

**Processes of recovery from Borderline Personality  
Disorder (BPD): A qualitative study**

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**Thesis declaration form**

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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## Overview

The processes facilitating recovery in Borderline Personality Disorder (BPD) are poorly understood. This thesis aimed to explore how recovery is reached, focusing on service users' perspectives.

Part 1 is a qualitative meta-synthesis of findings from 14 qualitative studies exploring service users' experiences of their treatment for BPD and their recovery journey. The findings highlighted areas of improvement that were important for service users, including developing self-acceptance and self-confidence, controlling difficult thoughts and emotions, practising new ways of relating to others, and making practical achievements. However, it was unclear how change in these areas was achieved.

Part 2 is a qualitative study exploring how recovery in BPD is reached through routine or specialist treatment, as perceived mainly by service users, but also by therapists and relatives. Three central processes that constituted service users' recovery journey were identified: fighting ambivalence and committing to taking action; moving from shame to self-acceptance and compassion; and moving from distrust and defensiveness to opening up to others. Four therapeutic challenges needed to be successfully addressed to support this journey: balancing self-exploration and finding solutions; balancing structure and flexibility; encouraging service users to confront interpersonal difficulties and practise new ways of relating; and balancing support and independence.

Part 3 is a critical appraisal of the challenges encountered in the research process and the ways in which these were addressed. The concept of reflexivity was used as a framework for considering the main issues.

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## **Part 1: Literature review**

### **Service users' experiences of treatment and recovery in Borderline Personality Disorder (BPD): a meta-synthesis of qualitative studies**

## **Abstract**

**Aims:** This review synthesised findings from qualitative studies exploring service users' experiences of their treatment for borderline personality disorder (BPD) and their recovery journey.

**Method:** Fourteen studies were identified through searches in three electronic databases. The Critical Appraisal Skills Programme was used to appraise the methodological quality of the studies. Thematic analysis was used to synthesise the findings.

**Results:** The meta-synthesis identified three main domains, each comprising several themes. The first domain, "Areas of change", suggested that service users make changes in four main areas: developing self-acceptance and self-confidence; controlling difficult thoughts and emotions; practising new ways of relating to others; and achieving things and developing hope. The second domain, "Helpful and unhelpful treatment characteristics", highlighted treatment elements that either supported or hindered recovery: treatment providing a sense of safety and containment; being cared for and respected; not being an equal partner in treatment; and treatment focusing on change. The third domain summarised the "Nature of change", which was described as an open-ended journey and a series of achievements and setbacks.

**Conclusions:** The meta-synthesis highlighted areas of improvement that appear important for service users. However, future research is needed to explore how change in these areas is achieved.



## Introduction

Borderline Personality Disorder (BPD) affects between 1% and 5.9% of the general population (Coid, Yang, Tyrer, Roberts, & Ullrich, 2006; Grant et al., 2008; Huang et al., 2009; NICE, 2009; Wittchen et al., 2011). Individuals with BPD experience difficulties in a wide range of areas, such as emotion regulation, relationships, and sense of identity. Up to 80% of those diagnosed with the disorder engage in self-harming behaviour and up to 10% take their own lives (Frances, Fyer & Clarkin, 1986; Gunderson, 1984; Zanarini et al., 2008).

People with BPD regularly use a wide range of services, including Accident and Emergency departments, community and specialist mental health care, and inpatient services (Zanarini, Frankenburg, Khera, & Bleichmar, 2001). In the UK between 37% and 67% of psychiatric inpatients at any given time meet criteria for this diagnosis (Ansell, Sanislow, McGlashan, & Grilo, 2007; Bender et al., 2001; DoH, 2003; Hörz, Zanarini, Frankenburg, Reich, & Fitzmaurice, 2010; Tyrer et al., 2003; Zanarini et al., 2008). Professionals caring for clients with such difficulties often find their treatment challenging and distressing (Markham & Trower, 2003; Skegg, 2005).

Despite the distress caused by BPD to those experiencing it and those treating it, epidemiological studies suggest that the symptoms of the disorder reduce substantially over time. Zanarini et al. (2003) found that 10 years after initial diagnosis only 26% of service users originally recruited upon admission in psychiatric hospitals met criteria for the diagnosis. Participants in that study received a range of generic community treatments following discharge from hospital, but less

than 5% of them had ever received any type of specialist psychological therapy that has proven effective in treating BPD.

A substantial number of randomised controlled trials (RCTs) have found a range of specialist psychotherapies for BPD to be effective (Stoffers et al., 2012). These therapies include Dialectical Behavioural Therapy (DBT), Mentalization-Based Treatment (MBT), transference-focused psychotherapy and schema therapy. The trials have shown that patients who receive specialist therapies are more likely to reduce self-harming behaviour and service use and to improve on several mood and social functioning indicators. However, several of these trials also have revealed that a large proportion of participants in the “control” arms, who received treatment as usual (eg., standard community treatment) or other forms of generic psychological therapy, also made significant progress (Bateman & Fonagy, 1999; Linehan, Armstrong, Suarez, Allmon, & Heard, 1991; Priebe et al., 2012).

Hence, evidence from epidemiological studies and RCTs indicates that people with BPD can make substantial symptom improvements through the use of either specialist therapy or generic psychological or standard community services. However, it remains unclear how service users experience the various treatments that they receive and whether they believe that these support them in making positive changes in their lives. Furthermore, we do not know whether service users see symptom improvement, commonly assessed in quantitative studies, as reflecting their own sense of recovery and well-being. Indeed, it is unclear how people experience recovery in BPD.

Qualitative studies exploring service users’ experiences of treatment and recovery might shed light into these important areas. Qualitative research can

provide a detailed understanding of service users' lived experiences of treatment, clarify complex and often contradictory aspects of such experiences, and illuminate their perspectives and expert knowledge on what works for them (Berry & Hayward, 2011; Timulak, 2009). A meta-synthesis of qualitative studies in this field could therefore offer a comprehensive picture of service users' experiences and views of the treatments they receive and the complex ways in which these might contribute to their recovery. Meta-synthesis is an established procedure of bringing together findings from existing qualitative studies. It can also highlight methodological issues in the literature and inform future qualitative research in similar areas (Timulak, 2007; 2009).

In this context, the present review aimed to synthesise findings from qualitative studies exploring service users' experiences of their treatment for BPD and their recovery journey. Gaining a better understanding of service users' experiences of change and their views on treatment characteristics and other processes that might facilitate this journey could contribute to the further development of specialist psychotherapies and generic treatment for BPD.

## **Method**

### **Inclusion and exclusion criteria**

The inclusion and exclusion criteria covered four areas:

#### *Participants*

Studies were included if participants were 18 years or older and had received treatment for BPD or other personality disorder (PD). Studies of individuals with mainly antisocial or dangerous and severe PD, or of offenders, were excluded.

Although the aim was to focus on the experiences of service users with BPD, specialist community PD services often offer therapy to people with a wider range of personality disorders (e.g., narcissistic, avoidant PD etc.). Individuals treated in such services often meet diagnostic criteria for BPD or present with similar difficulties (Lee et al., 2012; Zinkler, Gaglia, Arokiadass & Farhy, 2007). Therefore, it was decided not to exclude studies that described their participants as meeting criteria for PD rather than only BPD.

#### *Type of intervention*

Studies were included if the treatment consisted of any form of psychological therapy or generic mental health services eg., community mental health teams (CMHTs), care-coordination etc. Treatment could be delivered in a one-to-one or a group setting or a combination of the two. Studies conducted in forensic, high security settings were excluded.

#### *Study design/ method*

Only qualitative studies that focused on service users' experience of treatment and/ or recovery were included. Single-case design studies and studies exploring service users' experience of specific individual therapeutic events or techniques (eg., ruptures in the therapeutic alliance, imagery, dropping-out of therapy) were excluded.

#### *Publication type*

Only peer-reviewed, English language journal articles were included.

## **Databases and search terms**

Studies were identified through searches in three electronic databases: PsycInfo, Medline and Embase. The following combination of search terms was used.

Borderline personality disorder/ Personality disorder

AND

Client\*/ service user\*/ patient\*/ participant\*/ people/ women/ consumer\*

AND

Recover\*/ change\*/ therapy/ treatment/ care/ service\*

AND

Experience\*/ perspective\*/ feedback/ view\*/ perception\*/ reaction\*/ narrative\*

AND

Qualitative\*/ mixed-method\*/ interview\*/ focus group\*

The electronic database searches were complemented by citation searches and reviewing the reference lists of identified papers.

## **Study selection**

The study selection process is summarised in Figure 1. The searches in the three databases yielded a total of 1475 articles. Through initial scanning of their titles, 413 articles were deemed to be adequately relevant to have their abstracts read.

The 1062 articles that were not found to be relevant were excluded for various reasons, including investigating groups with Axis I diagnoses, comparing

characteristics of individuals with PD and Axis I disorders, using clearly quantitative methods (eg., randomised controlled trials), investigating groups of people with mainly antisocial PD or solely in forensic settings and not reporting results from primary research.

From the 413 abstracts read, 51 were considered sufficiently relevant to have their full-text read. The remaining 362 studies were excluded for a range of reasons, such as using only quantitative or single case study methodology, exploring only professionals' or family caregivers' experiences, exploring service users' experiences of living with BPD/ PD or of self-harming, but not their experiences of treatment or recovery, exploring service users' views solely of the medications they receive, investigating clients with mainly antisocial or other specific PD or exclusively in forensic settings.

From the 51 papers that were fully read, 36 were excluded. Some of them explored only specific isolated aspects of treatment, such as the use of imagery within a wider intervention (ten Napel-Schutz, Abma, Bamelis, & Arntz, 2011;), deciding to discontinue a specific therapy (Hummelen, Wilberg, & Karterud, 2007), attending care programme approach meetings (Rogers & Dunne, 2013) and so forth. Others only explored service users' experiences of being diagnosed with BPD or their experience of living with BPD/ PD, but not their perspectives on the treatment they received (eg., Horn, Johnstone, & Brooke, 2007; Holm, Bégat, & Severinsson, 2009). Some studies were excluded because they mainly reported the views of professionals or other stakeholders and service users' views could not be separated from other groups' perspectives (eg., Price et al., 2009). Some studies were excluded because participants had a wide range of diagnoses, with only a minority having a personality disorder (Gillard, White, Miller, & Turner, 2015). Lastly, one study was

excluded, despite meeting inclusion criteria, because the results were only presented in a short table with bullet points and were not described in the text (Barlow, Miller, & Norton, 2007).

Fifteen papers met the inclusion criteria. These reported findings from 14 studies. Perseius et al. (2003) and Perseius et al. (2005) reported findings from the same study. These two papers were treated as one study in the synthesis of the findings.

The citation searches and the review of the reference lists of these 15 identified papers did not yield any additional studies.

### **Data extraction**

A data extraction sheet was devised in order to consistently summarise the information provided in the studies that was relevant for the meta-synthesis. Information on study aims, participants' characteristics, received intervention, setting and data collection and analysis methods was extracted.

### **Appraisal of studies**

The Critical Appraisal Skills Programme (CASP, 2002) for qualitative research was used to aid the process of appraising the methodological quality and limitations of the included studies. This tool is commonly used in qualitative meta-syntheses and covers a range of methodological areas typically addressed in appraisal tools (Dixon-Woods et al., 2007). More specifically, it assesses ten main areas: the clarity of research aims; the suitability of qualitative methodology; the appropriateness of the research design and more specific qualitative approaches; the recruitment strategy; the data collection methods; the clear description of the relationship between participants and researchers; the consideration of ethical issues;

the data analysis methods; the clear presentation of findings; and the overall value of the research. A copy of the CASP is included in Appendix A.

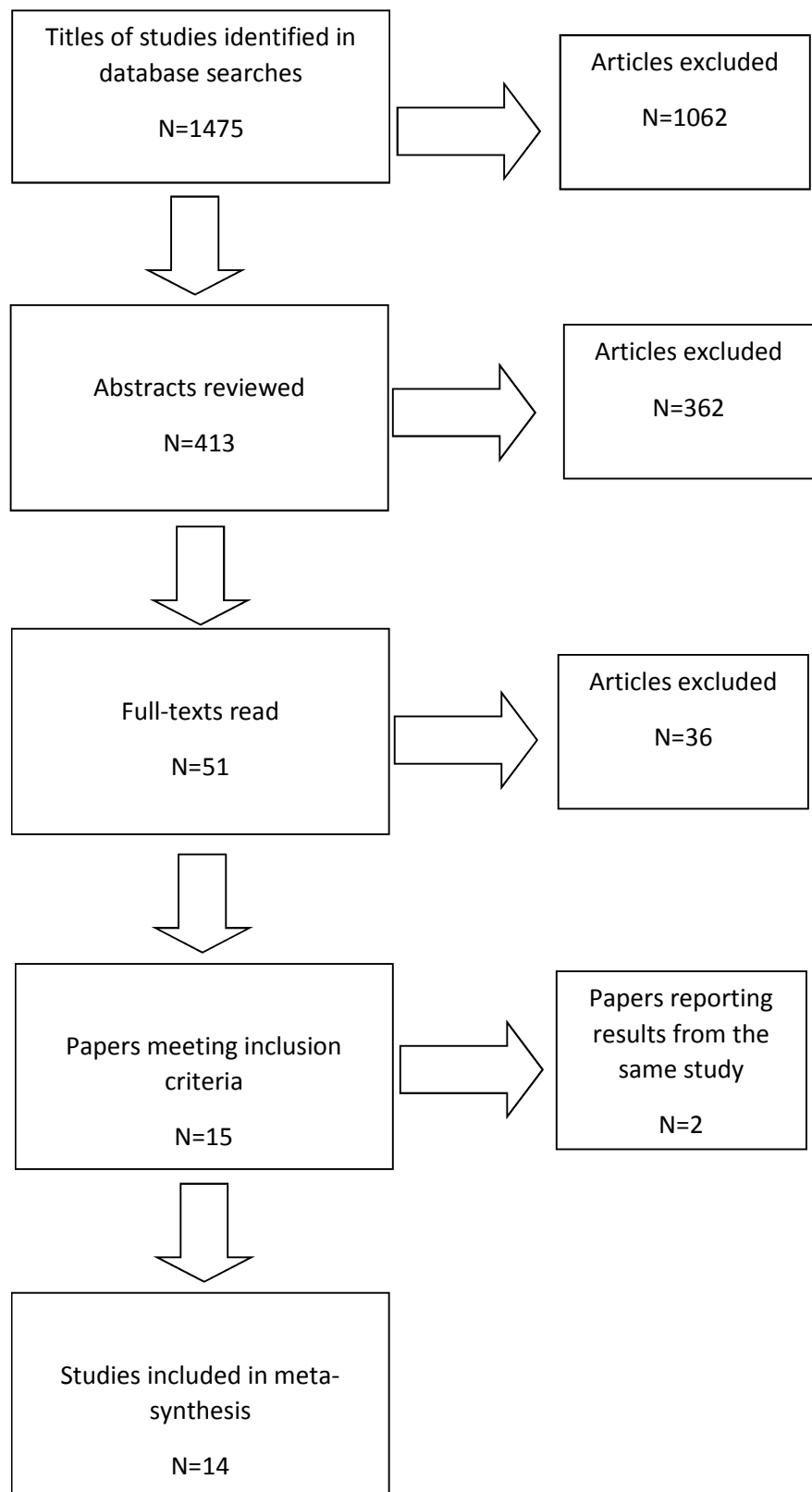
The CASP was not used with the purpose of providing an overall quality score for each study or of excluding individual studies, as it was felt important to synthesise all relevant evidence, even if some studies were appraised as methodologically poor (Atkins et al., 2008; Dixon-Woods et al., 2007). Rather, the aim in using this tool was to highlight methodological issues identified across the studies and reflect on how these should be taken into account when understanding the findings. However, it became apparent that methodologically rigorous studies, which provided a deeper description of themes, contributed more substantially to the themes identified in the meta-synthesis than studies with thin, mainly descriptive analyses.

### **Meta-synthesis method**

The synthesis of findings from the included studies was conducted using a thematic analysis approach, as described by Braun and Clarke (2006). The decision to use thematic analysis, rather than a more interpretative meta-synthesis approach, was based on guidance by the Cochrane group on qualitative meta-syntheses (Noyes & Lewin, 2011). More specifically, the aim of the present synthesis was to summarise a range of views expressed by service users on the various treatments they received and their recovery journey, rather than to develop a more interpretative explanatory theory. Hence, a thematic analysis approach was deemed suitable.



Figure 1. *The process of study selection*



Second, the existing qualitative studies in the area mainly included a thin description of themes, which would make any further interpretative analysis challenging.

All of the text in the results section of the published papers was treated as data for the current meta-synthesis. The synthesis cut across descriptive labels, including categories, themes and subthemes identified by the study authors; it used all presented topics and ideas as text to be synthesised (irrespective of which categories, themes or subthemes they came from). Hence, the topics and ideas presented in the included studies were reorganised into new domains and themes that reflected the aims of the present meta-synthesis. The original categories, themes and subthemes from which the new themes were synthesised were documented in detail in order to provide transparency.

The six phases of thematic analysis recommended by Braun and Clarke (2006) for primary qualitative research were followed for the purposes of the present meta-synthesis. In phase 1, the reviewer familiarised herself with the data by repeatedly reading the results sections of the existing papers, while searching for meanings and common topics. In phase 2, some initial codes that summarised the main ideas and topics in each study were produced. In phase 3, these initial codes were compared, contrasted and combined across studies to form overarching themes and subthemes. In phase 4, the emerging themes and subthemes were reviewed and further refined and developed. In phase 5, a more robust definition and the refined labelling of the themes and their inter-relationships was completed. The final phase involved writing up the meta-synthesis, which was a dynamic process that allowed further reflection on, and fine-tuning of, the themes.

The analysis process and the emerging codes, themes and subthemes at each phase were discussed and refined in regular meetings between the researcher and her supervisor.

## **Results**

### **Description of included studies**

The characteristics of the 14 included studies are presented in Table 1 and summarised here.

#### *Study aims*

Although all included studies explored service users' experiences of treatment and/ or recovery, some of the studies also examined additional topics that were not relevant for the present review, such as therapists' views or clients' experience of living with BPD. Nevertheless, in those studies, the findings that were relevant to the present meta-synthesis were clearly extractable.

#### *Participants*

The sample size in the included studies ranged from 5 to 60, with a total of 245 participants in all studies. The great majority of participants in most studies were female (207 across studies). Most studies recruited participants with a diagnosis of BPD, although three studies (Castillo, Ramon, & Morant, 2013; Gillard, Turner, & Neffgen, 2015; Haeyen, van Hooren, & Hutschemaekers, 2015) also included participants with other PD diagnoses.

### *Setting and treatment*

The majority of studies were conducted in Europe: six in the UK, one in Ireland, one in the Netherlands, one in Sweden and one in Norway. Of the remaining studies, two were set in the United States, one in Canada and one in South Africa.

The treatments received by participants varied. Seven studies included participants from specialist services: four DBT programmes, one art therapy programme within a specialist PD service and three other services (one offering a combination of a therapeutic community and crisis house approach, one unspecified specialist service, and one offering peer support groups). Five studies included participants from generic mental health services (including one offering only case management). One study recruited participants from both specialist (i.e. DBT and MBT) and generic services.

### *Data collection and analysis*

Data from 11 studies was collected via individual interviews; three studies conducted both individual interviews and focus groups. Two of the interview studies included additional sources of data, such as collage, poetry, diaries etc., but it was unclear how this data contributed to the analysis (Larivière et al., 2015; Perseus et al., 2003; 2005). Studies used various methods of analysis (see Table 1), which all involved the generation of themes from the data.

### **Methodological appraisal of studies**

As described in the methods, the CASP consists of 10 questions, which evaluate a range of methodological issues. For the purposes of the critical appraisal in this meta-synthesis, these questions were grouped under relevant headings, according to the wider areas that they covered, as described below.

