Borderline Personality Disorder: Clinical Outcomes and Personal Recovery

Rebecca Jones

Supervised by:

Professor James McGuire

Dr Laura Golding

Emma Hickey

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Chapter 1: Systematic Review

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Introductory chapter: Thesis Overview

This thesis focuses on outcomes and recovery from a diagnosis of borderline personality disorder (BPD). It comprises two distinct journal papers, namely a systematic literature review and an empirical paper.

Chapter one presents the findings from a systematic review of research on the long-term psychological and social outcomes for adults diagnosed with BPD. The paper begins by briefly describing the difficulties characteristic of a diagnosis of BPD, prevalence rates, a critique of the classification system and the author's stance, before outlining some of the associated literature and rationale for the literature review. The paper then goes on to synthesise the findings from 12 quantitative studies meeting the inclusion criteria for the review. The limitations of the papers are then considered, particularly highlighting the finding that studies exploring the experiences from service-user perspectives are clearly lacking in quantitative approaches which use psychometric measures. This provides a rationale for the necessity of qualitative studies to explore what recovery means for individuals with BPD.

Chapter two is an empirical study which supplements the existing findings from long-term research by exploring the recovery experiences described by individuals with a diagnosis of BPD. To the author's knowledge, this paper is only the second qualitative study in the UK to explore the concept of recovery in BPD and the first to explore experiences of recovery using an Interpretative Phenomenological Analysis (IPA) approach. The paper describes the existing literature for recovery in mental health and states the overall aims of the empirical paper which were to understand participants' personal experiences of the recovery process including what has facilitated and maintained their recovery. The paper goes on to discuss the methodology, procedure and analytic process, before synthesising the four main themes which were derived from analysing the interview transcripts from seven participants. Broadly, these themes refer to gaining motivation to change and recovery as an ongoing fluctuating process, whereby individuals learn to live with BPD by developing new skills to manage emotions and adapt behaviours. Additionally, for these participants recovery involved developing or transforming their sense of self and receiving support, both peer and

professional, as integral to their experience. To finish, the paper will discuss the meaning of the findings, how these relate to previous studies and how, by exploring individuals' experiences, this research contributes to the understanding of what constitutes recovery from BPD, and provides important clinical implications for effectively working with individuals with this diagnosis.

As both papers are written for publication in academic journals, it was not possible to give sufficient details regarding several parts of the study. Therefore, the appendices augment chapter one with details of the quality assessment, and chapter two with methodological considerations, all relevant documents for recruitment and the analytic process supplemented with an example of a transcript.

Whilst not wanting to assume how recovery is defined for individuals with BPD, for the purpose of this research, recovery is defined as a psychological concept referring to an experience of personal change; such that the individual may feel that their difficulties have reduced or are no longer present, that they have gained some control of their difficulties even if they are present, or that they have moved beyond their difficulties to a new state of being or way of living. There is no fixed definition of recovery that applies to everyone. In contrast, the term remission is a medical concept defined as the absence of observed signs or symptoms, or reduction of their levels in what is presumed to be a long-term condition.

University of Liverpool

The Long-term Psychological and Social Outcomes of a Diagnosis of Borderline Personality Disorder: A Systematic Review

Chapter 1: Systematic Review

Rebecca Jones

For submission to the Clinical Psychology Review (Author Guidelines in Appendix A)

Abstract

Until recently, long-term outcomes for individuals diagnosed with borderline personality disorder (BPD) have been relatively unknown. Recent findings have enabled a positive change in how BPD is understood. The aim of this review was to summarise the findings from long-term studies assessing the outcomes from BPD. Using a systematic strategy, the databases Medline, Scopus, Psycinfo and Web of Knowledge were searched for studies published in English between 2000 and 2013. Papers were selected which investigated an adult population diagnosed with BPD assessing a range of psychological, social, behavioural and symptomatic outcomes, with a three or more year follow-up period. Twelve quantitative papers were identified; nine papers were naturalistic cohort studies and three papers were treatment trials. Several studies found high rates of remission, with significant improvements over time. Considerable reductions in the core features and symptoms of BPD were found; however, impairments in social and vocational functioning persisted in a substantial proportion of individuals. Interpersonal difficulties, which are common amongst individuals diagnosed with BPD, were shown to decline over time but at slower rates. The naturalistic cohort studies and treatment trials yielded some comparable results. Further research exploring the mechanisms and experience of recovery is required to fill a gap in the literature and enable further understanding of individuals' recovery experiences.

Key words (MeSH headings): Borderline Personality Disorder; long-term; longitudinal; outcomes; psychological; social

Borderline personality disorder (BPD) is a highly disputed construct which is considered controversial and misunderstood; many question its validity and whether or not it is a bona fide disorder (Tyrer, 1999). The fifth edition of the Diagnostic and Statistical Manual-5 (DSM-5) (American Psychiatric Association; APA, 2013a) was published in 2013 and, despite eliminating the multi-axial system, the criteria for BPD have not changed from the earlier DSM-IV-TR (APA, 2000) edition. In both manuals, BPD is described as "a pervasive pattern of instability of interpersonal relationships, self-image, and affects, and marked impulsivity beginning by early adulthood" (American Psychiatric Association, 2010; p. 710). An alternative dimensional approach, which would be trait based, has been suggested in Section III of the DSM-5 (APA, 2013b) for diagnosing personality disorders. This section is provided to encourage further research to explore the utility of this approach. As this literature review focuses on studies which were published before the new edition of the DSM, the DSM-IV-TR definition will be used. To receive the diagnosis, a person needs to present with five or more of the nine criteria listed in the DSM-IV-TR, including efforts to avoid abandonment, recurrent suicidal or self-harming behaviour, affective instability, impulsive behaviour and chronic feelings of emptiness. An individual's difficulties must be problematic, persistent and pervasive to be considered a 'personality disorder' (Ministry of Justice National Offender Management Service & Department of Health, 2011; Emergence, 2014). Consequently, it is not unsurprising that, until recently, BPD has been considered by those working within a medical model of human distress, as a chronic and enduring condition with significant change seeming improbable.

It is important to highlight, as with any mental health diagnosis, that BPD is believed by some to be a socially constructed phenomenon which has no objective reality without the descriptions and labels given to it (Bjorklund, 2006; Walker, 2006). There exists over 200 different ways that an individual can meet criteria for BPD and it is often given alongside other DSM diagnoses, further contributing to its controversy (Hoffman & Burland, 2007). A danger of diagnosis is that professionals can fail to recognise the humanity of the person with the difficulties (Bateman & Krawitz, 2013). Recently the British Psychological Society's UK Division of Clinical Psychology (2013) called for a paradigm shift away from the use of diagnosis and its conceptualisation of psychological distress from a disease focused model, to one that helps restore personal meaning

within its environmental context (Johnstone, 2013) and is focused on describing an individual's difficulties in a meaningful and helpful way. Some service users, clinicians and researchers contest the use of medical vocabularies such as "symptoms", "mental illness" and "traits", and the belief that they represent what Walker (2006) called scientific "discovered truths". This perspective argues that the dominant psychiatric classification systems attempt to pigeonhole an individual's problems into diagnostic categories, rather than understanding their difficulties in the context of their life experiences (Johnstone, 2013; Pilgrim, 2013). As the papers reviewed use diagnostic and medical language, by necessity, the same language is used in this paper.

Longitudinal studies have been essential to inform knowledge of the long-term course and pattern of difficulties and to aid the development of appropriate services, with a focus on whether individuals can achieve remission, primarily defined as no longer meeting diagnostic criteria. Four large scale longitudinal studies conducted in the 1980s found that BPD was not necessarily a chronic condition but rather one that can change and improve (McGlashan, 1986; Paris, Brown & Nowlis, 1987; Plakun, Burkhardt & Muller, 1985; Stone, 1990). These studies provided largely unexpected yet encouraging and promising outcomes, therefore helping to develop an improved understanding of BPD and what clinicians and individuals can expect in the long-term. However, the studies conducted in the 1980s had significant methodological limitations such as poor follow-up and not measuring change from baseline to outcome and consequently are not considered entirely reliable and valid.

In recent years, the difficulties experienced by people diagnosed with BPD have received much needed attention from UK policy and research, possibly due to the realisation of the distressing consequences of the diagnosis (Sampson, McCubbin & Tyrer, 2006) and evidence from longitudinal studies that improvement is possible. *The National Service Framework for Mental Health* (Department of Health; DoH, 1999) set out to improve mental health services, later leading to the publication of '*Personality disorder: no longer a diagnosis of exclusion'* (DoH & National Institute for Mental Health, 2003). This was produced to facilitate the implementation of the *National Service Framework*, increasing recognition and understanding of personality disorders (PDs), and improving treatment approaches.

More recently, several longitudinal studies with much improved methodologies have been conducted to assess the nature of BPD, explore the variety of outcomes (psychological, social and symptomatic) for BPD and demonstrate the changes in these over time. These studies may have contributed towards a political and service shift in UK mental health services but also an improvement in understanding PDs. The National Institute of Health and Clinical Excellence (NICE, 2009) guidance for BPD suggests some key outcomes to consider when delivering psychological treatment, including quality of life, psychosocial functioning and symptomatic change.

The review aims to answer the question 'What is known about the long-term social and psychological outcomes of a diagnosis of BPD?', by synthesising and critically appraising the relevant literature exploring the long-term outcomes from BPD and rates of, what is defined as, remission, which would be particularly beneficial for clinical practice by informing clinicians' of the possible outcomes. To the author's knowledge, no review to date has integrated the social and psychological outcome findings for BPD, particularly those from the most recently published studies with more rigorous designs.

Methodology

The literature review was conducted using a systematic review process. To capture relevant papers, the electronic databases Psycinfo, Medline, Web of Knowledge and Scopus were searched from the year 2000. SIGLE was also searched for unpublished papers; however, no relevant papers were found. A limitation of searching on electronic databases is that not all relevant literature and papers may be identified; therefore, the electronic searches were supplemented by searching the reference lists of the key articles. NICE (2009) guidance for BPD was consulted as a guide to define outcomes and decide on key search terms. These included combinations of the following terms: "borderline personality disorder" OR "emotionally unstable personality disorder[1]" AND "outcome"

[1] UK International Classification of Diseases-10 (World Health Organisation, 2010) definition of EUPD: impulsivity, unpredictable mood, unable to control behavioural explosions. Two types: 1) impulsive type

OR “psychological outcome” OR “treatment outcome”, AND “longitudinal studies” OR “follow-up studies”. The search terms from NICE guidance such as “quality of life” were tried; however, when these were used alongside the above search terms, they did not return any results. It was therefore decided to keep the terms broad as above. Due to changes in mental health policy, such as *The National Service Framework for Mental Health* (DoH, 1999) and *‘Personality disorder: no longer a diagnosis of exclusion’* (DoH & National Institute for Mental Health, 2003), which aimed to improve mental health services by instigating positive change, and increase recognition of BPD, it was deemed appropriate to restrict this review to papers published after the year 2000.

Predetermined inclusion and exclusion criteria allows for greater reliability to identify appropriate papers and ensure that the review remains focused on a particular area. Studies included in the review had to meet the following criteria: i) investigated an adult (aged >18) population with a diagnosis of BPD or EUPD; ii) papers from international sources referring to the long-term outcomes of BPD; iii) assessing a range of psychological, social, behavioural and symptomatic outcomes; iv) outcome studies which used a three year follow-up or more; and v) papers written in English language. An initial search looking at follow-up periods of two plus years was carried out; however, inclusion of these studies would have made the data to review unmanageable. Therefore, studies having a three year or more follow-up were included. Longitudinal studies are typically used to map the long-term course of a disorder, therefore most long-term studies in the area are typically anywhere between five and 10 years. It was deemed that a longer period of time would be required to measure significant change and outcomes in social and psychological functioning. As the majority of long-term cohort studies followed participants who had received treatment either prior to or during the study, it was considered appropriate to also include clinical trials or intervention studies which had a lengthy follow-up period i.e. three or more years.

Studies were excluded if they were assessing outcomes of individuals with a diagnosis of BPD and other mental health difficulties; primarily assessing the factors which predict outcome; or

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(emotional instability, lack of impulse control); 2) borderline type (disturbance in self-image, chronic feelings of emptiness, intense and unstable relationships, self-destructive behaviour).

had less than three year follow-up. Papers using a retrospective design were excluded due to their limitations, such as reliance on accuracy of historical records, no blinding of assessors, and the possibility that important data may not be available. Many follow-up studies looked at predictors of recovery and outcome; however, it is not within the scope of this review to report on these findings. Earlier versions of the same papers, for example Zanarini, Frankenburg, Hennen, & Silk (2003) disseminating results at six years in a 10 year follow-up study were excluded. Articles, editorials and comments were also excluded.

The titles and abstracts of 56 potentially relevant papers were examined, and 34 citations were excluded as irrelevant. The remaining 22 were reviewed against the inclusion and exclusion criteria, and 12 studies were retained in the review (see *Figure 1*). Quality assessment tools are used in systematic reviews to guide the interpretation of the findings by evaluating the reliability and validity of the method and, therefore, the results of the included studies (Boland, Cherry & Dickson, 2014). In conducting and reporting systematic reviews, the Cochrane Handbook "explicitly discourages" the use of rating scales for quality assessment of included studies, as it over-simplifies disparate features that cannot be condensed into a single score without there being a risk of misrepresenting some aspects of study quality (Higgins & Green, 2011). Boland *et al.* (2014) suggest a checklist method rather than a scoring system, in order to capture important quality items. Additionally, there are several different quality assessment tools available, and researchers often draw on several quality assessment tools to develop a specific assessment for their review. A specific tool for evaluating long-term follow-up studies could not be located; therefore, the quality of the studies was assessed using a combination of existing quality assessment tools (Table 1). Items were combined from the Critical Appraisal Skills Programme cohort study checklist (CASP, 2010) and a checklist for longitudinal observational studies (Tooth, Ware, Bain, Purdie & Dobson, 2005). Tooth *et al.* (2005) developed and tested a checklist of criteria related to threats to the internal and external validity of longitudinal studies. For the quality assessment, papers were appraised against criteria indicating yes/ no/ unclear or not stated. These criteria were then used to explore potential biases and limitations of the study, and how these might impact on the interpretation of the findings, which are summarised in the Discussion section.

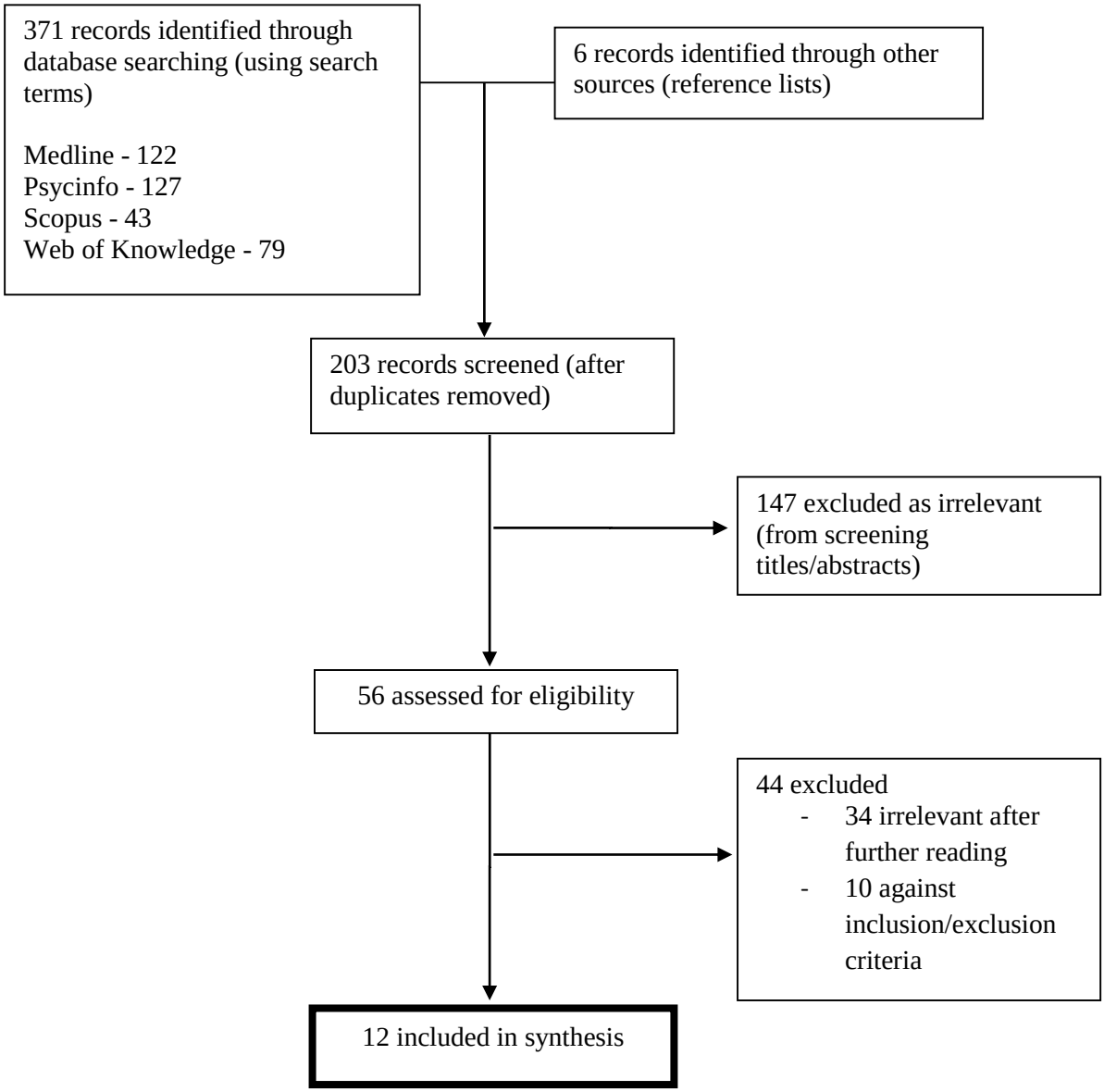

Figure 1. Flow chart of searches and study selection

To ensure a systematic procedure for evaluating the data, the core content (study characteristics, design, sample information) are summarised in Table 2 and the outcome measures and key findings are summarised in Table 3, enabling an accurate comparison of the papers. When reporting the results, it was deemed important to collapse the range of outcome findings into four categories based on the outcomes reported in the studies. These are summarised as follows: (A) whether participants met diagnostic criteria and symptomatic changes; (B) behavioural outcomes; (C) psychosocial outcomes (e.g. depression, anxiety, affect and cognition); and (D) interpersonal

outcomes. As nine papers are naturalistic cohort studies and three papers are treatment trials, the outcomes for both are reviewed separately and consideration is given as to whether the findings yield comparable results. As marked variations were found in terms of the outcome measures used and findings reported, quantitative data synthesis or meta-analysis were not deemed appropriate.

