 6 Days: 1

A71-2. Where will the research take place? *(Tick as appropriate)*

☑ England
☐ Scotland
☐ Wales
☐ Northern Ireland
☐ Other countries in European Economic Area

Total UK sites in study

Does this trial involve countries outside the EU?
○ Yes ● No

A72. What host organisations (NHS or other) in the UK will be responsible for the research sites? *Please indicate the type of organisation by ticking the box and give approximate numbers of planned research sites:*

☑ NHS organisations in England	3
☐ NHS organisations in Wales	
☐ NHS organisations in Scotland	
☐ HSC organisations in Northern Ireland	
☐ GP practices in England	
☐ GP practices in Wales	
☐ GP practices in Scotland	
☐ GP practices in Northern Ireland	
☐ Social care organisations	
☐ Phase 1 trial units	
☐ Prison establishments	
☐ Probation areas	
☐ Independent hospitals	
☐ Educational establishments	
☐ Independent research units	
☐ Other (give details)	
Total UK sites in study:	3

A76. Insurance/ indemnity to meet potential legal liabilities

***Note:** in this question to NHS indemnity schemes include equivalent schemes provided by Health and Social Care*

(HSC) in Northern Ireland

A76-1. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of the sponsor(s) for harm to participants arising from the management of the research? *Please tick box(es) as applicable.*

Note: Where a NHS organisation has agreed to act as sponsor or co-sponsor, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For all other sponsors, please describe the arrangements and provide evidence.

☐ NHS indemnity scheme will apply (NHS sponsors only)
☑ Other insurance or indemnity arrangements will apply (give details below)

[redacted] University legal liability cover will apply.

Please enclose a copy of relevant documents.

A76-2. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of the sponsor(s) or employer(s) for harm to participants arising from the design of the research? *Please tick box(es) as applicable.*

Note: Where researchers with substantive NHS employment contracts have designed the research, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For other protocol authors (e.g. company employees, university members), please describe the arrangements and provide evidence.

☐ NHS indemnity scheme will apply (protocol authors with NHS contracts only)
☑ Other insurance or indemnity arrangements will apply (give details below)

[redacted] University legal liability cover will apply.

Please enclose a copy of relevant documents.

A76-3. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of investigators/collaborators arising from harm to participants in the conduct of the research?

Note: Where the participants are NHS patients, indemnity is provided through the NHS schemes or through professional indemnity. Indicate if this applies to the whole study (there is no need to provide documentary evidence). Where non-NHS sites are to be included in the research, including private practices, please describe the arrangements which will be made at these sites and provide evidence.

☑ NHS indemnity scheme or professional indemnity will apply (participants recruited at NHS sites only)

☐ Research includes non-NHS sites (give details of insurance/ indemnity arrangements for these sites below)

Please enclose a copy of relevant documents.

PART C: Overview of research sites

Please enter details of the host organisations (Local Authority, NHS or other) in the UK that will be responsible for the research sites. *For NHS sites, the host organisation is the Trust or Health Board. Where the research site is a primary care site, e.g. GP practice, please insert the host organisation (PCT or Health Board) in the Institution row and insert the research site (e.g. GP practice) in the Department row.*

Research site		Investigator/ Collabo Contact	
		Title	
Institution name	[redacted] Partnership	First name/ Initials	Dr
Department name	[redacted] Recovery Team	Surname	[redacted]
Street address	[redacted], [redacted] [redacted]		[redacted]
Town/city	[redacted]		
Post Code	[redacted]		
		Title	
Institution name	[redacted] Partnership	First name/ Initials	Dr
Department name	[redacted] Recovery Team	Surname	[redacted]
Street address	[redacted] [redacted]		[redacted]
Town/city	[redacted]		
Post Code	[redacted]		
		Title	
Institution name	[redacted] Partnership	First name/ Initials	Dr
Department name	[redacted] Recovery Team	Surname	[redacted]
Street address	[redacted]		[redacted]
Town/city	[redacted]		
Post Code	[redacted]		

PART D: Declarations

D1. Declaration by Chief Investigator

1. The information in this form is accurate to the best of my knowledge and belief and I take full responsibility for it.

2. I undertake to abide by the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research.

3. If the research is approved I undertake to adhere to the study protocol, the terms of the full application as approved and any conditions set out by review bodies in giving approval.