Particular emphasis was placed on questions eight to ten, which evaluate the data analysis methods, the presentation of findings and the overall value of the research. These areas were the most relevant in assessing the overall contribution of each study to the understanding of service users' experiences of treatment and/ or recovery. The emphasis on these areas is also reflected in the presentation of the results of the present review, as studies that provided a "thick description" (Geertz, 1973) of the phenomenon they set out to investigate contributed more substantially to the themes synthesised here.

### *Research aims and design*

The first two questions of the CASP address the clarity of the research aims and the appropriateness of a qualitative methodology. All included studies were considered to have sufficiently stated their aims and justified the use of qualitative methods.

The third question refers to whether the research design was appropriate in addressing the research aims. This question is slightly unclear, although it seems to refer to the use of more specific qualitative approaches, such as interpretative or phenomenological approaches, grounded theory, participatory action research etc. Nine studies described using such methods and provided some justification of why they were chosen (Castillo et al., 2013; Fallon, 2003; Gillard et al., 2015; Haeyen et al., 2015; Holm & Severinsson, 2011; Katsakou et al., 2012; Langley & Klopper, 2005; Lariviere et al., 2015; Nehls, 2001).

Table 1. *Study characteristics*

Study	Aims	Sample	Setting	Intervention	Data collection method	Data analysis method
Castillo et al., 2013	To explore what service users view as recovery, what factors facilitate the recovery journey, and if/ how the service contributes to this process	60 participants with PD (13 male)	A specialist PD service in Colchester, UK	A service drawing on crisis house and therapeutic community models. The treatment included individual and group therapy, crisis coaching, and respite for those in crisis	Interviews and focus groups	Thematic analysis
Cunningham, 2004	To explore clients' perspectives on what is effective in DBT and why	14 women with BPD	A community DBT programme within an assertive outreach team in Michigan, United States	DBT	Interviews	No specified type of analysis
Fallon et al., 2003	To analyse participants' experiences of contact with mental health services and its impact	7 participants with BPD (3 male)	A variety of settings within a mental health trust in Salford, UK	Various unspecified interventions	Interviews	Grounded theory

Gillard et al., 2015	To explore participants' understandings of recovery	6 people with PD (3 male)	A specialist service in London, UK	Peer support groups	Interviews	Thematic and framework analysis techniques
Haeyen et al., 2015	To provide a systematic investigation of patients' experience of the benefits of art therapy	29 art therapy patients with a cluster B or C PD (2 male), who had received at least 15 sessions	A specialist PD mental health centre in the Netherlands	Art therapy, though all participants were simultaneously receiving some form of verbal therapy	Interviews (12 participants) and focus groups (17 participants)	Grounded theory
Hodgetts et al., 2007	To examine clients' perspectives of DBT and how the treatment affects their lives	5 participants with BPD and experience of DBT (1 male)	DBT service in Plymouth, UK	DBT	Interviews	Interpretative Phenomenological Analysis
Holm & Severinsson, 2011	To explore experiences of recovery, especially in terms of reducing suicidal ideas and behaviour	13 women with BPD	Various mental health settings in Stavanger, Norway	Not specified (we assume generic services)	Interviews	Thematic analysis
Katsakou et al., 2012	To explore service users' perspectives of recovery	48 service users with BPD (9 male)	Specialist and generic mental health services in East London, UK	DBT, MBT, generic mental health services	Interviews	Drawing on Grounded theory and thematic analysis

Langley et al., 2005	To explore what factors patients consider helpful in facilitating their mental health	6 participants with BPD (1 male)	The outpatients and psychotherapy unit of a specialist referral hospital in Johannesburg, South Africa	Inpatient and outpatient services, as well as individual and group therapy in private practice	Interviews	Interpretive descriptive approach
Lariviere et al., 2015	To explore participants' experiences of recovery	12 women with BPD	Two specialist programmes in two cities in Quebec, Canada.	Both programs had a multidisciplinary team and integrated various therapeutic approaches	Interviews and a collage	Thematic analysis
McSherry et al., 2012	To explore service users' views of an adapted DBT intervention and its impact on their well-being	8 participants with BPD (2 male) currently using an adapted DBT service	A community mental health centre in Dublin, Ireland	Adapted DBT	Interviews and focus groups	Thematic analysis
Morriss et al., 2014	To examine service users' lived experiences of accessing mental health services	9 participants with BPD (2 male) with significant contact with mental health services in the last 3 years	Voluntary sector organisations in the North West of England	General adult mental health services	Interviews	Thematic analysis



Nehls, 2001	To explore clients' experiences of having a case manager	18 clients (1 male) with BPD who had a case manager for at least 6 months	A community mental health centre in Wisconsin, United States	Case management	Interviews	Multistage data analysis
Perseus et al., 2003; 2005	To describe patients' perceptions of receiving DBT and their experiences of encounters with psychiatric care	10 women with BPD, who had received DBT for at least 1 year	Outpatient DBT service in Stockholm, Sweden	DBT	Interviews and biographical material (diary excerpts and poems)	Qualitative content analysis and a hermeneutic approach

However, it was difficult to judge the extent to which the researchers in each study followed the approaches that they claimed they did, mainly due to the brief descriptions of the research process in the included papers.

### *Sampling*

This section summarises information elicited in questions four and five of the CASP, which cover recruitment and data collection processes.

Only four studies (Castillo et al., 2013; Haeyen et al., 2015; Katsakou et al., 2012; Langley & Klopper, 2005) provided a clear description of the sampling process and the characteristics on the basis of which participants were included. The remaining studies reported that they recruited participants either with a BPD/ PD diagnosis or from a specialist service, but did not make any reference to further decisions regarding sampling. Similarly, only four studies clarified how many eligible participants chose not to take part and why (Katsakou et al., 2012; Langley & Klopper, 2005; McSherry, O'Connor, Hevey, & Gibbons, 2012; Perseius et al., 2003; 2005).

Only four studies (Haeyen et al., 2015; Katsakou et al., 2012; Langley & Klopper, 2005; Morris, Smith, & Alwin, 2014) reported taking saturation of themes into account, which is a recommended procedure for informing the ongoing sampling of participants (Strauss & Corbin, 1998). The remaining studies did not discuss this issue, with the exception of Gillard et al. (2015), where it was stated that saturation was not attempted.

### *Reflection on researchers' role and preconceptions*

This section summarises the relationship between researchers and study participants, which is addressed in question 6 of the CASP. Only one study

adequately described the researchers' background, role and potential preconceptions (Gillard et al., 2015). Three studies provided information on the researchers' backgrounds, but did not discuss how these might influence the analysis process (Castillo et al., 2013; Holm & Severinson, 2011; Katsakou et al., 2012). The remaining studies made no reference to these issues.

### *Ethics*

This section summarises information elicited in question 7 of the CASP, which refers to ethical considerations. Nine studies reported having approval from a research ethics committee and one study stated that it was approved by a "hospital investigational review board" (McSherry et al., 2012). Three of the remaining studies made no reference to formal ethics approval procedures (Castillo et al., 2013; Cunningham, Wolbert, & Lillie, 2004; Nehs, 2001), but briefly described gaining informed consent from participants. One study made no reference to ethical considerations (Haeyen et al., 2015).

### *Analysis and presentation of findings*

This section summarises findings from CASP questions eight to 10, which cover issues concerning data analysis, presentation of findings and the overall value of the research.

The description of analysis and the presentation of results in the majority of studies suggested that the analysis was a summary of ideas expressed by participants and did not provide a "thick description" (Geertz, 1973) of the phenomenon. The themes did not appear to follow a strong analytic narrative nor to identify patterns across the data. Furthermore, they were mostly presented as a list of poorly connected themes rather than as part of a conceptually meaningful synthesis of the

ideas that were expressed (Fallon, 2003; Hodgetts, Wright, & Gough, 2007; Holm & Severinson, 2011; Langley & Klopper, 2005; Lariviere et al., 2015; McSherry et al., 2012; Morriss et al., 2014; Nehls, 2001). In some cases (eg. Holm & Severinson, 2011), the themes did not appear internally coherent and the logic behind the grouping together of different ideas was not apparent. Two studies (Hodgetts et al., 2007; McSherry et al., 2012) stood out as particularly poor in terms of their analysis methods and a very thin description of results.

Three studies stood out as more methodologically rigorous, as they provided more than simple descriptions, i.e. themes with psychological meaning, and a more conceptual synthesis of participants' accounts (Castillo et al., 2013; Haeyen et al., 2015; Katsakou et al., 2012).

Credibility checks (Willig, 2013) were performed in most studies. The most common check was involving more than one researcher in the analysis. However, this appeared not to have taken place in four studies (Cunningham et al., 2004; Fallon, 2003; Langley & Klopper, 2005; McSherry et al., 2012).

### **Meta-synthesis**

The findings from the 14 studies were synthesised into three domains of themes (see Table 2). The first domain, "Areas of change", comprises four themes that describe experiences of progress in a range of areas. The second domain, "Helpful and unhelpful treatment characteristics", consists of four themes that describe treatment elements that either supported or delayed people in making progress. The last domain, "The nature of change", includes two themes describing individuals' perceptions of the process of moving forward.

Table 2 shows the corresponding domains, themes or subthemes in the included studies that contributed to the synthesis of the themes in the present review. The labels of some of these themes in the included studies have an obvious connection to the new themes; for example “Accepting self and building self-confidence” in Katsakou et al. (2012) is clearly connected to the theme “Self-acceptance and self-confidence” in the domain “Areas of change” in the meta-synthesis. In such cases, the included studies elaborated in some depth on ideas that were directly relevant to the meta-synthesis.

Other themes, however, might appear to have a less obvious connection to the themes in the meta-synthesis. For example, the theme “My case manager has stuck with me for years” in Nehls (2001) provided some evidence for the theme “Self-acceptance and self-confidence” of the meta-synthesis, despite the very different theme labels; more specifically, it briefly described that participants often believed that their case manager enhanced their sense of self-sufficiency. In these cases, the ideas presented in the included studies tended to be described briefly with relatively little depth.

### **Domain 1: Areas of change**

The majority of the studies described some areas of improvement for service users, which are presented below. However, with the exception of one study (Castillo et al., 2013), these areas were reported as a list of separate themes and not as interconnected parts of a recovery journey.

#### *Theme 1.1: Self-acceptance and self-confidence*

Thirteen of the 14 studies reported ideas about how treatment enhanced service users’ self-acceptance and self-confidence. These ideas were elaborated as

separate themes or subthemes in six of these studies (Castillo et al., 2013; Haeyen et al., 2015; Katsakou et al., 2012; Lariviere et al., 2015; McSherry et al. 2012; Perseius et al., 2003; 2005), whereas they were only briefly mentioned in the remaining seven.

The six studies that expanded on this topic reported that, through therapy, service users gained a better understanding of themselves and their difficulties. Individuals were able to make sense of their experiences and how these might have contributed to their struggles, which led them to become more accepting and compassionate towards themselves, less self-critical and able to reduce intense feelings of shame. They managed to integrate seemingly contradictory desires and aspects of themselves, which helped them develop a more coherent and stable sense of identity. This also allowed them to feel more confident in dealing with the rest of the world. They felt more competent and able to approach problems and make choices; they took responsibility for their lives and their efforts towards recovery and became more independent.

One of the studies that briefly made reference to this topic also described negative effects of treatment on participants' sense of identity (Morriss et al., 2014). It reported that when people felt criticised or blamed by professionals, they experienced being defined by the BPD label and seen as difficult patients, rather than distressed individuals. Such experiences made them feel empty and alienated.

Table 2. *Study characteristics*

Meta-synthesis domains and themes	Most relevant domains, themes or subthemes in included studies
<b>Domain 1: Areas of change</b>	
Theme 1.1: Self-acceptance and self-confidence	<p><b>Evidence from 13 studies</b></p> <p><i>Castillo et al. (2013)</i>: A sense of safety and building trust; Feeling cared for and creating a culture of warmth; Containing experiences and developing skills; Achievements, identity and roles</p> <p><i>Cunningham et al. (2004)</i>: Clients' assessment of DBT; Skills group; Relationships, Control of emotions, Level of hope</p> <p><i>Fallon (2003)</i>: Relationships</p> <p><i>Gillard et al. (2015)</i>: Reconciling the internal and external worlds; Feeling and thinking differently</p> <p><i>Haeyen et al. (2015)</i>: Perception and self-perception; personal integration; insight and comprehension</p> <p><i>Hodgetts et al. (2007)</i>: Internal processes; Non-specific factors</p> <p><i>Holm &amp; Severinsson (2011)</i>: The desire to recover by searching for strength; Recovering by being able to feel safe and trusted</p> <p><i>Katsakou et al. (2012)</i>: Accepting self and building self-confidence</p> <p><i>Lariviere et al. (2015)</i>: Person; Occupation</p> <p><i>McSherry et al. (2012)</i>: Therapy-specific factors; Renewed sense of identity; Impact of treatment on daily life</p> <p><i>Morriss et al. (2014)</i>: Non-caring care; It's all about the relationship</p> <p><i>Nehls (2001)</i>: My case manager has stuck with me for years</p> <p><i>Perseus et al. (2003; 2005)</i>: The therapy helps in accepting your feelings and not condemning (yourself or others); Your own responsibility and the stubborn struggle with yourself</p>
Theme 1.2: Taking control of emotions and thoughts	<p><b>Evidence from 8 studies</b></p> <p><i>Castillo et al. (2013)</i>: Containing experiences and developing skills; Hopes, dreams and goals and their relationship to recovery</p> <p><i>Cunningham et al. (2004)</i>: General reflections; Clients' assessment of DBT; Control of emotions; Level of suffering</p> <p><i>Gillard et al. (2015)</i>: Reconciling the internal and external worlds; Doing things differently; Feeling and thinking differently</p> <p><i>Haeyen et al. (2015)</i>: Emotion and impulse regulation; perception and self-perception; personal integration</p>

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*Katsakou et al. (2012)*: Taking control of emotions, mood and negative thinking  
*Lariviere et al. (2015)*: Person  
*McSherry et al. (2012)*: Therapy-specific factors; Impact of treatment on daily life  
*Perseius et al. (2003; 2005)*: The therapy provides skills to help conquer suicidal and self-harm impulses; Hopelessness and helplessness- will to struggle for a change

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Theme 1.3: New ways of relating to others

**Evidence from 14 studies**

*Castillo et al. (2013)*: A sense of safety and building trust; Feeling cared for and creating a culture of warmth; A sense of belonging and community; Containing experiences and developing skills  
*Cunningham et al. (2004)*: Skills group; Relationships; Control of emotions  
*Fallon (2003)*: Relationships  
*Gillard et al. (2015)*: Reconciling the internal and external worlds; Doing things differently  
*Haeyen et al. (2015)*: Behaviour change  
*Hodgetts et al. (2007)*: Non-specific factors  
*Holm & Severinsson (2011)*: The desire to recover by searching for strength; The struggle to be understood as the person you are; Recovering by refusing to be violated; Recovering by being able to feel safe and trusted  
*Katsakou et al. (2012)*: Improving relationships; Accepting self and building self-confidence  
*Langley et al. (2005)*: Trust takes time  
*Lariviere et al. (2015)*: Person; Environment; Obstacles to recovery  
*McSherry et al. (2012)*: Renewed sense of identity; Impact of treatment on daily life  
*Morriss et al. (2014)*: It's all about the relationship  
*Nehls (2001)*: My case manager has stuck with me for years  
*Perseius et al. (2003; 2005)*: The therapy helps in accepting your feelings and not condemning (yourself or others); Solitude, fearing relations- longing for love and fellowship; The group therapy- hard but necessary

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Theme 1.4: Achieving things and developing hope

**Evidence from 12 studies**

*Castillo et al. (2013)*: Achievements, identity and roles; Hopes, dreams and goals and their relationship to recovery; Containing experiences and developing skills  
*Cunningham et al. (2004)*: General reflections; Control of emotions; Level of hope; Clients' assessment of DBT  
*Gillard et al. (2015)*: Reconciling the internal and external worlds; Doing things differently  
*Haeyen et al. (2015)*: Behaviour change  
*Hodgetts et al. (2007)*: Evaluation of DBT

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*Holm & Severinsson (2011)*: Recovering by being able to feel safe and trusted  
*Katsakou et al. (2012)*: Practical achievements and employment  
*Langley et al. (2005)*: Hope  
*Lariviere et al. (2015)*: Person; Occupation  
*McSherry et al. (2012)*: Impact of treatment on daily life  
*Morriss et al. (2014)*: non-caring care; It's all about the relationship  
*Perseius et al. (2003; 2005)*: The therapy is life-saving

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**Domain 2: Helpful and unhelpful treatment characteristics**

Theme 2.1: Safety and containment

**Evidence from 7 studies**

*Castillo et al. (2013)*: A sense of safety and building trust; Containing experiences and developing skills; Learning the boundaries- love is not enough  
*Fallon (2003)*: Service responses  
*Haeyen et al. (2015)*: Art therapy versus verbal therapy  
*Nehls (2001)*: My case manager is more than a case manager; My case manager has stuck with me for years  
*Holm & Severinsson (2011)*: Recovering by being able to feel safe and trusted  
*Langley et al. (2005)*: Trust; Caring  
*Perseius et al. (2003; 2005)*: The therapy contract brings support and challenge

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Theme 2.2: Being cared for and respected

**Evidence from 12 studies**

*Castillo et al. (2013)*: Feeling cared for and creating a culture of warmth  
*Cunningham et al. (2004)*: Individual therapy  
*Fallon (2003)*: How accessible were the services?  
*Haeyen et al., (2015)*: Behaviour change  
*Hodgetts et al. (2007)*: Non-specific factors  
*Holm & Severinsson (2011)*: Recovering by being able to feel safe and trusted  
*Langley et al. (2005)*: Trust; Caring; Trying to understand; Professional  
*Lariviere et al. (2015)*: Environment  
*McSherry et al. (2012)*: Personal factors  
*Morriss et al. (2014)*: Non-caring care; It's all about the relationship  
*Nehls (2001)*: My case manager treats me like a person; My case manager is more than a case manager  
*Perseius et al. (2003; 2005)*: Respect and confirmation is the foundation; Not being understood and disrespectful attitudes

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Theme 2.3: Not being an equal partner in treatment

**Evidence from 9 studies**  
*Cunningham et al. (2004)*: Individual therapy; Skills trainers  
*Fallon (2003)*: How accessible were the services?; Negotiation  
*Hodgetts et al. (2007)*: Non-specific factors; External factors  
*Holm & Severinsson (2011)*: Recovering by being able to feel safe and trusted; The desire to recover by searching for strength  
*Katsakou et al. (2012)*: Balancing personal goals of recovery versus service goals  
*Langley et al. (2005)*: Trust; Caring; Professional  
*McSherry et al. (2012)*: Personal factors; Therapy-specific factors  
*Nehls (2001)*: My case manager treats me like a person; My case manager is more than a case manager  
*Perseius et al. (2003; 2005)*: Not being understood and disrespectful attitudes

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Theme 2.4: Focusing on change

**Evidence from 6 studies**  
*Nehls (2001)*: My case manager is more than a case manager; My case manager has stuck with me for years  
*Perseius et al. (2003; 2005)*: The method of therapy- brings understanding and focus on problems; The group therapy- hard but necessary; The poorly adapted tools of psychiatric care  
*Cunningham et al. (2004)*: Individual therapy; skills coaching  
*Hodgetts et al. (2007)*: Specific factors; Evaluation of DBT  
*Katsakou et al. (2012)*: Balancing personal goals of recovery versus service goals  
*Haeyen et al. (2015)*: Behaviour change

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**Domain 3: The nature of change**

Theme 3.1: An open-ended journey

**Evidence from 5 studies**  
*Castillo et al. (2013)*: Transitional recovery and how to maintain healthy attachment  
*Cunningham et al. (2004)*: Control of emotions  
*Gillard et al. (2015)*: Reconciling the internal and external worlds  
*Katsakou et al. (2012)*: Problems with the word recovery; Able to deal with things in a better way but not (fully) recovered  
*Lariviere et al. (2015)*: The concept of recovery for women with BPD: not consensually the best term to name their experience

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Theme 3.2: A series of achievements and setbacks

**Evidence from 6 studies**

*Fallon (2003)*: Movement; Negotiation

*Perseius et al. (2003; 2005)*: Fear of life, longing for death- fear of death, longing for life; Hopelessness and helplessness- will to struggle for a change; Solitude, fearing relations- longing for love and fellowship

*Cunningham et al. (2004)*: Level of suffering

*Katsakou et al. (2012)*: Recovery fluctuating; Able to deal with things in a better way but not (fully) recovered

*Lariviere et al. (2015)*: The concept of recovery for women with BPD: not consensually the best term to name their experience

*Gillard et al. (2015)*: Feeling and thinking differently

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### *Theme 1.2: Taking control of emotions and thoughts*

Seven studies made reference to the idea of gaining more control over feelings and negative thoughts. However, this was described in some detail in only five of these studies (Cunningham et al., 2004; Gillard et al., 2015; Haeyen et al., 2015; Katsakou et al., 2012; Lariviere et al., 2015).