Results

Findings are synthesised and a detailed examination of the evidence relevant to the research question and aims of this literature review is provided. The overall quality of the evidence is critically appraised in the Discussion section.

It is important to note that the studies included in the review use both remission and recovery as outcomes. The definitions of remission and recovery vary between studies, making it difficult to generalise the meaning of the concepts. The definitions of remission include no longer meeting criteria for BPD, as measured by the DIB-R and DSM –III (Bateman & Fonagy, 2008; Davidson *et al.,* 2010; Zanarini *et al.,* 2007; Zanarini *et al.,* 2012), and meeting two or fewer criteria for BPD (Gunderson *et al.,* 2011). Two studies measure 'recovery' which one defines as concurrent remission of symptoms as well as having good social and vocational functioning during the previous two years (Reed *et al.,* 2012) and the other as no longer meeting criteria for BPD and a GAF score of > 60 (Zanarini *et al.,* 2012). Despite slightly varying definitions, the terms remission and recovery will be used to reflect the unit of observation described in the studies.

Twelve studies were included in the review, following-up a total of 1973 participants. The mean follow-up period was 10.75 years, ranging from 5-27 years. Nine studies were longitudinal cohort studies and three were intervention trials investigating whether outcomes from therapy were maintained at follow-up. Eight studies were carried out in the USA, two studies in the UK (Bateman & Fonagy, 2008; Davidson *et al*., 2010) and one from Canada (Paris & Zweig-Frank, 2001), and Australia (Stevenson *et al*., 2005) respectively. All studies were prospective and recruited the majority of participants from inpatient services; however, two also recruited from outpatient services (Gunderson *et al.,* 2011; Skodol *et al.,* 2005).

Table 1. *Quality assessment*

Study reference	Checklist items	Selection bias			Recruitment			Blinding		Follow-up		Data collection		Attrition		Analysis		
		Target population defined	Representative of population	Percentage agreed to participate	Geographical location	Eligibility criteria	Power justification	Outcome assessor blind	Participant aware	Longitudinal methods stated	No. of participants at each	Valid	Reliable	Number (and reasons)	No. completing the study	Statistical methods appropriate	Missing data accounted for	Checklist items met
Paris & Zweig-Frank (2001)		Yes	Yes	Yes	Yes (in earlier paper)	Yes	N/A[2]	Yes	N/S[3]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	13
Skodol *et al.* (2005)		Yes	N/S (yes based on previous study)	Yes	N/S	Yes	No	Unclear[4]/ N/S	N/S	Yes	No (N/S)	Yes	Yes	No	Yes (%)	Yes	N/S	9
Zanarini *et al.* (2007)		Yes	No inpatient	Yes (in earlier paper)	Yes	Yes	N/A	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Unclear	12
Zanarini *et al.* (2008)		Yes	No inpatient	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes (%)	Yes	No	13
Choi *et al.* (2010)		Yes	No inpatient	Yes (in earlier paper)	Yes	Yes	N/A	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes (%)	Yes	Yes	14
Zanarini *et al.* (2010)		Yes	No inpatient	Yes (in earlier paper)	Yes	Yes	N/A	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	13
Gunderson *et al.* (2011)		Yes	Yes	Yes	Yes	Yes	N/A	Unclear	Yes	Yes	No (N/S)	Yes	Yes	Yes (no)	Yes (%)	Yes	Yes	13
Reed *et al.* (2012)		Yes	No inpatient	Yes	Yes	Yes	N/A	N/S	N/S	Yes	Yes	Yes	Yes	No	Yes (%)	Yes	Yes (baseline)	11
Zanarini *et al.* (2012)		Yes	No inpatient	Yes	Yes	Yes	N/A	Yes	N/S	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	13
Stevenson *et al.* (2005		Yes	Unclear	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Yes (2) Unclear	Yes (but not all)	Yes	Yes	Yes	N/A	12
Bateman & Fonagy (2008)		Yes	No inpatient	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	14
Davidson *et al.* (2010)		Yes	Yes	Yes (72)	Yes	N/S(yes in earlier paper)	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	14

[2] N/A – not applicable; for Power justification, all cohort studies had a high number of participants despite not reporting a power calculation
[3] N/S – not stated
[4] Unclear – unable to ascertain from the paper

Table 2. *Study characteristics*

Study reference	Design, follow-up (FU), comparison	Participant characteristics, N (baseline (BL) & FU)
Naturalistic cohort studies		
1) Paris & Zweig-Frank (2001)	Longitudinal, 27-years No comparison	-Baseline: 332 FU: 64 -52 females; 12 males
2) Skodol *et al.* (2005)	7-years, repeated measures 6 months, annually Comparison- other PDs, MDD	-175 Aged 18-45 -Treatment-seeking or recently in treatment
3) Zanarini *et al.* (2007)	Longitudinal, 10-years, repeated measures every 2 years McLean Study	-Baseline: 249 (72 controls) FU: 249
4) Zanarini *et al.* (2008)	Longitudinal, 10-years Comparison- Axis II McLean Study	-Baseline: 290 FU: 249
5) Choi-Kain, Zanarini, Frankenburg, Fitzmaurice & Reich (2010)	Longitudinal, 10-years, repeated measures every 2 years McLean Study	-Baseline: 290 (72 Axis II) FU: 249 -77.1% female; 87% white -Mean GAF 39.8 (major impairment)
6) Zanarini, Frankenburg, Hennen & Silk (2010)	Longitudinal, 10-years Comparisons- Axis II McLean Study of Adult development	-Baseline: 290 FU: 249 -77.1% female; Aged 18-35
7) Gunderson *et al*. (2011)	Longitudinal, 10-years, repeated measures at 6 & 12 months, then every 2 years Comparison- other PDs, major depressive disorder (MDD)	-111 Aged 18-45 -75% women; Outpatients and inpatients
8) Reed, Fitzmaurice & Zanarini (2012)	Longitudinal, 10-years Comparison- other PDs McLean Study	-Baseline: 290 FU: 249 -Aged 18-35
9) Zanarini, Frankenburg, Reich & Fitzmaurice (2012)	Longitudinal, 16-years, repeated measures- 2, 4, 6, and 8 years Comparison- other PDs McLean Study	-Baseline: 290 FU: 231 -Aged 18-35 -77.1% female; 87% white
Treatment trials		
10) Stevenson, Meares & D'Angelo (2005)	5-years, outcomes from 1 year psychotherapy intervention No comparison	-Baseline: 40 FU: 30 -19 females; 11 males
11) Bateman & Fonagy (2008)	RCT, experimental design, 8-years Mentalisation-based therapy (MBT) vs. treatment as usual (TAU)	-41
12) Davidson, Tyrer, Norrie, Palmer & Tyrer (2010)	RCT, experimental design, 6-years Cognitive behavioural therapy (CBT) vs. TAU BOSCOT study group	-Baseline: 106 FU: 76 (38 CBT–PD and 38 TAU) -84% female; White ethnicity

Table 3. *Study findings*

Study reference	Outcome measures (baseline and FU)[5]	Findings (A, B, C, D)
Naturalistic cohort studies		
1) Paris & Zweig-Frank (2001)	DIB-R SCID GAF Symptom Check List-90 (SCL-90) SAS-SR	A)5 met diagnostic criteria. Mean SCL-90 score 0.7 (mild symptoms) B)10.3% of suicides C)Mean GAF score 63.3; mean SAS-SR score 2.0. Limited level of functional improvements. Small but significant decrease on cognitive measure D)Significant decrease on relationship scale, largest improvement between 15-27 years
2) Skodol *et al.* (2005)	SCID-I/P DIPD-IV NEO-PI-R (based on Five Factor Model) LIFE The self-report Social Adjustment Scale (SAS-SR)	A)10% remitted in first 6 months, in association with situational changes B, C)frantic efforts to avoid abandonment, self-injury least stable criteria -instability, inappropriate, intense anger most stable over first 2 years C)Greater work, relationship, and leisure impairment than comparison. Improved symptoms and functioning correlated
3) Zanarini *et al.* (2007)	SCID-I DIB-R DIPD-R	A)88% period of remission. 50% achieved remission of 9 acute symptoms between baseline and 4-year FU. 50% first achieved remission of 9 temperamental symptoms between 6 and 10-year FU. Stormy relationships, devaluation/manipulation/sadism, and affective instability remission between 4 and 6-year FU
4) Zanarini *et al.* (2008)	DIPD-R SCID-I DIB-R Lifetime Self-Destructiveness Scale (LSDS) LSDS Follow-up Version (at each follow-up)	B)BL- 90% history of self-mutilation; FU- <18% engaging in self-mutilation -BL- 79% history of suicide; FU- <13% made a suicide attempt -Cutting (14%) and overdosing (8%) remained relatively common -BL- 75% history of deliberately physically self-destructive acts; FU- 75% did not harm themselves or attempt suicide. Relative risk of behaviours reduced by 85%
5) Choi-Kain *et al.* (2010)	SCID-I DIB-R (+ Interpersonal Relationship section) DIPD-R	D)50% achieved remission of active caretaking, discomfort with care, and dependency between 4 and 6-years. 50% endorsing the other 16 first achieved remission before 4-years B)Destructive and impulsive behaviours remit early -Core affectively-oriented symptoms/ temperamental or trait-like remit slower and decline less substantially, 15-25% still exhibited at 10-years
6) Zanarini *et al.* (2010)	Background Information Schedule (BIS) Structured Clinical Interview for DSM-III-R Axis I disorders (SCID-I) Revised Diagnostic Interview for Borderlines (DIB-R) DIPD-R FU-Revised Borderline Follow-up Interview (BFI-R)	C, D)Good overall psychosocial functioning in 60% without good functioning at baseline (failure in vocation rather than social) -80% who had good psychosocial functioning at baseline lost this over 10-years; 77.6% of these lost only vocational functioning, 40% regained their ability to function well - Changed definition of good psychosocial functioning to include part-time work- 82% would have achieved; 81% who lost this would have regained it over time

[5] For brief information on the measures, please refer to Appendix B.

	GAF	
7) Gunderson *et al*. (2011)	The Diagnostic Interview for DSM-III-R Personality Disorders (DIPD-R) Global social adjustment scale Longitudinal Interval Follow-up Evaluation (LIFE) Global Assessment of Functioning Scale (GAF)	A)85% remitted, 11% relapsed, 9% remained unwell (>5 criteria). Higher rate of change in earlier years B)Criteria reduced from 6.7 to 4.3 (mean year 1), decreased at 0.29 per year to 1.7 (FU) C)Clinically modest GAF improvements from 53 to 57 (mean), average score 56. GAF score >70 at baseline was 0%, 21% at FU. Improvement on LIFE -GSA- statistically significant improvement in social functioning D)Married/cohabiting increased from 3% to 41%, full-time employment from 19% to 36%
8) Reed *et al.* (2012)	DIPD-R SCID-I DIB-R Dysphoric affect scales (DAS)	A)50% achieved recovery; 73% (recovered), 47% (non-recovered) decline on DAS C)Mean DAS score- from 41.56 to 17.39; 46% lower in the recovered group at BL than non-recovered (recovered BL-35.44, FU-8.56; non-recovered BL-47.68, FU-26.74) -Severity of dysphoric states decreased for all at varying rates
9) Zanarini *et al.* (2012)	BIS SCID DIB-R DIPD-R Psychosocial functioning & treatment utilization; GAF	A)Remission- 99% (2-year remission); 78% (8-year remission) -Recovery- 60% (2-year); 40% (8-years). Both slower for BPD -Rates of recurrence ranged from 36% (2-year remission) to 10% (8-year remission)
Treatment trials		
10) Stevenson *et al.* (2005)	DSM scale; Cornell Index Number of outpatient visits; length and frequency of hospital admissions; daily drug use; self-destructive behaviour & violence; absence from work	A)40% no longer met diagnostic criteria. Cornell index score: BL-43; FU-25. B, C) Statistically significant within-patient changes over time were detected for all variables (pf 0.001 in all cases).
11) Bateman & Fonagy (2008)	Zanarini rating scale for DSM-IV BPD (ZAN-BPD) GAF Number of suicide attempts; service use; length and frequency of hospitalization; continuing outpatient care; medication use; psychological therapies; community support (medical records)	A)13% (MBT) and 87% (TAU) met diagnostic criteria. (d 1.4 95% CI 1.2-2.4) B)46% made at least one suicide attempt (MBT- 23%; TAU-74%). Significant difference in the number of suicide attempts. (d 1.4 95 % CI 1.3-1.5) TAU- reduction in hospitalisation, A&E visits, suicide attempts C)GAF scores >60 (MBT-46%; TAU-11%) (d 3 95% CI 2-12) Global social functioning remained impaired (d 0.8 95% CI -1.9-3.4) MBT employed for nearly three times as long as the TAU
12) Davidson *et al.* (2010)	SCID–II Beck Depression Inventory (BDI) Spielberger State–Trait Anxiety Inventory (STAI) Brief Symptom Inventory (BSI) Young Schema Questionnaire (YSQ) Social Functioning Questionnaire (SFQ) Inventory of Interpersonal Problems-Short form 32 (IIP-32) Acts of Deliberate Self-Harm Inventory	A)56% (CBT) and 52% (TAU) no longer met diagnostic criteria C)Improvements in depression (-0.58 95% CI -8.45-7.29), anxiety (-5.29 95% CI -11.3-0.69), general psychopathology, social functioning (-1.07 95% CI -3.49-1.36), and dysfunctional attitudes (0.28 95% CI -0.89-0.32), no statistically significant differences between groups B)73% TAU and 53% CBT made at least one suicide attempt. Self-harm declined- average of 4.88 episodes per month (first year) to 1.10 per month (6 years-both groups) -CBT showed a greater reduction in the number of in-patient days and suicidal acts

Naturalistic Cohort Studies

Remission and Recovery

Six cohort studies reported whether participants continued to meet diagnostic criteria at follow-up. Four studies used a combination of three measures, namely the Structured Clinical Interview for DSM-III-R Axis I disorders (SCID-I), the Diagnostic Interview for DSM-III-R Personality Disorders (DIPD-R), and the revised Diagnostic Interview for Borderlines (DIB-R). One used the DIB-R and the SCID (Paris & Zweig-Frank, 2001), and another used the DIPD-R alone (Gunderson *et al.,* 2011). Five studies found that between 76.5% and 99% of participants were in remission or no longer met diagnostic criteria at follow-up (Gunderson *et al*., 2012; Paris & Zweig-Frank, 2001; Zanarini *et al*., 2007; Zanarini *et al.*, 2010; Zanarini *et al*., 2012). Measuring recovery[6] rather than remission, Reed *et al.* (2012) found that only 50% achieved recovery and Zanarini *et al*. (2012) found that recovery occurred in 60% lasting two years and 40% lasting eight years, as opposed to 99% achieving a two-year remission.

Specific BPD Symptoms

Only four of the studies looked at the decline of specific diagnostic criteria. Gunderson *et al*. (2012) found that the number of criteria reduced from 6.7 to 1.7 at 10-years. In terms of remission of the characteristic features of BPD, four studies found distinctions between more acute/symptomatic features versus temperamental or trait-like features (Choi-Kain *et al*., 2010; Reed *et al*., 2012; Skodol *et al*., 2005; Zanarini *et al*., 2007). They found that acute symptoms (impulsive behaviour, self-harm, efforts to avoid abandonment) are more reactive and remit relatively early, whilst temperamental symptoms, which are affective in nature, (affective consequences when alone, fear of abandonment, discomfort with care, dependency) are slower to remit. In contrast, Gunderson *et al*. (2010) failed to confirm the acute versus temperamental divisions, finding that all nine criteria had similar rates of decline (about 50%) with a similar rank ordering of prevalence at all times. Paris & Zweig-Frank

[6] Recovery was defined as concurrent remission of symptoms as well as having good social and vocational functioning during the previous two years (Reed *et al.*, 2012), and no longer meeting criteria for BPD and a GAF score of >61 (Zanarini *et al.*, 2012).

(2001) used the Symptom Check List-90 (SCL-90) to assess a range of psychological and psychiatric symptoms, finding only a mild level of psychiatric symptoms at follow-up.

Behavioural Outcomes

Self-harm and suicide. Only Zanarini *et al*. (2008) assessed self-harm and suicide using the Lifetime Self-Destructiveness Scale (LSDS). They found that <18% engaged in self-mutilation and <13% reported two or more episodes at 10-year follow-up. Quite significantly, 75% of participants reported neither injuring themselves nor attempting suicide during the fifth follow-up period. Less than 13% reported making a suicide attempt and <5% reported >2 attempts at 10-year follow-up.

Despite not specifically measuring decline in self-injurious episodes, both Choi-Kain *et al*. (2010) and Skodol *et al*. (2005) found that destructive and impulsive behaviours e.g. self-injury and frantic efforts to avoid abandonment, remit significantly and relatively early in BPD.