4. I undertake to notify review bodies of substantial amendments to the protocol or the terms of the approved application, and to seek a favourable opinion from the main REC before implementing the amendment.

5. I undertake to submit annual progress reports setting out the progress of the research, as required by review bodies.

6. I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to security and confidentiality of patient or other personal data, including the need to register when necessary with the appropriate Data Protection Officer. I understand that I am not permitted to disclose identifiable data to third parties unless the disclosure has the consent of the data subject or, in the case of patient data in England and Wales, the disclosure is covered by the terms of an approval under Section 251 of the NHS Act 2006.

7. I understand that research records/data may be subject to inspection by review bodies for audit purposes if required.

8. I understand that any personal data in this application will be held by review bodies and their operational managers and that this will be managed according to the principles established in the Data Protection Act 1998.

9. I understand that the information contained in this application, any supporting documentation and all correspondence with review bodies or their operational managers relating to the application:

    - Will be held by the REC (where applicable) until at least 3 years after the end of the study; and by NHS R&D offices (where the research requires NHS management permission) in accordance with the NHS Code of Practice on Records Management.
    - May be disclosed to the operational managers of review bodies, or the appointing authority for the REC (where applicable), in order to check that the application has been processed correctly or to investigate any complaint.
    - May be seen by auditors appointed to undertake accreditation of RECs (where applicable).
    - Will be subject to the provisions of the Freedom of Information Acts and may be disclosed in response to requests made under the Acts except where statutory exemptions apply.
    - May be sent by email to REC members.

10. I understand that information relating to this research, including the contact details on this application, may be held on national research information systems, and that this will be managed according to the principles established in the Data Protection Act 1998.

11. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named below. Publication will take place no earlier than 3 months after issue of the ethics committee’s final opinion or the withdrawal of the application.

Contact point for publication*(Not applicable for R&D Forms)*

NRES would like to include a contact point with the published summary of the study for those wishing to seek further information. We would be grateful if you would indicate one of the contact points below.

● Chief Investigator
○ Sponsor

○ Study co-ordinator
○ Student
○ Other – please give details
○ None

Access to application for training purposes *(Not applicable for R&D Forms) Optional – please tick as appropriate:*

☑ I would be content for members of other RECs to have access to the information in the application in confidence for training purposes. All personal identifiers and references to sponsors, funders and research units would be removed.

Signature: ....

Print Name: Sarah Davidson

Date: 09/01/2015 *(dd/mm/yyyy)*

D2. Declaration by the sponsor's representative

If there is more than one sponsor, this declaration should be signed on behalf of the co−sponsors by a representative of the lead sponsor named at A64-1.

I confirm that:

1. This research proposal has been discussed with the Chief Investigator and agreement in principle to sponsor the research is in place.

2. Any necessary indemnity or insurance arrangements, as described in question A76, will be in place before this research starts. Insurance or indemnity policies will be renewed for the duration of the study where necessary.

3. Arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed.

4. Arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts.

5. The duties of sponsors set out in the Research Governance Framework for Health and Social Care will be undertaken in relation to this research.

6. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named in this application. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

7. Specifically, for submissions to the Research Ethics Committees (RECs) I declare that any and all clinical trials approved by the HRA since 30th September 2013 (as defined on IRAS categories as clinical trials of medicines, devices, combination of medicines and devices or other clinical trials) have been registered on a publically accessible register in compliance with the HRA registration requirements for the UK, or that any deferral granted by the HRA still applies.

Signature: ....

Print Name:

Post:

Organisation:

Date: *(dd/mm/yyyy)*

D3. Declaration for student projects by academic supervisor(s)

1. I have read and approved both the research proposal and this application. I am satisfied that the scientific content of the research is satisfactory for an educational qualification at this level.

2. I undertake to fulfil the responsibilities of the supervisor for this study as set out in the Research Governance Framework for Health and Social Care.

3. I take responsibility for ensuring that this study is conducted in accordance with the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research, in conjunction with clinical supervisors as appropriate.

4. I take responsibility for ensuring that the applicant is up to date and complies with the requirements of the law and relevant guidelines relating to security and confidentiality of patient and other personal data, in conjunction with clinical supervisors as appropriate.

Academic supervisor 1

Signature: ....