These five studies described that service users gained more control over their emotions, moods and negative thoughts. They became more aware of and able to experience emotions without disconnecting from them, but also to let go of negative emotions. This process often started in therapy, where individuals felt connected with their feelings and were able to make sense of conflicting emotions. They developed a more balanced emotional experience, including positive emotions and less dramatic mood swings. Service users also developed more helpful ways of thinking and were able to challenge negative thoughts. They could reflect on and analyse difficult situations before their emotions became too overwhelming and uncontrollable. This helped them to stop and think when in crisis, before impulsively reverting to harmful behaviours, such as self-harming or using drugs.

Two of these five studies reported that, despite these improvements, emotional difficulties remained present in service users' lives. Cunningham et al. (2004) reported that the majority of interviewees still experienced high levels of emotional suffering. Similarly, Gillard et al. (2015) described that some participants were unable to let go of a general sense of negativity and disconnection from their emotional experience.

The remaining two studies that briefly mentioned ideas about gaining control of emotions and thoughts did not highlight any additional aspects.

### *Theme 1.3: New ways of relating to others*

The idea of developing new ways of relating to others was mentioned in all 14 studies. However, only six reported this as a separate theme or subtheme and provided a more elaborate description of its various aspects (Castillo et al., 2013; Cunningham et al., 2004; Katsakou et al., 2012; Langley et al., 2005; Lariviere et al., 2015; Perseius et al., 2003; 2005).

In these six studies, participants described that, through therapy, they were able to socialise more and feel less isolated. They built more supportive relationships and ended abusive ones. They were able to trust others more, talk more openly about their emotions and suffering, and allow themselves to feel vulnerable in intimate relationships. This led them to feel more connected and develop a sense of belonging and feeling liked and cared for by others. This was often a process that started in group therapy, as participants developed relationships with peers.

Participants also described that they developed a better understanding of their behaviour in interpersonal contexts and its impact on other people. They were able to make sense of others' intentions, feelings and actions. This was subsequently linked to their finding better ways of communicating with people and being less aggressive; they became more assertive and able to tolerate and negotiate conflicts.

One of these six studies (Perseius et al., 2005) highlighted participants' ambivalence towards making changes in relationships. More specifically, it reported that interviewees felt torn between longing for love and fellowship and fearing close relationships.

The remaining eight studies that reported related ideas did not add any further understandings.

#### *Theme 1.4: Achieving things and developing hope*

Twelve studies mentioned the idea of practical achievements and/ or the related concept of hope. However, an elaborate description of these concepts as a separate theme or subtheme was given in only four of these studies (Castillo et al., 2013; Cunningham et al. 2004; Katsakou et al., 2012; Lariviere et al., 2015).

These four studies reported that service users described making changes in their lives, including confronting stressful situations, engaging more with community activities, managing their finances and household more effectively, and getting involved in voluntary or paid employment. They described developing more skills and feeling more able to deal with problems and the world as a whole. Participants also became more involved in activities that were meaningful to them, which led to them developing a sense of purpose and hope for the future.

The remaining eight studies that briefly referred to this area did not offer any additional ideas.

### **Domain 2: Helpful and unhelpful treatment characteristics**

The majority of the studies described treatment characteristics that either supported or hindered clients in making progress. These characteristics were presented as a list of separate treatment elements and there was no explicit reference to how they might be connected or interact with each other.

#### *Theme 2.1: Safety and containment*

The idea of safety and containment was mentioned in seven studies. However, it was elaborated only in three studies (Castillo et al., 2013; Langley et al., 2005; Perseus et al., 2003; 2005).

One of these studies (Castillo et al., 2013) explored participants' perceptions of developing a sense of safety. When the therapeutic environment and relationships within therapy were experienced as a safe haven, people could internalise this feeling of safety and feel contained. When therapy helped them make sense of their experiences and their difficulties, these felt less overwhelming and uncontrollable.

All three studies described setting boundaries and/ or having treatment contracts as necessary steps in developing a sense of stability, security and containment. Although such agreements were experienced as challenging and often frustrating, they were deemed helpful in tackling ambivalence and promoting commitment to therapy and change.

The remaining four studies that briefly referred to this topic did not provide any additional ideas.

### *Theme 2.2: Being cared for and respected*

The importance of feeling respected and cared for was referred to in 12 studies. However, it was elaborated in only five studies (Castillo et al., 2013; Langley et al., 2005; Morriss et al., 2014; Nehls, 2001; Perseus et al., 2003; 2005).

In those five studies, participants reported that they appreciated being listened to and understood, not being judged and feeling supported in making sense of and trying to deal with their struggles. Hence, therapists who were perceived as available and approachable, honest, accepting, interested and genuinely concerned about people's difficulties, were seen as facilitating progress and recovery.

On the other hand, when staff were perceived as distant, judgemental, unavailable or not understanding, people felt isolated, criticised and undeserving of

support. Similarly, when services only responded to risk issues, individuals felt that their underlying distress was ignored.

The remaining seven studies that briefly mentioned this topic did not contribute any additional understandings.

*Theme 2.3: Not being an equal partner in treatment*

The idea of not feeling like an equal partner in treatment was mentioned in nine studies. However, it was examined in depth as a separate theme in only one study (Fallon, 2001).

In that study, interviewees described that they often did not feel included as equal partners in their treatment. When they thought that therapy goals were imposed on them, rather than negotiated and agreed, they did not feel motivated to take responsibility and make progress. Similarly, when they perceived the therapy to be too rigid and inflexible, they thought that their liberty was restricted and felt powerless and angry. In contrast, when interviewees felt included in treatment decisions and plans, they felt valued and empowered. Overall, they reflected that therapies needed to strike a good balance between exerting some control when necessary (eg., when clients are at risk) and promoting independence in the long-term.

Three of the remaining studies that briefly referred to ideas about not participating in treatment also reported that when medical jargon or therapy-specific terminology was used, this was often experienced as intimidating and exclusive (Cunningham et al., 2014; Holm & Severinsson, 2011; McSherry, 2012).



#### *Theme 2.4: Focusing on change*

Six studies made reference to the idea of therapy promoting change. This was expanded upon as a separate theme or subtheme in only two studies (Cunningham et al., 2004; Perseius et al., 2003; 2005).

In these two studies, participants described that therapies with a clear focus on practically facilitating change were helpful. They thought that therapy needed to focus on solving problems, teaching them skills that they could apply in their lives, and offering support during crises. Therapists who were perceived as “pushing” clients towards change and challenging them to try harder were seen as effective. On the other hand, when therapy was perceived as too open-ended, with no clear focus on offering solutions, it was experienced as confusing and unhelpful.

In one of the remaining studies that briefly referred to promoting change, it was noted that practical help in areas such as housing, finances, and everyday needs was also appreciated by service users (Nehls, 2001).

### **Domain 3: The nature of change**

Seven studies made reference to the nature of change in BPD, describing it as an open-ended, dynamic process.

#### *Theme 3.1: An open-ended journey, not a dichotomous outcome*

Five studies referred to service users’ experiences of change as an open ended journey rather than a dichotomous outcome. Only three of those studies analysed this idea in some detail as a separate theme (Castillo et al., 2013; Katsakou et al., 2012; Lariviere et al., 2015).

In these three studies, making progress was described as an open-ended journey, consisting of small steps. This was summarised as a gradual ongoing process of personal development. Two studies reported that a “full” recovery, which would imply the absence of problems, was seen as an inappropriate way of conceptualising improvement in BPD, as it could reflect a sense of denial of enduring difficulties (Katsakou et al., 2012; Lariviere et al., 2015).

The remaining two studies that mentioned this topic did not add any further understandings.

### *Theme 3.2: A series of achievements and setbacks*

The idea that change involved a series of achievements and setbacks was mentioned in six studies. Two of those studies elaborated on this idea as a separate theme (Katsakou et al., 2012; Perseius et al., 2005).

In these two studies, progress was perceived as constant movement between achievements and setbacks. In Katsakou et al. (2012), participants described times when they felt better and in control, followed by periods when they felt unable to cope and defeated. However, they maintained a sense of moving forward and becoming more able to deal with difficulties.

Perseius et al. (2005) described that the process of making progress was often experienced as particularly challenging and draining. This was often reflected in a profound sense of ambivalence about whether to continue making an effort. Service users were described as feeling torn between longing for life and longing for death; between feeling hopeless and struggling to make meaningful changes; and between remaining isolated and reaching out to others.

No additional ideas were described in the remaining four studies that made reference to this topic.

## **Discussion**

The present review aimed to synthesise service users' experiences of treatment and recovery in BPD, as described in 14 qualitative studies. The meta-synthesis identified three main domains, each comprising several themes. The first domain, "Areas of change", suggests that service users make positive changes in four main areas, including developing self-acceptance and self-confidence, controlling difficult thoughts and emotions, practising new ways of relating to others, and achieving things and developing hope. The second domain, "Helpful and unhelpful treatment characteristics", highlighted treatment elements that service users believed either supported them or hindered them in making progress. These consisted of treatment providing a sense of safety and containment, being cared for and respected, not being an equal partner in treatment, and treatment focusing on change. Lastly, the third domain summarised the "Nature of change", which was described as an open-ended journey rather than a dichotomous outcome, and a series of achievements and setbacks.

The meta-synthesis highlighted areas of change that appear important and relevant for service users with BPD. Although some of the identified areas, such as developing hope and achieving things, reflect concepts of recovery described in the wider recovery literature and might be applicable to people with a wider range of difficulties (Leamy, Bird, Le Boutillier, Williams, & Slade, 2011; Slade, Amering, & Oades, 2008), the description of specific changes in some of the areas appears particularly relevant to BPD.

More specifically, the development of self-acceptance and self-confidence, as described in this review, goes beyond re-claiming a sense of identity after a diagnosis of mental illness, an idea commonly referred to in the wider recovery literature (Leamy et al., 2011). Indeed, it highlights how therapy might support people with BPD in understanding the origins of enduring feelings of shame and in developing different ways of making sense of and accepting themselves. Such feelings often emerge from poor early attachment relationships, which also contribute to profound difficulties in relating to others (Gilbert, 2010). In this context, the description of new ways of relating to others in this meta-synthesis offers a better understanding of specific challenges and improvements in this area, such as opening up and trusting others, tolerating a sense of vulnerability in close relationships, understanding others, and developing better ways of communicating. Finding new ways of managing negative thoughts and emotions is also closely linked to ongoing difficulties in BPD, which has been described as mainly a disorder of emotional dysregulation (Linehan, 1993).

However, it is worth noting that, with one exception, the studies included in the meta-synthesis did not explore processes of change, and therefore it remains unclear how change in the identified areas is achieved. The treatment characteristics identified and summarised in this meta-synthesis appear generic and do not offer new insights into how change in BPD might be facilitated through therapy. More specifically, feeling safe, contained, cared for and respected have been identified as positive treatment experiences for clients with a wide range of problems (Lemma, Target & Fonagy, 2011). Similarly, not participating in treatment decisions has been reported as contributing to dissatisfaction with and disengagement from various services (Katsakou et al., 2011; 2012). However, it is hard to imagine how such

generic treatment characteristics, in the absence of other processes, can play a substantial role in the treatment of a condition as complex as BPD. Thus, the more specific mechanisms of change and the ways in which treatments can facilitate these remain poorly understood.

Nevertheless, some of the treatment characteristics identified as helpful in this meta-synthesis might shed some light into more specific therapeutic approaches that could be helpful in BPD. For instance, setting clear boundaries and having treatment contracts or agreements were described as an effective way of providing containment. This finding is consistent with the current rationale in specialist therapies for BPD, including DBT and MBT, where emphasis is placed on enhancing service users' motivation to commit to their treatment by honouring agreements with therapists (Linehan, 1993; Bateman & Fonagy, 2006).

Similarly, focusing on change, which was identified as a helpful treatment element in this review, might be perceived as particularly helpful by service users who struggle with tackling ambivalence and taking action. This is also reflected in the theoretical underpinnings of cognitive and behavioural therapies for BPD, where a clear focus on actively implementing changes and solving problems is understood to be one of the main drivers of progress (Linehan, 1993; Davidson, 2008).

The description of service users' experience of change as an ongoing process involving a series of achievements and setbacks in this review mirrors understandings of recovery in a wide range of conditions, mainly in Axis 1 disorders, where recovery is also described as a continuing journey and a gradual process (Leamy et al., 2011; Slade et al., 2008; Slade et al., 2014). However, some aspects of this journey identified in this review might indeed be more relevant to individuals

with BPD. For example, service users' accounts of fluctuations between yearning for change and feeling defeated is particularly pertinent to individuals with BPD, who struggle with mood swings and ambivalence regarding change (Corradi, 2013). Similarly, the view that "full recovery" might be an inappropriate way of conceptualising improvements in BPD, which was expressed in some of the included studies, might reflect the presence of enduring difficulties that define people's sense of self throughout their lives and do not just manifest as symptoms of distinct episodes of mental illness (Shepherd, Sanders, Doyle & Shaw, 2015).

### *Limitations*

The findings of the present meta-synthesis were limited by the quality of the included studies, the majority of which provided a thin description of service users' experiences. It was challenging to strike a balance between presenting a meaningful synthesis of findings while also providing an accurate picture of the themes and analyses in the included studies, without making them appear more elaborate than they were. In this process, it became obvious that the three studies that were more methodologically rigorous and offered a thicker description of service users' expressed views (Castillo et al., 2013; Haeyen et al., 2015; Katsakou et al., 2012) contributed more substantially to the generation and the description of themes for the meta-synthesis.

Although the majority of studies reported thinly described and poorly connected themes, they were not excluded from the meta-synthesis. The CASP was used as a framework to highlight methodological issues and limitations in the included studies rather than as a checklist to exclude weak studies. It has been argued that when conducting a critical appraisal of qualitative studies for the purposes of a

meta-synthesis, the methodological shortcomings of a study need to be balanced against its potential contribution to gain a better understanding of the phenomenon under review (Edwards, Elwyn, Hood, & Rollnick, 2000). In the current review, it was decided to include all studies, regardless of methodological quality, in order to provide a more accurate presentation of the current knowledge base in this area and a comprehensive description of methodological shortcomings in the existing studies.

Lastly, the present review was limited by the fact that the literature searches, the identification of relevant papers, the synthesis of themes from the included studies and the critical appraisal were conducted mainly by a single researcher. Although relevant decisions at all stages were thoroughly discussed with her supervisor, it is recommended that more than one researcher be involved in the tasks listed above, in order to limit bias in decisions concerning the inclusion of studies, their critical appraisal and the synthesis of findings (Petticrew & Gilbody, 2004).

#### *Implications for clinical practice and future research*

The present review points to areas of improvement in psychological functioning that people with BPD have identified as both important and achievable. It is crucial that both specialist and generic services support individuals in making changes in these areas. Treatments addressing these areas may promote recovery by enhancing clients' commitment and engagement with services (Barnicot et al., 2012).

Given that service users experience change as a dynamic process involving a series of achievements and setbacks, therapies for people with BPD need to incorporate specific strategies to support them to remain hopeful, fight ambivalence and deal with setbacks. Some specialist therapies have developed mechanisms to address this challenge. For example, DBT provides a set of "commitment strategies"

to increase clients' sense of commitment to therapy and responsibility for personal change (Linehan, 1993).

The areas of change identified in this review could be used to inform the development of outcome measures that capture outcomes that are achievable and important to service users. Such measures might assess concepts related to self-acceptance and self-confidence; confidence in managing negative thoughts and emotions; relationship skills; and achievements in daily living skills. Such outcomes could then be routinely assessed both to evaluate individuals' progress and for research purposes.

Further research on processes of recovery is needed to offer a better understanding of how change can be achieved in BPD and how therapies can facilitate this process. Although existing studies identify areas of change that are important for people with BPD, they do not shed light on how improvements in these areas might be reached. Qualitative research exploring service users' experiences of recovery, particularly focusing on how they believe that they make progress and how therapy and other factors might support them in their journey, could bridge these gaps in our understanding of recovery in BPD. The perspectives of other groups, such as therapists and family caregivers, might also expand our understanding of recovery processes. This knowledge could inform the further development of existing therapies for BPD.



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## **Part 2: Empirical Paper**

### **Processes of recovery from Borderline Personality Disorder: a qualitative study**

## **Abstract**

**Aims:** This study aimed to explore how recovery in borderline personality disorder (BPD) is reached through routine or specialist treatment, as perceived mainly by service users, but also by therapists and relatives.

**Method:** Service users with a diagnosis of BPD were recruited from secondary mental health services, including two specialist services (Dialectical Behavioural Therapy and Mentalization-Based Treatment), three community mental health teams and a psychological therapies service. Semi-structured interviews exploring participants' perspectives on processes of recovery were conducted with 48 service users, 15 therapists and six relatives. The framework approach, a type of thematic analysis, was used to analyse the data.

**Results:** The findings were organized into two domains of themes. The first domain described three parallel processes that constituted service users' recovery journey: fighting ambivalence and committing to taking action; moving from shame to self-acceptance and compassion; and moving from distrust and defensiveness to opening up to others. The second domain described four therapeutic challenges that needed to be successfully addressed to support this journey: balancing self-exploration and finding solutions; balancing structure and flexibility; encouraging service users to confront interpersonal difficulties and practise new ways of relating; and balancing support and independence.

**Conclusions:** Therapies facilitating the identified processes may promote recovery. The relative contribution of each process to treatment outcomes could be examined in future research.

## **Introduction**

Borderline personality disorder (BPD) causes significant distress to those affected by the condition and is also a challenge for those treating it. Service users with BPD use considerable therapeutic resources (Higgit & Fonagy, 1992) and professionals involved in their care often feel overwhelmed and frustrated (Markham & Trower, 2003; Skegg, 2005). In the UK it has been estimated that at any given time 37-67% of inpatients in psychiatric hospitals meet the criteria for this diagnosis, while treating individuals with BPD and self-harming is also a common concern in day-to-day practice at Accident and Emergency departments of general hospitals and in community and specialist mental health settings (Ansell, Sanislow, McGlashan, & Grilo, 2007; Bender et al., 2001; DoH, 2003; Horz, Zanarini, Frankenburg, Reich, & Fitzmaurice, 2010; Tyrer et al., 2003; Zanarini et al., 2008).

Until recently, BPD was often seen as enduring and unresponsive to therapeutic interventions (DoH, 2003). However, a longitudinal epidemiological study has indicated that the prevalence of BPD among those receiving routine care in mental health services decreases substantially over time (Zanarini, Frankenburg, Hennen, & Silk, 2003). A 35% remission rate was observed at two years and a 50% remission rate at four years after the initial diagnosis, while 10 years later only 26% continued to meet criteria for the diagnosis. Participants in this investigation were recruited when they were inpatients and received community treatment afterwards, but less than 5% of them were ever in a form of specialist treatment with proven effectiveness for treating BPD.

Several randomised controlled trials (RCTs) have also found specialist psychotherapies for BPD to be effective (see Brazier et al., 2006 and Stoffers et al.,

2013 for a review). Most of these studies have compared Dialectical Behavioural Therapy (DBT) to other treatments and have reported overall favourable outcomes, suggesting that DBT is associated with reduced suicide attempts and self-harming behaviours, less use of crisis services and improvement in mood indicators. Based on the existing evidence, in the NICE guidelines for the treatment of BPD, DBT is recommended as the treatment of choice for “women with borderline personality disorder for whom reducing recurrent self-harm is a priority” (NICE, 2009). This guidance reflects the fact that the existing trials have tended to focus on women and that DBT primarily aims to reduce self-harming.