Psychosocial Outcomes

Global functioning. Two papers reported outcome scores from the Global Assessment of Functioning (GAF) scale where higher scores indicate improved functioning. Paris and Zweig-Frank (2001) found mean GAF scores of 60.7 at follow-up, indicating mild-moderate symptoms or some difficulty in social and occupational functioning. Gunderson *et al*. (2011) found that by follow-up, 21% of participants achieved a GAF score of >70, indicating good functioning; however, the mean GAF score overall was 57.

Social and vocational functioning. Three studies reported some improvements in social and vocational functioning. Using the Longitudinal Interval Follow-up Evaluation (LIFE), Gunderson *et al*. (2011) found improved employment rates from mild to satisfactory or good. Skodol *et al*. (2005) used the LIFE and the Social Adjustment Scale (SAS-SR) finding that compared to other PDs, only individuals showing some improvement in symptoms also showed progress in functioning. Zanarini *et al*. (2010) found that good psychosocial functioning, defined as having at least one emotionally

sustaining relationship and a successful employment/education record, was achieved in 60% of participants. However, 80% of those who had good psychosocial functioning at baseline lost this in the first two years due to loss of vocation.

***Affect and cognition*.** Four studies used specific measures of mood and cognitive states. Reed *et al*. (2012) used the Dysphoric Affect Scale (DAS) and found a significant decline in scores from 41.56 to 17.39 at follow-up. Dysphoric affective and cognitive states declined similarly, showing decreases of 61% and 68% respectively with more significant decline from baseline in recovered individuals, than non-recovered individuals. Core affective difficulties such as dysphoria, anxiety, depression, inappropriate intense anger, emptiness and affective instability were found to remit slower than other symptoms and were the most stable criteria over the first two years of follow-up (Choi-Kain *et al*., 2010; Skodol *et al*., 2005). Paris and Zweig-Frank (2001) found a small but significant decrease on the cognition scale of the DIB-R.

Interpersonal Outcomes

Only two studies specifically investigated interpersonal outcomes, defined as relational factors and difficulties in BPD. Paris and Frank-Zweig (2001) and Choi-Kain *et al.* (2010) assessed interpersonal outcomes using the Interpersonal Relationship Section of the DIB-R and found significant improvements in interpersonal relationship functioning over time. Choi-Kain *et al*. (2010) found that most interpersonal symptoms remit significantly, with less than 35% of individuals endorsing each of the 20 interpersonal features measured at follow-up. Paris and Zweig-Frank (2001) found particular improvements between 15-27 years. Zanarini *et al*. (2010) also found 60% had good psychosocial functioning, involving at least one emotionally supportive and sustaining relationship, and Gunderson *et al*. (2012) found that those married or cohabiting increased from 23% to 41% at 10-years.

Treatment Studies

Remission

All three treatment studies used measures to assess remission of BPD. Davidson *et al. (2*010) used the SCID-II; Stevenson *et al.* (2005) used the DSM scale and the Cornell Index; and Bateman and Fonagy (2008) used the Zanarini Rating Scale for Borderline Personality Disorder (ZAN-BPD). Stevenson *et al*. (2005) and Davidson *et al*. (2010) found comparable results; 40% and 54% in their treatment groups were in remission at five and six year follow-up. In contrast, Bateman and Fonagy (2008) found that 87% achieved remission at eight year follow-up in their Mentalisation-Based Therapy (MBT) group compared to 13% of their treatment as usual (TAU) group, finding a large effect size in favour of their MBT group. Davidson *et al.* (2010) used the Brief Symptom Inventory (BSI) and found improvements in general psychopathology, with no difference between groups. Improvements were maintained at follow-up in all three studies.

Stevenson *et al.* (2005) and Bateman and Fonagy (2008) share similarities in that participants maintained improvements at follow-up and continued to show improvements in symptoms years after treatment ending, indicated by the Cornell Index Scores and the ZAN-PD.

Behavioural Outcomes

***Self-harm and suicide*.** All three treatment studies assessed self-harm and/or suicide as an outcome. Two studies accessed medical records to review the number of self-destructive behaviours (Stevenson *et al*., 2005) and suicide attempts (Bateman & Fonagy, 2008) over the follow-up period and Davidson *et al*. (2010) used the Acts of Deliberate Self-Harm Inventory.

Both Davidson *et al*. (2010) and Stevenson *et al*. (2005) found that rates of self-harm per month declined significantly from 4.88 and 2 (median) at baseline, to 1.10 and 0 at follow-up. Davidson *et al.* (2010) found no difference between groups.

Both Davidson *et al.* (2010) and Bateman and Fonagy (2008) found comparable rates of suicide attempts in their TAU groups (73% and 74%), with less in the CBT group (54%) and even less

in the MBT group (23%), suggesting better outcomes for those who receive therapy. Despite less improvement, both also found that suicide attempts in the TAU groups steadily decreased over time.

Service use. Through reviewing the medical notes, reductions in hospitalisation, A&E visits and outpatient visits were found for both the MBT and TAU groups in Bateman and Fonagy's (2008) study and those receiving psychotherapy in Stevenson *et al.*'s (2005) study.

Psychosocial Outcomes

Global functioning. Bateman and Fonagy (2008) found a clinically significant moderate effect size for GAF scores between the MBT and TAU group. They found 46% of the MBT group, compared to 11% of TAU achieved a GAF score >60, suggesting the effectiveness of psychological intervention in improving global functioning.

Social and vocational functioning. Bateman and Fonagy (2008) found that vocational status gradually improved in the MBT group, who were employed three times longer than the TAU group. Davidson *et al*. (2010) found improvements in social functioning for both the CBT and TAU group. However, both studies concluded that individuals' global social functioning remained impaired.

Affect and cognition. Only Davidson and colleagues (2010) measured affect, cognition and dysfunctional attitudes using the Beck Depression Inventory, Spielberger State-Trait Anxiety Inventory and the Young Schema Questionnaire. They found reductions in depression, anxiety and dysfunctional attitudes, with no difference between both groups.

Interpersonal Outcomes. Using the Inventory of Interpersonal Problems-Short form 32, Davidson *et al*. (2010) found significant improvements in interpersonal problems at follow-up. Bateman and Fonagy (2008) also found a significant difference between TAU and the MBT group for interpersonal functioning, with those in the MBT group showing greater improvement.

Discussion

This review aimed to synthesise and critically appraise the relevant literature exploring the long-term outcomes from BPD, with the aim of informing clinicians' understanding of the possibility of change for individuals diagnosed with BPD. Twelve studies were included in the review, the majority of which show promising findings of reductions in many of the difficulties experienced. The findings from the naturalistic cohort studies and treatment studies will be compared, before drawing on the quality assessment to determine the strength of the studies reviewed and how this impacts on the conclusions that can be drawn.

Comparing the findings

Remission

Bateman and Fonagy (2008) found comparable results with all the cohort studies in terms of remission in their treatment group. Despite this, there remains some discrepancy between the two other intervention studies and the cohort studies. A potential reason for this may be that the majority of cohort studies showing higher rates of remission had a 10 year or more follow-up, compared to Davidson *et al*. (2010) and Stevenson *et al*. (2005) intervention studies with shorter follow-up periods. This is supported by the finding from Zanarini *et al.* (2012) cohort study that 47% of participants had achieved remission (lasting four years) at six year follow-up, which is comparable to the findings from both intervention trials. The much higher percentage of individuals achieving remission with longer-follow up periods suggests that improvements significantly increase long-term. A finding that warrants further consideration is the relatively low rates of remission in the TAU group at eight year follow-up (Bateman & Fonagy, 2008) compared to those reported in the cohort studies. Although it is unclear why there was such a vast difference, it is hypothesised that many participants in the cohort studies had received a form of therapeutic treatment during the course of the study, possibly contributing to improved rates of remission and impacting on the final results. Additionally, this finding may be explained by different sample compositions. Nevertheless, these findings may provide some evidence to suggest that BPD is not necessarily a persistent disorder as previous research might

suggest. When assessing a range of psychological and psychiatric symptoms, both Paris & Zweig-Frank (2001) and Davidson *et al.* (2010) found improvements in general psychopathology, with only a mild level of psychiatric symptoms at follow-up.

Behavioural Outcomes

Davidson *et al*. (2010), Stevenson *et al*. (2005) and Zanarini *et al.* (2008) found significant rates of decline in self-harming behaviour by follow-up, which occurred relatively early in the course of BPD. These findings were also consistent with those that suggest destructive and impulsive behaviours e.g. self-injury and frantic efforts to avoid abandonment, remit significantly and relatively early in BPD (Choi-Kain *et al*., 2010; Skodol *et al*., 2005).

Psychosocial Outcomes

The improved GAF scores in Bateman and Fonagy's (2008) study were comparable to those in the cohort studies. However, despite some improvements in overall functioning over time and many of the studies showing GAF scores of >60 to be attainable, the finding that social and vocational dysfunction persists in many individuals diagnosed with BPD was similar across most studies. The much longer follow-up period of 27 years for Paris and Zweig-Frank's study would also suggest that GAF scores may only increase minimally longer-term. This is consistent with the finding that remission is more common than recovery, as recovery involved concurrent remission of symptoms as well as having good social and vocational functioning or a GAF score of >61.

Interpersonal Outcomes

Findings reported in three of the cohort studies, namely Choi-Kain *et al.* (2010), Paris and Frank-Zweig (2001) and Zanarini *et al*. (2010), were comparable to those found in Davidson *et al.'s* (2010) treatment study, with all studies finding significant improvements in interpersonal relationship functioning over time. Contrary to the belief that interpersonal features are part of the enduring

pattern in BPD, many of these core difficulties experienced by individuals diagnosed with BPD were shown to decline overtime, but at slower rates than other difficulties.

Limitations of the Studies

Despite providing encouraging results, the studies included in this review are not without their limitations. Skodol *et al.'s* (2005) study met fewer of the criteria items on the quality assessment tool than any other study in the review. However, as this study was part of a larger study group (Collaborative Longitudinal Personality Disorder Study), checking earlier papers from this group showed that aspects such as reasons for drop out and geographical location were reported, but not stated in this particular journal paper.

Were the samples and findings generalisable and representative? Six of the studies in this review were carried out by the McLean Study of Adult Development and two studies by the Collaborative Longitudinal Personality Disorder Study; therefore, were reporting on the same sample. A possible limitation of this is that the results may not be generalisable to different populations or samples of individuals with BPD. Similarly, 11 of the studies reviewed recruited many of their participants from psychiatric inpatient units. This may suggest that participants' symptoms and distress, particularly with regard to self-destructive behaviours, were more severe and/or acute. It may be that difficulties experienced by those who have never accessed inpatient treatment may resolve in different ways, possibly making the results less representative and generalisable to those individuals.

In comparison to the cohort studies, both Stevenson *et al*. (2005) and Bateman and Fonagy (2008) had a relatively small sample size. Bateman and Fonagy (2008) acknowledge that participants may have felt loyalty to the research team due to their continued involvement with the service, thus resulting in biased results. This may mean that participants are showing improvement when there may not be, or that the service and/or treatment have a positive effect due to common factors in therapy (Imel & Wampold, 2008), such as the therapeutic relationship or alliance. Although participants may have benefitted from some common factors in TAU, this may be an explanatory factor for the

significant variance in outcomes between the MBT and TAU groups. Similarly, Bateman and Fonagy (2008) state that MBT contained a number of components, making it difficult to attribute change to a focus on or enhanced mentalisation alone, potentially limiting the reliability of outcomes for MBT.

Despite several cohort studies stating their aim to explore the natural course of BPD, a potential source of bias is that participants had received some form of treatment from mental health services. Although some studies stated what treatment participants had received such as psychological therapy or psychotropic medication, many did not report this (Choi-Kain *et al*., 2010; Paris & Zweig-Frank, 2001; Zanarini *et al*., 2010). Reed *et al*. (2012) reported that 90% of participants were in individual therapy and taking psychotropic medication at baseline, with 70% participating in each of these during each follow-up period. Moreover, those who acknowledged that treatment had been received did not track the effect over time. It is therefore unclear whether the symptomatic, behavioural and psychosocial improvements are due to the naturalistic course of BPD or intervention. It would be telling to assess the causes of change; for example, treatment or environmental. However, as there are known effective therapies for BPD, it would be unethical to withhold treatment intentionally.

It is also noted that studies had many more female participants than males. It may be that the experiences and outcomes of males are different and, therefore, the results may not be representative for a male population group. However, the samples in the studies may also reflect the higher proportion of females who receive a diagnosis of BPD compared to males.

Are the results reliable? An inherent flaw with all longitudinal design studies is the impact of repeated contact with research staff. There is potential for this to affect the outcomes and thus limit the reliability of findings; however, this is expected and difficult to overcome.

Some studies used self-report measures and relied on the participants as informants which may lower the reliability of outcomes (Gunderson *et al*., 2010; Zanarini *et al*., 2010). Using outside informants, such as family members, may have improved assessment validity. Zanarini and colleagues

(2010) were the only researchers to gather information from informants at the four year wave, finding a high concordance rate.

The length of diagnosis for individuals was not reported in any of the studies which would have been beneficial to consider as it may have impacted on the overall results. For example, individuals who remitted earlier may have received a diagnosis years prior to when the studies took place and, therefore, may have had more time, support from services and earlier therapeutic intervention.

Were the outcome measures used appropriate and reliable? All studies used reliable outcome measures. Davidson and colleagues (2010) did not carry out any formal inter-rater reliability for the SCID-II, possibly reducing reliability of the conclusions. However, the general picture, given the other quality items, suggests that the conclusions drawn from the study are reliable. Two studies reviewed medical notes to assess outcomes, which raises some issues in terms of reliability of the information gathered and recorded; however, these were used in combination with validated measures.

Having only used behavioural outcome measures, Stevenson *et al.'s*. (2005) study could have been improved by investigating other outcomes, such as psychological and social outcomes following treatment. Bateman and Fonagy (2008) did not repeat all baseline measures at outcome; consequently missing valuable outcome data. Similarly, Reed *et al*. (2012) only administered the DAS to 48% of their entire sample at baseline as this measure was only introduced after overall recruitment to the study, meaning that baseline data on 52% of individuals was missing and may have impacted on the findings at follow-up.

Although it was not in the scope of this review to elaborate on the findings compared to other mental health difficulties, 11 out of the 12 studies had a control group. A methodological limitation of Paris and Zweig-Frank's (2001) study was their lack of a comparison group. Despite having a control group, Stevenson *et al*. (2005) acknowledge that their control group was inadequate to make accurate comparisons and they did not directly compare them on all measures.

Were there adequate follow-up rates? Three out of the 12 studies reviewed had a poor follow-up rate (less than 30%). For Paris and Zweig-Frank (2001), 268 participants were lost by 27-year follow-up; as missing data were not accounted for (or at least this was not stated), it is unknown how the outcomes would differ at follow-up. However, they compared their follow-up sample with 99 of those interviewed at 15 years and found no significant difference in their demographics, DIB scores and GAF scores. Despite having a 44% drop out rate, Gunderson *et al*. (2011) adjusted for loss to follow-up when reporting their results. The baseline profiles of those who completed the study and those who dropped out are not reported in many of the papers, making it difficult to assess the characteristics of those individuals who drop out. This is a significant limitation, as further details of this would enable conclusions to be drawn around potential differences between individuals with more or less severe difficulties at baseline.

Summary

Drawing on the quality assessment, the overall methodological quality of the studies was fair. The studies reviewed have limitations which may reduce the generalisability of their findings. Specifically, the primary limitations are the smaller sample size in two of the 12 studies; recruitment primarily from inpatient units; and not providing the baseline profiles of those who dropped out. Despite these limitations, overall all of the studies have many strengths. All but two studies recruited large numbers of participants; all studies clearly reported the numbers of participants, and reported the number and reasons for attrition rates; most had long follow-up periods; all studies reported stringent eligibility criteria; and all studies used valid and reliable outcome measures. This suggests that the studies are measuring what they set out to do and that conclusions drawn have credibility. Despite not yielding comparable results with the cohort studies for all outcomes, for example remission, as stated above Davidson *et al.* (2010) and Stevenson *et al.* (2005) had a shorter follow-up compared to the cohort studies which may account for the difference. Nevertheless, both studies obtained similar

findings to each other. Additionally, most of the studies had similar findings, which further increases the confidence that can be held with regards to their findings.

The finding that social and vocational dysfunction persists warrants further consideration. This may be explained by the finding that interpersonal difficulties such as dependency, fear of abandonment and affective symptoms, which are strongly associated with psychosocial difficulties (Zanarini *et al.*, 2010), remain slower to decrease and thus serve to hinder individuals' ability to establish and maintain good social and vocational functioning. Clinicians are aware, from research and clinical practice, that individuals with a diagnosis of BPD face stigma both within mental health services and in the community (Aviram, Brodsky & Stanley, 2006; Fraser & Gallop, 1993; Nehls, 1998) which may also compound their difficulties in social and vocational domains. In addition, Reed *et al. (*2012) found that the inability to consistently work full-time is the primary reason why individuals have difficulty attaining 'full recovery' which involves good social and vocational functioning. Skodol *et al.* (2005) found that individuals diagnosed with BPD had significantly more negative life and interpersonal events, which predicted decreased psychosocial functioning over time and may have contributed to the limited improvements in work, social relationships and leisure activities.

Four cohort studies found distinct patterns in the remission of certain symptoms of BPD; however, there remains debate about the accuracy of the trait/temperamental features versus acute/symptomatic aspects of BPD due to conflicting results among the major studies. It is difficult to determine whether this difference reflects underlying clinical patterns or is due to factors such as different sample compositions, data collection methods, or unreported variables. These patterns are further challenged by the finding in two studies that affective and cognitive states, thought to be temperamental in nature, decline over time (Gunderson *et al*., 2011; Reed *et al*., 2012). This suggests that the difficulties which were previously thought to remain stable are as likely to diminish long-term as those predicted to be acute and episodic in nature and that an overall improvement in functioning is possible long-term.