Print Name: [redacted] [redacted]

Post: [redacted]

Organisation: [redacted] University

Date: 19/01/2015 *(dd/mm/yyyy)*

NHS
Health Research Authority
National Research Ethics Service

NRES Committee [redacted]

[redacted]

Telephone: [redacted]
Fax: [redacted]

07 April 2015

Miss Sarah Davidson
Trainee Clinical Psychologist
[redacted] [redacted] [redacted] University
[redacted]
[redacted] University
[redacted]
LA1 4YG

Dear Miss Davidson

Study title:	**What does the concept of recovery mean for the sense of self for people with a Borderline Personality Disorder Diagnosis?**
REC reference:	[redacted]
IRAS project ID:	**172053**

The Research Ethics Committee reviewed the above application at the meeting held on 27 March 2015. Thank you for attending to discuss the application.

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 Mrs Carol Ebenezer, nrescommittee.northwest-preston@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.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, 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.

a. The Committee would like to see the Participant Information Sheet revised to
  - i) Include a further sentence “You can stop the recording at any time, and ask for words to be deleted or changed” after “onto a digital audio recorder”
  - ii) Omit the whole reference to data being destroyed if they withdraw from the study
  - iii) Omit the words “if possible” from the paragraph on breaking confidentiality iv) Under who has reviewed the project add “and by the [redacted]
  - v) State that there is potential for a further interview if information needs to be checked/clarified.

b. The Committee would like to see the Introductory Letter revised to omit “and I look forward to hearing from you”

c. The Committee would like to see the Consent Form revised to include the version number and date of the Participant Information Sheet they have read

The Committee suggested, although this is not part of the opinion, that it might be better to have two interviews with each participant so as not to threaten the reliability of the methodology and to ensure that the interpretation is that of the participant and not the researcher.

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study.

Failure to provide the final versions to the REC may cause delay in obtaining permissions.

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 publically 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.

The sponsor must ensure that all participants enrolled into the study are registered with The Over Volunteering Prevention System (TOPS).

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 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).

Summary of discussion at the meeting

The Chair welcomed you to the REC and thanked you for attending to discuss the study. The Committee told you that this was a nice proposal and that the support offered was good.

Social or scientific value; scientific design and conduct of the study

The Committee noted that there would be only one interview and that it would last for only an hour and asked how you would include the participant in the interpretation.

You stated that you had thought about whether they would wish to be involved in the analysis and could take transcripts back to them.

The Committee suggested that it would be easier to say to the participants during the interview
“this is what I think you have said, is this correct?”, and you agreed to this.

The Committee asked whether it would be possible to do two interviews with each participant to further confirm you have their interpretation rather than her own.

You told the Committee that you were unlikely to do two interviews and imagined that the participants would be able to get their stories across in one session, unless there was so much information that they became tired and wanted another session.

The Committee suggested that during the analysis it might become obvious that information needs to be further clarified and advised it would be wise to state on the Participant Information Sheet that there is potential for a second interview.

Care and protection of research participants; respect for potential and enrolled participants’ welfare and dignity

The Committee noted that this is a vulnerable group and that debrief sessions were available should they be needed.

The Committee noted that these participants can have a tendency to overvalue the relationship and asked how this would be handled if the interview were done in the home.

You stated that this had been taken into account, and, as a result, you had decided not to offer home visits. You told the Committee that you have worked a lot with this patient *group and were aware of the boundaries and would liaise with the clinical team if necessary.*

Informed consent process and the adequacy and completeness of participant information The Committee requested changes as described in the decision below.

The Committee suggested that, as there are few participants, there is no need to withdraw data collected if a participant withdraws from the study.

Other general comments

The Committee pointed out that the reference in A 6 to DSM IV should read DSM V. You acknowledged this and had already noted it.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Zurich Municipal]		04 August 2015
Interview schedules or topic guides for participants [Sarah Davidson Interview Schedule Version 1.1]	1.1	09 February 2015
Letter from sponsor [[redacted] University]		02 March 2015
REC Application Form [REC_Form_05032015]	3.5	04 March 2015
Referee's report or other scientific critique report [Thesis feedback form]		
Research protocol or project proposal [Sarah Davidson Thesis Protocol]	1.1	19 January 2015
Summary CV for Chief Investigator (CI) [Sarah Davidson Research CV]		01 February 2015
Summary CV for supervisor (student research) [[redacted] [redacted]]		

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

After ethical review

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

User Feedback

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/qualityassurance/

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/NW/0237 **Please quote this number on all correspondence**

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

Yours sincerely

pp.