Mentalization-based treatment (MBT) for BPD has also been found effective. Several trials have demonstrated reductions in suicidality and service use and improvements in global and social functioning and BPD symptoms (Bateman & Fonagy, 1999; 2009; Jorgensen et al., 2013). These outcomes were maintained even when service users were followed-up for up to five years after discharge (Bateman & Fonagy, 2008).

Interestingly, however, in several of the DBT and MBT trials, improvements have also been found in the “control” arm. That is, some clients improved in terms of self-harming and mood indicators, even when they only received standard community treatment or generic psychological therapies (eg., Bateman & Fonagy, 2008; Linehan, Armstrong, Suarez, Allmon, & Heard, 1991; Priebe et al., 2012). This finding is in line with the epidemiological evidence noted, suggesting that some service users improve, even when they do not receive specialist therapies (Zanarini et al., 2008).

Hence, the evidence indicates that symptom improvement in BPD through various standard or specialist treatments is not only possible, but also more common than previously assumed (Fonagy & Bateman, 2006; NICE, 2009). Although this is a significant achievement and a relevant target for services, service users' perceptions of recovery and personal goals might include wider aspirations than mere symptom improvement.

Recent qualitative studies exploring service users' perceptions of recovery indicate that these include developing self-acceptance and self-confidence; building secure attachments and tackling isolation; gaining control over difficult thoughts, emotions and impulsivity; assuming responsibility; and actively implementing changes (Castillo, Ramon & Morant, 2013; Gillard, Turner, & Neffgen, 2015; Holm & Severinsson, 2011; Katsakou et al., 2012; Lariviere et al., 2015). These studies also suggest that service users' experience of recovery is better described as a journey, consisting of a series of achievements and setbacks, rather than as a static outcome. Yet, although service users see full recovery as a distant goal, their accounts suggest that they can learn how to better manage their difficulties and make meaningful progress.

However, these qualitative studies have several limitations. Most recruited participants from a single specialist BPD service. Therefore, the findings might reflect processes that occur mainly in those specific settings, rather than factors that facilitate recovery across a wider range of services. Although evidence indicates that service users can make improvements through different treatments, it remains unclear how recovery is facilitated across a range of different therapies and services and what common processes might support service users in their recovery journey.

More importantly, the studies did not have a clear focus on processes of recovery, but rather on general experiences and perceptions of recovery, as described by service users. Hence, our understanding of how recovery might be reached remains narrow. This echoes the conclusions of a recent review of quantitative studies, which highlighted that our knowledge of factors that lead to positive outcomes in BPD is limited, although a good client-rated therapeutic alliance was a consistent predictor of symptom improvement across studies (Barnicot et al., 2012).

### **Aims of the present study**

In summary, symptom improvement in BPD is more common than originally assumed. Yet, service users' perceptions of recovery include wider aspirations than mere symptom improvement. Although recovery is experienced as a journey, consisting of a series of achievements and setbacks, service users describe that they can make meaningful positive changes in their lives. What remains unclear, however, is how these positive outcomes might be reached.

The present qualitative study aimed to explore how recovery in BPD is reached through routine or specialist treatment, as perceived mainly by service users, but also by therapists and relatives. Understanding service users' perspectives on what specific treatment elements, personal resources and common processes might lead to positive outcomes across services could facilitate the further development of existing specialist psychotherapies, such as DBT and MBT, as well as the delivery of routine community care and generic psychological therapy. Moreover, exploring the views of therapists who deliver treatment to this group, and of significant others could offer a broader view of processes of recovery and allow for the triangulation of findings by including multiple perspectives.



## **Method**

### **Design**

This was an exploratory, qualitative, interview-based study. A qualitative approach was deemed suitable, as qualitative research has the potential to elucidate complex processes and offer insight into individuals' lived experience, while remaining rooted in the rich data that participants provide (Lincoln & Guba, 2000). Furthermore, in-depth qualitative interviews can offer a detailed understanding of how change might be achieved in therapy and what barriers might hinder this process (Hodgetts & Wright, 2007).

### **Ethics**

The study was approved by the East London NHS Research Ethics Committee (see Appendix B).

### **Setting**

Service users with BPD and a history of self-harming were recruited from specialist and generic secondary mental health services in London. These included two specialist BPD services (a DBT service and a therapeutic community using MBT), three community mental health teams (CMHTs) and a psychological therapies service. The latter service offered a range of psychological therapies, using cognitive behavioural, psychodynamic and integrative approaches.

### **Inclusion and exclusion criteria**

The inclusion criteria for participation in the study were:

1. A diagnosis of BPD (as reported by the participating services) and a history of self-harming. The definition of self-harming for the present study included self-injurious or other suicidal behaviours (eg., overdosing) that were made with the intention to self-harm.
2. Current or recent contact with specialist and/ or generic services.
3. Age above 18 years.

Individuals with severe learning disabilities, those whose English language skills were not sufficient for them to be interviewed in-depth and those unable to give informed consent were excluded.

## **Recruitment and sampling procedures**

### *Service Users*

Professionals from all participating services were asked to inform the researcher about eligible clients. Purposive sampling (Miles & Huberman, 1994) was used to ensure that the sample included interviewees with a range of clinical and demographic characteristics, i.e. co-morbid diagnoses, service use, ethnic background, age and gender. The aim was to include service users at different stages in their recovery journey, those who remained engaged with services and those who discontinued their various psychological therapies. New participants were invited to participate on the basis of their potential similarities or differences from those already in the sample. The recruitment of new service users stopped when saturation of the emerging themes was attained (Strauss & Corbin, 1998).

Once suitable service users were identified, they were introduced to the researcher by their key-worker. The researcher gave them detailed information about the study and asked for their consent to participate. The participant information sheet and consent form were handed to and discussed with potential participants during this process (see Appendices C and D). If written consent was obtained, participants provided information on their socio-demographic and clinical characteristics (eg., gender, age, ethnicity, employment, accommodation and partnership status, diagnosis).

### ***Therapists and relatives***

A subgroup of service users was asked to name a therapist and/ or a relative, partner or friend, whom they felt close to and were in at least weekly contact with, to be approached and asked to also take part in the study. (Relatives, partners and friends will be described in short as “relatives” in the text that follows).

The therapists and relatives were then contacted and asked for their consent to take part in the study. The participant information sheets and consent forms for therapists and relatives respectively were given to and discussed with potential participants during this process (see Appendices C and D). Socio-demographic data (eg., gender, age, ethnicity and type of relationship to the service users) were collected for therapists and relatives.

### **Characteristics of participants**

Forty-eight (89%) of the 54 eligible service users who were invited to participate in the study were interviewed. Four declined to take part and two initially expressed interest, but did not attend their agreed appointment for an interview.

Fifteen service users gave consent for their therapist to be interviewed. All 15 of these therapists agreed to take part in the study and were interviewed. Seven service users agreed for a relative to be contacted. Six of these took part; one of the relatives could not attend the interview, as she lived out of London.

A total of 69 interviewees (48 service users, 15 therapists and six relatives) participated in the study. Their characteristics are presented in Tables 1, 2 and 3 respectively. The majority of participants had received or were currently receiving a specialist therapy. This was DBT for almost half of the interviewees (23) and MBT for eight participants. Six participants were currently receiving or had recently completed other psychological therapies and 11 were using generic services. Nine had dropped out of some form of specialist or generic psychological therapy. The great majority of participants had received some form of psychological therapy in the past.

### **Interviews and topic guides**

In depth semi-structured interviews were conducted with study participants. Initial drafts of topic guides for interviews were produced by the researcher. The interview schedule for service users was then finalised in consultation with two service users with BPD and a history of self-harming, who had used routine and specialist services. Similarly, the interview schedules for interviews with therapists and relatives were fine-tuned in consultation with two therapists and a relative respectively. Drawing on guidelines for semi-structured interview schedules, the topic guides provided a set of questions that covered the main areas of interest, from which the interviewer or the interviewee could depart to further elaborate on individual ideas or experiences (Britten, 1995).

Study participants were asked to describe their (or their client's/ relative's) experiences of treatment, the elements of treatment that had been helpful or unhelpful and other events and factors that might have contributed to or hindered their recovery. They were asked to evaluate in detail the interventions that were offered to them and to discuss positive and negative aspects and ideas for change and improvement.

They were also asked to reflect on their (or their client's/ relative's) journey towards recovery and the various significant points, difficulties and achievements in this journey. The topics covered in interviews were similar for service users, therapists and relatives. However, each group's unique perspectives and experiences on these areas were sought. The interview schedules are presented in Appendix E.

The interview style was flexible, non-directive and guided mostly by open questions. The participants were encouraged to provide detailed accounts of their experiences and perspectives and bring up anything that they felt was important. The aim was to unravel interviewees' deeper meanings and uncover ideas that were not necessarily anticipated at the outset of the research (Britten, 1995).

Service users who were currently engaged with services were interviewed after they had used services for a minimum of four months, so that they had sufficient time to evaluate the therapy they received. The trainee conducted the majority of the interviews (45 out of the 69 interviews) and another three researchers interviewed the remaining participants. The interviews lasted between 30 and 120 minutes. All interviews were recorded and transcribed verbatim by a professional transcriber.

## **Data analysis**

During data collection, a preliminary analysis of themes emerging from the interviews was conducted to guide the sampling of new participants (Strauss & Corbin, 1998). This consisted of reading the interview transcripts as soon as they were produced, identifying emerging themes and reflecting on whether participants with similar or different characteristics and perspectives needed to be interviewed to develop the researcher's understanding of the research topics.

The "framework approach" (Ritchie & Spencer, 1994; Ritchie, Spencer, & O'Connor, 2003) was then used to analyse the data. This is a type of thematic analysis that is particularly suitable for large qualitative data sets, because it involves a structured, systematic procedure for coding and organising the data. Following this method, the analytical process involved a number of separate yet interconnected steps. Firstly, the researcher familiarised herself with the data, by reading the transcripts and identifying significant ideas and preliminary themes. An example of this step is presented in Appendix H. Thorough reading of transcripts from interviews with service users, therapists and relatives suggested that the emerging topics from the three different sources of data were sufficiently similar and that the three perspectives could therefore be analysed together.

Table 1. *Socio-demographic and clinical characteristics of service users*

	Total sample (N=48) N (%)
<b>Gender</b>	
Female	39 (81)
Male	9 (19)
<b>Age</b>	
Mean (range)	36.5 (18-58)
<b>Ethnicity</b>	
White	33 (69)
Black	5 (10)
Asian	10 (21)
<b>Employment</b>	
Unemployed	37 (77)
Voluntary work	3 (6)
Employed	8 (17)
<b>Accommodation</b>	
Independent accommodation	48 (100)
<b>Partnership</b>	
Living alone	28 (58)
Living with partner/ family	20 (42)
<b>Co-morbid Diagnoses</b>	
Any other PD	33 (48)
Depression/ dysthymia	21 (44)
Bipolar disorder	4 (8)
Schizoaffective disorder	4 (8)
Eating disorder	6 (13)
Anxiety disorder (PTSD, OCD, phobia)	8 (17)
Substance misuse	8 (17)
<b>Treatment</b>	
DBT	23 (48)
MBT	8 (17)
Other psychological therapy	6 (13)
Generic services	11 (23)
<b>Stage of treatment</b>	
Completed/ ongoing treatment <sup>a</sup>	28 (76)
Dropped out <sup>a</sup>	9 (24)
<b>Received counselling/ psychotherapy in the past</b>	
Yes	44 (92)
No	4 (8)
<b>Years in mental health services</b>	
0-5 years	28 (58)
6-10 years	16 (33)
11-15 years	4 (9)

<sup>a</sup> only applicable to those receiving psychological therapy (N=37)

Table 2. *Socio-demographic characteristics of therapists*

	Total sample (N=15) N (%)
<b>Gender</b>	
Female	8 (53)
Male	7 (47)
<b>Age</b>	
Mean (range)	40.1 (28-58)
<b>Ethnicity</b>	
White	12 (80)
Black	1 (7)
Asian	2 (13)
<b>Professional background</b>	
Psychologist	6 (40)
Psychiatrist	1 (7)
Nurse	5 (33)
Social worker	2 (13)
Support worker	1 (7)
<b>Type of therapy delivered</b>	
DBT	5 (33)
MBT	3 (20)
Generic Psychological therapy	3 (20)
CMHT support	4 (27)

Table 3. *Socio-demographic characteristics of relatives*

	Total sample (N=6) N (%)
<b>Gender</b>	
Female	2 (33)
Male	4 (67)
<b>Age</b>	
Mean (range)	44.8 (33-56)
<b>Ethnicity</b>	
White British	5 (83)
Asian	1 (17)
<b>Relationship to service user</b>	
Parent	1 (17)
Other relative	3 (50)
Partner	1 (17)
Friend	1 (17)



Hence, based on the topics identified at this initial stage, a thematic framework that captured the main ideas from interviews with service users, therapists and relatives was devised (see Appendix F). The interview transcripts were then indexed (coded) according to this framework using the MAXqda software for qualitative data analysis (version 2) (see Appendix H). Following this, charts summarising each service user's journey towards recovery were drawn. This allowed the researcher to maintain a picture of the data as a whole, by considering each participant's personal trajectory (see an example of this in Appendix G). The final stage of analysis involved mapping and interpreting the data. The researcher searched for overarching patterns and connections between themes and subthemes and aimed to answer the research questions in a way that coherently synthesised the interview data. Through these analytical steps, the researcher was guided into progressively more abstract understandings of the emerging themes, which was intended to facilitate the conceptual clarification of the themes and the development of more holistic interpretations. This was reflected in the finalised coding frame, which captured the domains and themes that summarised the findings (see Appendix I).

#### *Validity checks*

Following guidelines for good practice in qualitative research, several steps were taken to maximise the validity of the analysis (Mays & Pope, 2000). Firstly, the researcher reflected on and tried to minimise her own preconceptions by bracketing her prior beliefs and knowledge in the area, in order to remain curious and open to participants' perspectives and unique experiences (Chan, Fung & Chien, 2013).

The researcher was a 36-year-old Greek woman who had experience of working with clients with BPD, using both DBT and MBT approaches. She had also previously worked as a research fellow managing several projects on effective therapies for clients with BPD. Having worked as a therapist and having developed a strong interest in the treatment of BPD, she held a number of preconceptions about the strengths and weaknesses of DBT, MBT and more generic forms of therapy. For example, she valued a degree of structure and goal-orientation in therapy, but felt that a more flexible, deeper exploration of early attachments and relational patterns was necessary for recovery to occur. Yet, she actively attempted to remain aware of and reflect on her views throughout the research project both individually and during supervision, especially during data analysis and interpretation. She also regularly discussed the emerging themes with her supervisor and the other members of the research team, to ensure that different ways of examining the data were taken into account. Similarly, a comprehensive review of the literature in this area was delayed until after the analysis of the data, so that the analysis process could remain open to the ideas expressed by participants in the study (Chan, Fung & Chien, 2013).

A consensus approach in developing the understanding of the data was used at each stage of the analysis (Barker & Pistrang, 2005). The process of developing a framework to capture the emerging themes was inductive. The framework was initially developed by the researcher and was refined by herself and the primary supervisor to ensure that it included all identified topics that were relevant to the research questions. Following this, the researcher coded 14 interviews (20% of all interviews) together with another researcher to consider challenges in coding and further fine-tune the coding framework, a method described as multiple coding (Barbour, 2011). These included 10 interviews with service users, three with

therapists and one with a relative. The researcher then coded all the remaining interview transcripts. Once this was completed and the core themes were identified, the further fine-tuning and interpretation of the emerging themes was discussed with the research supervisors.

In addition, the researcher discussed the developed framework and the overall data analysis with a service user representative. Their feedback was intended to help the team further refine their understanding of the data and ensure that service users' perspectives were included in their interpretation.

As recommended in qualitative research (Miles & Huberman, 1994), quotations illustrating and providing evidence for the emerging themes were used throughout the analysis and in the final report of the findings to ensure that the analysis was grounded in the original data.

## **Results**

The findings were organized into two domains of themes (Table 4). The first domain, "Processes of recovery" consists of three themes describing central processes that constituted service users' recovery journey. The second domain, "Challenges in therapy", consists of four themes reflecting therapeutic challenges that needed to be successfully addressed to support this journey. The term "therapy" in this context includes both psychological therapies and treatment in generic mental health services.

Each of the three processes and four challenges are presented in turn. The source of quotations is indicated by participant ID numbers (e.g. SU1 for service user 1, T1 for the therapist of SU1, R4 for the relative of SU4 etc.). The type of therapy

they had received is also indicated. Ellipses signify that the quotations have been edited for brevity.

### **Domain 1: Processes of recovery**

This domain of themes is based mostly on service users' accounts, given that it focuses on the personal experience of recovery. However, therapists' and relatives' reports also contributed to the themes.

Trajectories of clients' recovery journeys were described in ways that suggested that there was no clear sequence between the three recovery processes: they occurred and developed simultaneously. Progress in one process usually also reflected progress in the other ones.

Each recovery process reflected a continuum, or movement between two poles: from long-standing difficulties at one end to better adjustment at the other. Recovery, however, was not experienced as a one-way journey, but rather as a series of achievements and setbacks, as clients typically moved back and forth between the two poles of each recovery process. During this movement, clients usually maintained an overall sense of moving forward, despite having to deal with setbacks.

#### ***Process 1: Fighting ambivalence and committing to taking action***

Service users described their recovery journey as a constant battle between being motivated and committed to changing and feeling defeated by past negative life experiences and giving up. Some clients described feeling scared of changing. They found it hard to let go of their ways of blocking difficult emotions, such as self-harming or drinking. These strategies, although harmful in the long-term, provided an instant sense of relief.

*“That’s like a safety for me and I don’t know whether I would cope completely not drinking... through a lot of stuff I went through, it [drinking] was my way of blocking it out, so I think I’m probably scared of all them feelings, if I don’t have that. I don’t know if I would be able to deal with that pain”.* (SU26, DBT)

Other common fears about progressing further in their recovery journey involved having to face difficult past experiences, dealing with potential failure and losing support from services. Such fears often made clients feel disheartened and ambivalent about changing. Although they wished that their lives were different, they often felt overwhelmed and experienced urges to give up.

*“Half of me of course wants to get better but the other half, it’s got to the point that I really don’t care anymore. That push that you need from yourself is not there anymore... I’m losing motivation”.* (SU34, generic services)

Therapists and relatives also noticed service users’ ambivalence and their oscillation between trying to change and giving up.

*“One of my memories of the journey is her being extremely ambivalent to start; on one hand she was saying I really want to come and asking for therapy; on the other hand her experience of coming to the room, she would sit with her side at me, not looking at me, she would refuse to talk to me; it felt very tenuous”.* (T41, other psychological therapy)

*“As soon as he runs into a problem and he feels that he’s not doing it, he is convinced that he’s never gonna be able to do it, so he gives up. Although he only half gives up, he goes on trying and making himself feel more miserable because he’s half trying and not quite doing it”.* (R2, DBT)

Some service users’ initial motivation to change was closely linked to not wanting to let significant others down (including families, friends and therapists) and to avoid feelings of guilt and shame that would arise as a result of that.

*“If anything goes wrong, I immediately think that [self-harming]’s what I want to do ... But I don’t cut because I don’t want to let [therapist] down, I don’t want to let [sister] down”.* (SU4, DBT)

Over time, however, clients started taking responsibility and ownership of their lives and their efforts towards recovery. They described reminding themselves of their long-term goals and the consequences of their actions. They often managed

to remain resilient despite setbacks, to persevere and push themselves forward. This process was also observed by therapists.