Despite significant positive change for the majority of participants over time, some studies made distinctions between those who did and did not 'recover'. It may be that individuals who did not recover had more severe, longer standing and chaotic difficulties at baseline but it remains fairly unclear as to why there is such a difference and what predicts this. It was not within the scope of this review to explore this; however, future reviews may benefit from exploring predictive factors of outcome and recovery, taking into consideration the severity of difficulties.

Limitations of this Review

Inevitably, there are limitations to this systematic review making it difficult to compare the long-term social and psychological outcomes. Firstly, studies used different definitions of remission and recovery. For example, remission was defined as meeting two or fewer criteria; no longer meeting criteria at one or more follow-up/ two years or more; or was given no definitions at all, making it problematic to generalise the concept of remission. Secondly, there was no consistent pattern of outcomes measured across all studies, with some using a variety of outcome measures and others focusing on particular outcomes, for example behavioural or interpersonal, making it difficult to synthesise findings. The lack of consistent measures used also highlights the disparity in what clinicians and researchers consider important outcomes for individuals diagnosed with BPD. Thirdly, many studies also considered 'comorbidity' and a limitation of this review is that only the results on individuals diagnosed with BPD alone were summarised; therefore, official comorbidity through diagnosis was not explored or reported upon. As it is also rare for an individual to only meet criteria for BPD and no other diagnosis, for the future it would be beneficial to summarise the outcomes for individuals who are also experiencing other mental health difficulties and in what way these differ from the results in this study.

Implications for Future Research

Future research may benefit from recruiting participants from outpatient and primary care services or a population based method to reduce sampling bias and ensure that findings are relevant

and generalisable for different levels and severity of difficulties. Additionally, it would be informative to provide the baseline details of individuals who do not complete the study, in order to make comparisons between the baseline characteristics of those who drop out and those who remain in the study, and those who achieve better outcomes.

Despite reporting a broad spectrum of outcomes, the majority of the existing research has investigated symptomatic reduction and global/ social functioning as opposed to psychological change. Future research would benefit from using a more homogenous set of measures, specifically gathering psychological outcomes for individuals with BPD, such as improved sense of control, self-belief and confidence, quality of life and an improved ability to cope. There also remains a gap in terms of how we understand an individuals' experience of remission or recovery, and the mechanisms of change by which this occurs. This has implications for further research exploring from a service user's perspective their experiences and views of recovery and highlighting the outcomes which they consider as important for them. It may be that the outcomes reported in quantitative studies are those easiest to measure or those which services and professionals quantify as important; nevertheless, further research would allow a comparison with what the individuals themselves consider important in their lives.

Clinical Implications

The review demonstrates that when assessing the course of BPD, considerable improvements over time are found for most of the difficulties experienced. This provides important clinical implications for adult mental health services, particularly for clinicians to foster hope that positive change and improvements are possible for individuals diagnosed with BPD. The finding that interpersonal features may take longer to remit supports the need for psychological therapies that focus on relational aspects, such as the capacity to mentalise, develop and maintain relationships and further develop skills in self-reflection. The findings regarding social and vocational functioning also emphasise the need for treatment that incorporates support to improve these important aspects of individuals' lives, through meaningful activities and increasing their vocational skills. It is anticipated

that therapies focusing on the core interpersonal difficulties in BPD will have a consequential effect on social and vocational difficulties. Nevertheless, in the absence of conclusive evidence to suggest that targeting one difficulty results in positive change in the other, therapy should aim to target interpersonal, social and vocational functioning. This may also highlight the significance of, and need for, provision of specialist services and evidence based therapies such as MBT and Dialectical Behaviour Therapy to help provide individualised care, support recovery and appropriately meet the needs of individuals with this diagnosis.

Conclusion

The results from this literature review raise some doubts about the medical conception of BPD as a persistent pattern of instability, as individuals with BPD can, and do, experience improvements in many aspects of their lives. This is important in that it provides hope for individuals experiencing these difficulties, but also for the professionals working within services whose role it is to offer encouragement and promote the possibility of remission or recovery in a system that has historically thought this improbable or even impossible. The finding that social and vocational difficulties can remain emphasises the importance of continued support to facilitate improvements in these areas. Despite providing positive outcomes, the studies reviewed predominately investigate outcomes determined by clinicians which are also often based on psychiatric diagnosis, for example remission and ‘symptom reduction’. There remains a gap in terms of research measuring psychological outcomes and exploring the experiences of individuals and what they view as important factors in their recovery or experience of personal change. Further research exploring the mechanisms and experience of recovery would be beneficial to improve understanding of the concept for individuals with BPD.

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University of Liverpool

An Exploration of the Recovery Experiences Described by People Diagnosed with Borderline Personality Disorder

Chapter 2: Empirical Paper

Rebecca Jones

For submission to Qualitative Research in Psychology (Author Guidelines in Appendix C)

Abstract

Despite quantitative studies showing promising findings, little is known about recovery from service users' perspectives with borderline personality disorder (BPD). This qualitative study explored experiences of the recovery process, in addition to what facilitates and sustains recovery. Seven women with a diagnosis of BPD were interviewed and their transcripts analysed using Interpretative Phenomenological Analysis. Four key themes were found: 1) "This isn't the life I want": motivation as a prerequisite to change; 2) Riding the bumps: learning to *live* with BPD; 3) Changes in perception of Self; and 4) Recovery as a relational process. Participants described their recovery as an ongoing, fluctuating and conscious process involving learning to live with perpetual aspects of their difficulties. Essential to recovery were reductions in impulsive behaviours and interpersonal difficulties, and the development of self-belief, awareness and autonomy which were facilitated by support. Clinical implications include an improved understanding of individuals' needs and the provision of effective, meaningful therapeutic interventions.

Keywords: Borderline Personality Disorder; individuals' experiences; recovery; interpretative phenomenological analysis; qualitative research.

Until recently, those working within a medical model of psychological distress considered borderline personality disorder (BPD) an enduring condition which was unresponsive to treatment (National Institute for Mental Health, NIMH, 2003), meaning that a concept of clinical recovery, referring to the absence of symptoms (Mental Health Care, 2012), was improbable. Consequently, individuals receiving this diagnosis have been open to stigma from mental health professionals who hold the belief that BPD is not treatable, and thus nothing can be done to support those diagnosed towards recovery (Sampson, McCubbin & Tyrer, 2006).

There are different perspectives with regard to the concept of recovery. There appears to be a lack of consensus regarding how recovery is understood and defined, making a common conceptualisation of the term complicated and difficult to measure (Slade, 2009). One of the key contributors to the recovery movement, Anthony (1993), described recovery as a personal process of developing coping strategies which enable a satisfying, hopeful and contributing life, where an individual can recover without complete elimination of their difficulties. Amongst other descriptions of recovery from qualitative literature are a personal process involving the development of new meaning and purpose in one's life, a new sense of self, changing attitudes and values, improved coping and acceptance which is often complex, time consuming and ongoing (Ajayi *et al.*, 2009; Andersen, Oades & Caputi, 2003; Anthony, 1993; Deegan, 1988; DoH, 2011). Deegan (1988) powerfully described recovery as an "ever deepening acceptance of our limitations" and "that in accepting what we cannot do or be, we begin to discover who we can be and what we can do" (p.53). The concept of recovery has been prominent for a number of years, with the Department of Health stating in their paper *The Journey to Recovery* (DoH, 2001) that recovery should be central to the delivery of mental health services. This was followed by the NIMH (2003) publishing *Personality Disorder: No longer a Diagnosis of Exclusion* and the Institute of Mental Health (2007) developing the "Knowledge and Understanding Framework"; a national framework supporting professionals to work effectively with individuals and critically reflect on the meaning of recovery for PD. It seems that the understanding of recovery may vary from a view that is similar to the idea of remission, that is a clinical definition of alleviation of symptoms (Mental Health Care, 2012), to a broader, person-

centred and experiential approach, as in this study, with some suggesting that there is limited utility of the medical model and its interventions (Pitt *et al.*, 2007).

Increasing research regarding the long-term outcomes of BPD and treatment effectiveness has started to change the view that significant improvements are improbable. Recent evidence has demonstrated that the characteristic features, such as impulsive and self-destructive behavior, feelings of emptiness and unstable relationship patterns, do decrease over time, with many individuals experiencing improved interpersonal functioning as well as reduced psychological distress (Jones, 2014). However, it was also found that, as opposed to recovery (which is defined as involving good psychosocial functioning), more participants experience 'remission' (defined as no longer meeting the diagnostic criteria for BPD) (Zanarini Frankenburg, Reich & Fitzmaurice, 2010). Additionally, sustained improvements are more problematic than for individuals with other forms of personality disorder (PD) (Zanarini, Frankenburg, Reich & Fitzmaurice, 2012), indicating that recovery may be complex. Effective treatments now exist that can alleviate the distressing emotions and behaviours experienced; consequently, individuals should be made aware that change is possible, regardless of current emotional difficulties (Fonagy & Bateman, 2006). This relatively recent understanding, primarily developed from studies measuring diagnostic change, means that the conceptualisation of recovery from BPD is under-researched. Thus, little is known, from a service-users' perspective, about the personal experiences and mechanisms by which recovery occurs, which is potentially invaluable for service provision.

It has been suggested that a "proscriptive, 'one size fits all' notion of 'recovery'" is unrealistic and should be used with caution when developing specialist PD services (Turner, Lovell & Brooker, 2011a, p. 342). This is because it does not acknowledge the constant challenges of living with the associated difficulties (Turner *et al.*, 2011a) and focuses on social interaction which may be problematic for individuals with interpersonal difficulties (Turner, Neffged & Gillard, 2011b). When exploring recovery within PD, it is viewed by some as a personal journey of growth (Castillo, Ramon & Morant, 2013) or as a journey to self-discovery, with some shared elements and divergences in how it is reached (Turner *et al.* 2011a), suggesting that the lack of a clearly defined recovery "journey" is

an important consideration. However, this has not been explored specifically within BPD. Turner *et al.* (2011b) conclude that more in-depth qualitative research is needed to understand the recovery needs of these individuals.

Holm and Severinsson (2011) explored how the recovery process facilitates change in suicidal- related behaviour of women with BPD. Recovery involved the desire to recover by searching for inner strength, feeling safe and trusted with others, enhanced self-development related to their childhood experiences and a struggle to assume responsibility. The development and maintenance of trust and hope, similar to what is considered important in traditional notions of therapeutic change, was also found.

In their study exploring views of recovery and personal aspirations using Grounded Theory and Thematic Analysis, Katsakou *et al*. (2012) found difficulties with the term recovery which was experienced by individuals with BPD as a continuous, dynamic process, characterised by periods of marked improvements followed by stages where managing life was difficult. Although disheartening and tiring, this fluctuation was considered a natural process. Recovery involved developing self-acceptance and self-confidence, gaining control over emotions and thoughts, improving relationships, social inclusion and employment, and making progress with destructive behaviours such as suicidality. Participants felt hopeful that they would develop strategies to effectively manage their difficulties; however, for most, the absence of difficulties was seen as a distant goal.

Research into recovery from psychosis (e.g. Pitt *et al.* 2007) and other mental health difficulties has enabled services to promote a model to meet the needs of individuals. Pitt and colleagues (2007) found themes of rebuilding the self through understanding and empowerment, rebuilding life through social support and actively participating in life, and hope for the future involving a desire to change. It cannot be assumed that a recovery model fits all and the limited research into the concept in relation to people diagnosed with BPD suggests that their recovery experiences may be different.

A range of studies to date, reported in Jones (2014), demonstrate that there is a lack of in-depth qualitative research exploring personal accounts of the process of change for people diagnosed

with BPD; therefore, this research is both timely and needed. The overall aim of this study was to explore recovery experiences among people with a diagnosis of BPD. The objectives to meet this aim were to: i) understand participants' personal experiences of the recovery process; ii) explore how they make sense of, and understand, the concept of recovery; and iii) obtain a picture of what has facilitated their recovery and what sustains it. This research may provide an enhanced understanding of what constitutes recovery from BPD, concomitantly helping services to develop an effective model when working with individuals.

Method

Design and Qualitative Methodology

A qualitative research design, using Interpretative Phenomenological Analysis (IPA) was used as it is concerned with the individual's experience and personal perception of a particular phenomenon i.e. recovery (Smith & Osborn, 2008). Given that the concept of recovery from BPD is in its early stages, qualitative methodology was chosen to gather rich and 'thick' descriptive accounts (Geertz, 1973). IPA has its theoretical foundations in phenomenology which is the study of *being* and *experience*, hermeneutics, which refers to the theory of interpretation and understanding (Ramberg & Gjesdal, 2013), and idiography, which refers to attention to the particular meaning for an individual, rather than establishing a universal understanding (Larkin, Watts & Clifton, 2006. Further details in Appendix D). Consideration was given to other qualitative methodologies (Appendix E) such as Grounded Theory; however, IPA was chosen as it allows exploration of how meaning and experiences are constructed by the individual and is therefore well-suited and pertinent for the study of recovery.

Procedure

Sample: size, strategy and characteristics

The aim in IPA research is to describe in detail the understandings of a specific group of people rather than to be representative and make general claims (Smith & Osborn, 2008). Using

Smith, Flowers and Larkin's (2009) recommendation of between four and ten participants for a professional doctorate, seven participants were interviewed.

Due to the focus on experience of a particular phenomenon, IPA research aims to recruit a fairly homogenous sample; therefore a purposive sampling method was applied to ensure that participants met certain characteristics. As stated by Smith *et al.* (2009), "the extent of this homogeneity varies from study to study" (p. 49). The issue of homogeneity was discussed in supervision, where there was a consensus that a group of women with a shared diagnosis, who had, or were receiving specialist treatments for BPD in a single NHS Trust, was sufficient for the purpose of this research. IPA is also interested in exploring the psychological variability of participants in a sample, and therefore the sample should not be an "identikit", as stated by Smith *et al.* (2009). In the present study, the sample is homogenous in that they all share a BPD diagnosis, are accessing or have accessed community mental health services and identify themselves as 'in recovery'. Although unintended, all participants were female and had or were engaging in specialist psychological therapies for BPD, namely Mentalisation-Based Therapy (MBT) and Dialectical Behaviour Therapy (DBT), thus increasing homogeneity and fitting with IPA. When areas of study are comparatively new, such as recovery and BPD, the sample and research question can be broader.

Participant demographics are provided in Table 1.

Table 1. *Participant demographics*

Demographic information	**Ashley**[7]	**Amy**	**Rachel**	**Kate**	**Hayley**	**Jenny**	**Lisa**
Gender	F	F	F	F	F	F	F
Age	24	32	38	26	48	26	45
Previous and/ or present psychological therapy	Yes DBT	Yes DBT MBT	Yes DBT MBT	Yes MBT CBT	Yes MBT	Yes DBT	Yes DBT MBT
Employment	Unemployed	Unemployed	Unemployed Voluntary work	Unemployed	Unemployed	Recently unemployed Voluntary work	Unemployed Voluntary work
Ethnicity	Caucasian	Caucasian	Caucasian	Caucasian	Caucasian	Caucasian	Caucasian

[7] All participants have been given pseudonyms and were given the option to choose their own.

All participants were Caucasian, ranging between 24-48 years, with the mean age of 34.14 years, and were eligible for the study if they met these broad inclusion criteria: Adults (18+); meeting criteria for a diagnosis of BPD (DSM) or emotionally unstable personality disorder (ICD-10; World Health Organisation, 2010); identifying themselves as at least having begun the recovery process; and English as first language or could speak/understand English sufficiently well to participate.

Diagnosis. Participants with a diagnosis of borderline personality disorder (BPD), who identified themselves as having begun their recovery, were recruited. The diagnosis of BPD had been discussed and shared with the service user by either a psychiatrist and/or a clinical psychologist at the service. The service where recruitment took place approached diagnosis through a collaborative discussion with service users regarding their symptoms and difficulties; clinicians use the criteria as stated in the diagnostic classification systems to make the diagnosis. Where appropriate, psychometrics such as the Standardised Assessment of Personality – Abbreviated Scale (SAPAS) are also used to inform the diagnostic process. All participants were engaged in, or had received, therapeutic treatment programmes specific to BPD, namely DBT and/ or MBT full programme. Within this service, all service users are assessed as meeting the diagnostic criteria for BPD prior to entering the therapeutic treatment programmes. All participants had been diagnosed, or had their diagnosis reviewed, within the last four years. All participants had also received written information and psycho-education sessions from psychological therapists regarding their diagnosis and agreed that their difficulties were encapsulated by the BPD diagnostic criteria. Clinicians at the service were asked to identify individuals based on them meeting these inclusion criterion; this was also verified by the author's internal supervisor at the respective Trust.

Considerations were given to the inclusion or exclusion of one participant, due to recent life events having impacted significantly upon her ability to talk about recovery. However, as parts of the interview were rich and pertinent to the aims, it was agreed with supervisors to include this participant.

Recruitment

Participants were recruited through Community Mental Health Teams (CMHTs) in a North West NHS Trust, where over 60 people are assessed annually who meet diagnostic criteria for BPD. Recruitment took place via attendance at the team meetings and liaison with the lead Clinical Psychologist of each team. Professionals were informed about the study and asked to approach appropriate potential participants with information sheets (Appendix F). Individuals who wished to participate were asked to sign a 'consent to be contacted' form and were contacted via telephone to discuss the research and arrange a time and venue to be interviewed.

Interview design and conduction

Semi-structured interviews were conducted which are optimal when exploring personal perspectives on sensitive topics (Mack *et al.*, 2005). This style is not intended to be prescriptive (Biggerstaff & Thompson, 2008) and therefore allows flexibility and probing of interesting areas (Smith, 1995). Semi-structured interviews are often used in phenomenological research as they allow for variability of individuals' experiences more than structured interviews which require predetermined questions and neutrality (Smith & Osborn, 2008).