Dr Patricia Wilkinson Chair

E-mail: nrescommittee.northwest-preston@nhs.net

Enclosures:	*List of names and professions of members who were present at the meeting and those who submitted written comments* *“After ethical review – guidance for researchers”*
Copy to:	[redacted], [redacted] *University* *Ms*[redacted] [redacted] [redacted] *NHS Trust*

[redacted]

Attendance at Committee meeting on 27 March 2015

Committee Members:

Name	*Profession*	*Present*	*Notes*
[redacted]	[redacted]	[redacted]	
[redacted]	[redacted]	Yes	[redacted]
[redacted]	[redacted]	[redacted]	
[redacted]	[redacted]	[redacted]	
[redacted]	[redacted]	Yes	
[redacted]	[redacted]	[redacted]	
[redacted]	[redacted]	[redacted]	
[redacted]	[redacted]	[redacted]	
[redacted]	[redacted]	Yes	
[redacted]	[redacted]	No	
[redacted]	[redacted]	No	
[redacted]	[redacted]	Yes	
[redacted]	[redacted]	[redacted]	
[redacted]	[redacted] Health	Yes	

Also in attendance:

Name	Position (or reason for attending)
[redacted]	[redacted]
[redacted]	[redacted]

Hi [redacted]

Many thanks for your correspondence. Please find attached the revised documentation, as requested by the committee.

Kind Regards,

Sarah

Sarah Davidson
Trainee Clinical Psychologist

[redacted]

[redacted]

From: [redacted]
Sent: 07 April 2015 09:27
To: Davidson, Sarah
Cc: Ethics (RSO) Enquiries; [redacted]
Subject: [redacted]

Please find the committee's decision

BW
[redacted]

[redacted]

XXXXXX

[redacted]

NEW central booking systems and electronic authorisation and submission from spring – **find out more**

The HRA is keen to know your views on the service you received – our short feedback form is available **here**

Please find acknowledgement that the conditions of the favourable opinion have been met

BW

[redacted]

[redacted]

NEW central booking systems and electronic authorisation and submission from spring – **find out more**

The HRA is keen to know your views on the service you received – our short feedback form is available **here**

Required Documentation for Trust R&D Permission

Information Required in All Cases

Is this project a clinical trial? *(IRAS project filter Q2: Clinical Trial of an Investigational Medicinal Product; Clinical investigation/ study of a medical device; Combined trial of IMP/ medical device; Other clinical trial of novel intervention or RCT comparing interventions in clinical practice)*	**Yes** ☐ **No** ☒

(Please provide Name, Job Title, Address, Email, Tel No)
NB: if the project is student, we may need to contact you in the future for a final report etc, in this instance please provide contact details other than the University

Day to Day Contact Details for the project	*Please insert here* *Sarah Davidson* *Trainee Clinical Psychologist* *s.davidson@[redacted].ac.uk* [redacted]
Your Employer's Contact Details; this should usually be your Line Manager	*Please insert here* [redacted] *s.[redacted]@[redacted].ac.uk* *[redacted]s@[redacted].ac.uk*
Proposed Start Date (once ethical* and trust approval have been given) **if ethics approval not required this is the date once Trust permission is in place*	*01.04.2015*
Support from the Services where you want to carry-out your research project	***Email approval from all site managers sent to*** [redacted]

Mandatory documentation for all submissions

Documents Required	Further Information	Tick
Research Protocol	Include questionnaires or interview schedules, advertisements/flyers, GP/ Consultant letters and any other documents that are included in the study *(with version numbers)*	Y
Research Participant Information Sheet	For all participants in the study *(with version number)*	Y
Research Participant Consent Form	For all participants in the study *(with version number)*	Y

Summary CV for CI/Local PI	Submit the CV of the researcher who will conduct the research locally. Please sign/date this document	Y
Data Protection Statement *(attached with the checklist)*	Please read, sign and date to confirm that you will adhere to this whilst carrying out your research project in the Trust	Y
Evidence of sponsorship & indemnity		Y