*“It only works if you’re going to put the work into it: all the homework, all the writing... There were times when I didn’t want to do that at all... But I did it religiously because I wanted to sort myself out. Because if you’re expecting someone to fix you, it’s not going to happen”.* (SU13, DBT)

*“During treatment, she was able to assume responsibility for some of the failures in her life, which was a big step... She actually accepted that “I want my life to be better, and what am I going to do to assume responsibility for that?” rather than blaming everyone”.* (T6, DBT)

As therapy progressed, participants felt able to implement changes in their lives. They became more aware of and challenged unhelpful ways of thinking and unrealistically high expectations. This allowed them to develop a more balanced view of the world and their lives.

*“A lot of things for me were black and white in the sense that everyone was either happy or you’re really miserable, and I sort of met in the middle and thought “you can’t be gloriously happy every day of the week, every hour of the day and you shouldn’t be miserable either”. So I’m more satisfied with my life, there’s good days and bad days, as with everybody, but I recognise it’s not a drama, it’s just a bad day and I get on with it and move on”.* (SU9, DBT)

Service users consequently started solving their problems, without avoiding them and letting them escalate. This included actively facing stressful situations, such as social interactions, eating and drinking problems and financial issues. Breaking down problems into small, practical steps and doing one thing at a time often helped in this process.

*“I’d let things build up in me, whereas now I deal with things... like say I’ve got to pay a bill, I’d say I’ll pay it next week. I’d leave it until the red letter, but now I don’t leave it. As soon as I get the bill, I pay it”.* (SU29, DBT)

Clients also developed specific strategies to deal with crises, so that they did not spiral out of control. These mainly consisted of distracting themselves by keeping busy and pausing and considering their options before acting impulsively.

Table 4. *Domains, themes and subthemes*

	Total sample (N=69) N (%)	Service users (N=48) N (%)	Therapists (N=15) N (%)	Relatives (N=6) N (%)
<b>Domain 1: Processes of recovery</b>				
<b>Process 1: Fighting ambivalence and committing to taking action</b>	<b>69 (100)</b>	<b>48 (100)</b>	<b>15 (100)</b>	<b>6 (100)</b>
Giving up, feeling held up by the past and scared of change	69 (100)	48 (100)	15 (100)	6 (100)
Not letting others down	37 (54)	30 (63)	5 (33)	2 (33)
Taking responsibility	58 (84)	40 (83)	13 (87)	5 (83)
Managing difficult thoughts	47 (68)	35 (73)	9 (60)	3 (50)
Taking practical steps to resolve problems and crises	54 (78)	40 (83)	9 (60)	5 (83)
Noticing progress and developing hope	36 (52)	22 (46)	10 (67)	4 (67)
<b>Process 2: Moving from shame to self-acceptance and compassion</b>	<b>67 (97)</b>	<b>46 (96)</b>	<b>15 (100)</b>	<b>6 (100)</b>
Feeling ashamed and blaming self for problems	38 (55)	29 (60)	7 (47)	2 (33)
Acknowledging problems and asking for help	23 (33)	19 (40)	4 (27)	0 (0)
Understanding self and difficulties	50 (72)	34 (71)	12 (80)	4 (67)
Self-acceptance, compassion and confidence	36 (52)	23 (48)	9 (60)	4 (67)
<b>Process 3: Moving from distrust and defensiveness to opening up to others</b>	<b>63 (91)</b>	<b>44 (92)</b>	<b>14 (93)</b>	<b>5 (83)</b>
Fear of being open and exposing oneself	37 (54)	29 (60)	6 (38)	2 (33)
Understanding relationships	26 (38)	18 (38)	8 (53)	0 (0)
Listening to others and communicating in a less angry way	24 (35)	16 (33)	6 (38)	2 (33)
Opening up and trusting others	40 (58)	25 (52)	13 (87)	2 (33)
Being assertive and negotiating boundaries	20 (29)	14 (29)	4 (27)	2 (33)
<b>Domain 2: Challenges in therapy</b>				
<b>Challenge 1: Balancing self-exploration and finding solutions</b>	<b>62 (90)</b>	<b>42 (88)</b>	<b>15 (100)</b>	<b>5 (83)</b>
Self-exploration is helpful	46 (67)	32 (67)	12 (80)	3 (50)
Focusing only on understanding the past is unhelpful	16 (23)	12 (25)	4 (27)	1 (17)
Problem-solving is valuable	47 (68)	34 (71)	11 (73)	4 (67)
<b>Challenge 2: Balancing structure and flexibility</b>	<b>58 (84)</b>	<b>39 (81)</b>	<b>15 (100)</b>	<b>4 (67)</b>
Structured, goal-oriented therapy with a clear rationale	27 (39)	16 (33)	8 (53)	3 (50)
Flexibility and choice	49 (71)	35 (73)	12 (80)	2 (33)
<b>Challenge 3: Confronting interpersonal difficulties and practising new ways of relating<sup>a</sup></b>	<b>50 (72)</b>	<b>31 (65)</b>	<b>13 (87)</b>	<b>6 (100)</b>
Feeling overwhelmed and exposed in group <sup>b</sup>	30 (64)	21 (62)	5 (63)	4 (80)
Practising relating to others in group <sup>b</sup>	33 (70)	22 (65)	7 (88)	4 (80)
Addressing conflicts and negotiating boundaries in the therapeutic relationship	27 (39)	12 (25)	9 (60)	6 (100)
<b>Challenge 4: Balancing support and independence</b>	<b>67 (97)</b>	<b>48 (100)</b>	<b>13 (87)</b>	<b>6 (100)</b>
Regular/ intensive therapy	39 (57)	25 (52)	10 (67)	4 (67)
Supportive therapist	53 (77)	40 (83)	8 (53)	5 (83)
Managing ending/ continuity of care	40 (58)	28 (58)	9 (60)	3 (50)

<sup>a</sup>Percentages for this domain are calculated for the whole sample and therefore might appear lower than in reality, as two of the three subthemes are only applicable to approximately half of the sample (see footnote b).

<sup>b</sup>Subthemes applicable to 34 service users with some experience of group therapy, 8 therapists with service users currently in group therapy and 5 relatives with service users currently in group therapy, a total of 47 participants. Percentages for these subthemes are calculated for these subgroups only.

*“Before, if anything that I found overwhelming [happened], the easiest way for me was to self harm... with DBT... I would try to distract myself, just 5 minutes, it wouldn’t seem so overwhelming after that... it gave me some time to think before I acted”. (SU12, DBT)*

Some clients described how noticing their progress made them feel more confident that change was possible. This helped them maintain their faith in therapy and remain committed to moving forward.

*“Talking about your experience it helps you to realise that you have moved on ... I can see there are benefits from being here and I have gained some knowledge, confidence... so there are aspects that have helped me... I think I’ve got this far and I want to move on into the next step”. (SU14, MBT)*

### ***Process 2: Moving from shame to self-acceptance and compassion***

Service users described their journey from feeling deeply ashamed of themselves and their difficulties to developing self-compassion. Over half of them initially viewed themselves very negatively and experienced strong negative emotions, including shame, guilt, hate and anger towards themselves.

*“My main talent is self-destruction... I had a real cliché self-hatred thing going on and I think that was the thing that held me back quite a lot” (SU5, DBT)*

Feelings of guilt and shame intensified when clients felt that they did not deal with situations effectively. At those times, they felt further disappointed in themselves and believed that they had failed other people.

*“I can’t be bothered to do this... and then I get guilt, because I think I’m letting people down, I’m letting myself down, so I’m beating myself up constantly”. (SU26, DBT)*

Service users often believed that they did not deserve to receive help and that they should be able to cope with their difficulties on their own.

*“When the only person who was being harmed was me, it didn’t feel like it was justified to go and seek help. I didn’t think that I deserved any help. From a very young age I was the one who dealt with things. I wasn’t the one who got helped. So I grew up dealing with things for myself by myself. And it’s impossible, you can’t do it”. (SU22, MBT)*



Over time, some service users started to acknowledge that they did have substantial difficulties and became more open to asking for and receiving professional help. This was often a slow and gradual process.

*“I felt as if I had to do everything on my own... Still that happens every now and then, but I do just give in and go, ok, I do need a bit of help”.* (SU20, MBT)

While in therapy, they gradually engaged in a journey of self-discovery. They described developing a better understanding of their emotions, thoughts and behaviour. They were able to make links between their life experiences and their current difficulties. Having a diagnosis that made sense to them was sometimes a step in this direction.

*“When they said I had Borderline Personality, it all added up... It all made sense... How I've been with relationships, how I've been with my children, how I was as a person”.* (SU29, DBT)

This increased understanding of their difficulties and the factors that had contributed to their development led to increased levels of self-acceptance and compassion. This was described by approximately half of the service users.

*“I'm a lot more tolerant with my own self and where I can have quite perfectionist instincts to go “well I can do it better, it's not good enough”, I've tried to be more chilled and nice with myself “you know that's actually very good what you've done already, you don't need to kill yourself”.* (SU8, DBT)

This in turn allowed them to feel more confident and gave them a sense of being more able to deal with life.

*“I feel more confident and I do approach problems. I keep on doing something and then thinking, well I wouldn't have done that last year... I'm stronger in myself”.* (SU4, DBT)

### ***Process 3: Moving from distrust and defensiveness to opening up to others***

Most service users described that they had spent a long time in their lives distrusting others and finding it hard to open up, express their feelings and establish

intimate relationships. They explained that they were reluctant to talk about difficult issues, for fear of feeling exposed, vulnerable or rejected by significant others.

*“Like in relationship with my mum or my dad, being able to express anger from the past... it’s more of a fear of losing control and thinking “have I let people down? and they are not gonna care for me and then how am I gonna cope?” (SU14, MBT)*

This difficulty in opening up to others and talking about emotions manifested itself both in clients’ personal relationships and in therapy. It often reflected problems in early attachments or a history of abusive relationships.

*“My personality, little [client’s name], she started getting uptight, she didn’t want to talk to no one, no one to know what had happened to her. And that’s why I stopped going... She’s scared. She don’t trust no one... I find it hard to trust people because of what happened to me when I was a kid. I had over 21 years of abuse”. (SU16, DBT)*

While in therapy, some participants started developing a better understanding of relationships. They became more aware of how their actions might affect other people, as well as the impact of other people’s behaviour on themselves. They described developing an understanding of other people as beings with their own thoughts, goals and struggles. In this context, they started acknowledging different perspectives to their own and developed less self-centered interpretations of other people’s motives and behaviour.

*“[DBT] it sorts you out: you can understand why you did this, you can understand why people did that to you... it opens your eyes, it makes you more relaxed, it makes you understand other people and people understand you. You get differences of opinions”. (SU27, DBT)*

Furthermore, a substantial minority of participants described developing more effective ways of communicating. They learned how to manage their anger when talking to other people and present their desires and perspectives more clearly.

*“It made me think what I wanted to say before I would say it and then say what I had to say without the anger. Now I plan what I’m gonna say and I say it in a quiet manner”. (SU1, DBT)*

They also became more able to listen to and take in what other people said. Therapists also noticed clients' increased ability to participate in two-way conversations rather than appearing solely preoccupied with their own worries.

*“By the end of the last session... she was actually listening. She was taking some of the things that we were saying in. Well, the beginning was just like letting it all out, and we'd just sit back and listen. Sometimes it was hard to even get a word in edgeways. But I saw an improvement in her. She would actually listen and comment about what we said, it was going in somewhere”.* (T33, generic services)

In this context, some service users felt that they became more supportive and able to contribute in relationships.

*“Trying to think about other people for a change, I'm really trying to do that - because I think I'm quite a selfish person. I find it difficult to listen to, even my friends... I've started maybe think more about how other people see me. I've stopped being so selfish... I actually leave my house to go see people now, rather than expect people to come to me all the time”.* (SU17, MBT)

As therapy progressed, approximately half of the service users felt supported to open up more in relationships. This process might have first started within the therapeutic relationship, but often generalized to other relationships. These participants felt more able to trust others and talk about their emotions and difficult experiences.

*“My therapist said the only way is to get your mother to come in and for you to tell her everything that's happened in the past... I got my mum in and told her... To finally get that off my chest and not feel guilty about that anymore was just brilliant. Since then I've felt like it's ok, because I haven't got anything to hide anymore”.* (SU13, DBT)

As participants became more engaged in relationships, some of them also became more able to confront and challenge other people and express their needs and desires in a more assertive way. This often meant that they negotiated different boundaries in existing relationships or ended relationships that they found unhelpful.

*“My mum [was] doing more or less most things, my daughter [was] doing the shopping, my boyfriend [was] doing jobs around the house and it was like I’ve got suffocated. So now I have got the guts to turn around and say no, I can do this, back up, I can do this!”*. (SU27, DBT)

Therapists also described how they encouraged clients to confront people who had been abusive and to move on with their lives.

*“She vented her anger at what had happened to her and how unfair it had been, and she found that really tough but actually afterwards it confirmed her feeling that it wasn’t her fault, reduced the shame a lot... she continued to feel angry with the abuser but not in a way that got in her way of her feeling OK about herself and her other relationships. She started to trust a bit other relationships, as she could distinguish them from the abuser, cause the anger got directed there”*. (T42, other psychological therapy)

## **Domain 2: Challenges in therapy**

This domain of themes describes four challenges that were perceived as important for therapies to address in order to support service users’ recovery journey. The themes are based primarily on clients' and therapists' accounts, although relatives also contributed their understanding and experience of challenges.

### ***Challenge 1: Balancing self-exploration and finding solutions***

The majority of service users and therapists described therapy as facilitating a process of self-exploration, which was invaluable in helping service users understand themselves and their difficulties.

*“It was repeated behavioural analyses that made me go “oh look, when I have contact with that person I self-harm as a result” and [therapist] was also very good because he never actually said he saw it immediately, the causal link, and he waited very patiently until I made the connection, because then for me it was a light bulb going on”*. (SU8, DBT)

*“I think having more of an understanding of what state of mind might lead her to take an overdose - getting a sense of what the triggers are - that piece of work has begun here... and I think because of more frequently reflecting on her state of mind, she’s at a less of a risk of that, because of ... understanding how she is doing on an emotional level”*. (T22, MBT)

However, a substantial minority of clients and relatives stated that therapy that only focused on understanding the past, without providing solutions to current problems, was not helpful. Such an approach often brought up difficult issues that they felt unable to deal with in the present.

*“The reason it didn't help was because they'd dig into very sensitive subjects that you keep locked away for your own protection, and when someone unlocks that back door, and it all -whoosh!- it comes flying out, and then it's a case of “oh well, finished now, I'll see you next week.” And you're sitting in the middle of this tornado... how do you just go straight back into normality again and go outside and get the bus?”.* (SU34, generic services)

*“Delving into his past and looking at issues, that just seemed to bring up a load of old memories, which just weren't doing him very good at all, and were making things a lot worse actually. He was getting worse, not better... Just made him hate his life and hate himself a lot more”.* (R9, DBT)

Service users and therapists pointed out that therapies that placed emphasis on finding solutions to present problems and offered advice and guidance were particularly beneficial. Clients appreciated learning specific skills on how to deal with difficulties, especially during periods of crisis. Therapists who could coach clients through such difficult periods were also seen as helpful.

*“[The therapists were] giving me solutions of how to deal step by step and if I was feeling bad about something, they would show me how to put everything in order... and they would give me tips and ring me and find out that I've taken those steps, and that was like a motivation for me to do that”.* (SU12, DBT)

Therapies that struck a balance between facilitating self-discovery and offering practical help were often described as ideal by therapists.

*“Someone just sitting there listening to her was not enough for her... she found it helpful when someone listened, but also gave her some support and advice and guidance”.* (T33, generic services)

### ***Challenge 2: Balancing structure and flexibility***

A substantial minority of service users described that they valued therapies that offered a structure that was clearly shared with and understood by them. More

specifically, they appreciated working towards specific therapeutic goals, being introduced to a treatment rationale and style, and agreeing on a specified format for their therapy.

*“I believed that having goals of ending self-harming behaviour and actually understanding the order in which we work on things- so we would work on suicidal thoughts first and then self-harm and then treatment-interfering behaviour- that made sense, and that was actually quite comforting”. (SU3, DBT)*

When these characteristics were missing, therapy was often experienced as too open-ended and confusing.

*“The counsellor I had then was all a bit wishy-washy. I just went and maybe talked a bit about bits and pieces, but there wasn’t really any structure to it”. (SU13, DBT)*

On the other hand, the majority of clients valued elements of flexibility both in therapies and in their therapists. For example, they appreciated collaboratively agreeing treatment goals and revising them if necessary, according to their current needs and insights. Similarly, they stressed the importance of therapists allowing them to follow their own pace, without putting too much pressure on them when they did not feel ready to address certain issues.

*“If you didn’t want to talk about anything, you didn’t have to, you could come back to it another day. Whereas other counsellors, it’s “oh you have to talk, if you want to get better”. The approach with [therapist] was not so much a softer approach, but more of a welcoming approach, so you could feel comfortable”. (SU42, other psychological therapy)*

Both service users and therapists reported that service users felt coerced and disrespected when they experienced therapists as rigid and inflexible in following therapeutic agendas. They also described disagreements in treatment goals that were hard to resolve or challenging times when therapists lost sight of service users' needs.

*“The times when she was in a mode where she just wanted to be thin and I was trying to ... go back to the goal of helping her eat more regularly, there would be conflict. I think sometimes it was me needing to step back from the goal and work more with what was going on for her that was putting her in the place where she just*

*wanted to be thin... There was a point in treatment where I got a bit carried to the idea of her eating regularly and forgot that she was still quite ambivalent about that, so we had a bit of rocky time with that". (T42, other psychological therapy)*

In this context, some therapists emphasized the importance of reaching a balance in therapy that took clients' current needs and priorities seriously into account, while maintaining some structure. However, it was often acknowledged that striking this balance could be challenging.

*"Because the treatment is so structured, which is in some ways a positive thing, I feel I don't really know what my client thinks sometimes, or what kind of stage of change they are in... or how they feel about working on self-harming. So, sometimes I just want to have some free time to explore what they think and their personal goals a bit more... some free space where I don't have to be adherent and do something according to the book... to just have some more flexibility". (T4, DBT)*

### ***Challenge 3: Confronting interpersonal difficulties and practising new ways of relating***

Most service users who received therapy in a group setting described it as initially daunting and overwhelming. They felt self-conscious when talking in front of other people, exposed and uncomfortable about sharing personal information. They described incidents when they felt that other clients in the group were obnoxious, dismissive, competitive or even bullying. They struggled to manage such challenging situations and sometimes left sessions feeling intimidated and embarrassed.

*"I think it was quite scary being chucked in halfway through... you were the newbie, that was quite daunting... you've got no idea what's going on at the beginning, and the thought of saying anything in that group is horrendous". (SU13, DBT)*

Other common experiences included feeling depressed and disheartened after listening to other people's difficulties and seeing oneself as belonging to a group of people with problems.

*“It’s difficult when you’re dealing with other people who have a lot of the same problems... sometimes it feels like this is a new identity; that this is who you are; you are part of this group of people who have these problems and sometimes that’s a bit hard to do”. (SU2, DBT)*

For most service users these challenges were perceived as a necessary initial difficulty that improved over time. For some, however, they contributed to their discontinuing therapy and feeling that change was too hard.

*“I feel like I’m gonna say the wrong answer... I’ve got this fear that people are laughing about what I’m gonna say and I close up then... I didn’t give it my best shot basically, I only went to group therapy once”. (C26, DBT)*

Relatives also reported finding it difficult to watch their loved ones struggle with attending a group.

*“The group was very daunting at first, I couldn’t see it working. I was even this is doing more harm than good, because it was just making her tired, making her really anxious”. (R4, DBT)*

As time went by, most of those clients who stayed in therapy groups started observing positive effects from persevering. They began to perceive the group as a nurturing environment, where they felt understood and supported. This made them feel less isolated and more “normal”, as they shared experiences and difficulties with others. They also started learning from and encouraging each other in their recovery journeys.

*“It is very comforting to be with a bunch of people who know where I’m coming from, so I don’t feel like a weirdo... it’s actually almost nurturing for me... This is like almost an adopted family for me... I can actually feel myself doing all the learning that perhaps I should have been doing donkeys years ago”. (SU22, MBT)*

Overall, service users and therapists perceived the group as a stimulating, yet protected environment that offered service users the opportunity to practise how to relate to other people in the outside world. More specifically, they could practise trusting others, opening up, tolerating people that they considered difficult and coping with a certain degree of anxiety.