The schedule was developed in line with the study's aims and objectives, consultation with supervisors and with experts by experience (EbE) of BPD as it was considered imperative to obtain the views of individuals who consider themselves to be in recovery or to have recovered. Interview questions explored the meaning of recovery to the individual; their own recovery experiences thus far; what was important to start, sustain and maintain their recovery; the potential role of services; and anything they felt still needed to happen (Appendix G). One pilot interview was conducted in order to evaluate the interview schedule, following which some questions were re-worded, prompts added to ensure adequate exploration and one presumptuous question was removed. The pilot interview was included in the final analysis due to its richness and given that only minor changes were made to the interview schedule.

Interview locations were the participant's home or CMHT as chosen by them. The researcher briefed participants about the research, revisited the information sheet, and invited questions before obtaining their informed consent (Appendix H). Brief demographic information was gathered prior to the interviews. Interview questions were omitted if already alluded to, and interesting areas followed up with additional questions. Interviews lasted between 50-90 minutes and were audio-recorded using a Dictaphone. The first two interviews were transcribed by the researcher to gain a sense of the data; the remaining interviews by a professional transcriber from the University.

Ethical considerations

Ethical approval was sought via the University of Liverpool's Doctorate in Clinical Psychology Research Committee, the NHS Research Ethics Committee (received on 24/01/2013) and the Research and Development Department at the Trust. Approval was granted by all three bodies (For the ethical approval letter, please see Appendix I). Ethical considerations were also addressed in the information sheet. A protocol was developed should individuals become distressed and a resource/contact list was devised in the event of these being required (Appendix J).

Reflexivity

Essential to IPA research is reflexivity, this is primarily because "any discoveries that we make must necessarily be a function of the relationship that pertains between researcher and subject-matter" (Larkin *et al*., 2006, p.107). For this reason, it is important to consider the personal characteristics of the researcher for their potential influence on the analysis. Consequently, reflective notes were kept throughout the research process (example in Appendix K).

To enhance reflexivity, but also to ensure quality and validity, the transcripts, with initial noting and emergent themes of three participants and the grouping of the superordinate themes of two participants were read by internal and external research supervisors, who validated the themes and how they were reached. The final clustering of themes from superordinate to sub-themes and master themes were also shared with and validated by the internal and external supervisors. Where aspects of

the analysis were questioned by the research supervisors, for example where themes were too descriptive or too interpretative, these were resolved by the author giving further details or incorporating feedback from the supervisors to amend interpretations and themes accordingly. Care was taken to ensure that themes could be traced back to the initial transcript and were close to the data.

Position of the Researcher

The researcher is a 26 year old white British female, who is currently training to be a Clinical Psychologist and has worked within the field of Clinical Psychology for four years with a range of clients presenting with mental health difficulties, including BPD.

In terms of reflexivity, it is important to state the researcher's epistemology and stance on the psychiatric diagnostic approach dominating mental health services, a position that has developed from clinical practice and training. Despite many clinicians in the mental health system viewing BPD as a diagnosis consisting of a set of criteria, the researcher is sceptical of the classification system which attempts to pigeonhole an individual's problems into diagnostic categories, rather than understand their difficulties in the context of their personal histories and life experience; she therefore believes that mental health difficulties are socially constructed concepts. Having worked in secondary care adult mental health services, the researcher has observed the stigma faced by individuals diagnosed with BPD and has speculated whether the challenges encountered by many professionals when working with these individuals have contributed to a hopeless outlook for the possibility of recovery. There is a range of contributory factors for these views including a limited understanding of the person in context which means professionals are less aware of the necessity for a nurturing, consistent and boundaried approach. This has, along with research demonstrating that positive change is entirely attainable, sparked an interest in exploring individuals' personal experiences; taking one step further to challenging the beliefs that have long been detrimental.

Analysis

The guidance given by Smith *et al.* (2009) was consulted whilst conducting the analysis. The stages below were carried out for all transcripts individually (for more information, see Appendix L):

1) Reading the transcripts a number of times to become familiar with the participants' accounts.
2) Using an idiographic approach, initial noting was made regarding the linguistic, conceptual and descriptive nature of the transcripts. Engaging in an "interpretative relationship with the text" (Smith, 1995, p.18), conceptual comments are preliminary interpretations of the participant's narrative, through focusing on their understanding of what they are discussing (Smith *et al*., 2009).
3) Transcripts and initial notes were used to identify emergent themes which reflected the meaning of the person's account; an example of this process with a transcript extract can be found in Appendix M.
4) Conceptually related emergent themes were then clustered to develop superordinate themes. Table 2 provides an example of clusters.
5) Clusters were then compared across the whole sample, looking for patterns, divergences and shared categories. Superordinate themes were then further clustered into sub-themes within master themes. At this stage, certain themes were discarded if they did not fit with the objectives or were not shared by many participants.

Table 2. *Example of Emergent themes clustered into a Superordinate theme (Rachel)*

Superordinate themes	Emergent theme
Learning to do things more adaptively/ positively *(Relabelled under sub-theme 2.2. Learning to do things more adaptively through psychological change)*	New found calmness (25, 569-71) Changing ways of being/ behavioural change (8, 180-83) Breaking old habits (value driven) (45, 1009-13) Doing things differently/positive behavioural change (46, 1040-43) Behavioural change (14, 322-26) Not acting upon intense feelings (24, 540-543) Different reaction, less impulsive (24, 543-46) Being with, not acting on feelings (24, 547-52) Being able to manage emotions (33,756-62) Pacing- not overloading self (28, 636-39)

Analysis

Overview of Themes

The aim of this study was to explore the recovery experiences described by individuals diagnosed with BPD. The analysis resulted in four master themes, each containing between two to four sub-themes (Table 3). Although the themes are discrete, some inevitably share commonalities. A table of master themes, sub-themes and superordinate themes with associated participants can be found in Appendix N.

Table 3. *Summary of Master themes and Sub-themes*

Master themes	Sub-themes
1)"This isn't the life I want": motivation as a prerequisite to change	1.1. Choosing life: gaining motivation from external reasons to change 1.2. "You need to fully want to, fully fully want to change": active process of readiness and a *want* to be different
2) Riding the bumps: learning to *live* with BPD	2.1. "…you will never ever ever ever stop climbing": recovery as a lifelong, fluctuating process 2.2. Learning to do things more adaptively through psychological change

	2.3. "It was always so black and white whereas now it's not": improved interpersonal effectiveness through increased ability to mentalise 2.4. Finding purpose and meaning in negative experience
3) Changes in perception of Self	3.1. Increased self-awareness 3.2. Development of self-belief 3.3. Autonomy and independence as an achievement and aspiration
4) Recovery as a relational process	4.1. "you want to, to know that they are actually there": the ongoing necessity for a secure base 4.2. Therapeutic relationships as vehicles for change

1. "This isn't the life I want": motivation as a prerequisite to change

The first master theme refers to precipitants to change, whereby participants described internal and/or external drives which served as a prerequisite to starting the recovery process.

1.1. Choosing life: gaining motivation from external reasons to change

Five participants talked about requiring an external reason which provided an internal motivation to make changes to their lives. A significant theme for Kate is that of needing to change for the sake of her children's future: "*it's either sort myself out or risk the kids getting took from Social Services. That fear has helped me want to be better even more"* (15, 342-44). This realisation that her difficulties were disallowing her to fulfil her parental role sparked a desire to find her identity as a mother, and as a person, in order to give her children what she missed: *"I want to change in order for them to have the relationship that they deserve with me"* (41, 930-31). Similarly, Amy spoke about necessitating a reason greater than herself: *"…one [reason for change] that always sticks in my mind for me is my daughter being taken off me."* (23, 510-11). The realistic possibility is ever present in her mind, as a reminder of what could be lost.

Rachel revisits the frequent thoughts which enabled her to continue with the process of trying to live, even when having thoughts to take her life:

"my husband he is[…] my pillar in my life and it's wonderful, I have three beautiful children I love to pieces and you know I have to be around for them and it's not just I have to, I want to be around for them" (9, 202-204).

There is a cognitive shift from an obligatory responsibility of having a role as a wife and a mother which once was not enough ("*before it was more I really don't care"*- 10, 210) to her own distress being outweighed by her aspiration to be alive and experience life with her family. Jenny spoke about requiring an external drive in the absence of any value she placed on her own life:

"[something] that's more important than you are because sometimes when you lose that sense of self you can't do it for you" (43, 978-80). Frequently speaking of her mother as her *raison d'être*; with a tone of sincerity and utmost positive regard, she states "*and that's what made me want it [to live]"* (45, 1014-15). It was notable that many participants did not view their own lives as a good enough reason, consequently needing something more *significant* to focus their energy on, perhaps until they could accept their own intrinsic value and change for themselves.

1.2. "You need to fully want to, fully fully want to change": active process of readiness and a *want* to be different

The desire to overcome their struggle, leading to motivation and determination to change, was present for most participants; internal readiness to change served as a precondition before any external intervention could be of use. In the quote below, Ashley emphasises a change for, and within, herself involving a want for a better life which allowed greater use of the support: *"no matter how much help was offered to me I didn't improve […] only when I decided this isn't the life I want (pause) that the help was helpful"* (17, 533-536). The frequent use of *"I"* and *"I'd"* emphasises the power of herself in the process of making decisions regarding change. Kate emphasised *"I didn't want to be that person anymore*" (24, 540). This suggests the ability to reflect from a third-person perspective the discontentment with her past self, which enabled her to develop a conception of the person she wanted

to be. However, for her and many other participants, recovery was inconceivable without desiring change: *"you've got to want it [recovery] before it will happen and I knew that"* (Kate: 25, 524-26).

Similarly, Jenny alluded to there being dissatisfaction with herself, her psychological states and functioning which summoned the motivation required to face the challenge ahead.
"If you put me not motivated through that process I wouldn't be where I am, no. I think a huge part of it was the decision that I am sick of living my life like this" (9, 195-97).

For several participants, this 'readiness' appeared to be generated from a desire to live, thus requiring action on their behalf to enable this to happen. Some spoke about a frustration with their lives, as if their way of living was an obstruction to change. Three participants engaged in a process of existential thinking, whereby they questioned their emptiness and how they wanted to live their life. For Jenny, wanting to *live* has meaning in terms of the quality of being *alive* over a state of desolate existence: "*wanting to not live like the way I was living because I weren't living, wanting to stop existing and wanting to start living"* (45, 1016-18). Rachel speaks about a transitioning process; from not caring for her life to philosophising led to an ability to find hope in a hopeless state, do what was required to become well and stay well, and believe there is a life beyond BPD: *"but it is worth living for there is so much you haven't done or seen and you know there is still a lot of life left, go with it […] do what's needed sometimes it's not joyful but so what"* (42, 964-966).

2. Riding the bumps: learning to *live* with BPD

All participants described recovery as a process of learning to live a fulfilling life *with* and *alongside* BPD, as some of their difficulties remained.

2.1. "…you will never ever ever ever stop climbing": recovery as a lifelong, fluctuating process

As the sub-theme denotes, many participants spoke about learning to manage the unremitting fluctuating recovery process, which was described as a continuous, ongoing "journey", oscillating between periods of stability and setbacks. Integral to this was a process of acceptance in terms of who

they are and the limitations their difficulties placed on them. Ashley contrasted recovery from BPD to an easily treated common cold:

"I don't think it's like a cold where you can have a cold and then get better, you just learn to live with it and the bumps and the hills you learn to ride them, you learn to go up and down and over them but you're never better" (26, 842-45).

The metaphor of *"bumps and hills"* implies that recovery is a non-linear process, and whilst there are challenges along the way, *"to ride them"* suggests acceptance and coping with a struggle. The emphasis on *"never [getting better]"* illustrates the perpetual process of adapting to live with BPD. Likewise, Jenny compares recovery to climbing "*the biggest mountain that you've ever climbed in your entire life"*, where the process of change *"will never ever ever stop"* (42, 960-63). This is symbolic of the everlasting challenge described by several participants, involving progress yet requiring one's own determination to overcome difficulties. Jenny also refers to accepting that recovery involves fluctuation and describes this as a continual process of management where she has to apply *"120%"*- *"I'm constantly working on being 'normal' […] on maintaining normal function and normal behaviour"* (30/31, 689-691). It is as if Jenny sees herself as fundamentally different, with habitual patterns of being; therefore, functioning as 'normal', as a socially constructed expectation, is a conscious and wholly effortful undertaking.

For Rachel, recovery is "*being able to cope with your illness in a way that it just doesn't stand in the way of living*" (1, 21-22). Where BPD has previously been a barrier to living functionally, the process has been acceptance of herself and trying to develop skills to find a way to manage. Amy remains doubtful about ever being free from some of her difficulties: *"I don't feel like any amount of therapy […] or a tablet would build up my trust with anybody and could stop my impulses"* (6, 123-25). Similarly, Lisa described her moods remaining changeable throughout recovery: *"I do get days like this, you know bad days and it's not going to be the end […] and just get through them"* (14, 453-54). *"The end"* implies a sense of anxiety that wellness is temporary. She emphasises persevering through *"bad days"* by normalising the inevitability of their occurrence and reminding herself that they will pass. In contrast, Rachel spoke about her recovery as a gradual process, occurring when

unaware, until she eventually noticed positive psychological change: *"it has felt like recovery has kind of crept up on me"* (48, 1091-92).

2.2. Learning to do things more adaptively through psychological change

For all participants, recovery involved acquiring adaptive living skills through increasing their ability to manage thoughts, self-regulate, and control impulsive behaviours. For Rachel, there is a clear temporal element; she frequently says *"used to"* implying that despite feeling the same, there is a change from past destructive behaviours to managing distress in a safer, less damaging way.

"I might still shout and scream and cry but I am more likely to actually go and dig my head under the pillows and just cry and be upset […]but <u>*not*</u> *do anything about it"* (24, 543-46).

The significant change is *not* acting which suggests strength of mind and effort to control behaviours that formerly would have been inconceivable. Similarly, Kate has found increased emotional stability, *"instead of like rollercoaster up and down each day"* (12, 261-62), with more effective coping strategies:

"if I get angry now then I go in the back garden and have a cig instead of […] just reacting before thinking" (24, 532-34) and *"to react in the right way means that there's no [negative] consequence for acting"* (25, 566-67).

Greater awareness of internal states has permitted a controlled and thoughtful outward response in contrast to the out of control feeling Kate previously experienced. The emphasis on *"acting"* suggests that whilst emotions are distressing, responding unhelpfully is equally damaging. Similarly, DBT has enabled Amy to increase her ability to manage emotions, achieving a state of 'wise mind' which is balanced and regulated: *"it's helped me quite a lot not to get into that emotional state, uhm, and to try and keep a balance of it"* (4, 81-82).

Many participants referred to the development of mindfulness skills to manage ongoing difficulties. Lisa said *"I'd got a book on my shelves about it so I read it and it was the* <u>*best thing ever,*</u> *cos it just makes me feel power in my head"* (8, 239-241) and *"I can do that and it really works"* (244). The change from *"it"* to *"I"* acknowledges her own role in successfully utilising mindfulness,

with the *"best thing ever"* implying gratefulness for finding something so effective which eventually becomes habitual, not requiring external resources, and gives a sense of control and confidence *("power in my head").* Hayley spoke about combining what works, utilising existing skills in meditation to bridge the gap, when she cannot mentalise and her emotions *"take over"*:
"I can then link that into my breaths, my changing breaths that I do for my meditation which then can bring me back into a place where I then can" (14, 322-23).

2.3. "It was always so black and white whereas now it's not": improved interpersonal effectiveness through increased ability to mentalise

An important aspect of the recovery experience is increasing awareness of self and others' viewpoints leading to improved relationships. Lisa talks about mentalisation skills requiring restructuring of cognitive processes, implying change in fundamental ways of thinking and being. She refers to MBT having *"helped me to be rational, especially in a group situation, because it can get quite heated sometimes, and if I don't react too much, that's good"* (30, 972-74). Talking in a deliberative way, *"rational"* suggests a new ability to be judicious in interpersonal situations and hold other perspectives in mind, which may be challenging. Not reacting *"too much"* suggests control over her thought processes and subsequent actions, and an ability to monitor herself and others. Similarly, Ashley states: *"[the therapist] challenging me has made me, has made it so I can see it from other peoples points of views"* (5, 132-40), later continuing "*that it wasn't always black and white*" (6, 167). This process involved appraising her own perspective and way of thinking, through being challenged, thus facilitating a broader awareness and recognition of multiple interpretations and mental states of others.

Likewise, Jenny talks about an increased ability to view the situation from an objective position: "*I can now think more clearly about when I am behaving or doing something, I am always thinking about what kind of impact that will have on other people*" (7, 153-55). *"Thinking clearly"* refers to a reflective capacity regarding herself and others. *"Always thinking"* suggests it is a constant, conscious internal process which has a positive impact on external relationships and understanding of

others. Kate stated *"I don't bite anymore"* (9, 197), referring to calmer responses to her ex-partner's hurtful and personal comments. It appears to be a combination of a changed belief about herself and a new understanding enabling her to interpret the situation differently:

"*…to call me a freak, weirdo, psycho, nutter and I just used to blow […]I don't have that reaction I don't even have that seeing red and not knowing what I'm doing, I've not had that since starting this [MBT]"* (9, 200-203).