Documentation required for research requiring REC Approval

Documents Required	Further Information	Tick
IRAS R&D Application Form (in PDF format)	www.nres.npsa.nhs.uk/ https://www.myresearchproject.org.uk/ Sections of the form require signatures and must be submitted either by post or email	Y
IRAS Site Specific Information Form (in PDF format)	The Declaration page should be signed by the PI and submitted either by emailed or post	Y
REC Letter showing favourable opinion (if received) **OR** **Written confirmation from the REC that ethical review is not required**	Your application may be submitted without this letter, however, formal approval will not be granted until it is received Please also submit all ethics correspondence letters with your application	
	In a few cases it is possible that a research study does not require ethical review. In this case you must submit written confirmation from the REC; an email is acceptable	

Documentation required for research that does not require REC approval

Please see guidance for full details of research that does not require REC approval.
Under the harmonised GAfREC (Governance Arrangements for Research Ethics Committees): http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_126474 certain types of research no longer require REC review, which includes a large proportion of research that involves NHS Staff only. However, where the Research Governance Framework for Health and Social Care applies, the research will continue to require management permission from host care organisations ("R&D approval").

Documents Required	Further Information	Tick
Simplified Version of the R&D Application Form **(in PDF format)** *[within the Integrated Research Application System (IRAS) in the project filter question 4, please select 'NHS/HSC Research and Development offices' only and this produces a simplified version of the application form]*	www.nres.npsa.nhs.uk/ https://www.myresearchproject.org.uk/ Sections of the form require signatures and must be sent in *(either electronic, scanned - emailed or post to the address provided below)*	
IRAS Site Specific Information (SSI) Form **(in PDF format)**	The Declaration page should be signed by the PI and sent in *(as above form)*	

Additional documentation for student research only

Documents Required	Further Information	Tick

Summary CV for Research Supervisor(s)		Y
University Ethics Approval Letter		

Documentation required for Clinical Trials of Investigational Medicinal Products (CTIMPs) only

(see http://www.ct-toolkit.ac.uk/)

Documents Required	Further Information	Tick
IRAS R&D Application Form (in PDF format)	www.nres.npsa.nhs.uk/ https://www.myresearchproject.org.uk/ Sections of the form require signatures and must be sent in *(either electronic, scanned - emailed or post to the address provided below)*	
IRAS Site Specific Information Form (in PDF format)	The Declaration page should be signed by the PI and sent in *(as above form)*	
REC Letter showing favourable opinion (if received) **OR** **Written confirmation from the REC that ethical review is not required**	Your application may be submitted without this letter, however, formal approval will not be granted until it is received.	
	In a few cases it is possible that a research study does not require ethical review. In this case you must submit written confirmation from the REC; an email is acceptable. Please also submit all ethics correspondence letters with your application	
Clinical Trial Agreement (CTA): Including contract/financial agreement, and statement of indemnity (Individual CTAs for each participating Trust).	For commercially contracted trials, the model Clinical Trial Agreement should be used.	
MHRA Approval – Clinical Trial Authorisation	http://www.mhra.gov.uk/index.htm	
EudraCT Number	European Clinical Trials Database https://eudract.emea.europa.eu/	
GCP Training Certificates	All members of the research team must have completed GCP Training and this must be in date within 2 years	

Please note if you are not a [redacted] Partnership NHS Foundation Trust member of staff you will need to submit relevant documentation to gain a letter of access or honorary research contract prior to commencing any research. For existing NHS staff this will be the NHS to NHS pre-engagement checks form; researchers with no contractual relationship with the NHS may need to submit via the research passport system.

Please return all required documentation together with this form electronically to:

Please also cc the R&D Manager: [redacted]

(please do not send hard copy originals in the post, except signature forms, if these cannot be scanned in & emailed)

Address:
Research & Development Department
[redacted]

If you have any questions regarding the approval process, please contact the R&D Department via the above or call [redacted]

Dear Sarah,

Re: NHS Trust Permission to Proceed

Our Ref: S0415

Project Reference: S0415

[redacted]

Email: [redacted]

Date: 16th April 2015

Sarah Davidson
[redacted]

[redacted] University
[redacted]
[redacted]

Project Title: **Recovery, Sense of Self and Borderline Personality Disorder**

I am pleased to inform you that the above project has received research governance permission.