*“We have some very tricky group members, but that’s part of group therapy and I have accepted that and I think that in a way is quite handy, cause if everyone was lovely in the group, it would be slightly false in a way, cause not everyone is lovely in the world. So having problem people to deal with is not such a bad thing”. (SU9, DBT)*

*“I see it [conflict between group members] as material that we can use... I think there has to be some element of that, that people find it a struggle and get in touch with things that are difficult”. (T22, MBT)*

In parallel to practising relating to others in groups, some clients also appreciated the opportunity to openly discuss and repair conflicts in their relationship with their therapists. Finding ways to address difficult issues and negotiate boundaries without ending relationships was seen as a valuable new skill for clients and as a rewarding challenge for therapists.

*“We were able to clarify points, and they were our little breakthrough moments... We were able to negotiate through, which I wouldn’t have been able to do before... I was actually able to sit, and stay, and work through it, and hear what she was saying... that’s been one of the biggest skills for me, being able to find my own identity amongst other people and feel assured to speak it”. (SU25, DBT)*

*“It was about being really transparent about what was going on. I suppose we reached an understanding where I would tell what I thought the conflict was, the difficulty, and made it very clear that it was ok for her to disagree, to be angry with me if I suggested a wrong thing and then we negotiated it together”. (T41, other psychological therapy)*

#### ***Challenge 4: Balancing support and independence***

Over half of the service users described needing intensive and regular therapy to start addressing their complex difficulties. Therapy that was at least a year long, included more than one modality (eg. group and individual) and was delivered by a team of therapists was seen as particularly beneficial. Therapies that were not regular and intense were seen as inadequate in supporting stable and long-term change.

*“I had already done some CBT before... but unfortunately it was only short-term. As soon as I stopped seeing the therapist and I was back out in the big wide world, everything comes back crashing down on me again... I can intellectually pick things up quite quickly. Emotionally however, I am but a small child and I need time to*

*learn stuff... [This treatment], because it's three times a week...and I know that I am going to be here for so much longer, I'm really being able to get into the ideas that have been given to me". (SU22, MBT)*

Clients also valued forming close relationships with their therapists. They cherished the opportunity to have someone to talk to and feel understood and accepted. Therapists who were supportive, approachable, compassionate, genuine, non-judgmental, encouraging, and containing were particularly appreciated. For some clients this was their first experience of a supportive relationship.

*"When I'm talking to [therapist] some things I've never talked about before, it's been quite painful, but then it's been released. It's been quite good that I've actually talked about it, and [therapist] hasn't judged me, so that's all been very nice". (SU4, DBT)*

In contrast, feeling disrespected and not taken seriously by professionals was often seen as a discouraging experience that delayed recovery.

*"The doctor said I caused too much distress to the other patients and perhaps this [day hospital] is not the best place for me... but I didn't really like the idea of them saying that... because surely that's a place for people that have issues... and that's what I had at that point. And I felt that somebody needed to help me rather than push me away". (SU36, generic services)*

The majority of service users felt that support needed to be balanced with promoting independence in therapy, especially towards its ending. The shift from intensive therapy to having to cope on their own was often experienced as abrupt. In some situations, they felt that this reflected the fact that therapies and/ or therapists did not manage successfully the transition between encouraging a degree of dependence and attachment in the beginning with fostering more independence towards the end. Some service users also reported that referrals to other services were not planned or executed smoothly.

*"I believe I was doing well at DBT because I was getting the attention of three hours a week in therapy, I was getting crisis coaching, I was having somebody who I was relying on to tell me what was the right thing to do... I now realise in hindsight, DBT hadn't identified the fact that I was over-reliant on my therapist and that I was*

*actually petrified and the only reason I stopped cutting is that I was scared of the consequences in therapy of what would happen... I was doing DBT for my therapist completely". (SU3, DBT)*

Service users stressed the importance of negotiating a safe, gradual ending that took into account the meaning of separations and endings in their history and their particular sensitivity to rejection and abandonment. When this did not occur, endings were experienced as sudden and overwhelming.

*"The ending of DBT is like a cord being cut... [Therapist] just went "oh you finish DBT, don't you?" and my heart just went "boooooosh" and I didn't want to show that I was devastated, I thought "why didn't he prepare me for this?" We got borderline personality, rejection is very hard... it's very abrupt; it didn't end the way I anticipated and I think I don't feel 100%". (SU1, DBT)*

Therapists echoed this view, noting that striking a good balance between providing adequate support and fostering independence was particularly challenging throughout therapy and especially towards the ending.

*"She was still using me very actively to help her healthy adult right till the end, and I really didn't want to be discharging someone until they're doing most of it a lot more independently. It was resource constraints that meant that I discharged her when I did, so I couldn't be confident that she won't relapse at some point". (T42, other psychological therapy)*

Similarly, some relatives described struggling to find a balance between offering support and protection to their loved ones while encouraging them to take challenges and become more autonomous.

*"It's all a wee bit too cozy. The fact that it's cozy is helping him in a way. He doesn't have a lot of pressure to do things that might make him feel bad or inadequate. But would it help him to get challenged? Yes, it would, if he managed to meet the challenge... if he didn't manage to do it, that was precisely the kind of thing that would send him into a depression, rather than getting support and enabling him to cope with things... At the moment we're not getting him onto that challenge, but somehow we'll have to, I think". (R2, DBT)*

## Discussion

This qualitative study explored service users' perspectives on how recovery in BPD is reached through specialist or routine treatment; therapists' and relatives' views were also obtained. The findings were organized into two domains of themes. The first domain described three central, parallel processes that constituted service users' recovery journey: fighting ambivalence and committing to taking action; moving from shame to self-acceptance and compassion; and moving from distrust and defensiveness to opening up to others. The second domain described four therapeutic challenges that needed to be successfully addressed to support this journey: balancing self-exploration and finding solutions; balancing structure and flexibility; encouraging service users to confront interpersonal difficulties and practise new ways of relating; and balancing support and independence.

The findings are consistent with previous qualitative studies indicating that recovery in BPD is experienced as a fluctuating movement between achievements and setbacks (Castillo et al., 2013; Katsakou et al., 2012; Lariviere et al., 2015; Perseus, Ekdahl, Asberg, & Samuelsson, 2005). However, the present study provides a more elaborate description of the main areas in which this movement occurs, i.e., developments in taking action, self-discovery and self-compassion, and relationships. Each of these individual areas has been described in previous studies as an area of change that is both relevant and achievable for people with BPD (Castillo et al., 2013; Katsakou et al., 2012; Shepherd, Sanders, Doyle, & Shaw, 2015).

The accounts of service users in the current study suggest that these three central processes co-occur simultaneously, with no clear sequence between them, and all contribute to service users' experience of recovery. Previous studies of

recovery in BPD have implied that implementing changes and taking action can only occur after progress in relationships has been made and secure attachments have been built. More specifically, building safe and trusting relationships has been described as enhancing self-development and motivating service users to work towards specific goals (Castillo et al., 2013; Holm & Severinsson, 2011; Shepherd et al., 2015). However, the participants' narratives in this study suggest that these processes are parallel, not sequential. Taking action was described as a more independent and intentional process than previous studies have suggested.

The participants' accounts also suggest that the three recovery processes occurred across a range of specialist and generic psychological therapies. This finding is consistent with the view that common processes, which are present across many psychological interventions, rather than specific strategies unique to individual therapeutic models, drive change in therapy (Wampold, 2010). Yet, it is worth considering to what extent specialist therapies for BPD, especially the two therapies received by some of the study participants, aim to support the identified recovery processes. DBT provides specific strategies to enhance clients' commitment to change and support them in taking action (Linehan, 1993), while MBT places an emphasis on understanding relationships and practising relating to others in a therapeutic context (Bateman & Fonagy, 2006). Both therapies work on self-acceptance and compassion by facilitating processes such as mindfulness and mentalisation respectively, which aim to help clients make sense of their emotions, thoughts, motivations and actions (Bateman & Fonagy, 2006; Linehan, 1993). Nevertheless, it appears that specific strategies to enhance taking action and developing a deeper understanding of relationships might be missing from MBT and

DBT respectively. Our findings suggest that both of these processes need to be facilitated for recovery to occur.

In this context, the findings of the present study point to how therapies might facilitate the identified recovery processes, by addressing specific therapeutic challenges. Two of the identified therapeutic challenges reflect perhaps the central tasks that therapists undertook to directly support these processes, namely balancing self-exploration with problem-solving and encouraging clients to practise relating to others in different ways. The first task involves ensuring that therapy focuses on assisting service users in making sense of their experiences and understanding and accepting themselves, while also supporting them in actively tackling problems and implementing changes. The second challenge refers to encouraging individuals to actively work on relationship difficulties and develop new ways of relating to others, including opening up and trusting others, tolerating conflicts and negotiating boundaries. Participants' accounts indicated that these new skills were first built in the therapy context, either in groups or within the therapeutic relationship, and were subsequently actively applied to relationships outside therapy.

Our findings also highlight another challenge that therapies need to successfully address, namely balancing support and promoting independence. Although this dilemma might not appear directly linked to the identified recovery processes, its resolution might be crucial in supporting service users to maintain their ability to self-manage in the long-term. Interestingly, service users' accounts suggest that therapies and/ or therapists did not always adequately manage the transition between encouraging a degree of dependence and attachment in the beginning of therapy with fostering more independence towards its end. Although specialist

therapies for BPD consider in their manuals how to manage the end of therapy in a way that enhances independent functioning and a sense of responsibility for ongoing recovery (Bateman & Fonagy, 2006; Linehan, 1993), it appears that this might not always be achieved in practice. As professionals working with individuals with BPD often feel overwhelmed by the intensity and the range of their difficulties (Skegg, 2005), working on longer-term goals, such as fostering independence, might not be seen as a priority during treatment. Nevertheless, this might be an oversight of clients' long-term needs and might contribute to increased service use.

### **Limitations**

Although the study aimed to explore processes of recovery across specialist and routine services, approximately two-thirds of the clients who took part had received a form of specialist therapy for BPD, and almost half (48%) had received DBT. Hence, the perspectives of clients receiving specialist treatment might be over-represented in the findings, which might consequently emphasise the processes that occur in specialist BPD services, especially DBT. Furthermore, as the specialist therapies explored in this study included only DBT and MBT, it is unclear whether clients' experiences of these interventions relate to other specialist therapies for BPD, like schema therapy or transference-focused psychotherapy.

Furthermore, the views of service users who completed therapy might be overrepresented in the sample, as only approximately a quarter (24%) of the participants in this study had discontinued their treatment. Nevertheless, a recent meta-analysis of completion rates for psychological therapy in this group generated an overall completion rate of 75% for up to year-long interventions and 71% for longer therapies (Barnicot, Katsakou, Marougka & Priebe, 2011), which is consistent

with rates of therapy completion in this study. Similarly, although the response rate for participation in the study was high, service users who declined to take part may have had different views and experiences. Lastly, participants in this study were recruited from services in one area of London and their experiences may not be generalisable to users of other services.

### **Implications for clinical practice**

This study identified three processes that service users experienced as central aspects of their recovery journey. Treatments facilitating these processes may enhance clients' commitment and engagement with services and promote recovery (Barnicot et al., 2012). However, it has been highlighted that specialist therapies for BPD often focus on limited areas of change, which might contribute to slow therapeutic progress (Farrell, Shaw & Webber, 2009; Zanarini et al., 2008). Although specialist therapies might need to have a clear focus on specific areas to promote change, not addressing all processes that clients identify as important might hinder recovery and lead to setbacks and continuous dependence on services (Katsakou et al., 2012).

Our findings suggest that not striking a good balance between offering support and fostering independence in therapy might also lead to similar outcomes for service users. Although it might be particularly challenging to focus on promoting independence when service users present with a multitude of immediate difficulties and risks, it remains crucial for this to be considered as a long-term therapy goal. Therapies might need to develop more specific strategies to successfully address this challenge.



## **Implications for future research**

The three central recovery processes and four underpinning therapeutic challenges identified in this study could provide a framework to guide future research in this area. The relative contribution of each recovery process to various outcomes, including clinical and recovery-oriented ones, could be further examined in quantitative research. This could highlight which processes are particularly important and need to be further developed within therapies.

Similarly, the extent to which specialist interventions for BPD support these recovery processes and address the four underpinning therapeutic challenges could also be investigated. This might then point to areas for the further development of existing therapies for BPD. Furthermore, the identified recovery processes could inform the development of standardised measures of personal recovery in BPD. The development of such measures could facilitate the wider inclusion of recovery concepts in both research and clinical practice.

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## **Part 3: Critical Appraisal**



This critical appraisal discusses some issues and challenges encountered in the research process and the ways in which these were considered and addressed. The first part addresses issues in conducting the qualitative meta-synthesis. The second part discusses challenges encountered while conducting the empirical study. The concept of reflexivity, including epistemological and personal reflexivity (Willig, 2013), will be used as a framework for considering these issues.

### **Challenges in conducting a meta-synthesis of qualitative studies**

This section describes challenges encountered when using a critical appraisal tool and some broader observations regarding the nature of qualitative evidence.

#### ***Using a critical appraisal tool***

When I started reading the papers that would be included in the meta-synthesis, the need to appraise their methodological quality became clear, especially as the included studies varied significantly in their methodological merits and limitations. Although the value of appraising the quality of existing evidence when conducting reviews is widely recognised, the use of specific criteria to evaluate qualitative research remains a contentious topic (Braun & Clarke, 2006). It has been argued that the rigid use of appraisal tools might lead to the exclusion of some studies from qualitative meta-syntheses. This could in the long-term stifle creativity, freedom and the use of a wide range of approaches in qualitative research (Dixon-Woods, Shaw, Agarwal & Smith, 2004).

After reviewing the literature on tools for conducting such appraisals, I decided to flexibly use the Critical Appraisal Skills Programme (CASP, 2002) for qualitative research to aid the transparent description of the methods and to highlight the range of quality and limitations in the included studies. This instrument is

commonly used in qualitative meta-syntheses and covers a range of methodological areas typically addressed in similar checklists (Dixon-Woods et al., 2007). More specifically, it assesses ten main areas: the clarity of research aims; the suitability of qualitative methodology; the appropriateness of the research design and more specific qualitative approaches; the recruitment strategy; the data collection methods; the clear description of the relationship between participants and researchers; the consideration of ethical issues; the data analysis methods, the clear presentation of the findings; and the overall value of the research (see Appendix A).

One of the issues that I found challenging was that the CASP seems to assume that the above methodological aspects all contribute equally to the overall quality of a study. In effect, all questions are scored as either 0 or 1 and thus they all equally contribute to the total score for each study. Yet, through reviewing the included papers, I thought that the most significant areas that determined the overall value of a study covered the data analysis process and presentation of findings. The analysis and presentation of results is the essence of any piece of research, as the description of findings determines whether a study provides a substantial, meaningful understanding of the phenomenon under investigation (Barbour, 2001; Dixon-Woods, Shaw, Agarwal & Smith, 2004; Kuper, 2008). Especially in qualitative research, studies that present a thick synthesis and description of themes provide more valuable insights into the phenomenon of interest (Geertz, 1973). I found this to be true for the studies reviewed here, as the studies that provided a thick description of themes, contributed more substantially to the understanding of recovery.

Hence, I decided not to use the CASP with the purpose of providing an overall quality score for each study or of excluding individual studies, as has often been suggested (CASP, 2002; Feder, Hutson, Ramsay & Taket, 2006). Instead, I

used it as a framework to highlight methodological issues identified across studies. Although I thought that it was important to summarise methodological issues in all areas of the CASP, I decided to place more emphasis on describing strengths and/ or shortcomings in the data analysis process and the presentation of the results, especially highlighting the degree of elaboration and thickness of themes across studies (Dixon-Woods et al., 2004).

### *Observations on reviewing qualitative evidence*

The process of reviewing qualitative evidence enabled me to further reflect on the nature of such evidence and the potential challenges in trying to appraise and make sense of it. Interestingly, I found that when the analysis and presented findings of a study were thin and provided no in-depth descriptions of themes, it was relatively straightforward to conclude that the study was poor and did not provide valuable new insights into the experiences of treatment and recovery in BPD. Undoubtedly, studies that provided more elaborate descriptions of themes and described interconnections between the various topics that emerged contributed more substantially to the understanding of the phenomenon under investigation.

However, given the fact that researchers' personal beliefs and preconceived ideas can have an impact on qualitative analysis, it was still challenging to establish the degree to which studies with such apparently richer analyses reflected participants' perspectives or, rather, the researchers' views and interpretations. Of course, I did not assume that researchers might have consciously attempted to favour their own ideas over participants' experiences. Nevertheless, having myself conducted the qualitative study presented in Part 2 of this thesis, I became more aware of the challenges in attempting to separate a researcher's own ideas and

perspectives from the analysis process, or to remain fully aware of the complex ways in which such ideas might have influenced the analysis and presentation of findings (Finlay, 2008).

These considerations were particularly relevant for one of the studies in the meta-synthesis. More specifically, Haeyen et al. (2015) provided an elaborate description of experiences of art therapy and how this might have supported service users in making progress. Although the themes appeared thick and meaningful, especially in comparison to most of the other studies, I was struck by the presentation of mainly positive views of art therapy and the relative lack of negative or challenging experiences. Although the authors reported that they explicitly recruited a participant who had expressed negative views, to ensure that such negative experiences were explored, I was unsure that this was a sufficient number in a total sample of 29 service users. This observation, coupled with the fact that the principal investigator was an art therapist, made me wonder how her personal beliefs might have influenced the analysis and presentation of findings.

Such observations while reviewing studies reminded me that qualitative evidence is by nature subjective (Lincoln & Guba, 2000). I did not view this as a limitation, but rather as a realistic way of conceptualising qualitative evidence that I wished to remain aware of. A degree of subjectivity is present in any form of research, including quantitative approaches, as researchers' interests and priorities cannot be totally divorced from the research process (Barker, Pistrang, N. & Elliott, 2016). I tried to further reflect on how this understanding might influence my work as a clinical psychologist. As a reader of research papers and a clinician who is interested in being informed by evidence, I think it is important to maintain a critical stance towards research findings. That is, I value the role of research findings in

clinical decision-making, but I also try to be curious, critical and reflective when drawing conclusions from research.

### **Challenges in conducting the research**

Acknowledging and reflecting on one's epistemological and personal beliefs and the ways in which these can influence the research process is a central part of conducting qualitative research (Etherington, 2004; Willig, 2013). This section describes how I attempted to address issues relating to both epistemological and personal reflexivity.

#### ***Epistemological reflexivity: Balancing previous knowledge with maintaining a not-knowing stance***

Epistemological reflexivity involves understanding how and to what degree one's assumptions about the nature of knowledge and reality affect the research process (Willig, 2013). Upon embarking on the research journey, I aimed to adopt a broad phenomenological approach, by exploring the lived experience and personal understandings and perspectives of research participants. I did not assume that the research findings would describe an objective truth or reality. Instead, although I was guided by pre-determined research questions and interview schedules, I tried to use them with flexibility and remain open to following the participants' lead and interests, as they emerged in interviews (Smith, Flowers & Larkin, 2009).

However, maintaining this not-knowing position and remaining genuinely neutral and open to participants' understandings was challenging, given my previous research and therapy experience in the area of BPD. This task was further complicated by the fact that when I started data collection, my previous knowledge mainly covered the theory and application of Dialectical Behavioural Therapy

(DBT). I was less knowledgeable about Mentalisation-Based Treatment (MBT) or other psychological and psychiatric treatments received by study participants. Hence, in parallel to trying to maintain an overall not-knowing approach during the interviews, I felt that I had to learn more about MBT and other therapeutic approaches. Although acquiring more knowledge of specific approaches when trying to remain open to participants' understandings might sound contradictory, an understanding of the full range of therapies was important in order to be able to follow and explore the material emerging in the interviews. This helped me to remain as unbiased as possible and not to pay more attention in interviews and during data analysis to processes that mainly occur in DBT, which I had been more familiar with.