2.4. Finding purpose and meaning in negative experience

Five participants described finding positive purpose for their negative experiences, both as a reality and an aspiration, as facilitating the recovery process. Rachel spoke about recovery enabling her to want to help others, in terms of an altruistic act to *"make a difference"*, *but* also to give purpose and meaning to her adversity:

"I want to have a life to make a difference [….]it makes me feel it was worthwhile that I had to go through, or went through, a really bad time of my life, erm but if it really means that it has helped other people, yeah, then it's worth it" (41/42,919-27)

Likewise, Hayley talked about considering a vocation from being an EbE and seeing herself as capable of helping others*:"'cause I understand what it's like, I mean I said to [the psychologist] when he did my interview and I said to [the psychologist], I'd love to run these MBT courses, he said you'd be good at it"* (32, 744-46). Through her shared experience with others, she has greater capacity to empathise and *"understand"* their difficulties, allowing her to use her experiences positively. Not dissimilarly, but more idiosyncratically, Jenny talks about the paradox of her difficulties also being positive qualities:

"it has been really difficult but it gives me a dimension and an ability to understand, an ability to reflect on things and feel things in a way that other people can't so in a sense it's a gift at the same time" (31, 707-10).

She has gone through a process of self-realisation, where difficulties previously considered 'problematic' are now viewed as 'unique qualities', enabling her to be more receptive to others and

feel things in a deeper way. It is likely that, when in the midst of chaos and despair, it would have been difficult to view these aspects of herself as enriching.

3. Changes in perception of Self

This theme describes the experience of a transformation or positive development in participants' view and sense of themselves which was essential in their recovery. These developments refer to personal changes within themselves as a result of self-discovery and therapeutic intervention.

3.1. Increased self-awareness

Many participants described recovery as being facilitated by a process (often through therapy) of developing an understanding of themselves. Ashley describes how learning about herself in the context of her past enabled a greater awareness of her present patterns of relating: *"Now, after my psychology and stuff I know why I'm saying no go away, cos I'm saying no go away so I've pushed them away before they can do it to me"* (14, 432-35). Similarly, Kate speaks about an increasing understanding of her difficulties being a necessary facilitating factor for change: "*I didn't really see as, not a problem but an issue, the issues are showing more now because I can see them more now*" (7, 143-45). For Hayley, she is learning about herself and what is required to feel better, such as becoming attuned to her emotions: *"I'm trying now to tune in with my feelings because I've realised that my feelings are the things that have been put on hold"* (15, 339-41). It is as though such aspects of herself have been difficult to acknowledge and give deserved attention to without this increased awareness of what she needs.

Rachel attributes her greater self-awareness to maturity, as a result of extensive life experience: "*I hate it but I think I'm more mature to understand things better and take that stance of stop and think about things more you know, I think it's life experience teach you a lot*" (48, 1100-02). This suggests a difficulty accepting that it is with time that she has gained awareness. *"Things"* is all encompassing, implying an increased understanding of herself, her thought processes, emotions and behaviours. However, she later acknowledges how therapy has "*given me the answers to the questions*

I have been asking over the years but perhaps not been quite as ready to know you know all the whys and how and where and […]actually work on that and actually understand it" (5, 99-102).

Participants spoke about the increasing ability to recognise triggers, and observe and manage their cognitions. Jenny reflects: *"I am able to pinpoint the point where I can see where my thoughts are starting to take me down a dark place and I can stop them"* (3, 49-51). A *"point"* implies a recognisable precipitant where thoughts *take* her, suggesting she perceives her cognitions as controlling her. The change is her own ability to become aware of her thoughts, and take action enabling her to "*break it [the chain of events] further up*" (3, 54) before they take effect.

3.2. Development of self-belief

Four participants referred to the development of self-belief, in terms of overcoming difficulties and progressing with their recovery. This was coupled with an increasing ability to be self-acknowledging of their achievements and self-compassionate, leading to a growing sense of self and self-realisation. Rachel reflects on conversations with her husband where she acknowledges her role in positive changes: *"in the past you would have done this you know, today you didn't […] then it's trying to acknowledge that I've done a good thing"* (47, 1071-75). She later continues *"sometimes, sometimes I do feel like patting myself on the back saying maybe I am bit further than some [people]"* (43, 985-87). The element of modesty in her discourse, coupled with the repetition of *"sometimes",* suggests a difficulty to self-praise and acknowledge her positives. However, the use of *"I"* shows a claiming narrative, whereby she takes ownership by congratulating herself and is able to reflect on her progress, signifying self-development. Similarly, Ashley engages in motivational and encouraging self-talk where she describes belief in her capacity to cope following a setback: "*it's hard to get through it again, but you can though, that's the thing, you can"* (11, 330-33). Later, her narrative suggests knowing that her progress is a result of herself: *"I feel good that I can think about it in that different way […] I'm proud of myself"* (14, 450-52).

Lisa often talks about a transition from having someone else to encourage and believe in her, to developing this for herself: *"It's helped me to start believing in myself*" (12, 376-77) and *"now I'm*

starting to feel that I am doing well for myself is great as well and I feel pleased when I do ok" (12, 384-86). Contrastingly, for Kate the development of trust and belief in herself is essential before she can use or consider others' feedback: *"you've got to believe in yourself before you believe anything that anyone else says"* (7, 139-141).

3.3. Autonomy and independence as an achievement and aspiration

Participants referred to independence both in terms of their sense of autonomy in the recovery process, and increasing agency as a goal. Rachel spoke about changes in her coping strategies whereby she may still struggle but–*"I am still alive and I have not had to have any intervention of any services"* (25, 555-56). She describes an ability to survive and deal with distress alone, which emphasises hope, personal achievement and increasing autonomy. For some participants, the ultimate goal would be to independently manage their difficulties, where absence of service involvement is symbolic of their recovery: *"it does seem like well if I can get rid of all that, I must be great (laughs)*" (Rachel: 34, 767-68).

Likewise, Lisa speaks powerfully about a sense of personal development in relation to herself as an independent and autonomous being: *"I am learning to grow as a person and to realise I can do without support sometimes and I can do without reassurance and standing on my own two feet"* (2, 50-53). She is developing resilience in order to function, cope and live without depending on support from others. For Kate, efforts to improve her coping and functioning have had a significant impact on her independent skills as a mother: *"I've needed them quite a lot in the past but I feel like I'm at the point now where I don't need Social Services"* (11, 249-50).

In divergence, some participants spoke about their autonomy in reaching this point serving as a motivational factor for moving forward. For example, Ashley says *"no matter how much you're struggling, that's in your head that I've worked too hard I don't want to lose it all this, I've worked too hard to achieve where I am now"* (7, 200-203). Through her own struggle, *"where I am now"* indicates that she has done it without others and has to consciously remind herself of her self-sufficiency in achieving wellness, which serves as self-encouragement to continue the journey.

4. Recovery as a relational process

All participants referred to the need for support from others, both professional and personal, in the process of change. Participants spoke about the presence of others and attachment relationships as a requisite for progress insofar as recovery not being possible without them.

4.1. "you want to, to know that they are actually there": the ongoing necessity for a secure base

Many participants spoke about how the approach from others is extremely influential in terms of their progress and how they see themselves, with consistency and acceptance from others increasing their self-development. For Ashley, access to the appropriate support at a specialist unit enabled her to become less dependent on services: "*if I hadn't have had individual therapy right […] I'd probably still be going in and out and in and out of hospital"* (21, 682-685). Similarly, Hayley described being isolated and lonely and that paying for therapy was her only means of moving towards improved functioning and recovery: *"'cause I couldn't deal with it all on my own so that, that's how I coped, that was my coping strategy"* (17, 384-85).

Many spoke about gaining security from access to services. There was a sense from some that coping will never be absent of services and that periods of instability requiring support are a natural part of experience. For example, Amy states *"when things are going well and everything's fine […]I still need the help of the Home Treatment Team and I don't feel like it's a negative"* (27, 605-07). Likewise, for Ashley, the integral role of support remains, where decisions regarding her need for support and stage of recovery is subjective: "*I know when I'll be ready for them to start reducing*" (23, 748-49). Rachel also spoke about the necessity of ongoing support, referring to her husband as her "*pillar"* and expecting the same consistency and unconditional support from mental health professionals: "*you want to, to know that they are actually there*" (23, 513-14). She later re-emphaises the value of ongoing support: *"it's ok to have a shit day, it's ok to feel or need someone supporting you, holding your hand, whatever it takes"* (34,776-77). There is a sense that generally Rachel can

function autonomously; however, words like “support” and “holding” symbolise the physical availability and presence of others when things are difficult.

For some, the mental health system was impacting negatively on their recovery progress, particularly where services were experienced as invalidating, inconsistent and disempowering. Amy spoke about numerous changes in her care reinforcing feelings of abandonment, and hindering positive change: “*so they gave me him [care-coordinator] for a bit and then started to trust him, then so, that stops you on your road to recovery”* (14, 318-20). This suggests that a person-centred, stable and consistent service served as a foundation for change for individuals.

4.2. Therapeutic relationships as vehicles for change

Participants spoke about the relationship with their therapist and/or other mental health professionals as a means of increasing their understanding through exploration of difficulties, and acting as a safe holding space to work through their difficulties and on their relationships. Lisa spoke about how her therapist challenged her, enabling the development of introspection and new understandings to *“sink in”*, which was only possible with the development of a trusting therapeutic alliance: *“I think it over, talk it over then, yes things seem to sink in better”* and *“she is coming straight back at me with a reason […] things that I just take for granted about myself my days there’s reasons for”* (6, 177-83). Similarly, Ashley talks about working beneath the surface with her therapist to overcome the distress resulting from past experiences: “*the longer I used to hide it the more it it bothered me inside cos when I did start talking about it it wasn’t bothering me inside cos I was sharing it”* (16, 498-00).

In the description below, Jenny captures how the therapeutic relationship, and overcoming challenges within it, enables learning to transfer into everyday life outside of therapy: *“the way we got through them and all those things it was like a little environment and example of the real world in a very safe setting where I could work how to function in the real world*” (6, 123-25). In a sense, the therapist was a containing person to test out a way of behaving in a focused way which provided real world applicability. She later emphasised the significance of the therapeutic environment: *“your outer*

world and your inner world become a reflection of each other" and putting herself *"around consistent people and consistent environment"* (17, 382-85). *"A reflection"* suggests almost a mirror image, where Jenny's previously chaotic thoughts, beliefs and emotions were influenced by the calm, consistent and predictable environment. For many of the participants, their environment, and especially their relationships, had a substantial impact on their ability to develop the skills to manage and were a necessary ingredient for personal change to take place.

Discussion

This study aimed to explore the experience of recovery in relation to BPD. In line with the research objectives, the interview schedule was designed to explore the meaning of recovery for individuals with BPD, in addition to what has facilitated and what maintains their recovery. Data gathered from semi-structured interviews were analysed using IPA, revealing four key themes: 1) "This isn't the life I want": motivation as a prerequisite to change; 2) Riding the bumps: learning to *live* with BPD; 3) Changes in perception of Self; and 4) Recovery as a relational process.

Participants described novel experiences and meanings of recovery; however, the themes also share similarities with findings from previous recovery literature. This study supports a conceptual model of recovery by Jacobson and Greenley (2001) which suggests that this process is affected by the reciprocal interaction between internal and external conditions. For example, internal factors may be readiness to change, self-development and acceptance, and external factors may be the provision of support and approach from others. Additionally, the findings have applicability in terms of theories of change, such as the Transtheoretical Model of Change (Prochaska, Redding & Evers, 2008), whereby individuals work through their ambivalence as a barrier to change (pre-contemplation), then focus on thinking about change (contemplation), before actively engaging in the process of making change by doing things differently (action and maintenance). The themes from the current study are also comparable to the processes of change (Prochaska *et al*., 2008); for example, self-liberation with

‘Changes in perception of Self’; helping relationships with ‘Recovery as a relational process’; and counter-conditioning with ‘Riding the bumps: learning to *live* with BPD’.

The first theme set a context for the experiences described by individuals, with motivation being a prerequisite to the recovery process. All participants referred to either having external reasons to change, as denoted in the first sub-theme, or wanting to change for themselves. Ultimately, this desire for change needed to occur before any therapeutic support could be meaningful. This was described as challenging, in terms of individuals being unable to cope with their difficulties, and wanting to change but lacking the independent skills to do so. The increased frustration with ‘existing’, comparable to the sense of emptiness experienced by many, as opposed to living a fulfilling and meaningful life was a significant motivator for seeking help and engaging with services. This theme shares some similarities with findings from Pitt *et al.* (2007) whereby participants described motivation to recover; however, this was enhanced by a process of empowerment which was less evident in this study. It remains unclear what enables individuals in this present study to move toward contemplation, and what is required to facilitate readiness for therapeutic change.

The second theme suggests that participants experienced recovery as a process of learning to live alongside their difficulties by dealing with and accepting aspects of themselves i.e. fluctuation in emotions that would not change. This echoes earlier findings from Deegan (1988) concerning the acceptance of limitation allowing a deeper discovery of themselves involving developing healthier, less destructive strategies which meant they were able to continue living. Despite this, recovery and the utilisation of coping strategies was described by most as an ongoing struggle like “climbing a mountain”, as one participant described. It was spoken about as an oscillating state, characterised by periods of progress and stability, and fluctuations in their ability to cope. Many participants spoke about having realistic expectations for the challenges ahead, which meant managing the requirements of living whilst constantly trying to implement change. This is comparable to previous studies where participants experienced recovery as an ongoing process requiring active effort, with improved functioning enabled by the development of coping strategies to manage remaining difficulties (Anthony, 1993; Katsakou *et al.*, 2012). Similarly, despite considering recovery as continuous and

happening over time, for all but one participant in this study the idea of recovery as absence of difficulties was considered an improbable goal (Katsakou *et al.*, 2012).

Participants also spoke about developing skills to actively and fully participate in their lives, which is likened to the findings from Pitt *et al.* (2007) where participants described their recovery as ultimately requiring them to be active, dealing with setbacks and taking on roles that gave them a sense of purpose. As part of developing strategies, participants in the present study described: 1) learning to do things differently, gaining emotional regulation/tolerance and reduction in impulsive behaviours, and 2) improved interpersonal effectiveness through increased capacity to mentalise and understanding themselves in relation to others. Similarly, participants in Katsakou and colleagues' (2012) study referred to gaining control over emotions and thoughts, leading to reduced self-destructive behaviours and improved relationships. This theme also reflects findings from quantitative studies, which show that destructive and impulsive behaviours decline relatively early in the course of BPD (Choi-Kain *et al*., 2010; Skodol *et al*., 2005). This could be supported by findings from the participants in this study, most of whom had only been diagnosed in the few years prior. Previous quantitative literature has also shown that interpersonal functioning improves over time and that individuals increasingly develop and maintain meaningful relationships (Choi-Kain *et al.*, 2010; Davidson *et al*., 2010; Paris and Frank-Zweig, 2001).

The findings in this present study are congruent with existing psychological interventions and research for the effectiveness of psychological therapies, such as DBT and MBT and generic treatment models such as Structured Clinical Management (SCM; Bateman & Krawitz, 2013), which specifically target some of the core difficulties characteristic of BPD. For example, in Bateman and Fonagy's (2008) study, individuals who received MBT showed a significant statistical decrease on measures of depression, suicidal acts and self-harming behaviour. In addition, DBT has been shown to significantly reduce the incidence of suicidal acts (Linehan *et al.*, 2006) and improve interpersonal functioning, depression, anxiety and social adjustment (Bohus *et al*., 2004). Participants in the present study referred to future goals of seeking employment, particularly in the field of mental health, both as an altruistic act and as serving to find purpose in their experiences. Katsakou *et al.* (2012) found

that participants reported getting involved in activities and employment throughout their recovery, however, this was presently not a reality for many in this study. This may be linked to findings from quantitative studies that have shown that individuals continue to experience difficulty in social and vocational functioning (Jones, 2014).

The third theme relating to positive changes in sense of self indicates that self-awareness and self-belief are necessary for increased autonomy and needed for progression in recovery. Participants spoke as if they were reconstructing themselves to enable the development of an identity where they were not defined by their difficulties. Therapeutic intervention to make sense of their experiences seemed integral to the development of aspects of themselves. However, there was a progression from requiring others to facilitate this to an increased capacity to become, in a sense, their own therapist and develop self-reliance. This is supported by literature suggesting that the environment and/or therapeutic relationship acts as a containing space to facilitate the development of attunement to oneself and autonomy (Siegel, 2010; Winnicott, 1965). This also shares similarities with Pitt *et al.'s.* (2007) study where recovery involved self-awareness which developed from therapeutic treatment and making sense on one's own terms, and an increased understanding of themselves which led to an enhanced sense of control. Additionally, they described learning to recognise their achievements which was echoed by many participants in this study, whereby self-compassion and self-praise was difficult to develop but proved invaluable in their recovery. Similarly, the process of developing self-belief, a sense of achievement and autonomy was mirrored in Katsakou *et al.'s* (2012) and Castillo *et al.'s* (2013) studies, where participants described developing self-confidence, self-acceptance and self-esteem.

All participants in the present study emphasised the necessity of consistent peer and/or professional support, often serving as a secure base to facilitate, maintain and found their recovery. This shares similarities with themes in other literature, such as 'Rebuilding social support' (Pitt *et al.*, 2007) and 'Feeling cared for' (Castillo *et al.*, 2013) where it was suggested that support from mental health professionals and wider social networks was essential for change to occur. Participants in this study emphasised the necessity and benefit of continued support from others, even as many of their

difficulties reduced. This finding echoes suggestions by Turner *et al.* (2011b) regarding the importance of therapeutic interventions which place emphasis on supporting individuals to increase their social interaction.

The therapist and/or others as a secure base and an attachment figure is also pertinent in this theme. This is in line with some of the earliest findings in attachment literature from Bowlby, regarding a secure and healthy attachment to the therapist allowing deeper exploration within therapy, and being considered central to the therapeutic process (Castillo *et al.*, 2013; Romano, 2007).