Please take the time to read through this letter carefully and contact me if you would like any further information. You will need this letter as proof of your permission.

Trust R&D permission covers all locations within the Trust; however you will only be allowed to recruit from the sites/services you have indicated in section 3 of the SSI application form. If you would like to expand recruitment into other services in the Trust that are not on the original SSI then you must contact the R&D department immediately to discuss this before doing so.

You also must ensure you have liaised with and obtained the agreement of individual service/ward managers before commencing recruitment in that service and you must contact the relevant service/ward managers prior to accessing the service to make an appointment to visit before you can commence your study in the Trust.

Please make sure that you take your Trust permission letter with you when accessing Trust premises and please include the Trust reference number on any correspondence/emails so that the services are assured permission has been granted.

[redacted]

Recruitment

Researchers must recruit the first participant to [redacted] Partnership NHS Foundation Trust within 30 days of being granted Trust permission and ensure that studies recruit to time and target.

National guidelines expect Trusts to report the date when the first participant is recruited to the study, therefore please can you provide this information at that point to the R&D department at [redacted]

If you have any concerns with recruitment please contact the R&D team immediately for assistance.

Monitoring

If your study duration is less than one year, you will be required to complete an end of study feedback report on completion. However if your study duration is more than one year, you will be required to complete a short electronic progress report annually and an end of study report on completion. As part of this requirement, please ensure that you are able to supply an accurate breakdown of research participant numbers for this Trust (recruitment target, actual numbers recruited). To reduce bureaucracy, progress reporting is kept to a minimum; however, if you fail to supply the information requested, the Trust may withdraw permission.

Honorary Research contracts (HRC)

All researchers with no contractual relationship with any NHS body, who are to interact with individuals in a way that directly affects the quality of their care, should hold Honorary Research NHS contracts. Researchers have a contractual relationship with an NHS body either when they are employees or when they are contracted to provide NHS services, for example as independent practitioners or when they are employed by an independent practitioner (*Research Governance Framework for Health and Social Care,* 2005). If a researcher does not require an HRC, they would require a Letter of Access (LoA). For more information on whether you or any of your research team will require an HRC or LoA please liaise with this office. It is your responsibility to inform us if any of your team do not hold Honorary Research NHS contracts/Letters of Access.

Staff involved in research in NHS organisations may frequently change during the course of a research project. Any changes to the research team or any changes in the circumstances of researchers that may have an impact on their suitability to conduct research MUST be notified to the Trust immediately by the Principal Investigator (or nominated person) so that the necessary arrangements can be put in place

Research Governance

The Research Governance Sponsor for this study is [redacted] **University**. Whilst conducting this study you must fully comply with the Research Governance Framework. This can be accessed at: http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4108962&chk=Wde1Tv For further information or guidance concerning your responsibilities, please contact your research governance sponsor or your local R&D office.

Risk and Incident Reporting

Much effort goes into designing and planning high quality research which reduces risk; however untoward incidents or unexpected events (i.e. not noted in the protocol) may occur in any research project. Where these events take place on Trust premises, or involve Trust service users, carers or staff, you must report the incident within 48 hours via the Trust incident

---

[redacted]

reporting system. If you are in any doubt whatsoever whether an incident should be reported, please contact us for support and guidance.

Regardless of who your employer is when undertaking the research within [redacted] Partnership NHS Foundation Trust you must adhere to Trust policies and procedures at all times.

Confidentiality and Information Governance
All personnel working on this project are bound by a duty of confidentiality. All material accessed in the Trust must be treated in accordance with the Data Protection Act (1998) For good practice guidance on information governance contact us.

Protocol / Substantial Amendments
You must ensure that the approved protocol is followed at all times. Should you need to amend the protocol, please follow the Research Ethics Committee procedures and inform all NHS organisations participating in your research.

Final Reports
At the end of your research study, we will request a final summary report so that your findings are made available to local NHS staff. The details from this report may be published on the NHS Trust internet site to ensure findings are disseminated as widely as possible to stakeholders.

On behalf of this Trust, may I wish you every success with your research. Please do not hesitate to contact us for further information or guidance.

Yours sincerely,

[redacted]

Dr [redacted]
Research & Development Manager

Cc: Dr [redacted] [redacted] [redacted]
[redacted]

[redacted]

[redacted]