To ensure that I was open to exploring different perspectives and processes present in all the treatments received by study participants, I explicitly attempted to involve other researchers with various backgrounds, therapists practising a range of approaches, and service users who had received a range of different treatments at various stages of the project. More specifically, service users, therapists and relatives were involved in the development of the interview schedule, so that this did not reflect only my own personal experiences and interests. Similarly, other researchers were involved in the ongoing analysis of the data, through co-developing a coding frame, coding interviews and discussing the research process and emerging findings.

Interestingly, at the stage of data analysis and writing up the findings, I was again working with clients with BPD in my final, year-long placement as a trainee clinical psychologist, using an MBT approach. Hence, by the end of the research process, I had acquired substantial understanding and experience of the theory and application of both DBT and MBT. To an extent, this was an additional challenge, when trying to maintaining a not-knowing stance towards the research data. These

issues will be further explored in the next section, which summarises challenges relating to personal reflexivity.

### *Personal reflexivity*

Personal reflexivity considers two aspects of the research experience. First, it examines how researchers' personal experiences, interests and views have influenced the research. Second, it considers how the research journey in turn affects and changes investigators personally and as researchers (Willig, 2013). Both these aspects of personal reflexivity will be discussed in this section.

#### *The impact of the researcher's personal experiences and interests on the research process*

Throughout the research project, my ideas, preferences and interests inevitably contributed to the way different ideas were explored in interviews, and subsequently analysed, interpreted, and presented in the research findings. To remain aware of the ideas that were crucial in shaping the project and the ways in which they might have influenced the research process, I attempted to bracket my preconceived beliefs, as much as I found possible (Ahern, 1999).

Bracketing involves becoming aware of one's preconceived ideas and labelling them in an effort to set them aside, so that they do not unduly influence the research (Morrow, 2005). The extent to which this is possible has sparked discussion among qualitative researchers. It has been acknowledged that completely putting aside one's preconceptions is not realistically achievable (Barker et al., 2016; Finlay, 2008). However, qualitative researchers make an effort to remain aware of their own experiences and beliefs and their potential impact on their research, and I tried to follow this approach while conducting this project.

Having worked as a DBT therapist prior to and during data collection, I had held various ideas regarding the usefulness and application of this therapy. Although I believed in the healing impact DBT could have on clients with BPD and valued the fact that the therapy had a clear focus on specific therapeutic goals, I was less drawn to some particular aspects of the therapy. More specifically, I sometimes felt uncomfortable about what I perceived as a degree of rigidity to which therapy goals had to be adhered to. Having conducted research in the area of coercion in psychiatry for a number of years prior to starting this research project, I believed that participation in treatment decisions, autonomy and choice were important elements of therapeutic relationships, which could empower service users and facilitate recovery. Hence, I struggled to accept the concept of fixed therapeutic goals, i.e., the reduction of self-harming, that clients have to comply with in DBT. Although I thought that having such fixed goals could provide a clear focus and be experienced as containing by clients, I felt that it could also be seen as paternalistic and as failing to encourage personal choice and empowerment. Hence, one of my personal interests in designing this project was to explore how service users experienced such potential conflicts and power dynamics in therapy.

Nevertheless, I tried to remain open to the possibility that such preoccupations were not shared by research participants. Although I found it impossible to completely put aside my interest in these areas, I tried to consider what I could do to maintain a phenomenological attitude at different stages of the project (Morrow, 2005). Hence, during interviews, I tried to follow areas that participants highlighted, rather than focusing on my own interests, and to encourage participants to expand on their personal meanings and understandings. Interestingly, during data analysis, it became apparent that service users did not on the whole experience



occasional disagreements in goals as particularly important or controversial. Indeed, the ideas expressed in this area were not substantial enough to form a separate theme or subtheme in the analysis, but only contributed to the subtheme “flexibility and choice” in the analysis in the theme of “challenge 2: balancing structure and flexibility”.

My developing clinical experience of using MBT in the treatment of people with BPD, which coincided with the data analysis and interpretation stage of the research project, also led to reflections on the strengths and limitations of MBT, DBT and other therapies for people with BPD. More specifically, working within a model that focuses on understanding and actively repairing relationship difficulties, I appreciated the focus on relationships and attachment styles in a group who substantially struggles in these areas. I also retrospectively saw the lack of in-depth focus on similar areas in DBT as a potential limitation for specialist therapies for BPD. At the same time, I viewed the lack of focus on actively implementing changes in MBT as a drawback, as people with BPD particularly struggle with ambivalence and indecision and require substantial support in taking action (Perseius, Ekdahl, Asberg & Samuelsson, 2005). My clinical experience as well as topics emerging from the research interviews and the ongoing interpretation of the data substantially contributed to the development of these ideas. Sometimes, it was difficult to disentangle whether these new understandings reflected my own developing beliefs from my clinical experience or participants’ ideas expressed in research interviews.

Hence, it was challenging to decide how to address these ideas. I wondered whether they were ideas that needed to be bracketed or an actual product of the ongoing analysis and interpretation of the research data. I tried to establish this, as far as possible, by revisiting the interviews and participants’ summaries of their personal

recovery trajectories. I concluded that the importance of working on relationships and promoting active change was frequently expressed in the research data. The understanding that facilitating both these processes might be crucial in the treatment of BPD was my own way of synthesising the emerging research ideas and integrating my developing evaluations from my clinical experience.

Therefore, I decided to stay close to the data as far as the presentation of the results was concerned and use my personal developing beliefs only in the discussion of the findings. To ensure that I was not imposing my personal perspectives on the analysis and interpretation of the data, I regularly discussed the emerging themes and domains, as well as the interpretation of the findings in meetings with my supervisor. Similarly, meeting a service user on a few occasions to discuss and make sense of the findings was particularly useful, as it enabled me to further reflect on the conclusions I was drawing and evaluate whether these appeared meaningful and relevant to someone who had been living with BPD and had received support from a wide range of services.

#### *The impact of the research journey on the researcher*

Approaching clients with curiosity and openness in the research interviews enabled me to relate to them in a different way, within what I experienced as a more equal power dynamic, in comparison to the dynamics operating in therapeutic relationships. Although as psychologists we aim to be collaborative, there is a clear power differential in therapeutic relationships, as therapists are by definition the “helpers” and clients are seen as those needing and receiving help (Yalom, 2003). In contrast, in qualitative research participants are the experts on their own experience and researchers come to them with a desire to understand and learn from their views

(Lincoln & Guba, 2000). Hence, although I was guided by research questions that I wanted to explore, I felt freed from trying to guide clients towards specific therapeutic goals or structures. Instead, I found myself interacting with them in a more flexible manner, following and exploring their views, appraisals, preferences and priorities.

This was a refreshing and enlightening experience at that stage of my development as a therapist, especially given that in my clinical work I was guided by DBT formulations as a way of conceptualising clients' difficulties and experiences. This different way of relating to service users made me reflect that their needs and understandings are much wider, richer and more complex than formulations presented in therapeutic manuals. Although I have always appreciated the clinical value of formulations in guiding therapy, having more flexible conversations with service users in research interviews reminded me that it is important to keep clients in mind as complex individuals, with a range of strengths and perspectives that might not be fully captured in shorthand formulations.

This understanding has had an impact on my clinical work with clients, as it has encouraged me to reflect on the importance of creating opportunities within therapy to explore clients' experiences of therapy. This in turn made me more aware of the relevance of using some systemic ideas alongside other therapeutic models, such as exploring clients' experiences of therapeutic conversations and remaining curious about their hopes, goals and positive qualities, instead of focusing on problems (Ekdawi, Gibbons, Bennett, & Hughes, 2000; White & Epston, 1990).

I also wondered how service users might have experienced power dynamics within a research relationship, and whether they found it different to a therapeutic

relationship. This sparked my interest in further exploring the experience of therapeutic and research relationships, the power dynamics operating within those and their potential link to recovery. Although this is merely an idea at this stage, I would be interested in conducting research in this area in my future career as a clinical psychologist.

Furthermore, some of the research findings were instrumental in shaping my understanding of recovery in this group and the way I now approach therapy with clients with BPD. For example, the understanding of recovery as an ongoing process characterised by a series of achievements and setbacks made me adjust my expectations of clients' progress and have a more realistic view of achievable outcomes. Until fairly recently, BPD was considered by many to be chronic and resistant to therapeutic interventions (DoH, 2003). This negative view of the prospect of recovery in BPD was later replaced by optimism in the face of newer evidence, which showed that clinical improvement and symptom remission are more common than previously assumed (Stoffers et al., 2012; Zanarini, Frankenburg, Hennen, & Silk, 2003). However, this might have led to the false belief that sustained recovery is easily achievable (Turner, Lovell, & Brooker, 2011). Listening to people's descriptions of recovery as an ongoing struggle made me reflect that it is very important to instil hope about the possibility for recovery, without suggesting that this is easily achievable and maintained, as this could lead to feelings of failure if recovery is not reached.

Lastly, combining clinical and research work while conducting this research project reminded me that the scientist-practitioner model (Page & Stritzke, 2006) was something that attracted me to clinical psychology prior to starting training. A few years later, this remains a central professional experience for me. Being able to

reflect on clinically relevant research questions and explore them in research, while also using research findings to inform my practice remains a model of working that I find valuable and enlightening. Coming to the end of my clinical training, I hope that working as a clinical psychologist will continue to offer me the opportunity to work as a scientist-practitioner and combine my research and clinical interests.

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**Appendix A:**

**Critical Appraisal Skills Programme (CASP) for qualitative  
research**

## Critical Appraisal Skills Programme (CASP, 2002)

10 questions to help you make sense of qualitative research

1. Was there a clear statement of the aims of the research?

Consider:

- What was the goal of the research?
- Why it was thought important?
- Its relevance

2. Is a qualitative methodology appropriate?

Consider:

- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- Is qualitative research the right methodology for addressing the research goal?

3. Was the research design appropriate to address the aims of the research?

Consider:

- If the researcher has justified the research design (e.g. have they discussed how they decided which method to use)

4. Was the recruitment strategy appropriate to the aims of the research?

Consider:

- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

5. Was the data collected in a way that addressed the research issue?

Consider:

- If the setting for data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, or did they use a topic guide?)
- If methods were modified during the study. If so, has the researcher explained how and why?
- If the form of data is clear (e.g. tape recordings, video material, notes etc.)
- If the researcher has discussed saturation of data

6. Has the relationship between researcher and participants been adequately considered?

Consider:

- If the researcher critically examined their own role, potential bias and influence during (a) Formulation of the research questions (b) Data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

7. Have ethical issues been taken into consideration?

Consider:

- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

8. Was the data analysis sufficiently rigorous?

Consider:

- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

9. Is there a clear statement of findings?

Consider:

- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researchers arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

10. How valuable is the research?

Consider:

- If the researcher discusses the contribution the study makes to existing knowledge or understanding e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature?
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

**Appendix B:**

**Letter of ethical approval**

**East London & The City REC Alpha**

2nd Floor, Burdett House  
Mie End Hospital  
Bancroft Road  
London  
E1 4DG

Telephone: 020 8223 8802

18 February 2009

Dr Christina Katsakou  
DBT psychotherapist and research project manager  
Unit for Social & Community Psychiatry  
Newham Centre for Mental Health  
Cherry Tree Way  
Glen Road  
E13 8SP

Dear Dr Katsakou

**Full title of study:** Processes of clinical improvement and personally-defined recovery from borderline personality disorder (BPD) and self-harming  
**REC reference number:** 09/H0704/14

The Research Ethics Committee reviewed the above application at the meeting held on 11 February 2009.

**Ethical opinion**

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

- a. Inclusion criteria. The question was asked why you had not included people who do not speak sufficient English. Ms Katsakou explained that she had no provisions for using interpreters. The Committee were satisfied with the response. No further action required.
- b. A28. Please delete the word 'chosen' and replace with 'invited'. Ms Katsakou agreed to do change this.
- c. Members had a number of concerns regarding the Patient Information Sheet:
  - Members felt that the language was a little heavy for patients who may not be in the best of health. It was felt that the language emphasised difficulties. Could you make this more neutral. Ms Katsakou agreed to do this.
  - Distress would be a risk to service users. The PIS should indicate what provisions will be made with key workers. Ms Katsakou indicated that recruiting through key workers they can give them an option and be made aware of it.
  - The PIS for (service users) should indicate that participants may be asked if there is a partner, relative or therapist they wish to mention.
  - All three PIS forms should indicate the possibility of delayed distress – and who could be contacted. Also, care team should be made aware.

- d. The consent form needs to indicate under what circumstances the normal conditions of confidentiality would be broken
- e. Copy of the Interview schedule was requested. Ms Katsakou pointed out that they were still in the process of writing the interviews. Members asked that you forward a copy once completed.

**Conditions of the favourable opinion**

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

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

Management permission at NHS sites ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

**Approved documents**

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Protocol	1	21 January 2009
Investigator CV	1	21 January 2009
Application	1	21 January 2009
Participant Information Sheet	1	21 January 2009
Participant Information Sheet	1	21 January 2009
Participant Information Sheet	1	21 January 2009
Participant Consent Form	1	21 January 2009
Compensation Arrangements	1	21 January 2009
Peer Review	1	21 January 2009
Questionnaire	1	21 January 2009
Interview Schedules/Topic Guides	1	21 January 2009
Covering Letter	1	21 January 2009
Checklist	1	21 January 2009

**Membership of the Committee**

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

**Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

#### After ethical review

Now that you have completed the application process please visit the National Research Ethics Website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

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

- Notifying substantial amendments
- Progress and safety reports
- Notifying the end of the study

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

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email [referencegroup@nres.npsa.nhs.uk](mailto:referencegroup@nres.npsa.nhs.uk).

09/H0704/14

Please quote this number on all correspondence

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

Yours sincerely

Dr Cliff Chaplin  
Vice-Chair

Email: [sandra.grote@nelondon.nhs.uk](mailto:sandra.grote@nelondon.nhs.uk)

Enclosures: *List of names and professions of members who were present at the meeting and those who submitted written comments "After ethical review – guidance for researchers"*

Copy to: *Ms Karin Albani*

East London & The City REC Alpha

Attendance at Committee meeting on 11 February 2009

Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
George Rice	Lay Member	No	
Mrs Joanne Apfel	Lawyer	No	
Dr Cliff Chaplin	Lecturer in Health Care Ethics	Yes	
Dr Ian Chikanza	Consultant/Senior lecturer in Rheumatology	No	
Mr Michael Craft	Lay Member	Yes	
Ms Alison Higgs	Lay Member	Yes	
Mr John Lynch	Lay Member	Yes	
Ms Sylvia Richards	Research Nurse	Yes	
Mr Andrew Webb	Clinical Pharmacology	Yes	
Ms Jenny White	Non-medical lay member	Yes	
Dr Ralph White	Non-medical lay member	Yes	
Gemma Dorer	Non-medical lay member	Yes	
Dora Opoku	Head of Midwifery	Yes	
Dr David Ingram	Clinical Neurophysiology	Yes	



## **Appendix C:**

### **Participant information sheets**

**Participant information sheet for participation in the research project (service users):  
“Processes of clinical improvement and recovery from BPD and self-harming”**

We are inviting you to take part in a research study, which we think may be important. The information which follows tells you about it and what will happen if you decide to take part. It is very important that you understand what is in this leaflet before agreeing to take part.

**It is YOUR choice whether or not you take part.**

Please ask any questions you want to about the research and we will try our best to answer them.

---

▪ **Why have you been identified as suitable to take part in the research?**

We are asking you to take part in this research as you receive treatment from secondary mental health NHS services for emotional difficulties and you might have received a diagnosis of borderline personality disorder.

▪ **What is the purpose of the research?**

People with such problems often have difficulties dealing with their emotions and feel distressed. Evidence shows that these problems can change and people can improve clinically and recover from the condition. However, it is not known how people can improve, what helps them get better and what gets in the way of their recovery. We are interested in hearing from you what your experiences are of using NHS services, what has helped you feel better and what has delayed your improvement and recovery.

▪ **What would participation in the research involve for you?**

If you participate in the research, it will involve you completing a short questionnaire (12 questions) on how satisfied you are with several things in your life and taking part in an interview with a researcher, which should last for a maximum of 60 minutes. The researcher will ask you questions about your experiences of using NHS services and what helped you recover or delayed your recovery from your emotional difficulties. You will receive £20 for attending the interview.

The researcher might also ask you if you would be happy to name a relative/ partner or friend and a therapist, as we would be interested in interviewing them on the same topic.

▪ **How will you or others benefit from taking part in the research?**

You may value the opportunity to reflect on your journey to improvement and recovery and problems that come in the way. You might also value having your opinions reflected in research. The information you provide may help to improve your treatment and more

generally help us to develop mental health services that are more helpful to you and other people in your situation.

- **Are there any potential risks for you taking part in the study?**

No. Taking part in the study will not affect your treatment in any way. If you feel upset discussing personal information during the interview, you can stop the interview, take a break or discuss your concerns with the interviewers who have experience working with people with emotional problems.

Also, your key-worker and your care team are aware of your participation in this study. Should you feel distressed at any later point due to taking part in the study interview, you could contact them and ask for their help.

- **What will happen to the information you provide?**

During the interview, the discussion will be tape-recorded. All information gathered during the study will be strictly confidential and your name will not be used for research purposes. All information will be stored in a secure locked filing cabinet and will not be used for any other research purposes. The audiotapes will be destroyed once the study is complete. The only people who may see information about your part in the study are members of the research team.

Confidentiality will only be broken in rare cases. For example, if you disclose that you are at high risk of making a suicide attempt or of putting someone else at risk, the services involved in your care will be informed.

If you require more information about the study you may contact Christina Katsakou or Stamatina Marougka.

You don't have to join the study. You are free to decide not to be in this study or to drop out at any time. If you decide not to be in the study, or drop out, this will not put at risk your ordinary medical care.

- **Has the research been reviewed by an appropriate research ethics committee?**

The research study has been reviewed and approved by the East London Research Ethics Committee A.

- **What happens if you would like more information about the study?**

You will always be able to contact a researcher to discuss the study:

**Name:** Christina Katsakou or Matina Marougka

**Address:** *Unit for Social and Community Psychiatry, Newham Centre for Mental Health, Glen Road, London E13 8SP* **Telephone number:** 020 7540 6755

**Emails:** [c.katsakou@qmul.ac.uk](mailto:c.katsakou@qmul.ac.uk) ; [s.marougka@qmul.ac.uk](mailto:s.marougka@qmul.ac.uk)

**Participant information sheet for participation in the research project (staff):**  
**“Processes of clinical improvement and recovery from BPD and self-harming”**

We are inviting you to take part in a research study, which we think may be important. The information which follows tells you about it and what will happen if you decide to take part. It is very important that you understand what is in this leaflet before agreeing to take part.

**It is YOUR choice whether or not you take part.**

Please ask any questions you want to about the research and we will try our best to answer them.

---

▪ **Why have you been identified as suitable to take part in the research?**

We are asking you to take part in this research as you are delivering treatment in secondary mental health NHS services for borderline personality disorder and self-harming.

▪ **What is the purpose of the research?**

People with borderline personality and self-harming often have difficulties dealing with their emotions and feel distressed. Evidence shows that these problems can change and people can improve clinically and recover from the condition. However, it is not known how people can improve, what helps them get better and what gets in the way of their recovery. We are interested in hearing from you what your experiences are of delivering NHS services, what has helped your service users feel better and what has delayed their improvement and recovery.

▪ **What would participation in the research involve for you?**

If you participate in the research, it will involve you taking part in an interview with a researcher, which should last for a maximum of 60 minutes. The researcher will ask you questions about your experiences of offering NHS services and what helped your service users recover or delayed their recovery from borderline personality and self-harming.

▪ **How will you or others benefit from taking part in the research?**

You may value the opportunity to reflect on your service users’ journey to improvement and recovery and problems that come in the way. You might also value having your opinions reflected in research. The information you provide may help to improve treatment and more generally help us to develop mental health services that are more helpful for service users with BPD and self-harming.