Clinical and Practical Implications

The findings indicate several implications for clinical practice. Firstly, the first theme ("This isn't the life I want": motivation as a prerequisite to change) suggests that individuals need to be ready and motivated to make changes. This provides important clinical implications in terms of determining readiness to change at assessment before considering intervention. Using the Transtheoretical Model of Change (Prochaska *et al.*, 2008) and motivational interviewing techniques at this time may be vital to support individuals to think about making change and what needs to happen to move them from precontemplation to action. This research would suggest that therapeutic intervention serves to foster hope for progress through validation of experiences in group therapy, provision of psychoeducation regarding BPD and the effective interventions, and small changes at the start of therapy increasing the possibility of change.

Secondly, many participants spoke about the importance of a therapeutic relationship and a secure base, both in terms of self-development and awareness, and to improve their functioning within interpersonal relationships. The value of a consistent environment and genuineness could not be emphasised more by participants. Research has long suggested that factors for an effective therapeutic relationship, such as validation, empathy, genuine positive regard, rupture and repair and having shared understandings (Bateman & Krawitz, 2013; Norcross, 2002) are key ingredients to foster secure attachment to clinicians. This study confirms the importance of providing a secure base where a consistent, predictable and genuine approach, coupled with sensitive challenge and support to

manage change, enables individuals to develop and autonomously make positive progress. It is important to note that this does not solely apply to therapists, but to all mental health professionals who are in contact with individuals diagnosed with BPD, and also for group settings where peer support could be seen as a safe foundation. Clinicians would benefit from specific training to emphasise the rationale and importance of establishing a relationship which fosters the development and recreation of a strong secure attachment to the professional, particularly where earlier attachments have been insecure.

Thirdly, within the sub-theme ‘Finding purpose and meaning in negative experience’, many participants spoke about their wish to use their experiences to provide hope and support to other people with similar difficulties, some aspiring for a career in mental health. This emphasises the importance of service-user involvement and initiatives such as co-production in service planning and delivery (Bouvaird, 2007), where EbEs are visible within teams (Slade, 2007). Involvement in service provision not only has potential to empower individuals in their recovery (Cooke, 2012), but will also prove invaluable for professionals and service-users to challenge stigma and beliefs regarding the possibility of change. However, findings in this present study and previous literature suggest that whilst participants described an increased ability to manage distress and mentalise, difficulties undertaking and maintaining employment, requiring independence, increased responsibility, and interacting socially, remain. Despite efforts to ensure that therapies do encourage autonomy, improved activities and vocations, services have a role in supporting individuals to consider training or development in meaningful and personally salient employment. Many NHS Trusts have employment support services or involvement schemes enabling individuals to take steps towards their desired vocation. Specifically, increased focus should be given to encourage individuals with this diagnosis to consider vocational opportunities, particularly in mental health and caring professions.

Strengths and Limitations

This is the first IPA study to explore the experiences of recovery described by individuals diagnosed with BPD. Despite a prior Grounded Theory and Thematic Analysis study exploring

recovery, and more specifically recovery goals (Katsakou *et al.*, 2012), this is the first study to date which captures in-depth, how recovery experiences are construed and made sense of by participants. These findings make an important contribution to understanding recovery in clinical practice. Additionally, the researcher endeavored to include as many participant excerpts as possible to ensure interpretations were grounded in the data.

However, the study is not without its limitations. Recruitment took place from teams where DBT, MBT and SCM are considered for individuals with a formal diagnosis of BPD. It was evident that the therapeutic approaches influenced what was important in participants' recovery; therefore, it cannot be assumed that their views and experiences are shared by those without any prior therapy experience. Nevertheless, the development of effective psychological interventions for BPD means that increasingly individuals accessing community services will have received therapy at some point. Purposefully trying to capture experiences which have not been shaped by therapy would be difficult as effective treatments are available for individuals with this diagnosis.

Despite being beneficial as it increases the homogeneity of the research, it is noted that only females participated in this study and therefore the recovery experiences of males may differ. However, the experiences described by participants were similar to previous research which included male and female participants (Katsakou *et al.*, 2012), suggesting that there may be shared experiences.

As the author was a novice IPA researcher, it was reflected that the interview style progressed and developed with each interview, possibly impacting upon the depth and richness of the data collected in the first two interviews. Supervision was utilised to discuss this and consider how the interview style could be adapted; consequently, the style of latter interviews was more likely to explore, at a deeper level, individuals' experiences by seeking out particular examples which enhanced the meaning of their descriptions.

Implications for Future Research

Some participants spoke about their experiences of having a diagnosis of BPD, both in terms of knowing that they had difficulties and receiving the diagnosis. Receiving a diagnosis was described

as a validating experience, decreasing participants' sense of being alone, whilst also increasing fear of stigma and being defined by the label. Participants provided interesting and valuable descriptions of their experiences of receiving the diagnosis; however, it was not within the objectives and scope of this research to include these. The author is aware of one paper by Rubovsky *et al*. (unpublished) who found, when exploring responses to the diagnosis, that hope increases upon receiving it; however, future research may benefit from exploring how receiving a diagnosis impacts on the recovery process. Additionally, in line with the first clinical implication, further research to determine what facilitates and enhances readiness to change could be essential in terms of intervening with individuals who are at precontemplative or contemplative stages of change.

Conclusion

This study enhances the understanding, within existing recovery literature, of the unique recovery experiences of those diagnosed with BPD. The research found four master themes, broadly referring to the necessity for motivation to change, learning to live with BPD, the development or changed perception of Self and the integral role of support. Participants significantly benefitted from therapeutic interventions which focused on increasing their ability to cope through improved management of emotions and interpersonal relationships, and encouraging the development of self-belief and awareness. For participants in this study, a recovery model within services would involve a consistent and reliable approach, whereby individuals are empowered to have a role in decision-making and in finding use for both adverse and recovery experiences through employment opportunities.

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Appendix A

Author Guidelines

Clinical Psychology Review

For full author guidelines see http://www.elsevier.com/journals/clinical-psychology-review/0272-7358/guide-for-authors

Manuscripts should be prepared according to the guidelines set forth in the Publication Manual of the American Psychological Association (6th ed., 2009). Of note, section headings should not be numbered.
Manuscripts should ordinarily **not exceed 50 pages**, *including* references. In general the References section should be limited to citations actually discussed in the text.
Authors can direct readers to the appendices in appropriate places in the text.

Essential title page information
Title. Concise and informative. **Note: The title page should be the first page of the manuscript document indicating the author's names and affiliations and the corresponding author's complete contact information.**

Abstract
A concise and factual abstract is required (not exceeding 200 words). This should be typed on a separate page following the title page. The abstract should state briefly the purpose of the research, the principal results and major conclusions. An abstract is often presented separate from the article, so it must be able to stand alone.

Keywords
Immediately after the abstract, provide a maximum of 6 keywords, using American spelling and avoiding general and plural terms and multiple concepts.

Footnotes
Footnotes should be used sparingly. Number them consecutively throughout the article, using superscript Arabic numbers.

Figure captions
Ensure that each illustration has a caption. Supply captions separately, not attached to the figure. A caption should comprise a brief title (**not** on the figure itself) and a description of the illustration.

Tables
Number tables consecutively in accordance with their appearance in the text. Place footnotes to tables below the table body and indicate them with superscript lowercase letters. Avoid vertical rules. Be sparing in the use of tables and ensure that the data presented in tables do not duplicate results described elsewhere in the article.

References
Citations in the text should follow the referencing style used by the American Psychological Association. You are referred to the Publication Manual of the American Psychological Association, Sixth Edition.

References should be arranged first alphabetically and then further sorted chronologically if necessary. More than one reference from the same author(s) in the same year must be identified by the letters "a", "b", "c", etc., placed after the year of publication. **References should be formatted with a hanging indent (i.e., the first line of each reference is flush left while the subsequent lines are indented).**

Appendix B

Information regarding measures used

SCID-I - diagnostic instrument used by clinicians

DIB-R - measures affect, cognition, impulse action patterns, and interpersonal relationships

DSM scale - a scale devised of 27 items making up the diagnostic criteria (DSM-III) for BPD

Cornell Checklist - symptom checklist for individuals with personality difficulties

Acts of Deliberate Self-Harm Inventory - a structured interview to assess the number of suicide attempts or self-harm since the last appointment

LSDS - a semi-structured interview to assess the number of episodes of self-mutilation and suicide attempts before and at follow-up

GAF - numeric scale (0 through 100) used by clinicians to rate subjectively the psychological, social, and occupational functioning in areas such as work or education, family relations, judgment, thinking, or mood

LIFE - clinician administered questionnaire to assess the longitudinal course of psychiatric diagnosis by collecting psychosocial and psychopathological information

SFQ - assesses self-care, domestic skills, community skills, social skills and responsibility

DAS - self-report measure containing 50 items selected to assess dysphoric affective and cognitive states reflective and characteristic of BPD

Appendix C

Authors Guidelines

Qualitative Research in Psychology
No specified word count
Manuscripts should be double-spaced throughout, especially the references. Pages should be numbered in order. The following items must be provided in the order given:

1)Title Page. *Authors and affiliations:* Authors should include their full name and the establishment where the work was carried out.

Abstract: Please provide an abstract of approximately 150 words. This should be readable without reference to the article and should indicate the scope of the contribution, including the main conclusions and essential original content.

Keywords: Please provide at least 5–10 key words.

2) Text. Subheadings should appear on separate lines. The use of more than three levels of heading should be avoided.
Footnotes should be avoided. If necessary, they should be supplied as end notes before the references.

3) References. The Harvard style of references should be used. The reference is referred to in the text by the author and date (Smith, 1997) and then listed in alphabetical order at the end of the article applying the following style:

Book: Hollway, W & Jefferson, T 2000, *Doing qualitative research differently: free association, narrative and the interview method*, Sage, London.
Edited book: Brown, LM 2001, 'Adolescent girls, class, and the cultures of feminity', in MJ Packer & MB Tappan (eds.), *Cultural and critical perspectives on human development*, SUNY Press, Albany, NY, pp. 219–240.
Journal article: Madill, A, Jordan, A and Shirley, C 2000, 'Objectivity and reliability in qualitative analysis: realist, contextualist and radical constructionist epistemologies', *British Journal of Psychology*, vol. 91, pp. 1–20.

4) Tables. These should be provided in a separate file from the text and should be numbered in sequence. Each table should have a title stating concisely the nature of information given.

5)Figure captions. These should be provided together on a page following the tables.

6) Figures. Figures should ideally be sized to reproduce at the same size. All figures should be numbered consecutively in the order in which they are referred to in the text. Qualifications (A), (B), etc., can only be used when the separate illustrations can be grouped together with one caption.

Appendix D

Theoretical contributions

Phenomenology was founded by Husserl; however, Heidegger, Merleau-Ponty and Satre are among its contributors. Despite having contrasting views on phenomenology, they share an interest in exploring what being human is like and how we have come to understand our experiences (Smith, Flowers & Larkin, 2009). During the analysis process, maintaining a phenomenological attitude that is open and non-judgmental, whilst bracketing (setting aside) prior assumptions and knowledge is essential (Biggerstaff & Thompson, 2008).

Schleiermacher, a major contributor to hermeneutics theory, upheld that interpretation involves both grammatical (textual meaning) and psychological (unique individuality of the speaker) interpretations (Smith *et al*., 2009). This level of interpretation enables identification of something which may be latent. Our perceptions of events are unavoidably influenced by our past experiences, existing beliefs and knowledge (Eatough & Smith, 2008). Therefore, IPA involves first seeking out the participants' sense of their experiences before interpreting "meaningful insights which exceeds or subsumes the claims of the participant" (Smith *et al.*, 2009, p.23); referred to as the 'double hermeneutic'. Key to this theory is the concept of the hermeneutic circle, which refers to the active relationship between the whole and the parts; therefore, IPA is an iterative and circular process of meaning-making (Eatough & Smith, 2008).

The third theoretical contribution comes from idiography. Its application to IPA is seen through the careful selecting of individuals within a specific group. IPA firstly considers these individual cases before making more general statements (across participants); therefore, enabling theoretical transferability (Smith *et al*., 2009).

References

Biggerstaff, D and Thompson, AR 2008, 'Interpretative phenomenological analysis (IPA): A qualitative methodology of choice in healthcare research', *Qualitative Research in Psychology*, vol. 5, pp. 214-224.

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Appendix E

Rationale and choice of methodology

Consideration was given to using Grounded Theory; however, this was rejected on the grounds that the objective was not to construct a theoretical explanation of recovery. More consideration was given to the use of Narrative Analysis, which offers the participant an opportunity to give a detailed narrative account of their experiences, emphasising temporal continuity and the experience as a journey (Murray, 2008). Although recovery may be considered by some as a "journey", using a narrative approach may have imposed or assumed a structure of recovery as a journey for a participant that is not in the participants mind. Discourse Analysis primarily focuses on the use and study of language within texts or a participant's talk. However, the aim of this research was to explore individuals' experiences and the meaning given to their experiences (Biggerstaff & Thompson, 2008), therefore, with a clear phenomenological approach which is not a core focus in Discourse Analysis.

References

Biggerstaff, D and Thompson, AR 2008, 'Interpretative phenomenological analysis (IPA): A qualitative methodology of choice in healthcare research', *Qualitative Research in Psychology*, vol. 5, pp. 214-224.

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Appendix F

Participant information sheet

'Recovery experiences of people with borderline personality disorder'
Version: 3 Date: 21/01/2013

I would like to invite you to take part in a research study. Before you decide if you would like to take part, I want you to understand why the research is being done and what it would involve for you, all of which is detailed in this information sheet. Should you be interested, I will go through the information sheet with you and answer any questions you may have. This will take about 10-15 minutes. You may talk to others about the study if you wish.

What is the purpose of this study?
This study is exploring the recovery experiences of individuals with borderline personality disorder (BPD). As there is limited research looking at recovery for individuals with BPD, I want to find out more about people's experiences. In particular, I want to explore how people describe and make sense of their experiences, what has facilitated their recovery and what recovery means to them. In doing this, the results of this study may also inform services of how best to meet the needs of individuals in the future.

The research is being carried out by …… as part of the Doctorate in Clinical Psychology training programme at the University of Liverpool.

You have been invited to participate as you have been identified by a member of your care team as someone who would meet the criteria of identifying yourself as being on the journey to recovery. It is thought that between 6 and 10 participants will take part in this study.

Once you have read the information sheet, it is up to you to decide whether you would like to join the study. If you would like to take part, I will then invite you to an interview where you will be asked to sign a consent form to participate. You are free to withdraw from the study at any time, without giving a reason and this would not affect the standard of care you receive. Withdrawing from the study will mean that all of your data will be destroyed and will not be used in the study.

What is involved in taking part?
Taking part would involve an interview which should last between 30-60 minutes. The interview will be audio recorded to make sure we capture everything that is said correctly. These recordings will be destroyed after they have been transcribed.

During the interview, you will be asked a number of open questions about recovery and your experiences. If there is anything you do not understand, you will be encouraged to ask the researcher who will clarify the question for you. You will only need to meet with the researcher for the interview on one occasion. We will speak on the telephone before the interview to discuss any questions you may and to provide any further information and arrange a convenient time for the interview. It is expected that from the time you agree to take part in the study to the interview will be a maximum of 2 months. You will be contacted when the results of the study are available should you wish to see them; this may be between a year and 2 years later.

The interview will take place at the location of your choice- probably at the service that you are accessing or at your home. If the interview takes place outside of your home, your travel expenses will be fully reimbursed.

What are the possible disadvantages?
The interview questions will require you to talk about your experiences and accounts of your recovery. Some of these experiences may be distressing for you to talk about, particularly if these have been difficult. It is up to you how much you want to say and you are under no obligation to talk about anything that might be distressing for you. You can stop the interview at any point if this happens and it will only continue if and when you feel ready to do so. You will be given the opportunity at the end of the interview to discuss any issues which arose that might have been difficult for you.

What are the possible benefits?
Although I cannot promise the study will help you, I hope that you may benefit from having the opportunity to talk about and reflect on your recovery experiences. Additionally, it is hoped that the study will further the understanding of recovery for individuals with BPD, possibly helping to improve the care people receive.

Confidentiality
What you say during the interview will be handled in confidence. The interview will be transcribed and the only other person who will have access to your interview transcripts apart from the researcher will be the researcher's supervisors at the university and the NHS trust. Any identifiable information, for example your name or where you live, will be concealed or removed so that you cannot be recognised before they have access. The transcripts will be stored securely at the university.

The only time confidentiality cannot be assured is if you were to disclose something that concerns the researcher, for example thoughts to harm yourself or anyone else. Should this happen, your care coordinator would be informed of this but I would talk to you about this before. The researcher has a duty to ensure your safety and the safety of others which is why such information would have to be dealt with appropriately.

Some direct quotes from each participant will be used in the results section when the research is written up. These quotes will be anonymised and you will be given a pseudonym and all identifiable information will have been removed. The transcripts will be retained for up to 6 months following the write up in case any amendments need to be made to the research paper. After this, the transcripts will be disposed of securely.

Who is organising and funding the research?
The University of Liverpool is the main sponsor and has funded the research.

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

What if there is a problem?
If you have a concern about any aspect of this study, you can speak to the researcher who will do their best to answer your questions ……. If you remain unhappy and wish to complain formally, you can do this ……

We hope that this information sheet has given you all the information required to decide if you would be interested in participating in the study. Should you wish to have more information about the research or have any further questions, please contact the researcher …… on …… or ……

Consent to be contacted

Once you have read the information sheet, if you are interested in taking part, please sign the 'consent to be contacted' form to consent for the researcher to contact you and return this to your care-coordinator who will pass your details on to the researcher.

Thank you for taking the time to read this information.

Appendix G

Interview schedule

My name is …. and I am a trainee clinical psychologist. I will be carrying out the interview today/asking you some questions today.

Explain consent procedure by going through the consent form. If participant consents, invite participants to sign the consent form.