- **Are there any potential risks for you taking part in the study?**

No. Taking part in the study will not affect your service users' treatment or your role in any way.

- **What will happen to the information you provide?**

During the interview, the discussion will be tape-recorded. All information gathered during the study will be strictly confidential and your name or the name of your service user will not be used for research purposes. All information will be stored in a secure locked filing cabinet and will not be used for any other research purposes. The audiotapes will be destroyed once the study is complete. The only people who may see information about your part in the study are members of the research team. If you require more information about the study you may contact Christina Katsakou or Matina Marougka.

You don't have to join the study. You are free to decide not to be in this study or to drop out at any time. If you decide not to be in the study, or drop out, this will not put at risk your ordinary medical care.

- **Has the research been reviewed by an appropriate research ethics committee?**

The research study has been reviewed and approved by the East London Research Ethics Committee A.

- **What happens if you would like more information about the study?**

You will always be able to contact a researcher to discuss the study:

**Name:** Christina Katsakou or Stamatina Marougka

**Address:** *Unit for Social and Community Psychiatry, Newham Centre for Mental Health, Glen Road, London E13 8SP*, **Telephone number:** 020 7540 6755

**Emails:** [c.katsakou@qmul.ac.uk](mailto:c.katsakou@qmul.ac.uk) ; [s.marougka@qmul.ac.uk](mailto:s.marougka@qmul.ac.uk)

**Participant information sheet for participation in the research project (relatives):**

**“Processes of clinical improvement and recovery from BPD and self-harming”**

We are inviting you to take part in a research study, which we think may be important. The information which follows tells you about it and what will happen if you decide to take part. It is very important that you understand what is in this leaflet before agreeing to take part.

**It is YOUR choice whether or not you take part.**

Please ask any questions you want to about the research and we will try our best to answer them.

---

▪ **Why have you been identified as suitable to take part in the research?**

We are asking you to take part in this research as you are a relative/ partner/ friend of someone receiving treatment from secondary mental health NHS services for emotional difficulties and might have been given a diagnosis of borderline personality disorder.

▪ **What is the purpose of the research?**

People with such problems often have difficulties dealing with their emotions and feel distressed. Evidence shows that these problems can change and people can improve clinically and recover from the condition. However, it is not known how people can improve, what helps them get better and what gets in the way of their recovery. We are interested in hearing from you what you think has helped your relative/ partner/ friend feel better and what has delayed their improvement and recovery.

▪ **What would participation in the research involve for you?**

If you participate in the research, it will involve you taking part in an interview with a researcher, which should last for a maximum of 60 minutes. The researcher will ask you questions about your relative/ partner/ friend’s experiences of using NHS services and what helped them recover or delayed their recovery. You will receive £20 for attending the interview.

▪ **How will you or others benefit from taking part in the research?**

You may value the opportunity to reflect on your relative/ partner/ friend’s journey to improvement and recovery and problems that come in the way. You might also value having your opinions reflected in research. The information you provide may help to improve the treatment for your relative/ partner/ friend and more generally help us to

develop mental health services that are more helpful to people with emotional difficulties.

- **Are there any potential risks for you taking part in the study?**

No. Taking part in the study will not affect your relative/ partner/ friend's treatment in any way. If you feel upset discussing personal information during the interview, you can stop the interview, take a break or discuss your concerns with the interviewers who have experience working with people with emotional problems.

- **What will happen to the information you provide?**

During the interview, the discussion will be tape-recorded. All information gathered during the study will be strictly confidential and your name or your relative/ partner/ friend's name will not be used for research purposes. All information will be stored in a secure locked filing cabinet and will not be used for any other research purposes. The audiotapes will be destroyed once the study is complete. The only people who may see information about your part in the study are members of the research team. If you require more information about the study you may contact Christina Katsakou or Stamatina Marougka.

You don't have to join the study. You are free to decide not to be in this study or to drop out at any time. If you decide not to be in the study, or drop out, this will not put at risk your ordinary medical care.

- **Has the research been reviewed by an appropriate research ethics committee?**

The research study has been reviewed and approved by the East London Research Ethics Committee A.

- **What happens if you would like more information about the study?**

You will always be able to contact a researcher to discuss the study:

**Name:** Christina Katsakou or Matina Marougka

**Address:** *Unit for Social and Community Psychiatry, Newham Centre for Mental Health, Glen Road, London E13 8SP*, **Telephone number:** 020 7540 6755

**Emails:** [c.katsakou@qmul.ac.uk](mailto:c.katsakou@qmul.ac.uk) ; [s.marougka@qmul.ac.uk](mailto:s.marougka@qmul.ac.uk)

**Appendix D:**  
**Participant consent form**



**Title of the Project:** Processes of clinical improvement and recovery from borderline personality disorder (BPD) and self-harming

**Name of Researchers:** Dr Christina Katsakou, Chief Investigator

Miss Stamatina Marougka, Research Assistant

*Written Consent Form*

**Name of Participant**

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**Name of Researcher**

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- ◆ The study organisers have invited me to take part in this research.
  
- ◆ I have read and understand what is in the information sheet dated 23/02/09 for the above study. I have a copy of the information to keep.
- ◆ I have had the chance to talk and ask questions about the study and have had these answered satisfactorily.
- ◆ I know what my part will be in the study and I know how long it will take.
- ◆ I understand that personal information is strictly confidential. I know my information will be stored on passworded NHS computers and the only people who may see this information are the research team.
- ◆ I understand that confidentiality will only be broken if I disclose that I am at high risk of making a suicide attempt or of putting someone else at risk and the services involved in my care will be informed.
- ◆ I freely consent to take part in the study.
- ◆ I can stop taking part at any time without giving any reason
- ◆ I know that the East London Ethics Committee A has seen and agreed to this study.
  
- ◆ I agree to take part in this study and to have my interview audio-recorded.
  
- ◆ If there are any problems or I want to find out more information about the research I know I can contact:  
Christina Katsakou or Stamatina Marougka, Unit for Social and Community Psychiatry  
Tel: 020 7540 6755

Participant signature: \_\_\_\_\_ Date: \_\_\_\_\_

I confirm that I have explained to the member of staff named above, the nature and purpose of the research to be undertaken.

Name: \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

**Appendix E:**  
**Interview Schedules**

### **Interview schedule for interviews with service users**

- Did you find your treatment helpful? In what ways?
- Do you believe that you have reduced self-harming since you started this treatment? In what ways do you think you have improved?

(Prompt) Do you feel that these improvements will be maintained and how?

- Do you feel that you have recovered from BPD? (Do you feel that you are now satisfied with your life?)/ Do you feel you have improved in any other way?
- Do you feel you can recover from BPD? What do you see as recovery?

(Prompt) How are you different in comparison to before you started treatment?

(Prompt) Have you achieved the goals you had in treatment? What were your goals? What have you achieved?

- Were the goals of the service and your own personal goals the same?
- If you have improved/ recovered, what helped you improve/ recover?
- Can you describe your journey to improvement/ recovery? What was the process?
- Were there any particularly significant points in the journey? Any “a-ha” moments? Can you describe them?

(Prompt) Do you think you would have improved/ recovered if you had not received this treatment?

- What other things in your life/ yourself helped you improve/ recover?

(Prompt) How did treatment combine with other helpful factors in your life?

- What do you think was helpful in this treatment? Are there any parts of the treatment that you found more helpful than others?
- What do you think was not helpful/ relevant in the treatment?
- Were there any points when you considered dropping out of treatment? What made you consider this? Why did you (not) drop out?

(Prompt) How was your relationship with your therapist/ care coordinator?

- What were your experiences with other treatments in the past? Describe what kind of treatments you had received (GP, CMHT, other psychotherapy).

- How did you find this treatment in comparison to previous treatments?

(Prompt) Do you think that other treatments could benefit from using elements from this treatment? Which elements? Use your own experience with previous treatments as an example.

(Prompt) Do you have any suggestions to improve the treatment you received? Is anything missing from this treatment?

(Prompt) Would you like anything to have been done differently?

(Prompt) What kind of treatment would you like to receive for your problems?

- If you have not improved/ recovered, what do you think got in the way?

(Prompt) Can you describe things that delayed your journey to improvement/ recovery? What was the process?

(Prompt) Were there any particularly significant points in the journey? Any problematic moments? Can you describe them?

(Prompt) Do you think you would have improved/ recovered if you had not received this treatment?

### **Interview schedule for interviews with therapists**

- Did you find this treatment helpful for your service user? In what ways?
- Do you believe that they have reduced self-harming since they started this treatment? In what ways do you think they have improved?
- Do you feel that they have recovered from BPD? (Do you feel that they are now satisfied with their life?)/ Do you feel they have improved in any other way?
- Do you feel they can recover from BPD? What do you see as recovery?

(Prompt) How are they different in comparison to before they started treatment?

(Prompt) Have they achieved the goals they had in treatment? What were their goals? What have they achieved?

- Were the goals of the service and their own personal goals the same?
- If they have improved/ recovered, what helped them improve/ recover?
- Can you describe their journey to improvement/ recovery? What was the process?
- Were there any particularly significant points in the journey? Any “a-ha” moments? Can you describe them?

(Prompt) Do you think they would have improved/ recovered if they had not received this treatment?

- What other things in their life/ themselves helped them improve/ recover?

(Prompt) How did treatment combine/ interact with other helpful factors in their life?

- What did you think was helpful for them in this treatment? Are there any parts of the treatment that you found more helpful than others?
- What did you think was not helpful/ relevant for them in the treatment?
- How did they find this treatment in comparison to previous treatments?

(Prompt) Do you think that other treatments could benefit from using elements from this treatment? Which elements?

(Prompt) Do you have any suggestions to improve this treatment? Is anything missing from this treatment?

(Prompt) Would you like anything to have been done differently?

- If they have not improved/ recovered, what do you think got in the way?

(Prompt) Can you describe things that delayed their journey to improvement/ recovery? What was the process?

(Prompt) Were there any particularly significant points in the journey? Any problematic moments? Can you describe them?

(Prompt) Do you think they would have improved/ recovered if they had not received this treatment?

### **Interview schedule for interviews with relatives**

- Did you find this treatment helpful for your relative? In what ways?
- Do you believe that they have improved since they started this treatment? In what ways do you think they have improved?
- Do you feel that these improvements will be maintained and how?
- Do you feel that they have recovered from their emotional problems/ BPD? Do you feel that they are now satisfied with their life?
- How are they different in comparison to before they started treatment?
- Have they achieved the goals they had in treatment? What have they achieved?
- Were the goals of the service and their own personal goals the same?
- If they have improved/ recovered, what helped them improve/ recover?
- Can you describe their journey to improvement/ recovery? What was the process?
- Were there any particularly significant points in the journey? Any “a-ha” moments? Can you describe them?

(Prompt) Do you think they would have improved/ recovered if they had not received this treatment?

- What other things in their life/ themselves helped them improve/ recover?

(Prompt) How did treatment combine/ interact with other helpful factors in their life?

- What do you think was helpful for them in this treatment? Are there any parts of the treatment that you thought were more helpful than others?
- What do you think was not helpful/ relevant for them in the treatment?
- How did they find this treatment in comparison to previous treatments?
- Would you like anything to have been done differently with your relative?
- If they have not improved/ recovered, what do you think got in the way?

(Prompt) Can you describe things that delayed their journey to improvement/ recovery? What was the process?

(Prompt) Were there any particularly significant points in the journey? Any problematic moments? Can you describe them?

(Prompt) Do you think they would have improved/ recovered if they had not received this treatment?

**Appendix F:**  
**Initial Thematic Framework**



## Processes of recovery

### Personal processes (facilitated by therapy)

Improving understanding and acceptance of problems/ self  
realising- accepting I have problems/ I need help  
improved awareness/ understanding of condition/  
behaviour/ self

having a diagnosis

accepting self/ self-confidence/ reduced guilt-shame

### Building relationships skills

understanding other people/ relationships

improving communication/ relationships

talking about problems/ trusting others

opening up in treatment

having supportive relationships

finishing unhelpful relationships/ confronting

### Enhancing motivation/ perseverance/ responsibility

pushing self/ responsibility/ thinking of consequences-goals  
to avoid shame from scars

trying for others

trying for therapist/ therapy/ making  
commitments

noticing progress

hope/ faith in treatment

### Taking action/ changing

controlling-challenging thoughts/ emotions

gradual steps/ one thing at a time

facing problems/ stop avoiding-hiding

life improvements (work, finances, housing)/ routine

exercise/ diet

reducing drugs/ alcohol

time/ natural changes in mood

crisis strategies

keeping busy/ distracting with activities

taking a step back/ not acting impulsively

removing means of self-harming

### Helpful treatment elements

#### Therapy characteristics

speed of referral process

therapy content

structure/ goal oriented

focusing on change/ guidance

learning skills

offering practical help i.e. housing

art/ creative elements

working on ending

therapy intensity/ regularity

intensive/ regular therapy

crisis support

something to do/ routine

communication between professionals/ services

including families/ friends

group setting

meeting people with similar issues helps

#### Therapist characteristics/ strategies

someone to talk to/being listened to/ understood

supportive/ caring  
assertive/ coaching  
respectful/ flexible (own pace/ preferences)  
self-disclosure  
humour  
therapeutic relationship  
addressing conflicts/ tension/ boundaries

## **Barriers to recovery and challenges**

### Personal

Not accepting problems/ self  
not realising/ accepting problems/ that I need help  
low self-esteem/ shame/ guilt  
myself  
Difficulties in relationships  
not opening up/ distrust of therapist/ services/ others  
no supportive relationships/ stigma  
Change is difficult/ Giving up/ losing motivation  
fear of changing  
instant positive consequences from problem behaviours  
change is too hard/ theory- practice gap  
giving up/ ambivalence  
being stubborn/ unwilling/ bitter  
thinking that nothing will change/ 'can't'  
unrealistic goals/ not dealing with setbacks

### Life events/ circumstances

long time with untreated problems/ trauma  
mood/ emotions/ other disorders  
negative thoughts/ no concentration

loss

negative life circumstances

drinking/ drugs

### Unhelpful treatment elements

#### Therapy content/ focus

disagreeing on goals/ not all problems targeted  
focus on the past/ off-loading/ no solutions- guidance  
no introduction to treatment/ no info on BPD  
too hard/ don't understand/ homework  
focusing only on medication/ side-effects

#### Therapy structure/ pace/ regularity/ length

too short/ not regular enough  
no continuity of care/ abrupt ending  
not independent/ relying too much on therapist/y  
overprotected by relatives  
system not knowing what to do/ unrealistic expectations

no structure/ no goals/ rules

group setting

group of people with problems

#### Therapist's characteristics

therapist not listening/ not supportive/ patronising  
rigid/inflexible/not following own pace/pushing  
negotiating boundaries/ relationship

## **Appendix G:**

### **Example of a participant's personal trajectory**

## **Parallel recovery processes**

### ***Personal processes***

Realising I have problems and accepting them

Approaching problems and learning how to deal with them

Setting small achievable goals, practising them repeatedly and gradually

Not wanting to let significant others down (eg. family, therapist)

Noticing progress and feeling more hopeful and confident

More assertive in relationships

Gradually allowing people to get closer

Improved relationships with family make you feel supported and offer enjoyment

### ***Processes occurring in therapy***

Being able to talk about your feelings and difficult experiences gives a sense of relief

Being treated as “normal” makes you feel better about yourself

Group daunting at first, which makes you feel disconnected and isolated

Gradually connecting with others in group

Observing other people’s progress and own progress in the group makes you feel more hopeful

Having intensive therapy, both individual and group

Long enough therapy

Feeling safe that there is someone to fall back on for support if you need it (eg. therapy offering support during crisis).

Gradually opening up

Learning how to notice and hold on to positive emotions and not dismiss them

### **Challenges in the recovery journey/ therapy**

Having a therapy contract and committing to stopping self-harming is difficult. It makes you feel guilty when you end up self-harming.

Not feeling fully recovered but dealing with problems in a better way

Accepting that recovery is going to be a long process, due to enduring traumatic past experiences

## **Appendix H:**

**Example of coding an interview extract (preliminary ideas,  
subthemes, themes, domains)**

Interview extract SU13	Preliminary ideas	Subthemes	Themes	Domains
<p>I think I used to worry so much about everything. I used to take – even if somebody looked fleetingly upset, I used to think it was something to do with me, my fault and then I'd self-harm as a result of that. But now I feel aware of that, and I realise I can stop myself from going down that track. Think it's fine, it's nothing to do with you. So I'm better at sorting out situations before they escalate...</p>	Worrying about everything			Processes of recovery
	Taking things personally	Feeling ashamed and blaming self for problems	Moving from shame to self-acceptance and compassion	
	Thinking it's my fault	Managing difficult thoughts		
	Self-harming as a result of blaming self for anything	Self-acceptance, compassion, confidence	Fighting ambivalence and committing to taking action	
	Aware of pattern of blaming self	Noticing progress and developing hope		
	Able to stop self from going into this pattern			
<p>I was always appalled with myself, there was always one thing or another that I was always beating myself up about, I go to the spot where I didn't really want to see my friends. I had nothing to offer. I was self-harming, which was my only way of dealing with</p>	Able to sort out situations before they escalate			Processes of recovery
	Appalled with self	Feeling ashamed and blaming self for problems	Moving from shame to self-acceptance and compassion	
	Beating self up about things	Fear of being open and exposing self		
	Didn't want to see friends			
	Feeling like having nothing to offer			
Self-harming was the only way of dealing with problems				

<p>things, then I was disgusted that I had done it afterwards, but it was just horrible. I felt like I was rubbish at my job, at everything. And now, I feel like I ‘ve got some things to offer, more confident and I ‘m really happy. And I can talk to people about things more easily...</p>	<p>Disgusted after having self-harmed Felt like being rubbish at everything Feeling more confident, like having things to offer Feeling happy Able to talk to people more easily</p>	<p>Self-acceptance, compassion and confidence Opening up and trusting others</p>	<p>Moving from distrust and defensiveness to opening up to others</p>	
<p>Filling in the diary cards was a pain, but again it was really helpful. Situations would happen that would make me flare up and I wouldn’t really think about them before. But because I had to write everything down, it was forcing me to think about it...it was really helpful to make out what was making me head towards self-harm.</p>	<p>Completing diary cards painful but helpful Not thinking about difficult situations before Writing things down made her think about things Really helpful to make sense of what made her head towards self-harm</p>	<p>Self-exploration is helpful Understanding self and difficulties</p>	<p>Balancing self-exploration and finding solutions Moving from shame to self-acceptance and compassion</p>	<p>Challenges in therapy Processes of recovery</p>

**Appendix I:**  
**Finalised coding frame**



## **Domain 1: Processes of recovery**

### **Process 1: Fighting ambivalence and committing to taking action**

Giving up, feeling held up by the past and scared of change

Not letting others down

Taking responsibility

Managing difficult thoughts

Taking practical steps to resolve problems and crises

Noticing progress and developing hope

### **Process 2: Moving from shame to self-acceptance and compassion**

Feeling ashamed and blaming self for problems

Acknowledging problems and asking for help

Understanding self and difficulties

Self-acceptance, compassion and confidence

### **Process 3: Moving from distrust and defensiveness to opening up to others**

Fear of being open and exposing oneself

Understanding relationships

Listening to others and communicating in a less angry way

Opening up and trusting others

Being assertive and negotiating boundaries

## **Domain 2: Challenges in therapy**

### **Challenge 1: Balancing self-exploration and finding solutions**

Self-exploration is helpful

Focusing only on understanding the past is unhelpful

Problem-solving is valuable

### **Challenge 2: Balancing structure and flexibility**

Structured, goal-oriented therapy with a clear rationale

Flexibility and choice

### **Challenge 3: Confronting interpersonal difficulties and practising new ways of relating<sup>a</sup>**

Feeling overwhelmed and exposed in group

Practising relating to others in group

Addressing conflicts and negotiating boundaries in the therapeutic relationship

### **Challenge 4: Balancing support and independence**

Regular/ intensive therapy

Supportive therapist

Managing ending/ continuity of care