Thank you for taking part. As explained on the information sheet, I am carrying out this research to understand what recovery means to people with borderline personality disorder. I am interested in your personal experiences and how you make sense of these, as well as what has facilitated your recovery. This project is separate from the service you are accessing and nothing you share with me today will be shared with your care coordinator, unless I have concerns regarding your safety or the safety of others, as stated on the information sheet.

The interview may last up to an hour. You are free to stop the interview or take a break at any time if you would like one. If you feel distressed or anxious during the interview, please tell me and we can stop for a break and I will check out with you what support you currently have, if needed. If this happens the interview will only continue if and when you are happy to do so.

If I feel concerned about your safety from anything you have told me, I may have to share what we talk about with your care coordinator so they can provide you with further support.

I would like to audio record the interview today to have an accurate record of what you say. Some quotations will be used in the research project but any identifiable information will be taken out and you will be given a pseudonym (which is another name) so no one will be able to identify you. Do I have your consent to record the interview?

Do you have any questions that you would like to ask before we start?

When you're ready we will start the interview.

1. **What does the term "recovery" mean to you?**
   (Prompts: Tell me about your recovery?
2. **Can you tell me about what was happening for you when you were unwell?**
   (**Prompts: What was going on for you at the time when you accessed services?**
   Can you tell me a bit about the difficulties you experience/ you were experiencing?)
3. **Were there any events or days that were a turning point for you? At what point did you recognise things had started to change for the better?**
   (Prompt: How did you know that you had begun recovering?)
4. **What changes have you experienced so far in your recovery?**
5. **What helped you in your recovery**?
   (Prompts: What helped you start your recovery?
   What helped you feel ready for recovery/to recover?)
6. **What else needs to happen/needs to be in place?**
7. **How has treatment from services impacted on your recovery? What was it about that that was helpful?**

(Prompt: Has support from mental health services helped your recovery? What support from services has been available to you that has helped you in your recovery?)

8. **What helps you sustain recovery?** or **What helps you keep well?**
9. **Is learning about and understanding your difficulties important to recovery?**
10. **Does "recovery" ever stop or does it continue forever or for a very long time?**
11. **Some people have said that they have had reasons to fear or wish to avoid recovery. What are your views on this? Are there any barriers to recovery?**
12. **What things in your life might impact on your recovery?**
13. **Is there anything else you would like to say about recovery**?

That is the end of the interview. Thank you very much for coming along today and talking about your experiences. I appreciate your taking part in the study.

Appendix H

Consent form

Title of Project: **'Recovery experiences of people with borderline personality disorder'**

Name of Researcher:

Please initial all boxes

1. I confirm that I have read and understand the information sheet dated 21/01/2013 (3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my care or legal rights being affected. ☐

3. I understand that the interview will be audio taped and agree to this. ☐

4. I understand that anonymous direct quotations may be used in the write up of the study and agree to this. ☐

5. I understand that relevant sections of the data collected during the study, which will be fully anonymised, may be looked at by the researcher's supervisors from the University of Liverpool and the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to the data collected. ☐

6. I understand that if I disclose anything that causes the researcher concern, for example that I have thoughts to harm myself or anybody else, the researcher has the duty to pass this information on to my care-coordinator. This will be discussed with me first. ☐

7. I would like to be contacted when the study has finished and is available to be accessed. ☐

8. I agree to take part in the above study. ☐

Name of Participant	Date	Signature
Name of researcher	Date	Signature of researcher

Appendix I

Central Liverpool NHS REC approval letter

Appendix J

Example signposting information

Your care-coordinator or duty worker:

CMHT	[Contact number]
Saneline	0854 767 8000
Samaritans	08457 909 090
MIND	0845 766 0316

(local) Women's Aid Refuge [Contact number]
Safe, temporary accommodation for women and their children experiencing domestic abuse. Support and advice to men experiencing domestic abuse.

Men's Advice Line 0808 801 0327
For Support for male victims of domestic abuse

Community Care [Contact number]
Provides a variety of support for people with mental health needs, including telephone advice and support, and a range of support groups.

Appendix K

Excerpt from reflexive diary

Interview process

I found it challenging to switch off the clinician/ clinical psychologist in me, and throughout all interviews, particularly where participants were talking about extremely difficult feelings and experiences. I often felt an urge to validate their anguish and reflect what they had said back, to ensure they felt listened to and understood. In clinical therapeutic work, this is a valuable skill and engagement tool which facilitates the therapeutic alliance; however, for IPA research such reflections may be considered as interpretations, thus effecting what the person then goes on to say. I became increasingly mindful of this with each interview, and tried to decrease the frequency of such comments. This may have had an impact on participants responses; however, it is hoped as such comments or reflections were only minimal, they would not have had a significant effect.

Participant 7 (excerpt from reflective diary)

When I arrived, Lisa was instantly very warm and friendly, with almost a motherly feel to her – possibly enhanced by the age difference between myself and her. She was very accommodating, offering me a drink and checking if I was ok. Her very gentle nature (in character, body language and tone of voice) almost came across as quite timid, anxious and potentially fragile. I wondered if this anxiety was in relation to the interview processes, or just a general anxious disposition? This was evidenced by nervous laughter and times where Lisa would check if she was answering questions properly by seeking reassurance. I wondered if there was some ‘anxiety performance’ regarding the interview? Despite this, she was very articulate and was able to speak about her experiences at some depth.

I wondered if any of the anxiety which she displayed was influenced by me. I was mindful that when she looked for reassurance, perhaps I was ‘too’ neutral, providing too few clues that she was doing well. I was aware that I wasn’t giving much away which did feel unnatural; however,

having received the previous interview transcripts and listening back on the recordings, I was surprised at how many times I used gentle utterances for acknowledgment and encouragement. These felt a bit excessive; therefore, I made a conscious effort to reduce this. I did however try to make up for this by encouraging her with the occasional “hmm” and several nods, gentle smiles, and at times also saying “that was good”, “that was really interesting” and “thank you”. It’s hoped that this compensated for my neutral stance and minimised her level of anxiety as the interview progressed.

Lisa appeared to ‘shut down’ after the question regarding any turning points. It’s reflected that I should have followed her lead at this time, asking further prompts regarding what she has previously said. I feel this happened for a number of reasons. Firstly, I was aware that many of my questions had been ‘directed’ by her talk, prompting interesting areas and asking for specific examples meaning that I wasn’t asking many of the questions from the interview schedule; this may have caused some anxiety in me to revisit the research question and aims in my head to ensure I was meeting these. Secondly, due to personal issues which were going on in my life at this time, it’s acknowledged that I may not have been as focused and ‘attuned’ to Lisa as I would normally be. I will need to be mindful of this when analysing this interview.

Appendix L

Analytic procedure

Steps	Process
1) Reading and re-reading the text	Emersion in the data through repeated reading of each transcript. Highlighting any parts of significance or interest. Noting initial impressions whilst reading.
2) Initial noting	Three types of noting: -Descriptive: describing the content of the participants talk -Linguistic: comments regarding the use of language, e.g. metaphors, pauses, change in tense, use of pronouns. -Conceptual: interpretative, involves more interrogative comments and questioning, moving away from what the person is saying at face value.
3) Emergent themes	This involves generating themes/key words which capture the quality of what is found in the text, grounded in the transcript whilst also having a level of abstraction. Each transcript revealed new themes.
4) Clustering themes	Looking at connections between the emergent themes to cluster (by abstraction, subsumption, polarization, contextualisation, numeration or function) them together under a superordinate heading. These were clustered in a table, with the page, line number and quote as identifiers. Checking back to the transcript to ensure that the themes connect to the data.
5) Moving onto the next case	Once one transcript was complete, repeat steps 1-4 with each transcript until all are analysed, trying to bracket ideas/themes from the previous cases.
6) Look for patterns across cases	Identify patterns amongst themes across all transcripts. Re-label themes as necessary (iterative process) and cluster further. Look for divergences and convergences amongst transcripts/themes, as well as shared themes and more unique aspects.
7) Identify final set of themes	Develop master themes and sub-themes, re-labelling or using superordinate themes which captured descriptions well.

Appendix M
Example of initial noting and emergent themes (Jenny)

Change in present self **Recognising triggers** **Active process of increasing control over thoughts** **Accepting difference** **Change in beliefs about self and others** **Diagnosis facilitating help** **Learning the skills to manage relationships effectively (diagnosis as facilitating factor?**	**47** **48** **49** **50** **51** **52** **53** **54** **55** **56** **57** **58** **59** **60** **61** **62** **63** **64** **65** **66** **67** **68**	that you've experienced then from when you felt that cloud? **Respondent:** do you mean how I'm different now to how I was back then? now I am able to pinpoint the point where I can see where my thoughts are starting to take me down a dark place and I can stop them before the emotions start to kick in with them, they maybe have started a little bit but I can stop it before it becomes I suppose if you look at the chain, the chain and all this I can break it further up. What can I do, I don't have this overwhelming need to be right, I've got, I can accept the fact that someone doesn't agree with me and that doesn't need, that doesn't mean that my view or my perspective is less valid than theirs or that I'm being rejected or misunderstood in any way it's just that they don't agree with me or they are different to me, that judgments only serve to cause frustration within yourself to avoid judgments on things, just to be more just more peaceful than I was like I still get like pissed off like I get (4.56) like I give him grrrr and I bit his head off and stuff like I suppose other people do that as well but erm the way I manage my relationships now, is far, you know I think it's even far superior to the way I see other people that haven't had diagnosis I feel like my ability to maintain my self-respect and my relationships and communicate effectively at the right time and in the right	Then and now- two distinct time periods, *change in tense* There's a point, a recognisable sign or trigger Sounds like thoughts have control over her "take me down a dark place"- thoughts can take her to somewhere negative, dark. Now taking control of her thoughts- it's stopping them before they affect her emotions *Emotions kick in- like a drug, taking effect* The chain- is she referring to chain analysis. Being able to make her own chain analysis and see before it gets to the next point how she can break or change this *Like she's reflecting on what she can do now which she couldn't before* It was an overwhelming need, not just a desire but a necessity, if we think about basic needs, can't survive without them, this need was destructive if not met. How has she begun to accept this? Realisation about validity of own beliefs, previously needed the reassurance from others as a sign that she is valid, acceptable, liked? If her opinions were wrong, so was she? Taking things less personally, previously perceived that it meant something about her, but recognizing that others have different beliefs, perspectives. Different to me- she's 'different'? Judgments, about self or others? Referring to wise mind accepts/mindfulness, not engaging in judgments. Judgments are detrimental? Peaceful- reduced impulsivity, changeable moods? 'Still'- difficulties remain, they're not absent. Isn't it normal to get pissed off though? Only human? Why would she bite his head off? Perhaps others do that too, but maybe the reasons/triggers for doing so are different? Not only is she functioning better in relationships but she also sees herself as more supreme- equipped with skills from training? Has had lessons in relationship functioning that she average person hasn't Diagnosis serving as means of receiving help Talking about a balance between being assertive in relationships and getting needs met. Effective communication seems key and was absent in the past. What makes it right time and right way? Requires awareness of self and others and ability to judge when this is appropriate is she saying that it's the experience of having BPD or receiving a diagnosis and thus treatment that has made her more superior? Is it that

Appendix N

Master themes, sub-themes and superordinate themes with associated participants

Master theme	**Sub-theme**	**Superordinate theme**	**Participants**
1. "This isn't the life I want": motivation as a prerequisite for change	1.1. Choosing life: gaining motivation from external reason to change	External motivators for change/ changing for others Fearing the future as a motivator for change Having a motivation greater than yourself: being a mum x2 Change necessitates drive and motivation Having external reason to change when self isn't enough Need for intrinsic motivation and desire to change Her mother as protective maintaining factor	Amy, Rachel, Kate, Jenny
	1.2. "You need to fully want to, fully fully want to change": Internal readiness and *want* to be different	Prerequisites to change: Wanting to *be* different "You need to fully want to, fully fully want to change": Internal readiness and want to be different Discontentment with just existing Choosing life starting the process of change Realising a want to live: an active process of recognition and revision Maintaining optimism for life Developing the ability to envisage a future Wanting to change but lacking independent skills Change necessitates drive and motivation The exhilaration of *living* following mere existence Choosing to live	Ashley, Rachel, Kate, Jenny

2. Riding the bumps: learning to live with BPD	2.1. "…you will never ever ever ever stop climbing" : recovery as a lifelong, fluctuating process	Establishing identity whilst accepting living 'with' BPD Living alongside BPD: "learning to ride the bumps" Learning to live *with* BPD Moving from denial to acceptance of the problem Core difficulties still remain Change over time Living with oscillating states within recovery The fear of going backwards providing positive momentum Recovery as a journey Changeable course of mood means a fluctuating recovery Believing recovery is a false sense of security Passage of time enables an unconscious process of recovery A lifelong journey: Realistic expectations for the challenge ahead Challenge of changing hardwired mental processes Recovery as a changing process Recovery as a non-linear process A lifelong process: the continuous effort of self-development? Preparing self for challenges ahead Managing the requirements of living whilst implementing change Recovery as a fluctuating process Fluctuating recovery (the whole) as a result of fluctuating moods (the parts) Anxious projection for the future Questioning the term 'recovery': a different definition Restless searching for ways to cope	Ashley, Amy, Rachel, Kate, Hayley, Jenny, Lisa
	2.2. Learning to do things more adaptively through psychological change	Adapting-to-develop rational thought, impulse control and distress tolerance Increased ability to cope through knowing yourself Pragmatic everyday coping strategies The use of therapeutic strategies Practical strategies for improving well-being Ability to engage in tasks of daily functioning Increased ability to manage overwhelming emotions Learning to live with difficulties that will remain Learning to 'do' things more adaptively/ positively Improved interpersonal skills Active process of acquisition and development of coping strategies and skills	Ashley, Amy, Rachel, Kate, Hayley, Jenny, Lisa

		Improved emotional regulation reducing impulsive responses Pragmatic solutions Envisaging a future of increased coping and stability Value in pragmatic coping strategies Development of resilience (living 'with' BPD) to overcome "colossal" hurdles Increased emotional awareness improving management Practical skills for internal change Positive gains of change Active use of acquired and existing skills The value of acceptance in managing difficulties Mindfulness as enabling present focused coping Helping others serving for personal gains	
	2.3. "it was always so black and white whereas now it's not": improved interpersonal effectiveness through increased ability to mentalise	Benefits of having thoughts challenged to develop mentalisation skills Improved interpersonal skills Improved interactions through increased ability to mentalise An increased threshold for management of stressful situations Positive change in cognition and interpretation Learning about the self through relationships with others Improved interpersonal skills and functioning Improved relational understanding Relational growth: The ability for rupture and repair	Ashley, Rachel, Kate, Jenny, Lisa
	2.4 Finding purpose and meaning in negative experience	Finding positive meaning and purpose in her adversity Radical acceptance of present situation A facilitator for positive change for others with BPD Positive use of negative experience *Owning* her positive attributes Personal identity: identity without a diagnosis Establishing identity Acceptance of who one is through a self-compassionate approach Finding a greater purpose for BPD: Using lived experience to help others	Rachel, Hayley, Jenny, Lisa
3. Changed perception of Self	3.1. Increasing self-awareness	Self-awareness of individual needs Continuous personal growth and self-awareness Increasing introspection of internal states Awareness of aspects of the self that need to be changed Increased self-awareness leading to developing an alternative identity	Ashley, Amy, Rachel, Kate, Hayley, Jenny, Lisa

		The significance of the past in understanding the self Increased awareness of psychological processes???? Increasing self-awareness aids understanding of values and needs Search for identity	
	3.2. Development of self-belief	Developing sense of self through self- belief and awareness Learning the skill of self-compassion Self-edification resulting from self-development Empowerment to recognise existing qualities and skills Development of self-belief enabling independent change Development of self-belief through self-realisation/ achievement The role of the self in developing a positive self image	Ashley, Rachel, Kate, Jenny
	3.3. Autonomy and independence as an achievement and aspiration	The role of "I" in achievements and independence Autonomy in decisions concerning care Having choice and control over input from services Increasing sense of agency over one's life Striving for independence Striving towards self-sufficiency and taking control Self-realisation as a goal and active process Being an active participant Empowerment to have choice over own life? Increasing sense of personal agency Increasing sense of ownership Becoming an autonomous being	Ashley, Amy, Rachel, Kate, Hayley, Jenny, Lisa
4. Recovery as a relational process	4.3. "you want to, to know that they are actually there": the ongoing necessity for a secure base	"You can't have one without the *other*": the imperative role of professional support The mental health system as disempowering and invalidating Fearing loss of support Tailored care enabling recovery Change shakes foundations The impact of others' negative beliefs and attitudes An inconsistent and depersonalising mental health system as a barrier The value of support Gaining from the consistency, truthfulness and acceptance from/of others Others as influential in recovery process The mental health system as negatively impactful on individual experience Acquisition of skills for management through support from others	Ashley, Amy, Rachel, Kate, Hayley, Lisa

		Acknowledgement and belief from others Support essential for change/ The integral role of support Support in maintenance of recovery A reciprocal being: gaining from positive relationships The necessity of others to develop self-belief and actualisation? The need for increased acceptance from others Recovery as a reciprocal process The availability of support throughout the recovery process Stability and consistency of services as foundation for change	
	4.1. Therapeutic relationships as vehicle for change	Needing to work through the past The requisite of psychological intervention Therapy providing validation of experiences Provision of explanation as validating Therapeutic intervention as a key ingredient for change The therapeutic dyad: allowing self-exploration and development Working beneath the surface: addressing the past to live in the present The necessity of trust in relationships The therapeutic relationship as vehicle to change The necessity for professional support and understanding The significance of recognition and approach from others Relinquishing the burden of the past Working through regret/ anguish related to past ‘battles’ Changed perspective on experiences (positives out of negative experiences) The therapeutic relationship as facilitator of change?	Ashley, Amy, Jenny, Lisa